First Session
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SENATE OF CANADA

Proceedings of the Standing Senate Committee on

Social Affairs, Science and Technology

Chair:
The Honourable MICHAEL KIRBY

Tuesday, November 23, 2004

Issue No. 4

THIRD REPORT OF THE COMMITTEE
Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada
(Reports 1, 2 and 3)

Première session de la
trente-huitième législature, 2004

SÉNAT DU CANADA

Délibérations du Comité sénatorial permanent des

Affaires sociales, des sciences et de la technologie

Président :
L'honorable MICHAEL KIRBY

Le mardi 23 novembre 2004

Fascicule n° 4

TROISIÈME RAPPORT DU COMITÉ
Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada
(Rapports 1, 2 et 3)

42190

THE STANDING SENATE COMMITTEE ON SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY

The Honourable Michael Kirby, *Chair*

The Honourable Wilbert J. Keon, *Deputy Chair*

and

The Honourable Senators:

* Austin, P.C.
  (or Rompkey, P.C.)
  Callbeck
  Cochrane
  Cook
  Cordy
  Fairbairn, P.C.
  Gill
  Johnson
  LeBreton
* Kinsella
  (or Stratton)
  Morin
  Pépin

*Ex officio members

(Quorum 4)

LE COMITÉ SÉNATORIAL PERMANENT DES AFFAIRES SOCIALES, DES SCIENCES ET DE LA TECHNOLOGIE

Président : L'honorable Michael Kirby

Vice-président : L'honorable Wilbert J. Keon

et

Les honorables sénateurs :

* Austin, C.P.
  (ou Rompkey, C.P.)
  Callbeck
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* Kinsella
  (ou Stratton)
  Morin
  Pépin

*Membres d'office

(Quorum 4)

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ORDER OF REFERENCE

Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

The Honourable Senator Kirby moved, seconded by the Honourable Senator Losier-Cool:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness.

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee and;

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

ORDRE DE RENVOI

Extrait des *Journaux du Sénat* du jeudi 7 octobre 2004 :

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Losier-Cool,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système des soins de santé au Canada en Octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale.

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la trente-septième législature soient déférés au Comité;

Que le Comité présente son rapport final au plus tard le 16 décembre 2005 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 mars 2006.

La motion, mise aux voix, est adoptée.

Le greffier du Sénat,

Paul C. Bélisle

Clerk of the Senate

REPORTS OF THE COMMITTEE

Tuesday, November 23, 2004

The Standing Senate Committee on Social Affairs, Science and Technology has the honour to table its

THIRD REPORT

Your Committee, which was authorized by the Senate on Thursday, October 7, 2004 to examine and report on issues concerning mental health and mental illness, now tables its first interim report entitled *Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada*.

Respectfully submitted,

RAPPORTS DU COMITÉ

Le mardi 23 novembre 2004

Le Comité sénatorial permanent des Affaires sociales, des sciences et de la technologie a l'honneur de déposer son

TROISIÈME RAPPORT

Votre Comité, qui a été autorisé par le Sénat le jeudi 7 octobre 2004 à examiner, pour en faire rapport, la santé mentale et la maladie mentale; dépose maintenant son premier rapport provisoire intitulé *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*.

Respectueusement soumis,

Le président,

MICHAEL KIRBY

Chair

SENATE  SÉNAT

CANADA

REPORT 1

Mental Health, Mental Illness and Addiction:

Overview of Policies and Programs in Canada

Interim Report of
The Standing Senate Committee On Social Affairs, Science And Technology

The Honourable Michael J.L.Kirby, Chair
The Honourable Wilbert Joseph Keon, Deputy Chair

November 2004

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ORDER OF REFERENCE

Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

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That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee; and

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

Paul C. Bélisle

Clerk of the Senate

The following Senators have participated in the study on the state of the health care system of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Michael J. L. Kirby, Chair of the Committee
The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retired)
Douglas Roche (retired)
Eileen Rossiter (retired)
Marilyn Trenholme Counsell

Ex-officio members of the Committee:

The Honourable Senators: Jack Austin P.C. or (William Rompkey) and Noël A. Kinsella or (Terrance Stratton)

Other Senators who have participated from time to time on this study:
The Honourable Senators Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne and Murray.

MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION: OVERVIEW OF POLICIES AND PROGRAMS IN CANADA

INTRODUCTION

In February 2003, during the Second Session of the Thirty-Seventh Parliament, the Standing Senate Committee on Social Affairs, Science and Technology received a mandate from the Senate to study the state of mental health services and addiction treatment in Canada and to examine the role of the federal government in this area. The Senate renewed the mandate of the Committee in the Third Session of the Thirty-Seventh Parliament (February 2004), and then again in the First Session of the Thirty-Eighth Parliament (October 2004).

This mandate reads as follows:

> That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness;
>
> That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee, and
>
> That the Committee submit its final report no later than December 16, 2005and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006[1].

For the purpose of this study, the Committee adopted a broad approach towards examining mental health, mental illness and addiction in terms of: the prevalence of mental disorders and their economic impact on various sectors of the Canadian society, including business, education and health care systems; relevant federal and provincial policies and programs; mental health strategies in other countries; mental health promotion, mental illness and suicide prevention; mental health related disease surveillance and research; access to and delivery of mental health services and addiction treatment; support to families and caregivers; and the potential for the development of a national action plan on mental health, mental illness and addiction in Canada.

[1] Debates of the Senate (Hansard), 1st Session, 38th Parliament, Volume 142, Issue 7, October 2004.

The Committee's study on mental health, mental illness and addiction includes four reports. The following table provides information on each individual report and the proposed timeframe for publication:

STUDY ON MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION INDIVIDUAL REPORTS AND PROPOSED TIMEFRAMES

Report	Content	Timing
First	Fact-based document providing historical background, overview of service delivery, respective roles of federal and provincial/territorial governments, assessments of policies and programs based on public testimony and literature review	November 2004
Second	International comparative analysis (Australia, Canada, New Zealand, the United Kingdom, and the United States)	November 2004
Third	An issues and options paper summarizing the issues which the Committee will address in its final report and raising options for addressing these issues	November 2004
Fourth	Recommendations for reform	November 2005

This report, which consists of eleven chapters, constitutes the first report by the Committee on mental health, mental illness and addiction. Chapter 1 summarizes the personal stories of one individual living with mental illness and three family members affected by mental illness who candidly shared their experience with the Committee. Chapter 2 provides further information on the impact of mental illness and addiction on affected individuals, their families and caregivers. Chapter 3 examines the issues of stigma and discrimination and their impact on individuals with mental illness and addiction. Chapter 4 defines the various concepts related to mental health, mental illness and addiction. Chapter 5 provides information on the prevalence of mental illness and addiction and their economic impact on Canadian society. Chapter 6 reviews the relationships between mental illness/addiction and work and examines ways to address mental illness and addition in the workplace. Chapter 7 provides a chronological overview of the development of mental health services and addiction treatment in Canada. Chapter 8 compares the organizational structure and level of integration of the mental health services and addiction treatment system in some provinces and highlights the major differences of all provincial mental health legislation. Chapter 9 provides an overview as well as an assessment of the direct and indirect roles of the federal government in mental health, mental illness and addiction. Chapter 10 provides an overview of the state of research into mental health, mental illness and addiction in Canada. Chapter 11 examines various ethical issues related to mental illness and addiction with a particular

focus on service delivery, research, capacity to consent to treatment, and privacy and confidentiality issues.

PART 1

The Human Face Of Mental Illness And Addiction

CHAPTER 1:
WITNESSES SHARE THEIR PERSONAL EXPERIENCES[2]

> *(…) I believe it is time to ask the opinion of service users and mental health experts. And who else but us are the experts in our disorders, needs and problems? We obviously cannot cure ourselves. We are people with a certain ability to think. We need to be heard, and I thank you for doing that.*
> *[Loïse (9:18).]*

INTRODUCTION

On February 26, 2003, the Committee embarked on its study on mental health, mental illness and addiction by putting a human face to the issue. More precisely, members of three families affected by mental illness and one individual with mental illness accepted our invitation to speak together about their experiences – how mental disorders affected their lives. These four witnesses came from all over the country with first-hand experience of mental health and addiction issues to tell their stories to the Committee. To make them comfortable enough to talk candidly, the Committee referred to them by their first names only. This chapter provides a summary of their testimony. It illustrates graphically why the study of mental health, mental illness and addiction has become such an emotional cause for the members of the Committee.

Throughout its study, the Committee also received evidence on the lives of many other Canadians affected by mental illness and addiction through public hearings, letters and e-mails. The experience these individuals shared with us is summarized in Chapter 2.

1.1 IN THEIR OWN WORDS

1.1.1 Loïse's Story

Loïse spoke to the Committee about her own experiences with mental health problems, specifically bipolar disorder:

> *Ten years ago, following the sudden death of my partner in life, I had an episode of manic psychosis. During that phase, you lie, you spend money, and you are sure you have money, and you believe what you're doing, which is out of context. You feel you could save the world during that*

[2] In this report, the testimony received by witnesses printed in the *Minutes of Proceedings and Evidence of the Standing Senate Committee on Social Affairs, Science and Technology* will be hereinafter referred to only by issue number and page number within the text.

> *period. I had an episode which lasted six months and ended with a suicide attempt. That was followed by four years of depression.*
>
> *At the emergency department of the hospital where I was taken, it was recommended that I go to a crisis centre. That was the start of nine years of unfailing support from community organizations and four years of continuous fighting to obtain the necessary psychological and pharmaceutical assistance from institutions and psychiatrists.*[3]

She recounted the number of times and the variety of health care professionals to whom she has had to retell her story over and over again:

> *For years, I had to tell and repeat my life story to the following persons: an emergency nurse, the emergency psychiatrist, a medical assessor at the crisis centre, a psychosocial worker at that centre – they talked about my life history and constantly went back to the traumas, the painful things, and each time I had to start all over from scratch – a psychiatrist at the hospital crisis centre, a social worker at the hospital, an intake officer at the CLSC, a CLSC caseworker, a psychosocial worker at the CLSC and the CLSC family physician. It was extremely painful (…). I don't know how I managed to go on. There were also an assessing psychiatrist on duty at the hospital, six different psychiatric nurses and four different psychiatrists at the outpatient clinic – because they often change – a psychiatrist specializing in mood disorders who had a therapy group, a psychiatrist and three residents, whom she was training at the mood disorder clinic – and, lastly, three years ago, a psychiatrist who is still monitoring me and with whom I feel I have a privileged relationship.*[4]

She also talked about there being little or no integration of services and supports and the important role community-based organizations played in her recovery:

> *With the energy I still have, I have decided to get involved at the community and advisory level on the city's regional health board. If I had not had the community services, I would not be here to speak with you today.*
>
> *Yes, the institutions eventually helped me, the psychiatrists too, but they could also have killed me by making me relive the awful traumas I had to face. The duplication, rigid parameters and problems of approach at the institutional level must expand, and they have to work with the*

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[3] Loïse (9:19).

[4] *Ibid.*

community agencies to help the users of those services find the help they need.[5]

Loïse stressed the importance of addressing the stigma and prejudices associated with mental illness and addiction:

> *Since being diagnosed with my disease, I have lost the esteem of some members of my family. I have had to fight that, and many people have had to do that as well.*
>
> *(…)*
>
> *The deep and persistent prejudices that still exist in our society must be addressed on an urgent basis either through media campaigns or by other means.*[6]

With respect to the media, she noted particularly:

> *We organize press conferences for the community sector, for users, to explain the various diseases to people, but no journalists ever come. However, if someone who is mentally ill commits an indictable offence, the headlines read, "Schizophrenic kills wife," "Manic depressive man abuses his children."' And yet, I've never seen, "Cancer patient kills his wife," or anything like that. In this regard, the media don't help matters. There is work to be done. In a more educated, specialized population, where there are fewer prejudices, things are better, but it's still a very serious problem.*[7]

1.1.2 Ronald's Story

Ronald spoke to the Committee about his life with his wife, who suffers from schizophrenia. He spoke about the onset of her disease about a decade after they were married in 1959 to today, and about how ill-equipped he was to help her then. "I had no idea what was going on. I was not familiar with mental illness," he said.[8] He explained:

> *I was married in 1959, and the first disorders began in the 1970s. We already had three children.*
>
> *(…)*
>
> *I have accepted my decision to stay with her, for better or for worse.*

---

[5] Loïse (9:19-20).
[6] Loïse (9:20).
[7] Loïse (9:27).
[8] Ronald (9:20).

> *At the time, my wife didn't want to be hospitalized because, in her mind, there was no disease. She was not ill. Since the disease did not exist, I had to find a way to have her hospitalized.*[9]

Ronald explained to the Committee the processes he went through to try to get help for his wife:

> *I spoke about the matter with my attending physician, who told me: "There's definitely something wrong with your wife; you should have her examined." But that required papers from two psychiatrists. The attending physician undertook to find two psychiatrists who would sign the papers and have her hospitalized.*
>
> *Once the papers were signed by the two psychiatrists, she didn't want to go to the hospital. I told her: "You go to the hospital on your own, or the police will come and get you." I had to go get a piece of paper from the judge, and she agreed to be hospitalized.*
>
> *She was hospitalized for three months and attempted suicide a number of times. Someone stayed in her room 24 hours a day for three months to prevent her from committing suicide. Lastly, she left the hospital under medication. At that time, she was taking neuroleptics (…). The crises gradually disappeared completely. The positive side of the disease, that is to say the hallucinations, religious delusions and so on, disappeared. But what appeared at that point, and what the drugs don't work on, was the negative side of the disease, that is to say the social side, the lack of self-confidence and personal hygiene, the feeling she had that she was worthless and that she was absolutely incapable of succeeding at anything, and so on. It's so subtle because she believes she's good for nothing and a failure; she also can't accept anyone loving her or telling her that she's good and able to succeed; that would be betraying what she actually believes.*
>
> *She definitely let herself go.*[10]

He told the Committee that, as his wife's disease progressed "we lost our friends and no longer had any social life, love life or sex life. Ultimately, we no longer had anything."[11] Talking about his life with his wife today, he said:

> *At home, my wife's disease and symptoms have disappeared. The psychiatrist sees my wife once every six months, but things aren't better. The entire negative side of the disease has worsened. Now she hardly ever*

---

[9] Ronald (9:20-21).
[10] Ronald (9:21).
[11] Ronald (9:21).

> *gets dressed, she has no initiative and she is interested in nothing. She registers for courses in literature and painting, but always drops out. She comes home discouraged.*
>
> *The children do not come to the house because they cannot cope with the situation.*[12]

Ronald felt alone in that there was little support available to help him understand his wife's illness and manage the situation properly:

> *At the time, I was alone. The situation was difficult, and I had no help. I had to deal with all that. How I managed to get through it all, I don't know. […] there was no violence. It was more emotional. My wife withdrew from the world. There was very little violence. It occurred on a few occasions. There were some suicide attempts because she had so little self-confidence. But it was very hard on the children.*[13]

Ronald also talked about his difficulty in obtaining the medical certificate required for eligibility tax breaks:

> *(…) at first, the psychiatrist signed a letter for me giving me a tax exemption, but the second one did not do that, and I am no longer entitled to the tax break. That is hard to take. Everyone thinks she's doing well because there's no obvious sign in her everyday life, except for her physical appearance.*[14]

He talked about a pilot project dealing with individualized care plans which, in his view, can only work with strong collaboration among the various mental health care professionals who are involved:

> *I remember an experiment that was conducted in which they talked about individual service plans. The mentally ill person was supposed to be the central person, and, around him or her, there was a team, the psychiatrist, the nurse and so on. That didn't work because they weren't able to bring the entire team together.*
>
> *Now it works in small organizations such as ours, where the nurse agrees to cooperate and the doctor as well.*[15]

In response to what was happening to his wife and family, Ronald went into volunteer work. Discovering that the best way to help relatives is to set up an organization to take care of individuals with mental disorders, he and other volunteers founded Le Pavois, an

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[12] Ronald (9:22).
[13] Ronald (9:30).
[14] Ronald (9:22-23).
[15] Ronald (9:36).

organization that strives to achieve social reintegration and rehabilitation through work. At Le Pavois, individuals with mental illness re-socialize through office workshops and cooking workshops. Once they have succeeded in a controlled environment, integration officers visit employers and try to find them internships and then jobs. Le Pavois also runs a second-hand clothing store, a photocopying service and a cafeteria at a provincial health and social service center. Ronald also stated:

> *These social businesses are an intermediate step enabling our members to move from Le Pavois to the actual labour market. We have realized that it is far too stressful for them to go directly into the labour market. Most are incapable of returning to the labour market.*[16]

1.1.3 Murray's Story

Murray spoke to the Committee about his son, affected by paranoid schizophrenia. On May 28, 2002, while a patient at the Royal Ottawa Hospital, he left the hospital grounds and found his way onto the Queensway (on a lane reserved for buses) where he was struck and killed by a city bus. He described his son prior to the onset of his illness in these words:

> *Before the onset of his illness, approximately six years ago, our son was an honours student, played in the school band and toured Canada and the United States as a member of it, was a first division soccer player, had many good friends and a wonderful, long-term girlfriend, and was a soul mate to his younger sister. In short, he had just about everything going for him.*
>
> *Things gradually started to go horribly wrong as he descended into the abyss of slow onset paranoid schizophrenia, the mental health care system and social services system.*[17]

He described to the Committee a health care system equipped only to respond to crisis:

> *Invariably, when things really went wrong it was because we could not access the health care system in a timely fashion for reasons of lack of beds, emphasis on community treatment, a missed opportunity for him to go in voluntarily, or shortage of staff and insecure facilities. It seemed impossible to circumvent a crisis. The system only responded to the crisis and only after weeks of drug rebounding, deterioration and many family pleadings and warnings to caregivers. Not once during the many times he was discharged from hospital was he discharged in a stable condition with insight and compliance with medication.*[18]
>
> *(…)*

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[16] Ronald (9:22).
[17] Murray (9:14).
[18] Murray (9:15).

> *Even when he was in the hospital there were serious problems to deal with: the failure to obtain service, preparation for certification hearings, doctors meetings, visits to hospitals, Ontario Disability Support Program filings, researching medication and treatment, attendance at support groups, and unsettling telephone calls from our hospitalized son. We worried about his possible flight from the hospital and feared the possibility of long-term brain damage due to the use of inappropriate medications.*[19]

Murray stated that the lack of services and supports had a serious negative impact on his son. He talked about the stress this placed on the entire family, their social network and finances:

> *As a consequence, he had unpredictable behaviour, outbursts of frustration and violent behaviour at any time of the day or night. This severely traumatized family members. We feared physical injury to our son and to family members, even while sleeping. We slept in shifts. The physical damage to our home was extensive and costly.*
>
> *(…)*
>
> *These fears created high levels of stress over the years [that] combined to result in mental and physical exhaustion, and worse.*
>
> *There was no such thing as a social life. We could not take him with us because he could not tolerate elevated levels of sensory input for any length of time. We could not leave him at home and a sitter was out of the question.*
>
> *The pain and suffering of my son's siblings included the loss of an entire university year, the trauma of police incursions into our home and the fear of their brother being injured or killed by police during numerous forced hospitalizations. Our daughter lost a soul mate and our surviving son will spend the rest of his life without his much beloved brother.*
>
> *This illness (…) limited our opportunity to earn a living. I lost business income and was fired by my employer due to low production. I managed only to maintain my existing client base. I could not gain new clients for three years. I often could not keep planned appointments, as I could not leave the house when my son was at home. I was fearful of arranging appointments in the evenings because I would have to leave my wife and*

[19] Murray (9:16).

> *daughter at home alone with my son. There was a high burn rate of our savings.*[20]

Murray also talked about how frustrated his family was by the restrictions of privacy legislation which did not allow health care providers to share information with them about his son's illness:

> *Why is it that the medical profession is not allowed to share information with family members when it has been shown that family support is beneficial to the patient? The patient is on meds because his thinking is affected; yet the medical profession believes that sharing information with a family member must be a decision of the patient, who cannot make a reasonable or thoughtful decision.*[21]

He stressed the need to find an appropriate balance between the right of the patient to be treated and involuntary treatment:

> *When it comes to balancing rights with forcing medication, as a parent, you are very concerned about your child's life and well-being, and it is not a question of his rights. He has a right to treatment, and he does not realize he needs it. He has a right to life, although he is incapable of maintaining it himself. It becomes very clear when you reach the point where his life is endangered.*[22]

Murray raised a question about the appropriate level of government funding for the diagnosis, treatment and research into mental disorders in comparison to other diseases:

> *My understanding is that both federal and provincial health dollars are to be spent on the health of all Canadians. Why is it that the most vocal and strongest lobby groups get the most money? We have statistics that we can provide on that subject. Meanwhile, these vulnerable people cannot speak for themselves and are left by the wayside. There are no political points to be made in spending money on these groups.*
>
> *(…)*
>
> *The rights issue is on our list of things that should be dealt with. It falls outside of the normal legal framework. When dealing with someone who does not have capacity, it is very awkward.*

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[20] Murray (9:15-16).
[21] Murray (9:18).
[22] Murray (9:28).

> *There are varying degrees of schizophrenia and the people who complain about their rights may have a minor form of the illness and feel that they are being persecuted and dealt with unfairly. It is a difficult issue.*[23][24]

Murray also raised concern about the lack of early intervention for mental disorders in comparison to other illnesses:

> *What sense does it make when there are many guidelines to determine if your family member has heart disease, depression, diabetes and so on, but there are no guidelines to tell if somebody is suffering from schizophrenia? The schools simply assume there is a drug problem and this leads to long lags in the treatment. Early treatment is critical.*[25]

1.1.4 David's Story

This was the fist time David had agreed to share his personal experience with anybody. He stressed that it was not an easy task to recount his story and insisted on the importance of not disclosing his identity:

> *(…) I want to put a human face on autism by telling you a bit about our family experience. This is the first time I have ever done this. (…) I was told that you wanted to hear a personal story, and that is what I will tell you.*
>
> *(…)*
>
> *I will let it all hang out, and that is why I would rather that my identity not be disclosed. Mine is a very personal experience that bares deep personal values and issues. I am not sure whether this presentation will upset me or stabilize me.*[26]

David has a 31-year-old son living with autism. He described his son as follows:

> *My son is 31 years old. We did not know the extent of his disability until he was 15, which is quite unlike the situation with most people with autism. My son is not classically autistic. He is high functioning; he can speak; he can read; he graduated from high school..*[27]
>
> *(…)*

---

[23] Murray (9:28-29).
[24] Murray (9:17).
[25] *Ibid.*
[26] David (9:6).
[27] *Ibid.*

> *My son, Adam, had problems in making friends when he was a young boy. We did not know he was autistic. He did not show autistic symptoms when he was two or three, which is when most people demonstrate their autistic tendencies. We did note he was aggressive, particularly towards strangers, and particularly aggressive toward the friends that his brother Andrew would bring home. People with autism do not like changes. They are resistant to change.*
>
> *We sensed that school was becoming more stressful for Adam as he became older. When he became 15 years of age, he refused to go to school. Other children gave him a hard time. They made fun of him, and he found recess time to be extremely stressful. He became very agitated and angry. He would go out for walks and would return in a burning rage. He would get so angry that he would break windows and pull out light fixtures in our home.*[28]

David described in detail years of misdiagnosis, inappropriate therapies and the family's eventual discovery of what was wrong with their son. He recalled:

> *We had no choice but to have him taken to a hospital, where he was admitted and diagnosed incorrectly with bipolar disorder. That was because our medical system did not have the capacity to diagnose autism at the time. It is not much better today. It soon became clear that this diagnosis was not accurate. The children's hospital sedated Adam with medication but did not do anything to resolve his basic problems.*
>
> *We have gone through a number of traumatic experiences. One was the night we had a call at two o'clock in the morning to tell us that Adam had left the hospital. He had jumped through the window onto the roof and then taken a ladder down onto the ground outside the hospital. By the time we got to the hospital Adam had been found by the police and was being treated for hypothermia. He never explained why he had taken such drastic action to jump out the window and climb out and run on the loose in his pyjamas in the middle of the night, but he frequently expressed his anger at us for putting him in hospital. Later, in his anger, he would pull out light fixtures. He became so aggressive and out of control that at one point we had to have him hospitalized in an adult psychiatric hospital, which was quite inappropriate for him but that was the only option available because it was only the adult psychiatric hospital that had the ability to control his access and to keep him restrained.*[29]

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[28] David (9:8-9).
[29] David (9:9).

David recalled that, had he and his wife had known more about autism, they would have been better able to help their son:

> *At that time, there was very little understanding of autism in our community, so there were no resources that we could access. Our son was different in the sense that he was not classically autistic. Even if he were born today, he would not have been immediately recognized as having autistic symptoms because he did not portray all of the most common symptoms of autism. He could speak. There seemed to be no physical impairment of his speech.*
>
> *Had we known what we were dealing with, we would not have wasted so much time. We wasted a large part of his life. I am [ambivalent] in my answer to this one. I asked my wife, "Would we have been better off if we had known what we were dealing with?" At one point, we both agreed that we would not have tried so hard. If we had known our son had a disability, we might not have pushed him so hard, because we did push him. We pushed him to the point where we endangered our health. Much of the stress that came out in his physical violence was, to a large extent, because we were pushing him to do things. That created a situation where we were living in a very dangerous environment in our home. We worried about fires and other dangerous situations. We pushed out the envelope really hard. That is one side of it.*
>
> *The other side is that, had we known what we were dealing with, we would not have wasted all of this time with family therapy and medications that were more appropriate for people with bipolar disorder. We would have taken a much more intelligent approach to trying to come to grips with our son's problem. We would have sought good advice on how to deal with the problem. The fundamental problem was one of communication.*[30]

David also talked about the fear and anger the family lives with:

> *Autism is worse than cancer in many ways, because the person with autism has a normal lifespan. The problem is with you for a lifetime. The problem is with you seven days a week, 24 hours a day, for the rest of your life. My wife and I expect to have responsibility for Adam until we die. We lose sleep over what will become of him after we are deceased. Our financial resources are depleted, so our ability to provide for him is limited.*[31]

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[30] David (9:23-24).
[31] David (9:12).

He spoke about the strain this mental illness has put upon his entire family, including Adam's siblings, on his and his wife's work, on their finances and on their social network:

> *My son's ability to communicate is limited, which limits his ability to socialize and to work. He has never worked in his life, and his disability has had a profound impact upon his brother Andrew and upon my wife and myself. It was a big cause of concern for my parents and my wife's parents, all of who are deceased.*[32]
>
> *(…)*
>
> *Up to the point when our problems escalated out of control, we used to entertain friends and associates in our home. We would have them into our home for dinner. We used to reciprocate invitations. We found inviting strangers into our house was hard on both Adam and us. He did not want strangers visiting with us. He has been known to go into the kitchen when my wife has been baking and dump everything on to the floor. That makes it difficult to prepare dinner. The result is, we hardly ever had friends in for dinner. We do not invite them and they do not invite us. Home is not necessarily a haven when living with a person with autism. (…) Having a family member with autism is a lonely, traumatic experience.*[33]

David also explained how the family copes with the lack of resources for adults with autism:

> *The problem with autism is that the family has to bear the full burden of responsibility, financially, emotionally and in every other way. Our family is bearing the full burden of this disability. We receive no help financially or medically. Because our son is high-functioning, government requires that he apply for support, sign the documents, and that, when the government decides that there is a renewal required for the application, Adam has to fill this out.*
>
> *He does not do it. We did have him on a small income support payment, but he was required to reapply. He delayed and he has now been cut off. He does not have the skills required to maintain access to support, but he is too high-functioning to have us appointed as his guardians to act on his behalf. We cannot go on vacation unless Adam's brother is at home. As I mentioned, he is a student at university and is unlikely to be spending much time at home in the future.*[34]

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[32] David (9:6).
[33] David (9:11).
[34] David (9:12).

With respect to community-based services and supports for adults affected with autism, David stated:

> *There are no services for adults with autism, except respite services for those who are lower functioning. Respite means babysitting, and the people who do respite work are paid minimum wage. After school, there is no structure in the life with a person with autism; there is just an abyss. The prospect of employment is remote without a lot of help, and the family has to shoulder the full burden.*[35]

David stressed the importance of recognizing that mental health is as important as physical health and that mental illness should be treated with the same sense of urgency as physical illness. He believes that the federal government should play a major role in achieving this:

> *There is no difference between someone who has a mental illness and someone who has a physical illness. That is the key question: Are we treating people with mental disorders with the same urgency that we treat people with physical disorders? I do not think we are. That is the fundamental question here. There is an equal public policy role for government in dealing with mental disorders. How do we do that? How do we change the environment out there?*
>
> *The reality is that a mental disorder does not have a sense of urgency because it is recognized that people with mental disorders will be around tomorrow, whereas people who have heart disorders or cancer have to be treated today because they may not be around tomorrow. That clouds the whole issue. We must do something about it.*
>
> *One thing we could do — and this is where your committee can play an important role — is for the Government of Canada, with regard to the transferring of funds for mental disorders, to put those funds in a fiscal envelope to be used only for mental disorders. That money cannot be used for anything else.*[36]

1.2 COMMITTEE COMMENTARY

> *You have to put a human face on it, as the chairman said. I do not know a better way to do that than to have people like the four people at this table stand up and be counted, to say things that are very difficult to say. That is why I think what they have done here today is very courageous.*

[35] David (9:13).
[36] David (9:37-38).

> *To be honest with you, I do not know another way to do it. People do not understand. Politicians do not understand. They have no understanding of what we go through. How do you provide that understanding? It is only when they have a family member or some relation who has this dilemma that they can relate to it. It is very difficult to understand unless you walk in our shoes.*
> *[David (9:34)]*

The Committee very much appreciates the sincere, thoughtful testimony made by David, Murray, Loïse and Ronald. Somehow, just saying thank you to them does not seem to be enough. We appreciate how difficult it was for them to come and talk with us the way they did.

Together, these four witnesses painted a picture for the Committee of the stigma, frustration, fear and anger that affect individuals with mental illness and addiction and their families, of the impact of their diseases on parents and siblings, on their social lives and on their finances. By telling their moving stories, which were very important to the Committee's work, these witnesses helped shed light on many issues such as access to care, lack of communication or collaboration between health care providers, a lack of resources and patient rights and privacy issues. All these issues are addressed in the following chapters of this report. We do so in the hope that our work will ultimately be of help to David, Murray, Loïse and Ronald and to the thousands of people like them across the country.

CHAPTER 2:
MENTAL DISORDERS TOUCH THE LIVES OF ALL CANADIANS

Mental illness hits everyone — rich, poor, male, female — of every race and creed.
[J. Michael Grass (17:43).]

INTRODUCTION

One of the reasons behind the Committee's decision to undertake an in-depth study of issues relating to mental health, mental illness and addiction in Canada was recognition by our members of their profound effects on our society: mental illness and addiction affect individual Canadians of all ages in all segments of the population. The initial phase of the Committee's study, that has formed the basis for this report, has only reinforced that recognition.

Perhaps it is a neighbour who has Alzheimer's, a sister who has experienced post-partum depression, a colleague who is on stress leave from work, an uncle struggling with alcoholism, or friends talking about eating disorders, suicidal thoughts, or childhood abuse. It has been estimated that one in five Canadians will be affected at some point during his or her lifetime by a mental illness or addiction. It is difficult to imagine a day going by without *all* of us, knowingly or unknowingly, being in a room, on a bus, at a restaurant, or elsewhere, with someone who has experienced a mental illness or addiction.

This chapter builds on the personal stories of Chapter 1. It describes the impact of mental illness and addiction on individuals, on families and other care providers, as well as on their communities. While seeking to expand the understanding of what it is like to live with a mental disorder oneself or to live with someone affected by one, it also presents other facets of the impact of mental illness and addiction that stretch beyond the borders of families and households to encompass schools, offices and the many other places where Canadians interact.

The focus of this chapter is on individual perceptions. It provides brief glimpses into the lives of some of the many Canadians who live with mental illness and addiction every day. The excerpts are primarily from evidence contained in letters and e-mails sent to the Committee, from public testimony, as well as from a number of site visits by the Committee, supplemented by information drawn from relevant websites. In many instances, the stories are those of loss – loss of jobs, of family, of self-respect – and of struggling to obtain needed care. But there are also positive stories that tell of gains – of knowledge of self and of social, medical and legal services and supports that can help individuals affected by mental illness and addiction to live productive and contributing lives.

The voices are many and fragmented. They come from individuals who use services and providers who give them. They are from mothers who care for children, and husbands who care for wives. They are from teachers who build social and other skills, employers who

adapt their workplaces, and community leaders who work to restore neighbourhoods. They are from people everywhere in Canada.

2.1 INDIVIDUALS LIVING WITH MENTAL DISORDERS

2.1.1 A State of Mind

Many individuals living with mental disorders offered comments on their own mental states, emphasizing particularly the way they are perceived by the larger society to fall under the label "crazy." One ended a long letter about his precarious, unsettled life with: "(…) and I'm not as crazy as people think I am."[37] Another remembered her first thoughts when diagnosed with a psychosis at age 16 years as: "Oh my God! I can't be one of those crazy people, with no home, no family, and no life."[38]

Even those who have the support of family and friends, who live in comfortable homes with regular meals and clean clothes, and who can access new therapies and the best drugs, talk about their sense of shame and failure, particularly as they see others accomplishing the goals they have set for themselves. They worry about the possible re-emergence of their symptoms. They know that they are viewed differently from other people and feel the loss of being "different". In the words of one woman, "it's worse for us because we know what we're missing."[39]

Pat Capponi, author, journalist, speaker and social activist who also refers to herself as a psychiatric consumer/survivor, told the Committee:

> *A mental patient is just that in the eyes of many. We are not entitled to be full human beings behind that label, not expected to have basic personalities that mirror those in the greater population, good and bad and everything in between. A schizophrenic is a schizophrenic, and every action is attributed to that disease and not to the underlying nature of the individual.*[40]

Many people associate mental illness and addiction with disgrace; affected individuals are often discredited and, unfortunately, set apart from the rest of society. Sadly, stigma – whether the result of self-stigmatization or public stigmatization – is the cause of much of the distress those individuals with mental illness and addiction experience in their daily lives.

2.1.2 A Perpetual Cycle

Individuals affected by mental illness and addiction pointed out also how the perpetual cycle of problems they confront makes it difficult to integrate themselves into the broader community and to remain there, leading meaningful and productive lives. Pat Capponi told the Committee that medication is often seen as the easiest single solution to the complex

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[37] Letter from John, no date.
[38] Letter from Tara, 28 November 2003.
[39] As reported by Pat Capponi, Brief to the Committee, April 2004, p. 2.
[40] Pat Capponi (7:49).

issues involved, but that this sometimes does little to address the real and continuing underlying concerns:

> *(…) funding has increasingly gone to keeping discharged patients in chemical straight jackets for the comfort of the mainstream community. If a client is depressed and upset that his life is so narrowly constricted, his medication is increased. If he is fearful of a landlord or unable to sleep in an over-crowded room, his medication is increased. If poverty leaves him hungry and restless, his medication is increased. And if he has the remaining life inside his body to be angry, the dosages will ensure that that anger is forgotten.*[41]

She also told the Committee about how the gulf between the haves and the have-nots is widening, creating particular difficulties for those living with mental illness and addiction:

> *More people are using the food banks and so the share for the chronic mental patient has been dramatically reduced. A landlord will rent his house to people who he thinks will be less disruptive than a former mental health patient. People get squeezed out. Shelters prefer to house immigrants or battered women because they will not be seen as potentially disruptive. The stigma about the crazy people that we are exists.*[42]

Again, the stigma associated with mental illness and addiction may deny affected individuals even such basic rights as shelter and housing.

2.1.3 An Uncoordinated State

Individuals concerned with all aspects of mental health and addiction emphasized the need for those living with these conditions to have access to a continuum of services and supports that includes affordable housing and short-term intensive support services for people immediately after their discharge from hospitals, shelters, or jails. But they also stressed that the delivery of these services and supports must be much better coordinated across the entire mental health and addiction "system" and better integrated with the services offered by the broader social sector.

One example illustrating the absence of that coordination involved a patient/client living on welfare with some social security money to rent an apartment as well as meet some other expenses. This person had a relapse, spent 15 days in an acute psychiatric unit, and as a consequence lost both the social security funding and his apartment. As a result, the government had to accommodate him in a more expensive hospital bed until a space in the community became available.[43]

Another example illustrates where early intervention and subsequent coordinated preventive action could have made a difference. A 25 year old man in Vancouver, in and out of foster

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[41] *Ibid.*
[42] Pat Capponi (7:70).
[43] Julio Arboleda-Florez, (11:69).

care and jails since he was 13 years old, was diagnosed for first time with bipolar disorder While on remand for three months for a break and enter committed to secure money for drugs. He was not tried but released on conditions, but, unfortunately, before long found himself back in jail. One condition of his release was that he continue taking three drugs: Ritalin, an antidepressant and methadone. Taken together these made him "hazy". He was provided $28 a week for food and accommodation, and found a small room on the downtown eastside. He could not afford transit, however, and had no support system in place. Within two weeks he had broken his probation after trying to connect with his father who had just been released from William's Head prison on Vancouver Island.[44]

Older Canadians are affected by many mental health issues that affect both their independence and the sense of control they have over their lives. For example, both for individuals with dementia and many others, a loss of access to transportation can mean the loss of contact with the outside world, of independence and of control. While public transportation may be an option for some, for others, it is simply not available. The Alzheimer Society recounted the stories of two individuals affected by the dementia. Trevor Jones, a career police officer was diagnosed at 57 years of age, while Jesse Roy, whose own mother had died of Alzheimer's, still lived in her own home and volunteered to help others when, at 77 years of age, she was diagnosed. Among their many concerns, both expressed anxiety particularly about the loss of independence when they lost their driving abilities. Trevor did not trust himself to take public transportation and was forced to rely on his wife and various friends for transportation. Jesse worried that having to give up driving would not only curtail her activities; ir would change her living arrangements and require her to move to a care facility.[45]

In all these cases, little or nothing in the way of a support system was available. Support services were either not available or not integrated in such a way as to providing the affected individuals with the desirable continuum of care.

2.1.4 An Underserved State

The provision of adequate services and the ability to access them by those in need was one of the most crucial issues raised by all individuals living with a mental disorder. One young person wrote: "I credit my good health and success in life to a revolutionary treatment approach for youth experiencing their first break with reality…I can say with confidence that early intervention saved my life."[46]

Her letter went on to note that access to such life-saving programs is limited because they exist primarily only as research models in teaching hospitals:

> *"Even in Ottawa, the nation's capital, the First Episode Program is grossly under funded with a waiting list of one year. People suffering their first episode (of psychosis) flounder at best to try and secure treatment. Many are afraid to reach out for help, others plainly*

[44] Fax from Margaret, April 28, 2004.
[45] Alzheimer Society of Canada, Brief to the Committee, 4 June 2003.
[46] Letter from Tara, 28 November 2003.

incapable of doing so because of the effects of the illness itself. Families are left to try and deal with what is an impossible situation."[47]

The need for early detection and intervention in the field of mental illness and addiction is clear. Eearly intervention can interrupt the negative course of many mental disorders, lessen long term disability and help to reduce the burden on families and other informal caregivers as well.

2.2 THOSE CARING FOR INDIVIDUALS WITH MENTAL ILLNESS

2.2.1 Parental Fears

Parents are the primary advocates for the interests of children who enter any part of the health care system. When dealing with mental health care, parents confront the reality that their roles as advocates and as providers of care will be a long term one. They must act as a continuous buffer between the affected individual and an often hostile larger community. With young children, parents must seek out for themselves a network of appropriate services and supports both within and beyond the health care sector. The need to exert themselves on behalf of their children often never stops until they themselves are incapacitated by age or illness.

Witnesses told the Committee that many parents fear most what will happen to their children when they can act no longer as their advocates. Phil Upshall, President of the Mood Disorders Society of Canada and the National Director of the Canadian Alliance on Mental Health and Mental Illness, recounted the story of family friends: "My family had two friends who had people with severe mental illnesses, totally incapable of treatment, living with them. The big fear in those families was what would happen to their son or daughter when they go."[48]

One 76 year old woman wrote the Committee about her many fears for her son who had been institutionalized for psychiatric treatment. She worried about the effectiveness of the treatment and the side effects that she had observed in her son. She wanted an investigation of the living and other conditions he confronted, but could not afford to pay the necessary legal fees out of her monthly pension. She said: "I don't want to die while my son is a prisoner patient in that place…Because I've seen what they do to patients with no living relatives."[49]

Another mother wrote about her autistic adult son, his problems with sleeping at night and his need for her to be available always, to tuck him in and reassure him so that he could get back to sleep. She wrote:

I worry about Stephen in the long term and short term. Will we ever get any programs in place to help him? What if I get sick? What if my

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[47] *Ibid.*
[48] Phil Upshall (9:30).
[49] Letter from Amy, 3 October 2003.

> *cancer comes back? What will happen to him ultimately? Who will care for him as I do when I cannot, simply because I won't be here.*[50]

Families are often the principal resource and the sole support available to individuals with mental illness and addiction. Because of the limited resources available in the hospital sector and the community, it is parents who house, care, supervise and provide financial assistance to their affected children. As those who recounted their experience above clearly demonstrated, this can be a source of enormous tension and emotional stress.

2.2.2 Parental Advocacy

Parents are deeply concerned for the welfare of their children when they enter the health care system for the treatment for mental illness. As lay persons, they feel inadequately equipped with the knowledge and resources needed to deal with the many challenges they know lie ahead. They worry about their being an insufficient level of care and that the care that is available may not always be delivered with the sensitivity their loved ones require. They worry about the cost of additional specialized care and of legal advice. Many parents and affected individuals stressed the need of those living with mental disorders to have available to them dedicated advocates to help them gain access to appropriate housing supports, as well as treatment and care.

One mother spoke of her experiences of navigating around obstacles in the current system; she wanted assurances that family members would have a "first right of refusal" to be part of the decision-making team, to obtain information about the affected family member's diagnosis and treatment, to consider options about the care provided.[51]

Some witnesses pointed that children with autism or those suffering from Foetal Alcohol Syndrome and Foetal Alcohol Effects (FAS/FAE) require constant care. They emphasized that many parents and caregivers not only experience social and emotional isolation from family, friends and their communities, but they also carry heavy financial loads as well in their effort to get help. Pam Massad, speaking about FAS/FAE noted that:

> *In their attempts to access the required services and supports for their child, many families experience serious financial burdens. Many provinces and territories do not offer financial support for specialized health services, educational supports and legal supports.*[52]

The father of a three year old son, Steven, diagnosed at the Children's Hospital of Eastern Ontario (CHEO) on December 8, 2003 to be suffering from autism, wrote about the lengthy and costly experience of trying to obtain appropriate treatment. "It has been now 261 days since then and we are on waiting lists. We have not received either one cent's worth of medically necessary treatment or financial assistance so far."[53] His e-mail went on to point

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[50] Letter from unidentified woman, February 2003.
[51] Letter from Irene, 7 avril 2003.
[52] Pam Massad (13:7).
[53] E-mail from Andrew, 25 August 2004.

out that the family had resorted to private care out of necessity, and now faced out of pocket costs of about $50,000 a year.

2.2.3 Parental Survivors

Parents may outlive their troubled children. While survivors of suicide speak of the desperate need to do something urgently to stop their "needless, unspeakable pain," those who are left behind after successful suicides are devastated by the loss of their loved one. Diane Yackel of the Centre for Suicide Prevention pointed out that each day, there are 10 more families in Canada "whose lives were unalterably changed because a father, a son, a sister, some family member, with some degree of intentionality, chose to die by suicide."[54]

She recounted the tragic stories of four mothers:

- The first concerned a woman whose two husbands had both died by suicide. "She came to see me at the point in time when her son- her only child – had hanged himself. Several weeks after her son's death, she was released from her work responsibilities because (quote) 'she no longer was a productive employee.' "
- Then there was the incapacitated mother. "She was frozen in time, unable to sleep anywhere but on her chesterfield near the front door of her home. This was the chesterfield from which she last saw her son, and from where she heard the gunshot. Perhaps, just perhaps if she stayed there long enough, he might come back through that front door again, and she would have a second chance to stop him from going into his bedroom and shooting himself."
- And the Aboriginal mother "whose 19 year-old daughter lay down on the railway tracks when life became too difficult for her to go on."
- And yet another mother, herself a widow, "who discovered and had to cut down the body of her 14 year old daughter hanging in their house."[55]

It is truly not possible to comprehend and convey the profound anguish of those left in the aftermath of suicide. The central message survivors of suicide have conveyed to the Committee is the need for a comprehensive suicide prevention strategy that includes both early identification of suicidal behaviour and crisis management.

2.3 THOSE PROVIDING MENTAL HEALTH AND ADDICTION SERVICES

2.3.1 Provider Access

In mental health, most of the many gatekeepers to the "system" are health care professionals who deliver treatment; others, however, such as teachers and social workers, also provide access to necessary services and supports. In Canada, access to such services and supports is unevenly distributed. Shortages are evident everywhere, but they are particularly severe in certain parts of the country.

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[54] Diane Yackel (6:47).
[55] Diane Yackel (6:46).

One brief submitted to the Committee highlighted the hardship afflicted on individuals with mental illness and addiction by restricted access to providers:

> *In Yukon, for example, there is at present no resident psychiatrist at all. The result is that people are forced to travel far from their homes to receive needed services – a hardship (ironically dubbed "Greyhound Therapy") that is doubly stressful for someone dealing with a mental health problem.*[56]

Providers told the Committee that they can often correlate at least part of the problem faced by individuals with mental illness and addiction with the physical and socio-economic conditions in which they live. One psychiatrist who provides home visits talked about the lives of some of her patients:

> *A significant number of my patients do not have a method of transportation and we are a large rural community spread over a vast area. Significant numbers of my patients live with many extended family members in inadequate housing; some homes still have dirt floors and no indoor plumbing or source of heating in the winter other than a woodstove.*[57]

She also recounted how it took almost six months for an older man with untreated paranoid schizophrenia to develop a relationship with her through his doorway before he felt comfortable enough to invite her inside with him.[58]

These stories point to the need for addressing the special mental health challenges faced by under-serviced rural and remote communities across the country.

2.3.2 Teachers and other School Service Providers

The role of teachers, schools and others in the early detection of mental disorders received considerable attention during the Committee's hearings. Many witnesses emphasized the importance of schools in early detection so that mental health problems and illnesses can be addressed before they cause lifelong negative effects. Several witnesses made connections between observed problems with reading and writing and psychological distress and/or mental disorders. As Tom Lips from Health Canada pointed out with respect to literacy, "there may be mental health reasons that contribute to illiteracy. As well, there are mental health impacts to being illiterate."[59]

At the same time, witnesses recognized that, although school remains the place where children spend most of their time and acquire many of their adaptive social skills, the current reality is that the resources available are thinly streched, making appropriate intervention more difficult to provide. Teachers face larger classes than they used to; this makes the

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[56] Canadian Mental Health Association, Brief to the Committee, June 2003.
[57] Dr Cornelia Wieman (9:53).
[58] *Ibid.*
[59] Tom Lips, Health Canada (11:25).

identification and confrontation of students with more and complicated individual problems extremely difficult. The services provided to schools by nurses, psychologists and social workers have also been significantly reduced. Some treatment approaches are so fragmented that they actually end in the middle of the school year.

Children with Attention Deficit Disorder (ADD), Attention Deficit Hyperactivity Disorder (ADHD), and learning disabilities have problems with impulsivity, attention and managing their behaviour. They may also have difficulty reading, distinguishing sounds and understanding the teacher.

The Committee heard that in Toronto the waiting list just for diagnosis in the publicly funded system is 18 months – almost 2 school years. Private access is available within a week or two to those who can afford $2000 for the services of a psychologist (of which approximately $300 may be covered by employer-sponsored insurance).[60]

Diane Sacks, President-Elect, Canadian Paediatric Society, pointed out how many children with ADD, ADHD and learning disabilities mask their difficulties until junior high school when they begin to fail:

> *They fail at a time when, for many, they feel that their bodies are also failing them. They are not strong enough, thin enough or definitely not tall enough. The pressures are enormous. Poor social skills, which go along with this condition, now cause rejection and peer conflicts. How can a failing, "dummy" teen with poor social skills, which is what untreated ADHD looks like, form the peer group we talked about as one the essential tasks of adolescence? He cannot. Self-esteem issues arise. This is directly related to acting out, bullying and problems with the law.*[61]

The fact that the onset of most adult mental health disorders occurs during childhood points, once again, to the need to devote more resources to early detection and intervention. Schools must be recognized as key players in the provision of mental health services and supports.

2.3.3 Primary Health Care Providers

The Committee was struck by the number of witnesses who talked about the significant breadth and range of services needed. Some pointed to the need for more training for primary care physicians in identifying mental disorders and in securing earlier interventions. Others talked about roles for nurse practitioners, social workers and psychologists. Many insisted upon the need to combine physical and mental care as part of the care continuum, pointing out how too often we treat the mind and the body differently, almost as if they were entirely separate entities.

The Canadian Psychological Association pointed to the particular psychological issues facing different individuals at different stages in their lives, such as:

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[60] Diane Sacks (13:53).
[61] Diane Sacks (13:51).

- a twelve year old who must adapt to a diabetic regimen that involves injections, daily blood testing, and dietary adjustments;
- a middle-aged man having survived a near fatal heart attack whose family members are obliged to modify their behaviours and relationships;
- a family caring for a parent with dementia at home;
- or a mother facing her demise from non-Hodgkin's lymphoma with the prospect of leaving behind two young children.[62]

In this vein, Dr. Cornelia Wieman, a psychiatrist from the Six Nations Mental Health Services (Ohsweken, Ontario), expressed concerns about adopting a narrow biological approach to mental illness. She provided an example that illustrated why simply prescribing an antidepressant for a patient would have been an inadequate response:

> *(…) I have a patient who last year lost a son to suicide while he was in police custody. The same year, she was diagnosed with kidney cancer and underwent to removal of her kidney by surgery. Her youngest daughter, aged 14, has coped with her brother's suicide by engaging in extremely risky behaviour including engaging in substance abuse, unprotected sexual activity and staying away from the home for days at a time. This woman has been on medical leave from work, which has caused a great deal of financial stress. She also has several extended family members living in her home. She is a widow with few social supports.*
>
> *Using this patient as an example, it would be unrealistic of me to simply prescribe her an antidepressant medication and reassure her that over time she will feel better. However, by prescribing her an antidepressant as well as activating a number of psychosocial supports, including counselling, and after working with her quite intensively over the period of a year at our clinic, she is finally feeling better. She returned to full-time employment this month.*[63]

She also pointed out that as a fee-for-service physician, she only gets paid for direct patient contact and not for time spent conferencing with other service providers about shared clients.

The discussion the Committee had with these witnesses suggests that we must re-think the way we address mental illness in relation to physical illness. We must also address the appropriate balance between a narrowly defined biomedical approach and psychosocial intervention. Appropriate incentives must be developed to ensure that health care providers can devote the time required to address the specific, usually time-consuming needs of individuals affected by mental illness and addiction.

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[62] Sam Mikail and John Service, *Presentation to the Commission on the Future of Health Care in Canada*, Ontario Psychological Association, 11 April 11 2002.

[63] Dr. Cornelia Wieman (9:54).

2.3.4 Provider Distress

Mental health professionals face their own anxieties. They are not always able to address the needs of their patients and their families as fully as or in ways they would like. In some instances, this is the result of a lack of sufficient resources; in others, they are aware that diagnosing a mental illness may require them to treat the individual and their family differently than if the problems were physical in nature.

One paediatric specialist spoke about gains made in the methods for diagnosing many childhood conditions and the insufficiency of research into methods for prevention and treatment. She observed that the search for appropriate services can become a major undertaking when:

> *(…) services that provide treatment are seriously underfunded and leave families scrambling for the few spaces that are available. Fragmentation of services mean these families and their primary care provider must look for new options almost on a yearly basis."*[64]

Other providers pointed out that it was not that long ago that treatment methods and attitudes we now find reprehensible were standard practice. For example, Dr. Michel Maziade, Head, Department of Psychiatry, Faculty of Medicine, University Laval (Quebec), stated:

> *In the 1950s and up until the late 1960s, psychoanalysis was very prevalent and everything was environmental. It is as if the brain did not exist at all. If you look at papers published at that time, all those disorders – schizophrenia, autism, and manic-depressive disorders – were the fault of the mother. It was always because the mother was lacking in education.*
>
> *(…)*
>
> *In those days, we accused people. I am a practising child and adolescent psychiatrist and I did that myself as a resident in the early 1970s. I was giving the parents the diagnoses for this terrible disorder and instead of providing support to them, as one would if their child had a cardiac disorder, I was accusing them because I was suggesting that they go to psychotherapy to help the child, because something was missing in the relationship. That was terrible.*[65]

2.4 MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION AT WORK

2.4.1 Workplace Secrets

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[64] Dr. Diane Sacks, President-Elect, Canadian Paediatric Society, Brief to the Committee, May 2003, p. 1.
[65] Dr. Michel Maziade (14:32).

In some workplaces, individuals with mental illness or addiction may have access to some assistance in dealing with their problems, but with or without these supports, they may still feel compelled to keep their personal struggle hidden. All too often, the fear of losing one's job or of being stigmatized by one's colleagues is enough to prevent individuals living with a mental disorder from seeking treatment. The Committee heard that it is common for employees to blame themselves and remain silent when they become depressed or unable to meet their employers' expectations because of a mental health or substance abuse problem.

Individuals tend to keep personal issues to themselves sometimes with negative consequences for their future employment as well as their well-being. These stories were brought to the Committee's attention. For example:

> Michael Koo, 34, says he was devastated when his coworkers complained in a performance evaluation that he wasn't pulling his weight. But Koo says he didn't feel comfortable explaining that a major depression was the reason for his low productivity. "My thought was, 'I can't afford to let them know what was going on, 'cause I'll lose my work'," he recalls, adding that stress leaves were associated with shame.
>
> Jane, a 30-year-old biologist, says she never discussed her clinical depression with her employer because she was afraid of losing respect. "People in the workplace want to be dealing with consistent and reliable colleagues," she says. "Being perceived as being vulnerable to depression limits how much people feel they can invest in you." Although she hid her depression, Jane says she lost all credibility with her company when her work began to suffer. "I would fall short on my commitments and was unable to justify my inability to produce according to expectations," she explains.[66]

These stories underline the importance of increasing awareness in the workplace about mental illness and addiction. An important step will have been taken once workplace managers have better knowledge of mental illness and addiction; they will be more willing to and capable of offering accommodation to those workers suffering from mental illness and addiction.

2.4.2 Workplace Successes

Individuals living with chronic mental illnesses have struggled to create a place for themselves in the workforce. Although traditional vocational rehabilitation has been available for decades, the development of "survivor" businesses is relatively recent. Pat Capponi outlined the struggle of the Ontario Council of Alternative Businesses to develop opportunities for chronic psychiatric patients in neighbourhoods where ratepayers, local politicians and businesses were hostile. She told the Committee that:

> *Our community began to see that there were possibilities out there for us. We began to have role models and leaders. We were achieving, breaking myths and assumptions about who and what we were, and we were forming a community. Chronic psychiatric patients showed commitment*

[66] According to information from http://www.heretohelp.bc.ca/.

> *in reporting to work on time. In acquiring new skills, lasting friendships were created and people grabbed every opportunity to learn from each other's experiences.*[67]

Work makes an important contribution to the process of recovery. Employment may reduce the frequency and severity of episodes of acute illness by providing structure, the opportunity for social connections and a fuller life. Regular remuneration also helps to reduce dependence on social assistance and the needs of individuals for mental health services and supports.

2.5 PEOPLE LIVING WITH MENTAL ILLNESS WHO ARE UNDER FEDERAL RESPONSIBILITY

2.5.1 Veterans

Concerns about the care of Canadian veterans took the Committee to Ste.-Anne-de-Bellevue Hospital in Quebec, the only facility for veterans still administered by Veterans Affairs Canada. Like many older Canadians, veterans prefer to stay at home as long as possible before entering long-term care facilities. By the time they enter such facilities, they can be quite frail. At Ste. Anne's anywhere from 50 to about 80 per cent of the residents are affected by some form of dementia. The loneliness and boredom experienced by many patients in such facilities are often exacerbated by mental disorder.

Bernard Groulx, Chief Psychiatrist at Ste. Anne's, outlined some of the specific issues encountered in caring for patients suffering from dementia:

> *These patients have severe problems. They wake up at night; they are disoriented in space, time and people; incontinent; they are emotionally unstable; they are hyperactive; frequently aggressive; have delusions and hallucinations; show a variety of agitated behaviour.*[68]

Specialized nursing approaches are essential to ensure a reasonable quality of life for these patients. The nursing staff at the hospital has to support families as well as the residents. A nurse at Ste. Anne's Hospital said: "I work a lot with the families, especially with Alzheimer's. I have to communicate with the families, make them comfortable and help them to understand the disease. (…) I support everything they have to go through, the hard times."[69]

2.5.2 Inmates

Inmates in federal correctional services fall under federal responsibility. Recent trends indicate that the proportion of the population of federal offenders with mental health and substance abuse problems is growing, even though overall prison admissions and

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[67] Pat Capponi (7:48).

[68] Bernard Groulx, Brief on Psychiatric Care at Ste. Anne's Veterans Hospital, provided to the Committee on 7 May 2003.

[69] Sarah Tyrrell, *Nurses – Always There For You: Caring For Families*, Veterans Affairs Canada, 2002.

institutional population have been in decline. Some, such as women and Aboriginal peoples, have particular needs.

Within Correctional Services Canada, the need for mental health treatment is acknowledged:

> *Mental health treatment for offenders is required if we want to reduce the disabling effects of serious mental illness in order to maximize each inmate's ability to participate electively in correctional programs; to help keep the prison safe for staff, inmates, volunteers and visitors; and to decrease the needless extremes of human suffering caused by mental illness.*[70]

Officials from the department also talked about the need to deal with offenders who require specialized mental health intervention in order to reduce the "revolving door" phenomenon:

> *There is what we call a revolving door between corrections, both federal and provincial, but also the community, where often people who are afflicted with mental health disorders find themselves in the criminal justice system. While mentally disordered offenders are often less likely to reoffend — including violently — they are more likely to return to prison due to a breach of their release conditions — often as a result of inadequate support while they are in the community.*[71]

This points to the need to develop better links between the federal and provincial governments and between the justice and the mental health service/support systems. Correctional Service Canada must do more to prevent the "revolving door" phenomenon.

2.5.3 First Nations and Inuit

Questions were raised concerning the inadequacy of access to individual counselling services for First Nations and Inuit patients under Health Canada's Non-Insured Health Benefits (NIHB) counselling program. The NIHB program supports clients "in crisis" or those who cannot access counselling through out-patient clinics funded by the province or who cannot pay for private counselling. But limited incomes, combined with transportation and access issues, mean that many individuals fall through the cracks.

According to Dr. Cornelia Wieman:

> *Presently, my patients can access individual counselling through the Non-Insured Health benefits program. (…) However, (…) the limit is 15 sessions with the possibility of renewing for a further 12. A total of 27*

[70] Françoise Bouchard, Director General, Health Services, Correctional Service Canada (7:53).
[71] Françoise Bouchard (7:54).

sessions for many people is not sufficient to help them adequately address their mental health concerns.[72]

Clearly, the NIHB program must be revised so as to better reflect the mental health needs of First Nations and Inuit peoples.

2.6 COMMITTEE COMMENTARY

Even with our somewhat broader look at the lives of individuals affected by mental illness and addiction the Committee is acutely aware that the preceding excerpts from the evidence received have only scratched the surface of what is a very large problem. It is impossible to fully enumerate the many groups of Canadians who are affected by mental illness and addiction and to portray fragments from all their lives.

In the remainder of this report the Committee has gathered together the evidence it has heard over the past 18 months. This is the first step in coming to grips with the enormous challenges that lie before us in developing a set of recommendations to improve the quality of life of those who are living with, and those who are directly or indirectly impacted by, mental illness and addiction. This includes all of us.

[72] Dr. Cornelia Wieman (9:55).

CHAPTER 3:
STIGMA AND DISCRIMINATION

3.1 INTRODUCTION

In the course of its hearings, the Committee heard from many witnesses about the enormous importance of addressing head on the problem of the stigmatization of, and discrimination against, individuals living with mental disorders. There was considerable discussion concerning how best to reduce stigmatization and combat discrimination, as well as over how to understand the relationship between these two phenomena.

There was widespread agreement on the absolutely central place occupied by these issues in considering how to improve access to and the delivery of mental health services and to enhance the mental health of Canadians more generally. Ms. Heather Stuart**,** Associate Professor, Community Health and Epidemiology, Queen's University, put it well in her testimony to the Committee:

> *We are in a community mental health model right now and so stigma and discrimination are the crux of the issue for us. They are our major barriers to the treatment of mental illness in our modern day. We expect, when we put people into the community, that the community will want them and nurture them. This is not happening.*[73]

The first section of this chapter looks at how to define the two phenomena, stigma and discrimination, how they are related, and some of the factors that contribute to their stubborn persistence. The second section explores the impact of stigma and discrimination on individuals living with mental disorders in order to better understand why many have described it as being worse than the burden of illness itself. The third section discusses the options and strategies that have been suggested to combat the stigmatization of individuals living with mental disorders and to reduce the discrimination they face. A section devoted to Committee Commentary concludes the chapter.

3.2 DEFINING STIGMA AND ITS RELATIONSHIP TO DISCRIMINATION

Two questions pervade the discussion of stigma and discrimination:

1. How does the stigmatization of individuals living with mental disorders relate to the discrimination they face?

2. Why is it so hard to change attitudes and reduce discrimination?

We will examine the second question in Section 3 of this chapter. As for the relationship between stigma and discrimination, some witnesses contended that the term stigma itself

[73] Second Session, 15:10.

tends to focus our attention on the wrong thing, and that it should be discarded in favour of talking in terms of discrimination. This was the view expressed by Ms. Nancy Hall, Mental Health Consultant:

> *I come from the school that calls it what it is, which is discrimination. In any of the other disability organizations in which I am involved, they do not use the word "stigma." It is a polite term. They use the word "discrimination." To me, discrimination is when someone with a mental illness is systematically treated differently from someone who does not have a mental illness.*[74]

The Committee nonetheless feels it is important to try to get a handle on what is meant by stigmatization. Although the relevant literature does not yield a single, universally-accepted definition that encompasses all the dimensions of this complex phenomenon,[75] stigma has variously been defined "as a sign of disgrace or discredit, which sets a person apart from others,"[76] and as "stereotypes that reflect a group negatively."[77] Ms. Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health, Canadian Institutes of Health Research, suggested to the Committee that:

> *…stigma might be seen as a veil over a person that prevents others from focusing on that person. There needs to be a way to lift that veil and take a look at the person and not see only things that are different about him or her.*[78]

Witnesses generally agreed that stigmatization involved attitudes, while, as Ms. Stuart said, "… the action is discrimination."[79] Dr. Julio Arboleda-Florèz, Professor and Head, Department of Psychiatry, Queen's University, put it this way:

> *…discrimination exists, but it is different from a stigma. A stigma concerns our attitude toward particular groups. Discrimination is a denial of legal entitlements that we all ought to be able access.*[80]

The connection between stigma and discrimination has been described in the literature as involving a number of overlapping elements that come together to form a continuum linking the development of negative stereotypes to actual discriminatory behaviour towards people with mental illness. Three key steps have been identified in this process:

1. Labelling or stereotyping

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[74] Second Session, 16:3.
[75] Bruce G. Link and Jo C. Phelan, "On Stigma and its Public Health Implications," Background Paper, National Institute of Health Stigma Conference.
[76] Peter Byrne, "Stigma of mental illness and ways of diminishing it," *Advances in Psychiatric Treatment* (2000) Vol. 6, p. 65.
[77] Patrick Corrigan and Robert Lundin, *Don't Call Me Nuts*, Recovery Press, 2001.
[78] Second Session, 16:10.
[79] Second Session, 15:27.
[80] Second Session, 11:70.

2. Developing prejudice

3. Practicing discrimination

Researchers have also distinguished between public stigmatization (ways in which the general public reacts to a group based on stigma about that group) and self-stigmatization (the reactions which individuals turn against themselves because they are members of a stigmatized group).[81] The following table provides an overview of the three components involved in the process of stigmatization of individuals living with mental disorders.

THREE LEVELS OF PSYCHOLOGICAL STRUCTURES THAT COMPRISE PUBLIC AND SELF-STIGMATIZATION

	Public Stigmatization	**Self-Stigmatization**
Stereotype:	Negative belief about a group, e.g. dangerousness, incompetence, character weakness	Negative belief about the self, e.g. character weakness, incompetence
Prejudice:	Agreement with belief and/or negative emotional reaction, e.g. anger, fear	Agreement with belief Negative emotional reaction e.g. low self-esteem, low self-efficacy
Discrimination: Behaviour response to prejudice	e.g., avoidance of work and housing opportunities	e.g., failure to pursue work and housing opportunities

Source: Amy C. Watson and Patrick W. Corrigan, "The Impact of Stigma on Service Access and Participation," a guideline developed for the Behavioural Health Management Project.

The development of stereotypes is a key part of the process of stigmatization of, and discrimination against, people with mental illness. Stereotyping involves using selective perceptions to place people in categories and exaggerating the differences between these various groups[82] ('them and us'). As with racial prejudice, stereotypes also make people easier to dismiss and, in so doing, the stigmatizer maintains social distance. In this regard, Ms. Hall also told the Committee that:

> *…as [a] Mental Health Advocate, nine out of ten people told me that once their diagnosis was acknowledged, once they were open about their diagnosis, people treated them systematically differently.*[83]

Stigmatizing stereotypes can be so strong that stigmatized people are thought to "be" the thing they are labeled. For example, some people speak of persons as being epileptics or schizophrenics rather than describing them as having epilepsy or schizophrenia. This is revealing with regard to mental illness because it is different for other diseases. A person *has* cancer, heart disease or the flu — they are one of "us," a person who just happens to be

[81] Amy C. Watson and Patrick W. Corrigan, "The Impact of Stigma on Service Access and Participation," a guideline developed for the Behavioural Health Management Project.
[82] Byrne (2000), *op. cit.*
[83] Second Session, 16:16.

beset by a serious illness. But the person *is* a "schizophrenic." Thus the whole person is stigmatized,[84] as Ms. Pat Capponi told the Committee:

> *A mental patient is just that in the eyes of many. We are not entitled to be full human beings behind that label, not expected to have basic personalities that mirror those in the greater population — good, bad and everything in between. A schizophrenic is a schizophrenic and every action is attributed to that disease and not to the underlying nature of the individual or his circumstances. A person who is bitter and angry or who is addicted to crack or other drugs does something terrible and a chorus of voices is raised against all who carry the same label.*[85]

There are a number of stereotypes that are commonly identified in the literature as being widely held about persons with serious mental illness. These include:

1. People with mental illness are dangerous and should be avoided.

2. People with mental illness have brought their problems upon themselves and are to blame for their disabilities since they arise from weak character.

3. They are incompetent or irresponsible and require authority figures to make decisions for them.

4. They are viewed as childlike and needing parental figures to care for them.

5. Poor prognosis: the view that there is little hope for recovery from mental illness.

6. Disruption in social interaction: the view that people with mental illnesses are not easy to talk to and have poor social skills.

7. People with mental illness are not as intelligent as others.

However, a very recent (June 2004) scientific survey of public perceptions of mental illness that was undertaken in Houston, Texas, (the first of its kind in a major metropolitan area)[86] produced some interesting and encouraging findings, that the study's authors believe are representative of mainstream attitudes in the United States as a whole. In the words of the study:

> *The data indicate that an overwhelming majority of the public at large has come to believe that mental illness is essentially a physiological disorder that ought to be treated like any other physical illness. Only a*

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[84] Link and Phelan, *op. cit.* Also, Keith Brunton, "Stigma," in the *Journal of Advanced Nursing*, No. 26, 1997.
[85] Third Session, 7:49.
[86] *Public Perceptions of Mental Illness*: A report to the Mental Health Association of Greater Houston by Stephen L. Klineberg, Ph.d., Rice University (June 2004).

tiny minority continues to believe that mental illness can be attributed to any sort of morally relevant defect of character.[87]

Moreover, by 56 to 31 percent, more than half of Harris County residents believe that most people being treated for mental illness are able to live a normal life. A clear plurality (47 percent) would not be concerned if they discovered that a person under treatment for a mental illness were living in their neighborhood, and a majority (by 51 to 42 percent) would be willing to pay higher taxes to improve access to mental health services in the Houston area.[88]

3.2.1 Self-Stigmatization

Self-stigmatization can be defined fairly easily. It is simply agreeing with the negative attitudes about mental illness and turning them against oneself. Persons living with mental illness who believe that other people devalue and reject people with mental illness will most likely fear that this rejection will be applied to them personally. Such a person may wonder, "Will others think less of me, reject me, because I have been identified as having a mental illness?" Then, to the extent that it becomes a part of their worldview, that perception can have serious negative consequences. Expecting and fearing rejection, people who have been hospitalized for mental illnesses may act less confidently, be more defensive, or they may simply avoid a threatening contact altogether.[89]

Self-stigmatization takes the form of "I am" statements such as the following:[90]

- *I really am unable to care for myself.*
- *I'm dangerous and could snap at any minute.*
- *I'm no different than a child.*
- *I can't handle responsibility.*
- *Don't give me money. I'll only blow it.*
- *I'm a bad person.*
- *Who would want to live next to a person like me?*
- *Everyone can plainly see I'm weird.*
- *I'm not worth the investment of time and resources.*
- *I have a weak personality.*
- *I am not able to do…*

Self-stigmatization has a broad and deleterious impact on the person with mental illness, and can worsen the course of his or her disorder. Persons who self-stigmatize are likely to have

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[87] *Ibid.*, p. 27.
[88] *Ibid.*, p. 28.
[89] Bruce G. Link, Elmer L. Struening, Sheree Neese-Todd, Sara Asmussen, Jo C. Phelan, "The Consequences of Stigma for the Self-Esteem of People With Mental Illnesses," *Psychiatric Services*, Vol. 51, No. 12, December 2001.
[90] Corrigan and Lundin, *op. cit.*

more problems and disabilities with their mental illness than people who do not internalize statements like those above. One reason is that people who self-stigmatize have poor self-esteem, and with the deprivation of self-esteem comes a loss of hope. Not only do such people believe they are not worthy of respect now, they believe things will not change in the future.[91] Ms. Rena Scheffer, Director, Public Education and Information Services, Centre for Addiction and Mental Health, told the Committee that:

> *On an individual level, stigma not only leads to low self-esteem, isolation and hopelessness, but all of those characteristics also have been found to be predictors of poor social adjustment, so people end up in an endless cycle of poorer quality of life.*[92]

People with diminished self-efficacy due to self-stigmatization are less likely to apply for jobs or apartments ("Someone who is mentally ill like me can't handle a regular job!").[93] Other people with mental illnesses try to avoid discrimination by simply concealing their illness. In doing so, however, they can incur more stress from the continuous fear of being discovered, from endangering their mental health by tending not to take time off even when they need it, and from remaining ineligible for appropriate accommodations for their disability that might have made their working lives easier and more enjoyable.

Self-stigmatization is also one of the factors that contributes to the fact that many people with diagnosable mental disorders do not seek treatment. When people fear being identified and labeled as having a stigmatizing condition, they may then delay or avoid seeking treatment. According to Ms. Scheffer:

> *Estimates are that two-thirds of people who require treatment for a mental illness do not seek help, largely because they are either unaware of the symptoms or because of the stigma associated with the illness or its treatment.*[94]

Dr. Richard Brière, Assistant Director of the Canadian Institutes of Health Research Institute of Neurosciences, Mental Health and Addiction offered the following analogy to the Committee:

> *People who need help often do not seek help because they are ashamed of what happens to them. If we can do something about the stigma attached to mental illness, you will have people bragging about it the way they do about heart disease, saying, "Well, I had a bypass." People will tell their friends about that, but many people will not talk about their mental illness problem.*[95]

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[91] *Ibid.*
[92] Second Session, 16:20.
[93] Watson and Corrigan, op. cit.
[94] Second Session, 16:19.
[95] Third Session, 6:55.

Families of individuals living with mental disorders can also take on board the fear of stigmatization, with potentially serious consequences. In her brief to the Committee, Ms. Stuart referred to a case in which a mother whose daughter's mental health was deteriorating initially avoided treatment out of fear that her daughter would be branded as "crazy" by medical personnel. Ultimately, the police had to intervene when the daughter's worsening condition degenerated into a full-blown crisis.[96]

Stigma is not a new phenomenon. In fact, stigmatization of people with mental disorders has persisted throughout history.[97] In this regard, Ms. Scheffer, in her brief to committee, referred to the renowned sociologist Erving Goffman who pointed out that the word stigma in the original Greek was used "to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier."[98] While the exact content of the mythology that contributes to the stigmatization of people with mental illness has no doubt changed in the intervening millennia, it is striking the extent to which the term still describes a situation in which the person being stigmatized is being set apart (and de-valued) because of certain behavioural or physical traits.

In general, given the significance of the phenomenon of stigma, the Committee agrees with Mr. John Arnett, Head, Department of Clinical Health Psychology, Faculty of Medicine, University of Manitoba, who argued that the process of stigmatization itself has a real and profound impact on individuals living with mental disorders. This is how he put it in his testimony:

> *We know that stigmatization is characterized by bias, distrust, stereotyping and so on. It frequently reduces an individual's access to resources and opportunities for housing and jobs and ultimately leads to low self-esteem, isolation and hopelessness. There is no question that this occurs in many cases independently of the limitations that may be imposed by the mental health disorders themselves. In other words, stigmatization seems to have an independent capacity to do this.*[99]

3.2.2 The Role of the Media and the "Attribution of Dangerousness" to Individuals Living With Mental Disorders

One factor that has often been cited as contributing to the persistence of stigmatization of persons with mental disorders is media coverage. About a third of people identify the media — including print, radio, television, and internet-based news, advice, entertainment and advertising — as their main source of information about people with mental illnesses.[100] Unfortunately, the media often reinforces myths and stereotypes about people with mental

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96 Brief to the Committee, May 14, 2003, p.3.

97 *Mental Health: A Report of the Surgeon General* of the United States, 1999. Also, Paul E. Garfinkel and David S. Goldbloom, "Mental health — getting beyond stigma and categories," *Bulletin of the World Health Organization*, 2000.

98 Brief to the Committee, May 28, 2003, p. 3.

99 Second Session, 16:7.

100 *Discrimination Against People with Mental Illnesses and their Families: Changing Attitudes, Opening Minds*, A Report of the BC Minister of Health's Advisory Council on Mental Health, April 2002.

illnesses. Analysis of ways in which film and print represent mental illness have shown that, in particular, two of the stereotypes of persons with mental disorders are spread by these sources: people with mental illness are "homicidal maniacs who need to be feared", and they are "childlike and need to be protected by parental figures."[101]

Content analyses of American television have shown that over 70% of major characters with a mental illness in prime time television dramas are portrayed as violent; more than one fifth are shown as killers.[102] The typical newspaper depiction of individuals with mental illnesses shows them to be psychotic, unemployed, transient, and dangerous—not as productive members of a family or community. Similar studies of newspapers in Canada and Britain have shown that stories featuring violent acts by people living with mental disorders appear more frequently and are given greater prominence than articles containing a more positive portrayal.[103]

Negative conditioning towards people with mental disorders that encourage stigmatization may begin at an early age. The first study of children's television programming in New Zealand and the U.S., published in 2000, concluded that "the frequent and casual use of fundamentally disrespectful vocabulary such as crazy, mad, nuts, twisted, wacko or loony demonstrated for children that such expressions are acceptable or even funny."[104] The researchers responsible for this study actively looked for, but were unable to identify, any positive attributes associated with those who were depicted as mentally ill, nor did they find any understanding of the suffering that mental illness involves.

Some of the stereotypical depictions of people with mental illness that occur regularly in the media include the following: rebellious free spirit; violent seductress; narcissistic parasite; mad scientist; sly manipulator; helpless and depressed female; and comedic relief.[105] Most often such characters have no identity outside of their stereotypical "crazy" behaviour, and are primarily identified by an inferred mental illness.

At the centre of media accounts and public misperceptions is the attribution of a propensity for violence to individuals living with mental disorders. For example, 88% of participants in focus groups conducted by the Ontario Division of the Canadian Mental Health Association in the early 1990s believed that people with a mental illness "are dangerous or violent."[106] Not only is this a persistent problem, but it would appear that it is getting worse over time. In the United States, attitudes toward mental illnesses have apparently become more infused with concerns about violence associated with these illnesses. Thus, between 1950 and 1996,

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101 Corrigan and Lundin, *op. cit.*

102 Sampson, Stephanie "Countering the Stigma of Mental Illness", online newsletter of the Anxiety Disorders Association of America (ADAA), May-June 2002. Accessed on March 11, 2004 at http://www.adaa.org/aboutADAA/newsletter/2002_stigma.htm.

103 Scott Simmie, *The Last Taboo* (Toronto: McClelland & Stewart, 2001) p. 304.

104 Wilson, Claire, Raymond Nairn, John Coverdale and Aroha Panapa, "How Mental Illness is Portrayed in Children's Television" *British Journal of Psychiatry* (2000) 176, p. 442.

105 Dara Roth Edney, "Mass Media and Mental Illness: A Literature Review" (Canadian Mental Health Association, Ontario Division, 2004) p. 3.

106 Scott Simmie *Out of Mind: An Investigation Into Mental Health* (Toriono: Atkinson Charitable Foundation, 1999) p. 65.

the proportion of Americans who describe mental illness in terms consistent with violent or dangerous behaviour nearly doubled.[107]

According to the U.S. Surgeon General this attribution of a propensity towards violence on the part of individuals living with mental disorders is a key factor in explaining the persistence of stigmatizing attitudes:

> *Why is stigma so strong despite better public understanding of mental illness? The answer appears to be fear of violence: people with mental illness, especially those with psychosis, are perceived to be more violent than in the past.*[108]

It is important to note that this fear of violence rests on what is largely a misperception of the facts. In the words of a Health Canada sponsored study, "there is no compelling scientific evidence to suggest that mental illness causes violence".[109] Some American studies have argued that at most 4% of all violent incidents have any connection to mental illnesses.[110] At the very least this strongly suggests that public fears are largely misplaced, although they are clearly widespread.

There is, however, evidence that suggests that people who do not receive treatment for their mental illness, or who have concurrent disorders (that is, individuals who have a mental disorder as well as a substance abuse disorder) are more likely to be violent than the general population. Still, there is very little risk of violence or harm to a stranger from casual contact with an individual who has a mental disorder and the overall contribution of mental disorders to the total level of violence in society is exceptionally small.[111] In this regard, Ms. Scheffer commented that, "as a predictor of violence, mental illness ranks far behind other risk factors like age, gender and history of violence or substance abuse."[112]

And Ms. Hall noted:

> *…the sad thing is that actually people with mental illness are more at risk of self-harm. In my province, a person a day commits suicide. Even though the reality is that they are more at risk of doing harm to themselves, the public perception is that they are indeed a danger to others, which simply is not the normative truth…*[113]

Ms. Jennifer Chambers, Empowerment Council Coordinator, Centre for Addiction and Mental Health, also shared the following insight with the Committee:

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107 Sampson, op. cit.
108 Surgeon General, ibid.
109 Julio Arboleda-Florez, Heather L. Holley, and Annette Crisanti Mental Illness and Violence: Proof or Stereotype, Health Canada, 1996, p. x.
110 Simmie, op. cit., p. 49.
111 *Ibid.*
112 Second Session, 16:21.
113 Second Session, 16:16.

> *One difficulty of shifting the discussion of the association between people in the mental health system and violence is the circular reasoning that happens. If a particularly violent crime is committed people say, "Oh, that person is sick, psycho, weird," so there is no way to get outside the debate, even if they were not considered to have any particular mental or emotional disturbance before committing the act.*[114]

The influence of media accounts can be enormous, both for the public in general and for those living with mental illnesses. One British study found that over 20% of the people they interviewed were more inclined to accept the media portrayal of people with mental illnesses as being prone to violent behaviour than they were to believe the reality they encountered in their own interaction with people living with mental disorders. An example was given of a young woman who lived near a mental hospital just outside Glasgow, Scotland, that has since closed. She had worked there as a volunteer and mixed with the patients. She told the researchers:

> *The actual people I met weren't violent — that I think they are violent, that comes from television, from plays and things. That's the strange thing — the people were mainly geriatric — it wasn't the people you hear of on television. Not all of them were old, some of them were younger. None of them were violent — but I remember being scared of them, because it was a mental hospital — it's not a very good attitude to have but it is the way things come across on TV, and films — you know, mental axe murders and plays and things — the people I met weren't like that, but that is what I associated them with.*[115]

The same study concluded that the most powerful negative effect seemed to be in the area of self-stigmatization. As one interviewee put it: "You see a programme and it shows a very bad image of what it feels like yourself and then you think, 'What are my neighbours going to think of it?'"[116]

3.2.3 Stigmatization of Mental Health Providers

Not only do individuals living with mental disorders suffer from misrepresentation in the media, but so too do mental health practitioners. One study indicated that since the mid-1960s, only three films portrayed therapists sympathetically (*Good Will Hunting*, 1997; *Ordinary People*, 1980; and *I Never Promised You a Rose Garden*, 1977). In every other instance, mental health practitioners were portrayed in one or more of the following ways: neurotic, unable to maintain professional boundaries, drug- or alcohol-addicted, rigid, controlling, ineffectual, mentally ill themselves, comically inept, uncaring, self-absorbed, having ulterior

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114 Second Session, 15:14.

115 Greg Philo, "Changing Images of Mental Distress" Chapter 4 of *Media And Mental Distress*, edited by Greg Philo (Longman: 1996), accessed at http://www.gla.ac.uk/Acad/Sociology/mental.htm on March 11, 2004.

116 *Ibid.*

motives, easily tricked and manipulated, foolish, and idiotic.[117] Such portrayals tend to convey the idea that helping others is an unworthy vocation requiring little skill or expertise.

Witnesses repeatedly indicated that stigmatization affects those who provide care and services to individuals living with mental disorders. Dr. Gail Beck, Acting Associate Secretary General, Canadian Medical Association, remarked that, "I regularly hear jokes that I am not a real doctor. That is not related to what I do in practice; it is related to the fact that there is a stigma and discrimination about the kind of illnesses that I treat." And Dr. Rémi Quirion, Scientific Director of the Canadian Institutes of Health Research Institute of Neurosciences, Mental Health and Addiction, told the Committee that:

> *Psychiatrists are still stigmatized compared with the other types of doctors. It is still often seen more as an art than a science. This needs to change. We need to make sure that the young students will be stimulated to go into psychiatry.*[118]

According to Ms. Manon Desjardins, Clinical Administration Chief, Adult Ultra Specialized Services Division, Douglas Hospital, recruiting medical students to the field remains a problem:

> *In universities, it is still far more prestigious to go for cardiac, surgery, [or] intensive care rather than psychiatry or geriatrics. Geriatrics and psychiatry are seen to be at just about the same level: they are not very attractive.*[119]

Ms. Maggie Gibson, Psychologist, St. Joseph's Health Care London, also pointed to the fact that the stigmatization of individuals living with mental disorders affects the whole range of service providers in the mental health field:

> *With respect to the issue of family and caregiver stress, I want to comment on the issue of stigma — in particular the neglected stigma associated with using long-term care services. We would benefit greatly from a cultural shift that takes a compassionate and pragmatic approach to identifying the best care options for both older people and their family members and allow for dependency, when it is part of the system. Systems that allow for dependency without devaluing people go a long way to improving mental health.*[120]

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[117] *Ibid.*, p. 5.
[118] Second Session, 14:29.
[119] Second Session, 14:124.
[120] Second Session, 17:15.

3.3 THE IMPACT OF STIGMATIZATION AND DISCRIMINATION

As noted earlier, for many people living with severe mental disorders, the stigmatization and discrimination they confront can be as important a source of distress as the illness itself. Ms. Stuart put it this way:

> *In the context of mental illness, consumers will describe stigma as worse than having a mental illness. It is perceived to be a second dimension of suffering, almost a second level of disease that they have to cope with that is more debilitating and disabling than the mental illness they suffer. You can well imagine some of the consequences of stigma. You are denied social standing and rights and social entitlements. You are actively discriminated against. We have to focus on the discrimination.*[121]

Her insistence on the need to deal with the discrimination that is the concrete result of stigmatizing attitudes was a recurring theme during the Committee's hearings. Mr. Patrick Storey, Chair, Minister's Advisory Council on Mental Health, Province of British Columbia, insisted to the Committee that:

> *…we need to recognize discrimination against people with mental illness and their family members as just as unacceptable as other forms of discrimination. We need to devote the same energy to its elimination that we devote to the elimination of other forms of discrimination.*[122]

In this same vein, Mr. John Service, Executive Director, Canadian Psychological Association, told the Committee about hearing a speech by "a young congressman from Rhode Island by the name of Kennedy"[123]:

> *He conceptualized the discrimination against people with mental illnesses in the United States as the same kind of discrimination experienced by Black people and by women in the 1950s and 1960s. He said it is the same system, and that we can correct it in the same way. He says you solve that systemic discrimination by doing what we know works in discrimination, which includes things like significant financial investments to turn the system and for affirmative action.*[124]

There are many ways that discrimination affects individuals living with mental disorders. They are routinely excluded from social life and can even be denied a variety of civil rights others take for granted. They are often denied basic rights in the areas of housing, employment, income, insurance, higher education, criminal justice, and parenting, among others.[125] People with mental illnesses also face rejection and discrimination by service

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121 Second Session, 15:10.

122 Second Session, 15:6.

123 Mr. Service is referring to Patrick Kennedy, the youngest of three children of Senator Edward M. Kennedy, who has represented the First Congressional District of Rhode Island since 1994.

124 Third Session, 5:38.

125 B.C. Report, *op. cit.*

providers in both the mental health and physical health care systems and discrimination by policy makers and the media.

Professors Bruce Link and Jo Phelan of Columbia University have proposed a useful way of dividing these different manifestations of discrimination into two broad categories: direct discrimination and structural discrimination.[126] In her testimony, Ms. Stuart offered a similar distinction, that between overt discrimination and "acts of omission":

> *More insidious is that you may neglect to do something just by virtue of the fact that you think something is not important. You may have a negative attitude or put something on the back burner. I like to think there is as much or more damage done by those acts of omission, at every level of policy or government. We can focus on overt discrimination, and there are certainly huge issues there, but I would like to see it go farther than that. I would like to see the acts of omission addressed as well. If we could get at the stigma and the attitudes that underlie both of those things, we might be in a better position. I recognize that that is difficult to do. Sometimes the actions are easier to address.*[127]

3.3.1 Direct Discrimination

Direct discrimination refers to the standard way of conceptualizing the connection between labelling/stereotyping and discrimination. It points to direct discriminatory behaviour on the part of the person who holds the stereotyped beliefs. Direct discrimination occurs most obviously when a person in a powerful role withholds an opportunity.[128] Landlords do not rent an apartment to someone because he or she was in a psychiatric hospital. Employers fail to offer a job interview because the person with mental illness has not worked recently.

The evidence indicates that this form of discrimination occurs with some regularity in the lives of people who are stigmatized. For example, in a Canadian survey of people with mental illnesses, half said the area in their life most affected by discrimination was housing. Research shows that a person's status as a psychiatric patient means he or she is less likely to be leased an apartment.[129]

There remains a considerable amount of discrimination in the workforce, by both employers and co-workers, towards people with mental illnesses. Surveys show that employers and workers still feel justified distrusting and discriminating against people with mental illnesses. As a result, people with serious mental illness, such as schizophrenia and related disorders, have the highest rate of unemployment and underemployment of all people with disabilities, at a rate of around 90%.[130]

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[126] Link and Phelan, *op. cit.*
[127] Second Session, 15:27.
[128] Corrigan and Lundin, *op. cit.*
[129] B.C. Report, *op. cit.*
[130] See Chapter 6, below.

A number of surveys have consistently found that anywhere from one-third to one-half of people with mental illnesses report being turned down for a job for which they were qualified after their illness was disclosed, or had been dismissed from their jobs, and/or forced to resign as a result of their mental illness. Surprisingly, the figures are not dramatically lower for employment of individuals living with mental illness within mental health agencies or for volunteer positions both inside and outside the mental health field.[131]

Not only do families of people with mental illnesses have to cope with the financial, practical and emotional stressors of caring, but they face a kind of 'discrimination by association.' They have to deal with strained relationships with other family members or friends, fear, violence, anxiety, conflict, lowered self-esteem, and guilt. Discrimination against family members often stems from misconceptions about the family's role in the causes of mental illness.[132]

3.3.1.1 Discrimination Within The Health Care System

The importance of dealing with discrimination against individuals living with mental disorders within the health care system itself was raised by numerous witnesses. There is much evidence, Canadian and international, that mental health professionals and health professionals in general can be among those who show discriminatory attitudes and behaviour toward their own clients. People with mental illnesses frequently note that their views are neither listened to, nor respected, and that mental health workers tend to focus on clinical issues of care to the exclusion of social issues. Studies have identified a lack of respectful treatment by GPs and emergency room clinicians as the most common complaint among people with mental illnesses.[133]

This is a somewhat puzzling phenomenon, as Ms. Stuart remarked:

> *Why are health care workers so stigmatizing? They are among the most knowledgeable people on mental illness that we have in our society. They are invariably identified as the people who are the worst offenders.*[134]

Other witnesses concurred that the problem was widespread. Mr. Storey told the Committee:

> *In the discussions we had with people with mental illness, it was remarkable that they all had stories to tell of mistreatment in emergency rooms, as well as hospitals generally. Even when they were presenting complaints of a physical nature, they were treated as mental patients.*[135]

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[131] B.C. Report, *op. cit.*
[132] *Ibid.*
[133] *Ibid.*
[134] Second Session, 15:24.
[135] Second Session, 15:6.

Dr. Jim Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, also pointed to hospital emergency rooms as a place where discrimination occurs, telling the Committee that:

> *One only needs to visit the local emergency room to see stigmatization by health care providers. Mental health clients wait the longest. Their privacy is violated. Their concerns are not dealt with appropriately.*[136]

This seemingly widespread discrimination within the health care system has many negative consequences for people in need of help. Ms. Pat Capponi pointed to the lack of trust that ensues:

> *We have learned that we cannot depend on those working within the system to advocate for us. We cannot even expect them to see us as full individuals behind our obscuring labels.*[137]

3.3.2 Structural Discrimination

However, discrimination against people with mental illnesses and their families is not limited to overt acts of discriminatory behaviour by one person directed at another. It can also take the form of what Link and Phelan call structural discrimination.

To see what they mean, suppose that because it is a stigmatized illness, less funding is dedicated to research on schizophrenia than for other illnesses and less money is allocated to adequate care and management. As a consequence, people with schizophrenia are less able to benefit from scientific discoveries than they would have been if the illness they happened to develop were not stigmatized. To the extent that the stigma of schizophrenia has created such a situation, a person who develops this disorder will be the recipient of structural discrimination regardless of whether or not anyone happens to treat him or her in a discriminatory way.

There are many ways in which this kind of structural discrimination based on stigmatization can occur. Stigma may influence access to treatment by creating undesirable conditions in treatment settings that make seeking help far less desirable than it would otherwise be. For example, there exists a fear of people with psychosis that is out of proportion to the actual risk that people with psychosis pose. To the extent that this fear increases recourse to the use of guards, locked wards, searches and the like, stigma produces very negative circumstances in the treatment environment that could easily make people want to avoid those settings.

Structural discrimination can also be manifested in the general levels of funding that are made available for research and treatment of mental illnesses (see Chapter 9, below). Moreover, within the health care community in general, mental health professionals often feel treated as second-class citizens by their professional peers, and mental health services,

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[136] Third Session, 7:18.
[137] Third Session, 7:51.

programs and research themselves still tend to be given a lower priority than physical health care issues.

3.4 REDUCING THE IMPACT OF STIGMA AND DISCRIMINATION

There are both individual and community- or socially-based approaches to reducing the impact of stigma and discrimination. On the one hand, individuals with mental illness can seek out strategies that allow them to cope with, or contest, the stigmatization and discrimination they encounter. On the other hand, socially- or community-based strategies can be developed to attempt to reduce the overall extent and impact of stigmatization and discrimination. In this section we will concentrate almost exclusively on the latter, but, before doing that, a few words on individual approaches are in order.

Broadly speaking, the literature identifies three strategies that are available to individuals living with mental illness:

1. They can attempt to completely conceal their illness from others with whom they interact;
2. They can practice selective avoidance, limiting their social interaction to people they know to be non-stigmatizers;
3. They can attempt to educate everyone with whom they come into regular contact about the nature of their illness.

As noted earlier, maintaining secrecy about one's mental illness can have many negative consequences. According to one study that explored the value of all these individual approaches, it is not just the first strategy listed above that can be counter-productive. Rather, the study concluded unequivocally that all three were harmful and that "using these methods made rejection more likely."[138]

Given the difficulties associated with these strategies based on individual action it would seem clear that, if there is to be progress in reducing both stigma and discrimination, some form of community or socially based intervention will be necessary. This follows from the fact that both stigma and discrimination are thoroughly social phenomena. They rely on the propagation of myths about individuals living with mental disorders within the institutions of society (schools, workplaces, the media, etc.), and take hold in discriminatory practices that can be enshrined or condoned by law and by tradition.

There is, however, likely no simple or single strategy to eliminate the stigma associated with mental illness.[139] In the first place, stereotypes such as those that sustain the stigmatization of people with mental illness are complex phenomena. They have components that are somewhat changeable but they also have some that are fiercely resistant to change.[140]

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138 The study was conducted in 1991 by Link, Mirotznik and Cullen and reported on by Keith Brunton in his article "Stigma," *op. cit.*, p. 894.

139 Surgeon General, *op. cit.*

140 B.C. Report, *op. cit.*

As noted earlier, the persistence over time of pervasive stigma attached to mental illness, despite growing knowledge and public awareness of the nature of these disorders, raises an important question with regard to the efficacy of education alone to reduce the effects of stigmatization on the lives of people with mental illness. Stigma was expected to abate with increased knowledge of mental illness, but just the opposite occurred: stigma in some ways intensified over the past 40 years even though understanding improved.[141]

Since stigmatizing opinions are not always closely related to the extent of knowledge about mental illness in general, it follows that campaigns to reduce stigma must be carefully planned and probably have to do more than simply increase knowledge of the stigmatized conditions.[142] One hypothesis that has been advanced to explain why information alone is unlikely to eliminate stigmatizing attitudes holds that stigmatizers need a new emotional experience rather than, or in addition to, a new explanatory model, before they would be likely to call into question any stereotypes they may have taken on board.[143]

Thus, the effectiveness of mass advertising campaigns in reducing stigma and discrimination has been challenged.[144] This is how Ms. Stuart put it:

> *With respect to anti-stigma interventions, how do we stop stigma and discrimination? We are learning from the World Psychiatric Association work that one size does not fit all. It is a waste of time and energy to embark on a large, public education campaign that is designed to improve literacy as an anti-stigma intervention because segments of the population have different views. They understand their risks differently depending on the diagnostic group.*[145]

Results are more promising when media campaigns are backed by ongoing community-based education and action. The general consensus internationally seems to be that public education campaigns are most effective when they are locally based and focused on the anxieties of their target groups.[146] In Ms. Stuart's words:

> *We are now talking about more focused and targeted interventions. We have had the best success in all of the things that we have tried by going into high schools and working with young people because they are more malleable.*[147]

Reducing stigma will therefore require campaigns that are carefully focussed and targeted to specific audiences. Two recent articles indicate that such carefully targeted campaigns can

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141 Surgeon General, *op. cit.*

142 Arthur H. Crisp, Michael, G. Gelder, Susannah Rix, Howard I. Meltzer and Olwen J. Rowlands, "Stigmatisation of people with mental illness," Royal College of Psychiatrists, 2000.

143 Rahman Haghighat, "A unitary theory of stigmatization," *British Journal of Psychiatry*, No. 178, 2001.

144 Heather Stuart and Julio Arboleda-Flôrez, "Community Attitudes Toward People With Schizophrenia," *Canadian Journal of Psychiatry,* No. 46, 2001.

145 Second Session, 15:12.

146 Peter Byrne, "Psychiatric Stigma," *British Journal of Psychiatry*, No. 178, 2001.

147 Second Session, 15:12.

indeed alter attitudes towards people living with mental health disorders. An evaluation of mental health awareness workshops directed at secondary school students in Britain concluded that "educational workshops with young people can have a small but positive impact on students' views of people with mental health problems."[148] An assessment of another British effort directed at police officers also indicated that workshop programs had a positive impact on attitudes, and that "targeting a group in the work-place provides the opportunity to challenge negative stereotypes while addressing specific work-based training needs, thus creating a more favourable learning environment for addressing attitudes and behaviours."[149]

One leading anti-stigma researcher, Otto F. Wahl, Professor of Psychology at George Mason University in Fairfax, Virginia, put it this way: "If we are going to truly eradicate stigma, we need to have a more concrete, practical and personalized understanding of its effects – that is, how stigma makes people feel and how it affects treatment and recovery."[150]

One possibility would therefore be to explore destigmatizing strategies that provide forums for the expression of fears that exist amongst the target group, in which people can ask questions and communicate their worries.[151] According to Ms. Stuart:

> *When we talked about targeting things, we were trying to target experiences. We figured out we had to get them at an emotional level. We had to make them aware that their whole system of beliefs was somehow ill-founded. One of the best ways to do that was to construct situations in which people who have a mental illness could meet people who have perhaps never met someone with a mental illness, under controlled and constructive kinds of situations. They would talk about their mental illness. They would convey factual information, but more important, they would convey information at a human level. That is what made the difference.*[152]

Indeed, it is contact with people with mental illness that appears to yield the best prospects for improving attitudes about mental illness. There is research that shows that members of the general public who are more familiar with mental illness are less likely to endorse prejudicial attitudes.[153] In this respect, Ms. Scheffer told the Committee that:

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148 Vanessa Pinfold, Hilary Toulmin, Graham Thornicroft, Peter Huxley, Paul Farmer and Tanya Graham, "Reducing psychiatric stigma and discrimination: evaluation of educational interventions in UK secondary schools" in the *British Journal of Psychiatry* (2003), 182, p. 344.

149 Vanessa Pinfold, P. Huxley, G. Thornicroft, P. Farmer, H. Toulmin, and T. Graham, "Reducing psychiatric stigma and discrimination: Evaluating an educational intervention with the police force in England," *Journal of Social Psychiatry and Psychiatric Epidemiology* (2003) 38, p. 343.

150 Sampson, *op cit*.

151 Haghighat, *op. cit.*

152 Second Session, 15:24.

153 Watson and Corrigan, *op. cit.*

> *The most promising strategy for impacting negative perceptions is increasing contact with mentally ill persons. No other strategy has been shown to be more effective.*[154]

This conclusion was further reinforced by the results of the Houston area survey of public perceptions of mental illness referred to earlier. Its authors wrote that:

> *We have been struck continually throughout these analyses by the dominating importance of personal knowledge in shaping public attitudes toward mental health issues. When respondents were asked if they knew of "anyone among your friends or family who has been diagnosed with a mental illness, including clinical depression," the 38 percent who answered in the affirmative were consistently and significantly more likely than the 62 percent without such personal experience to support both corporate and tax policies to ensure access to mental health services, to be unconcerned upon learning of a neighbor being treated for a mental illness, and to believe that most people undergoing treatment for mental illness are able to live a normal life.*[155]

However, recent research also suggests that the way in which contact with individuals living with mental disorders takes place may have a bearing on the extent to which stigmatizing attitudes are challenged. A study by researchers at the University of Chicago Center for Psychiatric Rehabilitation[156] reached a number of interesting conclusions. In the first place, the researchers confirmed previous work that showed that contact with individuals living with mental disorders "yields significant change in attitudes about mental illness."[157] As well, and contrary to their original expectations the researchers did not find any noticeable difference in the extent of the impact of the contact when contact was via videotape rather than *in vivo*.

However, they did find that stereotypes were not called into question when the contact with the person living with serious mental illness highlighted the symptoms of that illness rather than the possibility of recovery. Moreover, they concluded that their research offered a plausible explanation for why many health care providers remain vulnerable to embracing stigmatizing attitudes. In their words:

> *Meeting a person with mental illness whose symptoms and other problems are highlighted is not likely to challenge one's stereotype. This may be one reason why mental health service providers are likely to endorse the stigma of mental illness so highly. Treatment providers, especially inpatient clinicians, largely interact with people with mental*

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154 Second Session, 16:21.

155 *Op. cit.*, pp. 20-22.

156 Rebecca R. Reinke, Patrick W. Corrigan, Christoph Leonhard, Robert K. Lundin and Mary Anne Kubiak, "Examining Media's Use of Contact on the Stigma of Mental Illness," unpublished manuscript (n.d.), submitted to the *Journal of Nervous and Mental Disease.*

157 *bid.*, p. 10.

> *illness when they are acutely ill, a status which is likely to confirm the stereotype rather than challenge it. Most of these people are frequently discharged before recovery is evident so that the treatment provider does not have an experience that disconfirms the stereotype.*[158]

Ms. Scheffer also suggested that the most effective strategy "in creating understanding and acceptance is a comprehensive health promotion approach combined with a social marketing approach" that would "raise awareness, encourage seeking help and promote positive understanding."[159]

Mr. Service indicated that stigma can be reduced as a result of the successful treatment and care of individuals living with mental disorders. He told the Committee that:

> *Stigma is reducing significantly in certain populations. It is the populations who can access and use the service who do not have a problem because their neighbour, their friend, brother or cousin have accessed services and had a good experience. That is how you break down stigma. In our business that is also one of the best referrals. It is not from another professional, it is from somebody saying, "I went to see Mr. Service and he did not a bad job so you might want to try him out." That is how you get most of your referrals and that is how you break down stigma.*[160]

The need to involve individuals living with mental disorders in all aspects of efforts to eliminate stigma and discrimination, was further emphasized by witnesses. Ms. Chambers recommended to the Committee that:

> *a national education program…directed and delivered by survivors, should be launched to challenge the devastating prejudice and discrimination that exists in our community.*[161]

Ms. Capponi pointed to the broad anti-stigmatizing impact of facilitating the participation of individuals living with mental disorders in meaningful and productive undertakings:

> *We began to tackle poverty and powerlessness directly through the creation of psychiatric-survivor-run businesses. Led by my sister Diana, who had battled mental illness and heroin addiction, they lobbied and developed survivor businesses in the Province of Ontario — a radical departure from traditional vocational rehabilitation. Our community began to see that there were possibilities out there for us. We began to have role models and leaders. We were achieving, breaking myths and assumptions about who and what we were, and we were forming*

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[158] *Ibid.*, p. 11.
[159] Second Session, 16:21.
[160] Third Session, 5:48.
[161] Second Session, 15:16-17.

> *community. Chronic psychiatric patients showed commitment in reporting to work on time. In acquiring new skills, lasting friendships were created and people grabbed every opportunity to learn from each other's experiences. We were successfully attacking the stigma within and without the mental health system where millions of dollars spent on elaborate advertising campaigns had failed.*[162]

Several witnesses also pointed to the importance of learning from other communities that have had to confront issues relating to stigma and discrimination. Ms. Scheffer pointed to some of these in her testimony:

> *If we look to other groups who have suffered the effects of social stigma, like the gay and lesbian community or those with AIDS or cancer, they have successfully ended or minimized stigma by creating widespread change in attitudes.*[163]

And Mr. Brian Rush, Research Scientist, Social Prevention and Health Policy, Centre for Addiction and Mental Health, noted in the same vein:

> *The mental health field could learn a lot from the developmental disability field and the kind of investment it might take to support people in the community, which would still save money in addition to providing people with dignity, respect and a choice to live in the community and not in psychiatric institutions.*[164]

Ms. Shoush reminded the Committee that different communities will have their own distinctive approaches to helping individuals living with mental disorders, and that is therefore essential to adapt efforts to these varying realities. She told the Committee that:

> *Aboriginal communities would say that they have a different world view and that the community is the focus. They believe that the community unit deserves to be the focus of concern and that information to help the community be whole and well should be available and shared.*[165]

3.4.1 The Need for a National Strategy

Although it is clear that there will not be a miracle solution to the problems of stigma and discrimination, and that efforts to reduce their impact will have to be carefully tailored to many different circumstances, several witnesses also insisted on the importance of having a national mental health strategy. Mr. Phil Upshall, President, Mood Disorder Society of Canada, put it this way:

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[162] Third Session, 7:48.
[163] Second Session, 16:20.
[164] Third Session, 8:28.
[165] Second Session, 16:26.

> *The move towards a federal national strategy would be incredibly anti-stigmatizing. It would be a leadership model that would say to the rest of Canada, "This is something to which we need to pay attention." It would say to the rest of the provincial premiers and their health ministers that this is something that we will finally take seriously.*[166]

This view was supported by Dr. Blake Woodside, Chairman of the Board, Canadian Psychiatric Association, who told the Committee:

> *The first thing is to make mental health a public priority, so a declaration by the federal government that a national action plan for mental health was being developed would be a huge step in the right direction. Out of that would fall a wide variety of public educational activities that would help combat this discrimination and stigma.*[167]

Witnesses also argued that it was important to modify the *Canada Health Act* so that it placed physical and mental illness on an equal footing. This is not the case today since, for example, the *CHA* explicitly excludes psychiatric hospitals from its purview. Thus, Dr. Sunil Patel, President, Canadian Medical Association, pointed out:

> *Simply put, how are we to overcome stigma and discrimination if we validate these sentiments in our federal legislation? The CMA firmly believes the development of a national strategy and action plan on mental health and mental illness is the single most important step that can be taken on this issue…*[168]

The CMA proposed a number of measures that would redress this situation, including, as Dr. Patel outlined:

> *…amending the Canada Health Act to include psychiatric hospitals; adjusting the Canada Health transfer to provide for these additional insured services; re-establishing an adequately resourced federal organizational unit focused on mental illness and mental health and addictions;*[169]

For his part, Dr. Paul Garfinkel, Chair, Mental Health Working Group, Ontario Hospital Association, and President and Chief Executive Officer, Centre for Addiction and Mental Health, stressed the enormous symbolic value of reforming the *CHA*:

> *I think changing the Canada Health Act would be hugely powerful from a symbolic point of view. It would be saying that we are correcting a wrong. We did not understand mental illnesses years ago and now we*

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166 Third Session, 9:34.
167 Third Session, 5:26-27.
168 Third Session, 5:11
169 *Ibid.*

> *realize that they are like any other form of human pain and suffering. That would be dramatic.*[170]

Mr. Service also insisted on the significance of not treating mental health, mental illness and addictions as if they were fundamentally different from other health issues:

> *If we conceive of mental health, mental illness and addictions as part of and central to the operations of the entire health system, we then make an extremely important structural change that brings mental illness into prime time as opposed to it being ghettoized over here with just the "crazy people" that nobody has to really deal with or the "worried well" for whom we have no time to deal with.*[171]

Ms. Chambers stressed to the Committee that in order to assist individuals living with mental disorders to take full advantage of their rights, it was necessary also to provide specific resources at the national level. She told the Committee:

> *I would like to emphasize that hand-in-glove with the idea of educating people, it is important to have a national mental health legal advocacy resource that is accountable to consumers. It is not just prejudice in the general community, but particularly prejudice and discrimination in the mental health system itself — it is allowed under the law — that needs addressing. It is critical to have both those pieces involved.*[172]

3.4.2 The Need for Policy Reform

In general, witnesses suggested that policy can be easier to change than attitudes, and that every effort should be made to do so. This is how Ms. Stuart put it:

> *We are hoping that a third generation of research may focus on the kinds of social structure that … really perpetuate social inequity and discrimination — the structures and organizations, the policies and the programs that make this happen. It is difficult to change attitudes but you can change policies much more easily.*[173]

In this vein, Dr. Patel called for a "review of federal health policies and programs to ensure the mental illness is on par, in terms of benefits, with other chronic diseases and disabilities."[174] Mr. Storey gave the following illustration of the kinds of change that he feels are needed:

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[170] Third Session, 5:32.
[171] Third Session, 5:37.
[172] Second Session, 15:26.
[173] Second Session, 15:10.
[174] Third Session, 5:11.

> *A number of policy changes are required in addition to protecting the actual dollars for mental health. Medical billing schedules and procedures, extended health benefits, pension plans, et cetera, do not recognize the special features and challenges of mental illness and create unnecessary obstacles to recovery and health. For example, in British Columbia, a family doctor can bill for only four counselling sessions per patient per year; yet, most people with depression go to see their family doctor. Though antidepressant medication is a helpful adjunct, alone it is not sufficient to help people deal effectively with that sometimes debilitating condition. Doctors are not in a position to provide the help required for a person in a depression.*[175]

Finally, the need to adjust policy to changing social circumstances was stressed by Ms. Capponi:

> *There are more mentally ill people on the streets not because of a preference, but because the gulf between the haves and have-nots is getting wider and wider. More people are using the food banks and so the share for the chronic mental patient has been dramatically reduced. A landlord will rent his house to people who he thinks will be less disruptive than a former mental health patient. People get squeezed out. Shelters prefer to house immigrants or battered women because they will not be seen as potentially disruptive.*[176]

3.4.3 Addressing the Issue of Violence

However, many believe that the most likely reason for the increase in stigma in recent years is related to the exaggerated attribution of a propensity to commit acts of random violence to people living with serious mental illness. There is a perception that an increasing number of violent crimes are committed by individuals with severe psychiatric disorders.[177]

Witnesses suggested that a starting point for counteracting this exaggerated attribution of dangerousness to individuals living with mental disorders is to recognize what the best science tells us. Mr. Arnett summed up the essence of this for the Committee:

> *…there does appear to be some increased risk of violence from those with mental illnesses. It is wise to acknowledge that. This occurs particularly with those with severe mental illness and is magnified significantly when the individuals are also substance abusers.*[178]

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175 Second Session, 15:7.

176 Third Session, 7:70.

177 Treatment Advocacy Center, "Briefing Paper on Stigma and Violence," accessed at: http://www.psychlaws.org/BriefingPapers/BP9.htm.

178 Second Session, 16:8.

Because incidents of violence do occur, some authors believe that a reduction in stigma against people with mental illness is unlikely to take place until there has been a reduction in violent crimes committed by them.[179] They argue that it is necessary to avoid the kind of situation in which the average commuter riding a bus to work will face an anti-stigma poster proclaiming that "mentally ill persons make good neighbours" while simultaneously reading a newspaper article detailing the most recent violent act committed by a mentally ill person.

3.4.3 The Media and Efforts to Reduce Stigma and Discrimination

There are no ready-made strategies available for reducing inaccurate and stigmatizing portrayals of people with mental illnesses in the media, and for encouraging the media themselves to contribute actively to the destigmatization of mental illness.

One example of an initiative directed specifically at altering the portrayal of people with mental disorders in the media was a petition which criticized media coverage of mental illness signed by three thousand psychiatrists in Britain in April 1995. Among their proposals, they called for "a major debate to take place particularly within the media, within broadcasting and the press, to question the persistent replication of stigmatizing and false images of psychiatric illness." They also encouraged "the making of programmes which give a fair and accurate account of mental health issues [and asked] that the broadcasting and print industries produce codes of conduct to guide journalists in this area."[180]

In Australia a National Media Strategy was undertaken, where the government worked directly with the media to promote more positive messages about mental health and suicide prevention. The Australian media strategy operates in journalism schools and universities, where journalists are taught how they should approach these issues when reporting them to the community so as not to stigmatize individuals living with mental disorders.

Research also points to the importance of highlighting stories of successful recovery that, if they are presented properly, can both educate and entertain audiences. Some examples of positive media portrayal and discussion of mental health issues include:[181]

- The September 2001 issue of *Rosie* magazine, which focused on depression.
- The 1997 film *As Good as It Gets*, starring Jack Nicholson. In this film, Nicholson plays a romantic lead who has obsessive-compulsive disorder. The film accurately portrays the symptoms of this disorder and, even more encouragingly, shows the character, with the assistance of therapy and medication, winning the woman of his dreams and learning to live with and control his illness.
- The television series *Monk*, which debuted in 2002. The main character is a private detective named Adrian Monk suffering from obsessive-compulsive disorder. Played by Tony Shalhoub, Monk is given a realistic and respectful treatment, according to the National Alliance for the Mentally Ill (NAMI).

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[179] *Ibid.*
[180] Philo, op. cit.
[181] Roth Edney, op. cit., p. 9.

The struggle for more accurate and positive representation of mental illness and of the mentally ill in the mass media is often thought to be analogous to the struggles of other minority and disenfranchised groups. In the opinion of Greg Philo of the Glasgow Media Group, "the media will not change until there is a movement that demands it."[182]

3.5 COMMITTEE COMMENTARY

Overall, the evidence suggests that combating stigma and discrimination requires a multi-pronged effort. Any campaign to change attitudes will have to convey a complex message and be sustained over a long period of time, while rooting out the many forms of discrimination will require great determination and perseverance.

The Committee believes that there is a strong case to be made that each of the key phenomena, stigma and discrimination, must be tackled in appropriate ways. The battle can and must be waged on both fronts simultaneously. Campaigning and educating people to challenge stigmatizing attitudes should go hand in hand with resolute opposition to discrimination in whatever form it is perpetrated against individuals living with mental disorders. The Committee notes the success of other stigmatized groups in campaigning to reduce stigma and discrimination, and the real benefits this has yielded.

A number of key elements stand out from the testimony the Committee heard and the evidence it considered. First, the Committee sees much merit in the argument that the very fact of having a national mental health strategy (over and above the concrete elements of that strategy) will contribute to the struggle against stigma and discrimination. A national mental health strategy would focus public attention on mental health issues in unprecedented ways. Its adoption would indicate to people that the federal, provincial and territorial governments attach as much importance to fostering the mental health of Canadians and treating the mental illnesses that afflict them as they do to promoting the physical health of the population.

As part of establishing the parity of mental and physical health, and illness, the Committee took note of the suggestion that the *Canada Health Act* be opened to remove existing disparities. During its two-year study of the acute care sector, the Committee was wary of proposals to re-open the *CHA* because of the difficult debate that this would engender over which services should or should not come under the purview of the *Act*. However, with regard to this particular issue, the Committee feels that the option of modifying the *CHA* should be seriously examined, because of its potentially enormous symbolic value.[183]

Several elements stand out to the Committee as warranting inclusion in national efforts to reduce stigma and discrimination. First, it will be necessary to find ways of countering the attribution of an exaggerated propensity to violence to people living with serious mental illness. Second, efforts to reduce stigma and discrimination must be carefully targeted to maximize their effect. Moreover, the involvement of people living with mental disorders in the conception, design and delivery of these campaigns is essential to their success. It is also

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[182] *Ibid.*

[183] These issues are discussed in greater detail in Chapter 10, below.

important to demonstrate the possibility of recovery and to promote better mental health in order to encourage changes in attitudes towards people living with mental illness.

Finally, the Committee took note of the persistence of stigmatization and discrimination within the health care system in general, and even within the mental health care system itself. There are thus two levels at which it is necessary to work within the overall health care community. First, it is necessary to diminish the stigmatization of mental health workers within the broader health care community so that the structural discrimination that afflicts the mental health sector can be eradicated. Second, it is necessary to work with all health professionals to promote more positive perceptions of people living with mental illness.

PART 2

The Prevalence and Consequences of Mental Illness and Addiction

CHAPTER 4:
CONCEPTS AND DEFINITIONS

INTRODUCTION

The terms and concepts related to mental health, mental illness and addiction are not easy to define. Different countries have adopted differing terminology and, within countries, professionals and lay groups, organizations and associations often utilize different conventions in defining and describing key concepts relevant to mental health, mental illness and addiction. Consequently, one concept may be referred to by a variety of terms, while some terms will hold different meanings for different groups. Even within Canada, some terms have multiple meanings that are applied inconsistently, often creating confusion.

> **A respectful, common language to discuss mental illness and mental health is lacking between disciplines and sectors.**
> ***[Phil Upshall, President, Canadian Alliance on Mental Illness and Mental Health, Brief to the Committee, 18 July 2003, p. 8.]***

This chapter defines the various concepts **used throughout the report** related to mental health, mental illness and addiction. It is divided into nine sections related to: mental health and mental illness (Section 4.1); major mental disorders (4.2); substance use and addiction (4.3); co-morbidity, concurrent disorders and dual diagnosis (4.4); suicidal behaviour (4.5); services and supports (4.6); chronic disease management (4.7); promotion, prevention and surveillance (4.8) and, individuals with mental illness/addiction and recovery (4.9).

4.1 MENTAL HEALTH AND MENTAL ILLNESS

> *Mental illness undermines mental health, but mental health is more than simply the absence of illness. It is a fundamental resource of all human beings and an essential component of all health.*
> *[Tom Lips, Health Canada (11:7)]*

Mental health is defined as the capacity to feel, think and act in ways that enhance one's ability to enjoy life and deal with challenges.[184] Expressed differently, mental health refers to various capacities including the ability to: understand oneself and one's life; relate to other people and respond to one's environment; experience pleasure and enjoyment; handle stress and withstand discomfort; evaluate challenges and problems; pursue goals and interests; and, explore choices and make decisions.

(184) Health Canada, Mental Health Promotion Unit, *Mental Health Promotion: Promoting Mental Health Means Promoting the Best of Ourselves – Frequently Asked Questions.* http://www.hc-sc.gc.ca/hppb/mentalhealth/mhp/e_faq.html).

Good mental health is associated with positive self-esteem, happiness, interest in life, work satisfaction, mastery and sense of coherence. It is well recognized that good mental health enables individuals to realize their full potential and contribute meaningfully to society.[185]

By contrast, *mental health problems* refer to diminished capacities – whether cognitive, emotional, attentional, interpersonal, motivational or behavioural – that interfere with a person's enjoyment of life or adversely affect interactions with society and environment. Feelings of low self-esteem, frequent frustration or irritability, burn out, feelings of stress, excessive worrying, are all examples of common mental health problems.[186] Over the course of a lifetime, every individual will be likely, at some time, to experience mental health problems such as these. Usually, they are normal, short-term reactions that occur in response to difficult situations (e.g., school pressures, work-related stress, marital conflict, grief, changes in living arrangements) which people cope with in a variety of ways, employing internal resilience, family and community support, etc.

Mental health problems that resolve quickly, do not recur and do not result in significant disability do not meet the criteria required for the diagnosis of a mental illness. *Mental disorders* or *illnesses* generally refer to clinically significant patterns of behavioural or emotional function that are associated with some level of distress, suffering (even to the point of pain and death), or impairment in one or more functional areas (e.g., school, work, social and family interactions).[187]

A widely used definition of mental illness or mental disorder is taken from the American Psychiatric Association's Diagnostic and Statistical Manual, Fourth Edition. (…) It is a definition that allows for the possibility of either biological or psychological causes of illness. It excludes normal reactions to stressful situations.
[Tom Lips, Health Canada (11:9)]

There are many different forms of mental disorders. They vary widely in terms of the course and pattern of illness, the type and severity of symptoms produced and the degree of disability experienced. An individual may have only one or may have repeated episodes of illness separated by long periods of wellness. While some mental disorders are episodic or cyclical in nature, others are more persistent with lengthy or frequently recurring episodes. Individuals with persistent illnesses usually require long term treatment and support.

4.2 MAJOR MENTAL DISORDERS

In Canada, the classification of mental illnesses follows either the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association, or the International Classification of Diseases (ICD), Mental Health Section, published by the

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185 Canadian Alliance on Mental Illness and Mental Health, *A Call for Action – Building Consensus for a National Action Plan on Mental Illness and Mental Health*, Discussion Paper, 2000, p. 7. (http://www.mooddisorderscanada.ca/camimh/index.htm)

186 Thomas Stephens *et al.*, "Mental Health of the Canadian Population: A Comprehensive Analysis," *Chronic Diseases in Canada*, Vol. 20, No. 3, 1999.

187 Canadian Psychiatric Association, *Youth and Mental Illness*, not dated.

World Health Organization.[188] Each of the two classification systems lists more than 300 mental disorders that can be diagnosed; these are often grouped together on the basis of similarities in their symptoms or patterns of illness.

The complete list of mental disorder diagnoses is available in the DSM and ICD manuals. Some of the major groupings of mental disorders include: mood disorders (depression and bipolar disorders), anxiety disorders (generalized anxiety disorder, phobias, panic disorder, obsessive-compulsive disorder and post-traumatic stress disorder), psychotic disorders (schizophrenia and schizoaffective disorder), eating disorders (anorexia nervosa and bulimia), personality disorders, pervasive developmental disorders (autism and Asperger's disorder), attention deficit and disruptive behaviour disorders, and cognitive disorders (dementia and delirium from a variety of causes).[189] Substance use disorder is also included within the classification of mental disorders. In this report, substance use disorders are discussed in a separate section in order to highlight their importance and relationship to addiction.

> **When we talk about mental disorders, it is important to mention that the most prevalent of these are anxiety and depressive disorders. (…) The third major area is substance abuse (…). What that means is that these disorders are highly prevalent. In contrast, you will also be hearing about major psychiatric disorders, such as schizophrenia, bipolar affective disorder, and in adolescent children, and possibly in adults, autistic disorders. These are clearly major mental disorders.**
> ***[Dr. Alain Lesage, Canadian Academy of Psychiatric Epidemiology (11:12)]***

Mood disorders include both major depressive and bipolar disorders. *Major depressive disorder* (also referred to as unipolar depression) is characterized by one or more depressive episodes lasting at least two weeks. The core symptom is a sustained depressed mood (different than normal feelings of sadness) and/or a marked decrease in pleasure from or interest in usual activities. This is accompanied by four or more other symptoms characteristic of depression such as disturbance, fatigue or loss of energy, appetite and weight loss or gain, decreased ability to concentrate, think, and make decisions, and recurrent thoughts of death. Females have higher rates of major depression than males by a ratio of 2:1. *Bipolar disorder*, classically known as manic depressive illness, is a mental illness associated with dramatic mood swings ranging from mania to depression. Mania, a condition recognized since antiquity, is characterized by at least a week of an altered mood state of euphoria, labiality or irritability. Like depression, it is associated with a number of other related symptoms, often as the mirror image of depression, including a marked increase in energy, decreased need for sleep, elevated self-esteem, and a propensity for risky activities. Bipolar disorder usually begins in early adulthood; the average age of onset is around 18-24 years,

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188 The DSM classification system addresses psychiatric disorders only, and no other illness or disease categories. The DSM that is in common usage at the present time in Canada is a revision of the fourth edition (DSM-IV-TR) and it is anticipated that the fifth edition (DSM-V) will soon be released. ICD-10, the tenth edition of the ICD system, which addresses all disease areas and health conditions, is currently being adopted across Canada, replacing ICD-9, which until recently has been the standard diagnostic system in Canadian hospitals and health care organizations. Both the DSM and ICD classification systems are updated regularly by experts in an effort to refine diagnostic accuracy and incorporate new research evidence.

189 Canadian Mental Health Association, *Mental Illnesses*, pamphlet, not dated.

although it can sometimes start in childhood or as late as the 40s or 50s. Men and women are equally affected.[190]

Anxiety disorders may take many forms. They include: generalized anxiety disorder, specific phobias, panic disorder (with or without agoraphobia), obsessive-compulsive disorder and post-traumatic stress disorder. *Generalized anxiety disorder* is defined by a protracted period (i.e., over 6 months) of anxiety and worry that is accompanied by other symptoms such as muscle tension, fatigue, poor concentration, insomnia, and irritability. *Phobias* reflect marked fear of certain things (such as animals, insects, heights, elevators, etc.) or situations (social phobia); exposure to the object of the phobia, either imaginary, on video or in real life, invariably elicits intense anxiety which may include a panic attack. *Panic disorder* is diagnosed when an individual has experienced a number of unexpected panic attacks – periods with sudden onset of intense fear or discomfort, often associated with palpitations, rapid breathing, and a sense of impending doom – coupled with worries about further attacks. *Obsessive-compulsive disorder* involves either or both obsessions or compulsions which the individual recognizes as excessive or unreasonable. Obsessions consist of persistent, intrusive, inappropriate thoughts, ideas, impulses or images that cause marked anxiety or distress. Compulsions refer to repetitive behaviours (such as hand washing) or mental acts (such as counting) that sometimes occur in a ritualistic way or in response to an obsession. *Post-traumatic stress disorder* involves re-experiencing a traumatic event through dreams and recollections, avoiding stimuli reminiscent of the event, emotional numbing, and a heightened level of arousal; it occurs following a traumatic event in which the person experienced or witnessed threatened or actual physical harm (such as rape, child abuse, war/battle, or natural disaster). Overall, anxiety disorders affect men and women equally; they tend to begin early in life (during childhood or adolescence) and often persist for many years.[191]

Schizophrenia is a mental illness that typically emerges in late adolescence and early adulthood. Classically, it has often been a chronic, severe and disabling long term disorder. In the last decade, systematic efforts at earlier detection and comprehensive biopsychosocial intervention offer hope for a different trajectory for this often long term illness. Decades of genetic, brain imaging, and other lines of research support a biological model of schizophrenia, although its cause remains unknown. It seriously affects a person's thinking, causing hallucinations (such as hearing voices when there is no one there), delusions (fixed false beliefs such as the fear that strangers are following the ill person or wanting to hurt him/her), a loss of contact with reality and disrupted work and social interactions. The disease often begins slowly; once it has taken hold, it usually manifests itself in cycles of remission and relapse. Men and women are affected by schizophrenia with equal frequency.[192]

Eating disorders involve serious disturbance in eating behaviours. While some cases of eating disorders will resolve themselves spontaneously or with treatment during adolescence, others

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190 According to information from the Internet site of the Mood Disorders Society of Canada (http://www.mooddisorderscanada.ca/).

191 According to information from the Internet site of the Anxiety Disorders Association of Canada (http://www.anxietycanada.ca/).

192 British Columbia Schizophrenia Society, *Basic Facts About Schizophrenia*, April 2002.

may become chronic conditions. Some long term follow-up studies reveal death rates of up to 18% in affected individuals. The most common eating disorders include anorexia nervosa, bulimia nervosa and binge eating disorder. *Anorexia nervosa* is characterized by low body weight (under 85% of expected weight), intense fear of weight gain even when markedly underweight, an inaccurate perception of body weight or shape, denial of thinness, and an intense emphasis on weight as a yardstick of self-evaluation. *Bulimia nervosa*, by contrast, most commonly occur in individuals of normal body weight. It is characterized by recurrent episodes of gorging, followed by compensatory activities to eliminate the ingested calories (such as self-induced vomiting, abuse of laxatives or diuretics, intensive exercise, etc). It shares, with anorexia nervosa, however, many of the core psychological preoccupations with weight and shape. *Binge eating disorder* is a newly recognized condition featuring episodic uncontrolled consumption of food, without the compensatory activities of bulimia nervosa. Eating disorders usually arise in adolescence and affect females disproportionately.[193]

Personality disorders include a number of disorders that vary considerably in their characteristics and patterns or behaviour.[194] However, they all share the following characteristics: an enduring pattern of inner experience and behaviour that deviates from the expectations of society and behavioural patterns that are pervasive, inflexible and stable over time, creating distress or impairment.[195] Some forms of personality disorder result in suffering that primarily affects the individual (e.g., avoidant personality disorder, characterized by feelings of extreme discomfort and intense self-criticism in social circumstances, leading to marked loneliness and isolation despite intense longings for social contact). Other forms of personality disorder may not only cause distress to the individual, but also produce profound harm to others and incur substantial cost to society (e.g., antisocial personality disorder, a pervasive pattern of disregard for and violation of the rights of others that often includes repeated criminal activity, impulsive violent behaviour, deceitfulness and lack of remorse.) The onset of personality disorders usually occurs in adolescence or early adulthood, but they can also first manifest themselves in mid-adulthood. In contrast to the mental illnesses described previously, personality disorders are more intimately linked to the affected person's individual temperament and character.[196]

Autism is a mental disorder which emerges in childhood and which, for some affected individuals, may be an incapacitating and life-long disability. Generally, autistic individuals display the following: impaired ability to engage in social interaction; impaired communication skills; and specific behavioural patterns (e.g., preoccupation, resistance to change, adherence to non-functional routines and stereotyped and repetitive behaviours). Developmental delay or abnormality in interaction, language and play is evident before 3 years of age in affected individuals. Autism may be accompanied by other disabling conditions, such as seizures or significant cognitive (intellectual) delays.[197] The symptoms and deficits associated with autism, however, may vary. For example, some individuals with

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193 United States Surgeon General, *Mental Health: A Report of the Surgeon General*, 1999, p. 167.

194 Personality disorders include: borderline, antisocial, histrionic, narcissistic, avoidant, dependent, schizoid, obsessive-compulsive, and schizotypal personality disorders.

195 Paula Stewart, *A Report on Mental Illnesses in Canada*, Health Canada, October 2002, p. 70.

196 Paula Stewart (2002), pp. 72-73.

197 Autism Treatment Services of Canada, *What is Autism?*.

autism function at a relatively high level, with speech and intelligence intact, while others are developmentally delayed, do not speak, or have serious language difficulties.[198] Autism tends to be three-to-four times more common in males than females.

Attention Deficit Disorder (ADD) and *Attention Deficit Hyperactivity Disorder* (ADHD) are terms used to describe patterns of behaviour that appear most often in school-aged children. They adversely affect the learning process by reducing the child's ability to pay attention. Children with these disorders are inattentive, overly compulsive and, in the case of ADHD, hyperactive. They have difficulty sitting still, attending to one thing for a long period of time, and may seem overactive. ADD and ADHD are diagnosed 10 times more often in boys than in girls.[199] The attention deficits associated with these disorders may persist throughout childhood and adolescence into adulthood, whereas the symptoms of hyperactivity and impulsivity tend to diminish with age. Although many children with ADD and ADHD ultimately adjust, a higher proportion than in the population of unaffected individuals are more likely to drop out of school and fare more poorly in their careers later. As they grow older, some teenagers who have had severe ADHD since middle childhood experience periods of anxiety or depression. They may also be vulnerable to problems with substance abuse and antisocial behaviour.[200]

Alzheimer's disease is an organic brain disorder that leads to the loss of mental and physical functions. Together with a number of other illnesses including, for example, Parkinson's disease and Huntington's disease, it is classified as a degenerative disease of the central nervous system. Alzheimer's disease is the leading cause of dementia. Several changes occur in the brain of the affected individuals, notably a progressive loss of neurons from the cerebral cortex and other areas. Consequently, a person with Alzheimer's disease has less brain tissue than a person who does not have the illness; the shrinkage continues over time, affecting how the brain functions.[201] Memory loss is the most prominent early symptom of Alzheimer's disease, often followed by a slow deterioration of cognitive functions and personality features and physical capacity. Some individuals experience hallucinations, delusions, seizures and aggressive behaviour. Alzheimer's disease affects both men and women equally.[202]

Although not classified as mental disorders, *Fetal Alcohol Syndrome* and *Fetal Alcohol Effects* (FAS/FAE) are major birth defects leading to disturbance in brain function. Damage to fetal brain development is caused by the effects of the mother's drinking alcohol during pregnancy. Infants with FAS/FAE display irritability, jitteriness, tremors, weak suck reflexes, problems with sleeping and eating, failure to thrive, delayed development, poor motor control and poor habituation. In childhood, problems such as hyperactivity, attention problems, perceptual difficulties, cognitive deficits, language problems and poor motor coordination are common. In adolescence and adulthood, the primary difficulties are memory impairment, problems with judgment and abstract reasoning and poor adaptive

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198 National Institute of Mental Health, *Briefing Notes on the Mental Health of Children and Adolescents*, United States, not dated. (www.nimh.nih.gov).

199 Canadian Mental Health Association, *Children and Attention Deficit Disorders*, Pamphlet Series, not dated.

200 US Surgeon General Report (1999), p. 144.

201 Canadian Alzheimer's Disease Centre, http://www.alzheimercentre.ca/english/default.htm.

202 Sonya Norris, *Alzheimer's Disease*, PRB 02-39E, Library of Parliament, 2 October 2002.

functioning. Some common secondary disabilities, characteristic of adolescents and adults with FAS/FAE, include easy victimization, unfocused and distractable behaviour, difficulty handling money, problems in learning from experience, trouble understanding consequences and perceiving social cues, low frustration tolerance, inappropriate sexual behaviours, substance abuse and trouble with the law.[203]

4.3 SUBSTANCE USE AND ADDICTION

> *It is important to distinguish between substance use, abuse and dependence. Psychoactive substance use is very common. Abuse is less common and dependence affects only a minority of people who use psychoactive substances. The level of severity of consequences is higher for those with abuse and even higher for those with dependence.*
> *[Dr. David Marsh, Centre for Addiction and Mental Health (16:44)]*

According to Health Canada, *substance use* includes the use of any of a range of psychoactive substances – i.e., substances that have an effect on a person's mental state – including alcohol, non-prescription and prescription drugs, illicit drugs, solvents and inhalants. Patterns of use may range from abstinence, to occasional or regular use, to frequent heavy use, to full-blown substance abuse.[204]

Substance use disorders, which are considered to be mental disorders under both the DSM and the ICD, refers to a habitual pattern of alcohol or drug use that results in significant problems in work, relationships, physical health, financial well-being, and other aspects of a person's life. Substance use disorders encompass two sub-categories: substance abuse and substance dependence.[205] *Substance abuse* refers to a maladaptive pattern of use despite the affected person's knowledge of the negative consequences associated with such use. *Substance dependence* is characterized by a loss of control, preoccupation with and continued use of substance(s) despite its negative consequences.[206]

Dependence can be physical, psychological, or both. *Physical dependence* consists of tolerance (needing more of the substance for the same effect). *Psychological dependence* is present when a person perceives an intense need to use the substance in order to function effectively or in particular situations. The degrees of dependence range from mild to severe, the latter being characterized as addiction.[207]

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203 Fred J. Boland et al., *Fetal Alcohol Syndrome: Implications for Correctional Service*, Correctional Service Canada, July 1998.

204 Colleen Hood, Colin Mangham, Don McGuire and Gillian Leigh, Exploring the Links Between Substance Use and Mental Health, Section I ("A Discussion Paper") and Section II, ("A Round Table") Health Canada, 1996, p. 44. (http://www.hc-sc.gc.ca/hecs-sesc/cds/publications/index.htm)

205 Health Canada, *Best Practices – Concurrent Mental Health and Substance Use Disorders*, 2002, p. 8.

206 *Ibid.*, pp. 89-90.

207 BC Partners for Mental Health and Addictions Information, "What is Addiction?", The Primer – Fact Sheets on Mental Health and Addiction Issues, (http://mentalhealthaddictions.bc.ca/).

Addiction implies uncontrollable use of one or more substances, associated with discomfort or distress when that use is discontinued or severely reduced. Addiction may also describe certain other behavioural problems, such as *compulsive* or *pathological gambling*, which can be considered a process rather than a substance addiction. Research to date suggests that pathological gambling may progress in stages similar to those in alcoholism.[208]

In this report, we often use the term "addiction" to refer to the broad field of substance abuse. The *addiction treatment system* encompasses treatment, services and supports for those suffering from substance abuse and substance use disorders.

4.4 CO-MORBIDITY, CONCURRENT DISORDERS AND DUAL DIAGNOSIS

Co-morbidity simply denotes that two or more illnesses affect the same individual, whether two different mental disorders, two physical illnesses or a mental disorder and a physical illness. In this report, the concept of *co-morbidity* refers to the occurrence of a mental illness together with a physical illness. For example, epidemiological data show that 25% of arthritic patients have co-morbid depression or anxiety; there is a high level of co-morbidity between cancer, diabetes, respiratory problems, hypertension or migraine and some mental disorders. The interactions of physical and mental illnesses are, however, very complex.[209]

The term *concurrent disorders* most commonly refers to individuals who suffer from a mental illness and a substance use disorder at the same point in time. The relationships between mental illness and substance use are not straightforward. One the one hand, mental health problems/illnesses may act as risk factors for increased substance use (e.g., increased anxiety may lead to increased reliance on alcohol) and, on the other, substance abuse may act as a risk factor for increasing mental health problems/illnesses (e.g., problematic alcohol use may be a risk factor for depression). In other situations, a shared causal explanation may apply in which both disorders are promoted by a third factor such as genetic predisposition or family environment. Research indicates, however, that, in some circumstances, mental illness and substance use disorder occur independent of each other.[210]

> **In general terms, the "concurrent disorders" population refers to those people who are experiencing a combination of mental/ emotional/psychiatric problems with the abuse of alcohol and/or another psychoactive drugs. More technically speaking, and in diagnostic terms, it refers to any combination of mental health and substance use disorders, as defined for example on either Axis I and/or Axis II of DSM-IV.**
> ***[Brian Rush, Ph.D., CAMH, Brief to the Committee ,May 2004, p. 2.]***

In this report, *dual diagnosis* refers to individuals who have a mental health problem or illness together with developmental disability (formerly referred to as "mental retardation"). Because there are difficulties in diagnosing mental illness in a person with developmental disability, dual diagnosis is often unrecognized (undiagnosed) and untreated. Affected

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[208] Health Canada (1996), p. 30.
[209] Paula Stewart (2002), p. 22.
[210] Health Canada, *Best Practices – Concurrent Mental Health and Substance Use Disorders*, 2002.

individuals have complex and challenging needs and are certainly among the most vulnerable members of the Canadian population. They are more likely to experience abuse (more particularly sexual abuse), neglect and exploitation than other Canadians. They often "fall through the cracks."[211]

4.5 SUICIDAL BEHAVIOUR

The term *suicidal behaviour* encompasses completed suicide (death by suicide), attempted suicide (including intentional self-inflicted harm) and suicidal ideation (thinking about suicide). Suicidal behaviour is often the consequence of a number of factors that have interacted, including acute stressors and negative life events (e.g., bereavement, loss of employment, separation, illness), symptoms associated with an acute episode of mental illness or substance use disorder (e.g., psychosis, depression, intoxication), personality characteristics, social and/or economic circumstances.

> **The presence of mental health problems is probably the single most important predictor of suicide. Accordingly, approximately 90% of suicide cases meet the criteria for a psychiatric disorder, particularly major depression, substance use disorders and schizophrenia. However, it is only a minority of people with these diagnoses that will eventually commit suicide indicating that a psychiatric disorder may be a necessary, but insufficient risk factor for suicide.**
> ***[Dr. Gustavo Turecki, Brief to the Committee, 21 April 2004, p. 1.]***

While not itself a mental disorder, suicidal behaviour is highly correlated to mental illness and addiction. Studies indicate that more than 90% of suicide victims have a diagnosable mental illness or substance use disorder.[212] Suicide is the most common cause of death of individuals with schizophrenia. Suicide also accounts for 15% to 25% of all deaths among individuals with severe mood disorders.[213] Addiction often predisposes to suicidal behaviour by intensifying a depressive mood swing and by reducing self-control.[214]

4.6 SERVICES AND SUPPORTS

Traditionally, mental health care in the formal health care system has encompassed primary, secondary and tertiary care. Primary mental health care, i.e., first-line services, traditionally included simple diagnostic procedures, basic treatment, and referral to more specialized services as needed. A great deal of attention has been directed to enhance the capacity of primary mental health care given that it is now recognized that a large proportion of the population should receive services for mental health problems in this sector of the health care system. Secondary care is more specialized care that provides more extensive and

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211 Canadian Mental Health Association – Ontario Division, *Dual Diagnosis: People with Developmental Disability and Mental Illness – Falling Through the Cracks*, Fact Sheet, 1998.

212 BC Partners for Mental Health and Addictions Information, "Suicide: Follow the Warning Signs", *The Primer – Fact Sheets on Mental Health and Addictions Issues*.

213 According to data from the Canadian Mental Health Association – Ontario Division (http://www.ontario.cmha.ca/).

214 The Merck Manual on Diagnosis and Therapy, "Suicidal Behaviour", Section 15, Chapter 190.

complicated procedures and treatment; it may be provided within hospitals, clinics or office-based practices, on an inpatient or outpatient basis. Tertiary care is generally defined as specialized interventions delivered by highly trained professionals to individuals with problems that are particularly complex and difficult to treat in primary or secondary settings. In the mental health system, tertiary care also refers to the long term care that has historically been provided in large psychiatric hospitals to individuals with persistent mental disorders. Research and teaching activities are also undertaken within tertiary care institutions.

In this report, it is recognized that many and diverse services and supports are required by those who experience mental illnesses and substance use disorders and, as such, they are provided by numerous professional and non-professional service providers and organizations. These services and supports extend beyond those provided in the traditional mental health care system. A Canadian review of best practices suggests the need for the following core mental health and addiction services and supports[215]:

- *Case management* refers to the constant ongoing support provided to individuals with mental illnesses/substance use disorders to help them obtain the services they need. The case manager assesses needs, identifies skill deficits and refers the individual to providers of the appropriate services. Case management is intended to help patients/clients to develop skills for daily living, enhance their community tenure and prevent hospitalization. *Assertive Community Treatment* (ACT) is acknowledged to be the most appropriate model of case management to provide services to those with severe and persistent mental illnesses and concurrent disorders. In the ACT model, case management is provided by a multidisciplinary team in the community where the individual lives rather than in an office-based practice or an institution. The team involves psychiatrists, family physicians, social workers, nurses, occupational therapists, vocational specialists, etc., and is available to the patient/client 24 hour a day, 7 days a week.
- A wide range of *inpatient and outpatient services* are needed, including: counselling; psychotherapy; individual and group therapy; partial hospitalization (day treatment programs); acute home treatment (as an alternative to acute hospitalization); specialty services in both the community and psychiatric units/facilities; forensic psychiatry; and shared care. *Shared mental health care*[216] is of particular interest. This refers to a broad spectrum of collaborative activities between primary health care providers and psychiatrists or other mental health care providers; some have a strong clinical focus, integrating mental health services into primary health care settings, while others offer creative educational programs to primary health care providers through collaboration among academic departments.
- *Community supports, including housing, vocational services, supported education and supported employment* are important components of the spectrum of services required by individuals with mental disorders. It has been demonstrated that the availability of such community supports can substantially improve outcomes. It is recognized that

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[215] Health Canada, *Review of Best Practices in Mental Health Reform*, prepared for the Federal/Provincial/Territorial Advisory Network on Mental Health, 1997.

[216] The College of Family Physicians of Canada and the Canadian Psychiatric Association, *Shared Mental Health Care in Canada – A Compendium of Current Projects*, Spring 2002.

individuals with mental illness have the capacity to work and that employment programs should be encouraged for even the most disabled of individuals. Similarly, supported education programs enable individuals to return to school on a full-time basis. Evidence also suggests that community residential programs can successfully substitute for long-term inpatient care. Thus, a range of different housing alternatives (e.g. supervised group homes or other residential settings) should be provided.

- *Mental health crisis/emergency response* provides a broad range of services to address the widely varying manifestations of acute mental health/substance use. There are five essential components to the crisis response/emergency service: telephone crisis lines, mobile crisis outreach, walk-in crisis stabilization services, crisis residential (non-hospital) services, and hospital-based psychiatric emergency services.
- Most importantly, there should be a strong focus on *initiatives by individuals with mental illness and addiction and their families*: The involvement of individuals who themselves have had mental illness/addiction problems in the planning, delivery, management, evaluation and reform of mental health services and supports has led to the development of a wide range of consumer/family initiatives that provide information, education, training, self-help, mutual aid and peer support. More importantly, significant strides have been made in this domain with the recent development of consumer based businesses as a means to promote self fulfillment and a reduce dependence on social services.

In this report, the *mental health system* refers to the broad range of services and supports available to individuals with mental illness. Similarly, the *addiction system* describes the entire range of services aimed at preventing or reducing/treating substance abuse, substance use disorders and problematic gambling.

4.7 CHRONIC DISEASE MANAGEMENT AND SELF-MANAGEMENT

Chronic disease management is a relatively new approach that has been shown to be very effective in the long term treatment of diseases. The approach is based on the "Chronic Care Model" used by a United States national program called Improving Chronic Illness Care (ICIC) based in Seattle, Washington, at the MacColl Institute for Healthcare Innovation at the Group Health Cooperative of Puget Sound.[217]

> **Chronic disease management as an approach to mental health and addictions care emphasizes assisting individuals to maintain independence and to maintain optimal health through prevention, early detection, and management of chronic mental disorders and substance use disorders.**
> ***[Ministry of Health Services, British Columbia, Brief to the Committee, 9 September 2003, p. 7.]***

Chronic disease management rests on evidence-based clinical guidelines and protocols and involves many health care professionals and administrators througout all sectors of the health care system that share a common vision and collaborating on several

[217] For more information, please go the ICIC Website (http://www.improvingchroniccare.org./).

initiatives in parallel. This approach contrasts with the model of treating a care episode as a single event – a visit to a health care provider. In Canada and the United States, chronic disease management has been applied with great success to many chronic diseases, such as diabetes, arthritis and even asthma; it is now being contemplated for application to mental illness and addiction. Chronic disease management emphasizes community based care and aims to foster independence and fulfillment.[218]

An important element of chronic disease management is the active participation of affected individuals themselves in the management of their illnesses on a day-to-day basis. This participation of patients/clients is usually referred to as self-management. The concept of *self-management* does not mean that individuals deal with their illnesses or disorders on their own. It is a process that enables the individual to develop the knowledge, attitudes and skills necessary to manage his/her illness or disorder and to make improved use of existing health services and supports in order to access help when it is needed.[219]

4.8 PROMOTION, PREVENTION AND SURVEILLANCE

The goal of mental health *promotion* is to provide information to the public to raise and enhance awareness and understanding of mental health issues, reduce stigma and promote positive mental health. Mental health promotion also includes education and training of human resources in the formal mental health/addiction system.

> **Mental health literacy refers to knowledge and beliefs about mental disorders, which assist in the recognition, management or prevention of mental health and substance use problems, and mental and substance use disorders. Mental health literacy includes the ability to recognize specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking.**
> ***[Ministry of Health Services, British Columbia, Brief to the Committee, 9 September 2003, p. 9.]***

The concept of mental health literacy is often used in the context of mental health promotion. *Mental health literacy* refers to the knowledge, beliefs and abilities that support the recognition, management or prevention of mental illnesses or substance use disorders. A high public level of mental health literacy makes early recognition of and appropriate intervention in mental illnesses and substance use disorders more likely. It is also effective in reducing stigma.[220]

Prevention is categorized as *primary prevention* when directed at averting a potential mental health/substance use problem; *secondary prevention* is directed at early detection and includes the appropriate intervention to prevent or delay onset or mitigate a mental health problem;

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218 Mental Health and Addictions, Ministry of Health Services, Government of British Columbia, *Brief to the Committee*, 9 September 2003, p. 7.

219 BC Partners for Mental Health and Addictions Information, "Mental Health and Addictions Information Plan for Mental Health Literacy", *The Primer - Fact Sheets on Mental Health and Addictions Issues*, British Columbia.

220 *Ibid.*

tertiary prevention is directed at minimizing disability or avoiding relapse in a successfully treated, stable patient/client.

Surveillance usually refers to the ongoing systematic collection, analysis and interpretation of health-related data used to determine the occurrence of diseases, assess relevant needs and evaluate effectiveness of policies and programs. Currently, Canada has no national surveillance system for tracking mental illnesses and substance use disorders.[221]

4.9 INDIVIDUALS WITH MENTAL ILLNESS/ADDICTION AND RECOVERY

As described at the outset of this chapter, no commonly accepted language and terminology exist to describe all concepts and issues in the field of mental illness and addiction. There is little agreement in regard to the most respectful and appropriate terms to identify those individuals who themselves have experienced a mental illness or substance use disorder. Some individuals have very strong feelings about the language used in view of the societal stigmatization and pejorative labelling that is far too commonly encountered by individuals with mental illness and addiction.

Traditionally, individuals with mental illness and addiction being cared for by physicians are called patients. Other health professionals often refer to such individuals as *clients* or service users. The individuals may describe themselves by a number of terms, commonly consumers and survivors. Consumers usually refer to individuals with direct experience of significant mental health problems or mental illnesses who have used the resources available from the mental health system. Some individuals have chosen to refer themselves as survivors, a term that they feel acknowledges their strength in coping with mental illness and/or addiction. In this report, the Committee uses the terms *individuals with mental illness and addiction* or *patient/client*.

Individuals with mental illness and addiction often talk about recovery. *Recovery* is not the same thing as being cured. For many individuals, it is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for others, recovery means the reduction or complete remission of symptoms related to mental illness.

> **Recovery is a journey, rather than a destination. It is an active, ongoing, highly individualized process through which a person is encouraged to assume responsibility for his or her life, often in collaboration with friends, families, peers and professionals.**
>
> **Each person's recovery is unique. No two people will have the same path or use the same measures to mark the success of their recovery. The real test for recovery is when people feel that they have recovered and are living a quality of life that is not dominated by their past situation or their current symptoms and stresses.**
>
> ***[Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs, Ontario, December 2002, p. 28.]***

221 Paula Stewart, *The Development of a Canadian Mental Illnesses and Mental Health Surveillance System: A Discussion Paper*, prepared for the Canadian Alliance on Mental Illness and Mental Health, 1999 (unpublished).

In the field of mental health, recovery is a personal process of overcoming the negative impact of mental illness despite its continued presence. In the field of addiction, recovery describes an abstinence-based approach to substance use disorders, such as those practiced by Alcoholics Anonymous and Narcotics Anonymous. The recovery concept presupposes that, with the appropriate treatment and supports in place, individuals with mental illness and addiction can take charge of their lives, create new goals and aspirations, and engage in society as productive citizens.[222]

[222] Provincial Forum of Mental Health Implementation Task Force Chairs, *The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario*, December 2002, p. 21.

CHAPTER 5:
PREVALENCE AND COSTS

Mental disorders are not the exclusive preserve of any social group; they are truly universal. Mental and behavioural disorders are found in people of all regions, all countries and all societies.
[WHO (2001), p. 23.]

INTRODUCTION

Mental illness and addiction are common, affecting about 1 in 5 Canadians during their lifetines. They affect individuals of all ages, women and men, in all cultures and income groups. They are prevalent in all regions, both rural and urban. They have a huge economic impact, not only on the individual and his/her family, but also on the health care system, the broader social system, the workplace and society as a whole.

If mental illness were an infectious disease, it would constitute an epidemic in Canada. The number of people affected is overwhelming (…).
[Phil Upshall, President, Canadian Alliance on Mental Illness and Mental Health, Brief to the Committee, 18 July 2003, p. 4.]

To plan adequately and organize the delivery of needed services and supports and to develop sound public policy on mental health, it is essential to properly assess the prevalence and economic burden of mental illness and addiction. In this chapter, existing information on the prevalence and the economic cost of mental illness, addiction, pathological gambling and suicide in Canada is reviewed. Where data are available, some international comparisons are also presented.

Section 5.1 provides information on the prevalence of mental illnesses, substance use disorders and pathological gambling. Section 5.2 reviews the prevalence of suicidal behaviour. Section 5.3 examines the prevalence of mental illness and addiction in specific population groups, including Aboriginals, homeless people and inmates. Section 5.4 provides data on the economic burden of mental illness and addiction in Canada. Finally, the Committee makes some commentary and concluding remarks in Section 5.5.

5.1 PREVALENCE OF MENTAL ILLNESSES, SUBSTANCE USE DISORDERS AND PATHOLOGICAL GAMBLING

Canada does not collect, in a systematic manner, national data on the mental health status of Canadians, nor the extent of any particular mental illness.
[Phil Upshall, President, Canadian Alliance on Mental Illness and Mental Health, Brief to the Committee, 18 July 2003, p. 6.]

Data on *prevalence* provide estimates of the proportion of individuals in a population who suffer from an illness or a disorder. Prevalence rates differ depending on whether they refer to individuals who have a disease at a certain point in time (point prevalence), during a period of time (period prevalence – usually a year), or throughout their lifetime (lifetime prevalence).

Currently, there is no national database capable of providing precise information on the prevalence of all mental disorders for all age groups in Canada. Often, the best estimates are derived from epidemiological studies reported in the literature. However, the 2002 Canadian Community Health Survey (CCHS), Cycle 1.2 on Mental Health and Well-Being, carried out by Statistics Canada, provided for the first time prevalence rates for some mental illnesses, substance use disorders and pathological gambling. These are described below.

The Statistics Canada mental health survey that was published in the fall was an excellent start. That was the first population based survey of mental illnesses ever done in this country. Can you imagine if 2003 were the year of the first survey of heart disease or cancer in this country? That would be appalling. We need a better surveillance system.
[Dr. Blake Woodside, Chairman of the Board, Canadian Psychiatric Association (5:19)]

5.1.1 Canadians Aged 15 Years and Over

According to the CCHS (see Table 5.1), 1 out of every 10 Canadians aged 15 and over – about 2.6 million individuals – reported sympto
substance use disorders during the past year. Th
women as for men: some 1.4 million of wome
consistent with mental illnesses and/or substan
(or 10%) of men.

Mental illnesses and addictions know no boundaries. They can strike at any age and in any population.
[Canadian Psychological Association, Brief to the Committee, 2003, p. 5.]

There were, however, gender differences by type of disorder. Mood disorders and anxiety disorders were more common among women (6%) than men (4%), while substance use disorders were more common in men (4%) than women (2%).

TABLE 5.1

ONE-YEAR PREVALENCE OF MENTAL DISORDERS AMONG CANADIANS AGED 15 YEARS AND OLDER, 2002

	Total		Males		Females	
	Number (000's)	Rate (%)	Number (000's)	Rate (%)	Number (000's)	Rate (%)
Unipolar Depression	1,120	4.5	420	3.4	700	5.5
Bipolar Depression	190	0.8	90	0.7	100	0.8
Any Mood	**1,210**	**4.9**	460	**3.8**	**750**	**5.9**
Panic Disorder	400	1.6	130	1.1	270	2.1
Agoraphobia	180	0.7	40	0.4	140	1.1
Social Phobia	750	3.0	310	2.6	430	3.4
Any Anxiety	**1,180**	**4.7**	440	**3.6**	**740**	**5.8**
Alcohol Dependence	640	2.6	470	3.8	170	1.3
Illicit Drug Dependence	170	0.7	120	1.0	50	0.4
Any Substance Use	**740**	**3.0**	540	**4.4**	**200**	**1.6**
Total – Any Disorder	**2,600**	**10.4**	**1,190**	**9.7**	**1,410**	**11.1**

Statistics Canada, "Canadian Community Health Survey: Mental Health and Well-Being", *The Daily*, 3 September 2003.

The CCHS found that adolescents and young adults aged between 15 and 24 were more likely to report suffering from mental illnesses and/or substance use disorders than other age groups. In this age group, 18% reported having experienced mental illness and/or substance abuse, compared to 12% of those aged 25-44, 8% of those aged 45-64, and 3% of seniors 65 and over.

The CCHS survey was limited in the range of mental disorders observed in the Canadian population. This contrasts with the National Survey of Mental Health and Well-Being undertaken in Australia in 1997. The Australian survey covered a wider range of anxiety and affective mood disorders. It also distinguished between the harmful use of, and dependence on, alcohol and drugs. The Australian government also plans a survey of low prevalence psychotic disorders, such as schizophrenia.[223]

> **(…) we need to see co-occurring addiction and mental health problems as the norm, not the exception. To detect the presence of one problem should lead us to the assumption that the other is present unless it is determined otherwise.**
>
> ***[Wayne Skinner, CAMH, Brief to the Committee, May 2004, p. 2]***

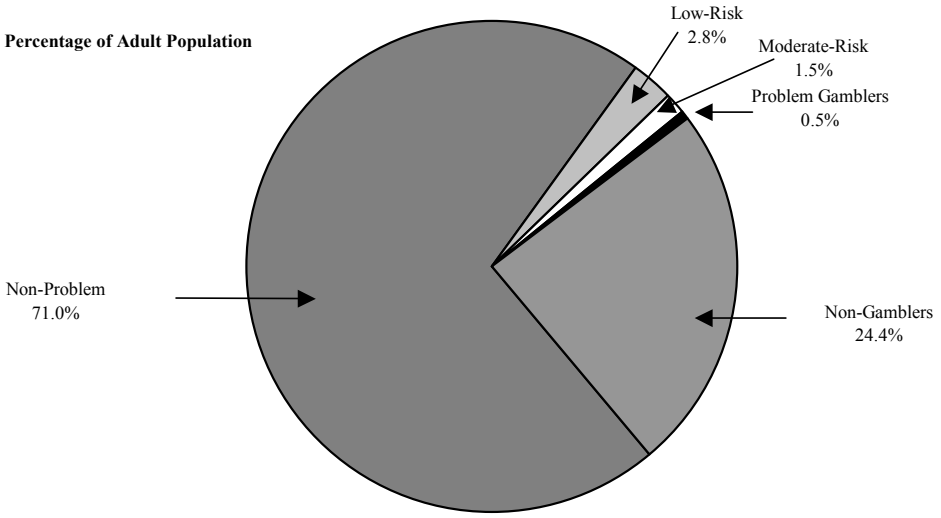
223 The Australian's National Survey of Mental Health and Well-Being covered the following anxiety disorders – panic disorder, agoraphobia, social phobia, generalized anxiety disorder, obsessive-compulsive disorder and post-traumatic stress disorder – and the following affective disorders – depression, dysthymia, mania, hypomania, bipolar disorder. In addition, it surveyed alcohol use

It is unfortunate that the CCHS survey did not correlate or cross-tabulate data in order to evaluate the prevalence rates of concurrent disorders (mental illness co-occurring with substance use disorder) among Canadians aged 15 and over. The insufficiency of the information on the prevalence of concurrent disorders creates obstacles to better understanding them and to the effective planning and development of appropriate services and supports for those affected. The design of the National Survey of Mental Health and Well-Being of Adults in Australia permitted an assessment of both concurrent disorders and co-morbidity (defined as the presence of both mental disorders and physical conditions).

> **Where there is gambling, there will be people with a problem.**
> ***[Katherine Marshall and Harold Wynne, "Fighting the Odds", p. 5.]***

In contrast to the Australian survey, the CCHS survey did provide information on problem or pathological gambling.[224] Some 1.2 million Canadians (or 5% of the adult population) in 2002 were estimated to have the potential to become problem gamblers or were so already (see Chart 5.1). 700,000 Canadians were at low risk (2.8%), some 370,000 individuals were at moderate risk (1.5%) and 120,000 were already problem gamblers (0.5%). Men (8%) who gambled were significantly more likely than women (5%) to be at-risk or problem gamblers. At-risk and problem gamblers were also, on average, younger than non-problem gamblers (40 versus 45) and less well educated (8% versus 5%).

CHART 5.1
GAMBLING BEHAVIOUR IN CANADA, 2002



Katherine Marshall and Harold Wynne, "Fighting the Odds", *Perspectives on Labour and Income* , Statistics Canada, Catalogue No. 75-001-XIE, Vol. 4, No. 12, December 2003.

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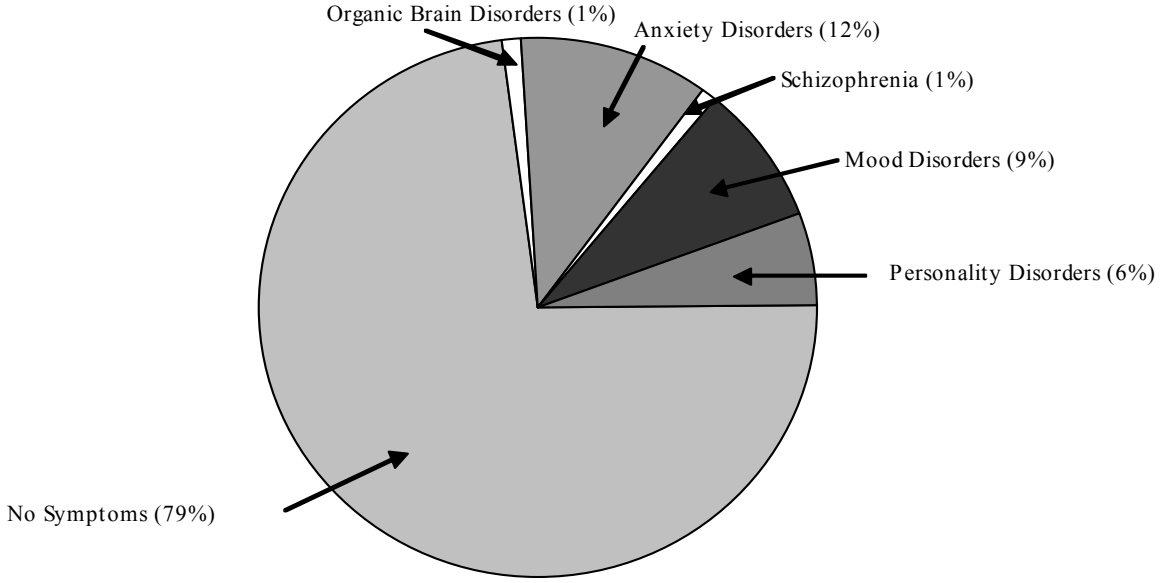
disorders and drug use disorders in terms of both harmful use and dependence. For more information, visit the website of the Australian Bureau of Statistics. (http://www.abs.gov.au/Ausstats/abs@.nsf/0/3F8A5DFCBECAD9C0CA2568A900139380?Open).

224 Data on gambling are analyzed in details by Katherine Marshall and Harold Wynne in "Fighting the Odds", *Perspectives on Labour and Income*, Statistics Canada, Catalogue No. 75-001-XIE, Vol. 4, No. 12, December 2003, pp. 5-13 (http://www.statcan.ca/).

Interestingly, the survey suggested a link between pathological gambling, mental illness and substance abuse. More precisely, 42% of problem gamblers reported a high or extreme level of stress in their lives; 24% of them reported having had a major clinical depression; and 15% reported being dependent on alcohol. The survey also found that 18% of problem gamblers had contemplated suicide in the past year.

Lifetime prevalence rates for mental illnesses and substance use disorders in Canada are based on various epidemiological studies. Data compiled by Paula Stewart and her colleagues (October 2002), showed that nearly one in five Canadian adults (21% of the population or 4.5 million individuals) will personally experience a mental illness in their lifetime.[225] Chart 5.2 illustrates the lifetime prevalence of mental illness among Canadian adults as derived from epidemiological studies.

CHART 5.2
MENTAL ILLNESSES IN CANADA: LIFETIME PREVALENCE AMONG ADULTS



Nota: Percentages may not add up to 100% as individuals may have symptoms in more than one category. Based on data provided by Paula Stewart et. al., *A Report on Mental Illnesses in Canada* , October 2002.

As illustrated above, anxiety disorders and mood disorders are the most common mental illnesses among Canadian adults; they affect 12% and 9% of adults respectively. Schizophrenia affects about 1% of the Canadian population. Dementia associated with Alzheimer's disease and organic brain disorders which are the result of physical disease or injury to the brain (e.g., AIDS dementia complex and vascular dementia), also affect some 1% of Canadian adults. Between 6% and 9% of adults in Canada suffer from personality disorders.

[225] Paula Stewart et al., *A Report on Mental Illnesses in Canada*, published by Health Canada, October 2002.

Similar rates of prevalence are found worldwide. With respect to point prevalence, the World Health Organization (WHO) reported in 2001 that mental illness and addiction at any point in time affect about 10% of the adult population – or some 450 million individuals worldwide.[226] In terms of lifetime prevalence, the WHO reported that, throughout their lifetime, more than 25% of individuals develop one or more mental illnesses.[227] The WHO also estimated that, throughout the world, one in four families has at least one member currently suffering from a mental illness or addiction.[228]

With respect to one-year prevalence rates, the WHO World Mental Health Survey Consortium found that mental disorders are highly prevalent in both developed and less developed countries, although there is substantial cross-national variation; the prevalence is low in Asian countries in particular. Anxiety disorders are the most common mental illnesses, with mood disorders next. Broken down by the degree of severity, a substantial proportion of disorders were classified as mild; smaller proportions of the samples were considered serious or moderate disorders, although they were often associated with significant impairment in carrying out usual activities.[229]

5.1.2 Children and Adolescents (0 to 19 Years of Age)

Based on various epidemiological studies, Charlotte Waddell and Cody Shepherd (October 2002) estimated overall and disorder-specific prevalence rates of some mental disorders in children and adolescents in British Columbia. Table 5.2 extrapolates from these rates to estimate the number of children and adolescents in Canada who may be affected by mental disorders.

The overall prevalence of mental illness in Canadian children and adolescents, at any given point in time, is about 15%. This translates into approximately 1.2 million of children and adolescents who experience mental illness and/or addiction of sufficient severity to cause significant distress and impaired functioning. The most common are anxiety (6.5%), conduct (3.3%), attention deficit (3.3%), depressive (2.1%) and substance use (0.8%) disorders.

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226 World Health Organization, *Mental Health : New Understanding, New Hope*, 2001, p. 23.

227 *Ibid.*

228 WHO (2001), p. 24.

229 The WHO World Mental Health Survey Consortium, "Prevalence, Severity, and Unmet Need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys", Journal of the American Medical Association, Vol. 291, No. 21, 2 June 2004, pp. 2581-2590.

TABLE 5.2

PREVALENCE OF MENTAL DISORDERS IN CHILDREN AND ADOLESCENTS[(a)]

MENTAL DISORDER	PREVALENCE RATE (%)	APPROXIMATE NUMBER
Anxiety Disorder	6.5	513,780
Conduct Disorder	3.3	260,842
ADHD	3.3	260,842
Depressive Disorder	2.1	165,990
Substance Abuse	0.8	63,234
Pervasive Developmental Disorder	0.3	23,713
Obsessive-Compulsive Disorder	0.2	15,809
Schizophrenia	0.1	7,904
Tourette's Disorder	0.1	7,904
Eating Disorder	0.1	7,904
Bipolar Disorder	less than 0.1	less than 7,904
ANY DISORDER	**15**	**1,185,645**

(a) Based on a population estimate by Statistics Canada of 7,904,300 children and adolescents (aged 0 to 19 years) in July 2002.

Source: Adapted from Charlotte Waddell and Cody Shepherd, *Prevalence of Mental Disorders in Children and Youth*, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, University of British Columbia, October 2002.

An important fact that is not captured in the table is the presence of two or more mental disorders occurring together. For example, an Ontario Child Health Survey reported that amongst children and adolescents who experienced a mental disorder, over two-thirds (68%) of them had two or more mental disorders. Similarly, a recent study of adolescents with substance use disorders found that over three quarters (76%) had concurrent anxiety, mood or behaviour disorders.[230]

Dr. Joseph H. Beitchman, Psychiatrist-in-Chief, Hospital for Sick Children (Toronto), stressed in his brief that most adult mental disorders begin or originate in childhood or adolescence; they are serious, lifelong illnesses.[231] This underscores the need for early detection and intervention. It also highlights that the best opportunities for prevention and reduction in the emergence of new cases are in childhood and adolescence. As pointed out by Charlotte Waddell et. al. (2002): "Good-quality epidemiological information is essential for developing sound public policies to improve children's mental health."[232] It is interesting to note that the National Mental Health Strategy adopted by the Commonwealth, State and Territory governments of Australia called for a child and adolescent survey to be undertaken

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230 Data quoted in Charlotte Waddell et. al., *Child and Youth Mental Health: Population Health and Clinical Services Considerations*, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, University of British Columbia, April 2002, p. 15.

231 Dr. Joseph H. Beitchman, Psychiatrist-in-Chief, Hospital of Sick Children (Toronto), Brief to the Committee, 30 April 2003, p. 7.

232 Charlotte Waddell et. al., "Child Psychiatric Epidemiology and Canadian Public Policy-Making: The State of the Science and the Art of the Possible", *Canadian Journal of Psychiatry*, Vol. 47, No. 9, November 2002, pp. 825-832.

as well as their National Survey of Mental Health and Well-Being of Adults. Such a study has never been done in Canada.

5.1.3 Seniors (65 Years and Over)

The CCHS survey, as reported above, found that, during the past year, some 3% of Canadians aged 65 and over (or some 107,283 seniors) reported symptoms associated with the five mental disorders and the two substance dependencies surveyed. The one-year prevalence rate was 1.8% for unipolar disorder, 0.2% for panic disorder, 0.9% for social phobia and 0.4% for agoraphobia. Mental illnesses and substance use disorders were more prevalent among women (3.2%) than men (2.5%). The survey also found that about 2% of Canadian seniors reported having had suicidal thoughts in the past twelve months.

Other information was presented to the Committee on the prevalence of mental disorders among Canadian seniors:

- The incidence of depression in seniors in long term care settings is three to four times higher than in the general population. The prevalence of mental disorders among nursing home residents is extraordinarily high, between 80% and 90%. The prevalence of psychosis ranges from 12% to 21% depending on how psychotic symptoms are measured.[233]
- Alzheimer's disease and related dementias currently affect more than 360,000 Canadians, including 1 in 13 over the age of 65 and 1 in 3 over 85 years of age. Women are more affected by the disease than men.[234]
- Estimates suggest that 25% to 50% of seniors who abuse or misuse alcohol also suffer from mental disorders.[235]
- The incidence of suicide among men 80 years old and over is the highest of all age groups (31 per 100,000 population).[236]

5.1.4 Canadian Forces[237]

> *The more than 83,000 CF members (Regular Force and Reserve) are doubly concerned by [mental disorders] as they are exposed not only to the problems of a "normal" life, but also to those of a high-risk career.*
> *[National Defence, Statistics Canada CF Mental Health Survey: A "Milestone", 2003.]*

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233 Dr. David Conn, Co-Chair, Canadian Coalition for Seniors Mental Health, Brief to the Committee, 4 June 2003, p. 4 and p. 6.

234 Alzheimer Society of Canada, Brief to the Committee, 4 June 2003, p. 3.

235 Margaret Gibson, Department of Psychology, University of Western Ontario, Brief to the Committee, 4 June 2003, p. 2.

236 Dr. David Conn (4 June 2003), p. 5.

237 National Defence, *Statistics Canada CF Mental Health Survey: A "Milestone"*, 2003.

The CCHS included a separate mental health survey of the Canadian Forces (CF). It found a one year prevalence rate of 7.6% and a lifetime rate of 16.2% for unipolar depression within the CF regular force; the comparable prevalence rates for reservists were respectively 4.1% and 9.7%. In the regular forces, the prevalence rate of social phobia is 3.6% (one year) and 8.7% (lifetime), and 2.3% and 7.1% for the reservists. The one year and lifetime prevalence of Post Traumatic Stress Disorder is 2.8% and 7.2% for members of the regular forces and 1.2% and 4.7% for reservists. The one year and lifetime prevalence of general anxiety disorder is 1.8% and 4.6% for members of the regular forces and 1.0% and 2.9% for reservists. The comparable prevalence of panic disorder is 2.2% and 5.0% in the regular forces, and 1.4% and 3.3% in reservists. The one year prevalence rate for alcoholism is 4.2% and the lifetime prevalence rate is 8.5% for the regular forces; the rates are respectively 6.2% and 8.8% for reservists.

5.1.5 FAE/FAS and Dual Diagnosis

The prevalence of Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE) in Canada has not been properly evaluated. Based on worldwide prevalence rates, Health Canada estimated that there were some 341,901 individuals with FAS/FAE in Canada in 2001. The prevalence rates of FAS/FEA in some communities, particularly among Aboriginal Canadians, are higher than the national average.[238]

At least one baby a day in Canada is born with fetal alcohol syndrome, FAS, a disability that will have repercussions for the child, his or her family and the community for the individual's entire life. FAS is the leading cause of preventable birth defects and developmental delays in Canada. It is more common than Down's Syndrome.
[Pam Massad, Health Canada (13:5)]

As described in Chapter 4, dual diagnosis refers to individuals who have a mental health problem or illness together with developmental disability (formerly referred to as "mental retardation"). Because of the difficulty of diagnosing mental illness in individuals with developmental disability, dual diagnosis is often unrecognized and untreated. Data indicate that between 1% and 3% of Canadians have moderate or severe developmental disability. Conservatively estimated, 30% of these individuals also have mental illness; some researchers estimate the prevalence as high as 50% to 60%.[239]

5.2 PREVALENCE OF SUICIDAL BEHAVIOUR

One in twenty-five Canadians will attempt suicide during their lifetime. [Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, University of British Columbia, At-a-Glance Suicide Facts]

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238 Health Canada, *Fetal Alcohol Spectrum Disorder*, Brief to the Committee, 30 April 2003.

239 Canadian Mental Health Association – Ontario Division, Dual Diagnosis: People with Developmental Disability and Mental Illness – Falling Through the Cracks, Fact Sheet, 1998.

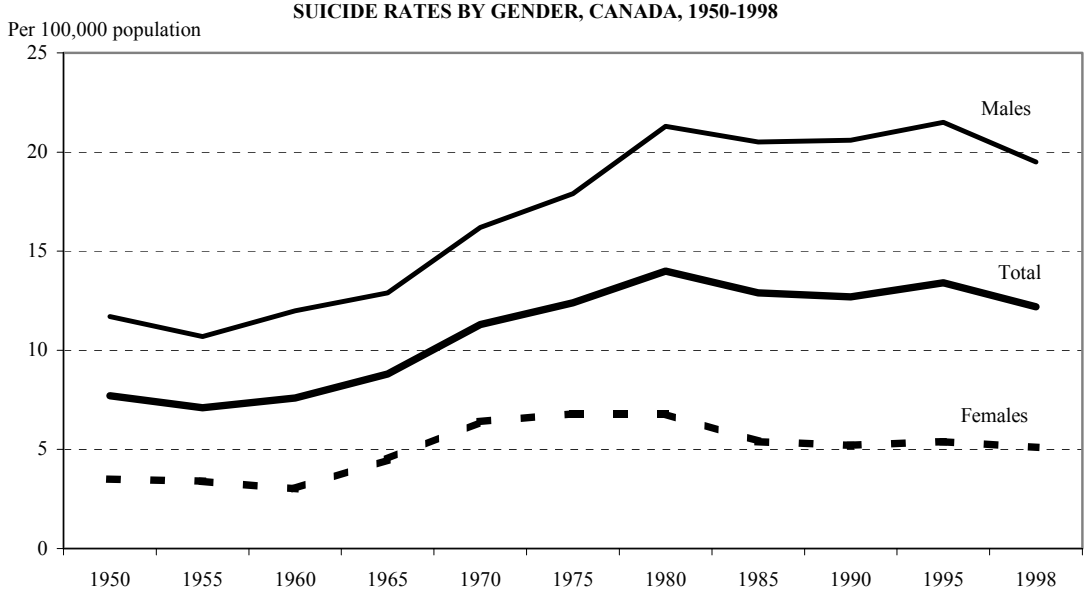
As discussed in Chapter 4, the concept of suicidal behaviour is broad, encompassing completed suicide (death by suicide), attempted suicide (including intentional self-inflicted harm) and suicidal ideation (thinking about suicide). This section presents recent data on the extent of suicidal behaviour in Canada and provides some international comparisons.

> **Suicide is a "stoppable" problem. It is an action, not an illness. (…) Moreover, attempted suicides, where the individual's actions have been non-fatal – are like the submerged unseen base of an iceberg.**
> ***[Diane Yackel, Centre for Suicide Prevention, Brief to the Committee.]***

5.2.1 Completed Suicides

Chart 5.3 shows that suicide rates in Canada rose sharply from 1950 to the early 1980s, with a peak in 1983, after which the rates remained more or less stable, with a slight decrease between 1995 and 1998 (latest year for which data are available).

CHART 5.3:
SUICIDE RATES BY GENDER, CANADA, 1950-1998



Source: Economics Division, Parliamentary Research Branch, Library of Parliament, March 2004. Data from the World Health Organization (2003).

In 1998, 3,699 Canadians took thei
distribution by age group is show
represented 2% of all deaths in Cana

> **Looking at the epidemiology of suicide we realize that suicide is an important problem from the public health perspective. It ranks among the 10 top causes of death for individuals of all ages.**
>
> ***[Dr. Gustavo Turecki, Director, McGill Group for Suicide Studies, McGill University (:)]***

TABLE 5.3

NUMBER OF SUICIDES AND SUICIDE RATES BY AGE GROUP AND SEX, CANADA, 1998

AGE	NUMBER OF SUICIDES	SUICIDE RATES (PER 100,000)

GROUP	TOTAL	MALES	FEMALES	TOTAL	MALES	FEMALES
5-14	46	30	16	1.2	1.5	0.8
15-24	562	457	105	13.5	21.6	5.1
25-34	701	568	133	13.7	22.1	5.2
35-44	895	713	182	19.0	30.3	7.7
45-54	672	513	159	19.2	29.0	9.2
55-64	366	296	70	15.5	25.9	5.8
65-74	260	201	59	14.9	26.7	6.0
75+	197	147	50	16.5	31.6	6.9
TOTAL	**3,699**	**2925**	**774**	**12.2**	**19.5**	**5.1**

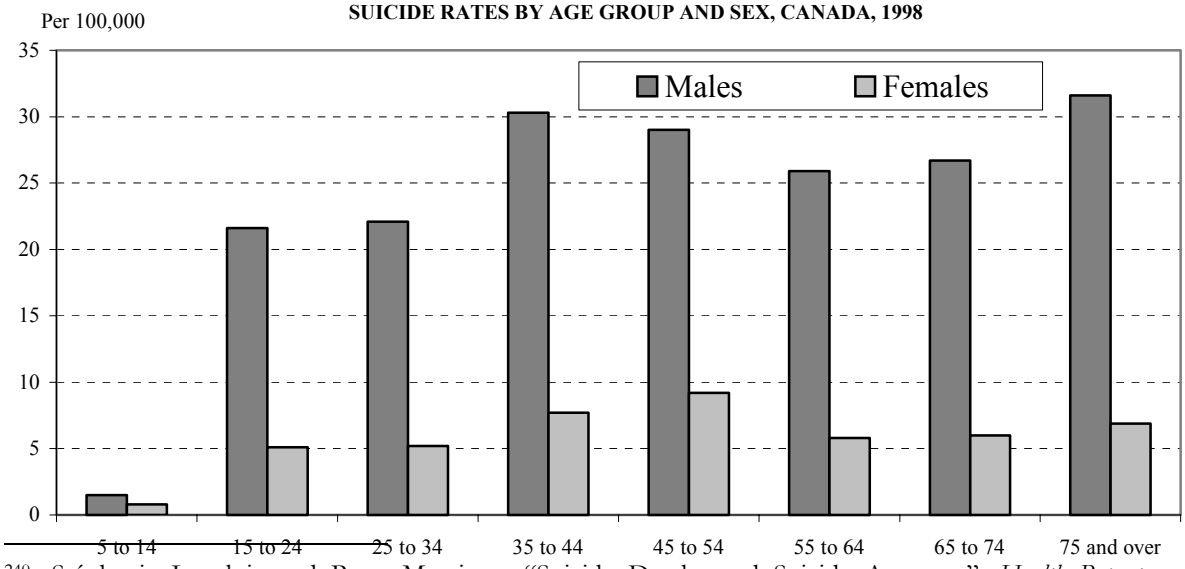
* Per 100,000 population.
Source: World Health Organization, *Suicide Prevention – Country Reports and Charts*, Geneva, 2003.

In every age group, males had a higher suicide rate than did females (see Chart 5.4); approximately four men committed suicide for every woman who did so.

According to Langlois and Morrison (2002), suicide was the leading cause of death for men in the age groups between 25 to 29 and 40 to 44, and for women between the ages of 30 to 34. For the three age groups from 10 to 14, 15 to 19 and 20 to 24, it was the second leading cause of death for both sexes, surpassed only by motor vehicle accidents.[240]

I am sure you will agree that taking one's own life at 14 or 15, while thousands or even millions of people fight against death every day, remains a paradox. Suicide among young Canadians is a serious problem that should be made a priority.
[Dr. Johanne Renaud,Centre hospitalier Sainte-Justine (13 :13-14)]

CHART 5.4
SUICIDE RATES BY AGE GROUP AND SEX, CANADA, 1998



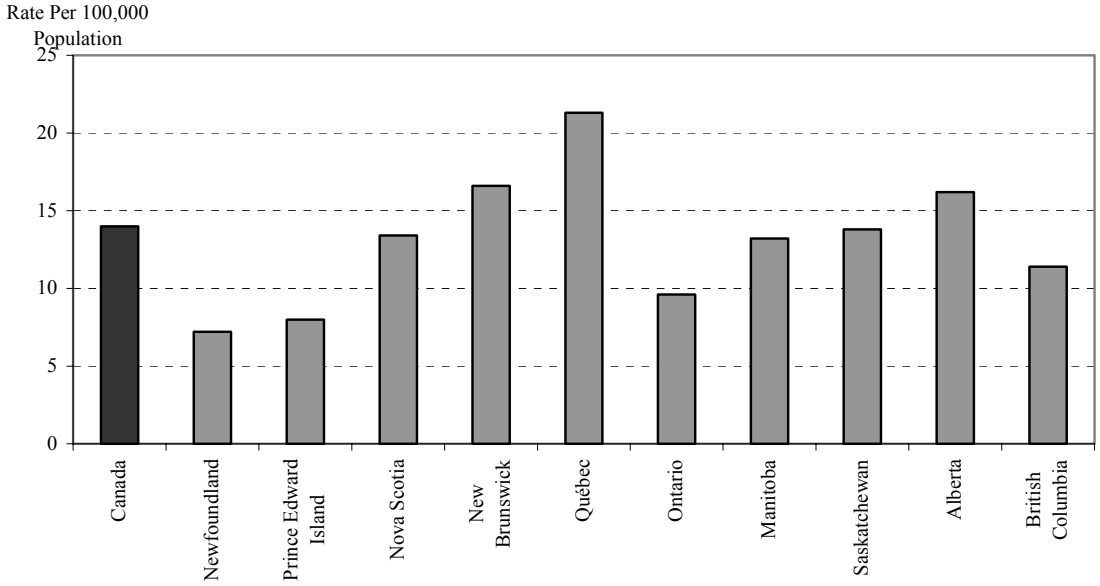
Source: Economics Division, Parliamentary Information and Research Services, Library of Parliament, March 2004. Data from the World Health Organization (2003).

[240] Stéphanie Langlois and Peter Morrison, "Suicide Deaths and Suicide Attempts", *Health Reports*, Statistics Canada, Catalogue 82-003, Vol. 13, No. 2, January 2002.

Langlois and Morrison (2002) also demonstrated large provincial differences in suicide rates. In 1998, Québec had the highest age-standardized suicide rate (21.3 suicide deaths per 100,000 population)[241], significantly above the national average of 14.0 suicide deaths per 100,000. New Brunswick and Alberta also exceeded the national average (16.6 and 16.2 suicide deaths per 100,000 respectively). Newfoundland, Prince Edward Island, Ontario and British Columbia reported rates significantly below the national average (see Chart 5.5).

According to WHO data, Canada's suicide rate for the entire population ranks 9th among 12 industrialized countries (see Chart 5.6). Age-standardized suicide rates range from a low of 7.5 per 100,000 population in the United Kingdom to a high of 22.5 in Finland. The suicide rate in Canada (12.2 per 100,000 population) is higher than that in the United States (10.7 per 100,000). It is important to note that international comparisons must be interpreted with caution as the methods for certifying the cause of death vary from one country to another.

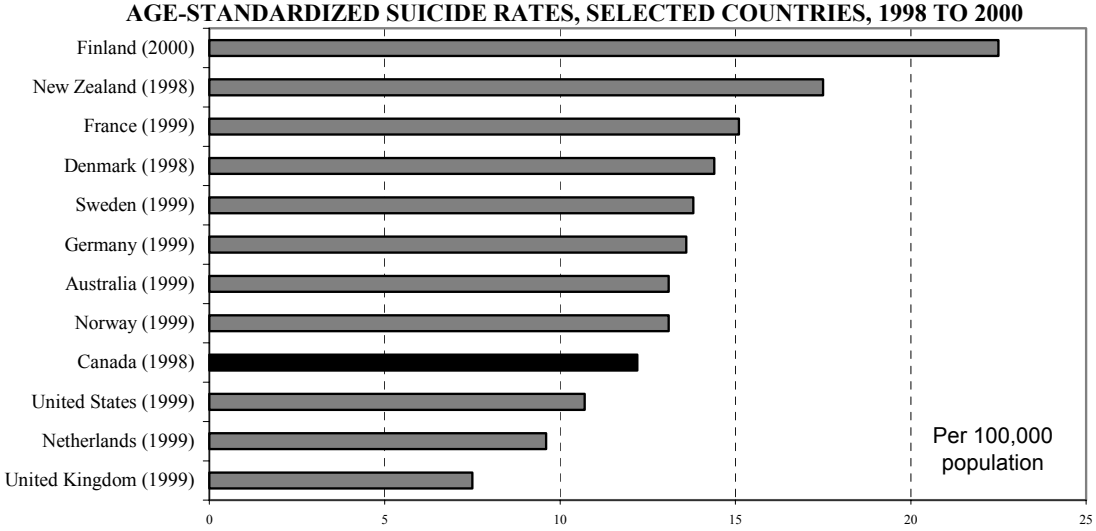
CHART 5.5
AGE-STANDARDIZED SUICIDE RATES IN CANADA BY PROVINCE, 1998



Source: Stéphanie Langlois and Peter Morrison, "Suicide Deaths and Suicide Attempts", *Health Reports* , Vol. 13, No. 2, January 2002.

241 With the exception of the territories.

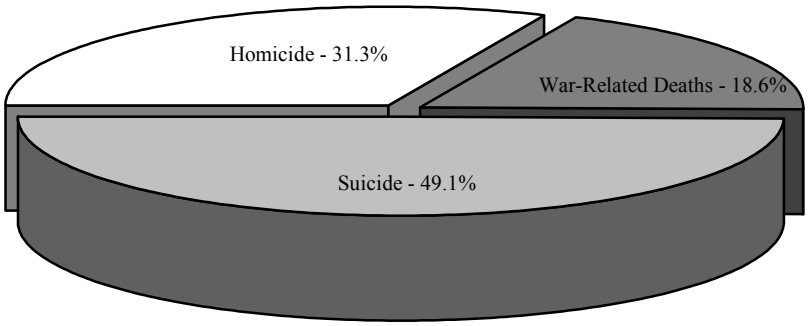
CHART 5.6:
AGE-STANDARDIZED SUICIDE RATES, SELECTED COUNTRIES, 1998 TO 2000



Source: Economics Division, Parliamentary Research Branch, Library of Parliament, March 2004. Data from the World Health Organization (2003).

Estimates from the WHO indicate that suicide is the leading cause of violent deaths worldwide, greater than homicide or war-related deaths (see Chart 5.7).

CHART 5.7:
ESTIMATED VIOLENCE-RELATED DEATHS WORLDWIDE, 2000



Source: World Health Organization, *World Report on Violence and Health* , Geneva, Table 1.2, October 2002, p. 10.

5.2.2 Attempted Suicides

While we know that the number of attempted suicides exceeds that of completed suicides, it is difficult to determine their number exactly. The World Health Organization estimates that there are as many as 20 attempts for every suicide death. In Canada, hospitalization rates are used as a measure of attempted suicides.

In 1998-1999, a total of 23,225 hospitalizations of Canadians aged 10 or older were related to attempted suicide and intentional self-inflicted injuries. Female hospitalization rates for attempted suicide were consistently higher than for males, except for the group 75 years and over (see Table 5.4). The hospitalization rate for attempted suicide among females peaked at age 15 to 19. Male hospitalization rates for attempted suicide were highest at ages 20 to 29 and 30 to 44. Hospitalization for attempted suicide was less common at older ages.

TABLE 5.4

HOSPITALIZATIONS FOR ATTEMPTED SUICIDE BY AGE GROUP AND SEX, CANADA, 1998-1999
(Rate Per 100,000 Age-Specific Population)

AGE GROUP	TOTAL	MALES	FEMALES
10 to 14	40.8	15.5	67.5
15 to 19	152.2	87.3	220.8
20 to 29	117.9	98.0	138.4
30 to 44	118.3	97.6	139.3
45 to 59	68.3	55.1	81.3
60 to 74	25.0	24.7	25.2
75 and over	21.0	27.6	17.2

Source: Stéphanie Langlois and Peter Morrison, "Suicide Deaths and Suicide Attempts", *Health Reports*, Statistics Canada, Catalogue 82-003, Vol. 13, No. 2, January 2002.

5.2.3 Suicidal Ideation

According to the CCHS, about 3.7% of Canadians aged 15 years and over had suicidal thoughts during the previous year (see Table 5.5). Women were slightly more likely than men to contemplate suicide (3.8% versus 3.6%). Suicidal ideation occurred three times more often among Canadians aged between 15 and 24 than those aged 65 or older (6.0% versus 1.7%).

TABLE 5.5

PERCENTAGE OF CANADIANS WHO HAD SUICIDAL THOUGHTS IN THE PAST 12 MONTHS, 2002

AGE GROUP	SUICIDAL THOUGHTS (%)
Total, 15 Years and Over	**3.7**
Men	3.6
Women	3.8
15-24 Years	**6.0**
Men	4.7
Women	7.3
25-64 Years	**3.6**
Men	3.7
Women	3.4
65 Years and Over	**1.7**
Men	1.3
Women	n.a.

n.a.: Not available due to extreme sampling variability.

Source: Economics Division, Parliamentary Information and Research Services, Library of Parliament, March 2004. Based on data from the Canadian Community Health Survey, Cycle 1.2, Mental Health and Well-Being, 2002.

5.3 SPECIFIC POPULATION GROUPS: ABORIGINAL PEOPLES, HOMELESS PEOPLE AND INMATES

Although mental disorders affect individuals of all genders, ages and cultures, and in all occupations, educational and income levels, it appears that the prevalence in some population groups is higher than in others. This section provides information on the prevalence of mental illness among Aboriginal peoples, homeless people and inmates.

5.3.1 Aboriginal Peoples

> *There is a significant amount of missing information in respect of the range of mental health problems [among Aboriginal Canadians]. There have been no studies to date that have really used up-to-date psychiatric epidemiological methods to estimate the range of psychiatric disorders in Aboriginal communities. Instead, we have health surveys that ask some general questions about people's understanding of their problems, their experience and their sense of what the dominant problems are. [Dr. Laurence J. Kirmayer, Department of Psychiatry, McGill University, Proceedings (9:41)]*

Although data on the prevalence of psychiatric disorders among Aboriginal peoples are quite limited, there is a consensus in the general literature that Aboriginal communities suffer significantly higher rates of mental illness, addiction and suicidal behaviour than the general population. What follows is a summary of key case studies and relevant findings.

- The Aboriginal Healing Foundation reported in 2003 on the mental health profiles of residential school survivors in British Columbia. Mental illness was indicated in all but two of the 127 case files examined. The most common mental disorders were post-traumatic stress disorder (64.2%), substance use disorder (26.3%) and major depression (21.1%). Half of those with post-traumatic stress disorder also had concurring mental disorders including substance use disorder (34.8%), major depression (30.4%); and, dysthymic disorder, a chronic form of depression (26.1%).[242]
- A 2002 report by Statistics Canada, which examined the health of the off-reserve Aboriginal population, found that Aboriginal peoples who live off-reserve were 1.5 times more likely than the non-Aboriginal population to have experienced a major depressive episode in the previous year. About 13% of the off-reserve Aboriginal population had experienced a major depressive episode in the year before the survey, compared with 7% for the non-Aboriginal population, suggesting that Aboriginal

[242] Aboriginal Healing Foundation, *Mental Health Profiles for a Sample of British Columbia's Aboriginal Survivors of the Canadian Residential School System, Research Series*, Ottawa, 2003.

peoples living in urban areas may experience feelings of alienation, isolation, marginalization and cultural dislocation.[243]

- The Flower of the Two Soils Project (1993) examined the relation among academic performance, psychosocial variables and mental health in Aboriginal children aged 11 to 18 years at several sites in the United States and Canada. The Canadian locations included parts of Manitoba and British Columbia. Among Aboriginal respondents, the most frequent diagnoses were disruptive behaviour disorders (22%), substance use disorders (18.4%), anxiety disorders (17.4%), affective disorders, including depression (9.3%), and post-traumatic stress disorder (5.0%). Almost half of the children with behaviour and affective disorders also reported concurrent substance use disorders.
- The 1996 Report of the Royal Commission on Aboriginal Peoples found that the suicide rate of Aboriginal Canadians was roughly three times that of the general population. Amongst Aboriginal adolescents, suicide occurred roughly five to six times more frequently than for their non-Aboriginal counterparts. The Commission reported that suicide was the leading cause of death among males aged 10 years to 49 years.[244]
- A study by Chandler and Lalonde (1998), in which they surveyed 196 Aboriginal communities in British Columbia over a five-year period, found wide variation across communities in the prevalence of suicidal behaviour. Communities with some measure of self-government had the lowest rates of suicide. They also found that land claims and education were the second and third most important factors in predicting low suicide rates in Aboriginal communities.[245]

Experts in the field suggest that, while many of the causes of mental illness, addiction and suicidal behaviour in Aboriginal and non-Aboriginal communities may be similar, there are added cultural factors in Aboriginal communities that affect individual decision-making and suicidal ideation. These cultural factors include past government policies, creation of the reserve system, the change from an active to a sedentary lifestyle, the impact of residential schools, racism, marginalization and the projection of an inferior self-image.[246]

5.3.2 Homeless Peoples

Measuring the prevalence of homelessness and the personal characteristics and state of the health of homeless persons presents significant challenges. The "Pathways to Homelessness Project" in the City of Toronto attempted, over an 18-month period, to estimate the prevalence of mental illness and addiction among people who are homeless. Key findings about lifetime prevalence rates included:

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243 Statistics Canada, "Health of the Off-Reserve Aboriginal Population", *The Daily*, 27 August 2002.

244 Royal Commission on Aboriginal Peoples, Choosing Life: A Special Report on Suicide Among Aboriginal Peoples, 1995.

245 J.J. Chandler and C. Lalonde, "Cultural Continuity as an Hedge Against Suicide in Canada's Fisrt Nations", *Transcultural Psychiatry*, Vol. 35, No. 2, 1998, pp. 191-219.

246 Laurence J. Kirmayer, Gregory M. Brass and Caroline L. Tait, "The Mental Health of Aboriginal Peoples: Transformations of Identity and Community", *Canadian Journal of Psychiatry*, Vol. 45, September 2000, pp. 607-616.

- Approximately 66% of homeless persons had a lifetime diagnosis of mental illness. This was 2-3 times the rate in the general population.
- About 66% of homeless persons had a lifetime diagnosis of substance abuse (of alcohol, marijuana and cocaine in particular), 4-5 times the rate in the general population.
- Some 86% of homeless persons had either a lifetime diagnosis of mental illness or substance abuse, 2-3 times the rate in the general population. In other words, only 14% of homeless persons exhibited no symptoms of either mental illness or substance abuse.
- Some 75% of homeless persons in every diagnostic category of mental illness also had substance abuse disorders.
- The lifetime prevalence rate of severe mental illness (psychotic disorders, including schizophrenia) was 5.7%, and that of mood disorder was 38%.
- Some 22% of homeless persons claimed that either mental illness (4%) or substance abuse (18%) was the reason for their becoming homeless.
- In the year immediately prior to becoming homeless, 6% of homeless persons had been in a psychiatric institution, 20% had received services for substance abuse, 25% had received psychiatric outpatient services, and 30% had spent time in police stations or jails.[247]

> **(…) contrary to popular misconceptions, only a small proportion of the homeless population suffers from schizophrenia, (…) affective [mood] disorders are much more common.**
> ***[Bill Cameron, Director General, National Secretariat of Homelessness, Brief to the Committee, 29 April 2004, p. 2.]***

A causal relationship between homelessness and mental illness/addiction remains difficult to establish because mental disorders can lead to homelessness, but they can also be caused by homelessness given the traumatic impact of being destitute and living on the streets.

5.3.3 Inmates

> *Research studies are confirming that those with serious mental health problems are being "trans-institutionalized": Canadian prisons have replaced former psychiatric hospitals or wards.*
> *[Canadian Mental Health Association, Brief to the Committee, June 2003, p. 21.]*

The prison population is another group in which mental illnesses and substance use disorders are more prevalent than in the general population. A study by Boe and Vuong

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247 Mental Health Policy Research Group, *Mental Illness and Pathways into Homelessness: Proceedings and Recommendations*, Toronto, 1998. Similar findings are reported by Stephen W. Hwang, "Homelessness and Health", in *Canadian Medical Association Journal*, Vol. 164, No. 2, pp. 229-233, 23 January 2001.

(2002) showed that, between 1997 and 2001, the percentage of new offenders with a diagnosis of mental illness on admission into federal custody rose from 6% to 8.5%, an increase of 40%. During the same period, the number of new offenders being prescribed medication to treat mental illness on admission increased by 80%, from approximately 10% to 18%.[248]

Data from Moloughney (2004) suggested that a high proportion of inmates have substance abuse problems on admission, with drug abuse being more commonly identified than alcohol abuse (see Table 5.6). His study showed that on average, some 3% of inmates were identified with a mental disorder at intake, with higher proportions in female (from 2.5% to 8.6%) than in male (from 1.4% to 3.3%) inmates. An average of 7% of male and female inmates were identified on psychological assessment as in need of immediate attention. Some 31% of female inmates and 15% of male inmates reported emotional or mental health problems at intake, and overall, 14% of inmates were under recent psychiatric or psychological treatment prior to incarceration. Substantial proportions of inmates (21% female and 14% male) had attempted suicide in the preceding 5 years.

Literature on offenders with mental disorders has shown that they are…

- **more vulnerable to arrest because of their behaviour**
- **more likely entangled in a cyclical pattern of recurrent and brief encounters with both the mental health and criminal justice system**
- **found in both provincial and federal correctional systems as well as under the care of provincial health systems in specialized forensic facilities**

[Correctional Service Canada, Brief to the Committee, April 2004, p. 3.]

There are no data from recent national studies that provide prevalence rates for specific mental disorders among federal inmates. The latest data are from 1988 for federal male inmates and 1989 for federal female inmates (see Table 5.7). Female inmates had substantially higher prevalence of all mental disorders than male inmates, with the exception of antisocial personality disorders.

[248] Roger Boe and Ben Vuong, "Mental Health Trends Among Federal Inmates", *FORUM on Corrections Research*, Vol. 14, no. 2, May 2002.

TABLE 5.6

PROPORTION OF INMATES IDENTIFIED AT INTAKE WITH MENTAL HEALTH PROBLEMS, 2002

	MALE			FEMALE		
	Min.	Med.	Max.	Min.	Med.	Max.
Alcohol Abuse	34.3	45.8	42.1	29.3	49.4	69..6
Drug Abuse	36.4	51.2	51.4	40.1	67.5	78.3
Appears mentally disordered	1.4	2.9	3.3	2.5	4.4	8.6
Emotional/mental health requiring immediate attention	4.4	7.3	7.6	6.8	15.4	17.1
Reporting emotional/mental health problems	11.4	15.7	13.6	17.08	40.4	37.1
Recent mental health intervention/hospitalization	10.6	14.5	15.3	12.2	24.7	19.6
Shows signs of depression	9.0	9.7	9.4	8.8	16.2	2.2
Previous suicide attempt(s)	9.5	14.5	16.4	10.9	23.4	41.3
May be suicidal	3.4	5.2	5.5	2.7	5.8	6.5

Nota: Min., Med. And Max. refer to minimum, medium and maximum security.

Source: Brent Moloughney, "A Health Care Needs Assessment of Federal Inmates in Canada", *Canadian Journal of Public Health*, Vol. 95, Supplement 1, March-April 2004, p. S37.

TABLE 5.7

LIFETIME PREVALENCE (%) OF MENTAL DISORDERS AMONG FEDERAL INMATES, CANADA

DISORDER	MALE (1988)	FEMALE (1989)
Major Depression	13.6	32.9
General Anxiety Disorder	31.9	19.7
Psychosocial Dysfunction	19.6	34.2
Antisocial Personality Disorder	57.2	36.8
Alcohol Use/Dependence	47.4	63.2
Drug Use/Dependance	41.6	50.0

Source: Correctional Service Canada, Brief to the Committee, April 2004, p. 9.

No studies have been done to determine if the prevalence rates of mental illnesses and substance use disorders among federal inmates have changed over time. Officials from Correctional Service Canada are of the view, however, that, based on recent trends, the percentage of the federal inmate population with mental health problems and disorders is growing, even though overall prison admissions and the institutional population counts are in decline.[249]

[249] Correctional Service Canada, Brief to the Committee, April 2004, p. 13.

5.4 ECONOMIC BURDEN OF MENTAL ILLNESS, ADDICTION AND SUICIDE

5.4.1 The Cost of Mental Illness

According to Stephens and Joubert (2001), the economic burden of mental illnesses (substance use disorders were not included in their study) in Canada was estimated to be $14.4 billion in 1998; direct health care costs amounted to $6.3 billion, and indirect costs related to lost productivity and premature death totalled $8.1 billion.[250] The relative magnitude of the major cost components is given in Table 5.8. Hospital care represented by far the largest direct cost, at $3.9 billion (26.9%) of the total burden of mental illness.

TABLE 5.8

ECONOMIC BURDEN OF MENTAL ILLNESSES IN CANADA, 1998

Cost Component	In Millions of Dollars	Percentage of total
Direct Costs (Health Care) (1):	**6,257**	**43.5**
▪ Medications	642	4.5
▪ Physicians	854	5.9
▪ Hospitals	3,874	26.9
▪ Other Health Care Institutions	887	6.2
Indirect Costs (Lost Productivity):	**8,132**	**56.5**
▪ Short Term Disability(2)	6,024	40.6
▪ Long Term Disability	1,708	11.9
▪ Premature Death	400	2.7
Total	**14,389**	**100.0**

(1) This category also includes $278 million in professional costs for social workers and psychologists incurred as a result of depression or distress.
(2) Attributable to depression and distress only.
Source: Thomas Stephens and Natacha Joubert, "The Economic Burden of Mental Health Problems", *Chronic Diseases in Canada*, Vol. 22, No. 1, 2001.

The principal indirect cost component was the value of short term disability, estimated at $6.0 billion, or some 40.6% of the total economic burden. The authors stressed that their data under-estimated the true situation due to the limitation of their dataset (only depression and distress were included were covered in their survey).

In 1998, mental illnesses accounted for 4.9% of the overall cost (direct and indirect) of disease in Canada. As such, they ranked seventh among all diseases, behind cardiovascular diseases (11.6%), musculo-skeletal diseases (10.3%), cancer (8.9%), injuries (8.0%), respiratory diseases (5.4%) and diseases of the nervous system (5.2%).[251] Mental illnesses were second only to cardiovascular disease in terms of direct health care costs alone.[252] In

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250 Thomas Stephens and Natacha Joubert, "The Economic Burden of Mental Health Problems", *Chronic Diseases in Canada*, Vol. 22, No. 1, 2001.
251 Health Canada, *Economic Burden of Illness in Canada, 1998*, Government of Canada, 2002.
252 *Ibid.*

terms of indirect costs, mental illnesses ranked fourth as the main cause of long term disability, behind musculo-skeletal diseases, diseases of the nervous system and cardiovascular diseases.[253]

A joint study by the World Health Organization, the World Bank and Harvard University – *The Global Burden of Disease Study* – estimated that mental illness, including suicide, accounts for 10.5% of the total burden of disease worldwide. Their projections show that this proportion could increase to almost 15% in 2020.[254] This study developed a single measure to allow comparison of the burden of disease across many different disease conditions. This measure, called the Disability Adjusted Life Year (DALY), reflects the number of years of healthy life lost due to premature death or disability. The study revealed that in established market economies, unipolar major depression ranks only second to ischemic heart disease in terms of DALYs. In comparison, cardiovascular disease and alcohol abuse rank 3rd and 4th respectively in terms of leading sources of DALYs. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contribute significantly to the total burden of illness as measured in terms of DALYs.[255]

It its 2001 report, the WHO stressed that the economic burden of mental illness is wide-ranging, long lasting and huge – but remains largely underestimated. In particular, in addition to meeting the expenses of treatment, the burden for families in which one member suffers from a mental illness ranges from economic difficulties to emotional reactions to the illness, from the stress of coping with disturbed behaviour, to the disruption of household routine and the restriction of social activities.[256]

5.4.2 The Cost of Substance Abuse

The total cost (direct and indirect) of alcohol abuse was estimated at $7.5 billion in Canada in 1992, while the cost of illicit drug abuse amounted to some $1.2 billion (see Table 5.9). The largest economic costs of alcohol abuse were $4.1 billion for lost productivity due to illness and premature death, $1.4 billion for law enforcement and $1.3 billion in direct health care costs. Similarly, the greatest cost associated with illicit drug abuse was lost productivity due to illness and premature death ($823 million), followed by law enforcement ($400 million) and direct health care costs ($88 million).

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253 *Ibid.*

254 The information on The Global Burden of Disease is well summarized by the National Institute of Mental Health, *The Impact of Mental Illness on Society*, January 2001. This fact sheet is available at www.nimh.nih.gov.

255 *Ibid.*

256 WHO (2001), pp. 24-25.

TABLE 5.9

THE COST OF ALCOHOL AND ILLICIT DRUG ABUSE IN CANADA, 1992

	ALCOHOL	ILLICIT DRUGS	TOTAL
	Millions of Dollars		
Direct Costs:	**3,385.6**	**547.9**	**3,933.5**
Health Care	1,300.6	88.0	1,388.6
Workplace (e.g.: EAP)	14.2	5.5	19.7
Social Programs	52.3	1.5	53.8
Prevention and Research	141.4	41.9	183.3
Law Enforcement	1,359.1	400.3	1,759.4
Other Costs	518.0	10.7	528.7
Indirect Costs (Productivity Losses Due To)::	**4,136.5**	**823.1**	**4,959.6**
Morbidity	1,397.7	275.7	1,673.4
Mortality	2,738.8	547.4	3,286,2
TOTAL	**7,522.1**	**1,371.0**	**8,893.1**

Source: Eric Shingle, Linda Robson, Xiaodi Xie, Jurgen Rehm *et. al.*, *The Costs of Substance Abuse in Canada*, Canadian Centre on Substance Abuse, 1996 (http://www.ccsa.ca/).

5.4.3 The Cost of Suicide

To date, no national figures on the economic cost of suicide deaths are available, although a 1996 study in New Brunswick estimated the average cost per suicide death (direct and indirect) to be $850,000.[257]

5.5 COMMITTEE COMMENTARY

Canada currently lacks a national information base to enable us to identify accurately the prevalence of either mental illness or addiction, to measure the mental health status of Canadians and to assist in the evaluation of policies, programs and services in the fields of mental health, mental illness and addiction. This is a major impediment to determining the need for and the level of provision of appropriate and adequate treatments and services. The recent release of Statistics Canada's Canadian Community Health Survey (CCHS) has helped to alleviate this situation by providing, for the first time, a set of data on some mental illnesses, substance use disorders and gambling. However, the Committee feels that this survey should be repeated soon and that its base should be expanded to cover a wider range of disorders. We also believe that a national study, like the one being planned in Australia, should be undertaken to assess the prevalence rates of mental disorders among children and adolescents.

The economic burden of mental illness, addiction and suicidal behaviour is enormous. It is clear that governments must take the necessary steps to contain or reduce such a heavy burden. The Committee concurs with the Canadian Psychological Association that mental

[257] Dale Clayton and Alberto Barceló, "The Cost of Suicide Mortality in New Brunswick, 1996", *Chronic Diseases in Canada*, Vol. 20, No. 2, 1999, pp. 89-93.

health is as essential to a healthy society as physical health. We believe that now is the time to develop mental illness and addiction policies and programs that reflect their burden, social and financial, to Canadian society.

The indirect costs attributable to mental illness and addiction – the cost of absenteeism and lost productivity – are substantial and exert great pressures in the workplace. In contrast to other illnesses, the indirect costs of mental disorders appear to be higher than the associated direct health care costs. In the next chapter, we examine the prevalence and consequences of mental illness and addiction in the workplace.

Mental health is at the core of a healthy society. The prevention and treatment of mental illness and addiction require the same attention and resources as any other disease based on prevalence, burden and outcomes research.

[Canadian Psychological Association, Brief, 2003, p. 12]

CHAPTER 6:
MENTAL ILLNESS, ADDICTION AND WORK

The effects of mental health are not just mental. (…) What is good for individual mental health is good for firm performance.
[Professor E. Kevin Kelloway, Saint Mary's University, Halifax][258]

INTRODUCTION

The relationship between mental illness/addiction and work can be characterized as bi-directional. On the one hand, mental illness and addiction are a major cause of absenteism from work, under-performance, employee turnover and reduced productivity. On the other hand, the workplace can be a major cause of stress affecting mental health and work performance. Some forms of workplace stress may even trigger the onset of mental illnesses and/or substance use disorders.

> **The employers have a vested interest to support a strong mental health system as a result of absenteeism, or loss of productivity, and financial losses.**
> ***[Rod Phillips, President and CEO, Warren Shepell Consultants, (18:9)]***

Whatever the direction of causality between mental illness and work, there is strong consensus among those who testified before the Committee that the workplace is a critical environment for the promotion of mental health, the early detection of mental illness and addiction, and the accommodation/integration of employees suffering from mental disorders. Such attributes of a healthy workplace will benefit not only the individual and the employer but society as a whole by enhancing Canada's productivity and reducing the overall economic burden of mental illness.

This chapter is divided into nine sections. Section 6.1 briefly describes the benefits of employment and the consequences of unemployment for individuals with mental illness and addiction. Section 6.2 summarizes the existing information on the prevalence of mental illness and addiction in the workplace. Section 6.3 provides some data on the cost related to mental illness and addiction in the workplace. Section 6.4 examines the issue of disability attributable to mental illness and addiction. Section 6.5 highlights the role of employers with respect to Employee Assistance Programs and accommodation for workers with mental illness. Section 6.6 summarizes the testimony heard by the Committee with respect to the role of governments in helping to reduce the economic cost of mental illness and addiction in the workplace. Section 6.7 provides some information on businesses established and run by individuals with mental illness and addiction. Section 6.8 discusses the need for a research agenda on mental illness, addiction and work. Section 6.9 presents the Committee's commentary.

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[258] E. Kevin Kelloway, Ph.D., Professor of Management and Psychology, Saint Mary's University (Halifax, Nova Scotia), Brief to the Committee, 2004.

6.1 THE BENEFITS OF EMPLOYMENT

Recently, Professor Heather Stuart, Community Health and Epidemiology, Queen's University, eloquently pointed out that:

> *(…) no single activity conveys a sense of self more so than work. Work influences how and where one lives, it promotes social contact and social support, and it confers title and social identity.*[259]

For those affected by mental illness and addiction, employment is an important contributor to recovery. It may aid recovery and reduce the frequency and severity of episodes of acute illness by providing structure, the opportunity for social connections and a fuller life. Through regular remuneration, employment can end or reduce dependence on social assistance and reduce individual need for mental health services and supports.

In contrast, loss or lack of employment due to mental illness may jeopardize a person's recovery. Income and standard of living are reduced, resulting in economic dependence and low self-esteem. Inadequate employment also leads to the loss of personal relationships with fellow workers, social marginalization and changed relationships with family and friends.

Many individuals with mental illness succeed in their employment without any assistance being provided to them; recent advances in treatment and drug therapy have increased their capacity to join the mainstream and live independently. Those who participate in the labour force contribute to Canada's productivity and competitiveness. Others, however, need assistance to get and keep a job. In this context, the issue of mental illness, addiction and work can be explored from three different perspectives. The first addresses the issue of making employment accessible to individuals who never had a job. The second emphasizes mental illness and addiction that may affect currently employed individuals. The third focuses on individuals who have lost their job due to mental illness or addiction and wish to reintegrate the labour market.

As discussed in Chapter 4, the onset of a mental disorder tends to occur in late adolescence or early adulthood, at a time when the affected person's education and training are not yet complete. The process of obtaining qualifications is interrupted, often never to be resumed. The young individuals affected are significantly disadvantaged, as their lack of skills and qualifications is a major lifelong barrier to their future employment.

For those who do find work, periods outside the labour force caused by their mental illness often impede re-entry into the labour force. Three key barriers apply. First, individuals may be subject to discrimination by their employer and/or work colleagues. Second, they may require flexible work arrangements that employers are unwilling, or do not know how to provide. And third, those who have been outside of the labour force for extended periods are unlikely to possess the type of credentials, skills and employment experiences that make them attractive to employers.

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[259] Heather Stuart, *Stigma and Work*, discussion paper commissioned by the workshop supported by the Institute of Population Health and the Institute of Neurosciences, Mental Health and Addiction of the Canadian Institutes of Health Research, April 2004, p. 80.

The Committee was told that unemployment rates among individuals with mental illness are unacceptably high. International evidence suggests that the unemployment rate of individuals affected by severe and persistent mental illness is around 90%. This contrasts with the approximately 50% unemployment rate of individuals with physical or sensory disabilities. In other words, only 10% of individuals with severe mental disorders who wish to work are judged capable of working and are in fact working.[260]

In Canada, information from the Canadian Psychiatric Association reveals that persons diagnosed with a mental illness are likely to experience long term unemployment, underemployment and dependency on social assistance. The Association believes that, of all individuals with disabilities, those with a mental illness face the highest degree of stigmatization in the workplace and the greatest barriers to employment opportunities.[261] A major problem with unemployment is that the longer a person is away from a job, the less likely it is that he or she will ever resume a productive work life. Statistics show that after six months on disability leave an individual has a 50% probability of returning to work; this is reduced to 20% after one year, and to 10% after two years.[262]

Two main factors make mental illness specifically a workplace issue. First, mental illness usually strikes younger workers. Second, many mental illnesses are both chronic and cyclical in nature, requiring treatment on and off for many years. There is a vital role for employers and government to play in addressing mental illness and addiction in the workplace, including through accommodation policies, return to work programs and disability management.

In saying this, the Committee is not suggesting that this is an easy or an inexpensive task for either employers or governments. Nevertheless, we feel strongly that increased attention to workplace mental health and addiction issues is essential.

6.2 PREVALENCE OF MENTAL ILLNESS AND ADDICTION IN THE WORKPLACE

There is currently no single source of information available in Canada that provides comprehensive and accurate information on the prevalence of mental illness and addiction in the workplace. However, a review of the relevant literature provides some indication of the scope of the problem:

- Addiction (alcohol and drug abuse) is a serious concern in the Canadian manufacturing sector. The rate of addiction among employees in this sector is estimated to be almost twice the national average; this may be a substantial under-estimate given that addiction in the workplace is often not reported. Levels of

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260 Gaston Harnois and Phyllis Gabriel (2000), *Mental Health and Work: Impact, Issues and Good Practices*, joint publication of the World Health Organization and the International Labour Organization, Geneva, 2000, p. 19.

261 Canadian Psychiatric Association, Mental Illness and Work, pamphlet available on the Internet (accessed on 15 June 2004).

262 Ontario Medical Association, *Mental Illness and Workplace Absenteeism: Exploring Risk Factors and Effective Return to Work Strategies*, April 2002.

anxiety and anger have been rising significantly among employees in the manufacturing sector over the last three years. A survey has shown anxiety disorders in the manufacturing sector to be more prevalent in male-dominant populations in which addictions issues are also present.[263]

- Compared to national averages, the rates of depression and anxiety are high in the information technology sector. Depression rates vary widely from one year to another, reflecting the volatility of the technology sector.[264]

- Some segments of the workforce appear to be more vulnerable to mental illness and addiction, in particular men and women in their prime working years who have had 10 to 14 years of service with the same employer, and new entrants to the labour market.[265]

- A recent survey indicates that more and more hospital workers are accessing employee assistance programs. Hospital workers are experiencing progressively higher levels of stress than workers in other sectors. This may be explained in part by hospital restructuring, downsizing and human resource shortages. Addressing stress in the hospital sector may be even more important than in other sectors since stress-related errors in patient care can have a very negative impact on patients.[266]

- Similarly, a survey by the Canadian Medical Association in 2003 reported that stress and dissatisfaction among physicians was rising. More particularly, the survey found that 45.7% of physicians were in an advanced state of burnout. In addition, women physicians appeared to be at a higher risk of suicide than others in the general population.[267]

- Relative to other sectors, workers in the retail and hospitality sectors face a number of particular stress factors in their work environments, for example, the occurrence and threat of armed robbery. Individuals working in the retail sector also report a higher incidence of domestic violence. Employees of both the retail and hospitality sectors report greater stress and depression symptoms than employees in most other sectors. Workers in the hospitality sector experience a higher frequency of substance use, including alcohol and tobacco, and a higher incidence of distress and anxiety than other workers.[268]

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263 Based on a sample size of 136 companies and 54,050 employees. Data from Warren Shepell Consultants Corporation, *Sector Review: Organizational Health & Wellness Trends in Manufacturing*, March 2003 (available at www.warrenshepell.com).

264 Based on a sample size of 153 organizations with 86,000 employees across Canada. Data from Warren Shepell Consultants Corporation, *Sector Review: Organizational Health & Wellness: Trends in Technology*, February 2003 (available at www.warrenshepell.com).

265 Global Business and Economic Roundtable on Addiction and Mental Health, *Roundtable Roadmap to Mental Disability Management in 2004-2005*, 25 June 2004, p. 4.

266 Warren Shepell Consultants Corporation, *Sector Review: Organizational Health & Wellness Trends in the Healthcare/Hospital Sector*, Winter 2004 (available at www.warrenshepell.com).

267 Dr. Sunil V. Patel, President, Canadian Medical Association, Brief to the Committee, 31 March 2004, p. 3.

268 Warren Shepell Consultants Corporation, *Sector Review: Organizational Health & Wellness Trends in Retail/Hospitality*, Winter 2004 (available at www.warrenshepell.com).

- The Canadian Bar Association reported alarming and increasing rates of depression and addiction among lawyers. The rate of alcoholism is three times that of the general population. It has been suggested that excessive working hours, relentless competition, and unyielding pressures by law firms for increased billable hours are important contributors to these problems.[269]

- In the Canadian workforce overall, some 3.5% of women and 3.0% of men report psychological distress (defined as depression and anxiety). Psychological distress tends to be high among workers in jobs with high demands but little latitude for decision-making. About 40% of workers in such jobs indicated high levels of psychological distress (see Table 6.1 below).[270]

TABLE 6.1

PERCENTAGE OF CANADIAN WORKERS REPORTING HIGH PSYCHOLOGICAL DISTRESS BY JOB DECISION LATITUDE AND JOB DEMANDS

JOB DEMANDS	JOB DECISION LATITUDE			
	High	Moderate	Low	Very Low
High	27	33	33	40
Moderate	24	26	30	35
Low	19	20	21	30
Very Low	16	18	22	20

Source: Kathryn Wilkins and Marie P. Beaudet, "Work Stress and Health", *Health Reports*, Statistics Canada, Catalogue 82-003, Winter 1998, Vol. 10, No. 3, p. 52.

- In Québec, a 2001 study by Bourbonnais and colleagues found that individuals who experienced work-related stress were twice as likely to have a mental illness than those who did not (23% versus 11% for men and 30% versus 15% for women).[271]

- Workplace stress and work-related conflict and harassment are among the top eight reasons why Canadian employees request help from an Employee's Assistance Program (EAP). Stress associated with work-related issues accounts for about 40% of all work-related EAP cases. The number of employees seeking help for work-related conflict has increased from 23 percent of all work related cases in 1999 to

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269 Bill Wilkerson, *Since September 11th – The Business State of Mind: Mental Health in the Knowledge Economy*, Speech before the "Beyond Awareness Conference (A Campaign to Reduce the Stigma of Mental Illness), 6 February 2002, p. 7.

270 Kathryn Wilkins and Marie P. Beaudet, "Work Stress and Health", *Health Reports*, Statistics Canada, Catalogue 82-003, Winter 1998, Vol. 10, No. 3, pp. 52-53.

271 Renée Bourbonnais, Brigitte Larocque, Chantal Brisson and Michel Vézina, «Contraintes psychosociales du travail», in *Portrait Social du Québec*, Institut de la Statistique du Québec, 2001, pp. 267-277.

close to nearly 30 percent in 2001. The number of employees seeking help for harassment almost tripled from 1999 to 2001.[272]

- In the United States, 40% of all EAP referrals in several leading companies relate to symptoms of depression.[273]

6.3 THE COST AND CONSEQUENCES OF MENTAL ILLNESS AND ADDICTION IN THE WORKPLACE

In the labour market, productivity can be linked to the concept of disability. More precisely, the less disabled a worker, the more productive she/he is and *vice versa*. Productivity is affected both by 'presenteeism' – days during which an individual is present at work but functions at less than full capacity – and by absenteeism – days during which an employee did not report to work.

Mental illness and addiction are among the most important causes of absenteeism and presenteeism worldwide: the 1998 report of the World Health Organization stated that "more working days are lost as a result of mental disorders than physical conditions."[274] In Canada, 20% of the normal work time of employees suffering from an undetected mental illness or addiction is not productive because it is "taken off". This is four times the rate of their co-workers.[275]

When compared with all other diseases (such as cancer and heart disease), mental illness and addiction rank first and second in terms of causing disability in Canada, the United States and Western Europe (see Chart 6.1).[276] Of the ten leading causes of disability worldwide, five are mental disorders: unipolar depression, alcohol use disorder, bipolar affective disorder, schizophrenia and obsessive-compulsive disorder.[277]

> **We would suggest that employers are already bearing a significant burden of the costs associated with mental health in Canada. In that sense, they are subsidizing what we have in the public health care system and, in some cases, compensating for deficiencies in that system.**
> ***[Rod Phillips, President and CEO, Warren Shepell Consultants (18:9)]***

As reported in Chapter 5, the value of lost productivity in Canada that is attributable to mental illness alone has been estimated at some $8.1 billion in 1998.[278] More recently, it has been estimated that if substance abuse is taken into account as well, Canada's economy loses

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272 Warren Shepell Consultants Corporation, *Workplace Trends Linked to Mental Health Crisis in Canada*, Press Release, 15 November 2002.

273 Bill Wilkerson, *A Business Charter for Mental Health an Addiction in the Knowledge Economy*, Speech to the Ontario Public Service Commission and Management Board, 25 September 2002, Toronto, p. 9.

274 World Health Organization, *Life in the 21st Century: A Vision for All*, Geneva, 1998.

275 Bill Wilkerson, *Text of Speech*, Warren Shepell Consultants Business Forum, 16 October 2002, p. 14.

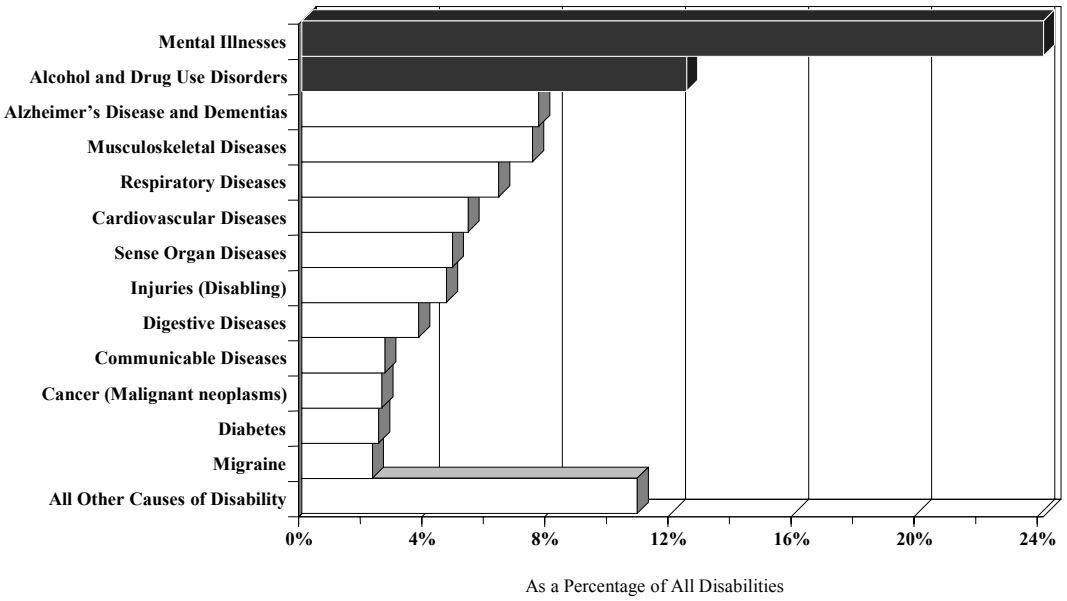
276 President's New Freedom Commission on Mental Health, *Interim Report*, United States, 29 October 2002.

277 *Ibid.*

278 According to calculation by Thomas Stephens and Natacha Joubert, "The Economic Burden of Mental Health Problems", *Chronic Diseases in Canada*, Vol. 22, No. 1, 2001.

some $33 billion annually to lost productivity caused by mental illness and addiction.[279] This corresponds to 19% of the combined corporate profits of all Canadian companies or to 4% of the national debt.[280] In other words, the business sector pays two-thirds of all costs associated with mental illness and addiction in the form of lost productivity, absenteeism, disability, wage replacement costs, employee group health care premiums and prescription drugs.[281]

CHART 6.1
CAUSES OF DISABILITY
CANADA, THE UNITED STATES AND WESTERN EUROPE, 2000



Note: Causes of disability for all ages combined. Measures of disability are based on the number of years of "healthy" life lost with less than full health (ie. YLD, years lost due to disability).
Source: President's New Freedom Commission on Mental Health, *Interim Report*, United States, 29 October 2002.

Overall, there are many consequences deriving from mental illness, addiction and work-related stress in the workplace (see Table 6.2). The Committee heard repeatedly that no one benefits from ignoring the existence of mental illness, addiction and occupational stress in the workplace and from the marginalization of potentially productive citizens– not the affected individuals, nor employer, nor society at large . Given both the economic and social costs associated with these disorders, it is essential that the public and private sectors urgently address the issue.

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279 Martin Shain et. al., *Mental Health and Substance Use at Work: Perspective from Research and Implications for Leaders*, Backgrounder, prepared for the Global Business and Economic Roundtable on Addiction and Mental Health, 14 November 2002 (unpublished).

280 Estimated by the Economics Division, Parliamentary Information and Research Services, Library of Parliament.

281 Bill Wilkerson (6 February 2002), p. 8.

Again, as the Committee noted at the end of Section 6.1, addressing this issue is not a simple task. Nonetheless, there are both economic reasons and compassionate ones that require that it be done.

TABLE 6.2

CONSEQUENCES OF MENTAL ILLNESS, ADDICTION AND WORK-RELATED STESS IN THE WORKPLACE

Absenteeism	• increase in overall sickness absence, particularly frequent short periods of absence • poor health (depression, stress, burnout) • physical conditions (high blood pressure, heart disease, ulcers, sleeping disorders, skin rashes, headache, neck- and backache, low resistance to infections)
Presenteeism	• reduction in productivity and output • increase in error rates • increased number of accidents • poor decision-making • deterioration in planning and control of work
Staff Attitude And Behaviour	• loss of motivation and commitment • burnout • staff working increasingly long hours but with diminishing returns • poor timekeeping • labour turnover (particularly expensive for companies at top levels of management)
Relationships at Work	• tension and conflicts between colleagues • poor relationships with clients • increase in disciplinary problems

Source: Gaston Harnois and Phyllis Gabriel, *Mental Health and Work: Impact, Issues and Good Practices*, joint publication of the World Health Organization and the International Labour Organization, Geneva, 2000, pp. 8-9.

6.4 MENTAL ILLNESS, ADDICTION AND DISABILITY

Coverage for disability resulting from psychiatric disorder should be available just as it is for disability resulting from either medical or surgical illness.
[Canadian Psychiatric Association][282]

The unpredictable and episodic nature of disability resulting from mental illness is an important factor that distinguishes it from many other disabilities. Individuals with mental

[282] Canadian Psychiatric Association, *Insurability of the Psychiatrically Ill or Those With a Past History of Psychiatric Disorder*, Position Paper, 1988.

illness tend to cycle between periods of illness and wellness. When they are symptom-free, they are usually able to work and carry out the normal tasks of life. During episodes of psychiatric illness, however, they may be incapable of functioning at a level that would permit them to work in regular employment.

> **Mental illness and addiction in Canada generates tremendous suffering and disability – a situation we do not believe would be tolerated for physical illnesses of similar prevalence and severity.**
> ***[Centre for Addiction and Mental Health, Brief to the Committee, 27 June 2003, p. 6.]***

The Committee was informed that disability claims attributable to mental illness have overtaken claims associated with cardiovascular disease as the fastest growing category of disability costs in Canada.[283] Currently, mental illness and addiction account for 60-65% of all disability insurance claims among selected Canadian and American employers.[284] It is expected that disability insurance claims for mental health problems and illnesses may climb to more than 50% of the total number of claims administered through employee group health plans over the next five years.[285]

The following sections provide information on the disability insurance claims associated with mental illness and addiction available through employer sponsored disability benefit plans, workers' compensation boards (WCBs), the Canada Pension Plan Disability program (CPP(D)) and Employment Insurance (EI).

6.4.1 Employer-Sponsored Disability Insurance Plans[286]

There are two types of disability income insurance plans offered by employers: short term (STD) and long term disability (LTD). STD plans replace a percentage of pre-disability employment earnings (70% for example) for periods less than one year of duration (e.g., six months). They are generally harmonized with sick leave, other employee benefits and EI benefits, providing continuity of income for the plan member who has suffered a disabling illness or injury.

LTD plans focus on longer periods of disability. They typically commence payments after the disabled individual has been off work for a significant period, such as six months, and replace a specified percentage of the person's pre-disability employment income, for example 70%. LTD benefits typically run for up to two years for recipients who are unable to perform their own jobs, and can continue to a limit of age 65 or the onset of retirement benefits for recipients who cannot perform their own or any reasonably comparable job. LTD benefits provided by the employer's plan may be reduced by the amount obtained by the recipient under CPP(D).

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283 Mental Health Works, *Mental Health in the Workplace: Facts and Figures*, Canadian Mental Health Association – Ontario Division, 2003.

284 Global Business and Economic Roundtable on Addiction and Mental Health (25 June 2004), p. 14.

285 Bill Wilkerson, *Mental Health – The Ultimate Productivity Weapon*, Summary of Remarks to the Industrial Accident Prevention Association Conference and Trade Show, Toronto, 22 April 2002, p. 5.

286 Unless otherwise indicated, the information contained in this section is based on the following document: Canadian Life and Health Insurance Association Inc., *The Role of Disability Income Insurance Plans in Canada's Disability Income System*, Submission to the House of Commons Sub-Committee on the Status of Persons with Disabilities, May 2003.

An important aspect of STD and LTD plans is the commitment to assiste recipients to return to the workplace, preferably to their own jobs, or to another job if that proves not to be feasible. Consistent with this commitment, disability income insurance plans are designed to ensure that there is a financial incentive for recipients to return to work; thus disability income replacement benefits do not exceed and are usually less than pre-disability employment income.[287]

There is no comprehensive Canadian survey that provides information on the total cost borne by employers for STD and LTD benefits associated with mental illness and addiction. The information given to the Committee on this issue is summarized below:

- Since 1994, depressive disorders alone have doubled as a percentage of STD and LTD claims and have grown 55% across all categories of disability-related absences from work. [288]
- Similarly, a 2002-2003 survey by Watson Wyatt Worldwide estimated that mental illness and addiction were the leading cause of STD claims, and 73% of the respondents confirmed that these disorders were also the leading cause of LTD claims.[289]
- An analysis by the Global Business and Economic Roundtable on Addiction and Mental Health estimates that between 640,000 and 1,075,000 full-time employees in Canada are currently on disability leave with mental illness as their primary or secondary diagnosis. This translates into 35 million days of work lost for the Canadian economy. In other words, mental illness and addiction account for 46% of all long term and short term disability claims.[290]

Three specific issues were raised with respect to employer-sponsored disability insurance plans. First, Watson Wyatt Worldwide, a global consulting firm focussing on human resources and group benefits and health care plans, stressed that all corporations should conduct a review of their STD and LTD claims in order to properly assess the incidence of mental illness and addiction in their workplaces. The results of the review would help to identify the type of action that is required.[291]

Second, it would be important to understand the influence that the type and extent of disability coverage have on the duration of claims in order to determine the conditions necessary to optimize individual situations. Disability insurance should not be a disincentive to work. In this context, the Canadian Psychiatric Association explained:

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287 Disability income insurance plans are frequently part of a group benefits program that includes extended health care coverage (which may include prescription drugs, special nursing services, and special services that fall outside government plans such as registered psychologists, chiropractors, massage therapists, etc.).

288 Bill Wilkerson (6 February 2002), p. 7.

289 Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, June 2003.

290 Global Business and Economic Roundtable on Addiction and Mental Health, "Full-Time Employees in Canada Losing 35 Million Days of Work a Year Due to Mental Disorders; Half of All Days Lost to Illness and Disability", Press Release, 14 July 2004.

291 Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, June 2003.

> *Disability insurance for any illness requires a precise definition of that illness. Whereas it is important that disabled psychiatric patients receive an adequate income to protect themselves from serious financial reverses over the time that they are not able to work, it is just as important to recognize that disability payments may constitute a major secondary gain actually impeding a patient's progress and delaying rehabilitation. There are two factors to be considered: a) the prevalent misconception that work is ipso facto stressful and likely to aggravate a diagnosed psychiatric disorder; and b) the recognition that some patients who have undergone a serious psychiatric disorder may want to avoid exposure to what they presume to be stressful factors at work because of lack of confidence even after they have improved clinically. It should be recognized that return to work as soon as possible is likely to improve the patient's self-esteem, re-establish him/her in a familiar social network and otherwise aid rehabilitation. There is some evidence that work deprivation may be one of the causes of psychiatric disorder.*[292]

Third, and perhaps more importantly, employers, managers and insurers must become more knowledgeable about mental illness and addiction in order to better manage disability claims. During a recent speech, Bill Wilkerson, co-founder and CEO, Global Business and Economic Roundtable on Addiction and Mental Health, commented:

> *In a landmark Supreme Court of Canada case in Saskatchewan, a woman was disabled by a mental disorder, was off work and on long-term disability and was in hospital. While there, her disability insurance benefits continued. Once released, they were cut off – this, incredibly, because her institutionalization established the criteria of her continued eligibility. The Supreme Court ruled the practice discriminatory, because those with physical disabilities remained eligible for their benefits outside hospital while recuperating at home.*
>
> *Meanwhile, were the insurer's practices simply obsolete or malevolent? Either way, the company suffered its own perceptual disorder of what the reality of mental illness is or isn't. The insurer, presumably, was confounded by the nature of mental disorders, by the treatment process and the critical even superior role of out-patient care and community family support in the patient's sustainable recovery.*
>
> *I tell this story not to belittle or criticize the insurance industry at large. I am part of that community and, to be sure, there are examples where the life and health insurance industry has shown leadership in the promotion of mental health. Rather, I speak to a broader point. This industry must develop a perspective based on knowledge of mental health issues. Like*

[292] Canadian Psychiatric Association (1988), *op. cit.*

business generally, the insurance sector needs a mental health education agenda.

An example of where this is especially true is in the comorbidity of mental illness and physical chronic diseases as this pertains to: origin and the duration of human disability; the complexity, lengths and risks of treatment and recovery; and, the pace and timing of the sufferer's return to work.

The insurance industry needs – at the levels of claims management – to know more about the medical science of mental health. (…). The industry needs to develop a knowledge base about the expanding universe of neuroscience and its illumination of the origins of behaviour.[293]

6.4.2 Workers' Compensation Boards

In all provinces and territories, Workers' Compensation Boards (WCBs) receive an increasing number of mental health related claims (referred to as "occupational stress") and, in a growing number of cases, the Boards have provided compensation for claims related to mental illness. A review of occupational stress claims reported to WCBs was undertaken by the Association of Workers' Compensation Boards of Canada to find out how many types of claims were filed on an annual basis, whether they were of an episodic or chronic nature, and how much compensation was paid in each case. This review proved to be very difficult. In many cases, the Boards do not collect this type of data, or if they do, the data are not comparable because the definitions employed by each WCB may be different (see Table 6.3). The review could not, therefore, provide a national perspective on the number of claims resulting from occupational stress and the associated costs of compensation.[294]

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[293] Bill Wilkerson, *Notes for Remarks*, 55th Annual Meeting of the Canadian Life Insurance and Medical Officers Association, 17 May 2004, p. 9.

[294] Association of Workers' Compensation Boards of Canada, *Occupational Disease and Occupational Stress Legislation and Policies*, 1998.

TABLE 6.3

WORKERS' COMPENSATION BOARDS IN CANADA: INTERJURISDICTIONAL COMPARISON OF OCCUPATIONAL STRESS COMPENSABILITY

Alberta	Compensation for occupational stress provided if: • there is a confirmed diagnosis under the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders; • the work-related events or stressors are the predominant cause of the injury; • the work-related events are excessive or unusual in comparison to the normal pressures experienced by the average worker in a similar occupation; and • there is objective confirmation of the events.
British Columbia	Compensable forms of stress include: • stress caused by a sudden and unexpected traumatic event; and • stress that results from a compensable injury such as severe anxiety following the amputation of a leg. Stress that is caused by the pressures encountered in daily personal and work life is not compensable.
Manitoba	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
New Brunswick	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
Newfoundland and Labrador	Legislative definition of injury covers stress only where it results from an acute reaction to a sudden and unexpected traumatic event and to exclude stress due to labour relations issues.
NWT & Nunavit	Claims for occupational stress are considered on a case-by-case basis.
Nova Scotia	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
Ontario	Mental stress is compensable in respect of situations where there is an acute response to a sudden and unexpected traumatic event arising out of and in the course of employment. Mental stress due to the employer's employment decisions does not entitle a worker to benefits.
Prince Edward Island	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
Quebec	Stress is compensable if the worker can show a relationship between the illness and the work or a risk in the work.
Saskatchewan	Compensation for occupational stress is specifically allowed for as a matter of policy where clear and convincing evidence is provided that the work stress was excessive and unusual; routine industrial relations actions taken by the employer are considered normal and not unusual.
Yukon	Post-traumatic stress considered compensable under legislation; current practice is to assess all other stress-related claims on a case-by-case basis.

Source: Paul Kishchuk, *Expansion of the Meaning of Disability*, paper commissioned by the Yukon Workers' Compensation Board, March 2003, p. 12.

A major issue raised with respect to compensation by WCBs concerns the fact that it is more difficult to prove the genesis of a mental disorder than it is of a physical illness. As a result,

there is some controversy about whether and how mental disorders should be covered under worker's compensation schemes. Under an occupational disease model, compensation for a disability is based on whether the disability arises from continuous exposure to hazardous conditions related to an individual's employment. Yet, most advanced etiological models of mental disorders include the variety of factors discussed in Chapter 4, such as genetic vulnerability, developmental circumstances and neurobiological factors, in addition to life events such as a stressful work environment. The relative weight of each of these dimensions is not yet understood, nor is it clear how they fit together. As a result, some WCBs are more reluctant than others to provide mental health related disability benefits. They are left wrestling with the question of the extent to which disability benefits related to mental disorders should be paid by worker's compensation rather than by health care insurance.[295]

6.4.3 Federal Income Security Programs

The Canada Pension Plan Disability program or CPP(D) is the largest single disability income program in Canada. It is generally the first payor of disability benefits preceding other entities such as provincial workers' compensation boards and private insurance companies.

CPP(D) benefits are paid to contributors under age 65 who have a physical or mental disability which is "severe and prolonged" (lasting at least one year and preventing work on a regular basis) and meets specific requirements relating to the level of earnings and years of contribution (contributions must have been paid in four out of the last six years).

In the past two decades, there has been a sharp increase in the number of CPP(D) beneficiaries due to mental illness. Between 1980 and 2000, the proportion of individuals receiving CPP(D) benefits attributable to mental disorders increased from 11% to 23%. Mental illness ranked second, behind disease of the musculoskeletal system, and affected a higher proportion of females than males. In 2000, mental disorders also represented the most prominent cause of CPP(D) disability among younger beneficiaries.[296]

For many years, individuals with mental illness and addiction and their representatives have raised concerns that CPP(D) does not address the question of mental illness and disability appropriately. More specifically:

- Many individuals with mental illness have limited work histories. Because mental illness often strikes in early adulthood at a time when education, job skills and careers are being developed, many of these individuals are not eligible for CPP(D) due to insufficient years of employment. Out of necessity, many turn to provincial social assistance programs for support.

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295 Carolyn S. Dewa, Alain Lesage, Paula Goering and Michèle Caveen, *The Nature and Amplitude of Mental Illness in the Workplace*, discussion paper commissioned by the workshop supported by the Institute of Population Health and the Institute of Neurosciences, Mental Health and Addiction of the Canadian Institutes of Health Research, April 2004, pp. 2-19.

296 Office of the Chief Actuary, *Canada Pension Plan – Experience Study of Disability Beneficiaries*, Actuarial Study No. 1, November 2002.

- To qualify for CPP(D) disability benefits, the beneficiary must accept the designation of "permanently unemployable" by declaring him/herself as entirely incapable of pursuing any employment on a regular basis. Because of the cyclical and unpredictable nature of mental disorders, individuals with mental illness can work, but often only on a part-time basis; they are not necessarily capable of achieving full financial independence. Individuals with mental illness and addiction have recommended that CPP(D) pay partial or reduced benefits rather than full benefits to enable them to work part-time while still retaining a portion of their benefits.
- Since disability is currently equated with permanent unemployability, individuals on CPP(D) are reluctant to look for or take employment for fear of losing their benefits. Those affected are penalized for trying to improve their circumstances even if they are not capable of participating in regular full-time work again.
- Some 66% of all initial applications to CPP(D) are denied and almost two-thirds of those rejected do not apply for reconsideration It has been suggested that the proportion of applications rejected from those with mental illness is much higher. Some experts claim that the system is designed in such a way as to discourage individuals from pursuing rightful claims. This is particularly true for individuals with mental disorders who, because of their illness, may lack the ability to "push the system".[297]

In its 2003 report, the House of Commons Standing Committee on Human Resources Development and the Status of Persons with Disabilities recognized that CPP(D) does not address the question of mental illness and disability appropriately. The Committee made a number of recommendations to ensure that CPP(D) takes into account of the cyclical and unpredictable nature of mental illnesses. In addition, it recommended that the federal government develop, in consultation with stakeholders and health care professionals, specific evaluation tools for these particular disabilities to be used in assessing eligibility for CPP(D).[298]

In its response to the House of Commons Committee's report, the federal government indicated that CPP(D) guidelines already recognize recurrent and episodic disabilities, including mental disorders, and that many individuals with mental disorders currently receive CPP(D) benefits. Furthermore, it stated:

> *The Government therefore does not believe regulations and guidelines need to be changed to accommodate the needs of individuals with episodic or recurring conditions. Because the determination of disability for CPP is based on the functional limitations that prevent a person from working, and not simply on a medical diagnosis or prognosis, the adjudication process is able to take into consideration the short- and*

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[297] Wendy Steinberg, *Position Paper on Federal Income Security Programs*, prepared for the Canadian Mental Health Association, December 2001.

[298] Subcommittee on the Status of Persons with Disabilities (Dr. Carolyn Bennett, Chair), *Listening to Canadians: A First View of the Future of The Canada Pension Plan Disability Program*, June 2003.

> *long-term impacts of recurrent or episodic medical conditions on the client's ability to function in the workplace.*[299]

Individuals with mental illness may also be eligible to receive EI benefits as a source of temporary income replacement. They have raised some concerns, however, with respect to EI:

- In terms of EI eligibility, employees who are dismissed because of "misconduct" or quit "without just cause" are not eligible for EI benefits. Due to stigma, individuals with mental illness in the workplace often conceal their illness. When they experience difficulty on the job, they may be fired or may quit as a result of their illness, but would not be in a position to claim EI benefits because they have not previously disclosed their illness.
- When a person applies for EI sickness benefits, he/she is required to obtain a medical certificate indicating how long the illness is expected to last. The unpredictable nature of mental illness makes it difficult to provide this kind of medical information.
- Individuals with mental illness and addiction share the view that EI should exempt individuals with recurring illnesses or disabilities from fulfilling the additional number of insurable hours required of those who are considered new to the labour force. In their view, without this exemption, individuals with mental illness are unjustly disadvantaged. Few are able to meet the eligibility criteria in terms of the total number of insurable hours required of new workers.

In his brief to the Committee, Dr. Sunil V. Patel, President of the Canadian Medical Association, recommended that the federal government review CPP(D) and other federal income support policies to ensure that mental illness is on a par with other chronic diseases and disabilities in terms of the benefits available to affected persons.[300]

6.5 THE ROLE OF EMPLOYERS

There is a compelling case for employers to address mental illness and addiction in the workplace. In the global economy, information and innovation have become the keys to competitive success. And using these keys requires skilled, motivated, reliable workers. Human capital – motivation, knowledge, perspective, judgement, the ability to communicate, share ideas and have relationships – drives the global economy. In short, it is mental performance that drives competitive success in the worldwide economy.[301] According to Bill Wilkerson, co-founder and CEO of the Global Business and Economic Roundtable on Addiction and Mental Health:

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299 Human Resources Development Canada, *Government of Canada's Response to "Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program"*, November 2003, p. 22.

300 Dr. Sunil V. Patel, President, CMA, Brief to the Committee, 31 March 2004, p. 5.

301 Bill Wilkerson (6 February 2002), p. 6.

> *(…) it falls to business to protect its strategic investment in its people – its vital asset – and, therefore, by definition of the economy of mental performance in which we compete, in their emotional and mental health.*[302]

The Committee heard over and over again that, given the burden of mental illness and addiction on society and on individual workers, and given the rising cost of occupational disabilities, employers must help to enhance the level of awareness about mental illness and addiction in their organizations; they also must devote more attention to improving access to treatment and rehabilitation services for workers through their EAPs. Employers must also place greater emphasis on work flexibility and accommodation for employees who suffer from mental illnesses.

> **Given recent estimates that about 75 per cent of the new jobs in the economy have to do with cognitive ability, not physical ability, and that the heavy lifting in the economy is now being done with people's minds, not with their backs, this aspect of mental disability is more significant than it might have been a number of years ago.**
> ***[Rod Phillips, President and CEO, Warren Sheppell ConsultantsCorporation (18:8)]***

Although the Committee was repeatedly told that employers had to do all the things listed in the previous paragraph, none of the testimony recognized explicitly how difficult this would be to do it in practice or how much it would cost. The Committee hopes therefore that during the nationwide public hearings which will follow the release of the Committee's Issues and Options paper in November 2004, we will receive advice on how employers can actually implement the changes suggested in the previous paragraphs and how much this would cost. Consistent with the Committee's earlier reports that contained recommendations for reform of the acute health care system, we are determined that the recommendations contained in our final report on mental health, mental illness and addiction, which will be released in November 2005, will be pragmatic and implementable, rather than merely pious statements of good intentions.

6.5.1 Employee Assistance Programs

EAPs are employer-sponsored
variety of workplace problems.
financial, marital or family-relate
or work-related (conflict on the j

Typically EAPs provide counselling, diagnostic, referral and treatment services. The staff of EAP programs usually hold a degree in a mental health or social service

> **Employee assistance programs, EAPs, play a role in the current system of how mental health is delivered in Canada. Essentially, they provide professional assessment, short-term counselling, and referral services as a benefit to employees. In most cases, Canadian EAPs also cover employees and their dependents, similar to drug or other employee benefit plans.**
> ***[Rod Phillips, President and CEO, Warren Shepell Consultants (18:8)]***

[302] Bill Wilkerson (6 February 2002), p. 8.

discipline (social work, psychology, psychiatry, counselling and/or marital and family therapy). Some services may also be contracted out to persons with other degrees, diplomas and qualifications.

EAP services are available both in private and public organizations and are usually administered completely independently of other programs within the organization. Confidentiality is the cornerstone of an effective EAP. The anonymity of clients, the confidentiality of interviews, the maintenance, transfer and destruction of files are subject to the applicable federal and provincial laws which define the conduct of counsellors. Generally, information may be released by an EAP counsellor only in situations where the client has provided informed and signed consent specifying what information is to be released and to whom.

The Committee was told that between 60 and 80 per cent of Canadians who are employed in a medium- or large-sized company (over 500 employees) currently have access to some form of EAP. According to Rod Phillips, President and CEO, Warren Shepell Consultants Corporation, EAPs are very effective; they have become the primary portal through which working Canadians often get their first access to mental health care and addiction treatment:

> *In many cases, in our experience, you would have about 85 per cent of the people who we see in a given year getting sufficient treatment through the EAP program that they would require no further treatment. About 15 per cent of the people would then be referred into community programs or into the public health care system.*[303]

EAPs also have a strong prevention component. Much of the work being done with employers focuses on wellness and other programs that support a healthy mental health work environment,

Watson Wyatt Worldwide have recommended that employers who do not offer EAPs should consider implementing such programs in order to address mental illness and addiction, and a variety of other issues. They pointed out that some insurers provide disability rate discounts to smaller employers who implement an EAP, usually through a preferred provider.[304]

For those organizations that already have an EAP in place, Watson Wyatt Worldwide recommended that their programs be reviewed and revised as needed to better address better the needs of employees affected by a mental illness and/or an addiction. Specific elements to be examined should include the need for meaningful reports, performance standards and user feedback. Internal reviews that compare EAP utilization and absenteeism data should be undertaken by operating units in order to identify internal 'best practices' which can then be introduced across the organization. Finally, Watson Wyatt

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[303] Rod Phillips (18:9).
[304] Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, June 2003.

Worldwide recommended that employees be told about the availability of the organization's EAP on an ongoing basis.[305]

Ash Bender and his colleagues (2002) warned that EAP programs are effective only when the working environments into which they are injected actively promote healthy workplaces. In other words, it is very important for employers to be well informed about mental illness and addiction, to address stigma and discrimination properly within their organization and to establish healthy workplaces.[306]

Another concern raised by Bender *et al.* related to the number of therapeutic sessions being offered to EAP clients; based on anecdotal evidence, these have decreased dramatically from 7 per individual to less than 3 over the last ten years. The authors concluded that the likelihood of effectively addressing any serious substance abuse or mental illness problem in this limited therapeutic timeframe would be low.[307] This concern requires particular attention.

6.5.2 Accommodation

> *The solution will certainly require involvement on the part of the workplace. We cannot consider the workplace as if it were a school or a hospital. It is an entity in itself, a family with its own rules and its own way of behaving and we cannot do without its involvement.*
> *[Jean-Yves Savoie, President, Advisory Board, Institute of Population and Public Health, CIHR (18:6)]*

Accommodation refers to "any modification of the workplace, or in the workplace procedures, that makes it possible for a person with special needs to do a job."[308] Just as individuals with physical disabilities may require physical aids or structural changes to the workplace, individuals with mental disorders most often require social and organizational accommodations to be made. These generally involve changes to the way things have traditionally been done in a particular workplace. Permitting someone with a mental illness to work flexible hours, for example, provides him or her access to employment in the same way that a ramp does for an individual in a wheelchair. Such accommodation does not constitute preferential treatment. Accommodation means equitable treatment for individuals with disabilities.[309]

According to the Canadian Psychiatric Association, accommodation should be built on positive arrangements that promote equality in employment, including:

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305 *Ibid.*

306 Ash Bender et al., *Mental Health and Substance Use at Work : Perspectives from Research and Implications for Leaders*, background paper prepared for the Global Business and Economic Roundtable on Addiction and Mental Health, 14 November 2002.

307 *Ibid.*

308 Lana M. Frado, *Diversity at Work: Accommodations in the Workplace for People with Mental Illness*, Canadian Mental Health Association, 1993, p. 8.

309 Lana M. Frado (1993), p. 10.

- Creating an environment in which arrangements are made in relation to the individual needs of each employee;
- Respecting the employee's desire for confidentiality as well as identifying specific the form and the degree of confidentiality required;
- Being willing to engage in joint problem solving;
- Making all arrangements voluntary for the employee, and being prepared to review plans periodically to meet changing needs;
- Being flexible in enforcing traditional policies;
- Being concrete and specific when identifying accommodations that are made. Putting them in writing is a good idea.[310]

One study suggests that the cost of accommodating an employee with a mental illness is fairly low, usually well under $500. Moreover, for those who get effective treatment, the employer will save between $5000 to $10,000 per employee per year in the cost of prescription drugs, sick leave, and average wage replacement alone. Employees who are diagnosed with depression and take appropriate medication will save their employer an average 11 days a year in prevented absenteeism.[311]

Another study found that over a 10 year period, 240 persons with serious mental illnesses were able to maintain gainful employment, largely because of formal work reintegration programs. These individuals earned $5 million, paid $1.3 million in income taxes, and saved the government an estimated $700,000 in welfare costs. The result was a net $2 million increase in collective wealth.[312]

For its part, the Global Business and Economic Roundtable on Addiction and Mental Health believes that employers must provide an appropriate environment for the promotion of good mental health, awareness of mental illness and addiction, early detection of mental illness and addiction, and integration of and accommodation for employees suffering from a mental disorder. In this regard, the Roundtable published the 12-step business plan to mental illness and addiction, summarized in Table 6.3.

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310 Canadian Psychiatric Association, op. cit.
311 Mental Health Works (2003), op. cit.
312 Gaston Harnois and Phyllis Gabriel (2000), op. cit., p. 47.

TABLE 6.3

12 STEP BUSINESS PLAN TO DEFEAT MENTAL ILLNESS AND ADDICTION AT WORK

Step One:	CEO briefing on mental illness and addiction
Step Two:	Early detection of mental illness and addiction
Step Three:	Reforming EAP and group health plans
Step Four:	Establishing a healthy mental workplace
Step Five:	Reducing the overflow of e-mail and voice-mail messages
Step Six:	Developing flexible return to work policies
Step Seven:	Educating managers and supervisors on connections between mental illness and physical illness
Step Eight:	Reducing emotional work hazards
Step Nine:	Promoting work/life balance policies
Step Ten:	Encouraging people to seek the necessary professional assistance
Step Eleven:	Monitoring the health status of the organization through specific targets
Step Twelve:	Eliminating the 10 main sources of workplace stress.

Source: Adapted from Bill Wilkerson, *Mental Health – The Ultimate Productivity Weapon*, Summary of Remarks to the Industrial Accident Prevention Association Conference and Trade Show, Toronto, 22 April 2002, pp. 10-14.

More recently, the Roundtable drafted its "Roadmap to Mental Disability Management" which unifies physical and mental health within a single environmental, health and safety system. The Roadmap also provides standards for governing return-to-work policy. More precisely:

- Employers do not need to know the nature of the diagnosis of the disabling illness that is involved in any given case. This information is private and confidential.
- Employers do need to understand, support and participate in return-to-work plans which will inevitably involve customized adjustments in the content of the employee's job or hours of work in order to make the transition go smoothly.
- Employers need to know that while the employee is coming back, he/she is not 100 per cent and gradual return-to-work is necessary to help the individual catch up with things, get up to speed and build tolerance and endurance.[313]

The Roadmap stressed that unions also share the responsibility to accommodate an employee's return-to-work. In particular, unions have a duty to represent their members at the higher end of the salary scale in matters concerning a disabled employee. This is particularly true when an employee is mentally disabled and the issue is termination.[314]

Again, the Committee wants to emphasize the critical importance of turning the goals and objectives described throughout Section 6.5 into achievable recommendations. The Committee will only be able to do this if it receives concrete suggestions from both workers and employers, along with estimates of what is would cost to implement these proposals.

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[313] Global Business and Economic Roundtable on Addiction and Mental Health (25 June 2004), p. 11.
[314] *Ibid.*, p. 23.

6.6 THE ROLE OF GOVERNMENTS

The Committee was told that governments must share responsibility with employers for shouldering the economic burden of mental illness and addiction in the workplace. According to Rod Phillips, such cost sharing could take the form of tax incentives:

> *Progressive employers are subsidizing Canada's inadequate public mental health care system. Their investment in mental health programs for their employees and family members should be encouraged through tax-based incentives and rebates, cost sharing, and joint service delivery. (…) The absence of accessible publicly-funded mental health services in Canada is a significant failing of our health care system. Given that a great percentage of the rising costs of mental illness are being borne by employers, there is a huge incentive for the costs associated with reducing these to be shared between employers and government. This avenue for cost sharing is, in our opinion, under explored and underused. I urge the Committee to consider innovative options.*[315]

For its part, the Canadian Mental Health Association (Ontario Division) strongly blamed governments from their lack of action with respect to mental illness and addiction:

> *For several years we have been talking about the projections by the World Health Organization that by 2020 mental illness will be the leading cause of days lost to disability. What we have not heard is the commitment that governments usually make when faced with a growing health problem, particularly one that impacts not only on the individual, but on society as a whole, including the economy. The WHO [projections] need to be treated as a challenge and wake up call, not an inevitable result.*
>
> *(…)*
>
> *Governments have an obligation to lead. The federal, provincial and territorial governments should commit to working together – and to support businesses – to achieve specific goals in terms of reducing the potential days lost to disability from mental illness. This requires a commitment on the part of all stakeholders to address the conditions that make people more vulnerable to mental illness and make the recovery or remission harder.*[316]

During the hearings that the Committee will hold on its Issues and Options paper, the Committee will be seeking advice on how governments should go about implementing the

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315 Warren Shepell, "Warren Shepell Calls for Tax Incentives to Support Employer Mental Health Programs", *Press Release*, 12 June 2003.

316 Canadian Mental Health Association (Ontario Division), Brief to the Committee, 12 June 2003, pp. 6-7.

suggestion that "governments have an obligation to lead". We need to hear the views of Canadians on what this actually means in practice.

6.7 BUSINESSES RUN BY INDIVIDUALS WITH MENTAL ILLNESS AND ADDICTION

During its hearings, the Committee learned about the Ontario Council of Alternative Business (OCAB). This is a provincial organization that assists in the development of economic opportunities for individuals with mental illness and addiction. It is an umbrella organization of 11 businesses operated by individuals with mental illness and addiction and which employ some 600 workers in various initiatives across the province.[317]

Evaluation of businesses run by individuals with mental illness and addiction demonstrates that individuals with mental disorders, even severe and persistent illnesses, can succeed and be competitive in the business they undertake.[318] The Committee strongly encourages the development of these initiatives.

6.8 A RESEARCH AGENDA ON MENTAL ILLNESS, ADDICTION AND WORK

The issues related to mental illness, addiction and work are complex and multifaceted. Society is confronted with a rapidly growing problem which has huge financial implications and involves a multitude of stakeholders. However, there is currently no coordinated comprehensive strategy for pursuing research, disseminating information, implementing results, and evaluating them. Such a strategy should include not only research on disease, treatment and therapy; it should also examine the relationship of the workplace to mental health, how therapies and treatments can be carried into the workplace and the home, as well as looking at how employers, employees and families can take action.

> **From the currently existing body of literature, we know that mental health problems present a serious threat to the nation's productivity. At the same time, we are only beginning to fully comprehend the prevalence and magnitude of the impact of mental health problems in the workplace. There is still much work to be done.**
>
> ***[Dewa, Lesage, Goering and Caveen, Nature and Amplitude of Mental Illness in the Workplace, April 2004.]***

The need for more research in the field of mental illness, addiction and work was highlighted in a recent workshop organized jointly by the Institute of Neurosciences, Mental Health and Addiction and the Institute of Population and Public Health of the Canadian Institutes of Health Research (CIHR). It enabled researchers to take stock of the nature and severity of mental illness and addiction in the workplace, to review the state of research in Canada in this field, and to develop a research agenda.

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[317] Additional information can be found at http://www.icomm.ca/ocab/.
[318] Heather Stuart (April 2004), p. 84.

Participants at the workshop identified many areas that require more research, such as: understanding the patterns of mental disorders among the different occupational groups and industry sectors; understanding the relationship between employer– sponsored benefits and the prevalence and pattern of disability related to mental illness; examining the relationship between stress at work and the onset of disability; understanding how mental health is affected by prominent trends in workplace organizational practices; identifying effective methods to improve diagnoses and treatment interventions for mental illnesses amongst working individuals; analyzing policy and guidelines that relate to occupational disability; and determining the scope and nature of stigma in work settings.

The Committee welcomes this initiative by CIHR. We hope that the workshop will lead to the development of a research agenda which will help advance the understanding of mental disorders and the disabilities they cause, and identify innovative business practices that can help employees with a mental disorder.

The Committee also heard about a research plan called the "Research and Return on Investment Initiative", a joint initiative undertaken by the Global Business and Economic Roundtable on Addiction and Mental Health, the Centre for Addiction and Mental Health and the Institute for Work and Health, that is funded by CIBC, TD Bank, Scotiabank, RBC, BMO and Great-West Life. The purpose of this research is to survey Canadian and American companies and gather and share information about successes in managing mental disability and facilitating the return-to-work of individuals with mental illness and addiction.[319] The Committee strongly encourages the Roundtable and business leaders to share best practices in the management of mental disability in the workplace and in the development of effective return-to-work strategies.

6.9 COMMITTEE COMMENTARY

The Committee agrees with numerous witnesses that securing and sustaining meaningful employment is beneficial to individuals with mental illness; it is also an essential part of the recovery process. In addition, we believe strongly that enabling these individuals to participate in the workforce can be beneficial to the companies employing them; recent advances in treatment now make it possible for people with mental illnesses to make valuable contributions in the workplace.

There is still a debate as to how much an employer wants to or should know concerning an employee's mental illness. The Committee is of the view that legislation should not allow disability to be a sufficient ground to refuse employment unless it is clearly impossible for the person to do the job. The assurance that there will be quick and easy access to appropriate mental health services and supports has been found to influence very positively the willingness of employers to offer employment to persons with mental illness. In the Committee's opinion, the disability associated with mental illness and addiction can no longer serve as an excuse to deny employment to those who want a job and are able to do it.

[319] Honorable Michael Wilson, *Text of Remarks*, CIHR IRSC Workshop, 28 April 2004.

There is no doubt that employers bear a large burden in terms of lost productivity as a result of mental illness and addiction in the workplace. The presence of mental health and addiction problems in the workplace triggers the following question: "to what extent are these disorders imported into the workplace by individual employees and to what extent are they engendered by the workplace itself?" Obviously, the answer given to this question has profound implications for strategies aimed at preventing and managing mental illness and addiction in the workplace; it could also impact substantially on how disability claims attributable to mental disorders should be managed.

The Committee believes that more research must be undertaken in the field of mental illness, addiction and work. For example, we believe that it is important to understand the influence that the type and extent of disability coverage have on the duration of claims and to define the best model. It is important to understand the influence of healthy and non-healthy workplaces on the incidence of mental illness claims. It is also important to assess the impact of EAP programs.

The Committee strongly supports the view that it is imperative to provide education and awareness programs to inform everyone in the workplace, from the top down, about the causes, symptoms and treatment of mental illness and addiction. This would help overcome the stigma associated with mental disorders. While the implementation of such programs cannot eliminate stigma or guarantee that all employees will seek early treatment, they would certainly reduce the stress faced by those suffering from mental illness and addiction.

We also agree with experts that return-to-work policies must be reviewed and revised where necessary. Mental disorders do not fit the typical model of disability; many employers still view disability in terms of a physical impairment. Accordingly, the needs of employees returning to work following a mental health-related absence may be quite different from those of an employee returning after back surgery. Existing return-to-work arrangements should be reviewed and revised to address such different situations.

Furthermore, the Committee believes that an organization's internal culture can make a huge difference to how mental illness and addiction is approached in the workplace. Employers should examine carefully all workplace issues (i.e., harassment, adversarial relationships between management and employees, etc.) that are creating unnecessary stress and hostility. Such situations have a detrimental impact on all employees, but especially on employees affected by mental illness and addiction. Employers should take steps to remedy problems that emerge as a result of such examinations.

Finally, the concern raised with respect to the need to review CPP(D) and EI in order to take into account the cyclical and unpredictable nature of mental disorders must be examined. The federal government should also consider how to share more equitably with employers the costs associated with mental illness and addiction.

SENATE SÉNAT
CANADA

RAPPORT 1

Santé mentale, maladie mentale et toxicomanie:

Aperçu des politiques et des programmes au Canada

Rapport provisoire du
Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

L'honorable Michael J.L.Kirby, président
L'honorable Wilbert Joseph Keon, vice-président

Novembre 2004

TABLE DES MATIÈRES

ORDRE DE RENVOI

Extrait des *Journaux du Sénat* du jeudi 7 octobre 2004

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Losier-Cool,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système des soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale ;

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la trente-septième législature soient déférés au Comité ;

Que le Comité présente son rapport final au plus tard le 16 décembre 2005 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 mars 2006.

La motion, mise aux voix, est adoptée.

Le greffier du Sénat,

Paul C. Bélisle

SÉNATEURS

Les sénateurs suivants ont participé à l'étude du Comité sénatorial permanent des affaires sociales, des sciences et de la technologies sur l'état du système de soins de santé (plus particulièrement sur la santé mentale):

L'honorable Michael J. L. Kirby, président du Comité
L'honorable Wilbert Joseph Keon, vice-président du Comité

Les honorables sénateurs:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retraitée)
Douglas Roche (retraité)
Eileen Rossiter (retraitée)
Marilyn Trenholme Counsell

Membres d'office du Comité:
Les honorables sénateurs: Jack Austin P.C. (ou William Rompkey) et Noël A. Kinsella (ou Terrance Stratton)

Autres sénateurs ayant participé de temps à autre à cette étude:
Les honorables sénateurs Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne et Murray.

SANTÉ MENTALE, MALADIE MENTALE ET TOXICOMANIE: APERÇU DES POLITIQUES ET DES PROGRAMMES AU CANADA

INTRODUCTION

En février 2003, lors de la deuxième session de la trente-septième législature, le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie a reçu pour mandat du Sénat d'étudier l'état des services de santé mentale et des traitements de la toxicomanie au Canada et d'examiner le rôle du gouvernement à cet égard. Le Sénat a revu le mandat du Comité lors de la troisième session de la trente-septième législature (février 2004), puis, de nouveau, lors de la première session de la trente-huitième législature (octobre 2004).

Ce mandat se lit ainsi :

> Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système de soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale;
>
> Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la deuxième session de la trente-septième législature soient déférés au Comité;
>
> Que le Comité présente son rapport final au plus tard le 16 décembre 2005.[1]

Pour cette étude, le Comité a adopté une démarche très globale dans le dessein d'examiner la santé mentale, la maladie mentale et la toxicomanie sur plusieurs plans : la prévalence des troubles mentaux et leurs répercussions économiques sur les divers secteurs de la société canadienne, notamment sur le monde des affaires, le milieu de l'éducation et les réseaux de soins de santé; les politiques et les programmes fédéraux et provinciaux pertinents; les stratégies en matière de soins de santé appliquées dans d'autres pays; la promotion de la santé mentale ainsi que la prévention de la maladie mentale et du suicide; la surveillance et la recherche relativement aux maladies mentales; l'accès aux services de santé mentale et de traitement des toxicomanies, et la prestation de ces services; le soutien aux familles et aux soignants; la possibilité d'élaborer un plan d'action national en matière de santé mentale, de maladie mentale et de toxicomanie au Canada.

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1 Débats du Sénat (Hansard), 1re session, 38e législature, vol. 142, fascicule 7, octobre 2004.

L'étude du Comité sur la santé mentale, la maladie mentale et la toxicomanie se décline en quatre rapports. Le tableau ci-dessous résume le contenu de chaque rapport et précise les échéances visées pour leur publication :

ÉTUDE DE LA SANTÉ MENTALE, DE LA MALADIE MENTALE ET DE LA TOXICOMANIE
RAPPORTS ET DATES PRÉVUES DE PUBLICATION

Rapport	Contenu	Date
Un	Document factuel donnant un historique et un aperçu de la prestation des services, du rôle respectif des gouvernements fédéral, provinciaux et territoriaux, ainsi que de l'évaluation des politiques et des programmes à partir des témoignages recueillis et d'un examen documentaire.	Novembre 2004
Deux	Analyse comparative à l'échelle internationale (Australie, Canada, Nouvelle-Zélande, Royaume-Uni et États-Unis).	Novembre 2004
Trois	Document résumant les enjeux et les options dont le comité traitera dans son rapport final et exposant les solutions pour régler ces enjeux.	Novembre 2004
Quatre	Recommandations de réforme	Novembre 2005

Le présent rapport sur la santé mentale, la maladie mentale et la toxicomanie comporte onze chapitres. Le chapitre 1 résume les témoignages d'une personne souffrant de maladie mentale ainsi que de trois membres de familles de malades qui ont bien voulu faire part de leur vécu au Comité. Le chapitre 2 apporte un complément d'information sur les répercussions que la maladie mentale et la toxicomanie peuvent avoir sur ceux et celles qui en souffrent, sur leurs familles et sur les soignants. Le chapitre 3 examine les questions de stigmatisation et de discrimination ainsi que leurs effets sur les personnes atteintes de maladie mentale ou de toxicomanie. Le chapitre 4 définit les divers concepts associés à la santé mentale, à la maladie mentale et à la toxicomanie. Le chapitre 5 donne des renseignements sur la prévalence de la maladie mentale et de la toxicomanie ainsi que sur leurs impacts économiques sur la société canadienne. Le chapitre 6 examine les liens entre la maladie mentale, la toxicomanie et le travail de même que les différentes façons de composer avec la maladie mentale et la toxicomanie en milieu de travail. Le chapitre 7 livre un aperçu chronologique de l'évolution des services de santé mentale et de traitement de la toxicomanie au Canada. Le chapitre 8 compare la structure organisationnelle ainsi que le niveau d'intégration des services en santé mentale et du système de traitement de la toxicomanie dans certaines provinces; en outre, il met en exergue les principales différences relevées dans les lois provinciales sur la santé. Le chapitre 9 présente un tour d'horizon et avance une évaluation du rôle direct et du rôle indirect que le gouvernement fédéral est appelé à jouer dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. Le chapitre 10 dresse l'état de la recherche en santé mentale, en maladie mentale et en toxicomanie au Canada. Le chapitre 11, enfin, examine les différents enjeux d'ordre éthique

dans les domaines de la maladie mentale et de la toxicomanie, surtout en ce qui a trait à la prestation des services, à la recherche, à la capacité de consentir au traitement de même qu'aux aspects touchant à la vie privée et à la confidentialité.

PARTIE 1

Le visage humain de la maladie mentale et de la toxicomanie

CHAPITRE 1:
DES TÉMOINS FONT PART DE LEUR VÉCU[2]

> *(…) je pense qu'il est temps que l'on demande l'avis des usagers des services et des gens qui sont les experts en santé mentale. Qui d'autres que nous connaît autant nos troubles, nos besoins et nos problèmes? Il est certain que nous ne pouvons pas nous guérir nous-mêmes. Nous sommes capables de penser. Nous avons besoin d'être entendus et je vous remercie de le faire.*
> *[Loïse (9:18).]*

INTRODUCTION

C'est le 26 février 2003 que le Comité a entrepris son étude sur la santé mentale, la maladie mentale et la toxicomanie en apportant une dimension humaine à tout ce dossier. En effet, trois familles concernées par la maladie mentale et une personne souffrant de ce genre de maladie ont accepté notre invitation à parler de leur vécu, c'est-à-dire de la façon dont ce genre de trouble a affecté leur vie. Ces quatre témoins, qui venaient de différentes régions du pays et avaient une expérience directe des questions de santé mentale et de toxicomanie, sont donc venus faire part de leur récit au Comité. Afin qu'ils soient suffisamment à l'aise pour témoigner franchement, les membres du Comité ne les ont appelés que par leur prénom. Le présent chapitre résume leurs témoignages qui montrent, de façon très imagée, pourquoi les membres du Comité ont été tellement touchés émotionnellement lors de cette étude de la santé mentale, de la maladie mentale et de la toxicomanie.

Tout au long de leurs travaux, que ce soit lors des audiences publiques, par lettre ou par courriel, les membres du Comité ont également entendu parler de la vie de nombreux autres Canadiens touchés par la maladie mentale et la toxicomanie. Le chapitre 2 résume donc l'expérience dont toutes ces personnes ont bien voulu nous faire part.

1.1 CE QU'ILS NOUS ONT DIT

1.1.1 Le récit de Loïse

Loïse a relaté ce qu'elle a vécu, elle qui souffre de trouble bipolaire :

> *Il y a dix ans, suite à la mort subite de mon compagnon, j'ai connu une phase maniaque. Quand on est dans cet état, on ment, on dépense à tort et à travers, on est certain d'avoir de l'argent, on est convaincu de ce que*

[2] Dans le présent chapitre, les extraits de témoignages apparaissant dans les délibérations du Comité sénatorial permanent des affaires sociales, des sciences et de la technologie sont simplement signalés par le numéro de la séance et le numéro de la page où se trouve le passage.

l'on fait mais on débloque. On est sûr qu'on pourrait sauver le monde durant cette période. Cette phase a duré six mois et elle s'est terminée par une tentative de suicide, puis de quatre années de dépression.

À l'urgence de l'hôpital où l'on m'a transportée, on m'a recommandé d'aller dans un centre de crises. Ce fut le début de neuf années du soutien sans faille que m'ont apporté des organismes communautaires et de quatre années de bataille continue pour avoir l'aide requise autant psychologique que pharmaceutique des institutions et des psychiatres.[3]

Elle s'est souvenue du nombre de fois où elle a dû raconter son histoire, encore et encore, à toute une diversité de professionnels de la santé :

Pendant des années, j'ai dû raconter et répéter l'histoire de ma vie aux personnes suivantes: une infirmière de l'urgence; la psychiatre de l'urgence; une évaluatrice du centre de crises; un intervenant psychosocial de ce centre — on parle de l'histoire de ma vie et on revient constamment aux traumatismes que j'ai vécus, aux choses douloureuses et chaque fois je dois recommencer à zéro — un psychiatre du centre de crises de l'hôpital; une travailleuse sociale de l'hôpital; un préposé à l'accueil du CLSC; un intervenant du CLSC; un travailleuse psychosociale du CLSC et un médecin de famille du CLSC. C'était extrêmement douloureux […]. Je ne sais pas comment j'ai pu continuer. Un psychiatre évaluateur de services à l'hôpital, six infirmières psychiatriques et quatre psychiatres de la clinique externe — parce que cela change souvent —, un psychiatre spécialiste des troubles de l'humeur ayant un groupe de thérapie, une psychiatre et trois résidants — qu'elle formait dans la clinique des troubles de l'humeur — et, enfin, il y a trois ans, une psychiatre qui me suis toujours et avec qui je considère avoir une relation privilégiée.[4]

Elle nous a aussi relaté le peu d'intégration de services et de moyens de soutien, quand il y en a, et le rôle important que les organismes communautaires ont joué dans son rétablissement :

Avec l'énergie qui me reste, j'ai décidé de m'engager au niveau communautaire et dans un rôle consultatif auprès de la Régie régionale de la santé de la ville. Si je n'avais pas eu le communautaire, je ne serais pas ici aujourd'hui pour vous parler.

Oui, en fin de compte, les institutions m'ont aidée, les psychiatres aussi. Toutefois, ils auraient pu aussi me tuer en me faisant revivre les traumatismes épouvantables auxquels j'ai dû faire face. Il faut régler les problèmes de dédoublement, de paramètres rigides et les difficultés d'approche qui existent dans les institutions qui doivent collaborer avec

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[3] Loïse (9:19).
[4] *Ibid.*

> *les organismes communautaires pour aider les consommateurs de ces services à trouver l'aide requise.*[5]

Loïse a insisté sur la nécessité d'éliminer la stigmatisation et les préjugés associés à la maladie mentale et à la toxicomanie :

> *Depuis le diagnostic de ma maladie, j'ai perdu, l'estime de certains membres de ma famille. J'ai eu à me battre contre cela et beaucoup de gens ont eu à le faire aussi.*
>
> *[…]*
>
> *Il va aussi falloir régler en urgence les préjugés profonds et tenaces qui existent encore dans notre société, soit par des campagnes médiatiques, soit par d'autres moyens.*[6]

Voici ce qu'elle nous a dit à propos des médias :

> *On organise des conférences de presse, que ce soit pour le communautaire, pour les usagers, pour expliquer aux gens les différentes maladies, mais il n'y jamais un journaliste ne s'y présente. Pourtant, si quelqu'un qui a une maladie mentale commet un acte criminel, les grands titres sont « Un schizophrène tue sa femme », « Un maniaco-dépressif maltraite ses enfants ». D'un autre côté, je n'ai jamais lu « Un cancéreux tue sa femme » ni quoi que ce soit du genre. À ce niveau, les médias n'arrangent pas les choses. Il y a du chemin à faire. Dans une population plus éduquée, spécialisée, où il y a moins de préjugés, cela passe mieux, mais c'est un problème encore très grave.*[7]

1.1.2 Le récit de Ronald

Ronald nous a relaté sa vie au côté de sa femme schizophrène. Il nous a raconté ce qui lui est arrivé, du début de la maladie de sa femme, une dizaine d'années après leur mariage en 1959, jusqu'à nos jours en précisant qu'il était alors mal outillé pour s'occuper d'elle : « Je n'avais aucun idée de ce qui se passait. La maladie mentale, je ne connaissais pas cela ».[8] Il devait rajouter :

> *Je me suis marié en 1959, les premiers troubles sont apparus vers les années 70. Il y avait déjà trois enfants présents.*
>
> *[…]*

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5 Loïse (9:19-20).
6 Loïse (9:20).
7 Loïse (9:27).
8 Ronald (9:20).

Ma décision de rester avec elle je l'ai assumée pour le meilleur et pour le pire.

À cette époque, ma femme ne voulait pas se faire hospitaliser parce que la maladie n'existait pas pour elle. Elle n'était pas malade. La maladie n'existant pas il fallait que je trouve le moyen de la faire hospitaliser.[9]

Ronald a expliqué au Comité les démarches qu'il a dû entreprendre pour obtenir de l'aide pour sa femme :

J'en ai parlé au médecin traitant qui m'a dit: «Il y a sûrement quelque chose qui ne va pas avec ta femme tu dois la faire examiner». Mais cela prenait le papier de deux psychiatres. Le médecin traitant s'était engagé à trouver deux psychiatres qui signeraient un papier et qui la feraient hospitaliser.

Une fois les deux papiers signés par les psychiatres, elle ne voulait pas venir à hôpital. Je lui ai dit: « tu viens à l'hôpital de ton propre chef ou c'est la police qui viendra te chercher ». J'ai dû aller chercher un papier du juge et elle a accepté de se faire hospitaliser.

Elle a été hospitalisée trois mois. Il y a eu des tentatives de suicide. Quelqu'un est resté dans sa chambre 24 heures sur 24 pendant trois mois afin qu'elle ne se suicide pas. Finalement, elle est sortie de l'hôpital sous médication. Elle prenait à ce moment des neuroleptiques […]. Les crises ont disparu à peu près complètement. Le côté positif de la maladie, c'est-à-dire les hallucinations, les délires religieux et ainsi de suite ont disparu. Mais ce qui est apparu à ce moment-là, ce sur quoi le médicaments n'ont aucune action, c'est le côte négatif de la maladie, c'est-à-dire le côté social, la non-confiance en soi, l'hygiène personnelle; elle a le sentiment qu'elle n'est bonne à rien, elle ne peut absolument rien réussir et ainsi de suite. C'est tellement subtil que, parce qu'elle se croit bonne à rien et incapable de réussir quoi que ce soit, elle ne peut pas non plus accepter qu'on l'aime, qu'on lui dise qu'elle est bonne et qu'elle est capable de réussir, cela serait trahir ce qu'elle croit être véritablement.

Elle se laisse définitivement aller.[10]

Il nous a expliqué que la maladie de sa femme a empiré : « nous avons perdu nos amis et nous n'avons plus de vie sociale, amoureuse ni sexuelle. Finalement, il n'y a plus rien ».[11] Quand il parle de sa vie avec sa femme aujourd'hui, voici ce qu'il dit :

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9 Ronald (9:20-21).
10 Ronald (9:21).
11 Ronald (9:21).

> *Pour ma femme, quand nous sommes entre nous, la maladie et les symptômes ont disparu. Le psychiatre voit ma femme une fois tous les six mois mais ce n'est pas mieux. Tout le côté négatif de la maladie a augmenté. Maintenant, c'est à peine si elle s'habille, elle n'a aucune initiative, rien ne l'intéresse. Elle s'inscrit à des cours de lettres, de peinture mais elle laisse toujours tomber en cours de route. Elle revient à la maison découragée.*
>
> *Les enfants ne viennent pas à la maison parce qu'ils ne peuvent pas faire face à cette situation.*[12]

Ronald s'est senti seul, parce qu'il ne recevait pas beaucoup d'appui pour l'aider à comprendre la maladie de sa femme et à gérer correctement la situation :

> *À ce moment j'étais seul et c'était difficile, car je n'avais pas d'aide. Je devais « composer » avec tout cela. Comment j'ai fait pour passer au travers, je ne le sais pas. [ ] il n'y a pas eu de violence. Cela a été plus du côté émotionnel. Ma femme s'est retirée du monde. Il y a eu très peu de violence, même si c'est arrivé à quelques occasions. Il y a eu des tentatives de suicide parce qu'elle avait si peu confiance en elle. Mais pour ce qui est des enfants, cela a été très difficile.*[13]

Ronald a raconté les difficultés auxquelles il s'est heurté pour obtenir le certificat nécessaire pour bénéficier d'un dégrèvement fiscal :

> *[…] De plus, au début le psychiatre me signait une lettre qui me permettait une exemption d'impôt; le deuxième ne le fait plus et je n'ai plus droit à mon compensation d'impôt. C'est difficile à prendre. Tout le monde pense qu'elle va bien parce que dans la vie de tous les jours rien ne se remarque si ce n'est son apparence physique.*[14]

Il nous a parlé d'un projet pilote portant sur des plans de soins individualisés qui, selon lui, ne peuvent fonctionner que si tous les professionnels de la santé mentale concernés collaborent effectivement :

> *Au début, je me souviens d'une expérience qui avait été faite où on parlait de plan de services individualisés. Tout devait tourner autour de la personne atteinte de maladie mentale; il devait y avoir une équipe : le psychiatre, l'infirmière, et cetera. Cela n'a pas fonctionné parce qu'on n'était pas capable de réunir toute l'équipe.*

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12 Ronald (9:22).
13 Ronald (9:30).
14 Ronald (9:22-23).

> *Actuellement cela fonctionne dans des petits organismes comme le nôtre où l'infirmière accepte de coopérer et le médecin aussi.*[15]

En réaction à ce qui est arrivé à sa femme et à sa famille, Ronald s'est lancé dans le bénévolat. Ayant constaté que la meilleure façon d'aider les proches de personnes souffrant de troubles mentaux consistait à mettre sur pied des organismes aptes à s'occuper de ces personnes-là, lui-même et d'autres bénévoles ont fondé Le Pavois, organisation qui prêche la réintégration sociale et la réadaptation par le travail. Le Pavois favorise la réinsertion sociale des personnes souffrant de maladie mentale grâce à des ateliers sur les activités de bureau et à des cours de cuisine. Quand l'évolution dans ce milieu contrôlé a donné les résultats voulus, des agents d'intégration rendent visite aux employeurs et essaient de trouver des stages, puis des emplois aux protégés du Pavois. Le Pavois administre aussi une friperie, un service de reprographie et une cafétéria dans le centre des services sociaux et de santé de la province. Voici ce que Ronald devait ajouter :

> *Ces entreprises sociales sont un palier intermédiaire pour que nos membres passent du Pavois au véritable marché du travail. On s'est rendu compte que le stress était trop important pour eux si on cherchait à les faire passer sur le véritable marché du travail. La plupart, d'entre eux ne sont pas capables de retourner sur le marché du travail.*[16]

1.1.3 Le récit de Murray

Murray a parlé de son fils atteint de schizophrénie paranoïde. Le 28 mai 2002, il est parti de l'Hôpital Royal d'Ottawa où il était traité pour aboutir sur le Queensway (dans une voie réservée aux autobus) et se faire happé mortellement par un autobus de la ville. Il nous a dit qui était son fils avant le début de sa maladie :

> *Avant l'apparition de la maladie, il y a environ six ans de cela, notre fils était inscrit au programme d'études spécialisées. Il faisait partie de l'orchestre de l'école et effectuait des tournées au Canada et aux États-Unis. Il jouait au soccer dans une équipe de première division. Il avait de nombreux amis et une charmante copine qu'il fréquentait depuis longtemps. Il était l'âme sœur de sa cadette. Bref, il avait un avenir prometteur.*
>
> *Les choses ont commencé à se détériorer petit à petit quand la schizophrénie paranoïde a fait sa lente apparition et que mon fils a dû recourir au régime de soins de santé mentale et aux services sociaux.*[17]

Il nous a décrit un système de santé uniquement conçu pour réagir à des crises :

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15 Ronald (9:36).
16 Ronald (9:22).
17 Murray (9:14).

> *Invariablement, quand les choses allaient très mal, c'était parce que nous ne pouvions avoir accès à des soins de santé en temps opportun pour diverses raisons : il n'y avait pas suffisamment de lits, il fallait s'adresser au centre de soins communautaires, il ne s'était pas fait interner volontairement, il n'y avait pas assez de personnel et les installations étaient peu sécuritaires. On arrivait difficilement à surmonter les crises. Le système ne faisait que réagir à la crise, et ce, seulement après des semaines de traitements de choc, une détérioration de la maladie, de nombreux appels lancés par la famille et des avertissements donnés aux fournisseurs de soins. Pas une seule fois on ne l'a renvoyé de l'hôpital dans un état stable, dans un milieu encadré où l'on s'assurerait qu'il prendrait ses médicaments.*[18]
>
> *[…]*
>
> *Même quand il était à l'hôpital, il y avait des problèmes à cause de l'absence de services, de la préparation des audiences d'accréditation, des visites de médecins, des visites aux hôpitaux, des demandes pour le programme ontarien de soutien aux personnes handicapées, de l'obtention de médicaments et de traitements, de la participation à des groupes de soutien et des appels téléphoniques troublants que nous recevions de notre fils hospitalisé. Nous avions peur qu'il s'échappe de l'hôpital et que la consommation de mauvais médicaments entraîne des séquelles cérébrales permanentes.*[19]

Pour Murray, le manque de services et de moyens de soutien a eu de graves conséquences pour son fils. Il a parlé du stress subi par toute la famille à cause de cela, et des effets négatifs sur son réseau social et ses finances :

> *Il avait donc un comportement imprévisible, des crises de folie et un comportement violent, à n'importe quelle heure de la journée ou de la nuit. Cela a eu pour effet de traumatiser considérablement les membres de sa famille. Nous avions peur que notre fils se blesse physiquement et qu'il blesse d'autres membres de la famille, même pendant leur sommeil. Nous dormions à tour de rôle. Les dégâts causés à la maison étaient considérables et coûteux.*
>
> *[…]*
>
> *Cette situation nous a occasionné beaucoup de stress au fil des ans, sans compter la fatigue mentale et physique, et même pire.*

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18 Murray (9:15).

19 Murray (9:16).

> *Nous ne pouvions pas avoir de vie sociale. Nous ne pouvions pas l'emmener avec nous parce qu'il ne pouvait pas tolérer des niveaux élevés de stimuli sensoriels pendant longtemps. Nous ne pouvions pas le laisser seul à la maison et il était hors de question de le faire garder.*
>
> *Mes autres enfants ont aussi souffert, parce qu'ils ont perdu toute une année d'université et qu'ils ont été traumatisés par les incursions de la police chez nous et la crainte que leur frère ne soit blessé ou tué par les policiers au moment de ses nombreuses hospitalisations forcées. Notre fille a perdu une âme sœur et notre autre fils va passer le reste de sa vie sans son frère bien-aimé.*
>
> *Cette maladie a […] limité nos possibilités de gagner notre vie. J'ai perdu des revenus de travail et j'ai été congédié par mon employeur en raison de ma faible production. J'ai tout juste réussi à conserver la clientèle que j'avais. Je n'ai pas pu trouver de nouveaux clients pendant trois ans. Je n'ai souvent pas pu tenir mes engagements étant donné que je ne pouvais pas quitter la maison quand mon fils était là. J'avais peur de prendre des rendez-vous le soir parce que je devais alors laisser ma femme et ma fille seules à la maison avec mon fils. Nos économies ont sérieusement fondu.*[20]

Murray nous a relaté les frustrations de sa famille occasionnées par la *Loi sur la protection des renseignements personnels* qui ne permettait pas au personnel soignant de lui communiquer des renseignements sur la maladie de son fils :

> *Pourquoi les médecins ne sont-ils pas autorisés à informer les membres de la famille quand on sait que le soutien de la famille est bénéfique pour le malade? Le malade prend des médicaments parce que son mode de pensée est perturbé; pourtant, les médecins estiment que c'est à lui de décider d'informer la famille bien qu'il ne soit pas en état de prendre de décisions raisonnables ou réfléchies.*[21]

Il a insisté sur la nécessité de parvenir à un bon équilibre entre le droit du patient d'être traité et la nécessité de le traiter contre son gré :

> *Quand vient le temps de mettre en équilibre les droits et la prise obligatoire de médicaments, en tant que parents, vous êtes très préoccupés par la vie et le bien-être de votre enfant, et ce n'est donc pas une question de droits. L'enfant a le droit d'être traité, mais il ne se rend pas compte qu'il en a besoin. Il a le droit à la vie, même s'il est incapable de veiller à*

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20 Murray (9:15-16).

21 Murray (9:18).

ses propres besoins. Il n'y a pas d'hésitation quand c'est sa vie qui est en danger.[22]

Murray a soulevé la question du niveau de financement gouvernemental approprié pour ce qui est de l'établissement des diagnostics, du traitement et de la recherche sur les troubles mentaux, par rapport à d'autres maladies :

> *Je pense que l'argent que les gouvernements fédéral et provinciaux destinent à la santé doit servir à la santé de tous les Canadiens. Comment se fait-il que les groupes de pression les plus critiques et les plus puissants obtiennent la plus large part des budgets? Nous avons des chiffres que nous pouvons fournir à ce sujet. Pendant ce temps, des personnes vulnérables qui ne peuvent pas se défendre sont laissées pour compte. Dépenser pour elles ne rapporte rien sur le plan politique.*
>
> *[…]*
>
> *La question des droits figure sur notre liste de points à régler. Elle échappe au cadre juridique normal. Quand on est aux prises avec un incapable, on se trouve dans une situation délicate.*
>
> *Il existe divers degrés de schizophrénie, et ceux qui se plaignent du non-respect de leurs droits sont peut-être atteints d'une forme légère de la maladie et estiment qu'ils sont persécutés et traités injustement. La question est délicate.*[23] [24]

Murray a aussi soulevé la question du problème de l'intervention précoce dans le cas des troubles mentaux, par rapport à ce qui se fait avec d'autres maladies :

> *Est-il raisonnable qu'il y ait beaucoup de lignes directrices pour déterminer si un membre de votre famille souffre de maladie cardiaque, de dépression, de diabète ou autre, mais qu'il n'y en ait aucune pour vérifier si quelqu'un souffre de schizophrénie? Les écoles présument simplement qu'il y a un problème de drogue, ce qui retarde beaucoup le traitement. Or, un traitement précoce est crucial.*[25]

1.1.4 Le récit de David

C'est la première fois que David acceptait de raconter son expérience personnelle à qui que ce soit. Il a bien précisé qu'il ne lui était pas facile de le faire et a insisté sur l'importance de protéger son identité :

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22 Murray (9:28).
23 Murray (9:28-29).
24 Murray (9:17).
25 *Ibid.*

[…] j'aimerais mettre un visage sur cette maladie en vous parlant un peu de notre expérience familiale. C'est la toute première fois que je fais une chose pareille. Il y a deux semaines, lorsque j'ai reçu votre invitation à comparaître, on m'a dit que vous vouliez entendre un témoignage personnel, eh bien, c'est ce que je vais vous livrer aujourd'hui.

[…]

Je vais me défouler; c'est pourquoi j'aimerais mieux que mon identité ne soit pas divulguée. Je vais vous raconter une expérience très intime tirée de graves problèmes personnels, mais qui forge des valeurs profondes. Je ne sais pas si cet exercice aura pour effet de me déstabiliser ou au contraire de me rasséréner.[26]

David a un fils autistique de 31 ans. Voici ce qu'il nous en a dit :

Mon fils a 31 ans. Nous ne connaissions pas l'étendue de son handicap jusqu'à ce qu'il atteigne l'âge de 15 ans, ce qui est une situation plutôt rare pour la plupart des autistes. Mon fils n'est pas un autiste classique. C'est un autiste de haut niveau; il parle; il lit; il a un diplôme d'études secondaires.[27]

[…]

Quand il était petit, mon fils Adam avait de la difficulté à se faire des amis. Nous ne savions pas qu'il était autiste. Il n'en présentait pas les symptômes lorsqu'il avait deux ou trois ans, l'âge auquel la plupart des autistes démontrent des tendances à la maladie. Nous avions remarqué qu'il était agressif, particulièrement à l'égard des étrangers et des amis que son frère Andrew invitait à la maison. Les autistes n'aiment pas les changements. Ils résistent à tout changement.

Nous avions aussi remarqué que, plus il vieillissait et plus l'école devait une source de stress pour Adam. À 15 ans, il a commencé à refuser d'aller à l'école. Certains enfants lui rendaient la vie difficile. Ils se moquaient de lui et mon fils trouvait les récréations extrêmement éprouvantes. Il devenait très agité et colérique. Il sortait se promener et rentrait à la maison dans une rage violente. Il était si en colère qu'il brisait les vitres des fenêtres de notre maison et arrachait les luminaires.[28]

David a décrit en détail les années de diagnostics erronés et de thérapies inadaptées avant que la famille découvre enfin ce qui n'allait pas avec ce fils :

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26 David (9:6).
27 *Ibid.*
28 David (9:8-9).

Nous n'avions pas d'autre solution que de l'envoyer à l'hôpital où les médecins ont diagnostiqué, à tort, un trouble bipolaire. Cela tient au fait qu'à l'époque, notre système médical n'avait pas la capacité de diagnostiquer correctement l'autisme. La situation s'est nettement améliorée depuis. Il est rapidement devenu clair que le diagnostic était erroné. Les médecins de l'hôpital pour enfants où était admis Adam lui administraient des sédatifs, mais ils n'ont absolument rien fait pour résoudre ses problèmes de base.

Nous sommes passés au travers d'expériences traumatisantes. Par exemple, je me souviens qu'une nuit, on nous a appelés à 2 heures du matin pour nous dire qu'Adam s'était échappé de l'hôpital. Il avait sauté par la fenêtre puis, une fois sur le toit, il était descendu par une échelle et avait quitté l'hôpital. Avant que ne nous soyons arrivés sur les lieux, Adam avait été retrouvé par la police et était traité pour hypothermie. Il ne nous a jamais expliqué pourquoi il avait décidé de sauter par la fenêtre et de s'échapper en pyjama en pleine nuit, mais il nous exprimait fréquemment sa colère de l'avoir envoyé à l'hôpital. Plus tard, dans sa rage, il arrachait les luminaires. Il était devenu si agressif et si incontrôlable que nous avons dû l'interner dans un hôpital psychiatrique pour adultes, ce qui était un endroit très inapproprié pour lui, mais restait l'unique solution envisageable car c'était le seul hôpital psychiatrique pour adultes capable de contrôler ses accès de furie et de le garder tranquille.[29]

Si David et son épouse en avaient su davantage sur l'autisme, ils auraient été mieux en mesure d'aider leur fils :

À l'époque, on en savait très peu sur l'autisme dans notre milieu, et il n'y avait aucune ressource à notre disposition. Notre fils ne souffrait pas de la forme la plus courante de l'autisme. Même s'il était né aujourd'hui, on n'aurait pas pu découvrir immédiatement qu'il était autiste, parce qu'il ne présentait pas les symptômes les plus courants de cette maladie : il pouvait parler; il ne semblait pas avoir d'anomalie physique sur le plan du langage.

Si nous avions su ce qu'il avait, nous n'aurions pas perdu autant de temps. Nous avons gâché une bonne partie de sa vie. Ma réponse est ambivalente à ce sujet. J'ai demandé à ma femme si, d'après elle, nous nous porterions mieux si nous avions su de quoi il s'agissait. Nous avons tous les deux convenu, à un moment donné, que nous n'aurions pas fait autant. Si nous avions su que notre fils était handicapé, nous ne l'aurions peut-être pas poussé autant, parce que c'est ce que nous avons

[29] David (9:9).

fait. Nous l'avons poussé au point de nuire à notre santé. Une bonne partie du stress qui s'est manifesté par sa violence physique était dans une large mesure causée par la pression que nous mettions sur lui. C'est ce qui a fait que nous vivions dans un climat très dangereux à la maison. Nous avions peur des incendies et d'autres incidents du genre. Nous l'avons poussé pas mal fort. C'est un côté de la médaille.

De l'autre côté, si nous avions su ce qu'il avait, nous n'aurions pas consacré autant de temps à la thérapie familiale et dépensé autant dans des médicaments convenant mieux à des personnes qui souffrent de trouble bipolaire. Nous aurions essayé de façon beaucoup plus intelligente de faire face au problème de notre fils. Nous aurions demandé des conseils sur la façon d'intervenir. C'est la communication qui a surtout fait problème.[30]

David nous a aussi parlé des craintes et de la colère ressenties par sa famille :

À bien des égards, l'autisme est pire que le cancer, parce que l'autiste a une longévité normale. Il doit vivre avec la maladie pendant toute sa vie, c'est-à-dire sept jours sur sept, 24 heures sur 24. Ma femme et moi serons responsables d'Adam jusqu'à notre mort. Nous passons des nuits blanches à nous demander ce qui va advenir de lui quand nous ne serons plus là. Nous n'avons pas beaucoup de ressources financières, ce qui veut dire que nous ne sommes pas en mesure de subvenir à tous ces besoins.[31]

Il nous a relaté la tension que cette maladie mentale avait provoqué chez toute sa famille, notamment chez les frères et sœurs d'Adam, sur le travail de sa femme et sur le sien, sur leurs finances et sur leur réseau d'amis :

Mon fils a une capacité de communication limitée, ce qui réduit son aptitude à converser et à travailler. Il n'a jamais travaillé de sa vie et son handicap nous a profondément marqué, son frère Andrew, ma femme et moi-même. C'était aussi un grand sujet de préoccupation pour mes parents et ceux de mon épouse, qui ne sont maintenant plus de ce monde.[32]

[…]

Nous avions l'habitude, avant que nos problèmes n'atteignent des proportions alarmantes, de recevoir des amis et des associés à la maison. Nous les invitions à dîner et répondions à leurs invitations. Or, le fait d'inviter des étrangers à la maison était difficile et pour Adam et pour

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30 David (9:23-24).
31 David (9:12).
32 David (9:6).

> *nous. Il ne voulait pas de ces visiteurs. Il lui est déjà arrivé d'aller à la cuisine pendant que ma femme préparait un repas et de tout jeter par terre. Il est très difficile, dans ces circonstances, de préparer un dîner. Aujourd'hui, nous recevons très peu. Nous n'invitons pas d'amis à la maison, et ils ne nous invitent pas non plus. La maison n'est pas nécessairement un havre de paix quand on vit avec une personne atteinte d'autisme […] On se sent seul, traumatisé.*[33]

David a aussi expliqué la façon dont la famille compose avec le manque de ressources pour les adultes autistiques :

> *Quand une personne est atteinte d'autisme, c'est la famille qui assume toutes les responsabilités, que ce soit sur le plan financier, émotionnel ou autre. Ma famille assume tout le fardeau de cette invalidité. Nous ne recevons aucune aide financière ou médicale. Parce que notre fils est un autiste de haut niveau, le gouvernement exige qu'il présente une demande d'aide, qu'il signe les formulaires et qu'il renouvelle sa demande, si besoin est.*
>
> *Adam ne le fait pas. Il touchait un revenu modeste, mais il devait présenter une nouvelle demande pour continuer de le recevoir. Comme il ne l'a pas fait, il ne reçoit plus rien. Il est incapable de remplir lui-même les formulaires. Toutefois, comme il est un autiste de haut niveau, il ne peut faire de nous ses tuteurs et nous demander d'agir en son nom. Par ailleurs, le seul temps que nous pouvons prendre des vacances, c'est quand le frère d'Adam est à la maison. Or, comme je l'ai déjà mentionné, il étudie à l'université, de sorte qu'il peu probable qu'il passe beaucoup de temps à l'avenir à la maison.*[34]

S'agissant des services et des moyens de soutien communautaire pour les adultes autistiques, voici ce que David nous a déclaré :

> *Les adultes atteints d'autisme n'ont accès à aucun service. Seuls des soins de relève sont offerts aux autistes de bas niveau. On entend par cela des services de garde, et les personnes qui les assurent touchent un salaire minimum. Aucune activité n'est prévue pour les autistes après l'école; il n'y a qu'un vide. À moins de bénéficier d'une aide importante, les perspectives d'emploi sont plutôt rares pour les autistes. La famille doit assumer tout le fardeau.*[35]

David a insisté sur la nécessité de reconnaître que la santé mentale est aussi importante que la santé physique et que la maladie mentale devrait être traitée avec le même sentiment

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33 David (9:11).
34 David (9:12).
35 David (9:13).

d'urgence que la maladie physique. Il croit que le gouvernement fédéral pourrait jouer un rôle déterminant à cet égard :

> *Il n'y a pas de différence entre une personne souffrant de maladie mentale et une autre souffrant de maladie physique. Reste à savoir si nous traitons les gens aux prises avec des problèmes de santé mentale avec le même empressement que nous traitons les personnes souffrant d'une maladie physique. Je doute que ce soit le cas. C'est le problème fondamental. Le gouvernement a le rôle d'appliquer une politique publique équitable pour lutter contre les problèmes de santé mentale. Comment pouvons-nous le faire? Comment pouvons-nous changer le milieu?*
>
> *Le fait est que les troubles de santé mentale ne déclenchent pas le même sentiment d'urgence, parce qu'il est clair que la personne qui en est atteinte sera là demain, alors que la personne souffrant de troubles cardiaques ou de cancer doit être traitée aujourd'hui, parce qu'elle pourrait ne plus être là demain. Cela jette une ombre au tableau. Nous devons faire quelque chose.*
>
> *Entre autres, et c'est là où votre comité peut jouer un rôle important, le gouvernement pourrait réserver les transferts de fonds pour le traitement des troubles mentaux en les mettant dans une enveloppe fiscale à part ne pouvant servir qu'au traitement des troubles mentaux. Cet argent ne pourrait être utilisé pour rien d'autre.*[36]

1.2 OBSERVATIONS DU COMITÉ

> *Il faut, comme l'a dit le président, donner une dimension humaine à la question. Je ne connais pas de meilleur moyen de le faire que de demander à des gens comme les quatre personnes qui sont venues ici de parler haut et fort, de dire des choses qui sont très difficiles à dire. C'est pourquoi j'estime que leur témoignage d'aujourd'hui est très courageux.*
>
> *Pour être honnête avec vous, je ne connais pas d'autre moyen de le faire. Les gens ne comprennent pas. Les politiciens ne comprennent pas. Ils n'ont aucune idée des difficultés que nous connaissons. Comment les leur faire comprendre? Ils arrivent à comprendre uniquement*

[36] David (9:37-38).

lorsqu'un proche ou de la parenté le vit. Il est très difficile de comprendre à moins d'être soi-même touché.
[David (9:34)]

Le Comité a beaucoup apprécié les témoignages sérieux et sincères de David, de Murray, de Loïse et de Ronald. Nous avons même le sentiment que les remercier simplement ne suffit pas. Nous comprenons à quel point il leur a été difficile de se présenter devant nous et de nous parler de la façon dont ils l'ont fait.

Ces quatre témoins ont illustré pour le Comité les stigmatisations, la frustration, la crainte et la colère qu'éprouvent les personnes souffrant de maladie mentale ou de toxicomanie ainsi que les membres de leurs parents. Ils nous ont parlé des répercussions de cette maladie sur leurs familles, sur les frères et les sœurs, sur leur vie sociale et sur leurs finances. En nous relatant ainsi des expériences touchantes, émouvantes, très importantes pour le travail du Comité, ces témoins ont levé le voile sur bien des problèmes comme l'accès aux soins, les défauts de communication ou de collaboration entre fournisseurs de soins de santé, le manque de ressources et les droits des patients de même que les questions de protection de la vie privée. Toutes ces questions sont traitées en profondeur dans les autres chapitres du présent rapport. Nous l'avons fait dans l'espoir que notre travail finira par apporter une aide à David, à Murray, à Loïse et à Ronald ainsi qu'aux milliers de personnes comme eux au pays.

CHAPITRE 2:
LES TROUBLES MENTAUX ONT UN EFFET SUR LA VIE DE TOUS LES CANADIENS

La maladie mentale peut toucher tout le monde – riche ou pauvre, homme ou femme – de n'importe quelle race ou croyance.
[J. Michael Grass (17 :43).]

INTRODUCTION

C'est parce qu'ils ont pris acte des effets profonds de la maladie mentale et de la toxicomanie sur notre société (qui touchent les Canadiens et les Canadiennes de tous âges et dans toutes les tranches de la population), que le Comité a notamment décidé d'entreprendre une étude approfondie des questions relatives à la santé mentale, à la maladie mentale et à la toxicomanie au Canada. La première étape de cette étude, qui constitue le fondement du présent rapport, n'a fait que conforter nos premières impressions.

Ce fléau touche tout le monde : un voisin souffrant d'Alzheimer, une sœur qui a vécu une dépression post-partum, un collègue en congé à cause du stress, un oncle aux prises avec un problème d'alcoolisme ou un ami qui parle de ses troubles de l'alimentation, de pensées suicidaires ou des mauvais traitements subis dans son enfance. On estime qu'un Canadien sur cinq sera, à un moment ou à un autre de sa vie, touché par la maladie mentale ou la toxicomanie. Il ne se passe pas un jour sans que nous *tous*, consciemment ou inconsciemment, ne nous trouvions dans une pièce, un autobus, une salle de restaurant ou ailleurs en présence d'une personne qui a ou a eu une maladie mentale ou un problème de toxicomanie

Le présent chapitre part des récits personnels du chapitre 1. Il décrit les effets de la maladie mentale et de la toxicomanie sur ceux et celles qui en sont atteints, sur leurs familles et sur les fournisseurs de soins, de même que sur la société en général. Dans les pages qui suivent, nous chercherons à mieux comprendre ce que représente le fait de vivre aux prises avec un problème de santé mentale ou au côté d'une personne se trouvant dans cette situation, et nous aborderons les autres facettes des répercussions de la maladie mentale et de la toxicomanie à l'extérieur du cercle familial, c'est-à-dire à l'école, au bureau et dans de nombreux autres lieux de rencontre pour les Canadiennes et les Canadiens.

Dans ce chapitre, il sera essentiellement question de perceptions individuelles. Nous lèverons brièvement le voile sur la vie au quotidien de nombreux Canadiens souffrant de maladie mentale ou de toxicomanie. Les extraits cités proviennent principalement de lettres et de courriels adressés au Comité, de témoignages publics, de même que de visites de certains établissements par les membres du Comité et de certains sites Internet. Le plus souvent, il est question de perte : perte d'emploi, perte de la famille, perte du respect pour soi et de la lutte à livrer pour obtenir les soins nécessaires. D'un autre côté, il y a aussi des récits plus positifs, ceux qui concernent des gains : découverte de soi et de la société, services médicaux

et juridiques et services de soutien grâce auxquels les personnes souffrant de maladie mentale ou de toxicomanie peuvent vivre une vie productive et contribuer à la société.

Les voix qui s'élèvent sont nombreuses et fragmentées. Ce sont celles des usagers des services et des personnes qui offrent ces services. Ce sont des voix de mères qui s'occupent de leurs enfants, de maris qui s'occupent de leurs épouses. Ce sont celles d'enseignants qui enseignent la sociabilité et d'autres aptitudes essentielles à leurs protégés, celles d'employeurs qui adaptent leur milieu de travail et de leaders communautaires qui oeuvrent à la revitalisation de leur voisinage. Ce sont les voix d'hommes et de femmes de partout au Canada.

2.1 PERSONNES ATTEINTES DE TROUBLES MENTAUX

2.1.1 Un état d'esprit

Plusieurs personnes souffrant de troubles mentaux se sont confiées à nous sur leur état d'esprit en insistant sur le fait que la société les étiquette toutes de « folles ». L'une d'elles conclut ici une longue lettre où elle parle de sa vie instable : « Je ne suis pas fou, comme beaucoup le pensent ».[37] Une autre se rappelle ce qui lui est d'abord venu à l'esprit quand, alors qu'elle était âgée de 16 ans, on a diagnostiqué chez elle une psychose : « Oh mon Dieu! Ce n'est pas possible que je fasse partie de tous ces fous qui n'ont pas de maison, pas de famille et pas de vie ».[38]

Même ceux et celles qui bénéficient de l'appui de leur famille et de leurs amis, qui résident dans des logements confortables, qui mangent régulièrement et qui portent des vêtements propres, qui peuvent se prévaloir des nouvelles thérapies et des meilleurs médicaments disponibles, parlent de leurs sentiments de honte et d'échec surtout en voyant les autres réaliser les objectifs qu'ils s'étaient eux-mêmes fixé. Ces gens-là redoutent la réapparition toujours possible de leurs symptômes. Ils savent qu'on les perçoit différemment des autres et ils se sentent même « différents ». Comme l'a bien précisé une femme : « c'est pire pour nous, parce que nous savons ce à côté de quoi nous passons ».[39]

Pat Capponi, auteure, journaliste, conférencière et animatrice sociale, qui se définit elle-même comme patiente psychiatrique chronique ayant un vécu psychiatrique, a déclaré au Comité :

> *Pour beaucoup, un patient psychiatrique reste un patient psychiatrique. Catégorisés comme tel, nous n'avons pas le droit d'être des êtres humains à part entière, ni d'avoir des personnalités de base, comme celles du reste de la population — bonnes, mauvaises, et tout ce qui existe entre les deux. Une personne schizophrène est une personne schizophrène, et*

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37 Lettre de John, non datée.

38 Lettre de Tara, 28 novembre 2003.

39 Mots rapportés par Pat Capponi, mémoire au Comité, avril 2004, p. 2.

> *chaque acte qu'elle pose est attribué à sa maladie et non à la nature sous-jacente de la personne ou de ses circonstances.*[40]

Beaucoup considèrent que la maladie mentale et la toxicomanie sont un déshonneur; il arrive souvent que les personnes touchées soient discréditées et malheureusement mises à part par la société. Il est malheureux de constater que cette stigmatisation – qu'il s'agisse d'auto-stigmatisation ou de stigmatisation publique – cause autant de détresse quotidienne chez les personnes atteintes de maladie mentale ou de toxicomanie.

2.1.2 Un cycle incessant

Les personnes souffrant de maladie mentale ou de toxicomanie nous ont rappelé à quel point il leur est difficile d'intégrer la société et d'y demeurer en y menant une vie productive à cause du cycle incessant des problèmes auxquels elles sont confrontées. Pat Capponi a indiqué au Comité que les médicaments sont souvent perçus comme la solution la plus simple à des questions par ailleurs complexes, mais qu'ils ne permettent pas vraiment de régler les problèmes sous-jacents réels et continus :

> *[…] l'argent a été de plus en plus alloué pour garder les patients sortants dans des camisoles de force chimiques, pour le confort et l'homogénéité de la communauté. Si un client est déprimé et en colère que sa vie soit aussi limitée, s'il a peur d'un propriétaire abusif, si la pauvreté le laisse dans la faim et la nervosité, on augmente sa dose de médicaments. Si ce qui lui reste de vie à l'intérieur exprime de la colère, les doses le lui feront oublier.*[41]

Elle a aussi indiqué au Comité qu'à cause de l'écart qui se creuse entre les nantis et les déshérités, ceux et celles qui souffrent de maladie mentale ou de toxicomanie sont confrontés à des difficultés particulières :

> *De plus en plus de gens ont recours aux services des banques alimentaires, ce qui veut dire que la part du malade mental chronique diminue. Un propriétaire va louer sa maison à des personnes qui, à son avis, seront plus tranquilles qu'un ancien patient atteint de troubles mentaux. Les gens sont de plus en plus laissés pour compte. Les refuges préfèrent ouvrir leurs portes aux immigrants et aux femmes battues au motif qu'ils posent moins de problèmes. Il y a toujours un stigmate associé aux troubles mentaux.*[42]

Là aussi, à cause de la stigmatisation rattachée à la maladie mentale et la toxicomanie, les personnes atteintes peuvent être privées du droit d'avoir un logement ou d'accéder à un refuge.

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40 Pat Capponi (7:49).
41 *Ibid.*
42 Pat Capponi (7:70).

2.1.3 Un problème de manque de coordination

Tous ceux et toutes celles qui sont concernés de près ou de loin par la santé mentale et la toxicomanie ont insisté sur le fait que les personnes souffrant de ces états doivent accéder à un continuum de services et de moyens de soutien (incluant un logement abordable et des services de soutien intensifs à court terme) tout de suite après leur sortie d'un hôpital, d'un refuge ou d'une prison. Ils nous ont, toutefois, également rappelé que la prestation de ces services et de ces moyens de soutien doit être mieux coordonnée dans tout le réseau de santé mentale et de toxicomanie, et qu'elle doit aussi être mieux intégrée avec les services offerts par le grand secteur des affaires sociales.

Ce défaut de coordination nous a été illustré par le cas d'un patient/client bénéficiaire de l'aide sociale qui, à ce titre, recevait une certaine somme pour louer un appartement et payer d'autres menues dépenses. Or, ce patient ayant fait une rechute, il a passé 15 jours dans une unité psychiatrique de soins intensifs ce qui lui a valu de perdre ses prestations d'aide sociale et donc son appartement. Ce faisant, le gouvernement a dû s'organiser pour qu'il passe plus de temps en milieu hospitalier en attendant qu'on lui trouve un logement ailleurs dans la collectivité.[43]

Un autre exemple montre qu'une intervention précoce suivie d'une action préventive coordonnée aurait pu changer l'issue des événements. C'est à l'âge de 25 ans qu'on a diagnostiqué chez un homme de Vancouver, qui avait passé sa vie entre les foyers d'accueil et les cellules de prison depuis l'âge de 13 ans, un trouble bipolaire lors d'une détention provisoire de trois mois pour une entrée par effraction qui devait lui fournir l'argent nécessaire pour acheter de la drogue. Il n'a pas été jugé et a été libéré sous condition, mais il n'a pas fallu longtemps avant qu'il se retrouve derrière les barreaux. On avait notamment fixé comme condition à sa remise en liberté qu'il continue de prendre trois médicaments : du Ritalin, un antidépresseur et de la méthadone. Or, ce cocktail lui « embrouillait les idées ». Comme il recevait 28 $ par semaine pour se nourrir et se loger, il avait trouvé une petite chambre dans le quartier est du centre-ville. Malheureusement, il n'avait pas assez d'argent pour emprunter les moyens de transport et ne bénéficiait d'aucun système de soutien sur place. Après avoir essayé d'entrer en communication avec son père, qui venait juste de sortir de la prison William's Head, sur l'île de Vancouver, il a enfreint les conditions de sa probation.[44]

Les Canadiens plus âgés sont aux prises avec de nombreux problèmes de santé mentale qui influent sur leur autonomie et sur la maîtrise de leur vie. Par exemple, pour ceux et celles qui souffrent de démence et pour bien d'autres, le fait de ne pas accéder à des moyens de transport peut être synonyme de perte de contact avec le monde extérieur, de perte d'indépendance et de perte de contrôle. Si les transports publics demeurent une option pour certains, pour d'autres ils sont tout simplement inaccessibles. La Société Alzheimer du Canada nous a relaté le cas de deux personnes souffrant de démence. C'est à l'âge de 57 ans qu'on a diagnostiqué cette maladie chez Trevor Jones, agent de police, tandis que Jesse Roy, dont la mère était morte d'Alzheimer, avait 70 ans, vivait encore chez elle et faisait du bénévolat pour aider les autres quand le verdict est tombé. Ces deux personnes se disaient

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43 Julio Arboleda-Florez, (11:69).

44 Télécopie de Margaret, 28 avril 2004.

particulièrement inquiètes de perdre leur autonomie à cause de leur incapacité à conduire. Trevor ne se faisait plus confiance pour prendre les transports publics et il devait s'en remettre à sa femme et à des amis pour se déplacer. Jesse, elle, craignait qu'en renonçant à la conduite automobile, elle devrait non seulement réduire ses activités mais aussi modifier ses habitudes de vie et se déménager dans un établissement de soins.[45]

Dans tous ces cas, peu ou rien n'est fait du côté des systèmes de soutien. Les services de soutien ne sont ni offerts ni intégrés en sorte de permettre aux personnes qui en ont besoin de bénéficier d'un continuum de soins.

2.1.4 Des services défaillants

Toutes les personnes souffrant de troubles mentaux ont parlé de l'importance d'avoir accès à des services adéquats et de la possibilité d'y accéder. Comme nous l'a décrit une jeune femme : « Je dois ma bonne santé et ma réussite dans la vie à un traitement révolutionnaire dans le cas des jeunes qui vivent leur première cassure par rapport à la réalité […] Je n'ai pas peur de dire que cette intervention précoce a sauvé ma vie ».[46]

Dans sa lettre, Tara précise que l'accès à des programmes de ce genre, qui sauvent la vie des gens, est limité parce qu'ils en sont surtout à l'étape de recherche dans les hôpitaux d'enseignement :

> *Même à Ottawa, notre Capitale nationale, le programme d'intervention aux premières épisodes psychotiques est nettement sous-financé et il faut attendre un an pour en bénéficier. Les personnes qui en sont à leur première épisode psychotique s'efforcent lamentablement d'obtenir un traitement. Beaucoup ont peur de demander de l'aide, d'autres en sont tout simplement incapables à cause des effets de la maladie. Les familles n'ont d'autres choix que de se débrouiller toutes seules et d'essayer de se sortir d'une situation impossible.*[47]

La nécessité de conduire une détection et une intervention précoces dans le domaine de la maladie mentale et de la toxicomanie est donc bien établie. Une intervention précoce peut permettre d'éviter que des troubles mentaux ne dégénèrent, de réduire l'incapacité à long terme et de contribuer à alléger le fardeau qui repose sur les familles et sur les autres aidants naturels.

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45 Société Alzheimer du Canada, mémoire présenté au Comité, 4 juin 2003.
46 Lettre de Tara, 28 novembre 2003.
47 *Ibid.*

2.2 CAS DE CEUX ET CELLES QUI S'OCCUPENT DE PERSONNES SOUFFRANT DE MALADIE MENTALE

2.2.1 Les craintes des parents

Les parents sont les premiers défenseurs des intérêts de leurs enfants quand ils entrent à un point quelconque du système de soins de santé. Face à la santé mentale, les parents prennent conscience qu'ils devront jouer ce rôle de défenseur et de fournisseur de soins pendant très longtemps. Ils deviendront un tampon permanent entre les malades et une société qui leur est trop souvent hostile. Quand ils ont de jeunes enfants, les parents doivent se débrouiller pour trouver des réseaux qui offrent les services et les moyens de soutien appropriés, à l'intérieur et à l'extérieur du secteur des soins de santé. Ils doivent se surmener pour leurs enfants jusqu'à ce qu'ils n'en soient plus capables à cause de l'âge ou de la maladie.

Selon certains témoins, le sort de leurs enfants, une fois qu'ils ne seront plus eux-mêmes en mesure de les défendre, est ce qui inquiète le plus les parents. Phil Upshall, président de la Société pour les troubles de l'humeur du Canada et directeur national de l'Alliance canadienne pour la maladie mentale et la santé mentale, nous a relaté l'histoire de deux amis de sa famille : « Ma famille avait deux amis ayant des proches atteints de maladies mentales graves, que l'on ne pouvait absolument pas traiter, et qui résidaient avec eux. La grande peur de ces familles c'était ce qui pourrait advenir de leur fils ou de leur fille après leur départ.[48] »

Dans une lettre qu'elle a adressée au Comité, une femme de 76 ans parle des nombreuses craintes qu'elle entretient au sujet de son fils interné pour des traitements psychiatriques. Elle doute de l'efficacité du traitement et craint les effets secondaires qu'elle a déjà observés chez son fils. Elle aurait voulu que l'on fasse enquête sur les conditions de vie et autres dans cet établissement, mais elle n'avait pas les ressources nécessaires à partir de sa maigre pension mensuelle pour assumer les frais juridiques nécessaires. Elle nous écrit : « Je ne veux pas mourir tant que mon fils est un patient prisonnier dans ces lieux […] Parce que j'ai vu ce qu'ils font aux patients qui n'ont pas de parenté.[49] »

Une autre mère nous a écrit au sujet de son fils adulte autistique qui a des problèmes pour dormir la nuit et qui a besoin d'elle en permanence; elle doit le border et le rassurer pour qu'il se rendorme.

> *Je m'inquiète de ce qu'il adviendra de Stephen dans l'immédiat et à plus long terme. Aura-t-on un jour accès à un programme pour lui? Et si je tombais malade? Si mon cancer revenait? Que lui arrivera-t-il au bout du compte? Qui s'occupera de lui comme je le fais quand je ne serai simplement plus là pour m'en occuper?*[50]

Les familles sont souvent la principale ressource et le seul soutien sur lesquels peuvent compter les personnes atteintes de maladie mentale ou de toxicomanie. À cause des ressources limitées dont dispose le secteur hospitalier et le secteur communautaire, ce sont

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48 Phil Upshall (9:30).

49 Lettre d'Amy, 3 octobre 2003.

50 Lettre d'une rédactrice anonyme, février 2003.

les parents qui doivent loger, s'occuper, encadrer et aide financièrement les enfants touchés. Comme nous venons de le voir, ceux qui nous ont relaté leur expérience montrent bien que tout cela peut être source d'énormes tensions et de stress émotionnel.

2.2.2 Les parents défenseurs

Les parents sont très soucieux du bien-être de leurs enfants quand ils intègrent le système de soins de santé pour faire traiter leur maladie mentale. Les profanes qu'ils sont estiment ne pas posséder les connaissances ni les ressources nécessaires pour faire face aux nombreux défis qui les attendent. Ils craignent ne pas apporter le niveau de soins nécessaire et que les soins disponibles ne soient pas dispensés avec toute la sensibilité dont leur progéniture a besoin. Ils s'inquiètent du coût des soins spécialisés et des conseils juridiques qu'ils devront obtenir en plus. De nombreux parents et patients ont tenu à nous rappeler que ceux et celles qui souffrent de troubles mentaux doivent pouvoir compter sur des défenseurs dévoués qui les aident à obtenir un logement approprié, des services de soutien ainsi que des traitements et des soins.

Dans sa lettre, une mère nous a relaté le parcours du combattant auquel elle a dû se livrer dans le système actuel : elle voulait avoir la garantie que les membres de la famille auraient un « premier droit de refus » en tant que partie prenante à la décision pour obtenir des renseignements sur le diagnostic et le traitement de leur cher patient, afin d'envisager les options possibles dans le cadre des soins offerts.[51]

Certains témoins ont souligné la nécessité d'offrir des soins constants aux enfants autistiques et à ceux atteints du syndrome d'alcoolisation fœtale ou souffrant des effets de l'alcool sur le fœtus (SAF/EAF). Ils ont insisté sur le fait que de nombreux parents et aidants naturels non seulement subissent une mise à l'écart sociale et un isolement émotionnel par rapport à leurs familles, leurs amis et la société, mais qu'ils doivent aussi assumer des fardeaux financiers très lourds dans leur tentative visant à obtenir de l'aide. S'agissant de SAF/EAF, Pam Massad devait préciser :

> *Dans leurs tentatives pour avoir accès aux services de soutien nécessaires à leurs enfants, les familles sont nombreuses à faire face à des charges financières très lourdes. En effet, beaucoup de provinces et de territoires n'offrent pas d'aide financière pour ceux qui veulent avoir des services de santé spécialisés, de l'encadrement pédagogique et du soutien juridique.*[52]

Le père d'un enfant de trois ans, Steven, pour qui l'on avait posé un diagnostic d'autisme à l'Hôpital pour enfants de l'est de l'Ontario (HEEO) le 8 décembre 2003, nous a écrit au sujet des délais et des coûts qu'il a dû subir afin d'obtenir les traitements appropriés. « Cela fait déjà 261 jours que nous patientons sur une liste d'attente. Jusqu'ici, nous n'avons pas reçu un seul sou en aide financière ni aucun traitement médical nécessaire ».[53] Dans le reste du courriel, ce père nous précise que la famille n'a d'autres choix que de recourir à des soins privés et qu'elle doit maintenant assumer de sa poche des coûts d'environ 50 000 $ par an.

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51 Lettre d'Irene, 7 avril 2003.

52 Pam Massad (13:7).

53 Courriel d'Andrew, 25 août 2004.

2.2.3 Les parents qui survivent à leurs enfants

Les parents peuvent voir partir leurs enfants en détresse. Ceux et celles qui ont connu le suicide dans leur entourage parlent de leurs besoins désespérés d'obtenir de l'aide pour mettre un terme à la « peine inutile et indescriptible » ressentie par ceux qui voient leur vie dévastée par la perte d'un être cher. Diane Yackel, du Centre de prévention du suicide, nous a précisé que, tous les jours au Canada, « plus de 10 familles de notre grand pays ont vu leur vie irréversiblement changée parce qu'un père, un fils, une sœur ou un proche a décidé, intentionnellement jusqu'à un certain point, de se suicider ».[54]

Elle nous a relaté les événements tragiques qu'ont traversé quatre mères :

- Le premier récit concernait une femme dont les deux époux s'étaient suicidés. « Elle est venue me consulter après que son fils, son unique enfant, se soit pendu. Plusieurs semaines après la mort de son fils, elle a été remerciée de ses services par son employeur parce qu'elle 'n'était plus un employé productif' ».
- Il y a aussi eu cette mère qui a perdu ses moyens. « Elle s'était figée dans le temps. Elle était incapable de dormir où que ce soit, sauf sur le sofa près de la porte d'entrée de la maison. C'était le sofa sur lequel elle avait vu pour la dernière fois son fils et duquel elle avait entendu le coup de feu. Il y avait peut-être une chance, une toute petite chance, si elle demeurait là suffisamment longtemps, pour qu'il franchisse à nouveau la porte et qu'elle ait une autre chance de l'empêcher d'aller dans sa chambre et de se tuer. »
- Il y a également eu cette mère autochtone dont la fille de 19 ans s'était couchée sur la voie ferrée quand le mal de vivre lui était devenu trop lourd à porter.
- Et puis, cette autre mère, elle-même veuve, qui a découvert le corps de sa fille de 14 ans pendu dans la maison et qui a dû couper la corde.[55]

Il est impossible d'appréhender pleinement et de faire passer l'angoisse profonde qui étreint ceux qui restent après un suicide. Ces personnes ont essentiellement indiqué au Comité qu'il fallait adopter une stratégie complète en matière de prévention du suicide incluant la détection précoce des comportements suicidaires et la gestion de crise.

2.3 CEUX ET CELLES QUI OFFRENT DES SERVICES DE SANTÉ MENTALE ET DE TOXICOMANIE

2.3.1 L'accès aux fournisseurs de soins

En santé mentale, la plupart des nombreux acteurs qui ouvrent la porte du « système » sont les professionnels de la santé qui dispensent des traitements, mais d'autres, comme les enseignants et les travailleurs sociaux, favorisent aussi l'accès aux services et aux moyens de soutien qui s'imposent. Au Canada, l'accès à ces services et moyens de soutien est inégal

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54 Diane Yackel (6:47).
55 Diane Yackel (6:46).

d'une région à l'autre. Les pénuries d'effectif sont perceptibles partout, mais elles sont critiques dans certaines parties du pays.

Un mémoire soumis au Comité décrit les difficultés auxquelles sont confrontées les personnes souffrant de maladie mentale ou de toxicomanie à cause d'un accès limité aux fournisseurs de soins :

> *Au Yukon, par exemple, on ne trouve actuellement aucun psychiatre résident. Résultat : les gens sont contraints de courir de grandes distances pour recevoir les services nécessaires – difficulté (ironiquement baptisée de « thérapie navette ») qui est doublement stressante pour celui ou celle qui est aux prises avec un problème de santé mentale.*[56]

Les fournisseurs, quant à eux, ont indiqué au Comité qu'ils sont souvent en mesure d'attribuer ne serait-ce qu'une partie des problèmes auxquels se heurtent les personnes souffrant de maladie mentale ou de toxicomanie à leur état physique ou à leur situation socioéconomique. Une psychiatre, qui fait des visites à domicile, nous a parlé de la vie de certains de ses patients :

> *Nombreux sont mes patients qui ne disposent de moyens de transport et notre collectivité rurale est très étendue. Un grand nombre d'entre eux vivent, en famille nombreuse, dans des logements inadéquats. Le sol de certains logements est encore en terre battue, il n'y a pas de plomberie, ni de chauffage pour l'hiver à part un poêle à bois.*[57]

Elle nous a également raconté qu'il lui avait fallu six mois pour établir une relation avec un vieil homme atteint de schizophrénie paranoïaque et avec qui elle ne s'était jusque là entretenue que derrière sa porte entrebâillée. Un jour enfin, il s'est senti suffisamment à l'aise pour l'inviter à l'intérieur.[58]

Ces récits nous montrent qu'il est nécessaire de relever les défis posés par la santé mentale dans les collectivités rurales et éloignées qui sont dépourvues de service.

2.3.2 Les enseignants et les autres fournisseurs de services en milieu scolaire

Le rôle des enseignants, des écoles et des autres en matière de détection précoce des troubles mentaux a fait l'objet d'une attention considérable lors des audiences du Comité. De nombreux témoins ont insisté sur le rôle important que jouent les écoles pour détecter assez tôt les problèmes de santé mentale et les maladies mentales avant que les troubles n'aient d'effets dommageables sur toute une vie. Plusieurs témoins ont établi des liens entre les problèmes constatés en lecture et en écriture et la détresse psychologique ou les troubles mentaux. Comme Tom Lips, de Santé Canada, l'a indiqué au sujet de l'alphabétisation, « il est possible que certains facteurs liés à la santé mentale contribuent à favoriser

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56 Association canadienne pour la santé mentale, mémoire au Comité, juin 2003.

57 Dr Cornelia Wieman (9:53).

58 *Ibid.*

l'analphabétisme. De plus, le fait d'être analphabète a forcément des incidences sur la santé mentale ».[59]

D'un autre côté, les témoins ont reconnu que, même si l'école demeure le lieu où les enfants passent le plus clair de leur temps et acquièrent leur aptitude sociale fonctionnelle, il ressort que les ressources disponibles étant particulièrement sollicitées, il est actuellement difficile d'assurer des interventions adaptées. Les enseignants ont des classes plus importantes que jadis. Ce faisant, il leur est extrêmement difficile de repérer et de confronter les élèves qui présentent davantage de problèmes complexes. Les services dispensés par le personnel infirmier, les psychologues et les travailleurs sociaux en milieu scolaire ont été considérablement réduits. Il arrive que les approches thérapeutiques soient tellement fragmentées qu'elles prennent fin en plein milieu de l'année scolaire.

Les enfants souffrant de troubles déficitaires de l'attention (TDA), d'hyperactivité avec déficit de l'attention (HDA) et de troubles de l'apprentissage sont impulsifs, ont de la difficulté à se concentrer et à gérer leur comportement. Ils peuvent aussi avoir de la difficulté à lire, à distinguer les sons et à comprendre l'enseignant.

Le Comité a appris qu'à Toronto la liste d'attente pour un simple diagnostic dans le système public est de 18 mois – soit près de deux années scolaires. L'accès au secteur privé est possible en moins d'une semaine ou deux pour ceux qui peuvent débourser 2 000 $ pour les services d'un psychologue (la plupart des régimes d'assurance des employeurs ne remboursant en moyenne que 300 $ pour les soins psychologiques).[60]

Diane Sacks, présidente désignée de la Société canadienne de pédiatrie, nous a signalé qu'un grand nombre d'enfants atteints de TDA ou de HDA ainsi que de troubles d'apprentissage masquent leur problème jusqu'au premier cycle du secondaire et qu'ils :

> *… commencent alors à accumuler les échecs, justement à un moment où beaucoup d'entre eux ont aussi l'impression que leur corps les trahit. Ils ne sont pas assez forts, pas assez minces et certainement pas assez grands. Les pressions sont énormes. Les faibles aptitudes sociales associées à ce problème entraînent des rejets et des conflits avec les pairs. Comment un adolescent «idiot», qui a de mauvaises notes et des aptitudes sociales déficientes — puisque c'est à cela que ressemblent les jeunes chez qui le THADA n'est pas traité —, peut-il se constituer un groupe de pairs, ce qui, comme nous l'avons déjà dit, est une des tâches essentielles de l'adolescence? Il en est incapable. Cela crée des problèmes d'estime de soi, qui sont directement liés aux problèmes de comportement et d'intimidation et aux démêlés avec la loi.*[61]

Le fait que l'apparition de la plupart des troubles de santé mentale chez les adultes surviennent dans l'enfance nous rappelle, une fois de plus, qu'il conviendrait de consacrer davantage de ressources à la détection et à l'intervention précoces. Il faut reconnaître le rôle

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59 Tom Lips, Santé Canada (11:25).
60 Diane Sacks (13:53).
61 Diane Sacks (13:51).

prépondérant que les écoles sont appelées à jouer dans la prestation des services et des moyens de soutien en santé mentale.

2.3.3 Les fournisseurs de soins primaires

Le Comité a été frappé par le nombre de témoins venus parler de l'importance et de la gamme des services nécessaires. Certains ont souligné la nécessité d'offrir plus de formation aux médecins de santé primaire dans le diagnostic des troubles mentaux et le déclenchement d'interventions précoces. D'autres nous ont entretenus du rôle des infirmières et infirmiers, des travailleurs sociaux et des psychologues. Beaucoup ont insisté sur la nécessité de combiner soins physiques et soins mentaux dans le cadre d'un continuum de soins, en rappelant que, trop souvent, nous traitons l'esprit et le corps à part, un peu comme s'il s'agissait de deux entités distinctes.

Les représentants de la Société canadienne de psychologie nous ont relaté les problèmes psychologiques particuliers auxquels sont confrontées différentes personnes à différentes étapes :

- Un adolescent de 12 ans, diabétique, doit s'adapter à un schéma posologique particulier assorti d'injections, de prélèvements sanguins quotidiens et d'ajustements sur le plan alimentaire.
- Les membres de la famille d'un homme d'âge moyen doivent modifier leur comportement et leurs relations parce qu'il a eu une crise cardiaque qui a failli lui être fatale.
- Une famille s'occupe à domicile d'un parent atteint de démence;
- Une mère fait face à sa fin prochaine à cause d'un lymphome non hodgkinien et va laisser derrière elle deux jeunes enfants.[62]

À cet égard, la Dre Cornelia Wieman, psychiatre auprès des Six Nations Mental Health Services (Ohsweken, Ontario), a exprimé certaines réserves face à l'adoption d'une approche biologique étroite dans le cas des maladies mentales. Pour elle, le simple fait de prescrire un antidépresseur à un patient risque, par exemple, d'avoir des conséquences non désirables :

> *[…] le fils de l'une de mes patientes s'est suicidé l'année dernière alors qu'il était en garde à vue. La même année, on a découvert qu'elle avait un cancer du rein, on l'a opérée pour lui retirer le rein. Sa plus jeune fille, âgée de 14 ans a réagi au suicide de son frère en adoptant un comportement à risque très élevé, notamment l'abus d'alcool ou d'autres drogues, des relations sexuelles non protégées et des fugues de plusieurs jours. Cette femme est en congé de maladie, elle est donc en très mauvaise situation financière. En outre, elle héberge beaucoup de membres de sa famille. C'est une veuve qui bénéficie de très peu d'aides sociales.*

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62 Sam Mikail et John Service, *Présentation à la Commission sur l'avenir des soins de santé au Canada*, Société canadienne de psychologie, avril 2002.

> *Il serait irréaliste, à mon sens, de ne prescrire à cette patiente qu'un antidépresseur et de l'assurer qu'elle se rétablira avec le temps. Cependant, en lui prescrivant un antidépresseur, mais aussi en lui offrant d'autres aides psychosociales, notamment du counselling, et après lui avoir donné un traitement assez intensif pendant un an dans notre clinique, elle s'est finalement rétablie et reprend un emploi à plein temps ce mois-ci.*[63]

Elle nous a aussi signalé qu'en sa qualité de médecin payée à l'acte, elle n'est rémunérée que pour les consultations en personne et non pour le temps passé à discuter avec d'autres fournisseurs de services sur les cas de clients communs.

D'après les échanges que les membres du Comité ont eus avec ces témoins, tout semble indiquer que nous devons repenser la façon dont nous traitons la maladie mentale par rapport à la maladie physique. Nous devons parvenir à un certain équilibre entre une approche biomédicale étroite et l'intervention psychologique. Il faut adopter des mesures incitatives appropriées pour que les fournisseurs de soins consacrent le temps nécessaire à répondre aux besoins spécifiques et généralement chronophages des personnes souffrant de maladie mentale ou de toxicomanie.

2.3.4 La détresse des fournisseurs de soins

Les professionnels de la santé mentale sont, eux aussi, aux prises avec certaines anxiétés. Ils ne sont pas toujours en mesure de répondre aussi bien qu'ils le souhaiteraient aux besoins de leurs patients et de leurs familles. Il arrive que cette situation soit le résultat de ressources insuffisantes, mais parfois, les professionnels sont conscients qu'en posant un diagnostic de maladie mentale ils seront peut-être obligés de traiter le patient et sa famille d'une autre façon que s'il s'était agi d'une maladie physique.

Une pédiatre nous a parlé des gains réalisés dans les méthodes d'établissement de diagnostic pour un grand nombre de maladies d'enfance et de l'écart, sur le plan de la recherche, constaté dans les méthodes de prévention et de traitement. Elle nous a fait remarquer que la recherche pour des services appropriés peut revêtir une importance vitale quand :

> *[…] les services qui dispensent les traitements souffrent d'un grave sous-financement et que les familles doivent rechercher désespérément les quelques rares places disponibles. À cause de la fragmentation des services, les familles et leurs fournisseurs de soins primaires doivent envisager de nouvelles options presque année après année.*[64]

D'autres fournisseurs nous ont rappelé que certaines attitudes et méthodes de traitement que l'on rencontrait il n'y a pas si longtemps chez des professionnels et qui sont maintenant jugées répréhensibles. Voici ce que le Dr Michel Maziade, chef du département de psychiatrie à la faculté de médecine de l'Université de Laval (Québec), nous a déclaré à cet égard :

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63 Dre Cornelia Wieman (9:54).

64 Dre Diane Sacks, présidente désignée, Société canadienne de pédiatrie, mémoire au Cabinet, mai 2003, p. 1.

Dans les années 50 et jusqu'à la fin des années 60, on utilisait beaucoup la psychoanalyse et tout dépendait du milieu. C'était comme si le cerveau n'existait pas du tout. Si vous regardez les documents publiés à l'époque, tous ces désordres — la schizophrénie, l'autisme, la psychose maniaco-dépressive — étaient la faute de la mère. C'était toujours parce que la mère n'avait pas l'éducation voulue.

[…]

À l'époque, on accusait les gens. Je suis psychiatre spécialisé dans l'enfance et l'adolescence et je l'ai fait moi- même comme résident au début des années 70. Je transmettais le diagnostic de cette maladie terrible aux parents et au lieu de les soutenir, comme je l'aurais fait si l'enfant avait eu une maladie cardiaque, je les accusais parce que je leur recommandais de faire de la psychothérapie pour aider leur enfant, parce qu'il manquait quelque chose dans leur relation avec cet enfant. C'était terrible.[65]

2.4 SANTÉ MENTALE, MALADIE MENTALE ET TOXICOMANIE AU TRAVAIL

2.4.1 Les secrets du milieu de travail

Dans certains milieux de travail, les personnes souffrant de maladie mentale ou de toxicomanie peuvent avoir accès à une certaine forme d'assistance pour faire face à leurs problèmes, mais même quand tel est le cas et que de tels services sont offerts, il leur arrive trop souvent de devoir taire cette lutte personnelle. Trop souvent, la crainte de perdre son emploi ou d'être stigmatisé par les collègues suffit à empêcher celui ou celle qui souffre d'un trouble mental de réclamer un traitement. Des témoins ont indiqué au Comité qu'il est courant que des employés se blâment eux-mêmes et gardent le silence quand ils sont déprimés ou incapables de satisfaire aux attentes de leurs employeurs à cause d'un problème de santé mentale ou d'abus de substances.

Les gens ont tendance à garder pour eux-mêmes des problèmes qui leur sont personnels, au risque parfois que leur carrière et leur bien-être en pâtissent. Le Comité a eu vent de plusieurs cas de ce type :

> Michael Koo, 34 ans, dit s'être senti dévasté quand ses collègues de travail se sont plaint, dans une évaluation de rendement, qu'il ne faisait pas sa part. Or, Michael Koo ne se sentait pas à l'aise d'expliquer que sa faible productivité était due à une dépression majeure. « Je me suis dit que je ne pouvais pas révéler ce qui m'arrivait, parce que j'aurais perdu mon travail », ajoutant qu'il était honteux de prendre des congés pour stress.

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65 Dr Michel Maziade (14:32).

> Jane, biologiste de 30 ans, dit n'avoir jamais parlé de sa dépression clinique avec son employeur parce qu'elle avait peur de perdre son respect. « Les gens au travail veulent avoir affaire à des collègues fiables et cohérents », ajoute-t-elle. « Le fait d'être perçue comme vulnérabilisée par la dépression limite la foi que les gens peuvent placer en vous ». Bien qu'elle ait caché sa dépression, Jane affirme avoir perdu toute sa crédibilité au travail quand son rendement a commencé à en souffrir : « Je ne respectais pas mes engagements et j'étais incapable de justifier mon inaptitude à produire en fonction des attentes de l'employeur. »[66]

Tous ces récits soulignent la nécessité de mieux sensibiliser le milieu de travail aux réalités de la maladie mentale et de la toxicomanie. Nous aurons franchi une étape importante dans ce sens une fois que les cadres en milieu de travail connaîtront mieux la maladie mentale et la toxicomanie, car ils seront ainsi davantage en mesure de proposer des aménagements pour les travailleurs et les travailleuses qui souffrent de maladie mentale ou de toxicomanie.

2.4.2 Les réussites dans le milieu de travail

Les personnes atteintes de maladie mentale ont dû se battre pour se faire une place au sein de la population active. La réadaptation professionnelle existe certes depuis des décennies, mais l'apparition d'entreprises composées de personnes ayant un vécu psychologique est relativement récente. Pat Capponi nous a décrit la lutte à laquelle elle a dû se livrer à l'Ontario Council of Alternative Businesses pour trouver des débouchés d'emploi à des patients psychiatriques chroniques dans des collectivités où les contribuables, les entreprises et les politiciens locaux étaient hostiles :

> *Notre communauté a commencé à se rendre compte qu'il y avait des possibilités pour nous. Petit à petit, nous nous sommes dotés de modèles et de chefs. Nous réussissions, nous détruisions les mythes et les idées préconçues sur ce que nous étions et nous formions une communauté. Les patients psychiatriques chroniques s'engageaient à arriver à l'heure au travail. En acquérant de nouvelles compétences, nous arrivions à créer des relations amicales durables et saisissions toutes les occasions d'apprendre des expériences des autres.*[67]

Le travail contribue énormément au rétablissement des patients. Le fait d'avoir un emploi peut permettre de réduire la fréquence et la gravité des épisodes de maladie aiguë parce qu'il offre une structure, la possibilité d'établir des liens sociaux et d'avoir une vie remplie. Pour des personnes souffrant de maladie mentale, le fait de percevoir un chèque de paie régulier permet aussi de réduire la dépendance de l'aide sociale et la nécessité de recourir à des services de santé et à des moyens de soutien spécialisés.

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66 Selon les renseignements recueillis sur le site http://www.heretohelp.bc.ca/.

67 Pat Capponi (7:48).

2.5 PERSONNE SOUFFRANT DE MALADIE MENTALE QUI RELÈVE DE LA RESPONSABILITÉ FÉDÉRALE

2.5.1 Les anciens combattants

La question des anciens combattants a amené le Comité à se déplacer à l'Hôpital de Ste-Anne-de-Bellevue, à Québec, seul établissement spécialisé encore administré par le ministère des Anciens combattants. À l'instar de nombreux Canadiens âgés, les anciens combattants préfèrent demeurer chez eux le plus longtemps possible avant d'être admis dans des établissements de soins de longue durée. Malheureusement, ils peuvent être en sérieuse perte d'autonomie au moment où ils sont admis dans ces institutions. À Ste-Anne, 50 à 80 p. 100 des résidents souffrent de démence à des degrés divers. La solitude et l'ennui ressentis par de nombreux patients dans ce genre d'établissement ne font qu'exacerber ces troubles mentaux.

Bernard Groulx, chef psychiatre à Ste-Anne, nous a parlé de certains des problèmes particuliers dans le cas des patients souffrant de démence.

> *Ces patients sont aux prises avec de graves problèmes. Ils se lèvent la nuit, sont désorientés dans le temps, dans l'espace et dans leurs relations avec les autres; ils sont incontinents, ils sont émotionnellement instables, ils sont hyperactifs, souvent agressifs, délirent ou hallucinent et affichent toute une variété de comportements agités.*[68]

La démarche des infirmières et infirmiers spécialisés est essentielle pour garantir une qualité de la vie raisonnable à ces patients. Le personnel infirmier de l'hôpital doit apporter son soutien aux familles tout autant qu'aux résidents. Une infirmière de l'Hôpital Ste-Anne nous a déclaré : « Je travaille beaucoup avec les familles, surtout dans les cas où un membre est atteint de la maladie d'Alzheimer. Je dois communiquer avec elles, les rendre plus à l'aise et les aider à mieux comprendre la maladie […] Je les soutiens dans toutes les épreuves qu'elles doivent traverser, dans les périodes difficiles ».[69]

2.5.2 Les détenus

Les détenus des pénitenciers fédéraux relèvent de la responsabilité d'Ottawa. Les tendances récentes indiquent que la proportion de délinquants fédéraux souffrant de troubles mentaux ou d'abus de substances est en augmentation, bien que les admissions en prison et les effectifs de détenus soient en déclin. Une partie de cette population, comme les femmes et les Autochtones, ont des besoins particuliers.

Le Service correctionnel du Canada a pris acte de la nécessité de dispenser des traitements en santé mentale :

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68 Bernard Groulx, mémoire sur les soins psychiatriques à l'Hôpital pour anciens combattants de Ste. Anne, remis au Comité le 7 mai 2003.

69 Sarah Tyrrell, *Les infirmières : Toujours la pour vous – la famille et les soins*, Anciens combattants Canada, 2002.

> *Les soins de santé mentale pour les délinquants servent à réduire les effets invalidants des maladies mentales graves afin d'optimiser la capacité de chaque détenu de participer de plein gré aux programmes correctionnels; à contribuer au maintien d'un milieu carcéral sûr pour le personnel, les détenus, les bénévoles et les visiteurs; et à atténuer les extrêmes inutiles de la souffrance humaine causée par la maladie mentale.*[70]

Les responsables du ministère nous ont aussi parlé de la nécessité de composer avec des délinquants qui exigent une intervention spécialisée en santé mentale afin de réduire le phénomène de va-et-vient des patients :

> *Il existe ce que l'on appelle une porte tournante entre les services correctionnels, à la fois fédéraux et provinciaux, mais également dans les communautés, où les gens atteints de troubles de santé mentale se retrouvent dans le système de justice criminelle. Alors que les délinquants ayant des troubles mentaux sont moins susceptibles de récidiver — notamment de manière violente —, ils sont plus susceptibles de retourner en prison à cause d'une violation de leur liberté conditionnelle, qui est souvent le résultat d'un soutien inadéquat lorsqu'ils réintègrent la société.*[71]

Tout cela nous indique qu'il faut instaurer de meilleurs liens entre le gouvernement fédéral et les gouvernements provinciaux et entre l'appareil de justice et les systèmes de services/moyens de soutien en santé mentale. Le Service correctionnel du Canada doit faire davantage pour enrayer ce phénomène de va-et-vient.

2.5.3 Les Premières nations et les Inuits

L'inadéquation de l'accès aux services de counselling individuel pour les patients des Premières nations et les patients inuits en vertu du Programme des services de santé non assurés (SSNA) de Santé Canada, a soulevé un certain nombre de questions. Le Programme SSNA s'adresse aux clients « en crise » et à ceux qui ne peuvent bénéficier des services de counselling offerts dans les cliniques externes financés par la province ou qui ne peuvent payer pour des services privés. Malheureusement, à cause de revenus limités et de problèmes de transport et d'accès, nombre de patients passent au travers des mailles du filet.

Selon la D^re^ Cornelia Wieman :

> *Mes patients ont maintenant accès au counselling individuel grâce au Programme des services de santé non assurés (SSNA). […] Toutefois […] la limite est fixée à 15 séances avec une possibilité d'un renouvellement de 12 autres séances. Un total de 27 séances ne suffit pas*

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70 Françoise Bouchard, directrice générale, Services de santé, Service correctionnel du Canada (7:53).

71 Françoise Bouchard (7:54).

à bien aider un grand nombre de patients à surmonter leurs problèmes de santé mentale.[72]

De toute évidence, il va falloir réviser le Programme SSNA afin qu'il réponde mieux aux besoins des Premières nations et des Inuits dans le domaine de la santé mentale.

2.6 OBSERVATIONS DU COMITÉ

Même s'ils n'ont fait que porter un regard très général sur la vie des personnes souffrant de maladie mentale ou de toxicomanie, les membres du Comité sont bien conscients que les extraits de témoignages ci-dessus ne font qu'aborder ce qui est un vaste problème. Il est impossible de dresser l'inventaire complet des nombreux groupes de Canadiennes et de Canadiens souffrant de maladie mentale ou de toxicomanie et de présenter un fragment de ce qu'ils vivent.

Dans le restant de ce rapport, le Comité présente des extraits des témoignages recueillis au cours des 18 derniers mois. Il s'agit-là de la première étape en vue d'appréhender les énormes défis qui nous attendent dans la formulation d'un ensemble de recommandations destinées à améliorer la qualité de vie de celles et de ceux qui souffrent de maladie mentale ou de toxicomanie ou qui en ressentent les effets directs ou indirects… Et nous sommes tous du nombre.

72 Dre Cornelia Wieman (9:55).

CHAPITRE 3:
STIGMATISATION ET DISCRIMINATION

3.1 INTRODUCTION

Durant ses audiences, le Comité a recueilli de nombreux témoignages indiquant qu'il est extrêmement important de s'attaquer directement au problème de la stigmatisation et de la discrimination que rencontrent les personnes souffrant d'un trouble mental. Les participants ont longuement discuté des meilleures méthodes envisageables pour réduire la stigmatisation et combattre la discrimination, ainsi que des mesures à prendre pour mieux comprendre la relation entre ces deux phénomènes.

Un très large accord est apparu sur l'importance primordiale de ces deux questions pour améliorer l'accès aux services de santé mentale et la prestation de ces services, et pour rehausser, de manière plus générale, la santé mentale des Canadiens. Mme Heather Stuart**,** professeure associée en santé communautaire et épidémiologie à l'Université Queen's, l'a fort bien exprimé devant le Comité :

> *Nous nous trouvons actuellement dans un modèle communautaire de santé mentale et donc la stigmatisation et la discrimination sont pour nous le nœud du problème. Ce sont nos principaux obstacles au traitement de la santé mentale à notre époque moderne. Lorsque nous relâchons les gens dans notre collectivité, nous espérons que la collectivité les acceptera et prendra soin d'eux. Ce n'est pas le cas.*[73]

Dans la première partie de ce chapitre, nous examinerons comment définir les deux phénomènes que sont la stigmatisation et la discrimination, comment ils sont reliés et quels sont les facteurs qui contribuent à leur persistance. Dans la deuxième partie, nous analyserons l'incidence de la stigmatisation et de la discrimination sur les personnes souffrant de trouble mental, afin de mieux comprendre pourquoi de nombreux témoins en arrivent à dire que leur fardeau est plus lourd que celui de la maladie elle-même. Dans la troisième partie, nous examinerons les solutions et stratégies recommandées pour lutter contre la stigmatisation des personnes souffrant de trouble mental et pour réduire la discrimination dont elles font l'objet. La dernière partie du chapitre sera consacrée aux observations du Comité.

3.2 STIGMATISATION : DÉFINITION ET LIEN AVEC LA DISCRIMINATION

Toute analyse de la stigmatisation et de la discrimination oblige à poser deux questions :

1. Quelle relation y a-t-il entre la stigmatisation dont souffrent les personnes atteintes de trouble mental et la discrimination dont elles sont l'objet?

[73] Deuxième session, 15:10.

2. Pourquoi est-il si difficile de changer les attitudes et de réduire la discrimination?

Nous examinerons la deuxième question dans la troisième partie de ce chapitre. En ce qui concerne la relation entre stigmatisation et discrimination, certains témoins ont soutenu que le mot stigmatisation a, en soi, tendance à détourner l'attention du vrai problème et qu'il faudrait le laisser de côté pour parler plutôt de discrimination. C'est l'opinion qu'a exprimée Mme Nancy Hall, consultante en santé mentale :

> *Je suis de l'école qui appelle les choses par leur nom et on parle bien de discrimination. Dans toutes les autres organisations de déficience auxquelles je participe, on n'utilise pas le mot « stigmatisation » qui est le terme poli employé pour désigner la « discrimination ». Quand une personne souffrant d'une maladie mentale est systématiquement traitée de façon différente, c'est de la discrimination à mes yeux.*[74]

Cela dit, le Comité pense qu'il est important de bien comprendre ce qu'on entend par stigmatisation. Bien qu'on ne trouve dans les études pertinentes aucune définition généralement acceptée pour exprimer tous les aspects de ce phénomène complexe,[75] la stigmatisation a déjà été définie comme un signe de rejet ou de discrédit, qui met une personne dans une catégorie différente des autres[76], et comme des stéréotypes donnant une image négative d'un groupe.[77] Selon Mme Bronwyn Shoush, membre du Conseil d'administration de l'Institut de la santé des Autochtones, qui fait partie des Instituts de recherche en santé du Canada :

> *… la stigmatisation peut être comparée à un voile couvrant le visage d'une personne et empêchant les gens de se concentrer sur elle. Nous devons trouver un moyen de lever ce voile, de regarder la personne et de ne pas voir seulement ses différences.*[78]

Les témoins sont généralement convenus que la stigmatisation est une question d'attitude, tandis que, comme l'a dit Mme Stuart, « l'action est la discrimination »[79]. Selon le Dr Julio Arboleda-Florèz, professeur et chef du Département de psychiatrie à l'Université Queen's :

> *… la discrimination existe, mais c'est bien différent de la stigmatisation. La stigmatisation se définit comme notre attitude par rapport à des groupes particuliers. La discrimination est un déni de droits juridiques auxquels nous devrions tous avoir accès.*[80]

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74 Deuxième session, 16:3.

75 Bruce G. Link et Jo C. Phelan, « On Stigma and its Public Health Implications,2 Background Paper, National Institute of Health Stigma Conference.

76 Peter Byrne, « Stigma of mental illness and ways of diminishing it, » *Advances in Psychiatric Treatment* (2000) Vol. 6, p. 65.

77 Patrick Corrigan et Robert Lundin, *Don't Call Me Nuts*, Recovery Press, 2001.

78 Deuxième session, 16:10.

79 Deuxième session, 15:27.

80 Deuxième session, 11:70.

Des chercheurs affirment que le lien entre stigmatisation et discrimination englobe un certain nombre d'éléments chevauchants qui s'intègrent pour former une chaîne ininterrompue débutant par l'élaboration de stéréotypes négatifs et aboutissant à un comportement discriminatoire envers les personnes atteintes de maladie mentale. Il existe à leur avis trois maillons essentiels dans cette chaîne :

1. croire aux étiquettes ou stéréotypes;
2. développer des préjugés;
3. se comporter de manière discriminatoire.

Les chercheurs font également une distinction entre la stigmatisation publique (manière dont le public en général réagit à un groupe en fonction de sa stigmatisation) et l'autostigmatisation (réactions que les individus s'infligent à eux-mêmes parce qu'ils font partie d'un groupe stigmatisé).[81] On trouvera dans le tableau ci-après un aperçu des trois éléments inhérents au processus de stigmatisation des personnes souffrant de trouble mental.

TROIS NIVEAUX DE STRUCTURES PSYCHOLOGIQUES CONSTITUANT LA STIGMATISATION PUBLIQUE ET L'AUTOSTIGMATISATION

	Stigmatisation Publique	**Autostigmatisation**
Stéréotype:	Opinion négative à propos d'un groupe, p. ex. violence, incompétence, faiblesse de caractère	Opinion négative à propos de soi, p.ex. faiblesse de caractère, incompétence
Préjugé:	Acquiescement avec l'opinion et/ou réaction émotionnelle négative, p.ex. colère, peur	Acquiescement avec l'opinion et réaction émotionnelle négative, p.ex. faible estime de soi, faible efficacité
Discrimination : réponse comportementale au préjugé	Par exemple, ne pas explorer les possibilités d'emploi et de logement	Par exemple, de ne pas explorer les possibilités d'emploi ou de logement

Source : Amy C. Watson et Patrick W. Corrigan, « The Impact of Stigma on Service Access and Participation, » ligne directrice établie pour le Behavioural Health Management Project.

Les stéréotypes sont un facteur clé de la stigmatisation et de la discrimination envers les personnes atteintes de maladie mentale. Stéréotyper les gens consiste à se fonder sur certaines images que l'on en a pour les cantonner dans des catégories précises et exagérer leurs différences par rapport à divers groupes[82] (distinguo « eux et nous »). Comme dans le cas des préjugés raciaux, les stéréotypes facilitent la mise à l'écart des personnes concernées, ce qui permet à celui qui stigmatise de maintenir l'écart social. C'est ce phénomène qui a amené Mme Hall à faire cette déclaration devant le Comité :

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81 Amy C. Watson et Patrick W. Corrigan, « The Impact of Stigma on Service Access and Participation, » ligne directrice formulée pour le Behavioural Health Management Project.

82 Byrne (2000), *op. cit.*

> *… en tant que défenderesse de la santé mentale, je peux vous affirmer que neuf personnes sur dix nous ont affirmé qu'une fois que leur diagnostic était connu et accepté par elles, les gens les traitaient systématiquement de façon différente.*[83]

Les stéréotypes qui stigmatisent peuvent avoir une force telle que les personnes stigmatisées sont assimilées au stéréotype. Par exemple, certains disent qu'une personne est épileptique ou schizophrène, plutôt que de dire qu'elle est atteinte ou qu'elle souffre d'épilepsie ou de schizophrénie. Cela est révélateur de l'attitude concernant les maladies mentales, parce qu'elles sont différentes des autres. Par exemple, on dit que quelqu'un *a* le cancer, une maladie cardiaque ou la grippe – c'est une personne comme « nous », mais qui a simplement la malchance d'être gravement malade. Par contre, on dit d'un autre qu'il *est* « schizophrène », ce qui stigmatise l'individu dans tout son être[84], comme l'a déclaré Mme Pat Capponi au Comité :

> *Pour beaucoup, un patient psychiatrique reste un patient psychiatrique. Catégorisés comme tels, nous n'avons pas le droit d'être des êtres humains à part entière, ni d'avoir des personnalités de base, comme celles du reste de la population — bonnes, mauvaises, et tout ce qui existe entre les deux. Une personne schizophrène est une personne schizophrène, et chaque acte qu'elle pose est attribué à sa maladie et non à la nature sous-jacente de la personne ou de ses circonstances. Une personne qui est amère et en colère, qui est dépendante du crack ou qui est autrement toxicomane commet un acte terrible et des centaines de voix s'élèvent contre tous ceux qui portent la même étiquette.*[85]

On trouve dans les études pertinentes un certain nombre de stéréotypes répandus au sujet des personnes ayant une maladie mentale grave, par exemple :

1. Elles sont dangereuses et il faut les éviter.

2. Elles sont responsables de leurs propres problèmes et de leur maladie qui découlent de leur faiblesse de caractère.

3. Elles sont incompétentes ou irresponsables et il faut que quelqu'un d'autre prenne leurs décisions pour elles.

4. Elles sont infantiles et ont besoin de figures parentales pour s'occuper d'elles.

5. Elles ont fort peu de chance de guérir de leur maladie mentale.

6. Elles ont des problèmes d'interaction sociale : il n'est pas facile de leur parler et elles ne savent pas se comporter en société.

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83 Deuxième session, 16:16.

84 Link et Phelan, *op. cit.* Voir aussi Keith Brunton, « Stigma, » *Journal of Advanced Nursing*, n° 26, 1997.

85 Troisième session, 7:49.

7. Elles ne sont pas aussi intelligentes que les autres.

Toutefois, une étude scientifique très récente (juin 2004) effectuée à Houston, au Texas, sur la manière dont la maladie mentale est perçue par le public (c'était la première étude de ce genre effectuée dans une grande ville)[86] a produit quelques résultats intéressants et encourageants qui, pense son auteur, reflètent l'attitude générale de la population aux États-Unis. Ainsi :

> *Les données révèlent qu'une majorité écrasante de la population considère que la maladie mentale est essentiellement un trouble d'ordre physiologique qu'il convient de traiter comme n'importe quelle autre maladie physique. Seule une infime minorité continue de croire que la maladie mentale peut être attribuée à un quelconque défaut de caractère à valeur morale.*[87]
>
> *De plus, plus de la moitié des résidents du Harris County (56 p. 100 contre 31 p. 100) croient que la plupart des personnes traitées pour une maladie mentale sont capables de mener une vie normale. Une pluralité notable (47 p. 100) n'aurait aucune inquiétude en découvrant qu'une personne traitée pour maladie mentale vit dans le même quartier, et une majorité (51 p. 100 contre 42 p. 100) serait prête à payer des impôts plus élevés pour améliorer l'accès aux services de santé mentale dans la région de Houston.*[88]

3.2.1 L'autostigmatisation

L'autostigmatisation est assez facile à définir. Elle revient simplement à intérioriser les attitudes négatives concernant la maladie mentale et à les retourner contre soi. Les personnes souffrant de maladie mentale qui croient que les autres méprisent et rejettent ceux et celles qui sont dans leur situation sont particulièrement susceptibles de craindre que ce rejet s'applique à leur cas personnel. Elles risquent de se demander : « Les autres auront-ils une mauvaise opinion de moi et vont-ils me rejeter parce que je suis identifiée comme personne ayant une maladie mentale? » Dans la mesure où cette perception finit par faire partie intégrante de leur vision du monde, elle risque d'avoir de graves conséquences. S'attendant au rejet et le redoutant même, les personnes hospitalisées pour une maladie mentale risquent d'avoir moins confiance en elles-mêmes, d'être plus sur la défensive ou, tout simplement, d'éviter tout contact menaçant.[89]

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86 *Public Perceptions of Mental Illness*: A report to the Mental Health Association of Greater Houston by Stephen L. Klineberg, Ph.d., Rice University (juin 2004).

87 *Ibid.*, p. 27.

88 *Ibid.*, p. 28.

89 Bruce G. Link, Elmer L. Struening, Sheree Neese-Todd, Sara Asmussen, Jo C. Phelan, « The Consequences of Stigma for the Self-Esteem of People With Mental Illnesses, » *Psychiatric Services*, vol. 51, n° 12, décembre 2001.

L'autostigmatisation prend la forme d'énoncés dits « définissants » du genre :[90]

- *Je suis incapable de me débrouiller seul.*
- *Je suis dangereux et je pourrais craquer à tout moment.*
- *Je ne suis comme un enfant.*
- *Je ne peux assumer aucune responsabilité.*
- *Il ne me faut pas me donner d'argent, je le gaspillerais.*
- *Je suis une mauvaise personne.*
- *Qui voudrait bien vivre auprès d'une personne comme moi?*
- *Tout le monde peut facilement voir que je suis anormal.*
- *Je ne mérite pas qu'on me consacre temps et ressources.*
- *Je suis une personne faible.*
- *Je suis incapable de...*

L'autostigmatisation a une incidence profonde et délétère sur la personne vivant avec une maladie mentale et cet effet peut aggraver l'évolution de sa maladie. Ceux qui s'autostigmatisent sont susceptibles de faire face à plus de problèmes et de handicaps avec leur maladie mentale que ceux qui n'intériorisent pas des énoncés de ce genre. Cela s'explique notamment par le fait que les personnes qui s'autostigmatisent ont une faible estime de soi, facteur qui engendre une perte d'espoir. Elles ne pensent pas seulement qu'elles ne méritent aucun respect dans l'immédiat, elles croient que les choses ne changeront pas[91]. Mme Rena Scheffer, directrice des Services d'éducation publique et d'information du Centre de toxicomanie et de santé mentale, s'est exprimée ainsi à ce sujet devant le Comité :

> *Au niveau individuel, non seulement la stigmatisation mène à une faible estime de soi, à l'isolement et au désespoir, mais il a été établi que toutes ces caractéristiques sont des indicateurs prévisionnels de faible adaptation sociale, tandis que les gens se retrouvent dans le cycle immuable d'une qualité de vie moindre.*[92]

Ceux dont l'efficacité est réduite à cause de l'autostigmatisation sont moins susceptibles de chercher un emploi ou un appartement (« Quelqu'un comme moi qui est aux prises avec une maladie mentale ne peut occuper un emploi régulier! »)[93]. D'autres personnes atteintes de maladie mentale essaient d'échapper à la discrimination en dissimulant simplement leur maladie. Toutefois, en agissant ainsi, elles s'exposent à un stress accru, à cause de la crainte permanente d'être découvertes, au risque d'aggraver leur maladie mentale en ayant tendance à ne pas prendre pour elles le temps dont elles auraient besoin, et à l'impossibilité d'obtenir un logement adapté à leur handicap qui pourrait pourtant faciliter leur vie professionnelle et leur rendre la vie plus agréable.

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90 Corrigan et Lundin, *op. cit.*
91 *Ibid.*
92 Deuxième session, 16:20.
93 Watson et Corrigan, *op. cit.*

L'autostigmatisation est également l'un des facteurs qui contribue au fait que de nombreuses personnes souffrant d'un trouble mental diagnosticable ne cherchent pas de traitement. Quand une personne craint d'être identifiée comme souffrant d'un trouble stigmatisant, elle risque de tarder à chercher un traitement, voire de l'éviter. Selon Mme Scheffer :

> *On estime que les deux tiers des gens nécessitant un traitement en santé mentale ne cherchent pas d'aide, principalement parce qu'ils sont soit inconscients des symptômes ou victimes de la stigmatisation associée à la maladie ou à son traitement.*[94]

Le Dr Richard Brière, directeur adjoint de l'Institut des neurosciences, de la santé mentale et des toxicomanies, qui fait partie des Instituts de recherche en santé du Canada, a proposé au Comité l'analogie suivante :

> *Bien souvent, les gens qui ont besoin d'aide ne vont pas en chercher, car ils ont honte de ce qui leur arrive. Si l'on peut atténuer la stigmatisation liée à la maladie mentale, les gens se vanteront de s'en être sortis, tout comme les personnes atteintes de troubles cardiaques se vantent d'avoir subi avec succès un pontage. S'ils n'hésitent pas à en parler à leurs amis, bien des gens cachent leur problème de santé mentale.*[95]

Les familles des personnes souffrant d'un trouble mental peuvent, elles aussi, intérioriser la crainte de la stigmatisation, ce qui peut avoir de graves conséquences. Dans le mémoire qu'elle a adressé au Comité, Mme Stuart évoque le cas d'une jeune fille dont la maladie mentale s'aggravait et dont la mère avait, au départ, évité de chercher un traitement par crainte que sa fille ne soit qualifiée de « folle » par le personnel médical. La police a finalement dû intervenir lorsque l'aggravation de la maladie de la fille a dégénéré en crise.[96]

La stigmatisation n'est pas un phénomène nouveau. De fait, la stigmatisation des personnes atteintes de trouble mental remonte aux débuts de l'humanité.[97] Dans son mémoire au Comité, Mme Scheffer a évoqué le célèbre sociologue Erving Goffman, qui a fait remarquer que le mot stigmate, en grec ancien, servait à décrire les signes corporels appliqués sur un sujet pour exposer quelque chose d'étrange et de mauvais le concernant.[98] Certes, la mythologie qui contribue à la stigmatisation des personnes souffrant d'une maladie mentale a incontestablement évolué au cours des siècles, mais il est frappant de voir dans quelle mesure le terme décrit toujours une situation dans laquelle la personne stigmatisée est mise à l'écart (et dévalorisée) à cause de certains traits comportementaux ou physiques.

De manière générale, considérant l'importance du phénomène de la stigmatisation, le Comité partage l'opinion de M. John Arnett, chef du Département de psychologie clinique de la

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94 Deuxième session, 16:19.

95 Troisième session, 6:55.

96 Mémoire au Comité, 14 mai 2003, p. 3.

97 *Mental Health: A Report of the Surgeon General* des États-Unis, 1999. Voir aussi Paul E. Garfinkel et David S. Goldbloom, "Mental health — getting beyond stigma and categories," *Bulletin de l'Organisation mondiale de la santé*, 2000.

98 Mémoire au Comité, 14 mai 2003, p. 3.

Faculté de médecine de l'Université du Manitoba, qui soutient que le processus même de stigmatisation a des conséquences réelles et profondes sur les personnes vivant avec une maladie mentale. Voici comment il s'est exprimé à ce sujet devant le Comité :

> *Nous savons que la stigmatisation se caractérise par les préjugés, la méfiance, les stéréotypes, et cetera. L'accès des individus au logement et à l'emploi est fréquemment réduit, ce qui débouche sur une faible estime de soi, sur l'isolement et le désespoir. Il est évident que ce phénomène se produit dans plusieurs cas indépendamment des limitations qu'imposent en eux-mêmes les troubles de santé mentale. En d'autres termes, la stigmatisation semble avoir le pouvoir indépendant de créer de telles situations.*[99]

3.2.2 Le rôle des médias et l'apposition de l'épithète « dangereuse » aux personnes souffrant d'un trouble mental

L'un des facteurs que l'on mentionne souvent pour expliquer la persistance de la stigmatisation des personnes vivant avec un trouble mental est le rôle des médias. Un tiers environ de la population affirme que les médias — presse écrite, radio, télévision, nouvelles sur Internet, dispensateurs de conseils, industrie du spectacle et publicité — constituent leur principale source d'information au sujet des personnes ayant une maladie mentale.[100] Hélas, les médias ont souvent tendance à renforcer les mythes et les stéréotypes au sujet de ces personnes. L'analyse de la représentation de la maladie mentale au cinéma et dans la presse écrite montre notamment que deux des stéréotypes sont répandus par ces sources : les personnes ayant une maladie mentale sont des maniaques meurtriers qu'il faut craindre et des personnes infantiles qui doivent être protégées par des figures parentales.[101]

Des analyses de contenu de la télévision américaine ont montré que plus de 70 p. 100 des principaux personnages ayant une maladie mentale dans les émissions télévisées de grande écoute sont présentés comme des personnes violentes et plus de 20 p. 100 comme des assassins.[102] La presse écrite décrit habituellement les personnes ayant une maladie mentale comme des psychotiques dangereux, sans emploi et sans logement — et pas comme des membres productifs d'une famille ou d'une communauté. Des études similaires de journaux au Canada et en Grande-Bretagne font ressortir que l'on trouve de manière plus fréquente et plus visible des articles traitant d'actes violents commis par des personnes atteintes d'un trouble mental que des articles présentant ces personnes sous un angle positif.[103]

Le conditionnement négatif à l'égard des personnes ayant un trouble mental, conditionnement qui favorise la stigmatisation, peut débuter dès l'enfance. La première étude

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99 Deuxième session, 16:7.

100 *Discrimination Against People with Mental Illnesses and their Families: Changing Attitudes, Opening Minds*, rapport du Conseil consultatif du ministre sur la santé mentale, C.-B., avril 2002.

101 Corrigan et Lundin, *op. cit.*

102 Sampson, Stephanie "Countering the Stigma of Mental Illness", bulletin électronique de la Anxiety Disorders Association of America (ADAA), mai-juin 2002, consulté le 11 mars 2004 à http://www.adaa.org/aboutADAA/newsletter/2002_stigmatisation.htm.

103 Scott Simmie, *The Last Taboo* (Toronto: McClelland & Stewart, 2001), p. 304.

consacrée aux émissions de télévision pour enfants en Nouvelle-Zélande et aux États-Unis, publiée en 2000, conclut que l'utilisation fréquente et banale de termes foncièrement méprisants (comme fou, dingue, mental, délirant, dément ou givré), montre aux enfants que ces termes sont acceptables, voire amusants.[104] Les auteurs de cette étude ont cherché attentivement, mais sans succès, des qualificatifs positifs quelconques associés aux personnages présentés comme ayant une maladie mentale, et ils n'ont trouvé aucune compréhension des souffrances associées à la maladie mentale.

Parmi les stéréotypes que l'on trouve régulièrement dans les médias en ce qui concerne les personnes ayant une maladie mentale, mentionnons : esprit rebelle; séductrice violente; parasite narcissique; scientifique fou; manipulateur vicieux; femme perdue et déprimée; personnage comique.[105] Dans la plupart des cas, ces personnes n'ont, dans leur représentation médiatique, aucune identité autre que leur stéréotype « fou » et elles sont essentiellement identifiées par une maladie mentale sous-entendue.

On trouve, au cœur des comptes rendus médiatiques et des idées fausses qu'entretient le public, la propension à la violence qu'on attribue aux personnes atteintes de trouble mental. Ainsi, 88 p. 100 des participants à une étude menée par la Division de l'Ontario de l'Association canadienne pour la santé mentale, au début des années 90, croyaient que les personnes atteintes de maladie mentale sont dangereuses ou violentes.[106] Il s'agit là d'un problème non seulement persistant mais aussi qui semble empirer avec le temps. Aux États-Unis, les attitudes concernant la maladie mentale semblent être de plus en plus fondées sur une crainte de violence associée à ce type de maladie. Entre 1950 et 1996, par exemple, la proportion d'Américains décrivant les maladies mentales dans des termes associés à un comportement violent ou dangereux a presque doublé.[107]

Selon le U.S. Surgeon General, cette attribution d'une propension à la violence chez les personnes atteintes de maladie mentale est un facteur clé pour expliquer la pérennité des attitudes de stigmatisation :

> *Pourquoi la stigmatisation reste-t-elle aussi forte, malgré une meilleure compréhension de la maladie mentale par le public? La réponse semble être la peur de la violence : les personnes atteintes de maladie mentale, notamment de maladie psychotique, sont perçues comme étant plus violentes qu'autrefois.*[108]

Il importe de souligner que cette peur de la violence procède en grande mesure d'une interprétation erronée de la réalité. Selon une étude commandée par Santé Canada, « il n'a

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104 Wilson, Claire, Raymond Nairn, John Coverdale et Aroha Panapa, « How Mental Illness is Portrayed in Children's Television » *British Journal of Psychiatry* (2000) 176, p. 442.

105 Dara Roth Edney, « Mass Media and Mental Illness: A Literature Review » (Association canadienne pour la santé mentale, Section de l'Ontario, 2004) p. 3.

106 Scott Simmie *Out of Mind: An Investigation Into Mental Health* (Toronto, Atkinson Charitable Foundation, 1999) p. 65.

107 Sampson, *op. cit.*

108 Surgeon General, *ibid.*

jamais été scientifiquement démontré, jusqu'ici, que la santé mentale cause la violence ».[109] Selon certaines études américaines, tout au plus 4 p. 100 de tous les actes violents ont un lien quelconque avec la maladie mentale.[110] Cela semble au minimum indiquer très fortement que les craintes du public sont essentiellement non fondées, même si elles sont manifestement très répandues.

Cela dit, certaines données portent à croire que les personnes qui ne reçoivent pas de traitement pour leur maladie mentale, ou qui souffrent de troubles multiples (par exemple, les personnes atteintes de maladie mentale et ayant un problème d'abus de substances), sont plus susceptibles d'être violentes que l'ensemble de la population. Malgré cela, le risque de violence ou de tort causé à un étranger suite à un contact occasionnel avec une personne atteinte de trouble mental reste très minime, et la contribution globale des maladies mentales au niveau total de violence dans la société est exceptionnellement petite.[111] De ce fait, selon Mme Scheffer : « En tant qu'indicateur prévisionnel de violence, la maladie mentale se retrouve bien avant, et de loin, d'autres facteurs de risque tels que l'âge, le sexe et les antécédents de violence ou d'abus de substance.[112] »

Et, comme l'a dit Mme Hall :

> *… Une chose triste est qu'en fait les gens souffrant d'une maladie mentale sont davantage susceptibles de se nuire à eux-mêmes. Dans ma province, une personne par jour se suicide. Même si la réalité est que les malades mentaux sont davantage susceptibles de se faire du mal à eux-mêmes, le public croit qu'ils représentent en fait un danger pour les autres, ce qui n'est simplement pas la réalité normative*[113]*…*

Mme Jennifer Chambers, coordonnatrice du Conseil d'habilitation du Centre de toxicomanie et de santé mentale s'est adressée en ces termes au Comité :

> *L'une des difficultés de déplacer la discussion portant sur l'association entre les gens qui se trouvent dans le système de santé mentale et la violence réside dans le raisonnement circulaire qui en découle. Si un crime particulièrement violent est commis, les gens disent: « Oh, cette personne est malade, psychotique, bizarre », si bien qu'il n'y a aucun moyen de sortir du débat, même si elle n'était pas considérée comme souffrant d'un trouble mental ou émotionnel particulier avant de commettre l'acte.*[114]

L'influence des médias peut être énorme, à la fois pour le grand public et pour les personnes atteintes de maladie mentale. Selon une étude britannique, plus de 20 p. 100 des personnes interrogées étaient plus disposées à accepter la représentation médiatique des personnes

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109 Julio Arboleda-Florez, Heather L. Holley, et Annette Crisanti : *Maladie mentale et violence : Un lien démontré ou un stéréotype?* Santé Canada, 1996, p. x.

110 Simmie, *op. cit.*, p. 49.

111 *Ibid.*

112 Deuxième session, 16:21.

113 Deuxième session, 16:16.

114 Deuxième session, 15:14.

atteintes de maladie mentale comme étant des personnes portées à la violence qu'à croire la réalité que leur communiquait leur propre interaction avec ces personnes. On trouve dans cette étude l'exemple d'une jeune femme habitant près d'un hôpital psychiatrique de la région de Glasgow, en Écosse, qui a depuis fermé ses portes. Elle y avait travaillé comme bénévole et avait donc eu de nombreux contacts avec les patients. Voici ce qu'elle a dit aux auteurs de l'étude :

> *Les gens que je rencontrais n'étaient pas violents — si je pense qu'ils sont violents, cela vient de la télévision, du théâtre et d'autres choses. C'est ça qui est bizarre — les patients étaient généralement des patients gériatriques — ce n'était pas les gens qu'on voit à la télévision. Tous n'étaient pas vieux, certains étaient relativement jeunes. Aucun n'était violent — mais je me souviens que j'en avais peur, parce que c'était dans un hôpital psychiatrique — ce n'est sans doute pas une bonne attitude à avoir mais c'est comme cela que les choses sont communiquées par la télévision et le cinéma — vous savez, les meurtres commis à la hache par des malades mentaux, les pièces de théâtre, des choses comme ça — le gens que j'ai rencontrés n'étaient pas du tout comme ça mais c'est l'image que j'en avais.*[115]

Les auteurs de cette étude ont conclu que l'effet négatif le plus puissant semble porter sur l'autostigmatisation. Comme l'a dit une personne interrogée : « On voit une émission qui donne une image très négative de qui nous sommes et on se demande ensuite : « Qu'est-ce que mes voisins vont en penser? »[116]

3.2.3 La stigmatisation des professionnels des soins en santé mentale

Ce ne sont pas seulement les personnes atteintes de trouble mental qui souffrent des idées fausses répandues par les médias, ce sont aussi les responsables des soins en santé mentale. Selon une étude, trois films seulement depuis le milieu des années 60 ont donné une image favorable des thérapeutes (*Will Hunting*, 1997; *Des gens comme les autres*, 1980; et *Jamais je ne t'ai promis un jardin de roses*, 1977). Dans tous les autres cas, les professionnels de la santé mentale étaient présentés de l'une ou plusieurs des manières suivantes : personne névrotique, incapable de respecter les limites professionnelles, abusant de drogue ou d'alcool, rigide, contrôlante, inefficace, souffrant elle-même de trouble mental, ridicule, froide, égoïste, ayant des objectifs cachés, facile à tromper et à manipuler, stupide et idiote.[117] De telles images ont tendance à donner l'idée qu'aider les autres est une vocation méprisable, exigeant peu de compétence ou d'expertise.

De nombreux témoins ont indiqué que la stigmatisation vise à la fois les personnes qui dispensent les soins et les personnes atteintes de trouble mental. La D^re^ Gail Beck, secrétaire générale adjointe intérimaire de l'Association médicale canadienne, a dit au Comité :

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115 Greg Philo, « Changing Images of Mental Distress », chapitre 4 de *Media And Mental Distress*, révisé par Greg Philo (Longman: 1996), consulté à http://www.gla.ac.uk/Acad/Sociology/mental.htm le 11 mars 2004.

116 *Ibid.*

117 *Ibid.*, p. 5.

« J'entends régulièrement des blagues sur nous, qui ne serions pas de véritables médecins! Et cela n'a rien à voir avec ce que je fais dans ma pratique; c'est dû au fait que le type de maladie que je soigne est stigmatisé et fait l'objet de discrimination. » Selon le Dr Rémi Quirion, directeur scientifique de l'Institut des neurosciences, de la santé mentale et des toxicomanies :

> *Les psychiatres sont toujours stigmatisés par rapport aux autres médecins. La psychiatrie est encore souvent considérée comme un art plutôt qu'une science. Il faut que cela change. Il faut veiller à inciter les étudiants à s'orienter vers la psychiatrie.*[118]

Selon Mme Manon Desjardins, chef de l'administration clinique de la Division des services ultraspécialisés pour adultes, de l'hôpital Douglas, recruter des étudiants en psychiatrie reste difficile :

> *Dans les universités, c'est encore beaucoup plus prestigieux d'aller en soins cardiaques, en chirurgie, en soins intensifs que d'aller en psychiatrie et en gériatrie. La gériatrie et la psychiatrie se situent à peu près au même niveau: ce n'est pas très attirant.*[119]

Mme Maggie Gibson, psychologue du Saint-Joseph's Health Center à London, a également souligné que la stigmatisation des personnes atteintes de trouble mental affecte tous les professionnels de la santé mentale :

> *À propos du stress de la famille et des personnes soignantes, je veux vous parler de la question des stigmates, en particulier du stigmate de négligence associé à l'utilisation des services de soins de longue durée. Nous bénéficierions grandement d'un changement de culture allant dans le sens d'une approche plus pragmatique et plus axée sur la compassion et pragmatique afin de recenser les meilleures options de soins pour les personnes âgées et les membres de leurs familles et faire en sorte que tout le monde puisse effectivement dépendre du système. En effet, les systèmes qui autorisent une relative dépendance sans dévaluer les gens contribuent à améliorer énormément la santé mentale.*[120]

3.3 IMPACT DE LA STIGMATISATION ET DE LA DISCRIMINATION

Comme nous l'avons déjà mentionné, la stigmatisation et la discrimination auxquelles font face bon nombre de personnes atteintes d'un trouble mental grave peuvent être une source de détresse aussi importante que la maladie elle-même. Comme l'a expliqué Mme Stuart :

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118 Deuxième session, 14:29.
119 Deuxième session, 14:124.
120 Deuxième session, 17:15.

> *Dans le contexte de la santé mentale, les consommateurs décriront la stigmatisation comme étant pire qu'avoir une maladie mentale. Elle est perçue comme une seconde dimension de la souffrance, quasiment un second niveau de maladie auquel il faut faire face et qui est plus débilitant et invalidant que la maladie mentale dont ils souffrent. Vous pouvez parfaitement imaginer certaines des conséquences de la stigmatisation. On vous refuse un statut social ainsi que des droits sociaux. Vous faites l'objet d'une discrimination active. Nous devons cibler la discrimination.*[121]

L'insistance avec laquelle elle a souligné la nécessité de faire face à la discrimination qui est le résultat concret de la stigmatisation est un thème qui est revenu souvent durant les travaux du Comité. Ainsi, M. Patrick Storey, président du Conseil consultatif du ministre sur la santé mentale, de la Colombie-Britannique, estime que :

> *…nous devons reconnaître la discrimination contre les personnes atteintes d'une maladie mentale et leur famille comme étant tout aussi inacceptable que les autres formes de discrimination. Nous devons consacrer la même énergie à son éradication que nous en consacrons à l'élimination des autres formes de discrimination.*[122]

Dans la même veine, M. John Service, directeur exécutif de la Société canadienne de psychologie, a parlé au Comité d'un discours qu'il avait entendu, prononcé par « un certain Kennedy, jeune membre du Congrès pour le Rhode Island »[123] :

> *Il avait conceptualisé la discrimination à l'endroit des personnes souffrant de maladie mentale aux États-Unis en l'associant à la discrimination dont étaient victimes les Noirs et les femmes dans les années 50 et 60. Il avait dit que c'était la même systémique et qu'il était possible de corriger cela de la même façon. Pour éliminer cette discrimination systémique, il suffit selon lui de faire ce qui produit déjà des résultats probants en matière de discrimination, par exemple investir abondamment pour adapter le système et faire de l'action positive.*[124]

La discrimination peut affecter de nombreuses manières différentes les personnes atteintes de trouble mental. Celles-ci sont régulièrement exclues de la vie sociale et peuvent même être privées de certains droits civils que tout le monde tient pour acquis. On les prive souvent de certains droits fondamentaux reliés notamment au logement, à l'emploi, au revenu, à l'assurance, à l'enseignement supérieur, à la justice pénale et aux fonctions parentales.[125] Les personnes atteintes de maladie mentale peuvent aussi être confrontées au rejet et à la

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121 Deuxième session, 15:10.

122 Deuxième session, 15:6.

123 M. Service parle ici de Patrick Kennedy, le cadet des trois enfants du sénateur Edward M. Kennedy, qui représente au Congrès le Premier district du Rhode Island depuis 1994.

124 Troisième session, 5:38.

125 Rapport de la C.-B., *op. cit.*

discrimination de la part des professionnels de la santé, aussi bien du secteur de la santé mentale que du secteur de la santé physique, ainsi que de la part des décideurs publics et des médias.

Les professeurs Bruce Link et Jo Phelan, de l'Université Columbia, ont proposé un classement utile de ces différentes formes de discrimination en deux grandes catégories : discrimination directe et discrimination structurelle.[126] Dans son témoignage, Mme Stuart a proposé une distinction similaire entre discrimination ouverte et « actes d'omission » :

> *Le fait que vous pouvez négliger de faire quelque chose simplement parce que vous pensez que ce n'est pas important est plus insidieux est. Vous pouvez avoir une attitude négative ou mettre quelque chose en veilleuse. J'aime penser qu'il y a autant, voire plus de tort causé par ces actes omis, à chaque niveau de la politique ou à chaque palier de gouvernement. Nous pouvons cibler la discrimination déclarée et il y a assurément d'énormes problèmes là, mais j'aimerais voir cela aller encore plus loin. J'aimerais que l'on se penche également sur les actes d'omission. Si nous pouvions arriver au stigmate et aux attitudes qui sous-tendent ces deux choses, nous serions peut-être dans une meilleure position. Je reconnais que cela est difficile à faire. Parfois, il est plus facile de se pencher sur les actions.*[127]

3.3.1 La discrimination directe

La discrimination directe désigne la manière habituelle de conceptualiser le lien entre les stéréotypes et la discrimination. Il s'agit d'un comportement discriminatoire direct de la part de la personne dont les opinions sont stéréotypées. Elle se manifeste de la manière la plus évidente lorsqu'une personne occupant un poste de pouvoir interdit l'accès à une opportunité[128], par exemple quand un propriétaire refuse de louer un appartement à quelqu'un qui a été en hôpital psychiatrique, ou lorsqu'un employeur refuse d'accorder une entrevue d'emploi à quelqu'un qui n'a pas travaillé récemment à cause d'une maladie mentale.

Des études ont montré que cette forme de discrimination se manifeste assez régulièrement dans la vie des personnes stigmatisées. Par exemple, lors d'une enquête canadienne menée auprès de personnes atteintes de maladie mentale, la moitié d'entre elle ont affirmé que c'est sur le plan du logement qu'elles souffrent le plus de discrimination. D'autres études ont montré que le fait qu'une personne ait été patiente dans un établissement de soins psychiatriques réduit sensiblement ses chances de parvenir à louer un appartement.[129]

Les personnes souffrant de maladie mentale font encore souvent l'objet de discrimination dans le monde du travail, autant de la part des employeurs que des collègues. Des enquêtes ont révélé que les employeurs et les travailleurs pensent toujours qu'il est parfaitement

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126 Link et Phelan, *op. cit.*
127 Deuxième session, 15:27.
128 Corrigan et Lundin, *op. cit.*
129 Rapport de la C.-B., *op. cit.*

légitime de se méfier des personnes souffrant de maladie mentale et de les traiter de manière discriminatoire. En conséquence, les personnes souffrant de maladie mentale grave, comme la schizophrénie et les troubles correspondants, sont celles qui connaissent les taux de chômage et de sous-emploi les plus élevés, autour de 90 p. 100, parmi toutes les personnes handicapées.[130]

Un certain nombre d'enquêtes ont uniformément montré qu'une proportion allant du tiers à la moitié des personnes atteintes de maladie mentale disent s'être vu refuser un emploi pour lequel elles étaient qualifiées après avoir révélé leur maladie, ou avoir été congédiées ou avoir été obligées de démissionner à cause de leur maladie mentale. Chose étonnante, les chiffres ne sont pas de beaucoup inférieurs en ce qui concerne l'emploi des personnes atteintes de maladie mentale travaillant pour des établissements de santé mentale ou exerçant bénévolement des fonctions à l'intérieur ou à l'extérieur du secteur de la maladie mentale.[131]

Les familles des personnes atteintes de maladie mentale ne doivent pas seulement faire face à des facteurs de stress d'ordre financier, pratique et émotif mais aussi à une sorte de « discrimination par association ». Elles sont confrontées à des relations tendues avec les autres membres de la famille ou avec les amis, et à des phénomènes de peur, de violence, d'anxiété, de conflit, de faible estime de soi et de culpabilité. La discrimination contre les membres de la famille émane souvent d'idées fausses quant au rôle de la famille dans les causes de la maladie mentale.[132]

3.3.1.1 Discrimination dans le système de soins de santé

De nombreux témoins ont souligné l'importance de s'attaquer à la discrimination dont font l'objet les personnes atteintes de trouble mental dans le système de soins de santé lui-même. Bon nombre d'études, canadiennes et internationales, ont montré que les professionnels de la santé mentale et les professionnels de la santé en général peuvent être à l'origine d'attitudes et de comportements discriminatoires envers leurs propres clients. Les personnes atteintes de maladie mentale soulignent fréquemment que l'on ne tient pas compte de leur opinion, qu'on ne leur témoigne aucun respect, et que les travailleurs de la santé mentale ont tendance à se concentrer uniquement sur les questions cliniques reliées aux soins, à l'exclusion des questions sociales. Des études ont montré qu'une des plaintes les plus fréquentes des personnes atteintes de maladie mentale est le manque de respect de la part des médecins et des employés des salles d'urgence.[133]

Ce phénomène est assez troublant, comme l'a dit Mme Stuart :

> *Pourquoi les travailleurs de la santé font-ils tant de stigmatisation? Ils figurent parmi les personnes les plus informées sur la maladie mentale dans notre société. On les identifie invariablement comme les gens qui sont les pires contrevenants.*[134]

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130 Voir le chapitre 6.
131 Rapport de la C.-B.*, op. cit.*.
132 *Ibid.*
133 *Ibid.*
134 Deuxième session, 15:24.

D'autres témoins ont confirmé que ce problème est très répandu. Ainsi, a dit M. Storey devant le Comité :

> *Au cours des discussions que nous avons eues avec des personnes souffrant de maladie mentale, ce qui était remarquable c'est qu'elles avaient toutes à raconter des histoires de mauvais traitement dans les salles d'urgence, ainsi que dans les hôpitaux en général. Même lorsqu'elles émettaient des plaintes de nature physique, elles étaient traitées comme des malades mentales.*[135]

Le Dr Jim Millar, directeur exécutif de la Santé mentale et des services fournis par les médecins au ministère de la Santé de la Nouvelle-Écosse, a également indiqué au Comité que les salles d'urgence des hôpitaux sont des lieux où se manifeste la discrimination :

> *On n'a qu'à se rendre dans une salle d'urgence pour constater la stigmatisation exercée par les fournisseurs de soins de santé. Les clients en santé mentale sont ceux qui attendent le plus longtemps, dont on viole la vie privée et dont les inquiétudes ne sont pas traitées de manière appropriée.*[136]

Cette discrimination apparemment généralisée au sein du système de santé a de nombreuses conséquences négatives pour les personnes ayant besoin d'aide. Ainsi, Mme Pat Capponi a fait ressortir le manque de confiance qui en découle :

> *Nous avons appris que nous ne pouvons dépendre de ceux qui travaillent dans ce système pour nous aider. Nous ne pouvons pas nous attendre à ce qu'ils nous perçoivent comme des personnes à part entière, derrière nos diagnostics obscurs.*[137]

3.3.2 Discrimination structurelle

La discrimination dont souffrent les personnes atteintes de maladie mentale et leurs familles ne se limite pas aux actes de discrimination ouverte d'une personne contre une autre. Elle peut aussi prendre la forme de ce que Link et Phelan appellent la discrimination structurelle.

Pour comprendre leur analyse, supposons que des budgets moins élevés soient consacrés à la recherche sur la schizophrénie qu'aux autres maladies, parce que c'est une maladie stigmatisée, et que l'on accorde moins d'argent à la prestation et à la gestion des soins. Cela veut dire que les personnes atteintes de schizophrénie seront moins susceptibles de bénéficier de découvertes scientifiques que si elles avaient été atteintes d'une maladie ne faisant pas l'objet de stigmatisation. Dans la mesure où c'est la stigmatisation de la schizophrénie qui aurait engendré une telle situation, une personne souffrant de ce trouble

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135 Deuxième session, 15:6.
136 Troisième session, 7:18.
137 Troisième session, 7:51.

ferait l'objet de discrimination structurelle, qu'elle soit ou non confrontée à un traitement discriminatoire de la part de quiconque.

Ce genre de discrimination structurelle fondée sur la stigmatisation peut se manifester de nombreuses manières. La stigmatisation peut influencer l'accès au traitement en créant des conditions de traitement tellement indésirables que l'on sera beaucoup moins porté à chercher un traitement que dans d'autres contextes. Par exemple, il existe à l'égard des personnes atteintes de trouble psychotique une crainte complètement disproportionnée par rapport au risque réel qu'elles posent. Dans la mesure où cette crainte accroît le recours à des gardes, au confinement ou à des fouilles, par exemple, la stigmatisation engendre un milieu de traitement extrêmement négatif qui pourrait facilement amener les personnes concernées à tout faire pour l'éviter.

La discrimination structurelle peut également se manifester dans les niveaux généraux de financement qui sont consacrés à la recherche et au traitement des maladies mentales (voir le chapitre 10). De plus, dans l'univers de la maladie mentale, de manière générale, les professionnels ont souvent le sentiment d'être traités comme des citoyens de seconde classe par leurs homologues, et les services, programmes et recherches reliés à la maladie mentale ont tendance à être traités de manière moins prioritaire que ceux qui concernent la santé physique.

3.4 RÉDUIRE L'IMPACT DE LA STIGMATISATION ET DE LA DISCRIMINATION

Il existe des méthodes individuelles et communautaires ou sociales pour réduire l'impact de la stigmatisation et de la discrimination. D'une part, les personnes atteintes de maladie mentale peuvent chercher des stratégies pour faire face au phénomène ou pour tenter de le contrer. D'autre part, on peut formuler des stratégies sociales ou communautaires pour tenter de réduire l'ampleur et l'impact du phénomène. Cette partie du rapport sera presque totalement consacrée aux stratégies sociales ou communautaires mais, avant d'en traiter, quelques mots s'imposent sur les démarches individuelles.

Dans l'ensemble, on recense dans les études pertinentes trois stratégies qui s'offrent aux personnes atteintes de maladie mentale :

1. tenter de dissimuler totalement leur maladie à autrui;

2. pratiquer l'évitement sélectif en limitant leur interaction sociale aux personnes qu'elles savent ne pas pratiquer la stigmatisation;

3. tenter d'expliquer la nature de la maladie à toutes les personnes avec qui elles entrent régulièrement en contact.

Comme nous l'avons déjà dit, préserver le secret au sujet de sa maladie mentale peut avoir maintes conséquences négatives. Selon une étude consacrée à la valeur respective de ces approches individuelles, il n'y a pas que la première stratégie susmentionnée qui peut être

antiproductive. Les auteurs de l'étude ont conclu sans aucune ambiguïté que les trois stratégies peuvent être néfastes et qu'elles rendent le rejet beaucoup plus probable.[138]

Considérant les difficultés que posent ces stratégies fondées sur l'action individuelle, il semble clair qu'il faut recourir à une certaine forme d'intervention communautaire ou sociale si l'on veut faire des progrès quelconques dans la réduction de la stigmatisation et de la discrimination. Cela découle du fait que ces deux phénomènes sont foncièrement sociaux. Ils dépendent de la propagation de mythes au sujet des personnes atteintes de trouble mental au sein des diverses institutions de la société (écoles, lieux de travail, médias, etc.) et ils s'enracinent dans des pratiques discriminatoires qui peuvent être favorisées ou encouragées par les lois et les traditions.

Il n'existe malheureusement aucune stratégie simple ou unique pour éliminer la stigmatisation de la maladie mentale,[139] d'abord parce que des stéréotypes tels que ceux qui nourrissent la stigmatisation sont des phénomènes complexes. On y trouve des éléments relativement variables mais aussi certains qui résistent férocement au changement.[140]

Comme nous l'avons vu, la stigmatisation historiquement omniprésente de la maladie mentale, malgré une éducation et une sensibilisation croissantes de la population quant à sa nature, soulève une question importante sur l'efficacité de l'éducation en tant que mécanisme unique pour réduire les effets de la stigmatisation. Certes, on espérait qu'une meilleure sensibilisation du public à la nature de la maladie mentale entraînerait une atténuation de la stigmatisation mais c'est tout le contraire qui s'est produit : d'une certaine manière, la stigmatisation s'est intensifiée au cours des 40 dernières années, alors même que la compréhension des maladies mentales s'améliorait.[141]

Comme les opinions stigmatisantes ne sont pas toujours pas étroitement liées à l'étendue des connaissances sur la maladie mentale, il s'ensuit de manière générale que les campagnes visant à réduire la stigmatisation doivent être soigneusement planifiées et viser probablement à faire plus que simplement améliorer la connaissance des états stigmatisés.[142] Une hypothèse avancée pour expliquer pourquoi la diffusion d'informations est peu susceptible, à elle seule, d'éliminer les attitudes stigmatisantes est que les stigmatiseurs ont besoin d'une nouvelle expérience émotionnelle éventuellement en sus d'un nouveau modèle explicatif pour pouvoir remettre en question les stéréotypes qu'ils peuvent avoir intériorisés.[143]

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138 L'étude a été effectuée en 1991 par Link, Mirotznik et Cullen et a été décrite par Keith Brunton dans son article « Stigma », *op. cit.*, p. 894.

139 Surgeon General, *op. cit.*

140 Rapport de la C.-B., *op. cit.*

141 Surgeon General, *op. cit.*

142 Arthur H. Crisp, Michael, G. Gelder, Susannah Rix, Howard I. Meltzer et Olwen J. Rowlands, « Stigmatisation of people with mental illness », Royal College of Psychiatrists, 2000.

143 Rahman Haghighat, « A unitary theory of stigmatization, » *British Journal of Psychiatry*, No. 178, 2001.

Voilà pourquoi d'aucuns ont contesté l'efficacité des campagnes d'information de masse lancées pour réduire la stigmatisation et la discrimination.[144] Voici comment Mme Stuart a formulé cette idée :

> *En ce qui concerne les interventions de lutte contre la stigmatisation, comment arrêter ce phénomène et la discrimination? Nous apprenons de l'Association mondiale de psychiatrie qu'il n'y a pas de solution unique. C'est une perte de temps et d'énergie de se lancer dans une vaste campagne d'éducation du public destinée à améliorer l'alphabétisation comme intervention d'anti-stigmatisation car les couches de la population ont des points de vue différents. Elles comprennent leurs risques différemment selon le groupe diagnostic.*[145]

Les résultats sont plus prometteurs quand les campagnes médiatiques s'appuient sur une activité continue d'éducation et d'action communautaires. Le consensus général, à l'échelle internationale, semble être que les campagnes d'éducation du public sont les plus efficaces quand elles sont enracinées au niveau local et axées sur les anxiétés des groupes cibles[146]. Selon Mme Stuart:

> *Nous parlons maintenant d'interventions plus centrées et plus ciblées. Nous avons connu le meilleur succès parmi toutes nos tentatives en nous rendant dans les écoles secondaires et en travaillant avec les jeunes car ils sont plus malléables.*[147]

Réduire la stigmatisation exigera donc des campagnes très ciblées et adaptées aux publics visés. Deux articles récents montrent que de telles campagnes bien ciblées peuvent effectivement modifier les attitudes à l'égard des personnes atteintes de trouble mental. Une évaluation des ateliers de sensibilisation à la santé mentale s'adressant à des étudiants d'écoles secondaires en Grande-Bretagne a révélé que, dans le cas des jeunes, cette formule peut avoir un effet minime mais positif sur ce qu'ils pensent des personnes atteintes de trouble mental.[148] L'évaluation d'une autre campagne britannique destinée à des policiers a également révélé que les ateliers donnent de bons résultats sur les attitudes et que cibler un groupe sur son lieu de travail offre la possibilité de remettre en question les stéréotypes négatifs tout en abordant les besoins spécifiques de formation au travail, ce qui engendre un milieu d'apprentissage plus favorable pour s'attaquer aux attitudes et aux comportements.[149]

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144 Heather Stuart et Julio Arboleda-Florèz, « Community Attitudes Toward People With Schizophrenia, » *Revue canadienne de psychiatrie,* n° 46, 2001.

145 Deuxième session, 15:12.

146 Peter Byrne, « Psychiatric Stigma, » *British Journal of Psychiatry*, n° 178, 2001.

147 Deuxième session, 15:12.

148 Vanessa Pinfold, Hilary Toulmin, Graham Thornicroft, Peter Huxley, Paul Farmer et Tanya Graham, « Reducing psychiatric stigma and discrimination: evaluation of educational interventions in UK secondary schools » dans *British Journal of Psychiatry* (2003), 182, p. 344.

149 Vanessa Pinfold, P. Huxley, G. Thornicroft, P. Farmer, H. Toulmin, et T. Graham, « Reducing psychiatric stigma and discrimination: Evaluating an educational intervention with the police force in England », *Journal of Social Psychiatry and Psychiatric Epidemiology* (2003) 38, p. 343.

L'un des premiers chercheurs en matière de lutte contre la stigmatisation, Otto F. Wahl, professeur de psychologie à l'Université George Mason de Fairfax, en Virginie, a déclaré à cet égard que, si nous voulons vraiment éradiquer la stigmatisation, nous devrons en comprendre les effets de manière plus concrète, pratique et personnalisée – c'est-à-dire comprendre comment les gens ressentent la stigmatisation et comment cela influe sur leur traitement et leur rétablissement.[150]

L'une des solutions pourrait donc consister à concevoir des stratégies de lutte contre la stigmatisation comprenant des tribunes grâce auxquelles les participants peuvent exprimer leurs craintes, poser des questions et communiquer leurs inquiétudes.[151] Pour Mme Stuart :

> *Lorsque nous avons parlé de cibler les choses, nous essayions de cibler les expériences. Nous avons réfléchi que nous devions les amener à un niveau émotionnel. Nous devions les amener à se rendre compte que tout leur système de croyances était quelque peu injustifié. L'une des meilleures façons de le faire a consisté à construire des situations dans lesquelles les malades mentaux pouvaient rencontrer des gens qui n'avaient peut-être jamais rencontré une personne atteinte d'une maladie mentale, dans des situations contrôlées et constructives. Ces personnes ont parlé de leur maladie mentale. Elles ont transmis des renseignements factuels mais, élément plus important, elles ont transmis des informations à un niveau humain. C'est ce qui a fait la différence.*[152]

De fait, ce sont les contacts avec les personnes atteintes de maladie mentale qui semblent offrir les meilleures chances d'amélioration des attitudes. Des recherches ont montré que les membres du public qui connaissent mieux les maladies mentales sont moins susceptibles d'intérioriser des préjugés[153]. Comme l'a dit Mme Scheffer au Comité :

> *La stratégie la plus prometteuse de toutes pour combattre les perceptions négatives est d'augmenter les contacts avec les malades mentaux. Aucune autre stratégie n'est plus efficace.*[154]

Cette conclusion a été renforcée par les résultats de l'étude menée dans la région de Houston au sujet de la manière dont le public perçoit la maladie mentale, étude que nous avons déjà évoquée. Ses auteurs affirment que :

> *Dans toutes ces analyses, nous avons continuellement été frappés par l'importance écrasante de la connaissance personnelle pour former les attitudes du public à l'égard des maladies mentales. Quand on a demandé aux répondants s'ils connaissaient quelqu'un parmi leurs amis ou dans leur famille qui a fait l'objet d'un diagnostic de maladie mentale,*

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150 Sampson, *op cit*.
151 Haghighat, *op. cit.*
152 Deuxième session, 15:24.
153 Watson et Corrigan, *op. cit.*
154 Deuxième session, 16:21.

> *y compris de dépression clinique, les 38 p. 100 qui ont répondu par l'affirmative étaient constamment et sensiblement plus susceptibles que les 62 p. 100 qui n'avaient pas eu de telle expérience personnelle d'appuyer des programmes d'entreprises et des politiques fiscales visant à assurer l'accès aux services de santé mentale, de n'avoir aucune inquiétude en apprenant qu'un voisin était traité pour une maladie mentale, et de croire que la plupart des gens suivant un traitement pour une maladie mentale sont capables de mener une vie normale.*[155]

Toutefois, des recherches récentes portent également à croire que la manière dont les gens entrent en contact avec les personnes atteintes d'un trouble mental peut avoir une influence sur le degré de remise en question des attitudes stigmatisantes. Ainsi, les auteurs d'une étude réalisée au Center for Psychiatric Rehabilitation[156] de l'Université de Chicago ont tiré un certain nombre de conclusions intéressantes. En premier lieu, ils ont confirmé les résultats d'études antérieures montrant que le contact avec des personnes atteintes de trouble mental engendre un profond changement d'attitude à l'égard de la maladie mentale.[157] En outre, et contrairement à leurs attentes originelles, les chercheurs n'ont constaté aucune différence notable quant à l'impact du contact lorsque celui-ci se faisait par bande vidéo plutôt que dans la vie réelle.

Toutefois, ils ont également constaté que les stéréotypes n'étaient pas remis en question lorsque le contact avec la personne atteinte de maladie mentale grave mettait plus en relief les symptômes de cette maladie que la possibilité de rétablissement. De plus, ils ont conclu que leur recherche offrait une explication plausible de la raison pour laquelle de nombreux professionnels de la santé mentale restent vulnérables à l'intériorisation d'attitudes stigmatisantes. À leur avis :

> *Rencontrer une personne atteinte de maladie mentale dont les symptômes et les autres problèmes sont mis en exergue est peu susceptible d'entraîner une remise en question des stéréotypes. C'est peut-être l'une des raisons pour lesquelles les professionnels de la santé mentale sont si susceptibles d'endosser la stigmatisation de la maladie mentale. Les personnes qui dispensent les traitements, notamment les cliniciens de services internes, entrent généralement en contact avec les personnes atteintes de maladie mentale lorsqu'elles sont gravement malades, situation qui risque plus de confirmer le stéréotype que de le remettre en question. La plupart de ces patients obtiennent généralement leur congé avant que leur rétablissement ne soit évident, ce qui signifie que le responsable du traitement ne profite d'aucune expérience concrète susceptible d'infirmer le stéréotype.*[158]

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155 *Op. cit.*, p. 20-22.

156 Rebecca R. Reinke, Patrick W. Corrigan, Christoph Leonhard, Robert K. Lundin et Mary Anne Kubiak, « Examining Media's Use of Contact on the Stigma of Mental Illness », manuscrit inédit adressé au *Journal of Nervous and Mental Disease.*

157 *Ibid.*, p. 10.

158 *Ibid.*, p. 11.

Mme Scheffer a également suggéré que la stratégie la plus efficace « pour améliorer la compréhension et l'acceptation est l'adoption d'une approche de promotion de la santé complète combinée à une approche de marketing social » conçue pour « conscientiser, encourager à obtenir de l'aide et favoriser une compréhension positive[159] ».

Selon M. Service, la stigmatisation peut être réduite au moyen d'un traitement efficace des personnes atteintes de trouble mental. Il a déclaré au Comité :

> *En ce qui concerne la stigmatisation, nous constatons dans la profession qu'elle est en train de diminuer. Elle se résorbe considérablement dans certains milieux, c'est-à-dire chez les gens qui ont accès aux services et s'en prévalent et qui n'ont pas de problème parce que leur voisin, leur ami, leur frère ou leur cousin se sont prévalus des services et en ont bénéficié. C'est ainsi que l'on élimine la stigmatisation. Dans notre secteur d'activité, c'est aussi l'un des meilleurs témoignages que l'on puisse avoir. Ça ne vient pas d'un autre professionnel mais de quelqu'un qui dit: « Je suis allé voir M. Service. Il m'a aidé et tu devrais aller le voir ». C'est ainsi que vous obtenez la plupart de vos clients et c'est ce qui fait disparaître la stigmatisation.*[160]

Les témoins ont également souligné la nécessité de faire participer les personnes atteintes de trouble mental à tous les aspects des efforts visant à éliminer la stigmatisation et la discrimination. Mme Chambers a recommandé au Comité :

> *… un programme d'éducation national… une campagne dirigée vers les survivants et orchestrée par eux pour contester le préjugé dévastateur et la discrimination qui existent dans notre collectivité.*[161]

Mme Capponi a mis l'accent sur les effets profondément antistigmatisation des efforts déployés pour faciliter la participation des personnes atteintes de trouble mental à des activités concrètes et productives :

> *Nous avons commencé à lutter contre la pauvreté et l'impuissance en créant directement des entreprises gérées par des patients psychiatriques sortants. Mené par ma sœur Diana, qui avait vaincu une maladie psychiatrique et la toxicomanie, notre groupe a fait des pressions et a créé des entreprises gérées par des patients sortants dans la province de l'Ontario — ce qui constituait une scission radicale avec la réhabilitation professionnelle traditionnelle. Notre communauté a commencé à se rendre compte qu'il y avait des possibilités pour nous. Petit à petit, nous nous sommes dotés de modèles et de chefs. Nous réussissions, nous détruisions les mythes et les idées préconçues sur ce que*

159 Deuxième session, 16:21.
160 Troisième session, 5:48.
161 Deuxième session, 15:16-17.

> *nous étions et nous formions une communauté. Les patients psychiatriques chroniques s'engageaient à arriver à l'heure au travail. En acquérant de nouvelles compétences, nous arrivions à créer des relations amicales durables et saisissions toutes les occasions d'apprendre des expériences des autres. Nous avons réussi à lutter contre la stigmatisation à l'intérieur et à l'extérieur du système de santé mentale, où des millions de dollars ont été dépensés pour des campagnes de publicité élaborées qui n'ont pas marché.*[162]

Plusieurs témoins ont également souligné qu'il est important d'apprendre ce qu'ont fait les autres communautés qui ont dû faire face à des problèmes reliés à la stigmatisation et à la discrimination. Mme Scheffer en a donné quelques exemples dans son témoignage :

> *Si nous jetons un coup d'œil aux autres groupes qui ont souffert des effets d'un stigmate social, comme la communauté des gais et des lesbiennes, les personnes atteintes du sida ou du cancer, ils sont parvenus à éliminer ou à réduire le stigmate en provoquant un vaste changement d'attitudes.*[163]

Dans le même ordre d'idées, M. Brian Rush, chercheur en Politique de prévention sociale et de santé au Centre de toxicomanie et de santé mentale, a précisé que :

> *Le domaine de la santé mentale pourrait beaucoup apprendre de celui de la déficience développementale et du genre d'investissement qui permettrait d'accueillir les patients dans leur collectivité, ce qui permettrait d'économiser tout en traitant les gens dans la dignité et le respect, et en leur donnant le choix de vivre au sein de leur collectivité plutôt que dans des établissements psychiatriques.*[164]

Mme Shoush a rappelé au Comité que des communautés différentes auront des méthodes différentes pour aider les personnes atteintes de trouble mental et qu'il est donc essentiel d'adapter les efforts à cette diversité des réalités. Elle a déclaré au Comité que :

> *Les communautés autochtones diraient qu'elles possèdent un point de vue différent sur le monde et que la communauté est l'élément central. Elles croient que la communauté mérite d'être le centre des préoccupations que l'information pouvant aider cette dernière à être entière et saine doit être disponible et partagée.*[165]

3.4.1 La nécessité d'une stratégie nationale

S'il est évident qu'il n'y a pas de solution miracle aux problèmes de stigmatisation et de discrimination, et que les efforts destinés à en réduire l'incidence devront être soigneusement

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162 Troisième session, 7:48.
163 Deuxième session, 16:20.
164 Troisième session, 8:28.
165 Deuxième session, 16:26.

adaptés à de nombreux contextes, plusieurs témoins ont également insisté sur l'importance d'adopter une stratégie nationale sur la santé mentale. Ainsi, selon M. Phil Upshall, président de la Société pour les troubles de l'humeur du Canada :

> *La mise en œuvre d'une stratégie nationale fédérale ferait beaucoup pour lutter contre la stigmatisation. Ce serait un modèle de référence pour le reste du Canada à qui l'on dirait « Voici ce à quoi nous devons faire attention ». Je dirais aux autres premiers ministres provinciaux et à leurs ministres de la Santé qu'ils doivent, enfin, prendre cela au sérieux.*[166]

Opinion qui est partagée par le Dr Blake Woodside, président du Conseil d'administration de l'Association des psychiatres du Canada, qui s'est adressé en ces termes au Comité :

> *Il faut premièrement faire de la santé mentale une priorité publique; une déclaration par le gouvernement fédéral qu'un plan d'action national est en préparation constituerait un pas dans la bonne direction. Il en découlerait une vaste gamme d'activités de sensibilisation qui participeraient à la lutte contre cette discrimination et cette stigmatisation.*[167]

Des témoins ont également déclaré qu'il importe de modifier la *Loi canadienne sur la santé* de façon à ce que la santé physique et la santé mentale soient placées sur un pied d'égalité, ce qui n'est pas le cas aujourd'hui car, par exemple, les hôpitaux psychiatriques sont explicitement exclus de son champ d'application. Voilà pourquoi le Dr Sunil Patel, président de l'Association médicale canadienne, a fait l'intervention suivante :

> *Autrement dit, comment arriverons-nous à surmonter le stigmate et la discrimination si nous les validons dans la législation fédérale? L'AMC est convaincue que l'élaboration d'une stratégie nationale et d'un plan d'action sur la santé mentale et la maladie mentale constitue l'étape la plus importante à franchir en la matière.*[168]

L'AMC a proposé un certain nombre de mesures pour corriger cette situation, notamment, comme l'a déclaré le Dr Patel :

> *… modifier la Loi canadienne sur la santé pour inclure les hôpitaux psychiatriques; rajuster le Transfert canadien en matière de santé pour prévoir que le gouvernement fédéral partage à la fois l'investissement ponctuel et le coût continu des services assurés supplémentaires; rétablir, à Santé Canada ou à la nouvelle agence canadienne de la santé publique,*

166 Troisième session, 9:34.
167 Troisième session, 5:26-27.
168 Troisième session, 5:11.

> *un service doté de ressources adéquates qui s'occupera uniquement de la santé mentale et des toxicomanies.*[169]

Pour sa part, le Dr Paul Garfinkel, président du Groupe de travail sur la santé mentale de l'Association des hôpitaux de l'Ontario, et président et directeur général du Centre de toxicomanie et de santé mentale, a souligné la valeur symbolique énorme d'une réforme de la LCS :

> *Modifier la Loi canadienne sur la santé aurait un énorme effet symbolique. Ce serait une façon de dire que nous réparons un tort. Il y a des années, nous ne comprenions pas la maladie mentale et aujourd'hui nous nous rendons compte qu'elle est semblable à toute autre forme de douleur ou de souffrance humaine. Ce serait radical.*[170]

M. Service a lui aussi insisté sur l'importance de ne pas traiter la santé mentale, la maladie mentale et les toxicomanies comme s'il s'agissait d'éléments foncièrement différents des autres questions de santé :

> *Si nous considérons que la santé mentale, la maladie mentale et la toxicomanie font partie et sont au centre des activités de tout le système de santé, nous procédons alors à un changement structurel extrêmement important qui amène la maladie mentale au premier plan au lieu de la confiner dans un ghetto en compagnie des « cinglés » dont personne ne doit vraiment s'occuper ou des « inquiets en bonne santé » dont nous n'avons pas le temps de nous occuper.*[171]

Selon Mme Chambers, si l'on veut aider les personnes atteintes de trouble mental à tirer pleinement parti de leurs droits, il faudra aussi leur consacrer des ressources particulières au palier national. Comme elle l'a affirmé au Comité :

> *J'aimerais souligner que, de concert avec l'idée d'éduquer les gens, il est important d'avoir une ressource nationale en matière de défense légale de la santé mentale ayant des comptes à rendre aux consommateurs. Ce ne sont pas seulement les préjugés dans la collectivité en général, mais en particulier les préjugés et la discrimination dans le système de santé mentale lui-même — c'est permis en vertu de la loi — qu'il faut aborder. Il est crucial d'impliquer ces deux éléments.*[172]

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169 *Ibid.*
170 Troisième session, 5:32.
171 Troisième session, 5:37.
172 Deuxième session, 15:26.

3.4.2 La nécessité de réformer les politiques

De manière générale, les témoins ont déclaré qu'il est plus facile de modifier les politiques que les attitudes et qu'il convient donc de déployer tous les efforts possibles à cet égard. Voici comment Mme Stuart a exprimé cette idée :

> *Nous espérons qu'une troisième génération de travaux de recherche pourra se concentrer sur les types de structures sociales… qui perpétuent vraiment l'inégalité sociale et la discrimination — les structures et les organismes, ainsi que les politiques et les programmes qui font en sorte que cela arrive. Il est difficile de changer les attitudes mais vous pouvez changer beaucoup plus facilement les politiques.*[173]

Dans le même ordre d'idées, le Dr Patel a dit qu'il faut « réviser les politiques et programmes fédéraux sur la santé pour faire en sorte que la maladie mentale se trouve sur le même pied que d'autres maladies et incapacités chroniques pour ce qui est des prestations[174] ». M. Storey a illustré quant à lui le genre de changements qui lui semblent nécessaires :

> *En plus de protéger les montants consacrés à la santé mentale, il faut effectuer un certain nombre de changements au niveau des politiques. Les modalités et les barèmes de facturation des services médicaux, les prestations d'assurance- maladie complémentaire, les régimes de pension, et cetera, ne reconnaissent pas les caractéristiques et les défis particuliers de la santé mentale et dressent des obstacles inutiles à la guérison et à la santé. En Colombie-Britannique, par exemple, un médecin de famille ne peut facturer que quatre consultations par an par patient; cependant, la plupart des gens souffrant d'une dépression vont voir leur médecin de famille. Même si les médicaments anti-dépressifs constituent un complément utile, seuls ils ne suffisent pas pour aider les gens à surmonter efficacement cet état parfois débilitant. Les médecins ne sont pas en mesure d'offrir l'aide nécessaire à une personne déprimée.*[175]

Finalement, Mme Capponi a souligné, elle aussi, la nécessité d'adapter les politiques à l'évolution du contexte social :

> *Il y a beaucoup plus de personnes atteintes de troubles mentaux dans les rues, non pas par choix, mais parce que l'écart entre les mieux nantis et les moins nantis va grandissant. De plus en plus de personnes ont recours aux services des banques alimentaires, ce qui veut dire que la part du malade mental chronique diminue. Un propriétaire va louer sa maison à des personnes qui, à son avis, seront plus tranquilles qu'un ancien patient atteint de troubles mentaux. Les gens sont de plus en plus laissés*

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173 Deuxième session, 15:10.
174 Troisième session, 5:11.
175 Deuxième session, 15:7.

> *pour compte. Les refuges préfèrent ouvrir leurs portes aux immigrants et aux femmes battues au motif qu'ils posent moins de problèmes. Il y a toujours un stigmate associé aux troubles mentaux.*[176]

3.4.3 Le problème de la violence

Bien des gens estiment, cependant, que le facteur qui explique le plus probablement l'augmentation de la stigmatisation ces dernières années procède d'une attribution exagérée aux personnes atteintes de maladie mentale grave de la propension à commettre des actes de violence gratuits. D'aucuns semblent croire qu'un nombre croissant de crimes avec violence sont commis par des personnes souffrant de troubles psychiatriques profonds.[177]

Si l'on veut contrer cette attribution exagérée de dangerosité aux personnes atteintes de trouble mental, ont dit plusieurs témoins, il va falloir tenir compte de ce que nous disent les meilleures études scientifiques, comme l'a résumé M. Arnett devant le Comité :

> *… les risques de gestes violents de la part de gens au psychisme troublé semblent être plus élevés. Il est sage de le reconnaître. Ces gestes se produisent particulièrement dans les cas de maladie mentale grave et encore davantage lorsque la maladie grave est accompagnée d'une toxicomanie.*[178]

Comme des actes de violence sont commis, certains chercheurs estiment qu'il est peu probable que l'on constate une réduction de la stigmatisation des personnes atteintes de trouble mental tant que l'on n'aura pas enregistré une réduction des crimes avec violence qu'elles commettent.[179] À leur avis, cela s'impose pour éviter que le citoyen moyen qui se rend au travail en autobus puisse voir une affiche condamnant la stigmatisation en ces termes : « les personnes atteintes de trouble mental sont de bons voisins » tout en lisant en même temps dans le journal un article relatant en détail le dernier acte violent commis par une telle personne.

3.4.4 Les médias et les efforts de réduction de la stigmatisation et de la discrimination

Il n'existe pas de stratégie miracle pour réduire la représentation médiatique inexacte et stigmatisante des personnes atteintes de trouble mental, ni pour encourager les médias à contribuer activement à la déstigmatisation.

On trouve cependant des exemples d'initiatives visant directement à modifier la représentation des personnes atteintes de trouble mental dans les médias. Ainsi, une pétition critiquant la couverture médiatique des maladies mentales a été signée par 3 000 psychiatres en Grande-Bretagne en avril 1995. Ils y réclamaient notamment l'ouverture d'un débat de

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176 Troisième session, 7:70.

177 Treatment Advocacy Center, "Briefing Paper on Stigma and Violence," consulté à : http://www.psychlaws.org/BriefingPapers/BP9.htm.

178 Deuxième session, 16:8.

179 Treatment Advocacy Center, *op. cit.*

fond, notamment dans les médias, à la télévision et dans la presse écrite, pour contrer la reproduction continuelle d'images stigmatisantes et fausses des maladies psychiatriques. Ils réclamaient aussi la production d'émissions rendant compte de manière juste et exacte des questions de maladie mentale [et demandaient] que la presse électronique et écrite adopte des codes de conduite pour guider les journalistes à ce sujet.[180]

En Australie, on a lancé une stratégie médiatique nationale dans le cadre de laquelle le gouvernement a collaboré directement avec les médias pour promouvoir des messages plus positifs au sujet de la maladie mentale et de la prévention du suicide. La stratégie australienne est mise en oeuvre dans les écoles de journalisme et dans les universités, de façon à enseigner aux journalistes comment ils devraient aborder ces questions lorsqu'ils s'adressent à la communauté, de manière à ne pas stigmatiser les personnes atteintes de trouble mental.

Des recherches ont également fait ressortir l'importance d'une mise en exergue des exemples de rétablissement couronné de succès, exemples qui, s'ils sont présentés correctement, peuvent à la fois éduquer et distraire le public. Mentionnons ici quelques cas de représentation médiatique positive et de discussion franche des questions de santé mentale[181] :

- la livraison de septembre 2001 du magazine Rosie, consacré à la dépression;
- le film de 1997 Pour le pire et pour le meilleur, avec Jack Nicholson qui joue un personnage atteint de névrose obsessionnelle. Les symptômes de ce trouble sont présentés de manière correcte et, ce qui est encore plus encourageant, le personnage, avec l'aide de la thérapie et de médicaments, réussit à gagner la femme de ses rêves et apprend à vivre avec sa maladie et à la contrôler;
- la série télévisée Monk, qui a débuté en 2002; le personnage principal est un détective privé, Adrian Monk, souffrant lui aussi de névrose obsessionnelle; joué par Tony Shalhoub, ce personnage est présenté de manière réaliste et respectueuse, selon la National Alliance for the Mentally Ill (NAMI).

Bon nombre de spécialistes pensent que le combat à mener pour assurer une représentation médiatique plus exacte et positive de la maladie mentale et des personnes qui en sont atteintes est analogue à la lutte qu'ont dû mener d'autres groupes minoritaires ou défavorisés. Selon Greg Philo, du Glasgow Media Group, les médias ne changeront pas tant qu'il n'y aura pas un mouvement de masse l'exigeant.[182]

3.5 OBSERVATIONS DU COMITÉ

Les témoignages recueillis permettent de penser qu'il faut déployer un effort tous azimuts pour combattre la stigmatisation et la discrimination. Toute campagne destinée à modifier les attitudes devra transmettre un message complexe pendant une longue période, alors que l'éradication des nombres formes de discrimination exigera beaucoup de détermination et de persévérance.

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180 Philo, *op. cit.*
181 Roth Edney, op. cit., p. 9.
182 *Ibid.*

Le Comité estime qu'il est parfaitement légitime d'aborder de manière appropriée chacun des deux phénomènes clés que sont la stigmatisation et la discrimination. On peut et on doit mener la bataille simultanément sur les deux fronts. Éduquer la population pour contrer les attitudes stigmatisantes doit aller de pair avec une opposition ferme à la discrimination, sous toutes ses formes, dont font l'objet les personnes atteintes de trouble mental. Le Comité prend note du succès qu'ont enregistré d'autres groupes stigmatisés lorsqu'ils ont mené des campagnes pour réduire la stigmatisation et la discrimination, et des bienfaits réels qui en ont découlé.

Certains facteurs clés ressortent clairement des témoignages recueillis par le Comité et des documents sur lesquels il s'est penché. Tout d'abord, le Comité est très sensible à l'argument voulant que le simple fait d'adopter une stratégie nationale sur la santé mentale (quels qu'en soient les éléments particuliers) contribuera à lutter contre la stigmatisation et la discrimination. Une stratégie nationale sur la santé mentale attirerait comme jamais l'attention du public sur les questions de santé mentale. Son adoption donnerait à la population le signal que les gouvernements fédéral, provinciaux et territoriaux attachent autant d'importance à assurer la santé mentale des Canadiens et à traiter les maladies mentales qu'à promouvoir la santé physique.

Afin d'assurer la parité entre la santé mentale et la santé physique, et entre les maladies correspondantes, le Comité prend note de la recommandation que l'on modifie la *Loi canadienne sur la santé* pour en éliminer les disparités actuelles. Durant son étude de deux ans du secteur des soins aigus, le Comité s'était montré réticent à l'idée de rouvrir la LCS étant donné le débat difficile qui en découlerait sur quels services devraient être ou non régis par la Loi. Toutefois, en ce qui concerne la santé mentale, le Comité pense qu'il faudrait sérieusement examiner la possibilité de modifier la LCS, étant donné l'énorme valeur symbolique d'une telle initiative.[183]

Le Comité estime qu'un certain nombre de mesures particulières devraient faire partie des efforts nationaux de réduction de la stigmatisation et de la discrimination. Tout d'abord, il faudra trouver le moyen de contrer l'attribution aux personnes atteintes de trouble mental grave d'une propension exagérée à la violence. Ensuite, les mesures de réduction de la stigmatisation et de la discrimination devront être attentivement ciblées afin d'en maximiser l'effet. Il faudra par ailleurs faire participer les personnes atteintes de trouble mental à la conception, à la formulation et à la prestation de ces campagnes, car ce sera essentiel pour en assurer le succès. Il importera aussi de démontrer que le rétablissement est possible et de promouvoir une meilleure santé mentale afin de favoriser les changements d'attitudes à l'égard des personnes souffrant de trouble mental.

Enfin, le Comité prend note de la persistance d'un phénomène de stigmatisation et de discrimination au sein même du système de soins de santé, de manière générale, tout comme au sein du système de soins de santé mentale. Il conviendra donc d'agir à ces deux niveaux à l'intention de toute la communauté de prestation de soins de santé. Premièrement, il faudra réduire la stigmatisation des professionnels de la santé mentale par le reste du monde de la santé, de façon à éradiquer la discrimination structurelle qui affecte ce secteur.

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183 Ces questions sont traitées plus en détail au chapitre 9.

Deuxièmement, il faudra travailler avec tous les professionnels de la santé pour promouvoir une image plus positive des personnes souffrant de trouble mental.

PARTIE 2

Prévalence et conséquences de la maladie mentale et de la toxicomanie

CHAPITRE 4:
CONCEPTS ET DÉFINITIONS

INTRODUCTION

> **On ne dispose pas d'une langue respectable et commune pour parler de maladie mentale et de santé mentale dans les divers secteurs et disciplines.** ***[Phil Upshall, président, Alliance canadienne pour la maladie mentale et la santé mentale, mémoire au Comité, 18 juillet 2003, p. 11.]***

La terminologie et les notions relatives à la santé mentale, à la maladie mentale et à la toxicomanie ne sont pas faciles à définir. La terminologie varie selon les pays et, dans un même pays, les groupes, organisations et associations de professionnels et de profanes emploient souvent des expressions différentes pour définir des concepts clés en matière de santé mentale, de maladie mentale et de toxicomanie. Une même notion peut donc être désignée par divers termes, et certains termes peuvent avoir un sens différent d'un groupe à l'autre. Même au Canada, quelques expressions ont plusieurs sens et sont appliquées sans uniformité, ce qui est fréquemment sources de confusion.

Le présent chapitre définit divers concepts (**qui seront repris au fil de ce rapport**) en matière de santé mentale, de maladie mentale et de toxicomanie. Il comprend neuf sections portant sur les thèmes suivants : santé mentale et maladie mentale (section 4.1); principaux troubles mentaux (4.2); usage de substances et toxicomanie (4.3); comorbidité, troubles concomitants et diagnostic mixte (4.4); comportement suicidaire (4.5); services et moyens de soutien (4.6); gestion des maladies chroniques (4.7); promotion, prévention et surveillance (4.8); personnes atteintes de maladie mentale ou de toxicomanie et rétablissement (4.9).

4.1 SANTÉ MENTALE ET MALADIE MENTALE

> *Les maladies mentales minent la santé mentale, mais la santé mentale ne se réduit pas à l'absence de maladies mentales. Il s'agit plutôt de la ressource essentielle de tous les êtres humains et d'une composante fondamentale de la santé vue sous tous ses angles.*
> *[Tom Lips, Santé Canada (11:7)]*

La *santé mentale* est définie comme la capacité de chaque personne de ressentir les choses, de réfléchir et d'agir de manière à mieux jouir de la vie, à mieux faire face aux défis.[184] Autrement dit, elle désigne diverses capacités, notamment celles de se comprendre et de comprendre sa vie; d'être en relation avec les autres et de réagir à son environnement; d'éprouver du plaisir et de jouir de la vie; de surmonter le stress et des états de malaise;

[184] Santé Canada, Unité de la promotion de la santé mentale, *Promouvoir la santé mentale, c'est promouvoir le meilleur de nous-mêmes – Foire aux questions.* (http://www.hc-sc.gc.ca/hppb/sante-mentale/psm/questions.html).

d'évaluer les défis et les problèmes; de poursuivre des buts et des intérêts; d'évaluer des choix et de prendre des décisions.

Une *bonne santé mentale* est associée à l'estime de soi, au bonheur, à l'envie de vivre, à la satisfaction au travail, à la maîtrise et à la cohérence. Il est bien connu qu'une bonne santé mentale permet aux gens de réaliser leur plein potentiel et de contribuer utilement à la société.[185]

Les *problèmes de santé mentale* sont, au contraire, synonymes de capacités réduites – cognitives, émotives, attentionnelles, interpersonnelles, motivationnelles ou comportementales – qui empêchent de jouir de la vie ou nuisent aux interactions de celui ou celle qui en souffre avec la société ou l'entourage. La faible estime de soi, la frustration ou l'irritabilité fréquente, l'épuisement professionnel, le stress et l'inquiétude excessive sont autant d'exemples de problèmes courants de santé mentale.[186] Tout le monde, à un moment donné de sa vie, éprouve des problèmes de santé mentale de ce genre. Ce sont habituellement des réactions normales à court terme face à des situations difficiles (comme les pressions scolaires, le stress professionnel, les conflits conjugaux, le chagrin, une modification de l'état matrimonial) qu'on surmonte de diverses façons en s'appuyant sur ses forces intérieures, sur sa famille ou sa communauté, par exemple.

Les problèmes de santé mentale qui se règlent rapidement, ne se reproduisent plus et n'entraînent pas d'incapacité importante, ne répondent pas aux critères de la maladie mentale. En revanche, on qualifie habituellement de *troubles mentaux* ou *maladie mentale* les comportements ou les réactions émotionnelles d'une sévérité marquée, auxquels sont associés un certain niveau de détresse, de souffrance (le mal, la mort) ou d'incapacité fonctionnelle (par exemple, à l'école, au travail, dans un contexte social ou familial).[187]

Une définition des maladies mentales ou troubles mentaux qui est couramment utilisée est tirée de la 4e édition du Diagnostic and Statistical Manual de l'American Psychiatric Association. (…) Selon cette dernière, la cause d'une maladie mentale peut être soit biologique, soit psychologique. Elle exclut cependant les réactions normales à une situation stressante.
[Tom Lips, Santé Canada (11:8)]

Il existe de nombreux types de troubles mentaux qui varient grandement en fonction de l'évolution et du profil de la maladie, du type et de la gravité des symptômes, ainsi que de la gravité de l'incapacité qui en découle. On peut recenser un seul épisode de maladie ou plusieurs épisodes répétés, espacés de longues périodes de bien-être. Si certains troubles mentaux sont de nature épisodique ou cyclique, d'autres sont plus persistants et comportent de longs ou fréquents épisodes récurrents. Ceux qui souffrent d'une maladie persistante reçoivent habituellement des traitements et bénéficient de moyens de soutien à long terme.

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185 Alliance canadienne pour la maladie mentale et la santé mentale, *Appel à l'action – Dégager un consensus à l'égard d'un plan d'action national sur la maladie mentale et la santé mentale*, 2000, document de discussion, p. 7. (http://www.camimh.ca/cfa/francais/FrenchCAMIMH2003.pdf)

186 Thomas Stephens *et al.*, « Mental Health of the Canadian Population: A Comprehensive Analysis », *Chronic Diseases in Canada*, vol. 20, n° 3, 1999.

187 Association des psychiatres du Canada, *La jeunesse et les maladies mentales* http://www.cpa-apc.org/MIAW/pamphlets/Youth_fr.asp, sans date.

4.2 PRINCIPAUX TROUBLES MENTAUX

Au Canada, la classification des maladies mentales suit, soit le Diagnostic and Statistical Manual of Mental Disorders (DSM) publié par l'American Psychiatric Association, soit la section sur la santé mentale de la Classification internationale des maladies (CIM), publiée par l'Organisation mondiale de la santé.[188] Chacun de ces deux systèmes de classification dresse la liste de plus de 300 troubles mentaux pouvant être diagnostiqués. Dans la plupart des cas, ces troubles sont regroupés en fonction de la similitude des symptômes ou du profil de la maladie.

La liste complète des diagnostics de troubles mentaux figure dans les manuels du DSM et dans la CIM. Certains des grands regroupements comprennent : les troubles de l'humeur (dépression et trouble bipolaire), les troubles anxieux (trouble d'anxiété généralisée, phobies, trouble panique, trouble obsessivo-compulsif et syndrome de stress post-traumatique), les troubles psychotiques (schizophrénie et trouble schizoaffectif), les troubles de l'alimentation (anorexie et boulimie), les troubles de la personnalité, les troubles du développement profonds (autisme et syndrome d'Asperger), le trouble déficitaire de l'attention et les troubles de comportement perturbateur, et les troubles cognitifs (démence et délire provoqué par diverses causes).[189] Les troubles liés à une substance psychoactive figurent également dans la classification des troubles mentaux. Dans le présent rapport, ils sont examinés dans une section distincte afin de mettre en évidence leur importance et leur rapport avec la toxicomanie.

Les *troubles de l'humeur* comprennent le trouble dépressif majeur et le trouble bipolaire. Le *trouble dépressif majeur* (également appelé dépression unipolaire) se caractérise par un ou plusieurs épisodes dépressifs d'une durée d'au moins deux semaines. Le principal symptôme est des baisses d'humeur soutenues (différentes des sentiments normaux de tristesse) et/ou une diminution marquée du plaisir tiré des activités habituelles ou de l'intérêt pour ces activités. À cela s'ajoutent au moins quatre autres symptômes caractéristiques de la dépression comme la perturbation, la fatigue ou la perte

> **Lorsqu'on parle de troubles mentaux, les troubles mentaux les plus prévalents sont les troubles anxieux, les troubles dépressifs. (…) Le troisième grand groupe concerne la toxicomanie (…). C'est donc dire que ces troubles courants sont très prévalents. En comparaison, vous allez également entendre parler de troubles mentaux graves, comme par exemple la schizophrénie, la psychose maniaco-dépressive et, chez les enfants adolescents, et éventuellement à l'âge adulte, les troubles d'autisme. Ce sont donc des troubles graves.**
> ***[Dr Alain Lesage, Académie canadienne d'épidémiologie psychiatrique (11:12)]***

188 Le système de classification du DSM ne porte que sur les troubles psychiatriques et exclut toute autre catégorie de maladie. Le DSM d'usage courant actuellement au Canada est une révision de la quatrième édition (DSM-IV-TR). La cinquième édition (DSM-V) devrait paraître bientôt. La CIM-10, la dixième édition du système CIM, qui porte sur toutes les maladies et conditions de santé, est adoptée actuellement dans l'ensemble du Canada. Elle remplace la CIM-9 qui, jusqu'à récemment, constituait le système standard de diagnostic dans les hôpitaux et les organisations de santé du Canada. Les systèmes de classification DSM et CIM sont tous les deux mis à jour périodiquement par des experts, afin de préciser l'exactitude des diagnostics et d'intégrer les nouvelles données scientifiques.

189 Association canadienne pour la santé mentale, *Les maladies mentales*, pamphlet, sans date.

d'énergie, la perte d'appétit, des fluctuations de poids, la diminution de la concentration, la difficulté de penser et de prendre des décisions, ainsi que des pensées morbides récurrentes. Les dépressions majeures sont deux fois plus fréquentes chez les femmes que chez les hommes. Le *trouble bipolaire*, également appelé psychose maniaco-dépressive, est une maladie mentale caractérisée par des sautes d'humeur spectaculaires, allant de la manie à la dépression. La manie, un état reconnu depuis l'Antiquité, se caractérise par au moins une semaine d'humeur altérée d'euphorie, de volubilité ou d'irritabilité. Comme la dépression, elle est associée à quelques autres symptômes connexes, souvent le contraire de ceux de la dépression, y compris une hausse marquée de l'énergie, une baisse du besoin de sommeil, une estime de soi accrue et une propension à se lancer dans des activités risquées. En général, le trouble bipolaire apparaît au début de la vie adulte, c'est-à-dire de 18 à 24 ans, cependant certains cas se déclarent dès l'enfance ou très tard dans la quarantaine ou la cinquantaine. Les hommes et les femmes sont affectés également.[190]

Les *troubles anxieux* peuvent prendre diverses formes. Ils comprennent le trouble d'anxiété généralisée, des phobies spécifiques, le trouble panique (avec ou sans agoraphobie), le trouble obsessivo-compulsif et le syndrome de stress post-traumatique. Le *trouble d'anxiété généralisée* se caractérise par une période prolongée (c.-à-d. de plus de six mois) d'anxiété et d'inquiétude accompagnée d'autres symptômes comme une tension musculaire, la fatigue, une mauvaise concentration, l'insomnie et l'irritabilité. Les *phobies* sont une crainte excessive de certains objets, actes, situations ou idées (animaux, insectes, hauteurs, ascenseurs, société, etc.). L'exposition à l'objet de la phobie, imaginaire, virtuel ou réel, suscite invariablement une anxiété intense, qui peut comprendre une attaque de panique. On parle de *trouble panique* dans le cas d'une personne ayant vécu plusieurs crises de panique inattendues –périodes caractérisées par le déclenchement soudain d'une peur ou d'un malaise intense souvent accompagnés de palpitations, de sensations de souffle court et de la peur d'une catastrophe imminente – conjuguées à la crainte de nouvelles crises. Le *trouble obsessivo-compulsif* comporte des obsessions ou des compulsions (ou les deux à la fois) que le malade reconnaît être excessives ou déraisonnables. Les obsessions comprennent des pensées, des idées, des impulsions ou des images persistantes, envahissantes et inappropriées qui sont cause d'une détresse prononcée. Les compulsions désignent des comportements répétitifs (comme le fait de se laver sans cesse les mains) ou des actes mentaux (comme compter) qui revêtent un caractère ritualiste ou qui s'inscrivent en réaction à une obsession. Le *syndrome de stress post-traumatique* consiste à revivre un événement traumatisant dans ses rêves ou ses souvenirs, à éviter les stimuli qui rappellent l'événement, à se désensibiliser affectivement et à se sentir plus alerte; il se produit après un événement traumatisant dans lequel la personne a été menacée ou blessée physiquement par un agent stressant (comme un viol, une agression sexuelle contre un enfant, une guerre ou un combat, ou une catastrophe naturelle). Pris globalement, les troubles anxieux atteignent tout autant les hommes que les femmes; ils apparaissent généralement tôt dans la vie (pendant l'enfance ou l'adolescence) et persistent souvent de nombreuses années.[191]

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190 D'après des renseignements affichés sur le site Internet de la Société pour les troubles de l'humeur du Canada (http://www.mooddisorderscanada.ca/).

191 D'après des renseignements affichés sur le site Internet de l'Association canadienne des troubles anxieux (http://www.anxietycanada.ca/).

La *schizophrénie* est une maladie mentale qui apparaît habituellement à la fin de l'adolescence et au début de l'âge adulte. Elle est typiquement considérée comme un trouble chronique, grave et incapacitant à long terme. Les efforts systématiques entrepris au cours de la dernière décennie en vue de dépister la maladie plus tôt et d'intervenir globalement au niveau biopsychosocial permettent d'espérer que l'on parviendra à infléchir le caractère implacable de cette maladie qui est souvent de longue durée. Des décennies de recherches portant notamment sur la génétique et l'imagerie cérébrale vont dans le sens d'un modèle biologique de la schizophrénie, encore que ses causes restent inconnues. Cette maladie influe sur la pensée et provoque des hallucinations (comme entendre des voix), des délires (convictions obsessives non fondées, comme la crainte d'être suivi par des inconnus ou être convaincu que des inconnus vous veulent du mal), une perte de contact avec la réalité et une perturbation des interactions professionnelles et sociales. Elle apparaît souvent lentement et, une fois bien établie, elle se caractérise en général par des cycles de rémissions et de rechutes. Les hommes et les femmes sont affectés également par la schizophrénie.[192]

Les *troubles de l'alimentation* se caractérisent par une grave perturbation des comportements alimentaires. Certains de ces troubles se règlent spontanément par eux-mêmes ou à l'aide de traitements durant l'adolescence, mais d'autres peuvent devenir chroniques. Selon des études de suivi à long terme, jusqu'à 18 p. 100 des personnes touchées peuvent mourir de cet état. Les troubles de l'alimentation les plus courants sont l'anorexie, la boulimie et l'alimentation compulsive. L'*anorexie* se caractérise par un faible poids (moins de 85 p. 100 du poids normal), par une crainte intense de grossir en dépit d'une perte de poids considérable, par une perception erronée de son poids ou de son apparence corporelle, par la négation de sa maigreur et par la grande importance accordée au poids dans la façon dont on s'évalue. La *boulimie nerveuse*, en revanche, frappe le plus souvent des personnes de poids normal. Elle se caractérise par des épisodes récurrents de frénésie alimentaire, suivies d'activités compensatoires visant à éliminer les calories ingérées (comme les vomissements volontaires, l'abus de laxatifs ou de diurétiques, l'exercice intense, etc.). Elle a cependant en commun avec l'anorexie de nombreuses préoccupations psychologiques de base relatives au poids et à l'apparence corporelle. L'*alimentation compulsive* est un trouble reconnu depuis peu caractérisé par des périodes d'ingestion incontrôlées d'aliments, sans les activités compensatoires de la boulimie nerveuse. Les troubles de l'alimentation (ou hyperphagie boulimique) apparaissent habituellement à l'adolescence et frappent surtout les femmes.[193]

Les *troubles de la personnalité* comprennent un certain nombre de troubles dont les caractéristiques et les profils de comportement varient grandement.[194] Ils partagent cependant tous les caractéristiques suivantes : modes durables d'expérience et de comportement qui sont contraires aux attentes de la société, et modes de comportement profonds, inflexibles et stables dans le temps et qui conduisent à la détresse ou à une déficience.[195] Certaines formes de ces troubles entraînent des souffrances surtout chez le malade (p. ex., le trouble de la personnalité évitante, caractérisé par les sentiments de malaise

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192 British Columbia Schizophrenia Society, *Basic Facts About Schizophrenia*, avril 2002.

193 United States Surgeon General, *Mental Health: A Report of the Surgeon General*, 1999, p. 167.

194 Les troubles de la personnalité comprennent les troubles de la personnalité limites, antisociale, histrionique, narcissique, évitante, dépendante, schizoïde, obsessio-compulsive et schizotypique.

195 Paula Stewart, *Rapport sur les maladies mentales au Canada*, http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/miic-mmac/pdf/men_ill_f.pdf, Santé Canada, octobre 2002, p. 70.

extrême et d'autocritique intense dans des situations sociales, qui mène à une solitude et à un isolement profonds malgré l'intense désir d'avoir des contacts sociaux). D'autres formes de troubles de la personnalité peuvent non seulement entraîner une grande détresse chez le malade, mais aussi avoir des conséquences néfastes profondes sur les autres et occasionner des coûts importants pour la société (p. ex., le trouble de la personnalité antisociale, qui se caractérise par l'irrespect et la violation des droits d'autrui, donne souvent lieu à une activité criminelle répétitive, à un comportement violent impulsif, à la duplicité et à l'absence de remord.) Bien que les troubles de la personnalité apparaissent habituellement à l'adolescence ou au début de la vie adulte, ils peuvent aussi se manifester au milieu de la vie adulte. Contrairement aux maladies mentales décrites jusqu'ici, les troubles de la personnalité sont reliés plus intimement au tempérament et au caractère des personnes qui en souffrent.[196]

L'*autisme* est un trouble mental qui apparaît dans l'enfance et qui, chez certaines personnes touchées, peut devenir une maladie incapacitante durant toute la vie. En règle générale, les autistes présentent les caractéristiques suivantes : difficulté à avoir des interactions sociales; problèmes de communication et comportements particuliers (p. ex., préoccupation, résistance au changement, attachement à des rituels sans fonction et comportements stéréotypés et répétitifs). Des retards ou anomalies de développement concernant l'interaction, la langue et le jeu sont évidents avant l'âge de 3 ans. L'autisme peut s'accompagner d'autres états incapacitants comme des crises ou d'importants retards cognitifs (intellectuels).[197] Les symptômes et déficits liés à l'autisme peuvent cependant varier. Par exemple, certains autistes fonctionnent à un niveau relativement élevé, le langage et l'intelligence étant intacts, tandis que d'autres, dont le développement est retardé, ne parlent pas ou ont de graves problèmes de langue.[198] L'autisme a tendance à être de trois à quatre fois plus fréquent chez les hommes que chez les femmes.

Le *trouble déficitaire de l'attention* (TDA) et l'*hyperactivité avec déficit de l'attention* (HDA) sont des termes employés pour décrire des structures de comportement qui se présentent généralement chez les enfants d'âge scolaire. Ils nuisent au processus d'apprentissage, car ils réduisent la capacité de l'enfant à être attentif. Les enfants présentant ces troubles sont inattentifs, excessivement impulsifs et, dans le cas de l'HDA, hyperactifs. Ils ont de la difficulté à se tenir tranquilles, à se concentrer sur une tâche particulière pour une longue période et peuvent sembler hyperactifs. Le TDA et l'HDA sont diagnostiqués dix fois plus souvent chez les garçons que chez les filles.[199] Les déficits de l'attention associés à ces troubles peuvent persister au-delà de l'enfance et de l'adolescence, tandis que les symptômes de hyperactivité et de l'impulsivité ont tendance à diminuer avec l'âge. Bien que de nombreux enfants souffrant de TDA et d'HDA finissent par s'ajuster, une proportion plus élevée que dans la population de personnes non touchées est susceptible d'abandonner l'école et d'avoir une carrière moins brillante plus tard. À mesure qu'ils vieillissent, certains adolescents souffrant d'HDA profonde depuis le milieu de leur enfance vivent des périodes

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196 Paula Stewart (2002), p. 72-73.

197 Association canadienne pour l'obtention de services aux personnes autistiques, *What is Autism?*.

198 National Institute of Mental Health, *Briefing Notes on the Mental Health of Children and Adolescents*, United States, sans date. (www.nimh.nih.gov).

199 Association canadienne pour la santé mentale, *Les enfants et les troubles déficitaires de l'attention*, http://www.cmha.ca/french/info_centre/mh_pamphlets/mh_pamphlet_17.htm, Série de dépliants, sans date.

d'anxiété ou de dépression. Ils peuvent également être plus enclins à abuser de substances et à afficher des comportements antisociaux.[200]

La *maladie d'Alzheimer* est un trouble cérébral organique qui entraîne la perte de fonctions mentales et physiques. À l'instar d'autres maladies, dont la maladie de Parkinson et la maladie de Huntington, elle est classifiée comme une maladie dégénérative du système nerveux central. La maladie d'Alzheimer est la principale cause de démence. Plusieurs changements se produisent dans le cerveau, notamment une perte progressive de neurones du cortex cérébral et d'autres régions. Cela étant, une personne atteinte de la maladie d'Alzheimer possède moins de tissu cérébral qu'un sujet sain; la diminution continue avec le temps et affecte le fonctionnement du cerveau.[201] La perte de mémoire est le principal symptôme précoce de la maladie, souvent suivi par une lente détérioration des fonctions cognitives, des caractéristiques de la personnalité et de la capacité physique. Certains malades ont des hallucinations, des délires, des crises et un comportement agressif. La maladie d'Alzheimer frappe les hommes et les femmes également.[202]

Bien qu'ils ne soient pas considérés comme des troubles mentaux, le *syndrome d'alcoolisation fœtale* et les *effets de l'alcool sur le fœtus* (SAF/EAF) constituent d'importantes déficiences congénitales qui perturbent la fonction cérébrale. Les dommages au cerveau du fœtus, qui occasionnent un retard de développement, découlent des effets de la consommation d'alcool par la mère durant la grossesse. Les nourrissons atteints du SAF ou souffrant des EAF présentent divers dysfonctionnements : irritabilité, agitation, tremblements, réflexe de succion défaillant, problèmes de sommeil et d'alimentation, retard de croissance, piètre motricité et défauts d'habituation. Il n'est pas rare d'observer ensuite chez l'enfant d'âge préscolaire des problèmes d'hyperactivité, des difficultés d'attention, des problèmes de perception et de langage ainsi que des troubles de motricité. À l'adolescence et à l'âge adulte, on constate principalement des troubles de la mémoire, des problèmes de jugement et des difficultés à raisonner dans l'abstrait ainsi qu'un mauvais comportement adaptatif. Parmi les incapacités secondaires les plus fréquemment observées chez les adolescents et les adultes atteints du SAF ou souffrant des EAF, mentionnons la victimisation que subissent fréquemment ces personnes, la difficulté à focaliser leur intérêt et une facilité à être distraits, la difficulté à faire un budget, des difficultés à tirer des leçons de leur expérience, des difficultés à comprendre les conséquences et à percevoir les indices sociaux, une faible tolérance à la frustration, un comportement sexuel inapproprié, la toxicomanie, des troubles mentaux ainsi que des démêlés avec la justice.[203]

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200 US Surgeon General Report (1999), p. 144.

201 Centre canadien de ressources sur la maladie d'Alzheimer, http://www.alzheimercentre.ca/francais/default.htm.

202 Sonya Norris, *La maladie d'Alzheimer*, PRB 02-39F, Bibliothèque du Parlement, 2 octobre 2002.

203 Fred J. Boland *et al.*, *Syndrome d'alcoolisme fœtal : répercussions pour le service correctionnel*, http://www.csc-scc.gc.ca/text/rsrch/reports/r71/r71e_f.shtml , Services correctionnels Canada, juillet 1998.

4.3 USAGE DE SUBSTANCES ET TOXICOMANIE

> *Il est important de faire la distinction entre la consommation et l'abus de drogues ainsi que la dépendance à celles-ci. La consommation de substances psychoactives est très courante. L'abus l'est moins et la dépendance ne touche qu'une minorité de gens qui consomment de telles substances. L'ampleur des conséquences est plus grande dans le cas de l'abus et encore plus importante dans celui de la dépendance.*
> *[Dr David Marsh, Centre de toxicomanie et de santé mentale (16:44)]*

D'après Santé Canada, l'*usage de substances* comprend la consommation de toute substance psychotrope – autrement dit, des substances qui ont un effet sur l'état mental – dont le tabac, l'alcool, les médicaments en vente libre ou sur ordonnance, les drogues illicites, les solvants et les produits pour inhalation. Le rythme de consommation va de l'abstinence à l'abus de substances en passant par une consommation occasionnelle ou régulière et une consommation fréquente et excessive.[204]

Les *troubles liés à une substance psychoactive,* qui sont considérés comme des troubles mentaux dans le DSM et dans la CIM, désignent la consommation habituelle d'alcool ou de drogues qui entraîne des problèmes importants sur les plans du travail, des relations personnelles, de la santé physique et financière et des autres aspects de la vie personnelle. Ils comprennent l'abus d'une substance et la dépendance à une substance.[205] L'*abus d'une substance* désigne un mode d'utilisation inadéquat même si la personne est conscience des conséquences négatives de cette consommation. La *dépendance à une substance* se caractérise par la perte de contrôle, la préoccupation concernant l'utilisation continue de substances malgré ses conséquences négatives.[206]

La *dépendance* peut être physique, psychologique ou les deux. La *dépendance physique* implique la tolérance (besoin de consommer davantage de la substance pour obtenir le même effet). On parle de *dépendance psychologique* dans le cas d'un sujet qui éprouve le besoin intense de consommer la substance afin de fonctionner efficacement ou dans des situations particulières. Les degrés de dépendance vont de léger à grave, la dépendance grave étant qualifiée de toxicomanie.[207]

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204 Colleen Hood, Colin Mangham, Don McGuire et Gillian Leigh, *Explorer les liens la santé mentale et l'usage de substances*, Section I (« Document de travail » et Section II, (« Table ronde ») Santé Canada, 1996, p. 44. (http://www.hc-sc.gc.ca/hecs-sesc/sca/pdf/discus_f.pdf)

205 Santé Canada, *Meilleures pratiques – Troubles concomitants de santé mentale et d'alcoolisme et de toxicomanie* , http://www.hc-sc.gc.ca/hecs-sesc/sca/pdf/concomitantsmeilleurespratiques.pdf, 2002, p. 8.

206 *Ibid.*, p. 102-103.

207 BC Partners for Mental Health and Addictions Information, "What is Addiction?", *The Primer – Fact Sheets on Mental Health and Addiction Issues*, (http://mentalhealthaddictions.bc.ca/).

La *toxicomanie* implique la consommation incontrôlable d'une ou de plusieurs substances et il y a apparition de malaises ou d'un sentiment de détresse lorsque cette consommation est interrompue ou grandement réduite. La toxicomanie peut également décrire certains autres problèmes de comportement, comme le *jeu compulsif* ou *pathologique* qui peut être considéré comme un processus plutôt qu'une toxicomanie. Les recherches effectuées jusqu'ici semblent en effet indiquer que le jeu pathologique s'installe progressivement, comme l'alcoolisme.[208]

Dans le présent rapport, nous employons fréquemment le mot « toxicomanie » pour désigner le vaste domaine de l'abus de substances. Le terme *système de traitement de la toxicomanie* comprend les traitements, les services et les moyens de soutien offerts aux personnes souffrant de toxicomanie et de troubles liés à la consommation de substances psychoactives.

4.4 COMORBIDITÉ, TROUBLES CONCOMITANTS ET DIAGNOSTIC MIXTE

La comorbidité signifie que deux maladies au moins sont présentes chez une même personne, qu'il s'agisse de deux troubles mentaux différents, de deux maladies physiques ou d'un trouble mental et d'une maladie physique. Dans le présent rapport, la notion de *comorbidité* désigne la présence d'une maladie mentale et d'une maladie physique. Par exemple, les données épidémiologiques ont révélé que 25 p. 100 des patients qui souffrent d'arthrite souffrent également de dépression ou d'anxiété comorbide; que la comorbidité est élevée en présence de cancer, de diabète, de troubles respiratoires, d'hypertension ou de migraine et de certaines maladies mentales. Les interactions entre la maladie physique et la maladie mentale sont cependant très complexes.[209]

L'expression *troubles concomitants* s'applique le plus souvent à des personnes atteintes simultanément d'une maladie mentale et d'un trouble lié à l'usage de substances psychoactives. Les liens entre la maladie mentale et la consommation de substances ne sont pas simples. D'une part, les problèmes de santé mentale et les maladies mentales peuvent constituer des facteurs de risque pour une consommation accrue de substances (p. ex., l'anxiété accrue peut mener à une consommation accrue d'alcool) et, d'autre part, l'abus de substances peut constituer un facteur de risque pour un accroissement des problèmes de santé mentale ou des maladies mentales (p. ex., une consommation excessive d'alcool peut constituer un facteur de risque de dépression). Dans d'autres situations, une cause commune peut expliquer le fait que

En règle générale, les « troubles concomitants » se retrouvent chez les personnes qui combinent des problèmes mentaux, émotifs ou psychiatriques et l'abus d'alcool et/ou d'autres drogues psychoactives. Sur un plan plus technique et dans la terminologie des diagnostics, ils désignent toute combinaison de troubles mentaux et de troubles liés à l'usage de substances, tels que définis par exemple sur l'axe I et/ou II du DSM-IV.
[Brian Rush, CTSM, mémoire au Comité, mai 2004, p. 2.]

208 Santé Canada (1996), p. 33.
209 Paula Stewart (2002), p. 22.

les deux troubles sont favorisés par un troisième facteur, tel que la prédisposition génétique ou le milieu familial. Les recherches indiquent cependant que la maladie mentale et le trouble lié à l'usage de substances sont parfois indépendants l'un de l'autre.[210]

Dans le présent rapport, *diagnostic mixte* s'applique aux personnes qui ont un problème de santé mentale ou une maladie mentale et une déficience développementale (ce qu'on appelait autrefois « arriération mentale »). Parce qu'il est difficile de diagnostiquer la maladie mentale chez une personne présentant une déficience développementale, il arrive souvent que le diagnostic mixte ne soit pas posé et donc que le problème ne soit pas traité. Les personnes dans cette situation ont des besoins complexes et délicats et comptent certainement parmi les membres les plus vulnérables de la population canadienne. Elles risquent plus que les autres Canadiens de vivre une agression (plus particulièrement une agression sexuelle), de connaître la négligence et l'exploitation. Elles passent souvent entre les mailles du filet.[211]

4.5 COMPORTEMENT SUICIDAIRE

L'expression *comportement suicidaire* englobe aussi bien le suicide réussi (décès par suicide) que les tentatives de suicide (y compris l'automutilation) et l'idéation suicidaire (pensées suicidaires). Le comportement suicidaire est souvent la conséquence de l'interaction de plusieurs facteurs comme des facteurs de stress aigus et des événements négatifs (p. ex., deuil, perte d'un emploi, séparation, maladie), de symptômes liés à un épisode grave de maladie mentale ou de trouble lié à l'usage de substances psychoactives (p. ex., psychose, dépression, intoxication), de traits de personnalité ou de circonstances sociales et/ou économiques.

> **La présence de problèmes mentaux est probablement la plus importante variable prédictive du suicide. Environ 90 p. 100 des suicides répondent aux critères d'un trouble psychiatrique, en particulier une dépression grave, des troubles liés à l'usage de substances psychoactives et la schizophrénie. Mais seule une minorité de personnes affectées par ces troubles se suicide, ce qui indique qu'un trouble psychiatrique pourrait constituer un facteur de risque nécessaire mais insuffisant pour le suicide.**
> ***[Dr Gustavo Turecki, mémoire au Comité, 21 avril 2004, p. 1.]***

Bien que le comportement suicidaire ne constitue pas, en soi, un trouble mental, la corrélation avec la maladie mentale et la toxicomanie est étroite. Les études indiquent que plus de 90 p. 100 des victimes de suicide ont une maladie mentale ou un trouble lié à l'usage de substances diagnosticable.[212] Le suicide est la cause la plus fréquente de décès chez les schizophrènes. Il représente également de 15 à 25 p. 100 des décès chez les personnes souffrant de graves troubles de l'humeur.[213]

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210 Santé Canada, , *Meilleures pratiques – Troubles concomitants de santé mentale et d'alcoolisme et de toxicomanie* , http://www.hc-sc.gc.ca/hecs-sesc/sca/pdf/concomitantsmeilleurespratiques.pdf, 2002.

211 Association canadienne pour la santé mentale – Division de l'Ontario, *Dual Diagnosis: People with Developmental Disability and Mental Illness – Falling Through the Cracks*, fiche documentaire, 1998.

212 BC Partners for Mental Health and Addictions Information, "Suicide: Follow the Warning Signs", *The Primer – Fact Sheets on Mental Health and Addictions Issues*.

213 D'après les données de l'Association canadienne pour la santé mentale – Ontario Division (http://www.ontario.cmha.ca/).

La toxicomanie prédispose souvent au comportement suicidaire en intensifiant les sautes d'humeur suicidaires et en réduisant la maîtrise de soi.[214]

4.6 SERVICES ET MOYENS DE SOUTIEN

Par le passé, les soins de santé mentale dans le système de santé classique comprenaient les soins primaires, secondaires et tertiaires. Les soins primaires, c.-à-d. les soins de première ligne, comprenaient habituellement les procédures de diagnostic simples, les traitements de base et l'aiguillage vers des services spécialisés, au besoin. On a accordé beaucoup d'attention à l'amélioration de la capacité des soins de santé mentale primaires, étant donné qu'il est désormais reconnu qu'un fort pourcentage de la population devrait recevoir des services reliés à des problèmes de santé mentale dans ce secteur du système de santé. Les soins secondaires sont des soins spécialisés qui comportent des procédures de traitement plus complètes et plus compliquées. Ils peuvent être offerts dans les hôpitaux, les cliniques ou les cabinets à des clients hospitalisés ou non. Les soins tertiaires désignent généralement les interventions spécialisées que conduisent des professionnels, ayant reçu une formation poussée, auprès de personnes qui ont des problèmes particulièrement complexes et qui sont réfractaires aux soins primaires et secondaires. Dans le système de soins de santé mentale, les soins tertiaires désignent également les soins de longue durée que l'on dispensait jadis dans les grands hôpitaux psychiatriques à des personnes souffrant de troubles mentaux persistants. La recherche et l'enseignement sont également des activités menées dans les établissements de soins tertiaires.

Dans le présent rapport, nous reconnaissons que ceux et celles qui souffrent de maladies mentales et de troubles liés à la consommation de substances psychoactives ont besoin de services et de moyens de soutien nombreux et variés. Ces services et ces moyens sont offerts par de nombreux fournisseurs de services et organismes professionnels ou non professionnels. Ils ne se limitent pas à ce qui est offert dans le système classique de soins de santé mentale. Un examen des meilleures pratiques canadiennes semble révéler un besoin pour les services et moyens de soutien de base qui suivent dans les domaines de la santé mentale et de la toxicomanie[215] :

- *Gestion de cas* : désigne le soutien constant et permanent offert aux personnes atteintes de maladie mentale ou de troubles liés à l'usage de substances afin de les aider à obtenir les services dont elles ont besoin. Le gestionnaire de cas évalue les besoins, détermine les compétences qui font défaut et dirige le client vers les fournisseurs de services pertinents. La gestion de cas vise à aider les patients/clients à acquérir des compétences utiles dans la vie quotidienne, à favoriser leur intégration dans la société et à prévenir leur hospitalisation. Le *traitement communautaire dynamique* est reconnu comme le modèle de gestion de cas le mieux adapté pour offrir des services à ceux et celles qui souffrent de maladies mentales persistantes et de troubles concomitants. Dans le modèle du traitement communautaire dynamique, la gestion de cas est assurée par une équipe multidisciplinaire au sein même de la collectivité où vit le

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214 *The Merck Manual on Diagnosis and Therapy*, "Suicidal Behaviour", Section 15, Chapter 190.

215 Santé Canada, *Examen des meilleures pratiques de la réforme des soins de la santé mentale*, http://www.hc-sc.gc.ca/hppb/sante-mentale/pubs/bp_review/f_index.html, préparé pour le Réseau de consultation sur la santé mentale fédéral, provincial et territorial, 1997.

patient/client plutôt que dans une clinique ou un établissement. Ces équipes soignantes sont notamment composées de psychiatres, de médecins de famille, de travailleurs sociaux, d'infirmières et d'ergothérapeutes, et elles offrent leurs services aux patients/clients 24 heures sur 24 jour, et sept jours sur sept.

- Il faut disposer d'un vaste éventail de *services internes et externes*, y compris dans les domaines suivants : counselling; psychothérapie; thérapie individuelle et collective; hospitalisation partielle (programmes de traitement de jour); traitements actifs à domicile (au lieu de l'hospitalisation); services spécialisés dans les établissements ou services communautaires et psychiatriques; psychiatrie médico-légale; et soins partagés. Les *soins de santé mentale partagés*[216] sont particulièrement intéressants. Ils désignent un vaste éventail d'activités concertées entre les fournisseurs de soins primaires et les psychiatres ou d'autres fournisseurs de soins de santé mentale primaires. Certains sont surtout cliniques et intègrent les services de santé mentale dans les services de santé mentale primaires, tandis que d'autres offrent des programmes éducatifs novateurs aux fournisseurs de soins de santé primaires par l'intermédiaire d'établissements d'enseignement participants.

- *Les services communautaires, y compris les services de logement, de formation professionnelle, d'aide aux études et d'aide à l'emploi* constituent des éléments importants de toute la gamme des services dont ont besoin les personnes souffrant de troubles mentaux. Il a été démontré que ces types de soutien communautaires peuvent améliorer grandement les résultats. Il est reconnu que les personnes atteintes de maladie mentale peuvent travailler et que les programmes d'emploi devraient être encouragés même pour les plus handicapées d'entre elles. De même, les programmes d'aide aux études permettent de retourner aux études à plein temps. Il semble également que les programmes communautaires d'aide au logement peuvent remplacer avec succès les soins hospitaliers à long terme. Il faudrait donc offrir diverses possibilités de logement (p. ex. foyers supervisés ou autres cadres résidentiels).

- *Les services d'urgence* offrent un vaste éventail de services applicables à des manifestations très variées de graves problèmes de santé mentale ou d'usage de substances. Les services d'urgence comportent cinq volets essentiels : lignes d'écoute téléphonique, services d'urgence mobiles, services de stabilisation de crise sans rendez-vous, services d'urgence internes (non hospitaliers) et services psychiatriques d'urgence dans les hôpitaux.

- D'abord et avant tout, il faudrait insister fortement sur les *initiatives des personnes atteintes de maladie mentale ou de toxicomanie et de leur famille*. La participation de personnes qui ont elles-mêmes éprouvé des problèmes de santé mentale ou de toxicomanie à la planification, à l'exécution, à la gestion, à l'évaluation et à la réforme des soins de santé mentale a permis de mettre en place un vaste éventail d'initiatives axées sur le consommateur et la famille, initiatives qui offrent des services d'information, d'éducation, de formation, d'auto-assistance, d'aide mutuelle et d'entraide. Plus encore : d'importants progrès ont été récemment accomplis dans ce domaine grâce à la création d'entreprises par des consommateurs qui souhaitent

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216 Collège des médecins de famille du Canada et Association des psychiatres du Canada, *Shared Mental Health Care in Canada – A Compendium of Current Projects*, printemps 2002.

promouvoir l'épanouissement personnel et réduire la dépendance envers les services sociaux.

Dans le présent rapport, le *système de soins de santé mentale* désigne le vaste éventail de services et de moyens de soutien mis à la disposition des personnes atteintes de maladie mentale. De même, le *système de traitement de la toxicomanie* désigne toute la gamme des services visant à prévenir ou à réduire et à traiter l'abus de substances, les troubles liés à une substance psychoactive et le jeu compulsif.

4.7 GESTION ET AUTOGESTION DES MALADIES CHRONIQUES

La gestion des maladies chroniques est une approche relativement nouvelle qui s'est révélée très efficace dans le traitement à long terme des maladies. Elle se fonde un modèle appelé « Chronic Care Model » appliqué dans le cadre d'un programme national américain appelé Improving Chronic Illness Care (ICIC) et établi à la Group Health Cooperative of Puget Sound du MacColl Institute for Healthcare Innovation, à Seattle, dans l'État de Washington.[217]

> **La gestion des maladies chroniques en tant que façon d'aborder les soins relatifs à la santé mentale et à la toxicomanie insiste sur l'aide apportée aux malades pour qu'ils conservent leur autonomie et sur le maintien d'une santé optimale grâce à la prévention, au dépistage précoce et à la gestion des troubles mentaux chroniques et des troubles chroniques liés à une substance psychoactive.**
> ***[Ministry of Health Services, Colombie-Britannique, mémoire au Comité, 9 septembre 2003, p. 7.]***

La *gestion des maladies chroniques* repose sur des lignes directrices et des protocoles fondés sur des données cliniques et elle fait appel à de nombreux professionnels et administrateurs de la santé, dans tous les secteurs du système de santé, qui ont une vision commune et collaborent à plusieurs initiatives parallèles. Elle contraste avec le modèle qui traite un épisode comme un événement unique, comme une visite chez un fournisseur de soins de santé. Au Canada et aux États-Unis, la gestion des maladies chroniques a donné d'excellents résultats dans le cas de nombreuses maladies chroniques comme le diabète, l'arthrite, voire l'asthme, et on envisage maintenant de l'appliquer aux maladies mentales et à la toxicomanie. La gestion des maladies chroniques insiste sur les soins communautaires et vise à encourager l'autonomie et l'épanouissement personnel.[218]

Un élément important de la gestion des maladies chroniques est la participation active des patients/clients à la gestion de leur maladie au quotidien. Cette participation est habituellement appelée l'autogestion. L'*autogestion* ne signifie pas que les malades s'occupent eux-mêmes de leur maladie ou de leur trouble. Il s'agit plutôt d'un processus qui permet au patient/client d'acquérir les connaissances, les attitudes et les compétences nécessaires pour

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217 Pour de plus amples renseignements, voir le site Internet d'ICIC (http://www.improvingchroniccare.org./).

218 Mental Health and Addictions, Ministry of Health Services, gouvernement de la Colombie-Britannique, *mémoire au Comité*, 9 septembre 2003, p. 7.

gérer soi-même sa maladie ou son trouble et de mieux utiliser les services et de moyens de soutien existants afin d'obtenir de l'aide au besoin.[219]

4.8 PROMOTION, PRÉVENTION ET SURVEILLANCE

La *promotion* de la santé mentale a pour but de renseigner la population afin de mieux faire connaître et comprendre les questions relatives à la santé mentale, à réduire la stigmatisation et à promouvoir une santé mentale positive. La promotion de la santé mentale comprend également l'éducation et la formation de ressources humaines dans le système officiel de santé mentale et de désintoxication.

> **La connaissance des maladies mentales désigne les connaissances et les opinions relatives aux troubles mentaux qui aident à reconnaître, gérer ou prévenir les problèmes de santé mentale et d'usage de substances, ainsi que les troubles mentaux et les troubles liés à l'usage de substances. Elle comprend la capacité de reconnaître des troubles particuliers; la capacité de trouver de l'information sur la santé mentale; la connaissance des facteurs de risque et des causes, des autotraitements et de l'aide professionnelle disponible; ainsi que les attitudes qui encouragent la reconnaissance et la recherche de l'aide pertinente.**
> ***[Ministry of Health Services, Colombie-Britannique, mémoire au Comité, 9 septembre 2003, p. 9.]***

Le concept de connaissance de la santé mentale est souvent utilisé dans le contexte de la promotion de la santé mentale. La *connaissance de la santé mentale* désigne les connaissances, opinions et aptitudes qui permettent de reconnaître, de gérer ou de prévenir les maladies mentales ou les troubles liés à une substance psychoactive. Un niveau élevé de connaissance de la santé mentale permet de reconnaître rapidement les maladies mentales et les troubles liés à une substance psychoactive et d'accroître la probabilité d'une intervention efficace. C'est également un moyen efficace de réduire la stigmatisation.[220]

La prévention comprend la *prévention primaire*, qui vise à éviter un éventuel problème de santé mentale ou de consommation de substances; la *prévention secondaire*, qui vise le dépistage précoce et comprend une intervention pertinente pour prévenir, retarder ou atténuer un problème de santé mentale; et la *prévention tertiaire* qui vise à atténuer le handicap ou à éviter une rechute chez un patient/client stable ou qui a été traité avec succès.

La *surveillance* désigne habituellement la collecte, l'analyse et l'interprétation permanentes et systématiques de données relatives à la santé utilisées pour déterminer la présence de maladies, évaluer les besoins pertinents et mesurer l'efficacité des politiques et programmes.

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219 BC Partners for Mental Health and Addictions Information, « Mental Health and Addictions Information Plan for Mental Health Literacy », *The Primer - Fact Sheets on Mental Health and Addictions Issues*, Colombie-Britannique.

220 *Ibid.*

À l'heure actuelle, le Canada n'a pas de système de surveillance national pour suivre les maladies mentales et les troubles liés à la consommation de substances psychoactives.[221]

4.9 PERSONNES ATTEINTES DE MALADIE MENTALE OU DE TOXICOMANIE ET RÉTABLISSEMENT

Comme nous l'avons vu au début de ce chapitre, il n'existe pas de terminologie commune pour décrire tous les concepts et problèmes dans le domaine de la maladie mentale et de la toxicomanie. On ne s'entend pas vraiment sur les termes les plus respectueux et convenables pour désigner les personnes qui ont vécu une maladie mentale ou un trouble lié à l'usage de substances. Certaines personnes ont des opinions très arrêtées sur la terminologie employée, étant donné la stigmatisation sociale des personnes atteintes de maladie mentale ou de toxicomanie et les étiquettes péjoratives employées beaucoup trop souvent à leur égard.

D'habitude, on appelle *patients* les personnes atteintes de maladie mentale ou de toxicomanie qui sont soignées par des médecins. Les autres professionnels de la santé les appellent souvent *clients* ou bénéficiaires. Les personnes en cause emploient parfois d'autres termes, comme consommateurs ou *réchappés*. Les consommateurs sont habituellement les personnes ayant vécu directement d'importants problèmes de santé mentale ou maladies mentales et qui ont fait appel aux ressources offertes par le système de santé mentale. Certains ont choisi de se qualifier de réchappés, terme qui, à leur avis, traduit leur capacité de faire face à la maladie mentale ou à la toxicomanie, ou aux deux. Dans le présent rapport, le Comité emploie les expressions *personne atteinte ou souffrant de maladie mentale ou de toxicomanie* et *patient/client*.

Les personnes souffrant de maladie mentale ou de toxicomanie parlent souvent de rétablissement. Le *rétablissement* n'est pas synonyme de guérison. Pour bien des gens, c'est une façon de mener une vie satisfaisante, prometteuse et productive, malgré les limites imposées par la maladie; pour d'autres, le rétablissement veut dire la réduction ou la rémission complète des symptômes de la maladie mentale.

Dans la perspective de la santé mentale, le rétablissement est un processus personnel qui consiste à surmonter l'incidence négative de la maladie mentale malgré sa présence continue. Dans l'optique de la toxicomanie, le rétablissement désigne une approche

> **Le rétablissement est un voyage plutôt qu'une destination. C'est un processus actif, permanent et très individualisé par lequel on est encouragé à assumer la responsabilité de sa vie, souvent en collaboration ave les amis, la famille, les pairs et les professionnels.**
>
> **Le rétablissement de chaque malade est unique. Il n'y a pas deux personnes qui suivent le même parcours ou emploient les mêmes moyens pour se rétablir. On peut croire à un rétablissement réel lorsque la personne a le sentiment de s'être rétablie et que sa qualité de vie n'est pas ternie par son état passé ni par des symptômes ou facteurs de stress actuels.**
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> ***[Rapport final du Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale, Ontario, décembre 2002, p. 28.]***

[221] Paula Stewart, *The Development of a Canadian Mental Illnesses and Mental Health Surveillance System: A Discussion Paper*, préparé pour l'Alliance canadienne pour la maladie mentale et la santé mentale, 1999 (inédit).

fondée sur l'abstinence face aux troubles liés à une substance psychoactive, notamment la démarche des Alcooliques anonymes et de Narcotiques anonymes. La notion de rétablissement suppose qu'avec les traitements et les moyens de soutien nécessaires en place, les personnes atteintes de maladie mentale ou de toxicomanie peuvent prendre leur vie en main, se fixer de nouveaux buts, avoir de nouvelles aspirations et contribuer de manière productive à la société.[222]

[222] Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale, *The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario*, décembre 2002, p. 21.

CHAPITRE 5:
PRÉVALENCE ET COÛTS

Les troubles mentaux ne sont pas le lot d'un groupe particulier : ils sont universels. Ils s'observent dans toutes les régions, tous les pays et toutes les sociétés.
[OMS (2001), p. 23.]

INTRODUCTION

La maladie mentale et la toxicomanie ne sont pas rares, puisqu'un Canadien sur cinq en souffre à un moment ou à un autre durant sa vie. Ces maux affectent les personnes de tous âges, femmes et hommes, dans toutes les cultures et toutes les tranches de revenu. Ils sont aussi présents à la campagne qu'à la ville. Ils ont des répercussions économiques énormes, pas seulement sur ceux et celles qui en souffrent et sur leurs familles, mais aussi sur le système de soins de santé, sur le système social au sens large du terme et sur le milieu de travail et la société.

Si la maladie mentale était une maladie infectieuse, on aurait une épidémie au Canada. Le nombre de personnes qui en souffrent est effarant […].
[Phil Upshall, président, Association canadienne pour la santé mentale, mémoire au Comité, 18 juillet 2003, p. 4.]

Afin de planifier et d'organiser comme il se doit la prestation des services et des moyens de soutien nécessaires et afin d'élaborer de bonnes politiques publiques en matière de santé mentale, il convient de bien évaluer la prévalence ainsi que le fardeau économique que représentent la maladie mentale et la toxicomanie. Le présent chapitre examine l'ensemble des renseignements dont nous disposons sur la prévalence et les répercussions économiques de la maladie mentale, de la toxicomanie, du jeu pathologique et du suicide au Canada. Le lecteur y trouvera également des comparaisons internationales chaque fois que de telles données existent.

La section 5.1 donne des renseignements sur la prévalence des maladies mentales, des troubles liés à la consommation de substances psychoactives et du jeu pathologique. La section 5.2 examine la prévalence des comportements suicidaires. La section 5.3 traite de la prévalence des maladies mentales et des toxicomanies dans certains groupes de la population, notamment chez les Autochtones, les sans-abri et les détenus. La section 5.4 fournit des données sur le fardeau économique que représente la maladie mentale et la toxicomanie au Canada. Enfin, le Comité fait part de certaines observations et de ses conclusions à la section 5.5.

5.1 PRÉVALENCE DES MALADIES MENTALES, DES TROUBLES LIÉS À DES SUBSTANCES PSYCHOACTIVES ET AU JEU PATHOLOGIQUE

Au Canada, on ne compile pas de façon systématique les données nationales sur l'état de santé mentale des Canadiens ou sur l'ampleur d'une maladie mentale en particulier.
[Phil Upshall, président, Association canadienne pour la santé mentale, mémoire au Comité, 18 juillet 2003, p. 6.]

La *prévalence* est la proportion de personnes qui, dans une population donnée, sont atteint d'une maladie ou d'un trouble. Les taux de prévalence diffèrent selon qu'il s'agit de personnes qui ont une maladie à un certain moment (prévalence ponctuelle), pendant une certaine période (prévalence périodique) ou tout long d'une vie (prévalence sur la vie).

Il n'existe actuellement au Canada aucune base de données nationale susceptible de fournir des données précises sur la prévalence de tous les troubles mentaux, pour toutes les tranches d'âges. Le plus souvent, les meilleures estimations sont tirées d'études épidémiologiques publiées dans la documentation spécialisée. Toutefois, l'Enquête sur la santé des collectivités canadiennes de 2002 (ESCC) – santé mentale et bien-être, cycle 1.2 – réalisée par Statistique Canada, nous a indiqué pour la toute première fois les taux de prévalence pour certaines maladies mentales, pour certains troubles liés à la consommation de substances psychoactives et pour le jeu pathologique. Ces prévalences sont commentées à la section suivante.

Le sondage publié à l'automne par Statistique Canada était un excellent point de départ, puisqu'il s'agissait là du premier sondage basé sur la population jamais fait au Canada sur les maladies mentales. Imaginez un peu la situation si on avait attendu 2003 pour faire le premier sondage sur les maladies cardiovasculaires ou sur le cancer? Ce serait scandaleux. Il nous faut donc un meilleur système de surveillance.
[Dr Blake Woodside, président du conseil, Association des psychiatres du Canada (5:19)]

5.1.1 Les Canadiens de 15 ans et plus

Selon l'ESCC (voir tableau 5.1), au cours de la dernière année, un Canadien sur 10 âgé de 15 ans et plus – soit environ 2,6 millions de personnes – a fait état de symptômes correspondant à des maladies mentales ou à des troubles liés à la consommation de substances psychoactives. La prévalence générale est à peu près la même chez les hommes et chez les femmes : 1,4 million de femmes environ (ou 11 p. 100 du total) ayant ressenti les symptômes caractéristiques de maladie mentale ou des troubles liés à l'usage de substances psychoactives, contre 1,2 million (10 p. 100) d'hommes.

La maladie mentale et la toxicomanie n'épargnent personne. Elles frappent à tout âge et tous les groupes de la population.
[Société canadienne de psychologie, mémoire au Comité, 2003, p. 5.]

Il existe, cependant, d'importantes différences entre les deux sexes, par type de trouble. Ainsi, les troubles de l'humeur et les troubles anxieux sont plus répandus chez les femmes (6 p. 100) que chez les hommes (4 p. 100), tandis que les troubles liés à la consommation de substances psychoactives sont plus répandus chez les hommes (4 p. 100) que chez les femmes (2 p. 100).

TABLEAU 5.1

PRÉVALENCE DES TROUBLES MENTAUX SUR UNE ANNÉE CHEZ DES CANADIENS ÂGÉS DE 15 ANS ET PLUS, 2002

	Total		Hommes		Femmes	
	Nombre (milliers)	Taux (%)	Nombre (milliers)	Taux (%)	Nombre (milliers)	Taux (%)
Dépression unipolaire	1 120	4,5	420	3,4	700	5,5
Dépression bipolaire	190	0,8	90	0,7	100	0,8
Toute forme d'humeur	**1 210**	**4,9**	460	**3,8**	**750**	**5,9**
Trouble panique	400	1,6	130	1,1	270	2,1
Agoraphobie	180	0,7	40	0,4	140	1,1
Phobie sociale	750	3,0	310	2,6	430	3,4
Toutes formes d'anxiété	**1 180**	**4,7**	440	**3,6**	**740**	**5,8**
Dépendance à l'alcool	640	2,6	470	3,8	170	1,3
Dépendances aux drogues illicites	170	0,7	120	1,0	50	0,4
Tous problèmes de dépendance à une substance	**740**	**3,0**	540	**4,4**	**200**	**1,6**
Tous troubles confondus	**2 600**	**10,4**	**1 190**	**9,7**	**1 410**	**11,1**

Statistique Canada, « Enquête sur la santé dans les collectivités canadiennes : Santé mentale et bien-être », *Le Quotidien*, 3 septembre 2003.

D'après les données de l'ESCC, les adolescents et les jeunes adultes de 15 à 24 ans sont plus susceptibles que n'importe quel autre groupe d'âge de souffrir de maladies mentales ou de troubles liés à la consommation de substances psychoactives. Dans ce groupe d'âge, en effet, 18 p. 100 ont fait état de symptômes caractéristiques d'une maladie mentale ou de troubles liés à l'usage de substances psychoactives, contre 12 p. 100 chez les 25 à 44 ans, 8 p. 100 chez les 45 à 64 ans et 3 p. 100 chez les 65 ans et plus.

> **(…) nous devons considérer que le phénomène de co-occurrence toxicomanie et maladie mentale constitue la norme et non l'exception. Le fait de détecter la présence d'un problème devrait nous amener à supposer que l'autre est également présent jusqu'à preuve du contraire.**
> ***[Wayne Skinner, CTSM, mémoire au Comité, mai 2004, p. 2]***

L'ESCC était limitée quant à la gamme des troubles mentaux observés dans la population canadienne, contrairement à la *National Survey of Mental Health and Well-Being* réalisée en Australie en 1997. L'enquête australienne a porté sur un éventail plus important de troubles anxieux et de troubles affectifs de l'humeur. Elle établit également une différence entre la consommation dangereuse d'alcool et de drogue et la dépendance à ces deux types de substances. Le gouvernement australien envisage aussi de réaliser une étude sur des troubles psychotiques à faible prévalence, comme la schizophrénie.[223]

Il est malheureux que l'ESCC n'ait pas recoupé ni rapproché certaines données afin d'évaluer les taux de prévalence de troubles concurrents (présence d'une maladie mentale et d'un trouble lié à l'usage de substances psychoactives) chez les Canadiens de 15 ans et plus. Ce manque d'information sur la prévalence des troubles concurrents nous empêche de mieux les comprendre et de planifier et d'instaurer efficacement des services et des moyens de soutien appropriés pour ceux et celles qui en souffrent. L'enquête nationale australienne sur la santé mentale et le bien-être des adultes a, quant à elle, été prévue pour permettre d'évaluer les troubles concurrents et la co-morbidité (définie par la présence de troubles mentaux et d'affection physique).

Les jeux de hasard s'accompagnent inévitablement d'un problème de jeu excessif.
[Katherine Marshall et Harold Wynne, « Contre vents et marées », p. 5.]

Cependant, contrairement à l'enquête australienne, l'ESCC a permis de recueillir des données sur le jeu excessif et le jeu pathologique.[224] En 2002, on estimait que quelque 1,2 million de Canadiens (soit 5 p. 100 de la population adulte) étaient des joueurs excessifs ou risquaient de le devenir (voir le graphique 5.1) : 700 000 courraient un faible risque (2,8 p. 100), 370 000 environ courraient un risque modéré (1,5 p. 100) et 120 000 étaient déjà des joueurs excessifs (0,5 p. 100). Les hommes (8 p. 100) étaient nettement plus susceptibles que les femmes (5 p. 100) d'être à risque ou de devenir des joueurs excessifs. Les joueurs à risque et les joueurs excessifs étaient, en moyenne, plus jeunes que les joueurs non excessifs (40 ans pour les premiers et 45 pour les seconds) et moins instruits (8 p. 100 par rapport à 5 p. 100).

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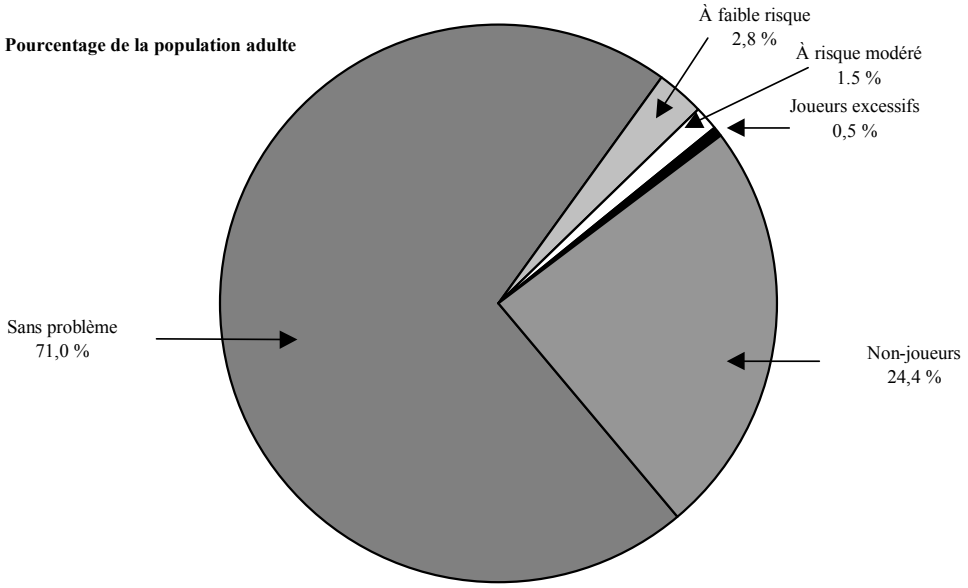
223 L'enquête nationale australienne sur la santé mentale et le bien-être a porté sur les troubles anxieux suivants : trouble panique, agoraphobie, phobie sociale, trouble de l'anxiété généralisée, trouble obsessif-compulsif et syndrome de stress post-traumatique. Elle a aussi porté sur les troubles affectifs suivants : dépression, dysthymie, manie, hypomanie et trouble bipolaire. De plus, cette enquête s'est penchée sur les troubles de consommation d'alcool et sur ceux liés à la consommation de drogues, tant pour ce qui est de la nocivité que de la dépendance. Pour plus d'informations à ce sujet, consulter le site Internet du Bureau australien de la statistique, à l'adresse : (http://www.abs.gov.au/Ausstats/abs@.nsf/0/3F8A5DFCBECAD9C0CA2568A900139380?Open).

224 Les données sur les jeux de hasard sont analysées en détail par Katherine Marshall et Harold Wynne dans « Contre vents et marées », *L'emploi et le revenu en perspective*, Statistique Canada, nº 75-001-XIE au catalogue, vol. 4, nº 12, décembre 2003, p. 5-13 (http://www.statcan.ca/).

GRAPHIQUE 5.1
COMPORTEMENTS ASSOCIÉS AUX JEUX DE HASARD AU CANADA, 2002



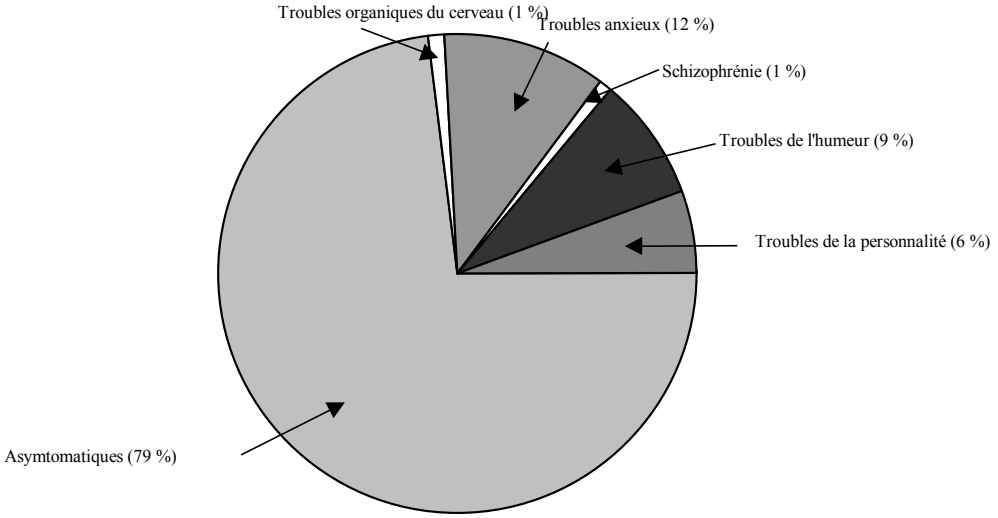
Katherine Marshall et Harold Wynne, « Contre vents et marées », *L'emploi et le revenu en perspective* , Statistique Canada, n° 75-001-XIF au catalogue, vol. 4, no 12, décembre 2003.

Il est intéressant de noter que l'enquête en question fait ressortir l'existence d'un lien entre le jeu pathologique, la maladie mentale et la consommation de drogues. Ainsi, 42 p. 100 des joueurs excessifs disent avoir connu des niveaux de stress élevés ou extrêmes durant leur vie, 25 p. 100 d'entre eux ont déclaré avoir eu une dépression clinique majeure et 15 p. 100 se sont dit dépendants à l'alcool. Le sondage a aussi permis de constater que 18 p. 100 des joueurs excessifs ont envisagé de se suicider dans les 12 mois précédents.

Les taux de prévalence sur une vie, dans le cas des maladies mentales et des troubles liés à la consommation de substances psychoactives au Canada, sont fondés sur des études épidémiologiques. Selon les données recueillies par Paula Stewart et ses collègues (octobre 2002), près d'un Canadien adulte sur cinq (21 p. 100, soit 4,5 millions de personnes) souffrira de maladie mentale à un moment ou un autre de sa vie.[225] Le graphique 5.2, qui illustre la prévalence sur une vie des maladies mentales au sein de la population canadienne adulte, est dérivée d'études épidémiologiques.

[225] Paula Stewart et al., *Rapport sur les maladies mentales au Canada*, publié par Santé Canada, octobre 2002.

GRAPHIQUE 5.2
LA MALADIE MENTALE AU CANADA : PRÉVALENCE SUR UNE VIE CHEZ LES ADULTES



Remarque : Il se peut que le total des proportions ne donne pas 100 p. 100, étant donné que certaines personnes peuvent présenter des symptômes dans plus d'une catégorie. Graphique fondé sur les données founies Paula Stewart *et al, Rapport sur les maladies mentales au Canada,* octobre 2002.

Comme on peut le voir, les troubles anxieux et les troubles de l'humeur sont les maladies mentales les plus répandues parmi la population canadienne adulte, puisqu'elles concernent respectivement 12 p. 100 et 9 p. 100 de cette population. La schizophrénie touche 1 p. 100 environ de la population canadienne. La démence associée à la maladie d'Alzheimer et les troubles organiques du cerveau, résultats de pathologies ou de lésions cervicales (comme l'encéphalopathie au VIH-1, la démence complexe et la démence vasculaire), touchent aussi 1 p. 100 environ des adultes canadiens. Au cours de leur vie, entre 6 p. 100 et 9 p. 100 des adultes canadiens souffriront de troubles de la personnalité.

On retrouve des taux de prévalence semblables ailleurs dans le monde. Pour ce qui est de la prévalence ponctuelle, dans son rapport de 2001, l'Organisation mondiale de la santé (OMS) signale que les troubles mentaux et la toxicomanie touchent environ 10 p. 100 des adultes à un moment donné ou à un autre de leur vie, soit quelque 450 millions de personnes sur la planète.[226] Pour ce qui est de la prévalence sur une vie, l'OMS indique que plus de 25 p. 100 de la population mondiale vient à souffrir un jour ou l'autre d'au moins une maladie mentale.[227] L'OMS estime aussi que, dans une famille sur quatre dans le monde, une personne au moins est atteinte d'une maladie mentale ou souffre de toxicomanie.[228]

S'agissant des taux de prévalence sur une année, le *World Mental Health Survey Consortium* de l'OMS a révélé que les troubles mentaux sont fortement prévalents dans les pays développés et les pays en développement, bien qu'il existe d'importants écarts d'un pays à l'autre, cette prévalence étant particulièrement faible en Asie. Les troubles de l'anxiété constituent les maladies mentales les plus courantes devant les troubles de l'humeur. La plupart de ces troubles sont qualifiés de « légers » selon un classement par degré de gravité, ceux considérés

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226 Organisation mondiale de la santé, La santé mentale : Nouvelle conception, nouveaux espoirs, 2001, p. 23.
227 Ibid.
228 OMS (2001), p. 24.

comme « graves » ou « modérés » étant moins nombreux, bien qu'ils soient souvent associés à un empêchement majeur à effectuer des activités routinières.[229]

5.1.2 Les enfants et les adolescents (de 0 à 19 ans)

S'appuyant sur différentes études épidémiologiques, Charlotte Waddell et Cody Shepherd (octobre 2002) ont estimé les taux de prévalence généraux et les taux propres à certains troubles mentaux chez les enfants et les adolescents en Colombie-Britannique. Le tableau 5.2 présente ces taux qui permettent de se faire une idée du nombre d'enfants et d'adolescents canadiens qui pourraient souffrir de troubles mentaux.

La prévalence ponctuelle des maladies mentales chez les enfants et les adolescents canadiens est d'environ 15 p. 100. Autrement dit, 1,2 million d'enfants et d'adolescents environ souffrent de maladie mentale ou sont atteints de toxicomanie à un degré de gravité suffisant pour occasionner chez eux une détresse importante et les empêcher de fonctionner. Les affections les plus courantes sont l'anxiété (6,5 p. 100), les troubles des conduites (3,3 p. 100), les déficit de l'attention (3,3 p. 100), la dépression (2,1 p. 100) et les troubles liés à la consommation de substances psychoactives (0,8 p. 100).

TABLEAU 5.2

PRÉVALENCE DES TROUBLES MENTAUX CHEZ LES ENFANTS ET LES ADOLESCENTS[(a)]

TROUBLES MENTAUX	TAUX DE PRÉVALENCE (%)	NOMBRE APPROXIMATIF
Trouble d'anxiété	6,5	513 780
Trouble des conduites	3,3	260 842
THADA	3,3	260 842
Trouble dépressif	2,1	165 990
Consommation de substances psychoactives	0,8	63 234
Trouble envahissant du développement	0,3	23 713
Trouble obsessif/compulsif	0,2	15 809
Schizophrénie	0,1	7 904
Syndrome de La Tourette	0,1	7 904
Trouble de l'alimentation	0,1	7 904
Trouble bipolaire	Moins de 0,1	Moins de 7 904
TOUT TROUBLE CONFONDU	**15**	**1 185 645**

(a) Données fondées sur une évaluation de Statistique Canada, réalisée en juillet 2002, fixant à 7 904 300 le nombre d'enfants et d'adolescents de 0 à 19 ans.

Source : Adapté de Charlotte Waddell et Cody Shepherd, *Prevalence of Mental Disorders in Children and Youth*, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Université de la Colombie-Britannique, octobre 2002.

229 OMS, World Mental Health Survey Consortium, « Prevalence, Severity, and Unmet Need for Treatment of Mental Disorders in the World Health Organization World Mental Health Surveys », *Journal of the American Medical Association*, vol. 291, nº 21, 2 juin 2004, p. 2581-2590.

Le tableau ci-dessus ne rend pas compte d'un fait important, soit la co-occurrence de deux troubles mentaux ou plus. Une enquête sur la santé des enfants en Ontario a, par exemple, permis de constater que les deux tiers (68 p. 100) des enfants et des adolescents atteint d'une maladie mentale souffrent simultanément de deux troubles mentaux ou plus. Plus récemment, une étude conduite sur des jeunes souffrant de troubles liés à la consommation de substances psychoactives a révélé que plus des trois quarts (76 p. 100) d'entre eux étaient atteints de troubles concurrents de l'anxiété, de l'humeur ou du comportement.[230]

Dans son mémoire, le Dr Joseph H. Beitchman, psychiatre en chef à l'Hôpital pour enfants de Toronto, insiste sur le fait que la plupart des troubles mentaux constatés chez les adultes puisent leurs racines dans l'enfance ou l'adolescence et qu'il s'agit donc de maladies graves dont on peut être atteint durant toute une vie.[231] Cela souligne la nécessité de détecter et d'intervenir très tôt. Cela nous rappelle aussi que les meilleures possibilités de prévention et de réduction des nouveaux cas se situent dans l'enfance et l'adolescence. Comme l'a souligné Charlotte Waddell et al. (2002) : « Il est essentiel de disposer de données épidémiologiques de qualité pour élaborer des politiques publiques valables afin d'améliorer la santé mentale des enfants ».[232] Il est intéressant de remarquer que, dans la stratégie nationale australienne sur la santé mentale adoptée par le Commonwealth, les gouvernements des États et des territoires réclament la tenue d'un sondage auprès des enfants et des adolescents en plus du sondage national sur la santé mentale et le bien-être des adultes. Une telle étude n'a jamais été réalisée au Canada.

5.1.3 Les personnes âgées (65 ans et plus)

Comme nous l'avons vu, l'ESCC a révélé qu'au cours de l'année dernière, quelque 3 p. 100 des Canadiens de 65 ans et plus (soit environ 107 283 personnes âgées) ont fait état de symptômes associés aux cinq troubles mentaux et aux deux types de dépendance à des substances visés par l'enquête. Le taux de prévalence sur un an était de 1,8 p. 100 dans le cas des troubles unipolaires, de 0,2 p. 100 dans celui des troubles de panique, de 0,9 p. 100 pour les phobies sociales et de 0,4 p. 100 pour l'agoraphobie. Les maladies mentales et les troubles liés à la consommation de substances psychoactives étaient davantage prévalents chez les femmes (3,2 p. 100) que chez les hommes (2,5 p. 100). L'enquête a également révélé que 2 p. 100 environ des personnes âgées au Canada ont eu des pensées suicidaires au cours des 12 derniers mois.

D'autres renseignements sur la prévalence des troubles mentaux chez les personnes âgées au Canada ont été communiqués au Comité :

- L'incidence de la dépression chez les personnes âgées pensionnaires de centres de soins de longue durée est de trois à quatre fois supérieure à celle de la population en

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230 Données citées par Charlotte Waddell et. al., in *Child and Youth Mental Health: Population Health and Clinical Services Considerations*, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Université de la Colombie-Britannique, avril 2002, p. 15.

231 Dr Joseph H. Beitchman, psychiatre en chef, Hôpital pour enfants de Toronto, mémoire au Comité, 30 avril 2003, p. 7.

232 Charlotte Waddell et al., « Child Psychiatric Epidemiology and Canadian Public Policy-Making: The State of the Science and the Art of the Possible », *Canadian Journal of Psychiatry*, vol. 47, n° 9, novembre 2002, p. 825-832.

général. La prévalence des troubles mentaux parmi les résidents de foyers pour personnes âgées est extraordinairement élevée, puisqu'ils se situent entre 80 et 90 p. 100. La prévalence des psychoses varie de 12 à 21 p. 100 en fonction des moyens utilisés pour mesurer les symptômes.[233]

- L'Alzheimer et les types de démence qui y sont associés touchent actuellement plus de 360 000 Canadiens (incluant une personne sur 13 de plus de 65 ans et une sur 3 de plus de 85 ans); les femmes sont plus concernées par cette maladie que les hommes.[234]
- Selon certaines estimations, 25 à 50 p. 100 des personnes âgées souffrant de problèmes d'alcoolisme à divers degrés sont également atteintes de troubles mentaux.[235]
- L'incidence du suicide chez les hommes de 80 ans et plus est le plus élevé de tous les groupes d'âge (31 par 100 000 habitants).[236]

5.1.4 Les Forces canadiennes[237]

> *Les membres des FC, représentant une communauté de plus de 83 000 (Force régulière et Réserve), sont doublement concernés par les maladies mentales ayant à subir, à la fois, les difficultés d'une vie « normale » et celles d'une carrière à haut risque.*
> *[Défense nationale, Enquête de Statistique Canada sur la santé mentale dans les FC : Une « étape clé », 2003.]*

L'ESCC comporte un volet distinct sur la santé mentale au sein des Forces canadiennes (FC). Celui-ci nous apprend que le taux de prévalence des dépressions unipolaires dans les rangs des membres de la force régulière est de 7,6 p. 100 sur une période d'un an et de 16,2 p. 100 au cours d'une vie. Les taux de prévalence comparables pour les réservistes sont respectivement de 4,1 p. 100 et de 9,7 p. 100. Au sein des forces régulières, le taux de prévalence des phobies sociales s'établit à 3,6 p. 100 sur un an et à 8,7 p. 100 sur une vie, et ils sont de 2,3 p. 100 et de 7,1 p. 100 respectivement pour les réservistes. Les prévalences sur un an et sur une vie dans le cas des troubles de stress post-traumatique sont de 2,8 p. 100 et de 7,2 p. 100 pour les membres des forces régulières et de 1,2 p. 100 et de 4,7 p. 100 pour les réservistes. Les taux de prévalence des troubles de l'anxiété généralisée sont de 1,8 p. 100 et de 4,6 p. 100 dans le cas des membres de la force régulière et de 1 p. 100 et de 2,9 p. 100 dans celui des réservistes. Les taux de prévalence équivalents dans le cas des troubles de panique sont de 2,2 p. 100 et de 5 p. 100 dans la force régulière et de 1,4 p. 100 et de 3,3 p.

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233 Dr David Conn, coprésident, Coalition canadienne pour la santé mentale des personnes âgées, mémoire au Comité, 4 juin 2003, p. 4-6.

234 Société Alzheimer du Canada, mémoire au Comité, 4 juin 2003, p. 3.

235 Margaret Gibson, Department of Psychology, University of Western Ontario, mémoire au Comité, 4 juin 2003, p. 2.

236 Dr David Conn (4 juin 2003), p. 5.

237 Défense nationale, *Enquête de Statistique Canada sur la santé mentale dans les FC : Une « étape clé »*, 2003.

100 chez les réservistes. Le taux de prévalence de l'alcoolisme sur un an est de 4,2 p. 100 et le taux sur une vie est de 8,5 p. 100 pour les forces régulières; ces taux sont respectivement de 6,2 p. 100 et de 8,8 p. 100 pour les réservistes.

5.1.5 EAF/SAF et diagnostics mixtes

La prévalence du syndrome d'alcoolisation fœtale et des effets de l'alcool sur le fœtus (SAF/EAF) au Canada n'est pas parfaitement connue. Partant des taux de prévalence mondiaux, Santé Canada a estimé que quelque 341 901 personnes étaient atteintes du SAF/EAF au Canada en 2001. Les taux de prévalence de SAF/EAF dans certains groupes de la société, surtout chez les Autochtones, sont supérieurs à la moyenne nationale.[238]

> **Il naît tous les jours au Canada au moins un enfant souffrant du syndrome de l'alcoolisme fœtal, le SAF, incapacité qui se répercute sur l'enfant, sa famille et tous ceux qui l'entourent, pendant toute sa vie. Les TSAF sont la première cause d'anomalie congénitale et de retard de développement complètement évitable au Canada. C'est une maladie plus courante que le syndrome de Down.**
> ***[Pam Massad, Santé Canada (13:5)]***

Comme nous l'avons vu au chapitre 4, on parle de diagnostic mixte dans le cas des personnes souffrant à la fois de maladies ou de troubles mentaux et de déficience développementale (qui a remplacé la « débilité mentale »). À cause de la difficulté que pose l'établissement d'un diagnostic de santé mentale chez les personnes souffrant de déficience développementale, il n'est pas rare que la faculté ne pose pas de diagnostics mixtes et que ces troubles concurrents ne soient pas traités. D'après les données disponibles, 1 à 3 p. 100 des Canadiens souffriraient de déficience mentale modérée à grave. Selon une estimation prudente, 30 p. 100 de ces personnes souffriraient aussi de maladie mentale; certains chercheurs estiment même que la prévalence pourrait être aussi élevée que 50 à 60 p. 100.[239]

5.2 PRÉVALENCE DES COMPORTEMENTS SUICIDAIRES

Un Canadien sur 25 commettra un tentative de suicide au cours de sa vie. [Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Université de la Colombie-Britannique, At-a-Glance Suicide Facts]

Comme nous l'avons vu au chapitre 4, la notion de comportement suicidaire est assez large, puisqu'elle englobe le suicide réussi (décès par suicide), les tentatives de suicide (y compris les automutilations) et l'idée de suicide (pensées suicidaires). Le présent chapitre

> **On peut prévenir le suicide. C'est un geste, pas une maladie. […] En outre, les tentatives de suicide, où le geste d'un individu n'a pas de conséquence fatale, sont comparables à la partie immergée et invisible de l'iceberg.**
> ***[Diane Yackel, Centre for Suicide Prevention, mémoire au Comité.]***

238 Santé Canada, Fetal Alcohol Spectrum Disorder, Mémoire au Comité, 30 avril 2003.

239 Association canadienne pour la santé mentale – Division de l'Ontario, *Dual Diagnosis: People with Developmental Disability and Mental Illness – Falling Through the Cracks*, feuillet d'information, 1998.

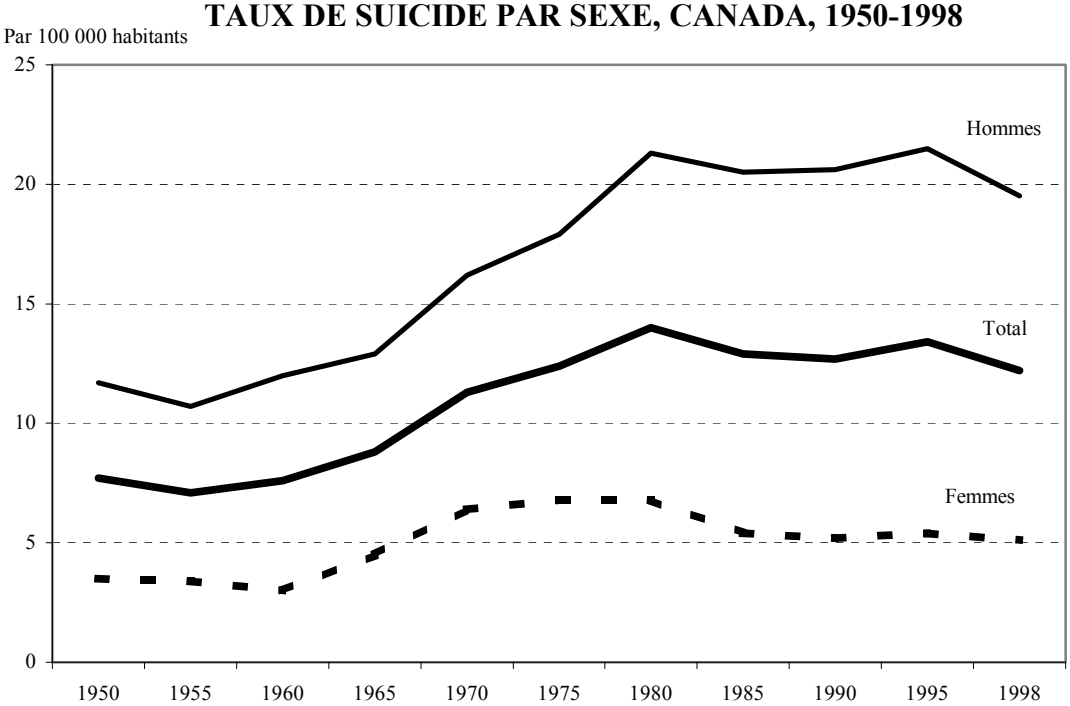
présente les données récentes sur la prévalence des comportements suicidaires au Canada et fournit quelques comparaisons internationales.

5.2.1 Les suicides réussis

Le graphique 5.3 révèle que le taux de suicide au Canada a progressé rapidement de 1950 au début des années 80, pour atteindre un sommet en 1983. Puis, le taux est demeuré relativement stable, enregistrant une légère baisse entre 1995 et 1998 (la dernière année pour laquelle des données existent).

GRAPHIQUE 5.3 :
TAUX DE SUICIDE PAR SEXE, CANADA, 1950-1998

GRAPHIQUE 1 :
TAUX DE SUICIDE PAR SEXE, CANADA, 1950-1998



Source : Division de l'économie, Direction de la recherche parlementaire, Bibliothèque du Parlement, mars 2004. Données de l'Organisation mondiale de la santé (2003).

En 1998, 3 699 Canadiens se sont ôté la vie, ce qui représente une moyenne de 10 suicides par jour. Le tableau 5.3 donne une répartition par groupe d'âge. Dans l'ensemble, les suicides réussis ont représenté 2 p. 100 de tous les décès au Canada en 1998.

À l'analyse de l'épidémiologie du suicide, force est de constater qu'il s'agit d'un phénomène important du point de vue de la santé publique. Il arrive au dixième rang des causes de décès des personnes de tous âges.
[Dr Gustavo Turecki, directeur, McGill Group for Suicide Studies, Université McGill]

TABLEAU 5.3

NOMBRE DE SUICIDES ET TAUX DE SUICIDE PAR GROUPE D'ÂGE ET PAR SEXE, CANADA, 1998

GROUPE D'ÂGE	NOMBRE DE SUICIDES			TAUX DE SUICIDE (PAR 100 000 HABITANTS)		
	TOTAL	HOMMES	FEMMES	TOTAL	HOMMES	FEMMES
5-14	46	30	16	1,2	1,5	0,8
15-24	562	457	105	13,5	21,6	5,1
25-34	701	568	133	13,7	22,1	5,2
35-44	895	713	182	19,0	30,3	7,7
45-54	672	513	159	19,2	29,0	9,2
55-64	366	296	70	15,5	25,9	5,8
65-74	260	201	59	14,9	26,7	6,0
75+	197	147	50	16,5	31,6	6,9
TOTAL	**3 699**	**2925**	**774**	**12,2**	**19,5**	**5,1**

* Par 100 000 habitants.

Source : Organisation mondiale de la santé, *Suicide Prevention – Country Reports and Charts*, Genève, 2003.

Dans chaque groupe d'âge, le taux de suicide chez les hommes était environ quatre fois supérieur à celui enregistré chez les femmes (voir le graphique 5.4).

Selon Langlois et Morrison (2002), le suicide a été la principale cause de décès chez les hommes de 25 à 29 ans et de 40 à 44 ans ainsi que chez les femmes de 30 à 34 ans. Pour les trois groupes d'âge de 10 à 14, 15 à 19 et 20 à 24, il s'agissait de la seconde cause de décès chez les deux sexes, derrière les accidents de la route.[240]

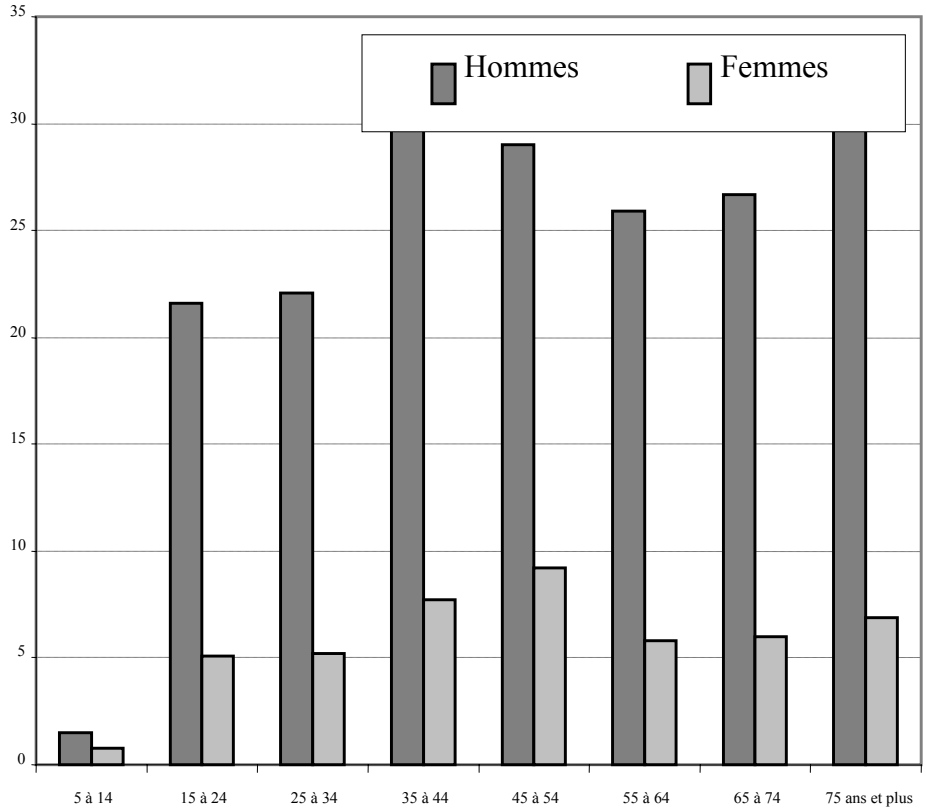
Vous serez d'accord avec moi que de se donner la mort à 14 ou 15 ans, alors que des milliers voire des millions de personnes se battent tous les jours contre la mort, demeure paradoxal. Le suicide chez les jeunes Canadiens est un problème grave qui doit faire l'objet d'une action prioritaire.
[Dre Johanne Renaud,Centre hospitalier Sainte-Justine (13:13-14)]

[240] Stéphanie Langlois et Peter Morrison, « Suicides et tentatives de suicide », rapports sur la santé, Statistique Canada, n° 82-003 au catalogue, vol. 13, no 2, janvier 2002.

GRAPHIQUE 5.4

TAUX DE SUICIDE PAR GROUPE D'ÂGE ET PAR SEXE, CANADA 1998

Par 100 000 habitants



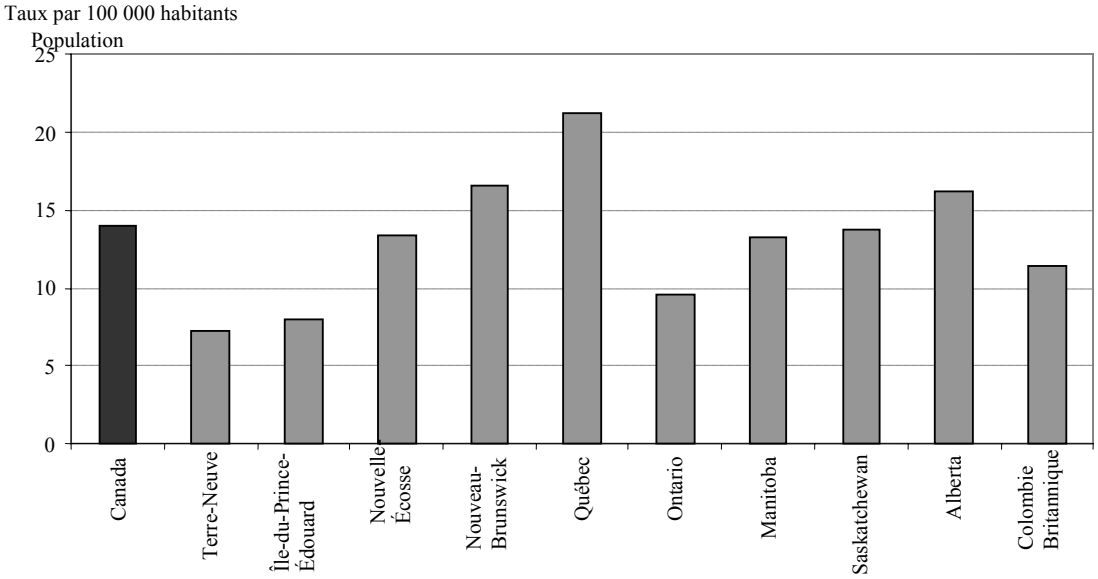
Source : Direction des affaires économiques, Direction de la recherche parlementaire, Bibliothèque du Parlement, mars 2004. Données provenants de l'Organisation modniale de la santé (2003).

Langlois et Morrison (2002) ont également fait ressortir l'existence d'importants écarts d'une province à l'autre en matière de taux de suicide. Ainsi, en 1998, c'est le Québec qui a connu le plus important taux de suicide chez les 10 ans et plus (21,3 morts par suicide par 100 000 habitants),[241] soit nettement plus que la moyenne nationale de 14 décès par suicide pour 100 000 habitants. Le Nouveau-Brunswick et l'Alberta dépassent également la moyenne nationale avec respectivement 16,6 et 16,2 morts par suicide par 100 000 habitants. Terre-Neuve, l'Île-du-Prince-Édouard, l'Ontario et la Colombie-Britannique présentent des taux de suicide nettement inférieurs à la moyenne nationale (voir le tableau 5.5).

Selon les données de l'Organisation mondiale de la santé (OMS), le taux de suicide au Canada (population en général) se situait au 9e rang parmi ceux de 12 pays industrialisés (voir le graphique 5.6). Les taux comparatif de suicide (en fonction de l'âge) vont d'un faible 7,5 par 100 000 habitants au Royaume-Uni à un énorme 22,5 par 100 000 habitants en Finlande. Le taux de suicide au Canada (12,2 par 100 000 habitants) est plus élevé que celui aux États-Unis (10,7 par 100 000 habitants). Il faut noter que les comparaisons internationales doivent être interprétées avec prudence car les méthodes d'attestation de décès varient d'un pays à l'autre.

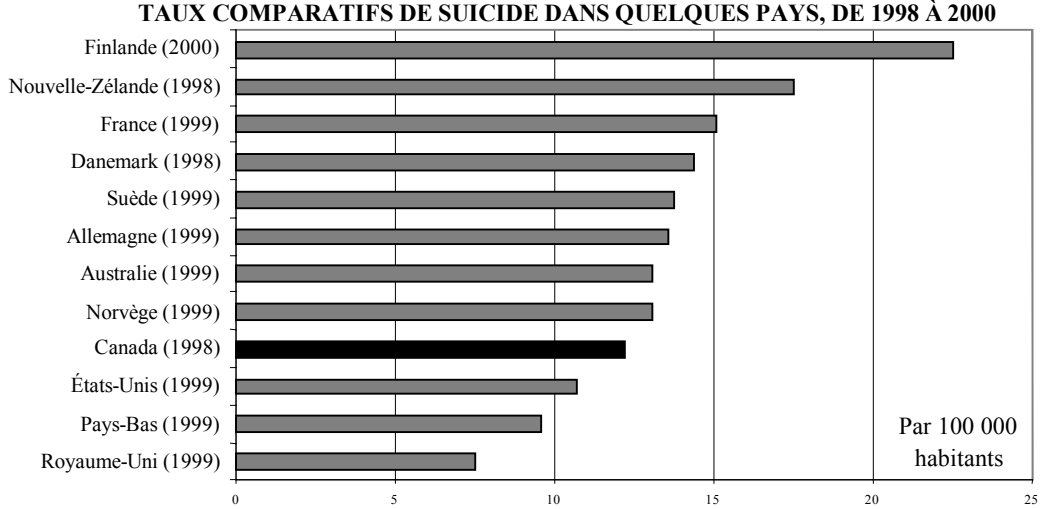
241 À l'exception des territoires.

GRAPHIQUE 5.5
TAUX DE SUICIDE COMPARATIF AU CANADA PAR PROVINCE, 1998



Source: Stéphanie Langlois et Peter Morrison, « Suicides et tentatives de suicide », *Rapports sur la santé*, Statistique Canada n°82-003 au catalogue, vol. 13, n° 2, janvier 2002.

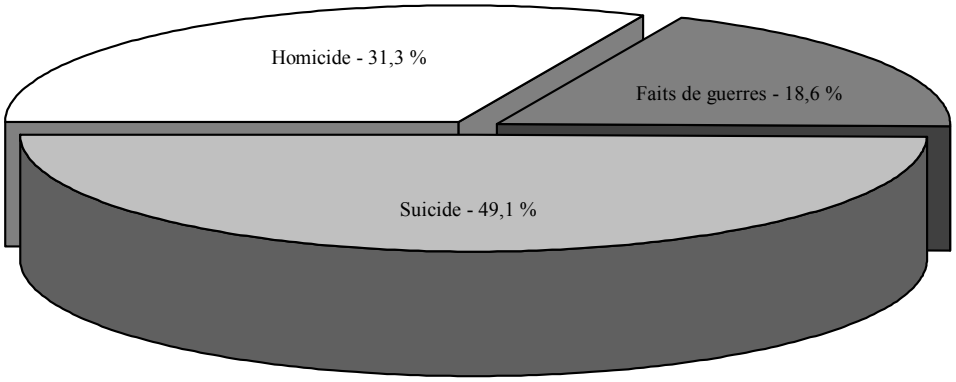
GRAPHIQUE 5.6 :
TAUX COMPARATIFS DE SUICIDE DANS QUELQUES PAYS, DE 1998 À 2000



Source : Division de l'économie, Direction de la recherche parlementaire, Bibliothèque du Parlement, mars 2004.
Données de l'Organisation mondiale de la santé (2003).

Selon les estimations de l'OMS, le suicide est la principale cause de morts violentes dans le monde, loin devant les homicides et les faits de guerre (voir graphique 5.7).

GRAPHIQUE 5.7 :
ESTIMATION DU NOMBRE DE MORTS VIOLENTES DANS LE MONDE, 2000



Source : Organisation mondiale de la santé, *Rapport mondial sur la violence et la santé* , Genève, tableau 1.2, octobre 2002, p. 10.

5.2.2 Les tentatives de suicides

Nous savons que le nombre de tentatives de suicide dépasse celui de suicides réussis, mais il est difficile d'en déterminer le nombre exact. L'Organisation mondiale de la santé estime qu'il y a environ 20 tentatives pour chaque suicide réussi. Au Canada, le taux d'hospitalisation sert à calculer le nombre de tentatives de suicide.

En 1998-1999, on a recensé 23 225 hospitalisations de Canadiens âgés de 10 ans et plus reliées à des tentatives de suicide et à d'autres blessures infligées volontairement. Le taux d'hospitalisation pour tentative de suicide chez les femmes était constamment supérieur à celui des hommes, sauf pour le groupe des 75 ans et plus (voir tableau 5.4). Le taux d'hospitalisation pour tentative de suicide chez les femmes atteignait un sommet chez les 15 à 19 ans. Le taux d'hospitalisation pour tentative de suicide chez les hommes atteignait un sommet chez les 20 à 29 ans et chez les 30 à 44 ans. Les hospitalisations pour tentative de suicide étaient moins fréquentes dans les groupes d'âge plus vieux.

TABLEAU 5.4

HOSPITALISATIONS APRÈS UNE TENTATIVE DE SUICIDE, PAR GROUPE D'ÂGE ET PAR SEXE, CANADA, 1998-1999 (par 100 000 habitants)

GROUPE D'ÂGE	TOTAL	HOMMES	FEMMES
10 - 14	40,8	15,5	67,5
15 - 19	152,2	87,3	220,8
20 - 29	117,9	98,0	138,4
30 - 44	118,3	97,6	139,3
45 - 59	68,3	55,1	81,3
60 - 74	25,0	24,7	25,2
75 et plus	21,0	27,6	17,2

Source : Stéphanie Langlois et Peter Morrison. « Suicides et tentatives de suicide », *Rapports sur la santé*, Statistique Canada, n° 82-003 au catalogue, vol. 13, nº 2, janvier 2002.

5.2.3 Les idées suicidaires

Selon l'Enquête sur la santé dans les collectivités canadiennes (cycle 1.2) de Statistique Canada, environ 3,7 p. 100 des Canadiens âgés de 15 ans et plus ont eu des idées suicidaires pendant l'année écoulée (voir le tableau 5.5). Les femmes y songeaient 5 p. 100 plus que les hommes (3,8 p. 100 contre 3,6 p. 100). Les idées suicidaires étaient trois fois plus fréquentes chez les Canadiens de 15 à 24 ans que chez ceux de 65 ans et plus (6,0 p. 100 contre 1,7 p. 100).

TABLEAU 5.5

POURCENTAGE DE REPONDANTS AYANT EU DES IDEES SUICIDAIRES AU COURS DES DOUZE DERNIERS MOIS, 2002

GROUPE D'ÂGE	IDÉES SUICIDAIRES (%)
Total, 15 ans et plus	**3,7**
Hommes	3,6
Femmes	3,8
15-24 ans	**6,0**
Hommes	4,7
Femmes	7,3
25-64 ans	**3,6**
Hommes	3,7
Femmes	3,4
65 ans et plus	**1,7**
Hommes	1,3
Femmes	n.d.

n.d. : Données non disponibles en raison de la grande variabilité d'échantillonnage.

Source : Division de l'économie, Service d'information et de recherche parlementaire, Bibliothèque du Parlement, mars 2004. À partir des données de l'Enquête sur la santé dans les collectivités canadiennes, cycle 1.2, santé mentale et bien-être, 2002.

5.3 GROUPES PARTICULIERS DE LA POPULATION : AUTOCHTONES, SANS-ABRI ET DÉTENUS

Bien que les troubles mentaux touchent les personnes de tous les sexes, de tous les âges et de toutes les cultures, dans tous les corps de métier, de tout niveau d'instruction et de revenu, il semble que leur prévalence est plus élevée dans certains segments de la population que dans d'autres. La présente section fournit des renseignements sur la prévalence des maladies mentales chez les peuples autochtones, les sans-abri et les détenus.

5.3.1 La population autochtone

> *Nous manquons beaucoup de renseignements sur l'éventail des problèmes de santé mentale (au sein de la population autochtone). À ce jour, aucune étude n'a vraiment utilisé des méthodes épidémiologiques psychiatriques récentes pour évaluer le taux des troubles mentaux dans les collectivités autochtones. Il y a, plutôt, des enquêtes sur la santé concernant la façon dont les gens comprennent leurs problèmes, leur expérience et ce qu'ils estiment être leurs problèmes essentiels. [Dr Laurence J. Kirmayer, département de psychiatrie, Université McGill, témoignages (9:41)]*

Bien que les données sur la prévalence des troubles psychiatriques parmi les peuples autochtones soient particulièrement limitées, la documentation affirme en général que les collectivités autochtones connaissent des taux de maladies mentales, de toxicomanies et de comportements suicidaires nettement plus élevés que ceux de la population en général. Voici un résumé des principales études de cas et des constats pertinents en la matière.

- Dans son rapport daté de 2003 et intitulé Profils de la santé mentale d'un échantillon d'Autochtones de la Colombie-Britannique survivants du régime canadien des pensionnats, la Fondation autochtone de guérison fait état de maladies mentales chez 125 des 127 personnes étudiées. Les troubles mentaux les plus répandus étaient le syndrome de stress post-traumatique (64,2 p. 100), les troubles liés à la consommation de substances psychoactives (26,3 p. 100) et les épisodes dépressif majeur (21,1 p. 100). La moitié des personnes chez qui l'on avait diagnostiqué un syndrome de stress post-traumatique présentaient aussi une co-morbidité avec d'autres troubles mentaux, y compris les troubles liés à la consommation de substances psychoactives (34,8 p. 100), la dépression majeure (30,4 p. 100) et le trouble dysthymique (26,1 p. 100).[242]
- Le rapport 2002 de Statistique Canada qui porte sur la santé des Autochtones vivant hors réserve révèle que cette population est 1,5 fois plus susceptible que la population non autochtone de subir un épisode dépressif majeur. Ainsi, 13 p. 100

[242] Fondation autochtone de guérison, *Profils de la santé mentale d'un échantillon d'Autochtones de la Colombie-Britannique survivants du régime canadien des pensionnats, collection recherche*, Ottawa, 2003.

environ des Autochtones résidant hors réserve ont vécu un épisode dépressif majeur dans les 12 mois ayant précédé la tenue de l'enquête, contre 7 p. 100 pour la population non autochtone, ce qui donne à penser que ceux et celles qui résident dans les régions urbaines peuvent se sentir aliénés, isolés, marginalisés et coupés de leur culture.[243]

- Le projet *Flower of the Two Soils* (1993) a consisté à étudier le lien existant entre rendement scolaire, les variables psycho-sociales et la santé mentale chez les enfants autochtones (âgés de 11 à 18 ans) habitant dans divers endroits dans l'ensemble des États-Unis et du Canada. Au Canada, ce sont certains coins du Manitoba et de la Colombie-Britannique qui ont été retenus. Les diagnostics les plus fréquents chez les répondants autochtones étaient les troubles de comportement perturbateur de l'ordre (22 p. 100) et les troubles liés à la consommation de substances psychoactives (18,4 p. 100), les troubles anxieux (17,4 p. 100), les troubles affectifs, notamment la dépression (9,3 p. 100), et le syndrome de stress post-traumatique (5 p. 100). Près de la moitié des enfants présentant des troubles du comportement et des troubles affectifs ont aussi déclaré avoir des troubles liés à la consommation de substances psychoactives.

- Les auteurs du *Rapport de la Commission royale sur les peuples autochtones de 1996* ont constaté que le taux de suicide chez les Autochtones est à peu près trois fois plus élevé que celui de la population canadienne générale. Chez les jeunes autochtones, le suicide était de cinq à six fois plus fréquent que chez les jeunes non autochtones. La Commission a indiqué que le suicide était la principale cause de décès chez les hommes de 10 à 49 ans.[244]

- Une étude signée Chandler et Lalonde (1998) – réalisée auprès de 196 communautés autochtones en Colombie-Britannique sur une période de cinq ans – a révélé des écarts considérables d'une communauté à l'autre quant à la prévalence des comportements suicidaires. Celles qui disposaient d'une certaine mesure d'autonomie gouvernementale présentaient les taux de suicide les plus faibles. Les chercheurs ont constaté que les revendications foncières et le niveau d'instruction étaient respectivement le deuxième et le troisième facteurs en importance pour prédire les taux de suicide faibles dans les collectivités autochtones.[245]

Selon les spécialistes du domaine, si une grande partie des cas de maladie mentale, de toxicomanie et de comportement suicidaire dans les collectivités autochtones et non autochtones se ressemblent, il existe en plus dans les collectivités autochtones des facteurs culturels qui influent sur la prise de décision individuelle et sur les idées suicidaires. Parmi ces facteurs culturels, mentionnons les anciennes politiques gouvernementales, la création du système de réserves, le passage d'un mode de vie actif à un mode de vie sédentaire, les

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243 Statistique Canada, « La santé des Autochtones vivant hors réserve », *Le Quotidien*, 27 août 2002.

244 Commission royale sur les peuples autochtones, *Choisir la vie : Un rapport spécial sur le suicide chez les Autochtones*, 1995.

245 J.J. Chandler et C. Lalonde, « Cultural Continuity as an Hedge Against Suicide in Canada's Fisrt Nations », *Transcultural Psychiatry*, vol. 35, nº 2, 1998, p. 191-219.

répercussions des pensionnats, le racisme, la marginalisation et la projection d'une image de soi détériorée.[246]

5.3.2 Les sans-abri

Il est particulièrement difficile de mesurer la prévalence chez les sans-abri, ainsi que leurs caractéristiques personnelles et leur état de santé. Grâce à son projet *Pathways to Homelessness*, la ville de Toronto a cependant cherché à évaluer la prévalence des maladies mentales et de la toxicomanie dans ce groupe sur une période de 18 mois. Voici les principaux constats établis quant aux taux de prévalence sur une vie :

- Près de 66 p. 100 des sans-abri présentaient des diagnostics de maladie mentale pour la vie. Ce taux est deux à trois fois plus élevé que celui de la population en général.
- Près de 66 p. 100 des sans-abri présentaient des diagnostics de troubles liés à la consommation de substances psychoactives pour la vie (alcool, marijuana et cocaïne en particulier), taux qui sont quatre à cinq fois plus élevés que ceux de la population en général.
- Quelque 86 p. 100 des sans-abri présentaient, soit un diagnostic à vie de maladie mentale ou de consommation abusive de substances (ce qui est deux à trois fois plus que pour la population en général). Autrement dit, 14 p. 100 seulement des sans-abri ne présentaient aucun symptôme de maladie mentale ou de troubles liés à la consommation de substances psychoactives.
- Quelque 75 p. 100 des sans-abri dans chaque catégorie de diagnostic de maladie mentale présentaient aussi des troubles liés à la consommation abusive de substances.
- Le taux de prévalence sur une vie des maladies mentales graves (troubles psychotiques, y compris la schizophrénie) était de 5,7 p. 100 et celui des troubles de l'humeur de 38 p. 100.

> **(…) contrairement à ce que l'on est couramment porté à croire, seule une petite proportion de la population itinérante souffre de schizophrénie[…] les troubles affectifs [de l'humeur] étant beaucoup plus fréquents.**
> ***[Bill Cameron, directeur général, Secrétariat national pour les sans-abri, mémoire au Comité, 29 avril 2004, p. 2.]***

- Quelque 22 p. 100 des sans-abri ont indiqué souffrir d'une maladie mentale (4 p. 100) ou de troubles liés à la consommation de substances psychoactives (18 p. 100), raisons pour lesquelles ils s'étaient retrouvés dans la rue.
- Dans l'année qui a précédé immédiatement leur basculement au statut de sans-abri, 6 p. 100 des personnes concernées avaient fréquenté un établissement psychiatrique, 20 p. 100 avaient été traités pour troubles liés à la consommation de substances

[246] Laurence J. Kirmayer, Gregory M. Brass et Caroline L. Tait, « The Mental Health of Aboriginal Peoples: Transformations of Identity and Community », *La Revue canadienne de psychiatrie*, vol. 45, septembre 2000, p. 607-616.

psychoactives, 25 p. 100 avaient reçu des services psychiatriques externes et 30 p. 100 avaient fréquenté les postes de police ou avaient été emprisonnés.[247]

Il demeure difficile d'établir un lien de cause à effet entre le statut de sans-abri et la maladie mentale ou la toxicomanie parce que les troubles mentaux peuvent conduire à l'itinérance, mais qu'ils peuvent aussi être provoqués par cette dernière à cause des répercussions traumatiques associées au fait de se retrouver dans la misère et de vivre dans la rue.

5.3.3 La population carcérale

Les recherches confirment que les personnes souffrant de troubles graves de santé mentale sont « trans-institutionnalisées » : les prisons canadiennes ont remplacé les ex-services ou hôpitaux psychiatriques.
[Association canadienne pour la santé mentale, mémoire au Comité, juin 2003, p. 21.]

La population carcérale est un autre groupe où les maladies mentales et les troubles liés à la consommation de substances psychoactives sont plus répandus que dans la population en général. Une étude réalisée par Boe et Vuong (2002) montre qu'entre 1997 et 2001 le pourcentage de primo-délinquants présentant un diagnostic de maladie mentale à leur admission dans un pénitencier fédéral est passé de 6 p. 100 à 8,5 p. 100, soit 40 p. 100 de plus. Durant la même période, le nombre de primo-délinquants à qui l'on a prescrit des médicaments en vue de traiter des troubles mentaux à leur admission a augmenté de 80 p. 100, pour passer de 10 p. 100 à 18 p. 100.[248]

Les données disponibles sur les délinquants souffrant de troubles mentaux font ressortir que, par rapport aux autres délinquants,

- **ils courent plus de risque d'être arrêtés à cause de leur comportement**
- **ils sont plus susceptibles de tomber dans une alternance d'épisodes brefs et récurrents de rechute et de démêlées avec la justice**
- **ils sont présents dans le système correctionnel fédéral et dans celui des provinces, aussi bien que dans les services de psychiatrie médico-légale des réseaux provinciaux de la santé.**

[Service correctionnel du Canada, mémoire au Comité, avril 2004, p. 3.]

Les données recueillies par Moloughney (2004) suggèrent qu'au moment de leur admission, une forte proportion de détenus présentent plus fréquemment des troubles liés à la consommation de substances psychoactives que des problèmes d'abus d'alcool (voir le tableau 5.6). Son étude fait ressortir qu'on diagnostique des troubles mentaux chez 3 p. 100 des détenus en moyenne au moment de leur arrivée, la proportion étant plus élevée chez les femmes (de 2,5 à 8,6 p. 100) que chez les hommes (de 1,4 à 3,3 p. 100). À l'occasion d'évaluations psychologiques, on a constaté qu'une moyenne de 7 p. 100 de tous les détenus exigeaient une attention immédiate.

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247 Mental Health Policy Research Group, *Mental Illness and Pathways into Homelessness: Proceedings and Recommendations*, Toronto, 1998. Des constats semblables ont été dressés par Stephen W. Hwang, « Homelessness and Health », dans *Journal de l'Association médicale canadienne*, vol. 164, nº 2, p. 229-233, 23 janvier 2001.

248 Roger Boe et Ben Vuong, « Les tendances en matière de santé mentale parmi les détenus sous responsabilité fédérale », *FORUM, recherche sur l'actualité correctionnelle*, vol. 14, nº 2, mai 2002.

Quelque 31 p. 100 des détenues et 15 p. 100 des détenus ont fait état de troubles émotionnels ou de problèmes de santé mentale au moment de leur incarcération et 14 p. 100 de l'ensemble de la population carcérale ont reçu un traitement psychiatrique ou psychologique avant leur incarcération. Des proportions élevées de détenus (21 p. 100 de femmes et 14 p. 100 d'hommes) ont tenté de se suicider dans les cinq années ayant précédé leur incarcération.

Nous ne disposons d'aucune donnée provenant d'études nationales récentes sur les taux de prévalence de certains troubles mentaux chez les détenus des institutions fédérales. Les dernières données disponibles remontent à 1988 dans le cas des hommes et à 1989 dans celui des femmes (voir le tableau 5.7). Ces dernières présentaient une prévalence légèrement plus élevée pour l'ensemble des troubles mentaux que les hommes, à l'exception des troubles de personnalité antisociale.

TABLEAU 5.6

PROPORTION DE DÉTENUS PRÉSENTANTS DES PROBLÈMES DE SANTÉ MENTALE AU MOMENT DE LEUR INCARCÉRATION, 2002

	HOMMES			FEMMES		
	Min.	**Moyen**	**Max.**	**Min.**	**Moyen**	**Max.**
Abus d'alcool	34,3	45,8	42,1	29,3	49,4	69,6
Abus de drogues	36,4	51,2	51,4	40,1	67,5	78,3
Troubles mentaux	1,4	2,9	3,3	2,5	4,4	8,6
Troubles mentaux/émotionnels exigeant une attention immédiate	4,4	7,3	7,6	6,8	15,4	17,1
Déclaration de troubles mentaux ou émotionnels	11,4	15,7	13,6	17,08	40,4	37,1
Intervention ou hospitalisation récente relative à des troubles mentaux	10,6	14,5	15,3	12,2	24,7	19,6
Signes de dépression apparents	9,0	9,7	9,4	8,8	16,2	2,2
Tentative(s) de suicide passée(s)	9,5	14,5	16,4	10,9	23,4	41,3
État suicidaire possible	3,4	5,2	5,5	2,7	5,8	6,5

Remarque : « Min. », « Moyen » et « Max. » représentent le degré de sécurité carcérale (minimum, moyen et maximum).

Source : Brent Moloughney, « A Health Care Needs Assessment of Federal Inmates in Canada », *Revue canadienne de santé publique*, vol. 95, supplément 1, mars-avril 2004, p. S37.

TABLEAU 5.7

PRÉVALENCE SUR UNE VIE (%) DES TROUBLES MENTAUX PARMI LES DÉTENUS FÉDÉRAUX, CANADA

TROUBLES	HOMMES (1988)	FEMMES (1989)
Dépression majeure	13,6	32,9
Anxiété générale	31,9	19,7
Troubles de dysfonctionnement psychologique	19,6	34,2
Troubles de personnalité antisociale	57,2	36,8
Consommation/dépendance d'alcool	47,4	63,2
Consommation/dépendance de drogue	41,6	50,0

Source : Service correctionnel du Canada, mémoire au Comité, avril 2004, p. 9.

Aucune étude n'a été entreprise en vue de déterminer si le taux de prévalence des maladies mentales et des troubles liés à la consommation de substances psychoactives chez les détenus fédéraux a évolué dans le temps. Des responsables du Service correctionnel du Canada estiment toutefois que, d'après les tendances actuelles, le pourcentage de détenus fédéraux souffrant de problèmes et de troubles de santé mentale est en augmentation, même si le nombre d'incarcérations et les effectifs de la population carcérale sont en baisse.[249]

5.4 FARDEAU ÉCONOMIQUE DES MALADIES MENTALES, DE LA TOXICOMANIE ET DU SUICIDE

5.4.1 Le coût des maladies mentales

Stephens et Joubert (2001) ont évalué à 14,4 milliards de dollars le fardeau économique des maladies mentales au Canada en 1998 (les troubles liés à la consommation de substances psychoactives étaient exclus de leur étude); les coûts directs en soins de santé étaient de 6,3 milliards de dollars et les coûts indirects reliés à la perte de productivité et à des décès prématurés atteignaient 8,1 milliards de dollars.[250] Le tableau 5.8 présente l'importance relative des principaux éléments de coût. Les soins en milieu hospitalier sont, de loin, les coûts indirects les plus importants, avec 3,9 milliards de dollars, soit 26,9 p. 100 du fardeau que représentent les maladies mentales.

[249] Service correctionnel du Canada, mémoire au Comité, avril 2004, p. 13.

[250] Thomas Stephens et Natacha Joubert, « Le fardeau économique des problèmes de santé mentale », *Les maladies chroniques au Canada*, vol. 22, nº 1, 2001.

TABLEAU 5.8

FARDEAU ÉCONOMIQUE DES MALADIES MENTALES AU CANADA, 1998

Élément de coût	En million de dollars	Pourcentage du total
Coûts directs (soins de santé) [1]:	**6 257**	**43,5**
▪ Médicaments	642	4,5
▪ Médecins	854	5,9
▪ Hôpitaux	3 874	26,9
▪ Autres établissements de soins de santé	887	6,2
Coûts indirects (productivité faible):	**8 132**	**56,5**
▪ Invalidité à court terme[2]	6 024	40,6
▪ Invalidité à long terme	1 708	11,9
▪ Mort prématurée	400	2,7
Total	**14 389**	**100,0**

(1) Cette catégorie comprend aussi les coûts de 278 millions de dollars en services professionnels (travailleurs sociaux et psychologues) occasionnés par les dépressions ou les cas de détresse.
(2) Attribuable uniquement à la dépression et à la détresse.
Source : Thomas Stephens et Natacha Joubert, « Le fardeau économique des problèmes de santé mentale », *Les maladies chroniques au Canada*, vol. 22, nº 1, 2001.

Le principal élément de coûts indirects est l'invalidité à court terme que les auteurs chiffrent à 6 milliards de dollars, soit quelque 40,6 p. 100 du fardeau économique total. Ils précisent que les résultats de leur étude sous-estiment l'ampleur de la situation à cause des limites que comportent leurs données (seules la dépression et la détresse ont été incluses dans cette enquête).

En 1998, les maladies mentales représentaient 4,9 p. 100 des coûts d'ensemble (directs et indirects) de la maladie au Canada. Ils se classaient ainsi au septième rang de toutes les maladies, derrière les maladies cardiovasculaires (11,6 p. 100), les maladies de l'appareil musculo-squellettique (10,3 p. 100), les cancers (8,9 p. 100), les blessures (8 p. 100), les maladies respiratoires (5,4 p. 100) et les maladies du système nerveux (5,2 p. 100).[251] La même année, les maladies mentales sont arrivées au second rang derrière les maladies cardiovasculaires sur le plan des coûts directs de soins de santé.[252] Pour ce qui est des coûts indirects, elles étaient au quatrième rang des principales causes d'invalidité à long terme, derrière les maladies de l'appareil musculo-squellettique, les maladies du système nerveux et les maladies cardiovasculaires.[253]

Une étude conjointe réalisée par l'Organisation mondiale de la santé, la Banque mondiale et l'Université Harvard – *La charge mondiale de morbidité* – a estimé que la maladie mentale, suicide y compris, représentait 10,5 p. 100 du fardeau économique total des maladies dans le monde.

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251 Santé Canada, Le fardeau économique de la maladie au Canada, 1998, gouvernement du Canada, 2002.
252 *Ibid.*
253 *Ibid.*

Selon les chercheurs, cette proportion pourrait atteindre près de 15 p. 100 en 2020.[254] Les chercheurs ont élaboré un indice unique pour permettre la comparaison du fardeau que représente la maladie pour différentes morbidités. Cet indice, connu sous le nom de *Années de vie corrigées de l'incapacité* (AVCI), désigne le nombre d'années passées sans incapacité et avant un décès prématuré. L'étude a révélé que la dépression majeure unipolaire arrive tout de suite derrière les cardiopathies ischémiques en termes d'AVCI dans les économies de marché établies. Les maladies cardiovasculaires et l'alcoolisme se classent respectivement en troisième et quatrième place en tant que principales causes d'AVCI. La schizophrénie, les troubles affectifs bipolaires, les troubles obsessifs-compulsifs, les troubles de panique et les troubles de stress post-traumatique contribuent aussi énormément au fardeau total de la maladie exprimée en AVCI.[255]

Dans son rapport de 2001, l'OMS souligne que le fardeau économique de la maladie mentale a des répercussions importantes, durables et marquées, répercussions qui demeurent tout de même largement sous-estimées. Le fardeau pour les familles de personnes souffrant d'une maladie mentale est à la fois important et varié : aux difficultés financières s'ajoutent la charge émotionnelle de la maladie, le stress dû au comportement perturbé du malade, le dérèglement de la vie de famille au quotidien et les entraves à la vie sociale.[256]

5.4.2 Le coût de la consommation abusive de substances

En 1992, on estimait à 7,5 milliards de dollars au Canada les coûts totaux (directs et indirects) de l'abus d'alcool, tandis que ceux associés à la consommation de drogues illicites atteignaient quelque 1,2 milliard de dollars (voir le tableau 5.9). Les coûts économiques les plus importants associés à l'abus d'alcool se répartissaient ainsi : 4,1 milliards de dollars au titre de la perte de productivité due aux maladies et aux décès prématurés, 1,4 milliard de dollars pour l'application des lois et 1,3 milliard de dollars en coûts indirects de soins de santé. Dans la même veine, les coûts les plus importants associés à l'abus de drogues illicites étaient la perte de productivité due à la maladie et au décès prématuré (823 millions de dollars), devant l'application des lois (400 millions de dollars) et les coûts directs en soins de santé (88 millions de dollars).

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254 Le National Institute of Mental Health a fort bien synthétisé les informations existantes sur le fardeau de la maladie dans le monde, dans *The Impact of Mental Illness on Society*, janvier 2001. Ce feuillet d'information est accessible à l'adresse www.nimh.nih.gov.

255 *Ibid.*

256 OMS (2001), p. 24-25.

TABLEAU 5.9

LE COÛT DE L'ABUS D'ALCOOL ET DE DROGUES ILLICITES AU CANADA, 1992

	ALCOOL	DROGUES ILLICITES	TOTAL
	Millions de dollars		
Coûts directs:	**3 385,6**	**547,9**	**3 933,5**
Soins de santé	1 300,6	88,0	1 388,6
Milieu de travail (ex. : PAE)	14,2	5,5	19,7
Programmes sociaux	52,3	1,5	53,8
Prévention et recherche	141,4	41,9	183,3
Application des lois	1 359,1	400,3	1 759,4
Autres coûts	518,0	10,7	528,7
Coûts indirects (perte de productivité due à)::	**4 136,5**	**823,1**	**4 959,6**
La morbidité	1 397,7	275,7	1 673,4
La mortalité	2 738,8	547,4	3 286 2
TOTAL	**7 522,1**	**1 371,0**	**8 893,1**

Source : Eric Shingle, Linda Robson, Xiaodi Xie, Jurgen Rehm *et. al.*, *Les coûts de l'abus de substances au Canada*, Centre canadien de lutte contre l'alcoolisme et les toxicomanies, 1996 (http://www.ccsa.ca/).

5.4.3 Les coûts du suicide

Jusqu'à présent, nous ne disposons d'aucune donnée sur les coûts économiques que représentent les morts par suicide, bien qu'une étude réalisée en 1996 au Nouveau-Brunswick ait évalué à quelque 850 000 $ les coûts moyens de chaque mort par suicide (coûts directs et indirects).[257]

5.5 OBSERVATIONS DU COMITÉ

On ne dispose actuellement pas de données récentes sur la prévalence et l'incidence de la maladie mentale au Canada qui permettraient de mesurer l'état de santé mentale des Canadiens et de contribuer à l'évaluation des politiques, des programmes et des services dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. Cette situation constitue un sérieux obstacle pour qui veut établir le besoin et la prestation de traitements et de services appropriés. La publication récente par Statistique Canada de l'*Enquête sur la santé dans les collectivités canadiennes* (ESCC) a contribué à régler en partie cette situation en fournissant, pour la première fois, un ensemble de données sur certaines maladies mentales, sur les troubles de consommation de substances psychoactives et sur le jeu. Le Comité estime cependant qu'il conviendrait de répéter cette enquête prochainement et d'en élargir la portée à davantage de troubles. Nous estimons, par ailleurs, qu'il conviendrait de réaliser une étude nationale, un peu comme celle prévue en Australie, pour évaluer les taux de prévalence des troubles mentaux chez les enfants et les adolescents.

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[257] Dale Clayton et Alberto Barceló, « Coût de la mortalité par suicide au Nouveau-Brunswick, 1996 », *Maladies chroniques au Canada*, vol. 20, nº 2, 1999, p. 89-93.

Le fardeau économique de la maladie mentale, de la toxicomanie et du comportement suicidaire est énorme. De toute évidence, les gouvernements devront prendre les mesures nécessaires pour contenir ou réduire ce genre de fardeau. Le Comité rejoint la Société canadienne de psychologie pour affirmer que la santé mentale est tout aussi fondamentale à une société saine que la santé physique. Nous croyons que le temps est venu d'adopter des politiques et des programmes en santé mentale et en toxicomanie qui traduisent le fardeau social et financier que représentent ces affections pour la société canadienne.

Les coûts indirects attribuables à la maladie mentale et à la toxicomanie – absentéisme et perte de productivité – sont loin d'être négligeables et ils exercent d'importantes pressions sur le milieu de travail. Par rapport aux autres maladies, les coûts indirects des troubles mentaux semblent être plus élevés que les coûts directs en soins de santé qui y sont associés. Dans le chapitre suivant, nous examinerons la prévalence et les conséquences de la maladie mentale et de la toxicomanie en milieu de travail.

La santé mentale est au coeur d'une société saine. La prévention et le traitement de la maladie mentale et de la toxicomanie exigent la même attention et le même niveau de ressources que n'importe quelles autres maladies au regard de leur prévalence, du fardeau qu'elles représentent et des résultats de la recherche.
[Société canadienne de psychologie, mémoire, 2003, p. 12]

CHAPITRE 6:
MALADIE MENTALE, TOXICOMANIE ET TRAVAIL

Les effets de la santé mentale ne sont pas seulement mentaux. […] Ce qui est bon pour la santé mentale d'une personne est bon pour le rendement de l'entreprise.
[Professeur E. Kevin Kelloway, Université Saint Mary's, Halifax][258]

INTRODUCTION

Le lien entre la santé mentale, la toxicomanie et le travail ne peut pas être qualifié de bidirectionnel. D'une part, la maladie mentale et la toxicomanie sont une grande cause d'absentéisme au travail, de mauvais rendement, de roulement du personnel et de baisse de la productivité. De l'autre, le milieu de travail peut être une grande cause de stress, qui influe sur la santé mentale et le rendement au travail. Certaines formes de stress professionnel peuvent même déclencher des maladies mentales ou des troubles liés à l'usage de substances psychoactives ou les deux.

Les employeurs ont directement intérêt à appuyer un bon régime de santé mentale en raison de l'absentéisme, de la perte de productivité et des pertes financières.
[Rod Phillips, président et directeur général, Les Consultants Warren Shepell, (18:9)]

Quel que soit le sens de la causalité entre la maladie mentale et le travail, les témoins qui ont comparu devant le Comité s'entendent généralement pour dire que le milieu de travail constitue un environnement crucial pour la promotion de la santé mentale, le dépistage précoce de la maladie mentale et de la toxicomanie, ainsi que les mesures d'adaptation et l'intégration des employés souffrant d'un trouble mental. Ces caractéristiques d'un milieu de travail en santé profiteront non seulement aux employés et aux employeurs mais aussi à la société dans son ensemble en augmentant la productivité du Canada et en réduisant le fardeau économique de la maladie mentale.

Le présent chapitre contient neuf sections. La section 6.1 décrit brièvement les avantages de l'emploi et les conséquences du chômage pour les personnes souffrant de maladie mentale et de toxicomanie. La section 6.2 résume l'information existante sur la prévalence de la maladie mentale et de la toxicomanie en milieu de travail. La section 6.3 présente quelques données sur le coût de la maladie mentale et de la toxicomanie dans le milieu de travail. La section 6.4 examine la question de l'invalidité attribuable à la maladie mentale et à la toxicomanie. La section 6.5 décrit le rôle des employeurs en ce qui concerne les programmes d'aide aux employés et les mesures d'adaptation en faveur des travailleurs atteints d'une maladie mentale. La section 6.6 résume les témoignages entendus par le Comité au sujet du rôle joué par les gouvernements pour réduire le coût économique de la maladie mentale et de la toxicomanie dans le milieu de travail. La section 6.7 fournit quelques renseignements sur les

[258] E. Kevin Kelloway, Ph.D., professeur de gestion et psychologie, Université Saint Mary's (Halifax, Nouvelle-Écosse), mémoire au Comité, 2004.

entreprises créées et dirigées par des personnes atteintes de maladie mentale ou de toxicomanie. La section 6.8 analyse le besoin d'un programme de recherche sur la maladie mentale, la toxicomanie et le travail. La section 6.9 présente les commentaires du Comité.

6.1 LES AVANTAGES DE L'EMPLOI

Récemment, Mme Heather Stuart, professeure au Département de santé communautaire et d'épidémiologie à l'Université Queen's, a indiqué éloquemment :

> *… aucune activité ne donne davantage le sentiment d'identité que le travail. Le travail influe sur le mode de vie et le lieu où l'on vit, favorise les contacts sociaux et le soutien social et procure un rang et une identité sociale.*[259]

Pour les personnes atteintes de maladie mentale ou de toxicomanie, l'emploi constitue un important facteur de rétablissement. Il peut contribuer au rétablissement et réduire la fréquence et la gravité des épisodes de maladie aiguë en donnant une structure, la possibilité d'interactions sociales et une vie mieux remplie. Par une rémunération régulière, l'emploi peut mettre fin à la dépendance envers l'aide sociale ou réduire cette dépendance et diminuer le besoin de services et moyens de soutien en santé mentale.

En revanche, la perte ou l'absence d'un emploi à cause d'une maladie mentale peut nuire au rétablissement. Le revenu et le niveau de vie diminuent, ce qui crée une dépendance économique et affaiblit l'estime de soi. Il y a également une disparition des contacts personnels avec les collègues de travail, une marginalisation sociale et une modification des rapports avec la famille et les amis.

De nombreuses personnes atteintes de maladie mentale réussissent dans leur travail sans aucune aide particulière. Les progrès récents des traitements et de la pharmacothérapie les rendent davantage en mesure de s'intégrer dans la société et de mener une vie indépendante. Celles qui travaillent contribuent à la productivité et à la compétitivité du Canada. D'autres ont cependant besoin d'aide pour trouver et garder un emploi. Dans ce contexte, la question de la maladie mentale, de la toxicomanie et du travail peut être explorée à partir de trois points de vue différents. Le premier examine les moyens de rendre l'emploi accessible à ceux qui n'ont jamais travaillé. Le deuxième insiste sur la maladie mentale et la toxicomanie qui peuvent frapper des personnes occupant déjà un emploi. Le troisième porte sur ceux qui ont perdu leur emploi à cause d'une maladie mentale ou de la toxicomanie et qui souhaitent réintégrer le marché du travail.

Comme nous l'avons vu au chapitre 4, les troubles mentaux ont tendance à se déclencher à la fin de l'adolescence ou au début de la vie adulte, à un moment où les études et la formation ne sont pas encore terminées. Le processus de préparation à l'emploi est interrompu et, bien souvent, il ne redémarre jamais. Les jeunes touchés sont très

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259 Heather Stuart, *Stigma and Work*, document de travail commandé pour l'atelier appuyé par l'Institut de la santé publique et des populations et l'Institut des neurosciences, de la santé mentale et des toxicomanies des Instituts de recherche en santé du Canada, avril 2004, p. 80.

désavantagés; l'absence de compétences et de qualifications constitue un important obstacle à leur emploi futur.

Pour ceux qui trouvent du travail, les périodes de retrait de la population active à cause de leur maladie mentale, malgré leur capacité de fonctionner correctement, les empêche souvent de réintégrer le marché du travail. Trois grands obstacles s'appliquent dans ce cas. Premièrement, les personnes visées peuvent faire l'objet de discrimination de la part de leur employeur ou de leurs collègues, ou des deux. Deuxièmement, elles peuvent avoir besoin d'un assouplissement de leurs conditions de travail que les employeurs hésitent à accorder ou ne savent pas comment accorder. Troisièmement, ceux qui se sont retrouvés hors du marché du travail pendant de longues périodes ne possèdent probablement pas le type de compétences, de qualifications et d'expérience de travail qui les rendrait intéressants pour les employeurs.

Le Comité a appris que les taux de chômage chez les personnes atteintes de maladie mentale sont inacceptables. Les études internationales semblent indiquer que le taux de chômage des personnes atteintes de maladie mentale grave et persistante se situe aux alentours de 90 p. 100. Il contraste avec le taux de chômage d'environ 50 p. 100 chez les personnes qui ont un handicap physique ou sensoriel. Autrement dit, seulement 10 p. 100 des personnes ayant un trouble mental grave et souhaitant travailler son jugées capables de le faire et travaillent effectivement.[260]

Au Canada, une brochure de l'Association des psychiatres du Canada révèle que les personnes atteintes d'une maladie mentale courent plus de risque de se retrouver au chômage à long terme, d'être sous-employé ou de recourir à l'aide sociale. L'Association croit que, parmi toutes les personnes atteintes d'une incapacité, les victimes de maladies mentales sont celles qui se heurtent le plus à la stigmatisation et aux obstacles dans leur carrière.[261] Le chômage pose un grand problème : plus on est sans emploi pendant longtemps, moins on a de chances de mener à nouveau une vie professionnelle productive. Les statistiques montrent qu'après six mois de congé pour invalidité, on a 50 p. 100 de chance de retourner sur le marché du travail; ces probabilités ne sont plus que de 20 p. 100 après un an et de 10 p. 100 après deux ans[262].

Deux principaux facteurs rendent la maladie mentale particulièrement problématique en milieu de travail. Premièrement, la maladie mentale frappe habituellement les jeunes travailleurs. Deuxièmement, de nombreuses maladies mentales sont à la fois chroniques et cycliques et exigent donc des traitements périodiques pendant de nombreuses années. Les employeurs et le gouvernement ont un rôle vital à jouer pour résoudre les problèmes de maladie mentale et de toxicomanie en milieu de travail, notamment par des mesures d'adaptation, des programmes de retour au travail et la gestion de l'invalidité.

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260 Gaston Harnois et Phyllis Gabriel (2000), *Mental Health and Work: Impact, Issues and Good Practices*, publication conjointe de l'Organisation mondiale de la santé et de l'Organisation internationale du travail, Genève, 2000, p. 19.

261 Association des psychiatres du Canada, La maladie mentale et le travail, http://www.cpa-apc.org/MIAW/pamphlets/Work_fr.asp, brochure affichée sur Internet (consultée le 15 juin 2004).

262 Ontario Medical Association, *Mental Illness and Workplace Absenteeism: Exploring Risk Factors and Effective Return to Work Strategies*, avril 2002.

Loin de l'idée des membres du Comité de sous-entendre qu'il s'agit là d'une tâche aisée ou peu coûteuse pour les employeurs du secteur privé ou pour les gouvernements.

6.2 PRÉVALENCE DE LA MALADIE MENTALE ET DE LA TOXICOMANIE DANS LE MILIEU DE TRAVAIL

Il n'y a actuellement pas au Canada de source unique de renseignements complets et exacts sur la prévalence de la maladie mentale et de la toxicomanie en milieu de travail. Mais l'analyse de la documentation existante donne une idée de l'ampleur du problème :

- La toxicomanie (alcoolisme et abus de substances) préoccupe gravement dans le secteur manufacturier canadien. Le taux de toxicomanie chez les employés de ce secteur est évalué à presque le double de la moyenne nationale; il pourrait être fortement sous-évalué puisqu'il arrive souvent que la toxicomanie en milieu de travail ne soit pas signalée. Les niveaux d'anxiété et de colère ont nettement augmenté parmi les employés du secteur de la fabrication au cours des trois dernières années. Une enquête a révélé que les troubles de l'anxiété dans le secteur de la fabrication sont plus fréquents dans les populations majoritairement masculines au sein desquelles les problèmes de toxicomanie sont également présents.[263]

- Par rapport à la moyenne nationale, les taux de dépression et d'anxiété sont élevés dans le secteur des technologies de l'information. Les taux de dépression varient grandement d'une année à l'autre, ce qui témoigne de l'instabilité du secteur de la technologie.[264]

- Certains groupes de la population active semblent plus vulnérables à la maladie mentale et à la toxicomanie, soit les hommes et les femmes dans la force de l'âge (entre la 10e et la 14e année de service chez le même employeur) et les nouveaux venus sur le marché du travail.[265]

- Une enquête récente indique que le personnel hospitalier accède de plus en plus aux programmes d'aide aux employés. Le personnel hospitalier est exposé progressivement à un niveau de stress plus élevé que dans les autres secteurs. Cela pourrait s'expliquer en partie par la restructuration des hôpitaux, les réductions d'effectifs et les pénuries de ressources humaines. Traiter le stress dans le secteur hospitalier est peut-être plus important que dans d'autres secteurs car, dans les soins

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263 D'après un échantillon de 136 entreprises comptant 54 050 employés. Données tirées de Les Consultants Warren Shepell, *Analyse du secteur : Les tendances en matière de santé organisationnelle et de mieux-être dans le secteur de la fabrication*, mars 2003 (affiché sur www.warrenshepell.com). http://www.warrenshepell.com/francais/recherche/recherche.asp#

264 D'après un échantillon de 153 organisations comptant 86 000 employés au Canada. Données tirées de Les Consultants Warren Shepell, *Analyse du secteur : Les tendances en matière de santé organisationnelle et de mieux-être dans le secteur de la technologie*, février 2003 (affiché sur www.warrenshepell.com). http://www.warrenshepell.com/francais/recherche/recherche.asp#

265 Global Business and Economic Roundtable on Addiction and Mental Health, *Roundtable Roadmap to Mental Disability Management in 2004-2005*, 25 juin 2004, p. 4.

aux malades, les erreurs liées au stress peuvent avoir des conséquences très négatives sur les patients.[266]

- De même, un sondage mené par l'Association médicale canadienne en 2003 a établi que le stress et l'insatisfaction sont à la hausse chez les médecins. Plus précisément, le sondage a révélé que 45,7 p. 100 des médecins sont en état d'épuisement avancé. De plus, les femmes médecins semblent plus exposées au suicide que la population en général.[267]

- Par rapport aux autres secteurs, les travailleurs des secteurs du commerce de détail et de l'hôtellerie sont confrontés à des facteurs de stress particuliers dans leur environnement de travail, notamment l'incidence et les risques de vol à main armée. L'incidence de la violence familiale dans le secteur du commerce de détail serait plus du double de la moyenne nationale. Les symptômes de stress et de dépression déclarés par le personnel des secteurs du commerce de détail et de l'hôtellerie sont plus importants que chez les employés de la plupart des autres secteurs. Le personnel du secteur de l'hôtellerie fait un plus grand usage de substances, y compris l'alcool et le tabac, que le personnel d'autres secteurs, et l'incidence du stress et de l'anxiété est plus élevée.[268]

- L'Association du Barreau canadien a signalé des taux alarmants et croissants de dépression et de toxicomanie chez les avocats. Le taux d'alcoolisme est trois fois plus élevé que dans la population en général. Il semblerait que les heures de travail excessives, la concurrence effrénée et les pressions insistantes des cabinets en vue d'accroître les heures facturables contribuent grandement à ces problèmes.[269]

- Dans l'ensemble de la population active canadienne, environ 3,5 p. 100 des femmes et 3,0 p. 100 des hommes signalent une détresse psychologique (définie comme la dépression et l'anxiété). La détresse psychologique a tendance à être plus grande chez les travailleurs dont les emplois sont très exigeants mais qui ont peu de latitude pour prendre des décisions. Environ 40 p. 100 des travailleurs dans ces types d'emplois ont affiché des niveaux de détresse psychologique plus élevés (voir le tableau 6.1 ci-dessous).[270]

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266 Les Consultants Warren Shepell, *Analyse du secteur : Les tendances en matière de santé organisationnelle et de mieux-être dans le secteur hospitalier*, hiver 2004 (affiché sur www.warrenshepell.com). http://www.warrenshepell.com/research/latest.asp#

267 Dr Sunil V. Patel, président, Association médicale canadienne, mémoire au Comité, 31 mars 2004, p. 4.

268 Les Consultants Warren Shepell, *Analyse du secteur : Les tendances en matière de santé organisationnelle et de mieux-être dans les secteurs du commerce de détail et de l'hôtellerie,* hiver 2004 (affiché sur http://www.warrenshepell.com/research/latest.asp#).

269 Bill Wilkerson, *Since September 11th – The Business State of Mind: Mental Health in the Knowledge Economy*, allocution à la conférence « Beyond Awareness » (A Campaign to Reduce the Stigma of Mental Illness), 6 février 2002, p. 7.

270 Kathryn Wilkins et Marie P. Beaudet, « Le stress au travail et la santé » *Rapports sur la santé*, Statistique Canada, n° au catalogue 82-003, hiver 1998, vol. 10, n°. 3, p. 52-53.

TABLEAU 6.1

POURCENTAGE DE TRAVAILLEURS CANADIENS SIGNALANT UNE DÉTRESSE PSYCHOLOGIQUE ÉLEVÉE, EN FONCTION DE LA LATITUDE DANS LES DÉCISIONS PROFESSIONNELLES ET LES EXIGENCES DU TRAVAIL

EXIGENCES DU TRAVAIL	LATITUDE DANS LES DÉCISIONS PROFESSIONNELLES			
	Grande	Moyenne	Faible	Très faible
Élevées	27	33	33	40
Modérées	24	26	30	35
Faibles	19	20	21	30
Très faibles	16	18	22	20

Source : Kathryn Wilkins et Marie P. Beaudet, « Le stress au travail et la santé » *Rapports sur la santé*, Statistique Canada, n° au catalogue 82-003, hiver 1998, vol. 10, n° 3, p. 52.

- Au Québec, une étude menée en 2001 par Renée Bourbonnais et ses collègues a révélé que les personnes qui subissent un stress professionnel risquent deux fois plus que les autres d'avoir une maladie mentale (23 p. 100 au lieu de 11 p. 100 chez les hommes et 30 p. 100 au lieu de 15 p. 100 chez les femmes).[271]
- Le stress professionnel ainsi que les conflits liés au travail et le harcèlement comptent parmi les huit principales raisons pour lesquelles les employés canadiens demandent de l'aide dans le cadre des programmes d'aide aux employés (PAE). Le stress lié à des problèmes professionnels représente environ 40 p. 100 de tous les dossiers des PAE. Le pourcentage d'employés qui demandent de l'aide à cause de conflits liés au travail est passé de 23 p. 100 en 1999 à près de 30 p. 100 en 2001. Le nombre d'employés qui demandent de l'aide à cause de harcèlement a presque triplé de 1999 à 2001.[272]
- Aux États-Unis, 40 p. 100 des dossiers des PAE dans plusieurs entreprises de pointe se rapportent à des symptômes de dépression.[273]

6.3 COÛTS ET CONSÉQUENCES DE LA MALADIE MENTALE ET DE LA TOXICOMANIE EN MILIEU DE TRAVAIL

Sur le marché du travail, la productivité peut être reliée à la notion d'invalidité. Plus précisément, moins le travailleur est invalide, plus il est productif et *vice versa*. La productivité dépend du présentéisme (jours pendant lesquels le travailleur est présent au travail, mais ne

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271 Renée Bourbonnais, Brigitte Larocque, Chantal Brisson et Michel Vézina, « Contraintes psychosociales du travail », dans *Portrait Social du Québec*, Institut de la Statistique du Québec, 2001, p. 267-277.

272 Les Consultants Warren Shepell, *Workplace Trends Linked to Mental Health Crisis in Canada*, communiqué, 15 novembre 2002.

273 Bill Wilkerson, *A Business Charter for Mental Health an Addiction in the Knowledge Economy*, allocution devant l'Ontario Public Service Commission and Management Board, 25 septembre 2002, Toronto, p. 9.

donne pas son rendement maximal) et de l'absentéisme (jours pendant lesquels l'employé ne se présente pas au travail).

La maladie mentale et la toxicomanie comptent parmi les plus importantes causes d'absentéisme et de présentéisme dans le monde : l'Organisation mondiale de la santé affirmait dans son rapport de 1998 le nombre de journées de travail perdues à cause de troubles mentaux dépassent désormais celui des journées perdues à cause de maladies physiques.[274] Au Canada, 20 p. 100 des heures normales de travail des employés qui souffrent d'une maladie mentale ou d'une toxicomanie non dépistée ne sont pas productives parce qu'elles ne sont pas travaillées. Ce taux est quatre fois plus élevé que chez leurs collègues de travail.[275]

Comparativement à toutes les autres maladies (comme le cancer et les maladies du cœur), les maladies mentales et la toxicomanie arrivent au premier et au deuxième rang des causes d'invalidité au Canada, aux États-Unis et en Europe de l'Ouest (voir le graphique 6.1).[276] Parmi les dix principales causes d'invalidité dans le monde, cinq sont des troubles mentaux : dépression unipolaire, alcoolisme, trouble bipolaire, schizophrénie et trouble obsessif-compulsif.[277]

Nous sommes d'avis que les employeurs paient déjà une partie importante des coûts liés à la santé mentale au Canada. En ce sens, ils subventionnent ce que nous avons dans le régime de soins de santé public et, dans certains cas, cela compense pour les lacunes de ce régime.
[Rod Phillips, président et chef de la direction, Warren Shepell Consultants (18:9)]

Comme nous l'avons indiqué au chapitre 5, la productivité perdue au Canada uniquement à cause des maladies mentales a été évaluée à quelque 8,1 milliards de dollars en 1998.[278] On a évalué récemment que, lorsque l'abus de substances est également pris en considération, l'économie canadienne perd quelque 33 milliards de dollars par année sous forme de productivité perdue à cause de la maladie mentale et de la toxicomanie.[279] Ce montant correspond à 19 p. 100 des bénéfices combinés de toutes les entreprises canadiennes et à 4 p. 100 de la dette nationale.[280] Autrement dit, les entreprises paient les deux tiers de tous les coûts liés à la maladie mentale et à la toxicomanie sous forme de pertes de productivité,

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274 Organisation mondiale de la santé, *La vie au 21e siècle : Une perspective pour tous*, Genève, 1998. http://www.who.int/whr2001/2001/archives/1998/index_fr.htm

275 Bill Wilkerson, *Text of Speech*, Warren Shepell Consultants Business Forum, 16 octobre 2002, p. 14.

276 President's New Freedom Commission on Mental Health, *Interim Report*, États-Unis, 29 octobre 2002.

277 *Ibid.*

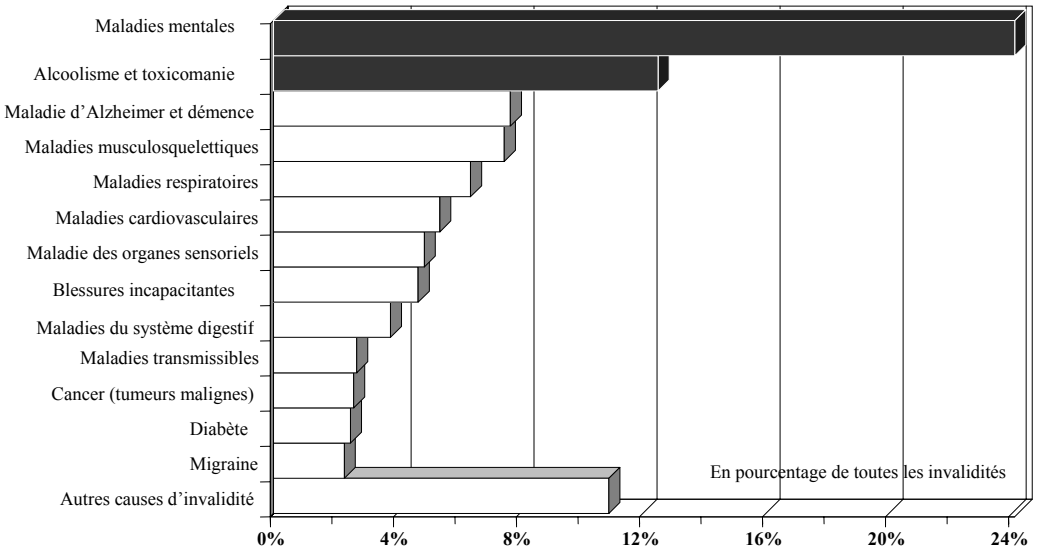
278 D'après des calculs effectués par Thomas Stephens et Natacha Joubert, « Le fardeau économique des problèmes de santé mentale au Canada », *Maladies chroniques au Canada*, vol. 22, n° 1, 2001. http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/cdic-mcc/22-1/index_f.html

279 Martin Shain et. al., Mental Health and Substance Use at Work: Perspective from Research and Implications for Leaders, document de travail préparé pour la Global Business and Economic Roundtable on Addiction and Mental Health, 14 novembre 2002 (inédit).

280 Évaluations de la Division de l'économie, Service d'information et de recherche parlementaires, Bibliothèque du Parlement.

d'absentéisme, d'invalidité, de coûts de remplacement des salaires, de primes d'assurance-maladie collective et de médicaments d'ordonnance.[281]

GRAPHIQUE 6.1
CAUSES D'INVALIDITÉ
CANADA, ÉTATS-UNIS ET EUROPE DE L'OUEST



Remarque : Causes d'invalidité pour tous les groupes d'âge. Les mesures de l'invalidité se fondent sur le nombre d'années « en santé » perdues à cause d'une santé sub-optimale (soit API, années perdues à cause d'une invalidité).

Source : President's New Freedom Commission on Mental Health, *Interim Report*, États-Unis, 29 octobre 2002.Source : President's New Freedom Commission on Mental Health, *Interim Report*, États-Unis, 29 octobre 2002.

Dans l'ensemble, les conséquences de la maladie mentale, de la toxicomanie et du stress professionnel en milieu de travail sont nombreuses (voir le tableau 6.2). Le Comité a entendu à maintes reprises que ni les personnes affectées, ni les employeurs, ni la société n'ont intérêt à ignorer l'existence de la maladie mentale, de la toxicomanie et du stress professionnel en milieu de travail et la marginalisation de citoyens qui pourraient être productifs. Étant donné les coûts économiques et sociaux de ces troubles, il est essentiel que les secteurs public et privé s'attaquent de toute urgence au problème.

Tout comme il l'a fait à la section 6.1, le Comité tient à préciser qu'il ne sera certainement pas facile de s'attaquer à ce genre de problèmes, mais c'est pourtant ce qu'il faudra faire au nom des règles économiques et de la compassion.

[281] Bill Wilkerson (6 février 2002), p. 8.

TABLEAU 6.2

CONSÉQUENCES DE LA MALADIE MENTALE, DE LA TOXICOMANIE ET DU STRESS PROFESSIONNEL EN MILIEU DE TRAVAIL

Absentéisme	• augmentation des absences pour cause de maladie, en particulier de la fréquence des courtes périodes d'absence • mauvaise santé (dépression, stress, épuisement) • troubles physiques (hypertension, maladies du cœur, ulcères, troubles du sommeil, éruptions cutanées, maux de tête, mal de cou et lombalgie, faible résistance aux infections)
Présentéisme	• baisse de la productivité et de la production • hausse des taux d'erreur • nombre accru d'accidents • mauvaises décisions • détérioration de la planification et du contrôle du travail
Attitude et comportement du personnel	• perte de motivation et d'engagement • épuisement • heures de travail de plus en plus longues pour obtenir des résultats de plus en plus faibles • difficulté à remplir les heures de travail • roulement de la main-d'œuvre (particulièrement coûteux pour les entreprises aux niveaux élevés de gestion)
Relations de travail	• tension et conflits entre collègues • mauvaises relations avec les clients • hausse des problèmes disciplinaires

Source : Gaston Harnois et Phyllis Gabriel, *Mental Health and Work: Impact, Issues and Good Practices*, publication conjointe de l'Organisation mondiale de la santé et de l'Organisation mondiale du travail, Genève, 2000, p. 8-9.

6.4 MALADIE MENTALE, TOXICOMANIE ET INVALIDITÉ

> *Des prestations d'invalidité en cas de troubles psychiatriques devraient être accordées comme elles le sont lorsque l'invalidité découle d'une maladie médicale ou chirurgicale.*
> *[Association des psychiatres du Canada]*[282]

La nature imprévisible et épisodique de l'invalidité découlant d'une maladie mentale est importante et diffère un peu par rapport à de nombreux autres types d'invalidité. Les personnes atteintes de maladie mentale ont tendance à alterner entre des périodes de maladie et de bien-être. Quand elles n'ont pas de symptômes, elles sont généralement capables de travailler et d'exécuter les tâches courantes de la vie. Durant les épisodes de maladie

[282] Association des psychiatres du Canada, *Insurability of the Psychiatrically Ill or Those With a Past History of Psychiatric Disorder*, énoncé de position, 1988.

psychiatrique cependant, elles peuvent être incapables de fonctionner à un niveau leur permettant d'occuper un emploi régulier.

> **La maladie mentale et la toxicomanie au Canada provoquent d'énormes souffrances et sont très invalidantes –situation qui, à notre avis, ne serait pas tolérée pour des maladies physiques d'une prévalence et d'une gravité comparable.**
> ***[Centre de toxicomanie et de santé mentale, mémoire au Comité, 27 juin 2003, p. 6.]***

Le Comité a été informé que les prestations d'invalidité attribuables à des maladies mentales dépassent maintenant les prestations relatives aux maladies cardiovasculaires, à titre de catégorie de coûts d'invalidité qui augmente le plus rapidement Canada.[283] À l'heure actuelle, les maladies mentales et la toxicomanie représentent de 60 à 65 p. 100 de toutes les demandes de prestations d'invalidité chez quelques employeurs canadiens et américains.[284] Il est prévu que les demandes de prestations d'invalidité relatives à des problèmes de santé mentale et des maladies mentales pourraient monter à plus de 50 p. 100 du nombre total de prestations administrées par les régimes collectifs d'assurance-maladie au cours des cinq prochaines années.[285]

Les sections qui suivent présentent de l'information sur les prestations d'invalidité liées à la maladie mentale et à la toxicomanie accordées par les régimes d'assurance-invalidité des employeurs, les commissions des accidents du travail, le programme de prestations d'invalidité du Régime de pensions du Canada (RPC-I) et l'assurance-emploi (AE).

6.4.1 Les régimes d'assurance-invalidité des employeurs[286]

Il existe deux types de régimes d'assurance-revenu en cas d'invalidité offerts par les employeurs, soit : les régimes d'assurance-invalidité de courte durée (ICD) et les régimes d'assurance-invalidité de longue durée (ILD). Les régimes ICD remplacent un pourcentage (70 p. 100 par exemple) du revenu d'emploi pré-invalidité pour des périodes inférieures à un an (p. ex., six mois). Ils s'harmonisent généralement aux congés de maladie, à d'autres avantages sociaux et aux prestations d'AE, ce qui permet une continuité du revenu en cas de maladie ou de blessure invalidante.

Les régimes ILD portent sur des périodes d'invalidité prolongées. Ils commencent habituellement à verser les prestations après une longue absence, par exemple six mois, et ils remplacent un pourcentage du revenu d'emploi pré-invalidité (par exemple 70 p. 100). Les prestations ILD sont habituellement versées pendant une période maximale de deux ans lorsque la personne est incapable d'exécuter les tâches de sa propre profession, ou plus

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283 Mental Health Works, *Mental Health in the Workplace: Facts and Figures*, Association canadienne pour la santé mentale – division de l'Ontario, 2003.

284 Global Business and Economic Roundtable on Addiction and Mental Health (25 juin 2004), p. 14.

285 Bill Wilkerson, *Mental Health – The Ultimate Productivity Weapon*, résumé de l'allocution prononcée au congrès de l'Association pour la prévention des accidents industriels, Toronto, 22 avril 2002, p. 5.

286 Sauf indication contraire, les renseignements fournis dans cette section se fondent sur le document suivant : Association canadienne des compagnies d'assurances de personnes Inc., *Le rôle des régimes d'assurance invalidité dans le système canadien de protection du revenu en cas d'invalidité*, mémoire au Sous-comité de la Chambre des communes sur la condition des personnes handicapées, mai 2003. http://www.clhia.ca/fr/submissions_fr/2003/Chambre%20des%20communes.pdf

longtemps, soit jusqu'à un âge maximal de 65 ans ou au début des prestations de retraite, si la personne est incapable d'occuper un emploi raisonnablement comparable. Les prestations ILD versées par le régime de l'employeur peuvent être réduites d'un montant équivalent à celui que le prestataire reçoit du RPC-I.

Les régimes ICD et ILD partagent un important objectif : ils encouragent les prestataires à reprendre le travail, de préférence leurs propres activités professionnelles ou, lorsque cela n'est pas possible, à occuper un autre type d'emploi. Ainsi, pour motiver les prestataires à retourner travailler, ils sont conçus de façon à ce que le revenu de remplacement n'excède pas le revenu pré-invalidité.[287]

Aucune enquête canadienne exhaustive n'a été menée pour obtenir de l'information sur le coût total des prestations ICD et ILD versées par les employeurs relativement à la maladie mentale et à la toxicomanie. L'information fournie au Comité à ce sujet se résume comme suit :

- Depuis 1994, les troubles dépressifs à eux seuls ont doublé en pourcentage des prestations ICD et ILD et ont augmenté de 55 p. 100 pour toutes les catégories d'absence du travail reliées à une invalidité.[288]
- De même, une enquête menée en 2002-2003 par Watson Wyatt Worldwide a évalué que la maladie mentale et la toxicomanie constituent la principale cause des prestations ICD, et 73 p. 100 des répondants ont confirmé que ces troubles étaient également la principale cause des prestations ILD.[289]
- Une analyse de la Global Business and Economic Roundtable on Addiction and Mental Health évalue que de 640 000 à 1 075 000 employés à plein temps au Canada sont actuellement en congé d'invalidité à cause d'une maladie mentale faisant l'objet d'un diagnostic primaire ou secondaire. Cela représente une perte de 35 millions de journées de travail pour l'économie canadienne. Autrement dit, la maladie mentale et la toxicomanie représentent 46 p. 100 de toutes les prestations d'invalidité de courte et de longue durée.[290]

Trois questions précises ont été soulevées au sujet des régimes d'assurance-invalidité des employeurs. Premièrement, Watson Wyatt Worldwide, expert-conseil mondial spécialisé dans les ressources humaines et les régimes d'avantages sociaux et d'assurance-maladie collectifs, a souligné que toutes les entreprises devraient examiner leurs prestations ICD et ILD afin d'évaluer correctement l'incidence de la maladie mentale et de la toxicomanie dans

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287 Les régimes d'assurance-revenu en cas d'invalidité font souvent partie d'un régime collectif d'avantages sociaux comportant des garanties d'assurance-maladie complémentaire (qui peuvent couvrir les médicaments sur ordonnance, les soins infirmiers spéciaux et des services spéciaux qui ne sont pas couverts par les régimes d'État comme les services de psychologues agréés, de chiropraticiens, de massothérapeutes, etc.).

288 Bill Wilkerson (6 février 2002), p. 7.

289 Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, juin 2003.

290 Global Business and Economic Roundtable on Addiction and Mental Health, "Full-Time Employees in Canada Losing 35 Million Days of Work a Year Due to Mental Disorders; Half of All Days Lost to Illness and Disability", communiqué, 14 juillet 2004.

leurs milieux de travail. Les résultats de cet examen permettraient de déterminer le type d'intervention nécessaire.[291]

Deuxièmement, il serait important de comprendre l'influence qu'exercent le type et la portée des prestations d'invalidité sur la durée des prestations afin de déterminer les conditions nécessaires pour optimiser les situations individuelles. L'assurance-invalidité ne devrait pas décourager de travailler. Dans ce contexte, l'Association des psychiatres du Canada a expliqué :

> *Pour de nombreuses maladies, l'assurance-invalidité exige une définition précise de la maladie. Il est important que les patients psychiatriques invalides touchent un revenu suffisant pour se protéger contre de graves ennuis financiers pendant qu'ils ne peuvent pas travailler, mais il est tout aussi important de reconnaître que les prestations d'invalidité constituent un gain secondaire important qui empêche le progrès du patient et retarde son rétablissement. Il y a deux facteurs à prendre en considération : a) l'idée fausse répandue que le travail est nécessairement stressant et risque d'aggraver un trouble psychiatrique diagnostiqué; et b) la reconnaissance du fait que certains patients qui ont subi un trouble psychiatrique grave peuvent souhaiter éviter de s'exposer à ce qu'ils présument être des facteurs stressants au travail, parce qu'ils manquent de confiance malgré une amélioration clinique de leur état. Il faudrait reconnaître que retourner au travail le plus rapidement possible renforcera probablement l'estime de soi du patient, le ramènera dans un réseau social familier et contribuera à son rétablissement. Il a été démontré que la privation du travail peut être une cause de trouble psychiatrique.*[292]

Troisièmement, et peut-être surtout, les employeurs, les gestionnaires et les assureurs doivent apprendre à mieux connaître la maladie mentale et la toxicomanie afin de mieux gérer leurs prestations d'invalidité. Dans une allocution récente, Bill Wilkerson, cofondateur et directeur général de Global Business and Economic Roundtable on Addiction and Mental Health, déclarait :

> *Un arrêt de la Cour suprême du Canada qui a fait jurisprudence a porté sur une femme de la Saskatchewan, handicapée par un trouble mental. En congé de maladie, elle recevait des prestations d'invalidité et a dû être hospitalisée. Pendant son hospitalisation, les prestations d'invalidité ont continué à être versées. Après avoir reçu son congé de l'hôpital, les prestations ont été interrompues parce que, aussi difficile à croire que cela puisse l'être, l'hospitalisation établissait les critères de l'admissibilité continue. La Cour suprême a tranché que cette pratique était discriminatoire, parce que les personnes handicapées physiquement*

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291 Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, juin 2003.

292 Association des psychiatres du Canada (1988), op. cit.

restaient admissibles aux prestations lorsqu'elles quittaient l'hôpital et se rétablissaient à la maison.

Les pratiques de l'assureur étaient-elles simplement désuètes ou malveillantes? D'une façon ou de l'autre, l'assureur a été atteint lui aussi par un trouble de perception puisqu'il s'est fait une mauvaise idée ce de que la maladie mentale est ou n'est pas en réalité. On peut supposer qu'il a été déconcerté par la nature des troubles mentaux, par le processus de traitement et par le rôle crucial, voire supérieur, des soins externes et du soutien de la communauté et de la famille dans le rétablissement durable de la patiente.

Je raconte cette histoire non pas pour rabaisser ou critiquer l'industrie de l'assurance en général. Je fais partie de cette collectivité et il y a certainement des exemples de situations où l'industrie de l'assurance-vie et de l'assurance-santé a fait preuve de leadership pour promouvoir la santé mentale. Mon propos a une portée plus large. Cette industrie doit définir son point de vue à partir d'une connaissance des problèmes de santé mentale. Comme les entreprises en général, le secteur de l'assurance a besoin d'être sensibilisé à la santé mentale.

C'est tout particulièrement vrai, par exemple, pour les aspects de la comorbidité de maladies mentales et de maladies physiques chroniques touchant à l'origine et à la durée de l'invalidité; à la complexité, à la durée et aux risques du traitement et du rétablissement; et au rythme et à la date du retour au travail.

Au niveau de la gestion des prestations, l'industrie de l'assurance doit mieux connaître la science médicale de la santé mentale. (…). L'industrie doit acquérir des connaissances sur l'univers grandissant des neurosciences et l'éclairage qu'elles peuvent apporter sur les origines du comportement.[293]

6.4.2 Les commissions des accidents du travail

Dans toutes les provinces et tous les territoires, les commissions des accidents du travail reçoivent un nombre grandissant de demandes de prestations reliées à la santé mentale (« stress professionnel ») et, dans un nombre grandissant de cas, les commissions ont accordé des prestations reliées à une maladie mentale. Un examen des demandes de prestations pour stress professionnel présentées aux commissions a été effectué par l'Association des Commissions des accidents du travail du Canada, afin de découvrir combien de types de demandes étaient déposées tous les ans, si les demandes étaient épisodiques ou chroniques et quel était le montant des prestations versées dans chaque cas. Cet examen s'est avéré très

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293 Bill Wilkerson, *Notes for Remarks*, 55e Assemblée annuelle de l'Association canadienne des directeurs médicaux en assurance-vie, 17 mai 2004, p. 9.

difficile. Dans bien des cas, les commissions ne collectent pas ce type de données ou, si elles le font, les données ne sont pas comparables parce que les définitions employées par les diverses commissions peuvent différer (voir le tableau 6.3). Par conséquent, l'examen n'a pas pu brosser un tableau national du nombre de demandes de prestations découlant du stress professionnel ni des coûts des prestations connexes.[294]

TABLEAU 6.3

COMMISION DES ACCIDENTS DU TRAVAIL AU CANADA : COMPARAISON INTERPROVINCIALES DES PRESTATIONS POUR STRESS PROFESSIONNEL

Alberta	Les prestations pour stress professionnel sont accordées lorsque : • il y a un diagnostic confirmé conformément au Diagnostic and Statistical Manual of Mental Disorders de l'American Psychiatric Association; • les événements ou agents stressants reliés au travail constituent la cause principale de la maladie; • les événements reliés au travail sont excessifs ou inhabituels par rapport aux pressions normales que subit un travailleur moyen dans un poste semblable; • il y a une confirmation objective des événements.
Colombie-Britannique	Les formes de stress indemnisables comprennent : • le stress est causé par un événement traumatique soudain et inattendu; • le stress qui découle d'un accident indemnisable, comme une grave anxiété après l'amputation d'une jambe. Le stress provoqué par les pressions subies dans la vie personnelle et professionnelle quotidienne n'est pas indemnisable.
Manitoba	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
Nouveau-Brunswick	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
Terre-Neuve et Labrador	La définition d'un accident au sens de la loi ne couvre le stress que lorsque ce dernier découle d'une réaction aiguë à un événement traumatique soudain et inattendu et exclut le stress découlant des problèmes de relations de travail.
T.N.-O. et Nunavut	Les demandes de prestations pour stress professionnel sont examinées au cas par cas.
Nouvelle-Écosse	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
Ontario	Le stress mental est indemnisable lorsqu'il y a une réaction aiguë à un événement traumatique soudain et inattendu découlant de l'emploi et en cours d'emploi. Le stress mental découlant des décisions d'emploi de l'employeur ne donne pas droit aux prestations.
Île-du-Prince Édouard	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
Québec	Le stress est indemnisable si le travailleur peut démontrer un lien entre la maladie et le travail ou un risque au travail.

294 Association des Commissions des accidents du travail du Canada, *Occupational Disease and Occupational Stress Legislation and Policies*, 1998.

Saskatchewan	Les prestations pour stress professionnel sont prévues expressément lorsqu'il est démontré clairement et de manière convaincante que le stress était excessif et inhabituel; les mesures courantes de relations de travail prises par l'employeur sont considérés normales et non inhabituelles.
Yukon	Le stress post-traumatique est admissible en vertu de la loi; la pratique actuelle consiste à évaluer au cas par cas tous les autres types de demandes de prestations reliées au stress.

Source : Paul Kishchuk, *Expansion of the Meaning of Disability*, étude commandée par la Yukon Workers' Compensation Board, mars 2003, p. 12.

Un important problème que soulèvent les prestations des commissions des accidents du travail est le fait qu'il est plus difficile de prouver la genèse d'un trouble mental que d'une maladie physique. Il y a donc une certaine controverse quant à savoir si et comment les troubles mentaux devraient être couverts dans un régime d'indemnisation des accidents du travail. Dans un modèle de maladie professionnelle, l'indemnisation en cas d'invalidité dépend du fait que l'invalidité découle d'une exposition continue à des conditions dangereuses en cours d'emploi. Or, la plupart des modèles étiologiques avancés des troubles mentaux incluent les divers facteurs dont il a été question au chapitre 4, tels que la vulnérabilité génétique, les circonstances du développement et des facteurs neurobiologiques, en plus d'événements de la vie comme un cadre de travail stressant. La pondération relative de chacun de ces aspects n'est pas encore bien comprise pas plus que les liens qui existent entre eux. Certaines commissions des accidents du travail hésitent donc davantage que d'autres à verser des prestations d'indemnité liées à la santé mentale. Elles sont encore à se demander dans quelle mesure des prestations d'invalidité reliées à des troubles mentaux devraient être versées par les régimes d'indemnisation des accidents du travail plutôt que par les régimes d'assurance-maladie.[295]

6.4.3 Les programmes fédéraux de sécurité du revenu

Le programme de prestations d'invalidité du Régime de pensions du Canada (RPC-I) est le plus important programme de prestations d'invalidité au Canada. Il est généralement le plus gros payeur de prestations d'invalidité comparativement à d'autres entités comme les commissions provinciales des accidents du travail et les assureurs privés.

Les prestations de RPC-I sont versées aux participants de moins de 65 ans qui souffrent d'une invalidité physique ou mentale « grave et prolongée » (durant au moins un an et empêchant d'occuper un emploi régulier) et qui répondent à certaines exigences particulières au sujet du niveau des revenus et des années de cotisation (des cotisations doivent avoir été versées pendant quatre des six dernières années).

Au cours des deux dernières décennies, on a constaté une forte hausse du nombre de bénéficiaires du RPC-I dont l'invalidité est reliée à une maladie mentale. De 1980 à 2000, la proportion de bénéficiaires recevant des prestations du RPC-I attribuables à des troubles

[295] Carolyn S. Dewa, Alain Lesage, Paula Goering et Michèle Caveen, *The Nature and Amplitude of Mental Illness in the Workplace*, document de travail commandé par l'atelier appuyé par l'Institut de la santé publique et des populations et l'Institut des neurosciences, de la santé mentale et des toxicomanies des Instituts de recherche sur la santé du Canada, avril 2004, p. 2-19.

mentaux est passée de 11 p. 100 à 23 p. 100. Les maladies mentales arrivaient au deuxième rang, derrière les maladies du système musculo-squelettique, et touchaient plus fortement les femmes que les hommes. En 2000, les troubles mentaux représentaient également la plus importante cause de prestations d'invalidité RPC-I chez les jeunes bénéficiaires.[296]

Pendant de nombreuses années, les personnes atteintes de maladie mentale et de toxicomanie et leurs représentants ont reproché au RPC-I de ne pas correctement tenir compte du problème de la maladie mentale et de l'invalidité. Les préoccupations exprimées sont les suivantes :

- De nombreuses personnes atteintes de maladie mentale ont une expérience limitée sur le marché du travail. Parce que la maladie mentale frappe souvent au début de l'âge adulte, à un moment où les études ne sont pas achevées, les compétences professionnelles encore limitées et les carrières encore jeunes, un grand nombre de ces personnes ne sont pas admissibles au RPC-I parce qu'elles n'ont pas travaillé un nombre suffisant d'années. Par nécessité, beaucoup d'entre elles demandent l'aide des programmes provinciaux d'assistance sociale.
- Pour avoir droit aux prestations d'invalidité du RPC-I, le bénéficiaire doit accepter d'être désigné « inapte au travail de façon permanente », se déclarant ainsi tout à fait incapable d'occuper un emploi régulier. En raison de la nature cyclique et imprévisible des troubles mentaux, les personnes souffrant de maladie mentale peuvent travailler, mais souvent seulement à temps partiel; elles ne sont pas nécessairement capables d'assurer leur indépendance financière. Les personnes souffrant de maladie mentale et de toxicomanie ont recommandé que le RPC-I verse des prestations partielles ou réduites au lieu de prestations intégrales, afin de leur permettre de travailler à temps partiel et de continuer de toucher une partie des prestations.
- Étant donné que l'invalidité est actuellement synonyme d'inaptitude permanente au travail, les bénéficiaires du RPC-I hésitent à chercher ou à accepter un emploi, par crainte de perdre leurs prestations. Les personnes touchées sont pénalisées lorsqu'elles cherchent à améliorer leur situation, même si elles ne sont pas capables de retourner travailler dans un emploi régulier à plein temps.
- Environ 66 p. 100 des premières demandes au RPC-I sont rejetées pour cause d'inadmissibilité et près des deux tiers des personnes dont la première demande est rejetée ne demandent pas un réexamen du dossier. Il se pourrait que la proportion de demandes rejetées soit beaucoup plus élevée dans le cas des personnes souffrant d'une maladie mentale. Certains experts soutiennent que le système est conçu de manière à décourager les gens à demander des prestations auxquelles ils ont droit. C'est particulièrement le cas des personnes atteintes de troubles mentaux qui, en

296 Bureau de l'actuaire en chef, *Régime de pensions du Canada – Étude d'expérience des bénéficiaires des prestations d'invalidité*, Étude actuarielle n° 1, novembre 2002. http://www.osfi-bsif.gc.ca/fra/bureau/actuaires/docs/CPP_Disability_Paper_f.pdf

raison de leur maladie, ne sont peut-être pas en mesure de se battre contre le système.[297]

Dans son rapport de 2003, le Comité permanent du développement des ressources humaines et de la condition des personnes handicapées de la Chambre des communes reconnaissait que le RPC-I ne répond pas correctement au problème de la maladie mentale et de l'invalidité. Le Comité a fait quelques recommandations afin que le RPC-I tienne compte de la nature cyclique et imprévisible des maladies mentales. Il recommandait en outre que le gouvernement fédéral élabore, en consultation avec les parties intéressées et les professionnels de la santé, des outils d'évaluation spécifiques à l'égard de ces troubles particuliers, afin de déterminer l'admissibilité au RPC-I.[298]

Dans sa réponse au rapport du Comité de la Chambre des communes, le gouvernement fédéral indiquait que les lignes directrices relatives au RPC-I reconnaissent déjà les invalidités récurrentes et épisodiques, dont les troubles mentaux, et que de nombreuses personnes atteintes de troubles mentaux reçoivent actuellement des prestations du RPC-I. Il ajoutait :

> *Le gouvernement ne croit donc pas qu'il est nécessaire de modifier les règlements et les directives pour tenir compte des besoins des personnes atteintes de maladies épisodiques ou récurrentes. Puisque la détermination de l'invalidité aux fins du RPC se fonde sur les limitations fonctionnelles qui empêchent une personne de travailler et non seulement sur un diagnostic ou un pronostic médical, le processus d'évaluation peut prendre en compte les répercussions à court et à long termes des maladies récurrentes ou épisodiques sur l'habileté du client à fonctionner en milieu de travail.*[299]

Les personnes atteintes de maladie mentale peuvent aussi avoir droit à des prestations d'AE comme source de revenu temporaire de remplacement. Elles ont cependant soulevé quelques préoccupations au sujet de l'AE :

- En ce qui concerne l'admissibilité à l'AE, les employés qui sont renvoyés pour « mauvaise conduite » ou qui démissionnent de leur emploi « sans motif valable » ne sont pas admissibles aux prestations d'AE. À cause de la stigmatisation, les personnes atteintes d'une maladie mentale cachent souvent leur maladie dans leur milieu de travail. Quand elles éprouvent des difficultés au travail, elles peuvent être renvoyées ou démissionner sous l'influence de leur maladie, mais elles ne pourraient

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297 Wendy Steinberg, *Exposé de principe sur les programmes fédéraux de sécurité du revenu*, document préparé pour l'Association canadienne pour la santé mentale, décembre 2001. http://www.cmha.ca/french/politiquedefensededroits/images/f_fed_income.pdf

298 Sous-comité de la condition des personnes handicapées (Dr Carolyn Bennett, présidente), *À l'écoute des Canadiens : Une première vision de l'avenir du Programme de prestations d'invalidité du Régime de pensions du Canada*, juin 2003. http://www.parl.gc.ca/Infocomdoc/37/2/sper/studies/reports/humarp05-f.htm

299 Développement des ressources humaines Canada, *Réponse du gouvernement du Canada au rapport intitulé « À l'écoute des Canadiens : une première vision de l'avenir du Programme de prestations d'invalidité du Régime de pensions du Canada »*, novembre 2003, p. 24. http://www.dsc.gc.ca/fr/psr/pub/rpc/invalidite/5erapport/5ereport.pdf

pas demander de prestations d'AE parce qu'elles n'auraient pas signalé leur maladie auparavant.

- Quand une personne demande des prestations de maladie de l'AE, elle doit obtenir un certificat médical indiquant combien de temps la maladie pourrait durer. La nature imprévisible de la maladie mentale permet difficilement de fournir ce genre de renseignements médicaux.
- Les personnes atteintes de maladie mentale ou de toxicomanie sont d'avis que l'AE ne devrait pas obliger les personnes atteintes de maladies ou invalidités récurrentes à travailler le nombre supplémentaire d'heures assurables exigé de ceux qui sont considérés comme des nouveaux venus sur le marché du travail. À leur avis, sans cette exonération, les personnes atteintes d'une maladie mentale sont désavantagées injustement. Peu sont en mesure de satisfaire les critères d'admissibilité relatifs au nombre total d'heures assurables exigées des nouveaux travailleurs.

Dans son mémoire au Comité, le Dr Sunil V. Patel, président de l'Association médicale canadienne, a recommandé que le gouvernement fédéral examine RPC-I et les autres politiques fédérales de soutien du revenu afin de s'assurer que la maladie mentale se trouve sur le même pied que d'autres maladies et incapacités chroniques pour ce qui est des prestations.[300]

6.5 RÔLE DES EMPLOYEURS

Les employeurs ont tout à fait intérêt à s'attaquer à la maladie mentale et à la toxicomanie en milieu de travail. Dans l'économie planétaire, l'information et l'innovation sont devenues les clés de la réussite concurrentielle. Or, l'utilisation de ces clés exige des travailleurs qualifiés, motivés et fiables. Le capital humain – la motivation, le savoir, les points de vue, le jugement, la capacité de communiquer, d'échanger des idées et d'entretenir des liens – est le moteur de l'économie planétaire. Bref, c'est le rendement mental qui fait tourner l'économie mondiale.[301] D'après Bill Wilkerson, cofondateur et directeur général de la Global Business and Economic Roundtable on Addiction and Mental Health :

> *… il incombe aux entreprises de protéger leurs investissements stratégiques dans leurs ressources humaines – leur actif vital – et donc, vu la définition du rendement mental de l'économie dans laquelle nous devons rivaliser, dans la santé émotive et mentale des employés.*[302]

Le Comité a entendu à maintes reprises que, vu le fardeau qu'imposent la maladie mentale et la toxicomanie sur la société et les travailleurs et vu le coût croissant de l'invalidité professionnelle, les employeurs doivent mieux faire connaître les maladies mentales et la toxicomanie dans leurs organisations; ils doivent également accorder plus d'attention à l'amélioration de l'accès aux services de traitement et de rétablissement des travailleurs, par l'entremise de leurs PAE. Les employeurs doivent également insister davantage sur la

300 Dr Sunil V. Patel, président, AMC, mémoire au Comité, 31 mars 2004, p. 3.
301 Bill Wilkerson (6 février 2002), p. 6.
302 Bill Wilkerson (6 février 2002), p. 8.

souplesse du travail et sur les mesures d'adaptation à l'intention des personnes qui souffrent d'une maladie mentale.

Certes, le Comité n'a cessé de répéter que les employeurs se doivent d'accomplir tout ce qui est énuméré au paragraphe précédent, mais aucun témoin ne nous a donné une idée de la difficulté de la tâche ni de son coût. Le Comité ne peut donc qu'espérer qu'à la faveur des consultations publiques nationales qui devraient suivre le dépôt de son document sur les enjeux et les options, en novembre 2004, il recueillera des avis sur la façon dont les employeurs pourront effectivement mettre en œuvre les changements suggérés aux paragraphes précédents et sur les coûts à envisager. Tout comme ce fut le cas pour ses rapports antérieurs qui ont recommandé la réforme du système de soins de santé ACTIFS, le Comité est déterminé à ce que son rapport final sur la santé mentale, la maladie mentale et la toxicomanie, qui sera publié en novembre 2005, renfermera des recommandations qui seront à la fois pragmatiques et applicables, plutôt qu'un simple énoncé de pieuses intentions.

Comme on a évalué récemment qu'environ 75 p. 100 des nouveaux emplois dans l'économie exigent une capacité cognitive, non pas une capacité physique, et que les gens ne travaillent plus autant avec leur dos qu'avec leur cerveau, cet aspect de l'incapacité mentale a davantage d'importance qu'il y a quelques années.
[Rod Phillips, président et directeur général, Les Consultants Warren Shepell (18:8)]

6.5.1 Les programmes d'aide aux employés

Les PAE sont des programmes d'employeur visant à atténuer et à contribuer à éliminer divers problèmes en milieu de travail. La source de ces problèmes peut être personnelle (problèmes juridiques, financiers, conjugaux ou familiaux, problèmes de santé mentale et maladies, y compris la toxicomanie) ou professionnelle (conflit au travail, harcèlement, violence, stress, etc.).

Les programmes d'aide aux employés, les PAE, jouent un rôle dans le système actuel pour ce qui est de la façon dont les programmes de santé mentale sont offerts au Canada. Essentiellement, ils offrent aux employés des services d'évaluation professionnelle, du counselling à court terme et des services d'aiguillage. Dans la plupart des cas, les PAE au Canada visent les employés et leurs personnes à charge, tout comme les autres régimes d'avantages sociaux des employés ou tout autre régime d'assurance-médicaments.
[Rod Phillips, président et directeur général, Les Consultants Warren Shepell (18:8)]

Habituellement, les PAE offrent des services de counselling, de diagnostic, d'aiguillage et de traitement. Le personnel de ces programmes possède habituellement un diplôme dans une discipline reliée à la santé mentale ou aux services sociaux (travail social, psychologie, psychiatrie, counselling et/ou thérapie de couple ou familiale). Certains services peuvent aussi être sous-traités à des personnes possédant d'autres titres de compétence et qualifications.

Les services des PAE sont offerts dans des organisations privées et publiques et habituellement administrés en totale indépendance des autres programmes de l'organisation. La confidentialité est la pierre angulaire d'un PAE efficace. L'anonymat des clients, la

confidentialité des entrevues, la tenue, le transfert et la destruction des dossiers sont assujettis aux lois fédérales et provinciales applicables, qui régissent la conduite des conseillers. En règle générale, l'information ne peut être divulguée par un conseiller de PAE uniquement lorsque le client a donné par écrit un consentement informé stipulant quelle information sera communiquée et à qui.

Le Comité a appris que de 60 à 80 p. 100 des Canadiens qui travaillent dans une moyenne ou une grande entreprise (plus de 500 employés) ont accès à une forme quelconque de PAE. D'après Rod Phillips, président et directeur général de Les Consultants Warren Shepell, les PAE sont très efficaces; ils sont devenus la principale porte qui donne un premier accès des travailleurs canadiens à des soins en santé mentale et des services de traitement de la toxicomanie :

> *Dans de nombreux cas, d'après notre expérience, environ 85 p. 100 des gens que nous voyons au cours d'une année reçoivent un traitement suffisant dans le cadre des programmes d'aide aux employés et ne nécessitent aucun autre traitement. Environ 15 p. 100 des gens sont ensuite aiguillés vers des programmes communautaires ou vers le régime de soins de santé public.*[303]

Les PAE insistent aussi fortement sur la prévention. Une grande partie du travail effectué avec les employeurs porte sur le mieux-être et d'autres programmes qui appuient un cadre de travail sain favorisant une bonne santé mentale.

Watson Wyatt Worldwide a recommandé que les employeurs sans PAE envisagent de mettre en place de tels programmes pour combattre la maladie mentale et toxicomanie, ainsi que divers autres problèmes. Ces experts-conseils ont fait remarquer que certains assureurs offrent des réductions des primes d'assurance-invalidité aux petits employeurs qui établissent un PAE, habituellement par l'entremise d'un fournisseur recommandé.[304]

Pour les organisations qui ont déjà mis en place un PAE, Watson Wyatt Worldwide recommandait que leurs programmes soient examinés et révisés au besoin afin de mieux répondre aux besoins des employés souffrant d'une maladie mentale et/ou de toxicomanie. Les éléments particuliers à examiner devraient comprendre la nécessité de rapports utiles, les normes de rendement et la rétroaction des utilisateurs. Des examens internes visant à comparer le recours au PAE et les données sur l'absentéisme devraient être effectués par les services d'exploitation afin de déterminer les « pratiques exemplaires » internes qui peuvent être répandues dans l'ensemble de l'organisation. Enfin, Watson Wyatt Worldwide recommandait que les services offerts par le PAE de l'organisation soient communiqués régulièrement aux employés.[305]

Ash Bender et ses collègues (2002) ont prévenu que les PAE ne sont efficaces que lorsque les milieux de travail dans lesquels ils sont implantés encouragent activement des milieux de travail en santé. Autrement dit, il est très important que les employeurs soient bien informés

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303 Rod Phillips (18:9).

304 Watson Wyatt Worldwide, *Addressing Mental Health in the Workplace*, juin 2003.

305 *Ibid.*

des maladies mentales et de la toxicomanie, afin de lutter efficacement contre la stigmatisation et la discrimination dans leur organisation et d'établir des milieux de travail sains.[306]

Une autre préoccupation soulevée par Bender *et al.* portait sur le nombre de séances de traitement thérapeutique offertes aux clients des PAE. D'après des données non scientifiques, ces séances auraient diminué considérablement et seraient passées de sept à moins de trois par personne au cours des dix dernières années. Les auteurs concluaient que la probabilité est faible de résoudre efficacement des problèmes graves d'usage de substance ou de maladie mentale par des traitements thérapeutiques.[307] Cette préoccupation exige une attention particulière.

6.5.2 Les mesures d'adaptation

> *La solution va nécessairement passer par l'implication des milieux de travail. Nous ne pouvons pas considérer les milieux de travail comme une école, comme un hôpital. C'est une entité en soi, c'est une famille en soi avec ses règles et son art d'agir et nous ne pourrons pas le faire sans eux.*
> *[Jean-Yves Savoie, président, Conseil consultatif, Institut de la santé publique et des populations, IRSC (18:6)]*

Les mesures d'adaptation désignent « une ou plusieurs modifications du milieu de travail ou des procédures du milieu de travail qui permettent à une personne ayant des besoins spéciaux d'effectuer une tâche[308] ». Alors que les personnes ayant une incapacité physique ont peut-être besoin d'une aide physique ou de changements structuraux du lieu de travail, les personnes ayant un trouble mental ont le plus souvent besoin de mesures d'adaptation sociale et organisationnelle. Ces modifications sont généralement des changements dans la façon dont les choses sont traditionnellement effectuées dans un lieu de travail particulier. Permettre par exemple à quelqu'un ayant une maladie mentale de travailler à des heures flexibles lui permet d'accéder à l'emploi, de la même façon qu'une rampe d'accès permet à une personne handicapée de se déplacer en fauteuil roulant. Ces mesures ne sont pas un traitement préférentiel. Elles signifient simplement un traitement équitable des personnes handicapées.[309]

D'après l'Association des psychiatres du Canada, les mesures d'adaptation devraient être axées sur des mécanismes positifs qui favorisent l'égalité d'emploi. Elles comprendraient les mesures suivantes :

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306 Ash Bender et al., *Mental Health and Substance Use at Work : Perspectives from Research and Implications for Leaders*, document de travail préparé pour la Global Business and Economic Roundtable on Addiction and Mental Health, 14 novembre 2002.

307 *Ibid.*

308 Lana M. Frado, *La diversité ça marche : l'accommodation en milieu de travail pour les personnes ayant une maladie mentale*, Association canadienne pour la santé mentale, 1993, p. 7. http://www.cmha.ca/english/routes/images/diversity_works_french.pdf

309 Lana M. Frado (1993), p. 9.

- Créer un environnement où les mesures d'adaptation sont établies en fonction des besoins individuels de chaque employé.
- Respecter le désir de confidentialité de l'employé et déterminer précisément la nature et l'ampleur de la confidentialité.
- Être disposé à se concerter pour résoudre les problèmes.
- Rendre toutes les mesures volontaires pour l'employé et être prêt à examiner les plans périodiquement pour s'adapter à l'évolution des besoins.
- Appliquer les politiques classiques avec souplesse.
- Définir concrètement et précisément les mesures d'adaptation à prendre. Ce serait une bonne idée de les mettre par écrit.[310]

Une étude semble indiquer que le coût des mesures d'adaptation relatives à un employé souffrant de maladie mentale est assez bas – la plupart coûtent bien moins de 500 $. Pour les employés qui reçoivent un traitement efficace, l'employeur économisera de 5 000 $ à 10 000 $ par employé par année en coûts de médicaments sur ordonnance, de congés de maladie et de remplacement du salaire moyen. Les employés diagnostiqués dépressifs qui prennent les médicaments pertinents feront épargner à leur employeur les coûts d'une moyenne de 11 jours par année d'absentéisme.[311]

Une autre étude a révélé que, sur une période de dix ans, 240 personnes ayant une maladie mentale grave ont pu garder un emploi rémunérateur en grande partie grâce à des programmes de réintégration du travail. Ces personnes ont touché 5 millions de dollars de revenus, versé 1,3 million de dollars d'impôts et fait épargner au gouvernement un montant estimatif de 700 000 $ en frais d'aide sociale. Le résultat net a été une hausse de 2 millions de dollars de la richesse collective.[312]

Pour sa part, la Global Business and Economic Roundtable on Addiction and Mental Health croit que les employeurs doivent offrir un environnement qui favorise la promotion d'une bonne santé mentale, la sensibilisation à la maladie mentale et à la toxicomanie, le dépistage précoce de la maladie mentale et de la toxicomanie, et l'intégration des employés souffrant d'un trouble mental ainsi que les mesures d'adaptation connexes. À cet égard, la table ronde a publié un plan d'action en 12 étapes pour lutter contre la maladie mentale et la toxicomanie, résumé au tableau 6.3.

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310 Association des psychiatres du Canada, *op. cit.*
311 Mental Health Works (2003), *op. cit.*
312 Gaston Harnois et Phyllis Gabriel (2000), *op. cit.*, p. 47.

TABLEAU 6.3

PLAN D'ACTION EN 12 ÉTAPES POUR LUTTER CONTRE LA MALADIE MENTALE ET LA TOXICOMANIE EN MILIEU DE TRAVAIL

1re étape :	Séance d'information pour renseigner le chef de la direction sur la maladie mentale et la toxicomanie
2e étape :	Dépistage précoce de la maladie mentale et de la toxicomanie
3e étape :	Réforme des PAE et des régimes d'assurance collective
4e étape :	Création d'un milieu de travail qui favorise la santé mentale
5e étape :	Réduction de la surabondance de courriels et de messages téléphoniques
6e étape :	Élaboration de politiques souples de retour au travail
7e étape :	Éducation des gestionnaires et des superviseurs sur les liens entre la maladie mentale et la maladie physique
8e étape :	Réduction des dangers émotifs en milieu de travail
9e étape :	Promotion de politiques de conciliation du travail et de la vie personnelle
10e étape :	Incitation des employés à demander l'aide professionnelle nécessaire
11e étape :	Surveillance de l'état de santé de l'organisation au moyen d'objectifs spécifiques
12e étape :	Élimination des 10 principales sources de stress en milieu de travail.

Source : Adapté de Bill Wilkerson, *Mental Health – The Ultimate Productivity Weapon*, résumé de l'allocution prononcée au congrès de l'Association pour la prévention des accidents industriels, Toronto, 22 avril 2002, p. 10-14.

La table ronde a rédigé récemment sa carte routière sur la gestion de l'incapacité mentale, qui regroupe la santé physique et la santé mentale dans un même système de santé et de sécurité environnementale. Cette carte routière établit également des normes régissant la politique de retour au travail. Plus précisément :

- Les employeurs n'ont pas besoin de connaître la nature du diagnostic de la maladie invalidante en cause dans une situation particulière. Cette information est privée et confidentielle.
- Les employeurs doivent comprendre, appuyer et mettre en place des régimes de retour au travail qui comprendront inévitablement des ajustements personnalisés de la nature du travail ou des heures de travail afin de permettre une transition en douceur.
- Les employeurs doivent savoir que, même si l'employé revient au travail, il n'est pas rétabli à 100 p. 100 et un retour graduel au travail s'impose pour aider l'employé à se remettre dans le bain, prendre de la vitesse et acquérir de la tolérance et de l'endurance.[313]

La carte routière insiste sur le fait que la responsabilité de faciliter le retour au travail d'un employé incombe également aux syndicats. Ainsi, les syndicats ont le devoir de très bien représenter leurs membres dans les dossiers relatifs à un employé handicapé. C'est particulièrement vrai dans le cas des employés handicapés mentalement et qu'il est question de cessation d'emploi.[314]

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313 Global Business and Economic Roundtable on Addiction and Mental Health (25 juin 2004), p. 11.

314 *Ibid.*, p. 23.

Encore une fois, le Comité tient à rappeler à quel point il sera déterminant de transformer les objectifs principaux et secondaires de la section 6.1 en recommandations réalisables. Cependant, il ne pourra y parvenir que si les travailleurs et les employeurs lui font des suggestions et si on lui donne une idée de ce que pourrait coûter la mise en œuvre des propositions en question.

6.6 RÔLE DES GOUVERNEMENTS

Le Comité a appris que les gouvernements doivent partager le fardeau économique de la maladie mentale et de la toxicomanie en milieu de travail. D'après Rod Phillips, ce partage des coûts devrait s'effectuer au moyen d'encouragements fiscaux :

> *Les employeurs progressistes subventionnent les lacunes du système public de soins de santé mentale du Canada. Leur investissement dans des programmes de santé mentale à l'intention des employés et des membres de leur famille devrait être encouragé par des encouragements et des allégements fiscaux, le partage des coûts et une prestation conjointe des services. […] L'absence de services de santé mentale publics accessibles au Canada constitue une grande lacune de notre système de santé. Étant donné qu'un fort pourcentage des coûts croissants de la maladie mentale est assumé par les employeurs, il conviendrait grandement que les coûts d'une réduction de ces frais soient partagés entre les employeurs et le gouvernement. À notre avis, la possibilité d'un partage des coûts est mal exploitée et sous-utilisée. J'encourage le Comité à envisager des solutions novatrices.*[315]

Pour sa part, l'Association canadienne pour la santé mentale (Division de l'Ontario) a grandement reproché aux gouvernements leur inertie au sujet de la maladie mentale et de la toxicomanie :

> *On nous a longtemps parlé des prévisions de l'Organisation mondiale de la santé à l'effet que la maladie mentale deviendra d'ici 2020 la principale cause d'absentéisme pour cause d'invalidité. On ne nous a cependant rien dit de l'engagement que prennent habituellement les gouvernements lorsque confrontés à un problème croissant dans le domaine de la santé, en particulier lorsqu'un tel problème touche non seulement l'individu, mais toute la société et même l'économie. On doit considérer [les projections] de l'OMS comme un défi et une provocation et non comme un résultat inévitable.*
>
> *(…)*

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315 Warren Shepell, "Warren Shepell Calls for Tax Incentives to Support Employer Mental Health Programs", *Communiqué*, 12 juin 2003.

> *Les gouvernements doivent prêcher par l'exemple. Les gouvernements fédéral, provinciaux et territoriaux devraient s'engager à collaborer tout en aidant les entreprises à réaliser leurs objectifs précis de réduction des journées d'invalidité attribuables à la maladie mentale. Cependant, on ne peut y parvenir que si tous les intervenants acceptent de s'attaquer aux conditions qui rendent les gens plus vulnérables à la maladie mentale et qui rendent plus ardu leur rétablissement ou leur rémission.*[316]

Lors de ses audiences sur le document concernant les enjeux et les options, le Comité cherchera à recueillir des avis sur la façon dont les gouvernements devraient s'y prendre pour aller dans le sens des responsabilités qu'on veut leur confier, soit de prendre les rênes en main. Les Canadiennes et les Canadiens devront nous indiquer ce que cela veut dire en pratique.

6.7 ENTREPRISES DIRIGÉES PAR DES PERSONNES SOUFFRANT DE MALADIE MENTALE OU DE TOXICOMANIE

Durant ses travaux, le Comité a entendu parler de l'Ontario Council of Alternative Business (OCAB). Cette organisation provinciale appuie la création de débouchés économiques pour les personnes atteintes de maladie mentale et de toxicomanie. Elle chapeaute 11 entreprises contrôlées par des personnes souffrant de maladie mentale et de toxicomanie qui emploient quelque 600 travailleurs dans des initiatives variées de plusieurs régions de la province.[317]

L'évaluation des entreprises dirigées par des personnes atteintes de maladie mentale et de toxicomanie démontre que les personnes souffrant de troubles mentaux, voire de maladies graves et persistantes, peuvent réussir et être concurrentielles dans leur secteur d'activité.[318] Le Comité encourage fortement le développement de ces initiatives.

6.8 PROGRAMME DE RECHERCHE SUR LA SANTÉ MENTALE, LA TOXICOMANIE ET LE TRAVAIL

Les enjeux reliés à la maladie mentale, à la toxicomanie et au travail sont complexes et multiples. Nous sommes confrontés à un problème dont l'ampleur grandit rapidement, qui a d'énormes conséquences financières et qui touche une multitude de parties intéressées. Il n'y a

> **D'après les études effectuées à ce jour, nous savons que les problèmes de santé mentale constituent un énorme danger pour la productivité de la nation. Mais nous ne faisons que commencer à bien comprendre la prévalence et l'ampleur de l'incidence des problèmes de santé mentale en milieu de travail. Il y a encore beaucoup à faire.**
> ***[Dewa, Lesage, Goering and Caveen, Nature and Amplitude of Mental Illness in the Workplace, avril 2004.]***

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316 Association canadienne pour la santé mentale (Division de l'Ontario), mémoire au Comité, 12 juin 2003, p. 7-8.

317 Des renseignements supplémentaires sont affichés à http://www.icomm.ca/ocab/.

318 Heather Stuart (avril 2004), p. 84.

cependant actuellement aucune stratégie coordonnée et exhaustive de recherche, de diffusion de l'information, de mise en œuvre et d'évaluation des résultats. En plus de porter sur la recherche sur la maladie, le traitement et la thérapie, une telle stratégie devrait également examiner le rôle du milieu de travail sur la santé mentale, comment les thérapies et les traitements peuvent être exécutés dans le milieu de travail et à la maison, comment les employeurs et les employés et leur famille peuvent prendre les choses en mains.

La nécessité de multiplier les recherches dans le domaine de la maladie mentale, de la toxicomanie et du travail est ressortie clairement d'un récent atelier organisé conjointement par l'Institut des neurosciences, de la santé mentale et des toxicomanies et l'Institut de la santé publique et des populations des Instituts de recherche en santé du Canada (IRSC). Cet atelier a permis aux chercheurs de mesurer la nature et la gravité de la maladie mentale et de la toxicomanie en milieu de travail, d'examiner l'état de la recherche au Canada dans ce domaine et d'élaborer un plan de recherche.

Les participants à l'atelier ont identifié de nombreux domaines qui exigent des recherches plus poussées. Ainsi, les recherches viseraient notamment à comprendre les tendances des troubles mentaux chez divers groupes professionnels et secteurs industriels; comprendre le lien entre les régimes d'employeurs et la prévalence et le profil de l'invalidité liée à la maladie mentale; examiner le lien entre le stress au travail et l'apparence d'invalidité; comprendre les effets sur la santé mentale de grandes tendances des pratiques organisationnelles en milieu de travail; déterminer des méthodes efficaces pour améliorer les diagnostics de maladie mentale et les traitements connexes chez les personnes qui travaillent; analyser les politiques et les lignes directrices relatives à l'incapacité professionnelle; et déterminer la portée et la nature de la stigmatisation en milieu de travail.

Le Comité se réjouit de cette initiative des IRSC. Nous espérons que l'atelier permettra d'élaborer un programme qui aidera à mieux comprendre les troubles mentaux et les incapacités qu'ils causent et à définir des pratiques novatrices qui aideraient les employés souffrant de troubles mentaux.

Le Comité a aussi entendu parler d'un plan de recherche appelé « Research and Return on Investment Initiative », initiative conjointe de la Global Business and Economic Roundtable on Addiction and Mental Health, du Centre de toxicomanie et de maladie mentale et de l'Institute for Work and Health, financée par la CIBC, la Banque TD, la Banque Scotia, RBC, BMO et la Great-West Compagnie d'assurance-vie. Ces recherches ont pour but d'interroger des entreprises canadiennes et américaines et de collecter et échanger de l'information sur les tentatives fructueuses de gérer l'incapacité mentale et le retour au travail de personnes atteintes de maladie mentale et de toxicomanie.[319] Le Comité encourage fortement la table ronde et les dirigeants du milieu des affaires à échanger les pratiques exemplaires concernant la gestion de l'incapacité mentale en milieu de travail et l'élaboration de stratégies efficaces de retour au travail.

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[319] Honorable Michael Wilson, *Text of Remarks*, Atelier des CIHR-IRSC, 28 avril 2004.

6.9 OBSERVATIONS DU COMITÉ

Le Comité convient avec de nombreux témoins qu'il est bénéfique pour les personnes atteintes de maladie mentale de trouver et de garder un emploi intéressant; cela fait également partie intégrante du processus de rétablissement. De plus, nous sommes fermement convaincus des bienfaits éventuels, pour les employeurs, d'une intégration de ces personnes dans la population active; les progrès récents constatés dans les traitements permettent désormais aux personnes qui souffrent d'une maladie mentale d'apporter une contribution utile au travail.

On se demande encore jusqu'à quel point un employeur devrait être informé de la maladie mentale d'un employé ou est justifié de vouloir se renseigner à ce sujet. Le Comité estime que, dans toute législation moderne, l'invalidité ne devrait pas constituer un motif suffisant pour refuser un emploi à moins que la personne soit clairement incapable de faire le travail. Il a été démontré que la garantie d'un accès rapide et facile aux services de santé mentale et aux moyens de soutien pertinents influe très positivement sur la volonté des employeurs d'offrir un emploi à des personnes souffrant de maladie mentale. De l'avis du Comité, l'incapacité liée à une maladie mentale et à la toxicomanie ne peut plus servir d'excuse pour refuser un emploi à ceux qui veulent et peuvent travailler.

L'incidence de la maladie mentale et de la toxicomanie sur la productivité perdue dont les employeurs doivent payer le prix est incontestablement très grande. La présence de maladies mentales et de la toxicomanie en milieu de travail soulève immédiatement la question suivante : dans quelle mesure ces troubles sont-ils importés par les employés dans leur milieu de travail et dans quelle mesure sont-ils provoqués par le milieu de travail? Il va de soi que la réponse a des conséquences profondes sur les stratégies visant à prévenir et à gérer la maladie mentale et la toxicomanie en milieu de travail; elle pourrait également avoir une grande incidence sur la façon dont devraient être gérées les demandes de prestations d'invalidité liées aux troubles mentaux.

Le Comité croit qu'il faudrait entreprendre d'autres recherches dans le domaine de la maladie mentale, de la toxicomanie et du travail. Par exemple, nous pensons qu'il est important de comprendre l'influence qu'exercent les types et l'ampleur des prestations d'invalidité sur la durée des prestations et de définir les conditions optimales. Il est important de comprendre l'influence qu'exercent des milieux de travail sains et malsains sur l'incidence des demandes de prestations d'invalidité liées à une maladie mentale. Il est également important d'évaluer l'incidence des PAE.

Le Comité est fermement convaincu qu'il est impératif d'offrir des programmes d'éducation et de sensibilisation afin d'informer tous les échelons de l'organisation sur les causes, les symptômes et le traitement de la maladie mentale et de la toxicomanie. Cela permettrait de dissiper la stigmatisation liée aux troubles mentaux. Même si la mise en œuvre de tels programmes ne peut pas garantir que tous les employés chercheront à obtenir un traitement rapide ou que la stigmatisation disparaîtra, elle contribuerait certainement à réduire le stress que subissent ceux qui souffrent de maladie mentale ou de toxicomanie.

Nous convenons également avec les experts que les politiques de retour au travail doivent être examinées et révisées en conséquence. Les troubles mentaux ne s'intègrent pas dans le

modèle habituel de l'invalidité; de nombreux employeurs envisagent encore l'invalidité en fonction d'une incapacité physique. Par conséquent, les besoins des employés qui retournent au travail après une absence liée à un problème de santé mentale peuvent être très différents de ceux des employés qui reviennent au travail après avoir subi une chirurgie. Les mécanismes actuels de retour au travail devraient être examinés et modifiés pour tenir compte de ces situations différentes.

De plus, le Comité croit que la culture interne d'une organisation peut faire une énorme différence dans la façon d'aborder la maladie mentale et la toxicomanie en milieu de travail. Les employeurs devraient examiner avec soin tous les problèmes en milieu de travail (harcèlement, relations conflictuelles entre la direction et les employés, etc.) qui provoquent un stress et une hostilité inutiles. Ces situations ont des conséquences négatives sur tous les employés, mais surtout sur ceux qui souffrent d'une maladie mentale ou de toxicomanie. Les employeurs devraient prendre des mesures pour remédier aux problèmes qui ressortent de ces examens.

Enfin, il faut donner suite à la préoccupation exprimée par beaucoup, soit la nécessité de revoir le RPC-I et l'AE afin de tenir compte de la nature cyclique et imprévisible des troubles mentaux. Le gouvernement fédéral devrait également chercher une façon de partager plus équitablement avec les employeurs les coûts de la maladie mentale et de la toxicomanie.

PART 3

Service Delivery and Government Policy in the Field of Mental Illness and Addiction

CHAPTER 7: MENTAL HEALTH SERVICE DELIVERY AND ADDICTION TREATMENT IN CANADA: AN HISTORICAL PERSPECTIVE

INTRODUCTION

The history of mental health services and addiction treatment in Canada parallels the European and American experience. The delivery of mental health services has, for the most part, evolved differently from the provision of addiction treatment throughout the last century. This has led to the emergence of two distinct systems of care and support – one for individuals with mental illness and another for individuals suffering from addiction. It is only during the last decade that efforts have been encouraged to better integrate the two systems.

The mental health service system and the addiction treatment system have struggled to provide the most compassionate and responsive treatment possible, but both have been dogged by the problem of stigma which had a negative impact on their development. Arising out of widespread misunderstanding and broad misconceptions, individuals with mental illness were often labelled as "idiots", "imbeciles" and "lunatics", while addiction problems were perceived as a sign of personal weakness. In some cases, a punitive attitude, exemplified by a desire to remove individuals with mental illness and addiction from public sight, has hampered the delivery of appropriate services. Despite many advances in models of care, policies and legislation, negative perception and stigma still persist today (see Chapter 3, above).

Although dramatic improvements have been made in the past two decades in the delivery of mental health services and addiction treatment, the Committee concurs with numerous witnesses that neither area has gained sufficient public support or government funding to ensure that Canadians obtain the same quality of services as they do when they receive treatment for physical illnesses, such as cancer or heart disease.

This chapter provides a chronological overview of the development of mental health services and addiction treatment in Canada. Section 7.1 summarizes the evolving views of mental illness that, over the course of time, have influenced the approach taken in Canada. Section 7.2 provides an historical perspective of the development of the mental health service system in Canada. Section 7.3 briefly reviews the evolution of the addiction treatment system.

7.1 EVOLVING VIEWS OF MENTAL ILLNESS THROUGHOUT THE CENTURIES[320]

> *The care of people with mental and behavioural disorders has always reflected prevailing social values related to the social perception of mental illness.*
> *[WHO, 2001, p. 49]*

For many centuries, religious, spiritual or cultural beliefs dominated the way in which individuals with mental illness were treated and regarded by society. Psychiatry is a "young" science relative to other scientific disciplines.

Stein and Santos (1998) recount that 5,000 year old skulls have been found in Eastern Mediterranean and North African countries with openings in them of up to two centimetres in diameter. It is thought that these holes were made by sharp instruments and that the procedure, trephination, was performed for therapeutic reasons. Some individuals were believed to have a mental illness which, at the time, was assumed to be the result of having evil spirits in their heads. The purpose of trephination was to allow the evil spirits to be released.[321]

In ancient Greece, individuals with severe mental illness were thought to be influenced by angry gods; they were undoubtedly abused. Those with relatively mild conditions remained free but were treated with contempt and humiliation.[322] According to Prince (2003), the cultural values of ancient Greece were precursors to the modern stigma that is associated with mental illness.[323]

In Europe, during the Middle Ages (5th to 16th century), people thought mental illness had supernatural causes and was associated with demonic or divine possession. The affected individual was either tortured, burned at the stake, hanged or decapitated to liberate the soul from demonic possession.[324]

In the 17th and early 18th centuries, the dominant view was that mental illness was an impaired physical state self-inflicted through an excess of passion. This view did not encourage compassion or tolerance; rather, it was used to justify poor living conditions and

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320 The information contained in this section is based on the following five documents: 1) Leonard I. Stein and Alberto B. Santos, *Assertive Community Treatment of Persons with Severe Mental Illness*, New York, 1998; 2) World Health Organization, "Historical Perspective", Section 3, in *The Mental Health Context*, Mental Health Policy and Service Guidance Package, Geneva, 2003; 3) World Health Organization, "Solving Mental Health Problems", Chapter 3 in *Mental Health: New Understanding, New Hope*, Geneva, 2001; 4) Pamela N. Prince, "A Historical Context for Modern Psychiatric Stigma", in *Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow*, published by the Psychiatric Patient Advocate Office, Ontario, 2003, pp. 58-60; 5) Canadian Mental Health Association, *More for the Mind – A Study of Psychiatric Services in Canada*, Toronto, 1963.

321 Stein and Santos (1998), p. 6.

322 Stein and Santos (1998), p. 6.

323 Prince (2003), p. 58.

324 WHO (2003), pp. 17-19, WHO (2001), p. 49, and Stein and Santos (1998), pp. 6-7.

the use of physical restraints in places of confinement. Some individuals were chained to walls or even kept in cages.[325]

In the late 18th century, Philippe Pinel, a French physician, and William Tuke, an English layman, pioneered the belief that those who behaved in strange and unexplainable ways did so because they were mentally ill. Pinel reformed the Bicêtre and Salpêtrière hospitals in France; he unchained the inmates and related to them as reasonable individuals, providing decent living conditions and treating them with respect. Similarly, Tuke, guided by humanistic ideals, founded the York Retreat in England where individuals with mental illness were provided with decent living conditions, related to in a respectful manner, and were expected to work to the extent they could.[326]

The approach developed by Pinel and Tuke became known as "moral treatment". Its success, based on considering of individuals with mental illness to be medical patients, led to the building of many psychiatric institutions, once known as "lunatic asylums", in European countries and the United States. In parallel, this period saw the field of psychiatry burgeon as a medical discipline.[327]

In the 19th and 20th centuries, a more "scientific approach" to the treatment of mental illness was introduced. Attempts were made to explain mental illness as a result of disease and/or damage to the brain, or as the sequella of congenital and hereditary defects. Because damaged, devitalized brain tissue cannot be renewed and little can be done to correct inherited constitutional defects, this new "scientific" approach led to an era of pessimism regarding the possibility of treatment.[328]

Asylum: A place of refuge and protection for people with long term mental illnesses who do not require acute hospital treatment, but do require ongoing supervision, care and treatment in a community facility or institution.
[The 1998 British Columbia Mental Health Plan, p. 85.]

It only dawned on people that a rational, even scientific, psychological treatment of mental illness was possible dawned only when thousands of World War I "shell shock" casualties demonstrated poignantly that everyone is vulnerable to psychological, social and physical stress and has a breaking point.[329] This realization led to the development of modern psychiatry and clinical psychology.

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325 Stein and Santos (1998), pp. 6-7.
326 Stein and Santos (1998), p. 8.
327 Stein and Santos, (1998), pp. 6-8, and WHO (2001), p. 49.
328 Canadian Mental Health Association (1963), p. 2.
329 *Ibid.*

7.2 DELIVERY OF MENTAL HEALTH SERVICES IN CANADA[330]

The evolution of mental health service delivery in Canada, as in other developed countries, has been marked by three distinct periods, beginning with a moral or humanitarian approach to treating mental illness, followed by institutionalization and, finally, deinstitutionalization.

7.2.1 Moral or Humanitarian Approach to Mental Illness (Before the 1900s)

Prior to Confederation, many individuals who suffered from mental illness were either jailed or cared for within the family home or by religious bodies.[331] At that time, few physicians practised psychiatry in either Upper or Lower Canada. There were even some who held that it was a waste of time to attempt any kind of treatment, either medical or psychological, for individuals with mental illness; they were considered incurable, non-functioning members of society.[332] The treatment of individuals with mental illness, then, was mostly custodial.

In the late 19th century, both Upper and Lower Canada borrowed from the European experience and developed a number of small institutions that patterned themselves after the Tuke and Pinel approaches to provide patients the benefit of moral or humanitarian treatment. Initially, however, there were insufficient moral hospitals to accommodate all who needed them. Many individuals with mental illness remained locked in a room in their homes, or were incarcerated with common criminals.

The success of moral treatment led eventually to the building of numerous large asylums across the country. Thus began the process of institutionalization for individuals with mental illness. Initially, the patient-to-staff ratio was sufficient to provide moral treatment and decent living conditions, but, for reasons explained below, most of these institutions were unable to sustain the success rate of the dedicated pioneers of moral treatment.

7.2.2 Institutionalization (1900 to 1960)

Following European and American experience, lunatic asylums proliferated across Canada.[333] These large institutions were usually self-contained and located in very isolated areas. Many

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330 The information contained in this section is based on the following nine documents: 1) Health and Welfare Canada, *Mental Health Services in Canada*, Ottawa, 1990; 2) .E. Appleton, "Psychiatry in Canada A Century Ago", *Canadian Psychiatric Association Journal*, Vol. 12, No. 4, August 1967, pp. 344-361; 3) Elliot M. Goldner, *Sharing the Learning – The Health Transition Fund: Mental Health*, Synthesis Series, Health Canada, 2002; 4) Cyril Greenland, Jack D. Griffin and Brian F. Hoffman, "Psychiatry in Canada from 1951 to 2001", in *Psychiatry in Canada: 50 Years*, Canadian Psychiatric Association, 2001, pp. 1-16; 5) Quentin Rae-Grant, "Introduction", in *Psychiatry in Canada: 50 Years*, Canadian Psychiatric Association, 2001, pp. ix-xiii; 6) Henri Dorvil et Herta Guttman, *35 Ans de Désintitutionalisation au Québec, 1961-1996*, Annexe 1 du rapport du Comité de la santé mentale du Québec intitulé *Défis de la Reconfiguration des Services de Santé Mentale*, 1998; 7) Julio Arboleda-Florez, *Mental Health and Mental Illness in Canada : The Tragedy and the Promise*, Brief to the Committee, 19 March 2003; 8) Paula Goering, Don Wasylenki and Janet Durbin, « Canada's Mental Health System », in *International Journal of Law and Psychiatry*, Vol. 23, No. 3-4, May-August 2000, pp. 345-359; 9) Donald Wasylenki, "The Paradigm Shift From Institution to Community", Chapter 7, in *Psychiatry in Canada: 50 Years*, Canadian Psychiatric Association, 2001, pp. 95-110.

331 Health and Welfare Canada (1990), p. 13.

332 V.E. Appleton (1967), pp. 344-361.

333 Elliot Goldner (2002), p. 1.

individuals with mental illnesses, once admitted, would spend the rest of their lives there. Some patients were admitted involuntarily using legal processes and were retained in locked wards. Treatment attempted to incorporate work through occupational or industrial therapy (which gave patients small amounts of remuneration), together with recreational and social activities. Relationships between the staff and patients were marked by paternalism. Most patients remained isolated from their families and communities.[334]

Many psychiatric treatments common in use in this period – hydrotherapy, insulin coma, crude psychosurgery (namely lobotomy) – have since fallen into disfavour or been abandoned as unethical or scientifically invalid.[335] Electroconvulsive therapy (or ECT), given initially without general anaesthetics or muscle relaxants, was a commonly used but controversial treatment.[336] The convulsions accompanying ECT often caused serious complications – seizures that lasted longer than expected, increased blood pressure, changes in heart rhythm, and compression fractures of the spine. Since then, ECT, while still the subject of controversy in some circles, has been widely recognized and endorsed by psychiatry and medicine generally as a safe and effective treatment for schizophrenia, severe depression and extreme mania.[337] The lack of effective treatments for patients with mental illness is generally acknowledged to have significantly contributed to the relatively low esteem in which psychiatry was held throughout this period.[338]

It should be noted that, during the process of institutionalization, efforts were made to promote mental health and de-stigmatize mental illness. For example, in 1948, the federal government established the Dominion Mental Health Grants to improve training and services. Funds from this source also led to the development of public awareness campaigns to promote the mental health of infants and children. "Mental Health Week" was designated in Canada for the first time in 1951. Similarly, during this period, the Canadian Mental Health Association fought to change the language used in legislation, and that also appeared in public discourse, that referred to individuals with mental illness as "idiots", "imbeciles", and "lunatics".[339]

After World War II, psychiatric institutions in Canada became overcrowded. In 1950, there were some 66,000 patients in psychiatric hospitals in Canada; they outnumbered patients in non-psychiatric hospitals.[340] Most psychiatric institutions operated at more than 100% capacity. Understaffing, overcrowding and the lack of effective treatments led to an emphasis on custody rather than therapy. Contrary to the initial intent of moral treatment,

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334 Greenland, Griffin and Hoffman (2001), p. 2.

335 Hydrotherapy, which is also called the water cure, is a mode of treating diseases by the copious and frequent use of pure water, both internally and externally. Insulin coma treatment was a rarely used treatment of mental illness by means of hypoglycaemic coma induced by insulin.

336 ECT is a procedure that consists in passing a small electric current through a region of the brain for a period of 1-3 seconds for the purpose of inducing neurochemical changes associated with the relief of psychiatric symptoms; the electrical stimulation also induces a brief seizure, whose appearance is modified by muscle-relaxing drugs. It generally lasts 20-30 seconds and then ends spontaneously. The patient is anaesthetized and asleep during the treatment and the seizure.

337 Health and Welfare Canada (1990), p. 13.

338 Quentin Rae-Grant (2001), p. x.

339 Greenland, Griffin and Hoffman (2001), p. 3.

340 Greenland, Griffin and Hoffman (2001),, p. 2.

institutional care became primitive and restrictive, relying on methods involving seclusion, as well as on chemical and physical restraints.[341] All these negative consequences contributed to the process of deinstitutionalization described in the following section.

7.2.3 Deinstitutionalization (1960 Up to Now)

> *(…) deinstitutionalization is not merely the administrative discharge of patients. It is a complex process in which de-hospitalization should lead to the implementation of a network of alternatives outside mental hospitals. In many developed countries, unfortunately, deinstitutionalization was not accompanied by the development of appropriate community services. (…) It has become increasingly clear that if adequate funding and human resources for the establishment of alternative community-based services do not accompany deinstitutionalization, people with mental disorders may have access to fewer mental health services and existing services may be stretched beyond capacity. (WHO, 2003, p. 18)*

> **[At] the time of the revolution in psychiatry (…) [w]e started by meeting with priests and community leaders to tell them that psychiatric patients are not dangerous, at least not any more dangerous than other people, and that they should be given a chance. We could not take patients out of psychiatric hospitals and integrate them into the community until they had acquired certain social skills. That is when social workers, psychological educators, started teaching psychiatric patients the skills they would require to function in society.**
> **[*Henri Dorvil, Professor, School of Social Work, UQAM (14:39)*]**

A number of factors encouraged the trend towards deinstitutionalization. First, as a result of overcrowding and understaffing, many psychiatric institutions were seen as non-therapeutic environments wherein individuals were thought to be housed and dealt with in an inhumane, custodial fashion. Second, numerous studies in Canada, Europe and the United States highlighted the negative impact of long term institutionalization on the well-being of individuals with mental illness. These included: indifference, apathy, passive obedience, self-neglect and, sometimes, aggressive behaviour, as well as substantial loss of social abilities, increased dependence and added chronic physical illness resulting from isolation, in addition to authoritarian relationships between staff and patients.[342] Third, with the advent of chlorpromazine – an effective medication that controls psychosis and severe mood disorders – and other neuroleptic medications came the hope that "cures" for severe and persistent mental illnesses such as schizophrenia were on the horizon (it is interesting to note that these early research findings stimulated considerable research interests in psychopharmacology and neuroscience in Canada). At the very least, it was expected that with these new medications

[341] Health and Welfare Canada (1990), p. 13.
[342] Dorvil and Guttman (1998), p. 116.

individuals with mental illness could live comfortable lives outside of hospitals, allowing them to resume the functions of everyday life without constant supervision and care. And fourth, financial incentives that were offered to provincial governments through federal-provincial cost-sharing arrangements to fund psychiatric units in general hospitals proved hard to resist.[343]

Two important national reports, along with the reports of several provincial commissions,[344] highlighted these observations and encouraged the shift toward deinstitutionalization. In 1963, the National Scientific Planning Council of the Canadian Mental Health Association released *More for the Mind* which insisted that mental illness should be dealt within the same organizational, administrative and professional framework as physical illness. It recommended that psychiatric services be integrated with the physical and professional resources of the rest of the health care system.[345]

Similarly, in 1964, the Royal Commission on Health Services, chaired by Emmett Hall stated: "Any distinction in the care of physically and mentally ill individuals should be eschewed as unscientific for all time". The Hall Commission recommended that patients capable of receiving care in general hospital psychiatric units should be moved from psychiatric hospitals with all due speed. It was expected that patients would occupy beds in psychiatric units of general hospitals for brief periods of time during episodes of illness, but otherwise would live successful and satisfying lives in their communities.[346]

Thus, in the 1960s the process of deinstitutionalization began. It was a long journey. Indeed, the deinstitutionalization process itself can be described in three distinctive phases covering the period beginning in the early 1960s and continuing to the present. The first phase (section 7.2.3.1) involved a shift from care in psychiatric institutions to care in the psychiatric units of general hospitals. The second phase (section 7.2.3.2) focussed on the need to expand mental health care into the community and to provide necessary community supports for individuals with mental illness and their families. In the third and current phase (section 7.2.3.3), the emphasis is on integrating the various mental health services and supports available within communities and enhancing their effectiveness.[347]

7.2.3.1 Psychiatric Units in General Hospitals (1960s)

> *Deinstitutionalization (…) evolved as a natural phenomenon following the advent of new pharmacological treatment, with the first era of anti-psychotic medication. Patients who spent years in institutions could now be treated with effective medications and their conditions often improved to the point that they could re-enter the*

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343 Donald Wasylenki (2001), pp. 95-110.

344 Such as the Bédard Commission in Québec (1961-1962) and the Blair Commission in Alberta (1967-1969).

345 Canadian Mental Health Association, *More for the Mind – A Study of Psychiatric Services in Canada*, Toronto, 1963.

346 As quoted and reported in Donald Wasylenki (2001), p. .96.

347 Donald Wasylenki (2001), pp. 95-110.

> *community. In following years, deinstitutionalization became a desirable goal. In the beginning of community psychiatry, it was thought that behavioural problems of many chronic patients were secondary to some form of "institutional neurosis". By taking steps to remove these patients from a pathological milieu and rehabilitating them in the society, it was hoped that social reinsertion would be successful for a large number of them.*
> *[Dr. Dominique Bourget, Forensic Psychiatrist, Royal Ottawa Hospital, Brief to the Committee, June 2003, pp. 2-3.]*

The first phase of the deinstitutionalization process involved discharging large numbers of long-term stay individuals from psychiatric hospitals both into the psychiatric units of general hospitals and directly into relatively unprepared communities. This resulted, during the 1960s, in the closing of several of Canada's larger, more isolated institutions. Long term hospitalization was slowly being replaced by shorter, intermittent stays. From 1960 to 1970, the number of patient days in psychiatric institutions was cut in half. The bed capacity of psychiatric hospitals decreased from approximately four beds per 1,000 population in 1964 to less than one bed per 1,000 in 1979.[348]

It was intended that this shift from psychiatric institutions to general hospitals' psychiatric units would have a significant impact, in particular by lessening the stigma associated with mental illness and psychiatry, as these illnesses and the practitioners who treated them became more closely integrated with the rest of medicine.[349]

Initially, both general hospitals and psychiatric institutions resisted the placement of psychiatric patients in general hospitals; some general hospitals did not want psychiatric patients, while some psychiatric institutions worried that their resources were being dramatically reduced.[350] However, there were benefits to shifting care to general hospitals. The general hospital units had the potential to enable early identification, to facilitate preventive psychiatry, and to treat a wide range of less serious psychiatric disorders.[351]

Unfortunately, the psychiatric units of general hospitals did not adequately serve the patient population discharged from the former psychiatric institutions. On the one hand, human and financial resources were not reallocated to general hospitals as individuals were discharged from psychiatric institutions. Indeed, studies in the late 1970s showed that individuals with severe and persistent mental illnesses who were treated in the psychiatric units of general hospitals benefited from far fewer resources than had been available in the psychiatric institutions in which they accommodated.[352]

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[348] Health and Welfare Canada (1990), p. 15.
[349] Donald Wasylenki (2001), pp. 107-109.
[350] Greenland, Griffin and Hoffman (2001), p. 4.
[351] Greenland, Griffin and Hoffman (2001), p. 7.
[352] Don Wasylenki (2001), p. 97.

On the other hand, general hospital psychiatric units tended to be used on a voluntary basis by middle and upper income individuals who were referred to them by private psychiatrists, while psychiatric institutions continued to provide services to poorer individuals and to those who had been admitted involuntarily. This, in effect, created a two-tiered system of mental health care: the general hospitals and psychiatric institutions served groups of patients that rarely overlapped.

Most importantly, the closing or downsizing of psychiatric institutions was achieved without providing adequate funding at the community level to provide for psychological support and rehabilitation outside the hospital. Thus, communities were left ill-prepared to provide discharged patients with appropriate support. Many individuals, disabled by persistent psychiatric illnesses, were left merely to subsist in the community. Although now living in a less restrictive environment, they received dramatically fewer services and less care if any care at all. According to numerous witnesses, this is a critical lesson that should never be forgotten in any movement to reform the mental health system.

The lack of proper services and supports in the community for those suffering from mental illnesses resulted in:

- a high frequency of relapse (back to the psychotic state) and, therefore, increased readmission rates to hospitals;
- the "revolving door syndrome", where patients, after readmission to the hospital and treatment, were discharged back to inadequate care in the community, only to become ill again and start the process all over again;
- increased homelessness;
- increased criminal behaviour and incarceration (sometimes for minor crimes).

This situation was tragic for individuals with mental illnesses and their families. Some experts came to believe that the deinstitutionalization policy itself was a major mistake. They came to believe that patients would be better off if they lived their lives in institutions. By and large, however, most experts, including individuals afflicted with mental illness, did not agree. They resisted joining the chorus for massive re-institutionalization and advocated the provision of long term services and supports for everyday needs so that they could live stable lives in the communities.

7.2.3.2 Community Mental Health Services and Supports (1970s and 1980s)

In this second phase of deinstitutionalization, the shift from institutional to community care continued with an emphasis not only on community mental health care *per se*, but also on community mental health supports.

In this phase, provincial governments began to fund mental health services outside the hospital setting, mainly in response to deficiencies in the general hospitals' psychiatric units. These services were provided by community mental health clinics. In addition, this phase also focussed on the need for an extensive array of community supports and services (such

as residential services, vocational rehabilitation programs, and income support) to maintain individuals with mental illness, particularly those with serious and persistent illnesses, in the community. People believed that a more balanced approach was needed in the allocation of funding for mental health services between expensive, facility-based, treatment-oriented care and community mental health care and support. Case management was needed to ensure the coordination of services in a community-based delivery system.

During this phase, proponents of community care were pitted against facility-based providers, and hospitals were seen to be part of the problem rather than part of the solution. Also, the interests of professionals were sometimes seen to be divergent both from those of individuals with mental illnesses and their families. Increasingly, provincial governments became less responsive to the advice of professionals and more responsive to the voice of individuals with mental illnesses and family members. Nongovernmental organizations, in particular, became especially strong and effective during this phase; pressure on governments to provide housing, income support, and opportunities for socialization matched the pressure that was exerted by professionals to secure treatment.[353]

> **History has taught us that mental health and mental illness transcend pure health boundaries, and intersect many social policy areas such as housing, income supports, social services, employment and justice.**
> ***[Canadian Mental Health Association, Brief to the Committee, June 2003, p. 1.]***

The 1970s and 1980s were also marked by advances in biological psychiatry, which showed that abnormal neurotransmitter systems may underpin at least some mental illness. Research in this area of psychiatry was also key in explaining the effectiveness of psychotropic medications. During this period, research done in Canada contributed significantly, both nationally and internationally, not only to expanding knowledge about the brain functions, but also to developing new drugs and to the better therapeutic management of mental disorders. These years were also marked by major contributions from Canadian scientists in the field of genetics and mental disorders, such as schizophrenia and bipolar disorder.

By the end of the 1980s, mental health services and supports, although they existed in most provinces, were not well integrated. Indeed, it was often said that these were "three solitudes" – psychiatric hospitals, psychiatric units in general hospitals and community mental health clinics, supports and services.

7.2.3.3 Enhancing Effectiveness and Integrating Mental Health Services and Supports (1990s to Present)

As in the previous phase, it was recognized that there was a need for more community mental service interventions, including more home visits, outreach services, mobile crisis mental health teams, as well as better partnerships with self-help groups, and more assertive community treatment (ACT) teams, etc. But in this third phase of the deinstitutionalization process, individuals with mental illness and their families, through various nongovernmental organizations, continued to pressure governments to provide more and better community supports in various areas such as housing, income support, employment opportunities, etc.

[353] Wasylenki (2001), pp. 107-109.

In contrast with the previous phase, however, this third phase has been marked by an emphasis on empirical research. In fact, there is an important trend toward the adoption of the "best practice" framework by policy makers, professionals, individuals with mental illness and family members. It is believed that the evidence-based approach will lead to a much greater degree of cooperation and collaboration in facilitating mental health reform. Hospitals (both general hospitals and psychiatric institutions) are no longer seen to be outside evolving systems of comprehensive care; rather, they are regarded as essential components even though they may require a rethinking of their key functions and mechanisms in order to better link facility and community-based care. This third and current phase is thus characterized by a greater degree of inclusiveness in planning and implementation activities as well as by a much clearer consensus on the reforms that are needed.[354]

In many provinces, the preferred model of mental health service delivery currently includes a broad range of coordinated community services operating in conjunction with the psychiatric units in general hospitals and an associated regional tertiary mental health care centre.

In my view, deinstitutionalization makes sense for most — not all — but only if the community has the service capacity; if society has been informed in an appropriate public education policy; if safe and affordable housing exists; and if enhanced employment opportunities exist. Can you imagine a time-sensitive institutionalized consumer is suddenly discharged to find employment in a stigmatized society where a "not-in-my neighbourhood" housing policy exists?
[Michael J. Grass (17:44)]

Major challenges remain, however. Simply put, mental illness has a social dimension that is not exhausted by the health care sphere. As those in larger cities are aware, the number of homeless people is increasing. As well, forensic psychiatry programs are under ever-increasing pressure for space. In addition, Canada is a multicultural society and mental health services and supports must accordingly be provided in a culturally appropriate manner.[355] Perhaps most importantly, the many and changing needs of children, adolescents and transitional-aged youth suffering from mental illnesses – the "orphans' orphan" – require major collaborative cross-sectoral action from the still poorly coordinated mental health, health care, social services, education, correctional, recreational, vocational and addiction systems.

7.3 PROVISION OF ADDICTION TREATMENT IN CANADA[356]

The development of addiction treatment in Canada has been characterized by five (5) distinct phases. The first phase, ending in the late 1940s, was dominated by moralistic attitudes and a general lack of attention to treatment. Some addiction treatment was

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354 Don Wasylenki (2001), pp. 107-109.

355 Quentin Rae-Grant (2001), p. xi.

356 This section is based on information provided in the two following documents: 1) Health Canada, "The Development of Alcohol and Other Drug Treatment in Canada", in *Profile of Substance Abuse Treatment and Rehabilitation in Canada,* Ottawa, 1999, pp. 3-5; 2) Colleen Hood, Colin McGuire and Gillian Leigh, *Exploring the Links Between Substance Use and Mental Health – A Discussion Paper*, prepared under contract to Health Canada, 1996.

available in private asylums and some counselling services were established in prisons. However, most individuals with addiction problems (either with alcohol or other drugs) had little access to treatment services. The dominant view was that these problems resulted from a "lack of will power" or from "personality defects".

The second phase, ending in the mid-1960s, was marked by a change in attitudes towards alcoholism and, to a lesser extent, towards problems involving other drugs. A major influence during this period was the growth of Alcoholics Anonymous (AA). AA promoted the view that alcoholism, although incurable, could be arrested if treatment was provided for withdrawal and the alcoholic followed a 12-step recovery program. With the support of some community leaders, AA members lobbied successfully for government-sponsored treatment and education programs. Efforts to secure government support for alcoholism services were also spurred by the view of alcoholism as a preventable and treatable "disease" rather than an expression or sequella of moral weakness.

During this phase, most provinces established departments, commissions or foundations to provide or coordinate addiction treatment services; many new services established. Initially, these agencies were principally concerned with alcohol-related problems but later, as individuals with addiction to other drugs began to increase in number, their mandates were expanded to encompass problems involving other drugs. It is important to note, however, that treatment for individuals who used illegal drugs took place in the shadow of a strong punitive approach to dealing with drug addiction.

In contrast with the moral model that « blamed the victim » for the development of addiction, the new view was that addiction was a disease caused by genetic and biological factors. No longer was the addict held personally responsible for engaging in « bad habits » since the determinants of their habitual behaviour were biogenetic factors beyond their individual control. The disease model was first advanced by academic specialists in the alcoholism field. In more recent years, the concept of alcoholism as a disease has been generalized to other habitual drug use.
[Ministry of Health Services, British Columbia, Every Door is the Right Door, May 2004, Appendix III, p. 72.]

The third phase began in the mid-1960s. It accompanied a surge in drug use and was characterized by a rapid expansion of addiction services. The most rapid growth occurred between 1970 and 1976. Of approximately 340 specialized agencies operating in 1976, two-thirds were established after 1970; expenditures on treatment services increased from $14 million to $70 million during the same period. The range of services established during this period included detoxification centres, outpatient programs, short- and long-term residential facilities and aftercare services. Some services for individuals with problems involving drugs other than alcohol were provided by programs established primarily to serve those with alcohol problems, but some specialized "drug" treatment services were also established during this period, including a number of therapeutic communities. Throughout this period, individuals in treatment were increasingly found to have been abusing other drugs simultaneously with alcohol.

The fourth phase began during the 1980s. It featured the relative autonomy of the provincial foundations and commissions within their respective health and social service systems. In many cases, addiction research, education and treatment occurred in systems

that paralleled but were far from fully integrated with the general community health and social services systems. Despite this, there was a growing appreciation for the role of non-specialized health and social services in identifying and supporting specialized substance abuse treatment services.

This phase can also be characterized by the diversification and specialization of alcohol and drug treatment services, and with growth in special services particularly for women, adolescents and Aboriginal peoples. This trend was driven by research indicating that individuals respond differently to different types of treatment and by a growing belief that treatment should be adjusted for different populations and types of addiction problems. While various modifications of the medical model of treatment were prevalent across the country, a number of other treatments based on cognitive, behavioural and social theories and research also emerged during this period, an approach that has come to be known as the cognitive-behavioural (CB) model. Canada's Drug Strategy, conceived as a multi-sectoral partnership, was launched in 1987. It helped stimulate a range of activity, including support for innovative treatment and rehabilitation services across the country.

The fifth and current phase, which began in the early 1990s, has been fuelled by dramatic changes in the structure of health service delivery across the country. Within a general environment fostering health care reform, most government addiction services have been integrated into community health and social services delivery systems. During this phase, there has been increased awareness of the need to better integrate alcohol and drug services, not only into the mental health service system, but also into larger social welfare policy and social support systems. Such integration of services is the result of the adoption of a population health approach in all provinces and territories. The holistic population health model emphasizes a complex set of health determinants – social, economic, cultural and environmental conditions, including behavioural choices – that impact both psychological status and biological states.

During this phase, new breeds of more potent drugs have emerged, putting young children and adolescents are at risk of addiction earlier than ever before. In addition, with the recent proliferation of gambling opportunities available to Canadians, problem gambling is an emerging concern in the field of addiction in many provinces and territories. Moreover, as corporate interest in addiction increases, the number of referrals from business and industry to Canadian addiction treatment services is growing.

7.4 COMMITTEE COMMENTARY

The stigma associated with mental illness and addiction in Canada has created serious obstacles to the provision of effective mental health services and addiction treatment. The Committee strongly believes that addressing stigma and discrimination is an important step towards the more efficient planning and provision of adequate mental health/addiction services and supports.

During the past 50 years, biomedical and clinical research, scientific advances in neuroscience, genetics and biology, and progress in cognitive and behavioural sciences have contributed to a better understanding of mental illnesses and substance use disorders. They

have led to the development of effective medications, treatments and therapies to which Canadian scientists have been major contributors. In fact, Canada was at the forefront of applying advances in neuroscience to mental disorders. In addition, the field of neuroscience has traditionally been a major international strength of Canadian research. Moreover recent breakthroughs may have a significant impact on the ability to treat many mental disorders including in preventing suicide. For example, advances in neurogenetics may help us better understand the nature of schizophrenia, while progress in neuropharmacology can yield gains in the treatment of depression. The Committee concurs with many witnesses that, thanks to health research, there are grounds for believing that the 21st century will see a significant improvement in the care and treatment of individuals with mental illness and addiction and perhaps in the prevention of diseases of this kind as well.

The deinstitutionalization process of the 1960s through the 1980s has yielded some important lessons with implications for how services and supports are delivered to individuals with mental disorders. In particular, significant reform at the system level must be undertaken to ensure the seamless provision of the full continuum of services and supports needed by individuals with mental illness and addiction. This can only be achieved through the integration of the 'three solitudes' – institutions, community services, and community supports – along with the integration of the currently separated systems – one for mental illness and the other for addiction. Individuals with mental illness and addiction must be regarded as people first, not as diagnoses or psychiatric labels. They must be engaged with their families in determining their path to recovery. This requires collaboration and the establishment of partnerships amongst players at all levels. Governments must play a leadership role in this very important undertaking.

The participation of individuals with mental illness and addiction and their families in community life must accompany every step along the road of reform and renewal. Individuals with mental illness/addiction and their families have important knowledge of how the system works (and doesn't work). The Committee concurs with numerous witnesses that, by including the perspectives of individuals with mental illness and addiction and their families in planning, policy making, service design and delivery, many false steps can be avoided.

CHAPTER 8: MENTAL ILLNESS AND ADDICTION POLICY AND LEGISLATION IN CANADA: REVIEW OF SELECTED PROVINCIAL FRAMEWORKS

INTRODUCTION

Policies, programs and legislation in the fields of mental health, mental illness and addiction are the responsibility of both provincial/territorial jurisdictions and the federal government and involve numerous departments and agencies. The organization, governance, funding and delivery of mental health services and supports and addiction treatment in Canada are primarily the responsibility of provincial and territorial governments. Provinces and territories also govern mental health legislation in their respective jurisdictions.

The federal government has a direct responsibility for the delivery of mental health services and addiction treatment to: Status Indians and Inuit; the military; veterans; civil aviation personnel; the RCMP; inmates in federal penitentiaries; arriving immigrants; and federal public servants. The federal government also has various responsibilities, such as health promotion and disease prevention; disease surveillance; health research; human rights; drug approval; employment and disability benefits; etc. which have direct or indirect implications for the provision of mental health services and supports and addiction treatment in the provinces and territories.

The purpose of this chapter is to provide a general overview of the role and responsibilities of provincial and territorial governments with respect to mental health, mental illness and addiction. The role of the federal government in the field of mental health, mental illness and addiction is discussed in detail in a subsequent chapter.

Section 8.1 briefly describes and compares the organizational structure and level of integration of the mental health services and addiction treatment system in selected provinces – Alberta, British Columbia, Nova Scotia, Ontario and Québec; it also provides some information on recent reforms. Section 8.2 identifies a number of problems related to the provincial/territorial systems arising out of the testimony received by the Committee. Section 8.3 examines the mental health acts of all Canadian jurisdictions and highlights the major differences among them. Section 8.4 present the Committee's commentary.

8.1 PROVINCIAL SYSTEMS OF MENTAL HEALTH SERVICES AND ADDICTION TREATMENT

8.1.1 Alberta[357]

The Ministry of Health and Wellness has responsibility for overall policy development, implementation, funding, service planning and evaluation in the fields of mental illness and addiction. Responsibility for the provision of community-based and facility-based mental health services is split between nine regional health authorities (RHAs) and the Alberta Mental Health Board. Provision of addiction treatment is the responsibility of the Alberta Alcohol and Drug Abuse Commission (AADAC).

Since the beginning of April 2003, the delivery of mental health services and the management of Alberta's four mental health facilities are the responsibility of the nine RHAs. Service delivery in the province encompasses Aboriginal mental health and reflects a strong integrated care/case management orientation. In other words, the vast majority of provision of front-line clinical services is under the direction of the RHAs and is integrated with the provision of physical health services.

The Alberta Mental Health Board, a provincial health authority accountable to the Minister of Health and Wellness, governs and operates province-wide services and programs such as forensic psychiatry, suicide prevention, tele-mental health (video-conferencing) and promotion activities. The Board also advises the Minister of Health and Wellness on matters related to the integration and performance of the provincial mental health system.

AADAC is a Crown agency accountable to the Minister of Health and Wellness. It is mandated to operate and fund services addressing alcohol, other drug and gambling problems (such as detoxification, residential treatment services; prevention, education, counselling), and to conduct related research. The Commission offers hospital-based addiction services in all regions. AADAC is also responsible for coordinating the implementation of the Alberta Tobacco Reduction Strategy.

RHAs, the Alberta Mental Health Board and AADAC work in partnership with the Ministry of Health and Wellness and other ministries and agencies in the implementation of the province-wide Children's Mental Health Initiative (July 2001). This Initiative focuses on reducing the risk of mental health problems and substance abuse and on providing support and treatment for children, adolescents and their families.

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357 Unless specified otherwise, the information contained in this section is based on the following documents: Provincial Mental Health Planning Project, *Advancing the Mental Health Agenda – A Provincial Mental Health Plan for Alberta*, April 2004; Alberta Children and Youth Initiative, *Children's Mental Health Initiative*, Fact Sheet, February 2004; Alberta Mental Health Board, *Brief to the Committee*, 2003; Alberta Alliance on Mental Illness and Mental Health, *Partnership, Participation, Innovation – A Blueprint for Reform*, March 2003; Alberta Health and Wellness, "Transition Underway to Fewer Health Regions, Integrated Mental Health", *News Release*, 23 January 2003; Alberta Mental Health Board, *Business Plan, 2002-2005*, 2002; Information on the website of the Alberta Alcohol and Drug Abuse Commission (www.aadac.com).

8.1.2 British Columbia[358]

In British Columbia, responsibility for policy development, implementation, funding, service planning, monitoring and evaluation in the fields of mental illness and addiction rests essentially with the Ministry of Health Services and the Ministry of State for Mental Health and Addiction Services. Responsibility for mental health policy for children and adolescents belongs to the Ministry for Children and Family Development which works in collaboration with the Ministry of Health Services and the Ministry of State for Mental Health and Addiction Services.

Governance, management and delivery of mental health services and addiction treatment, including community-based services, are the responsibility of RHAs which operate in 5 defined geographic areas. Core mental health and addiction services provided by the RHAs, with the assistance of the Ministry of Health Services, include: emergency response and short-term intervention services; intensive case management; outreach services; clinical services (assessment, diagnosis, treatment and consultation); addiction treatment (since 2002), preventive measures (research, education, early identification and intervention); psychosocial rehabilitation; case management and social supports, including respite care for family caregivers; residential services; and, when required, assistance in accessing housing, income assistance and rehabilitation services and benefits.

British Columbia has one large long-stay psychiatric hospital, Riverview Hospital, six community forensic psychiatric clinics and a Forensic Psychiatric Services Commission. RHAs are responsible for the community forensic psychiatric clinics. The Provincial Health Services Authority, the sixth health authority of the province, administers services provided province-wide by the Riverview Hospital and the Forensic Psychiatric Services Commission.

The Forensic Psychiatric Services Commission is a multi-site organization that provides specialized hospital and community-based assessment, treatment and clinical case management services for adults with mental illnesses and substance use disorders who are in conflict with the law. This unique, single-entry service ensures that forensic psychiatric clients have equitable access to mental health and addiction services throughout British Columbia.

The position of a provincial ministry of state responsible for mental health and addiction services in British Columbia is unique in Canada. It suggests strong recognition by the provincial government of mental illness and addiction as a serious public policy concern:

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358 Unless specified otherwise, the information contained in this section is based on the following documents: Mental Health and Addictions, Ministry of Health Services, British Columbia, *Brief to the Committee*, 9 September 2003; Mental Health and Addictions, Ministry of Health Services, British Columbia, *Development of a Mental Health and Addictions Information Plan for Mental Health Literacy, 2003-2005*, 4 February 2003; Government of British Columbia, *Child and Youth Mental Health Plan for British Columbia*, February 2003; Addictions Task Group, Kaiser Youth Foundation, British Columbia, *Weaving Threads Together – A New Approach to Address Addictions in BC*, March 2001; Minister's Advisory Council on Mental Health, *Moving Forward*, Annual Report, 2001; Ministry of Health Services, British Columbia, *Revitalizing and Rebalancing British Columbia's Mental Health System – The 1998 Mental Health Plan*, 1998; Information on the Website of the Provincial Health Services Authority (www.phsa.ca) and the British Columbia Mental Health Society or Riverview Hospital (www.bcmhs.bc.ca).

> *A unique approach has recently been implemented in British Columbia with the establishment of a Minister of State for Mental Health. This appears to be a direct acknowledgment of the importance of mental health issues within society and provides prominent office, with a seat in cabinet, to oversee governance and administration of the provincial mental health system.*[359]

British Columbia has tried to implement best practices in mental health care. This has translated into the development of regionally integrated mental health services, with tertiary care provided in smaller, community-based facilities.

In recent years, British Columbia has established an addiction planning framework (May 2004), a child and adolescent mental health plan (February 2003), a depression strategy (October 2002) and an anxiety disorders strategy (April 2002). These province-wide initiatives are aimed at improving the quality and effectiveness of prevention, early detection/intervention, treatment and supports to individuals with mental illness and addiction.

8.1.3 Nova Scotia[360]

The Department of Health is responsible for the planning, organization, funding, management, monitoring and evaluation of mental health services and addiction treatment. These functions are achieved mainly through the Mental Health Services Section and the Drug Dependency Services of the Department of Health. The nine RHAs (called "District Health Authorities") are responsible for the provision of mental health services and addiction treatment (alcohol, tobacco, drugs, gambling) in their respective geographic areas.

The Provincial Forensic Psychiatric Service, also administered by the Department of Health, provides inpatient treatment and assessment, and a few community support programs. All inpatient forensic psychiatric services are located in a single institution - the Nova Scotia Hospital.

The IWK Grace Health Centre is an academic health sciences centre affiliated with Dalhousie University. The IWK operates the provincial child and adolescent psychiatry unit, some outpatient clinics and telemedicine consultation services.

Nova Scotia was the first province to introduce, in 2003, formal standards for mental health service delivery. These standards were developed through collaborative efforts involving individuals with mental illness and addiction, their families, community groups and the

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[359] Dr. Elliot M. Goldner, *The Health Transition Fund – Sharing the Learning: Mental Health, Synthesis Series*, Health Canada, 2002, p. 11.

[360] Unless specified otherwise, the information contained in this section is based on the following documents : Canadian Mental Health Association (Nova Scotia Division), *2004 Report Card on Mental Health Services Core Standards*, 8 March 2003; Department of Health, Nova Scotia, *Strategic Directions for Nova Scotia's Mental Health System*, 20 February 2003; Department of Health, Nova Scotia, *Standards for Mental Health Services in Nova Scotia*, 20 February 2003; Roger Bland and Brian Dufton, *Mental Health: A Time for Action*, submitted to the Deputy Minister of Health, Nova Scotia, 31 May 2000; IWK Health Centre's Website (http://www.iwk.nshealth.ca/).

Mental Health Services Section of the Department of Health. It has been argued that more funding is needed to implement these standards province wide.[361]

8.1.4 Ontario[362]

Responsibility for the planning, organization, funding, management, monitoring and delivery of mental health services and addiction treatment rests with the Ministry of Health and Long-Term Care (MOHLTC). In contrast to other provinces, there are no RHAs in Ontario. There are 16 District Health Councils, but their mandate is limited to advising the Minister of Health on the health matters and needs in their respective districts; they do not control funding of any service, including mental health and addiction services. As a consequence, the many mental health services, supports and addiction treatment providers function largely independently of one another.

The MOHLTC also coordinates the provincial forensic strategy in partnership with the Ministry of Community, Family and Children's Services, the Ministry of the Attorney General, and the Ministry of Public Safety and Security.

The mental health and addiction treatment system in Ontario is currently in transition. In December 2002, 9 regional mental health implementation task forces released their reports on how to reform and renew the organization and delivery of mental health services and addiction treatment throughout the province. The main recommendation of these reports relates to the establishment of regional mental health authorities with responsibility for funding allocation and the delivery of mental health services and addiction treatment in their respective geographical areas. These regional systems would deliver a core basket of services and supports that would allow individuals to access a continuum of community-based services and supports where and when they need it. The Ontario government has not yet acted on the recommendations of these task forces.

8.1.5 Québec[363]

The *Ministère de la Santé et des Services Sociaux (MSSS)* (Department of Health and Social Services) has responsibility for planning, organization, management, funding, monitoring

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361 Canadian Mental Health Association (Nova Scotia Division), www.cmhans.org.

362 Unless specified otherwise, the information contained in this section is based on the following documents : Provincial Forum of Mental Health Implementation Task Forces, *The Time Is Now : Themes And Recommendations For Mental Health Reform In Ontario*, Final Report, December 2002; Forensic Mental Health Services Expert Advisory Panel, *Assessment, Treatment and Community Reintegration of the Mentally Disordered Offender*, Final Report, December 2002; Ministry of Health and Long-Term Care, *Make it Happen – Operational Framework for the Delivery of Mental Health Services and Supports*, Government of Ontario, 1999;

363 Unless specified otherwise, the information contained in this section is based on the following documents : Ministère de la Santé et des Services Sociaux, *Agir Ensemble – Plan d'action gouvernemental sur le jeu pathologique*, 2002-2005, Government of Québec, 2002; Ministère de la Santé et des Services Sociaux, *Plan d'action en toxicomanie, 1999-2001*, Government of Québec, 1998; Ministère de la Santé et des Services Sociaux, *Québec's Strategy for Preventing Suicide*, Government of Québec, 1998; Ministère de la Santé et des Services Sociaux, *Plan d'action pour la transformation des services de santé mentale*, Government of Québec, 1998, Comité de la santé mentale du Québec, *Défis de la reconfiguration des services de santé mentale*, Government of Québec, 1997.

and evaluation of mental health services and addiction treatment. The Minister for MSSS is guided in this responsibility by two distinct advisory bodies: the Comité de la santé mentale du Québec and the Comité permanent de lutte à la toxicomanie. The 18 RHAs are responsible for the provision of inpatient, outpatient and community mental health services and supports as well as addiction treatment in their respective regions.

The MSSS is responsible for implementing and coordinating the provincial action plan on addiction; the plan covers promotion, prevention, early detection and intervention, detoxification, social rehabilitation and reintegration. In addition, the MSSS coordinates Québec's Strategy for Preventing Suicide. The purpose of this strategy is to consolidate and coordinate the various suicide prevention efforts to ensure equitable access to essential services in all regions. Essential services include: telephone hotline on a 24/7 basis; suicide crisis intervention (assessment, referral services, support services, monitoring); post-intervention (individual or group debriefing services for friends, relatives and caseworkers within 48 hours of a completed suicide). The strategy involves not only governmental departments, but also RHAs, CLSCs, hospitals, suicide prevention centres, police, schools, youth centres, community organizations, etc.

8.1.6 Brief Comparative Analysis

In two important aspects, British Columbia is unique in its approach to mental health and addiction policy in Canada. It alone has a minister of state responsible for mental health and addiction who can bring mental health issues to the forefront in Cabinet discussions. And second, only in British Columbia have the policy framework, governance and service delivery for both mental health and addiction been integrated.

In Alberta, Nova Scotia, Ontario and Québec, responsibility for mental health and addiction policy development and service planning rests with the provincial department of health. A number of provincial reports have noted, however, that policy development which impacts on individuals with mental illness and addiction has not been well coordinated across various social policy ministries. This has diminished the impact which would be derived from more thorough, consultative and inclusive inter-ministerial planning among the several ministries that must inevitably be involved in the provision of services to individuals with mental illness and addiction.

In all provinces but Ontario (which does not have RHAs as yet), programs and services to support individuals with mental illness and addiction are organized and provided by RHAs. Devolution through regionalization has facilitated the tailoring of services and supports to meet regional needs more closely. It has also facilitated collaboration among the various stakeholders involved in service delivery.

Reform of the mental health and addiction treatment system is occurring in most jurisdictions. While there are variations across provinces, a number of best practices criteria have been identified and largely agreed upon:

1. a shift from hospital to community-based services to create a more balanced approach to the delivery of mental health/addiction services;

2. specified, protected funding for an integrated mental health and addiction treatment system, including community, hospital-based and community-based tertiary care;

3. a single point of accountability where responsibility for the operation of an integrated system at the local/regional level;

4. mechanisms for the meaningful involvement of individuals with mental illness and addiction and communities in decision-making.

During its hearings, the Committee did not hear from individuals with mental illness and addiction or others about whether a particular province, region or RHA can be considered as a model to emulate in terms of policy development, organizational structure, governance and service delivery. Significant questions remain. For example, should the central authority for mental illness and addiction be at the provincial rather than at the regional level? Has any province or region been particularly successful at integrating hospitals and community services and supports? How can mental health services and supports best be integrated with addiction treatment? Has a particular province or region been able to coordinate mental health and addiction services with the broader social system (education, housing, justice, income support, etc.)?

8.2 COMMON PROBLEMS IDENTIFIED WITH RESPECT TO PROVINCIAL/TERRITORIAL FRAMEWORKS FOR MENTAL ILLNESS AND ADDICTION

8.2.1 Fragmentation and Lack of Integration

The Committee heard repeatedly that the mental health and addiction system is not, in fact, a real system, but rather a complex array of services delivered through federal, provincial and municipal jurisdictions and private providers, including initiatives by individuals with mental illness/addiction themselves. This system is a mix of acute care services in general hospitals, specialized services for specific disorders or populations, outpatient community clinics, community-based services providing psychosocial supports (housing, employment, education, and crisis intervention) and private counselling, all of varying capacity and quality, often operating in silos, and all-too-frequently disconnected from the health care system. In most jurisdictions, there are limited if any ties between the "formal" mental health and addiction system and self-help initiatives that have taken root in communities nationwide. The result is, in most jurisdictions, a highly fragmented (non-) system that has become increasingly difficult to navigate by both individuals with mental illness and addiction and service providers.

Compounding this fragmentation is the fact that while mental health services/supports and addiction treatment are delivered by many different agencies, data information systems are not yet adequately linked across the sectors concerned (e.g. health, housing, education, family benefits, work environment, etc.). This makes it virtually impossible to monitor mental health services and addiction treatment other than those provided by hospitals or

primary health care providers where some records are kept and can be accessed under the right circumstances.

The Committee was told that ensuring coordinated access to a broad continuum of services and supports is critical to the development of an effective strategy to address mental illness and addiction. This means that governments must invest in the community-based sector, as well as in hospitals and other institutions. Many witnesses stressed that a broad continuum of services and supports, including supportive housing and income supports, is key to meeting effectively the different needs of individuals at different stages of their illness and recovery; it is also key to ensuring a responsive mental health and addiction system capable of preventing acute episodes of illness, or of reducing their intensity or duration. Moreover, it is imperative that addiction be included in mental health reform initiatives.

A review of selected documents from a number of jurisdictions suggests that most provinces face very similar problems and challenges with respect to the current delivery of mental health services and addiction treatment. These problems and challenges are summarized below:[364]

- First, as mentioned above, existing services and supports for individuals with mental illness and addiction are fragmented among many separate agencies and many access points. There is also the need to better integrate the mental health system with the health care system and the mental health system with the addiction treatment system.
- Second, the current mental health services system still reflects to a large extent an institutionally-driven philosophy of care; services and supports should be patient-centred and community-based.
- Third, the current mental health services system is not comprehensive; it does not provide the continuum of services and supports needed. As a result, individuals with mental illness and addiction often do not receive the services and supports they need when and where they need them.
- Fourth, historically, mental health services have been under-funded. This has been detrimental to those with severe and persistent mental disorders, particularly to those hardest to serve – individuals from different ethnocultural communities, people who are homeless, and those with concurrent disorders.

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364 Information based on the following documents: Department of Health, *Strategic Directions for Nova Scotia's Mental Health System*, Government of Nova Scotia, February 2003; Elliot M. Goldner, *Synthesis Series – Mental Health*, Sharing the Learning: The Health Transition Fund, Government of Canada, 2002; Government of Newfoundland and Labrador, *Valuing Mental Health – A Framework to Support the Development of a Provincial Mental Health Policy for Newfoundland and Labrador*, September 2001; Minister's Advisory Council on Mental Health, *Moving Forward*, Annual Report, Government of British Columbia, 2001; Ministry of Health, *Making It Happen – Operational Framework for the Delivery of Mental Health Services and Supports*, Government of Ontario, 1999; Comité de la santé mentale du Québec, *Défis – De la Reconfiguration des Services de Santé Mentale*, Gouvernement du Québec, October 1997; Health Systems Research Unit, Clarke Institute of Psychiatry, *Best Practices in Mental Health Reform*, Discussion Paper Prepared for the Federal/Provincial/Territorial Advisory Network on Mental Health, 1997; Alberta Mental Health Board, Building A Better Future – A Community Approach to Mental Health, Government of Alberta, March 1995.

- Fifth, there are major human resource shortages in the mental health sector.
- Sixth, there is a significant lack of measures of accountability in the mental health services system. The roles and responsibilities of service providers are not clearly set out and an information system is needed to support the planning and operation of a more effective, comprehensive system and to monitor the effectiveness of the services it provides.
- And seventh, widespread stigma persists throughout society despite many efforts to educate the general public and the health care system as a whole. It has been said that stigma is the largest barrier to change in every level of the system.

Several witnesses stressed that recovery from mental disorders requires much more than what are considered traditional mental health services. For certain individuals, recovery may require – in addition to medication, therapy and case management – access to housing, transportation, employment and peer support. Yet, the various mental health systems have been slow to acknowledge and respond to these needs. In many provincial reports, reference is made to mental health services "and supports" to highlight the critical importance of each in providing the tools that an individual with a mental illness may need to recover from his/her illness, to overcome isolation, and to gain or regain economic self-sufficiency.

The lack of coordination among the various sectors, the absence of clear authority at the regional level and limited community-based supports have had tragic consequences for individuals and society. As pointed out in Chapter 5, a significant number of individuals with severe mental illnesses are homeless, living on the streets or in public shelters. In addition, a high proportion of incarcerated individuals have a mental disorder. Many of these individuals are jailed for non-violent misdemeanours, others for "crimes of survival" such as stealing food, loitering, or trespassing; their incarceration is often the result of their unmet needs for mental health services or addiction treatment and for housing.

Many witnesses pointed to the particular needs of children and adolescents. In fact, the system of child and adolescent mental health services and supports has been called by witnesses the "orphan's orphan" of the health care system. Mental health services for children and adolescents at the provincial and territorial levels often involve a variety of departments and agencies (e.g., mental health, child welfare, young offender, addiction services, and special education services). There is general dissatisfaction in most jurisdictions with the present delivery of children and adolescents services. Information suggests that:

- The current system is highly fragmented; services are delivered in an uncoordinated fashion through multiple providers. The problems of children and adolescents do not come as neatly divided in terms of responsibility as government departments are.
- The prevalence of mental illnesses among children and adolescents far exceeds the capacity of the current service delivery system; there is a lack of access to needed services and there are long waiting lists for the limited services that are available.
- Mental health policies and programs have focussed largely on the treatment of the adult population; consequently, services for children and adolescents have developed slowly and only as an adjunct to programs for adults.

- There is insufficient funding for mental health services directed at children and adolescents.
- There is an urgent need to enhance preventive and early intervention services.
- Currently, many effective interventions are not made widely available to children and adolescents, and many ineffective interventions continue to be used even when shown to be more expensive and restrictive than available alternatives. Thus, there is a need to better incorporate research evidence about effective practices into decision making at all levels, including clinically.
- No clear goals and objectives have been set and few indicators of outcomes relevant to children and adolescents are reported on a regular basis to assess the performance and effectiveness of the system of mental health services.
- Nobody seems to be in charge, that is, there is no executive component with authority to cause the whole system of care to decide upon and implement coherent action.
- There are no external incentives for efficiency – surplus dollars must often be returned to central coffers rather than being reinvested locally.[365]

Witnesses also raised a number of concerns with respect to the specific needs of individuals with concurrent disorders (mental illness and addiction). These individuals may access needed services and supports through various entry points, either within the mental health system or within the addiction treatment sector. However, numerous barriers affect the ability of these individuals to access and obtain appropriate treatment:

- The mental health and addiction systems often operate in parallel, a barrier to ensuring that a person receives treatment for both problems in an integrated fashion. Current services provided for this population are poorly linked, both within and between the addiction and mental health systems.
- There are no systematic approaches and effective assessment tools to better identify this population.
- Because of inappropriate identification, individuals fail to receive proper care or receive care for only one disorder (either substance use or mental illness) but not both.
- Many mental health programs exclude individuals with active substance abuse problems, and similarly, many addiction programs exclude individuals with mental health problems.

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365 Federal/Provincial/Territorial Working Group on the Mental Health and Well-Being of Children and Youth, *Celebrating Success: A Self-Regulating Service Delivery System for Children and Youth*, Discussion Paper, Health Canada, 2000, pp. 8-10; External Advisory Committee for Child and Youth Mental Health, *Child and Youth Mental Health Plan for British Columbia*, February 2003 (Revised July 2004), pp. 4-9; Charlotte Waddell et. al. (April 2002).

- Staff in both the mental health and addiction fields need cross-training to improve the identification of this client population and provide better treatment planning based on client needs.
- The fear/stigma associated with both mental illness and addiction often prevents individuals with concurrent disorders from seeking treatment and may lead to self-medication.
- Individuals with concurrent disorders and their families lack information on existing services and how they may be accessed.

Very similar concerns – such as fragmentation, the existence of silos, stigma, lack of specialized human resources, the need for early intervention and preventative measures – were expressed with respect to the mental health needs of senior Canadians and individuals in forensic psychiatry services.

8.2.2 Community Services and Supports

While a higher proportion of individuals than ever will make a complete or significant recovery from their mental illness/addiction, the illness will continue to have a significant impact on aspects of the lives of many for long periods, even a life time. Once the initial symptoms have been diagnosed and controlled properly, individuals with mental illness and addiction need three broad types of services: relapse prevention, clinical services and rehabilitation/support services. All three elements require management; for an individual with mental illness and addiction, the process is called "case management".

As explained in Chapter 4, case management refers to the continuing and ongoing support provided to individuals with mental illnesses/substance use disorders to assist them to obtain needed services. When the severity of an individual's illness or the complexity of the system precludes the affected person from accessing the needed services him/herself, case management may be provided by clinical and support service staff. For individuals with multiple needs intensive case management is essential. While case management is highly regarded as a core function in the system, a number of different approaches to providing case management have been used.

Relapse prevention consists in helping individuals maintaining their recovery. The Committee was told that the most important component of relapse prevention is to ensure that the affected person continues to take his/her medication. Often, individuals stop taking their medication because they feel well and are no longer motivated to continue. They may also experience what they consider to be intolerable side effects and stop medication. In both cases, they then lose insight into the benefits of taking medication and suffer relapse of their illness. Once-a-day dosing and minimizing toxicity/side effects can help to reinforce patient compliance. However, education, counselling and regular monitoring are also vital to improve compliance. Witnesses told the Committee that developing standards and guidelines for relapse prevention measures, in consultation with health and educational authorities, is critical.

Clinical services are a core component of overall services and supports because many individuals do experience relapse. Even when they follow a treatment plan faithfully, many

individuals can become severely ill and require acute treatment. For some, where safety or complexity is an issue, hospital admission is also necessary. Clinical services include inpatient services, hospital-based clinics, support groups, information sessions, outpatient clinics, mental health centres, visiting clinical teams, emergency teams and a variety of other clinical services located in community settings; all are necessary to meet the varying needs of individuals with mental illness. Such clinical services, together with NGOs, are needed to provide a full spectrum of care for affected individuals and their families. Coordinating such a complex system is essential. Again, the Committee was told that clinical guidelines or standards are essential to promote their effectiveness and efficiency.

Rehabilitation and ongoing support services must be available to help optimize the quality of life of affected individuals and help them recover their abilities to the fullest extent possible. These services include: housing, ranging from professionally staffed group homes to independent apartments with regular consultation and the availability of 24-hour 7-day crisis response; vocational services including job finding and support and skill training; social and recreational services including assisting people to join in normal community activities and "drop in" places; and income support, as many individuals have difficulty in obtaining and maintaining employment. All these services and more should contribute to ensuring the continuum of care of a seamless system.

8.2.3 Uneven Regional Distribution and Quality of Services

The Committee was told that, as with other health services, mental health services and addiction treatment are especially lacking in rural and remote areas of the country, including most Aboriginal communities. In many such areas, there is no resident psychiatrist. The result is that individuals with mental disorders living in rural and remote regions and Aboriginal settings are forced to travel far from their homes to receive needed services. This hardship, ironically dubbed "Greyhound Therapy", is doubly stressful for someone affected by mental illness and addiction.

When individuals must travel from their communities to access mental health and addiction services, they are separated from their natural support systems and informal care networks that provide the kind of financial, emotional and social supports for recovery that are not found in the formal system. Although for some the anonymity of the city is a welcome respite from the shame and stigma that usually affect individuals with mental illness and addiction in a small community, being removed from that community can also compromise treatment interventions and outcomes.

The Canadian Mental Health Association pointed out that rural and remote communities also experience particular mental health issues such as those triggered by drought, flood and other environmental disasters. Such communities may also be characterized by compounding factors, such as lower educational and income levels, higher adolescent birth rates, a higher proportion of unwed mothers, and higher unemployment rates, that can contribute to the development and exacerbation of mental health problems and illnesses. According to the Association, transplanting urban professional mental health workers into

rural settings, even if they are willing to relocate, would not necessarily qualify or equip them to deal with the distinctive rural and cultural issues affecting their clients.[366]

8.2.4 Primary Health Care Sector

The primary health care sector is usually the first point of contact of individuals with mental illness and addiction with the health care system. Yet, the Committee heard repeatedly that many family physicians lack sufficient knowledge, skills and motivation to manage patients with mental illness and addiction, to accurately screen for mental disorders, or to navigate the appropriate referral pathways to access the more specialized mental health and addiction system. Dr. Sunil V. Patel, President of the Canadian Medical Association (CMA), told the Committee:

> *While family physicians can deal with a number of mental illnesses, most are not trained in the complicated medical management of severe mental illness. Many family physicians' offices are also not sufficiently resourced to deal with family counselling, or related issues such as housing, educational and occupational problems often associated with mental illness.*[367]

Witnesses also told the Committee that many provincial health care insurance plans limit the amount of mental health services that can be billed by family physicians. For example, Patrick Storey, Chair of the Minister's Advisory Board on Mental Health (British Columbia), stated:

> *Medical billing schedules and procedures, extended health benefits, pension plans, et cetera, do not recognize the special features and challenges of mental illness and create unnecessary obstacles to recovery and health. For example, in British Columbia, a family doctor can bill for only four counselling sessions per patient per year; yet, most people with depression go to see their family doctor. Though antidepressant medication is a helpful adjunct, alone it is not sufficient to help people deal effectively with that sometimes debilitating condition. Doctors are not in a position to provide the help required for a person in a depression.*[368]

Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, expressed similar view when he stated:

> *Even physician services are restricted. (…) Many provincial health plans restrict the number and types of mental health services that can be provided by general practitioners. In many cases, family practitioners are*

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366 Canadian Mental Health Association, Brief to the Committee, June 2003, pp. 8-9.

367 Dr. Sunil V. Patel, President of the Canadian Medical Association, Brief to the Committee, 31 March 2004, pp. 1-2.

368 Patrick Storey, Chair of the Minister's Advisory Board on Mental Health, British Columbia (15:8).

> *ill prepared to treat the serious mental disorders that appear [sic] in their offices. There is little support for education or on-site consultations.*[369]

Another concern brought to the attention of the Committee is that, currently, primary health care reform is occurring in relative isolation from the reform of the mental health and addiction system in communities across the country. Yet, many witnesses felt that these two systemic reforms ought to share the same goal of improving the provision of quality, accessible, comprehensive, integrated, timely services to all those who need them regardless of the type of underlying disease.

The Committee was told that progress could be made, however, with support for "shared mental health care" initiatives across the country. These initiatives, which stem from a partnership between the College of Family Physicians of Canada and the Canadian Psychiatric Association, appear to be a success story; they refer to collaborative activities between primary health care providers and psychiatrists. Some shared mental health care initiatives have a strong clinical focus and integrate mental health services within primary health care settings.[370]

Irene Clarkson, Executive Director, Mental Health and Addictions, British Columbia Ministry of Health Services, stated that shared mental health care initiatives within primary heath care settings would help to enhance early detection and intervention:

> *Through primary health care 60% of persons with mental disorders and substance use disorders currently access their services in B.C., and therefore improved primary care is a priority for change. (…) Evidence in the medical literature supports the delivery of these interventions by multidisciplinary teams. (…) In many instances physicians are the only source of mental health and addictions services for people at risk or with mental disorders and substance use disorders, therefore, attention to primary care can promote early detection and intervention for mental health and addictions problems which in turn leads to better long-term prognosis; allows for teaching clients self-management of their health; and, ensures ongoing, periodic assessments and treatment to promote stability and community tenure.*[371]

Many witnesses felt that the federal government could play a major role in ensuring that successful shared care initiatives continue to be funded and that best practice models be implemented and converted into permanent programs and policies in all provinces and territories.

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369 Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, Brief to the Committee, 28 April 2004, pp. 5-6.

370 Canadian Psychiatric Association and The College of Family Physicians of Canada, *Shared Mental Health Care in Canada – Current Status, Commentary and Recommendations*, A Report of The Collaborative Working Group on Shared Mental Health Care, December 2000.

371 Irene Clarkson, Executive Director, Mental Health and Addictions, British Columbia Ministry of Health Services Brief to the Committee, 9 September 2003, pp. 5-6.

8.2.5 Human Resources

Like other areas in the health care system, mental health services and addiction treatment suffer from a lack of coordinated planning for its human resources. There is no central planning mechanism to coordinate hiring or to ensure the appropriate distribution of appropriately qualified and experienced service personnel across communities. The growing geographical concentration of mental health and addiction professionals in large urban centres is also a major concern.

Witnesses told the Committee that there are chronic shortages of providers, including of psychiatric nurses, psychiatrists, social workers, case managers and occupational therapists with knowledge of mental health and addiction issues.

The growing need for expert services is exacerbated by a shortage of psychiatrists and limited access to psychologists. According to the Canadian Psychiatric Association, the ideal psychiatrist to population ratio (1:8,400) is far from being achieved, especially outside urban centres. To compound the problem, an increasing number of the Canada's 3,600 currently counted licensed psychiatrists are not working full time, particularly women and young graduates just entering the field who have made lifestyle choices to work fewer hours. Certain specialties are especially under-resourced, such as child, geriatric and forensic psychiatry. Individuals with concurrent disorders (mental illness and addiction) and dual diagnosis (mental disorder and developmental disability) have particularly limited access to appropriate psychiatric care.[372] In addition, particular groups such as immigrants/refugees lack a level of services appropriate to meet their needs.

For psychological services, equality of access appears to be the major problem. Publicly funded psychology services through hospitals or mental health clinic programs are spotty and limited in their availability. As general hospitals face budgetary constraints, their departments of psychology are frequently reduced or eliminated. Moreover, many low- and middle-income individuals, together with people who are unemployed and/or those who do not have private health care insurance, cannot afford to pay for private psychological services which are not covered under publicly funded provincial health care insurance.

Long waiting lists and significant delays in diagnosis, treatment and support are direct by-products of a mental health system that lacks the human resources to deliver care effectively. While there are no standardized sources of data currently available for compiling national information on waiting lists, provincial estimates depict a pretty grim picture. The Canadian Mental Health Association stated in its brief that:

> *(…) about half of the adult population who need services must wait for eight weeks or more – an eternity in the lifetime of a person, a family or a community struggling with serious mental illness or addiction. For some individuals, having to wait for services is the difference between life and death. While the crisis in surgical waiting lists makes the headline news, society remains fairly oblivious to the suffering and isolation of*

[372] Canadian Psychiatric Association, *Human Resource Planning for Psychiatry in Canada – A Background Paper*, unpublished document.

> *those experiencing a mental health crisis who suffer and wait in silence for critical and medically necessary supports. It is most tragic that when a person finally finds the strength and courage to reach out for help, more often than not their first contact with the mental health system becomes a discussion of how long they must wait.*[373]

Dr. Cornelia Wieman, Psychiatrist from the Six Nations Mental Health Services (Ohsweken, Ontario) informed the Committee that currently there are only four Aboriginal psychiatrists in Canada. In her view, it is important, indeed critical, to train an increased number of Aboriginal health professionals. This would help ensure that services are provided in a more culturally appropriate manner and remove some of the barriers to those seeking mental health services in communities universally acknowledged to have particular need for them.

> **My last plea in this area is that there is a common saying that "no one is irreplaceable" - so I ask you today : after 7 years of working in the Six Nations community and providing psychiatric services to over 400 patients for well over 600 episodes of care, who will replace me? (…) We desperately need to train more Aboriginal health professionals (…).**
> ***[Dr. Cornelia Wieman, Brief to the Committee, 13 May 2004, pp. 5-6.]***

Many recommendations were suggested to the Committee with respect to the planning of human resources in mental health, mental illness and addiction. For example, it was recommended that the provinces and territories, in partnership with the federal government, develop a long term plan that will ensure high quality appropriately trained service providers – both professionals and para-professionals – to address the mental health needs of Canadians. This plan would include:

- a detailed national human resource plan for mental health and addiction personnel based on forecasted needs and projected trends;
- a compilation of information on waiting lists; development of national standards and guidelines for maximum waiting times across the full continuum of mental health care and addiction treatment services;
- review of the effective use of alternatives to professionals outside the medical field, such as home support workers, social workers, peer support workers and informal social networks to decrease the demand for psychiatrists;
- creation of a task force to review and make recommendations on how to improve the knowledge of and training in mental health intervention and promotion strategies as part of the curricula of training of all health professionals and of undergraduate and graduate students within the health disciplines, education, social work and other related programs at the university and college levels.
- analysis of the extent to which interdisciplinary opportunities for joint education (undergraduate, graduate and continuing education) could be used between

[373] Canadian Mental Health Association, Brief to the Committee, June 2003, p. 8.

physicians and psychologists, nurses, social workers, occupational therapists and addiction counsellors;

- incentives for the recruitment and retention of mental health professionals and students in these disciplines;
- a study of various models of mental health service delivery in rural areas, including the use of telehealth.

8.2.6 Unmet Needs

> *[The] problem of access occurs across the continuum of services from primary care for common disorders to urgent and crisis services for more severe and persistent disorders. [Dr. Donald Addington, Professor and Head, Department of Psychiatry, University of Calgary, Brief to the Committee, 29 May 2003, p. 3.]*

Despite efforts by provinces and territories to improve the delivery of mental health services/supports and addiction treatment, a majority of Canadians suffering from mental illness and addiction still do not seek and receive professional help. Statistics Canada's Canadian Community Health Survey (CCHS), Cycle 1.2 on Mental Health and Well-Being, found that only 32% of those suffering from mental illnesses and substance use disorders saw or talked to a health professional during the 12 months prior to the survey.[374] These professionals included either a psychiatrist, a family physician, a medical specialist, a psychologist or a nurse.

When individuals did see a health professional for mental illnesses or alcohol or drug use and abuse, family physicians were most often consulted. Nearly 26% of those individuals surveyed consulted a family physician; some 12% consulted a psychiatrist, and 8% a psychologist. About 10% saw or talked to a social worker.

The CCHS also showed that adolescents and young adults (15 to 24 years old) were the least likely of all age groups to use any resources for mental illness and addiction than other age groups, although they exhibited higher prevalence rates for mental disorders. Only 25% of affected adolescents and young adults reported having consulted a professional or using other assistance during the previous year.

In his submission to the Committee, Phil Upshall, President of the Canadian Alliance on Mental Illness and Mental Health, enumerated the various factors that lead to unmet needs in mental health services/supports and addiction treatment:

> *"Why do people not receive treatment and, most likely, the other services they require?*

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[374] Statistics Canada, "Canadian Community Health Survey: Mental Health and Well-Being", *The Daily*, 3 September 2003.

- *In part, it is due to a general lack of awareness in the Canadian population of mental illness, or a lack of understanding of the symptoms of mental illness.*

- *Stigma stands in the way – the fear of having a mental disorder continues to be strong.*

- *Services are scarce. Governments choose to make their health investments in narrowly defined biomedical services at the expense of services for the mentally ill and those with psychological complications in physical illness and disability.*

- *Not all services are available to all Canadians. Only those with average to above average incomes can afford private practice services, and the mentally ill are often at the other end of the spectrum. They make up a disproportionately large percentage of marginalized populations – those without adequate income, housing or support systems to meet their basic needs.*

- *On the part of the medical community, low awareness and understanding of the symptoms of mental illness, and time constraints come into play."*[375]

Dr. Donald Addington, Professor and Head, Department of Psychiatry, University of Calgary, recommended the establishment of a patient charter that would establish standards for access to mental health services in primary health care, specialized mental health services and acute care.[376] In Ontario, the Champlain District Mental Health Implementation Task Force (2002) also recommended the creation of a "Provincial Mental Health Patients' Charter of Rights". The preamble of the proposed provincial patients' charter of rights stated:

> *People living with mental illness are entitled to the full range of rights and privileges as citizens of Canada, including the right to health care, income maintenance, education, employment, safe and affordable housing, transportation, legal services, and equitable health and other insurance, and are not limited to the rights listed in this Charter.*[377]

This charter would not be limited to mental health services but would also encompass broader social supports. More precisely, the proposed charter included, for example:

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375 Phil Upshall, President, CAMIMH, Brief to the Committee, 18 July 2003, p. 8.

376 Dr. Donald Addington, Professor and Head, Department of Psychiatry, University of Calgary, Brief to the Committee, 29 May 2003, p. 3.

377 Champlain District Mental Health Implementation Task Force, « Consumer Charter of Rights for Mental Health Services", in *Foundations for Reform*, Section 3.1.4, Ontario, December 2002.

- Mental heath services that are safe, secure, evidence-based, timely, culturally appropriate and relevant to the individual's needs;
- Services and supports that encourage the involvement of individuals with mental illness and addiction and are based on the principles of recovery, self-help and independent living and functioning;
- Treatment that is respectful of relevant legislation (Mental Health Act, Canadian Charter of Rights and Freedoms, etc.);
- Respect for privacy and informed choices.

Other witnesses suggested some form of "mental health equitable act", a piece of legislation intended to bridge the gap between physical illnesses and mental disorders in terms of public coverage and the services provided. Still, others supported the need for a "mental health advocate", a contact person for individuals experiencing difficulty in accessing needed mental health services and supports. A mental health advocate existed for some time in British Columbia, but the position was eliminated when the Ministry of State for mental illness and addiction was created.

8.2.7 Early Detection and Intervention

The high level of unmet needs in the field of mental illness and addiction underscores the importance of early detection and intervention. As a matter of fact, numerous witnesses stressed that early intervention – which encompasses detection, assessment, treatment and supports – can interrupt the negative course of many mental disorders and lessen long term disability. New understanding of the brain indicates that early detection and intervention can sharply improve outcomes and that long periods of abnormal thoughts and behaviour have cumulative effects that can limit a person's capacity for recovery. For example, the Schizophrenia Society of Canada stated:

> *For most diseases, the earlier they are detected and treated the better the expected outcome is for the person affected by the illness. (…) Unfortunately, because of a lack of public and professional knowledge about the symptoms, stigma and denial of the illness, many people delay seeking treatment. It is estimated that half of the people with schizophrenia go for an average of about 2 years before they receive a diagnosis and treatment after first manifesting symptoms.*
>
> *(…)*
>
> *Research has shown that the longer the psychotic symptoms are left untreated the worse the long term prognosis. There is greater evidence of brain damage in persons who experience long, untreated psychotic episodes compared to those who experience shorter, more efficiently treated episodes. In addition to longer periods of non-treatment causing more evidence of brain damage, the person is more likely to lose employment or*

educational standing, lose friends and interpersonal skills, and is more likely to run afoul of the law due to the symptoms of the illness.[378]

The benefits of early intervention extend to numerous mental illnesses and to individuals of all age groups. Without early intervention and treatment, child and adolescent disorders frequently continue into adulthood. If the system does not appropriately screen and treat them early, these childhood disorders are likely to persist and lead to a downward spiral of school failure, poor employment opportunities, and poverty in adulthood. No other set of illnesses damage so many children so seriously.

Currently, no agency or system is clearly responsible or accountable for children and adolescents suffering from mental disorders. They are invariably involved with more than one specialized service system, including mental health services, special education, child welfare, youth justice, addiction treatment, and health care.

Schools are where children spend most of each day. While schools are primarily concerned with education, good mental health is essential to learning as well as to social and emotional development. Because of this important interplay between mental health and academic success, schools should be partners in the mental health care of children.

Early intervention is also essential to reduce the pain and suffering of children, adolescents and adults who have concurrent disorders (mental illness and addiction). Too often, these individuals are treated for only one of the two – if they are treated at all. If one disorder remains untreated, both usually get worse and additional complications often arise, including the risk for other medical problems, unemployment, separation from families and friends, homelessness, incarceration, and suicide. The Committee was told that few providers or systems that treat mental illness or addiction adequately address the problem of concurrent disorders.

Early intervention should occur in readily accessible settings such as primary health care settings and schools and where a high level of risk for mental illness exists, such as youth justice and child welfare services. A coordinated approach is necessary together with training the school workforce to screen for and recognize early signs of mental illness; training primary health care providers; and eliminating barriers to publicly funded heath care insurance, particularly for psychology services.

8.3 MENTAL HEALTH LEGISLATION

In addition to their primary responsibility for delivering mental health services and addiction treatment within their jurisdiction, provinces and territories are responsible for enacting mental health legislation. Such legislation governs the provision of psychiatric treatment to individuals who are severely afflicted by mental illness and who are unable to seek out and accept needed care. At the present time, each province and territory has its own mental health act, except Nunavut in which the Northwest Territories law applies.

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[378] Schizophrenia Society of Canada, Brief to the Committee, 2004, p. 5.

All provincial and territorial mental health legislation defines criteria for involuntary admission to hospital for psychiatric treatment, treatment authorization and refusal, conditional leave, and review and appeal procedures. Without compulsory hospital admission and psychiatric treatment, individuals who will not accept voluntary treatment are abandoned to the consequences of their untreated illness. Individuals affected by untreated mental disorders have a high mortality rate and higher lifetime disability rates than those affected by most physical illnesses.

Mental health legislation is also meant to reflect a balance between the rights and dignity of the individual, the protection of society, and society's concern to help those not able to help themselves. In fact, all provincial and territorial legislation must comply with the *Canadian Charter of Rights and Freedoms*. The pertinent sections of the *Charter* are sections 7, 9, 12, 15, as well as section 1. Under section 7, an individual cannot be deprived of life, liberty or security of the person unless that deprivation is in accordance with the principles of fundamental justice; under section 9, a person is guaranteed the right not to be arbitrarily detained or imprisoned; under section 12, a person has the right not to be subjected to cruel and unusual treatment or punishment; and, under section 15, every person is equal under the law and has the right not to be discriminated against on the basis of mental disability. Although the *Charter* guarantees certain rights under the sections mentioned, a qualification under section 1 serves to limit the absolute scope of those guarantees. Under section 1, *Charter* rights are subject to reasonable, justifiable limits. Thus, a court may decide that the violation of a right that is guaranteed under the *Charter* is reasonable and therefore justified in today's society.[379]

> **While compulsory treatment will usually restore someone's freedom of thought from a mind-controlling illness and restore their liberty by releasing them from detention, their feelings of autonomy and legal and civil rights may be impacted. For this reason, it is necessary for legislation to balance all their needs and those of society as a whole.**
> ***[Gray, Shone and Liddle (2000), Canadian Mental Health Law and Policy, p. 5.]***

In 1984, prompted by anticipation that much of existing mental health legislation was susceptible to possible challenge under the *Charter*, a "Uniform Mental Health Act" was developed by a working group established under the Uniform Law Conference as a model for provincial mental health legislation. The working group consisted of a lawyer and a senior mental health official from each participating province and territory. The Uniform Mental Health Act was adopted by Uniform Law Conference representatives in 1987. The ensuing principles form the essence of the proposed Uniform Mental Health Act:

- A system that promotes voluntary admission and treatment with informed consent is preferred to compulsory services;
- Where there is no alternative to involuntary detention and treatment which limit a person's liberty or right to make decisions, these limitations must conform with the Charter;

[379] Maureen Anne Gaudet, Mental Health Division, Health Services Directorate, Health Programs and Services Branch, Health Canada, *Overview of Mental Health Legislation in Canada*, 1994, p. 4.

- A range of appropriate treatment options, including the least restrictive and intrusive alternatives, are offered and explained to the person;
- The duty of confidentiality of information in the medical file/record is heightened by the vulnerability of mentally-ill persons and the potentially severe consequences of improper release of such information;
- The patient has the right to view, for purposes of accuracy, documents gathered for the purpose of his/her medical treatment;
- If a person's rights and freedoms are affected by legislation, an independent body or a court can review the decision to determine whether or not the decision was reached fairly.[380]

Although the Uniform Mental Health Act was never implemented as such in each province and territory, many jurisdictions have enacted legislation which conforms with its fundamental principles. There remain, however, significant differences in the provisions of the relevant mental health statutes among the various jurisdictions. These differences can have profound effects on individuals with severe mental illness, many of whom may not receive timely needed treatment. They can also create significant ethical dilemmas for psychiatrists. Gray and O'Reilly (2001) pointed to the following major disparities:

Mental health legislation can be a critical factor in determining whether a person who is severely afflicted by mental illness does or does not receive psychiatric treatment and whether this treatment occurs in a timely fashion.
[Gray and O'Reilly, "Clinically Significant Differences Among Canadian Mental Health Acts", Canadian Journal of Psychiatry, Vol. 46, No. 4, May 2001, pp. 315-321.]

- In some jurisdictions, involuntary admission criteria stipulate that a person must be likely to cause serious physical harm to himself/herself or others (Alberta, Nova Scotia, Northwest Territories and Nunavut). In the other jurisdictions, the criteria for involuntary admission also include the potential of non-physical (mental) harm. The criterion which limits involuntary admission and treatment to physical harm raises ethical issues for psychiatrists, who may see a patient who is extremely distressed because of a psychotic illness but who is not likely to be dangerous (physically) to himself/herself or others. In such cases, while psychiatrists know that treatment would be quickly effective and would relieve suffering, they can neither hospitalize nor treat the affected person. As a result, some individuals with severe mental illness and in need of psychiatric treatment will not receive timely care. According to Gray, Shone and Liddle (2000): "The rise in the number of people with mental illness in prisons and homeless on the streets is blamed in part on laws restricting involuntary admission to the physically dangerous."[381]

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380 Maureen Anne Gaudet (1994), pp. 17-18.

381 John E. Gray, Margaret A. Shone and Peter F. Liddle, *Canadian Mental Health Law and Policy*, 2000, p. 5.

- Following involuntary admission, some jurisdictions do not allow the individual to refuse treatment (British Columbia, New Brunswick, Newfoundland, Québec and Saskatchewan)[382]; these provinces use an appointed officer of the state to authorize treatment (either the attending physician, the director of a psychiatric unit, a tribunal or the court). The other jurisdictions do allow a refusal, that may be overruled in the individual's best interests by a substitute decision-maker (either a guardian, relative, public trustee, review board or court). Still, three other jurisdictions (Ontario, Northwest Territories and Nunavut) honour a previously expressed wish not to be treated, even if that prolongs detention and suffering. All jurisdictions provide for a board or panel to review the validity of involuntary hospitalization. When the process for obtaining treatment authorization involves a tribunal, the court or a substitute decision-maker, there may be delays lasting a few days, months or even years before treatment can be provided.

> **Court processes can delay treatment of involuntary patients inordinately. Unfortunately, treatment must be stopped according to the Ontario Health Care Consent Act, as soon as a person appeals to the court. One study showed that where people appealed to the court, treatment was stopped for an average of 253 days. This means that people were detained against their will for over 8 months, causing undue anguish for the individual, the family and wasting a significant amount of taxpayer's money. A simple change to the law could remedy this problem.**
> ***[Schizophrenia Society of Canada, Brief to the Committee, 2004, p. 9.]***

- All jurisdictions recognize that compulsory treatment in the community is a less restrictive option compared to involuntary admission and treatment in hospital. Accordingly, provincial/territorial mental health acts contain provisions that authorize conditional leave from hospital or community treatment orders (CTOs). The conditional leave provisions authorize an involuntary patient to be discharged in the community; the patient remains under the authority of the hospital but is continuing his/her treatment there. Under the CTO (Saskatchewan and Ontario), the individual is not an involuntary patient but is put on the order for the purpose of compulsory treatment while living in the community. CTOs are intended to reduce the "revolving door syndrome", make hospital beds available to others and assist with integration into the community. For CTOs to be effective, however, the services and supports required to support the conditions must be available. A major criticism of CTOs is that the necessary services are not available out of hospital and, thus, individuals will fail in the community and be hospitalized. A similar criticism is that hospitals will prematurely discharge someone on leave and "dump" him/her on the community. Only four provincial mental health acts (British Columbia, Manitoba, Ontario and Saskatchewan) do not allow a person to be on CTO unless appropriate supports exist in the community.

It is clear that psychiatric management of individuals with severe episodes of mental illness differs greatly depending on where affected persons live in Canada. In some jurisdictions,

[382] In some cases, however, the patient may choose to have the court order the hospital to suspend treatment.

where individuals with severe mental disorders are admitted to hospital and treatment starts promptly, there is a good chance for their returning to "normal" daily activities. In other jurisdictions, many months, if not years, may elapse before an individual's mental health deteriorates to the point where he or she is deemed to be at risk of inflicting serious bodily harm on himself/herself or on others, sufficient to warrant involuntary hospitalization. Even when hospitalized, treatment may be delayed for months or years in jurisdictions in which its initiation is prevented while an appeal is outstanding or those concerned are bound by a previous, capable, applicable wish not to be treated.

In their review of provincial and territorial mental health legislation, Gray and O'Reilly (2001) commented:

> *It is of considerable concern that such disparities of practice exist among Canadian provinces and territories. There is an increasing body of evidence that the duration of untreated psychosis is correlated with a poor prognosis and that early intervention may prevent progression of the underlying disease process. Moreover, it is also clear that psychosis occurring at a young age can interfere with the completion of such important developmental tasks as schooling, vocational training, and psychosocial treatment. (…) [t]here is evidence (…) that higher rates of homelessness, violence, victimization, and criminalization occur when individuals with a mental illness are not treated than when they are treated. Conditional leave and community treatment order measures are now common in Canadian jurisdictions and are becoming widespread in other countries. They have been shown to effectively reduce hospitalization and to facilitate treatment adherence.*[383]

Should more uniformity among the various provincial and territorial mental health legislation be encouraged? Do disparities in mental health law reflect diverging views on the balance between protection of vulnerable persons, individual rights and freedom, and public safety? Gray, Shone and Liddle (2000) eloquently pointed out that, ultimately, mental health legislation is a matter of societal values:

> *Society must ask itself whether, in the name of freedom, people with a treatable brain illness who are escaping delusional enemies should be left suffering and homeless because they are not physically dangerous. Does society value the "right to be psychotic" to the degree that it should allow people to refuse treatment and, therefore, stay detained and warehoused at great public expense for long periods of time, putting themselves and others at risk of serious harm? Or should society keep people in hospitals when, with appropriate legislation, they could be at home in the community? Does society prefer to have people functioning in the community because they are legally required to take treatment or does it*

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[383] John E. Gray and Richard L. O'Reilly, "Clinically Significant Differences Among Canadian Mental Health Acts", *Canadian Journal of Psychiatry*, Vol. 46, No. 4, May 2001, p. 320.

want these people to have repeated psychotic episodes and involuntary hospitalizations? A compassionate and just society must weigh these options including concerns for minimizing state intrusion in people's lives.[384]

8.4 COMMITTEE COMMENTARY

All provinces and territories have undertaken the reform and renewal of their mental health care and addiction treatment system. Some jurisdictions are more advanced than others, but all share similar goal and principles. Similarly, most provinces face similar challenges and barriers to improving the provision of mental health services and supports and addiction treatment.

The Committee concurs with witnesses that the "silo philosophy" of policy planning and delivery of mental health services/supports and addiction must be addressed, through better integration, partnerships and collaboration. This is a critical step towards the development of a truly effective and genuine mental health and addiction system.

We also agree with witnesses that individuals with mental illness and addiction and non-governmental organizations must participate in the reform of the system. The development of a seamless system will only occur with the benefit of their first-hand experience and knowledge.

Achieving a truly seamless system of mental health services/supports and addiction treatment that is oriented to individuals with mental illness and addiction also requires tackling numerous challenges related to human resource planning and primary health care reform. In addition, more emphasis must be placed on early detection and intervention. In particular, the unique needs of children and adolescents must be addressed in a timely fashion.

The Committee also agrees that individuals living with severe mental disorders are particularly vulnerable and that, accordingly, the provision of mental health services and addiction treatment must reflect an appropriate balance between the rights of these individuals and the role of society in caring compassionately for them. It is important to decide whether the current disparities found in mental health legislation across the provinces and territories require formal review.

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[384] John E. Gray, Margaret A. Shone and Peter F. Liddle, *Canadian Mental Health Law and Policy*, October 2000, p. 358.

CHAPTER 9: MENTAL ILLNESS AND ADDICTION POLICIES AND PROGRAMS: THE FEDERAL FRAMEWORK

Given the level of burden of mental health issues and mental illness on society, Canadian governments can no longer afford to ignore reality. The time has come to redress historical imbalances. Canada can only achieve the holistic vision of mental health (…) if it addresses complex interrelated issues in a coordinated fashion. What is needed now is collaborative national leadership in a national action strategy. We hope that the federal government will embrace this challenge. As citizens, we all serve to benefit.
[Canadian Mental Health Association, Brief to the Committee, June 2003, p. 29.]

INTRODUCTION

This chapter examines the role and responsibility of the federal government in developing policies and programs in the field of mental health, mental illness and addiction. It also outlines various federal initiatives relevant to the development of an overall framework for mental health, mental illness, and addiction. In doing so, it attempts to separate the initiatives of the federal government for populations directly under its jurisdiction from others with a broader national focus involving multi-jurisdictional issues, notably those of primary concern to Canada's provinces and territories.

Section 9.1 provides an overview of the direct and indirect roles of the federal government in mental health, mental illness and addiction. Section 9.2 describes and assesses the direct role of the federal government with respect to the specific population groups that fall under its responsibility, including First Nations and Inuit; federal offenders; veterans and the Canadian Forces; Royal Canadian Mounted Police; and federal public servants. Section 9.3 examines federal interdepartmental coordination relevant to its direct role in mental health, mental illness and addiction. Section 9.4 reviews the roles and responsibilities of the federal government from a national perspective (indirect role); it also examines the legal and financial levers available to influence policy in the field of mental health, mental illness and addiction. Section 9.5 provides a general assessment of some federal policies and programs affecting the delivery of mental health services, addiction treatment and social supports. Section 9.6 discusses the potential for a national action plan. Section 9.7 examines mental health, mental illness and addiction from a population health perspective. Section 9.8 contains the Committee's commentary.

9.1 DIRECT AND INDIRECT ROLES OF THE FEDERAL GOVERNMENT

To provide a "picture" of the extent of the federal government's role in mental health, mental illness and addiction, the Committee's researchers searched the federal consolidated statutes and regulations using the terms "addiction", "disability", "mental disorder", "mental health", "mental illness", and "substance abuse". Table 8.1 provides the list of federal legislation that makes reference to these terms.

It appears clearly that the federal government has a role on two fronts in mental health, mental illness and addiction. On one front, it is *directly* responsible for specific groups of Canadians. According to the 2003 Canada's Performance Report to Parliament: "The federal government provides primary and supplementary health care services to approximately 1 million eligible people – making it the fifth largest provider of health services to Canadians. These groups include veterans, military personnel, inmates of federal penitentiaries, certain landed immigrants and refugee claimants, serving members of the Canadian Forces and the Royal Canadian Mounted Police, as well as First Nations populations living on reserves and the Inuit."[385] In addition, the federal government is a major employer with management of a large workforce with particular health-related concerns.

On the second front, the federal government is expected to bring a national perspective to the social policy field that includes mental health, mental illness and addiction. This is an *indirect* role incorporating broad responsibility to oversee the national interest of all Canadians. It discharges this responsibility in several ways, including funding transfers to the provinces, surveillance activities and data collection, funding and performance of research and development activities, drug approval process, the provision of income support and disability pension provisions for affected Canadians, social programming such as housing initiatives, funding the criminal justice system, and the operation of a number of programs to promote overall population health and well-being.

[385] Treasury Board of Canada, Canada's Performance 2003 – Annual Report to Parliament, Ottawa, 2004, p. 30.

TABLE 9.1

FEDERAL LEGISLATION WITH RELEVANCE TO MENTAL HEALTH, MENTAL ILLLNESS AND ADDICTION

Canada Elections Act
Canada Pension Plan
Canada Student Financial Assistance Act
Canada Student Loans Act
Canadian Centre for Occupational Health and Safety Act
Canadian Centre on Substance Abuse Act
Canadian Forces Superannuation Act
Canada Health Act
Canadian Human Rights Act
Canadian Institutes of Health Research Act
Controlled Drugs and Substances Act
Corrections and Conditional Release Act
Criminal Code
Department of Health Act
Emergencies Act
Excise Tax Act
Extradition Act
Federal-Provincial Fiscal Arrangements Act
Food and Drugs Act
Income Tax Act
Members of Parliament Retiring Allowances Act
Parliament of Canada Act
Pension Act
Pension Benefits Standards Act
Personal Information Protection and Electronic Documents Act
Privacy Act
Public Service Employment Act
Public Service Superannuation Act
Royal Canadian Mounted Police Superannuation Act
Supplementary Retirement Benefits Act
Vocational Rehabilitation of Disabled Persons Act
War Veterans Allowance Act
Youth Criminal Justice Act

Source: Law and Government Division, Library of Parliament.

In both roles, any consideration of a framework for mental health, mental illness and addiction cannot displace the primary responsibility of the provinces/territories for program design and delivery. There is, however, an overriding need to move toward a framework that works for all Canadians regardless of whether they fall under federal or provincial jurisdiction.

The distinction between the federal and the provincial/territorial responsibilities with respect to mental health addiction services has been clearly emphasized by Tom Lips, Senior

Advisor, Mental Health, Healthy Communities Division, Population and Public Branch, Health Canada, when he stated:

> *The federal and provincial-territorial roles and responsibilities differ where mental health and mental illness are concerned. (…) Provincial and territorial governments have primary responsibility for the planning and delivery of health services for the general population. As you know, federal transfer payments contribute to health services delivery. The federal government has a special mandate for health service delivery to certain populations, notably First Nations people on reserve and Inuit. It also undertakes national health promotion efforts. Both levels of government have been involved in health promotion, research and surveillance, and have collaborated to address some service delivery issues, for example, identifying best practices.*[386]

In fact, the range of federal programs and services relevant to mental health, mental illness and addiction is very large. It includes multiple initiatives aimed at specific groups under its direct responsibility and many endeavours to address broader national population concerns. The following sections examine the more specific federal and the broader national perspectives and, where possible, provide some information to assess those program and service activities.

9.2 THE FEDERAL DIRECT ROLE[387]

The following sections identify and assess the programs and initiatives in place for particular groups under direct federal jurisdictional responsibility.

9.2.1 First Nations and Inuit

Aboriginal peoples are defined in the *Constitution Act*, 1982 (section 35) as the "Indian, Inuit and Métis peoples of Canada." Despite this broad constitutional definition, the federal government currently takes responsibility only for Indian people residing on-reserve and specified Inuit. Health Canada estimates that it serves approximately 735,000 eligible First Nations and Inuit people.

The provincial and territorial governments have general responsibility for Aboriginal peoples living off-reserve, including Métis and non-status Indian populations. These groups have access to programs and services on the same basis as other provincial residents. These jurisdictional divisions, in combination with the multifaceted nature of the Aboriginal population in Canada, have created serious barriers to the establishment of a comprehensive plan for the development of a genuine system of mental health, mental illness and addiction.

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386 Tom Lips, Senior Adviser, Mental Health, Healthy Communities Division, Population and Public Health, Health Canada (11:6).

387 The information contained in this section is based on a paper by Nancy Miller-Chenier, *Federal Responsibility for the Health Care of Specific Groups*, Parliamentary Information and Research Services, Library of Parliament, forthcoming.

Over the years, the federal government has made several attempts to address mental illness and addiction in Aboriginal communities. In the early 1990s, the federal department of health, with the assistance of a multi-stakeholder steering committee, produced an "Agenda for First Nations and Inuit Mental Health." It also targeted Aboriginal peoples in broader strategies such as the Drug Strategy, Family Violence Prevention Initiative, and Building Health Communities Initiative. In 1996, the Royal Commission on Aboriginal Peoples drew particular attention to the mental health problems that were linked to poverty, ill health and social disorganization in many communities.

The federal government's response to the Royal Commission, *Gathering Strength – Canada's Aboriginal Action Plan,*[388] was announced in January 1998; it provided a strategy to begin a process of reconciliation and renewal of its relationship with Aboriginal peoples. Two significant initiatives had as their goal to give Aboriginal peoples more autonomy when addressing some of the concerns related to health and mental health. First, in 1998, the federal government funded the Aboriginal Healing Foundation, an Aboriginal-run, non-profit corporation to support community-based healing initiatives of Métis, Inuit and First Nations people on and off reserve directed to those who were affected by physical and sexual abuse in residential schools and to those affected indirectly by intergenerational impacts. Second, in 1999, Health Canada collaborated with several Aboriginal organizations to establish the National Aboriginal Health Organization. Officially incorporated as the "Organization for the Advancement of Aboriginal Peoples' Health", this new organization focuses on priority areas of health information and research, traditional health and healing, health policy, capacity building and public education.

In 2003, $1.3 billion over five years was committed to develop an effective and sustainable health care system for First Nations and the Inuit.[389] In the Throne Speech of February 2004, the federal government made further commitments aimed at ensuring a more coherent approach to multiple issues affecting Aboriginal communities. It promised to set up an independent Centre for First Nations Government, renew the Aboriginal Human Resources Development Strategy, expand the Urban Aboriginal Strategy, and establish a Cabinet Committee on Aboriginal Affairs.[390]

9.2.2 Assessment Relevant to First Nations and Inuit

At present, Health Canada and Indian and Northern Affairs Canada are the two major federal departments that provide health care, mental health services, addiction treatment and social services to First Nations and the Inuit.

Health Canada, through its First Nations and Inuit Health Branch, is responsible for the following programs that address mental illness and addiction:

- National Native Alcohol and Drug Abuse Program (NNADAP): This program is largely controlled by First Nations communities and organizations; it incorporates a network of 48 treatment centres and community-based prevention programs.

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[388] Indian and Northern Affairs Canada, *Gathering Strength–Canada's Aboriginal Action Plan*, Ottawa, 1997.
[389] Department of Finance Canada, *The Budget Plan 2003*, p. 13.
[390] Government of Canada, *Speech from the Throne, 2004*, pp. 9-11.

- National Youth Solvent Abuse Program: This program delivers, through 10 treatment centres, assessment, inpatient treatment and counseling intended for First Nations and Inuit adolescents with solvent abuse problems.
- Indian Residential Schools Mental Health Support Program: This program provides mental health and emotional support to eligible individuals who are resolving claims against the Government of Canada for abuse(s) suffered while attending Indian Residential Schools. It is provided by Health Canada in collaboration with Indian and Northern Affairs Canada.
- First Nations and Inuit Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) Initiative: This purpose of this initiative, which is part of the Canada Prenatal Nutrition Program, is to raise awareness about FAS/FAE and to deliver programs that provide mental health services to persons at risk and detoxification services for pregnant women at risk, their partners, and their families.
- Non-Insured Health Benefits (NIHB) Program: NIHB provides eligible registered Indians and recognized Inuit and Innu with medically necessary health-related goods and services that are not covered by other federal, provincial, territorial or third-party health insurance plans. These benefits complement provincial/territorial insured health services and include drugs, medical transportation, dental care, vision care, medical supplies and equipment, crisis intervention and mental health counseling.
- Aboriginal Head Start on Reserve: This initiative is designed to prepare young First Nations children for their school years, by meeting their emotional, social, health, nutritional and psychological needs. This initiative collaborates with Health Canada's Brighter Futures and Building Healthy Communities programs. Additional collaboration involves Human Resources Development Canada's Child Care Initiative and the Department of Indian and Northern Affairs' Kindergarten program, both at national and local levels, to ensure that Aboriginal Head Start on Reserve fills gaps and complements existing programs.[391]

At Indian and Northern Affairs Canada, social policy and programs include Child and Family Services, Social Assistance, Adult Care, the National Child Benefit program and other social services that address individual and family well-being. All have components relevant to mental health. Specific programs addressing mental illness and addiction include:

- Aboriginal Suicide Prevention Program: This program, which is provided in collaboration with the RCMP, teaches young adults and community caregivers how they can help prevent suicides. Participants are selected by elders and other Aboriginal community leaders.
- Aboriginal Shield Program: This program is provided in collaboration with the RCMP; it offers education on substance abuse to Aboriginal communities. The program assists Aboriginal and non-Aboriginal police officers as well as community leaders, health care workers, teachers and youth leaders.
- Family Violence Prevention Program: The program provides operational funding to shelters located in First Nations communities. It also funds community-based family

[391] Health Canada, *Report on Plans and Priorities, 2003-2004, Estimates*.

violence prevention programs that aim to prevent incidents of family violence on reserves.[392]

Witnesses told the Committee that federal programs addressing mental illness and addiction in First Nations and Inuit communities do not adequately address the needs of Aboriginal peoples. For example, Dr. Cornelia Wieman, Psychiatrist from the Six Nations Mental Health Services (Ohsweken, Ontario), talked about the psychiatric counseling sessions available under Health Canada's Non-Insured Health Benefits Program:

> *[Under NIHB], the limit is 15 sessions with the possibility of renewing for a further 12. A total of 27 sessions for many people is not sufficient to help them adequately address their mental health concerns. The mandate of the NIHB program is to provide support for clients in crisis or who cannot access counseling by other means. That counseling could be from an outpatient psychiatric clinic or health service that is funded by the provincial health care system. They could also pay for private counselling.*
>
> *The vast majority of my patients live on a limited income and would not be able to pay for private counseling. As a result of transportation and access issues, many are also not able to access counseling services in smaller communities nearby or in larger urban settings such as Brantford or Hamilton. You can tell that these people do fall through the cracks in the system.*[393]

Perhaps more importantly, witnesses identified the existing First Nations and Inuit program "silos" as a significant barrier to accessing needed mental health services and addiction treatment. Services and supports are provided without much collaboration by different departments, or by various departmental directorates or divisions. Moreover, the Committee was told that the current practice is to isolate problems on the basis of their symptoms – addiction, suicide, FAS/FAE, poor housing, lack of employment, etc. – and to design stand-alone programs to manage each one. This fragmented approach has had little success. Witnesses told the Committee that, in order to restore the well-being in First Nations and Inuit communities across the country, a significant re-thinking of, and departure from, current practice is needed.

> **Some of the recommendations that the Native Mental Health Association of Canada would like to offer is the elimination of operations of programs for services in what we call silos. Instead of funding for mental health, funding for social services and funding for other issues in the community, we favour more team approaches based on partnerships, so that what is available to a community is integrated and made available and accessible to our clients in a holistic way from the top to bottom — from policy-makers and planners to local governance.**
> ***[Brenda Restoule, Native Mental Health Association of Canada (9:51)]***

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[392] According to information provided on the Website of Indian and Northern Affairs Canada (http://www.ainc-inac.gc.ca/sg/sg4_e.html).

[393] Dr. Cornelia Wieman (9:55).

The Committee was also informed that the fragmentation of services set up to solve interconnected issues is a real problem. In particular, we heard that First Nations and Inuit are poorly served by government program delivery models that stress services to individuals over holistic, more culturally-appropriate, services to communities. For example, Dr. Laurence Kirmayer, Director, Division of Social and Transcultural Psychiatry, Department of Psychiatry, McGill University, stated:

> *Mental health perspectives tend to be focused on the individual and on individual vulnerability and affliction. This kind of data really points to the working of social forces – things that are affecting entire generations of people and we need to conceptualize it in that way. Within this pattern there is individual vulnerability; not everyone is affected the same way by the same adversity. However, the overall high rate suggests that many people are being affected and that there are things that lie outside of the individual that are at play. We have the challenge to characterize social forces and to think about ways of helping people to take that in hand.*[394]

Witnesses also stressed that the "one size fits all" approach to program and service delivery has not met the needs of Aboriginal peoples effectively. By and large, Aboriginal peoples know what their problems are, and are in better position to identify appropriate solutions, and to know what resources should be applied in accordance with community priorities. What this means, in structural terms, is that it would be far preferable for government departments to delegate to Aboriginal communities the authority to customize services and react flexibly to local circumstances. Accordingly, Aboriginal peoples should be supported in their development of their own solutions, rather than having solutions imposed upon them from "outside".

To be successful, community-based initiatives must be accompanied by the development, in parallel, of community capacity adequate to deliver such programs effectively. Witnesses identified a critical shortage – if not absence – of adequately trained mental health and addiction professionals. In this perspective, Dr. Wieman stated:

> *One of the important ways in which access to health services and health outcomes, including mental health, can be improved is by training an increased number of Aboriginal health professionals. Barriers to seeking various mental health services could be overcome and providing more culturally relevant care could be accomplished. The Royal Commission on Aboriginal Peoples in 1996 recommended that 10,000 Aboriginal peoples be trained as health professionals in the next 10 years. We are now only two years away from 2006, and I do not believe that we are anywhere near that goal. Estimates state that there are approximately 150 Aboriginal physicians in this country, most of whom have trained to be family physicians. Off the top of my head, I would estimate the*

[394] Dr. Laurence Kirmayer (9:42).

> *number of Aboriginal specialists at probably less than 25. I am only aware of two other Aboriginal psychiatrists in this country, with a fourth individual graduating from the residency program in Manitoba this June.*[395]

The Committee was also informed that the needs of Aboriginal peoples are complex and that short term approaches often fail. More precisely, short term funding can materially restrict the ability of Aboriginal governments to develop the long term strategies needed to address the needs of their communities. It can take years to develop effective programs, and often, the shorter the time frame of a given project, the less potential there is for it to be effective.

There was also a general consensus among witnesses that the current funding levels for mental health services and addiction treatment in First nations and Inuit communities are inadequate. Brenda Restoule, Psychologist and Ontario Board Representative, Native Mental Health Association of Canada, explained:

> *Current funding is already inadequate, at best, and does not meet the needs of the community and its members. Since the funding formula is based on population size, many communities receive a small amount of funding, making it difficult or, in many cases, impossible, to deliver mental health counselling and intervention services. Most communities must use their funding to establish mental health promotion and mental illness prevention programs. Although these types of programs are needed, the funding does not allow for a continuum of care that is desperately needed for First Nation communities.*
>
> *(…)*
>
> *The funding is so low for the salary of mental health workers that professionals such as social workers, psychologists and psychiatrists often do not find it desirable to work in First Nation communities.*[396]

The Committee was informed that some provinces have integrated Aboriginal issues within their mental health strategies. To be truly successful, then, federal initiatives for Aboriginal mental health either on reserve or off-reserve should harmonize with the relevant provincial mental health plans and implementation strategies.[397]

To sum up, federal and provincial programs directed to Aboriginal mental health, which focus on individuals or specific aspect of an issue, have been criticized for operating with a silo mentality that precludes their smooth coordination with other programs. The result is an hodge-podge of similar programs, different tiers of service delivery and a complex array

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[395] Dr. Cornelia Wieman (9:55-56).

[396] Brenda Restoule (9:49).

[397] According to Ray Block, CEO, Alberta Mental Health Board, Brief to the Committee, 28 April 2004, p. 9.

of funding mechanisms that is bewildering to the individuals they are intended to serve and their families and communities. Ideally, a holistic or global approach would entail government departments pooling their resources so that interconnecting factors such as health, education, housing, and employment needs of individuals, families and communities could all be met or at least alleviated in a planned, structured and integrated way. Horizontal government initiatives would assist Aboriginal communities to plan and coordinate services better.

> **The ways in which [mental health issues] have been addressed on behalf of Aboriginal people have not worked well. One of the results is that Aboriginal people are significantly over-represented in the criminal justice system and in the child welfare system. Aboriginal people have a significantly worse well-being and health status than other Canadians. We have heard from community members that that status will not change until we are able to focus on those communities rather than on individuals.**
> ***[Ms. Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health, CIHR (16 :10)]***

From a financial perspective, the lack of coordination often results in expensive and unnecessary program duplication. An environmental scan is required to determine what programs exist, where there is duplication across departments and organizations, where there are significant gaps in programming, as well as how best to maximize resources.

9.2.3 Offenders under the Federal Correctional System

Inmates in federal correctional institutions and others under the federal correctional system, those offenders who are sentenced to two years or more of incarceration, constitute another significant group of Canadians under federal health-related responsibility. Currently, Correctional Service Canada (CSC) manages about 12,600 inmates and 8,500 offenders on conditional release under parole officer supervision.[398] The quality of mental health services and addiction treatment for federal offenders is a consideration for CSC but it is secondary to the primary focus of corrections, which is described as the "criminogenic" needs.

Federal offenders come completely under federal responsibility and are not considered as beneficiaries of provincial health care insurance plans. Françoise Bouchard, Director General, Health Services at CSC, observed that the legislative health care mandate of federal corrections is through the *Corrections and Conditional Release Act*, which states:

> *The service shall provide every inmate with essential health care and reasonable access to non-essential mental health care that will contribute to the inmate's rehabilitation and successful reintegration into the community."*[399]

[398] Correctional Service Canada, *Report on Plans and Priorities, 2003-2004*, p. 5.
[399] Françoise Bouchard (7:50).

With respect to mental health care, the goal of CSC is to provide: "a continuum of essential care for those suffering from mental, emotional or behavioural disorders (…) consistent with professional and community standards."[400]

When admitted to the correctional system, each individual is assessed and asked fundamental questions about his/her mental health, mental illness and addiction. Following assessment, a correctional plan is developed for each offender and the offender is directed to either a regular institution or one in which treatment is available.

Over the last decade, CSC has issued specific directives on mental health services and addiction treatment provided to federal offenders. In 1994, directives from the Commissioner were implemented for psychological services, including assessment; therapeutic intervention; crisis intervention; program development, delivery and evaluation.[401] In 2002, directives on mental health services provided standards on assessment, diagnosis and treatment that affect the access to mental health professionals, emergency and community care, as well as transfers to psychiatric care and addiction treatment centres.[402] The same year, the CSC Commissioner issued directives for methadone maintenance treatment (diagnosis and treatment).[403] In 2003, directives for the purpose of offenders who are suicidal or self-injurious were released; they include prevention, assessment and treatment guidelines.[404] Also in 2003, a directive on health services was issued that stipulates that the cost of providing mental health and addiction treatment will be the responsibility of CSC.[405]

In addition to these directives, CSC has worked to develop a comprehensive health care strategy to address both the physical and mental health needs of offenders, including the integration of issues related to drugs and alcohol. Specific work on mental health policy included a 1991 Task Force report on mental health oriented to all offenders, a 1997 National Strategy on Aboriginal Corrections, and a 2002 mental health strategy for women offenders.

At CSC, the Aboriginal Initiatives Branch is mandated to create partnerships and strategies that enhance the safe and timely reintegration of Aboriginal offenders into the community. Aboriginal peoples represent less than 3% of the Canadian population, but account for 18% of the federally incarcerated population. Aboriginal-specific and culturally appropriate programs and services to address the needs of Aboriginal offenders in corrections include initiatives such as Aboriginal Healing Lodges (9 across Canada); Aboriginal Community Residential Facilities (23 across Canada); Aboriginal Community Reintegration Program;

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400 *Ibid.* (7:51).

401 John Edwards, Commissioner, *Commissioner's Directive – Psychological Services*, Correctional Service Canada, 30 December 1994.

402 Lucie McClung, Commissioner, *Commissioner's Directive – Mental Health Services*, Correctional Service Canada, 2 May 2002.

403 Irving Kulik, Assistant Commissioner, *Guidelines – Methadone Treatment Guidelines*, Correctional Service Canada, 2 May 2002.

404 Lucie McClung, Commissioner, *Commissioner's Directive – Prevention, Management and Response to Suicide and Self-Injuries*, Correctional Service Canada, 3 September 2003.

405 Lucie McClung, Commissioner, *Commissioner's Directive – Health Services*, Correctional Service Canada, 17 March 2003.

Elders working in institutions and in the community; and Transfers of Correctional Services to Aboriginal Communities (5 agreements signed).[406] CSC is also responsible for the "National Strategy on Aboriginal Corrections" (currently being revised) that focuses on Aboriginal programs, Aboriginal community developments, Aboriginal employment/recruitment and partnerships on Aboriginal issues.[407]

Women with particular mental health needs at all security levels may receive treatment in a specialized, separate 12-bed women's unit at the Regional Psychiatric Centre in the Prairies (RPC). This unit serves also as a national mental health resource for Anglophone women. Francophone women may receive treatment at Institute Phillipe Pinel in Montréal (Québec) where CSC has contracted for inpatient treatment services. Furthermore, the "2002 Mental Health Strategy for Women Offenders" provides a framework for the development of mental health services covering a continuum of care. The goal is to apply the elements of the strategy to all offenders and to include crisis intervention, acute care programs, chronic care programs, special needs units, outpatient treatment, consultation services, discharge and transfer planning, follow-up as well as interconnection with other programs and services.[408]

CSC also delivers the "Substance Abuse Program" which consists of a range of institutional and community-based programs that are matched to the severity of the offender's substance abuse problem. The program is cognitive-behavioural in orientation and includes a strong emphasis on structured relapse prevention techniques. The program is also responsible for the provision of methadone maintenance treatment.[409]

9.2.4 Assessment Relevant to Offenders under the Federal Correctional System

Officials from CSC told the Committee that mental health care and addiction treatment are required to: reduce the disabling effects of mental disorders in order to maximize each inmate's ability to participate electively in correctional programs, including their preparation for community release; help keep the prison safe for staff, inmates, volunteers and visitors; and decrease the needless extremes of human suffering caused by mental disorders.[410]

The Committee heard that access to mental health services and addiction treatment, however, requires an enhanced CSC response capacity. CSC has 5 specialized treatment centres[411] spread across the country, but they are not resourced at levels comparable to that of provincial forensic facilities. Although CSC has many psychologists, these are primarily engaged in risk assessment for conditional release decision-making. In addition, there is no

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406 Aboriginal Initiatives Branch, *Aboriginal Offenders Overview*, Correctional Service Canada.

407 Correctional Service Canada, *National Strategy on Aboriginal Corrections*.

408 Jane Laishes, Mental Health, Health Services, Correctional Service Canada, *The 2002 Mental Health Strategy for Women Offenders*, 2002.

409 Correctional Service Canada, *Substance Abuse Program*.

410 Correctional Service Canada, Brief to the Committee, April 2004, pp. 13-15.

411 The Shepody Healing Centre (Atlantic region) with 40 beds; the Archambault unit (Quebec region) with 120 beds; the Regional Treatment Centre (Kingston, Ontario) with 149 beds; the Regional Psychiatric Centre (Prairie region) is a 194 bed facility linked to the University of Saskatchewan through a special agreement; the Regional Treatment Centre in Abbotsford (Pacific region) with 192 beds.

specific training for correctional staff on mental illness and addiction.[412] With respect to the Mental Health Strategy for Women Offenders, the Committee was told that the challenge of this new approach is that women requiring mental health intervention must move to another part of the country to obtain needed services.

Witnesses also talked about the need for better links between the federal and provincial governments and between the justice system and the provincial mental health services system. For example, Ms. Bouchard from CSC stated:

> *There is a need for a comprehensive, inter-jurisdictional strategy for the identification and management of offenders with mental disorders. While we try to do a comprehensive assessment at reception, much still needs to be done in respect of those identifying offenders who have mental health problems early in their sentences. That should also occur within the provincial systems as early as possible.*
>
> *There is a need to have better links between the justice system and the health care system within the provinces. The search for solutions should start before imprisonment for those afflicted with mental health disorders. Within the federal corrections system, work is under way to improve capacities to assess and treat. However, we have no guarantees we will ever have additional resources to do that. We are, right now, conducting a review of our utilization of beds in our treatment centres to maximize and direct them to those who have the most needs. Sometimes that calls for a change of culture between correctional culture and treatment culture, so there is lots of work still to be done.*
>
> *Our last observation is the issue of continuity of care when people are released. This calls for better links between us, at the federal correctional level, and our provincial counterparts and the community mental health care out there. Partnerships are key to address those gaps, but what will be the incentive to create those partnerships?*[413]

The Committee also heard about some discriminatory aspects of the judicial system. For example, Patrick Storey, Chair of the Minister's Advisory Board on Mental Health (British Columbia), stated:

> *For federal offenders, it is difficult to access provincially funded mental health services in the community due to specific provisions of the Mental Health Act of British Columbia. This act is, in itself, discriminatory to this population. It directs that directors of provincial facilities not provide care to people from federal institutions. That is a federal government funding responsibility, and so people who are in federal prison with*

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412 Correctional Service Canada, Brief to the Committee, April 2004, p. 19.

413 Françoise Bouchard (7:54-55).

> *mental illness trying to get a release into the community will not get service from the local mental health centre or from other services, which is intolerable. (…) Federal and provincial correctional authorities and health authorities must work together to address these deficiencies and reduce the discrimination faced by people in conflict with the law.*[414]

In addition, the Committee was told that there is a need to harmonize better the Criminal Code with provincial mental health legislation. The Schizophrenia Society of Canada explained that under the Criminal Code a judge may order a person who is found not fit to stand trial to undertake treatment to make them fit. However, neither the judge nor the Board of Review can order treatment of a person found not criminally responsible based on mental illness to make them well enough to be discharged. The theory is that the provincial mental health acts will do that. In some provinces, however, that does not happen. The Schizophrenia Society of Canada recommended that the federal government should amend the Criminal Code to allow the Review Board to order treatment necessary for the probable release of a person affected by treatable mental illness. In their view, this is preferable to requiring the same person to stay incarcerated for an unreasonable time because the untreated illness makes him/her a significant threat to the safety of the public.[415]

Ms. Bouchard from CSC made some observations about the need for better community supports:

> *Addressing the needs of offenders who require specialized mental health intervention can reduce the "revolving door"' phenomenon. There is what we call a revolving door between corrections, both federal and provincial, but also the community, where often people who are afflicted with mental health disorders find themselves in the criminal justice system. While mentally disordered offenders are often less likely to reoffend – including violently – they are more likely to return to prison due to a breach of their release conditions – often as a result of inadequate support while they are in the community.*[416]

9.2.5 Veterans and Active Members of the Canadian Forces

Veterans Affairs Canada is responsible for delivering health services and pensions and for providing social and economic support to more than 150,000 aging Canadian veterans and members of the Canadian Forces (CF). The main beneficiaries are those veterans and civilians granted a pension or allowance.[417]

The *Canada Health Act* specifically excludes CF members from the definition of "insured persons". Therefore, CF members are not eligible for hospital care and physician services insured under provincial health care insurance plans.[418] The Canadian Forces Health

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[414] Patrick Storey (15:8-9).
[415] Schizophrenia Society of Canada, Brief to the Committee, 2004, p. 9.
[416] Françoise Bouchard (7:54).
[417] Veterans Affairs Canada, *Health Care Program*.
[418] National Defence, *Canadian Forces Health Services*, Fact Sheets.

Services (CFHS) is the designated health care provider for 83,000 Regular and Reserve Forces personnel at home and on deployment. The CFHS provides access to more than 85,000 providers across the country. Atlantic Blue Cross Care has responsibility for program administration and payment.

Veterans Affairs Canada administers Ste. Anne's Hospital, located in Ste-Anne-de-Bellevue, Québec. The hospital provides medical and paramedical services to its residing veterans, in addition to a wide range of recreational and social activities. Ste-Anne's Centre, part of the hospital, provides mental health services to CF members and veterans; it has developed specialized expertise in the fields of post traumatic stress syndrome and dementia.[419] Inpatient and outpatient care are also provided in contract hospital beds, in veterans' homes, and in hospitals of choice.

Veterans Affairs Canada also provides pensions for disability or death and economic support in the form of allowances to various groups. These include: members of the Canadian Forces and Merchant Navy veterans who served in the First World War, the Second World War or the Korean War; certain civilians who are entitled to benefits because of their wartime service; former members of the Canadian Forces (including those who served in Special Duty Areas) and the Royal Canadian Mounted Police; as well as survivors and dependents of military and civilian personnel.[420]

The Department of National Defence is responsible for "Strengthening the Forces", a health promotion initiative designed to assist CF and Regular and Primary Reserve members to take control of their health and well-being. Suicide prevention and substance abuse interventions for tobacco and alcohol are two important components of this initiative. Mental health is an issue of concern within Strengthening the Forces. Beside its focus on active living, injury prevention and nutritional wellness, the initiative includes: "Addiction Free" (alcohol and other drug abuse, tobacco use cessation, problem gambling) and "Social Wellness" (stress management, anger management, family violence prevention, healthy families, suicide prevention, and spirituality).[421]

Health Canada is responsible for occupational health and safety of CF members. The "Canadian Forces Member Assistance Program" is organized by the Workplace Health and Public Safety Program (WHPSP) at Health Canada; it is a 24/7 toll-free telephone service that provides confidential counseling services to help members and their families when they have personal concerns that affect their well-being or work performance.[422]

9.2.6 Assessment Relevant to Veterans and Canadian Forces

Several reports have identified gaps in the care and treatment of CF personnel by the Department of National Defence specifically and, by extension, Veterans Affairs Canada. These included: the McLellan and Stow reports in April 1998, the Goss Gilroy Report in

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419 Veterans Affairs Canada, *Ste. Anne's Hospital*.
420 Veterans Affairs Canada, *Disability Pensions*.
421 National Defence, *Strengthening the Forces*.
422 *Ibid.*

June 1998 and the October 1998 report from the House of Commons Standing Committee on National Defence and Veterans Affairs.[423]

The departments responded with a series of initiatives relevant to mental health. In April 1999, the DND-VAC Centre for the Support of Injured and Retired Members and Their Families opened in Ottawa to provide information, referral and assistance support to former and current CF members and their families. Subsequently, legislative and regulatory reform made access to services and benefits more equitable to all CF members, regardless of whether the injury occurred in Canada or on foreign deployment. In April 2001, Veterans Affairs launched an Assistance Service for former members of the CF and their families who require professional counseling.[424]

Recently, the major mental health focus for Veterans Affairs Canada and the Department of National Defence has been on the needs of CF members and veterans suffering from post-traumatic stress disorder and other operational stress injuries. In February 2004, they jointly announced a Canada Mental Health Strategy for the Canadian military. This strategy creates a network of mental health assessment and treatment facilities, educational forums, continuing education program and research for post-traumatic stress disorder and operational stress injuries.[425]

9.2.7 Royal Canadian Mounted Police

The Royal Canadian Mounted Police (RCMP) is an agency of the Ministry of Public Safety and Emergency Preparedness Canada. In addition to federal policing services for all Canadians, it provides policing services under contract to the three territories, eight provinces (all except Ontario and Quebec), approximately 198 municipalities and, under 172 individual agreements, to 192 First Nations communities. The on-strength establishment of the Force as of January 1, 2004, was 22,239.[426]

The definition of "insured persons" under the *Canada Health Act* excludes members of the RCMP. The administration of health care insurance for the RCMP has been the responsibility of Veterans Affairs Canada since 2003. Veterans Affairs Canada also assumes responsibility for the direct payment of disability pensions for approximately 3,800 RCMP pensioners as well as the provision of health care benefits for approximately 800 retired and civilian pensioners.[427]

9.2.8 Assessment Relevant to Royal Canadian Mounted Police

Information about mental health, mental illness and addiction concerns within the RCMP was not readily available to the Committee.

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423 Veterans Affairs Canada, *Government of Canada's Response to the Standing Committee on National Defence and Veterans Affairs on Quality of Life in the Canadian Forces*, 2001.

424 *Ibid.*

425 Veterans Affairs Canada, *Canada Mental Health Strategy*, Backgrounder, 27 February 2004.

426 Royal Canadian Mounted Police, *About the RCMP*.

427 "Veterans Affairs Canada and the Royal Canadian Mounted Police Partner to Improve Services", RCMP News Release, 17 February 2003.

9.2.9 Federal Public Servants

The federal government is a major employer. Although the size of its workforce diminished between March 1995 to March 2001 from 225,619 to 155,360 employees, it is reported to have grown in the last few years.

In its role as the general manager and employer of the federal public service, Treasury Board oversees benefits available to public servants such as the Public Service Health Care Plan that covers medical benefits and the Disability Insurance Plan that assures a reasonable level of income during periods of long-term physical or mental disability. It has mandated Health Canada to provide occupational health and safety services such as Employee Assistance Programs for Part I, Schedule I, Public Service employers.[428]

The Public Service Health Care Plan (PSHCP) is a private health care insurance plan established for the benefit of federal public service employees, CF members, the RCMP, members of Parliament, federal judges, employees of a number of designated agencies and corporations, and persons receiving pension benefits based on service in one of these capacities. The PSHCP is funded through contributions from the Treasury Board of Canada, participating employers, and the Plan members. The administrator, Sun Life Assurance Company of Canada, is responsible for the consistent adjudication and payment of eligible claims.[429]

PSHCP reimburses participants for all or part of costs they have incurred for eligible services and products, only after they have taken advantage of benefits provided by their provincial/territorial health care insurance plan or other third party sources of health care expense assistance. Eligible services and products are prescribed by a physician or a dentist who is licensed to practice in the jurisdiction in which the prescription is made. PSHCP reimburses eligible expenses on a "reasonable and customary" basis to ensure that the level of charges are within reason in the geographic area where the expense is incurred.[430]

PSHCP covers the cost of visits to a psychologist up to a certain specified limit of maximum eligible expenses. A psychologist prescription covers up to one year of services. The current rate of payment from the plan is about 80 percent of $1,000 per calendar year, covering between 5 and 6 sessions per client.

Under the Long Term Disability Insurance Plan, benefits are payable for up to 24 months in respect of any medically determinable physical or mental impairment which a) results in the withdrawal of any mandatory licence required by the employee to carry out his or her occupation or employment, or b) renders the employee completely incapable of performing substantially all of the essential duties of his or her occupation or employment.[431]

Short term counseling is offered through Employee Assistance Programs (EAP) that can assist people seeking help in juggling personal and work-related demands. A nationwide 24 hour toll-free (1-800) telephone line is operated by qualified and experienced bilingual

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[428] Treasury Board of Canada, *Information for Federal Employees*.
[429] Treasury Board of Canada, *Public Service Health Care Plan – Benefits Coverage and Plan Provisions*, July 2001.
[430] *Ibid.*
[431] Treasury Board of Canada, *Disability Insurance Plan*, November 1993.

counselors; access to counseling to over 600 qualified psychologists and social workers (or equivalent) is also provided. Referrals can also be made for employees with personal or work-related problems to resources within the Public Service or in the community, when appropriate, and follow-up is provided. Federal organizations that are clients of the Employee Assistance Society of North America include: Department of National Defence, Department of Veterans Affairs, Department of Justice, Office of the Auditor General of Canada, Health Canada, Parks Canada, Environment Canada, Citizenship and Immigration, Department of Indian Affairs and Northern Development, Fisheries and Oceans, and the Transport Safety Board.[432]

The services described above do not replace those provided by the Public Service Health Program. Within the Healthy Environments and Consumer Safety Branch at Health Canada, the Workplace Health and Public Safety Program (WHPSP, formerly called the Occupational Health and Safety Agency) is mandated by Treasury Board to provide occupational health and safety services (including psychological services) for Part I, Schedule I, Public Service employers.[433]

In addition, Critical Incident Stress Management Services (CISMS) are available for dealing with traumatic incidents such as the death or serious injury of a co-worker on the job, a mass casualty, a threat, personal assault or other forms of violence in the workplace. Employees in certain occupational groups known as "emergency service workers" (e.g., law enforcement officers, firefighters, nurses and other health care workers, search and rescue teams) are at greater risk of experiencing traumatic incidents. Services include education/prevention, intervention, and evaluation.[434]

9.2.10 Assessment Relevant to Federal Public Servants

Recent studies have explored the issue of stress and the need for the federal government as an employer to make a greater effort to ensure work/life balance and healthy living for its employees. In January 2003, the federally-sponsored National Study on Balancing Work, Family and Lifestyle conducted by Linda Duxbury and Christopher Higgins for Health Canada was released. It confirmed that employed Canadians wanted flexible work schedules, limits on overtime, opportunities for part-time work, telework and family care provisions to help them achieve a better sense of balance in their lives. The study included public (including 8 federal departments) as well as private sector employees and found that public servants take a significant number of "mental health" sick days and spend more on prescription drugs than private sector employees.[435]

Another study conducted in 2002 by the Association of Professional Executives of the Public Service of Canada (APEX) found a significant increase in rates for coronary and cardiovascular diseases (CVD), particularly hypertension, among public employees. It also pointed to other key indicators of health status that demonstrated gradual deterioration. Among respondents, 95% reported sleep disturbances and an average of only 6.6 hours sleep

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432 Treasury Board of Cannda, *Employee Assistance Program*.

433 Health Canada, *Workplace Health and Public Safety Program*.

434 Health Canada, Ibid., "Traumatic Stress Management".

435 Linda Duxbury, Christopher Higgins and Donna Coghill, *Voices of Canadians: Seeking Work-Life Balance*, Health Canada, January 2003.

per night; 15% reported depressed mood; 53% reported high levels of stress, almost twice the rate for the average Canadian of the same gender and age; and 19% reported musculo-skeletal problems related to tension. Overall, the data showed that as a group, public service executives experience stress in the high to extreme range.[436]

Bill Wilkerson, co-founder of the Global Business and Economic Roundtable on Addiction and Mental Health stated that: "As an employer, the public sector needs to look deep within itself," arguing that "we need governments as employers who lead by example in the promotion of mental health and prevention of mental disability." Referring to the APEX study, he noted that "more than fifteen per cent of executives in the public service suffer depression – 50 per cent higher than the national average. (…) For senior civil servants, psychotropic medication is the prescription drug of necessity in 17.5 per cent of all drug utilization."[437]

9.2.11 Landed Immigrants and Refugees

Citizenship and Immigration Canada (CIC) has responsibility for the assessment of landed immigrants and refugees. In the past 10 years, Canada has welcomed yearly an average of some 220,000 immigrants and refugees. A landed immigrant is one who has been granted the right to live in Canada permanently by immigration authorities. Refugees who are accepted to Canada are also landed immigrants. Refugee claimants do not have landed immigrant status; they arrive in Canada requesting to be accepted as refugees.[438]

Those claiming refugee status who are needy or living in a province with a three month eligibility waiting period for coverage under the provincial health care insurance plan can get emergency or essential health services through the Interim Federal Health Program at Citizenship and Immigration Canada (CIC). Landed immigrants arrange their own health care, including private insurance to cover the three month waiting period imposed in four provinces (British Columbia, Ontario, Quebec and New Brunswick).[439]

All applicants for permanent residence in Canada have a medical examination of their physical and mental condition. Based on this examination, applicants may be refused entry into Canada if they have a health condition that is likely to be a danger to public health or safety, or that could be very demanding on health or social services. Departmental information is not specific about possible responses to applicants with mental disorders of any severity.[440]

With the knowledge that newcomers to Canada face tremendous challenges, Citizenship and Immigration Canada has several programs aimed at easing the stress of integrating into Canadian society. The department works with provincial/territorial governments and non-governmental organizations on several initiatives relevant to the positive mental health of immigrants. These include:

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436 APEX, *Study on the Health of Executives in the Public Service of Canada*, 27 November 2002.
437 Bill Wilkerson, *Text of a Speech to the Royal Ottawa Hospital Business Luncheon*, 6 May 2004.
438 Citizenship and Immigration Canada, *Report on Plans and Priorities, 2003-2004*.
439 *Ibid.*
440 *Ibid.*

- Immigrant Settlement and Adaptation Program that funds organizations to provide services such as reception, orientation, interpretation, counselling and job search.[441]
- Host Program that matches new arrivals with Canadian volunteers who offer friendship and introduce them to services in their community.[442]
- Language Instruction for Newcomers to Canada Program that provides basic language instruction to adult immigrants to help them to integrate successfully.[443]

For refugee claimants, the Interim Federal Health Program is available to cover some health care costs. Administered by Citizenship and Immigration Canada, it ensures emergency and essential health services for needy refugee protection claimants and those protected persons in Canada who are not yet covered by provincial health care insurance plans. The 2002-2003 Departmental Performance Report refers to additional funding of $7.6 million for the Interim Federal Health program, but does not indicate the program's original cost.[444] The Report for Plans and Priorities for 2003-2004 refers to the program as a "$50 million federal health insurance program covering emergency and essential health care for refugee claimants."[445] There is no breakdown of particular expenditures that might relate to mental illness or addiction. However, these could be significant, given that many refugee claimants have been victims of torture and other threats to their mental health.

9.2.12 Assessment Relevant to Landed Immigrants and Refugees

No information was readily available to assess federal mental health policies and programs designed for landed immigrants and refugees.

9.3 FEDERAL INTERDEPARTMENTAL COORDINATION RELEVANT TO ITS DIRECT ROLE

In looking at federal government activities with respect to the specific groups under its responsibility, there is little evidence to suggest that there are specific population-targeted strategies, let alone a broad all-encompassing federal strategy applicable to all groups. Efforts are not apparent currently to develop an overall coordinated federal framework with collaboration by all involved departments or agencies. In most cases, there is little indication of a thorough and inclusive population specific strategy for addressing the mental health needs of any of the groups under federal responsibility. The provision of mental health services and addiction treatment and efforts toward mental health promotion and mental illness prevention remain highly fragmented, divided among numerous departments and departmental directorates.

There are, however, two examples of federal interdepartmental efforts to coordinate activities with respect to health care and substance abuse that may provide some lessons for

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441 Citizenship and Immigration Canada, *Immigrant Settlement and Adaptation Program*.
442 Citizenship and Immigration Canada, *Host Program*.
443 Citizenship and Immigration Canada, *Language Training*.
444 Citizenship and Immigration Canada, *Performance Report for the Period Ending March 31, 2003*.
445 Citizenship and Immigration Canada, *Report on Plans and Priorities, 2003-2004*, p. .34.

future efforts to do the same in the specific field of mental illness and addiction. These are the Health Care Coordination Partnership and Canada's Drug Strategy.

9.3.1 Federal Health Care Partnership[446]

The Federal Health Care Partnership, formerly called the Health Care Coordination Initiative, was established in 1994 by a partnership of federal departments that were separately providing health care products and services to specific groups of Canadians. These departments believed that they could lower costs and improve delivery by working together. At present, Veterans Affairs has the lead role with other partners including the Department of National Defence, the RCMP, the Canadian International Development Agency, Correctional Services, Citizenship and Immigration, the Treasury Board Secretariat, Public Works and Government Services, and the Privy Council Office.

The key objectives of the initiative are to negotiate joint agreements with professional associations, suppliers and retailers; coordinate purchases of specific health care supplies and services; improve the competitive environment by identifying alternatives to traditional service delivery; improve information sharing and collective decision making; facilitate joint policy analysis and development; support cooperative development of health and information management across federal jurisdiction; and create joint health promotion activities.

In 2002-2003, the partners jointly negotiated fees, bulk purchases and collaborative policy development that collectively resulted in improved quality of service to clients and $11.6 million in cost savings. Savings of $17.6 million were forecast for 2003-2004. To date however, although there is great potential for joint action, no such activities have been in the field of mental health, mental illness and addiction.

9.3.2 Canada's Drug Strategy

The initial 1987 National Drug Strategy emerged from concern about the abuse of illegal drugs. In 1988, a national non-governmental organization, the Canadian Centre on Substance Abuse, was created by legislation to provide a focus for efforts to reduce the health, social and economic harm associated with substance abuse.

In 1992, Canada's Drug Strategy was renewed and combined with the Driving While Impaired (DWI) Strategy. The continued objective was to reduce the harmful effects of substance abuse on individuals, families and communities by addressing both the supply of and demand for drugs. Coordinated by Health Canada (formerly the Department of National Health and Welfare), and involving several other departments, the Strategy sought to enhance existing programs and to fund new ones. Of the $210 million allocated to the initiative, 70% was directed to reducing the demand for drugs through prevention, treatment and rehabilitation and 30% to enforcement and control.

In 1998, the federal government reaffirmed its commitment to the principles of Canada's Drug Strategy. Health Canada continued in its lead role and provided the chair for the

[446] Treasury Board of Canada, *Federal Health Care Partnership*.

Assistant Deputy Ministers' Steering Committee on Substance Abuse and interdepartmental committees such as the Interdepartmental Working Group on Substance Abuse. The federal departments involved in the Strategy extended beyond those with direct responsibility for the health of Canadians; they included others with broader national and international relevance: Solicitor General, Foreign Affairs and International Trade, Finance, Canadian Heritage, Justice, Canada Customs and Revenue, Transport, Human Resources Development, Status of Women, Indian and Northern Affairs, Canada Mortgage and Housing Corporation, Treasury Board, and the Privy Council Office.

In its 2001 report, the Office of the Auditor General criticized Canada's Drug Strategy for its fragmented approach and called for changes to the organizational culture throughout the federal government to emphasize structures and processes to maximize the benefits of working horizontally. When the comprehensive Drug Strategy for Canada was renewed in May 2003, the federal government committed $245 million and the support of fourteen collaborating federal departments. There will be a report to Parliament on the Strategy's direction and progress in two years.

9.4 FEDERAL INDIRECT ROLE

In addition to its direct federal responsibility, the federal government has a major indirect role in developing a national, long term, cross-jurisdictional, integrated, mental health plan. Although some witnesses claimed that mental health has never been a priority for any level of government, they also stressed their belief that mental health, mental illness and addiction are concerns affecting the entire population of Canada. Therefore, the federal government, the ten provincial governments and the three territories have interconnected roles to play in meeting the health and health care needs of Canadians affected by mental illness and addiction.

There is, however, no centralized departmental capacity, either within Health Canada or any other federal department, or through some form of national structure, to coordinate or respond from a national perspective to the full gamut of mental health, mental illness and addiction issues. Moreover, few resources are devoted to the intergovernmental aspects of a national framework in this area. Currently, work through various federal, provincial and territorial forums is limited to exploring options in shared care initiatives in primary health care reform, homecare proposals, and telehealth. The federal government is sensitive to the need to approach all such issues in a way that respects the federal/provincial/territorial division of responsibilities and the primary responsibility of the provincial and territorial goverments for the provision of mental health services and addiction treatment.

A formal structure – the Federal/Provincial/Territorial Advisory Network on Mental Health – was established on 17 April 1986 to advise the Conference of Deputy Ministers of Health on ways and means of ensuring federal, provincial and territorial cooperation on mental health issues. It was mandated to:

- Consider issues delegated by the Conference of Deputy Ministers of Health, or accepted by a significant number of the provinces as matters where a general

consensus of informed opinion would be helpful, and make recommendations, where appropriate;

- Advise on the development and implementation of policies and programs for mental health services, with the aim of developing a uniformly high level of quality and effectiveness across Canada;
- Provide a forum to assist the provinces and territories in the development, organization and evaluation of mental health services within each jurisdiction;
- Serve as a forum for the presentation and exchange of information, relevant data, current research findings and expert opinion between the federal and provincial governments, universities and treatment settings, on problems of jurisdiction, organization, legislation, service delivery, evaluation and other relevant issues;
- Make proposals for federal, federal-provincial and provincial strategies for mental health promotion, to enhance the mental health status of the population at large and particularly that of children and adolescents;
- Receive reports on current mental health activities and programs at the national level and give advice, direction and support to these, as may be appropriate.[447]

The work of the F/P/T Advisory Network on Mental Health was at the time supported by the Mental Health Division of Health and Welfare Canada. This division was then part of the department's Health Services and Promotion Branch.[448] In the late 1990s, however, the Council of Deputy Ministers of Health withdrew its support for the F/P/T Advisory Network. As a result, it is now difficult to find funding even to bring together mental health policy makers from across the country so that they can share information and develop coherent policies and plans. A number of provinces still continue to participate in the F/P/T Advisory Network, but their work is limited by the funding they can provide themselves. According to Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, the dismantling of the F/P/T Advisory Network on Mental Health:

> *(…) has cut off a major venue for sharing and joint planning. Some jurisdictions continue to get together but struggle with funding. The number of meetings and jurisdictions participating has dropped off over the years. Special projects are funded on a formula basis with Ontario covering the majority of the costs with Health Canada second. Quebec does not participate.*[449]

What then could the federal government do to encourage national coordination, collaboration and partnerships in the field of mental health, mental illness and addiction? There are two different types of levers available – legal (or policy) and financial (or fiscal) – for potential use in the mental health, mental illness and addiction area. While the federal

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447 Health and Welfare Canada, *Mental Health Services in Canada, 1990*, Government of Canada, 1990, pp. 22-23.

448 *Ibid.*

449 Dr. James Millar, Nova Scotia Department of Health Brief to the Committee, 28 April 2004, p. 4.

government has *legal* authority through the power of criminal law, it has used its *fiscal* capacity to influence social policy. Neither lever, however, is well suited to achieve greater uniformity, establish and maintain standards, bring harmonization or establish national initiatives; these require a high degree of intergovernmental contact and willing collaboration.

9.4.1 Legal Levers

The federal government has several legal avenues for application in mental health, mental illness, and/or addiction. Over the years, criminal law, the *Charter of Rights and Freedoms* and human rights have been applied.

The *Criminal Code* has particular sections that relate to mental disorders. For example, a person can be found not criminally responsible for an offence on account of mental disorder. The Court can order the initial part of a custodial sentence to be served in a treatment facility, when an offender is found to be "suffering from a mental disorder in an acute phase" and is in need of immediate treatment.

With respect to addiction, Parliament has used the power of criminal law in several instances. This authority was used to pass laws regulating the sale, distribution and possession of psychoactive substances through the *Controlled Drugs and Substances Act*. The *Tobacco Act* provides for a broad range of restrictions on the composition of tobacco products, the access of young persons to tobacco products, tobacco product labelling, and tobacco product advertisement endorsement and sponsorship. For alcohol, the *Criminal Code* covers driving while impaired and the *Broadcasting Act* and the Code for the Broadcast Advertising of Alcoholic Beverages regulates advertising.

As discussed in the previous chapter, the *Canadian Charter of Rights and Freedoms* guarantees certain legal rights that have application in mental health and addiction. Relevant sections deal with such matters as the right to life, liberty and security and the right not to be subject to cruel and unusual punishment. The Charter also has emerged as a mechanism for the creation of national standards which Canadians can demand that both federal and provincial governments meet.

The *Canadian Human Rights Act* of 1977 provides a process for resolving cases of discrimination in areas of federal jurisdiction. Discriminatory actions and attitudes are discouraged by means of persuasion and education and by ensuring that those who have discriminated will bear the costs of compensating their victims. The Act applies to all federal government departments, agencies and Crown corporations, as well as federally regulated businesses and industries (e.g., banking, transportation and communications).

9.4.2 Financial Levers

Generally speaking, however, the federal government's involvement is essentially fiscal in nature. As long as it does not legislate directly in relation to matters within the provincial/territorial jurisdictions, the federal government has used its taxing and spending power to launch a number of social program initiatives that are national in scope. Restraints on transfer payments to the provinces in the 1990s, however, prompted many provinces to

demand that federal actions taken unilaterally with respect to transfers be replaced with processes involving greater provincial and territorial participation.

The federal spending power forms the basis for the *Canada Health Act* as well as for the current Canada Health Transfer and the Canada Social Transfer. It is the impetus for federal participation/incursion in other social policy areas such as housing and income security. The Canada Pension Plan (CPP), established by legislation in 1965, is another area where federal/provincial involvement. There are other such examples of social policy initiatives, income security for the disabled being one, that can enhance the mental health of all Canadians and, in particular, the quality of life of individuals with mental illness and addiction.

The area of mental illness, however, provides one example where the federal government's constitutional spending power was applied and then withdrawn over the last 55 years. From the National Health Grants of 1948 to the First Ministers' Accord on Health Care Renewal of 2003, federal funding arrangements have significantly affected mental illness and addiction either implicitly or explicitly.

Ambivalence over the place of mental health services in a national health care system was evident for many years the years. The 1948 National Health Grants Program, described as "the first stage in the development of a comprehensive health care insurance plan for all Canada," encouraged "expansion of health services" including those for mental illness.[450] One component of the program – the Mental Health Grant – was used to implement or expand mental health services, to strengthen professional and technical training facilities and to improve the quality and quantity of staff. In 1960-1961, the last year of the grant, some 53% of the funds were allocated to institutions, while 23% went to clinics and psychiatric units, 13% to training and 8% to research.[451]

In 1957, however, the federal government's *Hospital Insurance and Diagnostic Services Act* explicitly excluded psychiatric hospitals, although it did cover psychiatric services in general hospitals. This exclusion was based, at the time, by the view that mental hospitals provided custodial care and, as such, together with tuberculosis hospitals, nursing homes and other long term care institutions, they were not eligible for federal cost-sharing. In 1966, however, with the enactment of the *Medical Care Act*, public coverage was provided for physician services, including those provided by psychiatrists, regardless of setting.[452]

The *Federal-Provincial Fiscal Arrangements and Established Programs Financing Act, 1977* gave each province "block-funding", a federal transfer payment based on its population and paid partly in cash and partly in tax points. This Act, under its definition of "extended health care

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450 Department of National Health and Welfare, *Annual Report for the Fiscal Year Ended March 31, 1948*, Ottawa: King's Printer, 1948, p.77.

451 Health and Welfare Canada, *Mental Health Services in Canada, 1990*, Government of Canada, 1990, pp. 13-15.

452 *Ibid.*

services", listed mental hospitals together with nursing home intermediate care service; adult residential care service; home care service; and ambulatory health care service.[453]

In 1984, the *Canada Health Act* was enacted "to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."[454] Most provisions of the two previous insurance Acts were consolidated in the new law; but one major change related to the new definition of extended care services: all references to mental hospitals was deleted.

In the 1990s, the role of the federal government in health care nationally and by extension its role in mental health was further curtailed as its transfer payments to the provinces and territories were reduced. In 1996, the Canada Health and Social Transfer (CHST) was established, merging the Established Programs Financing (EPF) and the Canada Assistance Plan (CAP); this left the provinces to decide themselves how to allocate their block funding among health care, post-secondary education and social programs.[455]

When departmental legislation established Health Canada in 1996, it provided general guidance for the health minister concerning national health issues. More precisely, the *Department of Health Act* assigned responsibility to the Minister of Health to oversee "the promotion and preservation of the physical, mental and social well-being of the people of Canada."[456] This was interpreted as limiting the Minister to broad programs that promote and preserve mental and social well-being; monitoring mental health conditions or programs; conducting research and/or investigating mental health among other public health issues; and collecting and publishing statistics on mental health.

A turning point occurred in 1999 with the Social Union Framework and the related Health Accord that committed the federal government to increase funding for health care through the CHST, to ensure predictability of funding and to work collaboratively with all provincial and territorial governments to identify Canada-wide priorities and objectives.[457] By 2000, the First Minister's Communiqué on Health contained a pledge to "promote those public services, programs and policies which extend beyond care and treatment and which make a critical contribution to the health and wellness of Canadians."[458] In the 2003 Health Accord, the First Ministers agreed to provide first dollar coverage for a core set of fully portable home care services for community mental health services with access to them based on

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453 *Federal-provincial Fiscal Arrangements and Established Programs Financing Act 1977*, Chapter 10, 1977, Clause 27 subsection 8.

454 Canada Health Act, 1984 (An Act relating to cash contributions by Canada in respect of insured health services provided under provincial health care insurance plans and amounts payable by Canada in respect of extended health care services) Chapter C-6, 1984, Clause 3.

455 The CHST was established through separate budget bills tabled in February 1995 and March 1996. Its operation is governed by the *Federal-Provincial Fiscal Arrangements Act*.

456 *Department of Health Act*, 1996, chapter 8.

457 *A Framework to Improve the Social Union for Canadians*, An agreement between the Government of Canada and the Governments of the Provinces and Territories, 4 February 1999; and *The Federal, Provincial, Territorial Health Care Agreement*, 4 February 1999.

458 News Release, *First Ministers' Meeting Communiqué on Health*, September 2000.

need. The plan is to have a range of services available including case management, professional services and prescribed drugs by 2006.[459]

In addition to assistance with health-related services, the federal government has provided access to other programs to assist individuals with mental disability. For example, in 1961, the federal government agreed to share the cost of the Vocational Rehabilitation of Disabled Persons Program for mentally disabled persons of working age. In 1965, the Canada Pension Plan (CPP) offered disability benefits for a person with severe or prolonged mental disability. In 1966, the Canada Assistance Plan (CAP) offered the provinces 50% of the cost of shareable assistance and welfare services to people with disabilities, including mental disability.[460] Cost sharing under CAP was considered instrumental in establishing community based social services integral to the provision of effective mental health supports in the community.

At present, through its Office for Disability Issues, Social Development Canada is the focal point within the federal government for work on the participation of Canadians with disabilities in learning, work and community life. Its key objectives include fostering policy and program coherence; building the capacity of the voluntary sector; creating cohesive, action-oriented networks and providing knowledge and building awareness. Other players include Canada Revenue Agency. Under the *Income Tax Act*, an individual with a severe and prolonged mental or physical impairment, or a person caring for a person with such impairment, can claim a disability tax credit.

Homelessness is another area in which the federal government used its spending power to facilitate development of a national framework. More precisely, the federal government launched in 1999 the National Homelessness Initiative (NHI), a community-based approach designed to alleviate and prevent homelessness. The initiative involves partnerships with all levels of government, the private sector and the voluntary sector. Its multidisciplinary approach reflects the belief that homelessness has no single cause and that the problem requires interventions in a number of areas, including the provision of shelter, opportunities for employment, mental health care, programs to combat drug abuse and welfare services. It recognizes the diversity of the needs of the homeless and the requirement for "tailored" responses and solutions relevant to specific communities.[461]

While the federal government provides provinces and territories with funding in support of mental health services, social programs, income support and housing, the levels of funding for mental health services, per diem payments for transitional and supportive housing providers, and income assistance for individuals are all within provincial, territorial and municipal jurisdictions.

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459 News Release, *First Ministers' Accord on Sustaining and Renewing Health Care for Canadians*, 23 January 2003.

460 For more details on these federal programs, see William Young, *Disability: Socio-Economic Aspects and Proposals for Reform,* Current Issue Review 95-4E, Ottawa: Parliamentary Research Branch, 1997.

461 Government of Canada, *National Homelessness Initiative*.

9.5 ASSESSMENT OF THE FEDERAL ROLE WITHIN THE CURRENT NATIONAL FRAMEWORK

9.5.1 The *Canada Health Act*

> *(…) when the Canada Health Act was developed, mental health services provided in psychiatric hospitals were excluded. The Act provides that only medically mental health services provided in general hospitals and physician services will be covered by the Act. This significant omission has left those trying to provide mental health services at a serious disadvantage when providing community based services.*
> *[Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health (Brief to the Committee, 28 April 2004, p. 5.]*

As mentioned above and previously, the *Canada Health Act* expressly excludes from its definition of comprehensiveness services provided in psychiatric institutions. Numerous witnesses stated that this omission reinforces an artificial distinction between physical and mental illness and contributes to the stigma and discrimination associated with mental disorders. For example, Dr. Sunil V. Patel, CMA President stated:

> *(…) it is (…) important to recognize the deleterious effect of the exclusion of a "hospital or institution primarily for the mentally disordered" from the application of the Canada Health Act. Simply put, how are we to overcome stigma and discrimination if we validate these sentiments in our federal legislation?*[462]

Dr. Patel recommended that the *Canada Health Act* be amended to include psychiatric hospitals and that federal funding under the Canada Health Transfer be adjusted to provide for these additional insured services.

The Committee also heard that the exclusion of psychiatric hospitals from the *Canada Health Act* generates problems with respect to the principle of portability. More precisely, because psychiatric hospitals are explicitly excluded from the Act, they are not subject to reciprocal billing arrangements between provinces. Ray Block, CEO, Alberta Mental Health Board, stated that:

> *Case management also needs to be considered at a cross-jurisdictional level for those occasions when mental health patients from one jurisdiction need services while in another jurisdiction. Reciprocal arrangements relating to access and payment should facilitate their access to care as well as to the consistency and continuity of that care across jurisdictions. This*

[462] Dr. Sunil V. Patel, President, Canadian Medical Association, Brief to the Committee, 31 March 2004, p. 3.

would be a matter for discussion at a future federal/provincial/territorial Conference of Ministers of Health.[463]

Moreover, numerous witnesses pointed out that many mental health services are provided in the community by providers other than physicians and are thus not covered under the *Canada Health Act*. This is particularly true for services provided by psychologists. In this context, Dr. Diane Sacks, President, Canadian Paediatric Society, told the Committee:

> *(…) currently, the majority of professionals who offer [cognitive behavioural] therapy are uninsured by most provincial health plans. There are trained, regulated professionals that, if society's will was there, could treat many of our children and youth. (…) Having said that, there are professionals who can help make the diagnosis and treat these illnesses, but only if you have money, and lots of it. The waiting list to get the public school system or a community mental health centre to diagnose ADHD in Toronto today is 18 months – that is two full school years. That is if you do not have money. If you happen to have $2,000, I can get you a psychologist within a week or two who will make a diagnosis and, if necessary, lay out for the school an extensive program to help your child succeed. Most employer-run insurance programs cover an average of only $300 for psychology. Most public programs cover zero.*[464]

In its brief, the Centre for Addiction and Mental Health (Toronto) stated that the *Canada Health Act* should apply to more than general hospitals and physicians and should include home care and prescription drugs prescribed outside of hospitals. In the view of the Centre, public funding for the cost of medications would make a tremendous improvement in the lives of many individuals with mental illness who require long term pharmacotherapy. For these individuals, access to medication is key to their ability to maintain employment, housing and the other community connections that support treatment and recovery.[465]

Many witnesses supported the work already underway by First Ministers to expand home care to individuals with mental illness. They contended that any national home care program should encompass both mental illness and addiction.

9.5.2 Federal Funding

Federal transfers to the provinces and territories for the purpose of health care are provided under the Canada Health Transfer (CHT). There has never been any, nor is there now, an identified, specific transfer to any province or territory dedicated to mental health care and addiction treatment. Currently, as a result of the *2003 First Ministers' Accord on Health Care*

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463 Ray Block, CEO, Alberta Mental Health Board Brief to the Committee, 28 April 2004, p. 7.

464 Dr. Diane Sacks, President, Canadian Paediatric Society (13:53-54).

465 Centre for Addiction and Mental Health (Toronto), Brief to the Committee, 27 June 2003, p. 3.

Renewal, the CHT provides funding for acute community mental health care,[466] but no specific proportion of the transfer is expressly designed for this purpose.

The Mood Disorders Society of Canada recommended that federal transfer payments for the purpose of health care should have a portion dedicated specifically to the delivery of mental health care. The Society argued that two conditions should be attached to this funding: 1) provinces and territories should be prevented from reducing their spending on mental health care; 2) ongoing evaluations of provincial mental health care programs should be undertaken to ensure value for money.[467]

Another proposal to raise revenue to support the treatment and prevention of addiction was made to the Committee. Called the "Behavioural Insurance Model", this proposal is based on raising money for the purpose of addiction prevention and treatment through a certain dedicated percentage of revenues generated from behaviour associated with addiction (tobacco, alcohol, gambling).

The Ontario Federation of Community Mental Health and Addiction Programs informed the Committee that a Behavioural Insurance Model was introduced in 1999 by the Government of Ontario to fund an integrated array of services to address pathological gambling. Under this model, 2% of gross revenues from slot machines in provincial charity casinos and race tracks are dedicated to treatment, prevention and research. In 2002-2003, this formula generated approximately $36 million, an amount sufficient to support a comprehensive response to this serious problem.

In his brief, Dr. Wayne Skinner, Clinical Director, Concurrent Disorders Program, Centre for Addiction and Mental Health (Toronto), stated

> *(…) it is important to recognize that a number of behaviours that have addictive liability are regulated by the state, which also derives considerable tax revenue from them. This includes tobacco and alcohol, and more recently gambling. It has been estimated that more than half the revenues from alcohol and gambling come from 10 per cent of people who spend the most money on these activities. This 10 per cent population is the one at highest risk to being addicted to these behaviours. Given that over half of tax revenues from these behaviours are coming from that part of the population that is most vulnerable, government, if only from a crisis of conscience, should challenge itself to develop a proactive strategy toward the prevention, treatment and research of addictive behaviours and their mental health comorbidities. But beyond that, there is strong evidence that social spending to prevent and treat addiction and mental health problems provides an enviable return on investment. It is not unreasonable to expect that more of the revenues*

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466 Acute community mental health care refers to acute care provided in the community to individuals with mental illness who have an occasional acute period of disruptive behaviour; the aim is to prevent or minimize recurrent institutionalization.

467 Mood Disorders Society of Canada, Brief to the Committee, 12 May 2004, p. 7.

that behaviours with addictive potential provide be invested in helping people who are harmed by these behaviours.[468]

9.5.3 The National Homelessness Initiative (NHI)

In his submission to the Committee, Bill Cameron, Director General of the National Secretariat on Homelessness, stated that the NHI addresses mental health issues in two ways through 1) financial support for community initiatives and 2) partnership agenda on research.[469]

The "Horizon Housing Society" is an example of community-based initiatives funded through the NHI; the Society acquired an apartment building in Calgary to be used as transitional housing for individuals with mental illness and addiction who are homeless or at risk of becoming homeless. The research agenda includes issues surrounding the availability and accessibility of mental health services for homeless people, the incidence of mental illness among homeless people and the causal relationship between deinstitutionalization and homelessness. Research under the NHI is also undertaken in partnership with CIHR.[470]

According to Bill Cameron, many mental health services to homeless people end up being delivered in emergency departments. Moreover, the homeless population faces many barriers that impact their access to the mental health services they need. For example, many are unable to make health appointments, and their ability to access coordinated care is impaired by their lack of an address and/or place of contact. In particular, many women with serious mental disorders do not receive needed care, apparently because, in part, they are not perceived to have mental health problems and also because of a lack of services designed to meet the special needs of homeless women.[471]

Mr. Cameron also identified other major gaps in community services and supports directed to the homeless population, including emergency housing, supportive housing, and community-based mental health services.[472] According to Mr. Cameron, safe and affordable housing with individualized supports is a key factor in the in helping the homeless generally, but he stressed that this may not be enough for those with severe mental illness and addiction. Long term supporting facilities such as emergency shelters and supports and transitional housing are necessary to help the chronically homeless. There is also a need for preventative measures such as dedicated affordable housing for individuals discharged from psychiatric institutions and the provision of short term intensive support services to be available immediately to those discharged from acute care hospitals, shelters and jails.[473]

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468 Dr. Wayne Skinner, Clinical Director, Concurrent Disorders Program, Centre for Addiction and Mental Health (Toronto), Brief to the Committee, 2004, p. 6.

469 Bill Cameron, Director General of the National Secretariat on Homelessness, Brief to the Committee, 29 April 2004, p. 1.

470 *Ibid.*, pp. 1-2.

471 Bill Cameron (2004), p. 2.

472 Bill Cameron (2004), p. 3.

473 Bill Cameron (2004), p. 4.

9.6 THE NEED FOR A NATIONAL ACTION PLAN ON MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION

Witnesses told the Committee repeatedly that Canada needs a national action plan on mental health, mental illness and addiction. Many countries have already adopted such a national mental health policy or action plan. For example, in 1992, Australia developed a national mental health strategy to improve the lives of individuals with mental illness; also in 1992, the United Kingdom developed an action plan in five key health areas, one of which was mental health, which established targets for improvement of the health of individuals with mental illness and to reduce the suicide rate; in 1999, the report of the US Surgeon General made a commitment to improve mental health within the United States.[474]

> **Canada has no national framework for mental health. There is no national commitment to mental health services.**
> ***[Dr. James Millar, Nova Scotia Department of Health, Brief to the Committee, 28 April 2004, p. 4.]***

Canada is currently characterized by a serious lack of leadership on mental health, mental illness and addiction which, in the view of many witnesses and the Committee, has created a large void: there is no focus on mental illness and addiction within health care reform initiatives; there is no clear delineation of roles and responsibilities of the various stakeholders. Phil Upshall, President, Canadian Alliance on Mental Illness and Mental Health (CAMIMH), stated:

> *The current status of mental illness and mental health in Canada paints a very bleak picture, beginning with a large void in leadership. (…) no policies and very few processes exist to address mental illness and mental health at a national level in Canada. There is no clear identification of the roles and responsibilities of the government players involved. One of the most significant barriers to securing a national action plan appears to be the division of powers between provinces/territories and the federal government for health and social services. This need not be a hindrance to developing a coherent approach that will meet the needs of Canadians equitably.*[475]

Many witnesses recommended a strong lea
development of a national action plan. T
contributed significantly to the piecemea
addiction, to the development of various
duplication and waste of resources. For e
Mental Health and Physician Services, Nova

> **(…) the piecemeal work being done in isolation by the provinces, territories and advocacy groups is leading to duplication of effort and wasted resources.**
> ***[Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health (7:19).]***

> *Nationally, we are not doing*
> *(…) well. Provinces, individually, have been struggling with providing*

474 See the Committee's second report, Mental Health Policies and Programs in Selected Countries, for a full description of national mental health strategies in Australia, New Zealand, England and the United States.

475 Phil Upshall, President, CAMIMH, Brief to the Committee, 18 July 2003, p. 7.

> *appropriate services and developed various models from the Mental Health Commission of New Brunswick to the Alberta Mental Health Board. The federal government has not provided leadership in developing a national strategy.*[476]

Similarly, Dr. Sunil V. Patel, President, Canadian Medical Association, told the Committee:

> *Canada is the only G8 country without such a national strategy. This oversight has contributed significantly to fragmented mental health services, chronic problems such as lengthy waiting lists for children's mental health services and mental health.*[477]

National leadership on mental illness and addiction is long overdue. The federal government can play a major role in collecting national data, supporting research and knowledge dissemination, and educating Canadians about mental health, mental illness and addiction. Many witnesses stated that the federal government has a key role in addressing the housing, income and employment needs of individuals with mental illness and addiction. Moreover, there is the direct role of the federal government in the provision of mental health services and addiction treatment to Aboriginal peoples, federal inmates, the veterans and members of the Canadian Forces, RCMP and federal employees.

While numerous witnesses favoured national leadership, it was stressed that progress can only be achieved by the federal government in close partnership with the provinces and territories. For example, Dr. Pierre Beauséjour, Senior Medical Advisor, Alberta Mental Health Board, stated:

> *While we agree that national leadership by the federal government for the development of a national action plan on mental illness and mental health is crucial, we will propose that building consensus on national mental health goals, standards and accountability is imperative and that provincial/territorial leaderships in mental health are as necessary as federal leadership in that regard.*
>
> *We firmly believe that a result-oriented partnership approach, a clear redefinition of roles and responsibilities and a synergy of efforts between the federal government and the provinces/territories will be needed for the development and implementation of a national cross-jurisdictional policy framework on mental health.*[478]

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476 Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, Brief to the Committee, 28 April 2004, p. 3.

477 Dr. Sunil V. Patel, President, Canadian Medical Association Brief to the Committee, 31 March 2004, p. 2.

478 Dr. Pierre Beauséjour, Senior Medical Advisor, Alberta Mental Health Board, Brief to the Committee, 2003, p. 1.

Witnesses argued that the national framework must set standards for service delivery covering all aspects of mental health from prevention, promotion and advocacy through community-based services to inpatient and specialty services. It must also provide services throughout the lifespan and ensure clarity of roles and responsibilities along the continuum of care. In addition, because most mental illnesses have their roots in childhood and adolescence, there must be a new focus on child and adolescent mental heath. Child and adolescent mental health has been ignored for too long. We must deal with problems early at their root before serious damage is done. In addition to children and adolescents, population groups also identified as in need of urgent action include Aboriginal peoples, senior Canadians, federal inmates, women and landed immigrants.

> **Mental illness and poor mental health are significant contributing factors in suicide with more people dying worldwide from suicide than war and homicide combined. Increasing the quality of mental health, and responding to mental illness on a timely basis will save lives.**
> ***[Phil Upshall, President, CAMIMH, Brief to the Committee, 18 July 2003, p. 3.]***

Another priority area within a national action plan is suicide prevention. The fact is that Canada, unlike Australia, Finland, France, the Netherlands, New Zealand, Norway, Sweden, the United Kingdom and the United States, does not have a national suicide prevention strategy. Many witnesses who appeared before the Committee urged the federal government to work with the provinces/territories and relevant stakeholders in the development of such a strategy. According to Dr. Paul Links, Arthur Sommer Rotenberg Chair in Suicide Studies, countries that have implemented national strategies on suicide prevention have experienced reductions of between 10% to 20% in suicide rate.[479] Moreover, the Centre for Suicide Prevention told the Committee that only two provinces – New Brunswick and Quebec – have implemented a suicide-specific prevention strategy. Witnesses urged the federal government to work with the provinces/territories and relevant stakeholders in the development of a national suicide prevention strategy.

A number of witnesses mentioned that there is an opportunity to coordinate a national mental health strategy with the National Drug Strategy. Given the high rate of concurrent disorders (mental illness and addiction), it is critical that links be forged between them. For example, national monitoring of the prevalence of substance use disorders through the National Drug Strategy would be of tremendous benefit to efforts to plan services for individuals with concurrent disorders.

Through the Canadian Alliance on Mental Illness and Mental Health (CAMIMH), some 20 NGOs representing individuals with mental illness/addiction, their families and service provider organizations have reached a consensus on the need for a national action plan on mental health, mental illness and addiction.[480] This national action plan addresses four main areas: education and awareness; national policy framework; research; and surveillance:

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479 Dr. Paul Links (11:20).

480 The following organizations have joined together to form the Canadian Alliance on Mental Illness and Mental Health: Autism Society of Canada, Mood Disorders Society of Canada, Canadian Medical Association, Canadian Health Care Association, National Network for Mental Health, Canadian Council of Professional Psychology Programs, Canadian Federation of Mental Health Nurses,

- Public awareness campaigns and professional education in a wide range of social and medical courses can help reduce the stigma and discrimination that is associated with mental illness, addiction and suicidal behaviour.
- A national policy framework is required in terms of identifying and implementing best practices (for treatment, prevention and promotion) and planning human resources (psychiatrists, psychologists, psychiatric nurses, addiction specialists, social workers, etc.). National leadership is also necessary to develop a comprehensive cross-jurisdictional policy framework that can ensure equitable access to professional and community supports across the country.
- The federal government is best positioned to establish and support a national research agenda for mental health, mental illness and addiction. Priorities for research need to be identified, research funding needs to be increased, and the voluntary fundraising sector needs to be strengthened.
- A national surveillance system must be implemented to monitor accurately and evaluate the incidence and prevalence of mental illness and addiction (including suicidal behaviour). The information collected nationally could also be used to report on how well the system is meeting the needs of individuals with mental illness and addiction.[481]

Many witnesses stressed that a national action plan for mental health, mental illness and addiction can only be developed through collaboration among the federal government, provincial and territorial jurisdictions, NGOs and other stakeholders including individuals with mental illness/addiction. In this context, the Schizophrenia Society of Canada stated:

> *It will take the work of all levels of government, working in concert with non-governmental organizations, to create and facilitate a national action plan. (…) Existing, capable agencies such as hospitals, professional associations and volunteer organizations that have been acting as band-aids in the current system are poised to be part of the mental health care solution in Canada. The biggest challenge governments will face is coordinating a multi-tiered government system that was not designed to work together and integrating non-governmental organization into the system as a contributing partner. It is only through a concerted effort in these areas that Canada will witness a shift in mental health care that will effectively and efficiently treat and support individuals with mental*

Canadian Coalition for Seniors' Mental Health, College of Family Physicians of Canada, Canadian Psychiatric Research Foundation, Canadian Association for Suicide Prevention, Canadian Association of Occupational Therapists, Schizophrenia Society of Canada, Canadian Mental Health Association, Canadian Academy of Child Psychiatry, Canadian Association of Social Workers, Canadian Psychiatric Association, Canadian Psychological Association, Native Mental Health Association of Canada.

481 Canadian Alliance on Mental Illness and Mental Health, *A Call for Action: Building Consensus for a National Action Plan on Mental Illness and Mental Health*, Discussion Paper, September 2000.

illness and their families and reduce the burden to individuals, families and society caused by [mental disorders].[482]

As stated by Phil Upshall, CAMIMH President, action must be taken now:

> *The time is now. (…) It has been fifteen years since the federal government released Mental Health for Canadians: Striking a Balance. Its policy document linked the national health promotion vision of "Achieving Health for All" to mental health. Other major reports, together with numerous provincial and regional policy and discussion documents have recommended significant changes to improve services and programs for: individuals with serious mental illnesses, children's mental health services, suicide prevention, aboriginal peoples, and offender and prison populations. These reports continue to gather dust and Canadians continue to wait, as few of the recommendations and ideas have been implemented.*[483]

Overall, witnesses called for a commitment by all levels of government to act, to work together on developing common goals and on creating a cohesive, integrated national framework on mental health, mental illness and addiction. One overlooked element of federal government activity in this field appears to be its direct responsibility for over a million Canadians, some of whom are facing serious mental health issues.

9.7 AN APPROACH BASED ON POPULATION HEALTH

> *Not only must the health care system treat mental illness (…) but Canada needs to take proactive steps based on the broader health determinants to protect and preserve the mental health of its entire population, including those living with mental illness. Improving the social conditions that we know are necessary for overall good mental health (e.g. healthy physical and social environments, strong coping skills, along with health services) is essential to support positive mental health and recovery from mental illness. [Canadian Mental Health Association, Brief to the Committee, June 2003, p. 3.]*

Mental health, mental illness and addiction are strongly influenced by a wide variety of factors including biology and genetics, income and educational achievement, employment, social environment, and more. This fact points clearly to the need to address mental health,

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482 Schizophrenia Society of Canada Brief to the Committee, 2004, p. 3.

483 Phil Upshall, President, Canadian Alliance on Mental Illness and Mental Health, Brief to the Committee, 18 July 2003, p. 7.

mental illness and addiction from a population health approach, a broad perspective extending well beyond health care *per se*.

The Committee heard repeatedly that treatment and recovery are difficult to achieve when basic needs for shelter, income and employment are not met. Many witnesses pointed out that it would be good public policy to take action to address these needs since access to housing, income and employment has been demonstrated to improve clinical status, reduce hospitalization, and enable individuals with mental illness to stay in their homes and communities. Access to housing, income and employment are also key to someone's ability to participate in society and to enjoy the rights of citizenship free from stigma and discrimination.

Housing has been widely acknowledged as a priority in mental health policy at both the federal and provincial levels. What is needed now is action from both levels of government to implement new housing and supported housing programs based upon the foundation of existing policy and research that has shown convincingly that a diverse population of individuals with mental disorders can succeed in housing if appropriate supports are available. Appropriate housing and supports can substitute for long term inpatient care thereby decreasing society's and affected individuals' reliance on high cost hospital and institutional beds.

Access to adequate income and employment is another key determinant of health that must be a priority in any mental health strategy. Many individuals with mental illness must rely on government income programs, at some time during their illness, as their only source of income and access to prescription drug coverage. Unfortunately, many government income programs provide benefits that are too low, don't cover realistic living costs, create barriers to employment, and are not flexible enough to respond to the episodic nature of mental illness. In addition, disability is often defined too narrowly for many individuals with mental illness or addiction to qualify. In Ontario, for example, provincial income support programs exclude individuals affected by addiction from the definition of disability altogether. These systemic barriers within government income support programs must be addressed to ensure that individuals with mental illness and addiction are able to access the basic supports that will help restore them to health and keep them well.

Support for employment is also a key area in which governments can do more. Individuals with a range of mental health problems can succeed in employment if flexible supports, responsive to their changing needs throughout treatment and recovery are available. Greater emphasis must also be placed on ensuring that individuals with mental illness are meaningfully accommodated in the workplace. Access to skills development, training and education must also be improved by encouraging academic institutions and other learning environments to accommodate more appropriately individuals with mental illness.

9.8 COMMITTEE COMMENTARY

At present, the federal government has no comprehensive framework for mental health, mental illness and addiction federally or nationally. While several witnesses pointed to the fact that Canada stands alone among similar G8 countries in not having a national mental

health policy reaching across the applicable jurisdictional boundaries, others noted the absence of an integrated framework even at the federal level with its responsibility for the provision of mental health services and addiction treatment to specific groups.

The lack of a *federal* framework may be primarily a function of inadequate collaboration, cooperation and communication among the various federal departments that have involvement in related or overlapping areas. However, it may also be a consequence of the difficulties of trying to address the multiple needs of very diverse populations. Whatever the reason, the Committee believes that despite its direct responsibility for the mental health needs of specific groups in the Canadian population, the federal government has made too little effort to coordinate its initiatives internally. In these areas, the federal government has both the right and the obligation to act and can do so without intensive (or even any) negotiations with other jurisdictions.

Similarly, the absence of an overall *national* framework may be attributed to some extent to the lack of clear role differentiation in these areas where provincial/territorial responsibility takes precedence. In general, the *Constitution Act, 1867* gives the provinces power to legislate in the fields of health care, education, provincial jails, and the administration of the courts; while giving Canadian Parliament power over criminal law and procedure, as well as the management of penitentiaries. In addition to the power of criminal law, this leaves the federal government with two other potential constitutional powers when acting in a national capacity: its spending power; and the ability to pass laws for the peace, order and good government of Canada.

From both the federal and the national perspectives, it is obvious that the federal government's role with respect to mental health, mental illness and addiction is not limited to the activities of the Health Canada. Related policies, programs and services fall in the broader social sphere as well as in the justice arena, outside the traditional health care sector. Other federal departments such as Human Resources Development Canada, Indian and Northern Affairs Canada, Veterans Affairs Canada, Correctional Services Canada, Justice Canada are among those that currently play a role in federal and national initiatives. And at the workplace level, Treasury Board as the employer of public servants has a major role to play in assisting its employees with issues related to mental health and addiction.

In looking at federal government activities with respect to the specific groups under its responsibility, there is little evidence to suggest the existence of strategies targeted at specific populations, let alone a broad all-encompassing federal strategy. No current efforts to develop an overall coordinated federal framework with collaboration by all involved departments or agencies are apparent. In most cases, there is little indication of thought being given to the development of a thorough and inclusive population specific strategy for addressing the mental health needs of any of the groups under federal responsibility. The provision of mental health services and addiction treatment and efforts toward mental health promotion and mental illness prevention remain highly fragmented, provided by numerous departments and departmental directorates. More collaboration would lead to a more integrated approach towards mental health. This would be an important step toward a policy based on population health.

The Committee also concurs with witnesses that better links are needed between the federal and provincial governments and among the various overlapping systems – health care, mental health, addiction, justice, social supports, etc.

Finally, it would also be important for the federal government to lead by example. If it is to play a leadership role in the development of a truly national action plan on mental health, mental illness and addiction, it must also show that it is willing and capable of providing mental health services to the populations for which it has direct responsibility. Clearly, there is a need to correct the ambivalent approach taken over the years by the federal government about the place of mental health in its policies and programs.

PART 4

Research and Ethics

CHAPTER 10:
RESEARCH INTO MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION IN CANADA

We believe that research is our most important weapon in our search for a better understanding, improved treatments and eventually a cure for devastating mental illnesses.
[Canadian Psychiatric Research Foundation, Today, Newsletter, Vol. 3, No. 1, Spring 2003.]

INTRODUCTION

In Canada, the federal government is the major sponsor of research into mental health, mental illness and addiction, while university-based scientists in research institutes and university-affiliated hospitals are the major performers. The Canadian Institutes of Health Research (CIHR), through its Institute of Neurosciences, Mental Health and Addiction (INMHA), is the primary federal funding agency for research into mental health, mental illness and addiction.

As with all CIHR-funded health research, research in mental health, mental illness and addiction encompasses the full spectrum of activities ranging from biomedical, to clinical, to health services, and to population health research:

- Biomedical research pertains to biological organisms, organs and organ systems. For example, this type of research would study the level of serotonin (a brain chemical) in patients suffering from eating disorders such as Bulimia Nervosa.
- Clinical research relates to studies involving human participants, healthy and ill. An example would include clinical trials on humans to test the toxicity and effectiveness of a possible new treatment for schizophrenia that, in basic biomedical research, has shown promising results and can then be safely studied in terms of its net and comparative (relative to other drugs) benefit to patients.
- Health services research embraces the administration, organization and financing mental health services delivery and addiction treatment. An example might be research into the mechanisms for caring for patients with bipolar disorder, from the manner of their diagnosis, through their treatment in hospital, then on an out-patient basis, or at home, to their long-term follow-up through hospital and community care.
- Population health research focuses on the broad factors that influence mental health status (socio-economic conditions, gender, culture, literacy, genetics, etc.). An example might be a study using large databases of health information to learn whether the incidence of attention deficit and hyperactivity disorder is associated with environmental or other factors.

This chapter provides an overview of the state of research into mental health, mental illness and addiction in Canada. Section 10.1 summarizes the role and mandate of CIHR and INMHA and highlights a number of issues raised by witnesses. Section 10.2 provides information on federal research funding for mental health, mental illness and addiction and examines the question of whether funding should reflect the burden of disease. Section 10.3 briefly reviews other sources of funding for mental health and addiction research. Section 10.4 discusses issues related to the translation of research knowledge into actual services and supports for individuals with mental illness and addiction. Section 10.5 discusses the need for a national research agenda for mental health, mental illness and addiction. Section 10.6 provides some Committee commentary.

10.1 CIHR AND INMHA

> *In Canada, there has been a net improvement in the past three years following the creation of the Canadian Institutes of Health Research, as well as an improvement in research funding, particularly for mental health. However, there is still great room for improvement.*
> *[Michel Tousignant, Professor, Centre de recherche et d'intervention sur le suicide et l'euthanasie, Université du Québec à Montréal (14:41)]*

As part of its commitment to becoming one of the top five research nations in the world, the federal government created in 2000 the Canadian Institutes of Health Research (CIHR). CIHR is an arms-length organization reporting to the federal Minister of Health.

CIHR takes an innovative, multi-faceted, problem-based and multidisciplinary approach to health research. This approach applies all types of research (biomedical, clinical, health services, population health) to disease mechanisms, treatment, prevention and health promotion. The majority of research funded by CIHR is investigator-driven (70%); 30% is reserved for strategic initiatives to respond to health challenges and scientific opportunities of high priority to Canadians.

CIHR's approach to research is facilitated by its structure, which brings together researchers across disciplinary and geographic boundaries in its 13 Institutes, each of which addresses a specific domain of health research. One of these 13 institutes is the Institute of Neurosciences, Mental Health and Addiction (INMHA).[484]

INMHA's creation marked the first focal point established in Canada for research into mental health, mental illness and addiction. INMHA supports research to enhance mental health, neurological health, vision, hearing, and cognitive functioning and to reduce the burden of related disorders through prevention strategies, screening, diagnosis, treatment, support systems, and palliation. As shown in Table 10.1, INMHA covers a wide range of research areas.

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[484] The first three paragraphs of this section are based on information contained on CIHR's website, under "About CIHR – Who We Are" (http://www.cihr-irsc.gc.ca/e/about/7263.shtml#?).

TABLE 10.1

AREAS OF RESEARCH SUPPORTED BY INMHA

- Mental health and neurological health promotion policies and strategies
- Addiction prevention policies and strategies
- Health determinants – to elucidate the multi-dimensional factors that affect the health of populations and lead to a differential prevalence of health concerns
- Identification of health advantage and health risk factors related to the interaction of environments (cultural, social, psychological, behavioural, physical, genetic)
- Disease, injury and disability prevention strategies at the individual and population levels
- Head injury prevention, treatment, and rehabilitation
- Addiction, mental health, and dysfunction of the nervous system affecting sensation, cognition, emotion, behaviour, movement, communication, and autonomic function
- Clinical research and health outcomes research into diagnostic technologies and methods; therapies; treatment, care, and rehabilitation models (long and short-term)
- Co-morbidity of conditions and impacts on prevention, diagnosis, treatment, care and rehabilitation
- Design and implementation of health services delivery – from prevention, to screening, to diagnosis, to intervention or treatment, to rehabilitation, to palliation
- Development and implementation of health technologies and tools (e.g. imaging, bio-engineering, drug delivery technologies)
- Development, regulation, function and dysfunction of the central, peripheral, and autonomic nervous systems
- Human psychology, cognition and behaviour; sleep and circadian biology; pain
- Ethics issues related to research, care strategies, and access to care (e.g. informed consent; hospitalization; addiction, mental health and the justice system)

Source: CIHR's Website (http://www.cihr-irsc.gc.ca/e/institutes/inmha/9591.shtml#).

INMHA's strategic plan for 2001-2005 lays out five strategic priorities:

1. To foster and develop a capacity for innovation in research in neurosciences, mental health and addiction that will strengthen Canada's health research

milieu in these fields and enhance its competitive position on the international scene. The focus areas include training, strategic initiatives, research in emerging areas and, research in bioethics;

2. To pursue and sustain collaborative partnerships with governmental, non-governmental and volunteer health organizations as well as pharmaceutical and biotechnology industries that will enable the INMHA to share, develop, obtain or leverage resources required to accomplish its mandate;
3. To promote linkage and exchange between the research community and municipal, provincial and national levels of decision-makers as well as the users of research results, including NGOs, through structured efforts aimed at knowledge translation (see section below);
4. To develop the INMHA's presence on the international stage through joint research, training and funding initiatives with scienctific and research funding agencies in other countries; and,
5. To establish an organizational and an operational structure that will enable the INMHA to accomplish its goals.[485]

Witnesses and researchers largely supported CIHR's new approach to mental health, mental illness and addiction research. There also exhibited strong trust in the fairness and rigour of CIHR's peer-review mechanism. For example, in their paper to the Committee, Dr. Shitij Kapur and Dr. Franco Vaccarino, from the Centre for Addiction and Mental Health (Toronto), stated:

> *(…) there is an important recognition and valuation of the role of CIHR in [mental health, mental illness and addiction] research. The rigour and transparency that CIHR brings to its evaluations and competitions is highly regarded and is seen as an indispensable mechanism to fill the "investor-driven" spectrum of research.*[486]

Witnesses acknowledged the multidisciplinary approach taken by CIHR as a positive step in research into mental health, mental illness and addiction. For example, Dr. Alan Bernstein, President of CIHR, observed:

> *Canada has an exceptionally strong and internationally recognized neuroscience community. By creating a single Institute that embraces neuroscience, mental health and addiction, we have explicitly embraced an integrative vision that is helping to bring together laboratory-based neuroscientists, psychologists, psychiatrists, social scientists, and health services researchers to focus on mental health and addiction.*[487]

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485 Institute of Neurosciences, Mental Health and Addiction, *Strategic Plan – 2001-2005*, December 2001.

486 Shitij Kapur and Franco Vaccarino, Translating Discoveries into Care – Enhancing Research in Mental Illness and Addictions, paper commissioned by the Committee, 2004, p. 5.

487 Dr. Alan Bernstein, Letter to the Committee, dated 8 July 2003.

Dr. Rémi Quirion, Scientific Director of INMHA, also pointed to the excellence of research into mental health and mental illness in Canada, but stressed that research capacity was an issue in the field of addiction:

> *Canada is one of the world leaders in the area of neuroscience research. In terms of the impact of our discoveries in neuroscience, we rank second or third. We therefore have excellent capacity. We are quite strong in the area of mental health. We need to do some rebuilding on the addiction side: we lost many of our significant researchers in the 90s.*[488]

Furthermore, most witnesses welcomed the inclusion of population health research and health services research as part of CIHR's mandate. They explained that this contrasted with the historical focus of CIHR's predecessor, the Medical Research Council, on biomedical research. The Committee was told, however, that population health research and health services research remain relatively weak in the fields of mental health, mental illness and addiction. In their paper, Kapur and Vaccarino contended that it is important to redress this situation, given the effects of the broader determinants of health on mental illness and addiction.[489]

> **Research must inform mental health service delivery. We need to know what works and what doesn't. We need to make informed decisions. We also must translate research knowledge into action.**
> ***[Dr. James Millar, Nova Scotia Department of Health, Brief, 28 April 2004, p. 11.]***

With respect to health services research, a literature review suggested that there is still much to be learned in Canada about best practices to provide care and supports to individuals with mental illness and addiction whether in inpatient care, outpatient care, crisis response, housing, employment or self-help.[490] The authors of the review indicated that, for those interventions where there is the strongest evidence relating to their effectiveness, there remains a pressing need for more detailed information about what works for whom. Where the evidence of effectiveness is unclear, more creative approaches are needed to assess effectiveness of specific interventions when traditional randomized controlled trials are not feasible or appropriate. Identifying best practices is essential to guide decisions about who should receive treatment resources and where, what treatment interventions should be provided, and how to provide the assurance that the care delivered is appropriate for the patient/client's needs.

Although many witnesses lauded the unique Canadian approach of fostering collaboration amongst researchers and between researchers and other organizations, some complained about heavy restrictions and major obstacles that prejudice the validity and quality of research and consume too much of the researchers' time. For example, Michel Tousignant, Professor, Centre de recherche et d'intervention sur le suicide et l'euthanasie, Université du

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488 Dr. Rémi Quirion (14:9).

489 Kapur and Vaccarino (2004), p. 5.

490 Health Systems Research Unit, Clark Institute of Psychiatry, *Best Practices in Mental Health Reform – Discussion Paper*, prepared for the Federal/Provincial/Territorial Advisory Network on Mental Health, Health Canada, 1997, pp. 27-28.

Québec à Montréal, told the Committee that researchers could spend many months, sometimes up to year, to fulfill all INMHA/CIHR's criteria before even starting a research project. He explained that as many as three ethics committees – university, research centres and hospital, –review a proposal. While ethics committees exist to protect everyone's interests, Professor Tousignant pointed out that very little time is allocated by them to consult with researchers who may also be required to submit protocols to the Access to Information Commission, which further delays the initiation of research projects and places another layer of bureaucratic burden on investigators.[491]

10.2 FEDERAL FUNDING FOR RESEARCH INTO MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION

> *(…) the funding of mental health and addictions research in Canada is currently inadequate. Mental health and addictions are under funded in an absolute and a relative sense. When one combines this systemic under funding, with the impact of stigma, the limitations of the NGOs fund-raising in this area as well as the lack of commercial incentives for a lot of these activities, the under funding becomes even more acute. Given that the other constraints cannot be easily overturned (stigma, limits to fund-raising in this area, lack of commercial incentives) – it is critical that the federal government show leadership in securing fair funding for mental health and addictions research.*
> *[Dr. Shitij Kapur and Dr. Franco Vaccarino, Centre for Addiction and Mental Health (2004)]*

10.2.1 Level of Federal Funding

CIHR, the primary funding agency for mental health and addiction research in Canada, has allocated $93 million to INMHA from its total base budget of $623 million for the 2003-2004 fiscal year. About $33 million from the INMHA budget goes to mental health and addiction research, or 5.3% of the total envelope of CIHR health research funding. The remaining $60 million is spent on fundamental neuroscience research, some of which, along with other health research, may well also contribute to a greater understanding of mental illness and addiction.

Dr. Bernstein stressed that INMHA currently receives the largest allocation of CIHR funds, followed by the Institute of Circulatory and Respiratory Health ($64 million) and the Institute of Infection and Immunity ($52 million).[492]

INMHA, together with the Institute of Aboriginal People's Health, created the National Network for Aboriginal Mental Health Research (NNAMHR) in the spring of 2003 with a

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491 Professor Michel Tousignant (14:43).
492 Dr. Bernstein (8 July 2003).

budget of $170,000 per year for four years. Its mandate is to conduct research in partnership with Aboriginal communities and academic researchers with the goal of training new researchers and developing the research capacity necessary to address the particular mental health needs of Aboriginal peoples.

In addition to CIHR, federal funding for research into mental health, mental illness and addiction is also available from the Social Sciences and Humanities Research Council (SSHRC). In particular, SSHRC supports research in the broad area of social psychology. Some 1.5% (approximately $2.5 million) of its total base budget of $167.5 million went to mental health research in 2002-2003.[493]

The Natural Sciences and Engineering Research Council (NSERC) is the third and final federal funding agency for health research. Clinical psychology is not eligible for NSERC support nor is brain research a key focus. But NSERC will consider projects relating to fundamental psychological processes, their underlying neural mechanisms, their development within individuals and their evolutionary and ecological context. Funding allocations specific to mental health, mental illness and addiction are included within the category "psychology" under "brain, behaviour and cognitive science". In 2003, 113 projects were funded within this category at a cost of approximately $3.25 million,[494] which corresponds to 0.5% of the NSERC grants and scholarships budget of just over $600 million.

Other sources of federal funding for research into mental health, mental illness and addiction may include Statistics Canada, Canada's Drug Strategy (which funds the Canadian Centre on Substance Abuse), Health Canada, Correctional Service Canada (Addictions Research Centre), and the Canadian Health Services Research Foundation. The Committee did not receive information on the level of funding provided by these sources.

10.2.2 How Much Should the Federal Government Spend?

Several witnesses supported the view that the proportion of health research dollars allocated to mental health, mental illness and addiction was not adequate.

> **I want to make it very clear that the research in mental health and mental illnesses is underfunded in Canada compared with the costs to society.**
>
> ***[Dr. Rémi Quirion, INMHA (14:8)]***

In their report, Dr. Kapur and Dr. Vaccarino noted that there are no guidelines in Canada (nor elsewhere, for that matter) for what the total funding envelope for health research should be and how funding for health research should be allocated among disciplines/research fields. In the absence of such guidelines, they suggested two approaches: first, to examine health research funding as a function of the relative burden of illness, and second, to compare research funding patterns in other jurisdictions.[495]

As discussed in Chapter 5 and Chapter 6, the prevalence of mental illness and addiction in Canada is high and the economic burden enormous. Nearly as many individuals battle with

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[493] Information obtained from personal communication.
[494] Information obtained from the Website at: www.nserc.gc.ca.
[495] Dr. Kapur and Dr. Vaccarino (2004), p. 3.

depression as have cardiovascular disease. Many witnesses have argued reasonably that mental illness and addiction impact on society as powerfully as any other class of disease or condition and that this burden should be reflected directly in the funding dedicated to research into mental health, mental illness and addiction.

A paper by the Autism Society Canada ranked 14 diseases according to prevalence rates and CIHR dollars for research per affected person. AIDS, which affects 1 Canadian in 500, is the most richly funded area of research, receiving from CIHR over $1,500 per affected person. Attention deficit and hyperactivity disorder (ADHD), which affects as many as 1 Canadian in 17, is last on the list at $0.09 (nine cents) per affected person. Schizophrenia, probably the most disabling of mental illnesses, ranked 7th; it affects 1 in 100 and receives from CIHR about $84 per affected person. Autism, with a prevalence rate of 1 in 200, ranked 8th with CIHR funding amounting to $67.10 per patient/client.[496]

In a letter to the Committee, Dr. Alan Bernstein, President of CIHR, estimated that, if funding were to be provided in relation to the burden of disease, CIHR's support for mental illness and addiction would be at least $80 million per year. By this standard, CIHR's current expenditure of approximately $33 million is very low. Nevertheless, Dr. Bernstein maintained that research into mental health, mental illness and addiction receives an appropriate a proportion of CIHR's budget,[497] given that many factors have to be taken into account, including the capacity of researchers in the field to use research funding to best advantage.

The second approach suggested by Dr. Kapur and Dr. Vaccarino consists in comparing the federal government's performance in terms of funding research into mental health, mental illness and addiction to that of other industrialized countries. The National Institutes of Health (NIH) in the United States function similarly to CIHR through a number of "institutes", the relevant ones for comparison being the National Institute of Mental Health (NIMH), the National Institute of Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA). In 2003, the total envelope of funding to the NIH amounted to US $27 billion; NIMH received US $1.4 billion, NIDA US $1 billion and NIAA US $0.4 billion. Thus, research into mental health, mental illness and addiction in the United States received US $2.8 billion dollars, or just over 10% of the total funds allocated for health research, double the CIHR's 5.3%.[498]

In the United Kingdom, the main funding agency for biomedical research is the Medical Research Council (MRC) which funds six research areas: people and population studies, including health services and the health of the public; genetics, molecular structure and dynamics; cell biology, development and growth; medical physiology and disease processes; immunology and infection; and neuroscience and mental health. The most recent data available indicates that of the £292.6 million total base spending for the MRC in 2001-2002, some £74 million was allocated to neuroscience and mental health research and £18.9

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496 Autism Society Canada, *Canadian Autism Research Agenda and Canadian Autism Strategy: A White Paper*, March 2004.

497 Dr. Bernstein (8 July 2003).

498 Information obtained from the NIH Website at: www.gov.nih.

million specifically to research into mental illness. This corresponds to 6.5% of the total allocated for biomedical research.[499]

On the basis of this information, a number of researchers in the field contended that Canada's investment is not sufficient.

What measure should be used to determine the proportion of research funds for any given disease? Should it be merely prevalence rates, morbidity and mortality, disability, or the economic burden associated with the disease? Should funding be determined on the basis of international comparative analysis? Should it be allocated competitively on the basis of merit and promise among all the applications submitted to the granting agency concerned? Should it be determined after consideration of a combination of all of these measures?

Dr. Bernstein testified that formally allocating research spending on the basis of burden of disease to Canadian society implicitly assumes that there is no spill over in concepts, techniques or results from one area of research to another. He explained that some of the most important advances in one disease area had their origins in a completely different area. Therefore, it would not be appropriate to allocate research funding solely on the basis of prevalence rates or burden of disease.[500] Dr. Bernstein provided two examples:

> *CIHR is funding several teams, in Vancouver, Toronto and Québec city, to identify the genes involved in bipolar disease/schizophrenia. The science and technology to do this came out of a much broader goal to clone the genes involved in <u>any</u> human disease. It's reasonable to say that the identification of the gene(s) for human bipolar disease will be the single most important advance to date in bipolar disease research, and will transform approaches to diagnosis, treatment and perhaps prevention. And yet, the fundamental research that is making this possible had nothing originally to do with mental illness or indeed any particular human disease.*
>
> *CIHR's Institute of Aging, Genetics and Population and Public Health are planning a major initiative – The Canadian Lifelong Health Initiative (CLHI) – that will follow cohorts of newborns and seniors, and measure the genetic, psychosocial, economic, environmental and cultural determinants of health and disease. This initiative, which will require in excess of $100 million over 20-30 years, promises to tease out the multiple determinants of healthy aging and disease, particularly common and complex disorders like mental illness. How should we classify our investment in CLHI – mental illness, cardiovascular disease, arthritis, healthy aging, or all of the above?*[501]

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499 Information obtained from the MRC Website at: www.mrc.ac.uk.
500 Alan Bernstein (8 July 2003).
501 *Ibid.*

Determining the level of research funding on the basis of international comparisons also has drawbacks. First, a large number of countries should be examined before making such a comparison; second, the data should be truly comparable; and third, the research capacities of the countries concerned should also be truly comparable.

10.3 OTHER CANADIAN SOURCES OF FUNDING

10.3.1 Pharmaceutical Industry

The pharmaceutical industry is the largest single source of funding for health research in Canada. In 2002, the pharmaceutical industry invested $1.4 billion in health research and development, or approximately 36% of the total health research in the country.[502]

It is not known just how much funding of research by the pharmaceutical industry in Canada goes into mental illness and addiction. However, there are at present more than 100 potential pharmaceutical agents for a variety of mental disorders that are either in human clinical testing or awaiting approval.

These investments by the pharmaceutical industry are made both in laboratory research (in-house, in universities and in research institutes) to discover new molecules, and in clinical trials to test the efficacy of new agents on individuals with mental illness and addiction and look for side effects. Clinical trials in this category of patients raise many ethical issues, and these are discussed in Chapter 16.

As well, pharmaceutical companies support training and research in mental illness and addiction through CIHR's Industry Partnered Strategic Initiatives. Examples of recent multi-partnered initiatives involving CIHR and the industry include the Biological Mechanisms and Treatment of Alzheimer Disease Grants Program, the Neurobiology of Psychiatric Disorders and Addictions Program (both with AztraZeneca) and the Vascular Health and Dementia Initiative (with Pfizer).

Pharmaceutical research has had, and continues to have, a major impact on the provision of health care to individuals with mental disorders. For example, it was noted in Chapter 7 that the discovery of neuroleptic agents in the 1970s made possible the safe deinstitutionalization of many individuals with mental illness. More recently, new drugs for schizophrenia and depression have contributed to the reduction of treatment costs for these disorders; it has been estimated that these costs fell by more than 15% between 1992 and 1999 largely because new therapeutic drugs reduced the need for hospitalization.[503]

Important research is being pursued by the pharmaceutical industry in Canada. Agents are presently being tested for a number of conditions such as addiction to illicit drugs (for example, a therapeutic vaccine to treat cocaine addiction), and dependence on alcohol and

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502 Statistics Canada, "Estimates of Total Spending on Research and Development in the Health Field in Canada, 1988 to 2002", *Science Statistics*, Service Bulletin, Catalogue 88-001-XIB, Vol. 27, No. 6, September 2003.

503 See Pharmaceutical Research and Manufacturers of America (PhRMA), "New Medicines for Mental Health Help Avert a Spending Crisis", *Value in Medicines*, 14 January 2004.

tobacco.[504] Research on new agents for depression and for schizophrenia is also expected to improve greatly the prognosis for these conditions.[505]

Currently, the most prominent Canadian pharmaceutical companies in mental illness and addiction are Wyeth, Lilly, Glaxo-Smith-Kline (GSK) and Lundbeck. Lilly and GSK, with the addition of Pfizer, will continue to play a lead role in mental illness and addiction in Canada, given that these companies have a rich candidate drug pipeline in this area and are likely to invest heavily in future clinical trials.

10.3.2 Provincial Funding Agencies and NGOs

There are numerous other sources of funding for mental health, mental illness and addiction research. In most provinces, there are governmental bodies devoted to mental health and addiction research (e.g.: Réseau santé mentale du Québec; Ontario Mental Health Foundation, Alberta Mental Health Board; Manitoba Health Research Council, Centre for Addiction and Mental Health (Toronto), etc.).

> **There are two key ways for NGOs to support research. First, organizations can financially support research initiatives. Either through independent fundraising efforts, or by partnering with other organizations, NGOs have the ability to offer significant funds for research. (…)**
> ***[Dr. John Gray, President, Schizophrenia Society of Canada, Brief, 12 May 2004, p. 2.]***

There are also many voluntary health charities and foundations (NGOs) that are effective at responding to the needs of different disease groups. As an example, the Committee heard about the excellent working relationship between the Schizophrenia Society of Canada (SSC) and CIHR. Last year, SSC was able to provide $75,000 in matching funds for research.

The Committee also heard, however, that rarely are NGOs able to attract the funds required to sponsor research. Moreover, there are only two national non-profit organizations whose mandate specifically focuses on raising money and funding mental health and addiction research: the Canadian Psychiatric Research Foundation and NeuroScience Canada. The Canadian Psychiatric Research Foundation (CPRF) told the Committee that the stigma associated with mental illness and addiction creates significant barriers to its attracting appropriate publicity, getting corporate sponsorship, and raising research funding. This experience differs from other disease groups such as cancer and cardiovascular disease where the respective health charities are strong and successful fundraisers and supporters of research:

> **(…) there are not many [volunteer organizations] right now who raise a lot of money from the Canadian public, compared to the National Cancer Institute or the Heart and Stroke Foundation.**
> ***[Dr. Rémi Quirion (14:23]***

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504 See the Website of Canada's Research Based Pharmaceutical Companies (Rx&D) at: http://www.canadapharma.org/Patient_Pathways/Health_Info/02mentalheal/index_e.html.

505 *Ibid.*

> *CPRF faces a difficult challenge in raising awareness and research funds to determine the causes, treatments and ultimate cures for a variety of mental illnesses. Tragically, the stigma of mental illness persists and as a result, millions suffer unimaginable despair in silence, fearful of adverse personal consequences that public acknowledgement of their illnesses might bring. Under these conditions, awareness remains low, understanding minimal, support mechanisms few, misconceptions rife and critical funding for research is critically low.*[506]

Nevertheless, voluntary organizations still play an important role in research into mental health, mental illness and addiction in Canada, a role that must be recognized and expanded. Dr. Quirion told the Committee that when INMHA was created, it sought out and fostered collaboration with 60 volunteer and non-governmental organizations. These groups participated in drafting the Institute's strategic plan; they were also involved in developing a strategy for increased funding.[507]

Dr. Gray, from the SSC, also suggested that NGOs need to participate in the process of research. For example, where appropriate, NGOs can assist in the creation of research questions and their representatives can sit on review panels. He explained that, by doing so, scientists are better able to identify and conduct research that is most needed by the mental health and addiction sector. Importantly, their participation would reinforce the human aspects of science and be a continual reminder of the need for the practical application of research outcomes.[508]

A major concern raised with respect to research funding for mental health, mental illness and addiction is that there is currently no central database for all sources of funding. There is no information held by governments and non-governmental organizations on what is being investigated. The Canadian Psychiatric Research Foundation pointed out that there is no coordination among research funding bodies and no central responsibility for data collection. As a result, researchers find it difficult to negotiate their way through not only the government granting agencies, but also the private and the voluntary sector funding sources. Researchers are frequently not aware of similar research questions under investigation in different labs across the country. In many cases, the opportunity to collaborate would enhance productivity and work to eradicate the negative impact of competition among universities and hospitals. The Foundation recommended the establishment of a central database of research funding agencies that would encompass non-government sources of funding, a listing of what and where research is being conducted and a site for maintaining research findings.[509]

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[506] Canadian Psychiatric Research Foundation, Brief to the Committee, June 2003, p. 2.
[507] Dr. Rémi Quirion (14:24).
[508] Dr. John Gray, President, Schizophrenia Society of Canada, Brief to the Committee, 12 May 2004, p. 3.
[509] Canadian Psychiatric Research Foundation (June 2003), p. 6.

10.4 KNOWLEDGE TRANSLATION

> *In terms of applying research findings to daily life (…) we have to dare to encroach a little on the autonomy of the medical and teaching professions in this field.*
> *[Dr. Laurent Mottron, Professor, Department of Psychiatry, University of Montreal (14:21)]*

In their paper, Dr. Kapur and Dr. Vaccarino stressed to the Committee that the major impetus for health research in our society is the promise to deliver better outcomes for patients, their families and their communities.[510] This involves taking discoveries from the bench to the community where care and support is delivered, a process often referred to as "knowledge translation".

Although knowledge translation is within the CIHR's mandate, many witnesses testified that it is not done well in mental health and addiction research. Biomedical research has established that mental illness and addiction are disorders of the brain, providing promising leads into the genetics of mental illness and addiction, and elucidating the role of a wide array of risk-factors. Many new system-level best practices and identified many new opportunities for pharmacological interventions in these disorders have also been identified. But many believe that all too frequently these discoveries have remained with researchers in their laboratories and have had limited impact on patients and their families.[511]

This state of affairs was highlighted in the 1999 U.S. Surgeon General's Report entitled *Mental Health: A Report of the Surgeon General*. This 500-page publication, the first of its kind on mental health, confirmed that research has provided the knowledge needed to deliver effective treatment and better services for most mental disorders. The report also stated, however, that gaps exist between what have been shown to be optimally effective treatments and what many individuals receive in actual practice settings.[512]

Similarly, the United States President's New Commission on Mental Health, chaired by Michael F. Hogan, reported in 2003 on long delay that exist before research reaches practice. More precisely, the Commission stressed that the 15 to 20 year lag between discovering effective forms of treatment and incorporating them into routine patient care is far too long. The Commission also reported that, even when these discoveries become routinely applied at the community level, too often actual clinical practices are highly variable and often inconsistent with the original treatment model that was shown to be effective.[513]

The translation of a new idea or discovery into an accepted practice has three distinct phases. The first is the basic discovery that identifies a new genetic association, a new method of delivering care, a new way of engaging patients in therapy or a new idea for using an established treatment. The second phase is proof-of-principle, which involves translating

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510 Dr. Kapur and Dr. Vaccarino (2004), p. 6.
511 *Ibid.*
512 United States Surgeon General, *Mental Health: A Report of the Surgeon General*, 1999.
513 The President's New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America*, Final Report, 22 July 2003, p. 67.

that discovery into care and demonstrating that it works in a controlled setting, the clinical trial phase. The third phase, dissemination and application, involves incorporating the new practice into the community and into the pre-existing continuum of care.[514] Eric Latimer, a health economist at the Douglas Hospital (Montreal), told the Committee that mental illness and addiction research has had many successes at the level of discovery, especially given the level of funding and number of researchers involved, but that the other two phases remain major challenges and will require greater investment.[515]

Clinical trials are necessary to test the efficacy of basic discoveries; their completion requires appropriately trained and experienced clinician scientists. Some witnesses emphasized that insufficient numbers of physicians are participating in research and that a major deficiency remains the fact that not enough clinician scientists are being trained to carry out crucial clinical trials. Among the top priorities in INMHA's strategic plan for 2001-2005 is the creation of more training opportunities for clinician scientists.

The dissemination and application phase of knowledge translation involves bringing validated new ideas or practices into the community. As stated earlier, one of the strategic priorities for INMHA is to promote linkage and exchange through structured knowledge translation programs between the research community and the municipal, provincial and national levels of decision-makers as well as users of research results, including NGOs. While witnesses agreed that this is not only a laudable but also a necessary goal, they felt that it could not be achieved at the current funding level. During his testimony, Professor Tousignant suggested that research budgets should contain funds dedicated to "scientific popularization".[516]

The Committee was informed that knowledge translation and clinical research will be two of the top priorities of CIHR over the coming years. The Committee strongly supports this policy.

10.5 TOWARD A NATIONAL RESEARCH AGENDA FOR MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION

Mental health and mental illness are critical and we should have a national type of agenda.
[Dr. Rémi Quirion (14:34)]

The Committee heard that in the field of mental health, mental illness and addiction there is no coherent policy or strategy in place to deal with the complex issues involved and produce a coherent and coordinated response to them. Mental disorders are generally complex and chronic medical illnesses. Their determinants cut across many sectors, their management involves many different health professionals, and their impact on how society functions is broad. Witnesses stressed the need for better coordination of the efforts to deal with the many challenges posed by mental illness and addiction currently being undertaken by the

514 Dr. Kapur and Dr. Vaccarino (2004), p. 6.
515 Eric Latimer (14:44 to 14:48).
516 Professor Tousignant (14:43).

federal and provincial governments along with non-governmental organizations and the pharmaceutical industry. Dr. Kapur and Dr. Vaccarino stated:

> *(…) the issues of mental illness and addictions defy simple solutions. These illnesses have multiple determinants – biological, psychological and social, and adequate responses to them require coordination of multiple sectors. At present, research in these areas is a well-intentioned but uncoordinated effort. We strongly call for the development of a national policy or guiding framework to form the bases for a coordinated effort in the areas of Mental Health and Addictions Research.*[517]

Witnesses who addressed issues related to research in the mental health and addiction field unanimously agreed on the need for a national research agenda. In their view, such an agenda would build on current Canadian expertise, coordinate the research activities performed by a variety of actors (governments, non-governmental organizations, pharmaceutical corporations) that are now fragmented and ensure a balance between biomedical, clinical, health services and population health research applied to mental health, mental illness and addiction. Perhaps more importantly, many witnesses stressed that now is the time to address the critical issues in mental health and addiction research. In particular, Dr. Quirion stated eloquently:

> *The time is now. There is a great deal of expertise in Canada because of the national health care system. That allows us to collect data and to have data banks that are much more impressive than in the United States. Take the new genome research, for example.*
>
> *I think we could have a major impact and we should not be afraid to forge ahead. If we forge ahead with the expertise we currently have, we will succeed in finding the causes of brain diseases and of mental illnesses.*[518]

10.6 COMMITTEE COMMENTARY

The Committee notes that, during the past several decades, research in the fields of mental health, mental illness and addiction has advanced our understanding of how to improve the conditions of individuals with mental disorders and addiction. New treatments have made it possible to care for individuals in the community, without the need for long periods of confinement in public institutions. We are also closer to understanding the pathophysiology of mental disorders, and this knowledge has important implications for both treatment and prevention. The Committee also believes that research in the fields of mental health, mental illness and addiction can play an important role in informing policy decisions relating to the allocation of resources for treatments, services and supports that are needed by individuals with mental illness and addiction.

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[517] Kapur and Vaccarino (2004), pp. 11-12.
[518] Dr. Rémi Quirion (14:15).

The Committee also acknowledges the major contribution made by Canadian researchers in the area of mental illness and addiction. Canada leads both nationally and internationally in many research fields including neuroscience, psychopharmacology and genetics. It is critical that this historical strength be preserved and enhanced.

The Committee recognizes the federal government's role in creating CIHR and the decision to create INMHA. We also applaud the increase in federal funding allocated to CIHR in recent years. In particular, we wish to highlight the major contribution of Dr. Rémi Quirion, INMHA's Scientific Director, in the promotion and conduct of research into mental health, mental illness and addiction.

The Committee is of the opinion that research is of enormous importance, and that it points the way towards a path that can lead to fundamental solutions to the problem of mental illness and addiction in Canada. However, an adequate level of resources must be allocated to make progress down that path. We believe the federal government should devote additional funding to mental health and addiction research, including for the education and training of more researchers and clinician scientists in order to expand Canada's capacity to do first class research in this area. Similarly, voluntary organizations should be strongly encouraged to develop or strengthen their fundraising activities in order to raise research funds.

CHAPTER 11:
THE QUESTION OF ETHICS

INTRODUCTION

"Ethics" is usually defined as the systematic, reasoned attempt to understand values and principles underlying decisions about matters of fundamental human importance. Put simply, it is about the right and the good.

> **A general research question (…) regards diverse and sometimes opposed understandings of "ethics" or "the good" as it relates concretely to the care of persons trying to cope with a mental illness. Any response to particular ethical challenges entails some commitment to a more general notion of the good.**
>
> ***[Canadian Catholic Bioethics Institute, Brief to the Committee, 20 February 2004, p. 6]***

In many fields, difficult decisions usually involve consideration of numerous factors, each implicating different – and often conflicting – values, principles, viewpoints, beliefs, expectations, fears, hopes, etc. When facing such decisions, people may reach different conclusions not only because they consider different factors, but also because they weigh them against each other in different ways. The practical effect of the discipline of ethics is to help those who face difficult decisions to identify the inherent values and principles that apply, to weigh them against each other, and to come to the best possible decision.[519]

In the context of health and health care – either in practice, delivery or research – the ultimate goal of ethics is to improve the health and quality of life of individuals. In a paper commissioned by the Committee, Gordon DuVal and Francis Rolleston refer to long-standing and well-established ethical values and principles underlying this goal:

- beneficence and non-maleficence – to practice in accordance with established standards of quality care and the best interests of the patient, and not to harm him or her;
- autonomy – to show respect for the patient as an individual and to encourage the patient's right to self determination, choice, and the protection of sensitive information; and,
- justice – to ensure that patients and research subjects are treated fairly and resources are allocated based on considerations of equity and fairness.[520]

Other important values mentioned by DuVal and Rolleston include the familiar elements of virtuous behaviour such as compassion, honesty, promise-keeping, moral courage, patience, tolerance, preserving dignity and accountability, as well as community and relational values.[521] These key ethical dimensions are largely reflected in professional and institutional

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519 Senate Standing Committee on Social Affairs, Science and Technology, *Recommendations for Reform*, Volume Six, October 2002, p. 222.

520 Gordon DuVal and Francis Rolleston, *Ethics Issues in Mental Health,* document commissioned by the Committee, 20 April 2004.

521 *Ibid.*

codes of ethics and the law. Altogether, these principles and values guide decision-making in the programming and delivery of health services and supports, clinical care and related research.

This chapter examines various ethical issues related more specifically to mental illness and addiction. Section 11.1 analyzes ethical issues associated with the delivery of services and supports to individuals with mental illness. Section 11.2 discusses capacity to consent to treatment. Section 11.3 deals with privacy and confidentiality issues. Section 11.4 examines ethical issues with respect to specific population groups – children/youth, seniors and forensic patients. Section 11.5 discusses the ethical implications of advances in genetics and neuroscience. Section 11.6 reviews ethical concerns raised with respect to mental health and addiction research. Section 11.7 provides some Committee commentary.

At the root of many of the ethical issues and concerns canvassed throughout this chapter lies the social stigma associated with individuals affected by mental illness and addiction and their families. In itself, stigmatization contributes to a relative lack of compassion and withdrawal of the dignity and respect with which all individuals should be treated. In the end, stigmatization is at the base of injustice, the absence of beneficence and the inequality of access to needed services and supports.

> **I see three major ethical issues around mental health in Canada (…). The first problem in our society remains that of stigma of a mental health problem. (…)**
> ***[Mark Miller, Ethicist, St. Paul's Hospital, Saskatchewan, Letter to the Committee, 27 September 2003.]***

11.1 ACCESS TO SERVICES AND SUPPORTS

According to DuVal and Rolleston, the ethical issues that relate to the provision of services and supports arise from the fact that "society has not taken practical steps necessary to ensure justice and beneficence for individuals with mental illness and addiction, both within Canada's publicly funded health care system and beyond it."[522] First, the complexity of mental disorders significantly increases the challenges faced by society in addressing the need for effective services and supports for individuals with mental illness relative to other categories of illness. Second, proper diagnosis, treatment and the continuing care of mental disorders involve not only many different health care providers, but also, to an extent not found in other illnesses, other professions, such as school teachers, law enforcement officers, clergy, social workers. Absent a well coordinated health care system, individuals suffering from mental illness and addiction and their families have greater difficulty than most in accessing adequate health care, resulting in a form of systemic discrimination.

In their paper, DuVal and Rolleston argue that the relatively poor treatment of individuals with mental illness and addiction arises not simply because people or systems want to discriminate against them, but because of the factors that derive directly from the nature of mental disorders. Mental illness and addiction often show themselves through behavioural signs whereas almost all other illnesses present with physical signs. Behavioural aberrations caused by mental disorders are the basis for the fear and incomprehension that they

[522] *Ibid.*, p. 3.

engender in many individuals. Such behaviours often result in problems with, for example, law enforcement authorities, or in school, which then, in effect, become the first line of treatment.[523]

Although there is no justification for adopting different standards of access, quality of care or priority setting when treating individuals with mental illness and addiction as compared to individuals with physical illness, this does seem to happen. This is particularly problematic in crisis situations, when timely and effective care is required. Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, told the Committee:

> **People with schizophrenia are still treated like people with cancer were treated long ago, as if it were a moral disease instead of a physical one.**
> ***[Murray (9:18)]***

> *[We] must also put the same time emphasis on mental health as society does for physical health. It is unacceptable for people with chest pain to wait to determine the cause. If the cause is cardiac, people want immediate attention. Unfortunately, those with emotional pain do not get the same consideration. They will probably wait to seek help, wait further to see a professional caregiver, be treated with outdated and inappropriate methods, and continue to suffer much longer than is necessary.*[524]

Carlyn Mackey, Aurise Kondziela and Dorothy Weldon, from the Christ the King Family Support Group, wrote to the Committee that ethical standards that apply to mainstream medicine are not applied consistently to the provision of mental health care:

> *Ethical standards for the care and treatment of the mentally ill do not appear to be consistent with normal ethical standards of mainstream medicine. One must question the ethics of tolerating dysfunctional mental health systems, or systems which can even be described as non-systems. It follows that the ethical issues of continuing and knowingly discriminating against the mentally ill in the area of safe and adequate health care provision must be addressed at all levels of government.*[525]

An additional challenge in providing services and supports to individuals with mental illness arises because many different professions and areas of expertise are involved. DuVal and Rolleston offered the example of a school teacher who first brings to a family's attention the possibility that their child's difficulties in school may be due to Attention Deficit Hyperactivity Disorder (ADHD). In cases of disruptive behaviour, the school system will give the priority to the protection of other students. Actions such as disciplining, suspension

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523 *Ibid.*

524 Dr. James Millar, Executive Director, Mental Health and Physician Services, Nova Scotia Department of Health, (7:).

525 Carlyn Mackey, Aurise Kondziela and Dorothy Weldon (Christ the King Family Support Group - Winnipeg), Brief to the Committee, 24 October 2003, p. 2.

or expulsion reinforce stigmatization of the affected child. Retention in the school system requires special classes or special teaching support to minimize the impact on other students. If the mental illness leads to violence, law enforcement officers may become involved. Clergy may be an early recourse for affected individuals who feel themselves possessed by forces outside their control. Since recognition of mental illness by the sufferer himself or herself is so important to their management of their condition, school teachers, law enforcement officers, clergy and others in parallel professions often find themselves, sometimes inadvertently, thrust into the first line of diagnosis and treatment for individuals with mental illness.[526]

There are, however, multiple barriers based on split jurisdictions between the mental health system and the social services system which inhibit proper treatment of affected individuals. For example, Dr. Robert Quilty, a registered psychologist working with the Durham County School Board, informed the Committee about the "diagnostic halo" that inhibits the diagnosis and treatment of mental illnesses in children with developmental disorders. With autism, for example, this "halo" phenomenon often results in failure to recognize a disorder that could have been treated successfully if caught early enough. This problem is compounded by difficulties in entering children with developmental disability into behavioural service agencies within mental health agencies thus further clouding an already uncertain future. Children with high functioning autism (Asperger's Syndrome) may fare somewhat better. However, even with partially successful treatment, on reaching adulthood, developmentally disabled individuals who need further mental health care often do not receive it because they are labelled as being in need of community support; this is the result of the lack of coordination in service provision between various provincial ministries.[527]

As a consequence, the delivery of mental health services and addiction treatment is highly fragmented, disconnected and uncoordinated. For individuals with mental illness, the problem of navigating this complex system of services and supports is compounded by the nature of their illness. Numerous individuals with mental illness and addiction and other experts told the Committee that this lack of cohesion and coordination has led to an increase in addiction, homelessness and incarceration.

DuVal and Rolleston pointed out that the fragmentation of the system is evident even when it is clear that institutional care is required. A telling recent case in Ottawa, that has received extensive media attention, concerns a young woman with violent and self-destructive behaviour. The Children's Hospital of Eastern Ontario could not admit her because they do not have facilities for such patients; the Royal Ottawa Hospital, an adult institution which has the necessary secure facilities, could not take her because she is too young. This illustrates the serious ethical issues that flow from fragmentation of the "system" that is supposed to provide acute and long term care for patients of different ages and with differing mental conditions.[528]

The Committee was told that it is, above all, the family that usually bears the brunt of caring for an individual with mental illness who has been entrusted to home or community care

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[526] Gordon DuVal and Francis Rolleston (2004), p. 6.
[527] *Ibid.*, p. 10.
[528] *Ibid.*, p. 5.

where resources are, more often than not, inadequate or insufficient to meet their needs. Mark Miller, Ethicist, St-Paul's Hospital (Saskatoon), wrote:

> *And, I would say, the biggest ethical issue beyond the health care system itself is how often resources are lacking for family members caring for loved ones at home or in the community. Many parents, siblings and other caregivers are mostly abandoned to their own resources, which is grossly unfair and arguably creating more health problems among caregivers than necessary. Despair is not an uncommon feeling among families with a challenging member.*[529]

11.2 CONSENT AND CAPACITY ISSUES

Society preserves individual choice – the right to consent to, or to refuse treatment – based on the individual's fundamental right of autonomy. But for consent to mental health services or addiction treatment to be genuine, the individual must be mentally and legally capable of making that choice.

While decision-making capacity is essential for valid consent, applicable clinical tests to assess competence are controversial, especially for those with mental illness and addiction. Decision-making capacity includes in the ability to understand the relevant information concerning treatment, to appreciate the significance of that information, and to reason so as to weigh the available options logically.

> **In the context of mental illness, decision-making capacity can vary, and be highly dependent on the nature of the decision to be made. Difficulties relating to decision-making capacity include worries about capacity to manage financial affairs and to make personal care decisions, including decisions about housing.**
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> ***[DuVal and Rolleston (2004), p. 11.]***

Determinations of decision-making capacity raise special issues regarding the vulnerability of those suffering from mental disorders. Clinical assessments of decision-making capacity focus primarily on cognitive functioning. Because mental illness and addiction can affect cognition, individuals with such disorders, particularly in severe cases, will often lack decision-making capacity. They may do so intermittently, however, as in the case of a person suffering from addiction, or gradually, as in the case of a person who is aging, slowly succumbing to dementia or some other degenerative process affecting cognitive function. Adapting the delivery of services, as the patient fluctuates in, or gradually loses, his/her capacity, is a challenge for the mental health and addiction treatment system. Respect for the person requires that the changing or diminishing capacity is identified and diagnosed, and that the system adapt accordingly, in order not to infringe unduly on the autonomy of the person affected.

Non-cognitive as well as cognitive functioning can also be influenced by mental disorders in ways that affect decision-making. For example, clinical depression and other pathological affective states may diminish an individual's capacity to choose or reject treatment even

[529] Mark Miller, Brief to the Committee, 27 September 2003, p. 2.

though an understanding of the relevant information is largely unimpaired. Accepted conceptions of capacity do not account well for non-cognitive deficits such as the pessimism about the future that may characterize depression. The test for mental capacity is unclear in the presence of, for example, dominant but potentially transient feelings of hopelessness, worthlessness, or impulsivity.

Similarly, in patients with schizophrenia, the delusional and paranoid nature of the disease may undermine decision-making capacity in ways not clearly related to an absence or loss of cognition. Individuals suffering from addiction may have compromised decision-making by reason of difficulties in controlling the urge to engage in addictive behaviour. In some eating disorders, where a pathological body image distortion is experienced, the incapacity may be narrowly focused; the role of such distorted thinking in determining capacity is unclear.

Therefore, the clinical assessment of mental capacity in the presence of mental illness and addiction is a complex matter. Mental capacity to make decisions can exist at different levels and to varying degrees and can fluctuate over time. Yet, in law, upon expert testimony and at a given point in time the legal capacity to make decisions is decided by a judge. It is judged either to be present or absent in respect of distinct purposes (the capacity to care for one's property or to care for one's person, for example). There are no degrees of capacity or incapacity. The process for reviewing a judicial decision to establish protective supervision and to appoint a legal representative with each fluctuation in mental state can be time-consuming and cumbersome. In its brief to the Committee, the Canadian Catholic Bioethics Institute explained:

Mental health care is compromised when capacity is mistakenly denied or presumed.

[Canadian Catholic Bioethics Institute, Brief to the Committee, 20 February 2004, p. 3.]

> *The legal system tends to distinguish sharply between those who are deemed "capable" of decision-making regarding their health care and those who are incapable. Many persons with an active mental illness, such as severe depression or schizophrenia, may not meet the legal criteria for being declared "incapable", and yet they do have significant impairment of their ability to understand their condition, appreciate their options, make prudent decisions about their mental health care and follow through on these decisions. Since patient autonomy plays such a central role in contemporary medical ethics, it is helpful to consider the ethical challenges that arise when capacity is denied when in fact some level of capacity is retained, on the one hand, and when capacity is presumed when in fact it is significantly impaired, on the other.*[530]

The Committee was told that Ontario and some other provinces have legislated community treatment orders (CTOs). A CTO is a doctor's order, obtained with the affected person's consent, for an individual to receive treatment or care and supervision in the community. To give consent, the individual must be capable of consenting to treatment under the law. If

[530] Canadian Catholic Bioethics Institute, Brief to the Committee, 20 February 2004, p. 5.

found incapable of consenting under the law, and a substitute decision-maker has been authorized, the substitute decision-maker must consent to the CTO, even if the incapable person disagrees. There is concern among individuals with mental illness and addiction, however, that CTO legislation is too intrusive. Alternatively, families who in the absence of access to formal caregivers are sometimes the primary caregivers, believe that without such legislation they would at times lack the ability to help a loved one.

Witnesses explained that while family members and health care providers may wish to protect the health and well being of an individual who is vulnerable by reason of diminished capacity, it is still important to respect the individual's autonomy. It was suggested that families and health care givers must therefore tread a delicate balance between seeking to help an individual with mental illness/addiction and respect his/her autonomy – even partial autonomy. The answer is never black and white, but requires a response that seeks to understand the individual and the particularities of his/her condition.

More than with other types of disease, individuals with mental illness and addiction may lack insight into the existence and nature of the illness caused by their disorder. The result may be a high degree of mistrust of health care providers and high rates of refusal of treatment or of non-compliance. At what point does respecting a patient's refusal of treatment become tantamount to abandoning a vulnerable person in clear need of help or care when intervention or treatment is indicated?

There is little doubt that a person with unimpaired decision-making capacity may refuse treatment and that such refusal must be respected. However, when a person meets the legal standard of capacity – but nevertheless has compromised decision-making abilities – and is in need of care but refuses treatment, the situation for family members may be very difficult.

A related dilemma arises when a patient who is judged to be mentally and legally incapable of decision-making in respect of his or her own person resists the intervention needed to treat a mental disorder. Although a substitute decision-maker may legally authorize the treatment on behalf of the patient, the practical problem remains how to administer such treatment in the face of what may be stubborn resistance. The only available options may be to administer the treatment surreptitiously (such as by mixing medicine in food or drink), or employing force, or not at all.

Administering treatment using force or deception, particularly with vulnerable individuals such as those suffering from a mental disorder, raises serious ethical issues for family members and health care professionals. Force or deception may undermine trust, a vital ingredient in the relationship with the patient/client, making continued communication, cooperation and care even more difficult. Yet, it may be equally inappropriate *not* to provide treatment to a patient, who by virtue of incapacity, is vulnerable and in critical need of protection by some trusted person. Patients may later be grateful for treatment given against their will at a time when they were incapable of making treatment decisions or they may continue to harbour resentment and not seek treatment subsequently if their symptoms recur.

11.3 PRIVACY AND CONFIDENTIALITY

In its October 2002 report entitled *Recommendations for Reform*, the Committee explored the need to protect the privacy of electronic health records and their use in research. Considerations of privacy are equally and perhaps of greater concern in mental health, mental illness and addiction.

In their paper, DuVal and Rolleston suggest that a central presumption in society's preservation of privacy is that society as a whole, and each individual within it, benefits from strict preservation of the right of an individual to control the use of his or her personal information.[531]

> **It is always used in a crisis situation. (…) The person is considered a danger to self or others. (…) It is not a matter of casually sharing information. There is a purpose to the action, which is to give the person the best possible and the most knowledgeable assistance. That is not sharing information widely.**
>
> **[Nancy Hall, Mental Health Consultant (16:27-28]**

Moreover, the fiduciary relationship between health care provider and patient is built on trust and premised on the fundamental principle of confidentiality, as reflected in most professional codes of ethics. The testimony that we have heard, however, forces the Committee to ask whether our present legal and policy frameworks on privacy and confidentiality, which generally serve the mentally competent well, can act against the best interests of those who, because of the nature and pervasiveness of mental illness and addiction, become partially or completely dependent on the multiple care providers they encounter along the continuum of care. Mr. John Arnett, Head of the Department of Clinical Health Psychology, Faculty of Medicine, University of Manitoba, stated:

> *As a clinician, I cannot go down the hall to ask a colleague of mine, who has seen a patient that I am about to see, what they know that might help me to better evaluate that patient. The intent of the law is noble, there is no question about that, but it does impose limitations that impact negatively on patient care. A large part of patient care is having access to knowledge of history and information. The law creates a significant limitation.*[532]

Concern arising from strict observation of privacy and confidentiality rules also extends to the family of individuals with mental illness and addiction. Without the patient's permission, which those with mental illness/addiction may not be competent to give, a physician cannot share personal information with his or her caregivers, parents, siblings or children. Murray, whose paranoid schizophrenic son was killed by a bus after escaping from hospital, asked:

> *Why is it that the medical profession is not allowed to share information with family members when it has been shown that family support is beneficial to the patient? The patient is on meds because his thinking is*

[531] Gordon DuVal and Francis Rolleston (2004), p. 15.
[532] John Arnett (16:26).

> *affected; yet the medical profession believes that sharing information with a family member must be a decision of the patient, who cannot make a reasonable or thoughtful decision.*[533]

Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health, Canadian Institutes of Health Research, added to this by saying:

> *I wish to identify one area of law that I think has had a significant, negative impact in the mental health area and stigma in particular. Privacy legislation is seen, at least in Aboriginal communities and I believe it is true elsewhere, to be a detriment to promoting secrecy concerning health matters. It is seen as not allowing people to discuss matters and feel that they are a normal part of the human condition. They do not allow people who might be able to offer supports to have a way to do that in a timely way.*[534]

These thoughts were echoed by the brief from the Christ the King Family Support Group in Winnipeg which stated that: "confidentiality requirements are cited to justify lack of adequate information to family care-givers regarding the nature and severity of the illness". They further wrote that family members are excluded from information about medication, safety issues and the care and treatment plans at the time of discharge; that family concerns are arbitrarily dismissed and not documented in the patient's files; and that families are not adequately supported in attempting to cope with the devastating consequences of severe and persistent mental illnesses.[535] It should be noted, however, that in circumstances of clear, serious and imminent danger, a physician may have an overriding duty in law to break his/her patient's confidence in order to warn third parties and protect public safety.

11.4 SPECIAL POPULATIONS

11.4.1 Children/Adolescents

In previous chapters, the Committee described a number of issues concerning access to mental health services and supports for children and adolescents. In addition to these, mental health treatment for children and adolescents raises unique ethical challenges relating to vulnerability, decision-making capacity, and the use and disclosure of confidential information.

Mental health professionals must be aware of heightened vulnerability due to age when treating children and adolescents as well as the potential presence of co-occurring mental disorders and any history of social disruption. The capacity to consent to treatment interventions, and to do so voluntarily, is already compromised by mental illness but is even more difficult for young people. While parental and other family involvement in treatment

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533 Murray (9:18).

534 Bronwyn Shoush (16:12).

535 Carlyn Mackey, Aurise Kondziela and Dorothy Weldon (Christ the King Family Support Group - Winnipeg), Brief to the Committee, 24 October 2003.

can be extremely helpful, those providing care must be aware of the potential for mistrust, dysfunctional relationships, or undue pressure resulting from parental guilt or overprotective attitudes toward the child. Complex issues of confidentiality may arise when having to determine whether particular circumstances warrant disclosure of patient information to parents and/or relevant governmental or social service agencies.

11.4.2 Seniors

A variety of specific ethical issues are raised in the provision of mental health services to seniors. For example, many patients in geriatric in-patient units lack decision-making capacity and either have no close family or may be in conflict with family members. Geriatric patients are sometimes homeless; family members may be difficult to locate, uncooperative, uninvolved or reluctant to play a significant role. It is estimated that only 10 to 20% of such geriatric patients benefit from any active family participation, and the balance have no involved family members. Many senior patients "fall through the cracks", in that general hospitals may be ill equipped to manage individuals with mental illness and psychiatric hospitals may lack the resources to manage the patient's general medical condition. Thus, geriatric patients with mental disorders often receive inadequate care.

In psychiatric hospitals, staff may misread pain symptoms, while expressions of pain by elderly patients with mental illness are often not taken seriously in general hospitals. Inexperience with opiate pain medication and worries about drug interactions with antipsychotic and other psychiatric medications can lead to inadequate management of pain in this population. Anecdotal evidence indicates that care and pain control may well be inadequate; long waits for attention may be followed by discharge back to the psychiatric hospital where the care may also be inadequate.

Stigma often makes palliative care difficult for patients and their families to access. Staff may lack clear direction in caring for psychiatric patients who are at the end of life. They are often uncertain when to initiate aggressive treatment as opposed to treatment oriented primarily for pain management. Psychiatric nurses may have minimal experience using morphine and other narcotics and feel uncomfortable using them assertively.

11.4.3 Forensic Patients

In its written submission, the York University Centre for Practical Ethics stated:

> *Many inmates are in our prisons because of the emotional instability or mental disorder, and once there, are not given appropriate treatment unless they are threatening others or themselves. Moreover, their condition is likely to deteriorate in such an inappropriate environment.*[536]

DuVal and Rolleston identified two types of ethical dilemmas in relation to forensic psychiatry.[537] First, mental disorders, particularly when untreated, sometimes manifest in behaviour that would otherwise be seen as criminal. While individuals with mental disorders

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[536] Centre for Practical Ethics, York University, Brief to the Committee, 2004.
[537] Gordon DuVal and Francis Rolleston (2004), pp. 17-18.

who are accused of offences may sometime be found unfit to stand trial or not criminally responsible, police and courts often face a choice between referring mentally disturbed individuals for treatment or to the criminal justice system. Lack of effective training of police and other criminal justice officials may contribute to inappropriate referral of such persons away from mental health resources. Many believe that our jail and prison system house too many individuals with mental illness and addiction and insist that they, and society at large, would benefit from treatment rather than incarceration.

> **Are we incarcerating people because they are mentally ill rather than people who are fully capable who commit crimes? There are many mentally ill who are incarcerated. When in court, many of these people do not comprehend what is happening to them.**
> ***[The Salvation Army, Brief, October 2003, p. 3]***

The second issue is that mental health professionals practicing in forensic institutions have a "double agency" problem. In assessing a person charged with an offence, or in giving ongoing treatment to a person under the Provincial Review Board system, or otherwise giving evidence before administrative bodies or courts, these health care professionals have two distinct and often conflicting sets of obligations. Their obligations as medical caregivers to their patient are unquestioned duties that include acting in their patient's best interests, and to do no harm. But at the same time, they also have the perfectly legitimate obligation to society to offer their candid and objective judgement and advice to courts, Review Boards, and other administrative bodies with respect to the mental status, diagnosis, and prognosis of the persons under their care. Clearly, any such testimony and advice that places the priority on the benefits to society will not always be in the best interests of their patients/clients.

These conflicting obligations can be difficult to manage and can threaten the clinical relationship in a number of ways. Most importantly, while giving expert opinion serves a socially valuable role, the quality of care may be compromised because the forensic mental health practitioner is unable to promise the patient confidentiality. This has clear implications for the trust between the two. The practitioner may also be obliged to use information gathered in the clinical relationship that can be of detriment to the patient in court or administrative proceedings.

11.5 ETHICAL IMPLICATIONS OF ADVANCES IN GENETICS AND NEUROSCIENCE

11.5.1 Genetics and Mental Health

According to DuVal and Rolleston, the stigma associated with mental illness and addiction gives rise to particular worries about the privacy of genetic information and the traumatizing effects that disclosure may have on already vulnerable individuals. Genetic research and diagnosis relating to behaviours may be particularly threatening. Research thus far suggests that straightforward linkages between a given gene and specific psychiatric conditions are unlikely to be established. It seems more likely that genetic components of particular

phenotypes will involve complex interactions of genetic and environmental factors.[538] Still, safeguards must be in place to protect sensitive personal information, particularly that which alone, or when linked with other information, reveals, or may reveal some potential mental disorder or behavioural condition.

DuVal and Rolleston explained that attempting to adequately inform patients, or their surrogates, of genetic test results using the language of susceptibility and risk will raise difficult problems for individuals with mental illness and addiction. Affected and healthy individuals alike will have to cope with their own vulnerabilities. Social stigma and privacy risks complicate this burden, particularly since therapeutic benefit may lag behind diagnostic reliability. The genetic component of mental illness and addiction also raises challenging questions for families and relatives of the patient or research subject, where heritability patterns are often difficult to predict. The individual's right not to know must be balanced against the responsibility to inform people of a genetic predisposition. How this balance is reached will depend in part on the likelihood of the person's developing the condition concerned, when it might manifest itself, and the chances of their being able to take steps to prevent or reduce the effects of developing a mental illness in the future.[539]

The Committee was also informed of "genetic essentialism", the view that persons can be defined or characterized solely in terms of their genetic makeup. This raises special concerns for those with mental illness and addiction. People with genetic defects may come to feel they are flawed. Decisions about reproduction may also be affected; for some the availability of pre-natal screening may raise eugenic concerns. Since the social stigma of mental illness remains strong, worries about discrimination in insurance, employment, education, housing and others may be particularly acute.[540] Proper management of predictive genetic information is a challenge generally, and it is even more acute when dealing with those with mental illnesses that are already marked by social stigma.

11.5.2 Neuroscience and Mental Health

Recent advances in both the technological and theoretical understanding of neuroscience raise difficult ethical problems and challenge traditional notions of free will, responsibility and the self. Society's response to these issues will have far-reaching consequences, perhaps as much or more than those related to emerging genetic technologies.

Here we provide just a few of these issues raised by DuVal and Rolleston. Our evolving understanding of brain function and processes, together with developing imaging technology, will increasingly permit behaviours, personality traits and other mental events to be identified, monitored and correlated with observable changes in the brain. Employment, education, insurance, legal processes, immigration, counter-terrorism and other social activities and relationships may all be affected by the ability to identify and possibly predict both positive and negative behavioural dispositions to, for example, violence, addiction, dishonesty, stress, sympathy, cooperativeness and other behaviours.[541]

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538 *Ibid.*, p. 18.
539 *Ibid.*
540 *Ibid.*
541 *Ibid.*, p. 19.

Advances in neuroscience will also make cognitive and behavioural enhancements possible. DuVal and Rolleston contended that, aside from important questions about the ethics of enhancements involving behaviour, personality and cognitive abilities, there are real concerns for social justice if such enhancement technologies are initially expensive and available only to the wealthy and privileged. Further, as mental events become increasingly described in terms of brain structures and mechanisms, society may be obliged to re-examine accepted notions of free will, responsibility, and accountability – the so-called neuroscience of ethics. In the forensic context, for example, if criminal or other aberrant behaviour is found to be causally related to differences in brain structure or function, what would be the basis for appropriate criminal responsibility and punishment?[542]

11.6 ETHICS AND MENTAL HEALTH AND ADDICTION RESEARCH

As mentioned in the previous chapter, there has been an acceleration of clinical research into mental illness and addiction in the last two decades that has produced significant advances in treatment. Much of this important research, however, requires the participation of research subjects who suffer from mental disorders themselves.

In their paper, DuVal and Rolleston stressed that the history of psychiatric research is littered with public and private sector studies that have exploited the vulnerability of individuals with mental disorders, the neurologically impaired and developmentally disabled research subjects. In one particularly infamous example, the American CIA sponsored clinical trials conducted at the Allan Memorial Institute at McGill University during the 1950s and early 1960s in which psychiatric patients were given hallucinogenic drugs without their knowledge. The history of the unacceptable treatment of these vulnerable participants has played a pivotal role in the movement toward increased scrutiny and regulation of research involving human subjects; this provides an important context for the consideration of the ethics of research into mental illness and addiction.[543]

Advances in mental health science promise great benefits for those who suffer, or will come to suffer, from mental disorders and, in some cases, for research subjects themselves. While individuals with mental illness may be particularly vulnerable in a number of ways, research policies and regulations that focus primarily on their vulnerabilities and deficits could encourage and possibly exacerbate the stigmatization already suffered by this population. But on the other hand, it may be unjust to exclude, by overly restrictive regulation, those individuals with mental disorders who could benefit from their participation in research.[544]

There is a particular need for special precautions in research involving individuals with mental illness and addiction. While all subjects of clinical research are vulnerable to some degree, the vulnerability of individuals participating in clinical mental illness/addiction research warrants particular attention. On the other hand, most individuals with mental illness function reasonably well and it may be unnecessary to put too much focus on special regulations for research involving individuals with mental illness. Nevertheless, it is clear

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542 *Ibid.*
543 Gordon DuVal and Francis Rolleston (2004), pp. 19-20.
544 *Ibid.*, p. 20.

that ethical principles must be applied with care to the particular vulnerabilities of individuals with mental illness.[545]

An ethically appropriate framework for psychiatric research ethics balances rigorous protections for human subjects with recognition of the enormous social and individual benefits that flow from well-designed and ethically conducted scientific research. Ethical concerns that are particularly germane to mental health research and give rise to the need for special sensitivity and insight, include decision-making capacity and research design issues.

11.6.1 Decision-Making Capacity

This subject has been discussed in considerable detail earlier in this chapter. Decision-making capacity to give valid consent is an essential condition for research involving human subjects. The vigilance that must be applied when assessing decision-making capacity and determining the appropriate decision-maker in the context of clinical care, must be applied even more vigorously in the context of research where participation in a study may not be for the direct benefit of the patient concerned. For instance, article 21 of the *Civil Code of Quebec* requires that, in order for an adult who is incapable of giving consent to participate in research, substitute consent must be obtained not just by a family member (as in the context of necessary care), but by a formally appointed mandatory, tutor or curator. As a result of this heightened protection, however, incapable adults who do not have legally appointed representatives, cannot participate in research in Québec, apart from rare emergency situations.

11.6.2 Research Design Issues

Some study methodologies have drawn particular ethical scrutiny when used in mental health and addiction research, both because of their inherent risks and because the subject population are individuals with mental disorders. Three types of study design have raised particular ethical concerns.

- Placebo-Controlled Studies: The randomized, controlled trial is generally accepted as the "gold standard" experimental design for comparing the efficacy and safety of medications. Comparison with placebo is regarded by regulators as providing the best evidence for the efficacy and safety of a new medication. However, the use of a placebo control design has been strongly criticized where there is an existing established effective treatment for the disease being studied; such criticisms have been aimed prominently at research in psychiatry, where research subjects enrolled in the placebo arm of the trial might have to be deprived of their much needed existing treatment, suffer potential negative effects of withdrawal and potentially relapse into a state of mental illness for the duration of the study.
- Washout Studies: A washout study is one in which researchers discontinue the medication of a subject patient in order to study the patient in an unmedicated state or to initiate another therapy, often an experimental one. Accordingly, the existing medication is discontinued, usually following a gradual reduction in dosage. The withdrawal period typically must last long enough that the drug has completely

[545] *Ibid.*

cleared from the patient's system, so that the residual effects from the withdrawn medication do not confound the study results, or result in unwanted drug interactions. Depending on the particular study design and the medication involved, the washout can last indefinitely, or until acute symptoms return.

- Challenge Studies: A "challenge" study is one in which a psychopharmaceutical agent or psychological challenge is administered to research subjects under controlled conditions to measure or observe behavioural response, a neurobiological response (using brain imaging), or both. In psychiatry, these designs have proven to be extremely valuable in testing hypotheses and characterizing a variety of neurochemical and pathophysiological processes. Research of this kind may lead to improved predictions of treatment response and effective new therapies.[546]

In order for placebo-controlled clinical trials to be considered ethically permissible, certain conditions must prevail. Currently, in Canada, existing regulatory frameworks and national research ethics guidelines differ on what those conditions must be. One major difference between the existing *International Conference on Harmonization's (ICH) Harmonized Tripartite Guideline for Good Clinical Practice* (E-10) and the existing *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (TCPS) is that TCPS currently allows placebo-controlled trials only if no standard treatment is available to, appropriate for, or wanted by the individual, whereas ICH E-10 allows placebo-controlled trials to take place even if there is established effective treatment, as long as there is no risk of death or permanent ill effect to the individual. CIHR and Health Canada have undertaken a major initiative in an attempt to review the scientific, ethical and legal principles underlying these documents with a view towards harmonizing both national policies on the appropriate use of placebos in randomized controlled trials. The Committee highly encourages CIHR and Health Canada to pursue these collaborative efforts and to adopt and implement a harmonized national policy.

In the case of challenge studies, for practical reasons subjects must usually be deceived, or at best only partially informed about the details of the study. Even without impaired decision-making capacity, this has clear ethical implications for informed consent.

Despite a history that has included serious abuses, mental health and addiction research is vitally important, not least to those who suffer, and those who will come to suffer, from mental disorders. Clinical psychiatric research gives rise to challenging ethical dilemmas. The particular vulnerabilities attending mental illness/addiction merit particularly close attention to the design, review and conduct of research.

11.7 COMMITTEE COMMENTARY

As mentioned above, the Committee believes strongly that many of the ethical issues raised with respect to mental illness and addiction originate from the stigma associated with these disorders. Addressing stigma and discrimination through awareness campaigns designed for both mental health professionals, researchers and the general public would be an important step in responding to these ethical concerns.

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[546] *Ibid.*, pp. 20-21.

The ethical principles underlying the delivery of mental health services and addiction treatment – particularly those of beneficence and justice – must be addressed carefully and in a timely manner. It is clear that mental health and addiction lag behind other diseases and conditions covered under Canada's health care system. They are technologically less advanced and critically more fragmented, and the development of evidence-based guidelines to inform best practices has not reached the level of other specialties. For these reasons, the Committee believes very strongly that the prevention and treatment of mental illness and addiction should be coordinated across the wide spectrum of potential services both within and outside health care, and should be given priority in decisions about the allocation of scarce resources.

The Committee acknowledges that decision-making capacity may be impaired by mental illness and addiction, and also that not all mental disorders impair decision-making capacity. Furthermore, decision-making capacity of those suffering from mental illness and addiction may be impaired to varying degrees and at different times. Given the structure of existing laws that draw rather rigid conclusions about the presence or absence of decision-making capacity, and the relative inflexibility of changing or adapting protective supervision regimes, there should be a more fulsome debate about how to give meaningful effect to a person's partial and/or fluctuating capacity to make decisions for himself or herself. An appropriate balance must be struck between the respect owed to the right to individual autonomy and the need to protect vulnerable persons when their decision-making capacity is impaired by reason of mental illness or addiction.

With respect to privacy and confidentiality issues, the Committee is well aware that any erosion of privacy and confidentiality protections can have serious negative consequences on an individual's trust in his or her caregivers. However, as noted above, witnesses have told us that rigid adherence to privacy and confidentiality rules in certain circumstances can work against the interests of individuals whose mental health is compromised. The unique challenges they describe must be recognized when developing, interpreting and applying privacy and confidentiality rules, so as to allow health care providers and family caregivers to provide patients with the much needed support they sometimes require.

As stated in Chapter 10, the Committee strongly supports research into mental illness and addiction; it is the foundation for future advances in treatment and prevention. Research involving human participants must be designed and performed in accordance with the highest scientific and ethical standards and must protect the dignity of individuals and their families who make this valuable contribution to scientific progress.

The Committee acknowledges that individuals suffering from mental illness and addiction are particularly vulnerable as research subjects. It is therefore of paramount importance to protect the rights and well-being of those research participants, while promoting ethically responsible research. Research advances should not be pursued, however, at the expense of human rights and human dignity. But nor should protections be so stringent so as to exacerbate existing social stigma associated with mental illness and addiction and potentially exclude this vulnerable population from vitally important research that can improve scientific knowledge about their condition and even benefit them as individuals.

It is clear that interdisciplinary research is needed to address adequately many of the challenging ethical, legal and socio-cultural issues arising from mental illness and addiction. The Committee was told of the need to conduct this kind of research in a comprehensive and fundamental manner. In a letter to the Committee, Dr. Julio Arboleda-Florez, Professor and Head, Department of Psychiatry, Queen's University, suggested that there is a pressing need for further research into mental health ethics and research ethics to address effectively issues such as those discussed above:

> *There is not much applied ethical research in Canada or elsewhere and no oganizational or financial capacity. (…) Applied research in the sense of testing the social take and realities of ethical concepts, their transcultural reach and implications in terms of transcultural dissonances, their population acceptability, their social meaning, their ease of implementation, or even their usefulness, is sorely missing so the field is becoming a theoretical morass.*[547]

We believe that Canada could play an important leadership role in this regard, both nationally and internationally.

Finally, the Committee agrees with experts that the acute and complex ethical concerns that arise in the context of neuroscience and genetic research must be addressed carefully so as to understand better the underlying values and principles associated with these and other evolving and rapidly advancing technologies in modern medicine.

[547] Dr. Julio Arboleda-Florez, Brief to the Committee, 5 November 2003.

CONCLUSION

This report is the first comprehensive document on mental health, mental illness and addiction in Canada. It brings together, for the first time, historical analysis of the development of mental health and addiction services, a description of their current state and an assessment of how they are being delivered. It also provides the basis for a greater understanding of the mental health needs of Canadians, by describing the problems and challenges faced by individuals with mental illness and addiction.

This report was based on the testimony of many experts as well as on a review of relevant literature. This report is intended to serve as a useful reference document to anyone who wishes to participate in the Spring, 2005 phase of the Committee's study on mental health, mental illness and addiction.

During this next phase, the Committee will hold extensive public hearings across the country to hear the views of Canadians on how to reform and restructure the delivery of mental health services and addiction treatment. We hope that the Committee's report which will result from these hearings, and which will be released in November 2005, will serve as a catalyst for an informed debate on mental health, mental illness and addiction.

APPENDIX A:
LIST OF WITNESSES
THIRD SESSION OF THE 37TH PARLIAMENT
(FEBRUARY 2, 2004 – MAY 23, 2004)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alzheimer Society of Canada	Steve Rudin, Executive Director	June 4, 2003	17
As individuals	Thomas Stephens, Consultant	March 20, 2003	11
	Nancy Hall, Mental Health Consultant	May 28, 2003	16
	J. Michael Grass, Past Chair, Champlain District Mental Health Implementation Task Force	June 5, 2003	17
	Loïse David Murray Ronald	February 26, 2003	9
Canadian Academy of Psychiatric Epidemiology	Dr. Alain Lesage, Past President	March 19, 2003	11
Canadian Academy of Psychiatry and the Law	Dr. Dominique Bourget, President	June 5, 2003	17
Canadian Coalition for Senior Mental Health	Dr. David K. Conn, Co-Chair; President, Canadian Academy of Geriatric Psychiatry	June 4, 2003	17
Canadian Institute for Health Information	Dr. John S. Millar, Vice-President, Research and Analysis	March 20, 2003	11
	Carolyn Pullen, Consultant	March 20, 2003	11
	John Roch, Chief Privacy Officer and Manager, Privacy Secretariat	March 20, 2003	11
Canadian Institutes of Health Research	Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health	May 28, 2003	16

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Institutes of Health Research	Jean-Yves Savoie, President, Advisory Board, Institute of Population and Public Health	June 12, 2003	18
	Dr. Rémi Quirion, Scientific Director, Institute of Neurosciences, Mental Health and Addiction	May 6, 2003	14
Canadian Mental Health Association – Ontario Division	Patti Bregman, Director of Programs	June 12, 2003	18
Canadian Paediatric Society	Dr. Diane Sacks, President-Elect	May 1, 2003	13
	Marie-Adèle Davis, Executive Director	May 1, 2003	13
Centre for Addiction and Mental Health	Jennifer Chambers, Empowerment Council Coordinator	May 14, 2003	15
	Rena Scheffer, Director, Public Education and Information Services	May 28, 2003	16
Centre hospitalier Mère-enfant Sainte-Justine	Dr. Joanne Renaud, Child and Adolescent Psychiatrist; Young Investigator, Canadian Institutes of Health Research	April 30, 2003	13
Children's Hospital of Eastern Ontario	Dr. Simon Davidson, Chairman, Division of Child and Adolescent Psychiatry	May 1, 2003	13
CN Centre for Occupational Health and Safety	Kevin Kelloway, Director	June 12, 2003	18
Douglas Hospital	Eric Latimer, Health Economist	May 6, 2003	14
	Dr. James Farquhar, Psychiatrist	May 6, 2003	14
	Dr. Mimi Israël, Head, Department of Psychiatry ; Associate Professor, McGill University	May 6, 2003	14

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Douglas Hospital	Myra Piat, Researcher	May 6, 2003	14
	Ampara Garcia, Clinical Administrative Chief, Adult Ultraspecialized Services Division	May 6, 2003	14
	Manon Desjardins, Clinical Administration Chief, Adult Sectorized Services Division	May 6, 2003	14
	Jacques Hendlisz, Director General	May 6, 2003	14
	Robyne Kershaw-Bellmare, Director of Nursing Services	May 6, 2003	14
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, President and Chief Executive Officer, Warren Sheppell Consultants	June 12, 2003	18
Hamilton Health Sciences Centre	Venera Bruto, Psychologist	June 4, 2003	17
Health Canada	Tom Lips, Senior Advisor, mental Health, Healthy Communities Division, Population and Public Health Branch	March 19, 2003	11
	Pam Assad, Associate Director, Division of Childhood and Adolescence, Centre for Healthy Human Development, Population and Public Health Branch	April 30, 2003	13
Laval University	Dr. Michel Maziade, Head, Department of Psychiatry, Faculty of Medecine	May 6, 2003	14
Louis-H. Lafontaine Hospital	Jean-Jacques Leclerc, Director, Rehabilitation Services and Community Living	May 6, 2003	14
	Dr. Pierre Lalonde, Director, Clinique jeunes adultes	May 6, 2003	14

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
McGill University	Dr. Howard Steiger, Professor, Psychiatry Department; Director, Eating Disorders Program, Douglas Hospital	May 1, 2003	13
Province of British Columbia	Patrick Storey, Chair, Minister's Advisory Council on Mental Health	May 14, 2003	15
	Heather Stuart, Associate Professor, Community Health and Epidemiology	May 14, 2003	15
Queen's University	Dr. Julio Arboleda-Florèz, Professor and head, Department of Psychiatry	March 20, 2003	11
Registered Nurses of Canada	Margaret Synyshyn, President	May 29, 2003	16
Statistics Canada	Lorna Bailie, Assistant Director, Health Statistics Division	March 20, 2003	11
St.Joseph's Health Care London	Maggie Gibson, Psychologist	June 4, 2003	17
St. Michaels Hospital	Dr. Paul Links, Arthur Sommer Rothenberg Chair in Suicide Studies	March 19, 2003	11
Université du Québec à Montréal	Henri Dorvil, Professor, School of Social Work	May 6, 2003	14
	Dr. Michel Tousignant, Professor, Centre de recherche et intervention sur le suicide et l'euthanasie	May 6, 2003	14
University of British Columbia	Dr. Charlotte Waddell, Assistant Professor, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Faculty of Medecine	May 1, 2003	13

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Calgary	Dr. Donald Addington, Professor and Head, Department of Psychiatry	May 29, 2003	16
University of Manitoba	John Arnett, Head, Department of Clinical Health Psychology, Faculty of Medicine	May 28, 2003	16
	Robert McIlwraith, Professor and Director, Rural and Northern Psychology Program	May 29, 2003	16
University of Montreal	Laurent Mottron, Researcher, Department of Psychiatry, Faculty of Medicine	May 6, 2003	14
	Dr. Richard Tremblay, Canada Research Chair in Child Development, Professor of Pediatrics, Psychiatry and Psychology, Director, Centre of Excellence for Early Childhood Development	May 6, 2003	14
	Dr. Jean Wilkins, Professor and Paediatrics, Faculty of Medecine	May 6, 2003	14
	Dr. Renée Roy, Assistant Clinical Professor, Department of Psychiatry, Faculty of Medecine	May 6, 2003	14
University of Ottawa	Tim D. Aubry, Associate Professor; Co-Director, Centre for Research and Community Services	June 5, 2003	17
	Dr. Jeffrey Turnbull, Chairman, Department of Medicine, Faculty of Medicine	June 5, 2003	17

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Toronto	Dr. Joe Beitchman, Professor and Head, Division of Child Psychiatry, Department of Psychiatry; Psychiatrist-in-Chief, Hospital for Sick Children	April 30, 2003	13
	Dr. David Marsh, Clinical Director, Addiction Medicine, Centre for Addiction and Mental Health	May 29, 2003	16

APPENDIX B:
LIST OF WITNESSES
SECOND SESSION OF THE 37TH PARLIAMENT
(SEPTEMBER 30, 2002 – NOVEMBER 12, 2003)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alberta Mental Health Board	Ray Block, Chief Executive Officer	April 28, 2004	7
Alberta Mental Health Board	Sandra Harrison, Executive Director, Panning, Advocacy & Liaison	April 28, 2004	7
Anxiety Disorders Association of Canada	Peter McLean, Vice-President	May 12, 2004	9
As individuals	Charles Bosdet	April 29, 2004	7
	Pat Caponi		
	Don Chapman		
Australia, Government of (*by videoconference)*	Dermot Casey, Assistant Secretary, Health Priorities and Suicide Prevention Branch, Department of Health and Ageing	April 20, 2004	6
	Jenny Hefford, Assistant Secretary, Drug Strategy Branch, Department of Health and Ageing		
British Columbia Ministry of Health Services	Irene Clarkson, Executive Director, Mental Health and Addictions	April 28, 2004	7
Canadian Association of Social Workers	Stephen Arbuckle, Member, Health Interest Group	March 31, 2004	5
Canadian Medical Association	Dr. Sunil Patel, President	March 31, 2004	5
	Dr. Gail Beck, Acting Associate Secretary General		
Canadian Mental Health Association	Penny Marrett, Chief Executive Officer	May 12, 2004	9

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Nurses Association, the Canadian Federation of Mental Health Nurses and the Registered Psychiatric Nurses of Canada	Nancy Panagabko, President, Canadian Federation of Mental Health Nurses	March 31, 2004	5
	Annette Osten, Board Member, Canadian Nurses Association	March 31, 2004	5
Canadian Psychiatric Association	Dr. Blake Woodside, Chairman of the Board	March 31, 2004	5
Canadian Psychological Association	John Service, Executive Director	March 31, 2004	5
Centre for Addiction and Mental Health	Christine Bois, Provincial Priority Manager for Concurrent Disorders	May 5, 2004	8
	Wayne Skinner, Clinical Director, Concurrent Disorder Program		
	Brian Rush, Research Scientist, Social Prevention and Health Policy		
Centre for Suicide Prevention	Diane Yackel, Executive Director	April 21, 2004	6
Cognos	Marilyn Smith-Grant, Senior Human Resources Specialist	April 1, 2004	5
Correctional Service of Canada	Larry Motiuk, Director General, Research	April 29, 2004	7
	Françoise Bouchard, Director General, Health Services	April 29, 2004	7
Douglas Hospital	Dr. Gustavo Turecki, Director, McGill Group for Suicide Studies, McGill University	April 21, 2004	6
House of Commons	The Honourable Jacques Saada, P.C., M.P., Leader of the Government in the House of Commons and Minister responsible for Democratic Reforms	April 1, 2004	5

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Human Resources and Skills Development Canada	Bill Cameron, Director General, National Secretariat on Homelessness	April 29, 2004	7
Human Resources and Skills Development Canada	Marie-Chantal Girard, Strategic Research Manager, National	April 29, 2004	7
Institute of Neurosciences, Mental Health and Addiction	Richard Brière, Assistant Director	April 21, 2004	6
McGill University (*by videoconference)*	Dr. Laurence Kirmayer, Director, Division of Social and Transcultural Psychiatry, Department of Psychiatry	May 13, 2004	9
Mood Disorder Society of Canada	Phil Upshall, President	May 12, 2004	9
Native Mental Health Association of Canada	Brenda M. Restoule, Psychologist and Ontario Board Representative	May 13, 2004	9
New Zealand, Government of (*by videoconference)*	Janice Wilson, Deputy Director General, Mental Health Directorate, Ministry of Health	May 5, 2004	8
	David Chaplow, Director and Chief Advisor of Mental Health		
	Arawhetu Peretini, Manager of Maori Mental Health		
	Phillipa Gaines, Manager of Systems Development of Mental Health		
Nova Scotia Department of Health	Dr. James Millar, Executive Director, Mental Health and Physician Services	April 28, 2004	7
Ontario Federation of Community Mental Health and Addiction	David Kelly, Executive Director	May 5, 2004	8
Ontario Hospital Association	Dr. Paul Garfinkel, Chair, Mental Health Working Group	March 31, 2004	5

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Privy Council Office	Ron Wall, Director, Parliamentary Operations, Legislation and House Planning	April 1, 2004	5
Privy Council Office	Ginette Bougie, Director, Compensation and Classification	April 1, 2004	5
Public Service Alliance of Canada	John Gordon, National Executive Vice-President	April 1, 2004	5
	James Infantino, Pensions and Disability Insurance Officer		
Schizophrenia Society of Canada	John Gray, President-Elect	May 12, 2004	9
Simon Fraser University (*by videoconference)*	Margaret Jackson, Director, Institute for Studies in Criminal Justice Policy	April 29, 2004	7
Six Nations Mental Health Services	Dr. Cornelia Wieman, Psychiatrist	May 13, 2004	9
Treasury Board Secretariat	Joan Arnold, Director, Pensions Legislation Development, Pensions Division	April 1, 2004	5
U.S. Campaign for Mental Health Reform	William Emmet, Coordinator	April 1, 2004	5
U.S. President's New Freedom Commission on Mental Health (*by videoconference)*	Michael Hogan, Chair	April 1, 2004	5
United Kingdom, Government of (*by videoconference)*	Anne Richardson, Head of the Mental Health Policy Branch, Department of Health	May 6, 2004	8
	Adrian Sieff, Head of the Mental Health Legislation Branch		

APPENDIX C:
LIST OF INDIVIDUALS WHO RESPONDED TO A LETTER FROM THE COMMITTEE ON PRIORITIES FOR ACTION

CANADIAN RESEARCH GROUP

CancerCare Manitoba	Harvey Max Chochinov, MD, PhD, FRCPC, Canada Research Chair in Palliative Care, Director, Manitoba Palliative Care Research Unit, CancerCare Manitoba, Professor, Department of Psychiatry, Community Health Sciences and Family Medicine(Division of Palliative Care) University of Manitoba
Carleton University	Dr. Hymie Anisman, Canadian Research Chair in Neuroscience, Ontario Mental Health Foundation Senior Research Fellow
Douglas Hospital Reseach Centre	Ashok Malla, MD, FRCP Canada Research Chair in Early Psychosis, Professor of Psychiatry, McGill University, Director, Clinical Research Division
McGill University Health Centre	Eric Fombonne, MD, FRCPsych, Canada Research Chair in Child Psychiatry, Professor of Psychiatry, University McGill, Director, Montreal Children's Hospital
University of Alberta	Glen B. Baker, PhD, DSc, Professor and Chair, Canada Research Chair in Neurochemistry and Drug Development
University of Manitoba – Faculty of Medecine	Brian J. Cox, Ph.D., C. Psych., Canada Research Chair in Mood and Anxiety Disorders, Associate Professor of Psychiatry, Adjunct Professor, Departments of Community Health Sciences and Psychology

DEANS OF MEDICAL SCHOOLS

Kingston General Hospital	Samuel K. Ludwin, M.B.B., Ch., F.R.C.P.C., Vice-President, (Research Development)
McGill University Health Centre	Joel Paris, M.D., Professor and Chair, Department of Psychiatry
University of Alberta	Dr. L. Beauchamp, Dean, Faculty of Eduction
University of Sherbrooke	Pierre Labossière, P. Eng., Ph.D., Associate Vice-Rector, Research
University of Western Ontario	Dr. Carol P. Herbert, Dean of Medicine and Dentistry

ILLNESS RELATED GROUP

Canada's Research-Based Pharmaceutical Companies	Murray J. Elston, President
Eli Lilly Canada Inc.	Terry McCool, Vice-President, Corporate Affairs
GlaxoSmith Kline	Geoffrey Mitchinson, Vice-President of Public Affairs
Merck Frosst Canada	André Marcheterre, President
NSERC	Thomas A. Brzustowski, President
Ontario Mental Health Foundation	Howard Cappell, Ph.,D. (C.Psych) Executive Director
Roche Pharmaceuticals	Ronnie Miller, President & C.E.O.
Schizophrenia Society of Canada	Fred Dawe, President

MENTAL HEALTH ETHICS GROUP

Centre for Addiction and Mental Health	Paul E. Garfinkel, MD, FRCPC, President and CEO
McGill University – Douglas Hospital Research Centre	Maurice Dongier, Professor of Psychiatry

Parkwood Hospital, St.Joseph's Health Care London	Maggie Gibson, Ph. D., Psychologist, Veterans Care Program
Queen's University	J. Arboleda-Florèz, Professor and Head, Department of Psychiatry
Salvation Army – Territorial Headquarters Canada and Bermuda	Glen Shepherd, Colonel, Chief Secretary
St-Paul's Hospital	Mark Miller, C.S.s.R., Ph.D. Ethicist
University of Alberta	Wendy Austin, RN, Ph. D., Canada Research Chair, Relational Ethics in Health Care, Faculty of Nursing and John Dosseter Health Ethics Centre
University of Alberta, Faculty of Nursing	Genevieve Gray, Dean and Professor, Faculty of Nursing
University of British Columbia	Peter D. McLean, Ph.D. Professor and Director, Anxiety Disorders Unit
University of Western Ontario	Nancy Fedyk, Executive Assistant to the Dean
Winnipeg Regional Health Authority	Linda Hughes, Chair, WRHA Mental Health Ethics Committee
York University	David Shugarman, Director

PRESIDENT OF UNIVERSITY

Institute of Mental Health Research – University of Ottawa	Zul Merali, Ph. D., President and CEO
McGill University	Heather Munroe-Blum, Professor of Epidemiology and Biostatistics
University of Lethbridge	Lynn Basford, Dean, Health Sciences

GOVERNMENT RESPONSIBILITY

Canadian Coalition for Seniors	J. Kenneth Le Clair, MD, FRCPC, Co-Chair, Canadian Coalition for Seniors Mental Health, Professor and Chair, Geriatric Division, Department of Psychiatry, Queen's University, Clinical Director, Specialty Geriatric Psychiatry Program
Canadian Coalition for Seniors Mental Health	David K. Conn, MB., FRCPC, Co-Chair Canadian Coalition for Seniors Mental Health, Psychiatrist-in-Chief, Department of Psychiatry, Baycrest Centre for Geriatric Care, Associate Professor, Department of Psychiatry, University of Toronto, President, Canadian Academy of Geriatric Psychiatry
Canadian Institute of Health Research	Dr. Jeff Reading, PhD, Scientific Director – Institute of Aboriginal Peoples's Health
Canadian Mental Health Association	Bonnie Pape, Director of Programs & Research, Canadian Mental Health Association – National Office
Dalhousie University – Department of Psychology	Patrick J. McGrath, OC, PhD, FRSC, Co-ordinator of Clinical Psychology, Killam Professor of Psychology, Professor of Pediatrics and Psychiatry, Canada Research Chair, Psychologist IWK Health Centre
Dalhousie University, Faculty of Medicine	David Zitner, D. Ph., Director, Medical Informatics
Department of Health and Wellness New-Brunswick	Ken Ross, Assistant deputy Minister
Douglas Hospital Research Centre	Michel Perreault, Ph. D., Researcher, Douglas Hospital, Professor, Department of Psychiatry McGill University
Douglas Hospital Research Centre - Institute of Neurosciences, Mental Health and Addiction	Rémi Quirion, Scientific Director, (INMHA)

Faculty of Medicine – University of Ottawa	Jacques Bradwejn, MD FRCPC, DABPN, Chair of the Department of Psychiatry, Psychiatris-in-Chief, Royal Ottawa Hospital, Head of Psychiatrist, The Ottawa Hospital
Family Council: Empowering Families in Addictions and Mental Health	Betty Miller, Coordinator, The Family Council
Global Business and Economic Roundtable on Addiction and Mental Health – Affiliated with the Centre for Addiction and Mental Health	Bill Wilkerson, Co-Founder and Chief Executive Officer
Human Resources Development Canada	Deborah Tunis, Director General, Office for Disability Issues
McGill University Health Centre	Juan C. Negrete, MD, FRCP(C) Professor of Psychiatry, McGill University, Chair, Addictions Section, Canadian Psychiatric Association
McMaster University	Dr. Richard P. Swinson, MD, FRCPC, Morgan Firestone Chair in Psychiatry, Psychiatry & Behavioural Neurosciences, McMaster University, Chief, Department of Psychiatry, St.Joseph's Healthcare
NAHO National Aboriginal Health Organization	Judith G. Bartlett, M.D. CCFP, Chairperson
Ottawa Hospital	Paul Roy, MD, FRCPC, Assistant Professor of Psychiatry, University of Ottawa, Director, Ottawa First Episode Psychosis Program
Royal Ottawa Hospital	J. Paul Fedoroff, M.D., Associate Professor of Psychiatry, University of Ottawa, Research Director, Forensic Unit, Institute of Mental Health Research
Six Nations Mental Health Services	Cornelia Wieman, M.D., FRCPC, Psychiatrist
Syncrude	Eric P. Newell, Chairman & Chief Executive Officer

University of British Columbia – Mental Health Evaluation & Community Consultation Unit, Department of Psychiatry	Elliot Goldner, MD, MHSc, FRCPC, Head, Division of Mental Health Policy & Services
University of Ottawa – Office of the Vice-President, Research	Yvonne Lefebvre, Ph.D., Associate Vice-President, Research
University of Ottawa- School of Psychology	John Hunsley, Ph.D., C. Psych., Professor of Psychology
University of Toronto – Sunnybrook & Women's College Health Sciences Centre	Nathan Herrmann, M.D., F.R.C.P. (C)

SENATE SÉNAT
CANADA

RAPPORT 1

Santé mentale, maladie mentale et toxicomanie:

Aperçu des politiques et des programmes au Canada

Rapport provisoire du
Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

L'honorable Michael J.L.Kirby, président
L'honorable Wilbert Joseph Keon, vice-président

Novembre 2004

PARTIE 3

La prestation de services et la politique gouvernementale dans le domaine de la maladie mentale et de la toxicomanie

CHAPITRE 7: SERVICE DE SANTÉ MENTALE ET TRAITEMENT DE LA TOXICOMANIE AU CANADA : PERSPECTIVE ET HISTORIQUE

INTRODUCTION

L'histoire des services de santé mentale et du traitement de la toxicomanie au Canada est parallèle à celle de l'Europe et des États-Unis. Les services de santé mentale ont très souvent évolué différemment du traitement de la toxicomanie au cours du dernier siècle. Il en a résulté deux systèmes distincts de soins et de soutien, soit l'un pour les personnes atteintes de maladies mentales et un autre pour les personnes souffrant de toxicomanie. Ce n'est qu'au cours de la dernière décennie que l'on a cherché à favoriser une meilleure intégration des deux systèmes.

Le système de services de santé mentale et celui du traitement de la toxicomanie se sont efforcés d'offrir le traitement le plus compatissant et le mieux adapté possible, mais ils ont tous deux été affligés par la stigmatisation, qui a nui à leur développement. À cause de malentendus généralisés et d'idées fausses répandues, les gens atteints d'une maladie mentale étaient souvent qualifiées d'« idiots », d'« imbéciles » et d'« aliénés », tandis que les problèmes de toxicomanie étaient perçus comme un signe de faiblesse personnelle. Dans certains cas, une attitude punitive, illustrée par le désir d'isoler de la société les personnes atteintes de maladie mentale et de toxicomanie, a nui à la prestation de services appropriés. Malgré les nombreux progrès des modèles de soins, des politiques et des lois, les impressions négatives et la stigmatisation persistent encore de nos jours.

Même si des améliorations spectaculaires ont été apportées ces vingt dernières années dans la prestation des services de santé mentale et le traitement de la toxicomanie, le Comité convient avec de nombreux témoins qu'aucun de ces deux domaines n'a réussi à obtenir un appui public ou du financement gouvernemental suffisants pour que les services offerts soient de qualité égale à ceux que reçoivent les Canadiens dans le traitement de maladies physiques comme le cancer ou les maladies cardiaques.

Le présent chapitre donne un aperçu chronologique de l'évolution des services de santé mentale et du traitement de la toxicomanie au Canada. La section 7.1 résume l'évolution des points de vue sur la maladie mentale qui, au fil des siècles, ont influé sur l'approche adoptée au Canada. La section 7.2 présente un aperçu historique du développement du système de services de santé mentale au Canada. La section 7.3 analyse brièvement l'évolution du système de traitement de la toxicomanie.

7.1 ÉVOLUTION DES POINTS DE VUE SUR LA MALADIE MENTALE AU FIL DES SIÈCLES[320]

Les soins dispensés aux personnes atteintes de troubles mentaux et du comportement ont toujours reflété les valeurs sociales qui influent sur la perception de la maladie mentale dans la société.
[OMS, 2001, p. 49]

Pendant des siècles, les convictions religieuses, spirituelles ou culturelles ont dominé la façon dont les personnes atteintes d'une maladie mentale ont été traitées et considérées par la société. La psychiatrie est une science « jeune » par rapport à d'autres disciplines scientifiques.

Stein et Santos (1998) qu'on a trouvé des crânes de 5 000 ans, perforés de trous pouvant mesurer jusqu'à deux centimètres de diamètre, des pays de l'est de la Méditerranée et de l'Afrique du Nord. On croit que ces trous ont été percés avec des instruments acérés et que cette trépanation a été pratiquée pour des raisons thérapeutiques. Certains sujets étaient probablement atteints d'une maladie mentale et comme on croyait à l'époque qu'ils étaient possédés par de mauvais esprits, la trépanation avait pour but de libérer les mauvais esprits.[321]

Dans la Grèce antique, on croyait que les personnes atteintes d'une maladie mentale grave étaient sous l'influence des dieux en colère. Elles ont certainement subi de mauvais traitements. Celles dont la maladie était moins grave restaient libres, mais elles étaient méprisées et humiliées.[322] D'après Prince (2003), les valeurs culturelles de la Grèce antique annoncent la stigmatisation moderne à l'égard de la maladie mentale.[323]

Dans l'Europe du Moyen-Âge (du Ve au XVIe siècle), on croyait que la maladie mentale avait des causes surnaturelles et on l'associait à la possession diabolique ou divine. Les personnes touchées étaient torturées, condamnées au bûcher, pendues ou décapitées afin de libérer l'âme de la possession diabolique.[324]

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320 L'information contenue dans cette section se fonde sur les cinq documents suivants : 1) Leonard I. Stein et Alberto B. Santos, *Assertive Community Treatment of Persons with Severe Mental Illness*, New York, 1998; 2) Organisation mondiale de la santé, "Historical Perspective", section 3, in *The Mental Health Context*, Mental Health Policy and Service Guidance Package, Genève, 2003; 3) Organisation mondiale de la santé, « Résolution des problèmes de santé mentale », chapitre 3, dans *La santé mentale : Nouvelle conception, nouveaux espoirs*, Genève, 2001; 4) Pamela N. Prince, "A Historical Context for Modern Psychiatric Stigma", dans *Mental Health and Patients' Rights in Ontario: Yesterday, Today and Tomorrow*, publié par le Bureau de l'intervention en faveur des patients des établissements psychiatriques, Ontario, 2003, p. 58-60; 5) Association canadienne pour la santé mentale, *Au service de l'esprit – Une étude des services psychiatriques au Canada*, Toronto, 1963.

321 Stein et Santos (1998), p. 6.

322 Stein et Santos (1998), p. 6.

323 Prince (2003), p. 58.

324 OMS (2003), p. 17-19, OMS (2001), p. 49, et Stein et Santos (1998), p. 6-7.

Au XVIIe et au début du XVIIIe siècles, le point de vue dominant était que la maladie mentale constituait une déficience physique que l'on s'infligeait soi-même par excès de passion. Ce point de vue n'encourageait pas la compassion ni la tolérance; il servait plutôt à justifier des conditions de vie misérables et le recours à des entraves physiques dans des lieux de confinement. Certaines personnes étaient enchaînées aux murs et parfois même mises en cage.[325]

À la fin du XVIIe siècle, Philippe Pinel, médecin français, et William Tuke, quaker anglais, ont été les premiers à exprimer la conviction que ceux qui ont des comportements étranges et inexplicables souffrent d'une maladie mentale. Pinel réformera les hôpitaux de Bicêtre et de La Salpêtrière en France; il libèrera les aliénés de leurs chaînes et les considèrera comme des êtres raisonnables. Il leur offrira des conditions de vie convenables et les traitera avec respect. De son côté, guidé par des idéaux humanistes, Tuke fonde en Angleterre l'institut York Retreat où les personnes atteintes de maladie mentale jouissent de conditions de vie convenables, sont traitées avec respect et travaillent, dans la mesure où elles le peuvent.[326]

La démarche élaborée par Pinel et Tuke est devenue ce qu'on a appelé le « traitement moral ». Son succès, qui repose sur le fait qu'on considère les personnes atteintes d'une maladie mentale comme des patients médicaux, a mené à la construction de nombreuses institutions psychiatriques, autrefois appelées « asiles d'aliénés » dans les pays européens et aux États-Unis. C'est à cette époque que naît la psychiatrie, en tant que discipline médicale.[327]

Au XIXe et au XXe siècles, on adopte une approche « plus scientifique » du traitement de la maladie mentale. On tente d'expliquer la maladie mentale comme une conséquence d'une maladie du cerveau ou de dommages au cerveau, ou comme la séquelle d'anomalies congénitales ou héréditaires. Parce que les tissus cervicaux endommagés et dévitalisés ne peuvent se régénérer et qu'on ne peut pas faire grand-chose pour corriger un défaut héréditaire, cette nouvelle démarche « scientifique » mène à une ère de pessimisme dans le traitement.[328]

Asile : Lieu de refuge et de protection pour les personnes atteintes de maladies mentales à long terme qui n'ont pas besoin de soins hospitaliers actifs, mais qui ont besoin d'une supervision, de soins et de traitements continus dans un établissement ou institution communautaire.
[The 1998 British Columbia Mental Health Plan, p. 85.]

L'idée qu'un traitement psychologique rationnel, voire scientifique, de la maladie mentale est possible ne vient que lorsque des milliers de victimes de traumatisme dû à un bombardement pendant la Première Guerre mondiale démontrent d'une manière émouvante que tout le monde est vulnérable à un stress psychologique, social et physique et peut atteindre un point de rupture.[329] Cette découverte a mené au développement de la psychiatrie et de la psychologie clinique modernes.

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325 Stein et Santos (1998), pp. 6-7.
326 Stein et Santos (1998), p. 8.
327 Stein et Santos, (1998), p. 6-8, et OMS (2001), p. 49.
328 Association canadienne pour la santé mentale (1963), p. 2.
329 *Ibid.*

7.2 SERVICES DE SANTÉ MENTALE AU CANADA[330]

Comme dans d'autres pays développés, l'évolution de la prestation de services de santé mentale au Canada a été marquée par trois processus distincts : d'abord l'approche morale ou humanitaire à l'égard du traitement de la maladie mentale, suivie de l'institutionnalisation et enfin de la désinstitutionalisation.

7.2.1 L'approche morale ou humanitaire à l'égard de la maladie mentale (avant les années 1900)

Avant la Confédération, bon nombre de personnes atteintes de maladie mentale sont soit emprisonnées, soit prises en charge par la famille ou des organisations religieuses.[331] À l'époque, peu de médecins pratiquent la psychiatrie dans le Haut ou le Bas-Canada. Certains sont encore convaincus que toute forme de traitement, qu'il soit médical ou psychologique, des personnes atteintes de maladie mentale constitue une perte de temps, puisque ces personnes sont considérées comme des membres de la société incurables et non fonctionnels.[332] Le traitement des personnes souffrant de maladie mentale est donc essentiellement une fonction de garde.

À la fin du XIXe siècle, le Haut et le Bas-Canada s'inspirent de l'expérience européenne et créent quelques petites institutions qui prennent exemple sur les approches de Tuke et de Pinel pour offrir aux patients un traitement moral ou humanitaire. Au départ cependant, il n'y a pas assez d'hôpitaux moraux pour tous ceux qui en ont besoin. De nombreuses personnes atteintes d'une maladie mentale restent confinées dans une chambre à la maison ou sont incarcérées avec des criminels de droit commun.

Le succès du traitement moral finit par entraîner la construction de nombreux grands asiles dans toutes les régions du pays. C'est ainsi que débute le processus d'institutionnalisation des personnes souffrant de maladie mentale. Au début, le coefficient patients-personnel est assez élevé pour offrir un traitement moral et des conditions de vie convenables, mais pour des raisons que nous expliquerons ci-dessous, la plupart de ces institutions ne sont pas en mesure de maintenir le taux de réussite des pionniers dévoués du traitement moral.

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330 L'information contenue dans cette section se fonde sur les neuf documents suivants : 1) Santé et Bien-être social Canada, *Services de santé mentale au Canada*, Ottawa, 1990; 2) V. E. Appleton, « Psychiatry in Canada A Century Ago », *Canadian Psychiatric Association Journal*, vol. 12, n° 4, août 1967, p. 344-361; 3) Elliot M. Goldner, *De la connaissance à la pratique – Le Fonds pour l'adaptation des services de santé : La santé mentale*, Série de rapports de synthèse, Santé Canada, 2002; 4) Cyril Greenland, Jack D. Griffin et Brian F. Hoffman, « Psychiatry in Canada from 1951 to 2001 », dans *Psychiatry in Canada: 50 Years*, Association des psychiatres du Canada, 2001, p. 1-16; 5) Quentin Rae-Grant, « Introduction », dans *Psychiatry in Canada: 50 Years*, Association des psychiatres du Canada, 2001, p. ix-xiii; 6) Henri Dorvil et Herta Guttman, *35 ans de désintitutionalisation au Québec, 1961-1996*, Annexe 1 du rapport du Comité de la santé mentale du Québec intitulé *Défis de la reconfiguration des services de santé mentale*, 1998; 7) Julio Arboleda-Florez, *Mental Health and Mental Illness in Canada : The Tragedy and the Promise*, mémoire au Comité, 19 mars 2003; 8) Paula Goering, Don Wasylenki et Janet Durbin, « Canada's Mental Health System », dans *International Journal of Law and Psychiatry*, vol. 23, n°s 3-4, mai-août 2000, p. 345-359; 9) Donald Wasylenki, « The Paradigm Shift From Institution to Community », chapitre 7, dans *Psychiatry in Canada: 50 Years*, Association des psychiatres du Canada, 2001, p. 95-110.

331 Santé et Bien-être social Canada (1990), p. 15.

332 V.E. Appleton (1967), p. 344-361.

7.2.2 L'institutionnalisation (de 1900 à 1960)

S'inspirant de l'expérience européenne et américaine, les asiles d'aliénés prolifèrent au Canada.[333] Ces grandes institutions habituellement indépendantes se trouvent souvent dans des lieux très isolés. Une fois qu'elles y sont admises, de nombreuses personnes souffrant de maladie mentale y passent le reste de leur vie. Certains patients sont admis contre leur gré, à l'issue d'un processus juridique, et sont confinés dans des services dont les portes sont fermées à clé. Le traitement tente d'intégrer le travail grâce à l'ergothérapie ou à la réadaptation professionnelle (qui rémunère faiblement les patients), ainsi que par des activités récréatives et sociales. Les liens entre le personnel et les patients sont paternalistes. La plupart des patients restent isolés de leur famille et de leur collectivité.[334]

De nombreux traitements psychiatriques courants à cette époque – hydrothérapie, coma insulinique, psychochirurgie (en l'occurrence, la lobotomie) – ne sont plus en vogue ou ont été abandonnés pour des raisons scientifiques ou déontologiques.[335] La thérapie électroconvulsive (ou TEC), dispensée au départ sans anesthésie ni relaxants musculaires, est alors un traitement courant mais controversé.[336] Les convulsions qui accompagnent les électrochocs provoquent souvent de graves complications – des crises qui durent plus longtemps que prévu, une hausse de la tension artérielle, une modification du rythme cardiaque, et des fractures par tassement de la colonne vertébrale. Depuis, bien qu'elle continue de faire l'objet de controverse dans certains milieux, la TEC a été largement reconnue et sanctionnée par la psychiatrie et la médecine en général comme étant un traitement sûr et efficace de la schizophrénie, de la dépression grave et de la manie extrême.[337] On reconnaît généralement que l'absence de traitements efficaces pour les patients souffrant de maladie mentale a grandement contribué à l'opinion généralement peu favorable à l'égard de la psychiatrie durant toute cette période.[338]

Il convient de souligner qu'on s'est efforcé, durant la période de l'institutionnalisation, de promouvoir la santé mentale et de déstigmatiser la maladie mentale. Par exemple, en 1948, le gouvernement fédéral établit des subventions nationales à la santé mentale afin d'améliorer la formation et les services. Les fonds de cette source ont également mené à des campagnes de sensibilisation visant à promouvoir la santé mentale des bébés et des enfants. La « Semaine de la santé mentale » est désignée au Canada pour la première fois en 1951. Durant cette période également, l'Association canadienne pour la santé mentale lutte pour modifier la

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333 Elliot Goldner (2002), p. 1.

334 Greenland, Griffin et Hoffman (2001), p. 2.

335 L'hydrothérapie consiste à traiter des maladies par l'utilisation interne et externe, copieuse et fréquente d'eau pure. Le coma insulinique était un traitement rarement utilisé de la maladie mentale consistant à provoquer un coma hypoglycémique à l'aide d'insuline.

336 La TEC est une procédure qui consiste à faire passer un faible courant électrique dans une région du cerveau pendant une à trois secondes afin de provoquer des changements neurochimiques associés au soulagement de symptômes psychiatriques; la stimulation électrique provoque également une brève crise, dont l'apparence est modifiée par des relaxants musculaires. Elle dure généralement de 20 à 30 secondes et se termine ensuite spontanément. Le patient est anesthésié et endormi pendant le traitement et la crise.

337 Santé et Bien-être social Canada (1990), p. 15.

338 Quentin Rae-Grant (2001), p. x.

terminologie employée dans les lois, et parfois dans la publicité, qui qualifie les personnes souffrant de maladie mentale d'« idiots », d'« imbéciles » et d'« aliénés ».[339]

Après la Seconde Guerre mondiale, les institutions psychiatriques au Canada deviennent surpeuplées. En 1950, on dénombre quelque 66 000 patients dans les hôpitaux psychiatriques du Canada; ils sont plus nombreux que les patients dans les hôpitaux non psychiatriques.[340] La plupart des institutions psychiatriques fonctionnent à plus de 100 p. 100 de leur capacité. Le manque de personnel, le surpeuplement et l'absence de traitements efficaces font en sorte qu'on attache plus d'importance au confinement qu'à la thérapie. Contrairement à l'intention initiale de dispenser un traitement moral, les soins institutionnels deviennent primitifs et restrictifs; ils font appel à des méthodes comme le confinement ou la contention chimique et physique.[341] Toutes ces conséquences négatives ont contribué à la désinstitutionalisation décrite dans la section suivante.

7.2.3 La désinstitutionalisation (de 1960 à nos jours)

> *… la désinstitutionalisation n'est pas simplement un congé donné aux patients. Il s'agit d'un processus complexe dans lequel la déshospitalisation devrait mener à la création d'un réseau de services hors des hôpitaux psychiatriques. Malheureusement, dans de nombreux pays développés, la désinstitutionalisation n'a pas été accompagnée par le développement de services communautaires pertinents. […] Il est devenu de plus en plus clair que si du financement et des ressources humaines suffisantes pour l'établissement de services communautaires n'accompagnent pas la désinstitutionalisation, les personnes atteintes de troubles mentaux pourraient avoir accès à moins de services de santé mentale et les services existants pourraient être utilisés au-delà de leurs capacités. (OMS, 2003, p. 18)*

Quelques facteurs ont encouragé la tendance à la désinstitutionalisation Premièrement, à cause du surpeuplement et des pénuries d'effectifs, de nombreux établissements psychiatriques étaient considérés comme des environnements non thérapeutiques où les gens qui y séjournaient étaient tout simplement confinés et traités de manière inhumaine. Deuxièmement, de nombreuses études au Canada, en Europe et aux États-Unis ont fait ressortir les conséquences négatives de l'institutionnalisation à long terme sur le bien-être des personnes souffrant de maladie mentale : indifférence, apathie, obéissance passive, négligence de soi et, parfois, comportement agressif, importante perte d'habiletés sociales, dépendance accrue, et maladies physiques chroniques accrues découlant de l'isolement et des relations autoritaires entre le personnel et les patients.[342] Troisièmement, l'arrivée de la chlorpromazine –médicament efficace pour contrôler les psychoses et les troubles du

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339 Greenland, Griffin et Hoffman (2001), p. 3.
340 Greenland, Griffin et Hoffman (2001), p. 2.
341 Santé et Bien-être social Canada (1990), p. 15.
342 Dorvil et Guttman (1998), p. 116.

comportement graves – et d'autres médicaments neuroleptiques a fait naître l'espoir que des « cures » seraient bientôt découvertes pour des maladies mentales graves et persistantes comme la schizophrénie (il est intéressant de souligner que ces premiers résultats de recherches ont stimulé un intérêt considérable pour la recherche en psychopharmacologie et en neurosciences au Canada). Tout au moins, on espérait que, grâce à ces nouveaux médicaments, les personnes souffrant de maladie mentale pourraient mener une vie confortable hors des hôpitaux, ce qui leur permettrait de reprendre les fonctions de la vie quotidienne, sans faire l'objet d'une supervision et de soins constants. Quatrièmement, il s'est avéré difficile de résister aux encouragements financiers présentés aux gouvernements provinciaux par les ententes fédérales-provinciales de partage des coûts visant à financer des unités de psychiatrie dans les hôpitaux généraux.[343]

Deux rapports nationaux importants ainsi que ceux de plusieurs commissions provinciales[344] ont fait ressortir ces observations et encouragé la transition vers la désinstitutionalisation En 1963, le Conseil national de planification scientifique de l'Association canadienne pour la santé mentale publiait *Au service de l'esprit*, qui affirmait que la maladie mentale devrait être abordée dans le même cadre organisationnel, administratif et professionnel que la maladie physique. Il recommandait que les services psychiatriques soient intégrés aux ressources physiques et professionnelles des autres soins de santé.[345]

> **[À] l'époque de la révolution en psychiatrie […] [o]n a commencé par rencontrer les curés, les notables de la communauté pour dire que le patient psychiatrique n'est pas une personne dangereuse, du moins pas plus dangereuse que les autres, et qu'il fallait donc lui laisser sa chance. On ne pouvait pas faire sortir les patients de l'hôpital psychiatrique et les intégrer dans la communauté sans qu'ils aient acquis des habiletés sociales. C'est à ce moment-là que les travailleurs sociaux, les psycho-éducateurs, ont commencé à apprendre des habiletés aux patients psychiatriques pour qu'ils puissent fonctionner dans la société.**
> ***[Henri Dorvil, professeur, École de travail social, UQAM (14:39)]***

Par ailleurs, en 1964, la Commission royale sur les services de santé, présidée par Emmett Hall déclarait que toute distinction dans les soins aux personnes atteintes de maladies physiques ou mentales devrait être évitée à tout jamais, parce qu'elle ne repose sur aucun fondement scientifique. La Commission recommandait que les patients capables de recevoir des soins dans des unités de psychiatrie des hôpitaux généraux reçoivent leur congé des hôpitaux psychiatriques le plus rapidement possible. Il était prévu que les patients occuperaient des lits dans les unités de psychiatrie d'hôpitaux généraux pour de brèves périodes durant les épisodes de maladie, mais qu'autrement, ils mèneraient une vie réussie et satisfaisante dans leur collectivité.[346]

La désinstitutionalisation a donc commencé dans les années 60. La route fut longue. D'ailleurs, la désinstitutionalisation proprement dite a comporté trois phases distinctes,

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343 Donald Wasylenki (2001), p. 95-110.

344 Comme la Commission Bédard au Québec (1961-1962) et la Commission Blair en Alberta (1967-1969).

345 Association canadienne pour la santé mentale, *Au service de l'esprit – Une étude des services psychiatriques au Canada*, Toronto, 1963.

346 Tel que cité et signalé dans Donald Wasylenki (2001), p. 96.

commençant au début des années 60 et se poursuivant jusqu'à aujourd'hui. La première phase (7.2.3.1) a consisté à transférer les soins des établissements psychiatriques vers les unités de psychiatrie des hôpitaux généraux. La deuxième phase (7.2.3.2) a porté l'élargissement des soins de santé mentale dans la collectivité et les moyens de soutien communautaires dont avaient besoin les personnes souffrant de maladie mentale et leurs familles. Dans la troisième phase (7.2.3.3), qui se poursuit encore, on cherche à intégrer les divers services et moyens de soutien de santé mentale disponibles dans les collectivités et à accroître leur efficacité.[347]

7.2.3.1 Les unités de psychiatrie dans les hôpitaux généraux (années 60)

> *La désinstitutionalisation [...] a évolué en partie comme un phénomène naturel à la suite de l'arrivée de nouveaux traitements pharmacologiques, à l'ère des premiers médicaments anti-psychotiques. Des patients ayant passé des années en institution peuvent maintenant être traités grâce à des médicaments efficaces, leur état s'améliorant souvent à un point tel qu'ils peuvent réintégrer la collectivité. Au cours des années subséquentes, la désinstitutionalisation est devenue un but souhaitable. Au début de la psychiatrie communautaire, on a pensé que les problèmes comportementaux de nombreux patients souffrant de maladie chronique étaient consécutifs à une quelconque forme de « névrose institutionnelle ». En prenant des mesures pour retirer ces patients d'un milieu pathogène et en les réhabilitant dans la société, on espérait que la réinsertion sociale réussirait pour un grand nombre d'entre eux.*
> *[Dr Dominique Bourget, psychiatre légiste, Hôpital Royal d'Ottawa, mémoire au Comité, juin 2003, p. 2.]*

La première phase de la désinstitutionalisation a consisté à transférer un grand nombre de patients en soins de longue durée des hôpitaux psychiatriques vers les unités de psychiatrie des hôpitaux généraux et à les envoyer directement dans les collectivités relativement peu préparées. Tout au long des années 60, on a ainsi fermé plusieurs des plus gros établissements canadiens isolés. Les hospitalisations de longue durée ont petit à petit été remplacées par des séjours intermittents et plus courts. De 1960 à 1970, le nombre de journées d'hospitalisation par patient dans les institutions psychiatriques a diminué de moitié. Le nombre de lits dans les hôpitaux psychiatriques est passé d'environ quatre par 1 000 habitants en 1964 à moins d'un en 1979.[348]

On espérait que cette transition des institutions psychiatriques vers les unités de psychiatrie des hôpitaux généraux aurait une grande incidence en atténuant la stigmatisation associée à la

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347 Donald Wasylenki (2001), p. 95-110.
348 Santé et Bien-être social Canada (1990), p. 17.

maladie mentale et à la psychiatrie, à mesure que ces maladies et les spécialistes qui les traitaient seraient plus étroitement intégrés au reste de la médecine.[349]

Au début, les hôpitaux généraux et les institutions psychiatriques ont résisté au placement des patients psychiatriques dans les hôpitaux généraux, certains de ces établissements ne voulant pas de patients psychiatriques, tandis que des institutions psychiatriques s'inquiétaient de la réduction spectaculaire de leurs ressources.[350] Mais il y avait des avantages au transfert des soins vers les hôpitaux généraux dont les unités de soins avaient l'avantage et la possibilité de dépister rapidement la maladie, de donner des soins psychiatriques préventifs et de traiter un vaste éventail de troubles psychiatriques moins graves.[351]

Malheureusement, les unités de psychiatrie des hôpitaux généraux n'ont pas bien servi les patients qui ont quitté les anciennes institutions psychiatriques. D'une part, les ressources humaines et financières n'ont pas été réaffectées aux hôpitaux généraux quand les patients ont obtenu leur congé des institutions psychiatriques. D'ailleurs, des études menées à la fin des années 70 ont montré que les personnes souffrant de maladies mentales graves et persistantes étaient traitées dans les unités de psychiatrie d'hôpitaux généraux qui avaient beaucoup moins de ressources que n'en avaient les institutions psychiatriques où ils se trouvaient auparavant.[352]

D'autre part, les unités de psychiatrie des hôpitaux généraux étaient plutôt utilisées sur une base volontaire par des personnes à revenu moyen ou élevé qui y étaient dirigées par des psychiatres privés, tandis que les institutions psychiatriques offraient généralement des services à des personnes moins nanties et à celles qui y étaient admises contre leur gré. Cette situation a créé un système de soins de santé mentale à deux vitesses : les hôpitaux généraux et les institutions psychiatriques servaient des groupes de patients qui se chevauchaient rarement.

Fait plus important, la fermeture ou la réduction de la taille des institutions psychiatriques a été réalisée sans un financement suffisant au niveau communautaire pour que la collectivité puisse offrir un soutien psychologique et des services de réadaptation hors de l'hôpital. Les collectivités se sont donc retrouvées mal préparées pour offrir un soutien adéquat aux patients ayant reçu leur congé des institutions psychiatriques. De nombreuses personnes, handicapées par des maladies psychiatriques persistantes, arrivaient à peine à subsister dans la collectivité. Même si elles vivaient désormais dans un environnement moins restrictif, elles recevaient beaucoup moins de services et de soins, voire pas du tout. D'après de nombreux témoins, il s'agit d'une leçon cruciale qui ne devrait jamais être oubliée dans quelque réforme que ce soit du système de santé mentale.

L'absence de services et de moyens de soutien convenables dans la collectivité pour ceux qui souffraient de maladies mentales a eu les conséquences suivantes :

- fréquence élevée de rechutes (retour à l'état psychotique) et, par conséquent, hausse du taux de réadmission dans les hôpitaux;

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349 Donald Wasylenki (2001), p. 107-109.
350 Greenland, Griffin et Hoffman (2001), p. 4.
351 Greenland, Griffin et Hoffman (2001), p. 7.
352 Don Wasylenki (2001), p. 97.

- « Syndrome de la porte tournante », qui fait qu'après avoir été admis à nouveau et traités dans un hôpital, les patients retournaient vers des soins insuffisants dans la collectivité, redevenaient malades et recommençaient le cycle une fois de plus;
- itinérance accrue;
- hausse des comportements criminels et des incarcérations (parfois pour des délits mineurs).

Cette situation a été tragique pour les personnes souffrant de maladie mentale et leurs familles. Quelques experts en sont venus à croire que la politique de désinstitutionalisation était une grave erreur. Ils sont arrivés à la conclusion que les patients feraient mieux de vivre dans des institutions. Mais en règle générale, la plupart des experts et les personnes souffrant de maladie mentale n'étaient pas d'accord. Ils ont refusé de se joindre à ceux qui demandaient une réinstitutionalisation massive et ils ont préconisé la prestation de services et moyens de soutien à long terme pour les besoins quotidiens afin qu'on puisse mener une vie stable dans la société.

7.2.3.2 Les services et moyens de soutien communautaires de santé mentale (années 70 et 80)

Dans cette deuxième phase de la désinstitutionalisation, le passage des soins institutionnels aux soins communautaires s'est poursuivi avec une insistance non seulement sur les soins communautaires de santé mentale proprement dits, mais aussi sur les moyens de soutien communautaires en santé mentale.

Dans cette phase, les gouvernements provinciaux ont commencé à financer les services de santé mentale hors du milieu hospitalier, principalement pour combler des lacunes dans les unités de psychiatrie des hôpitaux généraux. Ces services étaient fournis par des cliniques communautaires de santé mentale. En outre, durant cette phase, on a insisté sur la nécessité de disposer d'un vaste éventail de moyens de soutien et de services communautaires (comme des services de logement, des programmes de réadaptation professionnelle, et un soutien du revenu) afin de maintenir les personnes souffrant de maladie mentale dans la société, en particulier celles qui souffraient de maladies graves et persistantes. On croyait qu'il fallait une approche plus équilibrée pour affecter le financement des services de santé mentale entre les soins coûteux axés sur le traitement dispensés dans des institutions et les soins et moyens de soutien communautaires de santé mentale. Il fallait gérer les cas afin d'assurer la coordination des services dans un système de prestation de services communautaires.

> **L'histoire nous a enseigné que la santé mentale et la maladie mentale transcendent les limites de la santé et recoupent de nombreux domaines de la politique sociale comme le logement, le soutien du revenu, les services sociaux, l'emploi et la justice.**
> ***[Association canadienne pour la santé mentale, mémoire au Comité, juin 2003, p. 1.]***

Durant cette phase, les défenseurs des soins communautaires se sont opposés aux défenseurs des soins en institutions, et les hôpitaux ont été considérés comme une cause du problème plutôt que comme un élément de solution. De plus, les intérêts des professionnels ont parfois paru diverger de ceux des personnes souffrant de maladie mentale et de leurs familles. Les gouvernements ont de

moins en moins tendu l'oreille aux conseils des professionnels et ont écouté davantage les personnes souffrant d'une maladie mentale et les membres de leurs familles. Les organisations non gouvernementales, en particulier, sont devenues fortes et efficaces durant cette phase; les pressions exercées sur les gouvernements pour qu'ils offrent un soutien du revenu et des possibilités de socialisation étaient aussi fortes que les pressions exercées par les professionnels en faveur d'un traitement.[353]

Les années 70 et 80 ont également été marquées par les progrès de la psychiatrie biologique, qui ont démontré que des systèmes de neurotransmetteurs anormaux peuvent sous-tendre la maladie mentale. La recherche dans ce domaine de la psychiatrie a également été essentielle pour expliquer l'efficacité des médicaments psychotropes. Durant cette période, la recherche au Canada a grandement contribué, à l'échelle nationale et internationale, non seulement à élargir les connaissances sur les fonctions du cerveau, mais aussi à trouver des médicaments modernes et à améliorer la gestion thérapeutique des troubles mentaux. Ces années ont également été marquées par des contributions importantes de scientifiques canadiens dans le domaine de la génétique et des troubles mentaux, comme la schizophrénie et le trouble bipolaire.

À la fin des années 80, même s'ils existaient dans la plupart des provinces, les services et moyens de soutien en santé mentale n'étaient pas bien intégrés. On a d'ailleurs parlé de « trois solitudes » pour décrire les hôpitaux psychiatriques, les unités de psychiatrie dans les hôpitaux généraux et les cliniques, les moyens de soutien et les services communautaires en santé mentale.

7.2.3.3 L'amélioration de l'efficacité et l'intégration des services et moyens de soutien en santé mentale (des années 90 à nos jours)

Tout comme dans la phase précédente, il était reconnu qu'il fallait davantage d'interventions des services communautaires de santé mentale comprenant des visites à domicile, des services d'information, des équipes mobiles d'intervention en cas de crise, des partenariats importants avec des groupes d'entraide, des équipes de suivi communautaire intensif, etc. Mais dans cette troisième phase de la désinstitutionalisation, les personnes souffrant de maladie mentale et leurs familles, par l'entremise de diverses organisations non gouvernementales, ont continué d'exercer des pressions sur les gouvernements pour qu'ils offrent des moyens de soutien communautaires plus nombreux et de meilleure qualité dans divers domaines comme le logement, le soutien du revenu, les possibilités d'emploi, etc.

Contrairement à la phase précédente, cependant, la troisième phase a été marquée par l'importance accordée à la recherche empirique. De fait, il y a une importante tendance vers l'adoption du cadre de « pratiques exemplaires » par les décideurs, les professionnels, les personnes atteintes de maladie mentale et les membres de leurs familles. L'approche fondée sur des preuves devrait permettre une coopération et une collaboration beaucoup plus grande, ce qui facilitera la réforme de la santé mentale. Les hôpitaux (hôpitaux généraux et institutions psychiatriques) ne sont plus considérés comme des éléments qui évoluent hors des systèmes de soins complets, mais plutôt comme des éléments essentiels qui doivent repenser leurs fonctions et leurs mécanismes clés afin de mieux relier les soins en

[353] Wasylenki (2001), p. 107-109.

établissement et les soins communautaires. Par conséquent, la troisième phase, qui se poursuit encore, se caractérise par une plus grande inclusion dans la planification et la mise en œuvre ainsi que par un consensus beaucoup plus clair sur les réformes nécessaires.[354]

Dans de nombreuses provinces, le modèle préféré de prestation de services de santé mentale comprend actuellement un vaste éventail de services communautaires coordonnés fonctionnant de pair avec les unités de psychiatrie des hôpitaux généraux et les centres régionaux connexes de soins de santé mentale.

À mon sens, la, désinstitutionalisation est légitime dans la plupart des cas — pas la totalité — mais seulement si la collectivité est capable de fournir des services, si la société a été informée au moyen d'une politique appropriée d'éducation publique, s'il existe des logements abordables et sûrs, et s'il existe des possibilités d'emploi. Peut-on imaginer qu'un consommateur institutionnalisé et pour qui chaque seconde compte soit soudainement obligé de trouver un emploi dans une société où il sera stigmatisé et où il aura peu de chances de trouver un logement? ***[Michael J. Grass (17:44)]***

Il reste cependant d'importants défis à relever. La maladie mentale est un phénomène social; elle ne se cantonne pas seulement au domaine des soins de santé. Comme le savent bien les citoyens des grandes villes, le nombre de sans-abri augmente. Les programmes de psychiatrie médico-légale ont de plus en plus besoin d'espace. De plus, le Canada est une société multiculturelle et il faut donc offrir des services de services de santé mentale et des moyens de soutien d'une manière qui tient compte des différences culturelles.[355] Mais peut-être avant tout, les nombreux besoins changeants des enfants, des adolescents et des jeunes adultes souffrant de maladies mentales – secteur le plus négligé de tous – nécessitent une importante intervention concertée entre tous les secteurs de la part des systèmes encore mal coordonnés de santé mentale, de soins de santé, de services sociaux, d'éducation, de services correctionnels, de services récréatifs, de programmes professionnels et de traitement de la toxicomanie.

7.3 TRAITEMENT DE LA TOXICOMANIE AU CANADA[356]

L'évolution du traitement de la toxicomanie au Canada se caractérise par cinq phases distinctes. La première, qui s'est terminée à la fin des années 40, est dominée par des attitudes moralistes et un manque général d'attention au traitement. Des asiles privés offrent alors certains traitements de la toxicomanie et certains services de counselling sont mis en place dans des prisons. Toutefois, la plupart des personnes ayant des problèmes de toxicomanie (liés à l'alcool ou à d'autres drogues) n'ont qu'un accès limité aux services de traitement. Le point de vue dominant est que ces problèmes découlent d'un « manque de volonté » ou de « troubles de la personnalité ».

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354 Don Wasylenki (2001), p. 107-109.

355 Quentin Rae-Grant (2001), p. xi.

356 Cette section se fonde sur des renseignements fournis dans les deux documents suivants : 1) Santé Canada, « Évolution du traitement de l'alcoolisme et des autres toxicomanies au Canada », dans *Profil – Alcoolisme et toxicomanie – Traitement et réadaptation au Canada,* Ottawa, 1999, p. 3-5 http://www.hc-sc.gc.ca/hecs-sesc/sca/pdf/profil.pdf; 2) Colleen Hood, Colin McGuire et Gillian Leigh, *Explorer les liens entre la santé mentale et l'usage de substances – Document de travail*, commandé par Santé Canada, 1996.

La deuxième phase, qui a pris fin au milieu des années 60, se caractérise par un changement d'attitude face à l'alcoolisme et, dans une moindre mesure, à l'égard des problèmes liés aux autres drogues. L'un des facteurs déterminants de cette transformation est la place grandissante que se taille le mouvement des Alcooliques Anonymes (AA). Les AA répandent l'idée que l'alcoolisme, quoique incurable, peut être contré, à condition que le sevrage s'accompagne d'un traitement et que l'alcoolique suive un programme de guérison en 12 étapes. Avec l'aide de figures de proue de la collectivité, les membres des AA, à force de pressions, réussissent à obtenir du secteur public qu'il finance les programmes de traitement et de sensibilisation. Ils appuient leurs démarches sur l'opinion que l'alcoolisme n'est pas un symptôme ou une séquelle de faiblesse morale, mais plutôt une « maladie » qu'on peut prévenir et traiter.

Durant cette phase, la plupart des provinces créent des ministères, des commissions ou des fondations chargés d'offrir ou de coordonner les services de traitement de la toxicomanie. De nombreux nouveaux services sont établis. Au départ, ces organismes devaient se concentrer sur les problèmes liés à l'alcool, mais par la suite, à mesure que les problèmes liés aux autres drogues se sont intensifiés, leur mandat a été élargi pour englober ce genre de problèmes. Il convient de noter toutefois que le traitement administré aux utilisateurs de drogues illicites était offert dans une optique fortement punitive.

Contrairement au modèle moral qui « blâme la victime » pour l'installation de la toxicomanie, le nouveau point de vue est qu'il s'agit d'une maladie causée par des facteurs génétiques et biologiques. La personne atteinte n'est plus tenue personnellement responsable de ses « mauvaises habitudes », étant donné que les facteurs déterminants de son comportement habituel sont des facteurs biogénétiques qu'elle ne maîtrise pas. Le modèle de la maladie est d'abord présenté par des universitaires spécialistes de l'alcoolisme. Ces dernières années, le concept de l'alcoolisme considéré comme maladie a été étendu à l'usage invétéré d'autres drogues.
[Ministry of Health Services, Colombie-Britannique, Every Door is the Right Door, mai 2004, annexe III, p. 72.]

La troisième phase a commencé au milieu des années 60. Elle débute au moment où la consommation de drogues augmente fortement et se caractérise par l'expansion rapide des services liés à la toxicomanie. La croissance la plus rapide a été enregistrée entre 1970 et 1976. Sur les quelque 340 organismes spécialisés actifs en 1976, les deux tiers avaient vu le jour après 1970; les dépenses pour les services de traitement sont passées de 14 millions de dollars à 70 millions de dollars pendant la même période. Parmi la gamme des services mis sur pied durant cette période, mentionnons les centres de désintoxication, les programmes de traitement ambulatoire, les établissements pour séjours courts et prolongés et les services de suivi. On offre alors des services destinés aux alcooliques à des personnes aux prises avec des problèmes liés à des drogues autres que l'alcool, mais on crée également certains services spécialisés de traitement des problèmes liés aux « drogues », y compris un certain nombre de communautés thérapeutiques. C'est durant cette période qu'on constate que les personnes qui suivent un traitement de lutte contre l'alcoolisme sont de plus en plus nombreuses à consommer aussi d'autres drogues.

La quatrième phase a commencé dans les années 80. Elle se caractérise par l'autonomie relative des fondations et commissions provinciales dans le cadre de leurs systèmes de santé

et de services sociaux respectifs. Dans bien des cas, les recherches sur la toxicomanie, la sensibilisation et le traitement évoluent en parallèle, mais sont loin de s'harmoniser avec les systèmes généraux de santé et de services sociaux communautaires. Malgré cela, le rôle de ces derniers dans le repérage et l'appui des services spécialisés de traitement de la toxicomanie devient de plus en plus apprécié.

Cette phase est en outre marquée par la diversification et la spécialisation des services de traitement et par la croissance du nombre de services spécialisés, notamment pour les femmes, les adolescents et les Autochtones. Cette tendance est appuyée par des recherches démontrant que les personnes réagissent différemment à différents types de traitement et par la conviction de plus en plus répandue que la thérapie devrait être adaptée aux besoins et aux problèmes particuliers des clients. S'il est vrai qu'on se contente généralement d'adopter diverses variantes du modèle de traitement médical à l'échelle du pays, des thérapies fondées sur des théories et des études cognitives, comportementales et sociales voient néanmoins le jour durant la même période. C'est ce qu'on a appelé le modèle cognitivo-comportemental. La Stratégie canadienne antidrogue, fruit d'un partenariat multisectoriel, est lancée en 1987 et sert à stimuler un éventail d'activités pancanadiennes à l'appui, notamment, de services de traitement et de réadaptation novateurs.

La cinquième phase, qui a commencé au début des années 90 et se poursuit actuellement, a découlé de changements spectaculaires dans la structure des services de santé canadiens. Dans une conjoncture générale favorable à la réforme des soins de santé, la plupart des services de traitement offerts par l'État ont été intégrés aux mécanismes communautaires de prestation de santé et de services sociaux. Dans cette phase, on est plus conscient de la nécessité d'étendre l'intégration des services de lutte contre l'alcoolisme et les autres toxicomanies, non seulement au système de soins de santé mentale, mais aussi à plus grande échelle, c'est-à-dire aux politiques de sécurité sociale et aux systèmes de soutien social. Cette intégration des services est le fruit de l'adoption d'un modèle de santé de la population par tous les gouvernements provinciaux et territoriaux. Le modèle global de la santé de la population insiste sur un ensemble complexes de déterminants de la santé – des facteurs sociaux, économiques, culturels et environnementaux, y compris des choix comportementaux – qui influent sur l'état psychologique et sur l'état biologique.

Durant cette phase, de nouveaux types de drogues plus puissantes sont apparus. Les jeunes enfants et les adolescents risquent de tomber dans la toxicomanie plus tôt que jamais. De plus, avec la récente prolifération au Canada des possibilités de s'adonner au jeu, un grand nombre de provinces et de territoires sont confrontés à une nouvelle dépendance, le jeu compulsif. En outre, à mesure que les entreprises s'intéressent de plus en plus à la toxicomanie, les entreprises et l'industrie dirigent de plus en plus de leurs employés vers les services canadiens de traitement de la toxicomanie.

7.4 OBSERVATIONS DU COMITÉ

La stigmatisation liée à la maladie mentale et à la toxicomanie au Canada a grandement entravé la prestation de services efficaces de santé mentale et de traitement de la toxicomanie. Le Comité est fermement convaincu que résoudre le problème de la stigmatisation et de la discrimination constitue une étape importante vers la planification et la prestation plus efficaces de services de santé mentale, de traitements et de moyens de soutien connexes.

Au cours des 50 dernières années, la recherche biomédicale et clinique, les découvertes scientifiques en neurosciences, en génétique et en biologie, et les progrès des sciences cognitives et comportementales ont permis de mieux comprendre les maladies mentales et les troubles liés à l'usage de substances. Ils ont permis le développement de médicaments, traitements et thérapies efficaces auxquels les scientifiques canadiens ont grandement contribué. De fait, le Canada a été à l'avant-garde de l'application des progrès en neurosciences aux troubles mentaux. De plus, les neurosciences ont constitué une importante force internationale de la recherche canadienne. Les percées récentes dans des domaines comme la neurogénétique et la schizophrénie ou la neuropharmacologie et la dépression, auront une grande incidence sur de nombreux aspects des troubles mentaux, y compris la prévention du suicide. Le Comité convient avec de nombreux témoins que, grâce à la recherche en santé, il y a lieu de croire que le XXIe siècle sera marqué par une amélioration importante des soins et des traitements offerts aux personnes atteintes de maladie mentale ou de toxicomanie et peut-être également de la prévention des maladies de ce genre.

La désinstitutionalisation des années 60 aux années 80 nous a enseigné quelques leçons importantes ayant des implications sur la façon d'offrir des services et des moyens de soutien aux personnes qui souffrent de troubles mentaux. Ainsi, il faut effectuer une importante réforme des systèmes afin d'assurer une prestation intégrée de toute la gamme des services et des moyens de soutien dont ont besoin les personnes atteintes de maladie mentale ou de toxicomanie. Cette réforme devra forcément passer par l'intégration des trois solitudes – les institutions, les services communautaires et les moyens de soutien communautaires – et par l'intégration des systèmes actuellement séparés – l'un pour la maladie mentale et l'autre pour la toxicomanie. Il faut commencer par considérer les personnes atteintes de maladie mentale ou de toxicomanie comme des êtres humains et non comme des diagnostics ou des étiquettes psychiatriques. Elles doivent participer, avec leurs familles, à la détermination de la voie vers le rétablissement. Il faut pour cela la collaboration des intervenants de tous les niveaux et des partenariats entre eux. Les gouvernements doivent jouer un rôle de leadership dans cette entreprise très importante.

La participation des personnes atteintes de maladie mentale et de toxicomanie ainsi que de leurs familles à la vie communautaire est essentielle à toutes les étapes de la réforme et du renouveau. Les personnes atteintes de maladie mentale ou de toxicomanie et leurs familles possèdent des connaissances importantes sur la façon dont le système fonctionne (et sur ce qui ne fonctionne pas). Le Comité convient avec de nombreux témoins qu'en tenant compte des points de vue des personnes atteintes de maladie mentale et de toxicomanie et de leurs

familles dans la planification, l'élaboration des politiques, la conception et la prestation des services, on évitera de nombreux faux-pas.

CHAPITRE 8: POLITIQUE ET LÉGISLATION EN MATIÈRE DE SANTÉ MENTALE ET DE TOXICOMANIE AU CANADA : ANALYSE DE QUELQUES CADRES PROVINCIAUX

INTRODUCTION

Les politiques, les programmes et la législation dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie incombent aux gouvernements provinciaux et territoriaux et au gouvernement fédéral, et font donc intervenir de nombreux ministères et organismes. Ce sont, toutefois, les gouvernements provinciaux et territoriaux qui s'occupent au premier chef de l'organisation, de la gouvernance, du financement et de la prestation des services de santé mentale ainsi que des moyens de soutien et des traitements des toxicomanies au Canada. Les provinces et les territoires régissent également les lois sur la santé mentale qui les concernent.

Le gouvernement fédéral est directement responsable de la prestation des services de santé mentale et des traitements de la toxicomanie dans le cas des Indiens inscrits et des Inuits, des militaires, des anciens combattants, du personnel de l'Aviation civile, de la GRC, des détenus des pénitenciers fédéraux, des nouveaux immigrants et des fonctionnaires fédéraux. Le gouvernement fédéral assume, par ailleurs, différentes responsabilités : promotion de la santé et prévention de la maladie; surveillance de la maladie; recherche en santé; droits de la personne; approbation des médicaments et drogues; prestations d'emploi et d'invalidité, etc. Toutes ces dimensions ont des répercussions directes ou indirectes sur la prestation des services de santé mentale, sur les moyens de soutien et sur les traitements des toxicomanies dans les provinces et dans les territoires.

Le présent chapitre a pour objet de donner un aperçu général du rôle et des responsabilités des gouvernements provinciaux et territoriaux en ce qui a trait à la santé mentale, à la maladie mentale et à la toxicomanie. Le rôle du gouvernement fédéral sur ces différents plans est analysé en détail dans un chapitre subséquent.

La section 8.1 décrit brièvement, avant de les comparer entre eux, la structure organisationnelle et le degré d'intégration des services de santé mentale et du système de traitement des toxicomanies dans certaines provinces (Alberta, Colombie-Britannique, Nouvelle-Écosse, Ontario et Québec). Il donne aussi des renseignements sur les réformes que ces provinces ont récemment entreprises. La section 8.2 dégage un certain nombre de problèmes propres aux systèmes provinciaux et territoriaux d'après les témoignages recueillis par le Comité. La section 8.3, quant à elle, examine les lois sur la santé mentale dans tous les ressorts au Canada et met en exergue les principaux aspects qui les diffèrent. La section 8.4, enfin, présente les observations du Comité.

8.1 SYSTÈMES PROVINCIAUX DE SERVICES DE SANTÉ MENTALE ET DE TRAITEMENT DES TOXICOMANIES

8.1.1 L'Alberta[357]

Le ministère de la Santé et du Mieux-être (Ministry of Health and Wellness) s'occupe de l'élaboration et de la mise en œuvre de l'ensemble des politiques, du financement, de la planification des services et de l'évaluation dans le domaine de la santé mentale et de la toxicomanie. Les régies régionales de la santé et l'Alberta Mental Health Board se partagent la responsabilité des services communautaires et institutionnels de santé mentale. Le traitement de la toxicomanie relève de l'Alberta Alcohol and Drug Abuse Commission (AADAC).

Depuis le 1er avril 2003, les services de santé mentale et l'administration des quatre établissements psychiatriques de la province sont assurés par les neuf régies régionales de la santé. La prestation des services dans la province englobe la santé mentale des Autochtones et traduit une forte préférence pour la gestion intégrée des soins et des cas. Autrement dit, la plupart des services cliniques dispensés en première ligne relèvent des régies régionales de la santé et sont intégrés aux services concernant la santé physique.

L'autorité provinciale en matière de santé mentale, l'Alberta Mental Health Board, qui relève du ministre responsable de la Santé et du Mieux-être, administre et dispense des services et des programmes provinciaux en matière de psychiatrie légale et de prévention du suicide. Il organise des vidéoconférences sur la santé mentale et diverses activités de sensibilisation. L'Alberta Mental Health Board conseille également le ministre de la Santé et du Mieux-être sur les questions liées à l'intégration et au rendement du réseau de services de santé mentale de la province.

L'AADAC est une commission mandataire de l'État qui relève également du ministre de la Santé et du Mieux-être. Elle est chargée de financer et de fournir des services en vue du traitement des problèmes liés à l'alcool, aux drogues ou au jeu (services de désintoxication, de traitement en établissement, de prévention, de sensibilisation et de consultation), et d'effectuer de la recherche dans ces domaines. L'AADAC offre des services de traitement des toxicomanies en milieu hospitalier dans toutes les régions desservies par les régies régionales de la santé et coordonne la mise en œuvre de la stratégie de lutte contre le tabac de l'Alberta (Alberta Tobacco Reduction Strategy).

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357 À moins d'indication contraire, les renseignements contenus dans la présente section proviennent des documents suivants : Provincial Mental Health Planning Project, Advancing the Mental Health Agenda – A Provincial Mental Health Plan for Alberta, avril 2004; Alberta Children and Youth Initiative, Children's Mental Health Initiative, fiche d'information, février 2004; Alberta Mental Health Board, Brief to the Committee, 2003; Alberta Alliance on Mental Illness and Mental Health, Partnership, Participation, Innovation – A Blueprint for Reform, mars 2003; Alberta Health and Wellness, « Transition Underway to Fewer Health Regions, Integrated Mental Health », Communiqué de presse, 23 janvier 2003; Alberta Mental Health Board, Business Plan, 2002-2005, 2002; renseignements obtenus sur le site Internet de la Alberta Alcohol and Drug Abuse Commission (www.aadac.com).

Les régies régionales de la santé, l'Alberta Mental Health Board et l'AADAC collaborent avec le ministère de la Santé et du Mieux-être ainsi qu'avec d'autres ministères et organismes à la mise en œuvre d'une initiative provinciale concernant la santé mentale des enfants, la Children's Mental Health Initiative (juillet 2001). Celle-ci vise principalement à prévenir les problèmes de santé mentale et de toxicomanie chez les enfants et les jeunes, et à leur fournir des traitements, ainsi qu'à leurs familles.

8.1.2 La Colombie-Britannique[358]

En Colombie-Britannique, l'élaboration et la mise en œuvre des politiques, le financement, la planification des services, la surveillance et l'évaluation dans le domaine de la santé mentale et de la toxicomanie relèvent essentiellement du ministère de la Santé (Ministry of Health Services) et du ministère d'État chargé des services de santé mentale et de toxicomanie (Ministry of State for Mental Health and Addiction Services). La santé mentale des enfants et des adolescents incombe au ministère du Développement des enfants et de la famille (Ministry for Children and Family Development), qui travaille en collaboration avec le ministère de la Santé et le ministère d'État chargé des services de santé mentale et de toxicomanie.

Les cinq régies régionales de la santé administrent et fournissent les services de santé mentale et de toxicomanie dans leur zone géographique respective. Elles assurent, avec l'assistance du ministère de la Santé, les services essentiels suivants : intervention en cas d'urgence et intervention à court terme; gestion des cas graves; services extérieurs; services cliniques (évaluation, diagnostic, traitement et consultation); traitement de la toxicomanie (depuis 2002); prévention (recherche, sensibilisation et dépistage et intervention précoces); réadaptation psychosociale; gestion des cas et soutien social, y compris les soins de relève à l'intention des aidants naturels, l'hébergement et, si nécessaire, de l'aide en vue de faciliter l'accès au logement, de l'aide au revenu ainsi que des services et des prestations de réadaptation.

La Colombie-Britannique compte un hôpital de grande taille voué aux soins psychiatriques de longue durée, le Riverview Hospital, six cliniques communautaires de psychiatrie légale et une commission de psychiatrie légale, la Forensic Psychiatric Services Commission. Les cliniques communautaires de psychiatrie légale relèvent des régies régionales de la santé. La régie provinciale de la santé (Provincial Health Services Authority) la sixième régie de la

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358 À moins d'indication contraire, les renseignements contenus dans la présente section proviennent des documents suivants : Mental Health and Addictions, Ministry of Health Services, Colombie-Britannique, *mémoire au Cabinet*, 9 septembre 2003; Mental Health and Addictions, Ministry of Health Services, Colombie-Britannique, *Development of a Mental Health and Addictions Information Plan for Mental Health Literacy, 2003-2005*, 4 février 2003; gouvernement de la Colombie-Britannique, *Child and Youth Mental Health Plan for British Columbia*, février 2003; Addictions Task Group, Kaiser Youth Foundation, Colombie-Britannique, *Weaving Threads Together – A New Approach to Address Addictions in BC*, mars 2001; Minister's Advisory Council on Mental Health, *Moving Forward*, Rapport annuel 2001; Ministry of Health Services, Colombie-Britannique, *Revitalizing and Rebalancing British Columbia's Mental Health System – The 1998 Mental Health Plan*, 1998; renseignements recueillis sur le site Internet de la Régie provinciale des services de santé (www.phsa.ca) ainsi que sur le site de la Mental Health Society ou de l'Hôpital Riverview (www.bcmhs.bc.ca).

santé de la Colombie-Britannique, administre les services offerts dans toute la province par le Riverview Hospital et la Forensic Psychiatric Services Commission.

La Forensic Psychiatric Services Commission est un organisme de services spécialisés réparti en plusieurs emplacements. Elle effectue des évaluations, fournit des traitements et gère les cas cliniques en milieu hospitalier et en milieu communautaire. Ses services s'adressent à des adultes souffrant de troubles mentaux ou de toxicomanie qui ont des démêlés avec la justice. Ce service à guichet unique, le seul dans son genre, assure à tous les résidents de la Colombie-Britannique dont le cas relève de la psychiatrie légale un accès équitable aux services de santé mentale et de toxicomanie.

L'existence, en Colombie-Britannique, d'un ministère d'État provincial chargé des services de santé mentale et de toxicomanie constitue un phénomène unique au Canada et montre que le gouvernement de cette province accorde une place importante à la santé mentale et à la toxicomanie dans ses politiques publiques, comme en témoigne l'extrait suivant d'un rapport de Santé Canada :

> *La Colombie-Britannique a récemment adopté une approche unique en son genre en nommant un ministre d'État à la santé mentale. Ce geste témoigne d'une reconnaissance directe de l'importance de la santé mentale dans la société et donne à ce secteur une autorité, renforcée par un siège au Cabinet, dont le rôle est d'assurer la gouvernance et l'administration du système provincial de santé mentale.*[359]

La Colombie-Britannique a institué des pratiques exemplaires en matière de soins de santé mentale, ce qui s'est traduit par la mise sur pied d'un réseau intégré dans lequel les services de santé mentale sont offerts à l'échelle régionale et les soins tertiaires, dans des établissements communautaires de petite taille.

Ces dernières années, la Colombie-Britannique a instauré un cadre de planification en toxicomanie (mai 2004), un plan de santé mentale pour les enfants et les adolescents (mai 2003), une stratégie de lutte contre la dépression (octobre 2002) et une stratégie de lutte contre les troubles anxieux (avril 2002). Ces initiatives appliquées à l'échelle de la province sont destinées à améliorer la qualité et l'efficacité de la prévention, de l'intervention et de la détection précoce, des traitements et des moyens de soutien dans le cas des personnes souffrant de maladie mentale ou de toxicomanie.

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[359] Elliot M. Goldner, *De la connaissance à la pratique – Le Fonds pour l'adaptation de services de santé – Série de rapports de synthèse : la santé mentale*, Santé Canada, 2002, p. 11.

8.1.3 La Nouvelle-Écosse[360]

Le ministère de la Santé (Department of Health), principalement par l'entremise de ses sections des Services de santé mentale et de la toxicomanie, est responsable de la planification, de l'organisation, du financement, de la gestion, de la surveillance et de l'évaluation des services de santé mentale et de toxicomanie. Les neufs régies régionales de la santé (District Health Authorities) assurent les services de santé mentale et le traitement des dépendances (alcool, tabac, drogues, jeu) dans leur zone géographique respective.

Le Provincial Forensic Psychiatric Service, service de psychiatrie légale également administré par le ministère de la Santé, évalue et traite les patients hospitalisés et gère quelques programmes de soutien communautaire. Tous les services de psychiatrie légale en milieu hospitalier sont regroupés en un seul établissement, le Nova Scotia Hospital.

L'IWK Grace Health Centre est un centre universitaire des sciences de la santé affilié à l'Université Dalhousie. Il gère l'unité provinciale de psychiatrie pour enfants et adolescents, de même que des cliniques externes et des services de télémédecine.

En 2003, la Nouvelle-Écosse est devenue la première province canadienne à instaurer des normes officielles pour régir la prestation des services de santé mentale. Ces normes ont été élaborées en collaboration avec des prestataires de services, des familles, des groupes communautaires et la Section des services de santé mentale du ministère de la Santé.[361]

8.1.4 L'Ontario[362]

La planification, l'organisation, le financement, la gestion, la surveillance et la prestation des services de santé mentale et de toxicomanie incombent au ministère de la Santé et des Soins de longue durée (MSSLD). Contrairement aux autres provinces, l'Ontario n'a pas de régie régionale de la santé. Elle est toutefois dotée de 16 conseils régionaux de santé, dont le rôle se limite à conseiller le ministre responsable de la Santé et des Soins de longue durée sur des questions liées à la santé et sur les besoins observés dans la région qu'ils représentent. En

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360 À moins d'indication contraire, les renseignements contenus dans la présente section proviennent des documents suivants : Association canadienne pour la santé mentale (chapitre de la Nouvelle-Écosse), *2004 Report Card on Mental Health Services Core Standards*, 8 mars 2003; Department of Health, Nouvelle-Écosse, *Strategic Directions for Nova Scotia's Mental Health System*, 20 février 2003; Department of Health, Nouvelle-Écosse, *Standards for Mental Health Services in Nova Scotia*, 20 février 2003; Roger Bland et Brian Dufton, *Mental Health: A Time for Action*, document soumis au ministre adjoint de la Santé, Nouvelle-Écosse, 31 mai 2000; site Internet du Centre de santé IWK (http://www.iwk.nshealth.ca/).

361 Association canadienne pour la santé mentale (chapitre de la Nouvelle-Écosse), www.cmhans.org.

362 À moins d'indication contraire, les renseignements contenus dans la présente section proviennent des documents suivants : Forum provincial des groupes de travail chargés d'étudier la mise en œuvre de la réforme des services de santé mentale, *The Time Is Now : Themes And Recommendations For Mental Health Reform In Ontario*, rapport final, décembre 2002; Groupe consultatif expert sur les services de psychiatrie légale, *Assessment, Treatment and Community Reintegration of the Mentally Disordered Offender*, rapport final, décembre 2002; ministère de la Santé et des soins de longue durée, *Make it Happen – Operational Framework for the Delivery of Mental Health Services and Supports*, gouvernement de l'Ontario, 1999.

conséquence, les divers organismes prestataires de services de santé mentale, de toxicomanie et de soutien œuvrent en grande partie indépendamment les uns des autres.

Le MSSLD coordonne par ailleurs la stratégie provinciale en matière de psychiatrie légale, avec l'appui du ministère des Services à la collectivité, à la famille et à l'enfance, du ministère du Procureur général et du ministère de la Sûreté et de la Sécurité publique.

Le réseau des services de santé mentale et de toxicomanie de l'Ontario est en période de transition. En décembre 2002, neuf groupes d'étude chargés d'étudier la mise en œuvre de la réforme des services de santé mentale ont publié leur rapport. Ils y proposent une démarche en vue de réformer et de renouveler l'organisation et les modes de prestation des services de santé mentale et de toxicomanie dans toute la province. La principale recommandation formulée dans ces rapports concerne la mise sur pied de régies régionales de la santé mentale, dont le mandat serait de financer et de dispenser les services de santé mentale et de toxicomanie dans leur zone géographique respective. Ces organismes régionaux offriraient une série de services et de moyens de soutien communautaire de base dont les citoyens pourraient se prévaloir en cas de besoin. Le gouvernement de l'Ontario n'a pas encore donné suite aux recommandations des groupes d'étude.

8.1.5 Le Québec[363]

Le ministère de la Santé et des Services Sociaux (MSSS) est responsable de la planification, de l'organisation, de la gestion, du financement, de la surveillance et de l'évaluation des services de santé mentale et de toxicomanie. Le Ministre est appuyé dans ses fonctions par deux organismes consultatifs indépendants : le Comité de la santé mentale du Québec et le Comité permanent de lutte à la toxicomanie. Dix-huit régies régionales de la santé fournissent, dans leur zone géographique respective, des services de santé mentale, de toxicomanie et de soutien aussi bien en milieu hospitalier qu'en clinique externe et en milieu communautaire.

Le MSSS met en œuvre et coordonne le plan d'action provincial de lutte contre la toxicomanie, qui vise la promotion, la prévention, le dépistage et l'intervention précoces, la désintoxication et la réadaptation et la réintégration sociales. Le MSSS coordonne aussi la Stratégie québécoise d'action face au suicide, dont l'objet est de consolider et de coordonner les divers efforts de prévention du suicide, afin de garantir un accès équitable aux services essentiels partout dans la province. Ces services sont : l'assistance téléphonique 24 heures sur 24, sept jours sur sept, l'intervention d'urgence (évaluation, surveillance, services d'orientation et de soutien) et la postvention (services d'intervention post-traumatique individuels et de groupe à l'intention des amis, des proches et des intervenants dans les

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363 À moins d'indication contraire, les renseignements contenus dans le présent document proviennent des documents suivants : Ministère de la Santé et des Services Sociaux, Agir Ensemble – Plan d'action gouvernemental sur le jeu pathologique, 2002-2005, gouvernement du Québec, 2002; Ministère de la Santé et des Services Sociaux, Plan d'action en toxicomanie, 1999-2001, gouvernement du Québec, 1998; Ministère de la Santé et des Services Sociaux, Québec's Strategy for Preventing Suicide, gouvernement du Québec, 1998; Ministère de la Santé et des Services Sociaux, Plan d'action pour la transformation des services de santé mentale, gouvernement du Québec, 1998, Comité de la santé mentale du Québec, Défis de la reconfiguration des services de santé mentale, gouvernement du Québec, 1997.

48 heures suivant l'événement). La Stratégie fait intervenir non seulement des ministères, mais aussi les régies régionales de la santé, les CLSC, les hôpitaux, les centres de prévention du suicide, les services de police, les écoles, les centres jeunesse, les organismes communautaires, etc.

8.1.6 Une brève analyse comparative

Sur deux plans très importants, la Colombie-Britannique se singularise dans la façon dont elle a envisagé ses politiques de santé mentale et de toxicomanie. C'est la seule province où l'on trouve un ministre d'État responsable de la santé mentale et de la toxicomanie, qui est donc en mesure de faire passer les questions de santé mentale à l'avant-plan des discussions au Cabinet. En outre, seule la Colombie-Britannique a intégré le cadre de politique, la gouvernance et la prestation des services pour la santé mentale et la toxicomanie.

En Alberta, en Nouvelle-Écosse, en Ontario et au Québec, la responsabilité en matière de formulation de politiques et de planification des services revient aux ministères provinciaux de la Santé. Toutefois, comme le mentionnent plusieurs rapports provinciaux, l'élaboration de politiques concernant les personnes atteintes de maladie mentale ou de toxicomanie n'a pas bien été coordonnée entre les différents ministères chargés de la politique sociale. Cette situation a atténué l'effet positif qu'aurait pu donner une planification plus complète, davantage ouverte et inclusive, faisant appel à plusieurs ministères qui sont incontournables dans la prestation des services aux personnes souffrant de maladie mentale ou de toxicomanie.

Dans toutes les provinces, sauf en Ontario (qui n'a pas encore de régie régionale), l'organisation et la prestation des services destinés aux personnes de tous âges souffrant de troubles mentaux ou de toxicomanie relèvent des régies régionales de la santé. Ce transfert de responsabilités par la régionalisation permet aux provinces d'adapter leurs services et leurs mesures de soutien aux besoins de chaque région, et facilite la collaboration entre les divers intervenants.

La plupart des provinces ont entrepris des réformes de leurs réseaux de services de santé mentale et de toxicomanie. À ce chapitre, elles reconnaissent grosso modo les mêmes pratiques exemplaires :

1. encourager la prestation de services de santé mentale et de toxicomanie en milieu communautaire plutôt qu'en milieu hospitalier, en gage d'une démarche équilibrée;

2. assurer le financement spécifique et protégé d'un réseau intégré de services de santé mentale et de toxicomanie, qui englobe les soins tertiaires dispensés en milieu communautaire et en milieu hospitalier;

3. prévoir un centre unique de responsabilité pour la gestion d'un réseau local intégré;

4. prévoir des mécanismes qui permettent aux prestataires de services et à la collectivité de participer véritablement aux décisions.

Lors des audiences, aucun des témoins, comme ceux souffrant d'une maladie mentale ou de toxicomanie, n'a proposé de province, de région ni de régie régionale de la santé en modèle à suivre pour la formulation de politiques, la structure organisationnelle, la gouvernance ou la prestation des services. De sérieuses questions demeurent. Ainsi, l'autorité centrale en matière de maladie mentale et de toxicomanie devrait-elle être provinciale plutôt que régionale? Une province ou une région est-elle parvenue à intégrer les hôpitaux, les services communautaires et les moyens de soutien? Comment parvenir au mieux à intégrer les services de santé mentale et les services de soutien avec les services de traitement des toxicomanies? Y a-t-il une seule région ou une seule province qui soit parvenue à coordonner les services de santé mentale et de toxicologie dans le cadre de leur système social en général (enseignement, logement, justice, soutien au revenu, etc.)?

8.2 PROBLÈMES COMMUNS CONSTATÉS DANS LES CADRES PROVINCIAUX/TERRITORIAUX RELATIFS À LA MALADIE MENTALE ET À LA TOXICOMANIE

8.2.1 La fragmentation et le manque d'intégration

Le Comité a régulièrement entendu dire que les systèmes de santé mentale et de toxicomanie ne sont pas de véritables systèmes mais qu'ils correspondent davantage à un faisceau inextricable de services offerts par les provinces, les municipalités et le fédéral de même que par des fournisseurs privés. Ces faisceaux comprennent également les initiatives entreprises par des particuliers qui souffrent eux-mêmes de maladie mentale ou de toxicomanie. Ces systèmes correspondent à une palette de services de soins actifs offerts dans les hôpitaux généraux, de services spécialisés destinés à traiter des populations ou des troubles bien précis, des cliniques externes communautaires, de services communautaires offrant un soutien psychologique (logement, emploi, enseignement et intervention en cas de crise), et de conseils privés, tous de capacité et de qualité variables fonctionnant souvent en vase clos et étant trop fréquemment déconnectés du réseau général de soins de santé. Dans la plupart des ressorts concernés, il n'existe que peu de lien entre le système de santé mentale et de toxicomanie « officiel » et les initiatives visant à stimuler l'autonomie (qui ont éclos à l'échelon communautaire un peu partout au Canada). Résultat : dans la plupart des provinces et des territoires, on trouve un système fortement fragmenté, ou l'absence de systèmes, dans lequel les personnes souffrant de maladie mentale et de toxicomanie et les fournisseurs de services ont de plus en plus de mal à naviguer.

Ce problème de la fragmentation est compliqué par le fait que, même si les services et les moyens de soutien en santé mentale et de traitement des toxicomanie sont offerts par différents organismes, il n'existe pas de connexion satisfaisante entre les systèmes des différents secteurs concernés (ex., la santé, le logement, l'enseignement, les allocations familiales, le milieu de travail, etc.). Cela étant, il est quasiment impossible de contrôler les services de santé mentale et de traitement des toxicomanies quand ils ne sont pas offerts par des hôpitaux ou des fournisseurs de soins primaires qui tiennent des dossiers auxquels on peut accéder quand il faut..

Le Comité a appris qu'il est fondamental de garantir un accès coordonné à un ensemble homogène de services et de moyens de soutien pour parvenir à une stratégie efficace en matière de maladie mentale et de toxicomanie. Cela revient à dire que les gouvernements doivent investir dans le secteur communautaire, de même que dans les hôpitaux et les autres institutions. De nombreux témoins ont tenu à rappeler qu'il est essentiel d'offrir un ensemble homogène de services et de moyens de soutien, incluant des logements avec service de soutien et un soutien du revenu, pour répondre à la gamme des besoins des patients, aux différentes étapes de leur maladie et de leur rétablissement. Cet ensemble est également nécessaire pour disposer d'un système de santé mentale et de toxicomanie adapté, pouvant éviter les épisodes aigues de la maladie ou permettant d'en réduire l'intensité ou la durée. Qui plus est, il est impératif que la toxicomanie fasse partie des initiatives de réforme en santé mentale.

À l'analyse de certains documents émanant de plusieurs provinces, nous en sommes venus à la conclusion que la plupart d'entre elles sont confrontées à des problèmes et à des défis semblables pour ce qui est de la prestation des services de santé mentale et des services de traitement des toxicomanies. Voici, résumés ci-dessous, quels sont ces problèmes et ces défis :[364]

- Tout d'abord, comme nous l'avons vu, les actuels services et moyens de soutien mis à la disposition des personnes souffrant de maladie mentale et de toxicomanie sont répartis entre plusieurs organismes et plusieurs points d'accès. Il conviendrait en outre de mieux intégrer le système de santé mentale au système de soins de santé et au système de traitement des toxicomanies.
- Deuxièmement, l'actuel système des services de santé mentale représente encore, dans une large mesure, une philosophie des soins qui repose sur le recours aux institutions; les services et les moyens de soutien devraient être axés sur le patient et sur la communauté.
- Troisièmement, l'actuel système de santé mentale n'est pas complet; il n'offre pas le continuum des services et des soutiens qui s'imposent. Ce faisant, il n'est pas rare que les personnes souffrant de maladie mentale et de toxicomanie ne bénéficient pas des services ni des moyens de soutien dont elles ont besoin, là et quand elles en ont besoin.

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364 Les renseignements présentés ici proviennent des documents suivants : Department of Health, *Strategic Directions for Nova Scotia's Mental Health System*, gouvernement de la Nouvelle-Écosse, février 2003; Elliot M. Goldner, *Série de rapports de synthèse – La santé mentale*, De la connaissance à la pratique – Le fonds pour l'adaptation de services de santé, gouvernement du Canada, 2002; gouvernement de Terre-Neuve et du Labrador, *Valuing Mental Health – A Framework to Support the Development of a Provincial Mental Health Policy for Newfoundland and Labrador*, septembre 2001; Minister's Advisory Council on Mental Health, *Moving Forward*, Rapport annuel, gouvernement de la Colombie-Britannique, 2001; ministère de la Santé, *Franchir les étapes : Cadre de prestation des services de santé mentale et des services de soutien connexes*, gouvernement de l'Ontario, 1999; Comité de la santé mentale du Québec, *Défis – De la Reconfiguration des Services de Santé Mentale*, gouvernement du Québec, octobre 1997; Unité de recherche de systèmes de santé, Clarke Institute of Psychiatry, *Best Practices in Mental Health Reform*, document de travail préparé pour le Réseau consultatif fédéral/provincial/territorial sur la santé mentale, 1997; Alberta Mental Health Board, Building A Better Future – A Community Approach to Mental Health, gouvernement de l'Alberta, mars 1995.

- Quatrièmement, les services de santé mentale ont toujours été sous-financés, ce qui a été préjudiciable à ceux et celles atteints de troubles mentaux graves et persistants, surtout pour les tranches de population les plus difficiles à servir, soit les personnes de communautés ethnoculturelles différentes, les sans-abri et les personnes atteintes de troubles concurrents.
- Cinquièmement, le secteur de la santé mentale connaît une très importante pénurie de personnel.
- Sixièmement, les mesures de responsabilisation au sein du système des services de santé mentale font gravement défaut. Le rôle et les responsabilités des fournisseurs de services sont mal énoncés et il faudrait pouvoir disposer d'un système d'information à l'appui de la planification et du fonctionnement d'un système qui soit plus efficace et plus complet et pour contrôler l'efficacité des services qu'il offre.
- Septièmement, la stigmatisation persiste à l'échelle de la société, malgré les efforts entrepris pour renseigner le grand public et les intervenants du système de soins de santé en général. D'aucuns affirment que ces sept stigmatisations constituent le principal obstacle au changement à tous les échelons du système.

Nombre de témoins sont venus nous rappeler que les troubles de santé mentale exigent beaucoup plus que ce que l'on considère comme des services traditionnels de santé mentale. Pour certains, le rétablissement peut exiger – en plus d'une thérapie, de médicaments et d'une gestion de cas – l'accès à un logement, aux transports, à un emploi et au soutien des pairs. De nombreux rapports provinciaux font état des services de santé mentale « et de soutien » pour illustrer leur importance déterminante en tant qu'instruments de rétablissement pour les personnes souffrant de maladie mentale, plus précisément pour les sortir de leur isolement et pour les aider à acquérir ou à retrouver leur autonomie financière.

Le manque de coordination entre les divers secteurs, l'absence de pouvoirs clairement définis à l'échelon régional et le soutien communautaire limité ont eu des conséquences tragiques pour les malades et pour la société. Comme nous l'avons vu chapitre 5, un grand nombre de personnes atteintes de maladie mentale sont sans domicile et elles sont contraintes de vivre dans la rue ou dans des refuges publics. De plus, un pourcentage élevé de personnes incarcérées souffrent de troubles mentaux. Plusieurs se retrouvent en prison pour des délits non violents, d'autres pour avoir commis des « crimes de survie », comme le fait de voler de la nourriture, de vagabonder ou d'entrer sans autorisation sur une propriété; c'est souvent parce que leurs besoins de services en santé mentale ou de traitement de toxicomanie et leurs besoins de logement n'ont pas été comblés que ces gens-là se retrouvent en prison.

De nombreux témoins ont parlé des besoins particuliers des enfants et des adolescents. D'ailleurs, certains témoins ont qualifié les services et les moyens de soutien en santé mentale « de parents les plus pauvres du système de soins de santé », dans le cas des enfants et des adolescents. Ces services de santé mentale, à l'échelon des provinces et des territoires, font souvent intervenir plusieurs ministères et organismes (ex., santé mentale, bien-être de l'enfance, jeunes délinquants, services de toxicomanie et services d'éducation spécialisée). Dans la plupart des provinces et des territoires, on constate que les services actuels offerts aux enfants et aux adolescents sont source de mécontentement. Voici ce qui ressort des renseignements que nous avons recueillis :

- L'actuel système est fortement fragmenté; les services offerts par les multiples fournisseurs ne sont pas coordonnés. Les problèmes des enfants et des adolescents ne donnent pas lieu à une répartition évidente des responsabilités entre les divers ministères concernés.
- La prévalence de la maladie mentale chez les enfants et les adolescents dépasse de loin la capacité des actuels systèmes de prestation de service. On constate des défauts d'accès aux services existants et de longues listes d'attente pour accéder aux services limités actuellement offerts.
- Les politiques et les programmes en santé mentale sont essentiellement axés sur le traitement de la population adulte. Ce faisant, les services aux enfants et aux adolescents n'ont évolué que lentement et uniquement en complément des programmes destinés aux adultes.
- Les services de santé mentale destinés aux enfants et aux adolescents ne sont pas suffisamment financés.
- Il existe un urgent besoin d'améliorer les services d'intervention préventive et d'intervention précoce.
- À l'heure actuelle, beaucoup d'interventions pourtant efficaces ne sont pas largement mises à la disposition des enfants et des adolescents et de nombreuses interventions non efficaces continuent d'être appliquées bien qu'elles soient plus coûteuses et plus restrictives que les autres solutions existantes. Ainsi, il conviendrait de mieux tenir compte des résultats de la recherche sur les pratiques efficaces à tous les niveaux, même au niveau clinique.
- Aucun objectif, ni à long terme ni intermédiaire, n'a été fixé et il n'est que rarement fait état d'indicateurs de résultat dans le cas des enfants et des adolescents, indicateurs qui permettraient d'évaluer le rendement et l'efficacité du système des services de santé mentale.
- Personne ne semble être responsable, autrement dit il n'existe pas de branche exécutive ayant le pouvoir d'amener le système de soins tout entier à décider d'une action cohérente et à la mettre en œuvre.
- Il n'existe aucune mesure d'incitation externe pour favoriser l'efficacité – les budgets supplémentaires doivent souvent être reversés dans les caisses du gouvernement plutôt que d'être réinvestis localement.[365]

Les témoins ont également parlé des besoins particuliers des personnes souffrant de troubles concourants (maladie mentale et toxicomanie), parce que cette situation les inquiétait. Les personnes concernées doivent pouvoir accéder à des services et à des moyens de soutien, en différents points d'entrée, que ce soit dans le cadre du système de santé mentale ou dans

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[365] Groupe de travail fédéral/provincial/territorial sur la santé mentale et le bien-être des enfants et de adolescents, *Celebrating Success: A Self-Regulating Service Delivery System for Children and Youth*, document de travail, Santé Canada, 2000, p. 8-10; External Advisory Committee for Child and Youth Mental Health, *Child and Youth Mental Health Plan for British Columbia*, février 2003 (révisé en juillet 2004), p. 4-9; Charlotte Waddell et. al. (avril 2002).

celui du traitement des toxicomanies. Malheureusement, nombre d'obstacles les empêchent d'accéder au traitement approprié :

- Les systèmes de santé mentale et de toxicomanie fonctionnent souvent en parallèle, ce qui empêche de traiter simultanément des personnes ayant besoin des deux types de traitement. Les services actuels offerts à cette population sont mal coordonnés, tout autant au sein des systèmes de santé mentale et de toxicomanie qu'entre ces deux systèmes.
- Il n'existe pas d'approche systématique ni d'instrument d'évaluation efficace permettant de mieux recenser cette population.
- À cause d'un mauvais diagnostic au départ, les personnes ne bénéficient pas de soins appropriés ou ne sont soignées que pour un seul des troubles dont elles souffrent (soit pour la consommation de substances psychoactives, soit pour maladie mentale, mais pas les deux).
- Nombre de programmes de santé mentale excluent les personnes souffrant de troubles liés à une substance psychoactive, tout comme de nombreux programmes de traitement des toxicomanies n'acceptent pas les personnes présentant des problèmes de santé mentale.
- Le personnel qui travaille dans le domaine de la santé mentale et celui qui oeuvre dans le domaine du traitement des toxicomanies devraient suivre une formation commune afin de mieux repérer cette population de clients et donc de mieux la traiter en fonction de ses besoins.
- La peur ou la stigmatisation associée à la maladie mentale et à la toxicomanie empêche très souvent les personnes souffrant de troubles concourants de réclamer des traitements et à opter éventuellement pour une automédication.
- Les personnes souffrant de troubles concourants et leurs familles ne sont pas suffisamment informées sur les services existants ni sur la façon d'y accéder.

Des préoccupations très semblables – comme la fragmentation, le cloisonnement, la stigmatisation, le manque de ressources humaines spécialisées, la nécessité de conduire des interventions précoces et de prendre des mesures préventives – ont été exprimées au sujet des besoins de santé mentale des personnes âgées ainsi que des clients des services de psychiatrie médicolégale.

8.2.2 Les services et les moyens de soutien communautaires

Si une partie de plus en plus importante de personnes souffrant de maladie mentale ou de toxicomanie se rétablit complètement ou en grande partie de ce qui les afflige, la maladie continue de marquer la vie de ces personnes pendant très longtemps, voire pour toujours. Une fois les premiers symptômes diagnostiqués et correctement contrôlés, les personnes souffrant de maladie mentale ou de toxicomanie ont besoin de trois grands types de service : la prévention de la rechute, les services cliniques et les services de réadaptation. Ces trois éléments exigent un certain degré de gestion et, dans le cas d'une personne atteinte de maladie mentale ou de toxicomanie, on parle alors de « gestion de cas ».

Comme nous l'avons expliqué au chapitre 4, la gestion de cas décrit le genre de soutien continu et régulier qu'il faut apporter aux personnes souffrant de maladie mentale ou de trouble associé à la consommation de substance psychoactive pour leur permettre d'obtenir les services voulus. Quand la gravité de la maladie ou la complexité du système empêche les personnes concernées d'accéder aux services dont elles ont besoin, la gestion de cas peut être assurée par du personnel clinique et par du personnel de service de soutien. En présence de besoins multiples, il est essentiel d'offrir une gestion intensive des cas. La gestion des cas est considérée comme une fonction de base du système, mais différentes approches ont été appliquées pour assurer la gestion de cas.

La prévention des rechutes consiste à aider les personnes à demeurer dans un état de rétablissement. Le Comité a appris que le plus important pour prévenir les rechutes consiste à faire en sorte que la personne concernée continue de prendre ses médicaments. Il arrive souvent que les patients arrêtent leur médication parce qu'ils ne se sentent pas bien ou qu'ils n'ont plus la motivation nécessaire pour continuer et ils peuvent aussi ressentir ce qu'ils considèrent comme des effets secondaires intolérables et donc arrêter leurs médicaments. Dans un cas comme dans l'autre, ils perdent de vue les avantages qu'ils auraient à suivre leur traitement et rechutent. L'application d'une posologie correspondant à une prise quotidienne et la réduction de la toxicité médicamenteuse ou des effets secondaires peuvent permettre d'inciter le patient à observer son traitement. Cependant, l'information du patient, les conseils qui lui sont prodigués et un contrôle régulier sont tout aussi fondamentaux pour améliorer l'observance thérapeutique. Des témoins ont déclaré au Comité qu'il fallait à tout prix élaborer des normes et des lignes directrices portant sur des mesures de prévention de la rechute, en consultation avec les responsables de la santé et de l'éducation.

Les services cliniques sont un élément de base des services et des moyens de soutien généraux parce que de nombreuses personnes rechutent. Même quand ils se conforment à leur régime de traitement, nombreux sont ceux qui peuvent tomber gravement malades et exiger des soins actifs. Pour certains dont la vie peut être en danger ou dont la maladie est particulièrement grave, l'admission en milieu hospitalier s'impose. Les services cliniques englobent les services aux hospitalisés, les cliniques hospitalières, les groupes de soutien, les séances d'information, les cliniques de soins externes, les centres de santé mentale, les équipes cliniques itinérantes, les équipes d'urgence et tout un éventail de services cliniques en milieu communautaire. Tous ces services cliniques sont nécessaires afin de répondre aux divers besoins des personnes souffrant de maladie mentale. De tels services, au même titre que les ONG, sont aussi nécessaires pour offrir tout l'éventail des soins dont les personnes touchées et leurs familles ont besoin. Or, il est essentiel de coordonner un système aussi complexe. À ce sujet également des témoins ont déclaré au Comité qu'il est essentiel de formuler des lignes directrices ou des normes cliniques pour promouvoir l'efficacité et l'efficience.

Il convient d'offrir des services de soutien permanents et de réadaptation afin d'optimiser la qualité de vie des patients et de les aider à récupérer leurs capacités dans toute la mesure du possible. Voici ce que comprennent ces services : logement allant des foyers collectifs où travaille un personnel professionnel à des appartements autonomes où l'on donne des consultations régulières, en passant par un service d'intervention de crise de 24 heures sur 24, sept jours sur sept; des services de formation professionnelle comprenant la recherche d'emploi, un cadre d'appui et la formation professionnelle; des services sociaux et récréatifs y

compris l'aide prodiguée à des personnes afin de leur permettre de prendre part à des activités communautaires normales et la mise à disposition de centres d'accueil; un soutien du revenu, parce que nombreux sont ceux qui ont de la difficulté à trouver un emploi et à le conserver. Tous ces services, et d'autres, devraient permettre de garantir le continuum des soins dans un système homogène.

8.2.3 L'inégalité dans la répartition régionale et la qualité des services

Le Comité a appris que, tout comme d'autres services de santé, les services de santé mentale et de traitement des toxicomanies manquent de spécialistes dans les régions rurales et éloignées du pays, notamment dans la plupart des communautés autochtones. Nombre de ces régions n'ont en effet pas de psychiatre résident. Résultat : les personnes souffrant de troubles mentaux, qui vivent dans les régions rurales ou éloignées et dans des communautés autochtones sont contraintes de parcourir de grandes distances pour bénéficier des services nécessaires. Ce genre de difficulté attribuée à ce que l'on a ironiquement appelé la « thérapie-navette » est doublement stressante pour les personnes atteintes de maladie mentale ou de toxicomanie.

Quand des personnes doivent parcourir de longues distances depuis leur lieu de résidence pour recevoir des services de santé mentale ou de désintoxication, elles sont coupées de leur réseau de soutien naturel et de soins informels qui leur apportent le genre de soutien financier, émotionnel et social dont elles ont besoin pour se rétablir. Ce sont des réseaux qu'elles ne trouvent pas dans le système officiel. Bien que, pour certains, l'anonymat de la ville soit synonyme d'éloignement par rapport à l'opprobre et à la stigmatisation – dont les personnes souffrant de maladie mentale ou de toxicomanie font souvent l'objet au sein des petites agglomérations – le fait d'être loin de chez soi peut aussi compromettre le traitement et les résultats du traitement.

L'Association canadienne pour la santé mentale a souligné que les agglomérations rurales et éloignées sont aux prises avec des problèmes particuliers dans le domaine de la santé mentale, comme dans le sillage d'une sécheresse, d'une inondation ou d'autres catastrophes écologiques. On constate également dans ces petites collectivités, la présence de facteurs aggravants comme des niveaux d'instruction et de revenus faibles, des taux de natalité élevés chez les adolescentes, une plus grande proportion de mères seules et des taux de chômage plus élevés, facteurs qui peuvent aussi contribuer à l'apparition et à même à l'aggravation de maladies et de troubles mentaux. Selon l'Association, le fait de transférer des professionnels en santé mentale de la ville à la campagne, même si ces derniers se prêtent volontiers à cet exercice, ne veut pas forcément dire qu'ils seront qualifiés ou équipés pour faire face aux problèmes culturels particuliers de leurs nouveaux clients.[366]

8.2.4 Le secteur des soins de santé primaires

Le secteur des soins de santé primaires est généralement le premier point de contact avec le système des soins de santé pour les personnes souffrant de maladie mentale ou de toxicomanie. Pourtant, le Comité a souvent entendu dire que de nombreux médecins de famille n'ont pas les connaissances, les compétences ni la motivation voulues pour s'occuper

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366 Association canadienne pour la santé mentale, mémoire au Cabinet, juin 2003, p. 8-9.

de patients souffrant de maladie mentale ou de toxicomanie, pour diagnostiquer correctement des troubles mentaux ou pour naviguer dans les dédales du système afin de pouvoir diriger les patients vers des spécialistes en santé mentale ou en toxicomanie. À ce sujet, le Dr Sunil V. Patel, président de l'Association médicale canadienne (AMC) devait indiquer au Comité :

> *Les médecins de famille sont en mesure de prendre en charge plusieurs maladies mentales, mais pour la plupart, ils et elles ne possèdent pas la formation nécessaire pour assurer le traitement médical complexe des maladies mentales graves. La plupart des cabinets de médecin ne sont pas bien équipés non plus pour faire du counselling familial ou s'occuper des problèmes de logement, d'éducation et de travail souvent associés à la maladie mentale.*[367]

D'autres témoins nous ont appris que de nombreux régimes d'assurance-maladie provinciaux plafonnent les montants que les médecins de famille peuvent facturer au titre des services de santé mentale. Par exemple, Patrick Storey, président du Conseil consultatif du ministre sur la santé mentale (Colombie-Britannique) nous a déclaré ce qui suit :

> *Les modalités et les barèmes de facturation des services médicaux, les prestations d'assurance- maladie complémentaire, les régimes de pension, et cetera, ne reconnaissent pas les caractéristiques et les défis particuliers de la santé mentale et dressent des obstacles inutiles à la guérison et à la santé. En Colombie-Britannique, par exemple, un médecin de famille ne peut facturer que quatre consultations par an par patient; cependant, la plupart des gens souffrant d'une dépression vont voir leur médecin de famille. Même si les médicaments anti-dépressifs constituent un complément utile, seuls ils ne suffisent pas pour aider les gens à surmonter efficacement cet état parfois débilitant. Les médecins ne sont pas en mesure d'offrir l'aide nécessaire à une personne déprimée.*[368]

Le Dr James Millar, directeur exécutif, Services de santé mentale et aux médecins, ministère de la Santé de la Nouvelle-Écosse, a exprimé un point de vue semblable :

> *Même les services offerts par les médecins font l'objet de restrictions. Les services offerts par les psychiatres sont entièrement financés, lorsqu'ils sont accessibles. Il existe actuellement une pénurie de psychiatres dans l'ensemble du pays. Environ 80 p. 100 des services de santé mentale sont offerts dans des centres de soins primaires qui ne font pas partie du système officiel de santé mentale. Plusieurs régimes provinciaux de soins médicaux imposent des restrictions quant au nombre et aux types de*

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367 Dr Sunil V. Patel, président de l'Association médicale canadienne, mémoire au Cabinet, 31 mars 2004, p. 1-2.

368 Patrick Storey, président du Conseil consultatif du ministre sur la santé mentale, Colombie-Britannique (15:8).

> *services de santé mentale pouvant être offerts par les omnipraticiens. Dans plusieurs cas, les médecins de famille ne sont pas préparés à bien traiter les patients atteints de troubles mentaux sérieux qui se présentent à leur cabinet. Il n'existe que très peu de soutien pour l'éducation ou pour les consultations sur place.*[369]

On nous a, par ailleurs, signalé que la réforme des soins de santé primaires, récemment entreprise, se fait en marge de la réforme du système de santé mentale et de toxicomanie dans toutes les localités du pays. Pourtant, de nombreux témoins estiment que ces deux réformes systémiques devraient obéir au même objectif, soit améliorer la prestation de services accessibles, complets, intégrés, opportuns et de qualité à tous ceux et à toutes celles qui en ont besoin, sans égard à leur maladie première.

Des témoins ont indiqué au Comité qu'il serait toutefois possible de réaliser des progrès, moyennant un appui pour les initiatives « de soins de santé mentale partagés » lancées un peu partout au pays. Ces initiatives, qui découlent d'un partenariat entre le Collège des médecins de famille du Canada et l'Association des psychiatres du Canada semblent donner d'excellents résultats. Elles visent les activités de collaboration entre les fournisseurs de soins de santé primaires et les psychiatres. Certaines initiatives de soins de santé mentale partagés ont une dimension clinique très importante et elles consistent à intégrer les services de santé mentale dans les établissements de soins de santé primaires.[370]

Irene Clarkson, directrice exécutive, Santé mentale et toxicomanie, ministère des Services de santé de la Colombie-Britannique, a indiqué au Comité que le partage entre les établissements de soins de santé mentale et les établissements de soins de santé primaires permettraient d'améliorer la détection et l'intervention précoces :

> *À l'heure actuelle, 60 p. 100 des personnes souffrant de troubles mentaux et de troubles liés à une substance psychoactive reçoivent leurs services, en Colombie-Britannique, par le truchement des soins de santé primaires, d'où la priorité que nous avons décidé d'accorder à l'amélioration des soins primaires. […] La documentation médicale prêche en faveur de ce genre d'intervention par des équipes multidisciplinaires. […] Dans bien des cas, les médecins sont la seule source de services en santé mentale et en toxicomanie pour les gens à risque ou pour les personnes souffrant de troubles mentaux et de troubles associés à la consommation de substances psychoactives; ce faisant, si l'on faisait davantage attention aux soins primaires, nous parviendrions : à favoriser une détection et une intervention précoce dans le cas des troubles de santé mentale et de toxicomanie, ce qui donnerait lieu à une amélioration des pronostics à long terme; à enseigner aux clients la façon*

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369 Dr James Millar, directeur exécutif, Services de santé mentale et aux médecins, ministère de la Santé de la Nouvelle-Écosse, mémoire au Cabinet, 28 avril 2004, p. 5-6.

370 Association canadienne des psychiatres et Collège des médecins de famille du Canada, *Shared Mental Health Care in Canada – Current Status, Commentary and Recommendations*, rapport du Collaborative Working Group on Shared Mental Health Care, décembre 2000.

de gérer eux-mêmes leurs problèmes de santé; à garantir des évaluations régulières et périodiques de même que des traitements pour promouvoir la stabilité de même que des séjours en milieu communautaire.[371]

De nombreux témoins estimaient que le gouvernement fédéral pourrait jouer un rôle de premier plan pour garantir la pérennité du financement des initiatives de soins partagées qui donnent des résultats et faire en sorte que les modèles de pratiques exemplaires soient mis en œuvre et donnent lieu à des politiques et à des programmes permanents dans toutes les provinces et dans tous les territoires.

8.2.5 Les ressources humaines

Comme les autres secteurs du système de soins de santé, les services de santé mentale et de traitement des toxicomanies souffrent d'un manque de planification coordonnée des ressources humaines. Il n'existe pas de mécanisme de planification centralisé permettant de coordonner l'embauche ou la répartition d'un personnel dûment qualifié et expérimenté entre les différentes localités. La concentration de plus en plus importante du professionnel de la santé mentale et du traitement des toxicomanies dans les grands centres urbains est un autre sujet de grande préoccupation.

Les témoins ont fait part au Comité des pénuries chroniques de fournisseurs, notamment d'infirmières en psychiatrie, de psychiatres, de travailleurs sociaux, de gestionnaires de cas et d'ergothérapeutes connaissant les problèmes de santé mentale et de toxicomanie.

La nécessité croissante de disposer de services experts est exacerbée par une pénurie de psychiatres et par un accès limité aux psychologues. Selon l'Association des psychiatres du Canada, nous sommes très loin du ratio idéal de psychiatres par nombre d'habitants (1 pour 8 400), surtout à l'extérieur des centres urbains. Le fait que de plus en plus des 3 600 psychiatres actuellement inscrits au Canada ne travaillent pas à temps plein – surtout parce qu'il s'agit de femmes et de jeunes diplômés qui arrivent tout juste sur le marché et qui ont décidé d'effectuer moins d'heures de travail – n'arrange pas les choses. Le manque de spécialistes est criant dans certaines spécialités, par exemple en pédopsychiatrie, en gérontopsychiatrie et en psychiatrie médico-légale. Les personnes souffrant de troubles concourants (maladie mentale et toxicomanie) ou faisant l'objet de diagnostics mixtes (trouble mental et de déficience développementale) éprouvent particulièrement des difficultés à accéder à des soins psychiatriques adaptés.[372] En outre, certains groupes comme les immigrants et les réfugiés ne bénéficient pas d'un niveau de services adapté à leurs besoins.

Dans le cas des services psychologiques, c'est légalité d'accès qui pose le plus problème. Les services financés par l'État, dispensés par des hôpitaux ou des cliniques de santé mentale, sont rares et d'accès limité. Comme ils sont aux prises avec des contraintes budgétaires, il n'est pas rare que les hôpitaux généraux réduisent la taille de leurs services de psychologie ou

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371 Irene Clarkson, directrice exécutive, Santé mentale et toxicomanie, ministère des Services de santé de la Colombie-Britannique, mémoire au Cabinet, 9 septembre 2003, p. 5-6.

372 Association des psychiatres du Canada, Human Resource Planning for Psychiatry in Canada – A Background Paper, document non publié.

les éliminent carrément. En outre, un grand nombre de personnes à revenu faible ou moyen, ainsi que les chômeurs ou ceux qui ne bénéficient pas d'assurance-maladie privée, ne peuvent se permettre de payer pour des services psychologiques privés qui ne sont pas couverts par les régimes provinciaux d'assurance-maladie.

L'allongement des listes d'attente et les retards très importants mis dans l'établissement des diagnostiques, dans la prestation des traitements et des services de soutien sont les conséquences directes d'un système de santé mentale qui ne dispose pas des ressources humaines nécessaires pour offrir efficacement les soins voulus. S'il n'existe actuellement aucune source normalisée de données susceptibles de se faire une idée des listes d'attente à l'échelle nationale, les évaluations provinciales, elles, nous présentent un tableau plutôt sinistre. Voici ce nous avons pu lire dans le mémoire de l'Association canadienne pour la santé mentale :

> *[…] environ la moitié de la population adulte ayant besoin de services doit attendre huit semaines ou plus – une éternité dans la vie d'une personne, d'une famille ou d'une collectivité aux prises avec des maladies mentales ou des cas de toxicomanie grave. Pour certains, l'attente de services est une question de vie ou de mort. Si ce sont les listes d'attente pour les chirurgies qui font la une des journaux, force est de constater que notre société ignore à peu près tout de la souffrance et de l'isolement de ceux et de celles qui traversent une crise de santé mentale, qui souffrent et qui attendent en silence de recevoir l'aide médicale nécessaire, voire critique dont ils ont besoin. Il est tragique que, lorsqu'une personne trouve enfin la force et le courage de réclamer de l'aide, la première chose qu'on lui dise quand elle prend contact avec le système de santé mentale, c'est combien de temps elle devra patienter.*[373]

La D[re] Cornelia Wieman, psychiatre des Six Nations Mental Health Services (Ohsweken, Ontario) a indiqué au Comité que l'on ne compte actuellement que quatre psychiatres autochtones au Canada. Selon elle, il est important voire crucial de former davantage de professionnels de la santé autochtones. Cela permettrait de nous assurer que les services offerts sont plus appropriés sur le plan culturel et de retirer des obstacles auxquels se heurtent ceux et celles qui désirent obtenir des services de santé mentale au sein de communautés qui, de l'avis de tous, ont des besoins particuliers pour ces gens-là.

> **Une dernière chose pour conclure ma supplique sur ce plan. On dit que personne n'est irremplaçable. Après sept ans de travail dans la communauté des Six Nations et après avoir vu plus de 400 patients en plus de 600 séances, je vous demande s'il y a quelqu'un pour me remplacer? […] Nous avons désespérément besoin de former plus de professionnels de la santé autochtones.**
> ***[D[re] Cornelia Wieman, mémoire au Comité, 13 mai 2004, p. 5-6.]***

Le Comité a reçu plusieurs recommandations relativement à la planification des ressources humaines en santé mentale, maladie mentale et toxicomanie. Ainsi, on nous a recommandé que les provinces et les territoires, en partenariat

373 Association canadienne pour la santé mentale, mémoire au Comité, juin 2003, p. 8.

avec le gouvernement fédéral, élaborent un plan à long terme prévoyant que des fournisseurs de services de haut niveau, correctement formés – c'est-à-dire des professionnels et des para-professionnels – répondent aux besoins des Canadiennes et des Canadiens en santé mentale. Le plan en question devrait comporter les éléments suivants :

- un plan de ressources humaines national précis en ce qui a trait au personnel des services de santé mentale et de toxicomanie, plan qui serait fondé sur les tendances et les besoins prévus;
- des données regroupées sur les listes d'attente; des normes et des lignes directrices nationales devant régir le temps d'attente maximum pour le continuum des services de soins de santé mentale et de traitement de la toxicomanie;
- un examen de l'efficacité de recours à d'autres personnels que des professionnels, hors du domaine médical, comme les travailleurs de soutien à domicile, les travailleurs sociaux, les travailleurs de l'entraide et les réseaux sociaux informels en vue de réduire la demande de psychiatres;
- la création d'un groupe de travail chargé d'examiner la façon d'améliorer les connaissances en matière d'intervention en santé mentale, de formuler des recommandations dans ce sens et de préparer une formation, et la promotion de stratégies dans le cadre des programmes de formation de tous les professionnels de la santé et des étudiants de premier et deuxième cycle dans les disciplines de la santé, dans l'enseignement, du travail social et d'autres programmes connexes offerts dans les universités et les collèges;
- une analyse de la mesure dans laquelle il serait possible de faire participer les médecins et les psychologues, les infirmières, les travailleurs sociaux, les ergothérapeutes et les intervenants en toxicomanie à des possibilités de formation interdisciplinaire (premier cycle, deuxième cycle et éducation continue);
- l'adoption de mesures incitatives axées sur le recrutement et le maintien en poste des professionnels de la santé et des étudiants dans ces disciplines;
- une étude des divers modèles de prestation des services de santé mentale en région rurale, dont la télémédecine.

8.2.6 Les besoins non comblés

> *Le problème de l'accès se pose dans tout le continuum des services, des soins primaires pour des troubles courants aux services d'urgence et de crise pour les troubles les plus graves et les plus persistants.*
> *[Dr Donald Addington, professeur et chef du département de psychiatrie, Université de Calgary, mémoire au Comité, 29 mai 2003, p. 3.]*

Malgré les efforts déployés par les provinces et les territoires afin d'améliorer les moyens de soutien et les services de santé mentale de même que les services de traitement des

toxicomanies, une majorité de Canadiennes et de Canadiens souffrant de maladie mentale de toxicomanie ne réclament ou ne reçoivent toujours pas d'aide professionnelle. L'Enquête sur la santé dans les collectivités canadiennes (ESCC), cycle 1.2 sur la santé mentale et le bien-être, de Statistique Canada, a révélé que 32 p. 100 seulement des personnes atteintes de maladie mentale ou de troubles liés à la consommation de substance psychoactive ont consulté un professionnel de la santé dans les 12 mois ayant précédé la tenue de l'enquête.[374] La consultation peut se faire auprès d'un psychiatre, d'un médecin de famille, d'un spécialiste, d'un psychologue ou d'une infirmière.

Dans le cas des personnes ayant consulté un professionnel de la santé pour une maladie mentale liée à la consommation simple ou abusive d'alcool ou de drogue, il s'agissait le plus souvent d'un médecin de famille. Près de 26 p. 100 des personnes interrogées ont consulté un médecin de famille, 12 p. 100 environ un psychiatre et 8 p. 100 un psychologue. Quelque 10 p. 100 d'entre elles se sont entretenues, en personne ou autrement, avec un travailleur social.

Il ressort également de l'ESCC que les adolescents et les jeunes adultes (15 à 24 ans) étaient les moins susceptibles de tous les groupes d'âge d'avoir recours aux ressources disponibles pour le traitement des maladies mentales et de la toxicomanie, bien que leur taux de prévalence de troubles mentaux soient le plus élevé. Seulement 25 p. 100 des adolescents et des jeunes adultes touchés ont déclaré avoir consulté un professionnel ou avoir bénéficié d'une autre forme d'assistance dans les 12 mois ayant précédé l'enquête.

Dans son mémoire au Comité, Phil Upshall, président de l'Alliance canadienne des maladies mentales et de la santé mentale, énumère les différents facteurs qui font que les besoins en services de santé mentale/moyens de soutien et traitement des toxicomanies ne sont pas comblés :

> *Pour quelle raison les gens ne reçoivent-ils aucun traitement et, fort probablement, les autres services dont ils ont besoin?*
>
> - *Ce phénomène est attribuable en partie au fait que la population canadienne en général est peu sensible à la maladie mentale ou à l'incompréhension des gens face aux symptômes de la maladie mentale.*
> - *La stigmatisation constitue un obstacle – la crainte de souffrir d'un trouble mental continue de nous hanter.*
> - *Les services sont rares. Quand ils investissent dans la santé, les gouvernements mettent la priorité sur les services biomédicaux spécialisés à l'intention des personnes aux prises avec la maladie mentale et de celles présentant des complications psychologiques sous forme de maladie physique et d'invalidité.*

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374 Statistique Canada, « Enquête sur la santé dans les collectivités canadiennes : Santé mentale et bien-être », *Le Quotidien*, 3 septembre 2003.

- *Les services ne sont pas tous offerts aux Canadiens, puisqu'il faut gagner un revenu supérieur à la moyenne pour se permettre les services d'une pratique privée et les malades mentaux sont souvent loin de gagner un revenu qui le leur permette. Ces derniers représentent un pourcentage disproportionné des populations marginalisées – ces gens sans revenu, logement ou réseau de soutien adéquat qui puisse répondre à leurs besoins élémentaires.*

- *Dans le milieu médical, on est peu sensibilisé aux symptômes de la maladie mentale et on les comprend peu, sans compter le manque de disponibilité qui joue également un rôle.*[375]

Le Dr Donald Addington, professeur et chef du département de psychiatrie à l'Université de Calgary, a recommandé l'adoption d'une charte du patient. Celle-ci fixerait les normes d'accès aux services de santé mentale dans le réseau des soins primaires, aux services de santé mentale spécialisés et aux soins actifs.[376] En Ontario, le groupe d'étude sur la mise en œuvre de la santé mentale dans le district de Champlain a également recommandé, en 2002, de créer une « charte des droits provinciale pour les patients en santé mentale ». Le préambule de cette charte des droits du patient se lirait ainsi :

> *Les personnes atteintes de maladie mentale peuvent prétendre à bénéficier de l'ensemble des droits et des privilèges accordés à tous les citoyens du Canada, notamment aux droits aux soins de santé, au maintien du revenu, à l'éducation, à l'emploi, à un logement sûr et abordable, au transport, aux services juridiques ainsi qu'à une santé équitable et à d'autres garanties qui ne sauraient être toutes énumérées dans la présente charte.*[377]

Cette charte ne se limiterait pas aux services de santé mentale, puisqu'elle engloberait également un vaste éventail de moyens de soutien sociaux. Voici, plus précisément, ce sur quoi elle porterait :

- services de santé mentale sûrs, garantis, fondés sur l'expérience clinique, opportuns, culturellement adaptés et pertinents aux besoins du patient;
- services et moyens de soutien incitant les personnes souffrant de maladie mentale ou de toxicomanie à se prendre en main et qui soient fondés sur les principes du rétablissement, de l'effort autonome ainsi que de la vie et du fonctionnement en autonomie;

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375 Phil Upshall, président, ACMMSM, mémoire au Comité, 18 juillet 2003, p. 8.

376 Dr Donald Addington, professeur et chef du département de psychiatrie, Université de Calgary, mémoire au Comité, 29 mai 2003, p. 3.

377 Champlain District Mental Health Implementation Task Force, « Consumer Charter of Rights for Mental Health Services", in *Foundations for Reform*, section 3.1.4, Ontario, décembre 2002.

- traitement respectueux des lois existantes (Loi sur la santé mentale, Charte canadienne des droits et libertés, etc.);
- respect de la vie privée et des choix informés.

D'autres témoins ont recommandé l'adoption d'une sorte de « loi sur l'équité en santé mentale » afin de combler le fossé entre les maladies physiques et les troubles mentaux en matière de couverture publique et de services offerts. D'autres, cependant, étaient davantage favorables à la nomination d'un « défenseur » en matière de santé mentale auquel pourraient d'adresser les personnes ayant de la difficulté à accéder à des services et à des moyens de soutien en santé mentale. En Colombie-Britannique, il y a eu un défenseur en santé publique, mais le poste a été aboli après la création du ministère d'État pour la santé mentale et la toxicomanie.

8.2.7 La détection et l'intervention précoces

La détection et l'intervention précoces sont d'autant plus nécessaires qu'énormément de besoins en maladie mentale et en toxicomanie ne sont pas comblés. D'ailleurs, de nombreux témoins nous ont déclaré que l'intervention précoce – qui englobe la détection, l'évaluation, le traitement et le soutien – peut interrompre le déroulement négatif des événements pour plusieurs troubles mentaux et atténuer l'incapacité à long terme. Les récentes découvertes sur le cerveau indiquent qu'une détection et une intervention précoces peuvent très nettement améliorer les résultats des traitements et que les pensées et les comportements anormaux sur de longues périodes peuvent avoir des effets cumulatifs risquant de limiter la capacité de rétablissement du patient. Voici d'ailleurs ce que nous a appris la Société canadienne de schizophrénie :

> *Pour la plupart des maladies, plus le diagnostic et le traitement interviennent tôt et meilleur sera le pronostic. […] Malheureusement, comme le grand public et les professionnels ne connaissent pas assez les symptômes, le problème de stigmatisation et de déni de la maladie, nombreux sont ceux et celles qui reçoivent des traitements tardifs. On estime que la moitié des schizophrènes doivent attendre environ deux ans avant d'être diagnostiqués et traités après l'apparition des premiers symptômes.*
>
> *[…]*
>
> *La recherche indique que, plus on tarde à traiter les symptômes psychotiques et plus le pronostic à long terme est pessimiste. On constate davantage de dommages au cerveau chez ceux et celles qui ont subi des épisodes psychotiques de longue durée, non traités, que chez les personnes ayant eu des épisodes plus courts et mieux traités. Outre que les dommages au cerveau sont directement proportionnels à la durée passée sans traitement, le patient risque de perdre son emploi ou son niveau de scolarisation, de perdre des amis et son entregent et il court beaucoup plus*

de risque d'avoir des démêlés avec la justice à cause des symptômes de sa maladie.[378]

Les avantages d'une intervention précoce se constatent dans le cas de nombreuses maladies et pour tous les groupes d'âge. Sans une intervention et un traitement précoces, il est fréquent que les troubles constatés chez les enfants et les adolescents se poursuivent à l'âge adulte. Si le système ne les détecte et ne les traite pas comme il se doit, ces troubles de l'enfance risquent de persister et de déboucher sur une spirale descendante caractérisée par l'échec scolaire, de piètres perspectives d'emploi et la pauvreté à l'âge adulte. Il n'existe pas une autre famille de maladie qui porte aussi gravement atteinte à un si grand nombre d'enfants.

Pour l'instant, aucun organisme ni aucun système n'est clairement responsable envers les enfants et les adolescents souffrant de troubles mentaux. Ces derniers n'ont d'autres choix que de faire affaire avec plus d'un service spécialisé, c'est-à-dire avec des services de santé mentale, des services d'éducation spéciale, de bien-être de l'enfance, de justice pour les jeunes, de traitement des toxicomanies et des soins de santé.

C'est à l'école que les enfants passent le plus clair de leurs journées. Si les écoles se préoccupent surtout d'éducation, il demeure que la bonne santé mentale des élèves est essentielle à l'apprentissage tout comme au développement social et émotionnel. À cause de cette interaction importante entre la santé mentale et la réussite scolaire, les écoles devraient être des partenaires dans les soins de santé mentale des enfants.

De plus, chaque intervention est essentielle pour atténuer la douleur et les souffrances des enfants, des adolescents et des adultes présentant des troubles concourants (maladie mentale et toxicomanie). Il arrive trop souvent que l'on traite ces gens-là pour un seul de leur problème, quand on les traite effectivement. Dès qu'un trouble n'est pas traité, ce sont les deux qui empirent et l'on constate souvent l'apparition d'autres complications, notamment les risques suivants : autres problèmes médicaux, chômage, séparation des familles et des amis, itinérance, incarcération et suicide. Le Comité a appris que trop peu de fournisseurs ou de systèmes de traitement des maladies mentales ou des toxicomanies s'attaquent efficacement au problème que posent les troubles concourants.

L'intervention précoce devrait prendre place dans des lieux facilement accessibles comme les cabinets et les cliniques de soins primaires de même que les écoles et partout où le risque de maladie mentale est présent comme dans les services de justice pour jeunes et de bien-être de l'enfance. Outre qu'il faut adopter une approche coordonnée, il est important : d'assurer la formation du personnel scolaire pour qu'il sache détecter et reconnaître les premiers signes de la maladie mentale; de former les fournisseurs de soins primaires; et d'éliminer les obstacles à l'assurance-santé publique, surtout pour les services psychologiques.

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378 Société de schizophrénie du Canada, mémoire au Cabinet, 2004, p. 5.

8.3 LOI SUR LA SANTÉ MENTALE

Outre qu'ils sont responsables, au premier chef, d'offrir les services de santé mentale et de traitement des toxicomanie dans leur domaine de compétence, les provinces et les territoires doivent adopter et appliquer des lois en santé mentale. Celles-ci régissent la prestation des traitements psychiatriques aux personnes gravement touchées par une maladie mentale et incapables de réclamer et d'accepter l'aide nécessaire. Pour l'instant, chaque province et territoire administre sa propre loi en matière de santé mentale, à l'exception du Nunavut où c'est la loi des Territoires du Nord-Ouest qui s'applique.

Toutes les lois provinciales et territoriales en matière de santé mentale définissent les critères d'admission non consentie dans les hôpitaux à des fins de traitement psychiatrique, les conditions d'autorisation et de refus de traitement, ainsi que les critères applicables aux congés conditionnels et aux procédures de révision et d'appel. Dans les cas où l'admission en hôpital et les traitements psychiatriques ne sont pas imposés, ceux et celles qui refusent de leur plein gré d'entreprendre un traitement volontaire se retrouvent seuls face aux conséquences de leur maladie non traitée. Les personnes souffrant de troubles mentaux non traités présentent un taux de mortalité et d'incapacité sur une vie plus élevé que la plupart des personnes atteintes d'une maladie physique.

> **En général, les traitements obligatoires permettent à la personne qui souffre d'une maladie entravant sa capacité de raisonner de retrouver sa liberté de pensées et de mouvements. Or, si on ne la traite pas contre son gré, elle risque d'avoir des séquelles sur le plan du sentiment d'autonomie et sur celui des droits légaux et civiques. C'est pour cette raison que la loi peut devoir réaliser l'équilibre entre les besoins des personnes malades et ceux de la société en général.**
> ***[Gray, Shone et Liddle (2000), Canadian Mental Health Law and Policy, p. 5.]***

Les lois sur la santé mentale sont également destinées à réaliser un équilibre entre les droits et la dignité de l'individu, la protection de la société et le souci de la société d'aider ceux et celles qui ne sont pas en mesure de s'aider eux-mêmes. D'ailleurs, Toutes les lois provinciales et fédérales doivent se conformer aux dispositions de la *Charte* qui constitue la loi suprême au Canada. Dans le contexte des questions de santé mentale, les articles pertinents de la *Charte* sont les articles 7, 9, 12 et 15 ainsi que l'article premier. En vertu de l'article 7, il ne peut être porté atteinte au droit de chacun à la vie, à la liberté et à la sécurité de sa personne qu'en conformité avec les principes de justice fondamentale. En vertu de l'article 9, chacun a droit à la protection contre la détention ou l'emprisonnement arbitraires. En vertu de l'article 12, chacun a droit à la protection contre tous traitements ou peines cruels et inusités. Enfin, en vertu de l'article 15, la loi s'applique également à tous, en tous ont droit à la même protection et au même bénéfice de la loi, indépendamment de toute discrimination, notamment des discriminations fondées sur les déficiences mentales. Bien que la *Charte* garantisse certains droits aux termes des articles précités, la réserve établie à l'article premier limite le caractère absolu de ces garanties. En effet, selon l'article 1, les droits reconnus par la *Charte* ne le sont qu'en deçà des limites raisonnables et justifiables. Un tribunal peut donc

décider que la violation d'un droit, même s'il est garanti par la *Charte*, est raisonnable et justifiée dans la société d'aujourd'hui.[379]

En 1984, craignant que les actuelles lois sur la santé mentale fassent l'objet de contestation au titre de la *Charte*, un groupe établi en vertu de la Conférence sur la loi uniforme a proposé une « loi uniforme sur la santé mentale » en tant que modèle de loi provinciale dans ce domaine. Ce groupe d'études était composé d'un avocat et d'un haut fonctionnaire en santé mentale pour chaque province et territoire participant. La loi uniforme sur la santé mentale a été adoptée par les représentants à la Conférence sur la loi uniforme en 1987. Les principes qui suivent constituent les fondements de la Loi uniforme sur la santé mentale proposée :

- Un régime qui privilégie l'admission et la détention en cure volontaire et le traitement avec le consentement éclairé du malade est préférable à des services obligatoires.
- Lorsqu'il n'y a pas d'autre choix que de recourir aux services obligatoires qui portent atteinte à la liberté d'une personne et à son droit de prendre des décisions, il faut respecter les dispositions de la Charte.
- On doit proposer au malade plusieurs types de traitements, y compris ceux qui sont les moins contraignants et les moins perturbateurs, en lui donnant les explications nécessaires.
- L'obligation de respecter la confidentialité des renseignements contenus dans le dossier médical d'un malade mental est d'autant plus importante que cette personne est vulnérable et que tout manquement à cet égard risque d'avoir de graves conséquences.
- Le malade a le droit d'examiner les documents réunis pour les besoins de son traitement médical, pour vérifier l'exactitude des renseignements qu'ils contiennent.
- Lorsqu'une décision prise en vertu de dispositions législatives porte atteinte aux droits et libertés d'une personne, un organisme indépendant ou un tribunal peut examiner une telle décision pour décider si elle est équitable ou non.[380]

La loi uniforme sur la santé mentale n'a jamais été mise en œuvre en tant que telle dans les provinces et les territoires, mais de nombreux ressorts ont adopté des lois qui en reprennent les principes fondamentaux. Il demeure, cependant, d'importantes différences d'un ressort à l'autre dans les dispositions des lois pertinentes sur la santé mentale. Les différences pourraient avoir d'importantes répercussions sur les personnes atteintes d'une maladie mentale grave, parce que beaucoup ne peuvent recevoir à

La Loi sur la santé mentale peut jouer un rôle déterminant pour établir si une personne, atteinte d'une maladie mentale grave doit ou non recevoir un traitement psychiatrique et si ce traitement doit être dispensé rapidement.
[Gray et O'Reilly, « Clinically Significant Differences Among Canadian Mental Health Acts », Canadian Journal of Psychiatry, vol. 46, nº 4, mai 2001, p. 315-321.]

379 Maureen Anne Gaudet, Division de la santé mentale, Direction des services de santé, Direction générale des programmes et des services de santé, Santé Canada, *Vue d'ensemble de la législation sur la santé mentale au Canada*, 1994, p. 4.

380 Maureen Anne Gaudet (1994), p. 17-18.

temps le traitement dont elles ont besoin. Ces différences peuvent aussi être la cause d'importants dilemmes pour les psychiatres. C'est ainsi que Gray et O'Reilly (2001) ont relevé les principales anomalies suivantes :

- Dans certains ressorts, les critères régissant l'admission contre le gré du patient précisent que la personne doit être susceptible de se blesser elle-même ou de causer des blessures physiques à d'autres (Alberta, Nouvelle-Écosse, Territoires du Nord-Ouest et Nunavut). Ailleurs, les critères en la matière comportent aussi la notion de blessure non physique (mentale). Les mesures qui limitent l'admission et le traitement involontaire à des seuls critères de blessure physique posent un problème d'ordre éthique aux psychiatres qui peuvent estimer qu'un patient est en détresse profonde à cause d'une maladie psychotique sans pour autant risquer de se blesser ni de blesser quelqu'un d'autre. Le cas échéant, même s'ils sont convaincus qu'un traitement permettrait d'alléger rapidement et efficacement cette détresse, ils ne peuvent ni hospitaliser le patient ni le traiter. Ce faisant, certaines personnes atteintes d'une maladie mentale grave et ayant besoin de traitements psychiatriques ne reçoivent pas de soins dans des délais raisonnables. Selon Gray, Shone et Liddle (2000) : « L'augmentation du nombre de personnes souffrant de maladie mentale qui se retrouvent en prison ou sans abri est en partie attribuable aux lois qui limitent l'admission involontaire au seul danger physique.[381] »

- À la suite de l'admission involontaire d'une personne, certaines provinces la contraignent à suivre un traitement (Colombie-Britannique, Nouveau-Brunswick, Terre-Neuve, Québec et Saskatchewan);[382] ces provinces ont recours à un agent de l'État pour autoriser le traitement (médecin traitant, directeur d'une unité psychiatrique ou tribunal). Les autres ressorts permettent au patient de refuser le traitement, mais un autre décideur peut renverser cette règle s'il en va de l'intérêt de la personne (soit un gardien, un parent, un curateur public, un Comité d'examen ou un tribunal). En revanche, l'Ontario, les Territoires du Nord-Ouest et le Nunavut respectent tout vœu antérieur exprimé par la personne de ne pas recevoir de traitement, même si cela doit prolonger sa détention et ses souffrances. Toutes les provinces et

Les procédures judiciaires peuvent retarder indûment le traitement de patients réfractaires. Malheureusement, le traitement doit être interrompu en vertu de la loi ontarienne sur le consentement aux soins de santé dès que la personne s'adresse à un tribunal. Une étude indique que la durée moyenne d'interruption du traitement est de 253 jours à compter du moment où un tribunal a été saisi. Cela veut dire que les personnes de trouvant dans cette situation ont été détenues contre leur gré pendant plus de huit mois, ce qui a été source, pour elles et pour leur famille, d'une angoisse inutile, et que l'on a gaspillé d'importantes sommes provenant des impôts des particuliers. Un simple changement à la loi permettrait de corriger ce problème.
[Société canadienne de schizophrénie, mémoire au Comité, 2004, p. 9.]

381 John E. Gray, Margaret A. Shone et Peter F. Liddle, *Canadian Mental Health Law and Policy*, 2000, p. 5.

382 Dans certains cas, toutefois, le patient peut demander au tribunal d'ordonner à l'hôpital de suspendre son traitement.

tous les territoires prévoient qu'un conseil ou une commission de révision examine la validité d'une hospitalisation non consentie. Quand, pour obtenir l'autorisation de traitement, il faut avoir recours à un tribunal ou à une autre personne chargée de prendre la décision, les délais peuvent aller de quelques jours à quelques années avant que le traitement ne commence.

- Tous les ressorts reconnaissent que le traitement obligatoire au sein de la communauté est moins restrictif que l'admission non consentie suivie d'un traitement en milieu hospitalier. Ce faisant, les lois provinciales et territoriales sur la santé mentale renferment des dispositions qui autorisent un congé conditionnel d'un hôpital ou l'émission d'ordonnance de traitement communautaire (OTC). Les dispositions permettant un congé conditionnel autorisent un patient réfractaire à se retrouver au sein de la communauté; le patient demeure toutefois sous l'autorité de l'hôpital, mais il peut poursuivre son traitement au sein de la communauté. En Saskatchewan et en Ontario, il n'est pas question de régler le cas de patients non consentants, mais de prévoir un traitement obligatoire pendant que la personne réside au sein de la communauté. Les OTC sont destinées à réduire le syndrome des va-et-vient, à réserver ainsi les lits d'hôpitaux aux autres malades et à aider ceux qui ont besoin de soins en santé mentale à intégrer la communauté. Toutefois, pour que les OTC soient efficaces, les services et les moyens de soutien doivent permettre de réaliser les conditions nécessaires. La principale critique adressée aux OTC concerne le fait que les services nécessaires ne sont pas offerts à l'extérieur des hôpitaux et que les patients ne réussiront pas au sein de la communauté et qu'ils devront être hospitalisés. Dans le même ordre d'idées, on reproche le fait que les hôpitaux vont faire sortir prématurément la personne et la « relâcher » dans la communauté. Seules quatre lois provinciales sur la santé (en Colombie-Britannique, au Manitoba, en Ontario et en Saskatchewan) interdisent qu'une personne soit visée par une OTC à moins qu'il existe des moyens de soutien appropriés dans la communauté.

Il est évident que la gestion psychiatrique des patients ayant vécu des épisodes graves de maladie mentale variera grandement selon le lieu de résidence de ces personnes au Canada. Dans certaines provinces ou territoires, là où l'admission et le traitement sont rapides, les personnes souffrant de troubles mentaux graves ont une bonne chance de reprendre un jour des activités quotidiennes « normales ». Ailleurs, plusieurs mois voire plusieurs années peuvent s'écouler avant que la santé mentale du patient se détériore au point qu'on juge qu'il risque de s'infliger des blessures corporelles graves ou d'en infliger à d'autres et que cet état mérite une hospitalisation contre son gré. Même après leur hospitalisation, ces personnes peuvent ne pas recevoir de traitement pendant plusieurs mois ou plusieurs années dans les ressorts où l'amorce des traitements est empêchée en attendant que l'appel soit tranché ou quand les personnes concernées ont émis, avant leur hospitalisation, le vœu de ne pas être traitées et que ce vœu doit être respecté en vertu de la loi.

Voici ce que Gray et O'Reilly (2001) disent à ce sujet dans leur examen des lois provinciales et territoriales sur la santé mentale :

> *Il est particulièrement inquiétant de constater de tels écarts de pratique entre les provinces et les territoires. Il est de plus en plus établi que la durée d'une psychose non traitée débouche sur un piètre pronostic mais*

> *qu'une intervention précoce peut permettre d'éviter la progression de maladie sous-jacente. Qui plus est, il est évident que les psychoses qui apparaissent à un jeune âge peuvent entraver la réalisation de tâches développementales importantes comme les études, la formation professionnelle et les traitements psychosociaux. […] La recherche indique que les taux d'itinérance, de violence, de victimisation et de criminalisation sont supérieurs dans le cas des personnes qui souffrent d'une maladie mentale n'ayant pas été traitée que dans celui de personnes dont la maladie a été traitée. Les congés conditionnels et les ordonnances de traitement communautaire sont maintenant utilisés un peu partout au Canada et à l'étranger. Ces mesures ont fait leur preuve dans la réduction des hospitalisations et dans la promotion de l'observance thérapeutique.*[383]

Devrait-on insister pour que les lois provinciales et territoriales en matière de santé soient davantage uniformisées? Les écarts constatés dans les lois sur la santé mentale traduisent-ils des points de vue divergents comme un équilibre à réaliser entre la protection des personnes vulnérables, les droits et libertés de la personne et la sécurité publique? Comme l'ont si bien fait remarquer Gray, Shone et Liddle (2000), en fin de compte, les lois sur la santé mentale sont affaire de valeurs sociétales :

> *La société doit se demander si, au nom de la liberté, il faut laisser la personne qui est atteinte d'une maladie cérébrale traitable et qui connaît les affres des délires en souffrance et sans abri parce qu'elle n'est pas physiquement dangereuse. La société est-elle favorable au « droit d'être psychotique » au point qu'il faudrait permettre à quiconque de refuser un traitement et donc de demeurer détenue pendant de longues périodes, aux frais de l'État, quitte à ce qu'elle court le risque de se blesser grièvement elle-même ou de blesser quelqu'un d'autre? Ou alors, la société doit-elle maintenir cette personne dans les hôpitaux quand, moyennant une loi adaptée, celle-ci pourrait être chez elle, au sein de leur communauté? La société préfère-t-elle que les gens fonctionnent au sein de leur communauté parce qu'ils sont légalement tenus de suivre leur traitement ou veut-elle les amener à connaître de nouveaux épisodes psychotiques et de nouvelles hospitalisations non consenties? Une société juste et compatissante doit sous-peser ces différentes options en tenant compte, notamment, du souci de réduire l'intrusion de l'État dans la vie des gens.*[384]

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383 John E. Gray et Richard L. O'Reilly, « Clinically Significant Differences Among Canadian Mental Health Acts », *Canadian Journal of Psychiatry*, vol. 46, nº 4, mai 2001, p. 320.

384 John E. Gray, Margaret A. Shone et Peter F. Liddle, *Canadian Mental Health Law and Policy*, octobre 2000, p. 358.

8.4 OBSERVATIONS DU COMITÉ

Toutes les provinces et tous les territoires ont entrepris la réforme et le renouvellement de leur système de soins en santé mentale et de traitement des toxicomanies. Certains ressorts sont plus avancés que d'autres, mais tous ont retenu les mêmes objectifs et les mêmes principes. En outre, la plupart des provinces sont confrontées à des défis et à des obstacles semblables dans leur tentative visant à améliorer la prestation des services de santé mentale et des moyens de soutien de même que les services de traitement des toxicomanies.

Le Comité rejoint les témoins pour affirmer qu'il faut mettre un terme à la « philosophie du cloisonnement » en matière de planification des politiques et de prestation des services et des moyens de soutien en santé mentale et en toxicomanie. Pour cela, il convient d'améliorer l'intégration, les partenariats et la collaboration. Ce travail sera fondamental pour parvenir à un système de traitement en santé mentale et en toxicomanie qui soit vraiment efficace.

Nous convenons aussi avec les témoins que les personnes souffrant de maladie mentale ou de toxicomanie et les organisations non gouvernementales doivent prendre part à la réforme du système. Il ne sera possible de mettre sur pied un système homogène que si nous faisons appel à leur vécu et à leur savoir.

Pour instaurer un tel système homogène de services et de moyens de soutien en santé mentale et en traitement des toxicomanie – système axé sur la personne –il faudra aussi relever de nombreux défis sur les plans de la planification des ressources humaines et de la réforme des soins de santé primaires. De plus, il faudra mettre davantage l'accent sur la détection et l'intervention précoces. Il faudra, tout particulièrement, répondre dans des délais raisonnables aux besoins des enfants et des adolescents.

Le Comité reconnaît aussi que les personnes souffrant de troubles mentaux graves sont particulièrement vulnérables et que les services de santé mentale et de traitement des toxicomanies doivent donc refléter un équilibre approprié entre les droits de ces personnes et le rôle de la société à s'en occuper de façon compatissante. Il importe de décider si les contradictions actuelles constatées dans les différentes lois provinciales et territoriales sur la santé mentale nécessitent un examen formel.

CHAPITRE 9: POLITIQUES ET PROGRAMMES VISANT LA SANTÉ MENTALE ET LA TOXICOMANIE: LE CADRE FÉDÉRAL

Compte tenu des niveaux de fardeau qu'imposent les problèmes de santé mentale et la maladie mentale à la société, les gouvernements du Canada ne peuvent plus ignorer la réalité. Le temps est venu de corriger les déséquilibres du passé. Le Canada ne peut atteindre la vision holistique de la santé mentale […] que s'il s'attaque de façon coordonnée aux questions complexes interreliées. Il faut désormais un leadership national coopératif dans une stratégie d'action nationale. Nous espérons que le gouvernement fédéral relèvera ce défi. En tant que citoyens, nous en profiterons tous.
[Association canadienne pour la santé mentale, mémoire au Comité, juin 2003, p. 31.]

INTRODUCTION

Le présent chapitre porte sur le rôle et la responsabilité du gouvernement fédéral en ce qui concerne l'élaboration de politiques et de programmes dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie. Il présente aussi diverses mesures fédérales qui aident à former un cadre général dans ce domaine. Une distinction est faite cependant entre les projets fédéraux visant les populations relevant directement de sa compétence et les autres projets de portée plus nationale qui touchent des questions plurigouvermentales, notamment celles qui intéressent principalement les provinces et les territoires.

La section 9.1 donne un aperçu du rôle direct et du rôle indirect que joue le gouvernement fédéral en matière de santé mentale, de maladie mentale et de toxicomanie. La section 9.2 décrit et évalue le rôle direct du gouvernement fédéral à l'égard des populations relevant spécifiquement de sa compétence, soit : les Premières nations et les Inuits; les détenus des pénitenciers fédéraux; les anciens combattants et les membres des Forces canadiennes; la Gendarmerie royale du Canada; les fonctionnaires fédéraux. La section 9.3 examine la coordination interministérielle en ce qui a trait au rôle direct du gouvernement fédéral. La section 9.4 aborde le rôle et les responsabilités du gouvernement fédéral sur le plan national (rôle indirect); il étudie aussi les leviers juridiques et financiers dont dispose le gouvernement pour influer sur la politique dans le domaine. La section 9.5 donne une évaluation générale des politiques et des programmes fédéraux ayant une incidence sur la prestation de services de santé mentale, de services de traitement de la toxicomanie et de moyens de soutien sociaux. La section 9.6 traite d'un plan d'action national envisageable. La section 9.7 examine la santé mentale, la maladie mentale et la toxicomanie du point de vue de la santé de la population et la section 9.8 présente les observations du Comité.

9.1 RÔLE DIRECT ET RÔLE INDIRECT DU GOUVERNEMENT FÉDÉRAL

Pour pouvoir brosser un tableau de l'étendue du rôle du gouvernement fédéral en matière de santé mentale, de maladie mentale et de toxicomanie, les attachés de recherche du Comité ont cherché dans les lois et règlements codifiés du Canada des expressions comme « toxicomanie », « invalidité », « troubles mentaux », « santé mentale », « maladie mentale » et « abus de substance ». Le tableau 9.1 dresse la liste des lois fédérales qui contiennent ces termes.

Le rôle du gouvernement fédéral dans ce domaine comporte manifestement deux volets. Il est, d'abord, *directement* responsable de certains groupes de Canadiens. D'après le rapport au Parlement sur le rendement du Canada en 2003 : « le gouvernement fédéral fournit des services de santé primaires et complémentaires à environ un million de personnes admissibles – ce qui en fait le cinquième plus important prestataire de soins de santé au Canada. Parmi ces personnes figurent notamment les anciens combattants, les militaires, les détenus des pénitenciers fédéraux, certains immigrants reçus et demandeurs du statut de réfugié, les membres en service actif des Forces canadiennes et de la Gendarmerie royale du Canada, ainsi que les membres des Premières nations vivant dans les réserves et les Inuits.[385] » De plus, le gouvernement fédéral est un important employeur dont le vaste effectif a ses propres préoccupations en matière de santé.

Deuxièmement, le gouvernement fédéral est censé donner une perspective nationale à la politique sociale, laquelle vise notamment la santé mentale, la maladie mentale et la toxicomanie. Il joue ainsi un rôle *indirect* de surveillance générale de l'intérêt public de tous les Canadiens à l'échelle nationale. Il s'acquitte de cette responsabilité de plusieurs façons : transferts de fonds aux provinces, surveillance d'activités et collecte de données, financement et exécution d'activités de recherche et de développement, homologation de médicaments, soutien du revenu et prestations d'invalidité pour les Canadiens visés, programmes sociaux comme des initiatives de logement, financement du système de justice pénale et réalisation d'un certain nombre de programmes visant à promouvoir de façon générale la santé et le mieux-être de la population.

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[385] Conseil du Trésor du Canada, Le rendement du Canada 2003 – Rapport annuel au Parlement, Ottawa, 2004, p. 30.

TABLEAU 9.1
LOIS FÉDÉRALES CONCERNANT LA SANTÉ MENTALE, LA MALADIE MENTALE OU LA TOXICOMANIE

Code criminel
Loi canadienne sur la santé
Loi canadienne sur les droits de la personne
Loi de l'impôt sur le revenu
Loi électorale du Canada
Loi fédérale sur l'aide financière aux étudiants
Loi fédérale sur les prêts aux étudiants
Loi réglementant certaines drogues et autres substances
Loi sur la pension de la fonction publique
Loi sur la pension de retraite de la Gendarmerie royale du Canada
Loi sur la pension de retraite des Forces canadiennes
Loi sur la protection des renseignements personnels
Loi sur la protection des renseignements personnels et les documents électroniques
Loi sur la réadaptation professionnelle des personnes handicapées
Loi sur la taxe d'accise
Loi sur le Centre canadien de lutte contre les toxicomanies
Loi sur le Centre canadien d'hygiène et de sécurité au travail
Loi sur le ministère de la Santé
Loi sur l'emploi dans la fonction publique
Loi sur le Parlement du Canada
Loi sur les aliments et drogues
Loi sur les allocations aux anciens combattants
Loi sur les allocations de retraite des parlementaires
Loi sur les arrangements fiscaux entre le gouvernement fédéral et les provinces
Loi sur les Instituts de recherche en santé du Canada
Loi sur les mesures d'urgence
Loi sur les normes de prestation de pension
Loi sur les pensions
Loi sur les prestations de retraite supplémentaires
Loi sur le système correctionnel et la mise en liberté sous condition
Loi sur le système de justice pénale pour les adolescents
Loi sur l'extradition
Régime de pensions du Canada

Source : Division du droit et du gouvernement, Service d'information et de recherche parlementaire, Bibliothèque du Parlement.

Dans un rôle comme dans l'autre, le cadre envisagé en matière de santé mentale, de maladie mentale et de toxicomanie ne saurait supplanter la responsabilité première des provinces et des territoires en matière de conception et de réalisation des programmes. Il reste toutefois une nécessité absolue d'établir un cadre applicable à tous les Canadiens, qu'ils relèvent de la compétence fédérale ou provinciale.

Tom Lips, conseiller principal en santé mentale à la Division de la santé des collectivités, Direction générale de la santé de la population et de la santé publique à Santé Canada, a clairement établi la distinction entre les responsabilités fédérales et les responsabilités provinciales/territoriales lorsqu'il est question de services de santé mentale et de traitement de la toxicomanie :

> *D'abord, les rôles et responsabilités des administrations fédérales/provinciales/territoriales sont différents dès lors qu'il s'agit de santé mentale et de maladie mentale […] C'est aux gouvernements provinciaux et territoriaux que revient la principale responsabilité d'assurer la planification et la prestation des services de santé destinés à l'ensemble de la population. Comme vous le savez, les transferts fédéraux permettent de financer en partie la prestation des services de santé. Le gouvernement fédéral a aussi un mandat particulier en matière de prestations de soins de santé à l'égard de certaines populations, notamment les membres des Premières nations vivant dans la réserve et les Inuits. Il est également chargé de la promotion de la santé à l'échelle nationale. Les deux paliers de gouvernement mènent des activités de promotion de la santé, de recherche et de surveillance, et ont conjugué leurs efforts pour régler certaines difficultés en matière de prestation de services – par exemple, en définissant des pratiques exemplaires.*[386]

En fait, l'éventail des programmes et des services fédéraux visant la santé mentale, la maladie mentale et la toxicomanie est très vaste. Il comprend des dispositions visant des groupes particuliers qui relèvent directement de la compétence d'Ottawa ainsi que de nombreuses mesures en réponse aux préoccupations de la population en général. Les sections qui suivent portent sur les aspects propres au gouvernement fédéral et sur les éléments généraux de portée nationale et, là où c'est possible, elles fournissent des éléments d'information afin de pouvoir évaluer ces programmes et services.

9.2 RÔLE DIRECT DU GOUVERNEMENT FÉDÉRAL[387]

Les sections qui suivent décrivent et évaluent les programmes et les projets existants à l'intention des groupes particuliers qui relèvent directement de la responsabilité fédérale.

9.2.1 Les Premières nations et les Inuits

La *Loi constitutionnelle de 1982* (article 35) définit les peuples autochtones comme étant « des Indiens, des Inuit et des Métis du Canada ». Malgré cette définition constitutionnelle assez générale, le gouvernement fédéral n'est actuellement responsable que des Indiens vivant dans

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386 Tom Lips, conseiller principal, Santé mentale, Division de la santé des collectivités, Direction de la santé de la population et de la santé publique, Santé Canada (11:6).

387 L'information contenue dans cette section est tirée d'un document de Nancy Miller-Chenier, *Federal Responsibility for the Health Care of Specific Groups*, Service d'information et de recherche parlementaires, Bibliothèque du Parlement, à venir.

les réserves et de certains Inuits. Santé Canada estime servir quelque 735 000 membres des Premières nations et Inuits admissibles.

Ce sont les gouvernements provinciaux et territoriaux qui assument la responsabilité générale des Autochtones vivant hors réserve, y compris les Métis et les Indiens non inscrits. Ces groupes ont accès à des programmes et à des services au même titre que les autres résidants. Ces domaines de compétence distincts, conjugués à la diversité de notre population autochtone, ont sérieusement nui à l'établissement d'un plan exhaustif pour l'élaboration d'un véritable système en matière de santé mentale, de maladie mentale et de toxicomanie.

Au fil des ans, le gouvernement fédéral a tenté à plusieurs reprises de régler les problèmes de maladie mentale et de toxicomanie dans les collectivités autochtones. Au début des années 90, le ministère fédéral de la Santé a produit, avec l'aide d'un comité directeur multilatéral, un Programme de santé mentale destiné aux Premières nations et aux Inuits. Il a aussi ciblé les peuples autochtones dans le cadre de stratégies générales comme la Stratégie anti-drogue, le Programme de la prévention de la violence familiale et le Programme pour des collectivités en bonne santé. En 1996, la Commission royale sur les peuples autochtones a attiré l'attention sur les problèmes de santé mentale associés à la pauvreté, à la maladie et à la désorganisation sociale dans de nombreuses collectivités.

En janvier 1998, le gouvernement fédéral a publié sa réponse au rapport de la Commission royale dans un document intitulé *Rassembler nos forces : le plan d'action du Canada pour les questions autochtones;*[388] celui-ci proposait une stratégie pour amorcer le processus de réconciliation et de renouvellement de sa relation avec les peuples autochtones. Deux importantes initiatives visaient à donner aux peuples autochtones plus d'autonomie face à certaines de leurs préoccupations liées à la santé physique et mentale. Tout d'abord, en 1998, le gouvernement fédéral a financé la Fondation autochtone de guérison, un organisme sans but lucratif administré par des Autochtones, afin d'appuyer les mesures de santé communautaire prises par des Métis, des Inuits et des membres des Premières nations dans les réserves et hors réserve. Ces mesures s'adressaient aux victimes de mauvais traitements et de violence sexuelle dans les pensionnats et aux personnes touchées indirectement par des répercussions intergénérationnelles. Deuxièmement, en 1999, Santé Canada a travaillé en collaboration avec plusieurs organismes autochtones afin de mettre sur pied l'Organisation nationale de la santé autochtone. Ce nouvel organisme, dont le nom officiel est Organisation pour la promotion de la santé des peuples autochtones, s'intéresse en priorité aux domaines de l'information et de la recherche en santé, aux méthodes traditionnelles employées pour rester en santé et guérir, à la politique de santé, au renforcement des capacités et à l'éducation publique.

En 2003, le gouvernement a décidé de consacrer 1,3 milliard de dollars sur cinq ans à l'élaboration d'un système de soins de santé efficace et viable pour les Premières nations et les Inuits.[389] Dans le discours du Trône de février 2004, Ottawa s'est en outre engagé à adopter une approche plus cohérente à l'égard des nombreuses questions touchant les collectivités autochtones. Le gouvernement fédéral a promis d'établir un centre indépendant

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388 Affaires indiennes et du Nord canadien, *Rassembler nos forces : le plan d'action du Canada pour les questions autochtones*, Ottawa, 1997.

389 Ministère des Finances du Canada, *Le plan budgétaire 2003*, p. 17.

sur le gouvernement des Premières nations, de renouveler la stratégie de développement des ressources humaines autochtones, de donner plus d'ampleur à la Stratégie pour les Autochtones vivant en milieu urbain et de créer un comité du Cabinet chargé des affaires autochtones.[390]

9.2.2 L'évaluation de la situation des Premières nations et des Inuits

À l'heure actuelle, Santé Canada et Affaires indiennes et du Nord canadien sont les deux principaux ministères fédéraux chargés des soins de santé, des services de santé mentale, du traitement de la toxicomanie et des services sociaux dispensés aux membres des Premières nations et aux Inuits.

Santé Canada, par le biais de sa Direction générale de la santé des Premières nations et des Inuits, s'occupe des programmes suivants qui concernent la maladie mentale et la toxicomanie :

- Programme national de lutte contre l'abus d'alcool et de drogue chez les Autochtones (PNLAADA) : ce programme est en grande partie pris en charge par les communautés et les organismes des Premières nations; il comprend un réseau de 48 centres de traitement et programmes de prévention communautaires.
- Programme national de lutte contre l'abus de solvants chez les jeunes : grâce à son réseau de dix centres de traitement, ce programme offre des services d'évaluation, de traitement des malades hospitalisés et de counselling à l'intention des adolescents des Premières nations et inuits ayant des problèmes d'abus de solvants.
- Programme de soutien en santé mentale des pensionnats indiens : ce programme offre un soutien en santé mentale et un soutien affectif aux demandeurs admissibles qui ont entamé une poursuite pour les mauvais traitements subis dans des pensionnats indiens et dont les recours contre le gouvernement du Canada sont en cours de règlement. Il est réalisé par Santé Canada en collaboration avec Affaires indiennes et du Nord canadien.
- Syndrome d'alcoolisation fœtale/effets de l'alcool sur le fœtus (SAF/EAF) : ce projet, qui fait partie du Programme canadien de nutrition prénatale, a pour objectif de mieux faire connaître le SAF/EAF et d'offrir des services de santé mentale aux personnes à risque ainsi que des services de désintoxication aux femmes enceintes à risque, à leurs partenaires et à leurs familles.
- Programme des Services de santé non assurés (SSNA) : ce programme offre aux Indiens inscrits et aux Inuits et Innus des biens et des services médicalement nécessaires non couverts par les régimes d'assurance-maladie provinciaux/territoriaux ou privés. Les avantages en question apportent un complément aux services de santé couverts par les provinces et les territoires et portent notamment sur les médicaments, le transport à des fins médicales, les soins dentaires, les soins de la vue, les fournitures et l'équipement médicaux ainsi que le counselling en santé mentale et en situation de crise.

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390 Le gouvernement du Canada, *Discours du Trône, 2004*, p. 11-13.

- Programme d'aide scolaire aux Autochtones dans les réserves : ce programme vise à répondre aux besoins affectifs, sociaux, sanitaires, nutritionnels et psychologiques des jeunes autochtones en vue de les préparer à l'école. Il est réalisé en collaboration avec les programmes Grandir ensemble et Pour des collectivités en bonne santé de Santé Canada. Il est mené en outre de concert avec l'Initiative visant la garde d'enfants de Développement des ressources humaines Canada et le Programme de maternelle du ministère des Affaires indiennes et du Nord canadien, tous les deux menés à l'échelon national et local, afin de faire en sorte que le Programme d'aide scolaire aux Autochtones dans les réserves comble les lacunes et complète les programmes existants.[391]

Le ministère des Affaires indiennes et du Nord canadien offre, dans le cadre de ses politiques et programmes sociaux, le Programme des services à l'enfance et à la famille, l'Aide sociale, le Programme de soins aux adultes, la Prestation nationale pour les enfants et d'autres services sociaux visant le mieux-être de l'individu et de la famille. Tous comportent des éléments concernant la santé mentale. Certains programmes visent plus particulièrement la maladie mentale et la toxicomanie, par exemple :

- Programme de prévention du suicide chez les Autochtones : ce programme, réalisé en collaboration avec la GRC, enseigne aux jeunes adultes et aux intervenants communautaires comment aider à prévenir le suicide. Les participants sont choisis par les dirigeants et les sages des collectivités autochtones.
- Programme du Bouclier autochtone : ce programme, réalisé en collaboration avec la GRC, fournit aux collectivités de l'information sur la toxicomanie. Il offre un soutien aux policiers autochtones et non autochtones, ainsi qu'aux dirigeants communautaires, aux travailleurs de la santé, aux enseignants et aux intervenants auprès des jeunes.
- Programme pour la prévention de la violence familiale : ce programme fournit des fonds d'exploitation aux refuges des collectivités des Premières nations. Il sert aussi à encourager les programmes communautaires qui ont pour objectif de prévenir la violence familiale dans les réserves.[392]

Des témoins ont informé le Comité que les programmes fédéraux visant la maladie mentale et la toxicomanie chez les Premières nations et les Inuits ne répondent pas adéquatement aux besoins des peuples autochtones. Ainsi, Dre Cornelia Wieman, psychiatre aux Six Nations Mental Health Services, à Ohsweken (Ontario), a parlé des séances de counselling psychiatrique offertes en vertu des Services de santé non assurés :

> *[Dans le cadre des SSNA,] la limite est fixée à 15 séances avec une possibilité d'un renouvellement de 12 autres séances. Un total de 27 séances ne suffit pas à bien aider un grand nombre de patients à surmonter leurs problèmes de santé mentale. La vocation du programme SSNA est de fournir un soutien aux clients en crise ou à ceux qui n'ont*

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391 Santé Canada, *Budget des dépenses de 2003-2004: Rapport sur les plans et les priorités*.

392 D'après les renseignements fournis sur le site Web du ministère des Affaires indiennes et du Nord canadien (http://www.ainc-inac.gc.ca/sg/sg4_f.html).

aucune autre possibilité de recevoir du counselling. Ce counselling pourrait être assuré par une clinique psychiatrique ou un service de santé externes financés par le système de soins de santé provincial qui pourrait aussi assumer les frais de counselling individuel.

Le revenu de la majorité de mes patients est limité et ils ne peuvent pas payer les frais de counselling individuel. À cause de problèmes de transport et d'accès, beaucoup d'entre eux peuvent aussi ne pas avoir accès aux services de counselling dans les petites collectivités avoisinantes ou dans les grandes agglomérations telles que Brantford ou Hamilton. Ces personnes sont, en fait, des laissés-pour-compte.[393]

Mais surtout, des témoins ont souligné que la façon dont les programmes à l'intention des Premières nations et des Inuits sont compartimentés en « silos » nuit beaucoup à l'accès aux services de santé mentale et de traitement de la toxicomanie. En effet, les divers ministères, directions ou divisions offrent les services et les moyens de soutien sans chercher à collaborer les uns avec les autres. De plus, on a tendance à isoler les problèmes en fonction de leurs symptômes – toxicomanie, suicide, SAF/EAF, logement insalubre, manque d'emploi, etc. – et à concevoir des programmes indépendants pour s'attaquer à chaque problème. Or, cette approche à la pièce connaît peu de succès. D'après les témoins qui ont comparu devant le Comité, il faudra repenser en profondeur les façons de faire et déroger à la pratique établie afin de rétablir le mieux-être des collectivités des Premières nations et des Inuits d'un bout à l'autre du pays.

L'une des recommandations de la Native Mental Health Association of Canada vise l'élimination des programmes de services dans ce que nous appelons l'effet de silos. Au lieu d'accorder un financement pour la santé mentale, les services sociaux et d'autres questions de la collectivité, nous favorisons des approches d'équipe fondées sur le partenariat afin que ce qui est disponible pour une collectivité soit intégré et rendu disponible et accessible à nos clients sous forme holistique descendante, des décideurs et des planificateurs aux autorités locales.
[Brenda Restoule, Native Mental Health Association of Canada (9:51)]

Le Comité a aussi été informé que le morcellement des services servant à régler des questions interreliées constitue un réel problème. Ainsi, les membres des Premières nations et les Inuits sont mal servis par des modèles de prestation de programmes gouvernementaux qui mettent l'accent sur les services offerts aux individus par opposition aux services holistiques à l'intention des collectivités, plus adaptés à la culture autochtone. Comme l'a déclaré le Dr Laurence Kirmayer, directeur de la Division de psychiatrie sociale et transculturelle, Département de psychiatrie, Université McGill :

[L]es perspectives en matière de santé mentale ont tendance à viser l'individu et la vulnérabilité et l'affliction individuelles. Ce genre de données reflète vraiment l'incidence des forces sociales, des facteurs influant sur des générations entières et c'est ainsi que nous devons les

393 Dre Cornelia Wieman (9:55).

> *considérer. Dans ce modèle, il y a une vulnérabilité individuelle; les gens ne réagissent pas tous de la même manière face à la même adversité. Toutefois, le taux élevé global laisse à penser que beaucoup de gens sont concernés et que des éléments extérieurs à l'individu sont en jeu. Il nous importe de définir les forces sociales et de réfléchir aux moyens d'aider les gens à s'en charger.*[394]

Les témoins ont aussi souligné que le fait d'offrir à tous des programmes et des services identiques ne répond pas efficacement aux besoins des peuples autochtones. En général, ces derniers connaissent leurs problèmes et sont mieux placés pour trouver des solutions adaptées et pour savoir quelles ressources doivent être utilisées en fonction des priorités de la collectivité. Sur le plan pratique, cela signifie qu'il serait de loin préférable que les ministères délèguent aux communautés autochtones le pouvoir d'adapter les services et de réagir avec souplesse aux circonstances locales. Parallèlement, il faudrait appuyer les peuples autochtones qui élaborent leurs propres solutions, plutôt que de leur imposer des solutions provenant de « l'extérieur ».

Pour que les initiatives communautaires réussissent, il faut, en parallèle, développer la capacité de la collectivité de réaliser les programmes efficacement. Or, les témoins ont signalé la grave pénurie, voire l'absence, de professionnels qualifiés en matière de santé mentale et de toxicomanie. À cet égard, Dre Wieman a déclaré:

> *[L]a formation d'un plus grand nombre de professionnels de la santé chez les Autochtones […] est une des meilleures façons d'améliorer l'accès aux services de santé et les résultats dans le domaine de la santé, y compris la santé mentale. Les obstacles à l'accès aux divers services de santé mentale pourraient être éliminés et des soins plus adaptés culturellement seraient offerts. En 1996, la Commission royale sur les peuples autochtones a recommandé la formation en médecine de 10 000 Autochtones au cours des 10 prochaines années. Il ne reste que deux ans pour arriver à 2006 et je crois que nous sommes encore très loin de cet objectif. Le nombre de médecins autochtones au Canada est d'environ 150, la plupart sont des médecins de famille. Je n'ai pas le chiffre exact sous la main, mais je crois que le nombre de spécialistes autochtones est probablement inférieur à 25. À ma connaissance, il y a deux autres psychiatres autochtones au Canada, un quatrième finit le programme de résidence au Manitoba en juin.*[395]

Le Comité a aussi été saisi du fait que les besoins des peuples autochtones sont complexes, et que les solutions à court terme échouent souvent. À dire vrai, un financement de courte durée risque d'empêcher les gouvernements autochtones d'élaborer les stratégies à long terme nécessaires pour répondre aux besoins de leurs collectivités. Il faut parfois des années

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394 Dr Laurence Kirmayer (9:42).

395 Dre Cornelia Wieman (9:55-56).

pour élaborer des programmes efficaces et, souvent, plus le délai accordé à un projet est court, moins il y a de chances que ce dernier soit efficace.

De plus, les témoins se sont en général entendus pour dire que les niveaux de financement actuels des services de santé mentale et de traitement de la toxicomanie chez les Premières nations et les Inuits sont insuffisants. Brenda Restoule, psychologue et représentante du conseil de l'Ontario, Native Mental Health Association of Canada, l'a expliqué ainsi :

> *Le financement actuel est déjà inadéquat et ne répond pas aux besoins de la collectivité et des membres. Étant donné que le financement est fonction de la population, de nombreuses collectivités en reçoivent un petit montant, ce qui rend difficile ou, dans un bon nombre de cas, impossible les services de counselling et d'intervention en santé mentale. La plupart des collectivités doivent utiliser leur financement pour promouvoir la santé mentale et élaborer des programmes de prévention des maladies mentales. Bien que ce type de programmes soit nécessaire, le financement ne permet par un continuum de soins dont ont désespérément besoin les collectivités des Premières nations.*
>
> *[…]*
>
> *Le financement est si peu élevé pour les salaires des travailleurs de santé mentale que des professionnels comme les travailleurs sociaux, les psychologues et les psychiatres ne sont pas intéressés à travailler dans les collectivités des Premières nations.*[396]

Le Comité a été informé que certaines provinces ont intégré les aspects autochtones dans leurs stratégies de santé mentale. Les stratégies fédérales destinées aux Autochtones vivant dans les réserves ou à l'extérieur devront, pour réussir, s'harmoniser avec les plans provinciaux sur la santé mentale et les stratégies connexes de mise en œuvre.[397]

> **Les moyens utilisés pour aborder [les problèmes de santé mentale] chez les peuples autochtones n'ont pas bien fonctionné. Une des conséquences de cette situation est la surreprésentation des peuples autochtones dans le système de justice pénale et dans les organismes de protection de la jeunesse. Le bien-être et l'état de santé des peuples autochtones laissent beaucoup plus à désirer que ceux des autres Canadiens. Les membres des communautés nous ont indiqué que cet état ne s'améliorerait pas tant que nous ne pourrons pas nous concentrer sur les communautés plutôt que sur les individus.**
> ***[Mme Bronwyn Shoush, commissaire, Institut de la santé des Autochtones, IRSC (16:10)]***

Pour résumer, les programmes fédéraux et provinciaux de santé mentale autochtone, qui se concentrent sur des individus ou sur des aspects particuliers d'une question, ont été critiqués parce que leur

396 Brenda Restoule (9:49).

397 D'après Ray Block, directeur général exécutif, Alberta Mental Health Board, mémoire au Comité, 28 avril 2004, p. 10.

compartimentation empêche une coordination aisée avec d'autres programmes. Le résultat est un ramassis de programmes semblables, une multiplicité de niveaux de services et un éventail complexe de mécanismes de financement déconcertants pour les personnes auxquelles ils sont destinés ainsi que leurs familles et les collectivités. Idéalement, dans une approche holistique ou globale, les ministères mettraient leurs ressources en commun afin de pouvoir répondre, du moins partiellement et de façon structurée et intégrée, à tous les besoins connexes touchant par exemple la santé, l'éducation, le logement et l'emploi pour les particuliers, les familles et les collectivités. Des initiatives gouvernementales à l'horizontale auraient pour avantage d'aider les collectivités à mieux planifier et coordonner leurs services.

Sur le plan financier, le manque de coordination donne souvent lieu à un dédoublement inutile et coûteux des programmes. Il faut une analyse de l'environnement afin de déterminer les programmes qui existent, les cas de chevauchement entre ministères et organismes, les lacunes importantes en matière de programmation et la meilleure façon d'utiliser les ressources.

9.2.3 Les délinquants relevant du système correctionnel fédéral

Les délinquants dans les établissements correctionnels fédéraux et les autres relevant du système correctionnel fédéral, soit les détenus purgeant une peine d'emprisonnement de deux ans ou plus, constituent un autre groupe important de Canadiens dont la santé est une responsabilité fédérale. À l'heure actuelle, le Service correctionnel du Canada (SCC) gère quelque 12 600 détenus et 8 500 délinquants en liberté sous condition sous la surveillance d'un agent de libération conditionnelle.[398] Le SCC se préoccupe de la qualité des services de santé mentale et du traitement de la toxicomanie des délinquants sous responsabilité fédérale, mais cette préoccupation cède le pas à l'objectif principal des services correctionnels, soit les besoins « criminogènes ».

Les délinquants sous responsabilité fédérale relèvent entièrement du gouvernement fédéral et ne sont pas considérés comme des bénéficiaires des régimes d'assurance-maladie provinciaux. Françoise Bouchard, directrice générale des Services de santé du SCC, souligne que le mandat législatif de ce dernier est établi dans la *Loi sur le système correctionnel et la mise en liberté sous condition* :

> *Le Service veille à ce que chaque détenu reçoive les soins de santé essentiels et qu'il ait accès, dans la mesure du possible, aux soins qui peuvent faciliter son adaptation et sa réinsertion sociales.*[399]

De plus, dans le domaine de la santé mentale, l'objectif du SCC est de fournir « aux détenus qui ont des troubles mentaux, caractériels et comportementaux (…) un continuum de soins essentiels selon les normes professionnelles et communautaires établies.[400] »

Chaque individu est évalué au moment de son admission dans le système correctionnel et des questions de base lui sont posées sur sa santé mentale, la maladie mentale et la

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398 Service correctionnel du Canada, *Rapport sur les plans et les priorités, 2003-2004*, p. 5.
399 Françoise Bouchard (7:50).
400 *Ibid.* (7:51).

toxicomanie. Après l'évaluation, un plan correctionnel est établi pour chaque détenu et celui-ci est orienté vers un établissement ordinaire ou un établissement qui offre des traitements.

Au cours des 10 dernières années, le SCC a publié des directives précises sur les services de santé mentale et le traitement de la toxicomanie fournis aux détenus sous responsabilité fédérale. En 1994, des directives du commissaire ont été mises en œuvre touchant les services psychologiques, qui comprennent notamment : l'évaluation; l'intervention thérapeutique; l'intervention en situation d'urgence; l'élaboration, l'application et l'évaluation de programmes.[401] En 2002, des directives en santé mentale ont établi des normes touchant l'évaluation, le diagnostic et le traitement qui influent sur l'accès à des professionnels de la santé mentale, les soins d'urgence et dans la collectivité ainsi que les transfèrements vers des centres de soins psychiatriques et de traitement de la toxicomanie.[402] La même année, le commissaire du SCC a publié des directives touchant le traitement à la méthadone (diagnostic et traitement).[403] En 2003, des directives ont été publiées concernant les détenus ayant des tendances suicidaires ou à l'automutilation; elles comprennent des lignes directrices sur la prévention, l'évaluation et le traitement.[404] En 2003, une directive sur les services de santé a été adoptée qui précise que le coût de prestation des services de santé mentale et de traitement de la toxicomanie incombe au SCC.[405]

En plus d'adopter ces directives, le SCC a travaillé à l'élaboration d'une stratégie exhaustive sur les soins de santé visant les besoins tant physiques que mentaux des délinquants, y compris les questions de réintégration liées à l'alcool et aux drogues. La politique de santé mentale a été façonnée par divers projets, dont le Rapport du Groupe de travail sur la santé mentale de 1991 qui visait tous les délinquants, la Stratégie sur les services correctionnels pour Autochtones de 1997 et la Stratégie en matière de santé mentale pour les délinquantes de 2002.

Au SCC, la Direction des initiatives pour les Autochtones est chargée de créer des partenariats et des stratégies pour favoriser la réinsertion sociale, au bon moment et en toute sécurité, des délinquants autochtones. Les Autochtones représentent moins de 3 p. 100 de la totalité de la population canadienne mais constituent 18 p. 100 de la population carcérale sous responsabilité fédérale. Les programmes et les services adaptés aux besoins et à la culture des délinquants autochtones comprennent notamment les éléments suivants : des pavillons de ressourcement (9 au Canada); des établissements résidentiels communautaires (23 au Canada); le Programme de réinsertion sociale des Autochtones; des aînés travaillant en établissement et dans la collectivité; le transfert des services correctionnels aux

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401 John Edwards, commissaire, *Directive du commissaire - Services de psychologie*, Service correctionnel du Canada, 30 décembre 1994.

402 Lucie McClung, commissaire, *Directive du commissaire – Services de santé mentale*, Service correctionnel du Canada, 2 mai 2002.

403 Irving Kulik, commissaire adjoint, *Lignes directrices sur le traitement à la méthadone*, Service correctionnel du Canada, 2 mai 2002.

404 Lucie McClung, commissaire, *Directives du commissaire – Prévention, gestion et intervention en matière de suicide et d'automutilation*, Service correctionnel du Canada, 3 septembre 2003.

405 Lucie McClung, commissaire, *Directive du commissaire – Services de santé*, Service correctionnel du Canada, 17 mars 2003.

collectivités autochtones (5 ententes signées).[406] Le SCC est aussi responsable de la Stratégie nationale sur les services correctionnels pour Autochtones (en cours de révision) qui met l'accent sur les programmes adaptés, les activités communautaires, le recrutement et l'emploi des, le recrutement et l'emploi et les partenariats sur les questions autochtones.[407]

Les femmes ayant des besoins particuliers en santé mentale peuvent, quel que soit leur niveau de sécurité, être traitées dans une unité spécialisée distincte de 12 lits réservés aux femmes au Centre psychiatrique régional des Prairies. Cette unité sert également de ressource nationale en santé mentale pour les femmes anglophones. Les femmes francophones peuvent obtenir des traitements à l'Institut Philippe Pinel à Montréal (Québec), où le SCC a passé des contrats pour obtenir des services de traitement de patientes hospitalisées. En outre, la Stratégie en matière de santé mentale pour les délinquantes de 2002 fournit un cadre pour l'élaboration de services de santé mentale couvrant tout un continuum de soins. L'objectif est d'appliquer les éléments de la stratégie à toutes les délinquantes et d'inclure l'intervention en situation d'urgence, les programmes de soins aigus, les programmes de soins chroniques, les unités pour besoins spéciaux, le traitement des malades externes, les services de consultation, la planification de la mise en liberté et des transfèrements, les suivis de même que les liens avec les autres programmes et services.[408]

Le SCC réalise aussi le Programme de prévention de la toxicomanie, composé d'un éventail de programmes institutionnels et communautaires, choisis en fonction de la gravité de la toxicomanie du délinquant. Le programme, à orientation comportementale et cognitive, est axé sur des techniques structurées de prévention des rechutes. Il comprend aussi le traitement d'entretien à la méthadone.[409]

9.2.4 L'évaluation de la situation des délinquants relevant du système correctionnel fédéral

Des représentants du SCC ont expliqué au Comité que les soins de santé mentale et le traitement de la toxicomanie sont nécessaires pour : réduire les effets invalidants des troubles mentaux afin d'optimiser la capacité de chaque détenu de participer de plein gré aux programmes correctionnels, notamment pour se préparer à réintégrer la collectivité; contribuer au maintien d'un milieu carcéral sûr pour le personnel, les détenus, les bénévoles et les visiteurs; atténuer l'extrême souffrance humaine que causent inutilement les troubles mentaux.[410]

Cependant, le Comité s'est fait dire que pour assurer l'accès aux services de santé mentale et de traitement de la toxicomanie, le SCC doit accroître ses capacités. Il compte cinq centres de traitement spécialisés[411] répartis d'un bout à l'autre du pays, mais il ne dispose pas des

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406 Direction des initiatives pour les Autochtones, *Délinquants autochtones – Aperçu*, Service correctionnel du Canada.

407 Service correctionnel du Canada, *Stratégie nationale sur les services correctionnels pour Autochtones*.

408 Jane Laishes, Santé mentale, Services de santé, Service correctionnel du Canada, *Stratégie en matière de santé mentale pour les délinquantes de 2002*, 2002.

409 Service correctionnel du Canada, *Programme de prévention de la toxicomanie*.

410 Service correctionnel du Canada, mémoire au Comité, avril 2004.

411 Le Centre de rétablissement Shepody (région de l'Atlantique), qui compte 40 lits; l'unité Archambault (région du Québec), 120 lits; le Centre régional de traitement de Kingston (Ontario), 149 lits; le

mêmes ressources que les établissements médico-légaux provinciaux. Le SCC compte de nombreux psychologues, mais ceux-ci se consacrent principalement à l'évaluation des risques en vue de la prise de décisions touchant la mise en liberté sous condition. De plus, le personnel correctionnel ne suit aucune formation particulière en santé mentale et toxicomanie.[412] En ce qui concerne la Stratégie en matière de santé mentale pour les délinquantes, cette nouvelle approche présente une difficulté, puisque les femmes nécessitant une intervention en santé mentale doivent se rendre ailleurs au pays pour obtenir les services nécessaires.

Les témoins ont aussi parlé de la nécessité d'améliorer les liens entre le gouvernement fédéral et les provinces, et entre l'appareil judiciaire et les systèmes provinciaux de services de santé mentale. Comme l'a expliqué Mme Bouchard, du SCC :

> *Il faut établir une stratégie [complète et intégrée] des besoins pour fins d'identification et de traitement des délinquants présentant des problèmes de santé mentale. Même si nous essayons de procéder à un examen lors de l'admission des délinquants, il reste beaucoup à faire en matière d'identification des délinquants atteints de problèmes de santé mentale, dès leur incarcération. C'est ce qui doit se produire dans les systèmes provinciaux également.*
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> *Il faut établir un lien entre le système de justice et les soins de santé au sein des provinces. La recherche des solutions doit débuter avant l'incarcération, pour les délinquants présentant des problèmes de santé mentale. Dans le système correctionnel fédéral, il faut améliorer la capacité de diagnostic et de traitement. Cependant, on ne nous garantit pas des ressources supplémentaires pour cela. Actuellement, nous faisons un examen de notre utilisation des lits dans nos centres de traitement, pour optimiser les ressources et les affecter à ceux qui en ont le plus besoin. Parfois, cela nécessite un changement de culture, entre la culture correctionnelle et la culture du traitement, ce qui veut dire qu'il reste beaucoup de travail à faire.*
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> *Notre dernière observation porte sur l'importance d'aplanir les conflits de compétences pour assurer la continuité des soins lors de la libération dans la communauté. Cela exige de meilleurs liens entre nous, le système correctionnel fédéral et nos homologues provinciaux ainsi que les professionnels des soins de santé mentale. Les partenariats sont la clé pour combler les lacunes de ce genre, mais qu'est-ce qui nous incitera à établir de tels partenariats?*[413]

Centre psychiatrique régional (région des Prairies), un établissement de 194 lits liés à l'Université de la Saskatchewan, par le biais d'une entente spéciale; le Centre régional de traitement d'Abbotsford (région du Pacifique), 192 lits.

412 Service correctionnel du Canada, mémoire au Comité, avril 2004.

413 Françoise Bouchard (7:54-55).

Le Comité a aussi été saisi de certains aspects discriminatoires de l'appareil judiciaire. Ainsi, Patrick Storey, président du Conseil consultatif du ministre sur la santé mentale (Colombie-Britannique), a déclaré :

> *Pour les délinquants fédéraux, il est difficile d'avoir accès à des services de santé mentale financés par la province dans la collectivité, en raison de dispositions spécifiques de la Loi sur la santé mentale de la Colombie-Britannique. Cette loi est, par elle-même, discriminatoire à l'égard de cette population. Elle ordonne aux directeurs des établissements provinciaux de ne pas offrir de soins aux personnes qui viennent d'institutions fédérales. C'est une responsabilité financière du gouvernement fédéral, si bien que les malades mentaux détenus dans une prison fédérale, qui essaient d'obtenir une libération dans la collectivité, n'obtiendront pas de services du centre local de santé mentale ou d'autres services, ce qui est intolérable. […] Les autorités correctionnelles fédérales et provinciales et les autorités sanitaires doivent collaborer pour s'attaquer à ces anomalies et réduire la discrimination à laquelle font face les personnes en conflit avec la loi.*[414]

De plus, le Comité a été informé qu'il faut mieux harmoniser le *Code criminel* et les lois provinciales touchant la santé mentale. Les représentants de la Société canadienne de schizophrénie ont expliqué qu'en vertu du *Code criminel*, un juge peut ordonner à une personne jugée inapte à subir son procès de suivre des traitements qui la rendront apte. Cependant, ni un juge, ni la commission d'examen ne peuvent ordonner le traitement d'une personne déclarée non responsable criminellement pour cause de troubles mentaux, en vue qu'elle se rétablisse assez pour être mise en liberté. En théorie, les lois provinciales en santé mentale permettent ce genre d'ordonnance, mais dans certaines provinces, aucune mesure n'est prise. Les représentants de la Société canadienne de schizophrénie recommandent que le gouvernement fédéral modifie le *Code criminel* afin que la commission d'examen puisse ordonner les traitements nécessaires pour favoriser la mise en liberté d'une personne atteinte d'une maladie mentale qui se soigne. Selon ces représentants, il vaut mieux prendre une telle mesure que d'obliger l'intéressé à rester incarcéré pendant une période déraisonnable parce que la maladie non traitée en fait une menace importante pour la sécurité du public.[415]

Mme Bouchard, du SCC, a souligné la nécessité de meilleurs soutiens communautaires :

> *En s'occupant des besoins des délinquants qui nécessitent des soins spécialisés de santé mentale, on peut réduire le phénomène de la « porte tournante ». Il existe ce que l'on appelle une porte tournante entre les services correctionnels, à la fois fédéraux et provinciaux, mais également dans les communautés, où les gens atteints de troubles de santé mentale se retrouvent dans le système de justice criminelle. Alors que les délinquants ayant des troubles mentaux sont moins susceptibles de récidiver —*

414 Patrick Storey (15:8-9).

415 Société canadienne de schizophrénie, mémoire au Comité, 2004.

notamment de manière violente —, ils sont plus susceptibles de retourner en prison à cause d'une violation de leur liberté conditionnelle, qui est souvent le résultat d'un soutien inadéquat lorsqu'ils réintègrent la société.[416]

9.2.5 Les anciens combattants et les membres actifs des Forces canadiennes

Anciens Combattants Canada est chargé d'offrir des services de santé et de pensions et de fournir un soutien social et économique à plus de 150 000 anciens combattants canadiens et membres des Forces canadiennes (FC). Les principaux bénéficiaires sont les anciens combattants et les civils auxquels une pension ou une allocation a été accordée.[417]

La *Loi canadienne sur la santé* exclut expressément les membres des Forces armées de la définition d'« assuré ». Par conséquent, les militaires ne sont pas admissibles aux soins hospitaliers et aux soins médicaux assurés en vertu des régimes d'assurance-maladie provinciaux.[418] Les Services de santé des Forces canadiennes constituent le fournisseur de soins de santé désigné pour 83 000 membres de la Force régulière et de la Réserve au Canada et lors de déploiements, et ils offrent accès à plus de 85 000 fournisseurs au pays. Le Service Croix Bleue de l'Atlantique se charge de l'administration du programme et des paiements.

Anciens Combattants Canada administre l'hôpital Sainte-Anne, situé à Sainte-Anne-de-Bellevue, au Québec. L'hôpital offre des services médicaux et paramédicaux aux anciens combattants en résidence, ainsi qu'un large éventail d'activités récréatives et sociales. Le Centre Sainte-Anne, qui fait partie de l'hôpital, fournit des services de santé mentale aux membres des Forces canadiennes et aux anciens combattants; il a développé une expertise spécialisée dans les domaines du syndrome de stress post-traumatique et de la démence.[419] Des soins aux patients hospitalisés et externes sont aussi fournis par le biais d'hôpitaux liés par contrat, de foyers pour anciens combattants et d'autres hôpitaux choisis par les intéressés.

Anciens Combattants Canada verse aussi à divers groupes des prestations d'invalidité ou de décès ainsi que du soutien économique. Parmi ces groupes figurent : les membres des Forces canadiennes et les anciens combattants de la marine marchande qui ont servi pendant la Première Guerre mondiale, la Seconde Guerre mondiale ou la guerre de Corée; certains civils admissibles à des prestations en raison de leur service en temps de guerre; des anciens membres des Forces canadiennes (y compris ceux qui ont servi dans des zones de service spécial) et de la Gendarmerie royale du Canada; les survivants et les personnes à charge de militaires et de civils.[420]

Le ministère de la Défense nationale réalise Énergiser les Forces, une initiative de promotion de la santé conçue pour aider les membres de la Force régulière et de la Première réserve à prendre en main leur santé et leur bien-être. La prévention du suicide et la lutte contre l'abus

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416 Françoise Bouchard (7:54).
417 Anciens Combattants Canada, *Programme de soins de santé.*
418 Défense nationale, *Services de santé des Forces canadiennes*, feuillets de documentation.
419 Anciens Combattants Canada, *L'hôpital Sainte-Anne*.
420 Anciens Combattants Canada, *Pensions d'invalidité*.

de tabac et d'alcool sont deux importants éléments de cette initiative. La santé mentale y occupe aussi une place importante. En plus de mettre l'accent sur la vie active, la prévention des blessures et le mieux-être en nutrition, l'initiative comprend les mesures suivantes : Absence de dépendance (abus d'alcool et de drogue, tabagisme, jeu compulsif) et Mieux-être social (gestion du stress et de la colère, prévention de la violence familiale, familles en santé, prévention du suicide et spiritualité).[421]

Santé Canada s'occupe de la santé et de la sécurité professionnelle des membres des FC. Le Programme d'aide aux militaires des Forces canadiennes est organisé par le Programme de santé au travail et de sécurité du public de Santé Canada; il s'agit d'un service téléphonique sans frais offert 24 heures par jour, 7 jours sur 7, qui fournit des services de counselling confidentiels aux militaires et à leurs familles lorsqu'ils ont des préoccupations personnelles qui influent sur leur mieux-être ou sur leur rendement au travail.[422]

9.2.6 L'évaluation de la situation des anciens combattants et des Forces canadiennes

Plusieurs rapports ont souligné des lacunes dans les soins et les traitements que reçoivent les membres des FC de la part du ministère de la Défense nationale en particulier et, par extension, d'Anciens Combattants Canada, soit : les rapports McLellan et Stow en avril 1998, le rapport Goss Gilroy en juin 1998 et le rapport produit en octobre 1998 par le Comité permanent de la défense nationale et des anciens combattants de la Chambre des communes.[423]

Ces ministères ont réagi en adoptant un train de mesures visant la santé mentale. En avril 1999, le Centre du MDN-AAC pour le soutien des militaires blessés ou retraités et de leurs familles a ouvert ses portes à Ottawa, afin de fournir de l'information, des services d'orientation et du soutien aux anciens membres et aux membres actuels des Forces canadiennes et à leurs familles. Par la suite, des réformes législatives et réglementaires ont rendu l'accès aux services et aux avantages plus équitable pour tous les membres des FC, que les blessures soient survenues au Canada ou au cours d'un déploiement à l'étranger. En avril 2001, Anciens Combattants Canada a lancé le Service d'aide pour les anciens membres des FC et leurs familles ayant besoin de counselling professionnel.[424]

Récemment, Anciens Combattants Canada et le ministère de la Défense nationale ont mis l'accent sur les membres des FC et les anciens combattants qui souffrent du syndrome de stress post-traumatique et d'autres traumatismes liés au stress opérationnel. En février 2004, ils ont annoncé conjointement la Stratégie en matière de santé mentale pour les militaires canadiens. Cette stratégie repose sur un réseau d'établissements d'évaluation et de traitement, des forums éducatifs, un programme de formation continue et des activités de recherche sur

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421 Défense nationale, *Énergiser les Forces*.

422 *Ibid.*

423 Anciens Combattants Canada, *Réponse du Gouvernement du Canada au rapport du Comité permanent de la défense nationale et des anciens combattants sur la qualité de vie dans les Forces canadiennes*, 2001.

424 *Ibid.*

le syndrome de stress post-traumatique et les autres traumatismes liés au stress opérationnel.[425]

9.2.7 La Gendarmerie royale du Canada

La Gendarmerie royale du Canada (GRC) est un organisme du ministère de la Sécurité publique et de la Protection civile du Canada. En plus de fournir des services de police fédérale à tous les Canadiens, elle fournit des services de police à contrat à trois territoires, à huit provinces (toutes sauf l'Ontario et le Québec), à quelque 198 municipalités et, conformément à 172 accords particuliers, à 192 collectivités des Premières nations. Au 1er janvier 2004, l'effectif de la Gendarmerie s'élevait à 22 239 membres.[426]

La définition des personnes assurées en vertu de la *Loi canadienne sur la santé* exclut les membres de la GRC. L'administration de l'assurance des soins de santé pour les membres de la GRC relève d'Anciens Combattants Canada depuis 2003. Ce ministère s'occupe également de verser directement des prestations d'invalidité à environ 3 800 retraités de la GRC, ainsi que de fournir des soins de santé à quelque 800 pensionnés civils et à la retraite.[427]

9.2.8 L'évaluation de la situation de la Gendarmerie royale du Canada

Le Comité ne disposait pas d'information sur les préoccupations à la GRC en matière de santé mentale, de maladie mentale et de toxicomanie.

9.2.9 Les fonctionnaires fédéraux

Le gouvernement fédéral est un employeur important. Son effectif a diminué entre mars 1995 et mars 2001, passant de 225 619 à 155 360 employés, mais il est réputé avoir augmenté de nouveau au cours des dernières années.

Dans son rôle de gestionnaire général et d'employeur de la fonction publique fédérale, le Conseil du Trésor s'occupe des avantages offerts aux fonctionnaires comme le Régime de soins de santé de la fonction publique qui couvre les prestations médicales et le Régime d'assurance-invalidité qui assure un niveau de revenu raisonnable pendant les longues périodes d'invalidité physique ou mentale. Il a chargé Santé Canada de fournir des services de santé et de sécurité au travail, comme les programmes d'aide aux employés, au nom des employeurs de la fonction publique mentionnés à la partie I de l'annexe I de la *Loi sur les relations de travail dans la fonction publique*.[428]

Le Régime de soins de santé de la fonction publique (RSSFP) est un régime privé de soins de santé à l'intention des employés de la fonction publique fédérale, des membres des Forces canadiennes et de la Gendarmerie royale du Canada, des députés, des membres de la magistrature fédérale, des employés de certains organismes désignés ainsi que des personnes qui reçoivent des prestations de retraite en fonction de leurs services dans la fonction

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425 Anciens Combattants Canada, *Stratégie en matière de santé mentale*, Article documentaire, 27 février 2004.

426 Gendarmerie royale du Canada, *Renseignements sur la GRC*.

427 Anciens Combattants Canada et la Gendarmerie royale du Canada unissent leurs efforts pour offrir de meilleurs services, communiqué de presse de la GRC, 17 février 2003.

428 Conseil du Trésor du Canada, *Information pour les employés du gouvernement fédéral.*

publique. Le Régime est financé grâce aux cotisations du Conseil du Trésor du Canada, des employeurs participants et des membres du Régime. L'administrateur, Sun Life du Canada, est chargé de statuer sur les demandes admissibles et de les régler.[429]

Le RSSFP rembourse à ses souscripteurs la totalité ou une partie des frais qu'ils ont engagés pour des services et des produits admissibles, seulement après qu'ils se soient prévalus des garanties offertes par leur régime d'assurance-santé provinciale/territoriale ou par des tiers assureurs des soins de santé. Les services et les produits admissibles doivent être prescrits par un médecin ou un dentiste titulaire d'un permis de pratique dans la compétence où ils sont prescrits. Le Régime rembourse les frais admissibles jugés « habituels et raisonnables », de façon à ce que les remboursements versés soient raisonnables dans le secteur géographique où les frais ont été engagés.[430]

Le Régime couvre les frais de visite chez un psychologue jusqu'à concurrence d'une limite précise de dépenses admissibles. Une prescription visant des services psychologiques est valable pendant un an. Le Régime prévoit actuellement un taux de remboursement de 80 p. 100 de 1 000 $ par année civile, ce qui correspond à 5 ou 6 sessions par client.

En vertu de l'Assurance-invalidité de longue durée, l'employé atteint d'une invalidité totale physique ou mentale médicalement vérifiable, qui soit entraîne le retrait de toute licence obligatoire requise par l'employeur pour l'exercice de ses fonctions ou de son emploi, soit rend l'employé entièrement incapable de remplir essentiellement toutes les tâches de son poste ou de son emploi, a droit à des prestations pendant une période d'au plus 24 mois.[431]

Les programmes d'aide aux employés offrent des services de counselling à court terme aux personnes qui ont besoin d'aide pour concilier les exigences de la vie personnelle et du travail. Des conseillers bilingues qualifiés et expérimentés offrent un service téléphonique sans frais (1-800) à l'échelle nationale, 24 heures sur 24; plus de 600 psychologues et travailleurs sociaux qualifiés (ou l'équivalent) offrent aussi leurs services. Les employés ayant des problèmes liés à leur vie personnelle ou au travail peuvent aussi être orientés vers des ressources au sein de la fonction publique ou dans la collectivité, s'il y a lieu, et un suivi est assuré. Les organismes fédéraux suivants sont des clients de la Employee Assistance Society of North America : le ministère de la Défense nationale, le ministère des Anciens Combattants, le ministère de la Justice, le Bureau du vérificateur général du Canada, Santé Canada, Parcs Canada, Environnement Canada, Citoyenneté et Immigration, le ministère des Affaires indiennes et du Nord canadien, Pêches et Océans et le Bureau de la sécurité des transports.[432]

Les services décrits ci-dessus ne remplacent pas ceux fournis dans le cadre du Programme de santé des fonctionnaires fédéraux. Le Conseil du Trésor a chargé le Programme de santé au travail et de sécurité du public (anciennement connu sous le nom d'Agence d'hygiène et de sécurité au travail), qui relève de la Direction générale de la sécurité environnementale et de la sécurité des consommateurs, de fournir des services en matière de santé et de sécurité au

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429 Conseil du Trésor du Canada, *Régime de soins de santé de la fonction publique – Protections et dispositions du Régime*, juillet 2001.

430 *Ibid.*

431 Conseil du Trésor du Canada, *Régime d'assurance-invalidité*, novembre 1993.

432 Conseil du Trésor du Canada, *Le programme d'aide aux employés*.

travail (ainsi que des services psychologiques) aux employeurs de la fonction publique mentionnés à la partie I de l'annexe I de la *Loi sur les relations de travail dans la fonction publique*.[433]

De plus, des Services de gestion du stress traumatique sont offerts pour aider les employés qui ont vécu un incident traumatique, comme le décès ou la blessure grave d'un collègue de travail, un incident impliquant un grand nombre de blessés, des menaces, une agression personnelle ou d'autres formes de violence en milieu de travail. Les employés de certains groupes professionnels appelés « travailleurs des services d'urgence » (p. ex. les agents d'application de la loi, les pompiers, les infirmières et les autres travailleurs de la santé, les équipes de recherche et de sauvetage) courent un plus grand risque de vivre des incidents traumatiques. Les services englobent la sensibilisation ou la prévention, l'intervention et l'évaluation.[434]

9.2.10 L'évaluation de la situation des fonctionnaires fédéraux

De récentes études ont porté sur le stress et la nécessité, pour le gouvernement fédéral en tant qu'employeur, de faire davantage pour aider ses employés à concilier travail et vie personnelle et à adopter des modes de vie sains. Mme Linda Duxbury et M. Christopher Higgins ont présenté en janvier 2003 une étude menée pour Santé Canada intitulée *Établir l'équilibre entre le travail, la famille et le style de vie : Une étude nationale*. Cette étude a confirmé que les Canadiens souhaitent des horaires de travail souples, des limites quant aux heures supplémentaires, la possibilité de travailler à temps partiel ou en télétravail et des dispositions en matière de soins à la famille pour les aider à mieux concilier tous les aspects de leur vie. L'étude, qui a porté sur des employés tant du secteur public (soit huit ministères fédéraux) que du secteur privé, a permis de constater que les fonctionnaires prennent un nombre important de congés de maladie « pour cause de santé mentale » et dépensent plus en médicaments d'ordonnance que les employés du secteur privé.[435]

Une autre étude, réalisée en 2002 par l'Association professionnelle des cadres supérieurs de la fonction publique du Canada (APEX) a permis de constater une augmentation sensible de l'incidence des maladies coronariennes et cardiovasculaires, en particulier l'hypertension, chez les cadres de la fonction publique. Elle a aussi révélé une détérioration graduelle d'autres indicateurs importants de la santé. Parmi les répondants, 95 p. 100 éprouvaient des troubles du sommeil et ne dormaient en moyenne que 6,6 heures par nuit; 15 p. 100 souffraient de tendances dépressives; 53 p. 100 signalaient de hauts niveaux de stress, presque deux fois le niveau des Canadiens moyens, de même sexe et du même âge; 19 p. 100 avaient des troubles musculo-squelettiques liés à la tension. Les données de l'étude montrent que les cadres, en tant que groupe, sont soumis à des niveaux de stress élevés, voire même extrêmes.[436]

Bill Wilkerson, cofondateur de la Global Business and Economic Roundtable on Addiction and Mental Health, a déclaré que le secteur public doit faire un examen de conscience

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433 Santé Canada, *Programme de santé au travail et de sécurité du public*.

434 Santé Canada, Ibid., Gestion du stress traumatique.

435 Linda Duxbury, Christopher Higgins et Donna Coghill, *Témoignages canadiens : À la recherche de la conciliation travail-vie personnelle*, Santé Canada, janvier 2003.

436 APEX, *Étude sur l'état de santé des cadres dans la fonction publique du Canada*, 27 novembre 2002.

approfondi, car les gouvernements doivent donner l'exemple, en tant qu'employeurs, en matière de promotion de la santé mentale et de prévention de la maladie mentale. Se reportant à l'étude de l'APEX, il a souligné que plus de 15 p. 100 des cadres supérieurs de la fonction publique souffrent de dépression, soit 50 p. 100 de plus que la moyenne nationale et que pour les hauts fonctionnaires, les médicaments psychotropes sont une absolue nécessité et correspondent à 17,5 p. 100 de tous les médicaments absorbés.[437]

9.2.11 Les immigrants reçus et les réfugiés

Citoyenneté et Immigration Canada (CIC) est chargé de l'évaluation des immigrants reçus et des réfugiés. Au cours des 10 dernières années, le Canada a accueilli en moyenne chaque année quelque 220 000 immigrants et réfugiés. Un immigrant est reçu quand les autorités lui octroient le droit de vivre au Canada en permanence. Les réfugiés acceptés au Canada sont aussi des immigrants reçus. Les demandeurs d'asile ne sont pas des immigrants reçus; ils arrivent au Canada et demandent d'être acceptés comme réfugiés.[438]

Les demandeurs d'asile nécessiteux ou vivant dans une province qui exige une période d'attente de trois mois pour l'admissibilité au régime d'assurance-maladie provincial peuvent obtenir des services de santé essentiels ou d'urgence par le biais du Programme fédéral de santé intérimaire offert par Citoyenneté et Immigration Canada (CIC). Les immigrants reçus prennent des dispositions pour leurs propres soins de santé, notamment en souscrivant à une assurance privée pour couvrir le délai de carence de trois mois imposé dans quatre provinces (Colombie-Britannique, Ontario, Québec et Nouveau-Brunswick).[439]

Tous ceux qui demandent la résidence permanente au Canada subissent un examen médical de leur état physique et mental. Il peut arriver, à la suite d'un examen, qu'un demandeur se fasse refuser l'entrée au Canada s'il présente un problème de santé susceptible d'en faire un danger pour la santé ou la sécurité publique ou un fardeau pour les services sanitaires ou sociaux. Le ministère ne fournit pas de renseignements très précis sur les réactions possibles aux demandeurs qui présentent des troubles mentaux graves.[440]

Conscient que les nouveaux venus au Canada font face à d'importantes difficultés, Citoyenneté et Immigration Canada offre plusieurs programmes visant à atténuer le stress de l'intégration dans la société canadienne. Le ministère travaille en collaboration avec les gouvernements provinciaux/territoriaux et des organismes non gouvernementaux afin de réaliser plusieurs projets pouvant favoriser la bonne santé mentale des immigrants, ainsi :

- le Programme d'établissement et d'adaptation des immigrants verse des fonds à des organismes pour que ceux-ci offrent par exemple des services d'accueil, d'orientation, d'interprétation, de counselling et de recherche d'emploi;[441]
- le Programme d'accueil associe les nouveaux arrivants à des bénévoles qui les reçoivent amicalement et leur font connaître les services qu'offre la collectivité;[442]

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437 Bill Wilkerson, *Texte d'un discours prononcé à un déjeuner d'affaires de l'Hôpital Royal d'Ottawa*, 6 mai 2004.
438 Citoyenneté et Immigration Canada, *Rapport sur les plans et les priorités de 2003-2004*.
439 *Ibid.*
440 *Ibid.*
441 Citoyenneté et Immigration Canada, *Programme d'établissement et d'adaptation des immigrants*.

- les Cours de langues pour les immigrants au Canada sont des cours de langue de base offerts aux immigrants adultes pour faciliter leur intégration.[443]

Les demandeurs d'asile peuvent avoir recours au Programme fédéral de santé intérimaire pour couvrir certains frais de soins de santé. Ce programme, administré par Citoyenneté et Immigration Canada, fournit des services de santé d'urgence et essentiels aux demandeurs d'asile nécessiteux et aux personnes protégées au Canada qui ne sont pas encore couvertes par les régimes d'assurance-maladie provinciaux. Le Rapport ministériel sur le rendement 2002-2003 fait était d'une injection supplémentaire de 7,6 millions de dollars pour ce programme, mais ne précise pas son coût de départ.[444] Il est question dans le Rapport sur les plans et les priorités de 2003-2004 d'un « programme fédéral de 50 millions de dollars visant les soins de santé essentiels et d'urgence à l'intention des demandeurs d'asile[445] ». Aucune ventilation n'est donnée des dépenses pouvant se rapporter à la maladie mentale ou à la toxicomanie. Cependant, ces frais risquent d'être élevés, étant donné que bon nombre des demandeurs d'asile ont été victimes de torture et d'autres incidents préjudiciables à leur santé mentale.

9.2.12 L'évaluation de la situation des immigrants reçus et des réfugiés

Le Comité ne disposait pas de renseignements lui permettant d'évaluer les politiques et les programmes fédéraux de santé mentale visant les immigrants reçus et les réfugiés.

9.3 COORDINATION INTERMINISTÉRIELLE EN CE QUI A TRAIT AU RÔLE DIRECT DU GOUVERNEMENT FÉDÉRAL

L'examen des activités du gouvernement fédéral en ce qui a trait aux groupes précis sous sa responsabilité ne permet guère de conclure à l'existence de stratégies ciblées sur des groupes précis, encore moins d'une vaste stratégie fédérale de portée universelle. Aucun effort apparent n'est actuellement déployé pour élaborer un cadre fédéral global et coordonné avec la collaboration de l'ensemble des ministères ou organismes concernés. Dans la plupart des cas, il existe peu d'indices de l'existence d'une stratégie réfléchie et inclusive visant à répondre aux besoins de l'un ou l'autre des groupes relevant de la responsabilité fédérale en matière de santé mentale. La prestation de services de santé mentale et de traitement de la toxicomanie de même que les efforts déployés en vue de promouvoir la santé mentale et de prévenir la maladie mentale demeurent très fragmentés et relèvent de plusieurs ministères et services ministériels distincts.

Deux initiatives interministérielles fédérales visant à coordonner les activités liées aux soins de santé et à l'abus de substances psychyactives pourraient toutefois figurer au nombre des exemples à suivre pour élaborer une stratégie d'intervention dans le domaine précis de la santé mentale et de la toxicomanie. Il s'agit du Partenariat fédéral pour les soins de santé et de la Stratégie canadienne antidrogue.

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442 Citoyenneté et Immigration Canada, *Programme d'accueil*.
443 Citoyenneté et Immigration Canada, *Cours de langues*.
444 Citoyenneté et Immigration Canada, *Rapport sur le rendement pour la période se terminant le 31 mars 2003*.
445 Citoyenneté et Immigration Canada, *Rapport sur les plans et les priorités, 2003-2004*, p. 42.

9.3.1 Le Partenariat fédéral pour les soins de santé[446]

Créé en 1994, le Partenariat fédéral pour les soins de santé, autrefois désigné Initiative de coordination des soins de santé, regroupe différents ministères fédéraux qui offrent tous individuellement des produits et des services de santé à des groupes précis de Canadiens. Ces ministères ont cru qu'en conjuguant leurs efforts, ils pourraient réduire leurs coûts et améliorer les services offerts. À l'heure actuelle, Anciens combattants y occupe une place prépondérante, aux côtés d'autres ministères participant comme le ministère de la Défense nationale, la GRC, l'Agence canadienne de développement international, les Services correctionnels, Citoyenneté et Immigration, le Secrétariat du Conseil du Trésor, Travaux publics et Services gouvernementaux et le Bureau du Conseil privé.

Les objectifs principaux consistent à négocier des ententes mixtes avec des associations professionnelles, des fournisseurs et des détaillants; à coordonner l'achat de fournitures médicales et de services de santé précis; à stimuler la concurrence par la recherche d'autres modes de prestation des services; d'améliorer l'échange d'information et la prise de décisions collectives; à faciliter l'analyse et l'élaboration conjointes de politiques; à soutenir l'élaboration concertée d'un mécanisme de gestion de l'information sur la santé à l'échelle fédérale et à organiser conjointement des activités de promotion de la santé.

En 2002-2003, les partenaires ont négocié conjointement des droits, des achats en vrac et des politiques communes qui, collectivement, ont contribué à améliorer la qualité des services offerts aux clients et ont procuré des économies de 11,6 millions de dollars. Des économies de 17,6 millions de dollars sont prévues pour 2003-2004. Jusqu'ici, malgré les immenses possibilités offertes par l'action concertée, rien de semblable n'a encore été fait dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie.

9.3.2 La stratégie canadienne antidrogue

L'adoption de la première stratégie nationale antidrogue en 1987 découlait de l'inquiétude suscitée par la consommation de drogues illicites au Canada. En 1988, une organisation nationale non gouvernementale, le Centre canadien de lutte contre l'alcoolisme et les toxicomanies, a été créée par voie législative afin de cibler les efforts pour réduire les méfaits pour la santé, la société et l'économie, attribuables à l'abus de substances psychoactives.

En 1992, la Stratégie canadienne antidrogue a été renouvelée et jumelée à la Stratégie de lutte contre la conduite avec facultés affaiblies. Elle avait cependant toujours pour objectif d'atténuer les conséquences nocives de la consommation de drogues pour les particuliers, les familles et les collectivités en agissant tant sur l'offre que sur la demande. Coordonnée par le ministère de la Santé nationale et du Bien-être social, cette stratégie faisait intervenir plusieurs autres ministères qui cherchaient à améliorer les programmes existants et à en financer de nouveaux. Des 210 millions de dollars affectés à ce programme, 70 p. cent ont servi à financer les efforts de réduction de la demande de drogues grâce à des mesures de prévention, de traitement et de réadaptation, et 30 p. cent ont été alloués à l'application de la loi et au contrôle.

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446 Conseil du Trésor du Canada, *Partenariat fédéral pour les soins de santé*.

En 1998, le gouvernement fédéral a réitéré son engagement à l'égard des principes de la Stratégie canadienne antidrogue. Santé Canada a continué d'occuper un rôle de premier plan et de présider le Comité directeur des sous-ministres adjoints sur l'alcool et les autres drogues et certains comités interministériels, notamment le Groupe de travail interministériel sur l'alcool et les autres drogues. Les ministères fédéraux qui sont parties prenantes à la Stratégie ne se limitent pas à ceux qui ont une responsabilité directe à l'égard de la santé des Canadiens; certains ont une envergure nationale et internationale plus grande : Solliciteur général, Affaires étrangères et Commerce international, Finances, Patrimoine canadien, Justice, Douanes et Revenu Canada, Transports, Développement des ressources humaines, Condition féminine, Affaires indienne et du Nord, Société canadienne d'hypothèques et de logement, Conseil du Trésor et Bureau du Conseil privé.

Dans son rapport de 2001, le Bureau de la vérificatrice générale déplorait l'approche fragmentée de la Stratégie canadienne antidrogue et demandait que la culture organisationnelle de l'ensemble de l'appareil fédéral soit modifié de manière à privilégier l'adoption de structures et de méthodes qui permettent de tirer pleinement parti des avantages du travail horizontal. Lors du renouvellement de la Stratégie canadienne antidrogue, en mai 2003, le gouvernement fédéral s'est engagé à verser 245 millions de dollars et à obtenir l'appui de 14 ministères fédéraux partenaires. Un rapport sur l'orientation et l'évolution de la Stratégie sera présenté au Parlement dans deux ans.

9.4 RÔLE FÉDÉRAL INDIRECT

Outre sa responsabilité fédérale directe, le gouvernement fédéral a aussi un rôle indirect et important à jouer dans l'élaboration d'un plan national multipartite à long terme en matière de santé mentale. Même si certains témoins soutiennent que la santé mentale n'a jamais été une priorité pour quelque ordre de gouvernement que ce soit, ils n'en demeurent pas moins convaincus que la santé mentale, la maladie mentale et la toxicomanie sont des problèmes qui affligent l'ensemble de la population canadienne. Par conséquent, les rôles du gouvernement fédéral, des dix gouvernements provinciaux et des trois gouvernements territoriaux sont interreliés lorsque vient le temps d'intervenir pour répondre aux besoins en soins de santé des Canadiens atteints de maladie mentale et de toxicomanie.

Il n'existe toutefois aucune capacité ministérielle centralisée, que ce soit à Santé Canada ou dans un autre ministère fédéral, ni aucune forme de structure nationale qui permette de coordonner à l'échelle nationale toute la gamme des enjeux relatifs à la santé mentale, à la maladie mentale et à la toxicomanie ou d'y réagir. De plus, peu de ressources sont consacrées aux aspects intergouvernementaux d'un cadre national dans ce domaine. À l'heure actuelle, le travail accompli par les intervenants fédéraux, provinciaux et territoriaux se limite à explorer différentes possibilités de projets conjoints de réforme des soins de santé primaires, ainsi que les propositions relatives aux soins à domicile et à la télésanté. Le gouvernement fédéral est sensible à la nécessité d'adopter à cet égard une approche qui tienne compte du partage des responsabilités entre les gouvernements fédéral, provinciaux et territoriaux et du fait que la prestation de services de santé mentale et de traitement de la toxicomanie relèvent d'abord des provinces et des territoires.

Une structure officielle, en l'occurrence le Réseau de consultation FPT sur la santé mentale, a été créée le 17 avril 1986 afin de conseiller la Conférence des sous-ministres de la Santé sur les moyens à prendre pour favoriser la collaboration fédérale, provinciale et territoriale sur les questions de santé mentale. Son mandat consistait à :

- examiner les questions transmises par la Conférence des sous-ministres de la Santé, ou pour lesquelles un nombre important de provinces désirent obtenir un consensus basé sur des avis éclairés, et formuler des recommandations au besoin;
- fournir des conseils en ce qui concerne l'élaboration et l'application de politiques et de programmes pour les services de traitement en santé mentale, dans le but d'assurer le maintien de services dont la qualité et l'efficacité soient uniformes partout au Canada;
- fournir une tribune pour aider les provinces et les territoires à mettre sur pied, à organiser et à évaluer les services de santé mentale sur leur territoire;
- permettre aux gouvernements fédéral et provinciaux, aux universités et aux centres de traitement d'échanger de l'information, des données pertinentes, des résultats de recherche récentes et des avis d'experts touchant les problèmes de compétence, d'organisation, d'ordre législatif, de prestation de services, d'évaluation et d'autres questions pertinentes;
- proposer des stratégies fédérales, fédérales-provinciales et provinciales pour la promotion de la santé mentale en vue d'améliorer l'état de santé mentale de l'ensemble de la population et en particulier des enfants et des jeunes;
- recevoir des rapports sur les activités et programmes de santé mentale en cours à l'échelle nationale et fournir au besoin des conseils, une orientation et un soutien aux responsables de ces activités et programmes.[447]

Le travail du Réseau de consultation FPT sur la santé mentale était à l'époque soutenu par la Division de la santé mentale de Santé et Bien-être social Canada, qui faisait alors partie de la Direction générale des programmes et des services de santé du ministère.[448] À la fin des années 90, la Conférence des sous-ministres de la santé a toutefois retiré son appui au Réseau de consultation FPT. En conséquence, il est maintenant difficile de trouver des fonds, ne serait-ce que pour réunir des décideurs de tout le pays œuvrant dans le domaine de la santé mentale, de façon qu'ils puissent échanger de l'information et élaborer des politiques et des plans cohérents. Un certain nombre de provinces continuent malgré tout de participer au Réseau de consultation FPT, mais la portée de leur travail est limitée par le financement qu'elles sont elles-mêmes en mesure de fournir. Selon le Dr James Millar, directeur exécutif, Santé mentale et Services médicaux, ministère de la Santé de la Nouvelle-Écosse, le démantèlement du Réseau de consultation FPT sur la santé mentale :

> *(…) a tari une source importante de partage et de planification conjointe. Certaines instances continuent de se réunir, mais elles doivent se battre*

447 Santé et Bien-être social Canada, *Services de santé mentale au Canada*, 1990, gouvernement du Canada, 1990, p. 26.

448 *Ibid.*

> *afin de trouver du financement. Le nombre de réunions et d'instances participantes a diminué au fil des ans. Certains projets spéciaux sont financés selon une formule où l'Ontario paie la majorité des coûts, avec le soutien de Santé Canada. Le Québec ne participe pas à cette initiative.*[449]

Que peut faire alors le gouvernement fédéral pour faciliter la coordination, la collaboration et les partenariats nationaux dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie? Deux différents types de leviers peuvent être utilisés à cette fin : les leviers juridiques (ou stratégiques) et les leviers financiers (ou fiscaux). Si le gouvernement fédéral a l'autorité *juridique* voulue grâce au pouvoir conféré par le droit pénal, c'est plutôt de sa capacité *fiscale* dont il se sert pour influencer la politique sociale. Ni l'un ni l'autre de ces leviers n'est toutefois suffisamment efficace pour assurer une plus grande uniformité, pour établir et appliquer des normes, pour faciliter l'harmonisation ou pour initier des projets d'envergure nationale, car cela exige énormément de communication intergouvernementale et une grande volonté de collaborer.

9.4.1 Les leviers juridiques

Le gouvernement fédéral dispose de plusieurs moyens juridiques pour intervenir en matière de santé mentale, de maladie mentale ou de toxicomanie. Au fil des ans, il a tour à tour invoqué le droit pénal, la *Charte des droits et libertés* et les droits de la personne.

Le *Code criminel* prévoit des dispositions particulières concernant les troubles mentaux. Par exemple, on peut exonérer une personne de toute responsabilité criminelle pour cause de troubles mentaux. Le tribunal peut ordonner que la première partie d'une peine d'emprisonnement soit purgée dans un centre de traitement, lorsqu'il juge qu'un contrevenant « souffre de troubles mentaux en phase aiguë » et a effectivement besoin de soins immédiats.

En ce qui a trait à la toxicomanie, le Parlement s'est servi à maintes reprises du pouvoir conféré par le droit pénal. Ainsi, il a adopté des lois pour réglementer la vente, la distribution et la possession de substances psychoactives par le biais de la *Loi réglementant certaines drogues et autres substances*. La *Loi sur le tabac* comporte pour sa part un vaste éventail de restrictions concernant la composition et l'étiquetage des produits du tabac, l'accès des adolescents à ces produits et la commandite d'événements par des compagnies de tabac. Dans le cas de l'alcool, le *Code criminel* pénalise la conduite avec facultés affaiblies, tandis que la *Loi sur la radiodiffusion* et le *Code de la publicité radiodiffusée en faveur des boissons alcoolisées* régissent la publicité.

Comme il est mentionné dans le chapitre précédent, la *Charte canadienne des droits et libertés* offre certaines garanties juridiques qui s'appliquent en matière de santé mentale et de toxicomanie. Les articles pertinents traitent de questions comme le droit à la vie, à la liberté et à la sécurité de sa personne et le droit à la protection contre tous traitements ou peines cruels et inusités. La Charte est aussi à l'origine de la création de normes nationales

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449 Dr James Millar, ministère de la Santé de la Nouvelle-Écosse, mémoire au Comité, 28 avril 2004, p. 4.

auxquelles les gouvernements fédéral et provinciaux peuvent devoir se conformer, si tel est le vœu des Canadiens.

La *Loi canadienne sur les droits de la personne* promulguée en 1977 met en place un processus de règlement des cas de discrimination dans les domaines de compétence fédérale. Elle crée un système de recours spécialisé qui mise sur la persuasion et l'éducation pour décourager quiconque d'agir et de se comporter de façon discriminatoire, et oblige les contrevenants à assumer les frais d'indemnisation de leurs victimes. La loi s'applique à tous les ministères et organismes fédéraux et aux sociétés d'État, ainsi qu'aux entreprises et aux secteurs d'activités assujettis à la réglementation fédérale (p.ex., banques, transports, et communications).

9.4.2 Les leviers financiers

De façon générale, l'intervention fédérale demeure toutefois essentiellement de nature fiscale. Dans la mesure où il ne légifère pas directement sur des questions relevant de la compétence des provinces et des territoires, le gouvernement fédéral utilise son pouvoir de taxation et de dépenser pour mettre en place divers programmes sociaux de portée nationale. Les restrictions imposées à l'égard des paiements de transfert aux provinces dans les années 90 ont toutefois incité bon nombre de provinces à demander que les mesures prises unilatéralement par le gouvernement fédéral relativement aux transferts soient remplacées par des mécanismes laissant place à une plus grande participation des provinces et des territoires.

Le pouvoir fédéral de dépenser constitue le fondement de la *Loi canadienne sur la santé* de même que des actuels Transfert canadien en matière de santé (TCS) et Transfert canadien en matière de programmes sociaux (TCPS). C'est ce qui explique la participation/ingérence fédérale dans d'autres sphères sociales, comme le logement et la sécurité du revenu. Le Régime de pensions du Canada (RPC), créé par voie législative en 1965, est un autre secteur où il y a une participation fédérale/provinciale. Il existe d'autres exemples semblables de mesures sociales, par exemple, la sécurité du revenu pour les handicapés, qui peuvent améliorer l'état de santé mentale de tous les Canadiens et, en particulier, la qualité de vie des personnes aux prises avec des problèmes de santé mentale et de toxicomanie.

La santé mentale est toutefois un exemple de domaine d'intervention où le pouvoir de dépenser conféré au gouvernement fédéral par la Constitution s'est appliqué au cours des 55 dernières années pour ensuite être retiré. Entre la création des Subventions nationales à la santé en 1948 et la conclusion de l'Accord des premiers ministres sur le renouvellement des soins de santé en 2003, les ententes de financement du gouvernement fédéral ont eu, implicitement ou explicitement, une grande incidence sur la situation nationale au chapitre de la santé mentale et de la toxicomanie.

L'ambivalence au sujet de la place occupée par les services de santé mentale dans le système national de soins de santé ne date pas d'hier. Le Programme de subventions nationales à la santé de 1948, qui est décrit comme une première étape vers la création d'un vaste régime d'assurance-maladie pour l'ensemble du Canada, prônait l'élargissement des services de

santé, notamment de ceux offerts pour traiter la maladie mentale.[450] L'un des éléments du programme, en l'occurrence la subvention à la santé mentale, a servi à mettre en œuvre et à étendre les services de santé mentale, à renforcer les établissements de formation professionnelle et technique et à améliorer la qualité et la quantité de personnel. En 1960-1961, dernière année d'existence de la subvention, quelque 53 p. cent des fonds ont été octroyés aux établissements, tandis que 23 p. cent allaient aux cliniques et aux services psychiatriques, 13 p. cent à la formation et 8 p. cent à la recherche.[451]

En 1957, la *Loi sur l'assurance-hospitalisation et les services diagnostiques* adoptée par le gouvernement fédéral a toutefois explicitement exclu les hôpitaux psychiatriques, même si sa portée englobait les services psychiatriques des hôpitaux généraux. Cette exclusion se fondait à l'époque sur l'argument selon lequel les hôpitaux psychiatriques offraient des soins en milieu surveillé et qu'à ce titre, ils n'étaient pas admissibles au programme fédéral de partage des frais, au même titre que les hôpitaux pour tuberculeux, les maisons de repos et les autres établissements de soins longue durée. En 1966, avec la promulgation de la *Loi sur les soins médicaux*, les services médicaux, y compris ceux offerts par des psychiatres, sans égard au lieu, ont toutefois été inclus au nombre des services financés par l'État.[452]

La *Loi de 1977 sur les accords fiscaux entre le gouvernement fédéral et les provinces et sur le financement des programmes établis* accorde à chaque province un « financement de base », c'est-à-dire un paiement de transfert fédéral proportionnel à la taille de sa population et versé en partie en espèces et en partie en points d'impôt. Dans sa définition de « services complémentaires de santé », cette loi inclut les hôpitaux psychiatriques, au même titre que les soins intermédiaires en maison de repos, les soins en établissement pour adultes, les soins à domicile et les soins ambulatoires.[453]

En 1984, la *Loi canadienne sur la Santé* a été adoptée afin « de protéger, de favoriser et d'améliorer le bien-être physique et mental des habitants du Canada et de faciliter un accès satisfaisant aux services de santé, sans obstacles d'ordre financier ou autre »[454]. La plupart des dispositions des deux lois antérieures sur l'assurance-hospitalisation ont été regroupées dans la nouvelle loi; mais l'une des différences majeures réside dans la nouvelle définition des services complémentaires de santé, où tous les passages faisant mention des hôpitaux psychiatriques ont été supprimés.

Dans les années 90, le rôle du gouvernement fédéral dans les soins de santé offerts à l'échelle nationale et, par extension, son rôle au chapitre de la santé mentale s'est de nouveau restreint en raison de la réduction de ses paiements de transfert aux provinces et aux territoires. En 1996, le Transfert canadien en matière de santé et de programmes sociaux (TCSPS) a été

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450 Ministère de la Santé nationale et du Bien-être social, *Rapport annuel pour l'exercice se terminant le 31 mars 1948*, Ottawa, Imprimeur du Roi, 1948, page 77.

451 Santé et Bien-être social Canada, *Les services de santé mentale au Canada*, *1990*, Gouvernement du Canada, 1990, p. 15.

452 *Ibid.*, p. 16.

453 *Loi de 1977 sur les accords fiscaux entre le gouvernement fédéral et les provinces et sur le financement des programmes établis*, chapitre 10, 1977, article 27, paragraphe 8.

454 *Loi canadienne sur la santé*, *1984* (*Loi concernant les contributions pécuniaires du Canada ainsi que les principes et conditions applicables aux services de santé assurés et aux services complémentaires de santé*), chapitre C-6, 1984, article 3.

créé, à la suite de la fusion du Financement des programmes établis (FPE) et du Régime d'assistance publique du Canada (RAPC). Ainsi, il allait dorénavant incomber aux provinces de décider elles-mêmes de la façon de répartir leur financement de base entre les soins de santé, l'enseignement postsecondaire et les programmes sociaux.[455]

La loi portant création de Santé Canada adoptée en 1996 donnait au ministre de la Santé une orientation générale concernant les questions touchant la santé nationale. De façon plus précise, la *Loi sur le ministère de la Santé* confiait au ministre de la Santé « la promotion et le maintien du bien-être physique, mental et social de la population ».[456] L'interprétation de cette disposition limitait l'intervention du ministre aux vastes programmes visant à promouvoir et à préserver le bien-être mental et social; à la surveillance des pathologies ou des programmes de santé mentale; à la conduite d'études ou d'enquêtes sur la santé mentale entre autres questions de santé publique et à la collecte de même qu'à la publication de statistiques sur la santé mentale.

Un tournant décisif s'est produit en 1999 avec la conclusion de l'Entente cadre sur l'union sociale et de l'Accord connexe sur la santé dans lesquels le gouvernement fédéral s'engageait à accroître le financement des soins de santé par le biais du TCSPS, à garantir la prévisibilité du financement et à collaborer avec l'ensemble des gouvernements provinciaux et territoriaux afin d'établir des priorités et des objectifs pancanadiens.[457] Dès l'an 2000, le Communiqué sur la santé pour la réunion des Premiers ministres renfermait un engagement à favoriser « les services publics, les programmes et les politiques qui, au-delà des soins et des traitements, contribuent de manière essentielle à la santé et au mieux-être de leurs citoyens ».[458] Dans l'Accord sur la santé de 2003, les premiers ministres ont convenu d'offrir une couverture intégrale et transférable pour un ensemble de services à domicile, des services communautaires de santé mentale devant être accessibles au besoin. Le plan est de pouvoir offrir d'ici 2006 un éventail de services comme la gestion de cas, des services professionnels et des médicaments sur ordonnance.[459]

En plus de soutenir financièrement les services liés à la santé, le gouvernement fédéral a mis en place d'autres programmes pour venir en aide aux personnes atteintes de maladie mentale. Par exemple, en 1961, il a accepté de partager le coût du Programme de réadaptation professionnelle des personnes handicapées pour qu'il profite aux handicapés mentaux en âge de travailler. En 1965, le Régime de pensions du Canada (RPC) a commencé à verser des prestations d'invalidité aux personnes atteintes d'un handicap mental grave ou prolongé. En 1966, le Régime d'assistance publique du Canada (RAPC) a offert de verser aux provinces la moitié du coût des services d'aide et de bien-être social à frais partagés destinés

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455 Le TCSPS a été créé par deux projets de loi budgétaires distincts respectivement déposés en février 1995 et en mars 1996. Son fonctionnement est régi par la *Loi sur les arrangements fiscaux entre le gouvernement fédéral et les provinces*.

456 *Loi sur le ministère de la Santé*, 1996, chapitre 8.

457 *Un cadre visant à améliorer l'union sociale pour les Canadiens,* Entente entre le gouvernement du Canada et les gouvernements provinciaux et territoriaux, 4 février 1999; et *l'Entente fédérale-provinciale-territoriale en matière de santé*, 4 février 1999.

458 *Communiqué sur la santé pour la réunion des Premiers ministres,* 11 septembre 2000.

459 Communiqué, Accord des Premiers ministres pour le renouvellement et la viabilité à long terme des soins de santé pour les Canadiens, 23 janvier 2003.

aux personnes handicapées, notamment aux handicapés mentaux.[460] Le partage des coûts en vertu du RAPC était considéré comme déterminant pour établir localement des services sociaux qui feraient partie intégrante des moyens de soutien offerts dans le domaine de la santé mentale.

À l'heure actuelle, grâce à son Bureau de la condition des personnes handicapées, Développement social Canada est le centre de liaison au gouvernement fédéral pour les partenaires qui travaillent à promouvoir la pleine participation des Canadiens handicapés aux activités d'apprentissage, au marché du travail et à la vie communautaire. Ses principaux objectifs consistent à favoriser la cohérence entre les politiques et les programmes, à renforcer la capacité du secteur bénévole; à créer des réseaux intégrés et orientés vers l'action, à fournir des connaissances et à faire un travail de sensibilisation. L'Agence du revenu du Canada est au nombre des autres partenaires. En vertu de la *Loi de l'impôt sur le revenu*, toute personne qui présente un handicap mental ou physique grave et prolongé ou toute personne qui en prend en soin, peut demander un crédit d'impôt pour personnes handicapées.

L'itinérance est un autre domaine où le gouvernement fédéral utilise son pouvoir de dépenser pour faciliter l'élaboration d'un cadre national. Ainsi, le gouvernement fédéral a lancé en 1999 l'Initiative nationale pour les sans-abri (INSA), qui préconise l'adoption d'une approche communautaire pour réduire et prévenir l'itinérance. L'initiative repose sur l'établissement de partenariats avec tous les ordres de gouvernement, le secteur privé et le secteur bénévole. Son approche multidisciplinaire découle de la conviction que l'itinérance n'a pas une cause unique et que le problème exige une intervention à de multiples niveaux, notamment au chapitre du logement, des perspectives d'emploi, des soins de santé mentale, des programmes de lutte contre la toxicomanie et des services de bien-être social. Elle reconnaît la diversité des besoins des itinérants et la nécessité d'offrir des solutions « adaptées » en fonction de chaque collectivité.[461]

Même si le gouvernement fédéral verse aux provinces et aux territoires un financement à l'appui des services de santé mentale, des programmes sociaux, du soutien du revenu et du logement, le financement des services de santé mentale, les versements journaliers aux fournisseurs de logement de transition et supervisés et l'aide au revenu sont tous de compétence provinciale, territoriale et municipale.

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460 Pour de plus amples détails sur ces programmes fédéraux, voir le document de William Young, *Les personnes handicapées, profil socio-économique et changements proposés*, Bulletin d'actualité 95-4F, Ottawa, Direction de la recherche parlementaire, 1997.

461 Gouvernement du Canada, *Initiative nationale pour les sans-abri*.

9.5 ÉVALUATION DU RÔLE DU FÉDÉRAL DANS L'ACTUEL CADRE NATIONAL

9.5.1 La *Loi canadienne sur la santé*

> *(…) lorsque la Loi canadienne sur la santé a été élaborée, les services de santé mentale offerts par les hôpitaux psychiatriques ont été exclus. Il y est stipulé que seuls les services de santé mentale, nécessaires d'un point de vue médical et offerts par les services des centres hospitaliers et les médecins, seront régis par la loi. Cette omission importante a sévèrement désavantagé ceux qui essaient de fournir des services de santé mentale dans le cadre de services communautaires.*
> *[Dr James Millar, directeur exécutif, Santé mentale et Services médicaux, ministère de la Santé de la Nouvelle-Écosse (mémoire au Comité, 28 avril 2004, p. 5.]*

Comme il est mentionné ci-dessus et précédemment, la *Loi canadienne sur la santé* exclut expressément de sa définition d'intégralité les services offerts par les établissements psychiatriques. De nombreux témoins ont affirmé que cette omission renforce l'établissement d'une distinction artificielle entre la santé physique et la santé mentale et contribue à alimenter la stigmatisation et la discrimination associées aux troubles mentaux. Voici, par exemple, ce qu'a dit à ce sujet le Dr Sunil V. Patel, président de l'AMC :

> *(…) il importe aussi de reconnaître l'effet nocif de l'exclusion de la Loi canadienne sur la santé des hôpitaux ou établissements destinés principalement aux personnes atteintes de troubles mentaux. Autrement dit, comment arriverons-nous à surmonter le stigmate et la discrimination si nous les validons dans la législation fédérale?*[462]

Le Dr Patel a recommandé de modifier la *Loi canadienne sur la santé* pour inclure les hôpitaux psychiatriques et de rajuster le Transfert canadien en matière de santé pour tenir compte de ces autres services assurés.

Le Comité s'est aussi fait dire que l'exclusion des hôpitaux psychiatriques de la *Loi canadienne sur la santé* complique l'application du principe de transférabilité. Ainsi, parce que les hôpitaux psychiatriques sont explicitement exclus, ils ne sont pas assujettis aux ententes de facturation réciproque entre les provinces. Voici ce qu'a souligné à ce sujet Ray Block, directeur général de l'Alberta Mental Health Board :

> *En outre, la gestion des cas doit être examinée du point de vue des compétences pangouvernementales dans les cas où les patients d'un*

[462] Dr Sunil V. Patel, président, Association médicale canadienne, mémoire au Comité, 31 mars 2004, p. 3.

> *territoire en particulier ont besoin de soins lorsqu'ils se trouvent dans un autre territoire. Des ententes de réciprocité concernant l'accès et le paiement devraient faciliter l'accès à des soins ainsi que l'uniformité et la continuité de ces derniers entre les territoires. Ce point devrait être débattu lors d'une prochaine conférence fédérale/provinciale/territoriale des ministres de la Santé.*[463]

De plus, de nombreux témoins ont fait valoir que bon nombre de services de santé mentale sont offerts dans les collectivités par des fournisseurs autres que des médecins et ne sont donc pas visés par la *Loi canadienne sur la santé*. C'est le cas particulièrement des services offerts par des psychologues. Voici ce qu'a dit à ce sujet la Dre Diane Sacks, présidente de la Société canadienne de pédiatrie :

> *(…) à l'heure actuelle, les professionnels qui offrent cette thérapie [thérapie cognitive du comportement] ne sont généralement pas couverts par la plupart des régimes d'assurance-maladie provinciaux. Ce sont des professionnels qualifiés et réglementés qui pourraient, si la société le voulait vraiment, traiter beaucoup de nos enfants et de nos adolescents. (…) Cela dit, il y a des professionnels qui peuvent aider à poser un diagnostic et à traiter ces maladies, mais seulement si vous avez de l'argent – beaucoup d'argent. La liste d'attente pour obtenir un diagnostic de THDA dans le système scolaire public ou dans un centre communautaire de santé mentale, à Toronto, est actuellement de 18 mois, soit l'équivalent de deux années scolaires complètes. Voilà ce qui se passe si vous n'avez pas d'argent. Mais si vous avez 2 000 $, je peux vous trouver un psychologue qui va vous faire un diagnostic dans une semaine ou deux et qui va, au besoin, établir pour l'école un programme complet afin d'aider votre enfant à réussir. La plupart des régimes d'assurance des employeurs ne couvrent en moyenne que 300 $ pour les consultations auprès de psychologues. Et la plupart des programmes publics ne couvrent absolument rien.*[464]

Dans son mémoire, le Centre de toxicomanie et de santé mentale (Toronto) affirme que la *Loi canadienne sur la santé* devrait s'appliquer non seulement aux hôpitaux généraux et aux omnipraticiens, mais aussi aux soins à domicile et aux médicaments prescrits en dehors des hôpitaux. De l'avis du Centre, le financement public du coût des médicaments améliorerait de beaucoup la vie de bon nombre de personnes souffrant de maladie mentale, qui ont besoin d'une pharmacothérapie à long terme. Dans leur cas, l'accès aux médicaments est essentiel pour leur permettre de conserver leur emploi, leur logement et leurs autres liens avec la collectivité qui contribuent à leur traitement et à leur guérison.[465]

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463 Ray Block, directeur général, Alberta Mental Health Board, mémoire au Comité, 28 avril 2004, p. 7.

464 Dre Diane Sacks, présidente, Société canadienne de pédiatrie (13:53-54).

465 Centre de toxicomanie et de santé mentale (Toronto), mémoire au Comité, 27 juin 2003, p. 3.

Bon nombre de témoins appuient le travail déjà entrepris par les premiers ministres afin d'étendre l'accès aux soins à domicile aux personnes atteintes de maladies mentales. Ils soutiennent que tout programme national de soins à domicile devrait s'appliquer aux personnes atteintes de maladie mentale ou de toxicomanie.

9.5.2 Le financement fédéral

Les transferts fédéraux aux provinces et territoires pour financer les soins de santé sont versés au titre du Transfert canadien en matière de santé (TCS). Il n'y a jamais eu et il n'y a pas non plus à l'heure actuelle de transfert expressément versé à une province ou à un territoire pour financer les soins de santé mentale et le traitement de la toxicomanie. À l'heure actuelle, aux termes de l'*Accord de 2003 des premiers ministres sur le renouvellement des soins de santé*, le TCS sert à financer les soins de santé mentale actifs offerts dans la collectivité,[466] mais aucune proportion précise du transfert n'est expressément réservée à cette fin.

La Société pour les troubles de l'humeur du Canada recommande qu'une partie des paiements de transfert fédéraux au titre des soins de santé serve expressément à financer la prestation de soins de santé mentale. La Société soutient que deux conditions devraient se poser à l'obtention de ce financement : 1) les provinces et les territoires ne devraient pas être autorisés à réduire leurs dépenses au titre des soins de santé mentale; 2) les programmes provinciaux de soins de santé mentale devraient faire l'objet d'évaluations constantes afin de garantir l'optimisation des ressources[467]

D'autres témoins ont proposé au Comité une solution qui consisterait à hausser les recettes perçues pour financer le traitement et la prévention de la toxicomanie. Selon le modèle dit « de garantie comportementale », une partie des fonds prélevés grâce aux activités qui s'appuient sur les comportements associés à une dépendance (tabac, alcool, jeu) pourrait servir à financer les programmes de prévention et de traitement de la toxicomanie.

La Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario a signalé au Comité que le gouvernement de l'Ontario a adopté un modèle de garantie comportementale en 1999 pour financer un ensemble de services intégrés de lutte contre la dépendance au jeu. Conformément à ce modèle, 2 p. cent des recettes brutes des machines à sous des casinos provinciaux à vocation caritative et des hippodromes sont investis dans le traitement, la prévention et la recherche. En 2002-2003, cette formule a généré environ 36 millions de dollars de recettes, soit un montant suffisant pour financer la mise en œuvre d'une solution globale à cet épineux problème.

Voici ce qu'affirme M. Wayne Skinner, directeur clinique, Programme des troubles concomitants, Centre de toxicomanie et de santé mentale (Toronto), dans son mémoire :

> *(…) il importe de reconnaître que plusieurs comportements à caractère toxicomagène sont réglementés par l'État qui en tire des revenus*

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466 L'expression « soins de santé mentale actifs offerts dans la collectivité » renvoie aux soins actifs offerts dans la collectivité à des personnes atteintes de maladie mentale qui ont à l'occasion des épisodes de comportement perturbateur en phase aiguë; l'objectif est de prévenir ou de réduire les placements récurrents en établissement.

467 Société pour les troubles de l'humeur du Canada, mémoire au Comité, 12 mai 2004, p. 7.

considérables. On pensera au tabac, à l'alcool et, plus récemment, au jeu. On estime que près de la moitié des recettes provenant de la vente d'alcool et des jeux de hasard sont attribuables à 10 p. cent des consommateurs qui dépensent le plus dans ces activités. Ce groupe, qui compose les 10 p. cent en question, est celui qui présente le plus de risques de développer une dépendance. Comme plus de la moitié des recettes perçues provient de ce segment plus vulnérable de la population, le gouvernement devrait envisager d'adopter des stratégies anticipatoires de prévention, de traitement et de recherche en matière de comportement toxicomanogène et de problèmes de comorbidité en santé mentale. De plus il ne fait aucune doute que l'argent investi dans les dépenses sociales visant à prévenir et à traiter les problèmes de toxicomanie et de santé mentale procure un excellent rendement. Il ne serait pas déraisonnable de s'attendre à ce qu'une plus grande part des revenus fiscaux générés par les comportements potentiellement toxicomanogènes soit réinvestie pour venir en aide aux personnes qui en subissent les méfaits.[468]

9.5.3 L'initiative nationale pour les sans-abri (INSA)

Dans son mémoire au Comité, Bill Cameron, directeur général du Secrétariat national pour les sans-abri, souligne que l'intervention de l'INSA en matière de santé mentale est de deux ordres : 1) financement de projets communautaires et 2) programme de partenariat en recherche.[469]

L'organisation « Horizon Housing Society » est un exemple de projet communautaire financé grâce à l'INSA. Elle a fait l'acquisition d'un immeuble à appartements à Calgary afin d'offrir des logements provisoires aux personnes atteintes de maladie mentale ou de toxicomanie, qui sont déjà itinérants ou risquent de le devenir. Le programme de recherche porte sur des questions comme la disponibilité et l'accessibilité des services de santé mentale pour les sans-abri, l'incidence de la maladie mentale chez les sans-abri et le lien de cause à effet entre la désinstitutionalisation et l'itinérance. La recherche financée grâce à l'INSA est aussi menée en partenariat avec les IRSC.[470]

Selon Bill Cameron, bon nombre de services de santé mentale offerts aux itinérants finissent par être dispensés par les salles d'urgence. De plus, les sans-abri sont confrontés à de nombreux obstacles qui rendent difficile l'accès aux soins de santé dont ils ont besoin. Par exemple, un grand nombre d'entre eux n'arrivent pas à obtenir un rendez-vous chez un médecin, et il leur est difficile de recevoir des soins coordonnés parce qu'ils n'ont pas d'adresse, ni d'endroit où il est possible de les joindre. Par ailleurs, de nombreuses femmes itinérantes atteintes de graves maladies mentales ne reçoivent pas les soins nécessaires, apparemment parce que leurs problèmes de santé mentale ne sont pas dépistés et aussi parce

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468 M. Wayne Skinner, directeur clinique, Programme des troubles concomitants, Centre de toxicomanie et de santé mentale (Toronto), mémoire au Comité, 2004, p. 6.

469 Bill Cameron, directeur général du Secrétariat national pour les sans-abri, mémoire au Comité, 29 avril 2004, p. 1.

470 *Ibid.*, p. 1-2.

que les services destinés à répondre aux besoins particuliers des femmes sans abri se font rares.[471]

M. Cameron a également fait mention d'autres lacunes importantes dans les services communautaires et l'aide aux sans-abri, notamment en ce qui concerne les logements d'urgence, les logements supervisés et les services de santé mentale offerts dans les collectivités.[472] Aux dires de M. Cameron, l'accès à un logement supervisé sûr et abordable est de façon générale un élément important de l'aide à offrir aux sans-abri, mais ce soutien n'est peut-être pas suffisant pour les personnes atteintes de maladies mentales ou de toxicomanies graves. Il faut avoir accès à des infrastructures de soutien à long terme, comme des logements et des services d'aide d'urgence ainsi que des logements de transition, pour venir en aide aux sans-abri chroniques. Des mesures préventives sont également nécessaires, par exemple, des logements abordables à l'intention des personnes qui viennent de terminer un séjour dans un établissement psychiatrique et des services de suivi intensifs à court terme pour celles qui viennent de sortir de l'hôpital, d'un refuge ou de prison.[473]

9.6 BESOIN D'UN PLAN D'ACTION NATIONAL SUR LA SANTÉ MENTALE, LA MALADIE MENTALE ET LA TOXICOMANIE

Les témoins ont maintes fois insisté auprès du Comité sur la nécessité pour le Canada de se doter d'un plan d'action national sur la santé mentale, la maladie mentale et la toxicomanie, comme bien d'autres pays l'ont déjà fait. Par exemple, en 1992, l'Australie a adopté une stratégie nationale en matière de santé mentale afin d'améliorer la vie des personnes atteintes de maladies mentales; la même année, le Royaume-Uni a élaboré un plan d'action dans cinq domaines clés de la santé, dont celui des maladies mentales, où sont énoncés les objectifs à atteindre au chapitre de l'amélioration de la santé des personnes atteintes de maladie mentale et de la réduction du taux de suicide; en 1999, le directeur des services de santé publique américains s'est engagé à améliorer la situation des personnes atteintes de maladie mentale aux États-Unis.[474]

> **Il n'existe pas de cadre national pour la santé mentale au Canada. Aucun engagement n'existe à l'échelle nationale pour les services de santé mentale.**
> ***[Dr James Millar, ministère de la Santé de la Nouvelle-Écosse, mémoire au Comité, 28 avril 2004, p. 4.]***

Le Canada souffre actuellement d'un cruel manque de leadership au chapitre de la santé mentale, de la maladie mentale et de la toxicomanie et, de l'avis de bien des témoins et du Comité, cette lacune a créé un immense vide : les tentatives de réforme des soins de santé ne mettent aucunement l'accent sur la maladie mentale et la toxicomanie; il n'y a aucune délimitation claire des rôles et des responsabilités des différents intervenants. Selon Phil Upshall, président de l'Alliance canadienne de la maladie mentale et de la santé mentale (ACMMSM) :

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471 Bill Cameron (2004), p. 2.
472 Bill Cameron (2004), p. 3.
473 Bill Cameron (2004), p. 4.
474 Voir le deuxième rapport du Comité : *Politiques et programmes de certains pays en matière de santé mentale*, pour une description complète des stratégies nationales en matière de santé mentale en Australie, en Nouvelle-Zélande, en Angleterre et aux Etats-Unis.

> *Le tableau actuel de la maladie mentale et de la santé mentale au Canada est très sombre, à commencer par le vide flagrant observé sur le plan du leadership. (…) Il n'existe aucune politique et très peu de mécanismes pour s'attaquer aux problèmes de maladie mentale et de santé mentale à l'échelle nationale au Canada. Les rôles et les responsabilités des intervenants gouvernementaux concernés restent vagues. Un des principaux obstacles à l'élaboration d'un plan d'action national semble résider dans la répartition des pouvoirs entre les provinces/territoires et le gouvernement fédéral dans le domaine de la santé et des services sociaux. Or, cela ne devrait pas nuire à l'adoption d'une approche cohérente qui permette de répondre de façon équitable aux besoins des Canadiens.*[475]

(…) La démarche fragmentaire des provinces, des territoires et des associations qui travaillent de manière isolée entraîne un double emploi et un gaspillage de ressources.
[Dr James Millar, directeur exécutif, Santé mentale et Services médicaux, ministère de la Santé de la Nouvelle-Écosse (7:19).]

Beaucoup de témoins ont recommandé que le gouvernement fédéral joue un rôle de premier plan dans l'élaboration d'un plan d'action national. L'actuel manque de leadership a, bien sûr, contribué de façon importante à la fragmentation de l'approche adoptée à l'égard de la maladie mentale et de la toxicomanie et à la mise en place de modèles différents d'un territoire de compétence à l'autre, d'où le double emploi et le gaspillage de ressources. Ainsi, le Dr James Millar, directeur exécutif, Santé mentale et Services médicaux, ministère de la Santé de la Nouvelle-Écosse, a tenu les propos suivants :

> *Au pays, nous n'avons pas une aussi bonne feuille de route. Individuellement, les provinces doivent lutter pour offrir des services appropriés et élaborer différents modèles qui vont de la Commission de la santé mentale du Nouveau-Brunswick à l'Alberta Mental Health Board. Le gouvernement fédéral n'a pas pris les devants pour élaborer une stratégie nationale.*[476]

De même, le Dr Sunil V. Patel, président de l'Association médicale canadienne, a affirmé ce qui suit au Comité:

> *Le Canada est le seul pays du G8 à ne pas avoir de stratégie nationale. Cette lacune a considérablement contribué à la fragmentation des services de santé mentale et au développement de problèmes chroniques, comme les*

475 Phil Upshall, président, ACMMSM, mémoire au Comité, 18 juillet 2003, p. 7.

476 Dr James Millar, directeur exécutif, Santé mentale et Services médicaux, ministère de la Santé de la Nouvelle-Écosse, mémoire au Comité, 28 avril 2004, p. 3.

longues listes d'attente pour obtenir des services de santé mentale pour enfants (…)[477]

Il est grand temps de mettre fin à l'absence de leadership national en matière de santé mentale et de toxicomanie. Le gouvernement fédéral peut jouer un rôle important dans la collecte de données nationales, dans le soutien de la recherche et dans la diffusion des connaissances de même que dans la sensibilisation des Canadiens aux problèmes de santé mentale, de maladie mentale et de toxicomanie. Bon nombre de témoins ont mentionné que le gouvernement fédéral avait un rôle crucial à jouer pour subvenir aux besoins de logements, de revenus et d'emplois des personnes atteintes de maladie mentale ou de toxicomanie. Il a de plus un rôle direct à jouer dans la prestation de services de santé mentale et de traitement de la toxicomanie à l'intention des Autochtones, des détenus sous responsabilité fédérale, des anciens combattants et des membres des Forces canadiennes, du personnel de la GRC et des fonctionnaires fédéraux.

Même si de nombreux témoins sont favorables à l'exercice d'un leadership national, certains soutiennent que la situation ne pourra progresser que si le gouvernement fédéral travaille en étroite collaboration avec les provinces et les territoires. Ainsi, le Dr Pierre Beauséjour, conseiller médical principal, Alberta Mental Health Board, a exprimé l'avis suivant :

> *Même si nous reconnaissons que l'élaboration d'un plan d'action national sur la santé mentale et la maladie mentale exige un leadership national de la part du gouvernement fédéral, nous sommes d'avis qu'il est absolument essentiel d'en arriver à un consensus sur les objectifs, les normes et les responsabilités applicables à l'échelle nationale en matière de santé mentale et que le leadership exercé par les provinces et par les territoires à en matière de santé mentale est aussi nécessaire que celui du gouvernement fédéral.*
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> *Nous croyons fermement qu'un partenariat axé sur les résultats, une nouvelle définition claire des rôles et des responsabilités et une synergie des efforts entre le gouvernement fédéral ainsi que les provinces et territoires sont nécessaires pour élaborer et mettre en place un cadre stratégique national multipartite en matière de santé mentale.*[478]

La maladie mentale et une mauvaise santé mentale sont d'importants facteurs qui contribuent au suicide, à une époque où plus de gens sur la planète meurent du suicide que des guerres et des homicides combinés. En améliorant la santé mentale et en réagissant sans tarder aux cas de maladie mentale, on parviendra à sauver des vies.
[Phil Upshall, président, ACMMSM, mémoire au Comité, 18 juillet 2003. p. 3]

Des témoins ont soutenu que le cadre national doit comprendre des normes relatives à la prestation des services pour tous les aspects de la

477 Dr Sunil V. Patel, président, Association médicale canadienne, mémoire au Comité, 31 mars 2004, p. 2.

478 Dr Pierre Beauséjour, conseiller médical principal, Alberta Mental Health Board, mémoire au Comité, 2003, p. 1

santé mentale, depuis la prévention, la promotion et la défense de la santé mentale en passant par les services offerts dans la collectivité ainsi que les services aux malades hospitalisés et les services spécialisés. Ce cadre doit couvrir toutes les périodes de la vie et doit veiller à ce que les rôles et les responsabilités soient clairement définis tout au long du continuum des soins. De plus, parce que la plupart des maladies mentales ont des racines dans l'enfance et l'adolescence, il faut accorder une attention particulière à la santé mentale des enfants et des jeunes. C'est là un aspect qui est depuis trop longtemps négligé. Nous devons nous attaquer au problème à la racine avant qu'il n'entraîne de graves séquelles. Outre les enfants et les adolescents, d'autres groupes ont aussi été mentionnés parmi ceux dont la situation exige une intervention immédiate, notamment les Autochtones, les aînés, les détenus sous responsabilité fédérale, les femmes et les immigrants reçus.

La prévention du suicide est un autre aspect prioritaire d'un éventuel plan d'action. Le fait est que le Canada, contrairement à l'Australie, à la Finlande, à la France, aux Pays-Bas, à la Nouvelle-Zélande, à la Norvège, à la Suède, au Royaume-Uni et aux États-Unis, n'a pas de stratégie nationale de prévention du suicide. Bon nombre de témoins qui ont comparu devant le Comité ont demandé instamment que le gouvernement fédéral travaille de concert avec les provinces/territoires et les intervenants pour élaborer une telle stratégie. Selon le Dr Paul Links, titulaire de la chaire Arthur Sommer Rotenberg d'études sur le suicide, dans les pays où il existe une stratégie nationale sur la prévention du suicide, le taux de suicide a baissé de 10 à 20 p. cent.[479] Par ailleurs, le Centre de prévention du suicide a indiqué au Comité que seulement deux provinces, soit le Nouveau-Brunswick et le Québec, ont adopté une stratégie expressément axée sur la prévention du suicide. Des témoins ont exhorté le gouvernement fédéral à travailler de concert avec les provinces/territoires et les intervenants pour élaborer une stratégie nationale de prévention du suicide.

Un certain nombre de témoins ont évoqué la possibilité de coordonner la stratégie nationale en matière de santé mentale et la Stratégie nationale antidrogue. Étant donné le taux élevé de troubles concomitants (maladie mentale et toxicomanie), il est crucial d'établir des liens entre les deux. Par exemple, une surveillance nationale de la prévalence des troubles liés à la consommation d'alcool ou de drogues dans le cadre de la Stratégie nationale antidrogue serait extrêmement utile aux efforts déployés pour planifier les services destinés aux personnes atteintes de troubles concomitants.

Par l'intermédiaire de la Alliance canadienne pour la maladie mentale et la santé mentale (ACMMSM), une vingtaine d'ONG représentant les personnes atteintes de maladie mentale ou de toxicomanie, leurs familles et les organismes fournisseurs de services sont arrivés à un consensus sur la nécessité d'un plan d'action national sur la santé mentale, la maladie mentale et la toxicomanie.[480] Ce plan d'action national comporte quatre grands volets : éducation et sensibilisation du public; cadre stratégique national; recherche et surveillance :

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479 Dr Paul Links (11:20).

480 Les organismes suivants se sont regroupés pour former l'Alliance canadienne pour la maladie mentale et la santé mentale : la Société canadienne de l'autisme, la Société pour les troubles de l'humeur du Canada, l'Association médicale canadienne, l'Association canadienne des soins de santé, le Réseau national pour la santé mentale, le Conseil canadien des programmes de psychologie professionnelle, la Fédération canadienne des infirmières et infirmiers en santé mentale, la Coalition canadienne pour la santé mentale des personnes âgées, le Collège des médecins de famille du Canada, la Fondation

- Des campagnes de sensibilisation du public et de la formation professionnelle dans un vaste éventail de sujets touchant le travail social et la médecine peuvent aider à réduire les stigmatisation et la discrimination associées à la maladie mentale, à la toxicomanie et au comportement suicidaire.

- Un cadre stratégique national est nécessaire pour déterminer et mettre en œuvre des pratiques exemplaires (de traitement, de prévention et de promotion) et planifier les ressources humaines (psychiatres, psychologues, infirmières et infirmiers en psychiatrie, spécialistes en toxicomanie, travailleurs sociaux, etc.). Un leadership national est également nécessaire pour élaborer un vaste cadre stratégique et multipartite permettant de garantir un accès équitable à une aide communautaire et professionnelle d'un bout à l'autre du pays.

- Le gouvernement fédéral est le mieux placé pour établir et soutenir un programme national de recherche en santé mentale, en maladie mentale et en toxicomanie. Les priorités de la recherche doivent être définies, le financement de la recherche doit être accru et la collecte de fonds par le secteur bénévole doit être renforcée.

- Un système national de surveillance doit être mis en œuvre pour surveiller de près et évaluer l'incidence et la prévalence de la maladie mentale et de la toxicomanie (ainsi que du comportement suicidaire). Les données recueillies à l'échelle nationale pourraient aussi servir à rendre compte de l'efficacité avec laquelle le système répond aux besoins des personnes atteintes de maladie mentale ou de toxicomanie.[481]

Beaucoup de témoins ont insisté sur le fait qu'un plan d'action national sur la santé mentale, la maladie mentale et la toxicomanie ne peut être élaboré qu'avec la collaboration du gouvernement fédéral, des provinces et territoires, des ONG et des autres intervenants, notamment les malades eux-mêmes. Dans ce contexte, voici la position exprimée par la Société canadienne de schizophrénie :

> *Tous les niveaux de gouvernement devront participer, de concert avec les organismes non gouvernementaux, pour créer un plan d'action national et en faciliter la mise en œuvre (…). Les autorités en place, comme les hôpitaux, les associations professionnelles et les organismes bénévoles qui ont servi de solution de fortune dans le système actuel, sont prêtes à être parties prenantes aux solutions retenues par le Canada en matière de soins de santé mentale. Le plus gros défi des gouvernements réside dans la coordination d'un système gouvernemental à niveaux multiples, qui au départ n'a pas été créé pour travailler de concert et intégrer des organismes non gouvernementaux comme partenaires à part entière. Seul un effort concerté dans ces secteurs permettra au Canada d'effectuer un*

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canadienne de recherche en psychiatrie, l'Association canadienne pour la prévention du suicide, l'Association canadienne des ergothérapeutes, la Société canadienne de schizophrénie, l'Association canadienne pour la santé mentale, la Société canadienne de pédiatrie, l'Association canadienne des travailleurs sociaux, l'Association des psychiatres du Canada, la Société canadienne de psychologie et la Native Mental Health Association of Canada.

481 Alliance canadienne pour la maladie mentale et la santé mentale, *A Call for Action: Building Consensus for a National Action Plan on Mental Illness and Mental Health*, document de travail, septembre 2000.

> *virage dans le domaine des soins de santé mentale, qui permettra de traiter et de soutenir efficacement les personnes atteintes de maladie mentale et leurs familles et de réduire le fardeau imposé aux particuliers, aux familles et à la société [en raison des troubles mentaux].*[482]

Comme l'a souligné Phil Upshall, président de l'ACMMSM, il faut prendre des mesures dès maintenant :

> *L'heure est à l'action (…) Quinze ans se sont écoulés maintenant depuis la publication du document de discussion du gouvernement fédéral intitulé La santé mentale des Canadiens : Vers un juste équilibre, dans lequel la vision nationale de promotion de la santé axée sur « la santé pour tous » est liée à la santé mentale. D'autres rapports importants de même que de nombreux documents de discussion et documents sur les politiques provinciales et régionales ont recommandé des changements importants pour améliorer les services et les programmes à l'intention des personnes atteintes de maladie mentale grave, et proposé des mesures concernant les services de santé mentale pour enfants, la prévention du suicide, les peuples autochtones, les contrevenants et la population carcérale. La poussière continue de s'accumuler sur ces rapports et les Canadiens continuent d'attendre, puisque peu des recommandations et des idées énoncées dans ces documents ont été mises en œuvre.*[483]

Dans l'ensemble, les témoins ont réclamé un engagement de la part de tous les ordres de gouvernement à agir et à travailler de concert à l'élaboration d'objectifs communs et à la création d'un cadre national intégré et cohérent sur la santé mentale, la maladie mentale et la toxicomanie. L'un des aspects qui semble avoir échappé au gouvernement fédéral à cet égard, c'est qu'il a la responsabilité directe de plus d'un million de Canadiens, dont certains sont aux prises avec de graves problèmes de santé mentale.

9.7 UNE APPROCHE BASÉE SUR LA SANTÉ DE LA POPULATION

> *Le réseau de soins de santé doit non seulement traiter la maladie mentale (…) mais le Canada doit prendre des mesures proactives reposant sur les grand déterminants de la santé afin de protéger et de préserver la santé mentale de toute sa population, y compris des personnes qui vivent avec la maladie mentale. Améliorer les conditions sociales qui, nous le savons, sont nécessaires au maintien d'un bon état général de santé mentale (p.ex., environnement social et matériel sain, solides capacités d'adaptation et services de*

482 Société canadienne de schizophrénie, mémoire au Comité, 2004, p. 3.

483 Phil Upshall, président, Alliance canadienne pour la maladie mentale et la santé mentale, mémoire au Comité, 18 juillet 2003, p. 7.

santé), est un élément essentiel pour influer positivement sur la santé mentale des malades et contribuer à leur rétablissement.
[Association canadienne pour la santé mentale, mémoire au Comité, juin 2003, p. 3]

La santé mentale, la maladie mentale et la toxicomanie sont fortement influencées par une grande variété de facteurs, notamment la biologie et la génétique, le revenu et la réussite scolaire, l'emploi, l'environnement social, etc. Cette réalité fait clairement ressortir la nécessité d'adopter à l'égard de la santé mentale, de la maladie mentale et de la toxicomanie une approche axée sur la santé de la population, dont la portée dépasse les soins de santé proprement dits.

Le Comité s'est fait dire à maintes reprises qu'il est difficile de traiter et de guérir un malade, lorsque les besoins fondamentaux au chapitre du logement, du revenu et de l'emploi ne sont pas satisfaits. Bien des témoins ont souligné qu'il serait sage que le gouvernement prenne des mesures pour répondre à ces besoins, puisqu'il a été démontré que l'accès à un logement, à un revenu et à un emploi améliore l'état clinique, réduit le nombre d'hospitalisations et permet aux personnes atteintes de maladie mentale de rester dans leur foyer et dans leur collectivité. C'est aussi une condition primordiale pour pouvoir participer à la société et jouir de ses droits de citoyen sans être victime de stigmatisation et de discrimination.

Le logement a été largement reconnu comme étant un aspect prioritaire de toute politique sur la santé mentale, tant au niveau fédéral que provincial. Ce qu'il faut maintenant, c'est une intervention de la part des deux ordres de gouvernement pour mettre en œuvre de nouveaux programmes de logements et de logements supervisés, puisque la politique et les études actuelles ont clairement démontré qu'il est possible à divers groupes de personnes souffrant de troubles mentaux de tenir un logement si elles disposent d'un soutien suffisant. L'accès à un logement et à un soutien convenables peut remplacer le recours à une hospitalisation à long terme et ainsi réduire la dépendance de la société et des principaux intéressés à l'égard des coûteuses places à l'hôpital et en établissement.

L'accès à un revenu suffisant et à un emploi est un autre déterminant clé de la santé qui doit être prioritaire dans toute stratégie sur la santé mentale. Bien des personnes atteintes de maladie mentale doivent, à un moment ou à un autre, dépendre des programmes gouvernementaux de soutien du revenu, qui sont leur seule source de revenu et grâce auxquels elles peuvent se procurer leurs médicaments sans frais. Malheureusement, bon nombre de ces programmes offrent de trop maigres prestations, ne sont pas réalistes dans leur évaluation du coût de la vie, créent des obstacles à l'emploi et ne sont pas suffisamment souples pour répondre à la nature épisodique de la maladie mentale. De plus, l'incapacité est souvent définie de façon trop restrictive, d'où l'impossibilité pour bien des personnes atteintes de maladie mentale ou de toxicomanie de se prévaloir de ces programmes. En Ontario, par exemple, les programmes provinciaux de soutien du revenu excluent purement et simplement les personnes aux prises avec des problèmes de toxicomanie de la définition d'incapacité. Ces obstacles systémiques dans les programmes gouvernementaux de soutien du revenu doivent être levés de façon que les personnes atteintes de maladie mentale ou de

toxicomanie puissent avoir accès à un soutien de base qui les aidera à recouvrer la santé et à rester en santé.

Le soutien à l'emploi est aussi un domaine clé où les gouvernements peuvent faire davantage. Les personnes aux prises avec divers problèmes de santé mentale sont capables d'occuper un emploi, si elles ont accès à des moyens de soutien adaptés qui tiennent compte de l'évolution de leurs besoins tout au long de leur traitement et de leur processus de guérison. Il y a aussi lieu de mettre davantage l'accent sur l'adoption de mesures pour vraiment adapter le milieu de travail aux besoins des personnes atteintes de maladie mentale. Il convient par ailleurs d'inciter les établissements d'enseignement et les autres milieux d'apprentissage à être mieux à l'écoute des besoins des personnes atteintes de maladie mentale de façon à leur faciliter l'accès aux programmes d'acquisition de compétences, de formation et d'études.

9.8 OBSERVATIONS DU COMITÉ

À l'heure actuelle, le gouvernement fédéral n'a aucun cadre général en matière de santé mentale, de maladie mentale et de toxicomanie, que ce soit à l'échelle fédérale ou nationale. Si plusieurs témoins ont insisté sur le fait que le Canada est le seul pays parmi ses homologues du G8 à ne pas avoir de politique nationale sur la santé mentale qui transcende les limites des différentes sphères de compétence, d'autres ont souligné l'absence d'un cadre intégré, même au niveau fédéral, où le gouvernement doit offrir des services de santé mentale et de traitement de la toxicomanie à des groupes précis.

L'absence de cadre *fédéral* tient peut-être principalement au fait qu'il n'y a pas assez de collaboration, de coopération et de communication entre les différents ministères fédéraux dont les mandats sont connexes ou se chevauchent. Toutefois, elle est peut-être aussi attribuable à la difficulté d'essayer de concilier les multiples besoins de groupes très diversifiés. Quelle que soit la raison, le Comité croit que malgré sa responsabilité directe à l'égard des besoins de groupes précis de la population canadienne en matière de santé mentale, le gouvernement fédéral ne s'est pas assez efforcé de coordonner ses initiatives à l'échelle nationale. Dans ces domaines, le gouvernement fédéral a à la fois le droit et l'obligation d'agir et peut le faire sans négociation intensive (ou même sans négociation du tout) avec d'autres instances.

De même, l'absence d'un cadre *national* global peut être attribuable dans une certaine mesure à l'absence de différentiation claire des responsabilités dans les domaines où les provinces et territoires ont préséance. En général, la *Loi constitutionnelle de 1867* confère aux provinces le pouvoir de légiférer dans les domaines des soins de santé, de l'éducation, des prisons provinciales et de l'administration des tribunaux, tandis qu'elle confère au Parlement du Canada le pouvoir de légiférer en matière de droit criminel et de procédure, ainsi qu'à l'égard de la gestion des pénitenciers. En plus du pouvoir qui lui est conféré en matière de droit criminel, le gouvernement fédéral dispose de deux autres pouvoirs constitutionnels dont il peut se prévaloir lorsqu'il intervient au niveau national : son pouvoir de dépenser et sa capacité d'adopter des lois pour assurer la paix, l'ordre et le bon gouvernement au Canada.

Tant du point de vue fédéral que national, il est évident que le rôle du gouvernement fédéral en ce qui a trait à la santé mentale, à la maladie mentale et à la toxicomanie ne se limite pas

aux activités de Santé Canada. Les politiques, programmes et services connexes relèvent davantage de la sphère sociale et de la justice, plutôt que du secteur traditionnel des soins de santé. D'autres ministères fédéraux, comme Développement des ressources humaines Canada, Affaires indiennes et du Nord Canada, Anciens combattants Canada, Services correctionnels Canada et Justice Canada, sont au nombre de ceux qui participent activement aux initiatives fédérales et nationales. En ce qui concerne le milieu de travail, le Conseil du Trésor, en sa qualité d'employeur des fonctionnaires, a un rôle important à jouer pour aider ses employés atteints de maladie mentale ou de toxicomanie.

L'examen des activités du gouvernement fédéral en ce qui a trait aux groupes précis sous sa responsabilité ne permet guère de conclure à l'existence de stratégies ciblées sur des groupes précis, encore moins d'une vaste stratégie fédérale de portée universelle. Aucun effort apparent n'est actuellement déployé pour élaborer un cadre fédéral global et coordonné avec la collaboration de l'ensemble des ministères ou organismes concernés. Dans la plupart des cas, il existe peu d'indices de l'existence d'une stratégie réfléchie et inclusive visant à répondre aux besoins de l'un ou l'autre des groupes relevant de la responsabilité fédérale en matière de santé mentale. Les services de santé mentale et de traitement de la toxicomanie de même que les efforts déployés en vue de promouvoir la santé mentale et de prévenir la maladie mentale demeurent très fragmentés et relèvent de plusieurs ministères et services ministériels distincts. Une plus grande collaboration permettrait d'en arriver à une approche mieux intégrée à l'égard de la santé mentale. Ce serait là un pas important vers l'adoption d'une politique axée sur la santé de la population.

Le Comité partage aussi l'avis de certains témoins selon lesquels il y a lieu de resserrer les liens entre les gouvernements fédéral et provinciaux de même qu'entre les différents systèmes qui se chevauchent – soins de santé, santé mentale, toxicomanie, justice, soutien social, etc.

Enfin, il serait également important que le gouvernement fédéral prêche par l'exemple. S'il doit jouer un rôle de premier plan dans l'élaboration d'un véritable plan d'action national sur la santé mentale, la maladie mentale et la toxicomanie, il doit aussi démontrer qu'il a la volonté et la capacité d'offrir des services de santé mentale aux groupes dont il a la responsabilité directe. De façon claire, il est temps de remédier à l'ambivalence démontrée au fil des ans par le gouvernement fédéral au sujet de l'importance accordée à la santé mentale dans ses politiques et ses programmes.

PARTIE 4

Recherche et éthique

CHAPITRE 10:
LA RECHERCHE DANS LES DOMAINES DE LA SANTÉ MENTALE, DE LA MALADIE MENTALE ET DE LA TOXICOMANIE AU CANADA

Nous croyons que la recherche constitue notre principale arme pour mieux comprendre les maladies mentales dévastatrices, améliorer les traitements et finir par trouver une cure.
[Fondation canadienne de la recherche en psychiatrie, Today, bulletin, vol. 3, n° 1, printemps 2003.]

INTRODUCTION

Au Canada, le gouvernement fédéral est le principal commanditaire de la recherche sur la santé mentale, la maladie mentale et la toxicomanie, tandis que ce sont surtout des chercheurs universitaires qui effectuent cette recherche dans des instituts de recherche et des hôpitaux universitaires. Les instituts de recherche en santé du Canada (IRSC), par l'entremise de l'Institut des neurosciences, de la santé mentale et des toxicomanies (INSMT), sont le principal organisme de financement fédéral pour la recherche sur la santé mentale, la maladie mentale et la toxicomanie.

Comme pour toute la recherche sur la santé financée par les IRSC, la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie porte sur tout le spectre des activités allant de la recherche biomédicale à la recherche clinique, en passant par la recherche sur les services de santé et la recherche sur la santé de la population :

- La recherche biomédicale concerne les organismes biologiques, les organes et les systèmes d'organes. Ce type de recherche pourrait porter, par exemple, sur le niveau de sérotonine (substance chimique du cerveau) chez les patients qui souffrent de troubles alimentaires comme la boulimie nerveuse.
- La recherche clinique consiste à étudier des personnes saines ou malades. Citons, à titre d'exemple, les essais cliniques conduits sur des humains pour déterminer la toxicité et l'efficacité d'un nouveau traitement de la schizophrénie qui a produit des résultats prometteurs lors de recherches biomédicales fondamentales, et ensuite pour comparer un nouveau médicament avec d'autres quant aux bienfaits réels pour les patients.
- La recherche sur les services de santé englobe la prestation, l'administration, l'organisation et le financement des soins de santé mentale et de traitement de la toxicomanie. Mentionnons, par exemple, la recherche de mécanismes pour traiter les patients qui ont un trouble bipolaire à partir des moyens de diagnostic, pendant le traitement à l'hôpital, en tant que patients externes, ou à la maison, puis pour assurer leur suivi à long terme par l'hôpital et dans le cadre de communautaires.

- La recherche sur la santé de la population est centrée sur l'étendue des facteurs qui influencent l'état de santé (conditions socio-économiques, sexe, culture, alphabétisation, génétique, etc.). Mentionnons, par exemple, une étude qui, grâce à une importante base de données contenant des informations personnelles sur la santé obtenues de plusieurs sources, doit permettre de déterminer si l'incidence du trouble déficitaire de l'attention et l'hyperactivité sont associés à l'environnement et à d'autres facteurs.

Le présent chapitre donne un aperçu de l'état de la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie au Canada. La section 10.1 résume le rôle et le mandat des IRSC et de l'INSMT et décrit quelques problèmes soulevés par les témoins. La section 10.2 fournit des renseignements sur le financement fédéral de la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie et pose la question de savoir si le financement devrait refléter le fardeau de la maladie. La section 10.3 examine brièvement les autres sources de financement de la recherche dans les domaines de la santé mentale et de la toxicomanie. La section 10.4 traite des questions relatives à l'application des connaissances acquises grâce à la recherche à des services et des moyens de soutien concrets dispensés aux personnes souffrant de maladie mentale ou de toxicomanie. La section 10.5 porte sur la nécessité d'un plan d'action national pour la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. La section 10.6 présente les observations du Comité.

10.1 IRSC ET INSMT

> *Au Canada, on a constaté une nette amélioration depuis trois ans à la suite de la fondation des Instituts de recherche en santé du Canada et du financement de la recherche, surtout en ce qui concerne la santé mentale. Cependant, il y a encore beaucoup d'améliorations à apporter.*
> *[Michel Tousignant, professeur, Centre de recherche et d'intervention sur le suicide et l'euthanasie, Université du Québec à Montréal (14:41)]*

Dans le cadre de son engagement à devenir l'une des cinq meilleures nations au monde dans le domaine de la recherche, le gouvernement du Canada a créé en 2000 les Instituts de recherche en santé du Canada (IRSC), organismes gouvernementaux autonomes qui relèvent du ministre fédéral de la Santé.

Les IRSC appliquent une démarche novatrice, multidisciplinaire et fondée sur les problèmes à l'égard de la recherche en santé. Cette démarche polyvalente comprend tous les types de recherche (biomédicale, clinique, services de santé, santé de la population) sur les mécanismes, le traitement et la prévention des maladies ainsi que sur la promotion de la santé. La plupart des recherches que subventionnent les IRSC sont entreprises par des chercheurs (70 p. 100); tandis que 30 p. 100 des fonds sont réservés aux initiatives stratégiques pour réagir aux problèmes de santé et exploiter les possibilités scientifiques hautement prioritaires aux yeux des Canadiens.

L'approche des IRSC à l'égard de la recherche est facilitée par leur structure, qui unit des chercheurs provenant de diverses disciplines et qui transcende les frontières géographiques grâce à leurs 13 instituts s'occupant chacun d'un domaine de recherche particulier. L'un d'entre eux est l'Institut des neurosciences, de la santé mentale et des toxicomanies (INSMT).[484]

La création de l'INSMT a établi le premier lieu de convergence de la recherche sur la santé mentale, la maladie mentale et la toxicomanie au Canada. L'INSMT appuie la recherche dont l'objet est d'améliorer la santé mentale et neurologique, la vision, l'audition et le fonctionnement cognitif, et à réduire l'incidence d'autres troubles connexes par le truchement de stratégies de prévention, de techniques de dépistage et de diagnostic, de traitements, de systèmes de soutien et de soins palliatifs. Comme le montre le tableau 10.1, l'INSMT effectue des recherches dans un grand nombre de domaines.

Le plan stratégique de l'INSMT pour 2001-2005 établissait cinq priorités :

1. Promouvoir l'innovation et créer des capacités d'innovation dans la recherche en neurosciences, en santé mentale et en toxicomanie, de manière à renforcer le milieu de la recherche en santé au Canada dans ces domaines et à améliorer sa position concurrentielle sur la scène internationale. Les champs d'intérêt comprennent la formation, les initiatives stratégiques, la recherche dans de nouveaux domaines et la recherche en bioéthique.

2. Créer et maintenir des partenariats de collaboration avec les organismes de santé gouvernementaux, non gouvernementaux et bénévoles, ainsi que les sociétés pharmaceutiques et de biotechnologie, qui aideront l'Institut à partager, mettre en valeur, obtenir ou augmenter les ressources requises pour remplir son mandat.

3. Promouvoir la création de liens et les échanges entre la communauté scientifique, les instances décisionnaires municipales, provinciales et nationales ainsi que les utilisateurs des résultats de recherche, comprenant les organisations non gouvernementales et bénévoles, au moyen d'efforts structurés axés sur la transmission des connaissances (voir la section ci-dessous).

4. Établir la présence des INSMT sur la scène internationale par des initiatives de recherche, de formation et de financement menées conjointement avec des organismes scientifiques et de financement de la recherche d'autres pays.

5. Établir une structure organisationnelle et opérationnelle qui permettra à l'INSMT d'atteindre ses objectifs.[485]

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484 Les trois premiers paragraphes de cette section s'inspirent de renseignements affichés sur le site des IRSC, à la rubrique « À propos des IRSC – Qui nous sommes » (http://www.cihr-irsc.gc.ca/f/7263.html).

485 Institut des neurosciences, de la santé mentale et des toxicomanies, *Plan stratégique – 2001-2005*, décembre 2001.

TABLEAU 10.1

DOMAINES DE RECHERCHE APPUYÉS PAR L'INSMT

- Politiques et stratégies de promotion des santés mentale et neurologique
- Politiques et stratégies de prévention de l'accoutumance
- Déterminants pour la santé - afin d'expliquer les facteurs multidimensionnels qui affectent la santé des populations et conduisent à une prévalence différentielle des soucis de santé
- Identification des avantages sanitaires et des facteurs de risque pour la santé reliés à l'interaction avec les environnements (culturel, social, psychologique, comportemental, physique, génétique)
- Stratégies de prévention de la maladie, des blessures et de l'invalidité aux niveaux de la personne et de la population
- Prévention, traitement et réadaptation des blessures à la tête
- Accoutumance, santé mentale et dysfonction du système nerveux affectant la sensation, la cognition, les émotions, le comportement, le mouvement, la communication et le fonctionnement autonome
- Recherche clinique et recherche sur les résultats des traitements en ce qui a trait aux technologies et méthodes de diagnostic; thérapies; modèles de traitement, soins et réadaptation (à long et court terme)
- Comorbidité des conditions et impacts sur la prévention, le diagnostic, le traitement, les soins et la réadaptation
- Conception et mise en ouvre de la prestation des services de santé : de la prévention, au dépistage, au diagnostic, à l'intervention ou au traitement, à la réadaptation et aux soins palliatifs
- Développement et mise en ouvre des technologies et outils en matière de santé (p. ex. : technologies d'imagerie, de bioingénierie et d'administration des médicaments)
- Développement, régulation, fonction et dysfonction des systèmes nerveux central, périphérique et autonome
- Psychologie humaine, cognition et comportement; sommeil et biologie circadienne; douleur
- Questions d'éthique reliées à la recherche, aux stratégies de soins et à l'accès aux soins (p. ex. : consentement éclairé; hospitalisation; accoutumance, santé mentale et système judiciaire)

Source : Site Internet des IRSC (http://www.cihr-irsc.gc.ca/f/9591.html)

Les témoins et les chercheurs appuient largement la nouvelle approche des IRSC en ce qui a trait à la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. Ils ont également très confiance dans l'équité et la rigueur du mécanisme d'examen par les pairs établi par les IRSC. Par exemple, dans leur mémoire au Comité, les

Drs Shitij Kapur et Franco Vaccarino, du Centre de toxicomanie et de santé mentale (Toronto), ont déclaré :

> *[…] le rôle des Instituts est reconnu et apprécié en recherche [sur la santé mentale, la maladie mentale et la toxicomanie]. La rigueur et la transparence des évaluations et des concours des ICRS sont bien appréciées et considérées comme un mécanisme indispensable dans ce spectre de la recherche où le « chercheur décide de son sujet.*[486]

Les témoins ont qualifié l'approche multidisciplinaire des IRSC d'étape positive pour la recherche sur la santé mentale, la maladie mentale et la toxicomanie. Par exemple, le Dr Alan Bernstein, président de l'IRSC, a fait observer ce qui suit :

> *Le secteur canadien des neurosciences est exceptionnellement fort et reconnu au niveau international. En créant un institut unique voué aux neurosciences, à la santé mentale et aux toxicomanies, nous avons explicitement adopté une démarche intégrée qui contribue à mettre en contact des neuroscientifiques travaillant en laboratoire, des psychologues, des spécialistes des sciences sociales et des chercheurs des services de santé qui se concentrent sur la santé mentale et les toxicomanies.*[487]

Le Dr Rémi Quirion, directeur scientifique de l'INSMT, a lui aussi insisté sur l'excellence de la recherche en santé mentale et en maladie mentale au Canada, mais il a ajouté que la capacité de recherche est problématique dans le domaine de la toxicomanie :

> *Le Canada est l'une des forces en recherche en neurosciences à travers le monde. On est classé deuxième ou troisième à travers le monde pour l'impact de nos découvertes en neurosciences. On a donc une bonne capacité. On est assez fort aussi en santé mentale. Il faut reconstruire du côté toxicomanies: nous avons perdu plusieurs de nos grands chercheurs dans les années 1990.*[488]

De plus, la plupart des témoins se sont réjouis de l'ajout de la recherche sur la santé de la population et de la recherche sur les services de santé dans le mandat des IRSC. Ils ont expliqué que cette nouvelle orientation contraste avec l'importance primordiale de la recherche biomédicale chez le prédécesseur des IRSC, le Conseil de recherche médicale. Le Comité a cependant appris que la recherche sur la santé de la population et la recherche sur les services de santé continuent de présenter une relative faiblesse dans la perspective de la santé mentale, de la maladie mentale et de la toxicomanie. Dans leur étude, les Drs Kapur et

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486 Shitij Kapur et Franco Vaccarino, Des découvertes aux soins : Favoriser la recherche sur la maladie mentale et les toxicomanies, document commandé par le Comité, 2004, p. 5.

487 Dr Alan Bernstein, lettre au Comité, datée du 8 juillet 2003.

488 Dr Rémi Quirion (14:9).

Vaccarino soutiennent qu'il est important de corriger la situation, étant donné les effets des grands facteurs déterminants de la santé sur la maladie mentale et la toxicomanie.[489]

> **La recherche doit alimenter la prestation de services de santé mentale. Nous devons savoir ce qui est efficace et ce qui ne l'est pas. Nous devons prendre des décisions éclairées. Nous devons également convertir le savoir issu de la recherche en actions concrètes.**
> ***[Dr James Millar, ministère de la Santé de la Nouvelle-Écosse, mémoire, 28 avril 2004, p. 11.]***

En ce qui concerne la recherche sur les services de santé, un examen documentaire nous a révélé qu'il reste encore beaucoup à apprendre au Canada relativement aux pratiques exemplaires de soins et de services offerts aux personnes atteintes de maladie mentale ou de toxicomanie, que ce soit dans les domaines des soins en clinique interne ou externe, de l'intervention et des services d'urgence, de l'aide en matière de logement, de l'emploi ou de l'autonomie.[490] Les auteurs de cette étude ont indiqué que, dans le cas des interventions où l'on possède le plus de données sur l'efficacité, il y a toujours un besoin pressant d'information détaillée sur ce qui fonctionne et pour qui. Lorsque les données sur l'efficacité sont moins claires, il faut adopter des démarches novatrices pour évaluer l'efficacité d'interventions particulières là où les essais traditionnels contrôlés sur échantillons aléatoires sont impossibles à réaliser ou inadéquats. Il est essentiel de cerner les pratiques exemplaires afin qu'elles guident les décisions sur les bénéficiaires des ressources de traitement et sur le lieu des interventions, sur les types de traitements qui devraient être offerts et sur la manière de s'assurer que les soins répondent aux besoins des patients ou des clients.

Même si de nombreux témoins ont louangé l'approche canadienne unique en son genre pour encourager la collaboration entre les chercheurs et entre les chercheurs et d'autres organisations, certains se sont plaints des lourdes restrictions et des obstacles importants qui nuisent à la validité et à la qualité de la recherche et qui accaparent trop les chercheurs. Par exemple, Michel Tousignant, professeur au Centre de recherche et d'intervention sur le suicide et l'euthanasie de l'Université du Québec à Montréal, a indiqué au Comité que les chercheurs peuvent passer des mois, voire jusqu'à un an, pour satisfaire à tous les critères de l'INSMT/IRSC, avant de commencer un projet de recherche. Il a expliqué qu'il peut y avoir jusqu'à trois comités d'éthique : dans les universités, les centres de recherche et les hôpitaux, pour examiner une proposition. Bien que les comités d'éthique existent pour protéger les intérêts de chacun, le professeur Tousignant a fait remarquer qu'ils allouent peu de temps à la consultation des chercheurs, qui doivent également remettre des protocoles à la Commission d'accès à l'information, ce qui retarde encore plus le début du projet de recherche et alourdit davantage le fardeau bureaucratique pour les chercheurs.[491]

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489 Kapur et Vaccarino (2004), p. 5.

490 Unité de recherche sur les systèmes de santé, Institut psychiatrique Clarke, *Examen des meilleures pratiques de la réforme des soins de la santé mentale : Document de discussion*, préparé pour le Réseau de consultation sur la santé mentale fédéral, provincial et territorial, Santé Canada, 1997, p. 28.

491 Professeur Michel Tousignant (14:43).

10.2 FINANCEMENT FÉDÉRAL DE LA RECHERCHE DANS LES DOMAINES DE LA SANTÉ MENTALE, DE LA MALADIE MANTALE ET DE LA TOXICOMANIE

> *… Le financement actuel de la recherche en maladie mentale et en toxicomanie est insuffisant au Canada. En termes relatifs comme absolus, cette recherche est sous-financée. Si on ajoute à ce sous-financement systémique l'impact de l'ostracisme, les limites des levées de fonds publiques des ONG dans ce domaine ainsi que le manque d'incitatifs commerciaux pour beaucoup de ces activités, le sous-financement devient encore plus criant. Comme ces contraintes sont difficiles à infléchir, il est d'autant plus essentiel que le gouvernement fédéral fasse preuve de leadership en garantissant un financement juste à la recherche sur la maladie mentale et la toxicomanie.*
> *[Dr Shitij Kapur et Dr Franco Vaccarino, Centre de toxicomanie et de santé mentale (2004)]*

10.2.1 L'ampleur du financement fédéral

Principale source de financement de la recherche sur la santé mentale et la toxicomanie au Canada, les IRSC ont versé 93 millions de dollars à l'INSMT à même leur budget de base de 623 millions de dollars pour l'exercice 2003-2004. Environ 33 millions de dollars du budget de l'INSMT est affecté à la recherche sur la santé mentale et les toxicomanies, soit 5,3 p. 100 de l'enveloppe globale du financement de la recherche sur la santé par les IRSC. Les 60 autres millions sont consacrés à la recherche fondamentale en neurosciences, dont une partie, comme d'autres recherches sur la santé, peut également contribuer à une meilleure compréhension de la maladie mentale et de la toxicomanie.

Le Dr Bernstein a indiqué que l'INSMT obtient actuellement la plus grosse part du financement des IRSC. Viennent ensuite l'Institut de la santé circulatoire et respiratoire (64 millions de dollars) et l'Institut des maladies infectieuses et immunitaires (52 millions de dollars).[492]

De concert avec l'Institut de la santé des Autochtones, l'INSMT a créé le Réseau national de recherche en santé mentale chez les Autochtones (RNRSMA) au printemps de 2003, doté d'un budget de 170 000 $ par année pendant quatre ans. Le mandat du Réseau consiste à mener des recherches en partenariat avec les collectivités autochtones et les chercheurs universitaires afin de former de nouveaux chercheurs et de développer les capacités de recherche nécessaires pour s'attaquer aux préoccupations et aux besoins particuliers des Autochtones.

En plus des IRSC, le Conseil de recherches en sciences humaines (CRSH) constitue une autre source fédérale de financement de la recherche dans les domaines de la santé mentale,

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492 Dr Bernstein (8 juillet 2003).

de la maladie mentale et de la toxicomanie. Ainsi, le CRSH appuie la recherche dans le domaine général de la psychologie sociale. Environ 1,5 p. 100 (quelque 2,5 millions de dollars) de son budget de base de 167,5 millions de dollars a été consacré à la recherche sur la santé mentale en 2002-2003.[493]

Le Conseil de recherches en sciences naturelles et en génie (CRSNG) est le troisième et dernier organisme fédéral de financement de la recherche sur la santé. La psychologie clinique n'est pas admissible aux subventions du CRSNG et la recherche sur le cerveau ne constitue pas non plus une priorité. Mais le CRSNG peut envisager d'appuyer des projets relatifs aux processus psychologiques fondamentaux, à leurs mécanismes neuronaux sous-jacents, au développement individuel et au contexte évolutif et écologique. Le financement de la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie est regroupé dans la catégorie « psychologie », à la rubrique « cerveau, comportement et science cognitive ». En 2003, 113 projets ont été financés dans cette catégorie et ont reçu environ 3,25 millions de dollars,[494] soit 0,5 p. 100 du budget des bourses et des subventions du CRSNG, qui s'est établi à un peu plus de 600 millions de dollars.

D'autres sources de financement fédéral de la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie pourraient comprendre Statistique Canada, la Stratégie canadienne antidrogue (qui finance le Centre canadien de lutte contre l'alcoolisme et les toxicomanies), Santé Canada, Services correctionnels Canada (Centre de recherche en toxicomanie), et la Fondation canadienne de la recherche sur les services de santé. Le Comité n'a pas obtenu d'information sur l'ampleur du financement fourni par ces sources.

10.2.2 Combien le gouvernement fédéral devrait-il dépenser?

Plusieurs témoins jugeaient insuffisant le pourcentage du financement de la recherche accordé à la santé mentale, la maladie mentale et la toxicomanie.

> **Je tiens à souligner que la recherche sur la santé mentale et les maladies mentales est sous financée au Canada compte tenu des coûts que ces maladies entraînent pour la société.**
> ***[Dr Rémi Quirion, INSMT (14:8)]***

Dans leur rapport, les Drs Kapur et Vaccarino font remarquer qu'il n'existe pas de lignes directrices au Canada (ni ailleurs, à vrai dire) sur ce que devrait être l'enveloppe totale de la recherche sur la santé ni de quelle façon le financement de cette recherche devrait être réparti entre les domaines et disciplines. En l'absence de tels repères, ils proposent deux approches : on peut considérer le financement en fonction du fardeau relatif de la maladie, et on peut examiner également le mode de financement d'autres pays aux prises avec les mêmes problèmes.[495]

Comme nous l'avons vu aux chapitres 5 et 6, la prévalence de la maladie mentale et de la toxicomanie au Canada est élevée et le fardeau économique est énorme. On compte presque autant de Canadiens aux prises avec la dépression que de Canadiens ayant une maladie

493 Information obtenue par communication personnelle.
494 Information tirée du site Internet à : www.crsng.gc.ca.
495 Kapur et Vaccarino (2004), p. 3.

cardiovasculaire. De nombreux témoins ont fait valoir que les effets de la maladie mentale et de la toxicomanie sur la société sont aussi importants que ceux de n'importe quelle autre catégorie de maladies ou de troubles et que ce fardeau devrait se refléter directement dans le financement de la recherche sur la santé mentale, la maladie mentale et la toxicomanie.

Une étude de la Société canadienne de l'autisme a classé 14 maladies en fonction de leur taux de prévalence et des subventions de recherche des IRSC par personne affectée. Le sida, qui frappe 1 Canadien sur 500, est l'un des secteurs de recherche les mieux subventionnés, car il reçoit des IRSC plus de 1 500 $ par personne affectée. Les troubles d'hyperactivité avec déficit de l'attention (THADA), qui affectent 1 Canadien sur 17, arrivent bons derniers avec 0,09 $ par personne affectée. La schizophrénie, probablement la maladie mentale la plus débilitante qui soit, arrive au 7e rang; elle affecte 1 Canadien sur 100 et obtient des IRSC environ 84 $ par personne touchée. L'autisme, avec un taux de prévalence de 1 sur 200, arrive au 8e et le financement des IRSC représente s'établit à 67,10 $ par patient/client.[496]

Dans une lettre au Comité, le Dr Alan Bernstein, président des IRSC, estime que, si le financement était proportionnel au fardeau que représente la maladie, les IRSC devraient consacrer au moins 80 millions de dollars par année à la recherche sur les maladies mentales et la toxicomanie. À cette aune, force est de constater que les dépenses actuelles des IRSC d'environ 33 millions de dollars sont très faibles. Le Dr Bernstein a néanmoins soutenu que la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie obtient un pourcentage approprié du budget des IRSC,[497] étant donné qu'il faut tenir compte de nombreux facteurs, notamment de la capacité des chercheurs d'utiliser de manière optimale les subventions de recherche.

La deuxième approche proposée par les Drs Kapur et Vaccarino consiste à comparer le rendement du financement fédéral de la recherche en santé mentale, en maladie mentale et en toxicomanie avec celui d'autres pays industrialisés. Les National Institutes of Health aux États-Unis fonctionnent un peu comme les IRSC, c'est-à-dire par l'entremise de quelques instituts. Les instituts pertinents à la comparaison sont le National Institute of Mental Health (NIMH), le National Institute of Drug Abuse (NIDA) et le National Institute on Alcohol Abuse and Alcoholism (NIAAA). En 2003, le budget total des NIH s'est élevé à 27 milliards de dollars américains. Sur ce montant, le NIMH a reçu 1,4 milliard, le NIDA, 1 milliard et le NIAA 0,4 milliard. La recherche sur la santé mentale, la maladie mentale et la toxicomanie aux États-Unis a donc obtenu 2,8 milliards de dollars américains, soit un peu plus de 10 p. 100 de l'ensemble des fonds consacrés à la recherche sur la santé… proportionnellement deux fois plus que ce qu'ont versé les IRSC (5,3 p. 100).[498]

Au Royaume-Uni, le principal organisme de financement de la recherche biomédicale est le Medical Research Council (MRC), qui subventionne six domaines de recherche : les études sur les personnes et la population, notamment les services de santé et la santé de la population; la génétique, la structure moléculaire et la dynamique; la biologie cellulaire, le développement et la croissance; la physiologie médicale et les processus de la maladie;

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496 Société canadienne de l'autisme, *Programme de recherche et Stratégie d'action pour l'autisme au Canada : un livre blanc*, mars 2004. http://autismsocietycanada.ca/finalwhite-french.pdf

497 Dr Bernstein (8 juillet 2003).

498 Information tirée du site Internet des NIH à : www.gov.nih.

l'immunologie et les infections; et les neurosciences et la santé mentale. Les données les plus récentes indiquent que, sur le budget total de 292,6 millions de livres du MRC en 2001-2002, quelque 74 millions de livres ont été affectés à la recherche en neurosciences et en santé mentale et 18,9 millions de livres à la recherche sur les maladies mentales. Ces montants représentent 6,5 p. 100 des montants affectés à la recherche biomédicale.[499]

À en juger par ces renseignements, quelques chercheurs dans le domaine ont soutenu que l'investissement du Canada est insuffisant.

Quels critères devraient déterminer le pourcentage des fonds de recherche accordés à une maladie donnée? Simplement la prévalence, la morbidité et la mortalité, l'incapacité ou le fardeau économique découlant de la maladie? Le financement devrait-il être déterminé en fonction d'une analyse comparative internationale? Par concours, en fonction du mérite de la recherche et de ses résultats possibles parmi toutes les demandes reçues par l'organisme de financement concerné? En tenant compte d'une certaine combinaison de ces critères?

Le Dr Bernstein a déclaré que le fait de strictement allouer les dépenses de recherche en fonction du fardeau que représente la maladie pour la société canadienne reviendrait à poser en hypothèse que les recherches effectuées dans un domaine n'ont pas de retombées sur les autres au niveau des concepts, des réactifs, des techniques et des résultats. Il a expliqué que les progrès les plus importants réalisés au sujet d'une maladie donnée ont leur origine dans des recherches dans un domaine tout à fait différent. Il ne conviendrait donc pas d'allouer les dépenses de recherche uniquement en fonction de la prévalence ou du fardeau de la maladie.[500] Le Dr Bernstein a donné deux exemples :

> *Les IRSC financent plusieurs équipes, à Vancouver, à Toronto et à Québec, qui cherchent à identifier les gènes responsables des maladies affectives bipolaires et de la schizophrénie. La science et la technologie qui permettent de le faire sont issues de travaux de bien plus vaste portée visant à cloner les gènes responsables de n'importe quelle maladie de l'homme. Il est raisonnable d'affirmer que l'identification des gènes responsables des maladies affectives bipolaires constituera la plus importante découverte de l'histoire de la recherche sur la schizophrénie et qu'elle va transformer le diagnostic, le traitement et peut-être même la prévention de la maladie. Pourtant, la recherche fondamentale qui est la condition préalable à ces recherches n'avait à l'origine absolument aucun rapport avec la maladie mentale voire avec la maladie chez l'homme.*
>
> *Les instituts du vieillissement, de la génétique et de la santé publique et de la population préparent une importante initiative, l'Initiative sur la santé des Canadiens à tous les stades de la vie (ISCSV) – qui suivra des cohortes de nouveau-nés et de personnes âgées et mesurera les déterminants génétiques, psychosociaux, économiques, environnementaux et culturels de la santé et de la maladie. Cette initiative, qui exigera un*

499 Information tirée du site Internet du MRC à : www.mrc.ac.uk.

500 Dr Bernstein (8 juillet 2003).

investissement de plus de 100 millions de dollars sur 20 à 30 ans, permettra de cerner les multiples déterminants du vieillissement sain et de la maladie, en particulier pour des maladies courantes et complexes comme les maladies mentales. Dans quelle catégorie classer nos investissements dans cette initiative – santé mentale, maladies cardiovasculaires, arthrite, vieillissement sain, ou toutes les catégories précitées?[501]

Fixer le montant du financement de la recherche en fonction de comparaisons internationales comporte aussi des inconvénients. Premièrement, il faudrait examiner un grand nombre de pays avant d'effectuer une telle comparaison; deuxièmement, les données devraient être vraiment comparables; et troisièmement, les capacités de recherche des pays en cause devraient elles aussi être vraiment comparables.

10.3 AUTRES SOURCES CANADIENNES DE FINANCEMENT

10.3.1 L'industrie pharmaceutique

L'industrie pharmaceutique est la plus importante source de financement de la recherche sur la santé au Canada. En 2002, elle a investi 1,4 milliard de dollars dans la recherche-développement sur la santé, soit environ 36 p. 100 de toute la recherche sur la santé effectuée au pays.[502]

Nous ne savons pas quelle proportion du financement de la recherche par l'industrie pharmaceutique canadienne est consacrée à la maladie mentale et à la toxicomanie. Mais plus d'une centaine d'agents pharmaceutiques potentiels pour divers troubles mentaux sont actuellement à l'étape des essais cliniques humains ou en attente d'homologation.

Ces investissements de l'industrie pharmaceutique sont effectués dans la recherche en laboratoire (à l'interne, dans les universités et les instituts de recherche), afin de découvrir de nouvelles molécules, et dans les essais cliniques, afin de mesurer l'efficacité et les effets secondaires de nouveaux agents sur les personnes atteintes de maladie mentale ou de toxicomanie. Les essais cliniques pour cette catégorie de patients soulèvent de nombreux problèmes éthiques analysés au chapitre 11.

De plus, les sociétés pharmaceutiques appuient la formation et la recherche dans les domaines de la maladie mentale et de la toxicomanie, par l'entremise des Initiatives stratégiques en partenariat avec l'industrie des IRSC. Des exemples récents d'initiatives de ce genre, alliant les IRSC et l'industrie, comprennent le Programme de subventions de fonctionnement sur les mécanismes biologiques et le traitement de la maladie d'Alzheimer, le Programme de neurobiologie des troubles psychiatriques et des toxicomanies (tous les deux

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501 *Ibid.*

502 Statistique Canada, « Estimations des dépenses totales au titre de la recherche et du développement dans le secteur de la santé au Canada, 1988 à 2002 », Statistique des sciences, Bulletin de service, n° 88-001-XIB au catalogue, vol. 27, n° 6, septembre 2003.

en partenariat avec AztraZeneca) et l'Initiative sur la santé vasculaire et la démence (avec Pfizer).

La recherche pharmaceutique a exercé et continue d'exercer une grande influence sur la prestation des soins de santé aux personnes atteintes de troubles mentaux. Par exemple, au chapitre 7, nous avons vu que la découverte d'agents neuroleptiques dans les années 70 a rendu possible la désinstitutionalisation sans danger de nombreuses personnes atteintes de maladie mentale. Plus récemment, de nouveaux médicaments pour traiter la schizophrénie et la dépression ont contribué à réduire les coûts de traitement de ces troubles; on estime que ces coûts ont baissé de plus de 15 p. 100 entre 1992 et 1999 en grande partie parce que de nouveaux médicaments thérapeutiques rendent l'hospitalisation inutile.[503]

L'industrie pharmaceutique canadienne poursuit des recherches importantes. Des agents sont actuellement mis à l'essai sous certaines conditions comme la toxicomanie (par exemple, un vaccin thérapeutique pour traiter les cocaïnomanes), ainsi que l'alcoolisme et le tabagisme.[504] La recherche sur de nouveaux antidépresseurs antipsychotiques devrait également améliorer de beaucoup le traitement de ces conditions.[505]

À l'heure actuelle, les sociétés pharmaceutiques canadiennes les plus actives dans les domaines de la maladie mentale et de la toxicomanie sont Wyeth, Lilly, Glaxo-Smith-Kline (GSK) et Lundbeck. Lilly et GSK, ainsi que Pfizer, continueront de jouer un rôle de premier plan dans la recherche sur la maladie mentale et la toxicomanie au Canada, étant donné qu'elles ont une longue liste de médicaments éventuels dans ce domaine et qu,elles investiront probablement massivement dans de futurs essais cliniques.

10.3.2 Les organismes de financement provinciaux et ONG

On recense de nombreuses autres sources de financement de la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. Dans la plupart des provinces, des organismes gouvernementaux effectuent des recherches sur la santé mentale et la toxicomanie (p. ex. le Réseau santé mentale du Québec; la Fondation ontarienne de la santé mentale, l'Alberta Mental Health Board; le Conseil manitobain de la recherche en matière de santé, le Centre de toxicomanie et de santé mentale (Toronto), etc.).

> **Les ONG peuvent appuyer la recherche de deux façons. Tout d'abord, les organisations peuvent financer des projets de recherche. En recueillant eux-mêmes les fonds ou en faisant appel à d'autres organisations, les ONG peuvent remettre des montants importants à la recherche.**
> ***[Dr John Gray, président, Société canadienne de schizophrénie, mémoire, 12 mai 2004, p. 3.]***

Il existe aussi de nombreux organismes de bienfaisance et fondations (ONG) dans le domaine de la santé qui répondent efficacement aux besoins de divers groupes et individus. Ainsi, le Comité a entendu parler de l'excellente relation de travail qui existe entre la Société canadienne de

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503 Voir Pharmaceutical Research and Manufacturers of America (PhRMA), "New Medicines for Mental Health Help Avert a Spending Crisis", *Value in Medicines*, 14 janvier 2004.

504 Voir le site Internet des Compagnies de recherche pharmaceutique du Canada (Rx&D) à : http://www.canadapharma.org/Patient_Pathways/Health_Info/02mentalheal/index_f.html.

505 *Ibid.*

schizophrénie (SCS) et les IRSC. L'an dernier, la SCS a pu fournir 75 000 $ de fonds de contrepartie affectés à la recherche.

> **… ceux [les organismes bénévoles] qui vont vraiment chercher beaucoup de sous dans le public canadien pour l'instant ne sont pas nombreux, en comparaison au National Cancer Institute ou aux Fondations des maladies du cœur.**
> ***[Dr Rémi Quirion (14:23]***

En revanche, le Comité a également appris que les ONG sont rarement capables d'attirer les fonds nécessaires pour parrainer la recherche. De plus, il n'existe que deux organisations nationales sans but lucratif dont le mandat consiste expressément à trouver du financement et à parrainer la recherche sur la santé mentale et la toxicomanie : la Fondation canadienne de la recherche en psychiatrie et NeuroScience Canada. La Fondation canadienne de la recherche en psychiatrie a déclaré au Comité que le caractère honteux de la maladie mentale et de la toxicomanie nuit grandement à une meilleure connaissance de ces troubles, à l'obtention de commandites d'entreprises et de financement pour la recherche. Cette situation contraste avec celles d'autres groupes de maladie comme le cancer et les maladies cardiovasculaires dont les organismes de bienfaisance respectifs sont solides et obtiennent de bons résultats dans leurs campagnes de financement et dans leur appui à la recherche :

> *La Fondation relève un défi de taille en cherchant à sensibiliser la population au problème des maladies mentales et à recueillir des fonds de recherche pour trouver les causes de diverses maladies mentales, leurs traitements et finalement, leurs remèdes. Malheureusement, le caractère honteux de la maladie mentale persiste. Par conséquent, des millions de personnes souffrent en silence d'un désespoir inimaginable, craignant que la révélation de leur maladie n'entraîne des conséquences néfastes sur le plan personnel. Dans ces conditions, on ne prend guère conscience des maladies mentales, on les comprend mal, les mécanismes de soutien sont peu nombreux, les fausses conceptions sont répandues et le financement essentiel à la recherche est dangereusement bas.*[506]

Les organisations bénévoles continuent cependant de jouer un rôle important dans la recherche sur la santé mentale, la maladie mentale et la toxicomanie au Canada, rôle qui doit être reconnu et élargi. Le Dr Quirion a indiqué au Comité que lorsque l'INSMT a été créé, il s'est associé à une soixantaine d'organisations bénévoles et non gouvernementales. Ces groupes ont participé à l'élaboration du plan stratégique de l'Institut ainsi qu'à l'élaboration d'une stratégie pour aller chercher plus de financement.[507]

Le Dr Gray, de la SCS, a également fait valoir que les ONG doivent participer au processus de recherche. Par exemple, elles peuvent parfois participer à la création des questions de recherche, et leurs représentants peuvent siéger aux comités d'examen. Il a expliqué que, de cette façon, les scientifiques sont mieux à même de faire les recherches les plus pressantes en

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506 Fondation canadienne de la recherche en psychiatrie, mémoire au Comité, juin 2003, p. 2.

507 Dr Rémi Quirion (14:24).

santé mentale et en toxicomanie. Leur participation renforce également l'aspect humain de la science et rappelle sans cesse les bienfaits de la recherche.[508]

Le financement de la recherche sur la santé mentale, la maladie mentale et la toxicomanie soulève une grande préoccupation : il n'existe actuellement pas de base de données centrale sur toutes les sources de financement. Les gouvernements et les organisations non gouvernementales ne tiennent pas de statistiques sur les sujets d'enquête. La Fondation canadienne de la recherche en psychiatrie a fait observer qu'il n'y a pas de coordination entre les organismes de financement de la recherche et aucune responsabilité centrale pour la collecte de données. Les chercheurs ont donc du mal à naviguer non seulement à travers les sources de financement fédérales, mais aussi à travers les sources des secteurs privé et bénévole. Souvent, les chercheurs ne savent pas que des questions de recherche semblables sont étudiées dans différents laboratoires du pays. Dans bien des cas, la possibilité de collaborer améliorerait la productivité et atténuerait les conséquences négatives de la concurrence entre les universités et les hôpitaux. La Fondation a recommandé l'établissement d'une base de données centrale sur les organismes de financement de la recherche, qui inclurait les sources de financement non gouvernementales, la création d'un répertoire des recherches en cours et d'un registre des résultats de la recherche.[509]

10.4 APPLICATION DES CONNAISSANCES

> *Dans le domaine de l'application dans la vie courante des acquis de recherche […] il faut probablement oser enfreindre un tout petit peu la liberté d'autonomie des professions médicales et enseignantes dans ce domaine.*
> *[Dr Laurent Mottron, professeur, Département de psychiatrie, Université de Montréal (14:21)]*

Dans leur étude, les Drs Kapur et Vaccarino font observer au Comité que le principal incitatif de la recherche médicale dans notre société, c'est la promesse d'un sort meilleur pour les malades, leur famille et leur milieu.[510] Cela implique que les découvertes sont transposées du laboratoire au milieu dans lequel les soins sont dispensés, processus qu'on appelle aussi « l'application des connaissances ».

Bien que l'application des connaissances relève du mandat des IRSC, de nombreux témoins ont indiqué qu'elle ne se fait pas bien dans la recherche sur la santé mentale et la toxicomanie. La recherche biomédicale, qui a établi que la maladie mentale et la toxicomanie sont des désordres du cerveau, a offert des pistes prometteuses en génétique, élucidé le rôle d'une vaste gamme de facteurs de risque, retenu les meilleures pratiques dans un grand nombre de nouveaux systèmes et confirmé beaucoup de traitements pharmacologiques. Mais

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508 Dr John Gray, président, Société canadienne de schizophrénie, mémoire au Comité, 12 mai 2004, p. 3.
509 Fondation canadienne de la recherche en psychiatrie (juin 2003), p. 6.
510 Kapur et Vaccarino (2004), p. 6.

beaucoup croient que, trop souvent, ces découvertes restent dissimulées dans les laboratoires et n'ont guère d'impact sur les malades et leur famille.[511]

Cette situation a été mise en évidence dans le rapport de 1999 du directeur du Service de santé publique des États-Unis intitulé *Mental Health: A Report of the Surgeon General*. Ce document de 500 pages, premier rapport que le directeur du Service de santé publique des États-Unis consacrait à la santé mentale, a confirmé que la recherche a permis d'acquérir les connaissances nécessaires pour offrir un traitement efficace et de meilleurs services pour la plupart des troubles mentaux. Mais il affirme également qu'il existe des lacunes entre les traitements dont l'efficacité optimale a été démontrée par la recherche et ceux que reçoivent en pratique de nombreux patients.[512]

Dans la même veine, la New Freedom Commission on Mental Health, commission du Président des États-Unis présidée par Michael F. Hogan, a signalé en 2003 les longs délais qui s'écoulent avant que la recherche ne soit appliquée dans la pratique. Plus précisément, la Commission a souligné que le délai de 15 à 20 ans entre la découverte d'un traitement efficace et son intégration dans les soins courants aux patients est beaucoup trop long. Elle a également indiqué que, même lorsque l'application de ces découvertes devient monnaie courante au niveau communautaire, les méthodes cliniques sont très variables dans la réalité et souvent incompatibles avec le modèle de traitement d'origine dont l'efficacité a été démontrée.[513]

Le transfert d'une nouvelle idée ou d'une découverte vers une pratique acceptée comporte trois étapes distinctes. La première est la découverte fondamentale : nouvelle association génétique, nouveau traitement, nouvelle façon d'engager les patients dans la thérapie, nouvelle façon d'utiliser un vieux médicament. L'étape suivante est la validation du principe, autrement dit, la transposition de la découverte en soins et la démonstration qu'elle est efficace dans un cadre contrôlé. C'est l'étape des essais cliniques. La troisième étape, celle de la dissémination et de l'application, consiste à faire passer la nouvelle pratique dans le milieu et l'intégrer dans le continuum préexistant des soins.[514] Eric Latimer, économiste de la santé à l'hôpital Douglas (Montréal), a déclaré au Comité que la recherche sur la maladie mentale et la toxicomanie a permis de nombreuses découvertes en regard de l'ampleur du financement et des chercheurs en cause, mais que les deux autres étapes demeurent problématiques et exigent des investissements accrus.[515]

Des essais cliniques s'imposent pour démontrer l'efficacité des découvertes fondamentales et la réalisation de ces essais nécessite des chercheurs-cliniciens bien formés et chevronnés. Certains témoins ont souligné que le trop peu de médecins participent à la recherche et qu'une lacune importante du programme de recherche tient au fait que trop peu de chercheurs-cliniciens sont formés pour réalisés des essais cliniques cruciaux. La principale priorité du plan stratégique de l'INSMT's pour 2001-2005 consiste notamment à créer plus de possibilités de formation pour les chercheurs-cliniciens.

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511 *Ibid.*

512 United States Surgeon General, *Mental Health: A Report of the Surgeon General*, 1999.

513 The President's New Freedom Commission on Mental Health, Achieving the Promise: Transforming Mental Health Care in America, rapport final, 22 juillet 2003, p. 67.

514 Kapur et Vaccarino (2004), p. 6.

515 Eric Latimer (14:44 à 14:48).

L'étape de la dissémination et de l'application des connaissances consiste à diffuser au sein de la collectivité les nouvelles idées ou pratiques validées. Comme nous l'avons déjà indiqué, l'une des priorités stratégiques de l'INSMT consiste à promouvoir les liens et les échanges entre les chercheurs et les décideurs municipaux, provinciaux et nationaux ainsi que les utilisateurs des résultats de la recherche, notamment les ONG, par l'entremise de programmes structurés d'application des connaissances. Même si les témoins ont convenu qu'il s'agit d'un objectif non seulement louable mais aussi nécessaire, ils estiment que cet objectif est impossible à atteindre avec le niveau de financement actuel. Dans son témoignage, le professeur Tousignant nous a indiqué que les budgets de recherche devraient réserver une part à la vulgarisation scientifique.[516]

Le Comité a appris que l'application des connaissances et la recherche clinique seront deux des principales priorités des IRSC dans les années qui viennent. Nous appuyons fortement cette politique.

10.5 VERS UN PROGRAMME NATIONAL DE RECHERCHE POUR LA SANTÉ MENTALE, LA MALADIE MENTALE ET LA TOXICOMANIE

> *La santé mentale et la maladie mentale sont de la plus haute importance, et le programme national devrait inclure la recherche de pointe.*
> *[Dr Rémi Quirion (14:34)]*

Le Comité a appris que, dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie, il n'y a pas de politique ni de stratégie cohérente pour résoudre les problèmes complexes qui se posent et réagir de manière cohérente et coordonnée. Les troubles mentaux sont généralement des maladies complexes et chroniques. Leurs déterminants chevauchent de nombreux secteurs, leur gestion exige l'intervention de différents professionnels de la santé et ils ont une grande incidence sur le fonctionnement de la société. Les témoins ont souligné la nécessité d'une meilleure coordination des efforts, afin de mieux faire face aux nombreux défis face à la maladie mentale et la toxicomanie, présentement relevés par le gouvernement fédéral et provinciaux ainsi que les organisations non gouvernementales et l'industrie pharmaceutique. Les Drs Kapur et Vaccarino ont déclaré :

> *[…] Les problèmes de la maladie mentale et de la toxicomanie résistent aux solutions simples. Ces maladies ont de multiples déterminants, d'ordre biologique, psychologique et social, et une réponse acceptable exige la coordination de multiples secteurs. À l'heure actuelle, la recherche dans ces domaines est bien intentionnée mais dépourvue de coordination. Nous réclamons vigoureusement une politique ou un cadre directeur national pour jeter les bases d'un effort coordonné en recherche sur la maladie mentale et la toxicomanie.*[517]

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516 Professeur Tousignant (14:43).
517 Kapur et Vaccarino (2004), p. 11.

Les témoins qui ont abordé des questions liées à la recherche sur la santé mentale et la toxicomanie s'entendaient sur la nécessité d'un programme de recherche national. Selon eux, un tel programme ferait fond sur le savoir-faire canadien actuel, coordonnerait les activités de recherche actuellement fragmentées que mènent divers acteurs (gouvernements, organisations non gouvernementales, sociétés pharmaceutiques) et assurerait un équilibre entre la recherche biomédicale, clinique, sur les services de santé et sur la santé de la population appliquée à la santé mentale, à la maladie mentale et à la toxicomanie. Mais surtout, de nombreux témoins ont insisté sur le fait qu'il faut s'attaquer maintenant aux problèmes cruciaux qui touchent à la recherche sur la santé mentale et la toxicomanie. Le Dr Quirion a été très éloquent à ce sujet :

> *En anglais, on dit souvent: «The time is now.» On a vraiment beaucoup d'expertise au Canada grâce au système de santé national. Cela permet de recueillir des données et d'avoir des banques de données beaucoup plus impressionnantes que celles des États-Unis. Je pense, par exemple, aux nouvelles recherches sur le génome.*
>
> *Je pense qu'on pourrait avoir un impact énorme et on ne devrait pas avoir peur de foncer. Si on fonce avec l'expertise qu'on a présentement, on va réussir à trouver des causes des maladies du cerveau, des maladies mentales.*[518]

10.6 OBSERVATIONS DU COMITÉ

Le Comité reconnaît qu'au cours des dernières décennies, la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie a permis de mieux comprendre comment améliorer le sort des personnes atteintes de maladie mentale ou de toxicomanie. De nouveaux traitements permettent de soigner les malades dans la collectivité, sans qu'il faille les confiner pendant de longues périodes dans des institutions publiques. On comprend mieux également la pathophysiologie des troubles mentaux, ce qui a d'importantes implications pour le traitement et la prévention. Le Comité croit également que la recherche dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie peut jouer un rôle important pour éclairer les décisions stratégiques relatives à l'affectation des ressources aux traitements, aux services et moyens de soutien dont ont besoin les personnes atteintes de maladie mentale ou de toxicomanie.

Le Comité reconnaît aussi la grande contribution des chercheurs canadiens dans les domaines de la maladie mentale et de la toxicomanie. Le Canada est un chef de file national et international dans de nombreux domaines de recherche, notamment en neurosciences, en psychopharmacologie et en génétique. Il est essentiel de préserver et d'accentuer cette puissance historique.

Le Comité reconnaît le rôle du gouvernement fédéral dans la création des IRSC et la décision de créer l'INSMT. Nous nous réjouissons également de l'accroissement du financement fédéral accordé aux IRSC ces dernières années. Nous tenons tout particulièrement à

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518 Dr Rémi Quirion (14:15).

souligner l'importante contribution du Dr Rémi Quirion, directeur scientifique de l'INSMT, dans la promotion et l'exécution de travaux de recherche sur la santé mentale, la maladie mentale et la toxicomanie.

Le Comité est d'avis que la recherche est très importante, qu'elle constitue un bon moyen de trouver des solutions fondamentales au problème de la maladie mentale et de la toxicomanie au Canada et qu'il faut accorder des ressources suffisantes pour progresser dans cette voie. Nous croyons que le gouvernement fédéral devrait financer davantage la recherche sur la santé mentale et la toxicomanie, y compris la formation d'un plus grand nombre de chercheurs et de chercheurs-cliniciens afin de renforcer la capacité du Canada de mener des recherches de haute qualité dans ce domaine. De même, les organisations bénévoles devraient être encouragés à développer ou renforcer leurs activités de levée de fonds afin d'accroître, elles aussi, le financement de la recherche.

CHAPITRE 11:
LA QUESTION DE L'ÉTHIQUE

INTRODUCTION

L'« éthique » désigne habituellement une tentative systématique et raisonnée de comprendre les valeurs et les principes qui sous-tendent les décisions sur des questions d'importance humaine fondamentale. Bref, l'éthique vise à déterminer ce qui est juste et bon.

> **Une question de recherche générale […] porte sur le sens différent et parfois opposé que l'on donne aux termes « éthique » ou « bien » en ce qui concerne leur application concrète aux soins aux personnes qui s'efforcent de lutter contre une maladie mentale. Toute réponse à des problèmes éthiques particuliers comporte un certain engagement envers la notion générale de bien.**
>
> ***[Institut canadien catholique de bioéthique, mémoire au Comité, 20 février 2004, p. 6]***

Dans beaucoup de domaines, les décisions difficiles nécessitent l'examen de multiples facteurs, mettant chacun en cause des valeurs, des principes, des points de vue, des convictions, des attentes, des craintes, des espoirs, etc., différents et souvent contradictoires. Face à de telles décisions, différentes personnes vont aboutir à différentes conclusions non seulement parce qu'elles considèrent des facteurs différents, mais aussi parce qu'elles les jugent les uns par rapport aux autres de façons différentes. L'effet pratique de l'éthique, comme discipline, est d'aider ceux qui doivent affronter des décisions complexes à en saisir les valeurs et les principes inhérents et à les peser les uns par rapport aux autres afin d'aboutir à la meilleure décision possible.[519]

Dans le contexte de la santé et des soins de santé – que ce soit dans la pratique, l'exécution ou la recherche – le but ultime de l'éthique consiste à améliorer la santé et la qualité de vie. Dans une étude commandée par le Comité, Gordon DuVal et Francis Rolleston indiquent les valeurs éthiques et principes bien ancrés qui sous-tendent ce but :

- bienfaisance et non-malfaisance – offrir des services en respectant les normes établies pour des soins de qualité et dans le meilleur intérêt du patient, et ne pas causer de tort à ce dernier;
- autonomie – respecter le patient en tant que personne et l'encourager dans son autodétermination et ses choix, et protéger les renseignements de nature délicate;
- justice – faire en sorte que les patients et les sujets de recherche soient traités équitablement et que les ressources médicales soient réparties en toute équité.[520]

Les autres valeurs importantes mentionnées par DuVal et Rolleston comprennent les éléments familiers du comportement vertueux comme : la compassion, l'honnêteté, les promesses tenues, le courage moral, la patience, la tolérance, la protection de la dignité et la

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519 Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, *Recommandations en vue d'une réforme*, Volume Six, octobre, p. 239-240.

520 Gordon DuVal et Francis Rolleston, *Questions d'éthique en santé mentale,* document commandé par le Comité, 20 avril 2004.

responsabilité, sans parler des valeurs communautaires et relationnelles.[521] Ces aspects moraux fondamentaux se traduisent largement dans les codes d'éthique des professions et des institutions ainsi que dans le droit. Collectivement, ces principes et valeurs guident les décisions relatives aux programmes et à la prestation de soins de santé, aux soins cliniques et à la recherche connexe.

Le présent chapitre examine diverses questions éthiques portant plus précisément sur la maladie mentale et la toxicomanie. La section 11.1 analyse les questions éthiques relatives aux services et aux moyens de soutien offerts aux personnes atteintes de maladie mentale. La section 11.2 traite de la capacité de consentir au traitement. La section 11.3 porte sur la protection des renseignements personnels et la confidentialité. La section 11.4 examine les questions éthiques relatives à des groupes particuliers – enfants et adolescents, personnes âgées et patients de médecine légale. La section 11.5 traite des répercussions des progrès en génétique et en neurosciences sur l'éthique. La section 11.6 examine les questions éthiques soulevées par la recherche sur la santé mentale et la toxicomanie. La section 11.7 présente quelques commentaires du Comité.

La stigmatisation sociale qui pèse sur les personnes atteintes de maladie mentale ou de toxicomanie et leur famille est au cœur d'un grand nombre des questions et préoccupations éthiques abordées dans le présent chapitre. En soi, la stigmatisation mène directement à un manque relatif de compassion et à une perte de la dignité et du respect auxquels toutes les personnes ont droit. En bout de ligne, elle est à la source même de l'injustice, de l'absence de bienfaisance et de l'inégalité d'accès aux services et aux soins.

> **Je vois trois grandes difficultés d'ordre éthique en ce qui a trait à la santé mentale au Canada […]. Le premier problème dans notre société demeure le stigmate d'un problème de santé mentale. […]**
> ***[Mark Miller, éthicien, St. Paul's Hospital, Saskatchewan, lettre au Comité, 27 septembre 2003.]***

11.1 ACCÈS AUX SERVICES ET AUX MOYENS DE SOUTIENS

D'après DuVal et Rolleston, le problème éthique associé aux services et aux moyens de soutien tient à ce que « la société n'a pas pris de moyens concrets pour protéger, dans le cas des personnes souffrant de maladies mentales, le droit à la justice et à la bienfaisance, tant dans le système de soins de santé public du Canada qu'ailleurs ».[522] Premièrement, la complexité de la santé mentale ajoute beaucoup à la difficulté de la société d'offrir les soins nécessaires pour traiter la maladie mentale aussi bien que les autres types de maladie. Deuxièmement, en plus des divers professionnels de la santé, beaucoup de professionnels participent à la pose du diagnostic, aux traitements et aux soins continus en cas de troubles mentaux. Ainsi, les enseignants, les responsables de l'application de la loi, le clergé et les travailleurs sociaux ont ici un rôle à jouer beaucoup plus grand qu'à l'égard des autres maladies. En l'absence d'un système de santé bien coordonné, les personnes atteintes de maladie mentale ou de toxicomanie et leurs familles ont plus de mal que la plupart des autres

521 *Ibid.*
522 *Ibid.*, p. 3.

citoyens à avoir accès à des soins de santé adéquats, ce qui entraîne une sorte de discrimination systémique.

Dans leur étude, DuVal et Rolleston soutiennent que la piètre qualité relative des traitements des maladies mentales ne vient pas tant du fait que le public ou les systèmes veulent discriminer ceux qui en souffrent, mais des facteurs directement liés à la nature des troubles mentaux. La maladie mentale et la toxicomanie se manifestent souvent par des comportements plutôt que par des symptômes physiques, contrairement à presque tous les autres types de maladie. Les comportements attribuables à des troubles mentaux engendrent de la peur et de l'incompréhension chez beaucoup de personnes. Ces comportements donnent souvent lieu à des problèmes avec les autorités réglementaires, par exemple, ou à des problèmes scolaires, et c'est ce qui détermine où s'effectuera la première intervention.[523]

Les schizophrènes sont encore traités de la façon dont on traitait les cancéreux il y a longtemps, comme si c'était une question morale et non physique.
[Murray (9:18)]

Bien que rien ne justifie l'adoption de normes différentes relatives à l'accès, à la qualité des soins ou à l'établissement de priorités pour traiter les maladies mentales ou la toxicomanie par rapport aux autres maladies physiques, la réalité semble différente. Cette distinction est particulièrement problématique dans les situations de crise, où il faut prodiguer des soins opportuns et efficaces. Le Dr James Millar, directeur exécutif des Mental Health and Physician Services au ministère de la Santé de la Nouvelle-Écosse, a déclaré au Comité :

> *[Nous devons] accorder la même importance à la santé mentale que celle que la société accorde à la santé physique. Il est inacceptable pour les personnes qui ressentent une douleur à la poitrine d'attendre qu'on en détermine la cause. S'il s'agit d'une maladie cardiaque, le patient veut être soigné immédiatement. Malheureusement, les personnes qui souffrent émotionnellement n'ont pas les mêmes exigences. En général, elles attendent pour demander de l'aide, elles attendent encore plus pour rencontrer un professionnel de la santé, elles sont traitées selon des méthodes dépassées et inappropriées et elles continuent de souffrir beaucoup plus longtemps que nécessaire.*[524]

Carlyn Mackey, Aurise Kondziela et Dorothy Weldon, du Christ the King Family Support Group, ont écrit au Comité que les normes éthiques de la médecine conventionnelle ne sont pas appliquées de manière uniforme dans la prestation de soins de santé mentale :

> *Les normes éthiques régissant le traitement de la maladie mentale ne semblent pas être conformes à celles auxquelles est assujettie la médecine conventionnelle. Sur le plan de l'éthique, il faut remettre en cause le fait que nous tolérons un système de soins de santé mentale dysfonctionnel ou*

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523 *Ibid.*

524 Dr James Millar, directeur exécutif, Mental Health and Physician Services, ministère de la Santé de la Nouvelle-Écosse, p. 9.

> *un système pouvant même être taxé de non-système. Il faudrait donc que tous les ordres de gouvernement s'attaquent aux problèmes d'ordre éthique découlant de la discrimination persistante et délibérée contre le malade mental, afin de pouvoir lui offrir des soins de santé sûrs et opportuns.*[525]

Les services et soutiens aux personnes atteintes de maladie mentale posent une autre difficulté, car ils font intervenir un grand nombre de professions et de secteurs de compétence. DuVal et Rolleston ont donné l'exemple de l'enseignant qui est le premier à attirer l'attention de la famille sur la possibilité que le trouble d'hyperactivité avec déficit de l'attention (THDA) soit la cause des difficultés scolaires de l'enfant. Dans les cas d'indiscipline, le système scolaire cherche à protéger les autres élèves. Des mesures disciplinaires, une suspension ou l'expulsion accentuent la tendance à l'ostracisme et à la stigmatisation. Le maintien dans le système scolaire exige des classes spéciales ou une aide à l'enseignement particulière pour réduire au minimum l'impact sur les autres élèves. Si la maladie mentale donne lieu à de la violence, des agents des forces de l'ordre peuvent intervenir. Les membres du clergé peuvent être les premières personnes contactées par des gens qui se sentent possédés par des forces extérieures. Comme il est si important que la personne atteinte de maladie mentale admette son état afin de pouvoir le gérer, enseignants, agents des forces de l'ordre, membres du clergé et autres professions parallèles sont souvent les premiers à poser le diagnostic et à entamer le traitement des personnes atteintes de maladie mentale.[526]

De multiples obstacles découlant de la répartition des champs de compétence entre le régime de santé mentale et le régime des services sociaux empêchent cependant un bon traitement. Par exemple, le Dr Robert Quilty, psychologue agréé travaillant au Durham County School Board, a informé le Comité de l'existence d'une sorte de « flou diagnostique » qui empêche de bien diagnostiquer et, par conséquent, de bien traiter les maladies mentales d'enfants ayant des troubles de développement, de sorte, par exemple, que des troubles d'autisme qui auraient pu être traités s'ils avaient été détectés plus tôt passent inaperçus. Le problème est aggravé par les difficultés que posent l'accès d'enfants ayant une débilité mentale aux organismes qui fournissent des services comportementaux au sein des structures de santé mentale, condamnant ainsi leur avenir déjà incertain. Les enfants autistes de haut niveau (syndrome d'Asperger) s'en tirent peut-être un peu mieux. Toutefois, même si leur traitement a été en partie réussi, à l'âge adulte, les patients qui ont un retard de développement et ont besoin d'autres soins de santé mentale sont rarement perçus comme tels parce qu'ils ont déjà été étiquetés comme nécessitant un soutien communautaire. C'est là un autre exemple du manque de coordination dans la prestation des services entre les divers ministères provinciaux.[527]

En conséquence, la prestation des services de santé mentale et de traitement de la toxicomanie se caractérise par une grande fragmentation, ainsi que par un manque de cohésion et de coordination. Pour les personnes atteintes de maladie mentale, le problème de

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525 Carlyn Mackey, Aurise Kondziela et Dorothy Weldon (Christ the King Family Support Group - Winnipeg), mémoire au Comité, 24 octobre 2003, p. 2.

526 Gordon DuVal et Francis Rolleston (2004), p. 6.

527 *Ibid.*, p. 11-12.

la navigation dans ce réseau complexe de services et de soins est exacerbé par la nature de leur maladie. De nombreuses personnes atteintes de maladie mentale ou de toxicomanie et d'autres experts ont déclaré au Comité que cette absence de cohésion et de coordination a accru la toxicomanie, l'itinérance et les incarcérations.

DuVal et Rolleston ont fait ressortir que la fragmentation du système est apparente, même lorsqu'il est clair que des soins institutionnels s'imposent. Le cas très médiatisé d'une jeune femme d'Ottawa au comportement violent et autodestructeur est très révélateur. L'hôpital pour enfants de l'Est de l'Ontario ne pouvait la prendre en charge parce qu'il n'est pas équipé d'installations pour accueillir de tels patients; l'hôpital Royal Ottawa, qui lui en a, ne pouvait pas l'accueillir parce qu'elle n'est pas assez âgée. Ce cas fait ressortir les graves problèmes éthiques qui découlent de la fragmentation du « système » en vigueur qui régit les soins de longue durée pour les patients dont l'âge et la condition mentale varient.[528]

Le Comité a appris que c'est surtout la famille qui doit dispenser l'essentiel des soins aux proches atteints de maladie mentale, même s'ils ont accès aux centres de soins à domicile ou de soins communautaires parce que les ressources de ces centres sont trop souvent inadéquates ou insuffisantes. Mark Miller, éthicien au St. Paul's Hospital (Saskatoon), a écrit :

> *Et je dirais que le plus grand problème d'éthique au-delà du système de santé proprement dit est le manque fréquent de ressources pour les membres de la famille qui s'occupent d'un proche à la maison ou dans la collectivité. Bien des parents, des enfants et d'autres aidants sont à toutes fins utiles abandonnés à leur sort, ce qui est tout à fait injuste et crée d'autres problèmes de santé chez les personnes aidantes. Le désespoir n'est pas rare dans les familles aux prises avec un membre en difficulté.*[529]

11.2 CONSENTEMENT ET CAPACITÉ DE CONSENTEMENT

La société protège le choix individuel – le droit de consentir à un traitement ou de le refuser – en fonction du droit fondamental de l'individu à l'autonomie. Mais pour que le consentement à des services de santé mentale ou de traitement de la toxicomanie soit valable, l'individu doit être mentalement et légalement apte à faire ce choix.

Bien que la capacité de prendre des décisions soit essentielle à un consentement éclairé valable, les critères qui conviennent pour évaluer la compétence prêtent à controverse, surtout dans le cas de personnes atteintes d'une maladie mentale ou de toxicomanie. La capacité de prendre des

Dans le contexte d'une maladie mentale, la capacité de prendre des décisions peut varier et dépend beaucoup de la nature de la décision à prendre. Parmi les difficultés liées à la capacité à prendre des décisions, on trouve des inquiétudes au sujet de la capacité de gérer ses finances personnelles et de prendre des décisions concernant les soins personnels, y compris au sujet du logement.

[DuVal et Rolleston (2004), p. 13.]

528 *Ibid.*, p. 6.

529 Mark Miller, mémoire au Comité, 27 septembre 2003, p. 2.

décisions est liée à la capacité de comprendre les renseignements pertinents concernant le traitement, de bien en saisir la portée et de raisonner de manière à pouvoir peser logiquement les choix qui s'offrent.

L'évaluation de la capacité décisionnelle soulève des questions particulières de vulnérabilité pour les personnes atteintes de troubles mentaux. Les évaluations cliniques de la capacité à prendre des décisions se concentrent essentiellement sur le fonctionnement cognitif. Comme les maladies mentales et la toxicomanie peuvent miner la cognition, les personnes atteintes, particulièrement dans les cas graves, sont souvent incapables de prendre des décisions. Elles peuvent cependant perdre cette faculté de manière intermittente, comme chez les personnes souffrant de toxicomanie, ou encore graduellement, comme chez les personnes qui vieillissent et tombent lentement dans la démence ou dans un autre processus dégénérescent qui affecte la fonction cognitive. Adapter la prestation des services en fonction des fluctuations ou de la perte graduelle de la capacité de décider constitue un défi de taille pour le système de santé mentale et le système de traitement de la toxicomanie. Le respect de la personne exige que les fluctuations ou la diminution des capacités soit dépistée et diagnostiquée et que le système s'adapte en conséquence, afin de ne pas empiéter indûment sur l'autonomie de la personne en cause.

Les fonctions cognitives et non cognitives peuvent aussi être compromises par des troubles mentaux qui perturbent de diverses manières la prise de décisions. Par exemple, la dépression clinique et d'autres états affectifs pathologiques peuvent réduire la capacité de choisir ou de rejeter un traitement, même si la compréhension de l'information pertinente n'est pas altérée. Les définitions usuelles de la capacité ne rendent pas bien compte des déficits non cognitifs, comme le pessimisme face à l'avenir qui peut caractériser la dépression. L'évaluation de la capacité donne des résultats imprécis en présence de sentiments dominants, mais peut-être passagers, de désespoir, d'impulsivité ou d'auto-dévalorisation, par exemple.

Chez les patients atteints de schizophrénie, la nature délirante et paranoïde de la maladie peut aussi compromettre la capacité de prendre des décisions d'une manière qui n'est pas clairement liée à l'absence ou à la perte de la cognition. Chez les individus qui souffrent d'une dépendance, la capacité de prendre des décisions peut être compromise par leur difficulté à maîtriser l'impulsion qui les pousse au comportement associé à la dépendance. Dans le cas de certains troubles de l'alimentation, où l'on observe une distorsion pathologique de l'image corporelle, l'incapacité peut être très restreinte, et le rôle de cette distorsion dans la détermination de la capacité n'est pas clair.

Les soins de santé mentale sont compromis lorsque la capacité est refusée ou présumée à tort.

[Institut canadien catholique de bioéthique, mémoire au Comité, 20 février 2004, p. 3.]

Par conséquent, l'évaluation clinique de la capacité mentale en présence de maladies mentales ou de toxicomanie est une entreprise complexe. La capacité mentale de prendre des décisions peut exister à divers niveaux et à divers degrés et peut fluctuer dans le temps. Or, en droit, après avoir entendu les témoignages d'experts, un juge détermine qu'à un moment donné la capacité légale de prendre des décisions existe ou n'existe pas à des fins précises (la capacité de prendre soin de ses biens ou de sa personne, par exemple). Il n'y a pas de degrés de capacité

ou d'incapacité. La révision d'une décision judiciaire d'établir un régime de protection et de désigner un représentant légal chaque fois que l'état mental fluctue peut prendre beaucoup de temps et être lourde. Dans son mémoire au Comité, l'Institut canadien catholique de bioéthique a expliqué :

> *Le système juridique tend à faire une distinction très nette entre les individus jugés « capables » de prendre des décisions concernant leur propre santé et ceux qui en sont incapables. Beaucoup d'individus atteints de maladies mentales comme la dépression profonde ou la schizophrénie pourraient ne pas répondre aux critères juridiques permettant de les déclarer « incapables » et pourtant, leur capacité de comprendre leur propre état, d'évaluer leurs possibilités, de prendre des décisions judicieuses à propos des soins à recevoir et de s'en tenir à ces décisions peut être gravement compromise. Puisque l'autonomie des patients est un élément prépondérant de l'éthique médicale contemporaine, il est utile d'envisager les difficultés qui surgissent à ce chapitre quand, d'une part, un patient est jugé incapable alors qu'il conserve un certain degré de capacité, et quand, d'autre part, on présume que le patient a conservé cette capacité alors qu'elle est en réalité gravement compromise.*[530]

Le Comité a appris que l'Ontario et certaines autres provinces ont légiféré pour établir des ordonnances de traitement en milieu communautaire (OTC). Une OTC est une ordonnance de médecin obtenue avec le consentement de la personne visée, par laquelle celle-ci accepte de recevoir un traitement ou des soins et une supervision en milieu communautaire. Afin de donner son consentement, il faut être légalement capable de consentir au traitement. Si la personne n'est pas légalement apte à donner son consentement et qu'un mandataire a été autorisé, le mandataire doit consentir à l'OTC, même si la personne inapte n'est pas d'accord. Certaines personnes atteintes de maladie mentale ou de toxicomanie craignent toutefois que la législation relative aux OTC n'empiète sur leurs droits. En revanche, certaines familles qui, parce qu'elles n'ont pas accès à des fournisseurs officiels de soins et qu'elles remplacent donc ces derniers, croient que sans cette mesure législative, elles seraient incapables d'aider un être cher.

Les témoins ont expliqué que, même lorsque les membres de la famille et les prestataires de soins souhaitent protéger la santé et le bien-être de personnes vulnérabilisées par leurs capacités réduites, il n'en demeure pas moins important de respecter l'autonomie de ces personnes. Les témoins ont précisé que les familles et les fournisseurs de soins doivent en arriver à un équilibre délicat dans leurs démarches pour aider une personne souffrant d'une maladie mentale tout en respectant son autonomie, même si elle n'est que partielle. La réponse n'est jamais tranchée, mais l'intervention doit être faite en fonction du patient et des particularités de son état.

Bien plus que les individus souffrant d'autres maladies, ceux qui sont atteints de troubles mentaux n'ont pas conscience de l'existence ni de la nature de leur maladie, à cause même de cette maladie. En conséquence, ils ressentent parfois beaucoup de méfiance à l'endroit des

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530 Institut canadien catholique de bioéthique, mémoire au Comité, 20 février 2004, p. 5.

intervenants de la santé mentale et ils sont nombreux à refuser les traitements ou à ne pas s'y conformer. Lorsqu'une intervention ou un traitement est clairement indiqué, à quel moment le respect du refus du traitement devient-il l'abandon d'une personne vulnérable qui a besoin d'aide ou de soins?

Il est évident qu'une personne dont la capacité de prendre des décisions est compromise peut refuser le traitement et que ce refus doit être respecté. La situation peut toutefois être très difficile pour les membres de la famille quand un patient ayant besoin de soins mais refusant le traitement satisfait aux normes juridiques de la capacité, malgré une capacité de prendre des décisions compromise.

Un dilemme semblable se pose lorsqu'un patient, qui a besoin de soins et qui est jugé incapable de prendre une décision, résiste à une intervention nécessaire pour traiter un trouble mental. Même si un mandataire peut légalement autoriser le traitement au nom du patient, il peut demeurer difficile d'administrer le traitement lorsque le patient oppose une résistance acharnée. Les seules options possibles peuvent être alors d'administrer le traitement à l'insu du patient (par exemple, en mélangeant les médicaments à la nourriture ou aux boissons), de recourir à la force ou d'y renoncer complètement.

L'administration d'un traitement par la force ou la tromperie, particulièrement à des personnes vulnérables comme celles souffrant de troubles mentaux, soulève d'importantes questions d'éthique pour les professionnels de la santé. Le recours à la force ou à la duperie peut miner considérablement la confiance, ce qui rend encore plus difficile la communication continue, la coopération et les soins. Pourtant, il peut être tout aussi déplacé de ne *pas* administrer le traitement à un patient qui, à cause de son incapacité, est vulnérable et a vraiment besoin d'être protégé par une personne de confiance. Les patients seront peut-être reconnaissants par la suite pour des traitements administrés contre leur gré au moment où ils étaient incapables de prendre une décision à cet égard ou, au contraire, ils pourront continuer d'éprouver du ressentiment et ne pas rechercher de traitement par la suite si leurs symptômes réapparaissent.

11.3 RENSEIGNEMENTS PERSONNELS ET CONFIDENTIALITÉ

Dans son rapport d'octobre intitulé *Recommandations en vue d'une réforme*, le Comité a examiné la nécessité de protéger la confidentialité des dossiers de santé électroniques et leur utilisation dans la recherche. La protection des renseignements personnels inquiète tout au tant, voire davantage, dans le contexte de la santé mentale, de la maladie mentale et de la toxicomanie.

Dans leur étude, DuVal et Rolleston affirment que la protection des renseignements personnels repose en grande partie sur l'hypothèse cruciale voulant que la société

> **Cette mesure est toujours utilisée en situation de crise. […] La personne est considérée un danger pour elle-même ou pour les autres. […] Il n'est pas question de divulguer l'information sur une base régulière. Il y a un motif pour l'action, qui est d'assister une personne le mieux possible et de la façon la mieux informée. Ce n'est pas ce qu'on appelle partager de l'information à grande échelle.**
> ***[Nancy Hall, Mental conseillère en santé mentale (16:27-28]***

dans son ensemble, et toutes les personnes qui la composent, profitent de la sauvegarde du droit inaliénable de chacun de contrôler l'utilisation des renseignements personnels qui le concernent.[531]

De plus, la relation fiduciaire entre le prestataire de soins de santé et le patient repose sur la confiance et sur le principe fondamental de la confidentialité, comme en témoignent la plupart des codes de déontologie des professions. Les témoignages que nous avons entendus nous obligent cependant à nous demander si nos cadres juridiques et politiques actuels en matière de protection des renseignements personnels – qui, en règle générale, servent bien les personnes mentalement compétentes – peuvent aller à l'encontre des intérêts de ceux qui, à cause de la nature et de l'omniprésence d'une maladie mentale ou de la toxicomanie, deviennent partiellement ou entièrement dépendants de multiples fournisseurs de soins tout au long du continuum de soins. M. John Arnett, chef du Département de santé psychologique à la Faculté de médecine de l'Université du Manitoba, a déclaré :

> *En tant que clinicien, je ne peux passer au bureau à côté pour demander à un collègue, qui a reçu un patient que je vais voir, ce qu'il sait qui pourrait m'aider à mieux évaluer ce patient. L'intention de la loi est noble, il n'y a pas de doute, mais elle impose réellement des limites qui ont un impact négatif sur les soins aux patients. En grande partie, les soins au patient consistent à avoir accès à ses antécédents et à ses renseignements personnels. La loi impose des limites importantes.*[532]

Les inquiétudes relatives à l'observation stricte des règles en matière de protection des renseignements personnels et de confidentialité s'appliquent également aux familles des personnes atteintes de maladie mentale ou de toxicomanie. Sans la permission du patient, que ce dernier peut être incapable d'accorder en cas de maladie mentale ou de toxicomanie, un médecin ne peut pas communiquer les renseignements personnels le concernant à ses parents, ses frères et sœurs ou ses enfants, qui doivent en prendre soin. Murray, dont le fils schizophrène paranoïde a été tué par un autobus après s'être évadé de l'hôpital, a posé la question :

> *Pourquoi les médecins ne sont pas autorisés à informer les membres de la famille quand on sait que le soutien de la famille est bénéfique pour le malade? Le malade prend des médicaments parce que son mode de pensée est perturbé et, pourtant, les médecins estiment que c'est à lui de décider d'informer la famille alors qu'il ne peut pas prendre de décision raisonnable ou réfléchie.*[533]

Bronwyn Shoush, commissaire, Institut de la santé des Autochtones, Instituts de recherche en santé du Canada, a ajouté :

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531 Gordon DuVal et Francis Rolleston (2004), p. 16.
532 John Arnett (16:26).
533 Murray (9:18).

> *Je voudrais mettre l'accent sur un domaine du droit qui, à mon avis, a eu un impact négatif sur le domaine de la santé mentale et sur les stigmates en particulier. Je fais référence à la législation relative à la protection de la vie privée. La législation est perçue, du moins par les communautés autochtones, mais aussi d'ailleurs selon moi, comme un désavantage. Elle préconise la confidentialité quand il est question de santé et les gens ont l'impression qu'elle les empêche de discuter des problèmes et de se voir comme des membres normaux de l'humanité. Les intervenants qui pourraient offrir un soutien ne peuvent le faire en temps opportun.*[534]

Ces idées ont été reprises dans le mémoire du Christ the King Family Support Group, de Winnipeg, qui a déclaré que « les exigences en matière de confidentialité sont invoquées pour justifier le manque d'information suffisante au prestataire de soins membre de la famille sur la nature et la gravité de la maladie ». Ce groupe a ajouté que l'on refuse de donner aux membres de la famille la moindre information sur les médicaments à prendre, les questions de sécurité et les plans en matière de soins et de traitements, au moment de donner congé de l'hôpital; que les préoccupations exprimées par les membres de la famille sont arbitrairement rejetées et non consignées dans les dossiers des patients; et que les familles ne sont pas suffisamment soutenues dans leur tentative de composer avec les conséquences dévastatrices d'une maladie mentale profonde et prolongée.[535] Il faut souligner cependant qu'en cas de danger clair, grave et imminent, un médecin peut avoir l'obligation prépondérante, en droit, de rompre la confiance de son patient afin de prévenir des tierces parties, dans le but de protéger la sécurité publique.

11.4 POPULATIONS SPÉCIALES

11.4.1 Les enfants et les adolescents

Dans les chapitres 2 et 9, le Comité a traité d'un certain nombre questions relatives à l'accès aux services de santé mentale et soutiens connexes pour les enfants et les adolescents. En plus de ces questions, le traitement de la santé mentale chez les enfants et les adolescents soulève des difficultés particulières d'ordre éthique relativement à leur vulnérabilité, à leur capacité de prendre des décisions et à l'utilisation et la divulgation de renseignements confidentiels.

Quand ils soignent des enfants et des adolescents, les professionnels de la santé mentale doivent être bien conscients de la vulnérabilité accrue de leurs patients en raison de l'âge et de la présence potentielle de troubles mentaux concomitants et d'antécédents de perturbation sociale. La capacité de consentir aux interventions de traitement et de le faire volontairement, déjà compromise par la maladie mentale, est encore plus difficile à faire pour les jeunes. La participation des parents et d'autres membres de la famille au traitement peut être extrêmement utile, mais les fournisseurs des soins doivent être pleinement conscients de la possibilité de méfiance, de dysfonctionnement familial ou de pressions indues découlant

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534 Bronwyn Shoush (16:12).

535 Carlyn Mackey, Aurise Kondziela et Dorothy Weldon (Christ the King Family Support Group - Winnipeg), mémoire au Comité, 24 octobre 2003.

de la culpabilité ou de l'attitude exagérément protectrice des parents à l'égard de l'enfant. Des questions de confidentialité complexes peuvent se poser lorsqu'il faut déterminer si des circonstances particulières justifient la divulgation de renseignements sur le patient aux parents et/ou à d'autres organismes gouvernementaux ou de services sociaux.

11.4.2 Les personnes âgées

Des questions morales spécifiques se posent dans la prestation de services de santé mentale aux personnes âgées. Par exemple, de nombreux patients dans une unité de malades gériatriques n'ont aucune capacité de prendre des décisions et n'ont aucun proche parent ou peuvent être en conflits avec les membres de leur famille. Les malades gériatriques sont parfois sans abris et les membres de leur famille peuvent être difficiles à trouver ou refuser de collaborer ou répugnent pour le moins de jouer un rôle important. On estime que seulement 10 à 20 p. 100 de ces patients bénéficient de la participation active de leur famille et que les autres n'ont aucun proche qui s'intéresse à leur cas. Beaucoup de malades âgés « passent au travers des mailles du filet », en ce sens que l'hôpital général est mal équipé pour s'occuper de personnes souffrant de maladie mentale, tandis que l'hôpital psychiatrique n'a pas toujours les ressources voulues pour dispenser les soins médicaux généraux voulus aux patients. Ainsi, les malades gériatriques souffrant de troubles mentaux sont souvent mal soignés.

Dans un hôpital psychiatrique, il arrive que le personnel interprète mal les symptômes de la douleur manifestés par des patients psychiatriques âgés, tandis que dans un hôpital général, il arrive souvent que les patients âgés qui souffrent de maladie mentale et se plaignent de douleur ne soient pas pris au sérieux. Le manque d'expérience du soulagement de la douleur à l'aide de médicaments opiacés et les inquiétudes que suscite l'interaction entre ces médicaments, les antipsychotiques et d'autres médicaments utilisés en soins psychiatriques peuvent entraîner une mauvaise gestion de la douleur pour ce groupe de patients. Selon certains témoignages, on trouverait dans ce groupe des exemples de patients mal soignés, notamment quant au soulagement de la douleur, et l'on signale aussi des cas de personnes qui, après avoir attendu longtemps, sont renvoyées à l'hôpital psychiatrique, où les soins peuvent être inadéquats.

À cause de la stigmatisation, les patients et leurs familles ont souvent de la difficulté à obtenir des soins. Parfois, le personnel n'a pas reçu d'instruction claire quant aux soins psychiatriques à donner aux patients qui touchent au terme de leur vie. Souvent, les soignants ne savent pas trop quand ils doivent appliquer un traitement énergique, par opposition à un traitement visant essentiellement à soulager la douleur. Les infirmières psychiatriques ont généralement moins d'expérience dans l'utilisation des analgésiques et des opiacés et hésitent parfois à les utiliser avec assurance.

11.4.3 Les patients de médecine légale

Dans son mémoire, le Centre for Practical Ethics de l'Université York a déclaré :

> *Beaucoup de détenus sont en prison parce qu'ils souffrent d'instabilité affective ou de troubles mentaux, et une fois incarcérés, ils ne reçoivent pas les traitements voulus à moins de constituer une menace pour les*

autres ou pour eux-mêmes. En outre, leur état ne peut manquer de se détériorer dans un environnement aussi inapproprié.[536]

DuVal et Rolleston dégagent deux types de dilemmes moraux dans le contexte de la médecine psychiatrique légale.[537] Premièrement, les troubles mentaux, en particulier lorsqu'ils ne sont pas traités, se manifestent parfois par un comportement qui serait autrement considéré criminel. Dans certains cas, les personnes souffrant de troubles mentaux qui sont accusées d'infraction peuvent être jugées inaptes à subir leur procès ou non criminellement responsables, mais il arrive souvent que la police et les tribunaux doivent choisir entre ordonner que les personnes souffrant de troubles mentaux se fassent soigner et les renvoyer vers le système de justice pénale. L'absence d'une formation efficace chez les policiers et les autres agents de l'appareil de justice pénale peut contribuer au mauvais aiguillage de personnes dans cette situation qui sont ainsi privées des ressources de santé mentale dont elles ont besoin. Bien des gens estiment que trop de personnes atteintes de maladie mentale ou de toxicomanie se retrouvent dans nos prisons et nos pénitenciers alors qu'il serait préférable, autant pour eux-mêmes que pour la société dans son ensemble, qu'ils soient soignés plutôt qu'incarcérés.

Mettons-nous en prison des personnes parce qu'elles ont une maladie mentale plutôt que des personnes entièrement capables qui commettent des crimes? Beaucoup de personnes ayant une maladie mentale sont incarcérées. En cour, bon nombre d'entre elles ne comprennent pas ce qui leur arrive.

[Armée du Salut, mémoire au Comité, octobre 2003, p. 3]

Le deuxième problème tient au fait que les professionnels de la santé mentale qui pratiquent en médecine légale ont un problème de dédoublement. Qu'il s'agisse d'évaluer une personne accusée d'une infraction, de prodiguer un traitement suivi à une personne dans le cadre d'une commission d'examen provinciale ou de présenter des preuves devant des organismes administratifs ou devant un tribunal, ces professionnels de la santé ont deux types d'obligations distinctes qui entrent parfois en conflit. D'une part, ils doivent s'acquitter des obligations incontestables du fournisseur de soins, fonctions qu'ils doivent remplir dans le meilleur intérêt des patients en évitant de leur faire du tort. D'autre part, ils ont l'obligation envers la société, tout à fait légitime, d'offrir leur avis et leur jugement d'une manière franche et objective devant des tribunaux, des commissions d'examen et d'autres organismes pénaux et administratifs pour se prononcer sur l'état mental, le diagnostic et le pronostic d'une personne qui reçoit leurs soins. Indubitablement, ces conseils et ces témoignages qui priorisent les avantages pour la société ne sont parfois pas dans le meilleur intérêt de leurs patients/clients.

Ces obligations contradictoires peuvent être difficiles à gérer et mettent en cause la relation clinique à plus d'un égard. De plus, même si le fait de donner une opinion d'expert correspond à un rôle social important, la qualité des soins peut en être diminuée si le fournisseur de soins en santé mentale travaillant dans le contexte judiciaire ne peut assurer la confidentialité au patient, ce qui a clairement des conséquences sur la confiance entre les deux. Le spécialiste peut également être obligé d'utiliser, peut-être au détriment du patient,

536 Centre for Practical Ethics, Université York, mémoire au Comité, 2004.
537 Gordon DuVal et Francis Rolleston (2004), pp. 19.

de l'information qu'il a recueillie dans le cadre de sa relation clinique, dans un contexte de poursuite judiciaire ou administrative.

11.5 RÉPERCUSSION DES PROGRÈS DE LA GÉNÉTIQUE ET DES NEUROSCIENCES SUR L'ÉTHIQUE

11.5.1 La génétique et la santé mentale

D'après DuVal et Rolleston, la stigmatisation sociale importante liée à la maladie mentale donne lieu à des inquiétudes particulières en ce qui concerne la confidentialité de l'information génétique et les effets traumatisants que leur divulgation peut produire sur un groupe de la population qui est déjà vulnérable. La recherche génétique et les diagnostics en ce qui concerne les comportements peuvent être particulièrement inquiétants. Les recherches récentes indiquent que la découverte de liens entre des gènes particuliers et des troubles psychiatriques particuliers est peu probable. Il semble plus probable que les composantes génétiques de certains phénotypes sont le fait d'interactions complexes entre des facteurs génétiques et des facteurs environnementaux.[538] Il faut pourtant mettre en place des balises pour protéger les renseignements personnels confidentiels, en particulier ceux qui, par eux-mêmes ou s'ils sont reliés à d'autres renseignements, révèlent ou peuvent révéler un trouble mental ou de comportement.

DuVal et Rolleston ont expliqué que tenter d'informer adéquatement les patients ou leurs représentants en parlant de susceptibilité ou de risque pose des problèmes difficiles aux personnes atteintes de maladies mentales ou souffrant de toxicomanie. Les personnes atteintes, tout comme les personnes en santé, devront faire face à leur propre vulnérabilité à certains troubles. La stigmatisation sociale et les questions de protection de la vie privée compliquent cette problématique, d'autant plus qu'il peut y avoir un décalage entre les bienfaits thérapeutiques et la fiabilité des diagnostics. La génétique de la maladie mentale soulève également des questions difficiles pour les familles et les parents du patient ou du sujet d'une recherche, parce que les profils d'héritabilité sont souvent difficiles à prévoir. Il faut trouver l'équilibre entre le droit de l'individu de ne pas savoir et la nécessité de l'informer d'une prédisposition génétique. La façon de parvenir à cet équilibre dépendra en partie de la probabilité que le trouble se développe, du moment où il pourrait se manifester et des possibilités de prendre des mesures pour prévenir ou réduire les effets d'une future maladie mentale.[539]

Le Comité a également été renseigné sur l'« essentialisme génétique » – l'idée selon laquelle on peut définir ou caractériser les personnes uniquement à partir de leur matériel génétique. Cette idée soulève des préoccupations particulières en ce qui concerne les personnes atteintes de maladie mentale ou souffrant de toxicomanie. Les personnes ayant des défauts génétiques en viennent à penser qu'elles sont « anormales ». Cela touche également les décisions en matière de procréation, et la disponibilité des dépistages prénataux peut soulever des problèmes eugéniques pour certaines personnes. Étant donné que la stigmatisation sociale liée à la maladie mentale demeure importante, il peut y avoir de

538 *Ibid.*, p. 20-21.
539 *Ibid.* p. 21.

grandes inquiétudes par rapport à la discrimination pour les assurances, l'embauche, l'éducation, le logement et d'autres questions.[540] Une bonne gestion de l'information en génétique prévisionnelle n'est généralement pas une tâche facile et elle l'est encore moins quand l'information porte sur des personnes atteintes de maladie mentale et sur qui pèse déjà la stigmatisation sociale.

11.5.2 Les neurosciences et la santé mentale

Les progrès récents de la technologie et des connaissances théoriques en neurosciences soulèvent de délicats problèmes éthiques et mettent en cause les notions traditionnelles du libre arbitre, de la responsabilité et du soi. Les réponses de la société à ces questions auront des effets profonds, peut-être aussi importants sinon plus que les questions relatives aux nouvelles technologies génétiques.

Nous ne présentons ici qu'un survol des problèmes soulevés par DuVal et Rolleston. Notre compréhension accrue des fonctions et des processus cérébraux de même que les progrès de la technologie de l'imagerie permettront de plus en plus d'identifier et de mesurer des comportements, des traits de personnalité et d'autres manifestations cérébrales et de les corréler avec des modifications observables du cerveau. L'emploi, l'éducation, les assurances, les actes judiciaires, l'immigration, le contre-terrorisme et d'autres activités sociales de même que les relations sociales sont autant d'aspects susceptibles d'être touchés par la capacité d'identifier et peut-être de prévoir des dispositions à certains comportements négatifs ou positifs, comme la violence, la dépendance, la malhonnêteté, le stress, la sympathie, la coopération, etc.[541]

Les progrès en neurosciences permettront également de réaliser des améliorations cognitives et comportementales. DuVal et Rolleston soutiennent que, outre les questions éthiques importantes qu'elles suscitent, les technologies de l'amélioration de comportement, de la personnalité et des capacités cognitives soulèvent des préoccupations de justice sociale bien réelles en supposant que de telles technologies d'amélioration coûtent cher et ne soient disponibles qu'aux biens nantis de la société. De plus, alors la structure et les mécanismes cérébraux des manifestations cognitives sont de plus en plus décrits, la société devra peut-être revoir les notions universelles du libre arbitre, de la responsabilité et de l'imputabilité – la neuroscience de l'éthique. Dans un contexte judiciaire, par exemple, si un comportement criminel ou tout autre comportement aberrant s'explique par des différences dans la structure du cerveau ou dans une fonction cérébrale, sur quoi faudra-t-il se baser pour établir la responsabilité criminelle et déterminer la sanction à imposer?[542]

11.6 ÉTHIQUE DE LA RECHERCHE SUR LA SANTÉ MENTALE ET LA TOXICOMANIE

Comme nous l'avons vu dans le chapitre précédent, la recherche clinique sur les maladies mentales et la toxicomanie s'est accélérée au cours des deux dernières décennies et a permis d'importants progrès dans les traitements. Une grande partie de cette importante recherche

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540 *Ibid.*
541 *Ibid.*
542 *Ibid.*

exige cependant la participation de sujets de recherche souffrant eux-mêmes de troubles mentaux.

Dans leur étude, DuVal et Rolleston insistent sur le fait que l'histoire de la recherche psychiatrique abonde de cas où les secteurs public et privé ont abusé de la vulnérabilité de malades mentaux, d'handicapés neurologiques et de personnes handicapés par un retard de développement qui ont servi de sujets de recherche. Un exemple particulièrement notoire est celui des essais cliniques parrainés par la CIA qui ont été faits dans les années 50 et au début des années 60 au Allan Memorial Institute à l'Université McGill sur des malades mentaux auxquels on avait administré des hallucinogènes à leur insu. L'histoire de ce traitement inacceptable de participants vulnérables a joué un rôle très important dans le mouvement exigeant une surveillance et une réglementation accrues de la recherche sur des sujets humains et constitue un antécédent important pour prendre en considération l'étude de l'éthique dans la recherche sur les maladies mentales et la toxicomanie.[543]

Les progrès de la recherche sur la santé mentale offrent de grands espoirs à ceux qui souffrent ou souffriront de maladies mentales et, dans quelques cas, aux sujets de recherche eux-mêmes. Bien que les personnes atteintes de maladie mentale puissent être vulnérables de diverses façons, les politiques et la réglementation en matière de recherche qui sont principalement axées sur leur vulnérabilité et leur déficience risquent de favoriser et peut-être exacerber la stigmatisation déjà ressentie par ce groupe. En revanche, il peut être injuste qu'une loi trop restrictive exclue les malades mentaux qui pourraient bénéficier d'une participation à la recherche.[544]

La recherche sur des personnes atteintes de maladie mentale ou souffrant de toxicomanie nécessite des précautions particulières. Bien que tous les sujets participant à la recherche clinique soient vulnérables jusqu'à un certain degré, la vulnérabilité des personnes participant à la recherche clinique sur les maladies mentales et la toxicomanie exige une attention particulière. Par contre, la majorité des personnes atteintes de maladie mentale fonctionne raisonnablement bien. En conséquence, il se pourrait qu'une trop grande attention portée à une réglementation spéciale en matière de recherche impliquant la majorité des personnes atteintes de maladie mentale soit inutile et stigmatisante. Toutefois, il ne fait aucun doute que les principes éthiques doivent être appliqués en portant attention aux vulnérabilités spécifiques aux personnes atteintes de maladie mentale.[545]

Un cadre éthique approprié pour l'éthique de la recherche psychiatrique établit un équilibre entre les protections rigoureuses des sujets humains et la reconnaissance des avantages sociaux et individuels considérables issus d'une recherche scientifique bien conçue et moralement acceptable. Les préoccupations éthiques qui sont pertinentes pour la recherche sur la santé mentale et qui font ressortir la nécessité d'une sensibilité et d'un discernement particuliers comprennent la capacité de prendre des décisions et les problèmes de conception de la recherche.

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543 Gordon DuVal et Francis Rolleston (2004), p. 22.

544 *Ibid.*

545 *Ibid.* p. 23.

11.6.1 La capacité de prendre une décision

Cet aspect a été examiné de manière assez approfondie au début du présent chapitre. La capacité de prendre la décision de donner un consentement valable est une condition essentielle de la recherche avec des sujets humains. La vigilance qui s'impose pour évaluer la capacité de prendre des décisions et déterminer qui constitue la personne pertinente pour prendre ces décisions dans le contexte des soins cliniques, s'impose encore plus dans le contexte d'une recherche où la participation à l'étude n'est peut-être pas directement avantageuse pour le patient visé. Ainsi, l'article 21 du *Code civil du Québec* exige que, pour qu'un adulte inapte à consentir consente à participer à une recherche, le consentement d'autrui doit être donné non pas seulement par un membre de la famille (comme dans le contexte des soins requis par l'état de santé), mais plutôt le mandataire, le tuteur ou le curateur désigné officiellement. En raison de cette protection accrue cependant, les adultes inaptes qui n'ont pas de représentants désignés légalement ne peuvent pas participer à des recherches au Québec, sauf dans de rares situations d'urgence.

11.6.2 Les problèmes de la conception de la recherche

Certaines études ont subi un examen éthique particulier lors de leur utilisation en recherche psychiatrique à cause de leur risque inhérent et aussi de la population des sujets atteints de maladie mentale. Trois modèles d'étude ont soulevé des problèmes d'éthique particuliers.

- Essais contrôlés avec placebo : L'essai contrôlé avec placebo aléatoire est généralement accepté comme le concept « étalon-or » expérimental pour comparer l'efficacité et l'innocuité des médicaments. La comparaison au moyen du placebo est considérée par les organismes de réglementation comme la meilleure preuve d'efficacité et d'innocuité de nouveaux médicaments. Cependant, l'essai contrôlé avec placebo a été vivement critiqué quand un traitement efficace établi existe pour la maladie étudiée. Ces critiques ont surtout visé la recherche en psychiatrie, où le sujet participant au volet placebo ne reçoit pas le traitement efficace établi, dont il a grandement besoin, souffre des éventuels effets de l'élimination du médicament et peut retomber dans un état de maladie mentale pendant la durée de l'étude.
- Essais avec élimination d'un médicament : Un essai avec élimination est une étude dans laquelle les chercheurs interrompent la médication d'un sujet de manière à étudier ce dernier en l'absence de médicament ou pour entreprendre une nouvelle thérapie, souvent une thérapie expérimentale. Cela étant, la médication existante est interrompue, habituellement après réduction graduelle de la posologie. Typiquement, la période d'élimination doit être suffisamment longue pour que le médicament soit complètement éliminé de l'organisme du sujet, de manière que les effets résiduels de la médication qui a été retirée ne viennent pas fausser les résultats de l'étude ou entraîner des interactions médicamenteuses indésirables. Selon la conception particulière de l'essai ou la médication en cause, l'élimination peut durer indéfiniment ou jusqu'à la réapparition des symptômes aigus.
- Essais avec provocation : Une étude de « provocation » est un essai dans lequel un agent psychopharmaceutique ou une provocation psychologique est administré à des sujets de recherche dans des conditions contrôlées pour mesurer ou observer la réaction comportementale ou une réaction neurobiologique à l'aide de l'imagerie

> cérébrale, ou les deux. En psychiatrie, ces études se sont révélées extrêmement précieuses pour tester des hypothèses et caractériser une variété de processus neurochimiques et pathophysiologiques. La recherche de ce type peut mener à des prévisions améliorées de la réponse à un traitement et à de nouvelles thérapies efficaces.[546]

Pour que des essais cliniques contrôlés avec placebo soient considérés éthiquement acceptables, certaines conditions doivent être remplies. À l'heure actuelle au Canada, les cadres réglementaires et les lignes directrices nationales sur l'éthique en recherche imposent des conditions différentes. Une grande différence entre la *Directive tripartite harmonisée pour les bonnes pratiques cliniques* (E-10) de la *Conférence internationale d'harmonisation (CIH)* et l'*Énoncé de politique des trois Conseils sur l'éthique de la recherche avec des êtres humains* est que l'Énoncé de politique permet actuellement les essais contrôlés avec placebo uniquement lorsqu'il n'existe pas de traitement normalisé ou que le sujet est réfractaire au traitement normalisé ou refuse ce traitement, tandis que la Directive tripartite permet les essais contrôlés même lorsqu'il existe un traitement efficace établi, à condition qu'il n'y ait aucun risque de décès ou d'effet secondaire permanent. Les IRSC et Santé Canada ont lancé une grande initiative en vue d'examiner les principes scientifiques, éthiques et juridiques qui sous-tendent ces documents et d'harmoniser les politiques nationales relatives à l'utilisation pertinente des placebos dans les essais contrôlés avec placebo aléatoire. Le Comité encourage fortement les IRSC et Santé Canada à poursuivre ces efforts concertés visant à adopter et mettre en œuvre une politique nationale harmonisée.

Pour des raisons pratiques, les essais avec provocation exigent souvent que les sujets soient gardés dans l'ignorance ou, au mieux, soient partiellement informés des détails de l'étude. Même lorsque la capacité de prendre des décisions n'est pas compromise, cette exigence a clairement des conséquences éthiques en ce qui concerne le consentement informé.

Malgré une histoire qui comprend des abus graves, la recherche sur les maladies mentales et la toxicomanie est cruciale, en premier lieu pour ceux qui souffrent de troubles mentaux et pour ceux qui en souffriront. La recherche psychiatrique clinique soulève des dilemmes très sérieux du point de vue éthique. La vulnérabilité particulière qui entoure les maladies mentales et la toxicomanie exige que l'on fasse très attention dans la conception, l'examen et la conduite de la recherche.

11.7 OBSERVATIONS DU COMITÉ

Comme nous venons de le voir, le Comité est fermement convaincu qu'un trop grand nombre des problèmes éthiques que soulèvent les maladies mentales et la toxicomanie découlent de la stigmatisation liée à ces troubles. Lutter contre la stigmatisation et la discrimination par des campagnes de sensibilisation s'adressant aux professionnels de la santé, aux chercheurs et au grand public constituerait un pas important pour résoudre ces problèmes éthiques.

Les principes éthiques qui sous-tendent la prestation de services de santé mentale et de traitement de la toxicomanie – en particulier ceux de la bienfaisance et de la justice – doivent

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546 *Ibid.*, p. 24-25.

être examinés avec soin et de manière opportune. Il est évident que les maladies mentales et la toxicomanie accusent un retard par rapport aux autres maladies et troubles pris en charge par le système de santé canadien. Elles sont technologiquement moins avancées et dangereusement plus fragmentées, et l'élaboration de lignes directrices fondées sur des données empiriques afin de faire connaître les pratiques exemplaires n'est pas aussi avancée que dans d'autres spécialités. Pour ces raisons, le Comité est fermement convaincu que la prévention et le traitement des maladies mentales et de la toxicomanie devraient être coordonnés dans l'ensemble du vaste éventail de services potentiels offerts dans le cadre des soins de santé ou en marge de ces soins, et devraient être prioritaires dans les décisions relatives à l'affectation de ressources limitées.

Le Comité reconnaît que la capacité de prendre des décisions peut être affaiblie par la maladie mentale et la toxicomanie et que les troubles mentaux ne réduisent pas tous cette capacité. En outre, la capacité de prise de décisions de ceux qui souffrent d'une maladie mentale ou de toxicomanie peut être réduite à divers degrés et à divers moments. Étant donné la structure des lois actuelles qui tirent des conclusions assez rigides sur la présence ou l'absence de capacité de prise de décision, et la rigidité relative qui empêche de modifier ou d'adapter les régimes de protection, il faudrait un débat plus complet sur la manière de tenir compte de la capacité partielle et variable de prendre des décisions pour soi-même. Il faut trouver un bon équilibre entre le respect du droit individuel à l'autonomie et la nécessité de protéger des personnes vulnérables lorsque leur capacité de prendre des décisions est affaiblie à cause d'une maladie mentale ou de la toxicomanie.

En ce qui concerne la protection des renseignements personnels et la confidentialité, le Comité est bien conscient que toute érosion des mesures de protection dans ces domaines peut avoir de graves conséquences sur la confiance que les patients placent dans ceux qui leur dispensent des soins. Toutefois, comme nous l'avons indiqué ci-dessus, les témoins nous ont déclaré que la stricte observance des règles relatives à la protection des renseignements personnels et à la confidentialité va parfois à l'encontre des intérêts des personnes dont la santé mentale est compromise. Il faut reconnaître les difficultés particulières que les témoins nous ont décrites lorsqu'on élabore, interprète et applique les règles en matière de protection des renseignements personnels et de confidentialité, afin que les prestataires de soins de santé et les aidants membres de la famille puissent donner aux patients l'appui dont ils ont parfois besoin.

Comme il l'a indiqué dans le chapitre 10, le Comité appuie fortement la recherche en maladie mentale et en toxicomanie. Cette recherche constitue la pierre angulaire des futurs progrès des traitements et de la prévention. La recherche sur des sujets humains doit être conçue et exécutée dans le respect des normes scientifiques et éthiques les plus élevées et doit protéger la dignité des individus et des familles qui apportent cette contribution précieuse aux progrès scientifiques.

Le Comité reconnaît que les personnes atteintes d'une maladie mentale ou de toxicomanie constituent des sujets de recherche particulièrement vulnérables. Il est donc primordial de protéger les droits et le bien-être de ces personnes qui participent aux recherches, tout en encourageant la recherche éthiquement responsable. Mais les progrès de la recherche ne devraient pas être poursuivis aux dépens des droits de la personne et de la dignité humaine. Par contre, les protections ne devraient pas non plus être si strictes qu'elles accentueraient la

stigmatisation sociale qui découle déjà de la maladie mentale et de la toxicomanie et pourraient exclure cette population vulnérable de recherches cruciales susceptibles d'améliorer les connaissances scientifiques sur son état et même d'être bénéfiques sur le plan individuel.

Il est évident qu'il faut effectuer de la recherche interdisciplinaire pour résoudre correctement un grand nombre des délicats problèmes éthiques, juridiques et socioculturels que posent les maladies mentales et la toxicomanie. Le Comité a été informé de la nécessité d'effectuer ces recherches de manière exhaustive et fondamentale. Dans une lettre au Comité, le Dr Julio Arboleda-Florez, professeur et chef du Département de psychiatrie, Université Queen's, a indiqué qu'il y a un besoin pressant d'intensifier les recherches en éthique de la santé mentale et en éthique de la recherche afin de trouver des solutions efficaces à des problèmes tels que ceux dont il a été question dans le présent chapitre :

> *Il ne se fait pas beaucoup de recherches appliquées au Canada ou ailleurs; on ne peut pas parler non plus de capacité d'organisation ou de capacité financière. […] La recherche appliquée qui vérifierait la perception dans la société des concepts éthiques et leur concrétisation, leur portée transculturelle et leurs conséquences en termes de dissonances d'une culture à l'autre, leur acceptation dans la population, leur signification sociale, leur facilité d'application ou même leur utilité, fait cruellement défaut, de sorte que ce domaine de recherche est en passe de s'enliser.*[547]

Nous croyons que le Canada pourrait jouer un important rôle de leadership à cet égard, à l'échelle nationale et internationale.

Enfin, le Comité convient avec les experts qu'il faut examiner avec soin les préoccupations sérieuses et complexes soulevées dans le contexte de la recherche en neurosciences et en génétique afin de mieux comprendre les valeurs et principes qui sous-tendent ces technologies et d'autres technologies de la médecine moderne dont l'évolution et les progrès sont très rapides.

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547 Dr Julio Arboleda-Florez, mémoire au Comité, 5 novembre 2003.

CONCLUSION

Le présent rapport est le premier document complet sur les questions de santé mentale, de maladie mentale et de toxicomanie au Canada. Il représente, pour la première fois, une analyse historique, un cocktail unique de survol du problème, de constat de la situation et d'évaluation de la prestation des services de santé mentale et de traitement de la toxicomanie. En décrivant les problèmes auxquels sont confrontées les personnes souffrant de maladie mentale ou de toxicomanie, il jette les bases nécessaires pour mieux appréhender les besoins en santé mentale des Canadiens et des Canadiennes.

Ce rapport est fondé sur le témoignage de nombreux experts de même que sur un examen de la documentation pertinente. Il se veut un document de référence utile pour toute personne qui voudrait participer à la phase d'étude sur la santé mentale, la maladie mentale et la toxicomanie que le Comité entamera au printemps 2005.

À l'occasion de cette prochaine étape, le Comité tiendra de vastes audiences publiques, partout au pays, afin de recueillir le point de vue des Canadiens et des Canadiennes sur la façon de réformer et de restructurer la prestation des services de santé mentale et de traitement de la toxicomanie. Nous espérons que notre rapport final, qui sera publié après ces audiences en novembre 2005, servira de catalyseur à un débat informé sur la santé mentale, la maladie mentale et la toxicomanie.

ANNEXE A:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
TROISIÈME SESSION DE LA 37E LÉGISLATURE
(2 FÉVRIER AU 23 MAI 2004)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	David Loïse Murray Ronald	26 février 2003	9
	J. Michael Grass, président sortant, Groupe de mise en oeuvre en santé mentale du district de Champlain	5 juin 2003	17
	Nancy Hall, conseillère en santé mentale	8 mai 2003	16
	Thomas Stephens, expert-conseil	20 mars 2003	11
Académie canadienne d'épidémiologie psychiatrique	Dr Alain Lesage, président sortant	19 mars 2003	11
Académie canadienne de psychiatrie et de droit	Dre Dominique Bourget, présidente	5 juin 2003	17
Association canadienne de la santé mentale de l'Ontario	Patti Bregman, directrice des programmes	12 juin 2003	18
Association des infirmières et infirmiers psychiatriques du Canada	Margaret Synyshyn, présidente	29 mai 2003	16
Centre hospitalier pour enfants de l'est de l'Ontario	Dr Simon Davidson, Chef, Section de psychiatrie de l'enfant et de l'adolescent	1er mai 2003	13
Centre hospitalier universitaire Mère-enfant Sainte-Justine	Dre Joanne Renaud, pédopsychiatre; chercheuse boursière, Instituts de recherche en santé au Canada	30 avril 2003	13

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Centre de toxicomanie et de santé mentale	Jennifer Chambers, coordonnatrice du Conseil d'habitation	14 mai 2003	15
	Rena Scheffer, directrice, Services d'informations et d'éducation du public	28 mai 2003	16
CN Centre for Occupational Health and Safety	Kevin Kelloway, directeur	12 juin 2003	18
Coalition canadienne pour la santé mentale des personnes âgées	Dr David K. Conn, coprésident; president, Académie canadienne de psychiatrie gériatrique	4 juin 2003	17
Colombie-Britannique, Province de la	Patrick Storey, président, Conseil consultative du minister sur la santé mentale	14 mai 2003	15
	Heather Stuart, professeure agrégée, Santé communautaire et épidémiologie		
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, président et directeur général, Les Consultants Warren Sheppell	12 juin 2003	18
Hamilton Health Sciences Centre	Venera Bruto, psychologue	4 juin 2003	17
Hôpital Douglas	Eric Latimer, économiste de la santé	6 mai 2003	14
	Dr James Farquhar, psychiatre		
	Dre Mimi Israël, chef, Département de psychiatrie; professeure agrégée, Université McGill		
	Myra Piat, chercheuse		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Hôpital Douglas	Amparo Garcia, chef clinico-administratif, Division des Services ultraspécialisés pour adultes	6 mai 2003	14
	Manon Desjardins, chef clinico-administratif, Division des Services sectorisés pour adultes		
	Jacques Hendlisz, directeur général		
	Robyne Kershaw-Bellmare, directrice des soins infirmiers		
Hôpital Louis-H. Lafontaine	Jean-Jacques Leclerc, directeur, Services de réadaptation et d'hébergement dans la communauté	6 mai 2003	14
	Dr Pierre Lalonde, directeur, Clinique des jeunes adultes		
Hôpital St. Michaels	Dr Paul Links, titulaire de la chaire Arthur Sommer Rothenberg d'études sur le suicide	19 mars 2003	11
Institut canadien d'information sur la santé	Dr John S. Millar, vice-président, Recherche et analyse	20 mars 2003	11
	Carolyn Pullen, expert conseil		
	John Roch, gestionnaire principale, Protection de la vie privée, Secrétariat de la protection de la vie privée		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Instituts de recherche en santé du Canada	Dr Rémi Quirion, directeur scientifique, Institut des neurosciences, de la santé mentale et des toxicomanies	6 mai 2003	14
	Bronwyn Shoush, commissaire, Institut de la santé des Autochtones	28 mai 2003	16
	Jean-Yves Savoie, président, Conseil consultatif, Institut de la santé publique et des populations	12 juin 2003	18
Santé Canada	Tom Lips, conseiller principal, Santé mentale, Division de la santé des collectivités, Direction générale de la santé de la population et de la santé publique	19 mars 2003	11
	Pam Assad, directrice déléguée, Division de l'enfance et de l'adolescence, Centre de développement de la santé humaine, Direction générale de la santé de la population et de la santé publique	30 avril 2003	13
Société Alzheimer du Canada	Steve Rudin, directeur exécutif	4 juin 2003	7
Société canadienne de pédiatrie	Dre Diane Sacks, présidente élue	1er mai 2003	13
	Marie-Adèle Davis, directrice exécutive		
Statistique Canada	Lorna Bailie, directrice adjointe, Division des statistiques sur la santé	20 mars 2003	11
St.Joseph's Health Care London	Maggie Gibson, psychologue	4 juin 2003	17

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Calgary	Dr Donald Addington, professeur et chef, Département de psychiatrie	29 mai 2003	16
Université de la Colombie-Britannique *(par vidéoconférence)*	Dre Charlotte Waddell, professeur adjointe, Unité d'évaluation de la santé mentale et des consultations communautaires, Département de psychiatrie, Faculté de médecine	1er mai 2003	13
Université Laval	Dr Michel Maziade, directeur, Département de spychiatrie, Faculté de médecine	6 mai 2003	14
Université du Manitoba	John Arnett, chef, Département de santé psychologique clinique, Faculté de médecine	28 mai 2003	16
	Robert McIlwraith, professeur et directeur, Programme de psychologie en milieu rural et nordique	29 mai 2003	
Université McGill	Dr Howard Steiger, professeur, Départment de psychiatrie; directeur, Clinique des troubles alimentaires, Hôpital Douglas	1er mai 2003	13
Université de Montréal	Laurent Mottron, chercheur, Département de psychiatrie, Faculté de médecine	6 mai 2003	14

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Montréal	Dr Richard Tremblay, titulaire, chaire de recherche du Canada sur le développement des enfants, professeur de pédiatrie, psychiatrie et psychologie, directeur, Centre d'excellence pour le développement des jeunes enfants	6 mai 2003	14
	Dr Jean Wilkins, professeur titulaire et pédiatre, Département de pédiatrie, Faculté de médecine		
	Dre Renée Roy, professeure adjointe de clinique, Département de psychiatrie, Faculté de médecine		
Université d'Ottawa	Tim D. Aubry, professeur associé; co-directeur , Centre de recherché sur les services communautaires	5 juin 2003	17
	Dr Jeffrey Turnbull, directeur, Département de médecine, Faculté de médecine		
Université du Québec à Montréal	Henri Dorvil, professeur, École de travail social	6 mai 2003	14
	Dr Michel Tousignant, professeur et chercheur, Centre de recherche et intervention sur le suicide et l'euthanasie		
Université Queen's	Dr Julio Arboleda-Florèz, professeur et chef du Département de psychiatrie	20 mars 2003	11

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Toronto	Dr Joe Beitchman, professeur et directeur, Division de la psychiatrie de l'enfant; psychiatre en chef, Hospital for Sick Children	30 avril 2003	13
Université de Toronto	Dr David Marsh, directeur des services cliniques, Médecine des toxicomanies, Centre de toxicomanie et de santé mentale	29 mai 2003	16

ANNEXE B:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
DEUXIÈME SESSION DE LA 37E LÉGISLATURE
(30 SEPTEMBRE 2002 – 12 NOVEMBRE 2003)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	Charles Bosdet Pat Caponi Don Chapman,	29 avril 2004	7
Alberta Mental Health Board	Ray Block, directeur général	28 avril 2004	7
	Sandra Harrison, directrice exécutive, Planification, défense des droits et liaison		
Alliance de la Fonction publique du Canada	John Gordon, vice-président executive national	1er avril 2004	5
	James Infantino, agent des pensions et assurances d'invalidité		
Association canadienne des travailleuses et travailleurs sociaux	Stephen Arbuckle, membre, Groupe d'intérêt lié à la santé	31 mars 2004	5
Association canadienne des troubles anxieux	Peter McLean, vice-président	12 mai 2004	9
Association canadienne pour la santé mentale	Penny Marrett, chef de la direction	12 mai 2004	9
Association des infirmières et infirmiers du Canada, la Fédération canadienne des infirmières et infirmiers en santé mentale et l'Association des infirmières et infirmiers psychiatriques du Canada	Nancy Panagabko, présidente, Fédération canadienne des infirmières et infirmiers en santé mentale	31 mars 2004	5
	Annette Osted, membre du Conseil d'administration, Association des infirmières et infirmiers psychiatriques du Canada		
Association médicale canadienne	Dre Gail Beck, secrétaire générale adjointe intérimaire	31 mars 2004	5
	Dr Sunil Patel, président		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Association des psychiatres du Canada	Dr Blake Woodside, président du Conseil d'administration	31 mars 2004	5
Australie, Gouvernement d' *(par vidéoconférence)*	Dermot Casey, secrétaire adjoint, Direction des priorités sanitaires et de la prévention du suicide, ministère de la Santé et de la Vieillesse	20 avril 2004	6
	Jenny Hefford, secrétaire adjointe, Direction de la stratégie contre la drogue, ministère de la Santé et de la Vieillesse		
Bureau du Conseil Privé	Ron Wall, directeur des relations parlementaires, Planification de la législation et des travaux de la Chambre/avocat	1er avril 2004	5
	Ginette Bougie, directrice, Rémunération et classification		
Centre for Suicide Prevention	Diane Yackel, directrice exécutive	21 avril 2004	6
Centre de toxicomanie et de santé mentale	Christine Bois, gestionnaire des priorités provinciales en matière de troubles concourants	5 mai 2004	8
	Wayne Skinner, directeur clinique, Programme de troubles concourants		
	Brian Rush, chercheur, Politique de prévention sociale et de santé		
Chambre des communes	L'honorable Jacques Saada, C.P., député, leader du gouvernement à la Chambre des communes et ministre responsable de la Réforme démocratique	1er avril 2004	5

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Citoyenneté et de l'Immigration, Ministère de la	Patricia Birkett, directrice générale par intérim, Direction générale de l'intégration	22 avril 2004	6
Cognos	Marilyn Smith-grant, spécialiste en ressources humaines	1er avril 2004	5
	Sean Reid, gestionnaire principal, Communication corporatives		
Fédération canadienne des contribuables	Bruce Winchester, directeur de recherche	22 avril 2004	6
Fédération des programmes communautaires de la santé mentale et du traitement des toxicomanies de l'Ontario	David Kelly, directeur exécutif	5 mai 2004	8
Hôpital Douglas	Dr Gustavo Turecki, directeur, Groupe McGill d'études sur le suicide, Université MGill	21 avril 2004	6
Institut des neurosciences, de la santé mentale et des toxicomanies	Richard Brière, directeur adjoint	21 avril 2004	6
Justice, Ministère de la	Manon Lefebvre, conseillère juridique	22 avril 2004	6
Mercer consultation en resources humaines	Bernard Potvin, conseiller principal	22 avril 2004	6
Native Mental Health Association of Canada	Brenda M. Restoule, psychologue et représentante du conseil de l'Ontario	13 mai 2004	9
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	Janice Wilson, directrice générale adjointe, Direction générale de la santé mentale, ministère de la Santé	5 mai 2004	8

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	David Chaplow, directeur et conseiller principal en santé mentale	5 mai 2004	8
	Arawhetu Peretini, gestionnaire, Santé mentale des Maoris		
	Phillipa Gaines, gestionnaire, Développement des systèmes de santé mentale		
Ontario Hospital Association	Dr Paul Garfinkel, président, Groupe de travail sur la santé mentale	31 mars 2004	5
Ressources humaines et Développement des compétences Canada	Bill Cameron, directeur général, Secrétariat national pour les sans-abri	29 avril 2004	7
	Marie-Chantal Girard, gestionnaire de la recherche stratégique, Secrétariat national pour les sans-abri		
Royaume-Uni, Gouvernement du *(par vidéoconférence)*	Anne Richardson, chef de la Direction des politiques en santé mentale, ministère de la Santé	6 mai 2004	8
	Adrian Sieff, chef de la Direction de la législation en matière de santé mentale		
Santé, Ministère de la de la Nouvelle Écosse	Dr James Millar, directeur exécutif, Santé mentale et services aux médecins	28 avril 2004	7
Secrétariat du Conseil du Trésor	Joan Arnold, directrice, Élaboration de la législation, Division des pensions	1er avril 2004	5
Service correctionnel du Canada	Larry Motiuk, directeur général, Recherches	29 avril 2004	7
	Françoise Bouchard, directrice générale, Services de santé		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Services de santé de la Colombie-Britannique, Ministère des	Irene Clarkson, directrice exécutive, Santé mentale et toxicomanie	28 avril 2004	7
Six Nations Mental Health Services	Dre Cornelia Wieman, psychiatre	13 mai 2004	9
Société canadienne de psychologie	John Service, directeur exécutif	31 mars 2004	5
Société canadienne de schizophrénie	John Gray, président élu	12 mai 2004	9
Société pour les troubles de l'humeur du Canada	Phil Upshall, président	12 mai 2004	9
Université McGill *(par videoconférence)*	Dr Laurence Kirmayer, directeur, Division de la psychiatrie sociale et transculturelle, Département de psychiatrie	13 mai 2004	9
Université Simon Fraser *(par vidéoconférence)*	Margaret Jackson, directrice, Institut d'études en politiques de justice pénale	29 avril 2004	7
U.S. Campaign for Mental Health Reform	William Emmet, coordonnateur	1er avril 2004	
U.S. President's New Freedom Commission on Mental Health *(par videoconférence)*	Michael Hogan, président	1er avril 2004	5

ANNEXE C:
LISTE DES INDIVIDUS QUI ONT RÉPONDU À UNE LETTRE DU COMITÉ AU SUJET DES PRIORITÉS POUR LA RÉFORME DANS LE SECTEUR DE LA MALADIE MENTALE

GROUPE CANADIEN DE RECHERCHE

Action cancer Manitoba	Harvey Max Chochinov, MD, PhD, MCRMC, titulaire d'une chaire de recherche du Canada en soins palliatifs, directeur de la Manitoba Palliative Care Research Unit d'Action cancer Manitoba
Hôpital Douglas, Centre de recherche de l'	Ashok Mall, MD, MCRMC, titulaire d'une chaire de recherche du Canada pour l'étude des premiers stades de la psychose, professeur en psychiatrie à l'Université McGill
Université Carleton	Dr Hymie Anisman, titulaire d'une chaire de recherche du Canada en neuroscience, chercheur supérieur attaché à la Fondation ontarienne de santé mentale
Université de l'Alberta	Glen B. Baker, PhD, DSc, professeur et titulaire d'une chaire de recherche du Canada en neurochimie et en développement de médicaments
Université du Manitoba, Faculté de médecine de l'	Brian J. Cox, docteur en psychiatrie, titulaire d'une chaire de recherche du Canada sur les troubles de l'humeur et sur les troubles anxieux, professeur agrégé de psychiatrie
Université McGill	Eric Fombonne, MD, MCRMC (Psych.), titulaire d'une chaire de recherche du Canada en psychiatrie de l'enfance et de l'adolescence, professeur de psychiatrie à l'Université McGill, directeur du Département de pédopsychiatrie de l'Hôpital pour enfants de Montréal

DOYEN D'UNIVERSITÉ

Centre universitaire de santé McGill	Joel Paris, MD, professeur titulaire et directeur du Département de psychiatrie
Hôpital général de Kingston	Samuel K. Ludwin, MBB, Ch., MCRMC, vice-président du développement à la recherche
Université de l'Alberta	Dr L. Beauchamp, doyen de la Faculté d'éducation
Université de l'Ouest de l'Ontario	Dr Carol P. Herbert, doyen de la Faculté de médecine et d'art dentaire
Université de Sherbrooke	Pierre Labossière, ing., PhD, vice-recteur adjoint à la recherche

GROUPE RELATIF À LA MALADIE

CRSNG	Thomas A. Brzustowski, président
La Fondation ontarienne de la santé mentale	Howard Cappell, PhD, c. psych., directeur exécutif
Société canadienne de schizophrénie	Fred Dawe, président

INDUSTRIE

Eli Lilly Canada Inc.	Terry McCool, vice-président des Affaires générales de la société
GlaxoSmith Kline	Geoffrey Mitchinson, vice-président des Affaires publiques
Les compagnies de recherche pharmaceutique du Canada	Murray J. Elston, président
Merck Frosst Canada Ltée	André Marcheterre, président
Roche Pharmaceutiques	Ronnie Miller, président-directeur général

GROUPE D'ÉTHIQUE EN SANTÉ MENTALE

Armée du Salut - Territoire du Canada et des Bermudes	Glen Shepherd, colonel et secrétaire en chef
Centre de recherche de l'Hôpital Douglas de l'Université McGill	Maurice Dongier, professeur en psychiatrie
Centre de toxicomanie et de santé mentale	Paul E. Garfinkel, MD, FRCP, président-directeur général
Hôpital St-Paul	Mark Miller, éthicien
Office régional de la santé de Winnipeg	Linda Hughes, présidente du Comité d'éthique en santé mentale de l'ORSW
St-Joseph's Health Care Centre du Parkwood Hospital de London	Maggie Gibson, PhD, psychologue du Programme des soins aux anciens combattants
Université de l'Alberta	Genevieve Gray, doyenne et professeure de la Faculté en soins infirmiers
Université de l'Alberta, Faculté des sciences infirmières et Centre John Dossetor d'éthique en santé de l'	Wendy Austin, inf. aut., titulaire d'une chaire de recherche du Canada
Université de la Colombie-Britannique	Peter D. McLean, PhD, professeur et directeur de l'Unité des troubles anxieux
Université de l'Ouest de l'Ontario	Nancy Feduk, adjointe exécutive au doyen de la Faculté de médecine et d'art dentaire
Université Queen's	J. Arboleda-Florèz, professeur et chef du Département de psychiatrie
Université York	David Shugarman, directeur

PRÉSIDENT D'UNIVERSITÉ

Institut de recherches en santé mentale de l'Université d'Ottawa	Zul Merali, PhD, président-directeur général
Université de Lethbridge	Lynn Basford, doyenne de la Faculté en sciences de la santé
Université McGill	Heather Munroe-Blum, professeure d'épidémiologie et de biostatistiques

RESPONSABILITÉ GOUVERNEMENTALE

Association canadienne de la santé mentale	Bonnie Pape, directrice des programmes et de la recherche au Bureau national de l'Association canadienne de la santé mentale
Cabinet du vice-recteur à la recherche de l'Université d'Ottawa	Yvonne Lefebvre, PhD, vice-présidente associée à la recherche
Centre de recherche de l'Hôpital Douglas	Rémi Quirion, directeur scientifiques de l'INSMT
Centre universitaire de santé McGill	Juan C. Negrete, MD, MCRMC, professeur de psychiatrie à l'Université McGill, président de la Section des toxicomanies, de l'Association des psychiatres du Canada
Coalition canadienne pour la santé mentale des personnes âgées	David K. Conn, MB, MCRMC, coprésident de l'Académie canadienne de psychiatrie gériatrique, professeur agrégé du Département de psychiatrie de l'Université de Toronto, président de l'Académie canadienne de psychiatrie gériatrique
Coalition canadienne pour la santé mentale des personnes âgées	J. Kenneth Le Clair, MD, MCRMC, coprésident de la Coalition canadienne pour la santé mentale des personnes âgées, professeur et directeur de l'Unité de gériatrie du Département de psychiatrie de l'Université Queen's, directeur clinique du Programme spécialisé de psychiatrie gériatrique
Développement des ressources humaines Canada	Deborah Tunis, directrice générale du Bureau de la condition des personnes handicapées

The Family Council : Empowering Families in Addictions and Mental Health	Betty Miller, coordonnatrice du Family Council
Global Business and Economic Roundtable on Addiction and Mental Health, affiliée au Centre de toxicomanie et de santé mentale	Bill Wilkerson, cofondateur et directeur général
Hôpital d'Ottawa	Paul Roy, MD, MCRMC, professeur adjoint en psychiatrie à l'Université d'Ottawa, directeur du programme « Premier épisode pour les maladies psychotiques » d'Ottawa
Hôpital royal d'Ottawa	J. Paul Fedoroff, MD, professeur agrégé de psychiatrie à l'Université d'Ottawa, directeur de recherche au Service médico-légal de l'Institut de recherche en santé mentale
Institut des neurosciences, de la santé mentale et des toxicomanies du Centre de recherche de l'Hôpital Douglas	Michel Perreault, PhD, chercheur à l'Hôpital Douglas
Instituts de recherche en santé du Canada	Dr. Jeff Reading, PhD, directeur scientifique de l'Institut de la santé des Autochtones
Ministère de la Santé et du Mieux-Être du Nouveau-Brunswick	Ken Ross, sous-ministre adjoint
ONSA : Organisation nationale de la santé autochtone	Judith G. Bartlett, MD, CMFC
Six Nations Mental Health Services	Cornelia Wieman, MD, MCRMC, psychiatre
Sunnybrook & Women's College Health Sciences Centre de l'Université de Toronto	N. Herrmann, médecin, MCRMC
Syncrude	Eric P. Newell, président-directeur général
Unité de l'évaluation de la santé mentale et des consultations communautaires du Département de psychiatrie de l'Université de la Colombie-Britannique	Elliot Goldner, MD, MScS, MCRMC, chef de la Division de la politique et des services de santé mentale

Université Dalhousie, Département de psychologie de l'	Patrick J. McGrath, OC, PhD, MSRC, titulaire de la chaire Killam de psychologie, professeur de pédiatrie et de psychiatrie, titulaire d'une chaire de recherche du Canada, psychologue au IWK Hospital
Université Dalhousie, Faculté de médecine de l'	David Zitner, PhD, directeur en informatique médicale
Université d'Ottawa, École de psychologie de l'	John Hunsley, PhD, c. psych., professeur en psychologie
Université d'Ottawa, Faculté de médecine de	Jacques Bradwejn, MD MCRMC, DABPN, président du Département de psychiatrie
Université McMaster	Docteur Richard P. Swinson, MD, MCRMC, titulaire de la chaire Morgan Firestone de psychiatrie et de neurosciences du comportement à l'Université McMaster, chef du Département de psychiatrie du St. Joseph's Healthcare Centre

SENATE SÉNAT
CANADA

REPORT 2

Mental Health Policies and Programs in Selected Countries

Interim Report of
The Standing Senate Committee On Social Affairs, Science And Technology

The Honourable Michael J.L.Kirby, *Chair*
The Honourable Wilbert Joseph Keon, *Deputy Chair*

November 2004

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ORDER OF REFERENCE

Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

The Honourable Senator Kirby moved, seconded by the Honourable Losier-Cool:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness.

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee; and

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

Paul C. Bélisle

Clerk of the Senate

The following Senators have participated in the study on the state of the health care system of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Michael J. L. Kirby, Chair of the Committee
The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retired)
Douglas Roche (retired)
Eileen Rossiter (retired)
Marilyn Trenholme Counsell

Ex-officio members of the Committee:

The Honourable Senators: Jack Austin P.C. or (William Rompkey) and Noël A. Kinsella or (Terrance Stratton)

Other Senators who have participated from time to time on this study:
The Honourable Senators Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne and Murray.

MENTAL HEALTH, MENTAL POLICIES AND PROGRAMS IN SELECTED COUNTRIES

INTRODUCTION: INTERNATIONAL COMPARISONS

This document is the second in a series of four reports by the Standing Senate Committee on Social Affairs, Science and Technology as part of its study on mental health, mental illness and addiction. The first report, entitled *Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada*, presents an overview of mental illness and addiction policies and services in Canada. This second report draws some lessons for mental health reform in Canada from descriptions of the mental health policies and programs in four selected countries. Together, the first and second reports provide background material that was used in the preparation of *Mental Health, Mental Illness and Addiction: Issues and Options in Canada*, the Committee's third report. The third report outlines the major issues facing the provision of mental health services and addiction treatment in Canada and presents potential policy options to address some of these issues. In the fourth and last report, which will be released in November 2005, the Committee will detail its recommendations for reform.

In the course of its two-year study of the acute care sector in Canada, the Committee recognized the importance in the health policy field of looking beyond the borders of one's own country. In fact, it devoted an entire volume of its six-volume study of Medicare to examining the experience of a variety of countries in order to glean lessons that could be applied in the Canadian context. Given Canada's relative backwardness in developing a national strategy to foster mental health and treat mental illness, it was evident to the Committee that international comparisons could provide a valuable reference point and a source of policy inspiration for the Committee's current investigation.

Due to each country's unique circumstances, there are important limits to the comparability of experience from one country to another. The complexity of health care systems, both in terms of funding arrangements and service delivery mechanisms, as well as their inextricable connections to the history, politics and culture of each nation, mean that it is never possible simply to transpose measures from one jurisdiction to another. The common nature of many of the issues confronting health care policy makers and practitioners throughout the industrialized world means, however, that there is much that can be gained from careful study of both the successes and failures elsewhere in the world.

Moreover, a comparative framework can be extremely useful in highlighting common dilemmas and challenges. It can help suggest questions for further study, point to issues that need to be discussed and offer policy options for action. In this spirit, this volume of the Committee's report is structured around four country studies (Australia, New Zealand,

England and the United States), followed by a chapter that synthesizes some of the key lessons for Canada.

Each of the country studies covers the same basic topics, although the specific details that are examined necessarily vary according to the particular experience of each country and depending on the documentation that was available. The Committee was greatly assisted by the testimony by videoconference of leading experts and policy makers from each of the countries it examined, and wishes to thank them for their help. In conducting this comparison, the Committee did not have the resources to do extensive field research and therefore relied on material that was readily available on the Internet or from the collections of the Library of Parliament.

With regard to substance abuse and addiction, testimony that was heard is referred to wherever possible. However, the Committee recognizes that it would require considerably more research into the policies and programs of each country before it could undertake a meaningful international comparison on this subject.

As best we could tell, there is no existing international comparison of mental health policy and practice available that takes into account the most recent developments in the countries that are studied as the Committee does in the chapters that follow. This part of the Committee's report may therefore also be of help to policy makers elsewhere who are examining the state of their mental health system. The Committee was guided in its choice of countries by recommendations from experts and practitioners, as well as by the need to select countries whose health care systems were broadly comparable to Canada's. The fact that two of the countries have federal systems (Australia and the United States) while two do not (New Zealand and the United Kingdom) provides an additional element of comparison.

CHAPTER 1:
MENTAL HEALTH CARE IN AUSTRALIA[1]

1.1 HISTORY AND OVERVIEW

1.1.1 General Health Care Provision in Australia

Like Canada, Australia has a federal system of government and health care is a shared responsibility between the national (or Commonwealth) government and sub-national governments (six States and two Territories). However, in Australia the Commonwealth government has a stronger role in health care than is the case in Canada. In particular, States and Territories in Australia are more dependent on the Commonwealth government for health care funding than are provincial governments in Canada. As in Canada, local governments (municipalities) in Australia play a relatively small role in health care.

The Commonwealth government is responsible for public policy making at the national level in the fields of public health, research and national health information management. It operates "Medicare", the national, publicly-funded health care insurance plan and regulates the private health care insurance industry. It also finances and regulates residential aged care (nursing homes) and, jointly with States and Territories, it funds and administers some community-based care and home care. Commonwealth funding for health care is derived from general taxation plus a dedicated health care levy of 1.5% on taxable income.

The State and Territory governments have primary responsibility for the management and delivery of publicly insured health services within their jurisdiction. They deliver public acute and psychiatric hospital services and a wide range of community and public health services including school health, dental care, maternal and child health. State and Territory governments are also responsible for the regulation of health care providers as well as for the licensing and approval of private hospitals. Health care funding by States and Territories is derived mostly from grants from the Commonwealth government, as well as from general taxation and user charges.

Medicare in Australia provides universal coverage to all citizens. Public health care insurance is broader in Australia than in Canada as it covers physicians, hospitals, prescription drugs and some community-based care and home care. In contrast to Canada, however, user

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[1] Unless otherwise indicated, the information in this chapter is drawn from the following: Commonwealth Department of Health and Ageing (2002) National Mental Health Report 2002: Seventh Report. Changes in Australia's Mental Health Services under the First Two Years of the Second National Mental Health Plan 1998-2000; Australian Health Ministers, National Mental Health Plan 2003–2008; Thornicroft, G. and V. Betts 2002, International Mid-Term Review of the Second National Mental Health Plan for Australia; Whiteford, Harvey, Ian Thompson and Dermot Casey, "The Australian Mental Health System," International Journal of Law and Psychiatry, Vol. 23, No. 3-4, 2000; Whiteford, Harvey, Bill Buckingham and Ronald Manderscheid, "Australia's National Mental Health Strategy," British Journal of Psychiatry (2002) 180; Groom, Grace, Ian Hickie and Tracey Davenport 'Out of Hospital, Out of Mind!' April 2003; SANE Mental Health Report 2002-03, SANE Australia; The Mental Health Council of Australia, Promoting the mental health of all Australians, a 2001 Federal Election Submission.

charges may be required for publicly insured health services and extra-billing by doctors above the scheduled fee is permitted. More specifically, Australian Medicare is made of three main components:

- The Medical Benefits Scheme (MBS) ensures access to physician services (outside of hospitals). The MBS lists a wide range of physician services and stipulates the fee applicable to each item (the "scheduled fee"), but only reimburses 85% of the doctors' scheduled fee. However, physicians are permitted to charge above the "scheduled fee."
- The Australian Health Care Arrangements (AHCAs) provide the basis for funding by the Commonwealth government to the States and Territories for hospital services. Funding by the Commonwealth government takes the form of annual block grants whose amounts are negotiated in five-year agreements with the States and Territories, who in return agree not to allow user charges for public hospital services.
- The Pharmaceutical Benefits Scheme (PBS), which is based on a national drug formulary, subsidises access to drugs prescribed outside of public hospital, with consumers making a co-payment on each prescription, subject to annual thresholds, which once reached lead to further reductions in the amount each individual pays.

As in Canada, some 70% of health care spending is financed by the public sector (46% by the Commonwealth government and 24% by State and Territory governments) and 30% by the private sector. The Commonwealth government is empowered under the constitution to collect income taxes and finances a greater proportion of Australian health care than does the federal government in Canada. It is the primary public insurer of prescription drugs and physician services and funds some 50% of hospital expenditures.

The states, and to a minor extent local governments, are responsible for the bulk of outlays. About 25% of State and Territory government budgets are allocated to health care and about 69% of those funds go to public hospitals. State government funding for health care comes from two main sources: first, Commonwealth general revenue and specific purpose grants, and second, the state general revenue base. The Commonwealth funds the states through block grants for health, which increasingly are tied to certain conditions, and through untied GST (Goods and Services Tax) payments.

In contrast to Canada, private health care insurance in Australia both complements and competes with Medicare. Private insurers may cover the same benefits as under the public plan and Australians can supplement their Medicare benefits through private health care insurance, but they cannot opt out of the publicly-funded system since they continue to pay their taxes. Private health insurance in Australia is fully community rated, meaning that there is no premium discrimination against people by virtue of age, sex, state of health or potential health risk.

On the delivery side, there are a small number of private for-profit hospitals built and managed by private firms providing public hospital services under arrangements with State/Territory governments. However, most acute care beds and emergency outpatient

clinics are in public hospitals. Private hospitals tend to provide less complex non-emergency care, such as simple elective surgery.

As Mr. Dermot Casey, Assistant Secretary, Health and Priorities and Suicide Prevention, for the Department of Health and Ageing, Government of Australia, told the Committee during his testimony by videoconference:

> *We think the private sector is an integral part of our health care system. The government's policy is such that people have choices in terms of where they receive their health care. […] We are trying to encourage all states and territories to have private facilities available because the government's policy is one system, multiple choice.*

1.1.2 The National Mental Health Strategy

The mental health of the Australian community has been a priority of Australian Commonwealth, State and Territory governments since 1992. Australia has benefited from a consistent political bipartisan approach to mental health reform during this time that has enabled it to set international benchmarks with regard to the design and implementation of national goals with respect to mental health and mental illness.

The National Mental Health Policy was adopted by all Australian states, territories and the Federal government in April 1992. The Policy, implemented through a series of 5-year National Mental Health Plans, became known as the National Mental Health Strategy.

This Strategy represented the first attempt to coordinate nationally the development of public mental health services. As in other Western nations, rapid reduction in psychiatric beds within Australia's public mental health system began during the mid 1960s. As elsewhere, the move to 'deinstitutionalization' in Australia was driven by a combination of new drug treatments, clinical practice developments and the emergence of the human rights movement that advocated the abolition of systems that isolated people with disabilities from the mainstream community.

Estimates suggest that Australia reached a peak of approximately 30,000 psychiatric beds in the early 1960s, a time when the population was about half of its current size.[2] During this period the isolation and custody of people with mental illnesses dominated the treatment culture and many beds were located in rural asylums, far from families and social networks. Overcrowding in these facilities was widespread, with wards built to cater for 25 people often housing up to 100 patients. However, the reduction in size of hospitals that began in the 1960s occurred in a policy environment that did not provide safeguards to ensure that alternative community services were developed to replace the functions of the shrinking institutions.

The National Mental Health Strategy was conceived in part to respond to this legacy created by extensive bed reductions and attempted to set a coherent direction that would guide future reform. The Strategy was agreed to by all Australian Health Ministers in 1992 and

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2 As of July 2004, the population of Australia was estimated to be 19,913,000.

established a collaborative framework between all levels of government to pursue 12 agreed priority areas over a five-year period under the First National Mental Health Plan (1993–1998), including the following:

- Expanding the proportion of acute psychiatric inpatient care provided in general hospitals rather than separate psychiatric hospitals;
- Including integrated mental health services within the mainstream organizational arrangements for general health services;
- Ensuring that each State, Territory and area/region had a plan for the mix of services available to its population;
- Reducing the size of, or closing, existing psychiatric hospitals and at the same time providing sufficient alternative acute hospital, accommodation and community based services;
- Increasing the number and range of community based supported accommodation services and ensuring an adequate range of services to meet consumer needs.

Another impetus for the introduction of the National Mental Health Plan was pressure exerted on the Commonwealth Government by the State and Territories, as Mr. Casey explained to the Committee:

> *It was interesting that the drive for change in Australia really came from the states and territories lobbying the federal government to take a role and become involved in mental health care. […] The argument was put that the federal government is incurring large levels of expenses but has no control upstream in terms of improving our response to mental health. That was in the late 1980s and early 1990s.*

The first plan was followed by The Second National Mental Health Plan, endorsed by all Australian Health Ministers in July 1998. It provided a second five-year (1998–2003) framework for activity at the national and State and Territory levels, building upon the achievements of the National Mental Health Policy and the First National Mental Health Plan. The essence of the Second Plan was to consolidate existing reforms and extend into additional areas of reform with a strong emphasis on population health issues and interventions.

Three additional priority themes emerged from the Second Plan:

- promotion and prevention;
- partnerships in service reform and delivery; and
- quality and effectiveness.

A third plan has recently been adopted. Its provisions will be outlined in the penultimate section of this chapter.

1.1.2.1 Assessment of the National Mental Health Strategy

An assessment conducted by international experts mid-way through the second plan concluded that the National Mental Health Strategy and its First and Second National Mental Health Plans reflected "exemplary mental health policy leadership that have produced significant achievements in mental health at all levels throughout Australia." Among the chief accomplishments highlighted by the international consultants were "the integration of mental health assessments and interventions in mainstream health delivery and the authentic inclusion of consumers and carers in mental health policy development at every level."

According to the international review, Australia, in many ways, "leads the world in mental health promotion, mental illness prevention, early intervention initiatives, and stigma reduction," setting "a standard for other nations in what can and should be done as a national policy initiative" and demonstrating how federal and state governments can agree through policy documents to address difficult social and health concerns. The international review suggested that "no other nation on earth has taken the time to focus its intellectual and political capital to develop such an extensive, measurable plan" and that "the Australian National Mental Health Strategy and the First and Second National Mental Health Plans are international exemplars for mental health policy," having captured the attention and imagination of the world.

Nonetheless, according to the Mental Health Council of Australia, the leading non-governmental advocacy group in mental health in Australia, in 1997 only 38% of people suffering from a mental disorder accessed mental health services. The Council notes that, despite the positive developments associated with the Mental Health Strategy, there remains widespread dissatisfaction with many aspects of mental health services in Australia.

1.2 COSTS AND FUNDING OF MENTAL HEALTH SERVICES

In 1999-2000, total spending on mental health services[3] by third party funders (Commonwealth and State/Territory governments as well as private insurers) was A$2.6 billion,[4] which represented approximately 6.6% of total gross recurrent expenditure on health services. Of this amount, the States/Territories spent A$1.6 billion or 60.8% of the

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3 Estimates of spending given here are drawn from the *National Mental Health Report (2002)* and only cover the provision of 'specialized mental health services'. This excludes a wide range of services needed by people affected by mental illness, such as general hospital and medical services, housing, income security, employment and training and general community support programs. The report notes that international comparisons of Australia's mental health spending as a share of total health expenditure are not reliable because different approaches are used in counting mental health expenditure. For example, some countries include amounts that are specifically excluded in Australian estimates such as drug and alcohol services, intellectual disability services, dementia care or housing and income security payments for mental health consumers.

4 As of 9 August 2004, the Australian dollar was worth just over 94 cents Canadian.

total, the Commonwealth government A$884M or 34.5% of the total, and private health funds A$120M, or 4.7% of the total.

Total recurrent spending on mental health services by the major funding authorities has increased by 44% over the course of the National Mental Health Strategy (1993-2000) when measured in constant 2000 prices. Total expenditure on health services increased by 42% over the same period, meaning that mental health has increased its position in terms of relative spending, but not significantly.

While the percentage of total health spending devoted to mental health services and related activity has remained relatively stable over the course of the National Mental Health Strategy, significant growth in Commonwealth outlays increased its share of total national spending on mental health from 27% in 1992-93 to 35% in 1999-2000. The main driver of this increase, accounting for 68% of increased Commonwealth spending, was growth in the costs of psychiatric drugs provided through the Pharmaceutical Benefits Scheme (PBS). Expenditure on psychiatric drugs has increased by 402% since 1992-93, nearly four times the rate of growth in overall PBS expenditure (105%) over the period.

The Australian Institute of Health and Welfare estimates that mental disorders accounted for approximately 30% of the non-fatal disease burden in 1996 and for 27% of years lost to disability. Lost productivity arising from mental health disorders is estimated to cost A$5 billion per year. People with mental disorders in Australia have five times the average number of workdays lost per year compared to those with physical disorders, and they account for an estimated 70 million work and school days lost each year.

From the inception of the original National Mental Health Policy, an issue of concern was to ensure that savings that resulted from the planned downsizing of stand alone psychiatric hospitals would be redirected back to new service development. All levels of government made a commitment to some form of budget protection so that such savings plus the benefits of additional funds provided under the National Mental Health Strategy would not be negated by a concurrent reduction in State and Territory funding. Specifically, the agreement between governments to protect mental health resources had two components:

- a commitment to maintaining the level of expenditure on mental health services; and
- a commitment to reinvest any resources released from closure or rationalisation of services back into mental health programs.

In this regard, Mr. Casey told the Committee that efforts to protect mental health spending had been successful, to the point that they were no longer needed:

> *In fact, one of fears of the federal government 10 years ago was that if we were to give money for mental health, then the states and territories would simply take it and spend it somewhere else. We had an agreement with them that they would maintain their level of funding if the federal government added to the pie. We actually tracked the dollars and the states and territories had to report to a system of monitoring expenditure.*

> *We do not need that system now, 10 years later, because governments, realizing how important this is at a jurisdictional level, would not use the money for something else because it has become such a political issue in the communities.*

The impact of the changes brought about during the period following the adoption of the Mental Health Strategy was to reduce Australia's reliance on institutional care, to strengthen community care alternatives and begin to address the inadequacies of mental health service systems that had been identified in numerous inquiries over the preceding decade. Over the first five years of the Strategy:

- spending on community services grew by 87% in real terms;
- resources released from institutional downsizing were re-invested in alternative services and provided approximately half of the additional funds used to expand community services.

From 1998-2000 expenditure on separate psychiatric hospitals were reduced by a further 13% so that by 1999-2000, stand alone hospitals accounted for only 23% of total service expenditure (compared to 49% in 1992-93). Moreover, spending on community based services increased by an additional 16% during this period, taking the total increase in expenditure on these services, since the commencement of the Strategy, to 117%. Approximately three quarters of the growth since the commencement of the Strategy has been directed to ambulatory care services,[5] so that by 1999-2000, 49% of total spending on mental health services was directed to community based services compared with 29% at the beginning of the Strategy.

The Seventh *National Mental Health Report* (2002) issued by the Commonwealth Department of Health and Ageing drew the following conclusions from its analysis of mental health spending trends since the commencement of the Strategy:

- The commitments made by all governments to protect mental health resources during a period of rapid change have been met. Total annual government expenditure on mental health has increased by 46% in real terms since 1992-93. Average annual growth in mental health expenditure has continued to increase under the Second National Mental Health Plan.
- Australia now spends $778 million more of public funds on mental health services – or $33 more per person per year – than it did at the commencement of the Strategy. Much of this increase has gone to expanding community services.
- Growth in mental health spending has simply mirrored overall health expenditure trends. Although significant in real terms, the implication is that mental health has maintained its 'share' of the total health dollar but not significantly increased its position.

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[5] Ambulatory care refers to all mental health services dedicated to the assessment, treatment, rehabilitation or care of non admitted inpatients.

- Commonwealth grants to States and Territories under the National Mental Health Strategy represent only 3% of annual State and Territory mental health spending but have acted as a stimulus in generating funding for new services and guiding the overall reform process. The collaborative foundation of the Strategy appears to have been successful in preventing the cost shifting that is the concern of many Commonwealth-State partnership initiatives.

Concerns have nonetheless been expressed by some that despite the success of the National Mental Health Strategy in increasing and redirecting expenditures on mental health services in Australia, there are still too few resources being devoted to the sector. For example, some mental health advocates claim that at 6.6% of total health spending, the level of spending on mental health in Australia remains below that of comparable countries, including New Zealand, the United Kingdom and Canada.

1.3 SERVICE DELIVERY AND ORGANIZATION

Services for people with mental illness in Australia are provided through a range of programs. In the public sector, the typical specialized mental health service delivery model involves services being provided for a defined catchment population, with the service integrated across hospital and community settings. Inpatient services are provided in general hospitals and in separate psychiatric hospitals. Community-based services comprise a range of service types, including clinic-based, mobile follow-up and treatment, and mobile crisis response services. Case management is often used to coordinate services provided in different settings. Housing, disability support, employment, and income security services are funded under other government programs. State and Territory governments continue to play the largest role in specialized mental health service delivery, as they are primarily responsible, either directly or indirectly, for the delivery and management of most services.

Substantial change in both the level and mix of inpatient services have occurred since the implementation of the National Mental Health Strategy. At the commencement of the Strategy in 1992:

- 73% of specialist psychiatric beds were located in stand alone institutions;
- only 29% of mental health resources were directed toward community based care;
- stand alone hospitals consumed half of the total mental health spending by States and Territories;
- and less than 2% of resources were allocated to non government programs aimed at supporting people in the community.

By June 2000, the total number of psychiatric beds available in the public sector had been reduced by 25% (1,991 bed reduction). When the Strategy began, only 55% of acute psychiatric beds were located in general hospitals. This had increased to 73% by the close of the First National Mental Health Plan in 1998. By June 2000, fully 80% of acute psychiatric beds were located in general hospitals as a result of the ongoing reduction in stand alone

acute services and a 13% increase (330 beds) in general hospital acute services. Over the life of the Strategy, the number of acute psychiatric beds located in general hospitals has increased by 51% or 990 beds.

The National Mental Health Strategy does not stipulate an optimum level or mix of inpatient services. Instead, the Strategy recognizes the different histories and circumstances of each jurisdiction and the need for plans to be based on an analysis of local population needs. The final balance of services may therefore differ substantially between the States and Territories. Early National Mental Health Reports noted a convergence between the States and Territories for an acute psychiatric bed provision level of around 20 beds per 100,000 population. Similar consensus on provision of non acute beds has not yet emerged.

1.3.1 Accommodation in the Community, Ambulatory Care and NGOs

The monitoring of community accommodation under the National Strategy has focused mainly on the extent to which each State and Territory has developed alternative community residential services staffed on a 24-hour basis. Units of this type, known variously as 'community care units', or 'psychiatric hostels', were proposed to replace the functions traditionally performed by long stay asylum beds located in psychiatric hospitals. By June 2000, a total of 1,382 24-hour staffed beds were available, a 68% increase above the June 1993 level.

At the national aggregate level, however, the growth in 24-hour staffed residential services (558 beds) is equivalent to only about a quarter of the reduction in long stay beds in psychiatric hospitals (2,285 beds). Development of community residential services has thus been patchy, with substantial variation between jurisdictions, and no consensus has emerged between the States and Territories on planning benchmarks for provision of specialized community residential services. Lack of development of such services by most jurisdictions has been identified as a significant issue in relation to the commitment by all States and Territories to develop a full range of community services to replace the historical functions of the stand alone psychiatric hospitals. In this regard, Mr. Casey told the Committee:

> *Yes, we have had some major reforms in relation to the service system. However, what we have not been able to do very well yet is to provide the employment responses, the housing responses and the social care models that ensure people who are living with a mental illness — and I think that is the term we use now, it is not something that will be cured, necessarily — are able to do so with the maximum social interaction and social participation that in itself will help to keep them stable and will help towards recovery. Medical treatment alone will not be an adequate response for people with mental health problems.*

Ambulatory care services refer to all mental health services dedicated to the assessment, treatment, rehabilitation or care of non admitted inpatients. The category comprises outpatient clinics (hospital and clinic based), mobile assessment and treatment teams, day programs and other services dedicated to the assessment, treatment, rehabilitation and care of people affected by mental illness or psychiatric disability who live in the community. By

1999-2000, the size of the clinical workforce engaged in the delivery of ambulatory mental health care was 90% greater than the pre-Strategy baseline year, equivalent to approximately 3,000 additional workers.

The National Mental Health Strategy also envisaged that a key role would be played by not-for-profit non government organizations (NGOs) in providing support services to consumers and carers whose lives are affected by mental illness. A wide range of services is provided by the sector including home-based outreach to support people living in their own homes, residential rehabilitation units, recreational programs, self help and mutual support groups, carer respite services and system-wide advocacy.

The first National Mental Health Report described funding to non government organizations as limited, and the services needed to support the carers of people with mental disorders as poorly developed at the beginning of the Strategy. Moderate improvement in the funding base occurred over the 1993-98 period with the sector increasing its share of annual mental health expenditure from 2% to 5%. By 1999-2000 this figure had increased to 5.4%.

The role played by non government organizations varies across the jurisdictions, reflecting differences in the way in which services are organized and delivered. Increasingly, in some jurisdictions, services provided by NGO's substitute for those formerly provided by 'government sector' or clinical services. For example, the State of Victoria has expanded its not-for-profit non government sector as a key provider of psychosocial rehabilitation programs, many of which were previously confined to clinical services, as well as funding new types of psychiatric disability support services. National consensus on desirable service models for developing the sector has not emerged under the National Mental Health Strategy.

1.3.2 Human Resources

Australia's current mental health workforce predominantly consists of general practitioners, psychiatrists, mental health nurses, occupational therapists, psychologists, social workers and others. The clinical workforce employed in public sector mental health services is estimated to have increased by 15% over the course of the Strategy, equivalent to approximately 2,100 additional staff. Fifty percent of the growth occurred under the Second National Mental Health Plan.

Accompanying the growth in numbers have been changes in both the settings in which people are employed and the staffing mix. A greater proportion of clinical staff is now working outside of hospitals and providing treatment in a range of community settings. Similarly, clinical workers in 1999-2000 accounted for a higher percentage of the total workforce (79%) than at the beginning of the Strategy (estimated 70%). This change has occurred as services are mainstreamed and moved to a community based focus. Since the commencement of the Strategy:

- Total staffing in inpatient services have decreased by 14% and accounted for 53% of the total staff in 1999-2000 compared with 71% in 1992-93;

- Combined staffing in ambulatory care and residential services has grown by 87% and accounted for 47% of the service delivery workforce in 1999-2000 compared with 29% in 1992-93;
- Medical staff have increased by 27% and made up 11% of the clinical workforce in 1999-2000;
- Allied Health staff – Psychologists, Social Workers and Occupational Therapists and other categories of therapists – have increased by 55%, accounting for 21% of the total in 1999-2000; and
- Nursing staff numbers have increased by 7% and represented 65% of the total 1999-2000 clinical workforce.

At the same time, workforce shortages have been reported by all jurisdictions and are particularly critical in nursing, affecting both the quantity and quality of care. Reports indicate that retention rates are decreasing across all disciplines of the mental health workforce, and the number of new graduates may not be sufficient to meet the burden of mental illness.

Moreover, inequities continue between the States and Territories in the availability of mental health professionals employed in the public sector. In particular, jurisdictions with significant rural areas to service have experienced difficulty in recruiting sufficient numbers of skilled staff. There are few standards to guide States and Territories in planning their workforce requirements and many challenges remain. For example:

- In terms of the nursing workforce, the overall nursing complement appears to be too limited to fill even current posts. The future is even more daunting as nursing is an ageing work force without sufficient new recruits, while the current strategy of the States and Territories appears to be to poach from each other's limited personnel pools.
- The medical psychiatric workforce is poorly distributed and largely sited in the metropolitan areas (86.1% of psychiatrists were located in capital cities, 5.4% in major urban areas, 4.9% in large rural centres, and 3.5% in other rural and remote locations).
- Psychologists are, by international standards, relatively few within State and Territory mental health services, and too often work as generic case managers. Psychologists' expertise is often unnecessarily diluted by their work as case managers at a time when increasing evidence supports the effectiveness of cognitive behavioural interventions for depression, anxiety-related and psychotic disorders.

Mr. Casey indicated to the Committee that the Australian government had introduced measures designed to facilitate the delivery of care to people living with mental illness by primary care physicians. In particular, he described a program introduced by the federal government three years ago that rewards general practitioners financially for spending more time with people with mental health problems. He explained that this program,

> *…gives [general practitioners] access to referral to psychologists as an essential part of the mental health treatment team, and it also improves their education and training and provides them with emergency consultation services so that they do not feel they are left to deal with the problem alone if they engage with their patients' mental health problems. We have been told that if you are a GP and someone comes into your consulting room and you think they have a mental health problem, you keep quiet, because if you open the dialogue, you will still be there 20 or 30 minutes later, and of course, fee for service is the treatment model. We have encouraged them by saying that if it will take 20 minutes, we will pay them extra for taking the time. Currently, about 15 per cent of our GP workforce has enrolled in this program. We have about 3,500 GPs who are now enrolled in this program and recognize themselves as people who can offer slightly more and better mental health care. That is a new program.*

1.3.3 Private Sector Mental Health Services

Strengthening the complementary roles of public and private sector mental health services emerged as a priority under the Second National Mental Health Plan. A range of mental health care services are provided by the private sector including services provided by psychiatrists in private practice funded through the Commonwealth Medicare Benefits Schedule, and hospital and community-based services provided by private hospitals, for which private health insurance funds pay benefits.

Private sector services also include limited services provided in general hospital settings and services provided by general practitioners and by other allied health professionals. Private psychiatric hospitals provide services predominantly by way of inpatient care. This reflects both the history of mental health services in Australia and the predominant way in which health insurance funds pay benefits for mental health care.

The private sector thus plays a key role in overall service delivery. By 1999-2000, the sector:

- provided 21% of total psychiatric beds (rising from 14% in 1992-93 as a result of a growth in the number of private beds combined with the reduction in the number available in the public sector);
- employed an estimated 12% of the national mental health workforce; and
- treated an estimated 50-60% of all people seen by the specialist mental health sector.

In this regard, Mr. Casey explained to the Committee that:

> *Our private sector is very complicated, but it does treat a pretty large proportion of the population, and the overall private sector, psychiatrists, GPs, and the private hospital providers, have all become part of the National Mental Health Strategy. It is not just a public sector strategy.*

There has been substantial growth in the private psychiatric hospital sector over the course of the National Mental Health Strategy. The number of hospital providers has increased by 36%, total inpatient bed capacity has grown by 28% and revenue by 48% between 1992-93 and 1999-2000. Alongside these changes the sector has shifted its overall pattern of care to one of providing a significantly greater proportion of services to its consumers on a same day care basis. Same day admissions have increased from 39% of total admissions in 1992-93 to 69% in 1999-2000. Estimated total revenue in 1999-2000 for private sector psychiatric units was $168.2 million, an increase in constant price terms of 48% since 1992-93.

Although 1.47% of Australians see a private psychiatrist at least once a year, access is uneven due to the concentration of providers in the capital cities, particularly Melbourne, Adelaide and Sydney. Little change in the distribution of services has occurred since the commencement of the National Mental Health Strategy.

1.3.4 Mental Health Service Provision to Indigenous Peoples

Ms. Jenny Hefford, Assistant Secretary, Drug Strategy Branch, Department of Health and Ageing, Government of Australia, told the Committee that Indigenous people have lower health ratings than non-indigenous Australians, and that their average life expectancy is some 20 years lower than for a non-indigenous Australian. She indicated that:

> *Indigenous people fare far worse in our system in terms of all substance use. Prevalence rates for smoking, for example, are far higher among indigenous Australians than among non-indigenous Australians. Substance abuse issues, particularly with alcohol and petrol sniffing, are extreme in some indigenous communities.*

Several reports have noted that the current delivery of mental health services for Indigenous people is not sufficiently tailored to the cultural specificities of these communities. The following have been identified among the reasons for this lack of cultural appropriateness:

- health professionals' lack of knowledge and understanding of Indigenous perspectives and cultures;
- an insufficient appreciation of the different ways in which Indigenous peoples conceptualize and define illness and health;
- a limited understanding of the nature and scope of mental health needs within Indigenous communities;
- a lack of consultation by Governments and medical professionals with Indigenous Australians;
- a lack of education and training for service providers.

Mr. Casey told the Committee that attitudes were evolving and that there was growing recognition that "Indigenous people have a lot to offer us in understanding the relationship between how you experience your world from your psychological and your social

perspective, and what implications that has for how you physically can live your life in terms of a sense of wellness."

1.4 ADDICTIONS AND SUBSTANCE ABUSE

Ms. Hefford told the Committee that "addiction/substance abuse issues are dealt with within our public health area and regarded as public health issues," rather than as mental health issues exclusively. She explained that the Australian approach relied on three pillars: (1) supply reduction, which involves using border controls as well as working to close down clandestine drug laboratories in order to remove the product from the streets; (2) demand reduction, which employs school-based drug education and government-run campaigns; and (3) harm reduction, which encompasses treatment services and diversion programs for young people, designed to keep them out of the criminal justice system.

She further indicated that the acute health care sector, and in particular the hospital sector, has only a very limited role. It provides detox programs and deals with situations such as overdose deaths, where things have gone badly wrong. The primary care sector, for its part, is largely focused on managing opiate dependency. General practitioners prescribe methadone and pharmacists administer methadone-type programs, for the 30,000 Australians currently in methadone programs.

Ms Hefford noted that "as many as 60 per cent or 70 per cent of clients of drug and alcohol treatment services have an underlying or undiagnosed mental health disorder." She concluded that despite still not reaching as many people as they would like, that much had improved in recent years. One of the things she pointed to in particular was the more collaborative approach that now prevailed across sectors and through various levels of government. She told the Committee:

> *We now have a strategy into which the federal government has put $1 billion over the last five or six years, and it involves health, law enforcement, education and customs at a federal, state and local level. We think that we are actually getting better at working through the issues because we have this cross-disciplinary, cross-sector approach. That means, for example, that we have been able to introduce early diversion programs for young people who are identified by the police as in possession of cannabis or small amounts of other drugs, and who are given the opportunity to choose not to have a sentence of any kind recorded but to go into assessment and treatment. Some of those things have been very successful. We have had between 30,000 and 40,000 young people diverted out of the judicial system and into treatment through that sort of process.*

1.5 PROMOTION AND PREVENTION

In general, a variety of mental health promotion and illness prevention initiatives have been pursued in Australia in the course of, and parallel to, the implementation of the National Mental Health Strategy.

Mr. Casey explained to the Committee that the adoption of a broader "whole population approach" to mental health issues led to carrying out large-scale mental health literacy campaigns throughout the community. In particular, in the mid-1990s a major television, cinema and newspaper advertising campaign was undertaken with the sole objective of making people aware there were mental health problems. This was followed by more focused initiatives, including a mental health promotion program for high schools, nearly 70 per cent of whom are now running the program.

As well, a separate, not-for-profit, private company funded by government, was established in October 2000 with the objective of promoting a better understanding of depression. Called "*beyondblue*", it works in partnership with health services, schools, workplaces, universities, media and community organisations, as well as people living with depression, to bring together their expertise around depression. In the annual report for 2002-2003 the Chairman of *beyondblue*, the Hon. Jeff Kennett wrote:

> *In 2000, when* beyondblue *started out, few people were willing to speak in public about depression and their experiences, media coverage was often negative, barriers in insurance and employment were considerable and there was no national voice or advocacy service for those whose lives were affected. Australian general practitioners were not rewarded directly for providing better services and no systems for improving access to non-drug treatments were available. While we still have many challenges in front of us, in 2003 we can report that major advances in all these areas have now been achieved.*

Another initiative that was undertaken was the National Media Strategy, where the government worked directly with the media to promote more positive messages about mental health and suicide prevention. The media strategy operates in journalism schools and universities, where journalists are taught how they should approach these issues when reporting them to the community so as not to stigmatize people living with mental illnesses.

Mr. Casey indicated that these various initiatives had helped improve "mental health literacy in the Australian population by about 10 percentage points since 1996." He also told the Committee that:

> *our hospital contact data and our health service contact data show that there is a greater proportion of the population seeking care than was the case when we did our epidemiology study. We would conclude from that that they are now at least more prepared to seek treatment — and of course there are many effective treatments.*

1.5.1 Suicide Prevention

Australia also has in place a framework for prevention of suicide and self-harm. Called *Living Is For Everyone* (LIFE), it is concerned with suicide in all age groups, with a particular focus on young people and young adults, for whom the loss of life years and potential is so great.

The LIFE Framework has four broad goals:

- Reduce deaths by suicide across all age groups in the Australian population, and reduce suicidal thinking, suicidal behaviour, and the injury and self-harm that result.
- Enhance resilience and resourcefulness, respect, interconnectedness and mental health in young people, families and communities, and reduce the prevalence of risk factors for suicide.
- Increase support available to individuals, families and communities affected by suicide or suicidal behaviours.
- To provide a whole of community approach to suicide prevention and to extend and enhance public understanding of suicide and its causes.

1.6 PROSPECTS FOR FUTURE REFORM

As noted earlier, a new National Mental Health Plan that builds on the work of the two previous plans has been adopted for the period 2003–2008. It acknowledges the complexity of the reform process and notes that while the first ten years of reform have seen an impressive start in terms of policy, there is still much to be achieved in terms of implementation. This conclusion echoes the concerns of advocacy groups who feared that the Mental Health Strategy was in the process of "losing momentum and faltering."[6]

The goal of the National Mental Health Plan 2003–2008 is to consolidate the achievements of the First and Second Plans, address the gaps identified in both, and take the National Mental Health Strategy forward with restated and new directions. The Plan explicitly adopts a population health framework that recognizes that health and illness result from the complex interplay of biological, psychological, social, environmental and economic factors at all levels – individual, family, community, national and global.

A number of key principles that underpin the reform process are enumerated in the plan, including:

- All people in need of mental health care should have access to timely and effective services, irrespective of where they live
- The rights of consumers, and their families and carers, must shape reform
- A recovery orientation should drive service delivery
- Investment in the workforce is essential

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6 SANE Mental Health Report, 2002-03, p. 2.

- Mental health reforms must occur in concert with other developments in the broader health sector
- Mental health reforms require a whole-of-government approach

The new Plan is guided by four priority themes. Outcomes and key directions for achieving these outcomes are identified, although the new Plan does not seek to specify projects to be funded within the new reform agenda. These themes are:

- Promoting mental health and preventing mental health problems and mental illness
- Increasing service responsiveness
- Strengthening quality
- Fostering research, innovation and sustainability

The following are amongst the outcomes that the plan seeks to achieve:

- Increase the extent to which mental health promotion is incorporated into policy and planning, at Commonwealth, State/Territory and local levels
- Increased extent to which mental health services adopt a recovery orientation
- National agreement on the broad levels and mix of services necessary to align current and future supply of and demand for mental health care across the lifespan
- Improved access to acute care, early intervention services, and to a range of community-based care alternatives
- Enhanced care pathways across the spectrum of care
- Reduced service system gaps and increased integration between private and public mental health services
- Improved coordination between the mental health sector and other areas of health
- Increased levels of full and meaningful consumer, family and carer participation in policy and in service planning, delivery and evaluation at all levels with evidence of improvement in quality
- Monitoring of the performance of mental health services regarding emotional and social wellbeing issues, through the collection and sharing of information and data
- Improved supply and distribution of the mental health workforce

1.7 COMMITTEE COMMENTARY

It is clear to the Committee that Canada has a great deal to learn from Australia in the field of mental health and mental illness. In particular, the consistent commitment for over a

decade by both the Commonwealth and State Governments in Australia to planning and monitoring progress through regular reporting has set international benchmarks that Canada is a long way from attaining. As well, the Committee was impressed by the explicit adoption of a population health framework for overall planning.

As a federal state, Australia has also demonstrated the importance of close cooperation between the various levels of government and of the benefits that can be derived by all communities when this collaboration is sustained. In addition, the Committee noted the importance attached by Australian authorities to adapting national targets and goals to regional and local conditions, and to ensuring that the implementation of agreed upon objectives respected the circumstances of various communities across the country. Moreover, the Committee was impressed by the efforts to include consumers and carers in mental health policy development.

The Committee also wishes to highlight two funding related issues. First, the Committee was struck by the success of efforts to 'ring fence' mental health funding as the Commonwealth government increased its proportion of mental health funding and as delivery of services became increasingly community based. According to the witnesses, the essential nature of adequate funding for mental health services has now been sufficiently demonstrated, and the commitment of all levels of government to sustain this funding become sufficiently secure, that it is no longer necessary to retain the formal agreements that were initially established to protect mental health funding.

Second, the Committee was pleased to see the success of the program recently introduced to improve the ability of general practitioners to participate in the treatment of people with mental health disorders. Enhanced training, and in particular adequate financial compensation for the actual time spent with patients presenting symptoms of mental health difficulties, as well as easier referring to mental health specialists, seem to the Committee to be measures that could enable the effective integration of mental health into primary care delivery.

Finally, the Committee took note of the many innovative approaches pioneered in Australia in raising public awareness about mental health issues, in particular the *beyondblue* campaign centred around depression, and believes that a closer study of a number of them is warranted in order to establish whether they could be adapted to the Canadian context.

CHAPTER 2:
MENTAL HEALTH CARE IN NEW ZEALAND[7]

2.1 HISTORY AND OVERVIEW

New Zealand is a small country of two islands in the Southern Pacific Ocean with a population of 4 million in 2004. At least 800 years before the first European settlers, New Zealand was first populated by Maori, of Eastern Polynesian ancestry. The main ethnic groups today include people of European descent, mostly from the United Kingdom and Ireland (75%), Maori (15%), Pacific Island people (6%) and Asian (4%).

The country became a colony of Great Britain with the signing of the Treaty of Waitangi in 1840 between Great Britain and the majority of Maori Tribes. This is one of New Zealand's founding constitutional documents and sets out a partnership with the Maori, acknowledging their need for self-determination, outlining the responsibilities of governments, as well as protecting Maori rights. A resurgence of Maori identity over the last 20 years has made this treaty a major focus of policy-making.

New Zealand has a parliamentary system of government and is an independent state within the British Commonwealth. The government system is unitary, that is, only one House of Representatives with executive authority vested in a Cabinet structure led by a Prime Minister.

The New Zealand health care system is funded mainly through general taxation, supplemented by out-of-pocket payments and private health insurance. In 1999/2000, 75% of health sector finance came from taxation, 15.7% from consumer out-of-pocket payments, and 6.3% from private insurance (although there is almost no coverage for mental illness by private insurers). The public share of health care funding decreased over the last two decades from 88% of the total in 1979/1980 to around 77% in 1994/1995, but has since increased slightly to reach 78% in 2000.

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7 Unless otherwise indicated, the information in this chapter is drawn from the following: Wilson, Janice, "Mental Health Services in New Zealand," *International Journal of Law and Psychiatry*, Vol. 23, No. 3-4, 2000; French, Sian, Andrew Old and Judith Healy *HiT Summary: New Zealand*, European Observatory on Health Care Systems, 2002; Conference Board of Canada, "New Zealand," in *Challenging Health Care System Sustainability: Understanding Health System Performance of Leading Countries*, June 2004; Powell, Gayla, "New Zealand's National Mental Health Strategy: Report on Progress 2000-2001," August 2002; Ministry of Health, New Zealand, *Looking Forward: Strategic Directions for Mental Health Services*, June 1994; Ministry of Health, *New Zealand, Moving Forward: The National Mental Health Plan for More and Better Services*, July 1997; New Zealand Information Service, *Mental Health Data, 1994*, Ministry of Health, New Zealand, 1998; Mental Health Commission, *Blueprint for Mental Health Services in New Zealand: How Things Need to Be*, December, 1998; Ministry of Health, New Zealand, *National Plan 2001-2003 – Project to Counter Stigma and Discrimination Associated with Mental Illness*, June, 2001; Mental Health Commission, *Briefing to the Incoming Minister of Health*, August, 2002; Ministry of Health, New Zealand, *Building on Strengths: A New Approach to Promoting Mental Health in New Zealand/Aotearoa*, December, 2002; Mental Health Commission, *Report on Progress 2001-2002: Towards Implementing the Blueprint for Mental Health Services in New Zealand*, April, 2003; Ministry of Health, New Zealand, *Like Minds, Like Mine – National Plan 2003-2005*, September, 2003.

Patients receive free state hospital outpatient and inpatient services although they must meet some or all of the costs of primary health care and make co-payments for pharmaceuticals (with concession cards available for low-income patients and those with chronic illnesses). New investment and reform of the primary health care system undertaken in 2004 has begun to decrease the level of individual out-of-pocket payments that are required.

The government retains overall responsibility for the health system but delivery is shared between the public, voluntary and for-profit sectors. Independent medical practitioners and specialists provide most ambulatory medical services, public hospitals provide most secondary and tertiary medical care, while the small private hospital sector specializes mainly in elective surgery and long-term care.

New Zealand governments in the 1990s went further than most countries in introducing market model practices into the health sector, including competition and a purchaser/provider split.[8] However, at the end of the decade, the Labour/Alliance government decided that the "internal market" had not delivered significant improvements in effectiveness and efficiency. In 2000, the government returned responsibility to district boards for funding and partly providing health services. It created 21 District Health Boards (DHBs) covering geographically defined populations, which both deliver services themselves and fund other providers to do so. These autonomous authorities are allocated their own resources in a three-year funding package, based on historical provider contracts. They are responsible to the Minister of Health for the health of their district populations, for setting their strategic direction, for appointing their chief executive, and for their own performance. Each board covers at least one large public sector hospital.

New Zealand health services generally are regarded as adequate in supply and of good quality. Although in 2004 the majority of DHBs are meeting their targets, there is a perception that hospitals are under-funded, causing long waits for elective surgery. Since 2001, primary health care is being reorganized with the introduction of Primary Health Organizations. These will be local non-profit organizations funded at least in part using a system of 'capitation,' that is based on the number of patients who are enrolled with each organization. The intention is to reduce the burden of out-of-pocket payments upon patients. To date, full funding, or 'universal coverage,' of primary care services has only been available to targeted groups on the basis of income or chronic illness. Dr. Janice Wilson, Deputy Director General, Mental Health Directorate, at the New Zealand Ministry of Health, told the Committee that the goal of the new primary health care strategy was to "progressively over the next five to 10 years build up that universal payment until it covers about 80 per cent of the population."

2.1.1 Mental Health Strategy

The National Mental Health Strategy was launched by the Government in June 1994 with the publication of *Looking Forward: Strategic Directions for the Mental Health Service.* The Strategy was developed further in a second document released in July 1997, the National Mental

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8 This term refers to the fact that, in the 1990s, several countries in which the same institutions were responsible for both funding and delivering health care services moved to separate these functions with the aim of increasing efficiency and stimulating competition.

Health Plan, *Moving Forward: The National Mental Health Plan for More and Better Services*. Overall, the Strategy articulated two key goals:

1. To decrease the prevalence of mental illness and mental health problems within the community;
2. To increase the health status of and reduce the impact of mental disorders on consumers, their families, caregivers, and the general community.

Dr. Wilson indicated that "the main thrust of the policy at that time was to get a framework around what is called deinstitutionalization." She told the Committee that policy was also partly driven by best practices internationally that pointed to the need to "take a more whole-of-government approach, linking with other sectors such as housing, employment, labour and so on" in order to make mental health services more community-based and integrated with other health services.

In 1996, a Mental Health Commission was established to ensure that the national mental health strategy was implemented. It consists of three Commissioners and its functions are:

- To monitor and report to Government on the performance of the Ministry of Health and the 21 District Health Boards in the implementation of Government's national mental health strategy;
- To work with the sector to promote better understanding by the public of mental health, and to reduce discrimination and prejudice against those with mental illness;
- To work to strengthen the mental health workforce.

The Commission released the *Blueprint for Mental Health Services in New Zealand* in 1998. The Blueprint provided a practical basis for Strategy implementation and has been accepted as government policy. Its objective is to give health boards and providers a clear view of the steps they can take to improve quality, and to provide consumers and families an understanding of what they should expect from a well functioning system. It is animated by a strong focus on recovery for those living with mental illness.

The national strategy now encompasses seven strategic directions, that are summarized briefly below:

> *Strategic Direction 1: Implementing community-based and comprehensive mental health services*. The objective is to offer services that would cover health promotion and mental illness prevention, assessment and early intervention, treatment, rehabilitation, and continuing care.
>
> *Strategic Direction 2: Encouraging Maori involvement in planning, developing and delivering mental health services*. This strategic direction is aimed at improving the mental health of Maori, so that it is at least as good as that of New Zealanders as a whole. The use of mental health services by Maori is considerably higher than by the rest of the population.

Strategic Direction 3: Improving the quality of care. The goal is to overcome some of the obvious gaps in services that were inherited from the past. It is hoped that service standards, quality assurance programmes and performance indicators to monitor effectiveness and efficiency will make sure that the national objectives are being achieved.

Strategic Direction 4: Balancing personal rights with protection of the public. This strategic direction aims to more clearly strike a balance between the mental health consumer's right to live in the community and the public's right for protection.

Strategic Direction 5: Developing a national alcohol and drugs policy. The intent behind this strategic direction is to better integrate existing alcohol and drug services, to use the mix of residential and outpatient treatment options more efficiently, and to provide more systematic care for people who have both an addiction and some form of mental disorder.

Strategic Direction 6: Developing the Mental Health Services Infrastructure. This strategic direction was added in 1997. It covers the "infrastructure" necessary for delivering more and better services – elements such as workforce development, data collection and analysis, and co-ordination between services. These elements had originally been seen as part of *Strategic Direction 3* but subsequently become recognized as important enough and complex enough to warrant a separate strategic direction of their own.

Strategic Direction 7: Strengthening Promotion and Prevention. This too was another strategic direction that was added to the Strategy in 1997 in order to place more emphasis on making progress towards achieving the goal of decreasing the prevalence of mental illness and mental health problems.

The elaboration of the mental health strategy in New Zealand was based on epidemiological evidence that indicated that one in five of the adult population has a diagnosable mental health problem at any one time. Of these, it is believed that about 3% of adults - and about 5% of children and young people under 20 years - have severe mental health disorders. A further 5% of adults have moderate to severe disorders, and 12% have mild to moderate disorders or problems.

The intention of the national strategy was to ensure that there are enough of the right kinds of mental health services to meet the needs of those adults and young people who have severe mental health disorders. The resource guidelines that are contained in the Blueprint provide estimates of the beds and community staff needed per 100,000 population, assuming that 3% of the population need such services. These guidelines were developed primarily for calculating national funding and service development requirements but are also used at a regional level.

The model of service provision that is employed in the *Blueprint* emphasises community service delivery, but also allows for acute inpatient services as well as rehabilitation and long-term hospital care. The guidelines also take into account development of services provided by consumers. The table below shows the national targets that were established by the *Blueprint* in 1998. These are adjusted as the population levels increase.

RESOURCE TARGETS, 1998			
Resource		**National target**	**National current**
Inpatient	Beds or 'care packages'[9]	1,535	1,424
Residential	Beds or 'care packages'	3,243	2,576
Community mental health	FTEs[10]	3,822	1,923
Community support	FTEs	1,284	388
Advisory services and initiatives (consumer and family)	FTEs	246	63
Access to newer anti-psychotic medication	People	8,500	3,547
Detoxification	Beds or 'care packages'	113	96
Residential alcohol and drug	Beds or 'care packages'	378	376
Community alcohol and drug FTEs	FTEs	614	262
Methadone treatments	Places	5,666	3,030
Mental illness prevention FTEs	FTEs	378	0

2.2 COSTS AND FUNDING OF MENTAL HEALTH SERVICES

Dr. David Chaplow, Director of Mental Health and Chief Adviser, Government of New Zealand, told the Committee that "having a costed plan with analysis of the gap between what existed and what we needed was a very powerful advocacy tool" in negotiations with the treasury in order to secure additional funding for mental health. Since the adoption of the mental health strategy, funding for mental health has indeed increased. Between

9 The 'Blueprint' indicates that while the most common measure for these services resources is 'beds', "a shift to the provision of 'care packages' is needed" (p. 41) but does not specify how these are to be defined with regard to each service.

10 Or "Full-Time Equivalent" position.

1993/1994 and 2001/2002, public funding for mental health services in New Zealand increased from $270 million to $725 million per annum. This represents an increase of approximately 127% after adjusting for inflation, and Dr. Wilson indicated that "we have had a commitment from the current government to continue the funding stream at this rate until at least 2007 because we have not yet completed all of the reform agenda."

Nonetheless, in general, the Mental Health Commission has noted that the starting point for recent increases in funding levels was a poorly resourced base. In its view, acceptable levels of service delivery in mental health have still not been met and there is still some way to go towards meeting the goals set by the Blueprint. According to Dr. Wilson,

> *They set targets and we have implemented about 75 per cent [to 2004]. Some parts of the country are closer to 60 per cent and some are almost fully implemented at close to 100. We have regional variation, depending on population growth and other factors.*

The Table below presents estimates made by the Commission in its 2002 Briefing to the incoming Minister of Health.

PERCENTAGE OF BLUEPRINT FUNDING TARGETS MET AS OF 2002	
Service Area	**Approximate level of funding at July 2002 to *Blueprint* guidelines**
Hospital Inpatient	89%
Community Clinical	69%
Community Non-Clinical	44–59%
Community Drug & Alcohol	74%
Methadone Services	65%
Child & Youth Community	63%

Consistent with the trend to more community-based services, 69% of mental health services funding (excluding pharmaceuticals and public health services) in 2001/2002 was for community services. This is up from 67% in the previous year and includes 57.4% of the District Health Board provider funding and almost all NGO funding. The proportion of mental health funding that is spent on services provided by non-government organisations (NGOs) has remained relatively stable over the last three years.

Despite the increases in funding, the Mental Health Commission continues to express concerns both over the level of funding and the commitment on the part of DHBs to actually spend the money that has been allocated to mental health. An additional and recurring concern has been that the impact of increased funding on levels of services has

been constrained by workforce shortages. This has meant that even where funding has been made available, many positions have gone unfilled.

The Commission has therefore reiterated its recommendations that:

- A sustainable funding path be identified for mental health services development, consistent with the directions of the national mental health strategy, implementation of the Blueprint, and the capacity of the sector to develop.
- Funding for mental health services targeted to the 3% of the population most severely affected by mental illness be protected by a clear and robust ring-fence.

2.3 SERVICE DELIVERY AND ORGANIZATION

The overriding goal of New Zealand's *Blueprint* for mental health is to ensure that 3% of the population has access to mental health services. For the whole of New Zealand, reported access to mental health services was approximately 1.7% of the population in 2001/2002. This was up slightly from 1.6% the previous year. However, during this time, data was not being collected from all NGOs, which means that the figures may under-represent the number of people being seen by services.

As elsewhere, the move away from dedicated psychiatric institutions has been occurring in New Zealand over the past quarter century. Although there is some variation around the country, most of the mental health services are community based and include services provided by mobile 24-hour crisis services, and in general hospital acute wards. By 2000, all acute psychiatric wards (with one exception) had been integrated into general hospitals and just about all of the 10 dedicated psychiatric institutions had closed completely, with a few retaining only forensic or other specialized services.

Despite this reorganization, Dr. Chaplow pointed out that,

> *…at no time have we diminished the total number of beds... We have spread those places in a variety of configurations, so that some are still configured in hospital units and some are in community placements.*

Thus, there are some hospital-based rehabilitation wards and a growing range of supported accommodation and vocational training options, as well as day programs and drop-in centers, often consumer-run. Most adults receiving mental health services have a clinical case manager and/or a community support worker.

The most recent *Report on Progress* issued by the Mental Health Commission highlights the following statistics for the year 2001-2002:

- The number of people admitted to inpatient services in New Zealand is small compared with the total receiving mental health services. During the six months to 30 June 2002, 0.14% of the total population (5,546 people) received inpatient

hospital care, compared with 1.7% receiving care of any kind from mental health services (63,271).

- During 2001/2002 there was no progress in the development of more general non-residential, adult community clinical services. The number of funded clinical staff positions in these services was 85% of the *Blueprint* guidelines compared to 87% in June 2001.
- Non-clinical community based services include home-based support, employment and education support, day activities and living skills, peer support and family support services. These services are provided primarily by support workers, nurse aides and cultural support workers working for NGOs in a therapeutic/support role. Resource levels in community non-clinical support services, have increased from 59% the previous year to 65% of the *Blueprint* guidelines.
- For the country as a whole, all general adult community residential beds slipped from 93% of the *Blueprint* guidelines in 2000/2001 to 83% in 2001/2002. Much of this reduction is due to a large NGO changing from providing residential services to providing community care in service users' homes, and thus does not reflect a reduction in capacity.

In New Zealand, as elsewhere, general practitioners are a first port of call for accessing mental health services. However, there are many in the community (particularly among the Maori and Pacific people communities), who do not use general practitioner services, and thus do not have access to the pathways into mental health care early enough.

The impact of user charges for primary health services on access to mental health services is also an issue. It has been recognized that these charges can be a barrier to the use of primary health services and therefore can encourage people with mild or moderate illness to try to access specialized mental health services (which may not have the same user charges) when they could be treated more appropriately by their primary medical services. Indeed there is even the concern that user charges may stop people going to any service at all. As noted earlier, efforts are underway to reorganize primary care delivery on a capitation model that could help reduce the impact of user charges.

2.3.1 Services to Maori

Ms. Arawhetu Peretini, Manager of Maori Mental Health, Government of New Zealand, explained to the Committee that:

> *The majority of [the Maori population] live in urban settings. They have no reservations. They tend to be fairly integrated into mainstream society. The majority exist probably in one city in particular in the northern part of the island, which is mostly urban. There has been, over the last 10 years, a call for many Maori to return to their tribal lands, or which about 90 per cent are rural based. However, the call has not occurred for many because most work in the urban settings.*

A leading expert, Professor Mason Durie, has suggested that "mental health problems are now the number one health concern for Maori." He notes as well that, "psychiatric admissions, alcohol and drug disorders, suicides and attempted suicides are increasing at a time when other health problems such as heart disease are decreasing."[11] Maori have many needs which are not being met by mental health services. Although accurate and up-to-date information on the prevalence of mental illness for Maori is not available, it is known that there are disproportionate numbers of Maori in crisis, acute inpatient, and forensic services. As Ms. Peretini noted,

> *Some of the problems have resulted from the fact that a lot of indigenous Maori within this country tend to appear at services at acute stages of mental illness.*

In addition, Maori have substantially higher rates of re-admission than non-Maori; these rates have risen steadily in recent years and are continuing to rise. Maori are also greatly over-represented in alcohol and drug services; alcohol and drug abuse and psychosis are the main reasons for Maori being admitted to a psychiatric ward or hospital.

Between 1 January and 30 June 2002, approximately 10,500 Maori were reported as being seen by mental health services, that is 1.9% of all Maori. Maori access mainstream mental health services as well as services specifically targeted to their needs. While acknowledging that there "are still gaps in a knowledge base about things such as admission and re-admission rates," Ms. Peretini told the Committee that:

> *We do know that some of the 21 services — because we did a survey three years ago now — are actually responsive to the needs of the Maori, by just incorporating a cultural assessment component as part of the clinical assessment. There were very few at that stage. Of nine district health boards, only seven had even considered policies around meeting the needs of indigenous people being admitted to the mainstream services. Of those seven, only three had cultural assessment tools that were well developed enough to be useful.*

Since 1998 there has been a significant increase in Maori providers and availability of services specifically for Maori. There have also been a number of initiatives to increase the number of skilled Maori in the mental health workforce. Ms Peretini elaborated on this point:

> *Two years ago, the Ministry of Health, as part of our workforce development strategy, commissioned the development and establishment of a Maori-focused workforce development organization. Almost a year ago, that organization undertook a series of surveys on our workforce. Rather than going into the detail, I will say is that we do not have a large*

[11] Quoted in the *Blueprint*, p. 56.

> *workforce. We currently have probably about five psychiatrists in training.*
>
> *… there have been educational quotas for certain themes in this country. They have existed for at least the past 20 years. We also have had some key leaders in Maori health who have become psychiatrists.*

The Maori Mental Health National Strategic Framework, was released in April 2002 after extensive consultation. The framework has the following five-year goals:

- to provide comprehensive clinical, cultural and support services to at least 3% of Maori, focused on those who have the greatest mental health needs
- to ensure that active participation by Maori in the planning and delivery of mental health services reflects Maori models of health and Maori measures of mental health outcomes
- to ensure that 50% of Maori adults seeking wellness will have a choice of mainstream or specialized Maori community mental health service
- to increase the number of Maori mental health workers, including clinicians, by 50% over 1998 levels

Dr. Chaplow indicated that New Zealand was "in an interim stage," during which "indigenous psychiatrists will have to be augmented or supplemented by others." However, he also affirmed that "one of the significant advances is that now Maori people own their services and own the challenge."

Dr. Wilson explained the importance of this development:

> *One of the key things about mental illness is that it affects the way that you think about yourself — your spiritual and cultural beliefs. People relate much better to people of their own culture. If you are the person with the illness, the relationship you have with your care provider — your doctor or nurse — is probably the most crucial thing to getting well and gaining recovery. If that person is able to understand your cultural belief system, then the chances of a successful outcome are better.*

2.3.2 Human Resources

Numerous commissions and reports have called attention to workforce development as an important part of resolving the existing problems that affect mental health service delivery in New Zealand. It is generally recognized that the current mental health workforce, although having increased significantly due to the national strategy development, still falls short of what is required by mental health consumers. For example, New Zealand has a shortage of psychiatrists when compared with other similar western countries. Dr. Chaplow told the committee that "in terms of world health statistics, such as the suggestion that there should

be one psychiatrist for 10,000 people per population, we only have one psychiatrist per 15,000 people here." But he insisted that:

> *The issue is how you utilize psychiatrists as part of the team. Also, psychiatrists tend to cluster near universities or schools. That is what happens. You often have an imbalance between urban and rural access to good psychiatry.*

Dr. Wilson further noted that human resource shortages were widespread:

> *In respect of the workforce overall, of course we are short throughout the system. It is not just psychiatrists. We have shortages of nurses, psychologists and all the other professionals. That is why we have a major workforce initiative that includes looking at how we recruit as well as retain.*

Reports from 2000/2001 also suggested that unfilled community positions for which funding was available were at about 6 or 7% of the total. Another challenge is in the recruitment and retention of the workforce outside the main centres, where the implications of the need to provide 24 hour coverage, along with the lack of peer support, and professional isolation create difficult working conditions.

The National Mental Health Workforce Development Coordinating Committee was established early in 1998 to co-ordinate workforce development throughout the sector and develop and implement a definitive framework on which to build the national regulation of mental health workforce development, and the allocation of resources for it. The Committee is led by providers and represents key stakeholders in the sector. However, there is still no comprehensive mental health workforce development plan.

Dr. Wilson also recounted that in recent years new types of mental health workers have been trained.

> *We have a new workforce, called community mental health support workers, that has been training over the last five years probably. They work predominantly in the NGO sector but they also work in the public mainstream sector. They are trained to support patients or consumers with mental illness, either in their homes or in formal residential settings in the community, or to help them work through the system. They would be the person who would go with them to the income support agency, to the employment agency, to help them battle the societal barriers.*

These community mental health workers receive formal qualifications set under the National Qualifications Framework. There are now about 2,000 new workers who have been granted a certificate in community mental health support work.

2.4 PROMOTION AND PREVENTION

In December 2002, following a two year period of consultation with over 200 individuals and organizations, the Ministry of Health issued the document *Building on Strengths* that outlines a national approach for mental health promotion for a five year period. *Building on Strengths* seeks to promote the mental wellbeing of New Zealanders and to reduce inequalities in mental wellbeing by improving the social, economic, cultural, political and physical environments in the country.

New Zealand's mental health promotion strategy recognises the need for co-operation between health and other sectors, including local government, other government departments and Maori, Pacific and other community groups and calls for the health sector to take a leadership and co-ordination role around mental health promotion.

Building on Strengths aims to achieve three things:

1. To enable individuals and communities to take action on their own behalf.
2. To outline planned priority actions for the Ministry of Health for mental health promotion.
3. To provide guidance to health sector providers and other sectors on what they can do to contribute to positive mental health and wellbeing for New Zealanders.

The strategy outlined in *Building on Strengths* has three specific goals:

- To reduce inequalities relating to mental health experienced by some groups.
- To create environments that are supportive of positive mental health.
- To improve individual and community resiliency skills.

To achieve these goals, five priority actions are detailed. They are to:

1. Reorient health services to reduce inequalities between socioeconomic groups.
2. Strengthen community action in mental health promotion activity.
3. Create safe and supportive environments within actions that create cohesive cities, communities, workplaces, schools, homes.
4. Develop personal skills by emphasising mental health protective factors such as resiliency, social support and life skill development.
5. Build healthy public policy through improved research and evaluation to identify and address mental health promotion needs.

The Ministry of Health currently spends several million dollars each year on mental health promotion, and *Building on Strengths* has been developed to provide a national framework for the continued allocation of these funds. It is not anticipated that any additional funding will be allocated to the campaign.

2.4.1 Project to Counter Stigma and Discrimination Associated with Mental Illness

A project to counter the stigma and discrimination associated with mental illness, called "Like Minds, Like Mine" was established as a five-year project in 1996, and was subsequently funded as an ongoing undertaking by government. Since its inception, activities sponsored by "Like Minds, Like Mine" have developed public awareness about aspects of mental illness, with an emphasis on the stigma faced by people with experience of mental illness. As a result, the project can now point to significant and quantifiable changes in attitudes among most sectors of the population.

Dr. Wilson helped the Committee understand the basis for this progress:

> *First, it is quite important to understand at the very beginning of this initiative or program, a significant amount of base research was undertaken. There was research done on attitudes in the community and on how people might respond to such an awareness raising. That went alongside our community development approach.*
>
> *Then [the] first national campaign was run and the research that followed indicated a surprising change in attitudes. There seemed to be increased understanding the common mental disorders such depression, anxiety disorders, alcohol addiction and so on.*

The most recent plan (for 2003-2005) therefore began a shift in emphasis towards reducing discrimination, now that it was felt that good progress had been made on the groundwork of awareness raising. The project plan has incorporated a specific human rights model which it has allied to a social model of disability, on the grounds that such a model has strong relevance to the discrimination faced by people with experience of mental illness.

The overall aims of the project are to:

- Enable all people with experience of mental illness to gain equality and respect and to enjoy the same rights as others.
- Change public and private sector policy to value and include all people with experience of mental illness.
- Create greater understanding, acceptance and support for all people with experience of mental illness.

Its more specific objectives include:

- Engaging the leadership and participation of individuals and groups of people with experience of mental illness.

- Advocating for non-discriminatory policies and practices within organizations that are responsible for housing, education, employment, income and access to goods and services, and within organizations that are responsible for mental health services.
- Using mass media, community education and other means to improve the social inclusion of people with experience of mental illness.
- Developing specific approaches by Maori, in recognition of their status under the Treaty of Waitangi, to address the discrimination faced by Maori with experience of mental illness.

Dr. Wilson indicated that the first iteration of the campaign had been "based on famous New Zealanders who were willing to talk publicly about their problems with depression and anxiety disorders," but that "the current campaign has moved away from the famous people to ordinary people who have also suffered significant illnesses such as manic-depressive or bipolar disorder, schizophrenia and so on. It focuses on them, their families and lives."

2.5 PROSPECTS FOR FUTURE REFORM

Dr. Wilson informed the Committee that work was currently underway on a second national mental health plan and that a draft would soon be taken to cabinet before engaging in wide consultations with the community. She hoped that this plan would be finalized and accepted by government before the end of 2004.

As well, in April 2004, the Mental Health Commission published an issues paper in order to gather feedback on how best to maintain and consolidate progress already made in providing mental health care in New Zealand and ensure that the *Blueprint* is able to keep up with changes and provide a relevant platform for the future. Ways forward may include:

- better application of the *Blueprint;*
- modifications to the *Blueprint* that make it easier to apply;
- substantive amendment of the *Blueprint;* or
- changes to funding, planning, contracting and service delivery practices.

The *Blueprint* was developed in 1997 and 1998, and so is now more than five years old. The issues paper notes that over that period there has been substantial change in the health sector and New Zealand society. The following are some of the factors it listed as requiring attention in updating the *Blueprint*:

- Structural changes – four regional health authorities and then the Health Funding Authority have been replaced by 21 DHBs, including three with populations of less than 50,000, and only four with populations over 400,000.
- Regional planning processes have emerged, using multiple stakeholder networks that have been superimposed on the statutory district health board structure.

- Emphasis on competition in the health sector has been replaced by expectations of coordination and collaboration and provider capability development.
- Expectations of the public, politicians, consumers, families, and clinicians regarding mental health service provision have increased.
- A new non-clinical workforce has emerged, primarily in NGOs, with nationally agreed minimum standards of training.
- There have been changes in clinical practice, including adoption of the recovery model and the National Mental Health Sector Standard, and widespread use of new generation antipsychotic medication.

The discussion and debate will guide the Commission in its next task of writing a companion or guidance note to support the *Blueprint* and look at how to adapt its implementation to changing circumstances.

2.6 COMMITTEE COMMENTARY

The Committee was greatly impressed by the progress New Zealand has achieved since the launch of its mental health strategy in 1994. New Zealand's experience offers further strong evidence of the crucial importance of sustained planning in the mental health field. In particular, the Committee took note of the fact that the existence of a detailed and carefully costed plan with very specific targets had contributed to the ability of the mental health community to secure a significant increase in government funding.

In addition, the focus during the process of deinstitutionalization in New Zealand on the development of comprehensive community-based services has allowed the reallocation of resources to take place so that there was no decline in the number of beds available to those in need. The Committee was also struck by the important role that an independent body, the Mental Health Commission has played in this process, and by the willingness of the government to adopt the recommendations made by the Commission.

Perhaps the aspect of New Zealand's efforts over the past decade that most impressed the Committee was the consistent attention to the needs of the indigenous Maori population. Making participation by Maori themselves a cornerstone of the strategic orientation would seem to have yielded important gains in terms of allowing this community to begin to take ownership of these programs and to infuse them with a much greater cultural sensitivity to their own needs. Moreover, the emerging success of efforts devoted to the training of Maori mental health professionals offers the Committee much encouragement that it is possible to grapple with these difficult issues.

Another dimension of initiatives to train needed personnel that seemed worthwhile to the Committee were the programs introduced to provide formal qualifications to community mental health workers in New Zealand. The Committee also notes that efforts in New Zealand to further improve access to primary care services and to reduce demand on secondary care services has involved taking measures to diminish the impact of user fees on

the behaviour of those in need of health care services. Experience in New Zealand thus provides additional evidence that user fees do act as a deterrent to seeking care.

In addition, the Committee will be interested to see if it is possible to draw on the experience of the smaller District Health Boards in New Zealand in order to find ways of improving the delivery of mental health services to Canadians living in rural and remote areas.

Finally, the Committee was impressed by the evolution of the efforts made in New Zealand to combat stigma and discrimination against people living with mental illness, and in particular the long-term funding commitment that was made by the government in this regard. As well, the Committee believes that the New Zealand experience points to the importance of building evaluation and data collection into the design of anti-stigma campaigns so that it is possible to learn from each experience and to adjust the focus as necessary.

CHAPTER 3:
MENTAL HEALTH CARE IN ENGLAND[12]

3.1 HISTORY AND OVERVIEW

The United Kingdom has the same Parliamentary system as Canada, but until the creation of devolved Parliaments in Scotland and Wales in recent years it had been a unitary state comprising Great Britain (England, Scotland and Wales) and Northern Ireland. The public health care system – the National Health Service (NHS) – is similar throughout the United Kingdom but managed by each jurisdiction separately. In this chapter we discuss mental health care in England, almost exclusively. We will refer to the United Kingdom when describing common features. The NHS was established in 1948, and within each jurisdiction remains amongst the more centrally managed and financed health care systems in the world.[13] Government is not only involved in the financing of health services but is also heavily involved in the management and delivery of services.

As in Canada, all people normally resident in the United Kingdom are eligible for health care insurance coverage under the NHS. The NHS does not specify an explicit list of services to be covered. However, the NHS is more comprehensive than Canadian Medicare as it covers physicians, hospitals, prescription drugs, dental care and optical services. There are no user charges for physician services in the United Kingdom and hospital and specialist services are also provided free-of-charge. User charges do apply to prescription drugs, dental and optical services. Unlike Canada, the United Kingdom also allows people to purchase private health care insurance covering the same benefits as the NHS, but supplied by providers working outside of the NHS.

In the United Kingdom, a larger proportion of health care spending is financed by the public sector (82%) than in Canada (70%). The NHS is financed mainly through central government general taxation together with an element of national insurance contributions made by employers and employees. User charges account for less than 3% of total NHS financing.

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12 Unless otherwise indicated the information in this chapter is drawn from the following: Department of Health, *National Service Framework for Mental Health*, 1999; Select Committee on Health, *Fourth Report: Provision of NHS Mental Health Services*, 2000; McCulloch, Andrew, Matt Muijen and Heather Harper, "New Developments in Mental Health Policy in the United Kingdom" *International Journal of Law and Psychiatry*, Vol. 23, No. 3-4, 2000; The Sainsbury Centre for Mental Health, "Mental Health Policy: the challenges facing the new Government," July 2001; Department of Health, *The Journey to Recovery – The Government's Vision for Mental Health Care*, Nov. 2001; National Institute for Mental Health in England, *Cases for Change – Policy Context*, 2002; Department of Health, *National Suicide Prevention Strategy for England*, Sept. 2002; Levenson, Ros, Angela Greatley and Janice Robinson, *London's State of Mind*, King's Fund Mental Health Inquiry, 2003; The Sainsbury Centre for Mental Health, *Money for Mental Health: A review of public spending on mental health care*, 2003; Commission for Health Improvement, *What CHI has found in mental health trusts (sector report)*, 2003; Social Exclusion Unit, *Mental Health and Social Exclusion*, Office of the Deputy Prime Minister, 2004.

13 Paul Wallace, writing in *The Economist* (July 17, 2004), notes that with 1.4 million employees, the NHS is the world's third largest employer, surpassed only by China's Red Army and the Indian Railways.

Many significant reforms of the management and provision of health services in the United Kingdom were undertaken during the 1990s. These reforms initially created an 'internal market,' meaning that certain market-oriented principles were introduced into the publicly-funded health care system. A "purchaser-provider split" altered the relationships between the regional health authorities and the hospitals, while the establishment of "GP Fundholding" modified the organization and shape of general family practices. The Labour government of Tony Blair, first elected in 1997, was critical of the internal market; it has since modified a number of significant features of the system, but has not sought to return it to its original form.[14]

Ms. Anne Richardson, Head of the Mental Health Policy Branch, Department of Health, Government of the United Kingdom explained to the Committee that since 2001, the National Health Service has had three tiers, with the Department of Health at the apex. She indicated that "the Department of Health develops policy as well as the systems and structures needed to deliver services. However, it does not actually implement that change directly." There are 28 Strategic Health Authorities (SHAs) that are responsible for managing the performance of local services. They vary in size from 20 to 30 staff per location and are in turn responsible for as many as 30 Primary Care Trusts (PCTs), which comprise the third tier.

PCTs are now at the centre of the NHS and will get 75% of the NHS budget. They are responsible for managing health services at the local level. Most PCTs cover populations of between 50,000–250,000 people, with the average size PCT serving around 100,000 people. There are now 302 PCTs across England. They do not all have the same level of experience and their expertise also varies.

PCTs directly provide primary care and community health services and commission[15] services from hospital trusts and other secondary and tertiary care providers. PCTs may also commission other primary care services, such as physiotherapy, alternative therapies, and counselling. As we shall see, PCTs are also involved in the commissioning of mental health services. In particular, as Ms. Richardson told the Committee, PCTs "have the job of looking at national standards and targets, balancing those against the needs of their local population and interpreting national standards for their local population."

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14 In fact, some analysts contend that the Labour Government is now engaged in a process of reintroducing the "internal market." Thus, Paul Wallace writes that this return to the "internal market" follows "a major policy shift after the 2001 election." (*Ibid.*)

15 Even in the United Kingdom there is still some confusion concerning the exact meaning of the term 'commissioning' and its relationship to the more familiar 'purchasing.' The two terms, both conceptually and in fact, tend to be used loosely. This is one common definition: *Commissioning* is the strategic activity of assessing needs, resources and current services, and developing a strategy to make best use of available resources to meet identified needs. Commissioning involves the determination of priorities, the purchasing of appropriate services and their evaluation. *Purchasing* is the operational activity set within the context of commissioning, of applying resources to buy services in order to meet needs, either at a macro/population level or at a micro/individual level.

3.1.1 Mental Health

Until the 1950s, the main form of provision for mentally ill people was the old Victorian asylum. As elsewhere, with the arrival of new medication and the idea that mentally ill people had a right to live in mainstream society, this began to change from the 1960s onwards. The old asylum hospitals began to close and more modern psychiatric units were provided in local general hospitals. Thus, hospital beds have been drastically reduced from 129,000 in 1968 to 91,000 in 1978, 63,000 in 1988/89 and 36,000 in 1998/99.

How best to manage the process of deinstitutionalization and its many ramifications continues to be at the centre of policy deliberations. In the initial years of this policy, it appears that policy makers under-estimated the level of continuous support which would be required by a relatively small group of severely disabled people who would previously have lived in the old asylums. Insufficient provision was made in the community to support these people. In particular, there was an absence of intensive health and social support and supported housing. This contributed to the idea in some circles that the policy itself – 'community care' – was wrong, despite international evidence showing that adequate community care leads to better outcomes for the vast majority of people living with mentally illness.

In recent years, mental health policy has been overhauled in a major attempt to create a working system of care which can support people with all types and severity of mental health problems. A series of policy initiatives by the new Labour Government towards the end of the 1990s have attempted to consolidate community based services around an appropriate balance between care and control, support and public safety.

The policy has been promulgated in the following publications produced by Government:

- A 1998 white paper, *Modernising mental health services: safe, sound and supportive*, set out to identify and fill the gaps in service provision. It articulated a vision of creating safe, sound and supportive mental health services, through a variety of measures including the introduction of more intensive community support services such as 'assertive outreach teams' to address the problems of people living in the community with complex needs;
- This was followed by the *National Service Framework (NSF) for Mental Health* which set detailed standards and targets for mental health services for adults with mental health problems aged between 18 and 65 years of age (see below);
- The *NHS Plan,* issued in 2000, extended the agenda described by the national service framework by detailing new services, including assertive outreach, crisis resolution (sometimes called home treatment) and early intervention in psychosis services. The plan introduced graduate primary care mental health workers, gateway workers and carer support workers and endorsed structural changes such as the creation of care trusts. It also considered the mental health workforce requirements and issues relating to recruitment and retention, leadership and training. The NHS Plan included £300 million of new revenue for mental health services.

The National Service Framework for Mental Health (NSF-MH) is a 10-year programme. This is how Ms. Richardson described the purpose of its seven standards to the Committee:

- Standard one is concerned with mental health promotion — that is all the action that is needed to help us take action against the stigma that there is surrounding mental ill health and the risks, to reduce risks of people developing mental ill health.
- Standards two and three were about mental health in primary care, which addressed the action that was needed to improve access to services by people with so-called common mental disorders.
- Standards four and five were about people with severe mental ill health — the relatively small proportion of the total group of people with mental health problems — who nonetheless carry the biggest risk in relation to death by suicide and other causes, and who also carry the highest levels of morbidity. I am thinking of people with a diagnosis of schizophrenia or bipolar disorder or very severe depression.
- Standard six concerned the action that was needed to improve services and supports for caregivers.
- Standard seven focused on all that we needed to do across the spectrum of mental health and social care services to reduce the risk of death by suicide.

We set out in the box below the seven standards in more detail.

NSF-MH STANDARDS
1. *Health and social services should:* • promote mental health for all, working with individuals and communities • combat discrimination against individuals and groups with mental health problems, and promote their social inclusion. 2. *Any service user who contacts their primary health care team with a common mental health problem should:* • have their mental health needs identified and assessed • be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it. 3. *Any individual with a common mental health problem should:* • be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care • be able to use *NHS Direct*, as it develops, for first-level advice and referral on to specialist helplines or to local services. 4. *All mental health service users on the Care Programme Approach (CPA) should:* • receive care which optimises engagement, prevents or anticipates crisis, and reduces risk • have a copy of a written care plan which — includes the action to be taken in a crisis by service users, their carers, and their care co-ordinators

— advises the GP how they should respond if the service user needs additional help
— is regularly reviewed by the care co-ordinator
— be able to access services 24 hours a day, 365 days a year.

5. *Each service user who is assessed as requiring a period of care away from their home should have:*
   - timely access to an appropriate hospital bed or alternative bed or place, which is
     — in the least restrictive environment consistent with the need to protect them and the public
     — as close to home as possible
   - a copy of a written after care plan agreed on discharge, which sets out the care and rehabilitation to be provided, identifies the care co-ordinator, and specifies the action to be taken in a crisis.

6. *All individuals who provide regular and substantial care for a person on CPA should:*
   - have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
   - have their own written care plan, which is given to them and implemented in discussion with them.

7. *Local health and social care communities should prevent suicides by:*
   - promoting mental health for all, working with individuals and communities (standard one)
   - delivering high quality primary mental health care (standard two)
   - ensuring that anyone with a mental health problem can contact local services via the primary care team, a helpline or an Emergency department (standard three)
   - ensuring that individuals with severe and enduring mental illness have a care plan which meets their specific needs, including access to services round the clock (standard four)
   - providing safe hospital accommodation for individuals who need it (standard five)
   - enabling individuals caring for someone with severe mental illness to receive the support which they need to continue to care (standard six)
     and in addition:
   - supporting local prison staff in preventing suicides among prisoners
   - ensuring that staff are competent to assess the risk of suicide among individuals at greatest risk
   - developing local systems for suicide audit to learn lessons and take any necessary action.

The NSF-MH was the first comprehensive statement that set out what was expected of health and social services in England. A new body, the National Institute for Mental Health in England (NIMHE), was set up to oversee the implementation of the service framework. As Ms. Richardson explained, NIMHE

> *has a series of eight regional development centres spread across England. Their job is to specifically help local services improve their closeness to targets. They set out models of best practice, visit local services and employ champions to raise the profile of the new service model and of the needs of people with mental illness. There are about 26 programs of*

> *work led through the National Institute for Mental Health, all of which have central funding. These programs are designed to support reform.*

Ms. Richardson gave the following example of one of these programs:

> *We have a Black and minority ethnic mental health program, currently funded to the tune of £2.5 million over the period to 2006. That will employ new community development staff and pump-prime about 80 community development projects, which will help us to [improve service to] users with mental health problems who come from Black and minority ethnic groups...*

NIMHE is organized in 8 regional offices, and each office is linked directly with local communities, trusts, NGOs and service users. This allows NIMHE to organize its contribution to implementing the NSF-MH and its technical assistance programs around a community integration approach.

Moreover, the NSF-MH directed each area to create a local implementation team (LIT) comprising representatives from service users, carers, local authority departments, Primary Care Groups, NHS Trusts and Health Authorities with a mandate to develop a local implementation plan. Initially, 126 LITs were established, and some have worked better than others. Ms. Richardson told the Committee that,

> *The LITs have been absolutely essential to such changes as we have been able to secure. I do not want to create a falsely positive picture because we have an enormously long way to go. We are nearly five years into this program and we have made significant change but there is a long way to go. The LITs have been essential for that and it is terribly important in thinking about the whole of the reform program to get that infrastructure right, from the beginning.*

In addition, the Government has since issued a detailed *Policy Implementation Guide* in support of the NSF-MH (2001), and published proposals for reforming the Mental Health Act (2002).

Despite many positive responses to the NSF-MH, some have been concerned that the resources provided were inadequate for the tasks ahead, while others have felt that the NSF-MH did not acknowledge the current debate about the medical versus social models of mental health. These critics saw the way that the NSF-MH referred to mental health problems as 'mental illness' as reflecting a failure to see users and survivors as people who have strengths as well as problems. Despite the various criticisms, for most commentators the NSF-MH has nonetheless given cause for optimism about the future of mental health services in the UK.

3.2 COSTS AND FUNDING OF MENTAL HEALTH SERVICES

A report issued in June 2004 by the Mental Health and Social Exclusion Unit under the Office of the Deputy Prime Minister provides the following figures on costs associated with mental illness in England:

- The overall costs of mental health problems in England are estimated to be £77.4 billion annually. The impact on quality of life, including premature mortality, accounted for well over half that figure.
- Output losses associated with missed employment opportunities were estimated at over £23 billion per year.
- The economic costs of suicide are estimated to be in the region of £5.3 billion.

In terms of spending, the Secretary of State for Health told the Parliamentary Select Committee on Health in 2000 that mental health services accounted for around 12% of the total hospital and community health services budget. Ms. Richardson indicated to the Committee that in 2001-02 this figure had risen to 13%. At the same time, she insisted that it was important to recognize that

> *Hospital and community health service expenditure is only a portion of the money that is spent on mental health. We also have social care spending, which goes down a separate route to local government for social services, education services and the like.*

In this regard, an estimate made by the Sainsbury Centre for Mental Health[16] (2003) suggested that about 80 per cent of total spending on mental health services is funded by the NHS. Of the remainder, 15 per cent comes from the social services budgets of local authorities, 3 per cent is covered by the Mental Health Grant (a ring-fenced grant for mental health services made available to local authorities by central government) and the balance comes from other sources, including user charges.

The Sainsbury Centre also estimated that around 75 per cent of total expenditure on mental health services corresponds to the direct costs of service provision (mainly staff costs), while the remaining 25 per cent is accounted for by indirect costs, overheads and capital charges.

As noted earlier, the NHS Plan envisaged increasing funding for mental health in order to pay for an expansion of services. In its report on mental health spending, the Sainsbury Centre calculated that cash spending on adult mental health services (NHS and local authority combined) increased by 7.1 per cent in 2002/03, and is planned to rise by 6.3 per cent in 2003/04. In both years, however, their analysis indicates that growth in expenditure on mental health services is significantly slower than the growth in overall spending on health and social care. This means that, adjusting for the effects of pay and price rises,

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[16] The Sainsbury Centre for Mental Health (SCMH) is a charity that works to improve the quality of life for people with severe mental health problems. It carries out research, development and training work to influence policy and practice in health and social care. The SCMH is affiliated to the Institute of Psychiatry at King's College, London. Its work is highly respected world-wide.

expenditure on mental health services will increase at less than half the rate of total spending on the NHS and social services over the two years 2002/03 and 2003/04.

The Sainsbury Centre thus concluded that despite its status as a priority service, the share allocated to mental health in NHS and social service budgets is falling. It notes that the rise in spending is also well below the average rate of increase of 11.5% per annum that is required to implement the National Service Framework for Mental Health in line with the Government's timetable. According to them, if the timetable is to be met, annual cash expenditure on mental health services would need to increase at nearly double the rate recorded in 2002/03 and 2003/04.

While they observe that there are local differences in spending patterns, the Sainsbury Centre concludes that these should not be allowed to obscure the "single most important finding" of their study, which is that at the national level current expenditure trends imply a widening gap between promise and performance in the delivery of better mental health services. In their view, decision makers are faced with a clear choice: either scale back the reform agenda or ensure that mental health gets more resources.

However, in her testimony to the Committee Ms. Richardson stated:

> *I think I have to challenge robustly the perception that there has not been an increase in resources for mental health in association with the national service framework. As I think I said earlier, the NHS plan set out how an additional £330 million over and above baseline would be invested in the NHS in order to fast-forward the national service framework by 2003-04.*

She also pointed out that:

> *Our evidence supports the fact that that money did go into mental health services. We know that up to April last year an additional £262 million was spent on mental health over and above the baseline figure for 2001.*

At the local level, however, there are additional challenges posed by the new ways in which funds are now directed to local needs. As noted earlier, locally run Primary Care Trusts (PCTs) now receive NHS funding directly from central government rather than through Health Authorities. PCTs are responsible for allocating these funds between different health services, including services for mental health, and also for setting local priorities for the future development of services. PCTs are the major source of funding for mental health care and in theory can redirect resources between services and providers according to local priorities.

A recent study was conducted by the King's Fund on mental health services in London (2003). It noted that although responsibility for commissioning most mental health services has now passed from health authorities to PCTs, "most PCTs appear to have been unable to devote as much time to mental health commissioning as might be expected from the *size* of their budgets, or as required, given the state of development of mental health services." The

Sainsbury Centre surveyed the Local Implementation Teams (LITs) that are responsible for putting the mental health reforms into practice. Overall, their analysis suggested that 58 per cent of LITs think that funding in 2003/04 is unlikely, on balance or otherwise, to be sufficient to maintain baseline services and deliver the Government's reform programme, while 42 per cent took a more optimistic view. Evidence from Local Delivery Plans, covering the three years to 2005/06, also indicates that there is likely to be under-performance against national targets and policy objectives.

More generally, mental health budgets are being squeezed as a result of a number of pressures. The most important of these are staff shortages (leading to high levels of spending on costly forms of temporary staffing), the rapid growth of prescribing costs and the requirement to pay off inherited debts. For example, the Sainsbury Centre gave an illustration of an extreme budget overrun: a trust in the south of England reported overspending £145,000 on advertising for staff and £1,672,000 on medical locums.

A report prepared for the Mental Health Providers Forum (MHPF) in 2002 estimates that expenditure on and by the voluntary sector in providing mental health services corresponds to about 10 per cent of public expenditure on mental health. The combined income of MHPF members in 2001/02 was £320 million, much of which was received from the NHS and local authorities for mental health services provided on a contractual basis. Residential care was the largest area of contracted activity with 69 per cent of total spending, followed by community services (23 per cent). The balance of expenditure went on a range of services including information, advocacy, research, campaigning, training and support for caregivers.

3.3 SERVICE DELIVERY AND ORGANIZATION

The modernization of mental health services in the UK is taking place within the context of significant organizational change. Within the public sector, the main organizational change of recent years has been the emergence of specialist mental health trusts, many of which are still in the process of being developed as a number of different agencies are amalgamated to create a single provider responsible for the broad spectrum of mental health services within each locality. Some of these providers have been set up as health and social care trusts, with unified budgets combining health and social service funding as well as common staffing and premises.

The development of these specialist mental health trusts is a new phenomenon, the majority having come into existence in April 2002. They replace an array of services that had previously been provided and managed by acute trusts, community trusts and some specialist mental health trusts. Mental health trusts vary across a range of dimensions, including: the size of their overall budgets, numbers of staff employed, numbers of inpatient beds, numbers of sites for delivering services and the range of geographical areas covered.

They also vary in terms of the range of client groups served. Many cater to people with learning difficulties. Most provide services for older people and for children and adolescents as well as for adults of working age. Increasingly, trusts may also provide "home treatment" or "crisis services", which aim to care for individuals experiencing acute mental distress to enable them to remain in the community, usually at home, instead of becoming hospital in-

patients. The NHS trusts providing general mental health services often also have access to a locked ward, or intensive care ward, where patients who need a higher level of physical security, or greater staff input than is possible on acute wards, can be cared for.

Both the Royal College of Nursing and the Royal College of Psychiatrists argued in their testimony to a Select Parliamentary Committee in 2000 that good quality community care is only possible if patients also have access to good quality in-patient care. The Select Committee received evidence from a variety of witnesses that indicated that much in-patient care was still of low quality. The Select Committee referred to a study by the Sainsbury Centre which suggested that the pressures on acute beds were so great that the environment was positively "untherapeutic", that services lacked clear goals, and links with community services were poor. The Mental Health Foundation similarly suggested to the Committee that the "real weakness" in the mental health service at present was to be found in acute wards.

A substantial proportion of mental health services are also provided in primary care settings. The Report on Mental Health and Social Exclusion indicated that "approximately nine out of ten adults with mental health problems, and one quarter with severe mental health problems receive all their support from primary care," and that "around 30 per cent of GP consultations concern mental health problems, usually depression, eating disorders and anxiety disorders."

At the same time, Ms. Richardson indicated that "it is fair to say that we have not had a formal strategy for the integration of primary and secondary care." However, she did inform the Committee about a particular initiative designed to improve the delivery of services at the primary care level. The NHS plan of 2000 set a target to develop 1,000 new graduate primary care mental health workers by December 2004, in order to help GPs manage and treat people of all ages with common mental health problems. In Ms. Richardson's terms, "the graduate worker is a new breed of worker." She described the program as follows:

> *…we had a group of able [university] graduates in our system who wanted to work in the NHS who could be trained, so the evidence suggested, to deliver brief, effective evidence-based treatments in primary care for people with common disorders… we set up 12 new programs of education and training across England to provide them with one year of post-graduate certificate level training offered on a day-release basis.*
>
> *Our graduate workers, thus far, tend to have qualifications in social sciences or psychology and are not nurses. That additional one year of post-graduate training qualifies them to deliver the kind of self-help, the information dissemination, and some of the brief effective cognitive behavioural treatments for people with common disorders.*

The NHS Plan also contained a number of other specific targets, including the creation of an additional 50 assertive outreach teams. According to Ms. Richardson, this goal has been met. She told the Committee that an assertive outreach team

> *…is a small multidisciplinary team consisting of anywhere between 9 to 15 staff. Their aim is to focus particularly on the estimated 1,500 people who are in the mental health service system with a severe mental illness and who are at particular risk of falling out of contact with services or of disengaging with their key workers.*
>
> *The assertive outreach team would start its work after a period of admission. Let us say, typically, a service user would have an admission to a psychiatric hospital, have a period of treatment and get a care plan. The assertive outreach team would follow up, as the name suggests, quite assertively. They would visit the person at home; if the person missed an appointment, they would chase it up. They might see the service user, the patient, in the place of his or her choosing. We know assertive outreach teams that work in the local launderette, and they will be trying to help ensure that the service user sticks with the care plan and does not fall out of contact.*

In addition to the major service providing agencies, there is usually a range of independent providers in most localities. Quite often these are voluntary sector agencies that are part of national bodies. The private sector can also be part of the local scene, most notably as providers of secure and special needs accommodation. As well, there are private landlords who have specialized in providing accommodation for people with mental health needs in certain areas.

3.3.1 Human Resources

There remain many serious problems across the UK with the recruitment and retention of mental health staff. Significant staffing shortages, primarily of psychiatrists and inpatient nurses, continue to have a major impact on clinical leadership and the quality of care. As noted earlier, problems recruiting and retaining staff lead to a high use of temp and agency staff. However, local experience varies, depending on working conditions, recruitment strategies and the attraction of particular organisations and localities.

In 2000, the Secretary of State for Health testified to a Parliamentary Committee that there were shortages of nurses, psychiatrists "and other specialist staff," but he also noted that the picture varied at both local and regional level and that the figure for nursing vacancies in mental health nursing (2.1%) was actually below the general nursing figure (2.6%). The Royal College of Psychiatrists estimated in its testimony to the Committee that there is "an average of something like 15 per cent consultant psychiatric vacancy across the country."

A study conducted by the Commission for Health Improvement (CHI) in 2003 indicated that many permanent staff are working excessive hours. At the same time, CHI was impressed by the commitment and dedication of clinical, non clinical and care staff to providing high quality care to service users across the sector, despite the fact that many staff work under considerable pressure in difficult environments.

3.3.2 Services to Minorities

The Report on Mental Health and Social Exclusion indicated that in the UK:

- People from ethnic minority groups are six times more likely to be detained under the Mental Health Act than white people;
- Rates of diagnosed psychotic disorders are estimated twice as high among African Caribbean people than white people, although they are three to five times more likely to be diagnosed and admitted to hospital for schizophrenia;
- South Asian women born in India and East Africa have a 40 per cent higher suicide rate than those born in England and Wales.

Statistical evidence presented to the Select Committee on Health in 2000 by the British Psychological Society also pointed to the tendency of ethnic minority patients to access services later, when they are more severely ill and more likely to be detained. Other evidence given to the Select Committee indicated that the services offered to visible minorities are often "inappropriate or insensitive." Some minority groups are also under-represented in services. It was pointed out to the Select Committee that women from South Asian communities, for example, make below-average use of formal mental health services and have an above-average suicide rate.

The reasons put forward by witnesses to the Select Committee as to why ethnic minority use of mental health services is significantly different from that of white patients fell into two broad categories: the inappropriateness of services and a failure by service providers to understand the needs of ethnic minority patients. The Select Committee expressed concern that despite the fact that these problems have been recognized for some years, change remains slow in coming.

3.4 PROMOTION AND PREVENTION

3.4.1 Countering Stigma and Discrimination

As noted above, the National Service Framework for Mental Health (Standard One) aims to ensure that health and social services promote mental health and reduce discrimination and social exclusion. Ms Richardson told the Committee that the Government began

> *in March 2001 by launching a national campaign called 'Mindout for Mental Health.' That campaign was aimed at tackling the stigma and discrimination faced by people with mental health problems. It was designed to support their social inclusion.*

This campaign lasted for three years and concluded in March 2004. One of the positive features of the 'Mindout' campaign that was identified in the report on Mental Health and Social Exclusion was its use of an 'Ambassador Bureau,' composed of more than 40 people with experience of mental health problems who were trained to speak to the media and

employers about their experiences. Evaluation found that ambassadors were perceived to make the campaign 'human and personal', and that hearing first-hand about mental health problems challenged misconceptions.

Another anti-stigma effort, the five-year 'Changing Minds' campaign organized by he Royal College of Psychiatrists' ended in late 2003. Ongoing campaigning work is also being pursued by number of voluntary organizations. Within governmental structures, the National Institute for Mental Health in England (NIMHE) has lead responsibility for tackling stigma and discrimination around mental health problems.

While there has thus been considerable effort to tackle stigma in England, the report on Mental Health and Social Exclusion notes that "this has not always been well co-ordinated, and has focused on education and awareness rather than achieving behavioural change." The report concluded that "two key lessons from the 'Mindout' campaign were the need for longer-term funding strategies and robust evaluation." It further cited a literature review of international work that had been commissioned by NIMHE that found that average spending on mental health awareness in England is lower and more short-term than in countries with more successful programmes (see table below). Thus while the report identified stigma and discrimination as being "the greatest barriers to social inclusion for people with mental health problems," it also concluded that "despite a number of campaigns, there has been no significant change in attitudes."

INTERNATIONAL SPENDING ON MENTAL HEALTH CAMPAIGNS PER HEAD OF THE GENERAL POPULATION*	
Mindout for mental health	1.44 pence
See Me, Scotland**	13 pence
Like Minds, Like Mine, New Zealand	$NZ1 (approx 36 pence)

* Figures are an approximation of overall spending divided by population, with annual spending averaged over the campaign. Each British pound is made up of 100 pence and is worth approximately CA$2.43.
** See box at next page.

The new strategy outlined in the report to combat stigma and discrimination is therefore based on the recognition that dealing with mental health problems requires more than a medical solution. In particular, the report argues that a positive response on the part of society to accommodate people's individual needs and to promote mental well-being is needed. To accomplish this, it sets out a 27-point action plan to bring together the work of government departments and other organizations in a concerted effort to challenge attitudes, enable people to fulfill their aspirations, and improve opportunities and outcomes for this excluded group.

SEE ME CAMPAIGN, SCOTLAND
See Me is an anti-stigma campaign run by an alliance of five Scottish mental health organisations and supported by the Scottish Executive. The campaign is a major part of the National Programme for Improving Mental Health and Well-being. It was launched in October 2002, and has almost £3 million of funding over four years (to 2005-06). It has been developed through extensive consultation with people with experience of mental health issues. The campaign works on a national level, underpinned by local activities. It uses multimedia advertising, supported by people with mental health problems trained to speak to the media. *See Me* includes a 'stigma stopwatch' that encourages people to respond to discriminating attitudes and language in the media. Recognition of the campaign has been maintained at 28 per cent.

The plan includes a programme to challenge negative attitudes and promote awareness of people's rights. This new anti-stigma programme is backed by a £1.1 million investment from the Department of Health and additional funding has been made available through other government departments. It will be led by NIMHE and, according to the Report, the programme will:

- be based on international evidence of what works, and learn from previous mental health and health promotion campaigns;
- target key audiences, in particular employers, young people and the media;
- deliver consistent, tested messages under a single brand;
- promote the positive contribution that people with mental health problems can make to society;
- have sustained funding to plan ahead;
- address issues of ethnicity and gender;
- provide a framework and materials to support local campaign work, targeting in particular issues facing deprived neighbourhoods;
- be clearly evaluated by a regular survey.

3.4.2 Suicide Prevention

There has been a National Suicide Prevention Strategy for England in place since 2002. It was developed to implement the target of reducing the death rate from suicide and undetermined injury by at least a fifth by the year 2010 that had been set out by the Government in a 1999 White Paper, *Saving Lives: Our Healthier Nation*.

The plan is seen as an on-going, co-ordinated set of activities that strives to be to be comprehensive, evidence-based, specific and subject to evaluation. It will be delivered as one of the core programmes of the National Institute for Mental Health in England (NIMHE). The plan sets six goals, each of which further embrace a number of more specific objectives. These goals, followed by the objectives, are listed in the box below.

Ms Richardson told the Committee that the strategy would appear to be bearing fruit:

> *The first report of progress with the strategy was published last year. There are encouraging signs that the rate of death by suicide is falling. The data for the last two years show the lowest rate yet. The three-year average for 2000-2002 was the lowest rate yet compared with the baseline that we set in 1995. Currently the rate is 8.9 deaths per 100,000 population. That compares moderately favourably with the European rate, which I think was 8.8 at last count.*

NATIONAL SUICIDE PREVENTION STRATEGY FOR ENGLAND

GOAL 1 To reduce risk in key high risk groups.

- Reduce the number of suicides by people who are currently or have recently been in contact with mental health services.
- Reduce the number of suicides in the year following deliberate self-harm.
- Reduce the number of suicides by young men.
- Reduce the number of suicides by prisoners.
- Reduce the number of suicides by high risk occupational groups.

GOAL 2 To promote mental well-being in the wider population.

- Promote the mental health of socially excluded and deprived groups.
- Promote mental health among people from black and ethnic minority groups, including Asian women.
- Promote the mental health of people who misuse drugs and/or alcohol.
- Promote the mental health of victims and survivors of abuse, including child sexual abuse.
- Promote mental health among children and young people (aged under 18 years).
- Promote mental health among women during and after pregnancy.
- Promote mental health among older people.
- Promote the mental health of those bereaved by suicide.

GOAL 3 To reduce the availability and lethality of suicide methods.

- Reduce the number of suicides as a result of hanging and strangulation.
- Reduce the number of suicides as a result of self-poisoning.
- Reduce the number of suicides as a result of motor vehicle exhaust gas.
- Reduce the number of suicides on the railways.
- Reduce the number of suicides as a result of jumping from high places.
- Reduce the number of suicides using firearms.

GOAL 4 To improve the reporting of suicidal behaviour in the media.

- Promote the responsible representation of suicidal behaviour in the media.

GOAL 5 To promote research on suicide and suicide prevention.

- Improve research evidence on suicide prevention.
- Disseminate existing evidence on suicide prevention.

GOAL 6 To improve monitoring of progress towards the *Saving Lives: Our Healthier Nation* target for reducing suicide.

- Monitor suicide statistics relevant to the goals and objectives in the strategy.
- Evaluate the national suicide prevention strategy.

3.5 PROSPECTS FOR FUTURE REFORM

Mental health services are now almost half way into the ambitious 10 year programme outlined in the National Service Framework (NSF), and much progress has been made. However, concerns remain about whether the goals that it set out will be fully met. For example, in 2000, the Commons Select Committee on Health described the system as a "patchwork quilt", with enormous variations in both standards of service and methods of service delivery around the country. In 2003, the Commission for Health improvement concluded that the historical legacy of the neglect of mental health services had still not been overcome.

Both the direction of reform and the concrete implementation of changes to the organization and delivery of services remain the subject of debate. Concerns have been expressed in recent reports over the priority accorded to mental health within the overall health system and over the implementation of the commissioning process for mental health services. More emphasis is seen as being given to the acute sector, particularly to reducing waiting times and extending patient choice, leaving the NSF and NHS Plan targets for mental health relatively low on the list of priorities.

Challenges also remain in the devolution of the commissioning of mental health services to local trusts so that the full benefits of this shift can be reaped. In particular, the dilution of expertise across a large number of commissioners has been identified as a potential source of problems. In spite of the positive developments associated with commissioning, there are commentators who have argued that the effectiveness of commissioning has a long way to go; and in the mental health field, commissioning seems particularly patchy and under-developed.

In its recent report, the Sainsbury Centre painted a picture of a system that is under a range of pressures which — taken together — in their eyes raise questions about the deliverability of the Government's reform agenda. They noted that it remains the case that the finances of many mental health providers are in a precarious state. At the same time, witnesses indicated to the Committee that the Government was committed to mental health reform and to making the necessary resources available.

3.6 COMMITTEE COMMENTARY

The Committee was very impressed by the scale of the planning that has taken place in England since the introduction of the National Service Framework for Mental Health in 1999, in particular the 10-year planning horizon and the detailed standards for service delivery that it sets out.

The Committee was also struck by the importance of the Local Implementation Teams that were established in order to translate and adapt the framework to local conditions, as well as by the emergence of mental health trusts that are designed to create a single local provider of mental health services. In the same vein, the Committee was impressed by the creation of a separate implementation arm, the National Institute for Mental Health in England, whose tasks include assisting in training, disseminating expertise and propagating best practices.

In general, the Committee noted the enormous challenge that confronts government in funding and organizing reform in the mental health sector. The Committee was further impressed by the careful attention paid to the assessment of the implementation of mental health reform both by governmental agencies and by non-governmental organizations in England.

It would also seem possible to conclude from recent experience in England that human resource shortages have the potential to engender serious short term financial consequences throughout the system, as well as to pose a threat to the realization of reform plans. In this regard, the training of graduate mental health workers to assist in the delivery of services at the primary care level struck the Committee as an important initiative.

Finally, the Committee was impressed by the ongoing commitment to fight stigma and discrimination that confront people living with mental health disorders, and, in particular by the scope of the initiatives announced in the report on Mental Health and Social Exclusion in June 2004. The UK experience also shows, however, that changing attitudes is no simple matter, and that adequate resources as well as perseverance are required. The Committee

noted as well that there are recent indications that mental health promotion and suicide prevention have contributed to declining suicide rates in England.

CHAPTER 4:
MENTAL HEALTH CARE IN THE UNITED STATES[17]

4.1 HISTORY AND OVERVIEW

The American health care system is unique in the extent to which it relies on the private sector both to provide health care coverage and deliver health services. Private sources account for 55% of health care financing, made up of private health care insurance (33%), out-of-pocket payments made by individuals under both public and private plans (17%), and other sources (5%). The majority of Americans receive their private insurance coverage through employer-sponsored plans.

The federal government contributes approximately 33% of total health care spending, with state and local governments paying the remaining 12%. The national government of the United States is responsible for administering and operating Medicare, which provides health care insurance for the elderly. Jointly with the states, it finances Medicaid for the poor and the State Children's Health Insurance Program (SCHIP) for children. Overall, public health care insurance covers about 24% of the population in the United States.

Medicare is a federal health care insurance plan for people 65 years of age and over, some people with disabilities under 65, and people with end-stage renal disease. Medicaid is a joint federal and state means-tested health care insurance plan available to people with low income. The federal government pays from half to over 75% of the cost incurred by individual states in providing coverage for the poor, depending on the wealth of individual states. It also establishes national guidelines for Medicaid eligibility and services. However, each state administers its own program and sets the rate of payment for services. All states are held to minimum requirements for eligibility and for required services but, with federal agreement, they may expand eligibility or services provided. Medicaid programs therefore vary from state to state.

4.1.1 Mental Health

In the words of a recent report by the President's New Freedom Commission on Mental Health, the current mental health care system in the United States "is a patchwork relic," that

[17] Unless otherwise indicated, the information in this document is drawn from the following sources: *Mental Health: A Report of the Surgeon General* (1999), in particular Chapter 6, "Organizing and Financing Mental Health Services"; U.S. Department of Health and Human Services, *National Strategy for Suicide Prevention: Goals and Objectives for Action* (2001); The President's New Freedom Commission on Mental Health *Final Report* (July, 2003) and *Interim Report* (October, 2002); Tanner, Jane "Mental Illness Medication Debate," *The CQ Researcher*, Feb. 6, 2004, pp. 109-118; Cunningham, Robert "The Mental Health Commission Tackles Fragmented Services: An Interview With Michael Hogan," *Health Affairs*, Web Exclusive, Sept. 9, 2003; Barry, Colleen L., and Jon R. Gabel, Richard G. Frank, Samantha Hawkins, Heidi H. Whitmore, and Jeremy D. Pickreign "Design Of Mental Health Benefits: Still Unequal After All These Years," *Health Affairs*, Vol. 22, No. 5, Sept.-Oct. 2003, pp. 127-37; Hogan, Michael F. "The President's New Freedom Commission: Recommendations to Transform Mental Health Care in America," *Psychiatric Services*, Vol. 54, No. 11, Nov. 2003, pp. 1467-1474; Mechanic, David and Scott Bilder, "Treatment Of People With Mental Illness: A Decade-Long Perspective," *Health Affairs*, Vol. 23, Number 4, July/August 2004.

is in need of "dramatic reform" because it "does *not* adequately serve millions of people who need care." Analysts agree that the American mental health services system defies easy description. In fact, the Report of the Commission insists that "the reality is that the mental health system looks more like a maze than a coordinated system of care."

Mental disorders and mental health problems in the United States are treated by a variety of caregivers who work in diverse, relatively independent, and loosely coordinated facilities and services—both public and private—that researchers refer to, collectively, as the de facto mental health service system. These programs exist at every level of government and throughout the private sector and have varying missions, settings, and financing.

About 15 percent of all adults and 21 percent of U.S. children and adolescents use services in the de facto system each year. The system is usually described as having four major components or sectors:

- The specialty mental health sector consisting of mental health professionals such as psychiatrists, psychologists, psychiatric nurses, and psychiatric social workers who are trained specifically to treat people with mental disorders.
- The general medical/primary care sector consisting of health care professionals such as family physicians, general internists, paediatricians, and nurse practitioners in office-based practice, clinics, acute medical/surgical hospitals, and nursing homes.
- The human services sector consists of social services, school-based counselling services, residential rehabilitation services, vocational rehabilitation, criminal justice/prison-based services, and religious professional counsellors.
- The voluntary support network sector, which consists of self-help groups, such as 12-step programs and peer counsellors, is a rapidly growing component of the mental and addictive disorder treatment system.

The de facto mental health service system is also divided into public and private sectors. The term "public sector" in this context refers both to services directly operated by government agencies (e.g., state and county mental hospitals) and to services financed with government resources (e.g., Medicaid, and Medicare). Publicly financed services may be provided by private organizations. The term "private sector" refers both to services directly operated by private agencies and to services financed with private resources (e.g., employer-provided insurance).

Most Americans (84 percent) have some sort of insurance coverage—primarily private insurance obtained through the workplace. However, its adequacy for mental health care is extremely variable across types of plans and sponsors. The public sector serves those individuals with no health insurance, those who have insurance but no mental health coverage, and those who exhaust limited mental health benefits in their health insurance.

Each sector of the de facto mental health service system has different patterns and types of care and different patterns of funding. According to the President's Commission, the causes of the fragmentation of the existing system are not a lack of commitment and skill on the part of those who deliver care, but rather stem from underlying structural, financing, and

organizational problems, whose roots go back to the 1950s when the move away from care in institutions to care in communities began.

De-institutionalization was motivated by reformers' desire to bring services to people in their communities, but its unintended consequence was that responsibility became scattered across levels of government and across multiple agencies. The shift began under President Dwight D. Eisenhower, but it got a big push when President John F. Kennedy signed the Community Mental Health Centers Construction Act in 1963. It set up a funding stream for local programs, with a goal of cutting state mental hospital populations by half.

This goal was far exceeded: only 40,000 hospital beds exist today for the mentally ill, compared with some 550,000 in 1955. However, goals for developing community mental health centers did not fare as well. Only about half the intended centers were initiated and federal funding covered only the seven-year start-up period. In 1981, the mental health centers program was replaced with a block grant for mental health.

But communities did not embrace the psychiatric patients who were thrust into their neighborhoods, and most of the money saved by closing state hospitals was not put back into community programs. "Jails and prisons have become the new institutions for many with severe mental disorders, with many others left to fend for themselves as homeless street people," Darrel A. Regier, director of research at the American Psychiatric Association, told the federal mental health commission.

At the same time, Mr. William Emmet, the co-ordinator for the U.S. Campaign for Mental Health Reform, told the Committee that:

> *In many ways, deinstitutionalization was a great success. There were many people who did not belong in the institutions, and they did leave and start living productive lives — or at least far better lives than they had in the institutions. The problem over time has been that people who formerly would have gone to institutions have not been able necessarily to get the services they need.*

And Michael Hogan, the Chair of the President's Commission on Mental Health, added in his testimony before the Committee:

> *None of us in the field would argue for a minute that we ought to go back. The system of institutions failed to touch most people. Those whom it did touch were confined very expensively and they did not get better. They received "three hots, a cot and health care," but they were never able to get a life. We cannot go back to that situation but we have not yet solved the problem of creating a care system that is well organized and robust enough to do a good job.*

Two years after President Kennedy's speech, Medicare and Medicaid were created. Over the years, states increasingly used Medicaid to pay for mental health care. This has led to Medicaid becoming the nation's largest purchaser of mental health care. Critics say that

states moved mental health care into Medicaid simply because the federal government picks up half the tab in a matching contribution, and pays up to 75 percent in poorer states.

The introduction of Medicaid also contributed to the decline of state-run psychiatric hospitals in three ways. First, Medicaid did not reimburse most care provided in these settings. Second, it did pay for acute care in psychiatric units of general hospitals, which became a preferred location for short term treatment. Finally, Medicaid paid for care in nursing homes and much of the decline in the use of state psychiatric hospitals is attributable to the transfer of elderly patients from state hospitals to nursing homes.

Within the framework of the American health care system, mental health care is unique because there are state- and county-administered care systems specifically for a category of illness. The Federal government now pays for most services for people with a serious mental illness, while responsibility for providing them rests with states and localities. However, most Federal resources are in mainstream programs (e.g., Medicaid, Medicare, Vocational Rehabilitation, housing) that are not always tailored to the specific requirements of mental health care and are usually administered by different state agencies. This often leaves consumers and families struggling to find appropriate services.

Moreover, because the provision of mental health care services has now been devolved to fifty states and hundreds of counties and local communities, there is considerable variability in the availability of these services. As Mr. Hogan put it in an interview, "if you've seen one state, you've seen one state."

Major changes have also occurred recently in the private sector, especially with the advent in the 1990s of managed care as the predominant way of organizing private insurance coverage.

4.2 COSTS AND FUNDING OF MENTAL HEALTH SERVICES

4.2.1 The Costs of Mental Illness in the United States

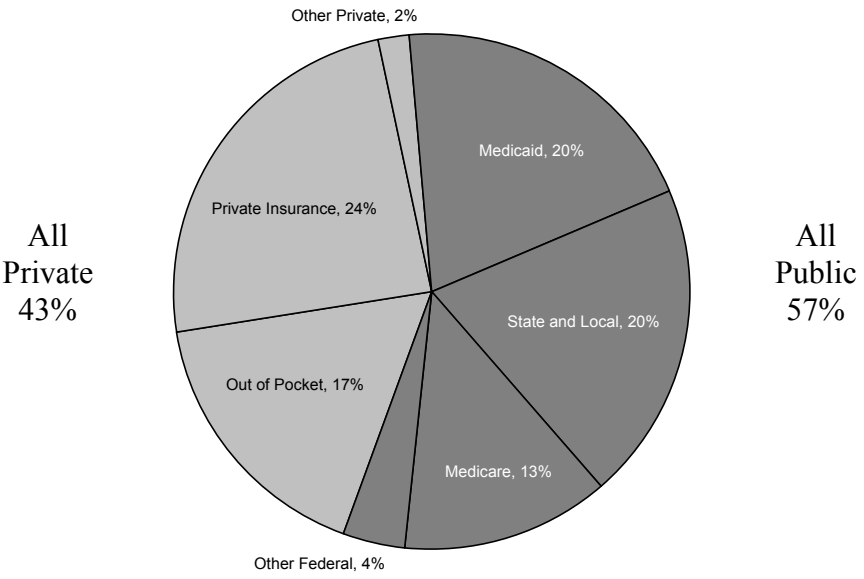
There are both direct and indirect costs of mental illness to the economy. The *indirect costs* of all mental illness imposed a nearly $79 billion loss on the U.S. economy in 1990. Most of that amount ($63 billion) reflects the loss of productivity because of illness. But indirect costs also include almost $12 billion in mortality costs (lost productivity due to premature death), and almost $4 billion in productivity losses for incarcerated individuals and for the time of individuals providing family care.

In 1996, the United States spent more than $99 billion for the *direct* treatment of mental disorders, as well as substance abuse, and Alzheimer's disease and other dementias. Of this, $69 billion was spent in 1996 for diagnosis and treatment of mental illness alone, representing 7% of total health care spending that year. More than 70% of direct mental health spending was for the services of specialty providers, with most of the remainder for general medical services providers.

In 1997, all public sources accounted for 57% of mental health spending, with all private sources covering the remaining 43% (Figure 1). Between 1986 and 1996, mental health expenditures grew at an average annual growth rate of more than 7 percent, compared with

overall rate for health care of more than 8 percent. According to the U.S. Surgeon General, this difference may stem from the greater reliance of mental health services on managed care cost-containment methods during this period. Among the fastest-rising expenses for mental health services were outpatient prescription drugs, which account for about 9 percent of total mental health direct costs.

DISTRIBUTION OF PUBLIC AND PRIVATE MENTAL HEALTH EXPENDITURES, 1997



4.2.2 Publicly Funded Mental Health Insurance

During the past two decades there have been important shifts in who pays for mental health care in the United States. The role of individual states in the direct funding of mental health care has been reduced, whereas Medicaid funding of mental health care has grown in relative importance. This is in part due to substantial funding offered to the states by the Federal government. However, Mr. Emmet noted that, "as a medical entitlement program [Medicaid] covers only certain approved services… and it requires matching contributions from the states that are increasingly difficult for the states to make in these tight budgetary times." One consequence of this shift is that Medicaid is now the largest payer of mental health services in the country and it has therefore become very influential in shaping the delivery of mental health care. Private insurance coverage has played a somewhat more limited role in mental health financing in recent years.

Some Federal funding is directed specifically to mental health programs. One such program, the Community Mental Health Services Block Grant, funded by the U.S. Department of Health and Human Services (HHS) through the Substance Abuse and Mental Health Services Administration (SAMHSA), provides funding to the States and territories. It totaled

approximately $433 million in 2002, but this amounted to less than 3% of the revenues of the State agencies involved.

In fact, larger Federal programs that are not focused on mental health care play a much more substantial role in the financing of mental health services. For example, through Medicare and Medicaid programs alone, HHS spends nearly $24 billion each year on beneficiaries' mental health care (a figure which does not include the state share of Medicaid). Moreover, the largest Federal program that supports people with mental illnesses is not a health services program but rather income support programs run by the Social Security Administration — Supplemental Security Income (SSI) and Social Security Disability Income (SSDI).

Escalating costs, especially for prescription drugs, have placed significant pressure on both individuals and states. In 2002, 25 states spent more money for Medicaid services than they had budgeted, and 28 expected to fall short when 2003 figures were tallied, according to the National Association of State Budget Officers. The federal government stepped in with a one-time infusion of extra cash for state Medicaid programs — a total of $10 billion paid out last year and this year. Between 1990 and 2000, Medicaid prescription costs rose fourfold — from $5.1 billion to $20.9 billion, according to the federal Center for Medicare and Medicaid Services.

4.2.3 Private Mental Health Insurance

As noted above, most Americans (84 percent) have some sort of insurance coverage— primarily private insurance obtained through the workplace. However, its adequacy for mental health care is extremely variable across types of plans and sponsors.

4.2.3.1 Basic Elements Of Private Mental Health Insurance Coverage

Historically, mental health coverage has been more limited than coverage for other medical services. Health plans have tended to require higher co-payments and to set more stringent limits on inpatient hospital days and outpatient visits for mental health treatment. Plans have also limited mental health coverage through the use of annual and lifetime dollar limits. Many have seen these restrictions as a reflection of the stigmatization of mental illness which remains a serious barrier to the provision of adequate care.

In recent years, legislation regulating insurance and fundamental changes in the delivery of mental health services have altered the environment in which mental health coverage is bought and sold. Parity legislation that has been introduced in the Congress and many state legislatures aims to eliminate the difference in insurance coverage for mental health care and other medical conditions. However, to date efforts to attain parity have had an uneven fate, with Congress, for example, not yet having passed such legislation.

Likewise, managed care has transformed the delivery of mental health care services over the past decade. Employers and health plans now frequently contract out administration of their mental health benefits to specialty managed behavioural health care organizations (MBHOs). These carve-outs use specialized expertise to manage utilization and to direct care to treatment in provider networks. Mental health is said to be the only sector of health care where managed care has successfully controlled costs.

A recent survey suggests that 98 percent of workers in the United States with employer-sponsored health insurance had coverage for mental health care in 2002. Ninety-six percent of covered workers had inpatient mental health coverage, while 98 percent had outpatient mental health coverage. From 1991 to 2002, the proportion of workers with some form of health insurance who were offered mental health benefits actually increased.

But although most workers with general health insurance were offered some coverage for mental health services in 2002, firms continued to place special limits on mental health benefits. As already noted, federal and state parity laws have been enacted in recent years in an effort to curb these insurance limitations. However, gaps in these federal and state parity laws have meant that differences in coverage between mental health and general medical benefits persist. Data indicates that 74 percent of covered workers were subject to an annual outpatient visit limit, and 64 percent were subject to an annual inpatient day limit. Although health plans have historically attempted to control costs by requiring that enrollees pay more at the point of service for mental health care compared with other medical services, a recent survey indicated that in 2002 only 22 percent of covered workers had higher cost sharing for mental health benefits

4.2.3.2 Organization Of Private Mental Health Coverage

Managed care has greatly altered the organization and delivery of mental health services. As noted earlier, firms increasingly opt to carve out the administration of mental health benefits to specialty companies. These organizations use specialized expertise to establish networks of providers, negotiate volume-related discount contracts, identify evidence-based treatment protocols, and develop other incentive programs to manage utilization and costs.

Health maintenance organizations were the first form of managed care. They initiated the practice of negotiating contracts to provide all medical services on a prepaid, per capita basis. Today, there exist a number of different types of managed care, such as Preferred Provider Organizations (PPOs — managed care plans that contract with networks of providers to supply services) and Point-of-Service plans (POS — managed care plans that combine features of capitated and fee-for-service insurance). As recently as 1988, insurance based on fee-for-service was the predominant method of financing health care, but managed care arrangements (HMO, PPO, or POS plans), now cover the majority of Americans.

In carve-out Managed Behavioral Health Care, segments of insurance risk—defined by service or disease—are isolated from overall insurance risk and covered in a separate contract between the payer (insurer or employer) and the carve-out vendor. Data suggest that about a third of people with employer sponsored health insurance were offered mental health care through carve-outs. Managed care has shown that it is able to reduce the cost of mental health services, but research is just beginning on whether managed care cost-reduction techniques affect access and quality.

There is concern that restrictive cost-containment strategies and various incentives to providers and facilities to reduce specialty referrals, hospital admissions, or length or amount of treatment may ultimately contribute to lowered access and quality of care. Mental health advocates have worried that strict benefit limitations expose people with serious mental illnesses to catastrophic expenses. Prior authorization constitutes an additional

organizational feature of managed behavioral health care. While it can encourage the use of evidence-based protocols by practitioners, prior authorization has also been used to control utilization. Prior authorization rules require physicians to obtain approval from a health plan or a carve-out prior to prescribing treatment. In 2002, half of all covered workers were required to obtain authorization prior to using outpatient specialty mental health services.

Despite the rise of managed care and behavioral health carve-outs, employees still carry a greater out-of-pocket cost burden for the use of mental health services in comparison with other illnesses. The one mental health benefit consistently on a par with general medical insurance is coverage for prescription drugs (although this may be because psychiatric medicines constitute one component of a package of Medicaid benefits and are not 'carved out'). Outpatient psychotropic drugs now constitute the fastest-growing cost in mental health care. According to a recent study, prescription drug use grew from 22 percent of total mental health care spending in 1992 to 48 percent in 1999 among people with employer-based health insurance.

In summary, continued benefit limits combined with powerful managed care techniques to control utilization have contributed to reduced growth in mental health spending compared with health spending overall; however, they also could signal access problems. In this vein, Mr. Hogan remarked that,

> *… managed care, funded adequately and done well, seems to be the best approach. The trouble is, often it is not funded adequately in the States and, if it is done poorly, it becomes a disaster.*

4.3 SERVICE DELIVERY AND ORGANIZATION

As noted earlier, the recent report by the President's Commission on Mental Health concluded that the mental health service delivery system in the United States needs dramatic reform. While many consumers do receive effective treatments and services, many others do not, as they confront a system in which available services are fragmented, driven by complex financing rules and regulations, and restricted by bureaucratic boundaries. As Mr. Hogan told the Committee:

> *There is this paradox of how there are many more services now than there were a decade ago, and the people who are lucky enough to use them do well. However, the fact that there are all these services has made things much more complicated at the community level, so families do not know where to turn when a problem is emerging. That is the challenge of fragmentation.*

The report by the President's Commission suggested that many of these problems are due to the "layering on" of multiple, well-intentioned programs without overall direction, coordination, or consistency. Given this situation, consumers can often feel overwhelmed and bewildered when they must access and integrate mental health care, support services, and disability benefits across multiple, disconnected programs that span Federal, State, and local agencies, as well as the private sector. Recent reports concur that the system's failings

lead to unnecessary and costly disability, homelessness, school failure, and incarceration. Mr. Hogan described the situation in the following terms:

> *The result has been this patchwork quilt where we have all these different federal agencies that have some responsibility for mental health care. They tend to work through the corresponding agency at the state level…The entities at the state level and then at the local level that are responsible for care are different bureaucracies and different systems, creating the situation where the person with mental illness and the family has to navigate what has become a terribly complicated system; and they must do this, by and large, when they are at their worst.*

While many people are given good care and manage to recover, the reality, according to the Interim Report of the President's New Freedom Commission, is that about one out of every two people in the United States who needs mental health treatment does not receive it.[18] Moreover, the individual who succeeds in accessing care may find that many treatments and services are simply unavailable, especially in rural areas. Also, the quality of care may be inadequate. A diagnosis may sometimes be missed, the dose of medication may be insufficient, or the length of treatment too short. For ethnic and racial minorities, the rate of treatment is even lower than that for the general population, and the quality of care is poorer.

At the same time, a recent article pointed out that there are areas where access to services in the United States is improving, in particular with regard to people suffering from serious mental illnesses (SMI). The authors, David Mechanic and Scott Bilder, write that:

> *The good news—contrary to frequent assertions in the mental health community as noted at the outset—is that access to care for people with SMI has improved, and there is evidence of progress even in the more proximate period between 1997 and 2001. People with SMI were more likely to receive mental health specialty services in 2001 than in 1997, but those with [other mental illnesses] and no mental illness each showed declines. Since the latter two populations are much larger than the population with SMI, these decreases in the aggregate may contribute to the perception that services are less available.*

They also note that:

> *Similarly, numbers of mental health providers have risen dramatically. Although the supply of traditional providers such as psychiatrists and psychiatric nurses has increased only modestly, there have been larger increases in psychology and social work and very large increases in counseling and psychosocial rehabilitation. Patient care full-time-*

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18 *Interim Report*, p. 3.

equivalent (FTE) staff in mental health organizations increased from 347,000 in 1986 to 532,000 in 1998.

4.3.1 General/Primary Care

The general medical/primary care sector consists of health care professionals such as family physicians, general internists, paediatricians, and nurse practitioners in office-based practice, clinics, acute medical/surgical hospitals, and nursing homes. More than 6 percent of the adult U.S. population use the general medical sector for mental health care, with an average of about 4 visits per year. The general medical sector has long been identified as the initial point of contact for many adults with mental disorders, and about half of the care for common mental disorders is delivered in general medical settings. Primary care providers actually prescribe the majority of psychotropic drugs for both children and adults.

While primary care providers appear positioned to play a fundamental role in addressing mental illnesses, recent reports have pointed to ongoing challenges in the areas of identification, treatment, and referral. Despite their prevalence, mental disorders often go undiagnosed, untreated, or under-treated in primary care. Although the number identified is increasing, primary care providers' rates of recognition of mental health problems are still low, and referrals from primary care to specialty mental health treatment are often never completed.

4.3.2 Specialty Care

The specialty mental health sector consists of mental health professionals such as psychiatrists, psychologists, psychiatric nurses, and psychiatric social workers who are trained specifically to treat people with mental disorders. The great bulk of specialty treatment is now provided in outpatient settings such as private office-based practices or in private or public clinics. Most acute hospital care is now provided in special psychiatric units of general hospitals or beds scattered throughout general hospitals. Private psychiatric hospitals and residential treatment centres for children and adolescents provide additional intensive care in the private sector. Public sector facilities include state/county mental hospitals and multi-service mental health facilities, which often coordinate a wide range of outpatient, intensive case management, partial hospitalization, and inpatient services. Altogether, slightly less than 6 percent of the adult population and about 8 percent of children and adolescents (ages 9 to 17) use specialty mental health services in a year.

4.3.3 Human Services

The human services sector consists of social services, school-based counselling services, residential rehabilitation services, vocational rehabilitation, criminal justice/prison-based services, and religious professional counsellors. In the early 1980s, about 3 percent of U.S. adults used mental health services from this sector.

4.3.3.1 Employment

People with mental illnesses have one of the lowest rates of employment of any group with disabilities in the United States — only about 1 in 3 is employed. High unemployment

occurs despite surveys that show the majority of adults with serious mental illnesses want to work, and that many could work with help. Unfortunately, according to recent reports, most people with serious mental illnesses do not receive any vocational rehabilitation services at all.

Many consumers with serious mental illnesses continue to rely on Federal assistance payments in order to have health care coverage, even when they have a strong desire to be employed. They face a financial disincentive to achieve full employment because they would lose Federal benefits if they become employed. Since most jobs open to these individuals have no mental health care coverage (according to a large, eight-State study, only 8% of people with mental illnesses who succeeded in returning to full time jobs had mental health coverage), they must choose between employment and coverage. Consequently, they depend on a combination of disability income and Medicaid (or Medicare), all the while preferring work and independence. In fact, they are the largest cohort — 35 percent — of those receiving federal income-assistance checks through the Social Security program for the disabled, called Supplemental Security Income (SSI). In this regard, Mr. Hogan told the Committee that:

> *The biggest single expenditure attributable to mental illness in this country is disability payments for people who have become disabled by mental illness. We send them a cheque every month. It is not adequate enough to live on. Essentially we make a deal with them that they have to stay disabled in order to get that cheque, which is a terrible situation. If we were to provide better care to them and help them get a job — it might not be a full-time, 40-hour job — everybody would be much better off.*

4.3.3.2 Housing

The lack of decent, safe, affordable, and integrated housing is one of the most significant barriers to full participation in community life for people with serious mental illnesses. Today, millions of people in the United States with serious mental illnesses lack housing that meets their needs. The shortage of affordable housing and accompanying support services causes people with serious mental illnesses to cycle among jails, institutions, shelters, and the streets; to remain unnecessarily in institutions; or to live in seriously substandard housing. People with serious mental illnesses also represent a large percentage of those who are repeatedly homeless or who are homeless for long periods of time.

Of the more than two million adults in the U.S. who have at least one episode of homelessness in a given year, 46% report having had a mental health problem within the previous year. A recent study shows that people who rely solely on SSI benefits — as many people with serious mental illnesses do — have incomes equal to only 18% of the median income in the United States and cannot afford decent housing in any of the 2,703 housing market areas defined by the U.S. Department of Housing and Urban Development (HUD).

Federal public housing policies can make it difficult for people with poor tenant histories, substance use disorder problems, and criminal records — all problems common to many

people with serious mental illnesses — to qualify for housing assistance or public housing units.

4.3.3.3 Services For Incarcerated People

About 7% of all incarcerated people in the United States have a current serious mental illness; the proportion with a less serious form of mental illness is substantially higher. People with serious mental illnesses in the U.S. who come into contact with the criminal justice system are often:

- Poor
- Uninsured
- Disproportionately members of minority groups
- Homeless
- Living with co-occurring substance abuse and mental disorders.

They are likely to continually recycle through the mental health, substance abuse, and criminal justice systems.

When they are put in jail, people with mental illnesses frequently do not receive appropriate mental health services. Many lose their eligibility for income supports and health insurance benefits that they need to re-enter and re-integrate into the community after they are discharged.

4.3.3.4 Access To Services In Rural Areas

In rural and other geographically remote areas of the United States, many people with mental illnesses have inadequate access to care, limited availability of skilled care providers, lower family incomes, and greater social stigma for seeking mental health treatment than their urban counterparts. As a result, rural residents with mental health needs in the U.S.:

- Enter care later in the course of their disease than their urban peers
- Enter care with more serious, persistent, and disabling symptoms
- Require more expensive and intensive treatment response.

Compounding the problems of availability and access is the fact that rural Americans have lower family incomes and are less likely to have private health insurance benefits for mental health care than their urban counterparts. Moreover, while most big cities with medical schools have plenty of psychiatrists, smaller cities often do not have enough, and rural areas typically have none.

4.3.3.5 Services To Minorities

Recent reports indicate that the mental health system in the United States has not kept pace with the diverse needs of racial and ethnic minorities, often under-serving or inappropriately serving them. For instance, African Americans are more likely to be over-diagnosed for schizophrenia and under-diagnosed for depression. In general, reports indicate that the system has neglected to incorporate respect or understanding of the histories, traditions, beliefs, languages, and value systems of culturally diverse groups. Misunderstanding and misinterpreting behaviors have led to tragic consequences, including inappropriately placing minorities in the criminal and juvenile justice systems. In this regard, Mr. Emmet told the Committee:

> *In the United States, we are finding that specific communities — that is to say African Americans or the Latino- Hispanic population — really do not avail the public mental health system in great numbers. We know that there is a great deal of stigma involved. We do know, however, that they work through the churches and different community organizations to try to address their problems.*

As a result, American Indians, Alaska Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanic Americans tend to bear a disproportionately high burden of disability from mental disorders. This higher burden does not arise from a greater prevalence or severity of illnesses in these populations. Rather, according to recent reports, it stems from receiving less care and poorer quality of care.

4.3.3.6 Services For Children

Almost 21 percent of children and adolescents (ages 9 to 17) in the United States had some evidence of distress or impairment associated with a specific diagnosis and also had at least a minimal level of impairment on a global assessment measure. Almost half of this group (almost 10 percent of the child/adolescent population) had some treatment in one or more sectors of the de facto mental health service system, and the remainder (more than 11 percent of the population) received no treatment in any sector of the health care system. This translates to a majority of children and adolescents with mental disorders in the U.S. not receiving any care. However, Mechanic and Bilder point to data that indicate that "children's mental health problems are receiving more attention than in earlier periods." In particular, they cite

> *Analyses by Sherry Glied and Alison Evans Cuellar of the 1987 and 1998 National Medical Expenditure Survey [that] noted a 60 percent increase in children with a treated disorder.*

Nonetheless, the General Accounting Office (GAO) recently issued a report that illustrates one serious consequence of the state of mental health services for children and adolescents in the U.S. Thousands of parents have felt themselves obliged to place their children into the child welfare or juvenile justice systems each year so that they may obtain the mental health services they need. Parents who have exhausted their savings and health insurance face the wrenching decision of surrendering their parental rights and tearing apart their families to

secure mental health treatment for their troubled children. The GAO report estimates that, in 2001, parents were forced to place more than 12,700 children in the child welfare or juvenile justice systems as the last resort for those children to receive needed mental health care treatment. According to the President's Mental Health Commission, these numbers are actually likely an undercount because 32 states, including the five largest, were unable to provide data on the number of children affected.

According to the GAO report, several factors contribute to the practice of "trading custody for services," including:

- Limitations of both public and private health insurance
- Inadequate supply of mental health services
- Limited availability of services through mental health agencies and schools
- Difficulties meeting eligibility rules for services.

A lack of access to mental health treatment is thus leading thousands of parents to surrender custody of their children with severe psychiatric disorders to child-welfare agencies and juvenile detention solely to get treatment.

4.4 PROMOTION AND PREVENTION

There are many initiatives underway in the United States with regard to mental health promotion and the prevention of mental illness, substance abuse and addiction. For example, the Committee was told that the National Association of State Mental Health Program Directors is currently in the process of approving a position statement calling for the development of policies and practices for the:

- Promotion of positive mental health,
- Earliest possible identification and intervention in mental health problems,
- Reduction of the incidence of mental illness and suicide,
- Prevention of disability due to mental illness and co-occurring conditions, and
- Prevention of conditions commonly associated with mental illness, including medical illness, substance abuse, and trauma.

To further illustrate the concrete efforts being undertaken in this area, we concentrate below on the National Strategy for Suicide Prevention.

4.4.1 National Strategy for Suicide Prevention

The National Strategy for Suicide Prevention (National Strategy or NSSP) evolved out of a series of initiatives by both governmental and non-governmental actors in the late 90s. In

early 2000, the Secretary of Health and Human Services officially established the National Strategy Federal Steering Group to facilitate its initiation.

The overall aims of the strategy are to:

- Prevent premature deaths due to suicide across the life span
- Reduce the rates of other suicidal behaviors
- Reduce the harmful after-effects associated with suicidal behaviors and the traumatic impact of suicide on family and friends
- Promote opportunities and settings to enhance resiliency, resourcefulness, respect, and interconnectedness for individuals, families, and communities.

The document, *Goals and Objectives for Action* was released in 2001 in order to articulate of a set of goals and objectives and to provide a roadmap for action. It presents the 11 goals and 68 objectives for this component of the National Strategy. A set of activities will be developed for each objective in the next phase of the NSSP.

The goals of the Strategy refer to broad and high-level statements of general purpose that are meant to guide planning around an issue, and that focus on the end result of the work. The objectives of the Strategy narrow the goal by specifying the who, what, when and where associated with obtaining the goal. Finally, activities specify how these objectives will be reached.

The Goals of the Strategy are to:

- Promote awareness that suicide is a public health problem that is preventable
- Develop broad-based support for suicide prevention
- Develop and implement strategies to reduce the stigma associated with being a consumer of mental health, substance abuse and suicide prevention services
- Develop and implement community-based suicide prevention programs
- Promote efforts to reduce access to lethal means and methods of self-harm
- Implement training for recognition of at-risk behavior and delivery of effective treatment
- Develop and promote effective clinical and professional practices
- Improve access to and community linkages with mental health and substance abuse services
- Improve reporting and portrayals of suicidal behavior, mental illness and substance abuse in the entertainment and news media
- Promote and support research on suicide and suicide prevention
- Improve and expand surveillance systems

The National Strategy is designed to serve as a model that can be adopted or modified by States, communities, and tribes as they develop their own suicide prevention plan. In this sense, the National Strategy is seen as articulating a framework for national efforts, while also seeking to assist local groups in making suicide prevention into a higher priority for action.

A significant next step that is envisaged as part of the National Strategy is to develop an operating structure or coordinating body that could become the national focus for prevention activities and provide a mechanism for engaging public will. The document *Goals and Objectives for Action* envisions this body as a public/private partnership, that could shepherd the development of an action agenda, although it acknowledges that, to expedite progress, the development of a coordinating body and an action agenda might have to proceed in tandem.

4.5 PROSPECTS FOR FUTURE REFORM

The President's New Freedom Commission on Mental Health, the first presidential mental health commission in 25 years, published its final report in July, 2003. The Commission was created by the White House in February 2001 as part of a broad cross-disability action plan, the New Freedom Initiative, that encompassed ten proposals designed to "tear down the barriers that face Americans with disabilities today."

Because Presidential attention to mental health is rare, the Commission set itself the goal of galvanizing change at all levels—not just in the federal government. Drawing on the experience of past commissions, the New Freedom Commission concluded that its objective should be to foster progress by staged, incremental, changes in major federal programs such as Medicaid, Medicare, and Social Security, rather than by seeking "big-bang" reform measures or increased support for specific mental health programs. Mr. Hogan explained the strategy behind the report to the Committee in these terms:

> *The logic of what our group proposed was to try to sidestep the notion of reform or reorganization. We had a sense that reform had gotten us into this mess, and we had to have a different language or concept. We ended up being galvanized around this notion of transformation. We do not know exactly what it means, but we think that this transformation means that actions are necessary at many levels. It is not just a federal problem such that the wisdom will flow out of the national capital and local people will adapt. We need local action as well and we need small and large actions, not just large and unachievable actions. For example, creating a situation wherein individual patients and families are more empowered in their own treatment sounds like a small change but, in the long run, it may be more potent or revolutionary than larger changes. We propose the idea of national vision for mental health care and the establishment of national goals, which we hope would serve to motivate and organize people…*

In addition to its interim (October, 2002) and final reports, the Commission also developed a series of detailed reports on components of mental health care that will be published later as working papers, in the hope that this will help create an agenda that could serve the field well in future years.

The interim report identified five major barriers to care:

- Fragmentation and gaps in care for children,
- Fragmentation and gaps in care for adults with serious mental illnesses,
- High unemployment and disability for people with serious mental illnesses,
- Lack of care for older adults with mental illnesses, and
- Lack of national priority for mental health and suicide prevention.

However, the aspect of the interim report that seemed to attract the most attention was the Commission's statement that, "the system is in shambles." This language was criticized by some as too strong, but the Commission stuck by its indictment of what it saw as a failed system in order to set the stage for strong recommendations in its final report.

The Final report is animated by a focus on the idea of recovery. Mr. Hogan told the Committee that they were inspired to adopt this orientation by a remark that former First Lady Rosalynn Carter made to them:

> *Ms. Carter said that…there was one thing that we have going for us today that did not exist a generation ago. One thing has changed that is more significant than anything else: we now understand today that recovery is possible for any individual with a mental illness.*

Recovery is seen by the Commission as a process of positive adaptation to illness and disability, linked strongly to self-awareness and a sense of empowerment that could give people with mental illness a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness. The Commission members united around the view that the possibility of improvement and hope should be available to all individuals who have a mental illness. Mr. Hogan amplified this point in his testimony to the Committee:

> *This is a simple but powerful statement that has several meanings in the mind of our commission. First, it is possible for people to get better even if we might have thought years ago that they were "hopeless cases." Second, even if people have a serious illness that may affect them for a decade or longer, they can achieve a good quality of life with the right kind of support. Recovery is not necessarily just a miracle cure but it can be a case of coping well with a devastating illness. Third, recovery for people in the mental health system is beginning to imply hope as a core ingredient of our approach to care, as opposed to a notion that is more passive and oriented to maintenance.*

In its report, the Commission identified the magnitude of the fragmentation of the system and recognized that the complexity of making changes in mental health care makes reform a daunting task. It was clear to the Commission that no single reform measure is sufficient to produce needed change, but also that simultaneous large-scale reform of multiple programs would be unlikely to lead to the desired change. In particular, the Commission emphasized the importance of developing individualized plans for treatment, although, as Mr. Hogan explained:

> *We do not know exactly how to do this, but we believe we need to move in the direction of care being more individualized and geared to a personalized effort so that the family and the individual have greater input and control of their care plan. That does not imply total control but rather a genuine partnership with professionals, as opposed to simply getting a diagnosis and taking the medicine.*

In order to create a shortlist of benchmarks to be tracked and monitored, the Commission proposed six national goals for mental health care, and organized its nineteen major recommendations around the achievement of these goals (see box below). Mr. Emmet stressed to the Committee that:

> *The six goals for transformation of the system laid out by the commission in its final report are actionable…at the local, state and federal levels. While the commission report is intentionally short on detail, it does provide a very useful and farsighted framework for getting at the central problem that was identified by the Surgeon General in his report — that is, we know what services work but we make it very difficult for those who need them to get them.*

The members of the Commission are under no illusion that their report, no matter how well received it is in the mental health community, will by itself transform a fragmented and often troubled system. However there are some signs that the current U.S. administration is prepared to follow through on implementing the report. The director of the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration (SAMHSA) was charged with taking the lead in developing the implementation approach. The administration also included in its proposed budget for fiscal year 2005 an appropriation of $44 million to fund the implementation of the comprehensive statewide planning recommendation contained in the report. While the budget has yet to be acted on, this proposal has received the strong endorsement of the mental health advocacy community.

The Commission hopes that its diagnosis and treatment plan will be able to build on the many strengths of the system—effective treatments, dedicated clinicians, passionate advocates, and the essential ingredient of hope. As Mr. Hogan noted in an interview, "developing a good treatment plan is necessary—but certainly not sufficient—for progress and recovery."

Mr. Hogan also pointed out that in order to be successful, implementation activities must be both "top-down" and "bottom-up." National leadership is needed for activities such as anti-

stigma campaigns and for change in federal programs, while it is also necessary for people recovering from mental illness to demand greater participation in the development of their treatment plans. In his view, "only time will tell whether participants in mental health care can establish a shared commitment to the changes that are needed and whether the political and economic environments that we work in will allow, support, or thwart change."

It is worth noting that two other pieces of legislation, both with bipartisan support, are currently under consideration. They have been passed by the Senate and are awaiting action by the House of Representatives. The first would provide for youth suicide prevention efforts and counseling for college students. The second is the *Mentally Ill Offender Treatment and Crime Reduction Act*, which would authorize grants supporting collaborative community efforts to divert people with mental illness from the criminal justice system.

GOALS AND RECOMMENDATIONS OF THE PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH

GOAL 1 Americans Understand that Mental Health Is Essential to Overall Health.

- Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.
- Address mental health with the same urgency as physical health.

GOAL 2 Mental Health Care Is Consumer and Family Driven.

- Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.
- Involve consumers and families fully in orienting the mental health system toward recovery.
- Align relevant Federal programs to improve access and accountability for mental health services.
- Create a Comprehensive State Mental Health Plan.
- Protect and enhance the rights of people with mental illnesses.

GOAL 3 Disparities in Mental Health Services Are Eliminated.

- Improve access to quality care that is culturally competent.
- Improve access to quality care in rural and geographically remote areas.

GOAL 4 Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.

- Promote the mental health of young children.
- Improve and expand school mental health programs.
- Screen for co-occurring mental and substance use disorders and link with integrated treatment strategies.
- Screen for mental disorders in primary health care, across the lifespan, and connect to treatment and supports.

GOAL 5 Excellent Mental Health Care Is Delivered and Research Is Accelerated.

- Accelerate research to promote recovery and resilience, and ultimately to cure and prevent mental illnesses.
- Advance evidence-based practices using dissemination and demonstration projects and create a public-private partnership to guide their implementation.
- Improve and expand the workforce providing evidence-based mental health services and supports.
- Develop the knowledge base in four understudied areas: mental health disparities, long-term effects of medications, trauma, and acute care.

GOAL 6 Technology Is Used to Access Mental Health Care and Information.

- Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.
- Develop and implement integrated electronic health record and personal health information systems.

4.6 COMMITTEE COMMENTARY

The Committee feels that there is much to learn from attempts made in the United States to grapple with the consequences of the fragmentation of mental health care services across multiple jurisdictions and various government departments. Fragmentation limits access to services and hampers the ability of service providers to share innovations and spread excellence.

The Committee was therefore very impressed with the general orientation of the report of the President's New Freedom Commission on Mental Health, especially its focus on patient-centred solutions. These include being animated by a vision of recovery for all, as well as insisting on the need to involve consumers in the design and implementation of individualized care plans. The Committee recognizes that there are many obstacles that stand in the way of transforming the Commission's vision into reality, many of which stem from the fragmentation of the system it describes in its reports.

The Committee also noted the strong place accorded to fostering research on mental health and mental illness and to promoting the adoption of technologies that will enhance care and service delivery, and recognizes that this is consistent with the pre-eminent international role occupied by American researchers and scientists.

Moreover, the Committee considers that the Report's emphasis on the provision of appropriate services at a community level is entirely appropriate and extremely important. Similarly, the Committee believes that American experience points to the critical importance of promoting greater cooperation across the various levels of government, and between various departments within each level of government.

Finally, the Committee notes that such an orientation requires a national focus in order to mobilize as many resources as possible, while simultaneously recognizing that efforts must be sustained at every level if reform is to occur. The fact that the New Freedom Commission eschewed a 'big bang' approach echoes the conclusions that the Committee reached with regard to the acute care sector in Canada in its October 2002 report on the Health of Canadians.

CHAPTER 5: COMPARING MENTAL HEALTH CARE IN THE FOUR COUNTRIES STUDIED

5.1 INTRODUCTION

As was noted in the introduction to this report, the complexity of health care systems, both in terms of funding arrangements and service delivery mechanisms, as well as their inextricable connections to the history, politics and culture of each nation, mean that it is never possible simply to transpose measures from one jurisdiction to another. The common nature of many of the issues confronting health care policy makers and practitioners throughout the industrialized world means, however, that there is much that can be gained from careful study of both the successes and failures elsewhere in the world. In this chapter, the Committee draws on its review of the experience of four countries to glean some lessons for efforts in Canada to reform mental health care delivery and enhance the mental health of Canadians. The structure of this chapter follows the template that was used in each of the country studies.

5.2 HISTORY AND OVERVIEW

The Committee notes the striking extent to which the experience of deinstitutionalization is similar in all the countries reviewed. In the first place, roughly the same set of factors provided the impetus for deinstitutionalization in all them. These were:

- the introduction of new treatment methods, especially new drugs, accompanied by
- changing attitudes towards the nature of mental illness, and
- growing belief that treatment was most effective when it took place in the community.

Second, in each of the countries studied (as well as in Canada) the process of closing down old psychiatric hospitals proceeded more quickly than the deployment of new resources into the community, creating many situations where people living with mental illness were left to fend for themselves. Moreover, difficulties associated with the lack of resources to accomplish the shift to the community were often compounded by resistance to this transfer in the communities themselves, where attitudes built up over many years were slow to change.

A third point that is worth noting is the way in which, in several of the countries studied, deinstitutionalization was one of the factors that stimulated efforts to establish a national strategy for improving the delivery of services to people living with mental illness. This prompts the question as to why a similar process of deinstitutionalization that occurred in Canada did not yield the same result in this country, where the country remains without a national mental health, mental illness and addiction strategy of any kind to this day, in contrast to all other G8 countries.

It is tempting to look at the structure of Canadian federalism as one factor that may have played a role in discouraging a national focus on mental health. However, given that coherent national planning began in one of the federal countries studied (Australia) as early as 1992, the factor that explains the different trajectory in Canada cannot be federalism, *per se*.

Rather, a plausible hypothesis might be that because the federal government in Canada is not involved in the delivery of services to the population as a whole, it did not feel the pressure to respond to the massive shifts in service delivery that were occurring on the ground. Still, one could wonder why, given its role in the delivery of services to specific population groups (see Vol. 1, Ch. 9), the federal government did not draw the appropriate lessons from the weaknesses in its own delivery system and realize that the provinces had to be facing similar problems.

Finally, it is relevant to note that the trend for the federal government to transfer funds to the provinces with no strings attached (which culminated in the creation of the CHST in the mid-nineties), left the provinces to cope as best they could with the rapidly changing context in which mental health services were being delivered.

5.3 COSTS AND FUNDING OF MENTAL HEALTH SERVICES

A first point that the Committee wishes to emphasize with regard to comparisons of costs and funding across different countries concerns the comparability of the data. In presenting their data on spending on mental health, the authors of the 2002 National Mental Health Report in Australia make the important point that countries measure mental health spending in very different ways and that it is therefore extremely difficult to make direct comparisons. For example, they note (as indicated in the chapter on Australia) that some countries include amounts that are specifically excluded in Australian estimates such as drug and alcohol services, intellectual disability services, dementia care or housing and income security payments for mental health consumers.

In general, then, it would not appear to be possible to establish guidelines based on best practices with regard to overall mental health spending. However, there is enough data on spending trends over time within each country to draw provisional conclusions about the factors that contribute to greater attention being paid to mental health funding needs, and on ways of ensuring the sustainability of that funding. It is also possible to compare the funding priorities of different countries, although here the variability in the extent of data easily available from one country to the next constrains the robustness of the conclusions it is possible to draw.

Readers may have noticed that the data presented from Australia stands out for its level of detail and for the longitudinal comparisons it affords. The Australians have now produced seven National Mental Health Reports that allow for a much more detailed understanding of the evolution of mental health spending over time than is possible in any of the other countries studied. The Committee believes that this provides a clear indication of the value of consistent data collection and reporting.

Moreover, as the debate over the adequacy of mental health funding in England indicates, it is also important to look not only at absolute increases in the funding for mental health, but also at whether new investments in mental health are keeping pace with those in the broader health care sector. Thus, if growth in mental health spending lags behind growth in overall health care spending, then the relative position of the mental health sector suffers, even if more money is being spent. This is of particular importance in the context of attempting significant reform or when particular efforts are being made to bring spending in mental health into line with broader health spending.

A related point concerns the advisability of 'ring-fencing' mental health spending in order to ensure that funds allocated to treating mental illness do not get absorbed into general health spending, or to guarantee that transfers from one level of government to another represent real increases in mental health spending and are not clawed back by cutting existing services even as new ones are added. The Australian experience in this regard is worth highlighting. As witnesses told the Committee, new federal money was initially ring-fenced, but as the importance of this funding became widely appreciated over time by all levels of government, measures specifically designed to protect mental health resources were no longer needed.

The Committee believes that it is significant that in three of the four countries examined, the development of national mental health strategies correlates with increases in funding for mental health services and activities. As witnesses noted, the existence of a carefully documented set of needs in the mental health sector can constitute a powerful tool in lobbying government for the resources that are required. Moreover, the existence of clear benchmarks and targets are essential to making it possible to monitor the implementation of a national strategy, and to make sure that funding commitments are sustained over time. The evidence clearly indicates that the development and implementation of a national mental health strategy can only be successful if adequate resources are allocated to the task.

The Committee also notes the important efforts being made in some of the countries examined to decentralize funding decisions and bring them closer to the communities in which people live and access services. In particular, the experience of devolving the 'commissioning' of mental health services to the Primary Care Trusts in England provide a valuable reference point for attempts to bring control of funding closer to the ground and to have funding better adapted to local priorities. At the same time, the evidence also indicates that devolution is a complex undertaking and that along with the decentralization of decision-making must come a broad dissemination of the expertise needed to successfully manage the increased budgets involved.

Measures to control escalating costs are also important and, in particular, the rising costs of pharmaceuticals is of ongoing concern. In Canada, particular attention will have to be paid to this question, given the significant variations that exist in publicly funded prescription drug insurance across the country. Finally, the American experience with managed care is also relevant with regard to balancing efforts to contain costs against the importance of ensuring access to needed services and therapies.

5.4 SERVICE DELIVERY AND ORGANIZATION

As noted earlier, the first observation that needs to be made with regard to the delivery of mental health services is that a shift from primary reliance on institutional care to the primary emphasis being placed on services delivered in the community has happened in all the countries studied. This shift has been accompanied by concerns over the adequacy of the resources available at the community level to cope with the demand, as well as by the recognition of the need to coordinate and integrate service delivery so that the many 'silos' are broken down and each person has access to the services they require, regardless of which government department or agency (or non-governmental body) is responsible for their delivery.

Two institutions that stand out as having contributed to facilitating this transition are the independent Mental Health Commission in New Zealand and the National Institute for Mental Health in England (NIMHE). The Committee notes in particular that the former has played an important role both in helping to set service standards and in monitoring the implementation of mental health planning, while the latter has played a vital role in actual implementation and in spreading best practices. It is worth emphasizing that both countries developed highly detailed targets and standards (the Blueprint in New Zealand and the National Service Framework–Mental Health in England) as part of their respective strategies.

The importance placed on the individualization of care plans in New Zealand, the U.S. and England is also highly noteworthy. The growing emphasis on the ability of people living with mental illness to recover as well as on the need for practitioners to develop individualized, consumer-centred (and controlled) plans is having a significant effect on the approach to delivering mental health services in the community.

It would seem fair to conclude, as did Michael Hogan in the United States, that overcoming the fragmentation of service delivery requires action both from the top down and the bottom up. Managing the plethora of agencies and government bodies involved in the delivery of services can be assisted by having some outside, independent body that can take a 'whole-of-government' perspective. At the other end, the individualization of care plans and the coordination of service delivery can help all those who need them to access the services they require.

In every country reviewed, physicians and other providers involved in the delivery of primary care shoulder most of the responsibility for the largest portion of people receiving mental health services. At the same time, people living with serious and persistent mental illnesses continue to rely on the availability of more specialized mental health services. This has presented common challenges in all the countries surveyed. In the first place, there has been concern that family physicians are poorly remunerated for their efforts to provide mental health counseling and treatment by fee for service payment systems. Second, there has been concern that family physicians do not have access to sufficient resources to adequately deal with the scale of the demands they face relating to mental health care. Finally, the relative lack of coordination between primary and secondary care has repeatedly been raised as an issue and points to the crucial importance of delivering integrated, efficient care.

Despite, or perhaps because of, the shift in emphasis to providing care and service delivery in the community, inequities in access persist across a number of axes. It was noted in several countries that services to people living in rural areas are significantly less available than they are to people living in urban areas.

As well, there is widespread agreement that services targeted at minorities are not sufficiently tailored to their needs. Services need to be culturally appropriate if they are to be as accessible to these communities as they are to the majority ones. In particular, the training of health care professionals from minority groups, especially from Aboriginal or Indigenous communities, was identified by several countries as one means of encouraging a greater cultural appropriateness of mental health services.

This ties in with the final point the Committee wishes to note, namely the human resource shortages that exist in all of the countries studied, and that affect just about all providers involved in the delivery of mental health services. Shortages were still noted even in some countries, such as Australia and New Zealand, where increased mental health funding had led to increases in the supply of some provider groups. On the positive side, the Committee was impressed by efforts to formalize and credentialize the qualifications of community mental health workers as one way of increasing the human resource supply.

5.5 PROMOTION AND PREVENTION

The Committee notes that the evidence from its review of four countries would seem to support one of the lessons that was drawn in the recent (June 2004) British report on *Mental Health and Social Exclusion*. It concluded that uncoordinated campaigns of limited duration did not result in measurable change in stigmatizing attitudes, and pointed to the need for long-term funding for efforts to combat stigma and discrimination. On the other hand, according to witnesses and documentary evidence from both Australia and New Zealand, these countries have been able to measure changes in attitudes and behaviours as their ongoing campaigns against stigma and discrimination have unfolded over a number of years.

While it would be unwise to read too much into this evidence, there is nonetheless every reason to see it as supporting the need for sustained funding, long term planning, and ongoing evaluation, if campaigns against stigma and discrimination are to maximize their effect. Moreover, these campaigns would seem to benefit from being adaptable to a variety of circumstances so that they can be acted on by different jurisdictions.

Thus, the 'Like Minds, Like Mine' campaign in New Zealand started out using famous New Zealanders to communicate its message, but later shifted to a focus on 'ordinary' people and their families. It is also worth noting that as they began to see some progress in changing stigmatizing attitudes, the campaign in New Zealand has evolved towards placing greater emphasis on reducing discrimination. Australian experience suggests the value of having campaigns operate at national, regional and local levels, as well as the need to target the stigmatization of specific illnesses alongside broader themes.

The design of the American National Strategy for Suicide Prevention also points to the importance of using national resources in a way that can set an example for smaller

jurisdictions and encourage them to adapt national models to their particular requirements. At the same time, the experience in a number of countries underscores the importance of having a body that can become the focus for national efforts to combat stigma and discrimination and can play a role in coordinating them at the national level.

Building a strategy for monitoring the outcomes of these efforts into the design of the campaigns themselves is also strongly suggested by our international review. This, in turn, points to the need for there to be widespread consultation from the outset amongst the various levels of government, providers, NGOs as well as users of mental health services and their families. In addition, there is evidence that reaffirms the benefits of enabling people with experience of mental disorders to tell their stories as a way of combating stigma, as well as of the importance of working with the media to try to eliminate negative stereotypes and replace them with more positive accounts of people living with mental illness.

Finally, the Committee found that the design of the new English campaign proposed in the report on *Mental Health and Exclusion* to be quite comprehensive, and wishes to highlight its main emphases. It will:

- target key audiences, in particular employers, young people and the media;
- deliver consistent, tested messages under a single brand;
- promote the positive contribution that people with mental health problems can make to society;
- have sustained funding to plan ahead;
- address issues of ethnicity and gender;
- provide a framework and materials to support local campaign work, targeting in particular issues facing deprived neighbourhoods;
- be clearly evaluated by a regular survey.

5.6 PROSPECTS FOR FUTURE REFORM

It is clear to the Committee from this four-country survey that reform strategies must be carefully adapted to the particular circumstances confronted by each country. Not only must the state of mental health services and care be carefully assessed to establish priorities for action, but the complex realities of each country's political system and social values must be taken into account in the design of any reform program.

In this vein, the Committee notes that the precise design and implementation of reform strategies in countries that have unitary forms of government are likely to prove difficult to adapt to the Canadian federal context, where the delivery of health care services to the general population remains the constitutional responsibility of the provinces. Nonetheless, the specific and detailed targets and standards that have been the hallmark of reform efforts in both England and New Zealand (which are both unitary states) provide an invaluable reference point. Moreover, each country, whether it is structured as a unitary or federal state,

has multiple levels within its health care system, and ongoing attempts to coordinate mental health reform across these various jurisdictions constitute a further indication of the importance of undertaking action at all levels.

The Committee also notes the obvious advantages of engaging in a long term, integrated planning process to improve the state of mental health and the delivery of mental health care services in all the countries surveyed. Only such a process allows for the possibility of systematically building on each successive iteration of reform planning, and also greatly increases the chances of adapting reform efforts to changing circumstances.

Finally, the complexity and range of services involved in promoting mental health and providing for the needs of people living with mental illness suggest that a 'big bang' reform initiative that attempts to do everything at once is unlikely to succeed. This further implies that reform efforts must simultaneously tackle problems from the 'top down' and the 'bottom up'.

5.7 COMMITTEE COMMENTARY

With regard to the broad outlines of the mental health strategies that have been adopted in the four countries studied, the Committee believes that there are a number of trends that are worth highlighting:

- A tendency to focus on recovery as the vision that animates mental health thinking, where recovery is understood as a process of positive adaptation to illness and disability that could give people with mental illness a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness;
- A growing emphasis on the need for individualized plans for treatment and care (especially for people living with serious mental illness) as well as a recognition that family and consumer participation in the planning of treatment should be encouraged;
- The reaffirmation of the need to deliver services in the community, as well as insisting on the importance of the ongoing monitoring of their delivery and of striving to integrate them to the greatest extent possible (so that the limitations imposed by service delivery in 'silos' can be overcome);
- The importance of deploying national resources towards mental health promotion, in particular with regard to campaigning against stigma and working to diminish discrimination;
- The need to eliminate disparities in the extent of services available to people, whether these disparities are caused by services being offered in culturally inappropriate ways, or by the unavailability of some services in rural regions of the country.

The unifying factor behind all these elements would appear to be a stronger focus on the organization of services to best meet patient or service user needs, an emphasis the

Committee strongly endorses, and which echoes the patient-centred approach the Committee advocated for the acute care sector as well. The means for achieving these objectives that stands out from our survey of four countries is to set actionable targets that engage the entire mental health community, and to establish measurable criteria for the ongoing monitoring of reform efforts. Comprehensive human resource planning in the mental health field, as well as adequate funding for research and its dissemination are also suggested as key elements of a national strategy to foster mental health and treat mental illness.

APPENDIX A:
LIST OF WITNESSES
IN THIRD SESSION OF THE 37TH PARLIAMENT
(FEBRUARY 2, 2004 – MAY 23, 2004)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alzheimer Society of Canada	Steve Rudin, Executive Director	June 4, 2003	17
As individuals	Thomas Stephens, Consultant	March 20, 2003	11
	Nancy Hall, Mental Health Consultant	May 28, 2003	16
	J. Michael Grass, Past Chair, Champlain District Mental Health Implementation Task Force	June 5, 2003	17
	Loïse David Murray Ronald	February 26, 2003	9
Canadian Academy of Psychiatric Epidemiology	Dr. Alain Lesage, Past President	March 19, 2003	11
Canadian Academy of Psychiatry and the Law	Dr. Dominique Bourget, President	June 5, 2003	17
Canadian Coalition for Senior Mental Health	Dr. David K. Conn, Co-Chair; President, Canadian Academy of Geriatric Psychiatry	June 4, 2003	17
Canadian Institute for Health Information	Dr. John S. Millar, Vice-President, Research and Analysis	March 20, 2003	11
	Carolyn Pullen, Consultant		
	John Roch, Chief Privacy Officer and Manager, Privacy Secretariat		
Canadian Institutes of Health Research	Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health	May 28, 2003	16

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Institutes of Health Research	Jean-Yves Savoie, President, Advisory Board, Institute of Population and Public Health	June 12, 2003	18
	Dr. Rémi Quirion, Scientific Director, Institute of Neurosciences, Mental Health and Addiction	May 6, 2003	14
Canadian Mental Health Association – Ontario Division	Patti Bregman, Director of Programs	June 12, 2003	18
Canadian Paediatric Society	Dr. Diane Sacks, President-Elect	May 1, 2003	13
	Marie-Adèle Davis, Executive Director		
Centre for Addiction and Mental Health	Jennifer Chambers, Empowerment Council Coordinator	May 14, 2003	15
	Rena Scheffer, Director, Public Education and Information Services	May 28, 2003	16
Centre hospitalier Mère-enfant Sainte-Justine	Dr. Joanne Renaud, Child and Adolescent Psychiatrist; Young Investigator, Canadian Institutes of Health Research	April 30, 2003	13
Children's Hospital of Eastern Ontario	Dr. Simon Davidson, Chairman, Division of Child and Adolescent Psychiatry	May 1, 2003	13
CN Centre for Occupational Health and Safety	Kevin Kelloway, Director	June 12, 2003	18
Douglas Hospital	Eric Latimer, Health Economist	May 6, 2003	14
	Dr. James Farquhar, Psychiatrist		
	Dr. Mimi Israël, Head, Department of Psychiatry ; Associate Professor, McGill University		

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Douglas Hospital	Myra Piat, Researcher	May 6, 2003	14
	Ampara Garcia, Clinical Administrative Chief, Adult Ultraspecialized Services Division		
	Manon Desjardins, Clinical Administration Chief, Adult Sectorized Services Division		
	Jacques Hendlisz, Director General		
	Robyne Kershaw-Bellmare, Director of Nursing Services		
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, President and Chief Executive Officer, Warren Sheppell Consultants	June 12, 2003	18
Hamilton Health Sciences Centre	Venera Bruto, Psychologist	June 4, 2003	17
Health Canada	Tom Lips, Senior Advisor, mental Health, Healthy Communities Division, Population and Public Health Branch	March 19, 2003	11
	Pam Assad, Associate Director, Division of Childhood and Adolescence, Centre for Healthy Human Development, Population and Public Health Branch	April 30, 2003	13
Laval University	Dr. Michel Maziade, Head, Department of Psychiatry, Faculty of Medecine	May 6, 2003	14
Louis-H. Lafontaine Hospital	Jean-Jacques Leclerc, Director, Rehabilitation Services and Community Living	May 6, 2003	14
	Dr. Pierre Lalonde, Director, Clinique jeunes adultes		

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
McGill University	Dr. Howard Steiger, Professor, Psychiatry Department; Director, Eating Disorders Program, Douglas Hospital	May 1, 2003	13
Province of British Columbia	Patrick Storey, Chair, Minister's Advisory Council on Mental Health	May 14, 2003	15
	Heather Stuart, Associate Professor, Community Health and Epidemiology	May 14, 2003	15
Queen's University	Dr. Julio Arboleda-Florèz, Professor and head, Department of Psychiatry	March 20, 2003	11
Registered Nurses of Canada	Margaret Synyshyn, President	May 29, 2003	16
Statistics Canada	Lorna Bailie, Assistant Director, Health Statistics Division	March 20, 2003	11
St.Joseph's Health Care London	Maggie Gibson, Psychologist	June 4, 2003	17
St. Michaels Hospital	Dr. Paul Links, Arthur Sommer Rothenberg Chair in Suicide Studies	March 19, 2003	11
Université du Québec à Montréal	Henri Dorvil, Professor, School of Social Work	May 6, 2003	14
	Dr. Michel Tousignant, Professor, Centre de recherche et intervention sur le suicide et l'euthanasie		
University of British Columbia	Dr. Charlotte Waddell, Assistant Professor, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Faculty of Medecine	May 1, 2003	13

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Calgary	Dr. Donald Addington, Professor and Head, Department of Psychiatry	May 29, 2003	16
University of Manitoba	John Arnett, Head, Department of Clinical Health Psychology, Faculty of Medicine	May 28, 2003	16
	Robert McIlwraith, Professor and Director, Rural and Northern Psychology Program		
University of Montreal	Laurent Mottron, Researcher, Department of Psychiatry, Faculty of Medicine	May 6, 2003	14
	Dr. Richard Tremblay, Canada Research Chair in Child Development, Professor of Pediatrics, Psychiatry and Psychology, Director, Centre of Excellence for Early Childhood Development		
	Dr. Jean Wilkins, Professor and Paediatrics, Faculty of Medecine		
	Dr. Renée Roy, Assistant Clinical Professor, Department of Psychiatry, Faculty of Medecine		
University of Ottawa	Tim D. Aubry, Associate Professor; Co-Director, Centre for Research and Community Services	June 5, 2003	17
	Dr. Jeffrey Turnbull, Chairman, Department of Medicine, Faculty of Medicine		

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Toronto	Dr. Joe Beitchman, Professor and Head, Division of Child Psychiatry, Department of Psychiatry; Psychiatrist-in-Chief, Hospital for Sick Children	April 30, 2003	13
	Dr. David Marsh, Clinical Director, Addiction Medicine, Centre for Addiction and Mental Health	May 29, 2003	16

APPENDIX B:
LIST OF WITNESSES
IN THE SECOND SESSION OF THE 37TH PARLIAMENT
(SEPTEMBER 30, 2002 – NOVEMBER 12, 2003)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alberta Mental Health Board	Ray Block, Chief Executive Officer	April 28, 2004	7
Alberta Mental Health Board	Sandra Harrison, Executive Director, Panning, Advocacy & Liaison	April 28, 2004	7
Anxiety Disorders Association of Canada	Peter McLean, Vice-President	May 12, 2004	9
As individuals	Charles Bosdet	April 29, 2004	7
	Pat Caponi		
	Don Chapman		
Australia, Government of (*by videoconference)*	Dermot Casey, Assistant Secretary, Health Priorities and Suicide Prevention Branch, Department of Health and Ageing	April 20, 2004	6
	Jenny Hefford, Assistant Secretary, Drug Strategy Branch, Department of Health and Ageing		
British Columbia Ministry of Health Services	Irene Clarkson, Executive Director, Mental Health and Addictions	April 28, 2004	7
Canadian Association of Social Workers	Stephen Arbuckle, Member, Health Interest Group	March 31, 2004	5
Canadian Medical Association	Dr. Sunil Patel, President	March 31, 2004	5
	Dr. Gail Beck, Acting Associate Secretary General		
Canadian Mental Health Association	Penny Marrett, Chief Executive Officer	May 12, 2004	9

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Nurses Association, the Canadian Federation of Mental Health Nurses and the Registered Psychiatric Nurses of Canada	Nancy Panagabko, President, Canadian Federation of Mental Health Nurses	March 31, 2004	5
	Annette Osten, Board Member, Canadian Nurses Association	March 31, 2004	5
Canadian Psychiatric Association	Dr. Blake Woodside, Chairman of the Board	March 31, 2004	5
Canadian Psychological Association	John Service, Executive Director	March 31, 2004	5
Centre for Addiction and Mental Health	Christine Bois, Provincial Priority Manager for Concurrent Disorders	May 5, 2004	8
	Wayne Skinner, Clinical Director, Concurrent Disorder Program		
	Brian Rush, Research Scientist, Social Prevention and Health Policy		
Centre for Suicide Prevention	Diane Yackel, Executive Director	April 21, 2004	6
Cognos	Marilyn Smith-Grant, Senior Human Resources Specialist	April 1, 2004	5
Correctional Service of Canada	Larry Motiuk, Director General, Research	April 29, 2004	7
	Françoise Bouchard, Director General, Health Services	April 29, 2004	7
Douglas Hospital	Dr. Gustavo Turecki, Director, McGill Group for Suicide Studies, McGill University	April 21, 2004	6
House of Commons	The Honourable Jacques Saada, P.C., M.P., Leader of the Government in the House of Commons and Minister responsible for Democratic Reforms	April 1, 2004	5

Human Resources and Skills Development Canada	Bill Cameron, Director General, National Secretariat on Homelessness	April 29, 2004	7
Human Resources and Skills Development Canada	Marie-Chantal Girard, Strategic Research Manager, National	April 29, 2004	7
Institute of Neurosciences, Mental Health and Addiction	Richard Brière, Assistant Director	April 21, 2004	6
McGill University (*by videoconference)*	Dr. Laurence Kirmayer, Director, Division of Social and Transcultural Psychiatry, Department of Psychiatry	May 13, 2004	9
Mood Disorder Society of Canada	Phil Upshall, President	May 12, 2004	9
Native Mental Health Association of Canada	Brenda M. Restoule, Psychologist and Ontario Board Representative	May 13, 2004	9
New Zealand, Government of (*by videoconference)*	Janice Wilson, Deputy Director General, Mental Health Directorate, Ministry of Health	May 5, 2004	8
	David Chaplow, Director and Chief Advisor of Mental Health		
	Arawhetu Peretini, Manager of Maori Mental Health		
	Phillipa Gaines, Manager of Systems Development of Mental Health		
Nova Scotia Department of Health	Dr. James Millar, Executive Director, Mental Health and Physician Services	April 28, 2004	7
Ontario Federation of Community Mental Health and Addiction	David Kelly, Executive Director	May 5, 2004	8
Ontario Hospital Association	Dr. Paul Garfinkel, Chair, Mental Health Working Group	March 31, 2004	5

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Privy Council Office	Ron Wall, Director, Parliamentary Operations, Legislation and House Planning	April 1, 2004	5
	Ginette Bougie, Director, Compensation and Classification		
Public Service Alliance of Canada	John Gordon, National Executive Vice-President	April 1, 2004	5
	James Infantino, Pensions and Disability Insurance Officer		
Schizophrenia Society of Canada	John Gray, President-Elect	May 12, 2004	9
Simon Fraser University (*by videoconference)*	Margaret Jackson, Director, Institute for Studies in Criminal Justice Policy	April 29, 2004	7
Six Nations Mental Health Services	Dr. Cornelia Wieman, Psychiatrist	May 13, 2004	9
Treasury Board Secretariat	Joan Arnold, Director, Pensions Legislation Development, Pensions Division	April 1, 2004	5
U.S. Campaign for Mental Health Reform	William Emmet, Coordinator	April 1, 2004	5
U.S. President's New Freedom Commission on Mental Health (*by videoconference)*	Michael Hogan, Chair	April 1, 2004	5
United Kingdom, Government of (*by videoconference)*	Anne Richardson, Head of the Mental Health Policy Branch, Department of Health	May 6, 2004	8
	Adrian Sieff, Head of the Mental Health Legislation Branch		

APPENDIX C:
LIST OF INDIVIDUALS WHO RESPONDED TO A LETTER FROM THE COMMITTEE ON PRIORITIES FOR ACTION

CANADIAN RESEARCH GROUP

CancerCare Manitoba	Harvey Max Chochinov, MD, PhD, FRCPC, Canada Research Chair in Palliative Care, Director, Manitoba Palliative Care Research Unit, CancerCare Manitoba, Professor, Department of Psychiatry, Community Health Sciences and Family Medicine(Division of Palliative Care) University of Manitoba
Carleton University	Dr. Hymie Anisman, Canadian Research Chair in Neuroscience, Ontario Mental Health Foundation Senior Research Fellow
Douglas Hospital Reseach Centre	Ashok Malla, MD, FRCP Canada Research Chair in Early Psychosis, Professor of Psychiatry, McGill University, Director, Clinical Research Division
McGill University Health Centre	Eric Fombonne, MD, FRCPsych, Canada Research Chair in Child Psychiatry, Professor of Psychiatry, University McGill, Director, Montreal Children's Hospital
University of Alberta	Glen B. Baker, PhD, DSc, Professor and Chair, Canada Research Chair in Neurochemistry and Drug Development
University of Manitoba – Faculty of Medecine	Brian J. Cox, Ph.D., C. Psych., Canada Research Chair in Mood and Anxiety Disorders, Associate Professor of Psychiatry, Adjunct Professor, Departments of Community Health Sciences and Psychology

DEANS OF MEDICAL SCHOOLS

Kingston General Hospital	Samuel K. Ludwin, M.B.B., Ch., F.R.C.P.C., Vice-President, (Research Development)
McGill University Health Centre	Joel Paris, M.D., Professor and Chair, Department of Psychiatry
University of Alberta	Dr. L. Beauchamp, Dean, Faculty of Eduction
University of Sherbrooke	Pierre Labossière, P. Eng., Ph.D., Associate Vice-Rector, Research
University of Western Ontario	Dr. Carol P. Herbert, Dean of Medicine and Dentistry

ILLNESS RELATED GROUP

Canada's Research-Based Pharmaceutical Companies	Murray J. Elston, President
Eli Lilly Canada Inc.	Terry McCool, Vice-President, Corporate Affairs
GlaxoSmith Kline	Geoffrey Mitchinson, Vice-President of Public Affairs
Merck Frosst Canada	André Marcheterre, President
NSERC	Thomas A. Brzustowski, President
Ontario Mental Health Foundation	Howard Cappell, Ph.,D. (C.Psych) Executive Director
Roche Pharmaceuticals	Ronnie Miller, President & C.E.O.
Schizophrenia Society of Canada	Fred Dawe, President

MENTAL HEALTH ETHICS GROUP

Centre for Addiction and Mental Health	Paul E. Garfinkel, MD, FRCPC, President and CEO
McGill University – Douglas Hospital Research Centre	Maurice Dongier, Professor of Psychiatry

Parkwood Hospital, St.Joseph's Health Care London	Maggie Gibson, Ph. D., Psychologist, Veterans Care Program
Queen's University	J. Arboleda-Florèz, Professor and Head, Department of Psychiatry
Salvation Army – Territorial Headquarters Canada and Bermuda	Glen Shepherd, Colonel, Chief Secretary
St-Paul's Hospital	Mark Miller, C.S.s.R., Ph.D. Ethicist
University of Alberta	Wendy Austin, RN, Ph. D., Canada Research Chair, Relational Ethics in Health Care, Faculty of Nursing and John Dosseter Health Ethics Centre
University of Alberta, Faculty of Nursing	Genevieve Gray, Dean and Professor, Faculty of Nursing
University of British Columbia	Peter D. McLean, Ph.D. Professor and Director, Anxiety Disorders Unit
University of Western Ontario	Nancy Fedyk, Executive Assistant to the Dean
Winnipeg Regional Health Authority	Linda Hughes, Chair, WRHA Mental Health Ethics Committee
York University	David Shugarman, Director

PRESIDENT OF UNIVERSITY

Institute of Mental Health Research – University of Ottawa	Zul Merali, Ph. D., President and CEO
McGill University	Heather Munroe-Blum, Professor of Epidemiology and Biostatistics
University of Lethbridge	Lynn Basford, Dean, Health Sciences

GOVERNMENT RESPONSIBILITY

Canadian Coalition for Seniors	J. Kenneth Le Clair, MD, FRCPC, Co-Chair, Canadian Coalition for Seniors Mental Health, Professor and Chair, Geriatric Division, Department of Psychiatry, Queen's University, Clinical Director, Specialty Geriatric Psychiatry Program
Canadian Coalition for Seniors Mental Health	David K. Conn, MB., FRCPC, Co-Chair Canadian Coalition for Seniors Mental Health, Psychiatrist-in-Chief, Department of Psychiatry, Baycrest Centre for Geriatric Care, Associate Professor, Department of Psychiatry, University of Toronto, President, Canadian Academy of Geriatric Psychiatry
Canadian Institute of Health Research	Dr. Jeff Reading, PhD, Scientific Director – Institute of Aboriginal Peoples's Health
Canadian Mental Health Association	Bonnie Pape, Director of Programs & Research, Canadian Mental Health Association – National Office
Dalhousie University – Department of Psychology	Patrick J. McGrath, OC, PhD, FRSC, Co-ordinator of Clinical Psychology, Killam Professor of Psychology, Professor of Pediatrics and Psychiatry, Canada Research Chair, Psychologist IWK Health Centre
Dalhousie University, Faculty of Medicine	David Zitner, D. Ph., Director, Medical Informatics
Department of Health and Wellness New-Brunswick	Ken Ross, Assistant deputy Minister
Douglas Hospital Research Centre	Michel Perreault, Ph. D., Researcher, Douglas Hospital, Professor, Department of Psychiatry McGill University
Douglas Hospital Research Centre - Institute of Neurosciences, Mental Health and Addiction	Rémi Quirion, Scientific Director, (INMHA)

Faculty of Medicine – University of Ottawa	Jacques Bradwejn, MD FRCPC, DABPN, Chair of the Department of Psychiatry, Psychiatris-in-Chief, Royal Ottawa Hospital, Head of Psychiatrist, The Ottawa Hospital
Family Council: Empowering Families in Addictions and Mental Health	Betty Miller, Coordinator, The Family Council
Global Business and Economic Roundtable on Addiction and Mental Health – Affiliated with the Centre for Addiction and Mental Health	Bill Wilkerson, Co-Founder and Chief Executive Officer
Human Resources Development Canada	Deborah Tunis, Director General, Office for Disability Issues
McGill University Health Centre	Juan C. Negrete, MD, FRCP(C) Professor of Psychiatry, McGill University, Chair, Addictions Section, Canadian Psychiatric Association
McMaster University	Dr. Richard P. Swinson, MD, FRCPC, Morgan Firestone Chair in Psychiatry, Psychiatry & Behavioural Neurosciences, McMaster University, Chief, Department of Psychiatry, St.Joseph's Healthcare
NAHO National Aboriginal Health Organization	Judith G. Bartlett, M.D. CCFP, Chairperson
Ottawa Hospital	Paul Roy, MD, FRCPC, Assistant Professor of Psychiatry, University of Ottawa, Director, Ottawa First Episode Psychosis Program
Royal Ottawa Hospital	J. Paul Fedoroff, M.D., Associate Professor of Psychiatry, University of Ottawa, Research Director, Forensic Unit, Institute of Mental Health Research
Six Nations Mental Health Services	Cornelia Wieman, M.D., FRCPC, Psychiatrist
Syncrude	Eric P. Newell, Chairman & Chief Executive Officer

University of British Columbia – Mental Health Evaluation & Community Consultation Unit, Department of Psychiatry	Elliot Goldner, MD, MHSc, FRCPC, Head, Division of Mental Health Policy & Services
University of Ottawa – Office of the Vice-President, Research	Yvonne Lefebvre, Ph.D., Associate Vice-President, Research
University of Ottawa- School of Psychology	John Hunsley, Ph.D., C. Psych., Professor of Psychology
University of Toronto – Sunnybrook & Women's College Health Sciences Centre	Nathan Herrmann, M.D., F.R.C.P. (C)

SENATE SÉNAT
CANADA

RAPPORT 2

Politiques et programmes de certains pays en matière de santé mentale

Rapport provisoire du
Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

L'honorable Michael J.L.Kirby, *président*
L'honorable Wilbert Joseph Keon, *vice-président*

Novembre 2004

TABLE DES MATIÈRES

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ORDRE DE RENVOI

Extrait des *Journaux du Sénat* du jeudi 7 octobre 2004

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Losier-Cool,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système des soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale ;

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la trente-septième législature soient déférés au Comité ;

Que le Comité présente son rapport final au plus tard le 16 décembre 2005 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 mars 2006.

La motion, mise aux voix, est adoptée.

Le greffier du Sénat,

Paul C. Bélisle

SÉNATEURS

Les sénateurs suivants ont participé à l'étude du Comité sénatorial permanent des affaires sociales, des sciences et de la technologies sur l'état du système de soins de santé (plus particulièrement sur la santé mentale):

L'honorable Michael J. L. Kirby, president du Comité
L'honorable Wilbert Joseph Keon, vice-président du Comité

Les honorables sénateurs:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retraitée)
Douglas Roche (retraité)
Eileen Rossiter (retraitée)
Marilyn Trenholme Counsell

Membres d'office du Comité:
Les honorables sénateurs: Jack Austin P.C. (ou William Rompkey) et Noël A. Kinsella (ou Terrance Stratton)

Autres sénateurs ayant participle de temps à autre à cette étude:
Les honorables sénateurs Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne et Murray.

POLITIQUES ET PROGRAMMES DE CERTAINS PAYS EN MATIERE DE SANTE MENTALE

INTRODUCTION: COMPARAISONS INTERNATIONALES

Le présent document est le deuxième d'une série de quatre rapports produits par le Comité sénatorial des affaires sociales, de la science et de la technologie dans le cadre de son étude sur la santé mentale, la maladie mentale et la toxicomanie. Le premier rapport, intitulé Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada, donne une idée générale des politiques et des services concernant la maladie mentale et la toxicomanie au Canada. Il tire les enseignements qui pourraient être utilement appliqués à la réforme de la santé mentale chez nous à partir d'une analyse des politiques et des programmes de quatre autres pays. Le premier et le deuxième rapports combinés nous ont fourni les données de base pour préparer notre troisième rapport : Santé mentale, maladie mentale et toxicomanie : Problèmes et options. Celui-ci décrit les grands défis associés à la prestation des services de santé mentale et de traitement de la toxicomanie au Canada et propose des politiques pour s'attaquer à certains des problèmes soulevés. Dans son quatrième et dernier rapport, qui sera publié en novembre 2005, le Comité formulera ses recommandations de réforme.

Dans son étude du secteur des soins actifs au Canada, à laquelle il a consacré deux ans, le Comité s'est rendu compte à quel point il est important, dans le domaine de la politique de la santé, de ne pas se limiter à ce qui se passe à l'intérieur de nos propres frontières. C'est ainsi qu'il a consacré un volume entier sur les six concernant l'assurance-maladie, à un survol de l'expérience de plusieurs pays afin de tirer des enseignements susceptibles d'être appliqués au contexte canadien. Ayant constaté le retard relatif du Canada dans l'élaboration d'une stratégie nationale de promotion de la santé mentale et du traitement des maladies mentales, le Comité a éprouvé la nécessité d'effectuer des comparaisons internationales afin de disposer d'une référence valable et d'un repère intéressant en matière de formulation de politiques.

Comme la situation de chaque pays est particulière, la comparaison entre les expériences de chacun est forcément très limitée. Il peut être impossible de transposer les mesures prises d'un pays à l'autre à cause de la complexité des réseaux de soins de santé, tant du point de vue des modalités de financement que de celui des mécanismes de prestation de services, et à cause de l'enracinement de ces réseaux dans l'histoire, la politique et la culture de chaque pays. Cependant, étant donné que dans nos sociétés industrialisées les décideurs et le personnel traitant se heurtent à des problèmes semblables, il y a beaucoup à gagner d'une étude attentive de ce qui fonctionne et de ce qui ne fonctionne pas ailleurs dans le monde.

Qui plus est, il peut être extrêmement utile de disposer d'un cadre de comparaison pour dégager les dilemmes et les défis communs. Un tel cadre peut permettre de formuler des questions pour orienter de futures études, cerner les aspects à débattre et proposer des orientations de politiques. Le présent volume de notre rapport s'articule donc autour de quatre études de pays (l'Australie, la Nouvelle-Zélande, l'Angleterre et les États-Unis) et il se conclut par un chapitre établissant la synthèse des principaux enseignements que le Canada doit retenir.

Dans chaque cas, notre analyse porte sur les mêmes sujets de base, mais elle varie forcément dans le détail en fonction de l'expérience de chaque pays et de la documentation qui était disponible. Dans ses travaux, le Comité a bénéficié d'un sérieux coup de pouce venu d'éminents experts et décideurs de chaque pays étudié. Ces personnes, à qui nous adressons ici tous nos remerciements, ont témoigné par vidéoconférence. Pour effectuer la comparaison en question, le Comité ne disposait pas des ressources nécessaires pour effectuer une recherche poussée sur le terrain et il a donc dû s'en remettre aux documents accessibles sur Internet ou à ceux des collections de la Bibliothèque du Parlement.

Pour ce qui est de la consommation abusive de substances et de la toxicomanie, le Comité s'est, autant que possible, fondé sur les témoignages recueillis lors de ses séances. Toutefois, il est bien conscient qu'il faudrait effectuer beaucoup plus de recherches sur les politiques et les programmes de chaque pays avant d'entreprendre une quelconque comparaison internationale valable à ce sujet.

Pour autant que nous sachions, il n'existe pas de comparaison internationale des politiques et des pratiques en matière de santé mentale qui tienne compte des derniers développements dans les pays étudiés. Du moins, il n'en existe pas qui ressemble à celle que nous présentons dans les chapitres suivants. Cela étant, cette partie du rapport pourrait également aider les décideurs d'autres pays qui s'intéressent à la situation de leur propre système de santé mentale. Pour sélectionner les pays étudiés, le Comité a suivi les recommandations d'experts et de gens de terrain, sans compter que nous avons tenu à choisir des pays dont les systèmes de santé étaient à peu près comparables au nôtre. Le fait qu'il existe un système fédéral dans deux de ces pays (en Australie et aux États-Unis) et un système unitaire dans deux autres (Nouvelle-Zélande et Royaume-Uni) constitue un autre élément de comparaison.

CHAPITRE 1:
LES SOINS DE SANTÉ MENTALE EN AUSTRALIE[1]

1.1 HISTORIQUE ET APERÇU

1.1.1 La prestation des soins de santé généraux en Australie

Étant donné que l'Australie, comme le Canada, a un régime politique fédéral, la responsabilité de son système de soins de santé est partagée entre le gouvernement national (ou du Commonwealth) et les gouvernements infranationaux (c'est-à-dire ceux des six États et des deux territoires). Le gouvernement du Commonwealth joue cependant un plus grand rôle à l'intérieur du système de soins de santé que le gouvernement fédéral au Canada. Les États et les territoires dépendent notamment davantage du gouvernement du Commonwealth que les gouvernements provinciaux ne dépendent du fédéral au Canada pour ce qui est du financement de ces soins. En Australie comme au Canada, les gouvernements locaux (les municipalités) jouent un rôle relativement limité dans les soins de santé.

Le gouvernement du Commonwealth est responsable de la formulation, pour l'ensemble du pays, des politiques d'intérêt général dans les domaines de la santé publique, de la recherche en santé et de la gestion à l'échelle nationale de l'information sur la santé. Il administre « Medicare », qui est le régime national d'assurance-santé financé par l'État, et réglemente l'industrie privée de l'assurance-santé. Il finance et réglemente également les soins dispensés dans les foyers pour personnes âgées et finance et administre conjointement avec les États et les territoires certains soins de santé communautaires et à domicile. Le gouvernement du Commonwealth finance les soins de santé à partir de l'ensemble des taxes et des impôts ainsi que d'un impôt spécial au titre des soins de santé de 1,5 p. 100 prélevé sur le revenu imposable.

Les gouvernements des États et des territoires sont responsables, au premier chef et dans les limites de leur secteur de compétence, de la gestion et de la prestation des services de santé assurés par l'État. Ils fournissent les services de soins hospitaliers actifs et psychiatriques publics et une vaste gamme de services communautaires et de santé publique, ce qui inclut la santé en milieu scolaire, les soins dentaires et la santé des enfants et des mères. Ils territoires sont également responsables de la réglementation des fournisseurs de soins de santé, de la délivrance des permis et de l'agrément des hôpitaux privés. Le financement des soins de

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1 À moins d'indication contraire, les renseignements contenus dans le présent chapitre proviennent des sources suivantes : Commonwealth Department of Health and Ageing (2002) *National Mental Health Report 2002*: *Seventh Report. Changes in Australia's Mental Health Services under the First Two Years of the Second National Mental Health Plan 1998-2000*; Australian Health Ministers, *National Mental Health Plan 2003–2008*; Thornicroft, G. et V. Betts 2002, *International Mid-Term Review of the Second National Mental Health Plan for Australia*; Whiteford, Harvey, Ian Thompson et Dermot Casey, « The Australian Mental Health System, » *International Journal of Law and Psychiatry*, vol. 23, nº 3-4, 2000; Whiteford, Harvey, Bill Buckingham et Ronald Manderscheid, « Australia's National Mental Health Strategy, » *British Journal of Psychiatry* (2002) 180; Groom, Grace, Ian Hickie et Tracey Davenport « *Out of Hospital, Out of Mind!* » avril 2003; *SANE Mental Health Report 2002-03*, SANE Australia; The Mental Health Council of Australia, *Promoting the mental health of all Australians, a 2001 Federal Election Submission.*

santé par les États et les territoires australiens provient essentiellement de subventions du gouvernement du Commonwealth, de l'ensemble des taxes et des impôts et des frais d'utilisation des services de santé.

En Australie, le régime d'assurance-maladie est obligatoire et il garantit donc une couverture universelle. Le régime public d'assurance-santé est plus étendu en Australie qu'au Canada, puisqu'il englobe les médecins, les hôpitaux, les médicaments vendus sur ordonnance et certains soins de santé communautaire et à domicile. Contrairement à ce qui se fait au Canada, il permet d'imposer des frais d'utilisation et une surfacturation pour des services de santé assurés par l'État. Le Medicare australien comporte plus exactement trois grands volets :

- Le Medical Benefits Scheme (MBS), régime d'assurance médicale qui garantit l'accès aux médecins (non rattachés à des hôpitaux). Le MBS répertorie une vaste gamme de services médicaux et prescrit les honoraires qui s'appliquent à chaque élément (les « honoraires prévus »), mais ne rembourse que 85 p. 100 des honoraires inscrits au barème des médecins. Par contre les médecins peuvent charger des honoraires plus élevés que ce qui est prévu au barème.
- Les Australian Health Care Arrangements (AHCA), accords sur les soins de santé qui servent de fondement au financement fournit par le gouvernement du Commonwealth aux États et aux territoires pour les services hospitaliers. Les fonds versés pour ces derniers par le gouvernement du Commonwealth revêtent la forme de subventions annuelles globales dont les montants sont négociés dans le cadre de l'établissement d'ententes quinquennales avec les États et les territoires, qui, en retour, acceptent de ne pas autoriser l'imposition de frais d'utilisation pour les services des hôpitaux publics.
- Le Pharmaceutical Benefits Scheme (PBS), régime d'assurance-médicaments reposant sur un formulaire pharmaceutique national qui assure gratuitement l'accès aux médicaments prescrits à l'extérieur des hôpitaux, sous réserve de seuils annuels. Une fois atteints, ces seuils donnent lieu à de nouvelles réductions des sommes que les particuliers doivent assumer.

En Australie, comme au Canada, quelque 70 p. 100 des dépenses affectées à la santé sont financées par le secteur public (46 p. 100 par le gouvernement du Commonwealth et 24 p. 100 par les gouvernements des États et des territoires) et 30 p. 100 par le secteur privé. La Constitution australienne permet au gouvernement du Commonwealth de percevoir des impôts sur le revenu; celui-ci finance une plus grande proportion des soins de santé que ne le fait le gouvernement fédéral au Canada. C'est le principal assureur public de médicaments vendus sur ordonnance et de services de médecins, puisqu'il finance environ 50 p. 100 des dépenses des hôpitaux.

Les États et, dans une moindre mesure, les gouvernements locaux sont responsables du gros des dépenses publiques. Environ 25 p. 100 de leurs budgets sont affectés aux soins de santé et à peu près 69 p. 100 de ces fonds sont alloués aux hôpitaux publics. Le financement des soins de santé par les gouvernements des États provient principalement de deux sources : premièrement, des recettes générales et des crédits limitatifs ciblés accordés par le

gouvernement du Commonwealth et, deuxièmement, de l'assiette des revenus généraux des États eux-mêmes. Le gouvernement du Commonwealth finance les États par le biais de subventions globales au titre de la santé, qui sont de plus en plus conditionnelles, et de versements inconditionnels de la TPS (taxe sur les produits et les services).

Par rapport à ce qui se fait au Canada, les régimes privés d'assurance-santé australiens s'inscrivent à la fois en complément et en concurrence du régime d'État. Les assureurs privés peuvent offrir les mêmes prestations que celles prévues par le régime public et les Australiens peuvent compléter la couverture de Medicare, mais ils ne peuvent se retirer du système public financé par leurs impôts. En Australie, les régimes complémentaires d'assurance sont tarifiés sans distinction, ce qui veut dire qu'aucun *malus* ni *bonus* n'est imputé aux prestataires en fonction de leur âge, de leur sexe, de leur état de santé ou des risques potentiels qu'ils courent.

Pour ce qui est de la prestation des services, on recense en Australie un petit nombre d'hôpitaux privés à but lucratif bâtis et administrés par des entreprises privées et qui offrent des services hospitaliers en vertu de certaines modalités conclues avec les gouvernements de l'État et des territoires. Il demeure que la plupart des lits pour soins actifs et des cliniques de soins externes d'urgence se trouvent dans les hôpitaux publics. En règle général, les hôpitaux privés offrent des soins non urgents et moins complexes, comme les chirurgies électives simples.

Comme devait l'affirmer M. Dermot Casey, secrétaire adjoint, Direction des priorités sanitaires et de la prévention du suicide au ministère de la Santé et de la vieillesse du gouvernement de l'Australie, durant son témoignage par vidéoconférence :

> *Nous pensons que le secteur privé fait partie intégrante de notre régime de soins de santé. La politique du gouvernement est telle que les gens ont le choix quant à l'endroit où ils reçoivent leurs soins de santé. [...] Nous essayons d'encourager tous les États et les territoires à avoir des établissements privés, car la politique du gouvernement est d'avoir un seul système, mais de multiples choix.*

1.1.2 La stratégie nationale en matière de santé mentale

Depuis 1992, la santé mentale est une priorité pour les gouvernements du Commonwealth, des États et des territoires. Opposition et majorité se sont entendus sur la ligne à tenir pour réformer les soins de santé mentale, ce qui a permis à l'Australie d'appliquer des points de repère internationaux à la définition et l'adoption d'objectifs nationaux en matière de promotion de la santé et de prévention des maladies mentales.

C'est ainsi que la National Mental Health Policy (politique nationale en matière de santé mentale) a été adoptée par tous les États et les territoires et par le gouvernement fédéral en avril 1992. On a appelé cette politique, mise en œuvre au moyen d'une série de plans nationaux en matière de santé mentale d'une durée de 5 ans, la National Mental Health Strategy (stratégie nationale en matière de santé mentale).

Celle-ci a été la première tentative destinée à coordonner, à l'échelle nationale, la mise en place de services publics de santé mentale. On a commencé en Australie, comme dans d'autres pays occidentaux, au milieu des années 60 à réduire rapidement et sans aucune planification le nombre de lits à l'intérieur du réseau public d'établissements psychiatriques. Comme ailleurs, c'est une combinaison d'éléments (c'est-à-dire des traitements à l'aide de nouveaux médicaments, des progrès du côté des pratiques cliniques et l'émergence du mouvement en faveur des droits de la personne qui préconisait l'abolition des systèmes isolant les personnes handicapées de l'ensemble de la collectivité) qui a entraîné en Australie la marche vers la « désinstitutionalisation ».

Selon certaines estimations, le nombre maximum de lits réservés aux soins psychiatriques, environ 30 000, aurait été atteint au début des années 60, époque où la population de ce pays correspondait à peu près à la moitié de sa population actuelle.[2] À ce moment-là, l'isolement et la garde (en milieu fermé) des gens qui souffraient d'une maladie mentale dominaient la culture thérapeutique et bien des lits réservés aux malades psychiatriques étaient situés dans des « asiles » ruraux, loin de leurs familles et de leurs réseaux sociaux. Le surpeuplement de ces établissements était général, puisqu'on entassait souvent souvent jusqu'à 100 patients dans des pavillons normalement destinés à pourvoir aux besoins de 25 personnes. La réduction de la taille des hôpitaux amorcée dans les années 60 s'est cependant inscrite à l'intérieur du cadre d'une politique qui garantissait aucunement la mise sur pied de services communautaires en relève des établissements en voie de dispariton.

La stratégie nationale en matière de santé mentale (SNSM), en partie pensée pour réagir à l'héritage de la réduction non planifiée du nombre de lits réservés aux soins psychiatriques, visait à établir une orientation cohérente qui guiderait une future réforme des services de santé mentale. Cette stratégie, approuvée en 1992 par tous les ministres australiens de la Santé, a établi un cadre de collaboration entre tous les ordres de gouvernement destiné à assurer la poursuite, échelonnée sur 5 ans, de 12 thèmes prioritaires convenus en vertu du First National Mental Health Plan (1993–1998), premier plan national en matière de santé mentale. Ses objectifs consistaient, entre autres, à :

- accroître la proportion de soins psychiatriques actifs pour malades hospitalisés fournis dans les hôpitaux généraux par rapport à celle des soins du même type assurés dans les hôpitaux psychiatriques séparés;
- inclure des services intégrés de santé mentale à l'intérieur de l'ensemble des dispositions relatives à l'organisation des services de santé générale;
- veiller à ce que chaque État, territoire et région aient un plan relatif à la combinaison des services offerts à sa population;
- réduire la taille ou fermer des hôpitaux psychiatriques et, en même temps, fournir suffisamment de services de soins actifs en milieu hospitalier, de services d'hébergement et de services de santé communautaire de substitution;
- accroître le nombre et la gamme de services d'hébergement supervisés offerts en milieu communautaire et assurer d'une gamme suffisante de services pour répondre aux besoins des usagers de soins de santé mentale.

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2 En juillet 2004, la population de l'Australie était estimée à 19 913 000 habitants.

L'adoption du régime national de santé mentale a, par ailleurs, été accélérée par les pressions exercées par le gouvernement du Commonwealth sur l'État et les territoires, comme M. Casey l'a expliqué au Comité :

> *Il est intéressant de noter que l'élan favorable à un changement en Australie est venu en réalité des États et des territoires qui demandaient au gouvernement fédéral d'assumer un rôle et d'intervenir en matière de soins de santé mentale. […] On a soutenu que le gouvernement fédéral engageait des dépenses très élevées, mais qu'il n'exerçait aucun contrôle en amont, c'est-à-dire en vue d'améliorer ce qui se faisait en santé mentale. Voilà pour le contexte vers la fin des années 80 et au début des années 90.*

Le premier plan national en matière de santé mentale a été suivi d'une seconde mouture que tous les ministres australiens de la Santé ont approuvée en juillet 1998. Ce nouveau plan fournissait un deuxième cadre quinquennal d'action (échelonné de 1998 à 2003) aux niveaux national, des États et des territoires. Il s'appuyait sur les réalisations liées à la politique nationale en matière de santé mentale et sur le premier plan national en la matière. Ce deuxième plan national visait principalement à consolider les réformes effectuées et en apporter dans d'autres domaines en mettant fortement l'accent sur les questions et les interventions reliées à la santé de la population.

Trois autres thèmes prioritaires sont apparus dans ce deuxième plan national :

- promotion et prévention;
- partenariats en matière de réforme et de prestation des services;
- qualité et efficacité.

Un troisième plan national vient d'être adopté. L'avant-dernière partie du présent chapitre en donne un aperçu.

1.1.2.1 L'évaluation de la stratégie nationale en matière de santé mentale

Des experts internationaux qui ont effectué une évaluation à mi-terme de la réalisation du deuxième plan national en matière de santé mentale ont conclu que la Stratégie nationale et les premier et deuxième plans nationaux en matière de santé mentale (qui découlent de la Stratégie) reflètent un leadership exemplaire sur le plan des politiques en matière de santé mentale qui a mené en Australie à d'importantes réalisations dans le domaine, et ce, à tous les niveaux. Parmi les principales réalisations en question, ces consultants internationaux ont souligné l'intégration des évaluations et des interventions en matière de santé mentale à la fourniture des soins ordinaires ainsi que l'inclusion véritable des usagers de services de santé mentale et de leurs soignants dans le processus d'élaboration des politiques en matière de santé mentale, et ce, à tous les niveaux.

Selon les experts internationaux en question, à bien des égards, l'Australie est le chef de file mondial sur le plan de la promotion de la santé mentale, de la prévention de la maladie mentale, des mesures d'intervention précoce adoptées pour la combattre et de la réduction de la stigmatisation s'y rattachant. Ils estiment en outre que l'Australie fixe une norme pour d'autres pays en ce qui a trait à une initiative stratégique nationale qu'il est possible de mettre sur pied, qu'il faudrait lancer et qui montre comment les gouvernements central et les États (ou des provinces) d'un régime fédéral peuvent s'entendre et énoncer des principes en vue pour s'attaquer à des problèmes sociaux et de santé difficiles à régler. Les experts internationaux susmentionnés ont laissé entendre dans leur rapport d'examen qu'aucun autre pays n'a pris le temps de canaliser son capital intellectuel et politique pour élaborer un plan dont les objectifs mesurables sont aussi ambitieux. Ils affirment aussi que la stratégie australienne en matière de santé mentale de même que le premier et le deuxième plan national en matière de santé mentale sont des modèles internationaux pour les politiques dans ce domaine, ce qui a capté l'attention et l'imagination du monde entier.

D'après le Conseil de la santé mentale, principal groupe de pression non gouvernemental en matière de santé mentale, seulement 38 p. 100 des Australiens qui souffraient d'un trouble mental ont cependant pu avoir accès à des services de santé en 1997. Ce conseil a souligné qu'on est encore aujourd'hui grandement insatisfait de bien des aspects des services de santé mentale en Australie, malgré les progrès réalisés dans la foulée de la stratégie nationale en matière de santé mentale.

1.2 COÛTS ET FINANCEMENT DES SERVICES DE SANTÉ MENTALE

Les dépenses pour les services de santé mentale[3] effectuées en Australie par des tierces parties bailleurs de fonds (soit les gouvernements du Commonwealth, des États et des territoires ainsi que les assureurs privés) ont atteint 2,6 milliards de dollars australiens en 1999-2000,[4] ce qui représentait environ 6,6 p. 100 de l'ensemble des dépenses brutes courantes affectées aux services de santé. Sur ces 2,6 milliards de dollars australiens, les États et les territoires en ont dépensé 1,6 en tout, le gouvernement du Commonwealth, 884 millions et les fonds privés de santé, 120 millions, soit, respectivement, 60,8, 34,5 et 4,7 p. 100.

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3 Les estimations de dépenses fournies ici sont tirées du *National Mental Health Report (2002)* et n'englobent que la fourniture des « specialized mental health services » (services spécialisés de santé mentale). Elles excluent une vaste gamme de services dont ont besoin les gens atteint d'une maladie mentale, comme les services médicaux et hospitaliers généraux, de logement, de sécurité du revenu, d'emploi et de formation et les programmes généraux de soutien communautaire. On a noté dans le rapport susmentionné que les comparaisons au niveau international des dépenses au titre de la santé mentale de l'Australie exprimées sous forme de part du total des dépenses au titre de la santé ne sont pas fiables, parce qu'on utilise d'un pays à l'autre des méthodes différentes pour comptabiliser de telles dépenses. On inclut, par exemple, dans certains pays dans les limites des dépenses en question pour des montants qui sont expressément exclus des estimations australiennes comme les sommes consacrées aux services assurés aux alcooliques, aux toxicomanes et aux handicapés intellectuels, aux soins fournis aux personnes souffrant de démence ou au logement de toutes ces catégories de patients et aux versements de prestations de sécurité du revenu aux usagers de soins de santé mentale.

4 Le 9 août 2004, le dollar australien valait un peu plus de 94 cents canadiens.

On constate que les dépenses courantes pour les services de santé mentale en Australie, dépenses effectuées par les principaux responsables du financement, ont augmenté de 44 p. 100 en tout dans la période d'application de la SNSM (entre 1993 et 2000; dépenses exprimées ici en prix constants de 2000). Les dépenses allouées aux services de santé se sont accrues de 42 p. 100 dans la même période, ce qui signifie que les dépenses affectées aux soins de santé mentale ont relativement augmenté, mais n'y ont pas grimpé de façon significative.

Si le pourcentage du total des dépenses au titre de la santé consacrées aux services de santé mentale et aux activités qui s'y rattachent est demeuré relativement stable dans la période d'application de la SNSM, le gouvernement du Commonwealth australien a porté sa part du total des dépenses nationales affectées aux services de la santé mentale, passant de 27 p. 100 en 1992-1993 à 35 p. 100 en 1999-2000. Le principal élément moteur de cette augmentation, qui représente 68 p. 100 de la hausse des dépenses du gouvernement du Commonwealth australien, a été la croissance des coûts des médicaments utilisés en psychiatrie et fournis par l'entremise du Pharmaceutical Benefits Scheme. Les dépenses de ce dernier pour les médicaments utilisés en psychiatrie ont augmenté de 402 p. 100 entre 1992-1993 et 1999-2000, ce qui correspond à presque 4 fois le taux d'accroissement de l'ensemble des dépenses du PBS (105 p. 100) enregistrées dans la même période.

L'Australian Institute of Health and Welfare, institut de la santé et du bien-être de l'Australie, estime que pour 1996, il fallait attribuer aux troubles mentaux environ 30 p. 100 du fardeau financier dû aux maladies non mortelles et 27 p. 100 des années de travail et d'études perdues en raison de handicaps. Il estime également que les pertes de productivité découlant de troubles de santé mentale coûtent 5 milliards de dollars australiens par année. Selon cet organisme, les gens qui souffrent de troubles mentaux sont, en Australie, la cause de 5 fois plus de jours de travail perdus annuellement que ceux et celles qui souffrent de troubles somatiques, et que cela représente chaque année 70 millions de jours de travail et d'études.

Depuis l'entrée en vigueur de la politique nationale en matière de santé mentale originale, les Australiens veillent à ce que les économies qui découlent de la réduction planifiée du nombre et de la taille des hôpitaux psychiatriques autonomes soient réaffectées à la mise sur pied de nouveaux services de santé mentale. Tous les ordres de gouvernement ont pris l'engagement de maintenir leurs budgets d'une façon ou d'une autre afin qu'une réduction simultanée du financement des soins de santé mentale par les États et les territoires ne réduise pas à zéro les gains obtenus grâces aux économies ni les fonds additionnels dérivés de la SNSM. L'entente entre gouvernements destinée à conserver les ressources affectées à la santé mentale comportait deux volets :

- l'engagement de maintenir le niveau des dépenses affectées aux services de santé mentale;
- l'engagement aussi de réinvestir les ressources libérées à la suite de la fermeture ou de la rationalisation de services de santé mentale dans des programmes de santé mentale.

À cet égard, M. Casey a déclaré au Comité que les tentatives visant à maintenir le niveau de financement des soins de santé mentale ont si bien abouti que plus aucune mesure n'est nécessaire sur ce plan :

> *En fait, l'une des craintes du gouvernement fédéral, il y a dix ans, c'était que si nous donnions de l'argent pour la santé mentale, les États et les Territoires se contenteraient de le prendre et de le consacrer à autre chose. Nous avions une entente stipulant qu'ils maintiendraient leur niveau de financement si le gouvernement fédéral augmentait le montant total. Nous avons suivi à la trace l'argent dépensé, et les États et Territoires devaient faire rapport à une instance de contrôle des dépenses. Nous n'avons plus besoin de ce système aujourd'hui, dix ans plus tard, parce que conscients de l'importance de cet aspect à leur niveau et de la controverse politique que cela occasionnerait dans les collectivités, les gouvernements ne dépenseraient pas ces montants à d'autres fins.*

Les changements apportés dans la période qui a suivi l'adoption de la SNSM visaient à réduire la dépendance de l'Australie envers les soins en établissement, à renforcer les solutions de rechange en matière de soins de santé communautaire et à commencer à combler l'insuffisance des réseaux de services de santé mentale constatée lors des nombreuses enquêtes menées au cours de la décennie précédente. Dans les cinq premières années d'application de la SNSM :

- les dépenses affectées aux services communautaires ont augmenté de 87 p. 100 en chiffres absolus;
- les ressources libérées à la suite de la réduction du nombre/de la taille des établissements hospitaliers ont été réinvesties dans des services de rechange et ont fourni environ la moitié des fonds additionnels utilisés pour développer les services communautaires.

À partir de 1998-1999, les dépenses affectées aux hôpitaux psychiatriques séparés ont été réduites de 13 autres pour cent si bien qu'en 1999-2000, les établissements psychiatriques autonomes ne représentaient que 23 p. 100 du total des dépenses allouées aux services de santé mentale (comparativement à 49 p. 100 en 1992-1993). En outre, les dépenses affectées aux services communautaires ont augmenté de 16 p. 100 durant cette période, ce qui a porté l'augmentation des dépenses allouées à ces services depuis l'entrée en vigueur de la SNSM à 117 p. 100 en tout. Étant donné que les trois quarts environ de la hausse des dépenses effectuées depuis le début de l'application de la stratégie en question ont été affectés aux services de soins ambulatoires.[5] En 1999-2000, 49 p. 100 du total des dépenses consacrées aux services de santé mentale étaient alloués à des services communautaires, contre 29 p. 100 au début de l'application de la stratégie.

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[5] Les soins ambulatoires s'appliquent à tous les services de santé mentale consacrés à l'évaluation, au traitement, à la réhabilitation ou aux soins de patients traités en externe.

Dans le septième rapport national sur la santé mentale (publié en 2002), à la suite de son analyse des tendances observées en dépenses de santé mentale depuis l'application de la SNSM, le ministère de la santé et du vieillissement du Commonwealth australien tire les conclusions suivantes :

- Les engagements pris par tous les gouvernements australiens pour conserver les ressources affectées à la santé mentale durant une période où les choses ont évolué rapidement ont été respectés. Les dépenses qu'ils affectent chaque année à la santé mentale ont progressé de 46 p. 100 en chiffres absolus depuis 1992-1993. Les dépenses allouées à la santé mentale ont, en moyenne, continué d'augmenter chaque année en vertu aux termes du deuxième plan national en matière de santé mentale.
- On dépense maintenant en Australie 778 millions de dollars de plus en fonds publics au titre des services de santé mentale – ou 33 $ de plus par personne et par année – qu'on le faisait dans les débuts de la SNSM. Une bonne partie de cette augmentation est affectée au développement des services communautaires.
- L'augmentation des dépenses affectées à la santé mentale reflète simplement les tendances observées sur le plan de l'ensemble des dépenses allouées à la santé. Résultat : la « part » du total des dépenses en santé consacrée à la santé mentale est demeurée la même et elle n'a pas beaucoup augmenté, même si elle est importante en chiffres absolus.
- Les subventions qu'accorde le gouvernement du Commonwealth aux États et aux territoires en vertu de la SNSM ne représentent que 3 p. 100 de leurs dépenses annuelles à ce titre, mais elles ont permis de générer des fonds pour de nouveaux services et de guider l'ensemble du processus de réforme. La SNSM, fondée sur la collaboration, semble avoir permis d'empêcher un phénomène de transfert des coûts qui inquiète bien de promoteurs d'initiatives de partenariat entre les gouvernements du Commonwealth et des États australiens.

Certains ont cependant fait observer que la SNSM a permis d'accroître et de réaffecter les dépenses pour les services de santé mentale en Australie, mais qu'on alloue encore trop peu de ressources à ce secteur. Des défenseurs et des promoteurs des services de santé mentale soutiennent, par exemple, que le niveau des dépenses affectées à la santé mentale en Australie (6,6 p. 100 du total des dépenses en santé), demeure inférieur à celui des constaté dans des pays comparables, y compris le Canada, la Nouvelle-Zélande et le Royaume-Uni.

1.3 PRESTATION ET ORGANISATION DES SERVICES

En Australie les services en santé mentale sont offerts par le truchement de tout un éventail de programmes. Dans le secteur public, le modèle type de prestation de services spécialisés en santé mentale donne lieu à la fourniture de services à un bassin de population déterminé et il y a intégration des services entre milieu communautaire et milieu hospitalier. On y fournit des services aux malades hospitalisés dans les hôpitaux généraux et dans les hôpitaux psychiatriques séparés. Les services de soins communautaires dans ce pays comprennent une gamme de types de services, y compris des services cliniques, de suivi et de traitements mobiles et d'intervention d'urgence (mobiles également). On pratique souvent la gestion de

cas pour coordonner les services fournis dans différents milieux. Les services de logement, de soutien aux handicapés, d'emploi et de sécurité du revenu sont financés en vertu d'autres programmes gouvernementaux. Les gouvernements des États et des territoires continuent à jouer le rôle le plus important en matière de prestation de services spécialisés en santé mentale parce qu'ils sont, directement ou indirectement, les principaux responsables de la fourniture et de la gestion de la plupart des services.

Le niveau et la combinaison des services fournis aux malades hospitalisés ont énormément changé depuis les débuts de la SNSM. Quand cette stratégie est entrée en vigueur, en 1992 :

- 73 p. 100 des lits réservés aux soins psychiatriques étaient situés dans des établissements autonomes;
- 29 p. 100 seulement des ressources allouées à la santé mentale étaient affectées aux soins de santé communautaire;
- les hôpitaux psychiatriques autonomes représentaient la moitié du total des dépenses affectées à la santé mentale par les États et les territoires;
- moins de 2 p. 100 des ressources étaient allouées à des programmes non gouvernementaux destinés à aider des gens qui vivaient dans la collectivité.

En juin 2000, les 1 991 lits jusque-là`réservés aux soins psychiatriques dans le secteur public avait été diminués de 25 p. 100. Au début de l'application de la SNSM, 55 p. 100 seulement des lits réservés aux soins psychiatriques actifs étaient situés dans les hôpitaux généraux, proportion qui a grimpé à 73 p. 100 à la fin de la mise en œuvre du premier plan national en matière de santé mentale, en 1998. En juin 2000, au moins 80 p. 100 des lits réservés aux soins psychiatriques actifs étaient situés dans les hôpitaux généraux à cause de la réduction alors en cours des services de soins actifs dans les hôpitaux psychiatriques autonomes et d'une augmentation de 13 p. 100 du nombre de lits (par rapport à 330) dans les services de soins actifs des hôpitaux généraux. Depuis l'entrée en vigueur de la SNSM, le nombre de lits réservés aux soins psychiatriques actifs situés dans les hôpitaux généraux a augmenté de 51 p. 100, soit de 990.

La SNSM ne prescrit pas de niveau optimal ni de combinaison optimale pour ce qui est des services aux patients hospitalisés. Elle reconnaît plutôt les conditions et les contextes historiques différents de tous les secteurs de compétence et la nécessité que les plans en matière de santé mentale reposent sur une analyse des besoins de la population locale. Il peut donc exister d'énormes différences sur le plan des services entre les États et les territoires. On soulignait dans les premiers rapports nationaux sur la santé mentale que les États et les territoires australiens s'entendaient généralement pour disposer d'une vingtaine de lits de soins psychiatriques actifs par 100 000 habitants. Il ne s'est pas encore dégagé de consensus semblable au sujet de la fourniture des lits autres que ceux réservés aux soins psychiatriques actifs.

1.3.1 L'hébergement au sein de la collectivité, les soins ambulatoires et les ONG

La surveillance de l'hébergement au sein de la collectivité, établie selon la SNSM, consiste principalement à déterminer dans quelle mesure chaque État et chaque territoire mettent sur pied des services de logement communautaires de substitution, supervisés 24 heures sur 24. Il a été a proposé de créer des services de ce genre, connus sous divers vocables comme « community care units » (services de soins communautaires) et « psychiatric hostels » (foyers psychiatriques), pour qu'ils prennent la relève des services traditionnellement assurés dans les services de soins de longue durée des hôpitaux psychiatriques. En juin 2000, l'Australie offrait 1 382 lits à l'intérieur de services communautaires d'hébergement supervisés, soit 68 p. 100 de plus qu'en juin 1993.

Au niveau agrégé à l'échelle nationale, cependant, l'augmentation du nombre de lits réservés aux soins psychiatriques dans les services de logement en milieu communautaire supervisés (558) ne représente qu'un quart environ de la diminution des lits de soins de longue durée dans les hôpitaux psychiatriques (2 285). L'essor des services de logement en milieu communautaire a donc été inégal, variant énormément d'un État ou d'un territoire à l'autre. Aucun consensus entre ces derniers ne s'est encore dégagé au sujet de points de référence en matière de planification pour la fourniture de services spécialisés d'hébergement dans la collectivité. Il a été établi que la création d'un nombre insuffisant de services du genre par la plupart des secteurs de compétence constitue un problème important étant donné l'engagement de tous les États et territoires australiens à mettre sur pied une gamme complète de services communautaires pour prendre la relève des services traditionnellement assurés par les hôpitaux psychiatriques autonomes. À ce sujet, M. Casey devait indiquer au Comité :

> *Nous avons effectivement réformé toute la prestation des services. Cependant, ce que nous n'avons pas très bien réussi, c'est d'intervenir au niveau de l'emploi, du logement et des soins sociaux pour faire en sorte que ceux qui souffrent de maladie mentale — je crois que c'est l'expression que nous utilisons actuellement puisque la personne ne guérira pas forcément — sont capables de le faire dans un contexte d'interaction sociale maximale et de participation à la vie sociale qui, comme telles, les aideront à demeurer stables et à se rétablir. Le traitement médical à lui seul n'est pas une réponse adéquate aux problèmes des personnes atteintes de troubles mentaux.*

Les services de soins ambulatoires désignent tous les services de santé mentale qui consistent exclusivement à évaluer, à traiter, à réadapter et à soigner les malades non hospitalisés. Cette catégorie comprend : les services de consultations externes (des hôpitaux et des cliniques); les équipes mobiles d'évaluation et de traitement; les programmes de jour et les autres services qui visent uniquement à évaluer, à traiter, à réadapter et à soigner les personnes souffrant d'une maladie mentale ou d'une déficience psychique qui vivent dans la collectivité. En 1999-2000, on comptait 90. p. 100 de plsu de personnel clinique affecté à la fourniture de soins ambulatoires en santé mentale que durant l'année de référence (antérieure à la date d'application de la SNSM), ce qui représente environ 3 000 personnes de plus.

Dans le cadre de la SNSM, on a aussi prévu que les organisations non gouvernementales (ONG) à but non lucratif joueraient un rôle clé dans la prestation des services de soutien aux usagers de soins en santé mentale et à leurs soignants. Le secteur des ONG offre une vaste gamme de services, y compris des programmes d'extension des services à domicile pour aider les gens qui emménagent dans leur nouveau chez-soi, des services de remise en état des logements, des programmes de loisirs, des groupes d'entraide et de soutien mutuel ainsi que des services de relève des soignants et de défense et de promotion des droits des malades dans tout le réseau de la santé.

Dans le premier rapport national sur la santé mentale en Australie, on pouvait lire que le financement octroyé aux ONG était limité et que les services nécessaires pour aider les soignants de personnes souffrant de troubles mentaux étaient mal conçus dans les premiers temps de l'application de la SNSM. La base de financement du secteur des ONG s'est relativement améliorée entre 1993 et 1998, sa part des dépenses annuelles consacrées à la santé mentale ayant grimpé de 2 à 5 p. 100 durant cette période, avant de passer à 5,4 p. 100 en 1999-2000.

Le rôle que jouent les ONG varie d'un ressort à l'autre, ce qui reflète les différences sur le plan de l'organisation et de la prestation des services. Dans certains secteurs de compétence, les services fournis par les ONG remplacent de plus en plus ceux jadis assurés par le secteur gouvernemental ou les services cliniques. L'État de Victoria, par exemple, a transformé les ONG à but non lucratif en principaux fournisseurs de programmes de réadaptation psychosociale, dont beaucoup étaient précédemment limités à des services cliniques, et finance les nouveaux types de services de soutien en cas de déficience psychique. La SNSM n'a pas encore permis de dégager un consensus national au sujet des modèles de prestation de services souhaitables pour le développement du secteur des ONG.

1.3.2 Les resources humaines

Le personnel des services de santé mentale en Australie est, actuellement, surtout composé d'omnipraticiens, de psychiatres, d'infirmières et infirmiers spécialisés en santé mentale, d'ergothérapeutes, de psychologues et de travailleurs sociaux. On estime que le personnel clinique employé dans les services publics de santé mentale a augmenté de 15 p. 100 depuis l'adoption de la SNSM, ce qui équivaut à une environ 2 100 employés de plus. La moitié de cette augmentation a été enregistrée pendant l'application du deuxième plan national en matière de santé mentale.

Cet accroissement du personnel s'est accompagné de changements tant sur le plan des installations que sur celui de la composition des effectifs. Une plus grande proportion du personnel clinique travaille maintenant à l'extérieur des hôpitaux et dispense des traitements au sein d'une gamme de milieux communautaires. En outre, le personnel clinique représentait une plus grande proportion (79 p. 100) du total des effectifs en 1999-2000 qu'au début de l'application de la SNSM (70 p. 100, d'après les estimations). Ce changement s'est produit pendant l'intégration des services et leur transfert au milieu communautaire. Depuis le début de l'application de la SNSM :

- le personnel des services en milieu hospitalier a diminué de 14 p. 100 en tout (il représentait 53 p. 100 de l'ensemble des effectifs en 1999-2000 contre 71 p. 100 en 1992-1993);
- les effectifs des services de soins ambulatoires et des services en milieu d'hébergement ont augmenté de 87 p. 100 (ils représentaient 47 p. 100 du personnel affecté à la prestation de services en 1999-2000 contre 29 p. 100 en 1992-1993);
- le personnel médical s'est accru de 27 p. 100 (il équivalait à 11 p. 100 du personnel clinique en 1999-2000);
- l'effectif paramédical (psychologues, travailleurs sociaux, ergothérapeutes et autres thérapeutes) a augmenté de 55 p. 100 (contre 21 p. 100 du total des effectifs en 1999-2000);
- le personnel infirmier s'est accru de 7 p. 100 (il constituait 65 p. 100 de l'ensemble du personnel clinique en 1999-2000).

En même temps, tous les ressorts ont signalé des pénuries de personnel qui sont particulièrement graves dans le secteur des soins infirmiers, ce qui influe tant sur la quantité que sur la qualité des soins de santé. Des rapports indiquent que les taux de conservation des effectifs diminuent actuellement dans toutes les disciplines de la santé mentale et que le nombre de nouveaux diplômés n'est peut-être pas suffisant pour faire face au fardeau qu'impose la maladie mentale.

Par ailleurs, il existe encore entre les États et les territoires des iniquités sur le plan du nombre de professionnels de la santé mentale dans le secteur public. Ce sont surtout les États et les territoires qui ont de vastes régions rurales qui éprouvent de la difficulté à recruter suffisamment de personnel qualifié. Comme il existe peu de normes pour aider les États et les territoires australiens à prévoir leurs besoins de main-d'œuvre, il reste bien des défis à relever. Par exemple :

- L'effectif infirmier semble trop insuffisant pour doter ne serait-ce que les postes actuels. L'avenir est encore plus décourageant, puisque ce personnel vieillit, qu'il n'y a pas suffisamment de recrues pour le remplacer et que la stratégie actuelle des États et des territoires australiens semble consister à débaucher les employés des bassins limités d'autres secteurs de compétence.
- Les psychiatres sont mal répartis et ils sont, en grande partie, établis dans les régions métropolitaines (86,1 p. 100 d'entre eux exerçant dans les capitales, 5,4 p. 100, dans les grandes régions urbaines, 4,9 p. 100, dans les grands centres urbains et 3,5 p. 100, dans les régions rurales et éloignées).
- D'après les normes internationales, les psychologues sont relativement peu nombreux à l'intérieur des services de santé mentale des États et des territoires australiens et ils sont beaucoup trop souvent utilisés comme gestionnaires de cas génériques. Leur utilisation comme gestionnaires de cas dilue souvent inutilement leurs compétences et leurs connaissances spécialisées à un moment où de plus en plus d'éléments prouvent l'efficacité des interventions sur le plan des comportements

cognitifs pour traiter les troubles dépressifs reliés à l'anxiété et les troubles psychotiques.

M. Casey a précisé au Comité que le gouvernement australien a adopté des mesures destinées à faciliter la prestation de soins aux personnes souffrant de maladie mentale par les médecins primaires. Il nous a notamment décrit un programme adopté par le gouvernement fédéral il y a trois ans dont l'objet est de récompenser financièrement les omnipraticiens qui consacrent davantage de temps aux personnes ayant des problèmes de santé mentale. Ce programme, nous a-t-il déclaré :

> *[…] donne la possibilité [aux omnipraticiens] de faire intervenir des psychologues comme membres essentiels de l'équipe de traitement de la maladie mentale et cela améliore leur formation et leurs connaissances et leur assure des services de consultation d'urgence de manière qu'ils ne se sentent pas seuls pour régler le problème lorsqu'ils acceptent de s'occuper des problèmes de santé mentale de leurs patients. On nous a dit que si vous êtes omnipraticien et que quelqu'un se présente à votre cabinet et que vous pensez que cette personne a un problème de santé mentale, vous restez silencieux, parce que si vous ouvrez le dialogue, vous serez encore là vingt ou trente minutes plus tard et, évidemment, le paiement à l'acte est le mode de traitement en vigueur. Nous les avons encouragés en leur disant que si cela prend vingt minutes, nous allons les payer davantage pour avoir consacré ce temps aux malades. À l'heure actuelle, environ 15 p. 100 de notre main-d'oeuvre d'omnipraticien s'est inscrite à ce programme. Nous disposons donc de 3 500 omnipraticiens qui participent à ce programme et qui se reconnaissent comme des gens qui peuvent offrir un peu plus de soins en santé mentale et des soins un peu meilleurs. Il s'agit d'un nouveau programme.*

1.3.3 Les services de santé mentale du secteur privé

La priorité du deuxième plan national australien en matière de santé mentale était le renforcement des rôles complémentaires en santé mentale entre les services du secteur public et ceux du secteur privé. Ce dernier offre une gamme de services de soins de santé mentale, y compris des services fournis par des psychiatres de pratique privée qui sont financés grâce au Medicare Benefits Schedule du gouvernement du Commonwealth et des services de soins hospitaliers et de santé communautaire assurés par des hôpitaux privés, pour lesquels des fonds privés d'assurance-santé versent des prestations.

Les services du secteur privé incluent également des services limités fournis par les hôpitaux généraux et des services assurés par les omnipraticiens et d'autres professionnels de la santé. Les hôpitaux psychiatriques privés dispensent principalement des soins aux malades hospitalisés, ce qui est conforme à l'historique des services de soins de santé en Australie et à la principale façon dont les fonds d'assurance-santé versent des prestations pour la fourniture de soins de santé mentale.

Le secteur privé joue donc un rôle clé dans la prestation de l'ensemble des services. En 1999-2000, ce secteur :

- fournissait 21 p. 100 du total des lits réservés aux soins psychiatriques (par rapport à 14 p. 100 en 1992-1993, en raison d'une augmentation du nombre de lits offerts dans ce secteur combinée à la réduction du nombre de lits offerts dans le secteur public);
- employait, d'après les estimations, 12 p. 100 de tous les professionnels australiens de la santé mentale;
- traitait, toujours d'après les estimations, entre 50 et 60 p. 100 de tous les gens vus par les spécialistes du secteur de la santé mentale.

Voici, à ce sujet, ce que M. Casey a expliqué au Comité :

> *Notre secteur privé est très compliqué, mais il traite une assez grande proportion de la population, et le secteur privé dans son ensemble, psychiatres, médecins de famille et hôpitaux privés, est devenu partie intégrante de la stratégie nationale en matière de santé mentale. Ce n'est pas seulement une stratégie du secteur public. Nous avons obtenu l'adhésion du secteur privé. En un sens, quiconque veut s'occuper de santé mentale dans notre pays doit adhérer au club et être perçu comme partie intégrante de la stratégie, faute de quoi il se retrouve sur la touche quant aux grandes décisions politiques prises à l'échelle nationale.*

On a enregistré d'énormes augmentations dans le secteur des hôpitaux psychiatriques privés depuis l'entrée en vigueur de la SNSM. Le nombre de fournisseurs de soins de santé mentale en milieu hospitalier s'est accru de 36 p. 100 et le nombre de lits pour malades hospitalisés de 28 p. 100 en tout, tandis que les recettes ont progressé de 48 p. 100 entre 1992-1993 et 1999-2000 dans ce secteur. Parallèlement à ces changements, le secteur a transformé son modèle général de prestation de soins en un modèle qui consiste à fournir à ses clients une proportion beaucoup plus élevée de services suivant la formule des soins dispensés le jour de l'admission. De 1992-1993 à 1999-2000, le nombre d'admissions d'une journée a grimpé de 39 à 69 p. 100 de toutes les admissions. On estime qu'en 1999-2000 dans le secteur privé, les recettes des services psychiatriques ont atteint 168,2 millions de dollars, soit une augmentation à prix constant de 48 p. 100 depuis 1992-1993.

Même si 1,47 p. 100 des Australiens voit un psychiatre de pratique privée au moins une fois par an, l'accès à ce genre de service est inégal en raison de la concentration des fournisseurs de soins psychiatriques dans les capitales (Melbourne, Adelaïde et Sydney, en particulier). La répartition des services a peu changé depuis l'entrée en vigueur de la SNSM.

1.3.4 La prestation des services de santé mentale aux aborigènes

Mme Jenny Hefford, secrétaire adjointe, Direction de la stratégie contre la drogue au ministère de la Santé et de la vieillesse, a indiqué au Comité que les aborigènes présentent un tableau de santé moins reluisant que celui des Australiens non aborigènes et que leur espérance de vie est de quelque 20 ans inférieure à ces derniers. Elle devait ajouter :

> *Les aborigènes ont des taux beaucoup plus élevés chez nous pour toutes les toxicomanies. Le taux de tabagisme, par exemple, est beaucoup plus élevé parmi les aborigènes que parmi les autres Australiens. Les problèmes de toxicomanie, surtout l'alcoolisme et l'inhalation d'essence, atteignent des proportions extrêmes dans certaines communautés aborigènes.*

Plusieurs rapports soulignent que la prestation de services de santé mentale destinés aux aborigènes n'est actuellement pas assez adaptée aux spécificités culturelles de ces communautés. Voici certaines des raisons avancées pour expliquer ce manque de pertinence culturelle :

- connaissance et compréhension insuffisantes chez les professionnels de la santé, des points de vue et de la culture des aborigènes;
- connaissance insuffisante des différentes façons dont les gens conceptualisent et définissent la maladie et la santé;
- compréhension limitée de la nature et de l'ampleur des besoins en santé mentale au sein des communautés aborigènes;
- trop petit nombre de consultations menées par les gouvernements et par les professionnels de la santé auprès des aborigènes australiens;
- manque d'éducation et de formation.

M. Casey, quant à lui, a précisé au Comité que les attitudes évoluent et qu'on admet de plus en plus que « les aborigènes ont beaucoup à nous offrir pour ce qui est de comprendre la relation entre la façon dont on fait l'expérience du monde qui nous entoure sous l'angle psychologique et social, et les répercussions que tout cela peut avoir dans la manière de vivre physiquement sa vie en éprouvant un sentiment de mieux-être ».

1.4 TOXICOMANIE ET ABUS DE SUBSTANCES

Mme Hefford a indiqué au Comité que « les dossiers des toxicomanies sont traités à même le volet santé publique », qu'ils sont considérés comme une question relevant de la santé publique plutôt qu'en tant que problème exclusif de santé mentale. Elle a précisé que l'approche australienne reposait sur trois piliers : 1) la réduction de l'offre, c'est-à-dire la surveillance des frontières et la fermeture des laboratoires clandestins afin de retirer le produit de la rue; 2) la réduction de la demande par le recours à des campagnes gouvernementales et à une éducation des jeunes dans les écoles axée sur la drogue; 3) la réduction des préjudices, qui concerne les services de traitement et les programmes d'orientation pour les jeunes, afin de leur éviter d'avoir des démêlés avec la justice.

Elle devait ajouter que le secteur des soins de courte durée, en particulier du côté des hôpitaux, ne joue qu'un rôle très limité. Il administre des programmes de désintoxication et s'occupe des décès causés par les surdoses, quand les choses vont au plus mal. Le secteur des soins primaires, quant à lui, cible essentiellement la dépendance envers les opiacés. Les

médecins de pratique générale prescrivent de la méthadone et les pharmaciens administrent des programmes de distribution de ce produit, programmes dont 30 000 Australiens bénéficient actuellement.

Mme Hefford devait ajouter que « jusqu'à 60 ou 70 p. 100 de la clientèle des services de traitement de la toxicomanie et de l'alcoolisme ont un trouble mental sous-jacent ou non diagnostiqué ». Elle a conclu son propos en affirmant que, même si certains d'entre eux passent encore au travers des mailles du filet, les choses se sont améliorées ces dernières années. Elle a insisté sur la démarche davantage coopérative qui prévaut entre les secteurs et entre les divers ordres de gouvernement.

> *Nous avons maintenant une stratégie dans laquelle le gouvernement fédéral a injecté un milliard de dollars au cours des cinq ou six dernières années. Elle englobe la santé, le maintien de l'ordre, l'éducation et les douanes au niveau fédéral, au niveau des États et au niveau local. Nous croyons mieux travailler en réalité à régler les problèmes grâce à cette approche transsectorielle et transdisciplinaire. Cela signifie, par exemple, que nous avons réussi à lancer des programmes de déjudiciarisation hâtive pour les jeunes qui se font prendre par les policiers en possession de cannabis ou de petites quantités d'autres drogues et auxquels on offre la possibilité de ne pas avoir de verdict enregistré contre eux à condition de se soumettre à une évaluation et à un traitement. Certaines de ces mesures ont connu beaucoup de succès. Ainsi, entre 30 000 et 40 000 jeunes ont été écartés du système judiciaire et ont reçu des traitements grâce à ce processus.*

1.5 PROMOTION ET PRÉVENTION

À la faveur de la SNSM et parallèlement à cette dernière, les Australiens ont administré toute une diversité de projets de promotion de la santé et de prévention de la maladie.

M. Casey a expliqué au Comité que le fait, pour l'Australie, d'avoir « commencé à tenir compte de la population globale en matière de santé mentale » a donné lieu à de vastes campagnes d'information dans le domaine. Dans le milieu des années 90, des campagnes de publicité ont été entreprises à la télévision, au cinéma et dans les journaux avec, pour seul objectif, de sensibiliser la population aux problèmes de santé mentale. Ces actions ont été suivies par des initiatives plus ciblées, notamment par un programme de promotion de la santé mentale au secondaire, ce qui a donné de bons résultats puisque près de 70 p. 100 des écoles l'offrent.

Par ailleurs, une société privée sans but lucratif, financée par le gouvernement, a été créée en octobre 2000 avec pour objectif de mieux faire connaître la dépression. Ce projet, baptisé « *beyondblue* » (plus que du cafard), est administré en partenariat avec les services de santé, les écoles, le milieu de travail, les universités, les médias et les organismes communautaires, et en collaboration avec les personnes souffrant de dépression afin de pouvoir bénéficier de leur

expérience en la matière. Dans le rapport annuel de 2002-2003, le président de *beyondblue*, l'honorable Jeff Kennett, écrit :

> *En 2000, au début du projet, rares étaient ceux qui étaient prêts à prendre publiquement la parole au sujet de la dépression et de leur expérience. Le traitement dans les médias était souvent négatif, les obstacles sur les plans de l'assurance et de l'emploi étaient considérables et il n'existait, à l'échelon national, aucun porte-parole ni aucun service de défense pour ceux et celles atteints de cette maladie. Les médecins généralistes de l'Australie n'étaient pas directement récompensés quand ils offraient de meilleurs services et rien n'était prévu pour favoriser l'accès à des traitements non pharmaceutiques. Si, en 2003, bien des défis demeurent, de grands progrès ont été réalisés sur tous ces plans.*

La National Media Strategy (stratégie nationale d'intervention auprès des médias) est un autre projet dans le cadre duquel le gouvernement a collaboré directement avec les médias afin de promouvoir un discours moins négatif sur la santé mentale et la prévention du suicide. Dans le cadre de cette stratégie, appliquée dans les écoles de journalisme et les universités, on enseigne aux futurs journalistes comment ils devraient traiter de ces questions quand ils en rendent compte à la collectivité en sorte de ne pas stigmatiser ceux et celles qui sont atteints de maladies mentales.

M. Casey a indiqué que ces diverses initiatives ont permis d'améliorer « la sensibilisation de la population australienne à l'égard de la maladie mentale d'environ 10 p. 100 depuis 1996 », et il devait ajouter :

> *[…] nos données sur les prises de contact avec les hôpitaux et sur des prises de contact avec les services de santé révèlent que la proportion de la population qui cherche à obtenir des soins est plus grande qu'au moment où nous avons réalisé notre étude épidémiologique. Nous pourrions en conclure qu'au moins les gens sont maintenant plus prêts à chercher un traitement — et, évidemment, il y a de nombreux traitements efficaces.*

1.5.1 La prévention du suicide

L'Australie dispose d'un cadre d'action en matière de prévention du suicide et de l'automutilation baptisé *Living Is For Everyone* (LIFE) (La vie pour tous). Ce cadre traite du suicide dans toutes les tranches d'âge, mais il concerne particulièrement les adolescents et les jeunes adultes chez qui on peut le plus déplorer le caractère prématuré du décès et la perte de potentiel.

Le cadre LIFE obéit à quatre grands objectifs :

- Réduire les décès dus au suicide dans toutes les tranches d'âge de la population australienne et réduire les pensées suicidaires, les comportements suicidaires ainsi que les blessures et l'automutilation qui en découlent.

- Améliorer le ressort psychologique et la capacité d'initiative, le respect, le sens de l'interdépendance et la santé mentale chez les adolescents, leurs familles et la société en général, et réduire la prévalence des facteurs de risque du suicide.
- Accroître les moyens de soutien mis à la disposition des particuliers, des familles et des collectivités touchés par le suicide ou les comportements suicidaires.
- Mettre en œuvre un ensemble d'approches communautaires en matière de prévention du suicide et faire en sorte qu'une plus grande partie de la population comprenne le suicide et ses causes.

1.6 PERSPECTIVES DE RÉFORME

Comme nous l'avons souligné précédemment, l'Australie a adopté un nouveau plan national en matière de santé mentale, pour la période 2003 à 2008, qui s'appuie sur les réalisations découlant des deux plans nationaux précédents en la matière. On reconnaît dans ce nouveau plan la complexité du processus de réforme et on y souligne que l'on a été témoin au cours des dix premières années de réformes d'un impressionnant début sur le plan de l'élaboration des politiques, mais qu'il y a encore beaucoup de choses à réaliser au niveau de leur application. Cette conclusion fait écho aux préoccupations de groupes de pression qui craignaient que la SNSM ne soit « en perte de vitesse et chancelante ».[6]

Le plan national en matière de santé mentale 2003-2008 a pour but de consolider les réalisations des premier et deuxième plans nationaux en la matière, de s'attaquer aux lacunes recensées dans ces deux documents et de faire progresser l'application de la SNSM au moyen d'orientations reformulées ou nouvelles. Dans ce plan, on adopte explicitement un cadre de promotion de la santé de la population qui part du principe que la santé et la maladie découlent de l'interaction complexe de facteurs biologiques, économiques, environnementaux, psychologiques et sociaux, et ce, à tous les niveaux : personnel, familial, communautaire, national et mondial.

Le plan en question énumère un certain nombre de principes clés qui étayent le processus de réforme, y compris les suivants :

- tous ceux et toutes celles qui ont besoin de soins de santé mentale devraient avoir accès dans des délais raisonnables à des services efficaces de santé mentale, indépendamment de l'endroit où ils vivent;
- les droits des usagers de soins de santé mentale, de leurs familles et de leurs soignants doivent façonner le processus de réforme;
- le rétablissement devrait orienter la prestation des services de santé mentale;
- il faut absolument investir dans le personnel affecté aux services de santé mentale;
- les réformes en matière de santé mentale doivent se produire parallèlement à d'autres progrès à l'intérieur du secteur élargi de la santé;

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(6) SANE Mental Health Report, 2002-2003, p. 2.

- les réformes en matière de santé mentale exigent une approche pangouvernementale.

Quatre thèmes prioritaires guident le nouveau plan national en matière de santé mentale. On y définit les résultats attendus et les orientations clés pour y arriver, même si l'on n'y cherche pas à préciser des projets à financer dans le cadre du nouveau programme de réformes. Ces thèmes sont les suivants :

- promouvoir la santé mentale et prévenir les problèmes de santé mentale et la maladie mentale;
- accroître la souplesse des services de santé mentale;
- renforcer la qualité des services de santé mentale;
- favoriser la recherche, l'innovation et la viabilité dans le domaine des services de santé mentale.

Voici quelques-uns des résultats que le plan susmentionné vise à atteindre :

- accroissement du degré d'intégration de la promotion de la santé mentale aux politiques et aux plans en matière de santé mentale en ce qui concerne le Commonwealth, les États, les territoires et les administrations locales;
- accroissement du degré d'adoption, par les services de santé mentale, du rétablissement comme orientation;
- entente à l'échelle nationale au sujet des niveaux élevés et de la combinaison des services nécessaires pour harmoniser maintenant et ultérieurement l'offre et la demande de soins de santé mentale;
- accroissement de l'accès aux soins actifs, aux services d'intervention précoce et à une gamme de solutions de rechange en matière de soins de santé communautaire;
- amélioration des voies d'accès aux soins pour toute la gamme des soins offerts;
- réduction des lacunes des réseaux de services et meilleure intégration entre les services publics et les services privés de santé mentale;
- accroissement de la coordination entre le secteur de la santé mentale et les autres secteurs de la santé;
- augmentation, à tous les niveaux, du degré de participation utile des usagers de soins de santé mentale, de leurs familles et de leurs soignants à l'élaboration des politiques ainsi qu'à la planification, la prestation et l'évaluation des services de santé mentale; l'amélioration de la qualité de ces services devra être palpable;
- processus de surveillance du rendement des services de santé mentale sur le plan du bien-être émotif et social, grâce à la collecte et à l'échange d'informations et de données;

- accroissement de l'offre de professionnels de la santé mentale et amélioration de leur répartition.

1.7 OBSERVATIONS DU COMITÉ

Les membres du Comité ont eu la très nette impression que le Canada avait beaucoup à apprendre de l'Australie dans le domaine de la santé et de la maladie mentale. Ils ont surtout retenu le fait que l'engagement constant des gouvernements du Commonwealth et des États en matière de planification et de suivi des progrès (grâce à des rapports réguliers0, a fixé un modèle international que le Canada est encore loin d'atteindre. De plus, les membres du Comité ont été impressionnés par l'adoption explicite d'un cadre de santé en matière de planification globale.

L'Australie, qui est un État fédéral, nous a aussi prouvé à quel point il est important de resserrer la collaboration entre les divers ordres de gouvernement, puisque tout le monde peut en tirer d'intéressants avantages. De plus, le Comité prend acte de l'importance que les autorités australiennes accordent à la nécessité d'adapter les objectifs nationaux aux réalités régionales et locales et de veiller à ce que la réalisation d'objectifs convenus tienne compte de la situation des différentes collectivités.

Qui plus est, le Comité a été impressionné par les efforts déployés par l'Australie pour faire participer les usagers et le personnel soignant à la formulation de la politique en santé mentale. Le Comité profite de l'occasion pour souligner deux aspects qui concernent le financement. Tout d'abord, les membres ont été frappés de constater à quel point le gouvernement du Commonwealth a abouti dans ses tentatives visant à canaliser le financement de la santé mentale, alors même qu'il a augmenté sa part de financement de la santé mentale et que les services étaient de plus en plus offerts au niveau de la communauté. Selon les témoins, il n'est plus nécessaire, dans ce pays, de prouver le caractère essentiel d'un financement suffisant pour les services de santé mentale et, comme tous les ordres de gouvernement se sont effectivement engagés à ce titre, les ententes officielles qui avaient été conclues à l'origine pour garantir le financement des soins de santé mentale ne sont désormais plus utiles.

Deuxièmement, le Comité se réjouit de constater les succès remportés par le programme qui a récemment été adopté pour améliorer la participation des omnipraticiens au traitement des personnes souffrant de problèmes de santé mentale. L'amélioration de la formation et, surtout, le versement d'une indemnité financière en rapport avec le temps véritablement passé auprès de patients présentant des symptômes de troubles mentaux, de même que l'assouplissement des modalités de renvoi des patients aux spécialistes de la santé mentale nous sont apparues comme des mesures susceptibles de favoriser une véritable intégration de la santé mentale au niveau des soins primaires.

Enfin, le Comité a pris acte des nombreuses approches novatrices adoptées par l'Australie pour sensibiliser le public sur les questions de santé mentale, surtout à la faveur de la campagne *beyondblue* axée sur la dépression. Les membres du Comité pensent qu'il conviendrait d'étudier de plus près certaines de ces approches pour déterminer dans quelle mesure il serait possible de les adapter au contexte canadien.

CHAPITRE 2:
LES SOINS DE SANTÉ MENTALE EN NOUVELLE-ZÉLANDE[7]

2.1 HISTORIQUE ET APERÇU

La Nouvelle-Zélande est un petit pays constitué de deux îles. Elle est située dans le sud de l'océan Pacifique et compte 4 millions d'habitants (en 2004). Elle a d'abord été peuplée par les Maoris, dont les ancêtres étaient originaires de Polynésie orientale, au moins 800 ans avant les premiers colons européens. Aujourd'hui, les principaux groupes ethniques sont les Européens d'origine, pour la plupart du Royaume-Uni et de l'Irlande (75 p. 100), les Maoris (15 p. 100), les Polynésiens (6 p. 100) et les Asiatiques (4 p. 100).

Le pays est devenu une colonie de la Grande-Bretagne suite au traité de Waitangi signé en 1840 par la Grande-Bretagne et la majorité des tribus maories. Ce traité, qui est l'un des documents constitutionnels fondateurs de la Nouvelle-Zélande, prend acte d'un partenariat avec les Maoris, puisqu'il reconnaît leur besoin d'autodétermination, énonce les responsabilités des gouvernements et protége les droits des Maoris. La résurgence de l'identité maorie au cours des 20 dernières années a fait de ce traité un pivot du dispositif d'élaboration des politiques.

La Nouvelle-Zélande est une démocratie parlementaire et un État indépendant au sein du Commonwealth britannique. Le Parlement ne compte qu'une chambre, la Chambre des représentants, et le pouvoir exécutif est exercé par un cabinet dirigé par un premier ministre.

Le système de santé néo-zélandais est principalement financé par les recettes fiscales, suppléées par les déboursements des usagers et l'assurance-maladie privée. En 1999-2000, l'État a contribué pour 75 p. 100 au budget de la santé, les usagers pour 15,7 p. 100 et les assureurs privés pour 6,3 p. 100 (bien que les assureurs privés n'offrent quasiment aucune protection pour les maladies mentales). La part publique du budget de la santé diminue

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7 À moins d'indication contraire, les renseignements contenus dans le présent chapitre proviennent des sources suivantes : Wilson, Janice, « Mental Health Services in New Zealand, » *International Journal of Law and Psychiatry*, vol. 23, nº 3-4, 2000; French, Sian, Andrew Old et Judith Healy *HiT Summary: New Zealand*, Observatoire européen des sytèmes de soins de santé, 2002; Conference Board du Canada, « La Nouvelle-Zélande », in *Challenging Health Care System Sustainability: Understanding Health System Performance of Leading Countries*, juin 2004; Powell, Gayla, « New Zealand's National Mental Health Strategy: Report on Progress 2000-2001, » août 2002; ministère de la Santé, Nouvelle-Zélande, *Looking Forward: Strategic Directions for Mental Health Services*, juin 1994; ministère de la Santé, *New Zealand, Moving Forward: The National Mental health Plan for More and Better Services*, juillet 1997; Service de l'information de la Nouvelle-Zélande, *Mental Health Data, 1994*, ministère de la Santé, Nouvelle-Zélande, 1998; Commission de la santé mentale, *Blueprint for Mental Health Services in New Zealand: How Things Need to Be*, décembre 1998; ministère de la Santé, Nouvelle-Zélande, *National Plan 2001-2003 – Project to Counter Stigma and Discrimination Associated with Mental Illness*, juin 2001; Commission de la santé mentale, *Briefing to the Incoming Minister of Health*, août 2002; ministère de la Santé, Nouvelle-Zélande, *Building on Strengths: A New Approach to Promoting Mental Health in New Zealand/Aotearoa*, décembre, 2002; Commission sur la santé mentale, *Report on Progress 2001-2002: Towards Implementing the Blueprint for Mental Health Services in New Zealand*, avril 2003; ministère de la Santé, Nouvelle-Zélande, *Like Minds, Like Mine – National Plan 2003-2005*, septembre 2003.

depuis une vingtaine d'années, puisqu'elle est passée de 88 p. 100 en 1979-1980 à environ 77 p. 100 en 1994-1995, bien qu'elle soit en légère hausse depuis 2000 (78 p. 100).

Les patients bénéficient gratuitement de soins ambulatoires et hospitaliers, mais ils doivent payer tout ou une partie des soins primaires et payer leur quote-part des médicaments (les patients à faible revenu et ceux souffrant de maladies chroniques ayant droit à une carte dite de concession). Grâce à de nouveaux investissements et à la réforme du système de santé primaire entreprise en 2004, les particuliers ont de moins en moins à payer de leur poche.

Le gouvernement conserve la responsabilité générale du système de santé, mais la prestation des soins est partagée entre les secteurs public, bénévole et à but lucratif. Les omnipraticiens et les spécialistes indépendants assurent le gros des soins ambulatoires et les hôpitaux publics le gros des soins secondaires et tertiaires tandis, les hôpitaux privés se spécialisant surtout dans les chirurgies électives et les soins de longue durée.

Dans les années 90, les gouvernements néo-zélandais ont, plus que dans la plupart des pays, introduit des pratiques de marché dans le secteur de la santé, y compris les concepts de concurrence et de séparation entre acheteur et fournisseur.[8] Cependant, à la fin de la décennie, le gouvernement travailliste-allianciste décidait que le « marché interne » n'avait pas amélioré sensiblement l'efficacité et l'efficience des services. En 2000, il a redonné à des conseils de district la responsabilité financière et la tâche de fournir en partie les soins de santé. Il a ainsi créé 21 District Health Boards (ou DHB, pour Conseils de santé de district) desservant des populations géographiquement définies, qui fournissent les soins eux-mêmes ou financent d'autres pour le faire. Ces autorités autonomes reçoivent leurs ressources dans le cadre d'un régime de financement triennal établi d'après les contrats de fourniture passés et sont responsables, auprès du ministre de la Santé, de leur orientation stratégique, de la nomination de leur directeur, de la santé de leur population et de leur propre rendement. Chaque district compte au moins un grand hôpital public.

On considère que les services de santé néo-zélandais répondent généralement à la demande et qu'ils sont de bonne qualité. En 2004, la majorité des DHB respectent leurs objectifs, mais les gens ont tout de même l'impression que les hôpitaux sont sous-financés, d'où les longues liste d'attente pour les chirurgies électives. En 2001, la Nouvelle-Zélande a entamé la restructuration de son système de soins primaires en mettant sur pied des organismes de soins primaires à but non lucratif financés, du moins en partie, par capitation, c'est-à-dire en fonction du nombre de patients inscrits auprès de chaque organisme. Le but visé est de réduire l'importance de la quote-part que doivent verser les patients. Jusqu'ici, seuls quelques groupes particuliers bénéficient d'un financement complet, autrement dit d'une « couverture universelle », des services de soins primaires parce qu'ils ont de faibles revenus ou souffrent d'une maladie chronique. La D^re^ Janice Wilson, directrice générale adjointe, Direction générale de la santé mentale au ministère de la Santé, a précisé au comité que l'objectif de la nouvelle stratégie en matière de soins primaires consistait à « étendre progressivement les paiements universels, d'ici cinq à dix ans, à près de 80 p. 100 de la population ».

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8 Cette expression rappelle le fait que, dans les années 90, plusieurs pays où les mêmes institutions étaient chargées à la fois d'assurer le financement et d'offrir les services de soins de santé ont opté pour une séparation de ces fonctions afin d'accroître l'efficacité des services et de stimuler la concurrence.

2.1.1 La stratégie de santé mentale

La Stratégie nationale de santé mentale a été introduite par le gouvernement en juin 1994 par la publication de *Looking Forward: Strategic Directions for the Mental Health Service*. Elle a été développée dans un deuxième document publié en juillet 1997, le Plan national de santé mentale, *Moving Forward: The National Mental Health Plan for More and Better Services*. Dans l'ensemble, elle poursuit deux grands objectifs :

1. Réduire la prévalence de la maladie mentale et des problèmes de santé mentale dans la population;
2. Relever le statut sanitaire des troubles mentaux et réduire leur impact sur les usagers et leurs familles, sur les soignants et sur le grand public.

La Dre Wilson nous a indiqué que « le principal objet de la politique, à ce moment, était de rationaliser ce qu'on appelle la désinstitutionnalisation ». Elle a ajouté que cette politique répond aussi en partie aux pratiques exemplaires adoptées à l'échelle internationale, pratiques qui soulignent la nécessité d'« adopter une approche gouvernementale plus globale en faisant le lien avec d'autres secteurs, comme le logement, l'emploi, la main-d'œuvre, et cetera » afin de rapprocher les services de la collectivité et de les intégrer dans les autres services de santé.

En 1996, une commission de la santé mentale a été chargée de mettre en œuvre la stratégie nationale de santé mentale. Composée de trois commissaires, elle exerce les fonctions suivantes :

- Mesurer l'efficacité du ministère de la Santé et des 21 conseils de santé de district à mettre en œuvre la stratégie nationale de santé mentale et faire rapport de ses constatations au gouvernement;
- Travailler en collaboration avec le secteur pour mieux faire connaître la santé mentale au public et pour réduire la discrimination et les préjugés à l'endroit des personnes atteintes de troubles mentaux;
- Travailler à renforcer le personnel de la santé mentale.

La Commission a publié le *Blueprint for Mental Health Services in New Zealand* en 1998. Il s'agit d'un plan de mise en œuvre de la stratégie qui a été accepté comme politique gouvernementale. Il est question de donner aux conseils de santé et aux soignants un aperçu clair des mesures qu'ils peuvent prendre pour améliorer la qualité et faire comprendre aux usagers et à leurs familles ce qu'ils sont en droit d'attendre d'un système qui fonctionne bien.

La stratégie nationale comporte sept orientations stratégiques dont voici un bref résumé :

> *Orientation stratégique 1 : Mettre en œuvre en milieu communautaire des services de santé mentale complets*. Il s'agit d'offrir des services de promotion de la santé et de prévention des maladies mentales, d'évaluation et d'intervention précoces, de traitement, de rééducation et de soins continus.

Orientation stratégique 2 : Encourager la participation des Maoris à la planification, à la formulation et à la fourniture des services de santé mentale. Il s'agit d'améliorer la santé mentale des Maoris pour qu'elle soit aussi bonne que celle de l'ensemble de la population néo-zélandaise. La prévalence des troubles mentaux est sensiblement plus élevée chez les Maoris que dans le reste de la population.

Orientation stratégique 3 : Améliorer la qualité des soins. Il est question de combler certaines des lacunes évidentes héritées du passé. On espère que les objectifs nationaux seront atteints grâce à des normes de service, à des programmes d'assurance de la qualité et à des indicateurs d'efficience et d'efficacité.

Orientation stratégique 4 : Concilier les droits individuels avec la protection du public. Il s'agit d'assurer un meilleur équilibre entre le droit des usagers de soins de santé mentale à vivre dans la collectivité et le droit du public à la protection.

Orientation stratégique 5 : Élaborer une politique nationale de lutte contre l'alcoolisme et la toxicomanie. Il s'agit de mieux intégrer les services d'aide aux alcooliques et aux toxicomanes, de mieux exploiter la palette des soins en établissement et des soins ambulatoires et de fournir des soins plus systématiques aux alcooliques ou toxicomanes atteints d'un trouble mental.

Orientation stratégique 6 : Développer l'infrastructure des services de santé mentale. Cette orientation stratégique a été ajoutée en 1997. Il s'agit de l'« infrastructure » nécessaire pour assurer des services plus nombreux et meilleurs – d'éléments comme le perfectionnement de la main-d'œuvre, la collecte et l'analyse de données et la coordination entre les services. Ces éléments relevaient auparavant de l'*Orientation stratégique 3*, mais ils ont été jugés assez importants et complexes pour faire l'objet de leur propre orientation stratégique.

Orientation stratégique 7 : Renforcer la promotion et la prévention. Cette orientation stratégique a également été ajoutée en 1997 afin de mettre davantage l'accent sur la réduction nécessaire de la prévalence de la maladie mentale et des problèmes de santé mentale.

L'élaboration de la stratégie de santé mentale en Nouvelle-Zélande a été basée sur des données épidémiologiques selon lesquelles un adulte sur cinq souffre d'un problème de santé mentale diagnosticable. On estime qu'environ 3 p. 100 des adultes – et environ 5 p. 100 des enfants et des adolescents de moins de 20 ans – sont atteints d'un trouble mental grave. Par ailleurs, 5 p. 100 des adultes souffrent d'un trouble modéré à grave et 12 p. 100 d'un trouble ou d'un problème léger à modéré.

La stratégie nationale vise à ce que les services soient offerts en qualité et en nombre voulus pour répondre aux besoins de 3 p. 100 des adultes et de 5 p. 100 des enfants et des adolescents souffrant d'un trouble mental grave. Les lignes directrices relatives aux ressources, contenues dans le *Blueprint*, fournissent une estimation du nombre de lits et d'agents en milieu communautaire dont il faut disposer par 100 000 habitants dans l'hypothèse où 3 p. 100 de la population a besoin de ces services. Ces lignes directrices ont été élaborées surtout pour calculer les budgets et les besoins d'expansion des services à l'échelle nationale, mais elles sont aussi utilisées au niveau régional.

Le modèle de fourniture des services employé dans le *Blueprint* met l'accent sur les soins en milieu communautaire, mais prévoit aussi des soins actifs en établissement ainsi que des services de rééducation et des soins de longue durée en établissement. Les lignes directrices tiennent également compte du développement des services fournis par les usagers. Le tableau suivant résume les objectifs fixés par le *Blueprint* en 1998. Les objectifs nationaux sont ajustés en fonction de la croissance démographique.

OBJECTIFS CONCERNANT LES RESSOURCES, 1998			
Ressources		**Objectif national**	**Niveau national actuel**
En hôpital	Lits ou « postes de soins »[9]	1 535	1 424
En établissement	Lits ou « postes de soins »	3 243	2 576
En milieu communautaire	ÉTP[10]	3 822	1 923
Soutien communautaire	ÉTP	1 284	388
Services et initiatives de conseil (usagers et familles)	ÉTP	246	63
Accès aux nouveaux anti-psychotiques	Personnes	8 500	3 547
Désintoxication	Lits ou « postes de soins »	113	96
Services aux alcooliques et toxicomanes en établissement	Lits ou « postes de soins »	378	376
Services aux alcooliques et toxicomanes en milieu communautaire	ÉTP	614	262
Traitement à la méthadone	Endroits	5 666	3 030
Prévention de la maladie mentale	ÉTP	378	0

9 Selon le « Blueprint », si la mesure la plus répandue pour ces services est celle du nombre de lits, il est nécessaire d'offrir désormais un « assortiment de soins » (p. 41 du plan néo-zélandais qui ne définit cependant pas ce à quoi doit ressembler chaque service).

10 Poste « équivalent temps plein ».

2.2 COÛTS ET FINANCEMENT DES SERVICES DE SANTÉ MENTALE

Le Dr David Chaplow, directeur et conseiller principal en santé mentale, gouvernement de la Nouvelle-Zélande, a indiqué au Comité que le fait de disposer d'un « plan assorti de données sur les coûts de réalisation, avec une analyse de l'écart entre ce qui existait et ce dont nous avions besoin, a été un outil de promotion très puissant » dans les négociations avec le Trésor en vue d'obtenir un financement supplémentaire pour la santé mentale. Depuis l'adoption de la stratégie de santé mentale, le budget de la santé mentale a augmenté. Entre 1993-1994 et 2001-2002, le financement public des services de santé mentale en Nouvelle-Zélande est passé de 270 à 725 millions de dollars par an, soit une hausse d'environ 127 p. 100 compte tenu de l'inflation. La Dre Wilson a précisé : « le gouvernement actuel s'est engagé à maintenir le financement à ce niveau au moins jusqu'en 2007 parce que nous n'avons pas encore terminé tous les éléments de notre programme de réforme ».

La Commission de la santé mentale note cependant que, dans l'ensemble, le point de départ des récentes augmentations budgétaires était trop faible. À son avis, les niveaux de services de santé mentale ne sont toujours pas à un niveau acceptable et il y a encore place à l'amélioration pour atteindre les objectifs du *Blueprint*. Selon la Dre Wilson,

> *La Commission a fixé des objectifs et nous avons atteint un taux de couverture d'environ 75 p. 100. Le pourcentage est proche de 60 p. 100 dans certaines régions du pays, tandis qu'il est de presque 100 p. 100 dans d'autres. Nous avons des écarts régionaux qui dépendent de la croissance démographique et d'autres facteurs.*

Le tableau suivant présente les estimations que la Commission a utilisées dans le document d'information qu'elle a adressé au nouveau ministre de la Santé.

POURCENTAGE DES OBJECTIFS DE FINANCEMENT DU *BLUEPRINT* EN 2002

Secteur de service	Niveau de financement approximatif en juillet 2002 par rapport aux lignes directrices du *Blueprint*
Services hospitaliers	89%
Services communautaires en clinique	69%
Services communautaires hors clinique	44–59%
Services communautaires aux alcooliques et aux toxicomanes	74%
Services de méthadone	65%
Services communautaires aux enfants et aux adolescents	63%

Dans le cadre de la tendance à la communautarisation des services, 69 p. 100 des crédits de santé mentale (à l'exclusion des médicaments et des services de santé publique) sont allés aux services dispensés en milieu communautaire en 2001-2002. Ce chiffre représente une hausse de 67 p. 100 par rapport à l'année précédente et inclut 57,4 p. 100 des crédits de prestation des conseils de santé de district (DHB) et la presque totalité des fonds des organisations non gouvernementales (ONG). Comme l'indique le tableau précédent, la proportion du budget de santé mentale affectée aux services fournis par des (ONG) est restée stable au cours des trois dernières années.

En dépit de l'augmentation des budgets, la Commission de la santé mentale continue d'exprimer des préoccupations quant au niveau global de financement et à l'engagement des DHB à dépenser effectivement les crédits affectés à la santé mentale. Elle déplore également que l'effet de l'augmentation des budgets sur les niveaux de service soit restreint par des pénuries de main-d'œuvre. En effet, même quand il y a des fonds, beaucoup de postes restent vacants.

La Commission a donc réitéré ses recommandations :

- Une filière de financement durable doit être établie pour assurer le développement des services de santé mentale en fonction des orientations de la stratégie nationale de santé mentale, de la mise en œuvre du *Blueprint* et de la capacité du secteur à se développer.
- Les crédits de santé mentale affectés aux 3 p. 100 de la population qui sont le plus sévèrement touchés par la maladie mentale doivent être protégés par une obligation de dépenser claire et strictement limitée.

2.3 PRESTATION ET ORGANISATION DES SERVICES

Le but premier du *Blueprint* est de faire en sorte que 3 p. 100 de la population aient accès aux services de santé mentale. Pour l'ensemble de la Nouvelle-Zélande, l'accès déclaré aux services de santé mentale concernait 1,7 p. 100 de la population en 2001-2002 contre 1,6 p. 100 l'année précédente. Cependant, comme les données n'ont pas été obtenues de toutes les ONG pendant cette période, il se peut que l'accès aux services soit sous-estimé.

En Nouvelle-Zélande comme ailleurs, la désinstitutionnalisation des malades psychiatriques se poursuit depuis un quart de siècle. Bien que la situation varie d'une région à l'autre, la plupart des services de santé mentale sont fournis en milieu communautaire, notamment par des équipes mobiles d'intervention d'urgence de 24 heures et par les hôpitaux généraux dotés de services de soins psychiatriques actifs. En 2000, tous les services de soins psychiatriques actifs (à une exception près) étaient intégrés aux hôpitaux généraux et la quasi-totalité des 10 établissements psychiatriques étaient complètement fermés, seuls quelques-uns ayant conservé des services de psychiatrie légale ou d'autres services spécialisés.

Voici ce que le Dr Chaplow a tout de même déclaré au Comité

> *nous n'avons jamais diminué le nombre total de lits qu'il y avait dans les anciens asiles. Nous avons réparti ces places sous diverses formes: il y en a encore dans les hôpitaux et il y en a dans la collectivité.*

Il existe quelques services de rééducation en milieu hospitalier et un éventail croissant de formules d'hébergement et de formation professionnelle assistés ainsi que des programmes de jour et des centres d'accueil, souvent administrés par les usagers. La plupart des adultes qui reçoivent des services de santé mentale sont encadrés par un gestionnaire de cas ou un travailleur de soutien en milieu communautaire.

Le dernier *Report on Progress* publié par la Commission de la santé mentale contient les statistiques suivantes pour 2001-2002 :

- Le nombre de personnes hospitalisées est faible comparativement à celui des personnes qui reçoivent des services de santé mentale. Dans les six premiers mois de 2002, 0,14 p. 100 de la population totale (5 546 personnes) a été traitée en milieu hospitalier contre 1,7 p. 100 par les services de santé mentale (63,271).
- En 2001-2002, il n'y a pas eu d'expansion des services cliniques communautaires pour adultes hors établissement. Le nombre des postes de personnel clinique financés dans ces services atteignait 85 p. 100 de l'objectif du *Blueprint* contre 87 p. 100 en juin 2001.
- Les services non cliniques dispensés en milieu communautaire englobent le soutien à domicile, le soutien à l'emploi et à l'éducation, les activités de jour et l'acquisition des compétences psychosociales, les services d'entraide et de soutien familial. Ces services sont assurés surtout par des travailleurs de soutien, des aides-infirmières et des travailleurs de soutien culturel travaillant pour des ONG dans un rôle de thérapie ou de soutien. Les ressources affectées aux services de soutien non cliniques dispensés en milieu communautaire sont passées de 59 p. 100 l'année précédente à 65 p. 100 de l'objectif du *Blueprint*.
- Dans l'ensemble du pays, le nombre de lits résidentiels offerts aux adultes en milieu communautaire a diminué, passant de 93 p. 100 de l'objectif du *Blueprint* en 2000-2001 à 83 p. 100 en 2001-2002. Comme cette réduction tient en grande partie au fait qu'une grosse ONG a cessé d'offrir des services résidentiels pour ne plus offrir que des soins à domicile, il n'y a pas eu réduction de la capacité.

Comme ailleurs dans le monde, en Nouvelle-Zélande, l'accès aux services de santé mentale passe par les omnipraticiens. Cependant, nombreux sont les Néo-Zélandais (notamment parmi les Maoris et les Polynésiens) qui ne s'adressent pas aux omnipraticiens et ils n'ont donc pas accès aussi rapidement qu'il le faudrait aux services de santé mentale.

L'impact des frais d'utilisation au titre des soins primaires sur l'accès aux services de santé mentale pose également problème. Il est admis que ces frais peuvent constituer un obstacle à l'utilisation des soins primaires et qu'ils peuvent donc inciter les gens atteints d'une maladie légère ou modérée à s'adresser aux services de santé mentale spécialisés (qui n'ont pas les mêmes frais d'utilisation) alors qu'ils pourraient être traités convenablement par les

fournisseurs de soins primaires. On craint même que les frais d'utilisation ne découragent complètement les gens de s'adresser au système de santé. Comme nous l'avons vu plus haut, des efforts sont en cours pour réorganiser la prestation des soins primaires en fonction d'un modèle de capitation qui pourrait réduire l'impact des frais d'utilisation.

2.3.1 Les services aux Maoris

Mme Arawhetu Peretini, gestionnaire en santé mentale des Maoris au gouvernement de la Nouvelle-Zélande, a expliqué ce qui suit au Comité :

> *Ils (les Maoris) vivent surtout en milieu urbain. Nous n'avons pas de réserves. Les aborigènes sont dans une grande mesure intégrés dans le reste de la société. La majorité vit probablement dans une ville du nord de l'île. Ces 10 dernières années, nous avons eu un mouvement préconisant le retour des Maoris dans leurs terres tribales, dont environ 90 p. 100 se trouvent dans des régions rurales. Toutefois, beaucoup n'ont pas suivi le mouvement parce qu'ils travaillent dans des agglomérations urbaines.*

Un grand spécialiste, le professeur Mason Durie[11] estime que les troubles mentaux sont devenus le problème de santé numéro un des Maoris. Les séjours en hôpital psychiatrique, l'alcoolisme et la toxicomanie, le suicide et la tentative de suicide sont en hausse alors que les autres problèmes de santé comme la cardiopathie sont en baisse. Les Maoris ont de nombreux besoins auxquels ne répondent pas les services de santé mentale. Bien qu'on ne dispose pas de données exactes et actuelles sur la prévalence de la maladie mentale chez les Maoris, on sait qu'il y a un nombre disproportionné de Maoris dans les services de crise, de soins actifs et de psychiatrie légale. Comme devait le préciser Mme Peretini :

> *Certains des problèmes découlent du fait que beaucoup de Maoris tendent à se présenter dans les services à des stades aigus de maladie mentale.*

Qui plus est, les taux de réadmission des Maoris sont sensiblement plus élevés que ceux des non-Maoris et ils ne cessent d'augmenter depuis plusieurs années. Les Maoris sont également sur-représentés dans les services d'aide aux alcooliques et aux toxicomanes; c'est d'ailleurs le plus souvent pour cause d'alcoolisme, de toxicomanie ou de psychose qu'ils sont admis dans les services ou les hôpitaux psychiatriques.

Entre le 1er janvier et le 30 juin 2002, environ 10 500 Maoris ont été accueillis par les services de santé mentale, soit 1,9 p. 100 de tous les Maoris. Les Maori s'adressent aux services généraux de santé mentale ainsi qu'aux services axés sur leurs besoins. Tout en reconnaissant qu'il « reste encore des lacunes dans notre connaissance de chose tels que les taux d'admission et de réadmission », Mme Peretini devait nous préciser :

> *Ayant réalisé une enquête il y a trois ans, nous savons que certains des 21 districts répondent vraiment aux besoins des Maoris parce qu'ils ont*

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11 Cité dans *Blueprint*, p. 56.

> *inclus dans leur évaluation clinique une composante d'évaluation culturelle. Très peu le faisaient auparavant. Sur neuf commissions de santé de district, sept seulement avaient, à un moment ou un autre, envisagé d'adopter des politiques visant à répondre aux besoins des aborigènes admis dans les services généraux. Sur ces 7, trois seulement avaient des outils d'évaluation culturelle assez développés pour être utiles.*

Depuis 1998, on constate une amélioration sensible du nombre de fournisseurs de soins maoris et de la disponibilité des services destinés expressément aux Maoris. On a également pris un certain nombre d'initiatives pour augmenter le nombre de Maoris qualifiés au sein du personnel de santé mentale. Mme Peretini nous a apporté une précision à cet égard :

> *Il y a deux ans, le ministère de la Santé a pris la décision, dans le cadre de notre stratégie de développement de la main-d'œuvre, d'établir une organisation axée sur les Maoris pour la formation et le perfectionnement de la main-d'œuvre. Il y a environ un an, cette organisation a réalisé une série d'enquêtes sur notre population active. Plutôt que de vous donner les détails des résultats, je dirai que nous n'avons pas une main-d'œuvre très importante. À l'heure actuelle, elle se limite probablement à cinq psychiatres en formation.*
>
> *[…] nous avons fixé des quotas pour l'enseignement de certaines disciplines en Nouvelle-Zélande. Nous le faisons depuis au moins 20 ans. Nous avons également quelques leaders maoris du domaine de la santé qui sont devenus psychiatres.*

Le Cadre stratégique national pour la santé mentale des Maoris a été publié en avril 2002 après de vastes consultations. Voici les objectifs à atteindre en cinq ans :

- fournir des services cliniques, culturels et auxiliaires complets à au moins 3 p. 100 des Maoris, notamment à ceux dont les besoins en santé mentale sont les plus grands;
- veiller à ce que la participation active des Maoris à la planification et à la prestation des services de santé mentale reflète les modèles de santé maoris et les critères maoris de santé mentale;
- veiller à ce que 50 p. 100 des adultes maoris en quête de mieux-être aient le choix entre les services de santé mentale généraux et les services destinés à leur communauté;
- augmenter de 50 p. 100 par rapport aux niveaux de 1998 le nombre des travailleurs maoris en santé mentale, y compris les cliniciens,

Le Dr Chaplow a indiqué que la Nouvelle-Zélande est « dans une étape de transition » où « il faudra augmenter le nombre de psychiatres aborigènes ou leurs adjoints ou d'autres ». Toutefois, le témoin a ajouté qu'« un des aspects les plus importants des progrès réalisés est que les Maoris s'occupent eux-mêmes de leur service et relèvent eux-mêmes les défis ».

La D[re] Wilson a expliqué l'importance de ce genre d'évolution :

> *La maladie mentale a ceci de particulier qu'elle touche la façon dont vous vous envisagez vous-même ainsi que vos croyances sur le plan spirituel et culturel. Les gens communiquent beaucoup mieux avec ceux de leur propre culture. Si vous êtes un patient, votre relation avec la personne qui vous soigne, que ce soit un médecin ou une infirmière, est probablement le facteur le plus critique qui agisse sur la guérison. Si cette personne peut comprendre votre culture et vos croyances, les chances d'un résultat positif sont sensiblement meilleures.*

2.3.2 Les ressources humaines

Plusieurs commissions et rapports ont fait remarquer que le développement de la main-d'œuvre est en mesure de contribuer grandement à régler les problèmes de prestation des services de santé mentale en Nouvelle-Zélande. Il est généralement admis que, bien que le personnel de santé mentale ait augmenté considérablement grâce à la mise en œuvre de la stratégie nationale, il ne suffit toujours pas pour répondre aux besoins de la population. Par exemple, il y a en Nouvelle-Zélande une pénurie de psychiatres par rapport aux autres pays occidentaux semblables. Le Dr Chaplow a indiqué au Comité que « dans les statistiques sur la santé dans le monde, on dit qu'il faudrait avoir un psychiatre pour 10 000 personnes. Nous n'en avons qu'un pour 15 000 », tout en insistant sur le fait suivant :

> *Le problème, c'est de savoir comment utiliser les psychiatres comme membres de l'équipe. De plus, les psychiatres ont tendance à se regrouper autour des universités ou établissements d'enseignement. Souvent, il y a déséquilibre entre la ville et la campagne, pour ce qui est de l'accès à de bons services de psychiatrie.*

La D[re] Wilson devait ajouter que la pénurie de ressources humaines a gagné tous les secteurs :

> *Dans l'ensemble de l'effectif, il va sans dire que nous sommes à court dans tout le système. Il n'y a pas que les psychiatres. Nous avons des pénuries d'infirmières, de psychologues et de toutes sortes d'autres professionnels. C'est pourquoi nous avons une initiative importante qui porte sur le recrutement et le maintien à l'effectif.*

Des rapports de 2000-2001 indiquent que les postes vacants budgétisés en milieu communautaire comptaient pour 6 à 7 p. 100 du total. Il est également difficile de recruter et de conserver du personnel en dehors des grands centres, les conditions de travail étant rendues difficiles par la nécessité d'assurer les services 24 heures sur 24, par le manque de soutien des pairs et par l'isolement professionnel.

Établi au début de 1998, le Comité national de coordination du personnel de santé mentale a pour tâche de coordonner le développement de la main-d'œuvre dans l'ensemble du secteur, d'élaborer et de mettre en place un cadre définitif de réglementation nationale et de dotation

en ressources du développement du personnel de santé mentale. Il est dirigé par les fournisseurs de soins et représente les principaux intervenants du secteur. Cependant, il n'y a toujours pas de plan global de développement du personnel de santé mentale.

Selon la Dre Wilson, de nouveaux types de travailleurs en santé mentale ont été formés au cours des dernières années.

> *Nous avons un nouveau groupe de travailleurs, les travailleurs du soutien communautaire en santé mentale, qui reçoivent une formation depuis probablement cinq ans. Ils travaillent surtout dans le secteur des ONG, mais ils travaillent aussi dans le secteur public principal. Ils reçoivent une formation pour aider les patients ou consommateurs qui ont des troubles mentaux, que ce soit à domicile ou dans des unités résidentielles communautaires, ou pour les aider à se débrouiller avec le système. Ils peuvent par exemple les accompagner au service du soutien du revenu, au service de l'emploi, pour les aider à surmonter les obstacles sociaux.*

Ces travailleurs du soutien communautaire en santé mentale sont dûment qualifiés en vertu du cadre national de certification. Ils sont ainsi environ 2 000 à avoir reçu un certificat en travail de soutien communautaire en santé mentale.

2.4 PROMOTION ET PRÉVENTION

En décembre 2002, après deux années de consultation auprès de plus de 200 particuliers et organisations, le ministère de la Santé a publié un document intitulé *Building on Strengths* (S'appuyer sur nos forces) qui décrivait l'approche nationale en matière de promotion de la santé pour les cinq années suivantes. *Building on Strengths* vise à promouvoir le bien-être mental des Néo-zélandais et à réduire les inégalités sur ce plan en améliorant les milieux sociales, économiques, culturels, politiques et physiques au pays.

La stratégie néo-zélandaise en matière de promotion de la santé mentale prend acte de la nécessité d'instaurer une collaboration entre les secteurs de la santé et les autres secteurs, notamment les administrations locales, les autres ministères et les Maoris, les groupes communautaires du Pacifique et les autres et il invite le secteur de la santé à prendre l'initiative en coordonnant la promotion de la santé mentale.

Building on Strengths vise à réaliser trois objectifs :

1. Permettre aux particuliers et aux collectivités d'agir de leur propre chef.
2. Décrire les actions prioritaires que le ministère de la Santé envisage de conduire au chapitre de la promotion de la santé mentale.
3. Donner une orientation aux fournisseurs de services en santé et aux autres secteurs d'activité afin qu'ils puissent contribuer à l'amélioration de la santé mentale et du bien-être mental des Néo-zélandais.

La stratégie décrite dans *Building on Strengths* énonce trois objectifs bien précis :

- Réduire les inégalités dont sont victimes certains groupes en matière de santé mentale.
- Créer un environnement favorable à l'amélioration de la santé mentale.
- Améliorer le ressort psychologique des particuliers et des collectivités.

Pour permettre la réalisation de ces objectifs, cinq priorités ont été énoncées :

1. Réorienter les services de santé afin de réduire les inégalités entre les différents groupes socioéconomiques.
2. Renforcer l'action communautaire en matière d'activité de promotion de la santé mentale.
3. Instaurer un milieu favorable et sûr grâce à des mesures destinées à resserrer la cohésion sociale au sein des villes, des petites agglomérations, du milieu de travail, des écoles et des foyers.
4. Améliorer les compétences personnelles en agissant sur les facteurs favorables à la santé mentale comme le ressort psychologique, le soutien social et les compétences psychosociales.
5. Instaurer une politique publique saine par l'amélioration de la recherche et de l'évaluation en vue de recenser les besoins en matière de promotion de la santé mentale et de répondre à ces besoins.

Le ministère de la Santé est en train de consacrer plusieurs millions de dollars chaque année sur le chapitre de la promotion de la santé mentale et *Building on Strengths* a justement été publié pour proposer un cadre national de financement soutenu. Il n'est pas prévu que la campagne fasse l'objet d'un financement supplémentaire.

2.4.1 Le projet de lutte contre la stigmatisation et la discrimination associées à la maladie mentale

Le projet de lutte contre la stigmatisation et la discrimination associées à la maladie mentale appelé « Like Minds, Like Mine » (Tu penses, donc je suis!) a été lancé pour cinq ans en 1996 et financé par la suite en permanence par le gouvernement. Depuis le début, les activités parrainées par « Like Minds, Like Mine » visent à sensibiliser le public à la maladie mentale et notamment à la stigmatisation dont sont victimes ceux qui en souffrent ou en ont souffert. Le projet est ainsi parvenu à faire évoluer de façon quantifiable les attitudes dans la plupart des secteurs de la population.

La D^re^ Wilson a permis aux membres du Comité de comprendre les fondements des progrès réalisés :

> *D'abord, il est très important de comprendre qu'au tout début de cette initiative ou de ce programme, des recherches de base considérables ont été*

entreprises. Elles ont porté sur les attitudes dans la population et sur les réactions que susciterait une campagne de sensibilisation. Cette démarche s'est déroulée parallèlement à notre approche de développement communautaire.

La première campagne nationale a eu lieu, et les recherches qui ont suivi ont révélé une évolution étonnante de l'attitude. On semblait mieux comprendre les troubles mentaux courants comme la dépression, les troubles anxieux, l'alcoolisme, et cetera.

Comme on estime avoir fait des progrès substantiels en matière de sensibilisation, le tout dernier plan (2003-2005) vise plutôt à réduire la discrimination. Il allie un modèle des droits de la personne à un modèle social de la déficience, qui a une forte analogie avec la discrimination dont sont victimes ceux qui font l'expérience de la maladie mentale.

Voici les grands objectifs du projet :

- Permettre à tous ceux qui font l'expérience de la maladie mentale d'obtenir l'égalité et le respect et de jouir des mêmes droits que les autres.
- Modifier la politique des secteurs public et privé de manière à valoriser et à inclure tous ceux qui font l'expérience de la maladie mentale.
- Mieux faire comprendre, accepter et appuyer tous ceux qui font l'expérience de la maladie mentale.

Voici quelques-uns de ses objectifs plus précis :

- Assurer le leadership et la participation des particuliers et des groupes qui ont l'expérience de la maladie mentale.
- Préconiser des politiques et des pratiques non discriminatoires au sein des organisations responsables du logement, de l'éducation, de l'emploi, du revenu et de l'accès aux biens et services et au sein des organisations responsables des services de santé mentale.
- À l'aide des médias de masse, de l'éducation communautaire et d'autres moyens, favoriser l'inclusion sociale de ceux qui font l'expérience de la maladie mentale.
- En reconnaissance de leur statut aux termes du traité de Waitangi, faire mettre au point par les Maoris des stratégies de lutte contre la discrimination dont sont victimes les Maoris qui font l'expérience de la maladie mentale.

La D^re^ Wilson nous a précisé que la première version de la campagne avait fait « appel à des Néo-Zélandais très connus qui étaient disposés à parler publiquement de leurs problèmes de dépression et de troubles anxieux » mais que « La campagne actuellement en cours a laissé tomber les personnalités connues pour faire appel à des gens ordinaires qui ont été atteints

de maladies assez graves, comme la manie-dépression ou le trouble bipolaire, la schizophrénie, et cetera. L'accent est mis sur ces personnes, leur famille, leur vie »

2.5 PERSPECTIVES DE RÉFORME

La D[re] Wilson nous a appris qu'un second plan national en matière de santé mentale était en cours de préparation et qu'une première mouture serait bientôt soumise au Cabinet avant d'entreprendre de vastes consultations avec le milieu. Elle espère que celui-ci sera mené à terme et qu'il sera accepté par le gouvernement avant la fin de 2004.

En avril 2004, la Commission de la santé mentale a publié un document de consultation pour obtenir des idées sur les meilleurs moyens de poursuivre et de consolider les progrès déjà réalisés en matière de soins de santé mentale en Nouvelle-Zélande et pour faire en sorte que le *Blueprint* s'adapte à l'évolution des circonstances et serve de base à l'avenir. Parmi les moyens possibles à employer, mentionnons :

- améliorer l'application du *Blueprint*;
- modifier le *Blueprint* afin d'en faciliter l'application;
- modifier sensiblement le contenu de *Blueprint*;
- modifier les modalités de financement, de planification, d'adjudication des contrats et de prestation des services.

Élaboré entre 1997 et 1998, le *Blueprint* a plus de cinq ans. Le document de consultation note que, pendant cette période, beaucoup de choses ont changé dans le secteur de la santé et dans la société néo-zélandaise. Voici quelques-uns des facteurs qu'on estime devoir prendre en compte au moment de mettre à jour le *Blueprint* :

- Changements structurels – quatre régies régionales de la santé, puis l'Autorité de financement de la santé ont été remplacées par 21 District Health Boards, dont trois desservent moins de 50 000 habitants et quatre seulement desservent plus de 400 000 habitants.
- Des processus de planification régionaux se sont fait jour en utilisant de multiples réseaux d'intervenants qui se sont superposés à la structure législative des DHB.
- L'accent mis sur la concurrence dans le secteur de la santé a été remplacé par des attentes en matière de coordination et de collaboration et de développement des capacités des fournisseurs.
- Les attentes du public, des politiciens, des usagers, des familles et des cliniciens en matière de services de santé mentale ont augmenté.
- Un nouveau personnel non clinique s'est constitué, principalement dans le cadre d'ONG, personnel dont la formation est assujettie à des normes nationales.

- Il y a eu des changements dans la pratique clinique, y compris l'adoption d'un modèle de rétablissement et de la Norme nationale du secteur de la santé mentale et l'utilisation répandue des antipsychotiques de la nouvelle génération.

La discussion et le débat vont orienter la Commission dans la tâche qui lui incombe à présent, soit de rédiger une note d'accompagnement ou d'interprétation à l'appui du *Blueprint* et d'adapter sa mise en œuvre à l'évolution des circonstances.

2.6 OBSERVATIONS DU COMITÉ

Le Comité a été fortement impressionné par les progrès réalisés par la Nouvelle-Zélande depuis l'adoption de sa stratégie en matière de santé mentale, en 1994. L'expérience néo-zélandaise est une autre preuve de l'importance déterminante que revêt une planification suivie dans le domaine de la santé mentale. Le Comité a particulièrement pris note du fait que l'existence d'un plan détaillé, soigneusement chiffré, assorti d'objectifs bien précis, a aidé le milieu de la santé mentale à obtenir du gouvernement qu'il augmente sensiblement son niveau de financement.

De plus, le fait que la Nouvelle-Zélande se soit attardée à mettre sur pied des services communautaires complets lors du processus de désinstitutionnalisation a permis la réaffectation des ressources en sorte d'éviter une diminution du nombre de lits occupés par ceux et celles qui en ont besoin. Nous avons aussi été frappés par le rôle très important joué par un organisme indépendant, la Commission de la santé mentale, dans le cadre de ce processus et par la détermination du gouvernement d'adopter les recommandations de cette commission.

C'est sans doute l'attention régulière que la Nouvelle-Zélande a accordée au cours de la dernière décennie aux besoins de la population Maori qui a surtout impressionné le Comité. Il semble que le fait d'avoir tablé sur la participation des Maoris à l'orientation stratégique a permis de réaliser des gains notoires parce qu'il a ainsi été possible à cette communauté de s'approprier les programmes qui lui étaient destinés et d'y apposer son empreinte culturelle. Qui plus est, l'aboutissement récent des efforts de formation de professionnels maoris en santé mentale nous donne à penser qu'il existe des façons de s'attaquer à ces délicates questions.

Les programmes adoptés en vue de conférer des titres officiels aux travailleurs communautaires en santé mentale constituent une autre dimension des initiatives de formation d'un personnel nécessaire, initiatives qui semblent porter fruit en Nouvelle-Zélande. Le Comité a pris note que les efforts déployés par ce pays en vue d'améliorer l'accès aux services de soins primaires et de réduire la demande de services de soins secondaires a nécessité l'adoption de mesures pour atténuer l'impact des frais d'utilisation sur le comportement de ceux et de celles qui ont besoin de soins de santé. L'expérience néo-zélandaise constitue donc une autre preuve que les tickets modérateurs ont un effet dissuasif sur les patients potentiels.

Par ailleurs, nous serions curieux de voir s'il est possible de s'inspirer de l'expérience des conseils de santé de district en Nouvelle-Zélande pour améliorer la prestation des services de santé mentale aux Canadiens qui résident dans les régions rurales et éloignées.

Enfin, les membres du Comité ont été impressionnés par l'évolution des efforts déployés par la Nouvelle-Zélande pour combattre la stigmatisation et la discrimination dont souffrent les personnes atteintes de maladie mentale, surtout par l'engagement du gouvernement d'assurer un financement à long terme à cet égard. L'expérience néo-zélandaise nous rappelle l'importance de constituer des bases de données et d'évaluer l'information recueillie pour concevoir des campagnes de lutte contre la stigmatisation en vue de tirer les enseignements qui s'imposent de chaque expérience et de corriger le tir au besoin.

CHAPITRE 3:
LES SOINS DE SANTÉ MENTALE EN ANGLETERRE[12]

3.1 HISTORIQUE ET APERÇU

Bien que, jusqu'à la création récente des parlements écossais et gallois, son système parlementaire ait été le même que celui du Canada, le Royaume-Uni a tout de même été un État unitaire comprenant la Grande-Bretagne (Angleterre, Écosse et pays de Galles) et l'Irlande du Nord. Le système de santé publique – le National Health Service, soit le Service national de la santé (SNS) – est le même partout au Royaume-Uni, mais son administration relève de chaque juridiction qui le compose. Dans le présent chapitre, nous traiterons presque exclusivement des soins de santé en Angleterre et nous ne parlerons du Royaume-Uni que pour décrire les éléments communs. Établi en 1948, le SNS figure toujours parmi les systèmes de soins de santé dont l'administration et le financement sont les plus centralisés au monde.[13] Le gouvernement central assure non seulement le financement des services de santé, mais aussi une partie importante de la gestion et de la prestation des services.

Comme au Canada, toutes les personnes qui résident normalement au Royaume-Uni sont admissibles aux garanties de l'assurance maladie en vertu du SNS. Le SNS n'a pas une liste précise des services qu'il garantit. Cependant, il est plus complet que le régime d'assurance-maladie canadien car il garantit les services offerts par les médecins, les services hospitaliers, les médicaments délivrés sur ordonnance, les soins dentaires et d'optique. Il n'existe pas de frais d'utilisation à l'égard des services des médecins au Royaume-Uni et les services hospitaliers et des spécialistes sont offerts gratuitement. Des frais d'utilisation s'appliquent aux médicaments délivrés sur ordonnance, aux services dentaires et aux services optiques, et, contrairement au Canada, le Royaume-Uni autorise l'achat d'assurance-maladie privée offrant les mêmes garanties que le SNS si ces services sont offerts par des fournisseurs qui travaillent hors du SNS.

Au Royaume-Uni, la partie des dépenses relatives aux soins de santé financée par le secteur public (82 p. 100) est plus importante qu'au Canada (70 p. 100). Le SNS est financé principalement par le système général d'imposition du gouvernement central, ainsi que par

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12 À moins d'indication contraire, les renseignements contenus dans le présent chapitre proviennent des sources suivantes : ministère de la Santé, *National Service Framework for Mental Health*, 1999; Select Committee on Health, *Fourth Report: Provision of NHS Mental Health Services*, 2000; McCulloch, Andrew, Matt Muijen et Heather Harper, « New Developments in Mental Health Policy in the United Kingdom » *International Journal of Law and Psychiatry*, vol. 23, nº 3-4, 2000; The Sainsbury Centre for Mental Health, « Mental Health Policy: the challenges facing the new Government, » juillet 2001; ministère de la santé, *The Journey to Recovery – The Government's Vision for Mental Health Care*, novembre 2001; National Institute for Mental health in England, *Cases for Change – Policy Context*, 2002; ministère de la Santé, *National Suicide Prevention Strategy for England*, septembre 2002; Levenson, Ros, Angela Greatley et Janice Robinson, *London's State of Mind*, King's Fund Mental Health Inquiry, 2003; The Sainsbury Centre for Mental Health, *Money for Mental Health: A review of public spending on mental health care*, 2003; Commission for Health Improvement, *What CHI has found in mental health trusts (sector report)*, 2003; Social Exclusion Unit, *Mental Health and Social Exclusion*, cabinet du vice-premier ministre, 2004.

13 Paul Wallace dans *The Economist* (17 juillet 2004) fait remarquer qu'avec ses 1,4 million d'employés, le SNS est le troisième plus important employeur au monde, derrière l'armée rouge chinoise et les chemins de fer indiens.

un élément de contribution au fonds national auquel participent les employeurs et les employés. Les frais d'utilisation comptent pour moins de 3 p. 100 du financement total du SNS.

De nombreuses réformes importantes de la gestion et de la prestation des services de santé au Royaume-Uni ont été entreprises dans les années 90. Celles-ci ont initialement créé un « marché intérieur », c'est-à-dire que certains principes axés sur le marché ont été insérés dans le régime des soins de santé financés publiquement. Un « partage acheteur-fournisseur » a modifié les relations entre les autorités régionales de la santé et les hôpitaux, tandis que l'établissement « d'enveloppes budgétaires pour les omnipraticiens » a modifié l'organisation et la forme des pratiques de médecine générale. Le gouvernement travailliste de Tony Blair, élu la première fois en 1997, était contre l'existence d'un marché intérieur en matière de santé; il a depuis lors modifié un certain nombre de caractères importants du régime, mais n'a pas cherché à retourner à la formule d'origine.[14]

Mme Anne Richardson, chef de la Direction des politiques en santé mentale, ministère de la Santé au gouvernement du Royaume-Uni, nous a expliqué que, depuis 2001, le Service national de la santé comporte trois niveaux, le ministère de la Santé chapeautant le tout. Elle a précisé que « le rôle du ministère de la Santé est d'élaborer des politiques ainsi que les systèmes et les structures nécessaires pour assurer les services. Cependant, il ne s'occupe pas directement de la mise en oeuvre de ce changement ». On dénombre par ailleurs 28 autorités sanitaires stratégiques (ASS) qui sont chargées d'administrer le bon fonctionnement des services locaux. Elles sont de taille variable (de 20 à 30 employés par emplacement) et peuvent assumer la responsabilité d'une trentaine de groupes de soins primaires (GSP), lesquels constituent le troisième niveau.

Les GSP, qui sont chargés de la gestion des services de santé, sont maintenant au centre du SNS et ils bénéficient de 75 p. 100 du budget du SNS. La plupart des GSP desservent des populations de 50 000 à 250 000 personnes, un GSP moyen servant quelque 100 000 personnes. On dénombre actuellement 302 GSP en Angleterre qui n'ont pas tous le même niveau d'expérience ni de compétence.

Les GSP offrent directement les soins primaires, ainsi que les services de santé communautaires et ils commandent des services[15] aux groupes hospitaliers et à d'autres fournisseurs de soins secondaires et tertiaires. Les GSP peuvent également commander

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14 En fait, certains analystes soutiennent que le gouvernement travailliste vient d'entreprendre un retour au « marché interne », ce qui a amené Paul Wallace à écrire que ce mouvement de balancier s'inscrit dans la foulée de l'important basculement politique qui a suivi les élections de 2001. (*Ibid.*)

15 Même au Royaume-Uni, il règne encore une certaine confusion quant au sens exact à donner au terme « commissioning » (que nous avons traduit ici par commander) et à son rapport avec le terme plus familier « purchasing » (acheter). Tant conceptuellement que dans les faits, ces deux mots semblent être employés assez librement. Il existe cependant une définition commune : *Commander* correspond à l'activité stratégique qui consiste à évaluer un besoin, des ressources et des services courants et à élaborer une stratégie afin d'utiliser au mieux les ressources disponibles pour satisfaire les besoins constatés. Qui dit commander, dit déterminer des priorités, acheter les services appropriés et les évaluer. *Acheter* est l'activité opérationnelle qui s'inscrit dans le contexte d'une commande et qui consiste à mettre des ressources en œuvre afin d'acquérir des services en sorte de satisfaire des besoins, soit à un niveau macro, ou à celui de la population, soit à un niveau micro ou à celui de l'individu.

d'autres services de soins primaires (services de physiothérapie, thérapies alternatives et counselling) et, comme nous le verrons, des services de santé mentale. Mme Richardson a indiqué au Comité que le travail des GSP sert « à interpréter les normes et les objectifs nationaux en fonction des besoins de leur population locale ».

3.1.1 La santé mentale

Jusqu'aux années 50, la principale forme de soin des personnes atteintes de maladie mentale était l'asile de type victorien. Comme ailleurs, avec l'arrivée de nouveaux médicaments et une prise de conscience publique voulant que les personnes atteintes de maladie mentale ont le droit de vivre dans la société, cette situation a commencé à changer à partir des années 60. On a commencé à fermer les vieux hôpitaux afin d'installer des unités psychiatriques plus modernes dans les hôpitaux généraux locaux. Ainsi, le nombre de lits d'hôpital avait diminué considérablement en 1978, passant de 129 000 en 1968 à 91 000 en 1978, à 63 000 en 1988-1989 et à 36 000 en 1998-1999.

Il est fort possible que le débat politique continuera de porter sur la meilleure façon d'administrer le processus de désinstitutionnalisation et sur ses nombreuses ramifications. Dans les premières années de l'application de cette politique, il semble que les décideurs aient sous-estimé le niveau de soutien requis par un groupe relativement petit de personnes lourdement handicapées qui vivaient auparavant dans des asiles datant d,une autre époque. On n'a pas prévu les ressources nécessaires pour accueillir ces personnes dans la collectivité. En particulier, il n'existait ni soutien intensif à la santé et aux services sociaux, ni logement subventionné. Cette situation a contribué à entretenir, dans certains cercles, l'impression que la politique elle-même, celle des « soins communautaires », était mauvaise, malgré l'évidence sur le plan international des résultats améliorés obtenus grâce aux soins communautaires pour la grande majorité des personnes atteintes de maladie mentale.

Au cours des dernières années, la politique relative à la santé mentale a été modifiée considérablement pour créer un système de soins efficace adapté aux personnes souffrant de problèmes de santé mentale de tous les genres et de tous les niveaux de gravité. La série d'initiatives politiques prises au cours des années 90 a visé à consolider les services communautaires par la recherche d'un équilibre approprié entre les soins et le contrôle, et entre le soutien et la sécurité publique.

La politique a été promulguée dans les publications suivantes produites par le gouvernement :

- Un livre blanc, paru en 1998 sous le titre *Modernising mental health services: safe, sound and supportive*, avait pour objet de recenser et de combler les lacunes en matière de prestation de services. Il exprimait une vision pour la création de services de santé mentale axés sur la sécurité, le bon sens et le soutien, par le biais de différentes mesures, y compris la création de services de soutien communautaires plus actifs, comme les « équipes d'intervention affirmative » afin de s'occuper des problèmes des personnes vivant dans la collectivité et dont les besoins sont complexes.
- Ce livre blanc a été suivi du document sur le cadre du service national intitulé *National Service Framework for Mental Health (NSF-MH)*, soit le Cadre national de

service en matière de santé mentale, qui fixait des normes et des objectifs détaillés pour les services de santé mentale des adultes de 18 à 65 ans ayant des problèmes de santé mentale (voir ci-après);

- Le *NHS Plan,* c'est-à-dire le plan du SNS, publié en 2000, prévoyait l'amélioration du programme décrit dans le *National Service Framework* en y ajoutant de nouveaux services, notamment l'intervention affirmative, la résolution des situations de crise (parfois appelée traitement à domicile) et l'intervention précoce dans les services psychotiques. Ce plan prévoyait l'arrivée de diplômés en soins primaires de santé mentale, de travailleurs qui orientent la clientèle et de travailleurs d'appui aux fournisseurs de soins et il favorisait les modifications structurelles comme la création de groupes de soins. Il contenait également les exigences relatives à la main-d'œuvre en santé mentale et les questions liées au recrutement et au maintien en poste, au leadership et à la formation. Le Plan du SNS comportait un financement nouveau de 300 millions de livres pour les services de santé mentale.

Le *National Service Framework for Mental Health* est un programme décennal. Mme Richardson a décrit au Comité les sept normes autour desquelles il s'articule :

- La première concerne la promotion de la santé mentale — c'est-à-dire toutes les mesures nécessaires pour vous aider à lutter contre les préjugés qui entourent la maladie mentale et réduire les risques que les personnes développent une maladie mentale.
- Les normes deux et trois portaient sur la santé mentale et les soins primaires, afin de prendre les mesures nécessaires pour améliorer l'accès aux services par des personnes atteintes de ce qu'on appelle des troubles mentaux courants.
- Les normes quatre et cinq concernent les personnes ayant une grave maladie mentale — la proportion relativement faible du groupe total de personnes ayant des problèmes de santé mentale — qui néanmoins présentent le plus de risques de décès par suicide et autres causes, et qui présentent aussi les taux les plus élevés de morbidité. Je songe entre autres aux personnes diagnostiquées schizophrènes, bipolaires ou très gravement déprimées.
- La norme six portait sur les mesures nécessaires pour améliorer les services et les mécanismes de soutien à l'intention des personnes qui prodiguent des soins.
- La norme sept mettait l'accent sur toutes les mesures nécessaires dans l'ensemble du réseau des soins de santé et des services sociaux pour réduire le risque de suicide.

L'encadré suivant présente les sept normes en question.

NORMES « NSF-MH »

1. *Les services de santé et les services sociaux devraient :*
   - favoriser la santé mentale pour tous, grâce au travail auprès des personnes et des collectivités;
   - lutter contre la discrimination à l'égard des personnes et des groupes ayant des problèmes de santé mentale, et favoriser leur insertion sociale.

2. *Tout utilisateur de services qui communique avec son équipe de soins de santé primaires et qui souffre d'un problème de santé mentale commun devrait :*
   - faire identifier et évaluer ses besoins en santé mentale
   - se voir offrir des traitements efficaces, y compris le renvoi aux services spécialisés afin d'obtenir une évaluation plus poussée, ainsi que les traitements et les soins dont il a besoin.

3. *Toute personne souffrant d'un problème de santé mentale devrait :*
   - pouvoir communiquer en tout temps avec les services locaux qui peuvent répondre à ses besoins afin de recevoir les soins appropriés;
   - pouvoir utiliser le service NHS Direct, à mesure qu'il sera mis en place, afin d'obtenir une opinion de premier niveau et le renvoi à des lignes secours spécialisées ou aux services locaux.

4. *Tout utilisateur de services de santé mentale rattaché au service « Care Programme Approche (CPA) » devrait :*
   - recevoir des soins qui optimisent la responsabilisation, préviennent ou anticipent les crises et qui réduisent les risques;
   - posséder un exemplaire écrit d'un plan de soins qui
     - — inclue les mesures à prendre, en situation de crise, par les utilisateurs, par leurs fournisseurs de soins et par leurs coordonnateurs de soins;
     - — informe l'omnipraticien des mesures à prendre si l'utilisateur a besoin d'autres services;
     - — soit révisé régulièrement par le coordonnateur de soins;
     - — permette d'accéder aux services 24 heures sur 24, toute l'année durant.

5. *Tout utilisateur de services qui a fait l'objet d'une évaluation et qui a besoin de recevoir des soins hors de son domicile pendant un certain temps devrait :*
   - pouvoir accéder en temps voulu à un lit ou à un local, dans un hôpital ou dans un autre lieu approprié, qui soit :
     - — situé dans un environnement qui soit le moins contraignant possible, compte tenu de la nécessité de le protéger et de protéger le public,
     - — situé le plus près possible de son domicile;
   - posséder un exemplaire écrit d'un plan du suivi convenu après le congé, document dans lequel sont indiqués les soins et la réadaptation à recevoir, le nom du coordonnateur de soins et les mesures à prendre en cas de situation de crise.

6. *Toute personne qui prodigue régulièrement des soins importants à une personne en vertu du CPA devrait :*
   - subir une évaluation de ses besoins en matière de soins de santé et de ses besoins physiques et mentaux, au moins une fois par année;
   - posséder son propre plan de soins qui lui est remis et qui est appliqué après discussion avec elle.

7. *Les collectivités locales de soins de santé et de services sociaux devraient prévenir le suicide :*
   - en favorisant la santé mentale pour tous, en travaillant avec les individus et avec les collectivités (norme un);
   - en dispensant des soins primaires de haute qualité (norme deux);
   - en s'assurant que toute personne qui a un problème de santé mentale puisse communiquer avec les services locaux par l'entremise du Groupe de soins primaires, d'une ligne secours ou à un service d'urgence (norme trois);
   - en s'assurant que les personnes atteintes de maladie mentale grave et prolongées possèdent un plan de soins qui réponde à leurs besoins particuliers, y compris l'accès aux services en tout temps (norme quatre);
   - en offrant des locaux sûrs dans les hôpitaux aux personnes qui en ont besoin (norme cinq);
   - en permettant aux personnes qui s'occupent des personnes atteintes de maladie mentale grave d'obtenir l'appui sont elles ont besoin pour continuer de s'en occuper (norme six);

   et enfin :
   - en appuyant le personnel des prisons locales en matière de prévention du suicide chez les prisonniers;
   - en s'assurant que le personnel possède les compétences nécessaires pour évaluer le risque de suicide chez les personnes les plus à risque;
   - en élaborant des systèmes locaux d'examen des suicides afin d'en tirer des leçons et améliorer la prévention.

Le *NSF-MH* était le premier document à indiquer ce qu'on attendait des services de santé et des services sociaux en Angleterre. Un nouvel organisme, l'Institut national de santé mentale (NIMHE, pour National Institute for Mental Health in England) a été chargé de superviser la mise en œuvre du cadre de service. Comme Mme Richardson l'a expliqué, le NIMHE

> *… compte une série de huit centres de développement régional dispersés un peu partout en Angleterre. Le travail de ces centres consiste particulièrement à aider les services locaux à mieux atteindre leurs objectifs. Ils établissent des modèles de pratiques exemplaires, visitent les services locaux et font appel à des porte-parole chargés de mieux faire connaître le nouveau modèle de services et les besoins des personnes qui ont une maladie mentale. Il existe environ 26 programmes de travail qui relèvent de l'Institut national de la santé mentale et qui disposent tous d'un financement central. Ces programmes sont destinés à appuyer la réforme.*

Mme Richardson a donné l'exemple suivant pour l'un des programmes administrés par le NIMHE :

> *[N]ous avons un programme de santé mentale à l'intention des Noirs et des minorités ethniques, dont le financement à l'heure actuelle est de 2,5 millions de livres jusqu'en 2006. Ce programme emploiera du nouveau personnel affecté au développement communautaire et servira à mettre sur pied environ 80 projets de développement communautaire, ce qui nous permettra d'améliorer les services de santé mentale à l'intention des Noirs et des groupes de la minorité ethnique qui ont des problèmes de santé mentale.*

Le NIMHE comprend huit bureaux régionaux qui travaillent chacun directement au contact des collectivités locales, des GSP, des ONG et des utilisateurs de service. Ce faisant, le NIMHE est en mesure d'organiser sa contribution pour mettre en œuvre le *NSF-MH* ainsi que ses programmes d'assistance dans le cadre d'une approche d'intégration communautaire.

Le *NSF-MH* prévoyait en outre la création, dans tous les domaines visés, d'équipes locales de mise en oeuvre (ÉLMO) composées de représentants des utilisateurs de services, du personnel soignant, des autorités locales compétentes, des Groupes de soins primaires, des Groupes du SNS et des autorités de la santé, ayant pour mandat d'élaborer un plan local de mise en oeuvre. Initialement, 126 ÉLMO ont été créées, certaines ayant fonctionné mieux que d'autres. À cet égard, Mme Richardson nous a précisé ce qui suit :

> *Sans ces équipes de mise en oeuvre locales, nous n'aurons absolument pas pu apporter tous les changements que nous avons réussi à instaurer. Je ne veux pas brosser un tableau trop optimiste car il nous reste encore beaucoup de chemin à parcourir. Il y a maintenant presque cinq ans que le programme a été lancé, et nous avons apporté des changements considérables, mais il reste encore beaucoup à faire. Les équipes de mise en oeuvre locales ont joué un rôle essentiel à cet égard, et il est très important dans le cadre du programme de réforme de s'assurer dès le départ d'avoir l'infrastructure qui convient.*

De plus, le gouvernement a depuis lors produit un Guide détaillé de la mise en œuvre de la politique afin de soutenir le NSF-MH (en 2001) et il a publié des propositions de réforme du *Mental Health Act* (Loi sur la santé mentale) en 2002.

Malgré les nombreuses réactions positives au NSF-MH, certains s'inquiétaient de l'insuffisance des ressources disponibles par rapport à la tâche à accomplir, tandis que d'autres pensaient que le NSF-MH ne prenait pas en compte le débat en cours sur les modèles médicaux et les modèles sociaux en santé mentale. Ces critiques pensaient que l'appellation « maladie mentale » donnée aux problèmes de santé mentale révélait une incapacité de considérer les clients actuels et les ex-clients comme des personnes ayant des points forts et pas uniquement des problèmes. Malgré les différentes critiques, pour la plupart des commentateurs du NSF-MH, il y avait lieu de se montrer optimiste quant à l'avenir des services de santé mentale au Royaume-Uni.

3.2 COÛTS ET FINANCEMENT DES SERVICES DE SANTÉ MENTALE

Un rapport, publié en juin 2004 par l'Unité de santé mentale et d'exclusion sociale, qui relève du cabinet du vice-premier ministre, donne les chiffres suivants quant aux coûts de la maladie mentale en Angleterre :

- Le coût global annuel des problèmes de santé mentale dans ce pays est évalué à 77,4 milliards de livres. L'incidence sur la qualité de vie, notamment à cause de la mortalité prématurée, représente plus de la moitié de ce chiffre.
- Les pertes de rendement, associées aux chances d'emploi ratées, sont estimées à plus de 23 milliards de livres par an.
- Les coûts économiques du suicide seraient de quelque 5,3 milliards de livres.

En 2000, le Secrétaire d'État à la Santé a déclaré devant le Select Committee sur la santé que les services de santé mentale représentaient 12 p. 100 du budget total des services de santé hospitaliers et communautaires. Mme Richardson a indiqué au Comité qu'en 2001, 2002, cette proportion est passée à 13 p. 100. D'un autre côté, elle a insisté sur le fait qu'il ne faut pas perdre une chose de vue :

> *[L]es dépenses en services de santé communautaires et hospitaliers ne représentent qu'une partie des fonds consacrés à la santé mentale. Nous avons aussi des dépenses en soins sociaux, qui sont engagées séparément par les administrations locales pour les services sociaux, les services d'éducation et d'autres.*

Plus récemment, une estimation du Sainsbury Centre for Mental Health[16] (2003) indiquait qu'environ 80 p. 100 des dépenses totales au chapitre des services de santé mentale étaient financées par le SNS. Quant au reste, 15 p. 100 proviennent des budgets relatifs aux services sociaux de compétences locales, 3 p. 100 sont assurés par la Subvention pour la santé mentale (réservée aux services de santé mentale offerte aux administrations locales par le gouvernement central) et le reste provient d'autres sources, y compris les frais d'utilisation.

Le Centre Sainsbury a en outre estimé qu'environ 75 p. 100 des dépenses totales relatives aux services de santé mentale correspondent aux coûts directs de la prestation des services (surtout en personnel), tandis que les 25 p. 100 restant correspondent aux coûts indirects, aux frais généraux et aux intérêts et remboursements des emprunts.

Comme nous l'avons indiqué plus haut, le plan du SNS a prévu l'accroissement du financement de la santé mentale afin de permettre l'expansion des services. Dans son rapport sur les dépenses en santé mentale, le Centre Sainsbury a calculé que les charges en trésorerie pour les services de santé mentale des adultes (du SNS et des autorités sanitaires

[16] Le Sainsbury Centre for Mental Health (SCMH) est un organisme de bienfaisance qui cherche à améliorer la qualité de vie des personnes atteintes de problèmes de santé mentale graves. Il effectue des recherches et conduit des activités de développement et de formation afin d'influencer les politiques et les pratiques dans le domaine des soins de santé et du bien-être. Le SCMH est affilié à l'Institute of Psychiatry du King's College, à Londres. Ses travaux sont très respectés dans le monde entier.

locales combinées) ont augmenté de 7,1 p. 100 en 2002-2003 et qu'une augmentation de 6,3 p. 100 est prévue pour 2003-2004. Au cours de ces deux exercices, cependant, l'analyse indique que la croissance des dépenses relatives aux services de santé mentale est beaucoup plus lente que la croissance globale des dépenses relatives à l'ensemble des soins de santé et des services sociaux. Cela signifie que, compte tenu de l'augmentation des salaires et des prix, les dépenses relatives aux services de santé mentale augmenteront de moins de la moitié du taux des dépenses totales pour le SNS et les services sociaux au cours des deux années 2002-2003 et 2003-2004.

Le Centre Sainsbury a ainsi conclu que, malgré le statut de service prioritaire de la santé mentale, la part qui accordée à ce secteur dans les budgets relatifs au SNS et aux services sociaux est en baisse. Il souligne que l'augmentation des dépenses sont très inférieurs au taux moyen d'augmentation annuelle de 11.5 p. 100 nécessaire à la mise en œuvre du cadre national de services en santé mentale (NSF-MH) selon le calendrier du gouvernement. D'après le Centre, pour que le calendrier soit respecté, il faudrait que le taux d'augmentation des dépenses annuelles en espèces pour les services de santé mentale soit deux fois supérieur à ceux de 2002-2003 et de 2003-2004.

Le Centre Sainsbury constate bien des différences locales dans les régimes de dépense, mais il conclut qu'elles ne doivent pas obscurcir la conclusion la plus importante de son étude qui indique qu'au niveau national, la tendance actuelle en matière de dépenses laisse prévoir un écart croissant entre les promesses et les résultats dans le domaine de la prestation de meilleurs services de santé mentale. Selon le Centre, les décideurs doivent de toute évidence choisir entre ralentir le programme de réforme et affecter davantage de ressources à la santé mentale.

Toutefois, dans son témoignage, Mme Richardson a déclaré au Comité :

> *Tout d'abord, je dois contester vivement la notion selon laquelle le cadre du service national n'a pas prévu une augmentation des ressources destinées à la santé mentale. Comme je crois l'avoir dit plus tôt, le plan du SNS établit qu'un montant de 300 millions de livres supplémentaires, en sus du financement de base, sera investi dans le service national de santé pour accélérer sa mise en oeuvre d'ici 2003-2004.*

Et elle a souligné :

> *Les indications dont nous disposons corroborent le fait que ces fonds ont effectivement été affectés aux services de santé mentale. Nous savons que jusqu'en avril de l'année dernière, un montant supplémentaire de 262 millions de livres a été consacré à la santé mentale en plus du financement de base prévu pour 2001.*

À l'échelon local, il semblerait que l'écart entre les ambitions du programme de réforme et la réalité des restrictions du financement de la santé mentale soit amplifié par les nouvelles façons dont les fonds sont maintenant attribués pour les besoins locaux. Comme nous

l'avons vu, les Groupes de soins primaires (GSP), gérés localement, obtiennent maintenant leur financement du SNS directement du gouvernement central plutôt que des autorités sanitaires. Les GSP sont responsables de la répartition de ces fonds entre les différents services de santé, y compris les services de santé mentale, et aussi de l'établissement des priorités locales pour le développement futur des services. Les GSP sont la principale source de financement des soins de santé mentale et en principe, ils peuvent réorienter les ressources vers les services et vers les fournisseurs en fonction des priorités locales.

Une étude récente a été menée par le *King's Fund on mental health services* à Londres en 2003. Elle indique qu'en dépit du fait que la responsabilité de commander la plupart des services de santé mentale soit passée des mains des autorités sanitaires à celles des GSP, la plupart des GSP semblent avoir été incapables de consacrer beaucoup de temps à cette obligation, contrairement à que ce qu'on attendait d'eux en raison de la *taille* de leurs budgets ou contrairement aux exigences, en raison de l'état du développement des services de santé mentale. Le Centre Sainsbury a effectué un sondage auprès des Équipes locales de mise en œuvre (ÉLMO), qui sont chargées de mettre en place les réformes en matière de santé mentale. L'analyse suggère que, dans l'ensemble, 58 p. 100 des ÉLMO pensent que le financement pour 2003-2004 sera vraisemblablement insuffisant, tout compte fait, pour maintenir les services de base et appliquer le programme de réforme du gouvernement, tandis que 42 p. 100 d'entre elles se disaient plus optimistes. Les chiffres des plans locaux de prestation pour trois ans, jusqu'en 2005-2006, indiquent aussi que le rendement sera vraisemblablement inférieur aux objectifs nationaux et à ceux des politiques.

Plus généralement, les budgets pour la santé mentale sont comprimés à cause d'un certain nombre de pressions, dont les principales sont la pénurie de personnel (qui occasionne des dépenses supérieures pour l'embauche de personnel temporaire), l'augmentation rapide des coûts de prescription et l'obligation de rembourser les dettes accumulées. Par exemple, le Centre Sainsbury a présenté un cas de dépassement extrême du cadre du budget : un groupe du sud de l'Angleterre a déclaré avoir dépensé en trop 145 000 £ pour de la publicité de recrutement et 1 672 000 £ pour des médecins suppléants.

Dans un rapport présenté devant le *Mental Health Providers Forum* (MHPF) en 2002, on estimait que les dépenses effectuées pour et par le secteur bénévole pour la prestation des services de santé mentale correspondent à environ 10 p. 100 des dépenses publiques pour la santé mentale. Les recettes combinées des membres du MHPF en 2001/2002 s'élevaient à 320 millions de livres, la majorité de ces fonds provenant du SNS et des autorités sanitaires locales en matière de services de santé mentale offerts dans le cadre de marchés de service. Les soins à domicile constituaient la partie la plus importante des activités confiées par commande, avec 69 p. 100 des dépenses totales, suivis par les services communautaires, avec 23 p. 100. Le reste des dépenses s'étalait sur différents services, dont l'information, la défense des droits, la recherche, les campagnes, la formation et l'appui aux soignants.

3.3 PRESTATION ET ORGANISATION DES SERVICES

La modernisation des services de santé mentale au Royaume-Uni se fait dans le contexte d'une réorganisation importante des services. Le principal changement apporté dans le secteur public ces dernières années a été l'émergence de groupes de spécialistes de la santé

mentale qui, dans plusieurs cas, sont toujours en voie de développement alors que diverses agences ont été amalgamées en vue de constituer un fournisseur unique pour l'ensemble des services de santé mentale dans chaque localité. Certains de ces fournisseurs sont constitués en groupes de soins de santé et de services sociaux ayant un budget unifié pour la santé et les services sociaux et un personnel et des locaux communs.

La création de tels groupes de spécialistes de la santé mentale est un phénomène nouveau puisque la majorité d'entre eux n'existent que depuis avril 2002. Ils remplacent toute une gamme de services qui étaient jusque là fournis et gérés par des groupes de soins actifs, des groupes communautaires et certains groupes de spécialistes de la santé mentale. Ces groupes présentent une grande diversité de caractéristiques comme l'importance de leur budget d'ensemble, le nombre d'employés, le nombre de malades hospitalisés, le nombre de lieux de prestation de services et le territoire géographique desservi.

Ces groupes se différencient aussi par la clientèle desservie. Plusieurs s'intéressent aux difficultés d'apprentissage et la plupart offrent des services aux personnes âgées, de même qu'aux enfants, aux adolescents et aux adultes en âge de travailler. De plus en plus, ces groupes offrent des soins à domicile ou des « services d'urgence » pour répondre à des cas individuels de souffrance morale aiguë, afin que ces personnes puissent demeurer dans la collectivité, le plus souvent chez elles, au lieu d'être hospitalisées. Les groupes du SNS qui assurent la prestation de services de santé mentale généraux peuvent souvent avoir accès à une unité de soins fermée à clé ou à une unité de soins intensifs pouvant accueillir les patients qui ont besoin d'une sécurité physique accrue ou de la présence d'un personnel plus nombreux que dans une aile de soins actifs.

Dans leurs témoignages devant le *Select Committee* sur la santé, en 2000, le Royal College of Nursing et le Royal College of Psychiatrists ont soutenu que la qualité des soins communautaires n'est possible que si les malades peuvent aussi être hospitalisés dans un établissement de qualité. Divers témoins ont dit au Comité que ces centres de soins sont encore de qualité inférieure. On a renvoyé le Comité à une étude du Centre Sainsbury selon laquelle les pressions exercées pour l'utilisation de lits de soins actifs sont telles que le milieu n'a rien de « thérapeutique », que les services n'ont pas de buts précis et que les liens avec la collectivité sont médiocres. La Mental Health Foundation a aussi laissé entendre au Comité que la « faiblesse réelle » des services de santé mentale se situe dans les unités de soins actifs.

Une bonne partie des services de santé mentale sont aussi offerts dans un cadre de soins primaires. Selon les chiffres avancés dans le Rapport sur la santé mentale et l'exclusion sociale, 90 p. 100 des patients ayant des problèmes de santé mentale et un quart de ceux atteints de troubles graves de santé mentale sont traités dans le cadre de soins primaires, et 30 p. 100 des consultations en pratique générale comportent un élément de santé mentale (il s'agit le plus souvent de dépressions, de troubles de l'alimentation et de troubles anxieux).

D'un autre côté, Mme Richardson nous a déclaré « Le fait est que nous n'avons pas de stratégie en tant que telle pour l'intégration des soins primaires et secondaires ». Toutefois, elle a décrit au Comité une initiative particulière destinée à améliorer la prestation des services au niveau de soins primaires. Le plan du SNC pour 2000 fixe à 1 000 le nombre de travailleurs en santé mentale qui devront être diplômés dans le domaine des soins primaires d'ici décembre 2004, afin d'aider les omnipraticiens à consulter et à traiter les gens de tous

âges atteints de problèmes de santé mentale communs. Pour Mme Richardson, « le travailleur diplômé est une nouvelle espèce». Elle devait d'ailleurs nous décrire le programme en ces termes :

> *[…] nous avions dans le système un groupe de diplômés aptes qui voulaient travailler au SNS et qui pouvaient recevoir une formation, selon les données recueillies, pour fournir brièvement et efficacement en matière de soins primaires des traitements fondés sur des données probantes aux patients souffrant de troubles courants. Nous avons […] constitué 12 nouveaux programmes de formation dans toute l'Angleterre pour leur offrir un programme externe de formation d'un an menant à l'obtention d'un certificat d'études supérieures.*
>
> *[…] Nos travailleurs qui font des études plus poussées ont généralement une formation en sciences sociales ou en psychologie et ne sont pas des infirmiers ou des infirmières. La formation supplémentaire d'un an qu'ils reçoivent après l'obtention de leur diplôme les prépare à donner des conseils en matière d'auto-assistance, à diffuser de l'information et à traiter efficacement sur de courtes périodes les personnes atteintes de troubles communs en tentant d'agir sur leur comportement cognitif.*

Le plan du SNS fait également état d'autres objectifs particuliers, dont la mise sur pied de 50 autres équipes d'intervention d'urgence, objectif qui, selon Mme Richardson, a été atteint. Elle nous a d'ailleurs expliqué ce qu'est une équipe d'intervention affirmative :

> *[…] Il s'agit d'une petite équipe multidisciplinaire composée de neuf à quinze personnes. Elle s'occupe particulièrement des quelque 1 500 patients du système de services de santé mentale qui ont une maladie mentale grave ou qui risquent plus particulièrement de perdre contact avec les services ou de ne plus communiquer avec leurs travailleurs principaux. Ce groupe particulier d'utilisateurs de services compte parmi ceux qui posent le plus de défis. Ils ont habituellement une longue histoire, une maladie mentale grave, sont atteints de schizophrénie, par exemple. Il s'agit assez souvent d'itinérants, sans domicile fixe.*
>
> *L'équipe d'intervention affirmative commence son travail après une période d'admission. Par exemple, généralement, un utilisateur de services est admis à un hôpital psychiatrique, reçoit un traitement pendant un certain temps et suit un plan d'intervention. L'équipe d'intervention affirmative assure un suivi, de façon assez affirmative, comme son titre l'indique. Elle rend visite à la personne chez elle; si la personne ne se rend pas à un rendez-vous, elle vérifie ce qui s'est passé. Ses membres peuvent rencontrer l'utilisateur de services, le patient, à l'endroit de son choix. Nous connaissons des équipes d'intervention affirmative qui travaillent à la buanderie du coin, et ces travailleurs*

essaient de faire en sorte que l'utilisateur de services suive son plan d'intervention et ne s'isole pas.

En plus des grands organismes, on trouve habituellement des fournisseurs indépendants dans la plupart des localités. Bien souvent, ce sont des organismes du secteur bénévole qui font partie d'organisations nationales. Le secteur privé peut aussi être actif sur la scène locale, surtout dans un rôle de fournisseur d'installations sécuritaires et d'installations répondant à des besoins spéciaux. De même, il y a des propriétaires privés qui offrent des logements spécialisés aux personnes qui ont des besoins en santé mentale dans certaines régions.

3.3.1 Les resources humaines

Le Royaume-Uni fait toujours face à de sérieux problèmes de recrutement et de maintien en poste de travailleurs de la santé mentale. Les importantes pénuries de personnel, surtout de psychiatres et d'infirmières et d'infirmiers dans les hôpitaux, continuent d'avoir des conséquences majeures sur le leadership clinique et sur la qualité des soins offerts. Comme nous l'avons indiqué précédemment, les problèmes de recrutement et de maintien du personnel entraînent le recours à un nombre élevé d'employés temporaires et à du personnel d'agences. Toutefois, les expériences locales varient selon les conditions de travail, les stratégies de recrutement et l'attrait qu'exercent certaines organisations et localités.

En 2000, le Secrétaire d'État à la Santé parlé, devant un comité parlementaire, des pénuries d'infirmières et d'infirmiers, de psychiatres et « d'autres personnels spécialisés » mais il a ajouté que la situation variait aux niveaux local et régional et que les chiffres sur le nombre de postes vacants en soins infirmiers en santé mentale (2,1 p. 100) étaient inférieurs au nombre de postes vacants en soins infirmiers généraux (2,6 p. 100). Dans son témoignage devant ce même comité, le Royal College of Psychiatrists a estimé qu'en moyenne, le taux de vacances pour les psychiatres consultants est d'environ 15 p. 100.

Une étude menée en 2003 par la *Commission for Health Improvement* (Commission sur l'amélioration de la santé – CAS) indique que plusieurs employés permanents travaillent de trop longues heures. La Commission a aussi été impressionnée par l'engagement et le dévouement du personnel clinique, non clinique et chargé d'administrer des soins, à offrir des soins de haute qualité aux usagers dans l'ensemble du secteur, bien que plusieurs employés aient été soumis à des pressions considérables dans des milieux de travail difficiles.

3.3.2 Les services aux minorités

Le rapport sur la santé mentale et l'exclusion sociale précise qu'au Royaume-Uni :

- les membres de groupes minoritaires ethniques sont six fois plus susceptibles d'être détenus en vertu du Mental Health Act (loi sur la santé mentale) que les Blancs;
- on estime que l'on diagnostique deux fois plus de troubles psychotiques chez les Afro-antillais que chez les Blancs, même s'ils sont trois à cinq fois plus susceptibles que ces derniers d'être admis dans les hôpitaux après un diagnostic de schizophrénie;

- les femmes sud-asiatiques nées en Inde et en Afrique de l'Est présentent des taux de suicide qui sont 40 p. 100 plus élevés que celles nées en Angleterre et au pays de Gales.

Les données statistiques présentées par la British Psychological Society dans son témoignage devant le *Select Committee* sur la santé en 2000 soulignent la tendance chez les patients de minorités ethniques à tarder pour obtenir des services : ils attendent que la maladie se soit aggravée et risquent davantage d'être hospitalisés. D'autres témoins ont indiqué que les services offerts aux minorités visibles sont souvent « inappropriés » ou « dépourvus d'humanité ». Certains groupes minoritaires sont également sous-représentés dans les services. Par exemple, les femmes de communautés sud-asiatiques recourent moins que la moyenne aux services de santé mentale officiels et affichent un taux de suicide supérieur à la moyenne.

Les motifs avancés par les témoins devant ce comité du Parlement britannique pour expliquer que les membres de minorités ethniques ont moins souvent recours aux services de santé mentale diffèrent grandement de celles qui caractérisent les patients de race blanche et sont de deux ordres : les services ne seraient pas adaptés et les fournisseurs de services ne comprennent pas les besoins des patients de minorités visibles. Le *Select Committee* s'est dit préoccupé par la lenteur des changements bien que ces problèmes soient connus depuis quelques années déjà.

3.4 PROMOTION ET PRÉVENTION

3.4.1 La lutte à la stigmatisation et à la discrimination

Comme nous l'avons indiqué précédemment, la première norme du Cadre national de service en matière de santé mentale vise à faire en sorte que les services de santé et les services sociaux fassent la promotion de la santé mentale et de la lutte à la discrimination et à l'exclusion sociale. Mme Richardson a indiqué au Comité que son gouvernement avait débuté le tout

> *… en mars 2001, par une campagne nationale intitulée « Mind Out for Mental Health ». Par cette campagne, nous voulions lutter contre la stigmatisation et la discrimination auxquelles se heurtent les personnes qui ont des problèmes de santé mentale. La campagne visait à favoriser leur inclusion dans la société.*

Cette campagne, qui a duré trois ans, s'est terminée en mars 2004. Dans le rapport sur la santé mentale et l'exclusion sociale, on apprend qu'elle a surtout donné lieu à l'instauration d'un « bureau de porte-parole » composé de plus de 40 personnes ayant une expérience des troubles en santé mentale et qui ont été formées pour faire part de leur expérience aux médias et aux employeurs. L'évaluation réalisée au terme du programme a révélé que ces ambassadeurs avaient donné un côté « humain et personnel » à la campagne et que les idées fausses avaient été mises à mal par ces témoins directs.

L'autre projet de lutte à la stigmatisation, la campagne « Changing Minds » (Changer d'esprit) du Royal College of Psychiatrists, s'est terminée à la fin 2003, après avoir été lancée cinq ans plus tôt. Un certain nombre d'organismes bénévoles poursuivent d'ailleurs cette campagne et, au sein de l'appareil gouvernemental, c'est l'Institut national de santé mentale (NIMHE) qui est chargé de la lutte contre la stigmatisation et la discrimination associées à la santé mentale.

Malgré les efforts considérables déployés en Angleterre pour lutter contre la stigmatisation, on note cependant, dans le rapport sur la santé mentale et l'exclusion sociale, que cette campagne n'est pas toujours bien coordonnée et qu'elle a été essentiellement axée sur l'information et la sensibilisation du public plutôt que sur les changements de comportement. Le rapport conclut que les deux principales leçons qu'il faut retenir de la campagne « Mindout » sont : la nécessité de disposer de stratégies de financement à long terme et la nécessité de conduire une évaluation solide. Le même rapport cite un examen documentaire contenu dans un document international qui a été commandé par le NIMHE et qui constate que le niveau moyen de dépenses au chapitre de la sensibilisation à la santé mentale en Angleterre est inférieur et qu'il s'étale sur moins longtemps que dans les pays administrant des programmes qui donnent de meilleurs résultats (voir le tableau ci-dessous). Bien que le rapport qualifie la stigmatisation et la discrimination de plus importants obstacles à l'inclusion sociale des personnes souffrant de problèmes de santé mentale, il conclut que, malgré les campagnes menées jusqu'alors, on n'a pas constaté de changement marqué d'attitude.

DÉPENSES INTERNATIONALES DANS LES CAMPAGNES SUR LA SANTÉ MENTALE, PAR HABITANT (POPULATION GÉNÉRALE)*	
Mindout for mental health	1,44 pence
See Me, Scotland**	13 pence
Like Minds, Like Mine, New Zealand	1 $NZ1 (environ 36 pence)

* Les chiffres sont une approximation des dépenses globales divisées par la population, les dépenses annuelles moyennes étant établies pour la durée de la campagne. La livre britannique, qui vaut environ 2,43 $CAD, comporte 100 pence.
** Voir le cadre ci-dessous.

La nouvelle stratégie décrite dans le rapport en vue de lutter contre la stigmatisation et la discrimination part donc de l'hypothèse selon laquelle, pour véritablement composer avec les problèmes de santé mentale, il faut recourir à plus qu'une solution médicale. Le rapport soutient notamment qu'il faut obtenir de la société qu'elle réagisse positivement aux besoins des particuliers et à la promotion du bien-être mental. Pour y parvenir, il fixe un plan d'action en 27 points qui vise à coordonner l'action des ministères et des autres organismes concernés en vue de modifier les attitudes, de permettre aux gens de réaliser leurs aspirations et d'améliorer les possibilités et la situation globale de ce groupe d'exclus.

LA CAMPAGNE ÉCOSSAISE *SEE ME*
See Me est une campagne de lutte contre la stigmatisation, administrée par un regroupement de cinq organisations écossaises de santé mentale, qui est financée par la branche exécutive de l'Écosse. Lancée en octobre 2002, elle est un élément important du programme national d'amélioration de la santé mentale et du bien-être. Elle est dotée d'un budget de 3 millions de livres sur quatre ans (jusqu'en 2005-2006). Elle est notamment le produit de consultations poussées avec des personnes qui ont connu les affres de la maladie mentale. Bien que d'envergure nationale, elle s'appuie sur des activités locales et repose sur de la publicité multimédia ainsi que sur l'intervention, auprès des médias, de porte-parole qui ont eux-mêmes eu des problèmes de santé mentale. *See Me* comporte un volet sur la stigmatisation qui consiste à inciter la population à réagir aux attitudes et aux propos discriminatoires relevés dans les médias. La reconnaissance de la campagne est régulièrement de 28 p. 100.

Le plan comporte un programme destiné à lutter contre les attitudes négatives et à sensibiliser la population aux droits des gens. Ce nouveau programme de lutte contre la stigmatisation a fait l'objet d'un investissement de 1,1 million de livres par le ministère de la Santé et d'un financement additionnel provenant d'autres ministères. Il sera orchestré par le NIMHE et, selon le rapport :

- il sera fondé sur les expériences internationales qui ont donné des résultats et sera inspiré des leçons tirées de campagnes de promotion antérieures dans le domaine de la santé et de la santé mentale;
- il ciblera des auditoires clés, surtout les employeurs, les jeunes et les médias;
- il proposera des messages cohérents et éprouvés, sous une seule et même bannière;
- il fera la promotion de la contribution que les personnes souffrant de problèmes de santé mentale peuvent apporter à la société;
- son avenir sera assuré par un financement suivi;
- il traitera des questions d'ethnicité et de questions propres à chacun des sexes;
- il proposera un cadre et des documents d'appui au travail local par l'accent placé sur les questions particulières auxquelles sont confrontées les communautés démunies;
- il sera clairement évalué à la faveur de sondages réguliers.

3.4.2 La prévention du suicide

L'Angleterre s'est doté d'une stratégie nationale en matière de prévention du suicide en 2002. Celle-ci visait à réduire d'au moins un cinquième d'ici 2006 le nombre de décès par suicide et de blessures de causes indéterminées, objectif qui a été repris d'un livre blanc du gouvernement en 1999 et intitulé *Saving Lives: Our Healthier Nation*.

La stratégie est perçue comme un ensemble d'activités permanentes et coordonnées se voulant complètes, fondées sur des constats, spécifiques et sujettes à évaluation. Elle fera partie des programmes de base de l'Institut national de la santé mentale (NIMHE). La stratégie énonce six objectifs assortis chacun de plusieurs sous-objectifs spécifiques. L'encadré ci-après présente justement les objectifs et sous-objectifs en question.

Mme Richardson a indiqué au Comité que la stratégie semblait porter fruit :

> *Le premier rapport d'étape relatif à la stratégie a été publié l'an dernier. Le rapport était encourageant en ce sens que le taux de suicide est à la baisse. Les données des deux dernières années montrent qu'il est au plus bas niveau jamais atteint. La moyenne sur trois ans pour 2000 à 2002 était le plus bas niveau par rapport au niveau de référence que nous avons établi en 1995. À l'heure actuelle, le taux est de 8,9 décès par 100 000 habitants. C'est un taux qui se compare assez favorablement avec le taux européen, qui s'élevait à 8,8 selon les dernières données, si je ne m'abuse*

STRATÉGIE NATIONALE DE PRÉVENTION DU SUICIDE EN ANGLETERRE
OBJECTIF 1 Réduire le risque chez les groupes à haut risque. • Réduire le nombre de suicides chez les personnes qui sont ou ont été récemment en contact avec des services de santé mentale. • Réduire le nombre de suicides dans l'année suivant une tentative délibérée d'automutilation. • Réduire le nombre de suicides chez les jeunes hommes. • Réduire le nombre de suicides chez les prisonniers. • Réduire le nombre de suicides dans les groupes professionnels à haut risque.
OBJECTIF 2 : Promouvoir le bien-être mental au sein de la population en général. • Promouvoir la santé mentale des exclus sociaux et des démunis. • Promouvoir la santé mentale auprès des personnes appartenant aux minorités noires et ethniques, notamment auprès des femmes asiatiques. • Promouvoir la santé mentale chez les personnes qui consomment des drogues ou de l'alcool à mauvais escient. • Promouvoir la santé mentale chez les victimes et les ex-victimes de violence, notamment chez ceux et celles ayant subi des actes de violence sexuelle dans leur enfance. • Promouvoir la santé mentale auprès des enfants et des adolescents (de moins de 18 ans). • Promouvoir la santé mentale auprès des femmes pendant et après une grossesse. • Promouvoir la santé mentale auprès des personnes âgées. • Promouvoir la santé mentale chez les personnes endeuillées par un suicide.

OBJECTIF 3 Réduire l'accessibilité et la létalité des méthodes de suicide.

- Réduire le nombre de suicides par pendaison ou strangulation.
- Réduire le nombre de suicides par auto-empoisonnement.
- Réduire le nombre de suicides par inhalation de gaz d'échappement de véhicule.
- Réduire le nombre de suicides sur les voies ferrées.
- Réduire le nombre de suicides par des sauts dans le vide.
- Réduire le nombre de suicides par armes à feu.

OBJECTIF 4 Améliorer la façon dont les comportements suicidaires sont traités dans les médias.

- Faire la promotion d'une représentation responsable des comportements suicidaires dans les médias.

OBJECTIF 5 Promouvoir la recherche sur le suicide et la prévention du suicide.

- Améliorer les données de recherche sur la prévention du suicide.
- Diffuser les données actuelles sur la prévention du suicide.

OBJECTIF 6 Améliorer le suivi des progrès réalisés en fonction de l'objectif énoncé dans *Saving Lives: Our Healthier Nation* afin de réduire le nombre de suicides.

- Assurer un suivi des statistiques sur le suicide au regard des objectifs principaux et secondaires de la stratégie.
- Évaluer la stratégie nationale en matière de prévention du suicide.

3.5 PERSPECTIVES DE RÉFORME

Bien que les services de santé mentale en soient maintenant à mi-chemin du programme de dix ans décrit dans le cadre du National Service Framework (NSF), plusieurs interrogations demeurent quant à la possibilité de réaliser les ambitieux objectifs établis au début. Certaines questions restent sans réponse à propos des points faibles hérités du passé et des répercussions des changements déjà amorcés. Par exemple, en 2000 le Comité spécial des Communes sur la santé a dit du système qu'il était une « courtepointe en patchwork » comportant d'énormes variations en matière de normes de services et de méthodes de prestation de services dans l'ensemble du pays. En 2003, la Commission pour l'amélioration de la santé concluait que l'héritage historique de négligence des services de soin de santé n'avait toujours pas été surmonté.

Le débat a toujours cours relativement à l'orientation de la réforme et à la mise en œuvre de changements concrets au sein de l'organisation de même que la prestation de services. Des rapports récents font état de préoccupations concernant la priorité accordée à la santé mentale dans le système de santé et le recours au processus de commande pour les services

de santé mentale. Il semble que l'on insiste davantage sur le secteur des soins actifs, particulièrement en vue de parvenir à réduire les périodes d'attente et d'ouvrir les choix offerts aux patients, ce qui fait des objectifs en santé mentale du NSF et du SNS des points relativement mineurs dans la liste des priorités.

Le transfert du pouvoir de commander les services de santé mentale aux groupes de soins locaux, afin de récupérer tous les avantages associés à ce type de changement, continue de faire problème. Il a surtout été question de la dilution de l'expertise entre un grand nombre de centres de commande. Malgré les développements positifs constatés au sein de ces centres, plusieurs observateurs soutiennent qu'il reste encore beaucoup à faire en matière d'efficacité. Dans le domaine de la santé mentale, le processus de commande semble particulièrement irrégulier et sous-développé.

Dans un rapport récent, le Centre Sainsbury fait état d'un système soumis à des pressions diverses qui, collectivement, entraînent une remise en question de la capacité de donner suite au programme de réforme du gouvernement. Le rapport précise aussi que la situation financière de nombreux fournisseurs de soins de santé mentale est précaire. En conclusion, il y a des écarts importants entre les exigences pour la mise en oeuvre d'une politique nationale et la disponibilité des ressources pour y parvenir.

3.6 OBSERVATIONS DU COMITÉ

Les membres du Comité ont été très impressionnés par l'ampleur de la planification réalisée en Angleterre depuis l'adoption du Cadre national de services en matière de santé mentale, en 1999, surtout par la planification sur 10 ans et par l'adoption des normes précises destinées à encadrer la prestation des services.

Le Comité a également été frappé par le rôle important des équipes locales de mise en œuvre créées pour appliquer le cadre en l'adaptant aux conditions locales de même que par les nouveaux groupes de soins primaires qui se veulent des fournisseurs locaux uniques de services de santé mentale. Dans le même ordre d'idée, le Comité a été impressionné par la décision de mettre sur pied une branche distincte chargée de la mise en œuvre du cadre, l'Institut national de santé mentale (NIMHE), qui a pour tâche de contribuer à la formation, à la diffusion du savoir et à la propagation des pratiques exemplaires.

Le Comité n'a pas manqué de prendre note du défi énorme auquel le gouvernement est confronté en matière de financement et d'organisation de la réforme dans le secteur de la santé mentale. Nous avons aussi été impressionnés par tout le soin qui a été apporté en Angleterre à l'évaluation de réforme de la santé mentale, tant par les organismes gouvernementaux que par les organisations non gouvernementales.

On pourrait également conclure, d'après la récente expérience anglaise, que la pénurie de ressources humaines risque d'avoir de graves conséquences financières à court terme sur l'ensemble du réseau et de menacer l'aboutissement des plans de réforme. À cet égard, le Comité n'a pas manqué de remarquer que la formation des travailleurs en santé mentale, qui doivent contribuer à la prestation des services de soins primaires, est une initiative importante.

Enfin, le Comité a été impressionné par l'engagement soutenu à combattre la stigmatisation et la discrimination dont sont victimes les personnes qui souffrent de troubles de santé mentale. C'est surtout l'ampleur des initiatives annoncées dans le rapport sur la santé mentale et l'exclusion sociale, en juin 2004 qui a retenu notre attention. L'expérience du Royaume-Uni nous montre aussi, malheureusement, qu'il n'est pas simple de changer les attitudes et qu'il faut, pour y parvenir, faire preuve de persévérance et déployer les ressources nécessaires. Le Comité a aussi remarqué que, récemment, la promotion de la santé mentale et la prévention du suicide semblent avoir contribué à faire fléchir les taux de suicide en Angleterre.

CHAPITRE 4:
LES SOINS DE SANTE MENTALE AUX ÉTATS-UNIS[17]

4.1 HISTORIQUE ET APERÇU

Le système de soins de santé des États-Unis est unique en ce sens qu'il repose exclusivement sur le secteur privé, à la fois pour la prestation des services et pour la couverture des soins. Les sources privées, qui assument 55 p. 100 du financement des soins de santé, comprennent les assurances privées, les quote-parts des particuliers au chapitre des régimes publics et privés (17 p. 100) et d'autres sources (5 p. 100). La majorité des Américains sont assurés dans le cadre de régimes offerts par leurs employeurs.

Le gouvernement fédéral contribue à hauteur de 33 p. 100 environ aux dépenses totales de soins de santé, les gouvernements des États et les administrations locales assumant la différence (12 p. 100). L'administration et le bon fonctionnement de Medicare (régime d'assurance-maladie) sont assumés par le gouvernement national qui administre une assurance de soins de santé pour les personnes âgées. En collaboration avec les États, il finance Medicaid (pour les pauvres) ainsi que le State Children's Health Insurance Program (SCHIP), soit le programme d'État d'assurance-santé pour les enfants. Dans l'ensemble, le régime public d'assurance-santé couvre environ 24 p. 100 de la population américaine.

Medicare est un régime d'assurance-santé fédéral qui s'adresse aux 65 ans et plus, à certaines personnes de moins de 65 ans mais qui sont invalides de même qu'à des personnes atteintes de maladies rénales en phase terminale. Medicaid est un régime d'assurance-santé conjoint, gouvernement fédéral-États, fondé sur les moyens et qui est offert aux personnes à faible revenu. Le gouvernement fédéral assume de 50 à plus de 75 p. 100 de la note des différents États. Washington fixe également les lignes directrices nationales en matière d'admissibilité et de services de Medicaid. Toutefois, chaque État administre son propre programme et fixe les montants qu'ils assument pour chaque service. Tous les États sont tenus de respecter des critères minimums en matière d'admissibilité et de services obligatoires mais, dans le cadre d'une entente conclue avec le gouvernement fédéral, ils peuvent être plus généreux dans les niveaux d'admissibilité et les services offerts. Ce faisant, le programme Medicaid peut varier d'un État à l'autre.

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17 À moins d'indication contraire, les renseignements contenus dans le présent chapitre proviennent des sources suivantes : *Mental Health: A Report of the Surgeon General* (1999), plus particulièrement le chapitre 6, « Organizing and Financing Mental Health Services »; département de la santé des services humains, *National Strategy for Suicide Prevention: Goals and Objectives for Action* (2001); The President's New Freedom Commission on Mental Health *Final Report* (juillet 2003) et *Interim Report* (octobre 2002); Tanner, Jane « Mental Illness Medication Debate, » *The CQ Researcher*, 6 février 2004, p. 109-118; Cunningham, Robert « The Mental Health Commission Tackles Fragmented Services: An Interview With Michael Hogan, » *Health Affairs*, Web Exclusive, 9 septembre 2003; Barry, Colleen L. et Jon R. Gabel, Richard G. Frank, Samantha Hawkins, Heidi H. Whitmore et Jeremy D. Pickreign « Design Of Mental Health Benefits: Still Unequal After All These Years, » *Health Affairs*, vol. 22, nº 5, septembre-octobre 2003, p. 127-37; Hogan, Michael F. « The President's New Freedom Commission: Recommendations to Transform Mental Health Care in America, » *Psychiatric Services*, vol. 54, nº 11, novembre 2003, p. 1467-1474; Mechanic, David et Scott Bilder, « Treatment Of People With Mental Illness: A Decade-Long Perspective, » *Health Affairs*, vol. 23, nº 4, juillet-août 2004.

4.1.1 La santé mentale

Pour reprendre le contenu d'un rapport récent de la President's New Freedom Commission on Mental Health (commission sur la santé mentale mise sur pied dans le cadre de l'initiative *Liberté nouvelle*), le système actuel de soins de santé mentale aux États-Unis est une relique faite d'éléments disparates qui nécessite une réforme dynamique parce qu'il *ne* dessert *pas* de façon appropriée les millions de personnes qui ont besoin de soins. Les analystes s'accordent à dire qu'il est difficile de décrire simplement le système américain de soins de santé mentale. En fait, dans son rapport, la Commission insiste sur le fait que le système de soins de santé mentale s'apparente davantage à un labyrinthe qu'à un système de soins coordonné.

Aux États-Unis, les troubles mentaux et les problèmes de santé mentale sont traités par tout un éventail de fournisseurs de soins qui travaillent dans divers établissements ou services – tant publics que privés – relativement indépendants et vaguement coordonnés que les chercheurs désignent collectivement sous le vocable de « système *de facto* des services en santé mentale ». Ces programmes existent dans tous les ordres de gouvernement et dans l'ensemble du secteur privé, et leur mission, leur cadre de réalisation de même que leur cadre financier varient de l'un à l'autre.

Chaque année, environ 15 p. 100 de la population adulte et 21 p. 100 des enfants et des adolescents aux États-Unis utilisent des services offerts dans le cadre du système *de facto*. On décrit généralement ce système comme un ensemble comportant quatre grandes composantes ou secteurs principaux :

- Le secteur des soins spécialisés de santé mentale regroupe les professionnels de la santé, comme les psychiatres, les psychologues, les infirmières psychiatriques et les travailleurs sociaux en psychiatrie qui ont reçu une formation spécialisée axée sur le traitement des personnes souffrant de troubles mentaux.
- Le secteur des soins médicaux généraux et des soins primaires regroupe les professionnels de la santé, comme les internistes généraux, les pédiatres et les infirmiers praticiens oeuvrant dans des cabinets, des cliniques, des hôpitaux de soins actifs et spécialisés en chirurgie et dans des maisons de soins infirmiers.
- Le secteur des services à la personne comprend les services sociaux, les services de counselling en milieu scolaire, les services de réadaptation en établissement, la réadaptation professionnelle, la justice pénale et les services en milieu carcéral, de même que les conseillers religieux professionnels.
- Le secteur du réseau de soutien bénévole, qui comprend les groupes d'entraide comme les programmes en 12 étapes et les pairs-conseillers, est une composante en croissance rapide du système de traitement de la maladie mentale et de la toxicomanie.

Le système *de facto* des services en santé mentale se divise en outre entre secteur public et secteur privé. Dans ce contexte, le terme « secteur public » renvoie tant aux services fournis directement par des organismes gouvernementaux (comme les hôpitaux psychiatriques des États et des comtés) qu'aux services financés par des ressources gouvernementales (par ex., Medicaid et Medicare). Il arrive que des services financés par l'État soient fournis par des

organismes privés. Le terme « secteur privé » englobe les services fournis directement par des organismes privés et les services financés au moyen de ressources privées (comme les régimes d'assurance des employeurs).

La plupart des Américains (84 p. 100) sont assurés d'une façon ou d'une autre, le plus souvent par un régime privé offert par leurs employeurs. Cependant, l'efficacité de ce type d'assurance dans le cas des soins de santé mentale varie grandement d'un régime et d'un promoteur à l'autre. Le secteur public prend en charge les personnes qui n'ont pas d'assurance maladie, celles dont le régime d'assurance ne couvre pas les soins de santé mentale et celles qui ont atteint leur plafond d'indemnités dans le cadre de leur régime d'assurance santé.

Chaque secteur du système *de facto* réunit des programmes et des types de soins différents et utilise différents modes de financement. Selon la Commission présidentielle (ci-après *la Commission*), la fragmentation du système actuel n'est pas causée par le manque d'engagement ni de compétences des fournisseurs de soins mais découle plutôt de problèmes structuraux, financiers et organisationnels sous-jacents, dont les racines remontent aux années 50 lorsque les soins en établissement ont été abandonnés au profit des soins dans la communauté.

La désinstitutionnalisation, motivée par le désir des réformateurs d'assurer des services aux patients dans leur collectivité, a eu comme effet pervers de disperser la responsabilité entre les différents ordres de gouvernement et entre de multiples organismes. Le processus a débuté sous la présidence de Dwight D. Eisenhower, mais s'est accéléré lorsque le président John F. Kennedy a signé le Community Mental Health Centers Construction Act (loi sur la construction de centres communautaires de santé mentale) en 1963. Cette loi prévoyait la mise en place d'un mécanisme de financement pour les programmes locaux et avait comme objectif de réduire de moitié le nombre de malades internés dans les hôpitaux psychiatriques des États.

Cet objectif a été largement dépassé puisque, de nos jours, les hôpitaux n'ont plus que 40 000 lits pour malades mentaux, comparativement à quelque 550 000 en 1955. Malheureusement, la création des centres communautaires de santé mentale n'a pas donné les résultats escomptés. En effet, la moitié seulement des centres prévus ont été construits et le financement assuré par le fédéral n'a couvert que les sept premières années. En 1981, le programme des centres de santé mentale a été remplacé par une subvention globale pour la santé mentale.

En revanche, les collectivités n'ont pas accueilli les malades mentaux qui se sont retrouvés sur leur territoire et une petite partie seulement des économies réalisées grâce à la fermeture des hôpitaux d'État a pas été réinvestie dans des programmes communautaires. Darrel A. Regier, directeur de la recherche de l'American Psychiatric Association, a affirmé devant la Commission fédérale sur la santé mentale que les prisons et autres lieux de détention sont devenus les nouveaux établissements pour de nombreuses personnes souffrant de troubles mentaux graves, tandis que nombre d'autres malades ont été laissés à eux-mêmes et sont devenus des sans-abri.

À la même époque, M. William Emmet, coordonnateur de la campagne pour la réforme de la santé mentale aux États-Unis, déclarait à notre Comité :

> *À bien des égards, la désinstitutionnalisation a été une grande réussite. Bien des gens qui n'auraient pas dû se trouver en institution en sont partis et ont commencé à mener des vies productives — ou tout au moins à avoir des vies beaucoup plus intéressantes que celles qu'ils auraient menées en institution. Le problème qui s'est posé avec le temps, c'est que des gens qui autrefois auraient été placés en institution n'ont pas été nécessairement en mesure d'obtenir les services dont ils avaient besoin.*

Pour sa part, Michael Hogan, président de la Commission sur la santé mentale, devait ajouter :

> *… aucun de ceux qui oeuvrent dans ce domaine n'oserait prétendre un seul instant que nous devrions faire machine arrière. Le système des institutions n'est pas parvenu à joindre la plupart des gens. Dans les cas où il y est arrivé, ces gens étaient gardés à grands frais et n'ont pas vu leur condition s'améliorer. Ils avaient trois repas chauds par jour, un lit et des soins de santé, mais ils n'ont jamais pu vraiment vivre. Nous ne pouvons pas revenir à cette situation mais nous n'avons pas encore réglé le problème qui consiste à créer un système de soins bien organisé et suffisamment solide pour faire du bon travail.*

Les programmes Medicare et Medicaid ont été créés deux ans après le discours du président Kennedy. Au fil des ans, les États ont eu de plus en plus recouru à Medicaid pour les soins de santé mentale, ce qui a eu pour résultat que ce programme est devenu le plus important acheteur de soins de santé mentale aux États-Unis. Les critiques ont dit que les États avaient placé les soins de santé mentale sous l'ombrelle de Medicaid simplement parce que le gouvernement fédéral assume la moitié des frais sous la forme d'une contribution de contrepartie et paie jusqu'à 75 p. 100 des coûts dans les États les plus pauvres.

L'introduction de Medicaid a également contribué de trois façons au déclin des hôpitaux psychiatriques d'État. D'abord, Medicaid ne remboursait pas la plupart des soins offerts par ces établissements. Deuxièmement, ce régime ne payait pas pour les soins actifs dispensés dans les unités psychiatriques des hôpitaux généraux qui étaient devenus les emplacements de choix pour les traitements de courte durée. Enfin, Medicaid payait pour les soins dans les foyers d'accueil et une grande partie de l abaisse de fréquentation des hôpitaux psychiatriques d'État est attribuable au transfert de patients âgés des hôpitaux d'État à des foyers.

Aux États-Unis, les soins de santé mentale se distinguent des autres soins de santé parce qu'ils sont offerts dans le cadre de systèmes administrés par l'État ou par le comté qui sont conçus spécialement pour une catégorie donnée de maladie. Le gouvernement fédéral paie maintenant pour la plupart des services dispensés aux personnes atteintes d'une maladie mentale grave, tandis que les États et les municipalités se chargent de subvenir à leurs besoins. Cependant, la majeure partie des ressources fédérales sont regroupées dans des programmes réguliers (par ex., Medicaid, Medicare, réadaptation professionnelle, logement) qui ne sont pas nécessairement adaptés aux exigences précises des soins de santé mentale et qui sont, le plus souvent, administrés par différentes agences gouvernementales. Pour cette

raison, les consommateurs et les familles sont souvent obligés de se débattre pour obtenir les services voulus.

Qui plus est, comme la fourniture des services de soins de santé mentale est maintenant dévolue aux cinquante États et aux centaines de comtés et de collectivités locales, la disponibilité de ces services varie largement d'un endroit à l'autre. Dans une entrevue, Michael F. Hogan devait déclarer à cet égard : « Quand vous avez vu un État, eh bien, vous n'en avez vu qu'un seul ».

Dernièrement, d'importants changements ont également été apportés dans le secteur privé, notamment à la suite de la mise en place du régime de soins gérés en tant que principal moyen d'organisation de la couverture dans le cadre des régimes d'assurance privée, dans le courant des années 90.

4.2 COÛTS ET FINANCEMENT DES SERVICES DE SANTÉ MENTALE

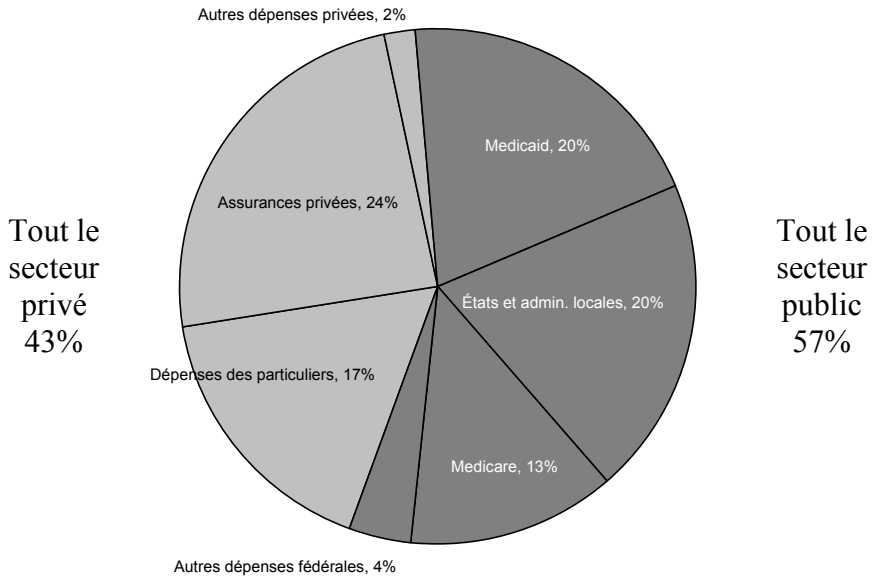
4.2.1 Les coûts de la maladie mentale aux États-Unis

La maladie mentale impose des coûts tant directs qu'indirects à l'économie. Ainsi, en 1990, l'économie américaine a subi une perte de près de 79 milliards de dollars à cause des *coûts indirects* de la maladie mentale (prise dans son ensemble). La plus grande partie de ce montant (63 milliards de dollars) reflète la perte de la productivité attribuable à la maladie. Cependant, les coûts indirects englobent également près de 12 milliards de dollars en frais liés à la mortalité (perte de productivité due au décès prématuré) et près de 4 milliards de dollars au titre de la perte de productivité dans le cas des détenus et des aidants naturels pour le temps que ces derniers consacrent aux soins à la famille.

En 1996, les États-Unis ont dépensé plus de 99 milliards de dollars pour le traitement *direct* des troubles mentaux de même que pour la toxicomanie, la maladie d'Alzheimer et d'autres formes de démence. De ce montant, 69 milliards de dollars ont été consacrés au diagnostic et au traitement de la maladie mentale seule, soit 7 p. 100 de la totalité des dépenses en soins de santé cette année-là. Plus de 70 p. 100 des dépenses directes en santé mentale ont été affectées aux services de fournisseurs spécialisés tandis que le reste a été en majeure partie consacré aux fournisseurs de services médicaux généraux.

En 1997, dans l'ensemble, les sources publiques assumaient 57 p. 100 des dépenses en santé mentale tandis que les sources privées se chargeaient des 43 p. 100 restant (figure 1). Entre 1986 et 1996, les dépenses en santé mentale ont progressé à un rythme annuel moyen de plus de 7 p. 100, par rapport au taux global pour les soins de santé qui était, lui, supérieur à 8 p. 100. Selon le Directeur du Service de santé publique des États-Unis, cet écart est peut-être attribuable au fait que, pendant cette période, les méthodes de limitation des coûts des soins gérés ont été appliquées avec plus de rigueur dans le secteur des services de santé mentale. Les médicaments prescrits aux malades externes, soit environ 9 p. 100 de la totalité des coûts directs des services de santé mentale, sont au nombre des dépenses qui ont connu la hausse la plus rapide dans le secteur des services de santé mentale.

VENTILATION DES DÉPENSES PUBLIQUES ET PRIVÉES EN MATIÈRE DE SANTÉ MENTALE, 1997



4.2.2 L'assurance santé mentale financée par l'État

Au cours des vingt dernières années, d'importants changements ont été apportés en matière d'attribution des responsabilités pour le paiement des coûts des soins de santé mentale aux États-Unis. Le rôle de chaque État dans le financement direct des soins de santé mentale a été réduit tandis que le financement des soins de santé mentale dans le cadre de Medicaid s'est relativement élargi. Cette situation est due en partie à l'aide financière importante que Washington consent aux États. Cependant, M. Emmet devait nous déclarer ce qui suit à ce sujet : « Medicaid est un programme d'assurance-maladie qui ne couvre cependant que […] certains services approuvés et il dépend de contributions de contrepartie des États, que ces derniers ont de plus en plus de mal à verser en cette période de difficultés financières ». Cette réorientation a notamment comme conséquence que Medicaid assume maintenant la majeure partie des coûts des services de santé mentale aux États-Unis et que, de ce fait, il exerce une très grande influence sur la prestation des soins de santé mentale. Ces dernières années, les régimes d'assurance privés ont joué un rôle plus limité au chapitre du financement des services de santé mentale.

Le gouvernement fédéral offre une aide financière qui est spécialement destinée aux programmes de santé mentale. C'est notamment le cas du Community Mental Health Services Block Grant (programme de subventions globales aux services communautaires de santé mentale), financé par le Department of Health and Human Services (HHS) (ministère de la Santé et des Services sociaux), par le truchement de la Substance Abuse and Mental Health Services Administration (SAMHSA) (administration des services de santé mentale et de lutte contre la toxicomanie), qui offre une aide financière aux 59 États et territoires. Au total, l'aide financière accordée dans le cadre de ce programme s'est chiffrée à quelques 433

millions de dollars en 2002, mais ce montant représente moins de 3 p. 100 des revenus de ces agences d'État.

En fait, les grands programmes fédéraux qui ne sont pas axés sur les soins de santé mentale jouent un rôle beaucoup plus important au chapitre du financement des services de santé mentale. Par exemple, par le seul truchement des programmes Medicare et Medicaid, le ministère de la Santé et des services sociaux dépense près de 24 milliards de dollars chaque année pour la fourniture de soins de santé mentale aux bénéficiaires (cette proportion n'inclut pas la part des États au chapitre de Medicaid). En outre, les deux plus importants programmes fédéraux d'aide aux personnes atteintes d'une maladie mentale ne sont pas des programmes de services de santé. Il s'agit du Supplemental Security Income (SSI) (supplément de revenu garanti) et de la Social Security Disability Insurance (SSDI) (assurance invalidité de la sécurité sociale) administrés par la Social Security Administration (administration américaine de la sécurité sociale).

La hausse vertigineuse des coûts, surtout dans le cas des médicaments prescrits, impose des pressions énormes tant sur les particuliers que sur les États. La National Association of State Budget Officers (association nationale des agents de budget des États) a annoncé qu'en 2002, 25 États ont dépensé davantage pour les services Medicaid qu'ils ne l'avaient prévu dans leur budget et que 28 États prévoyaient une insuffisance de ressources lorsque les données de 2003 ont été produites. Le gouvernement fédéral est intervenu de façon ponctuelle et a injecté des fonds supplémentaires dans les programmes Medicaid des États : 10 milliards de dollars en tout versés l'an dernier et cette année. Selon le Federal Center for Medicare and Medicaid Services (centre fédéral des services Medicare et Medicaid), entre 1990 et 2000, les coûts des prescriptions assumés par Medicaid ont quadruplé, passant de 5,1 milliards de dollars à 20,9 milliards de dollars.

4.2.3 L'assurance santé mentale privée

La plupart des Américains (84 p. 100) sont assurés d'une façon ou d'une autre – dans la majorité des cas, ils le sont par une assurance privée offerte par leur employeur. Cependant, en ce qui concerne les soins de santé mentale, la couverture consentie par ces assurances varie beaucoup d'un régime et d'un promoteur à l'autre.

4.2.3.1 Les éléments de base de l'assurance santé mentale

La couverture offerte pour les services de santé mentale a toujours été plus limitée que celle disponible pour les autres soins médicaux. En règle générale, les régimes de soins médicaux prévoient des quotes-parts plus élevées et limitent davantage le nombre autorisé de journées d'hospitalisation et de consultations externes pour les soins de santé mentale. Ils prévoient aussi une couverture limitée pour les services de santé mentale (sous la forme de plafonds financiers annuels et maximums à vie.

Ces dernières années, des dispositions législatives réglementant les assurances et des changements fondamentaux apportés dans la fourniture des services de santé mentale ont eu pour effet de modifier l'environnement dans lequel s'effectuent les achats et les ventes dans le domaine de l'assurance santé mentale. Les lois déposées au Congrès et dans de nombreux autres organes législatifs aux États-Unis, vise à réglementer la parité pour gommer les écarts

entre la couverture assurée pour les soins de santé mentale et celle prévue pour d'autres problèmes de santé. Toutefois, les efforts déployés jusqu'à présent pour parvenir à la parité n'ont pas tous abouti puisque le Congrès, par exemple, n'a pas encore adopté de loi dans ce sens.

Dans le même ordre d'idée, les soins gérés ont transformé la fourniture des services de santé mentale au cours des dix dernières années. De nos jours, il n'est pas rare que les employeurs et les administrateurs des régimes de soins de santé confient l'administration des indemnités pour maladie mentale à des organismes spécialisés de soins gérés de santé comportementale (MBHO). Ainsi, on fait appel à une expertise spécialisée pour la gestion de l'utilisation et pour l'orientation des soins afin d'assurer la prestation de traitements efficaces dans les réseaux de fournisseurs. On dit que la santé mentale est le seul secteur des soins de santé où les soins gérés ont effectivement permis de contrôler les coûts.

Selon un sondage récent, en 2002, 98 p. 100 des travailleurs américains ayant une assurance santé de l'employeur bénéficiaient d'une couverture pour des services de santé mentale. Quatre-vingt-seize pour cent des travailleurs assurés avaient une assurance hospitalisation pour des soins de santé mentale tandis que 98 p. 100 d'entre eux avaient une assurance pour des services de santé mentale en consultation externe. Entre 1991 et 2002, la proportion des travailleurs détenteurs d'une assurance santé à qui des indemnités pour cause de maladie mentale ont été offertes a, en fait, augmenté.

Cependant, bien que la plupart des travailleurs ayant une assurance santé générale se soient vu offrir une couverture pour des services de santé mentale en 2002, les entreprises ont continué de plafonner les indemnités consenties pour maladie mentale. Ces dernières années, l'administration fédérale et les États ont adopté des lois sur la parité dans le dessein de mettre un frein aux limites imposées par les assureurs. Malgré tout, à cause de lacunes dans les lois sur la parité édictées par le gouvernement fédéral et par les États, des différences persistent entre les indemnités pour cause de maladie mentale et les indemnités pour cause de maladie générale. Les données disponibles indiquent que 74 p. 100 des travailleurs assurés avaient droit à une consultation externe par an et que 64 p. 100 d'entre eux avaient droit à un jour d'hospitalisation par an. Bien que, par le passé, les administrateurs des régimes d'assurance santé se soient efforcés de limiter les coûts en exigeant que les souscripteurs versent une quote-part supérieure au point de service pour les soins de santé mentale que pour les autres services médicaux, un sondage récent révèle qu'en 2002, 22 p. 100 seulement des travailleurs assurés bénéficiaient d'une participation accrue au titre des indemnités pour cause de maladie mentale.

4.2.3.2 L'organisation de l'assurance santé mentale privée

Les soins gérés ont grandement modifié l'organisation et la fourniture des services de santé mentale. Comme nous venons de le voir, les entreprises sont de plus en plus nombreuses à confier l'administration des indemnités pour cause de maladies mentales à des sociétés spécialisées. Ces organisations ont recours à une expertise spécialisée pour établir des réseaux de fournisseurs, négocier des contrats à rabais en fonction du volume, établir des protocoles de traitement fondés sur les résultats et élaborer d'autres programmes d'encouragement pour la gestion de l'utilisation et des coûts.

Les organisations de soins de santé intégrés (HMO) ont été la première forme de soins gérés. Elles ont instauré la négociation de contrats portant sur la fourniture de l'ensemble des services médicaux dans le cadre d'un régime de coûts prépayés, calculés par tête. Aujourd'hui, il existe un certain nombre de types différents de soins gérés, par exemple les Preferred Provider Organizations (PPO) (organismes dispensateurs de services à tarifs préférentiels) [dans le cadre de programmes de soins gérés, des contrats sont conclus avec des réseaux de fournisseurs de services] et les programmes Point-of-Service (POS) (programmes au point de service), qui sont des programmes de soins gérés présentant des caractéristiques à la fois du paiement par capitation et du paiement à l'acte. En 1988, l'assurance fondée sur le paiement à l'acte était encore la principale méthode utilisée dans le secteur des soins de santé mais, de nos jours, la majorité des Américains sont couverts par des ententes concernant les soins gérés (programmes des HMO, des PPO ou des POS).

Dans le cadre des programmes de soins gérés de santé comportementale dits « sur mesure », certains éléments du risque assuré – défini par service ou par maladie – sont séparés du risque assuré global et couverts dans le cadre d'un contrat distinct conclu entre le payeur (l'assureur ou l'employeur) et le fournisseur retenu. D'après les données, le tiers environ des détenteurs d'une assurance santé de l'employeur se seraient vu offrir une assurance santé mentale dans le cadre de tels contrats sur mesure. Il est établi que la formule des soins gérés permet de réduire les coûts des services de santé mentale, mais on commence tout juste à étudier dans quelle mesure les techniques de réduction des coûts de soins gérés influent sur l'accès et sur la qualité des services.

D'aucuns craignent en effet que les stratégies restrictives visant à endiguer les coûts, associées aux diverses mesures destinées à inciter les fournisseurs et les établissements à réduire le nombre de patients aiguillés vers des spécialistes, le nombre d'admissions en milieu hospitalier ainsi que la durée ou l'importance des traitements dispensés, ne contribuent à une dégradation de l'accès à des soins de qualité. L'autorisation préalable est une autre caractéristique organisationnelle des soins gérés de santé comportementale. Certes, si elle peut avoir pour résultat d'inciter les omnipraticiens à appliquer des protocoles fondés sur l'expérience clinique, l'autorisation préalable risque aussi d'influer sur le niveau d'utilisation. Suivant les règles d'autorisation préalable, les médecins doivent obtenir l'autorisation des responsables de l'assurance santé ou du fournisseur du contrat sur mesure avant de prescrire un traitement. En 2002, la moitié des travailleurs assurés étaient tenus d'obtenir une autorisation avant d'utiliser des services spécialisés de santé mentale en consultation externe.

En outre, malgré la hausse des soins gérés et des programmes de soins de santé comportementale sur mesure, les employés continuent d'assumer eux-mêmes une part des coûts des services de santé mentale qui plus élevée que pour toute autre maladie. La seule indemnité pour cause de maladie mentale qui demeure sur le même pied que l'assurance médicale générale est la couverture pour les médicaments prescrits (bien que cela soit peut-être dû au fait que les médicaments psychotropes font désormais partie de l'ensemble des avantages sociaux de Medicaid et qu'ils ne sont pas visés par les contrats sur mesure). Les médicaments psychotropes prescrits dans les services de consultations externes représentent le coût qui connaît la croissance la plus rapide dans le secteur des soins de santé mentale. D'après une étude récente, le coût des médicaments prescrits a augmenté, passant de 22 p. 100 des dépenses totales pour les soins de santé mentale en 1992 à 48 p. 100 en 1999 chez les détenteurs d'une assurance santé de l'employeur.

En résumé, le plafonnement des restrictions aux indemnités combinée à des techniques solides de soins gérés pour le contrôle de l'utilisation ont contribué à réduire la croissance des dépenses en santé mentale comparativement à l'ensemble des dépenses en santé; cependant, ces mesures pourraient également causer des problèmes sur le plan de l'accès. À cet égard, M. Hogan nous a fait remarquer ce qui suit :

> *Les soins gérés, s'ils sont financés de façon adéquate et bien pratiqués, semblent être la meilleure approche. Le problème est que souvent, aux États-Unis, ils ne sont pas financés de façon adéquate, et si l'on s'y prend mal, cela devient un désastre.*

4.3 ORGANISATION ET FOURNITURE DES SERVICES

Comme nous l'avons vu, dans son dernier rapport, la Commission sur la santé mentale a conclu que le système de fourniture des services de santé mentale aux États-Unis a besoin d'une sérieuse réforme. De nombreux consommateurs reçoivent des traitements et des services efficaces, mais ce n'est pas le cas pour tous et beaucoup font face à un système dans lequel les services disponibles sont fragmentés, assujettis à des règles et à des règlements financiers complexes et restreints par des lourdeurs bureaucratiques. M. Hogan devait d'ailleurs nous affirmer à cet égard :

> *Paradoxalement, il existe beaucoup plus de services maintenant qu'il y a une dizaine d'années, et ceux qui ont la bonne fortune d'y recourir s'en portent bien. Cependant, la multiplication de tous ces services fait que les choses se sont beaucoup compliquées à l'échelle communautaire, si bien que les familles ne savent pas à qui s'adresser quand un problème surgit. C'est l'inconvénient de la fragmentation.*

Le rapport de la Commission présidentielle laisse entendre que bon nombre de ces problèmes sont attribuables à la stratification de programmes multiples bien intentionnés mais sans aucune orientation, coordination, ni harmonisation globale. À cause de cette situation, les consommateurs se sentent souvent dépassés et déroutés lorsqu'ils doivent obtenir et intégrer des soins de santé mentale, des services de soutien et des prestations d'invalidité par le truchement des multiples programmes distincts qui sont offerts par divers organismes – qui fédéraux, qui des États et qui locaux – de même que par le secteur privé. Des rapports récents reconnaissent que les lacunes du système ont des conséquences tant inutiles que coûteuses, par exemple l'invalidité, l'itinérance, l'échec scolaire et l'incarcération. M. Hogan a décrit ainsi la situation :

> *Nous en sommes ainsi arrivés à une mosaïque de programmes où les soins de santé mentale relèvent d'une multitude d'organismes fédéraux différents. Ces organismes exercent généralement leur activité en collaboration avec l'organisme étatique correspondant. […] Il existe donc des structures et des systèmes différents au niveau étatique et au niveau local qui assurent la prestation des soins, de sorte que les malades mentaux et leurs familles doivent essayer de s'y retrouver dans ce qui est*

devenu un véritable dédale de programmes, et ce, alors qu'ils sont généralement plus vulnérables.

Nombreux sont ceux qui reçoivent de bons soins et qui parviennent à se rétablir mais, dans les faits, selon le rapport de la Commission présidentielle,[18] aux États-Unis, environ une personne sur deux ayant besoin d'un traitement pour un problème de santé mentale ne le reçoit pas. En outre, il peut arriver que la personne qui parvient à accéder à des soins constate que de nombreux traitements et services ne sont tout simplement pas disponibles, notamment en milieu rural. Aussi, il peut arriver que la qualité des soins laisse à désirer. Il arrive parfois qu'un diagnostic ne soit pas établi comme il le devrait, que la médication soit mal dosée ou que la durée du traitement soit trop brève. Dans le cas des minorités ethniques et raciales, le taux de traitement est encore plus bas que dans la population générale et la qualité des soins est moindre.

D'un autre côté, un article récent soulignait que l'accès aux services aux États-Unis est en voie d'amélioration dans certains domaines, surtout pour les personnes souffrant de maladies mentales graves (MMG). Selon les auteurs David Mechanic et Scott Bilder :

> *La bonne nouvelle c'est que – contrairement au genre d'hypothèse que l'on pose fréquemment dans le milieu de la santé mentale – l'accès aux soins pour les personnes souffrant de MMG s'est amélioré, et tout indique que la situation s'est encore améliorée tout récemment, entre 1997 et 2001. Les personnes souffrant de MMG étaient plus susceptibles en 2001 qu'en 1997 de recevoir des services spécialisés en santé mentale, mais celles souffrant d'autres maladies mentales ou n'étant pas atteintes de telles maladies avaient plus difficilement accès à ces services. Comme les deux derniers groupes sont plus importants que celui des personnes souffrant de MMG, le fléchissement constaté au niveau agrégé pourrait contribuer à entretenir la perception que les services sont moins accessibles.*

Les deux auteurs font par ailleurs remarquer ce qui suit :

> *En outre, le nombre de fournisseurs de soins de santé mentale a considérablement augmenté. Bien que celui des professionnels traditionnels, comme les psychiatres et les infirmiers en psychiatrie n'aient connu qu'une augmentation modeste, force est de constater que les augmentations ont été importantes surtout dans le secteur de la psychologie et du travail social et que l'augmentation a même été très forte du côté du counselling et de la réadaptation psychosociale. L'effectif des professionnels s'occupant des patients (exprimé en équivalents temps plein) dans les organismes de santé mentale est passé de 347 000 en 1986 à 532 000 en 1998.*

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18 *Interim Report*, p. 3.

4.3.1 Les soins généraux et primaires

Le secteur des soins médicaux généraux et des soins primaires regroupe les professionnels de la santé, par exemple les internistes généraux, les pédiatres et les infirmiers praticiens travaillant dans des cabinets, des cliniques, des hôpitaux de soins actifs et spécialisés en chirurgie et dans des maisons de soins infirmiers. Plus de 6 p. 100 de la population adulte aux États-Unis a recours au secteur des soins médicaux généraux pour obtenir des soins de santé mentale, ce qui donne une moyenne d'environ 4 consultations par an. Depuis longtemps, le secteur des soins médicaux généraux est considéré comme le premier point de contact pour de nombreux adultes atteints de troubles mentaux et environ la moitié des soins fournis pour des troubles mentaux courants sont prodigués dans des établissements de médecine générale. En fait, les fournisseurs de soins primaires prescrivent la majeure partie des médicaments psychotropes administrés tant chez les enfants que chez les adultes.

Les fournisseurs de soins primaires semblent en mesure de jouer un rôle fondamental pour le traitement des maladies mentales mais, d'après des rapports récents, des problèmes persistent sur les plans du dépistage, du traitement et de l'aiguillage. Malgré leur prévalence, il n'est pas rare que les troubles mentaux ne soient pas diagnostiqués ou qu'ils soient mal ou pas traités dans le secteur des soins primaires. Bien que le nombre de cas signalés soit en hausse, le nombre de diagnostics posés dans les services de soins primaires demeure faible et il n'est pas rare que ces services n'orientent pas les patients vers le secteur du traitement spécialisé en santé mentale.

4.3.2 Les soins spécialisés

Le secteur des soins spécialisés en santé mentale regroupe les professionnels de la santé mentale, par exemple les psychiatres, les psychologues, les infirmières psychiatriques et les travailleurs sociaux en psychiatrie qui ont reçu une formation spécialisée pour le traitement des personnes atteintes de troubles mentaux. À l'heure actuelle, les traitements spécialisés sont en grande partie fournis dans des services de consultations externes, comme des cabinets privés, ou dans des cliniques privées ou publiques. La majeure partie des soins actifs dispensés en milieu hospitalier est actuellement fournie dans des unités psychiatriques spéciales à l'intérieur des hôpitaux généraux ou dans des lits répartis dans les différentes unités des hôpitaux généraux. À cela s'ajoutent les soins intensifs fournis dans les hôpitaux psychiatriques privés et les centres privés de traitement en établissement pour les enfants et les adolescents. Les installations publiques comprennent les hôpitaux psychiatriques des États et des comtés de même que des établissements de santé mentale polyvalents qui, souvent, coordonnent un large éventail de services de consultations externes, de gestion intensive des cas, d'hospitalisation à temps partiel et de services aux hospitalisés. Dans l'ensemble, un peu moins de 6 p. 100 de la population adulte et environ 8 p. 100 des enfants et des adolescents (de 9 à 17 ans) utilisent des services spécialisés de santé mentale au cours d'une année

4.3.3 Les services à la personne

Le secteur des services à la personne comprend les services sociaux, les services de counselling en milieu scolaire, les services de réadaptation en établissement, la réadaptation professionnelle, la justice pénale et les services en milieu carcéral ainsi que les conseillers

professionnels religieux. Au début des années 80, environ 3 p. 100 des adultes américains ont utilisé les services de santé mentale offerts dans ce secteur.

4.3.3.1 L'emploi

Le taux d'emploi des personnes atteintes de maladie mentale est l'un des plus faibles parmi ceux et celles qui sont atteints d'incapacité aux États-Unis – seule une personne sur trois environ ayant un emploi. Le chômage demeure élevé malgré les sondages qui révèlent que la majorité des adultes souffrant de maladies mentales graves veulent travailler et que beaucoup de malades pourraient travailler s'ils recevaient une aide. Malheureusement, selon les rapports récents, la plupart des personnes atteintes de maladies mentales graves ne reçoivent absolument aucun service de réadaptation professionnelle.

Nombreuses sont les personnes souffrant de maladies mentales graves qui continuent de compter sur l'aide financière du gouvernement fédéral afin de conserver leur couverture pour soins de santé, même si elles désirent grandement avoir un emploi. Elles font face à un facteur dissuasif d'ordre financier, car si elles occupent un emploi à temps complet, elles n'ont plus droit aux prestations fédérales. Étant donné que la plupart des emplois auxquels ces personnes ont accès n'offrent pas de couverture pour les soins de santé mentale (d'après une vaste étude portant sur 8 États, seulement 8 p. 100 des personnes atteintes de maladie mentale ayant réussi à retourner à temps complet sur le marché du travail bénéficiaient d'une assurance santé mentale), elles doivent choisir entre l'emploi et la couverture. En conséquence, ces personnes dépendent de leur rente d'invalidité et de Medicaid (ou Medicare) mais elles préfèreraient travailler et être autonomes. En fait, elles composent la cohorte la plus importante – 35 p. 100 – des bénéficiaires des prestations d'aide au revenu versées par le gouvernement fédéral par le truchement du programme de sécurité sociale pour les personnes invalides, le Supplemental Security Income (SSI) (supplément de revenu garanti). À cet égard, M. Hogan devait préciser au Comité :

> *Quelle est la plus grosse dépense liée à la maladie mentale chez nous? Ce sont les paiements d'invalidité versés aux gens devenus invalides du fait de la maladie mentale. Nous leur envoyons un chèque chaque mois — pas assez pour vivre décemment. Cela revient à leur dire qu'ils doivent rester invalides pour bénéficier de ce chèque, ce qui est une situation terrible. Si nous leur donnions de meilleurs soins et si nous les aidions à trouver un travail — pas nécessairement un travail à plein temps, à raison de 40 heures par semaine — chacun s'en porterait beaucoup mieux.*

4.3.3.2 Le logement

Le manque de logements intégrés décents, sécuritaires et abordables est l'un des plus importants obstacles à la pleine participation à la vie communautaire qui se pose aux personnes souffrant de maladies mentales graves. Actuellement, des millions de personnes aux États-Unis atteintes de maladies mentales graves ne disposent pas d'un logement répondant à leurs besoins. À cause de la pénurie de logements abordables et de services de soutien connexes, les personnes souffrant de maladies mentales graves font la navette entre

les prisons, les établissements, les abris et la rue, elles restent plus longtemps que nécessaire en établissement ou elles demeurent dans des logements dangereusement insalubres. Les personnes souffrant de maladies mentales graves forment également une grande proportion des sans-abri à répétition ou de longue durée.

Sur plus de deux millions d'adultes américains qui ont été sans-abri pendant un temps au cours d'une année donnée, 46 p. 100 ont fait état d'un problème de santé mentale dans les douze mois ayant précédé leur itinérance. Une étude récente montre que les personnes qui comptent uniquement sur les prestations du programme SSI – ce qui est le cas de nombreuses personnes souffrant de maladies mentales graves – ont un revenu égal à seulement 18 p. 100 du revenu médian et qu'elles n'ont pas les moyens d'avoir un logement décent dans un des 2 703 marchés du logement définis par le U.S. Department of Housing and Urban Development (HUD) (ministère de l'Habitation et du Développement urbain).

Aux termes des politiques fédérales en matière de logement social, il peut être difficile pour des personnes ayant de mauvais antécédents de locataire, des problèmes de toxicomanie et des casiers judiciaires – autant de problèmes courants chez de nombreuses personnes atteintes de maladies mentales graves – de satisfaire aux exigences pour l'obtention d'une aide au logement ou d'unités de logement social.

4.3.3.3 Les services aux personnes incarcérées

Environ 7 p. 100 de tous les détenus aux États-Unis sont atteints d'une maladie mentale grave et la proportion des détenus souffrant de formes graves est encore beaucoup plus élevée. Aux États-Unis, les personnes atteintes de maladies mentales graves qui ont maille à partir avec le système de justice pénale sont souvent :

- pauvres
- sans assurance
- membres de groupes minoritaires en nombre disproportionné
- sans abri
- toxicomanes et en même temps atteintes de troubles mentaux.

Il est probable que ces personnes demeureront dans le cycle sempiternel du système de santé mentale, de la toxicomanie et de la justice pénale.

Il est fréquent que les personnes atteintes de maladies mentales ne reçoivent pas de services appropriés à leur cas après leur incarcération. Nombre d'entre elles perdent leurs droits à l'aide au revenu et aux prestations d'assurance santé dont elles ont besoin pour réintégrer la société après leur mise en liberté.

4.3.3.4 L'accès aux services en milieu rural

Pour de nombreux Américains souffrant de maladies mentales, qui vivent en milieu rural et dans les autres régions éloignées, l'accès aux soins est difficile, la disponibilité de fournisseurs de soins compétents est insuffisante, le revenu familial est faible et un stigmate social plus grand frappe les personnes qui doivent être traitées pour un problème de santé mentale,

comparativement à leurs homologues vivant en milieu urbain. En conséquence, les personnes ayant des besoins en santé mentale et résidant en milieu rural aux États-Unis :

- entament le processus de soins plus tard que leurs homologues urbains, une fois la maladie déjà bien installée;
- entament le processus de soins alors que les symptômes se sont aggravés, sont plus persistants et plus handicapants;
- nécessitent un traitement plus coûteux et intensif.

S'ajoute au problème de la disponibilité et de l'accès le fait que les Américains vivant en milieu rural ont un revenu familial inférieur et sont moins susceptibles d'avoir une assurance santé privée couvrant les soins de santé mentale que leurs homologues en milieu urbain. En outre, si la plupart des grandes villes où se trouvent des facultés de médecine regorgent de psychiatres, c'est loin d'être le cas dans les petites villes où ils sont en nombre insuffisant et pire encore en milieu rural où il n'y en a généralement pas.

4.3.3.5 Les services aux minorités

Des rapports récents indiquent que le système de santé mentale aux États-Unis ne suit pas le rythme des divers besoins des minorités raciales et ethniques et que, le plus souvent, il répond de façon insuffisante ou inappropriée aux besoins de cette clientèle. Par exemple, chez les Afro-américains, la schizophrénie est souvent sur-diagnostiquée tandis que la dépression est fréquemment sous-diagnostiquée. En règle générale, les rapports indiquent que, dans le cadre du système, on ne respecte pas ou l'on ne comprend pas les antécédents, les traditions, les croyances, les langues ni les systèmes de valeurs des groupes différents sur le plan culturel. L'incompréhension et la mauvaise interprétation des comportements ont eu des conséquences tragiques, y compris le fait que des membres des minorités ont été placés, à tort, entre les mains des systèmes de justice pénale ou du système judiciaire pour les jeunes. À ce sujet, voici ce que M. Emmet a indiqué au Comité :

> *Aux États-Unis, on constate que certaines communautés — les Afro-américains et les Latino-américains — font rarement appel aux systèmes de soins de santé quand il s'agit de maladies mentales. La stigmatisation y est pour beaucoup. Toutefois, on sait aussi qu'ils s'adressent aux églises et à d'autres organismes communautaires pour essayer de faire face à leurs problèmes.*

En conséquence, les Amérindiens, les autochtones de l'Alaska, les Afro-américains, les Américains d'origine asiatique, les insulaires du Pacifique et les Hispano-américains tendent à porter un fardeau excessivement lourd, par rapport aux autres groupes, pour ce qui est de l'incapacité due aux troubles mentaux. On ne saurait attribuer cette situation à la prévalence accrue ou à la gravité des maladies dans ces populations. Selon des rapports récents, le problème serait plutôt dû au manque de soins fournis à ces personnes et à la piètre qualité des soins offerts.

4.3.3.6 Les services aux enfants

Aux États-Unis, près de 21 p. 100 des enfants et des adolescents (de 9 à 17 ans) montrent des signes de détresse ou d'incapacité associés à un diagnostic précis et une invalidité minimale par rapport à une échelle d'évaluation globale. Presque la moitié de ce groupe (près de 10 p. 100 des enfants et des adolescents) a reçu un traitement dans un ou plusieurs secteurs du système de services de santé mentale *de facto*, le reste (plus de 11 p. 100 de la population) n'a reçu aucun traitement dans aucun des secteurs du système de soins de santé. Ainsi, la majorité des enfants et des adolescents atteints de troubles mentaux aux États-Unis ne reçoivent aucun soin. Toutefois, Mechanic et Bilder soulignent que, d'après les données disponibles, les enfants souffrant de problèmes de santé mentale reçoivent plus d'attention que par le passé. Ils citent plus particulièrement l'analyses de Sherry Glied et Alison Evans Cuellar des Enquêtes nationales de 1987 et de 1998 sur les dépenses médicales, analyse selon laquelle le nombre d'enfants traités pour de tels troubles a augmenté de 60 p. 100.

En outre, le General Accounting Office (GAO) (Bureau de comptabilité générale) a récemment publié un rapport mettant en exergue l'une des graves conséquences de l'état des services de santé mentale pour les enfants et les adolescents aux États-Unis. Il semble que des milliers de parents sont obligés de confier leurs enfants, année après année, à des organismes de protection de la jeunesse ou du système judiciaire pour jeunes afin qu'ils puissent obtenir les services de santé mentale dont ils ont besoin. Les parents qui ont épuisé leurs économies et leurs indemnités d'assurance santé doivent prendre une décision déchirante : renoncer à leurs droits de parents et briser leur famille afin que leurs enfants perturbés reçoivent des soins en santé mentale. D'après les estimations du rapport du GAO, en 2001, plus de 12 700 enfants ont dû être confiés – par leurs parents – à des organismes de protection de la jeunesse ou au système de justice pour jeunes, en dernier recours pour que ces enfants reçoivent les soins de santé mentale dont ils avaient besoin. Selon la Commission sur la santé mentale, ces chiffres sont probablement inférieurs à la réalité parce que 32 États, y compris les cinq États les plus grands, n'ont pu fournir de données sur le nombre d'enfants touchés.

D'après le rapport du GAO, plusieurs facteurs contribuent à la décision d'« échanger la garde contre des services », y compris :

- les restrictions des assurances santé publiques et privées;
- l'offre insuffisante de services de santé mentale;
- la disponibilité restreinte de services par le truchement des organismes de santé mentale et des écoles;
- les difficultés à satisfaire aux critères d'admissibilité aux services.

Ainsi, à cause du manque d'accès aux soins en santé mentale, des milliers de parents doivent abandonner la garde de leurs enfants atteints de troubles mentaux graves aux organismes d'aide sociale à l'enfance et aux centres de détention des jeunes seulement pour obtenir un traitement.

4.4 PROMOTION ET PRÉVENTION

Plusieurs projets ont été lancés aux États-Unis au titre de la promotion de la santé mentale et de la prévention de la maladie mentale, de l'abus de substances et de la toxicomanie. Ainsi, le Comité a appris que la National Association of State Mental Health Program Directors (Association nationale des directeurs de programme de santé mentale dans les États) est en train d'approuver un document de position réclamant l'adoption de politiques et de pratiques en matière de :

- promotion de comportements propices à une bonne santé mentale;
- détection des problèmes de santé mentale et d'interventions les plus précoce possibles;
- réduction de l'incidence des maladies mentales et du suicide;
- prévention de l'incapacité due à la maladie mentale et aux états de co-morbidité;
- prévention des états couramment associés à la maladie mentale, notamment les autres maladies, la consommation abusive de substances et les traumatismes.

Afin de mieux illustrer les efforts réellement entrepris dans ce domaine, nous allons à présent nous attarder sur la stratégie nationale de prévention du suicide.

4.4.1 La stratégie nationale de prévention du suicide

La National Strategy for Suicide Prevention (Stratégie nationale de prévention du suicide ou SNPS) est le résultat d'une série d'initiatives entreprises par des acteurs gouvernementaux et non gouvernementaux à la fin des années 90. Au début 2000, le secrétaire à la Santé et aux services sociaux a mis sur pied un groupe directeur au niveau fédéral, chargé de lancer la stratégie nationale en question.

Celle-ci poursuit les objectifs généraux suivants :

- Prévenir les morts prématurées dues au suicide à tous les âges.
- Réduire les taux d'autres comportements suicidaires.
- Réduire les effets délétères associés aux comportements suicidaires et les traumatismes qu'occasionne le suicide chez les membres de la famille et les amis.
- Cultiver les occasions et les lieux susceptibles d'améliorer le ressort psychologique, la débrouillardise, le respect et le sens de l'interdépendance pour les suicidaires, leurs familles et leur milieu.

Le document intitulé *Goals and Objectives for Action* (Objectifs d'action), publié en 2001, était destiné à présenter un ensemble d'objectifs principaux et secondaires et à proposer une feuille de route pour l'action. Celui-ci présente donc 11 objectifs principaux et 68 objectifs secondaires pour cette dimension de la stratégie nationale. Dans la prochaine phase de la SNPS, un ensemble d'activités sera élaboré pour chaque objectif secondaire.

Les objectifs principaux de la stratégie se présentent sous la forme d'énoncés généraux, de niveau supérieur, destinés à orienter la planification sur les différents thèmes abordés, en fonction du résultat visé. Les objectifs secondaires de la stratégie précisent les objectifs principaux en indiquant qui doit faire quoi, quand et où pour parvenir à l'objectif principal. Enfin, les activités précisent la façon dont les objectifs secondaires seront réalisés

Les onze objectifs principaux de la stratégie sont les suivants :

- Promouvoir l'idée que le suicide est un problème de santé publique pouvant être évité.
- Élaborer des moyens de soutien à la prévention du suicide qui reposent sur une assise large.
- Élaborer et mettre en œuvre des stratégies destinées à réduire la stigmatisation associée au fait que l'on fréquente les services de santé mentale, de traitement des toxicomanies ou de prévention du suicide.
- Élaborer et mettre en œuvre des programmes communautaires de prévention du suicide.
- Promouvoir les efforts déployés en vue de rendre plus complexe l'accès aux méthodes et moyens d'automutilation létaux.
- Organiser une formation axée sur la détection des comportements à risque et sur la prestation de traitements efficaces.
- Élaborer et promouvoir l'adoption de pratiques cliniques et professionnelles efficaces.
- Améliorer l'accès aux services de lutte contre l'abus de substances et aux services de santé mentale, et favoriser les liens au niveau communautaire.
- Améliorer la façon dont le comportement suicidaire, la maladie mentale et l'abus de substances sont présentés dans les médias de divertissement et d'information, et améliorer la façon dont les médias traitent de ces aspects.
- Promouvoir et financer la recherche sur le suicide et la prévention du suicide.
- Améliorer et étendre les systèmes de surveillance.

La stratégie nationale se veut un modèle que les États, les collectivités et les tribus souhaitant se doter de leur propre plan de prévention du suicide pourront appliquer ou modifier. Ainsi, la stratégie nationale proposerait un cadre d'action national, mais serait aussi un moyen d'aider les groupes locaux à faire en sorte que la prévention du suicide soit davantage prioritaire.

L'importante étape suivante envisagée dans le cadre de la stratégie nationale est la création d'une structure d'administration ou d'un organisme de coordination qui chapeautera l'ensemble des activités de prévention et fournira un mécanisme de mobilisation de la population. *Goals and Objectives for Action* donne une idée de ce à quoi pourrait ressembler cet organisme, produit d'un partenariat secteur public-secteur privé. Celui-ci pourrait se charger

de formuler un programme d'action, même si l'on se rend bien compte que, pour accélérer les choses, il faudra peut-être mener de front la mise sur pied de cet organisme et la préparation du programme d'action.

4.5 PERSPECTIVES DE RÉFORME

La President's New Freedom Commission sur la santé mentale, première commission présidentielle chargée de ce sujet en 25 ans, a publié son rapport final en juillet 2003. La création de la Commission a été annoncée par la Maison blanche en février 2001 dans le cadre d'un vaste plan d'action sur les handicaps multiples baptisée New Freedom Initiative. Cette initiative comportait dix propositions visant à abattre les barrières auxquelles se heurtent aujourd'hui les Américains ayant une déficience.

Étant donné que la présidence s'attarde rarement sur la santé mentale, la Commission s'est fixé comme objectif de galvaniser le changement à tous les niveaux et pas seulement au sein du gouvernement fédéral. Tirant profit de l'expérience de commissions passées, la New Freedom Commission s'est fixé pour but de favoriser le progrès par des changements échelonnés et progressifs au sein des grands programmes fédéraux comme Medicaid, Medicare et la sécurité sociale, plutôt que de viser des mesures de réforme chocs ou un soutien accru à divers programmes de santé mentale. Voici en quels termes M. Hogan nous a décrit la stratégie qui sous-tend ce rapport :

> *Ce que notre commission a fini par proposer reposait sur l'idée qu'il fallait essayer de contourner la notion de réforme ou de restructuration. Nous avions l'impression que la réforme était à l'origine du fouillis actuel et qu'il nous fallait trouver un nouveau concept ou un nouveau terme. Nous avons fini par opter pour le concept de transformation, qui nous a galvanisés. Nous ne savons pas exactement ce que cela veut dire, mais nous pensons que la transformation exige des mesures différentes à bien des niveaux différents. Le problème n'est pas que fédéral, et il ne faut donc pas compter que la sagesse va surgir de la capitale nationale et se répandre à l'échelle locale où les gens devront s'y adapter. Il faut aussi des mesures à l'échelle locale, et il faut des mesures de grande envergure et de moindre envergure, les mesures d'une portée très vaste et irréalisables ne suffisant pas. Ainsi, cela peut paraître mineur comme changement que de créer un contexte dans lequel les patients à titre individuel et leurs familles peuvent davantage décider eux- mêmes de leur traitement, mais ce changement pourrait avoir un effet beaucoup plus important, voire révolutionnaire, que des changements de plus grande envergure. Nous proposons l'idée d'une vision nationale des soins de santé mentale et l'établissement d'objectifs nationaux, qui serviraient, nous l'espérons, à motiver et à organiser les gens …*

En plus de son rapport provisoire (octobre 2002) et de son rapport final, la Commission a produit une série de rapports détaillés sur certains aspects des soins de santé mentale. Ces

rapports seront publiés ultérieurement en tant que documents de travail dans l'espoir que cela facilitera l'élaboration d'un programme d'action utile pour l'avenir.

Le rapport provisoire relève cinq obstacles majeurs aux soins :

- la fragmentation et les lacunes dans les soins aux enfants;
- la fragmentation et les lacunes dans les soins aux adultes souffrant de différentes maladies mentales;
- les taux élevés de chômage et d'incapacité chez les personnes souffrant de graves maladies mentales;
- le manque de soins aux personnes âgées souffrant de maladies mentales;
- l'absence de priorité nationale en santé mentale et prévention du suicide.

Toutefois, l'aspect du rapport provisoire qui semble avoir le plus attiré l'attention est la déclaration de la Commission selon laquelle le système est dans un état pitoyable. Certains estimaient que c'était aller trop loin, mais la Commission a maintenu son constat d'échec du système et pavé la voie à des recommandations bien senties que son rapport final allait contenir.

Le rapport final se caractérise par l'accent mis sur le rétablissement. M. Hogan a raconté que la Commission s'est inspirée d'une remarque de l'ex-première dame des États-Unis, Rosalynn Carter, pour adopter cette orientation :

> *Mme Carter nous a dit que nous avions un avantage dans notre réflexion qui n'existait pas il y a une génération. Le changement le plus important qui soit survenu, c'est que nous savons maintenant que le rétablissement est une possibilité pour n'importe quelle personne qui a une maladie mentale.*

Le rétablissement est considéré par la Commission comme un processus d'adaptation positive à la maladie et à l'incapacité, fortement lié à la conscience de soi et au sens de l'autonomisation susceptibles de conférer aux personnes souffrant d'une maladie mentale le moyen de vivre une vie satisfaisante, remplie d'espoir et utile, malgré les contraintes imposées par leur état. Les membres de la Commission ont fait bloc autour de l'opinion selon laquelle toutes les personnes qui souffrent d'une maladie mentale devraient avoir la possibilité de s'améliorer et d'espérer. M. Hogan nous a précisé ce dont il retournait, dans son témoignage :

> *Il s'agit là d'une déclaration simple mais puissante qui recouvre plusieurs notions, de l'avis de la commission. Premièrement, les gens peuvent améliorer leur état de santé mentale même si, auparavant, on les considérait comme des «cas désespérés». Deuxièmement, même ceux qui ont une maladie grave qui les suivra pendant des années ils peuvent atteindre une bonne qualité de vie s'ils ont le soutien qu'il leur faut. Le*

> *rétablissement n'est pas nécessairement une guérison miraculeuse; il peut s'agir simplement de savoir bien composer avec une maladie dévastatrice. Troisièmement, s'il y a possibilité de rétablissement, c'est que l'espoir doit être une composante essentielle des soins en santé mentale, qui, de ce fait, ne seront plus aussi passifs et axés sur les soins d'entretien.*

Dans son rapport, la Commission indique à quel point le système est fragmenté et reconnaît que la réforme des soins de santé mentale est une tâche déconcertante, étant donné la complexité des changements à apporter. Pour la Commission, il est clair qu'aucune mesure de réforme unique n'engendrera le changement nécessaire, mais il est également clair que la réforme simultanée et à grande échelle de plusieurs programmes ne procurerait pas non plus le changement souhaité. Plus précisément, la Commission a insisté sur l'importance de formuler des plans de traitement individualisés bien que, comme M. Hogan nous l'a dit :

> *Nous ne savons pas exactement comment la chose pourrait se faire, mais nous sommes d'avis qu'il faut s'orienter vers des soins plus individualisés et davantage axés sur un effort personnalisé afin que la famille et le patient aient davantage leur mot à dire dans le plan de traitement. Ce que nous préconisons, ce n'est pas un pouvoir de décision absolue, mais plutôt un véritable partenariat avec les professionnels, au lieu que le rôle du patient se limite à recevoir le diagnostic et à subir les traitements.*

Afin d'établir une liste restreinte de repères à respecter, la Commission propose six objectifs nationaux en soins de santé mentale et oriente ses 19 grandes recommandations sur l'atteinte de ces objectifs (voir l'encadré ci-après). M. Emmet a tenu à insister sur ce qui suit dans son témoignage devant notre Comité :

> *Les six objectifs de la transformation du système qui ont été énoncés par la commission dans son rapport final peuvent être réalisés, comme l'a expliqué le Dr Hogan, par des mesures prises aux niveaux local, étatique et fédéral. Si elle a évité à dessein d'entrer dans le détail dans ce rapport, la commission y élabore un cadre bien pensé et axé sur une vision à long terme qui permettra de s'attaquer au nœud du problème, tel qu'il avait été défini dans le rapport du directeur du Service de santé publique, à savoir que les services donnent de bons résultats mais que nous en rendons l'accès très difficile pour ceux qui en ont besoin.*

Les membres de la Commission ne se font pas d'illusion; ils ne croient pas que leur rapport, malgré l'excellent accueil que lui a réservé le milieu de la santé mentale, suffira à lui seul à transformer un système fragmenté et souvent perturbé. Toutefois, certains signes tendent à montrer que le gouvernement actuel est disposé à donner suite au rapport. Le directeur du Centre des services en santé mentale du SAMHSA a été chargé de diriger l'élaboration d'une méthode de mise en oeuvre des recommandations. L'administration actuelle prévoira un crédit de 44 millions de dollars dans son projet de budget pour 2005 en vue de financer les plans de mise en oeuvre de ses recommandations dans tous les États. Bien que cet

engagement budgétaire n'aie pas encore abouti, la proposition a reçu un fort appui du milieu d'intervention communautaire en santé mentale.

La Commission espère que son diagnostic et son plan de traitement permettront de mettre à profit les nombreuses forces du système : des traitements efficaces, des cliniciens consciencieux, des intervenants passionnés et – ingrédient indispensable – l'espoir. Comme l'a indiqué M. Hogan dans une entrevue, « l'élaboration d'un bon plan de traitement est une chose nécessaire, mais cela ne suffit certainement pas à assurer le progrès et le rétablissement ».

M. Hogan avance en outre que, pour réussir, les interventions doivent être descendantes et montantes. Une direction nationale est requise pour les activités comme les campagnes de lutte contre la stigmatisation et la modification des programmes fédéraux, et les gens qui récupèrent d'une maladie mentale ont le droit de réclamer une plus grande participation à l'élaboration des plans de traitement qui les concernent. À son avis, le temps seul nous dira si les bénéficiaires de soins de santé mentale pourront s'engager conjointement face aux changements requis et si les contextes politique et économique dans lesquels nous évoluons permettront le changement, le favoriseront ou y feront obstacle.

Il convient ici de souligner que deux autres mesures sont en cours d'étude avec l'appui des deux partis. Celles-ci ont été adoptées par le Sénat et attendent de passer devant la Chambre des représentants. La première vise la prévention du suicide chez les adolescents et la prestation de conseils aux étudiants. La deuxième, le *Mentally Ill Offender Treatment and Crime Reduction Act* (loi sur le traitement et la réduction de la criminalité chez les délinquants malades mentaux) permettrait de verser des subventions destinées à stimuler tous les efforts communautaires déployés en vue d'éviter que les personnes souffrant de maladies mentales n'aient des démêlés avec le système de justice pénale.

OBJECTIFS ET RECOMMENDATIONS DE LA PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH
OBJECTIF 1 Les Américains comprennent que la santé mentale est indispensable à la santé globale. • Élaborer et réaliser une campagne nationale visant à réduire les stigmates associés au fait de réclamer des soins, ainsi qu'une stratégie nationale de prévention du suicide. • Aborder la santé mentale avec le même sentiment d'urgence que dans le cas de la santé physique. **OBJECTIF 2** Les soins de santé mentale répondent au consommateur et à la famille. • Élaborer un plan individualisé de soins pour chaque adulte souffrant d'une maladie mentale grave et chaque enfant souffrant d'un trouble émotionnel grave. • Faire intégralement participer les consommateurs et les familles à l'orientation du système de soins de santé mentale vers le rétablissement. • Orienter les programmes fédéraux pertinents en sorte d'améliorer l'accès aux services en santé mentale et la reddition de comptes en la matière. • Créer un plan global de santé mentale. • Protéger et améliorer les droits des personnes souffrant de maladies mentales.

OBJECTIF 3 Les inégalités dans les services de santé mentale sont éliminées.

- Améliorer l'accès à des soins de qualité qui tiennent compte des sensibilités culturelles.
- Améliorer l'accès à des soins de qualité dans les régions rurales et éloignées.

OBJECTIF 4 Le dépistage précoce, l'évaluation et le renvoi à des services sont monnaie courante.

- Promouvoir la santé mentale des jeunes enfants.
- Améliorer et élargir les programmes scolaires de santé mentale.
- Dépister la cooccurrence de maladies mentales et de troubles liés à la consommation de drogues et établir des liens avec des stratégies intégrées de traitement.
- Dépister les maladies mentales dans le cadre des soins de santé primaires, tout au long de la vie, et établir des liens avec le traitement et les soutiens.

OBJECTIF 5 Des soins de santé mentale d'excellente qualité sont prodigués et la recherche est intensifiée.

- Intensifier la recherche en faveur du rétablissement et de la résilience et trouver finalement un remède et des moyens de prévention.
- Favoriser des pratiques fondées sur des faits au moyen de projets de diffusion et de démonstration et créer une association publique-privée pour orienter leur réalisation.
- Améliorer et élargir les effectifs qui fournissent des services de santé mentale et un soutien fondés sur des faits.
- Développer la base de connaissances dans quatre sous-domaines étudiés : inégalités en santé mentale, effets à long terme des médications, traumatismes et soins actifs.

OBJECTIF 6 La technologie est utilisée pour donner accès aux soins de santé mentale et à l'information.

- Utiliser la technologie de la santé et la télésanté pour améliorer l'accès aux soins de santé mentale et leur coordination, spécialement pour les Américains résidant dans des régions éloignées ou au sein de populations mal desservies.
- Concevoir et réaliser des systèmes électroniques intégrés de dossiers de santé et de renseignements personnels sur la santé.

4.6 OBSERVATIONS DU COMITÉ

Le Comité estime que nous avons beaucoup à apprendre des tentatives déployées aux États-Unis pour s'attaquer aux conséquences de la fragmentation des services de soins en santé mentale qui sont répartis entre différents niveaux de compétence et plusieurs ministères. Une telle fragmentation limite l'accès aux services et entrave la capacité des fournisseurs de services à bénéficier mutuellement de ce qui est novateur et à miser sur l'excellence.

Les membres du Comité ont été très impressionnés par l'orientation générale du rapport de la President's New Freedom Commission sur la santé mentale, surtout par son intérêt à trouver des solutions axées sur les patients. Nous n'avons notamment pas manqué de

remarquer le désir de favoriser la guérison chez tous et toutes, de même que l'insistance placée sur la nécessité de faire participer les usagers à la conception et à la réalisation de régimes de soins individualisés. Le Comité prend acte des nombreux obstacles qui s'opposent à la réalisation de la vision de la Commission, obstacles dont plusieurs découlent de la fragmentation du système que la Commission a décrit dans son rapport.

Le Comité prend également note de la place prépondérante accordée à la stimulation de la recherche sur la santé mentale et la maladie mentale et à la promotion de technologies dont l'adoption permettra d'améliorer la prestation des soins et des services. Nous constatons que ces aspects sont conformes au rôle international de premier plan que jouent les chercheurs et les scientifiques américains.

Qui plus est, les membres du Comité estiment que la place prépondérante que ce rapport accorde à la prestation de services communautaires adaptés est à la fois appropriée et extrêmement importante. Dans le même ordre d'idées, l'expérience américaine nous rappelle à quel point il importe de promouvoir la collaboration entre les divers ordres de gouvernement de même qu'entre leurs différents ministères ou services.

Enfin, les membres du Comité constatent qu'une telle orientation exige une mobilisation nationale afin de mettre en œuvre le plus grand nombre de ressources possible sans perdre de vue que, pour aboutir, les réformes entreprises doivent être soutenues à tous les échelons. En évitant de proposer la solution de la « table rase », la New Freedom Commission a rejoint les conclusions auxquelles notre Comité était parvenu au sujet du secteur des soins actifs au Canada, dans son rapport d'octobre 2002 sur la santé des Canadiens.

CHAPITRE 5:
COMPARAISON DES SOINS DE SANTÉ MENTALE DANS LES QUATRE PAYS ÉTUDIÉS

5.1 INTRODUCTION

Comme nous l'avons fait remarquer dans l'introduction du présent rapport, à cause de la complexité des systèmes de soins de santé (tant pour ce qui est des modalités de paiement que des mécanismes de prestation des services) et des liens inextricables qui existent entre ces systèmes et l'histoire, les politiques et la culture de chaque pays, la transposition des mesures d'un pays à l'autre ne peut se faire simplement. Le caractère commun de la plupart des enjeux auxquels les décideurs et les praticiens sont confrontés dans le domaine des politiques de soins, partout dans le monde industrialisé, signifie toutefois qu'il y a beaucoup à gagner d'une étude attentive de ce qui fonctionne et de ce qui ne fonctionne pas ailleurs. Dans le présent chapitre, le Comité part de son examen de l'expérience de quatre pays pour tirer certains enseignements sur ce qui se fait au Canada en vue de réformer la prestation des soins de santé mentale et d'améliorer la santé mentale des Canadiennes et des Canadiens. La structure du présent chapitre reprend celle utilisée dans les études de pays.

5.2 HISTORIQUE ET APERÇU

Le Comité a été frappé de constater que la désinstitutionalisation a été vécue un peu de la même façon dans tous les pays examinés. Tout d'abord, ce sont presque toujours les mêmes facteurs qui ont poussé ces pays à opter pour la désinstitutionalisation :

- adoption d'une nouvelle méthode de traitement, surtout de nouveaux médicaments, accompagnée
- d'un changement d'attitudes envers la nature de la maladie mentale
- d'une conviction croissante que les traitements sont plus efficaces en milieu communautaire.

Deuxièmement, dans chaque pays étudié (tout comme au Canada), la fermeture des hôpitaux psychiatriques est intervenue plus rapidement que le déploiement de nouvelles ressources communautaires, ce qui a donné lieu à de nombreuses situations où les personnes souffrant de maladie mentale ont dû se débrouiller seules. Qui plus est, les difficultés soulevées par le manque de ressources pour passer à des soins communautaires ont souvent été compliquées par la résistance à ce transfert dans les collectivités urbaines où de vieilles attitudes ne changeaient que lentement.

Il convient, en troisième lieu, de remarquer que dans de nombreux pays étudiés la désinstitutionalisation a été un des facteurs qui a stimulé l'adoption de stratégies nationales dont l'objet était d'améliorer la prestation de services aux personnes souffrant de maladie mentale. Il y a donc lieu de se poser la question suivante : Pourquoi la désinstitutionalisation au Canada n'a-t-elle pas donné lieu aux mêmes résultats, puisque nous n'avons pas encore de

stratégie nationale en matière de santé mentale, de maladie mentale et de toxicomanie, contrairement à tous les autres pays du G8?

On pourrait être tenté de pointer du doigt le fédéralisme canadien parce qu'il peut-être empêché que la santé mentale ne devienne une priorité nationale. Toutefois, comme l'un des pays fédéraux étudiés (l'Australie) a entamé dès 1992 une planification nationale cohérente, le fédéralisme, en tant que tel, n'explique pas le parcours différent suivi par le Canada.

Il y aurait sans doute une explication plus valable : le fait que, le gouvernement fédéral au Canada ne prenant pas part à la prestation des services à la population en général, il n'a pas ressenti la nécessité de réagir aux profonds changements survenus dans la prestation des services sur le terrain. On pourrait tout de même se demander pourquoi, étant donné son rôle dans la prestation des services à certains groupes de la population (voir le chapitre 9 du volume 1), le gouvernement fédéral n'a pas tiré les enseignements qui s'imposaient des faiblesses que présente son propre système de prestation de services et pourquoi il ne s'est pas rendu compte que les provinces étaient confrontées à des problèmes identiques.

Enfin, il convient de remarquer qu'à cause de la tendance d'Ottawa de transférer des fonds aux provinces sans exigence de contrepartie (ce qui a abouti à la création du TCSPS au milieu des années 90), les provinces ont dû composer de leur mieux avec le contexte changeant dans lequel s'inscrivait la prestation des services de santé mentale.

5.3 COÛTS ET FINANCEMENT DES SERVICES DE SANTÉ MENTALE

Pour ce qui est des comparaisons relatives aux coûts et au financement entre les différents pays, le Comité tient d'abord à souligner les problèmes qui se posent sur le plan de la comparabilité des données. En présentant leurs données sur les dépenses en santé mentale, les auteurs du *National Mental Health Report* (2002) (Rapport national sur la santé mentale) en Australie ont bien précisé que tous les pays ne mesurent pas les dépenses en santé mentale de la même façon et qu'il et donc extrêmement difficile d'établir des comparaisons directes. Ainsi, les auteurs de ce rapport (comme nous l'avons vu dans le chapitre sur l'Australie) font remarquer que certains pays incluent des montants qui sont spécifiquement exclus des estimations australiennes, comme les services dispensés aux alcooliques, aux toxicomanes et aux handicapés intellectuels, les soins fournis aux personnes souffrant de démence ou concernant les logements de ces dernières et les versements des prestations de sécurité du revenu aux usagers des soins de santé mentale.

Il ne semble donc généralement pas possible d'établir des lignes directrices fondées sur des pratiques exemplaires en matière de dépenses globales en santé mentale. Toutefois, il existe suffisamment de données sur les tendances que présentent ces dépenses dans le temps, dans chaque pays, pour qu'on puisse tirer certaines conclusions *a priori* relativement aux facteurs qui méritent qu'on accorde plus d'attention aux besoins de financement de la santé mentale et sur les façons de garantir la pérennité de ce financement. On peut également comparer les priorités de financement des différents pays, bien qu'il existe ici certaines variations dans la mesure où, comme il est difficile d'obtenir des données comparables d'un pays à l'autre, les conclusions qu'on peut tirer ne sont pas aussi solides.

Le lecteur se sera peut-être rendu compte que les données présentées dans le cas de l'Australie sont remarquables par leur degré de détail et par le fait qu'elles permettent des comparaisons longitudinales. Les Australiens viennent de produire leur septième rapport national sur la santé mentale qui rentre encore plus dans le détail et qui permet de comprendre mieux que pour n'importe quel autre pays étudié l'évolution dans le temps des dépenses en santé mentale. Le Comité estime que cela montre bien à quel point il importe de faire preuve de régularité dans la collecte et la diffusion des données.

Qui plus est, comme l'illustre le débat sur l'adéquation du financement de la santé mentale en Angleterre, il convient également non seulement d'examiner les augmentations en chiffres absolus du niveau de financement de la santé mentale, mais aussi de se demander si les nouveaux investissements dans ce domaine progressent au rythme de ceux effectués dans le secteur plus général des soins de santé. Ainsi, si la croissance des dépenses en santé mentale traîne de l'arrière derrière celles des dépenses globales en soins de santé, la position relative du secteur de la santé mentale est affectée, même si ce secteur reçoit davantage d'argent que dans le passé. Cette considération revêt une importance particulière dans le contexte d'un projet de réforme en profondeur ou d'une tentative visant à aligner les dépenses en santé mentale sur celles de la santé en général.

Parallèlement à cela, il y a la question du bien-fondé du ciblage des dépenses en santé mentale pour s'assurer que les fonds vont bien au traitement des maladies mentales et qu'ils ne sont pas absorbés dans les dépenses générales de la santé ou pour garantir que les transferts d'un ordre de gouvernement à un autre constituent de véritables augmentations des dépenses en santé mentale qui ne sont pas ensuite amputées par la disparition de services offerts jusque-là, même si de nouveaux sont ajoutés. À cet égard, l'expérience australienne est chargée d'enseignement. Comme des témoins l'ont indiqué au Comité, les fonds fédéraux supplémentaires ont d'abord été ciblés, mais comme ce financement a été de plus en plus apprécié par les différents ordres de gouvernement au fil du temps, il a fallu adopter des mesures particulières pour protéger les ressources en santé mentale qui n'étaient plus nécessaires.

Les membres du Comité ont tout de même trouvé remarquable que, dans les trois ou quatre pays examinés, l'adoption de stratégies nationales en matière de santé mentale s'est accompagnée d'une augmentation du niveau de financement des services et des activités dans le domaine. Comme les témoins l'ont indiqué, des documents qui informent sur les besoins du secteur de la santé mentale peuvent être de puissants instruments de pression politique sur les gouvernements afin de les amener à augmenter les ressources nécessaires. Qui plus est, il faut pouvoir s'appuyer sur des repères et des objectifs clairs afin de contrôler la mise en œuvre d'une stratégie nationale et de s'assurer que les engagements financiers seront respectés dans le temps. D'après les témoignages et les documents que nous avons recueillis, la formulation et l'application d'une stratégie nationale en matière de santé mentale ne peuvent aboutir que si elle s'accompagne d'une affectation suffisante des ressources.

Le Comité prend également note des importants efforts déployés dans certains pays pour décentraliser les décisions de financement et pour les aligner davantage sur les besoins des collectivités dans lesquelles les gens vivent et utilisent les services. L'expérience anglaise, qui a consisté à confier la responsabilité de « commander » les services de santé mentale aux groupes de soins primaires, peut être un point de référence utile pour toute tentative visant à

confier davantage la maîtrise du financement à la base et à mieux adapter le financement aux priorités locales. D'un autre côté, les témoignages et la documentation nous indiquent aussi que ce transfert de responsabilité est une tâche complexe et que la décentralisation de la prise de décision doit être accompagnée d'une répartition plus générale des compétences pour favoriser l'administration des budgets supplémentaires.

Les mesures destinées à contrôler l'augmentation des coûts sont également importantes, surtout dans le cas des produits pharmaceutiques dont la hausse des prix est une préoccupation constante. Au Canada, il faudra apporter une attention toute particulière à cette question étant donné les écarts importants qui existent chez nous entre les différents régimes provinciaux d'assurance-médicament. Enfin, l'expérience américaine dans le cas des soins gérés est tout aussi intéressante, parce qu'elle vise à réaliser un équilibre entre les efforts déployés pour contenir les coûts et la garantie d'un accès aux services et aux thérapies nécessaires.

5.4 PRESTATION ET ORGANISATION DES SERVICES

Nous avons vu qu'en matière de prestation de services en santé mentale, il fallait commencer par reconnaître que tous les pays étudiés sont passés d'un régime de soins essentiellement institutionnel à un régime de soins de type communautaire. Cette transition a soulevé des préoccupations quant à l'adéquation des ressources disponibles à l'échelon communautaire pour faire face à la demande. On s'est aperçu également qu'il fallait coordonner et intégrer la prestation des services pour parvenir à abatte les nombreuses cloisons existantes et faire en sorte que chacun ait accès aux services dont il a besoin, peu importe quel ministère ou organisme ministériel (ou organisme non gouvernemental) est responsable de la prestation des soins.

La Mental Health Commission (Commission de la santé mentale) en Nouvelle-Zélande et le National Institute for Mental Health (ou NIMHE) en Angleterre sont les deux institutions qui se distinguent pour avoir facilité ce genre de transition. Le Comité a pris plus particulièrement note du fait que la commission néo-zélandaise a joué un rôle important, tant pour instaurer des normes de service que pour contrôler la mise en œuvre de la planification en santé mentale, tandis que l'institution britannique a joué un rôle déterminant dans l'application et la diffusion des pratiques exemplaires. Il convient, ici, de remarquer que les deux pays se sont fixé des normes et des objectifs élevés et précis (le *Blueprint* en Nouvelle-Zélande et le Cadre national de service en santé mentale en Angleterre) dans le contexte de leurs stratégies respectives.

L'accent placé sur l'individualisation des régimes de soins en Nouvelle-Zélande, aux États-Unis et en Angleterre est un autre aspect digne de mention. L'importance croissante accordée à la capacité des personnes souffrant d'une maladie mentale de se rétablir, de même qu'à la nécessité pour les praticiens d'élaborer des plans personnalisés, axés sur les clients (et contrôlés) a un effet marqué sur l'approche retenue dans la prestation des services communautaires en santé mentale.

On pourrait donc conclure, comme l'a fait Michael Hogan des États-Unis, que pour compenser l'éclatement survenu dans la prestation des services, il faudra que les

interventions soient descendantes et montantes. Il est possible, pour administrer la pléthore d'agences et d'organismes gouvernementaux prenant part à la prestation des services, de faire appel à des organismes extérieurs, indépendants, en mesure d'adopter un point de vue d'ensemble sur le fonctionnement du gouvernement. D'un autre côté, la personnalisation des régimes de soins et la coordination de la prestation des services pourraient aider ceux et celles qui ont besoin de ce genre de service à s'en prévaloir à la demande.

Dans tous les pays examinés, les médecins et les autres fournisseurs de soins primaires assument la plupart des responsabilités du gros des clients des services de soins de santé mentale. D'un autre côté, les personnes souffrant d'une maladie mentale grave et persistante continuent de dépendre de l'accès à des services de santé mentale plus spécialisés. Cette situation a été un problème dans tous les pays étudiés. Tout d'abord, il est inquiétant de constater que les systèmes de rémunération à l'acte ne permettent pas de dédommager suffisamment les médecins de famille pour qu'ils traitent les maladies mentales ou donnent des conseils dans ce domaine. Deuxièmement, il y a le problème soulevé par le fait que les médecins de famille n'ont pas accès à suffisamment de ressources pour pouvoir véritablement composer avec l'ampleur de la demande en matière de soins de santé mentale. Enfin, le défaut de coordination entre les soins primaires et les soins secondaires est un problème régulièrement soulevé, problème qui souligne l'importance primordiale d'offrir des soins intégrés et efficaces.

En dépit – ou devrait-on peut-être dire plutôt, à cause – du basculement à la faveur des soins et des services communautaires, les inégalités d'accès persistent sur plusieurs plans. Nombre de pays ont constaté que les résidents des régions rurales ont accès à beaucoup moins de services que ceux des régions urbaines.

Par ailleurs, presque tout le monde s'entend pour dire que les services qui sont censés s'adresser spécifiquement aux minorités ne sont pas vraiment adaptés à leurs besoins. Il faut que ces services soient adaptés sur le plan culturel afin de les rendre accessibles à ces minorités, comme c'est le cas pour la majorité. Plusieurs pays ont déterminé que la formation de professionnels de la santé appartenant à des groupes minoritaires, surtout aux communautés autochtones ou aborigènes, était une façon d'améliorer la pertinence culturelle des services de santé mentale.

Cela nous amène au dernier aspect que le Comité tient à mentionner, c'est-à-dire la pénurie de ressources humaines constatée dans tous les pays étudiés, pénurie qui touche presque tous les fournisseurs de services de santé mentale. Le phénomène a été constaté même dans des pays comme l'Australie et la Nouvelle-Zélande où l'augmentation des budgets de la santé mentale a donné lieu à un accroissement de l'offre par certains groupes de fournisseurs. Sur une note plus positive, les membres du Comité ont été impressionnés par les tentatives déployées en vue de décerner et de reconnaître officiellement le titre de travailleur communautaire en santé mentale en tant que moyen d'augmenter les ressources humaines.

5.5 PROMOTION ET PRÉVENTION

La situation constatée dans quatre pays semble appuyer les enseignements tirés dans un récent rapport britannique (juin 2004), sur la santé mentale et l'exclusion sociale. Ce rapport

conclut que des campagnes non coordonnées de durée limitée ne donnent pas lieu à des changements notoires dans les attitudes qui sont source de stigmatisation, et il précise que pour combattre la stigmatisation et la discrimination, un engagement budgétaire à long terme est nécessaire. D'un autre côté, d'après les témoins que nous avons entendus et les documents que nous avons examinés au sujet de l'Australie et de la Nouvelle-Zélande, force est de constater que ces deux pays sont parvenus à modifier de façon visible les attitudes et les comportements grâce à des campagnes de lutte contre la stigmatisation et la discrimination qui durent depuis plusieurs années.

Il faut se garder de sauter aux conclusions à partir de ces constats, mais nous avons toutes les raisons de croire que, si nous voulons que les campagnes de lutte contre la stigmatisation et la discrimination produisent un maximum d'effet, il faudra y consacrer un financement et une planification à long terme prolongée par une évaluation suivie. Qui plus est, il semble que ce genre de campagne soit particulièrement efficace quand on peut l'adapter à toute une diversité de situations en sorte qu'elle puisse être reprise par différents pays.

Ainsi, pour le lancement de leur campagne « Like Minds, Like Mine », les Néo-Zélandais ont fait appel à une figure emblématique native du pays, avant de mettre ensuite l'accent sur des gens ordinaires et sur leurs familles. En outre, quand les Néo-zélandais ont constaté certains progrès du côté des attitudes stigmatisantes, ils ont décidé de mettre davantage l'accent sur la lutte contre la discrimination. L'expérience australienne, quant à elle, nous a enseigné les bienfaits de campagnes menées simultanément aux échelons national, régional et local de même que la nécessité de cibler la stigmatisation sur certaines maladies selon des thèmes assez larges.

Aux États-Unis, la stratégie nationale de prévention du suicide fait fond sur l'exploitation des ressources nationales afin de donner un exemple que les États et administrations locales peuvent reprendre et pour les inciter à adapter les modèles nationaux à leurs besoins propres. Dans la même veine, l'expérience de plusieurs pays souligne l'importance qu'il y a de pouvoir compter sur un organisme apte à être le point de convergence des efforts déployés à l'échelle nationale pour combattre la stigmatisation et la discrimination et à assurer la coordination de ces efforts à l'échelon national.

Nous avons conclu de notre examen de la situation internationale qu'il y a tout à gagner à voir ce que donne ce genre d'effort et à bâtir les campagnes à partir des constats posés. Autrement dit, il convient de tenir de vastes consultations, dès le début, auprès des divers ordres de gouvernement, des fournisseurs, des ONG ainsi que des utilisateurs des services de santé mentale et leurs familles. En outre, nous avons constaté les bienfaits de faire témoigner les personnes souffrant de troubles mentaux afin de combattre la stigmatisation et de collaborer avec les médias pour essayer d'éliminer les stéréotypes négatifs et de les remplacer par des récits plus positifs de personnes souffrant de maladie mentale.

Enfin, le Comité a trouvé que la nouvelle campagne anglaise proposée dans le rapport sur la santé mentale et l'exclusion est très complète, et il désire profiter de l'occasion pour en rappeler les principaux axes. Cette campagne :

- ciblera des auditoires clés, surtout les employeurs, les jeunes et les médias;

- proposera des messages cohérents et éprouvés, sous une seule et même bannière;
- fera la promotion de la contribution que les personnes souffrant de problèmes de santé mentale peuvent apporter à la société;
- sera assurée par un financement suivi;
- traitera des questions d'ethnicité et de problématique hommes-femmes;
- proposera un cadre et des documents d'appui au travail local par l'accent placé sur les questions particulières auxquelles sont confrontées les communautés démunies;
- sera clairement évaluée à la faveur de sondages réguliers.

5.6 PERSPECTIVES DE RÉFORME

À partir de cette étude de quatre pays, il est apparu clairement aux membres du Comité que toute stratégie de réforme doit être soigneusement adaptée à la situation particulière de chaque pays. Il faut non seulement évaluer soigneusement l'état des services et des soins de santé mentale afin d'établir des priorités d'action, mais il faut aussi tenir compte des réalités complexes du système politique et des valeurs sociales de chaque pays pour formuler un plan de réforme.

À ce sujet, nous pensons qu'il risque d'être difficile d'adapter au contexte fédéraliste canadien des stratégies de réforme conçues et mises en œuvre dans des pays dotés de formes de gouvernement unitaire puisque, chez nous, la prestation des services de soins de santé au grand public demeure une responsabilité constitutionnelle relevant des provinces. Quoi qu'il en soit, les objectifs et les normes précises et détaillées qui ont été la marque des programmes de réforme en Angleterre et en Nouvelle-Zélande (deux États unitaires) sont d'excellentes références. Qui plus est, le système de soins de santé d'un pays, qu'il s'agisse d'un État unitaire ou d'un État fédéral, comporte de multiples paliers et les tentatives régulières visant à coordonner la réforme de la santé mentale entre ces différents paliers sont une autre indication de l'importance qu'il y a d'agir à tous les niveaux.

Le Comité a également constaté que tous les pays étudiés ont eu intérêt à entreprendre une planification intégrée à long terme afin d'améliorer l'état de la santé mentale et de la prestation des services de soins en santé mentale. Ce n'est qu'ainsi que l'on peut parvenir à s'appuyer sur chaque strate précédente de la réforme et donc à augmenter considérablement les chances d'adapter cette réforme aux circonstances changeantes.

Enfin, la complexité et l'éventail des services entrant en jeu dans la promotion de la santé mentale et dans la réponse aux besoins des personnes qui souffrent d'une maladie mentale permettent de penser qu'une réforme du type « table rase » ne peut qu'être vouée à l'échec. En outre, la réforme doit consister à régler les problèmes par le haut et par le bas.

5.7 OBSERVATIONS DU COMITÉ

Le Comité a retenu un certain nombre de tendances des grandes orientations adoptées dans les stratégies de santé mentale des quatre pays étudiés :

- tendance à miser sur le rétablissement. Il s'agit ici d'une vision propre au raisonnement appliqué en santé mentale où l'on envisage le rétablissement comme un processus d'adaptation positive à la maladie et à l'incapacité pour que les personnes souffrant d'une maladie mentale puissent vivre une vie satisfaisante, pleine d'espoir et contribuer à la société malgré les limitations que leur impose la maladie;
- une insistante croissante sur les plans individualisés de traitement et de soins (surtout pour les personnes souffrant de maladie mentale grave), de même que la reconnaissance du fait qu'il faut inciter les membres de la famille et les patients eux-mêmes à participer à la planification des traitements;
- la réaffirmation de la nécessité d'offrir des services au sein de la collectivité et l'importance accrue accordée au contrôle suivi de la prestation de services et de l'effort mis pour les intégrer, dans la mesure du possible (pour que l'on puisse s'affranchir des limitations caractéristiques d'une prestation de service « cloisonnée »;
- l'importance de mettre à disposition des ressources nationales pour promouvoir la santé mentale, surtout dans le cas des campagnes contre la stigmatisation et la lutte contre la discrimination;
- la nécessité d'éliminer les disparités dans la limite des services offerts, que ces disparités soient dues au fait que les services ne tiennent pas compte des différences culturelles ou qu'ils ne soient pas offerts dans certaines régions rurales du pays.

Le facteur qui semble unir tous ces éléments est l'insistance accrue que l'on place sur l'organisation des services en vue de mieux répondre aux besoins des patients ou des utilisateurs du service, formule à laquelle le Comité adhère pleinement et qui rappelle, d'ailleurs, l'approche axée sur le patient que le Comité avait recommandée pour le secteur des soins actifs. Pour réaliser les objectifs qui se dégagent de notre étude des quatre pays en question, il nous faudra fixer des buts atteignables auxquels tout le milieu de la santé mentale devra adhérer et établir des critères mesurables afin de contrôler en permanence le travail de réforme. Il semble, d'un autre côté, qu'une stratégie nationale d'amélioration de la santé mentale et du traitement de la maladie mentale doive notamment s'appuyer sur les piliers suivants : planification détaillée concernant les ressources humaines dans le domaine de la santé mentale et financement suffisant pour la recherche et pour la diffusion du savoir.

ANNEXE A:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
TROISIÈME SESSION DE LA 37E LÉGISLATURE
(2 FÉVRIER AU 23 MAI 2004)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	David Loïse Murray Ronald	26 février 2003	9
	J. Michael Grass, président sortant, Groupe de mise en oeuvre en santé mentale du district de Champlain	5 juin 2003	17
	Nancy Hall, conseillère en santé mentale	8 mai 2003	16
	Thomas Stephens, expert-conseil	20 mars 2003	11
Académie canadienne d'épidémiologie psychiatrique	Dr Alain Lesage, président sortant	19 mars 2003	11
Académie canadienne de psychiatrie et de droit	Dre Dominique Bourget, présidente	5 juin 2003	17
Association canadienne de la santé mentale de l'Ontario	Patti Bregman, directrice des programmes	12 juin 2003	18
Association des infirmières et infirmiers psychiatriques du Canada	Margaret Synyshyn, présidente	29 mai 2003	16
Centre hospitalier pour enfants de l'est de l'Ontario	Dr Simon Davidson, Chef, Section de psychiatrie de l'enfant et de l'adolescent	1er mai 2003	13
Centre hospitalier universitaire Mère-enfant Sainte-Justine	Dre Joanne Renaud, pédopsychiatre; chercheuse boursière, Instituts de recherche en santé au Canada	30 avril 2003	13

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Centre de toxicomanie et de santé mentale	Jennifer Chambers, coordonnatrice du Conseil d'habitation	14 mai 2003	15
	Rena Scheffer, directrice, Services d'informations et d'éducation du public	28 mai 2003	16
CN Centre for Occupational Health and Safety	Kevin Kelloway, directeur	12 juin 2003	18
Coalition canadienne pour la santé mentale des personnes âgées	Dr David K. Conn, coprésident; president, Académie canadienne de psychiatrie gériatrique	4 juin 2003	17
Colombie-Britannique, Province de la	Patrick Storey, président, Conseil consultative du minister sur la santé mentale	14 mai 2003	15
	Heather Stuart, professeure agrégée, Santé communautaire et épidémiologie		
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, président et directeur général, Les Consultants Warren Sheppell	12 juin 2003	18
Hamilton Health Sciences Centre	Venera Bruto, psychologue	4 juin 2003	17
Hôpital Douglas	Eric Latimer, économiste de la santé	6 mai 2003	14
	Dr James Farquhar, psychiatre		
	Dre Mimi Israël, chef, Département de psychiatrie; professeure agrégée, Université McGill		
	Myra Piat, chercheuse		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Hôpital Douglas	Amparo Garcia, chef clinico-administratif, Division des Services ultraspécialisés pour adultes	6 mai 2003	14
	Manon Desjardins, chef clinico-administratif, Division des Services sectorisés pour adultes		
	Jacques Hendlisz, directeur général		
	Robyne Kershaw-Bellmare, directrice des soins infirmiers		
Hôpital Louis-H. Lafontaine	Jean-Jacques Leclerc, directeur, Services de réadaptation et d'hébergement dans la communauté	6 mai 2003	14
	Dr Pierre Lalonde, directeur, Clinique des jeunes adultes		
Hôpital St. Michaels	Dr Paul Links, titulaire de la chaire Arthur Sommer Rothenberg d'études sur le suicide	19 mars 2003	11
Institut canadien d'information sur la santé	Dr John S. Millar, vice-président, Recherche et analyse	20 mars 2003	11
	Carolyn Pullen, expert conseil		
	John Roch, gestionnaire principale, Protection de la vie privée, Secrétariat de la protection de la vie privée		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Instituts de recherche en santé du Canada	Dr Rémi Quirion, directeur scientifique, Institut des neurosciences, de la santé mentale et des toxicomanies	6 mai 2003	14
	Bronwyn Shoush, commissaire, Institut de la santé des Autochtones	28 mai 2003	16
	Jean-Yves Savoie, président, Conseil consultatif, Institut de la santé publique et des populations	12 juin 2003	18
Santé Canada	Tom Lips, conseiller principal, Santé mentale, Division de la santé des collectivités, Direction générale de la santé de la population et de la santé publique	19 mars 2003	11
	Pam Assad, directrice déléguée, Division de l'enfance et de l'adolescence, Centre de développement de la santé humaine, Direction générale de la santé de la population et de la santé publique	30 avril 2003	13
Société Alzheimer du Canada	Steve Rudin, directeur exécutif	4 juin 2003	7
Société canadienne de pédiatrie	Dre Diane Sacks, présidente élue	1er mai 2003	13
	Marie-Adèle Davis, directrice exécutive		
Statistique Canada	Lorna Bailie, directrice adjointe, Division des statistiques sur la santé	20 mars 2003	11
St.Joseph's Health Care London	Maggie Gibson, psychologue	4 juin 2003	17

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Calgary	Dr Donald Addington, professeur et chef, Département de psychiatrie	29 mai 2003	16
Université de la Colombie-Britannique *(par vidéoconférence)*	Dre Charlotte Waddell, professeur adjointe, Unité d'évaluation de la santé mentale et des consultations communautaires, Département de psychiatrie, Faculté de médecine	1er mai 2003	13
Université Laval	Dr Michel Maziade, directeur, Département de spychiatrie, Faculté de médecine	6 mai 2003	14
Université du Manitoba	John Arnett, chef, Département de santé psychologique clinique, Faculté de médecine	28 mai 2003	16
	Robert McIlwraith, professeur et directeur, Programme de psychologie en milieu rural et nordique	29 mai 2003	
Université McGill	Dr Howard Steiger, professeur, Départment de psychiatrie; directeur, Clinique des troubles alimentaires, Hôpital Douglas	1er mai 2003	13
Université de Montréal	Laurent Mottron, chercheur, Département de psychiatrie, Faculté de médecine	6 mai 2003	14

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Montréal	Dr Richard Tremblay, titulaire, chaire de recherche du Canada sur le développement des enfants, professeur de pédiatrie, psychiatrie et psychologie, directeur, Centre d'excellence pour le développement des jeunes enfants	6 mai 2003	14
	Dr Jean Wilkins, professeur titulaire et pédiatre, Département de pédiatrie, Faculté de médecine		
	Dre Renée Roy, professeure adjointe de clinique, Département de psychiatrie, Faculté de médecine		
Université d'Ottawa	Tim D. Aubry, professeur associé; co-directeur , Centre de recherché sur les services communautaires	5 juin 2003	17
	Dr Jeffrey Turnbull, directeur, Département de médecine, Faculté de médecine		
Université du Québec à Montréal	Henri Dorvil, professeur, École de travail social	6 mai 2003	14
	Dr Michel Tousignant, professeur et chercheur, Centre de recherche et intervention sur le suicide et l'euthanasie		
Université Queen's	Dr Julio Arboleda-Florèz, professeur et chef du Département de psychiatrie	20 mars 2003	11

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Toronto	Dr Joe Beitchman, professeur et directeur, Division de la psychiatrie de l'enfant; psychiatre en chef, Hospital for Sick Children	30 avril 2003	13
Université de Toronto	Dr David Marsh, directeur des services cliniques, Médecine des toxicomanies, Centre de toxicomanie et de santé mentale	29 mai 2003	16

ANNEXE B:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
DEUXIÈME SESSION DE LA 37E LÉGISLATURE
(30 SEPTEMBRE 2002 – 12 NOVEMBRE 2003)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	Charles Bosdet Pat Caponi Don Chapman,	29 avril 2004	7
Alberta Mental Health Board	Ray Block, directeur général	28 avril 2004	7
	Sandra Harrison, directrice exécutive, Planification, défense des droits et liaison		
Alliance de la Fonction publique du Canada	John Gordon, vice-président executive national	1er avril 2004	5
	James Infantino, agent des pensions et assurances d'invalidité		
Association canadienne des travailleuses et travailleurs sociaux	Stephen Arbuckle, membre, Groupe d'intérêt lié à la santé	31 mars 2004	5
Association canadienne des troubles anxieux	Peter McLean, vice-président	12 mai 2004	9
Association canadienne pour la santé mentale	Penny Marrett, chef de la direction	12 mai 2004	9
Association des infirmières et infirmiers du Canada, la Fédération canadienne des infirmières et infirmiers en santé mentale et l'Association des infirmières et infirmiers psychiatriques du Canada	Nancy Panagabko, présidente, Fédération canadienne des infirmières et infirmiers en santé mentale	31 mars 2004	5
	Annette Osten, membre du Conseil d'administration, Association des infirmières et infirmiers du Canada		
Association médicale canadienne	Dre Gail Beck, secrétaire générale adjointe intérimaire	31 mars 2004	5
	Dr Sunil Patel, président		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Association des psychiatres du Canada	Dr Blake Woodside, président du Conseil d'administration	31 mars 2004	5
Australie, Gouvernement d' *(par vidéoconférence)*	Dermot Casey, secrétaire adjoint, Direction des priorités sanitaires et de la prévention du suicide, ministère de la Santé et de la Vieillesse	20 avril 2004	6
	Jenny Hefford, secrétaire adjointe, Direction de la stratégie contre la drogue, ministère de la Santé et de la Vieillesse		
Bureau du Conseil Privé	Ron Wall, directeur des relations parlementaires, Planification de la législation et des travaux de la Chambre/avocat	1er avril 2004	5
	Ginette Bougie, directrice, Rémunération et classification		
Centre for Suicide Prevention	Diane Yackel, directrice exécutive	21 avril 2004	6
Centre de toxicomanie et de santé mentale	Christine Bois, gestionnaire des priorités provinciales en matière de troubles concourants	5 mai 2004	8
	Wayne Skinner, directeur clinique, Programme de troubles concourants		
	Brian Rush, chercheur, Politique de prévention sociale et de santé		
Chambre des communes	L'honorable Jacques Saada, C.P., député, leader du gouvernement à la Chambre des communes et ministre responsable de la Réforme démocratique	1er avril 2004	5

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Citoyenneté et de l'Immigration, Ministère de la	Patricia Birkett, directrice générale par intérim, Direction générale de l'intégration	22 avril 2004	6
Cognos	Marilyn Smith-grant, spécialiste en ressources humaines	1er avril 2004	5
	Sean Reid, gestionnaire principal, Communication corporatives		
Fédération canadienne des contribuables	Bruce Winchester, directeur de recherche	22 avril 2004	6
Fédération des programmes communautaires de la santé mentale et du traitement des toxicomanies de l'Ontario	David Kelly, directeur exécutif	5 mai 2004	8
Hôpital Douglas	Dr Gustavo Turecki, directeur, Groupe McGill d'études sur le suicide, Université MGill	21 avril 2004	6
Institut des neurosciences, de la santé mentale et des toxicomanies	Richard Brière, directeur adjoint	21 avril 2004	6
Justice, Ministère de la	Manon Lefebvre, conseillère juridique	22 avril 2004	6
Mercer consultation en resources humaines	Bernard Potvin, conseiller principal	22 avril 2004	6
Native Mental Health Association of Canada	Brenda M. Restoule, psychologue et représentante du conseil de l'Ontario	13 mai 2004	9
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	Janice Wilson, directrice générale adjointe, Direction générale de la santé mentale, ministère de la Santé	5 mai 2004	8

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	David Chaplow, directeur et conseiller principal en santé mentale	5 mai 2004	8
	Arawhetu Peretini, gestionnaire, Santé mentale des Maoris		
	Phillipa Gaines, gestionnaire, Développement des systèmes de santé mentale		
Ontario Hospital Association	Dr Paul Garfinkel, président, Groupe de travail sur la santé mentale	31 mars 2004	5
Ressources humaines et Développement des compétences Canada	Bill Cameron, directeur général, Secrétariat national pour les sans-abri	29 avril 2004	7
	Marie-Chantal Girard, gestionnaire de la recherche stratégique, Secrétariat national pour les sans-abri		
Royaume-Uni, Gouvernement du *(par vidéoconférence)*	Anne Richardson, chef de la Direction des politiques en santé mentale, ministère de la Santé	6 mai 2004	8
	Adrian Sieff, chef de la Direction de la législation en matière de santé mentale		
Santé, Ministère de la de la Nouvelle Écosse	Dr James Millar, directeur exécutif, Santé mentale et services aux médecins	28 avril 2004	7
Secrétariat du Conseil du Trésor	Joan Arnold, directrice, Élaboration de la législation, Division des pensions	1er avril 2004	5
Service correctionnel du Canada	Larry Motiuk, directeur général, Recherches	29 avril 2004	7
	Françoise Bouchard, directrice générale, Services de santé		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Services de santé de la Colombie-Britannique, Ministère des	Irene Clarkson, directrice exécutive, Santé mentale et toxicomanie	28 avril 2004	7
Six Nations Mental Health Services	Dre Cornelia Wieman, psychiatre	13 mai 2004	9
Société canadienne de psychologie	John Service, directeur exécutif	31 mars 2004	5
Société canadienne de schizophrénie	John Gray, président élu	12 mai 2004	9
Société pour les troubles de l'humeur du Canada	Phil Upshall, président	12 mai 2004	9
Université McGill *(par videoconférence)*	Dr Laurence Kirmayer, directeur, Division de la psychiatrie sociale et transculturelle, Département de psychiatrie	13 mai 2004	9
Université Simon Fraser *(par vidéoconférence)*	Margaret Jackson, directrice, Institut d'études en politiques de justice pénale	29 avril 2004	7
U.S. Campaign for Mental Health Reform	William Emmet, coordonnateur	1er avril 2004	
U.S. President's New Freedom Commission on Mental Health *(par videoconférence)*	Michael Hogan, président	1er avril 2004	5

ANNEXE C:
LISTE DES INDIVIDUS QUI ONT RÉPONDU À UNE LETTRE DU COMITÉ AU SUJET DES PRIORITÉS POUR LA RÉFORME DANS LE SECTEUR DE LA MALADIE MENTALE

GROUPE CANADIEN DE RECHERCHE

Action cancer Manitoba	Harvey Max Chochinov, MD, PhD, MCRMC, titulaire d'une chaire de recherche du Canada en soins palliatifs, directeur de la Manitoba Palliative Care Research Unit d'Action cancer Manitoba
Hôpital Douglas, Centre de recherche de l'	Ashok Mall, MD, MCRMC, titulaire d'une chaire de recherche du Canada pour l'étude des premiers stades de la psychose, professeur en psychiatrie à l'Université McGill
Université Carleton	Dr Hymie Anisman, titulaire d'une chaire de recherche du Canada en neuroscience, chercheur supérieur attaché à la Fondation ontarienne de santé mentale
Université de l'Alberta	Glen B. Baker, PhD, DSc, professeur et titulaire d'une chaire de recherche du Canada en neurochimie et en développement de médicaments
Université du Manitoba, Faculté de médecine de l'	Brian J. Cox, docteur en psychiatrie, titulaire d'une chaire de recherche du Canada sur les troubles de l'humeur et sur les troubles anxieux, professeur agrégé de psychiatrie
Université McGill	Eric Fombonne, MD, MCRMC (Psych.), titulaire d'une chaire de recherche du Canada en psychiatrie de l'enfance et de l'adolescence, professeur de psychiatrie à l'Université McGill, directeur du Département de pédopsychiatrie de l'Hôpital pour enfants de Montréal

DOYEN D'UNIVERSITÉ

Centre universitaire de santé McGill	Joel Paris, MD, professeur titulaire et directeur du Département de psychiatrie
Hôpital général de Kingston	Samuel K. Ludwin, MBB, Ch., MCRMC, vice-président du développement à la recherche
Université de l'Alberta	Dr L. Beauchamp, doyen de la Faculté d'éducation
Université de l'Ouest de l'Ontario	Dr Carol P. Herbert, doyen de la Faculté de médecine et d'art dentaire
Université de Sherbrooke	Pierre Labossière, ing., PhD, vice-recteur adjoint à la recherche

GROUPE RELATIF À LA MALADIE

CRSNG	Thomas A. Brzustowski, président
La Fondation ontarienne de la santé mentale	Howard Cappell, PhD, c. psych., directeur exécutif
Société canadienne de schizophrénie	Fred Dawe, président

INDUSTRIE

Eli Lilly Canada Inc.	Terry McCool, vice-président des Affaires générales de la société
GlaxoSmith Kline	Geoffrey Mitchinson, vice-président des Affaires publiques
Les compagnies de recherche pharmaceutique du Canada	Murray J. Elston, président
Merck Frosst Canada Ltée	André Marcheterre, président
Roche Pharmaceutiques	Ronnie Miller, président-directeur général

GROUPE D'ÉTHIQUE EN SANTÉ MENTALE

Armée du Salut - Territoire du Canada et des Bermudes	Glen Shepherd, colonel et secrétaire en chef
Centre de recherche de l'Hôpital Douglas de l'Université McGill	Maurice Dongier, professeur en psychiatrie
Centre de toxicomanie et de santé mentale	Paul E. Garfinkel, MD, FRCP, président-directeur général
Hôpital St-Paul	Mark Miller, éthicien
Office régional de la santé de Winnipeg	Linda Hughes, présidente du Comité d'éthique en santé mentale de l'ORSW
St-Joseph's Health Care Centre du Parkwood Hospital de London	Maggie Gibson, PhD, psychologue du Programme des soins aux anciens combattants
Université de l'Alberta	Genevieve Gray, doyenne et professeure de la Faculté en soins infirmiers
Université de l'Alberta, Faculté des sciences infirmières et Centre John Dossetor d'éthique en santé de l'	Wendy Austin, inf. aut., titulaire d'une chaire de recherche du Canada
Université de la Colombie-Britannique	Peter D. McLean, PhD, professeur et directeur de l'Unité des troubles anxieux
Université de l'Ouest de l'Ontario	Nancy Feduk, adjointe exécutive au doyen de la Faculté de médecine et d'art dentaire
Université Queen's	J. Arboleda-Florèz, professeur et chef du Département de psychiatrie
Université York	David Shugarman, directeur

PRÉSIDENT D'UNIVERSITÉ

Institut de recherches en santé mentale de l'Université d'Ottawa	Zul Merali, PhD, président-directeur général
Université de Lethbridge	Lynn Basford, doyenne de la Faculté en sciences de la santé
Université McGill	Heather Munroe-Blum, professeure d'épidémiologie et de biostatistiques

RESPONSABILITÉ GOUVERNEMENTALE

Association canadienne de la santé mentale	Bonnie Pape, directrice des programmes et de la recherche au Bureau national de l'Association canadienne de la santé mentale
Cabinet du vice-recteur à la recherche de l'Université d'Ottawa	Yvonne Lefebvre, PhD, vice-présidente associée à la recherche
Centre de recherche de l'Hôpital Douglas	Rémi Quirion, directeur scientifiques de l'INSMT
Centre universitaire de santé McGill	Juan C. Negrete, MD, MCRMC, professeur de psychiatrie à l'Université McGill, président de la Section des toxicomanies, de l'Association des psychiatres du Canada
Coalition canadienne pour la santé mentale des personnes âgées	David K. Conn, MB, MCRMC, coprésident de l'Académie canadienne de psychiatrie gériatrique, professeur agrégé du Département de psychiatrie de l'Université de Toronto, président de l'Académie canadienne de psychiatrie gériatrique
Coalition canadienne pour la santé mentale des personnes âgées	J. Kenneth Le Clair, MD, MCRMC, coprésident de la Coalition canadienne pour la santé mentale des personnes âgées, professeur et directeur de l'Unité de gériatrie du Département de psychiatrie de l'Université Queen's, directeur clinique du Programme spécialisé de psychiatrie gériatrique
Développement des ressources humaines Canada	Deborah Tunis, directrice générale du Bureau de la condition des personnes handicapées

The Family Council : Empowering Families in Addictions and Mental Health	Betty Miller, coordonnatrice du Family Council
Global Business and Economic Roundtable on Addiction and Mental Health, affiliée au Centre de toxicomanie et de santé mentale	Bill Wilkerson, cofondateur et directeur général
Hôpital d'Ottawa	Paul Roy, MD, MCRMC, professeur adjoint en psychiatrie à l'Université d'Ottawa, directeur du programme « Premier épisode pour les maladies psychotiques » d'Ottawa
Hôpital royal d'Ottawa	J. Paul Fedoroff, MD, professeur agrégé de psychiatrie à l'Université d'Ottawa, directeur de recherche au Service médico-légal de l'Institut de recherche en santé mentale
Institut des neurosciences, de la santé mentale et des toxicomanies du Centre de recherche de l'Hôpital Douglas	Michel Perreault, PhD, chercheur à l'Hôpital Douglas
Instituts de recherche en santé du Canada	Dr. Jeff Reading, PhD, directeur scientifique de l'Institut de la santé des Autochtones
Ministère de la Santé et du Mieux-Être du Nouveau-Brunswick	Ken Ross, sous-ministre adjoint
ONSA : Organisation nationale de la santé autochtone	Judith G. Bartlett, MD, CMFC
Six Nations Mental Health Services	Cornelia Wieman, MD, MCRMC, psychiatre
Sunnybrook & Women's College Health Sciences Centre de l'Université de Toronto	N. Herrmann, médecin, MCRMC
Syncrude	Eric P. Newell, président-directeur général
Unité de l'évaluation de la santé mentale et des consultations communautaires du Département de psychiatrie de l'Université de la Colombie-Britannique	Elliot Goldner, MD, MScS, MCRMC, chef de la Division de la politique et des services de santé mentale

Université Dalhousie, Département de psychologie de l'	Patrick J. McGrath, OC, PhD, MSRC, titulaire de la chaire Killam de psychologie, professeur de pédiatrie et de psychiatrie, titulaire d'une chaire de recherche du Canada, psychologue au IWK Hospital
Université Dalhousie, Faculté de médecine de l'	David Zitner, PhD, directeur en informatique médicale
Université d'Ottawa, École de psychologie de l'	John Hunsley, PhD, c. psych., professeur en psychologie
Université d'Ottawa, Faculté de médecine de	Jacques Bradwejn, MD MCRMC, DABPN, président du Département de psychiatrie
Université McMaster	Docteur Richard P. Swinson, MD, MCRMC, titulaire de la chaire Morgan Firestone de psychiatrie et de neurosciences du comportement à l'Université McMaster, chef du Département de psychiatrie du St. Joseph's Healthcare Centre

SENATE SÉNAT
CANADA

REPORT 3

Mental Health, Mental Illness and Addiction:

Issues and Options for Canada

Interim Report of
The Standing Senate Committee On Social Affairs, Science And Technology

The Honourable Michael J.L.Kirby, Chair
The Honourable Wilbert Joseph Keon, Deputy Chair

November 2004

TABLE OF CONTENTS

ORDER OF REFERENCE

Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

The Honourable Senator Kirby moved, seconded by the Honourable Losier-Cool:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness.

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee; and

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

Paul C. Bélisle

Clerk of the Senate

The following Senators have participated in the study on the state of the health care system of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Michael J. L. Kirby, Chair of the Committee
The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retired)
Douglas Roche (retired)
Eileen Rossiter (retired)
Marilyn Trenholme Counsell

Ex-officio members of the Committee:

The Honourable Senators: Jack Austin P.C. or (William Rompkey) and Noël A. Kinsella or (Terrance Stratton)

Other Senators who have participated from time to time on this study:
The Honourable Senators Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne and Murray.

MENTAL HEALTH, MENTAL ILLNESS AND ADDICTION: ISSUES AND OPTIONS FOR CANADA

INTRODUCTION

The purpose of this paper is to outline the major issues facing the provision of mental health services and addiction treatment in Canada, to present potential policy options to address some of these issues, and to launch a public debate to enable Canadians to provide input on how the issues should be addressed.

Two companion reports are being released, along with this Issues and Options paper, that summarize the background material used in the preparation of this paper. The first, entitled *Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada*, presents an overview of mental health, mental illness and addiction policies and services in Canada.[1] The second, *Mental Health Policies and Programs in Selected Countries*, draws some lessons for mental health reform in Canada from descriptions of the mental health policies and programs in four selected countries: Australia, New Zealand, the United Kingdom and the United States.[2] The Committee encourages strongly respondents to review carefully the two companion reports when preparing their submissions to the Committee.

The policy issues, questions and options contained in this paper have been developed, in part, on the basis of information the Committee received from its public hearings. From February 2003 to May 2004, the Committee heard 104 witnesses and held 24 public hearings over a total of 55 hours. In addition, the Committee received 114 submissions and 43 letters. The Committee also commissioned two papers, one on research and the other on ethics. Moreover, the Committee has made extensive use of the academic and professional literature on mental health, mental illness and addiction.

The Committee is eager to receive the views of Canadians on what the most appropriate public policy responses should be to the matters raised in this Issues and Options paper, whether by a provincial/territorial government or the federal government. The Committee will hold public hearings throughout the country, during the period from February to June, 2005. Then, in November 2005, the Committee will publish its recommendations on how best to address the issues and questions raised.

The Committee will hold public hearings throughout the country, during the period from February to June, 2005. Then, in November 2005, the Committee will publish its recommendations on how best to address the issues and questions raised.

This Issues and Options paper can be viewed as an executive summary of the findings and observations contained in the two companion reports. This paper cannot be read on its own without reference to the first and second reports. **Therefore, the Committee**

[1] thereafter referred to as the "First Report" in this document.
[2] thereafter referred to as the "Second Report".

strongly encourages readers to refer to the appropriate sections of the first and second reports as they review the list of issues, questions and options contained in this report.

This report has been structured to reflect the perspective of patients/clients as its primary focus. For example, the discussion of service delivery issues is from the point of view of the individual receiving the service/support rather than from that of the institution or organization providing it. Similarly, the issues raised focus on the particular needs of specific population subgroups – children and adolescents, seniors, Aboriginal Canadians, individuals with complex mental health needs – rather than on specific mental disorders.

The report also deals with the services and supports required to meet adequately patient/client needs. It raises issues related to the appropriate public policy response to mental health human resources, primary health care reform, mental health research, and the use of technology (such as electronic patient records and telehealth).

Finally, the Issues and Options paper concludes with a series of questions about what the role of the federal and provincial/territorial governments should be in improving Canada's system of mental health and addiction treatment services. For example, what should the key elements of federal and provincial mental health, mental illness and addiction action plans be? How should progress on implementing such plans be monitored, and how should governments be held accountable for implementing their plans effectively and by whom? How should improvements in mental health services and addiction treatment be financed? If more funding is needed, how should any new funds be obtained and from what sources?

The Committee realizes that making recommendations is not enough! Implementation is essential if its work on mental health, mental illness and addiction is to be truly useful.

The Committee urges everyone interested in mental health, mental illness and addiction issues to participate in our forthcoming consultation phase, either by testifying during the period from February to June 2005, or by sending us a letter or a brief setting out your views. The quality of our final report and its recommendations, indeed the well-being of all individuals living with mental illness and addiction throughout Canada, depends on an open debate of the issues, questions and options presented in this paper and on the Committee receiving generous "feedback".

The Committee realizes that making recommendations is not enough! Implementation is essential if its work on mental health, mental illness and addiction is to be truly useful. We also recognize that no matter how intellectually sound they may be, reports that meet excessive resistance from vested interests will simply gather dust. Therefore, the Committee is particularly anxious to receive guidance on the practical issues associated with maximizing the chances of its recommendations being acted upon. Given the level of resistance to

The Committee understands fully that progress will be made only when a very large proportion of those involved in mental health, mental illness and addiction issues is prepared to make a meaningful contribution to change – including the way they each contribute to and participate in the "system".

change which exists in any large system, especially one that involves as many players as does mental health and addiction, producing recommendations on which action can and will be taken is difficult, yet it is a prime goal of the Committee. Having said that, the Committee understands fully that progress will be made only when a very large proportion of those involved in mental health, mental illness and addiction issues is prepared to make a meaningful contribution to change – including the way they each contribute to and participate in the "system".

CHAPTER 1:
DELIVERY OF SERVICES AND SUPPORTS

The Committee has in mind a mental health and addiction treatment system with two key characteristics: it is patient-centered and is focused on recovery. It tailors services to meet the needs of individual patients/clients in a culturally appropriate manner. It provides early diagnosis and treatment to individuals soon after the onset of the mental illness and addiction.

It is also a seamless system in which services and supports are accessible, of high quality, and are well coordinated and integrated. In this system, the silo approach that currently dominates the provision of mental health services and addiction treatment (and too much of the health care "system" generally) is completely disbanded.

1.1 A PATIENT/CLIENT-CENTERED SYSTEM ORIENTED TOWARD RECOVERY AND WITH PERSONALIZED CARE PLANS

A major criticism of mental health services and supports and addiction treatment in Canada is that it is largely organized around (and often for the convenience of) providers, not patients/clients. Rather than the system adapting to meet their needs, it seems that individuals with mental illness and addiction are expected to adapt to fit into the system and access services and supports only when and where the system can provide them.[3]

A major criticism of mental health services and supports and addiction treatment in Canada is that it is largely organized around (and often for the convenience of) providers, not patients/clients.

This rather damning observation is confirmed in several provincial reports that have acknowledged that the delivery of mental health services and supports and addiction treatment needs to be more strongly person-oriented. To improve the quality of patients'/clients' lives, safe, timely and effective treatments, services and supports should be coordinated around the needs of individuals with mental illness and addiction.[4]

Our international comparative analysis showed that in other countries changes have been made to the mental health/addiction system to make them more patient/client centred.[5] For example, personalized care plans that focus strongly on recovery have been introduced in some countries for every individual with severe mental disorders.

Providing services and supports that are tailored to meet individual needs is fundamental to recovery.

[3] First Report, Chapter 8.
[4] First Report, Chapter 8, Section 8.2.1.
[5] Second Report, Chapter 5, Section 5.7.

Providing services and supports that are tailored to meet individual needs is fundamental to recovery. Personalized care plans provide a detailed description of the particular services and supports individuals with mental illness and addiction need to achieve and maintain recovery; they are responsive to the changing needs of patients/clients as they evolve during the course of an illness and throughout the individual's lifespan.[6] Funding for implementation of personalized care plans usually follows the patient/client. Individuals who need multiple services and supports and/or their families should not have to bear the burden of coordination and access to services (as they largely do now); that burden should be shared by the providers of the necessary services and supports.

The Committee has become convinced that the *status quo* is not an option. What, then, is necessary to make the mental health/addiction system more patient/client oriented? Should it go all the way to personalized care plans, and if so, for which types of patients/clients? What types of information should these plans contain, that is, what should be the content of such a plan? What changes are needed in the current service delivery structure to implement personalized care plans for individuals with mental illness and addiction? Who should coordinate the implementation of the personalized care plan for each patient/client?

The Committee has become convinced that the *status quo* is not an option. What, then, is necessary to make the mental health/addiction system more patient/client oriented?

Would changing the method of remunerating individual and institutional providers to one in which the money follows the patient/client provide an incentive sufficiently strong to achieve a system of truly patient/client oriented mental health and addiction services and supports? If so, what changes are necessary to implement such a new funding/remuneration system? If not, what are the incentives and how should they be introduced into the system to stimulate the changes required to make the system truly patient/client oriented? More generally, what would be the implications of having "the money following the patient"?

What are the incentives and how should they be introduced into the system to stimulate the changes required to make the system truly patient/client oriented?

Moreover, in its first report, the Committee noted that decision-making capacity of those suffering from mental illness and addiction may be impaired to varying degrees and at different times.[7] Accordingly, how can a patient/client oriented system ensure an appropriate balance between the rights of individuals with severe mental disorders and the role of society in caring compassionately for them while also protecting itself? Do the current disparities found in mental health legislation across the provinces and territories require formal review so as to achieve a more uniform, national, legislative framework?

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[6] First Report, Chapter 4, Section 4.9.

[7] First report, Chapter 8 (Section 8.3) and Chapter 11 (Section 11.2).

1.2 CULTURALLY APPROPRIATE DELIVERY OF SERVICES AND SUPPORTS

Some population groups in Canada encounter specific access problems and receive services of diminished quality due to cultural, linguistic and geographical barriers. They include Aboriginal peoples, individuals from culturally and linguistically diverse backgrounds, and people living in rural and remote areas. The absence of culturally appropriate services and supports has had a strong negative impact on many individuals.

Increasingly Canadians come from different cultural and linguistic backgrounds. What mechanisms must be put in place to deliver services and supports in a culturally appropriate manner? Is there a specific role for the federal government, given its responsibility for the promotion of multiculturalism? In addition, what are the views of Canadians from official language minorities with respect to their access to the mental health/addiction system? What can the federal government do to help ensure that language is not barrier to receiving needed care? [The federal government's role with respect to the provision of mental health services and addiction treatment to Aboriginal communities is addressed in more detail in Chapter 2 (Section 2.2) and Chapter 7 (Section 7.1) of this report.]

Increasingly Canadians come from different cultural and linguistic backgrounds. What mechanisms must be put in place to deliver services and supports in a culturally appropriate manner?

1.3 SYSTEM COORDINATION AND INTEGRATION WITH STRONG FOCUS ON COMMUNITY-BASED DELIVERY

Individuals with mental illness and addiction often feel bewildered and overwhelmed when they must not only access services and supports, but also integrate for themselves mental health care, addiction treatment, support services (housing, education, etc.), and disability benefits across multiple, disconnected programs that span federal, provincial and regional agencies, as well as several nongovernmental organizations.[8] How can the burden of coordinating and integrating services and supports be shared equitably between the system itself and affected individuals and their families?

How can the burden of coordinating and integrating services and supports be shifted to the system itself and away from affected individuals and their families?

Reforming the silo approach that currently dominates the provision of mental health services and addiction treatment so that seamless service delivery is provided would require many existing service delivery organizations to give up their autonomy. What tools could be used to put a seamless system of mental health services and supports and addiction treatment in place? What incentives are needed to overcome the difficulties associated with getting existing organizations to work together – to give up their autonomy in favour of interdependence? There appears to be significant duplication and overlap among the great

[8] First Report, Chapter 8, Section 8.2.1.

number of NGOs delivering services and supports to individuals with mental illness and addiction; how can this problem be eliminated?

What incentives are needed to overcome the difficulties associated with getting existing organizations to work together – to give up their autonomy in favour of interdependence?

What is the best way of integrating addiction services and programs into a genuine system of mental health services? How can mental health/addiction services be best coordinated with other more broadly defined social sector "silos" (housing, education, employment, income support, etc.)? Other than top down command-and-control, what incentives are there available to speed up the changes needed in the mental health/addiction system? Should increased connectiveness between different programs and administrative structures be achieved informally through positive relationships, or formally through Memorandums of Understanding or service agreements? When beginning systemic integration, which community services and supports should be given priority? Are localized pilot projects a good idea?

There are many such questions as yet unanswered. How can Canada develop and adopt clear descriptions of the roles and responsibilities of the various organizations involved in the delivery of mental health services and supports and addiction treatment? In particular, what should be the roles and responsibilities of the federal government, the provincial/territorial governments, regional health authorities, various provincial government ministries and agencies (health, education, social services, housing, justice, welfare, etc.), mental health providers, nongovernmental organizations, self-help groups, etc.?

How should public funding be allocated to encourage collaboration between and within the addiction and mental health fields? What form of funding would provide the most appropriate and effective incentives to achieve this objective? Which type of funding or mechanism could help achieve better coordination between the mental health/addiction system and the broader social system? [The issue of funding is addressed in detail later in Chapter 8 (Sections 8.1 and 8.2) of this report.]

How should public funding be allocated to encourage collaboration between and within the addiction and mental health fields? What form of funding would provide the most appropriate and effective incentives to achieve this objective?

1.4 EARLY DETECTION AND INTERVENTION

Early intervention is fundamental to arrest progression towards full-blown disease; it is important also in controlling symptoms and improving outcomes. The earlier the initiation of a proper course of treatment, the better the patient's/client's prognosis.[9]

Important in all age groups, early intervention is particularly important in children and adolescents. The onset of most adult mental disorders occurs during adolescence and young

[9] First Report, Chapter 8, Section 8.2.7.

adulthood when early intervention can significantly reduce disruptions to an individual's educational, occupational, and social development. Gains made at this time often have lifelong impact.

To put more emphasis on early detection of and intervention in mental disorders among children and adolescents, what would be required in terms of: school mental health programs, mental health screening for high school aged children, and screening for dual diagnosis and concurrent disorders? What changes must be made to the health care system, the mental health/addiction system, the education system, and the broader social service system to facilitate early intervention? [Children's and adolescents' issues are addressed in greater detail in Chapter 2 (Section 2.1) of this report.]

To put more emphasis on early detection of and intervention in mental disorders among children and adolescents, what would be required in terms of: school mental health programs, mental health screening for high school aged children, and screening for dual diagnosis and concurrent disorders?

Early detection and intervention should also be viewed through the lenses of a population health perspective. Improving the social conditions that we know are necessary for overall good mental health (e.g. healthy physical and social environments, strong coping skills, etc.) is essential to support positive mental health and recovery from mental disorders. This includes addressing the root causes of mental illness and addiction through public policy with respect to poverty, homelessness, education, etc., and the need to develop community capacity to deal adequately with these issues.

What role should the federal government play in the development and implementation of a population health approach aimed at the mental health of Canadians? Which federal departments should be involved? How can the federal government encourage the provinces/territories and other stakeholders to collaborate closely in addressing the root causes of mental illness and addiction?

1.5 ENHANCING ACCESS

Despite the efforts by all provinces and territories to improve the delivery of mental health services/supports and addiction treatment, a majority of Canadians suffering from mental disorders still do not seek and receive professional help. The Canadian Community Health Survey (CCHS) recently done by Statistics Canada showed that only 32% of individuals with mental illness and addiction saw or talked to a health professional (either a psychiatrist, a family physician, a medical specialist, a psychologist, a social worker or a nurse) during the 12 months prior to the survey.[10]

What could be done to improve this situation? One possibility is to establish a patient charter that would set standards for access to mental health services in primary health care, specialized mental health services and acute care. The Champlain District Mental Health Implementation Task Force (2002) in Ontario recommended the creation of a "Provincial

[10] First Report, Chapter 8, Section 8.2.6.

Mental Health Patients' Charter of Rights". Others have suggested some form of "mental health equitable act", legislation intended to bridge the gap between physical illnesses and mental disorders in terms of the services provided and their public funding. Still, others have advocated appointing "mental health advocates", officials who individuals having difficulty accessing needed mental health services and supports could contact for assistance. A mental health advocate existed for some time in British Columbia, but the position was eliminated when the Ministry of State for mental illness and addiction was created.[11] The Committee invites the views of readers on this set of options or others that might be pursued.

In its report of October 2002, the Committee recommended the establishment of a Health Care Guarantee along with a maximum needs-based waiting time set for primary health care consultations, specialist referrals, diagnostic tests and surgery.[12] In the current context of defining acceptable waiting times for access to health services, is there a need to set national standards with regard to access to mental health services and addiction treatment?

In the current context of defining acceptable waiting times for access to health services, is there a need to set national standards with regard to access to mental health services and addiction treatment?

Clearly, input from patients/clients will be needed increasingly as changes to the mental health/addiction system are developed and implemented. In the meantime, should the federal government (and each provincial/territorial government) establish a mental health/addiction advisory committee that is representative of the wide range of individuals with mental illness and addiction to facilitate the development of a patient-oriented system? If some other mechanism is preferable, what should that mechanism be?

Should the federal government (and each provincial/territorial government) establish a mental health/addiction advisory committee that is representative of the wide range of individuals with mental illness and addiction to facilitate the development of a patient-oriented system?

[11] *Ibid.*

[12] *Recommendations for Reform*, October 2002, Chapter 6.

CHAPTER 2:
SPECIFIC POPULATION GROUPS

The Committee has been convinced of the applicability of the adage "one size does not fit all". Individuals with mental illness and addiction are not homogenous. They are individual persons, each unique as all persons are; they should be respected as such. But they can be categorized to fall roughly within a number of population sub-groups, each with its own particular challenges and service delivery needs: children and adolescents, Aboriginal peoples, seniors, and individuals with especially complex needs, just to name a few.

2.1 CHILDREN AND ADOLESCENTS

As indicated in our first report, the overall prevalence of mental illness in Canadian children and adolescents, at any given point in time, is about 15%. This translates into approximately 1.2 million children and adolescents who experience at any point in time mental illness and/or addiction of sufficient severity to cause significant distress and impaired functioning. The most common mental illnesses among children and adolescents are anxiety (6.5%), conduct (3.3%), attention deficit (3.3%), depressive (2.1%), substance use (0.8%), and autism and other pervasive developmental disorders (0.3).[13]

There is considerable dissatisfaction in most jurisdictions with the existing delivery of children and adolescent services. Child and adolescent mental health services and supports have been called the "orphan's orphan" of the health care system, a term that has its origin in the frequent reference to mental health as the "orphan" of the Canadian health care system.

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At the provincial/territorial level, the delivery of mental health services to children and adolescents is highly fragmented and uncoordinated; usually a variety of departments and agencies (e.g., mental health, primary health care, hospitals, child welfare, schools, young offender, addiction services, and special education services) is involved. Compounding the problem, most mental health policies and programs have largely focussed primarily on the adult population; consequently, services for children and adolescents have developed slowly and only as an adjunct to adult programs.

How can we best achieve a seamless, well coordinated, network of services and supports to address the prevalence of mental disorders among children and adolescents building on the current layering of multiple, well intentioned but uncoordinated programs? What specific measures need to be adopted in order to foster the mental

How can we best achieve a seamless, well coordinated, network of services and supports to address the prevalence of mental disorders among children and adolescents?

[13] First Report, Chapter 5, Section 5.1.2.

health of children and adolescents? Should the first step be for the various governmental departments and agencies to develop, in collaboration with other stakeholders, an inter-ministerial strategy for children and adolescent mental health? Subsequently, should formal protocols be developed and implemented to ensure effective collaboration and communication among the various players? Should each provincial government establish an agency or department with prime responsibility for children and adolescent mental health?

A number of provinces – such as Alberta, British Columbia and Prince Edward Island – have implemented specific mental health strategies for children. What can be learned from provincial initiatives? Are there particular provincial/territorial or regional models that the Committee should examine?

The value of providing mental health services within the school setting is intuitively apparent. Schools offer familiar environments to intervene with children and adolescents with mental health problems and in many jurisdictions are recognized as key players in the provision of mental health services and supports. What services and supports could be provided in an efficient and cost-effective manner in the school system?

What services and supports could be provided in an efficient and cost-effective manner in the school system?

Mental health services and supports for children and adolescents are not easy to find in most communities. When services are available, usually there are long waiting lists for access to service. It is clear that in most communities service capacity must be increased to provide a basic level of accessible services. The Committee was advised that when appropriate, services should be delivered in places where children, adolescents and their families spend most of their time (e.g., schools and homes) and at appropriately flexible times of day. This raises a series of further questions. How much funding is needed to increase capacity? How serious are the shortages of professionals in the field of children and adolescent mental health? Should more training in the early detection of mental disorders in children and adolescents be provided to primary health care providers and educational personnel? Should researchers in mental health devote more attention and resources to issues affecting children and adolescents?

Should researchers in mental health devote more attention and resources to issues affecting children and adolescents?

The Committee heard about the specific mental health care needs of those making the transition from adolescence to adulthood. In particular, the question of the general interface between systems and services set up for children and adolescents and those established for adults was raised. On the one hand, the need for mental health services and supports will likely continue following an adolescent's 18th birthday; children and adolescent mental health services, however, are generally no longer accessible when he/she turns 18. On the other, the period of transition from childhood to adulthood can be difficult, and requirements for mental health services and supports may actually increase rather than decrease during this important developmental period. How can the various systems work in an integrated, collaborative and timely manner to prepare and plan for adolescents experiencing the

Should new programs and services be developed to facilitate the transition to adult mental health services delivery programs?

transition into adulthood? Should new programs and services be developed to facilitate the transition to adult mental health services delivery programs?

2.2 ABORIGINAL PEOPLES

As noted in our first companion report, Aboriginal peoples are defined in the *Constitution Act*, 1982 (section 35) as the "Indian, Inuit and Métis peoples of Canada." Despite this broad constitutional definition, the federal government currently assumes responsibility only for Indian peoples residing on-reserve and specified Inuit populations. At present, Health Canada and Indian and Northern Affairs Canada are the two major federal departments that provide health care, mental health services, addiction treatment and social services and supports to First Nations on reserve and Inuit people.[14]

The provincial and territorial governments are responsible for Aboriginal peoples living off-reserve, including the Métis and non-status Indians who have access to programs and services on the same basis as other provincial residents. The multifaceted nature of the Aboriginal population in combination with these jurisdictional divisions in Canada, have created serious barriers to the establishment of a comprehensive plan for dealing with mental health, mental illness and addiction among Aboriginal Canadians.[15]

The multifaceted nature of the Aboriginal population in combination with these jurisdictional divisions in Canada, have created serious barriers to the establishment of a comprehensive plan for dealing with mental health, mental illness and addiction among Aboriginal Canadians.

Although data on the prevalence of psychiatric disorders among Aboriginal peoples are quite limited, there is consensus in the literature that Aboriginal communities suffer significantly higher rates of mental illness, addiction and suicidal behaviour than the general population. Moreover, the prevalence rates of foetal alcohol syndrome/foetal alcohol effects (FAS/FAE) in some Aboriginal communities are higher than the national average.[16]

Experts in the field suggest that, while many of the causes of mental illness, addiction and suicidal behaviour in Aboriginal and non-Aboriginal communities may be similar, there are added cultural factors in Aboriginal communities that affect individual decision-making and suicidal ideation. These cultural factors include past government policies, creation of the reserve system, the change from an active to a sedentary lifestyle, the impact of residential schools, racism, marginalization and the projection of an inferior self-image.[17]

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[14] First Report, Chapter 9, Section 9.2.1.
[15] *Ibid.*
[16] First Report, Chapter 5, Section 5.3.1.
[17] *Ibid.*

Several issues bear directly on the provision of mental health services and addiction treatment to Aboriginal communities:

- First, the system is highly fragmented. Services and supports are provided by different levels of government, different departments, and/or various departmental directorates or divisions, all without much collaboration. This fragmentation is illustrated by the current practice of isolating symptomatic problems – addiction, suicide, FAS/FAE, poor housing, lack of employment, etc. – and designing stand-alone programs to try to manage each one separately.

- Second, the habits of dependency have been fostered for a long time. Government departments must delegate to Aboriginal communities the authority to customize services and react flexibly to local circumstances. In other words, Aboriginal peoples should be supported in the development of their own solutions, rather than having solutions imposed on or provided for them. Such a change would foster the development of more culturally appropriate, and therefore effective, services and supports.

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- Third, there is a critical shortage of adequately trained Aboriginal mental health and addiction professionals. For example, there are only 4 Aboriginal psychiatrists in Canada.

- Finally, some provinces have integrated Aboriginal issues with their province-wide mental health strategies. In those circumstances, federal programs for Aboriginal mental health on or off reserve should be harmonized with the provincial mental health plans and implementation strategies.

What should be the top priorities for the federal government as it starts the process of changing the way it delivers mental health services and addiction treatment to Aboriginal Canadians? What would be the most appropriate structures to ensure that Aboriginal peoples have adequate input into the design of services they need? How can the federal government organize itself to deliver those services most efficiently and effectively? Should the federal government offer financial incentives to encourage Aboriginal Canadians to train to become mental health workers?

What should be the top priorities for the federal government as it starts the process of changing the way it delivers mental health services and addiction treatment to Aboriginal Canadians?

Perhaps more importantly, given unnecessary and expensive duplication of uncoordinated programs, who should take responsibility for carrying out an environmental scan to determine what programs exist and identify duplication among governments, departments and organizations, significant gaps in programming, and how best to maximize the effective use of available resources?

2.3 SENIORS

Experts in the field contend that, with the rapid growth of the aging population, there will be an unprecedented demand on the system's current capacity to address seniors' mental health needs. Depression, dementia, delusional disorders and delirium are the most common mental illnesses among senior Canadians. The incidence of mental disorders in seniors in long term care settings and nursing homes is much higher than in the general population. The incidence of suicide among men 80 years of age or older is the highest of all age groups.[18]

Seniors with mental illness and addiction are a particularly vulnerable segment of the population with unique health needs. Many seniors mistakenly believe that mental health problems, such as depression or cognitive impairment, are part of the normal aging process and that no effective treatments are available. Mental illnesses in seniors may be confused or masked by other co-morbidity and concurrent disorders that can make accurate diagnosis and treatment of mental illness particularly difficult.

Seniors with mental illness and addiction are a particularly vulnerable segment of the population with unique health needs.

All this highlights the need for health care providers who are specialized in the care of seniors with mental health disorders, including those who reside in institutional settings. This raises the question as to whether the curriculum in faculties of medicine and nursing schools should be revised so as to provide additional education and training in the mental health needs of seniors.

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The Committee was told that current service delivery models do not meet the complex and ever changing mental health needs of seniors. Again, the lack of coordination among service providers compounds effective approaches to more appropriate and effective assessment, treatment and prevention of mental illness. Are there particular issues that impede the coordination and integration of needed services and supports needed by seniors?

Are there particular issues that impede the coordination and integration of needed services and supports needed by seniors?

There is limited published research specifically addressing best practices in mental health for seniors and the pressing need for the development of sophisticated, feasible, validated best practice guidelines to guide professionals who must manage simultaneously multiple mental illnesses together with physical problems in aging Canadians. Who should take responsibility for developing these best practices guidelines?

[18] First Report, Chapter 5, Section 5.1.3.

There is also a need to provide a coordinated range of supports to the family caregivers of seniors with mental disorders; the economic value of those support services is enormous. Currently, the support provided to family caregivers is very limited, usually insufficient to be of much help and is geared primarily to the needs of the affected family member, not to the needs of the caregiver.

What could the federal government do to alleviate the burden that now falls on the shoulders of thousands of family caregivers? What support services do caregivers need? Should the federal government consider adjusting the Canada Pension Plan, the Employment Insurance program and the Canada Labour Code to accommodate the needs of individuals who leave the workforce to provide care to a parent suffering from severe mental illness? How much would such changes cost? Are the current federal tax provisions adequate to compensate informal caregivers for the time and resources they provide?

What could the federal government do to alleviate the burden that now falls on the shoulders of thousands of family caregivers?

Similarly, what are the needs of elderly parents who are the primary caregivers of adult children with mental illness and addiction? What type of support (financial, respite) do these senior caregivers need?

What are the needs of elderly parents who are the primary caregivers of adult children with mental illness and addiction?

2.4 INDIVIDUALS WITH COMPLEX NEEDS

Canadians with complex mental health needs include individuals suffering from concurrent disorders (mental illness and addiction) and dual diagnosis (mental illness and developmental disability), as well as some homeless people and some inmates. Systematic approaches and effective assessment tools to identify better this population are lacking and, because they are often inappropriately identified, many individuals fail to receive proper care.

Those with concurrent disorders and dual diagnosis need help and services from several sectors – mental health, addiction, health care, education, and social services. Again, it is essential to integrate mental health services with addiction treatment services as well as the developmental and mental health sectors. The Committee is anxious to obtain the opinion of Canadians on the set of issues and options related to concurrent disorders and dual diagnosis that need to be addressed.

The Committee is anxious to obtain the opinion of Canadians on the set of issues and options related to concurrent disorders and dual diagnosis that need to be addressed.

Mental illnesses and substance use disorders are more prevalent among homeless people and inmates than in the general population; their prevalence among these segments of the Canadian population is growing. Improving access to the

With respect to the specific mental health needs of homeless individuals, we would like to hear Canadians' views on the issues and options that need to be addressed.

services and supports these individuals need requires inter-jurisdictional collaboration.

The Committee addresses the issues and options related to the mental health needs of federal inmates in Chapter 7 of this report. With respect to the specific mental health needs of homeless individuals, we would like to hear Canadians' views on the issues and options that need to be addressed. For example, what role can the federal government play in the context of the National Homelessness Initiative?

CHAPTER 3:
THE WORKPLACE

Two main factors make mental illness and addiction a critical workplace issue. First, mental disorders usually strike younger workers and second, many mental illnesses are both chronic and cyclical in nature, requiring treatment on and off for many years. Given the economic costs associated with these disorders – primarily those of absenteeism and lost productivity – it is essential that employers and governments join forces to address this issue on an urgent basis.

3.1 EMPLOYERS

Employers can play a vital role in dealing with mental illness and addiction among workers, in terms of disability management, accommodation policy and return-to-work programs. The global economy, in which information and innovation have become the keys to competitive success, requires skilled, motivated, reliable workers. Human capital – the motivation, knowledge, perspective, judgement, the ability to communicate, share ideas and to make and maintain strong relationships – drives competitiveness in the global economy.[19]

Employers can play a vital role in dealing with mental illness and addiction among workers, in terms of disability management, accommodation policy and return-to-work programs.

With respect to employer-sponsored disability insurance plans, the Committee is concerned with three specific issues. First, all corporations should conduct a review of their short-term and long-term disability claims in order to assess the prevalence of mental illness and addiction in their organizations. Second, employers should review the type and extent of disability coverage offered and their effect on the duration of claims in order to design optimally effective employer-sponsored disability insurance plan. And third, employers, managers and insurers must become more knowledgeable about mental illness and addiction.[20]

Large employers usually sponsor employee assistance programs (EAPs) which pay for (usually a limited number of) counselling sessions for their workers. EAP programs are designed to assist the employee in dealing with a variety of workplace problems. The Committee was told that EAPs need revision to address better the needs of employees dealing with mental illness and addiction; most do not provide sufficient therapeutic sessions to address mental illness and addiction effectively.[21]

The Committee was also told that employers need to take steps to accommodate individuals with mental illness and addiction in their workplaces. Such accommodation refers to "any

[19] First Report, Chapter 6, Section 6.5.
[20] First Report, Chapter 6, Section 6.4.1.
[21] First Report, Chapter 6, Section 6.5.1.

modification of the workplace, or the workplace procedures, that make it possible for a person with special needs to do a job." Permitting someone with a mental disorder to work flexible hours, for example, provides access to employment as a ramp does for an individual in a wheelchair. The needs of an employee returning to work following a bout of mental illness may be quite different from those of an employee returning after back surgery. Existing return-to-work arrangements should be reviewed and revised to address those different needs.[22]

An organization's internal culture can make a huge difference to how mental illness and addiction are approached in the workplace. How can employers help to enhance the level of awareness about mental illness and addiction throughout their organizations? Perhaps more importantly, what can be done to enhance the knowledge of employers and managers about mental illness and addiction and their ability to help employees living with these disorders?

What can be done to enhance the knowledge of employers and managers about mental illness and addiction and their ability to help employees living with these disorders?

The Committee was informed that employers in some companies and institutions – such as Alcan Inc., the Canadian Imperial Bank of Commerce and Dofasco Inc. to name a few – are devoting more attention to mental health and addiction problems in the workplace with great success. Are there other success stories the Committee should hear about? What should be done to increase awareness about these company leaders' knowledge and experience?

Many Canadians have supplementary employer-sponsored health care insurance that covers an element of mental health care. How adequate are the levels of coverage in private health care insurance plans? Do they need to be expanded and, if so, in what areas of mental health is the expansion most needed? What specific changes in policy are required to ensure that disability insurance is not a disincentive for someone affected by mental illness or addiction to return to work? What would motivate employers best to devote more attention to improving access to treatment and rehabilitation services for workers through their EAPs?

What would motivate employers best to devote more attention to improving access to treatment and rehabilitation services for workers through their EAPs?

How can employers most effectively provide work flexibility and otherwise accommodate employees who suffer from a mental disorder? What steps should they take to remedy workplace situations that impact detrimentally on all employees, and especially on those affected by mental illness and addiction?

Are there specific suggestions/ideas for policies that would encourage businesses to employ individuals with mental illness and addiction, even if only on a part-time basis? In particular, are there programs that could be targeted specifically to adolescents disadvantaged by having

[22] First Report, Chapter 6, Section 6.5.2.

little education and no specific skill sets in addition to their mental illness that would enable them to get a job?

The Global Business and Economic Roundtable on Addiction and Mental Health has proposed a twelve-step program to defeat mental illness and addiction at work.[23] What is the evidence that this program works? If it does work well, what can governments do to encourage companies to adopt it? Should the federal government, in conjunction with the Roundtable, establish a joint working group to encourage its adoption?

Are there programs that could be targeted specifically to adolescents disadvantaged by having little education and no specific skill sets in addition to their mental illness that would enable them to get a job?

3.2 WORKERS' COMPENSATION BOARDS

In all provinces and territories, Workers' Compensation Boards (WCBs) receive an increasing number of claims related to mental health related (referred to as "occupational stress"); in a growing number of cases, they have provided compensation for such claims. A major issue raised with respect to compensation under WCBs concerns the fact that it is more difficult to prove the genesis of a mental disorder than it is of a physical illness. As a result, some WCBs are reluctant to provide mental health related disability benefits. They and affected workers are left to wrestle with the question of the extent to which disability benefits related to mental disorders should be paid for by worker's compensation versus health care insurance.[24] How can uniformity be achieved among the various WCBs in relation to mental illness and addiction? Should WCBs' policies with respect to mental health related claims be reviewed and by whom? What role should the Association of Workers' Compensation Boards of Canada play in bringing a national perspective to needed research and harmonization of benefit provisions?

How can uniformity be achieved among the various WCBs in relation to mental illness and addiction? Should WCBs′ policies with respect to mental health related claims be reviewed and by whom?

3.3 FEDERAL INCOME SECURITY PROGRAMS

The Committee was told about the need to review the Canada Pension Plan Disability Program (CPP(D)) and the Employment Insurance (EI) program in order to take into account the unpredictable and frequently cyclical nature of mental disorders.[25]

With respect to CPP(D), some individuals with mental disorders may not be eligible because of an insufficiently long employment history (contributions must have been paid in four out of the last six years). The Committee was advised that applicants must accept the designation of "permanently unemployable" to qualify for CPP(D) disability benefits. Many

[23] First Report, Chapter 6, Table 6.3.
[24] First Report, Chapter 6, Section 6.4.2.
[25] First Report, Chapter 6, Section 6.4.3.

individuals with mental disorders can work, but often only on a part-time basis. In addition, over 66% of individuals with mental illness and addiction are denied their initial application for eligibility and two-thirds of them do not appeal or re-apply.

Should the federal government change the CPP(D) in order to provide partial or reduced rather than full benefits to enable individuals with mental disorders to retain a portion of their benefits while still working part-time? Should CPP(D) staff members receive training to increase their awareness of mental illness and addiction? What other changes are needed so that CPP(D) can deal more equitably with workers suffering from mental illness and addiction?

Should the federal government change the CPP(D) in order to provide partial or reduced rather than full benefits to enable individuals with mental disorders to retain a portion of their benefits while still working part-time?

With respect to EI, employees who are dismissed because of "misconduct" or quit "without just cause" are not eligible for EI benefits. Due to the associated stigma, individuals with mental illness in the workplace often conceal their illness. When they experience difficulty on the job, they may be fired or may quit under the influence of their illness, but are not in a position to claim EI benefits because they have not disclosed their illness previously. Also, when a person applies for EI sickness benefits, he/she is required to obtain a medical certificate indicating how long the illness is expected to last. The unpredictable nature of mental illness makes it difficult to provide this kind of medical information.

What changes should be made to EI with respect to the way the program serves individuals with mental illness and addiction? For example, should individuals subsequent to leaving employment be found to be affected by mental illness and addiction be exempted from the requirement to fulfill the total number of insurable hours now required for eligibility? What other possible changes should the federal government consider?

What changes should be made to EI with respect to the way the program serves individuals with mental illness and addiction?

Some have suggested to the Committee that the federal government should find ways to share more equitably with employers the costs associated with mental illness and addiction in the workplace.[26] What mechanisms could be used to develop the basis of such cost sharing and to implement it?

3.4 THE FEDERAL GOVERNMENT AS AN EMPLOYER

The federal government is a major employer. In its role as the employer of the federal public service, Treasury Board oversees the health care benefits available to public servants under the Public Service Health Care Plan and the Disability Insurance Plan. These assure a reasonable level of income during periods of long term physical or mental disability. In

[26] First Report, Chapter 6, Section 6.6.

addition, Health Canada is mandated to provide occupational health and safety services to federal employees, including Employee Assistance Programs.[27]

The Committee invites the views of federal employees and their representatives on the quality and effectiveness of federal efforts in promoting mental health and preventing mental disability among public servants.

How effective is the federal government as an employer in accommodating individuals with mental illness and addition? How good are its return-to-work policies? What needs to be improved so that the federal government can lead by example in its role of employer?

How effective is the federal government as an employer in accommodating individuals with mental illness and addition? What needs to be improved so that the federal government can lead by example in its role of employer?

[27] First Report, Chapter 9, Sections 9.2.9 and 9.2.10.

CHAPTER 4: SPECIFIC ISSUES

4.1 COMBATING STIGMA AND DISCRIMINATION

The Committee considers the problem of the stigmatization of, and discrimination against, individuals with mental illness and addiction to be of enormous importance.

Stigmatization and discrimination affect individuals with mental illness and addiction in many ways. They are routinely excluded from social life and can even be denied a variety of civil rights others take for granted. They are often denied basic rights in housing, employment, income, insurance, higher education, criminal justice, and parenting.

Individuals with mental illness and addiction also face discrimination and rejection by service providers both in the mental health system and the broader health care system and discrimination by policy makers and the media. For many individuals with mental illness and addiction, the stigmatization and discrimination they confront can be as important a source of distress as the disorder itself.[28]

For many individuals with mental illness and addiction, the stigmatization and discrimination they confront can be as important a source of distress as the disorder itself.

Because the stigma of mental illness is the cause of much of the distress individuals with mental illness and addiction experience in their daily lives, should it be more bluntly described for what it really is – discrimination – rather than stigma? Surely it is discrimination when someone with a mental illness is systematically treated differently from someone who is not affected by a mental illness. Has the word stigma become a polite linguistic way of justifying discrimination?

Has the word stigma become a polite linguistic way of justifying discrimination?

The Committee has had considerable discussion of how best to reduce stigmatization and combat discrimination. Doing so requires a multi-pronged effort sustained over a long period of time and includes: ongoing community-based education and action, media campaigns, and forums of exchange between affected individuals and other Canadians to enhance public awareness, and professional awareness campaigns to reduce structural discrimination in the health care system and in the mental health system itself.[29]

Several witnesses stressed the importance of developing a national anti-stigma strategy. Its adoption would indicate to Canadians that the federal, provincial and territorial governments attach equal importance to fostering mental health as they do to promoting the physical health of the population.

[28] First Report, Chapter 3, Section 3.3.
[29] First Report, Chapter 3, Section 3.4.

Importantly, several witnesses stressed the importance of developing a national anti-stigma strategy. The Committee was told that such a strategy would focus powerfully public attention on mental health and addiction issues. Its adoption would indicate to Canadians that the federal, provincial and territorial governments attach equal importance to fostering mental health as they do to promoting the physical health of the population.[30] At the same time, many witnesses noted that it is important to carefully target anti-stigma efforts and that the evidence indicates that overly general campaigns do not yield the desired results.

The Committee's review of mental health promotion initiatives in other countries pointed out that successful public awareness campaigns to combat stigma and discrimination require sustained funding, long term planning and ongoing evaluations. In addition, such campaigns, notably in Australia and New Zealand, seem to benefit from being tailored to a variety of circumstances, population groups and communities. Our international review also underscores the need from the outset for widespread consultation among the various levels of government, providers, NGOs and, most importantly, affected individuals themselves and their families.[31]

In addition to a campaign by governments, is there also a role for the media in trying to change Canadians' attitudes towards individuals with mental illness and addiction? If so, what should that role be? Are there public awareness strategies that have been particularly successful in Canada to reduce stigma and discrimination (such as the Canadian Strategy on HIV/AIDS) from which lessons could be learned?

Is there also a role for the media in trying to change Canadians' attitudes towards individuals with mental illness and addiction?

The Committee was also told that the most effective strategy for combating stigma and discrimination was to increase the amount of contact with individuals living with mental illness and addiction. In this regard, we learned that the United Kingdom established an Ambassador Bureau composed of more than forty individuals with mental illness and addiction who were trained to speak to the media and employers about their experiences.[32] It was successful in giving the anti-stigma campaign a personal and very human face. Should Canada establish a similar group?

The United Kingdom established an Ambassador Bureau composed of more than forty individuals with mental illness and addiction who were trained to speak to the media and employers about their experiences.[1] Should Canada establish a similar group?

Similarly, in Australia, a national mental health strategy was undertaken in journalism schools to teach journalists how to report in ways that do not stigmatize individuals with mental disorders and encourage the media to promote positive messages about mental health.[33] Should the federal government, working jointly with the media, develop a similar strategy in Canada? How much would it cost and how should it be funded?

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[30] First Report, Chapter 3, Section 3.4.1.
[31] Second Report, Chapter 5, Section 5.5.
[32] Second Report, Chapter 3, Section 3.4.1.
[33] Second Report, Chapter 1, Section 1.5.

Finally, there is need to increase the awareness among health care professionals about mental illness and addiction. Mental health care providers and addiction workers themselves are not immune from the influence of stigmatization of their patients/clients. How prevalent is this form of stigmatization? Should the curriculum in faculties of medicine and nursing schools be revised so as to provide additional education and training on mental illness and addiction? Is this an area of provincial responsibility, or can the federal government play a role? What other measures can be targeted at health care workers in order to reduce discrimination?

More generally, what can governments do to increase everybody's awareness that mental health is as important as physical health to the well-being of Canadians and that, as a corollary, the delivery of services and supports for mental illness and addiction is as critical as is the provision of health services for physical conditions?

More generally, what can governments do to increase everybody's awareness that mental health is as important as physical health to the well-being of Canadians and that, as a corollary, the delivery of services and supports for mental illness and addiction is as critical as is the provision of health services for physical conditions?

4.2 SUICIDE PREVENTION

Every year, some 3,700 Canadians commit suicide. It is the leading cause of death for men aged 25 to 29 and for women aged 30 to 34. In addition, a large number of other Canadians attempt suicide each year. In 2002, about 4% of Canadians aged 15 years and over had suicidal thoughts.[34]

In its first report, the Committee noted that, while not itself defined as a mental disorder, suicidal behaviour is highly correlated to mental illness and addiction; more than 90% of suicide victims have a diagnosable mental illness or substance use disorder. Suicide is the most common cause of premature death of individuals with schizophrenia and accounts for 15% to 25% of all deaths among individuals with severe mood disorders. Addiction often predisposes an individual to suicidal behaviour by intensifying a depressive mood swing and by reducing self-control.[35]

Unlike Australia, Finland, France, the Netherlands, New Zealand, Norway, Sweden, the United Kingdom and the United States, Canada does not have a national suicide prevention strategy. According to the Centre for Suicide Prevention, only two provinces – New Brunswick and Québec – have implemented suicide-specific prevention strategies. Many would like the federal government to work with the provinces/territories and relevant stakeholders in the development of a national strategy.

Unlike Australia, Finland, France, the Netherlands, New Zealand, Norway, Sweden, the United Kingdom and the United States, Canada does not have a national suicide prevention strategy.

A number of programs and activities could be included in a national suicide prevention strategy, namely:

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[34] First Report, Chapter 5, Section 5.2.
[35] First Report, Chapter 4, Section 4.5.

- Public awareness campaigns to address the stigma associated with suicidal behaviour.
- Population health strategies to address the determinants of health, including housing, income security, education, employment and community attitudes towards those affected by mental illness and addiction.
- Prevention programs for adolescents, for individuals at high risk of suicidal behaviour, and for families in which a member has attempted or committed suicide.
- Equitable access to co-ordinated, integrated services, including crisis counselling by telephone and the treatment of mental illness and addiction.
- Measures to reduce access to lethal means of suicide, particularly firearms, medication and dangerous bridges and other sites.
- Training of service providers and educators in the early identification of suicidal behaviour and crisis management.
- Research and evaluation to inform the development of effective suicide prevention programs and to evaluate the effectiveness of health and social services in preventing suicide.

Who among the federal, provincial, territorial governments, and nongovernmental organizations should be involved in the development of a national suicide prevention strategy? What should be its specific goals and objectives? What programs and activities should be part of a national suicide prevention strategy? How much would it cost and how should it be funded? Should there be a single national strategy, or should each level of government establish its own?

Who among the federal, provincial, territorial governments, and nongovernmental organizations should be involved in the development of a national suicide prevention strategy? What should be its specific goals and objectives? What programs and activities should be part of a national suicide prevention strategy?

CHAPTER 5: HUMAN RESOURCES

Professionals of many kinds are involved in the provision of mental health services and supports and addiction treatment. They include primary health care physicians, psychiatrists, addiction specialists, psychologists, registered psychiatric nurses, social workers, nurse practitioners, occupational therapists, case managers, addiction counsellors, special care educators, etc. The Committee was told that, as in other areas in the health care system, there are critical shortages of providers. The geographic mal-distribution of mental health and addiction professionals is also of concern.[36] Other countries face similar human resource challenges in the field of mental illness and addiction.[37] The Committee was also informed about a critical need to reform the primary health care sector with the view to improving people's access to mental health services and to expanding shared mental health care initiatives across the country.

As in other areas in the health care system, there are critical shortages of providers in the field of mental illness and addiction.

5.1 SUPPLY OF MENTAL HEALTH AND ADDICTION HUMAN RESOURCES

Although the Committee heard repeatedly about shortages of providers,[38] there is currently no national database that provides even a rough, much less a detailed, breakdown of the supply of human resources in the field of mental illness and addiction. At present, it is unclear if there actually is a shortage of mental health/addiction service providers in Canada and, if so, how serious it is. This is another example of how poor the state of health information generally is in Canada.

Are there specific categories of providers which are in particularly short supply? Have some provinces been more successful than others in addressing the perceived shortages of professionals practising in the field of mental illness and addiction?

This lack of information creates very serious obstacles to the appropriate planning of mental health and addiction human resources, notably the implementation of a national human resource strategy in the field of mental health, mental illness and addiction.[39]

How can credible, realistic estimates be made of the human resources currently at work and required in a restructured mental health/addiction system? What role should the federal government play in helping the provinces and territories to ensure an appropriate supply of professionals in this field throughout the country? How can the federal government get

[36] First report, Chapter 8, Section 8.2.5.
[37] Second Report, Sections 1.3.2, 2.3.2, 3.3.1, 4.3,1, 4.3.2 and 4.3.3.
[38] First Report, Chapter 8, Section 8.2.5.
[39] *Ibid.*

involved in human resource planning in the mental health/addiction sector without encroaching on provincial/territorial jurisdiction?

What elements should such a national human resource strategy encompass (planning, training, review of scope of practices, etc.)? What programs and incentives should be put in place to encourage people to become engaged in mental health and addiction services? The Committee invites views on the challenges and opportunities to develop and implement a human resource strategy.

The objective of a human resource strategy should be to ensure that the right skills and services are delivered in a culturally appropriate manner by the right person at the right time. How could we expand and enhance the education and training for mental health and addiction professionals and workers to meet the objective of providing culturally appropriate services?

What role should the federal government play in helping the provinces and territories to ensure an appropriate supply of professionals in this field throughout the country?

It is obvious that the current geographic mal-distribution of mental health and addiction professionals leads to reduced access to necessary services and supports in Canada's rural and remote regions.[40] How could such under-service be alleviated? The Committee wants to hear Canadians' views on the types of incentives that could be put in place to address the shortages of mental health and addiction personnel in rural and remote areas.

It is obvious that the current geographic mal-distribution of mental health and addiction professionals leads to reduced access to necessary services and supports in Canada's rural and remote regions. How could such under-service be alleviated?

5.2 PRIMARY HEALTH CARE SECTOR

The primary health care sector is usually the first point of contact with the health care system for individuals affected by disease and injuries of all kinds, including mental illness and addiction. Yet, the Committee has been told that primary health care providers may lack sufficient knowledge, skills and financial incentives to meet the needs of patients with mental illness and addiction, to accurately screen for mental disorders, and/or to help patients navigate the appropriate referral pathways to access more specialized mental health and addiction services.[41] If primary health care providers are to be the primary gatekeepers for a patient's entry into treatment for mental illness and addiction, what needs to be done to improve mental health care at the primary care level? How can this be achieved, given the current major shortage of family physicians, nurses and other health care professionals in Canada?

If primary health care providers are to be the primary gatekeepers for a patient's entry into treatment for mental illness and addiction, what needs to be done to improve mental health care at the primary care level?

[40] First Report, Chapter 8, Section 8.2.3.
[41] First Report,Chapter 8, Sectio 8.2.4.

There is a need to increase awareness about mental illness and addiction among health care professionals. How much training in the field of mental illness and addiction should family physicians, nurse practitioners and other health care professionals receive while in medical and nursing schools? Should the curricula in nursing schools and faculties of medicine be revised so as to provide additional education and training on mental illness and addiction?

Some recommended to the Committee that medical billing schedules be modified so as to provide an incentive to family physicians to devote more time to individuals with mental illness and addiction when they need it.[42] This has been done in Alberta and Québec, following the initiation of such a program in Australia three years ago with great success. Family physicians who must take extra time to address the specific needs of individuals affected by mental disorders should have their fee-for-service rates adjusted to provide appropriate compensation.[43] Should such a program be started in provinces where there has not yet been such an adjustment to the fee schedule?

Another recommendation to the Committee called for the development of more shared mental health care initiatives across the country. This refers to collaborative work between primary health care providers and psychiatrists. Some such shared mental health care initiatives have a strong clinical focus and integrate mental health services within primary health care settings. The Committee was told that the federal government could play a major role in ensuring that successful shared mental health care initiatives continue to receive funding and that best practice models be implemented and incorporated in permanent programs and policies in all provinces and territories.[44]

Many provinces are in the process of reforming their primary health care sector. How can collaborative working relationships between primary health care providers and mental health professionals be encouraged? For example, should psychiatrists function as consultants to, or as members of, multidisciplinary primary health care teams? What specialized and/or institutionally-based mental health and addiction services could be relocated effectively to primary health care settings? What are the major barriers to implementing shared mental health care? What are the financial barriers? Do current scope of practice rules need to be changed to accommodate shared mental health care? In its current support to primary health care reform, should the federal government explicitly encourage shared mental health care? How much funding would be necessary to implement more broadly this approach?

How can collaborative working relationships between primary health care providers and mental health professionals be encouraged?

How can psychologists and social workers be made a part of a team of mental health service providers? Where would the money come from to pay for their services,

How can psychologists and social workers be made a part of a team of mental health service providers?

[42] *Ibid.*
[43] Second Report, Section 10.3.2.
[44] First Report, Chapter 8, Section 8.2.4.

given that they are not members of the medical profession with billing privileges under the *Canada Health Act* and therefore their services are not covered under Canada's publicly funded health care insurance system?

5.3 COMMUNITY SUPPORT WORKERS AND POLICE OFFICERS

A wide range of workers provide community supports to individuals with mental illness and addiction. These workers are members and/or employees of various nongovernmental organizations as well as of numerous social agencies (welfare, income support, employment, etc.).

Five years ago, New Zealand implemented a training program to provide formal certification to community mental health support workers.[45] What types of training are currently available to, and required of, a community mental health support worker in Canada? Should there be more uniformity in the training and education of community mental health support workers? Should training programs similar to that provided in New Zealand be developed? If so, what institutions should provide that training? Should provincial/national licensing bodies comparable to those of the self-regulating health professions be charged with regulating such workers? Should the federal government provide specific financial support to help launch a training program?

Five years ago, New Zealand implemented a training program to provide formal certification to community mental health support workers.[1] What types of training are currently available to, and required of, a community mental health support worker in Canada?

The Committee is also aware that, increasingly, it is often the police officer who first comes into contact with persons in the midst of a mental health crisis rather than health care agencies or providers. Oftentimes, individuals with severe mental disorders have nowhere to go when experiencing a crisis. When there is a crisis, police officers are the ones who are called to intervene. We were told, however, that law enforcement officers often lack the training and policy guidance on how to intervene when someone is in the midst of a mental health crisis. What should be done to improve the training of police officers to enable them to deal more effectively with individuals with mental illness and addiction? How can we increase the safety of those involved in the intervention and help to ensure that law enforcement officers use the least amount of force when apprehending someone who is experiencing a mental health crisis?

What should be done to improve the training of police officers to enable them to deal more effectively with individuals with mental illness and addiction? How can we increase the safety of those involved in the intervention and help to ensure that law enforcement officers use the least amount of force when apprehending someone who is experiencing a mental health crisis?

[45] Second Report, Chapter 2, Section 2.3.2.

5.4 SUPPORTING CAREGIVERS

Families are often the principal resource and the sole support available to individuals with mental illness and addiction. Because of the limited resources available in the health care system and the community, it is parents who house, care, supervise and provide financial assistance to their affected children.

Do families living with someone affected by mental illness or addiction have adequate access to the resources they need to help their loved ones?

Several studies have shown that this situation can be a source of enormous tension and emotional stress as well as financial strain for those close to individuals affected by mental illness and addiction. Do families living with someone affected by mental illness or addiction have adequate access to the resources they need to help their loved ones? Are families adequately equipped to deal with their relatives affected by mental illness and addiction?

Families are an integral part of the care provided to individuals with mental illness and addiction. They are benevolent and effective allies in limiting the pain and suffering their relatives are living with. Should family caregivers be more involved in the care and treatment of the affected members? How and in what form should we encourage their participation in the formal mental health/addiction system?

CHAPTER 6: NATIONAL INFORMATION DATABASE, RESEARCH AND TECHNOLOGY

The Committee believes strongly that excellence in mental health services and addiction treatment depends on a strong commitment to developing a national information database, fostering research on how to manage health information generally and that related to mental health and addiction in particular, and to using information and communications technology appropriately. This would greatly help to inform and guide decisions, the setting of policies and priorities, and improve outcomes for individuals with mental illness and addiction.

6.1 CANADIAN COMMUNITY HEALTH SURVEY

The 2002 Canadian Community Health Survey (CCHS), Cycle 1.2 on Mental Health and Well-Being, carried out by Statistics Canada, provided for the first time prevalence rates for some mental illnesses, substance use disorders, suicidal ideation, and pathological gambling. It did not, however, cover the wide range of anxiety and affective mood disorders as did the National Survey of Mental Health and Well-Being undertaken in Australia in 1997. The Australian survey also distinguished between the harmful use of, and dependence on, alcohol and drugs, and permitted an assessment of both concurrent disorders and co-morbidity. The Australian government also plans a survey to assess the prevalence rates of mental disorders among children and adolescents as well as a survey of psychotic disorders of lower prevalence, such as schizophrenia.[46]

The CCHS survey should be repeated on a regular basis and its base should be expanded to cover a wider range of mental disorders, age groups and population sub-groups. Canada does not currently collect data on an ongoing basis on the prevalence of mental illness and addiction among Aboriginal peoples, homeless peoples and the prison population – groups that appear to be at higher risk for mental disorders than the general population.[47]

The CCHS survey should be repeated on a regular basis and its base should be expanded to cover a wider range of mental disorders, age groups and population sub-groups.

Should Statistics Canada undertake a survey of children and adolescents as will be done in Australia? Should Statistics Canada be asked to expand its next Canadian Community Health Survey to include, as the Australia survey does, questions which enable an assessment of both concurrent disorders and co-morbidity? What can be done to improve the information available on the prevalence of mental disorders among Aboriginal peoples, homeless people and the prison population? With what frequency should the CCHS be undertaken? Should we share our survey methodology with other countries to allow meaningful international comparisons?

What can be done to improve the information available on the prevalence of mental disorders among Aboriginal peoples, homeless people and the prison population?

[46] First Report, Chapter 5, Section 5.1 and 5.2.
[47] First Report, Chapter 5, Section 5.3.

6.2 NATIONAL INFORMATION DATABASE

Canada currently lacks a national information base on the prevalence of mental illness and addiction. We also lack the information system required to measure the mental health status of Canadians and to evaluate policies, programs and services in the fields to mental health, mental illness and addiction.

Canada currently lacks a national information base on the prevalence of mental illness and addiction. We also lack the information system required to measure the mental health status of Canadians and to evaluate policies, programs and services in the fields to mental health, mental illness and addiction. This is a major impediment to determining the level of mental health services and addiction treatments that the provinces/territories and the country need, and the quality of services currently provided.

The Canadian Alliance on Mental Illness and Mental Health is advocating the development of a national information system for mental health, mental illness and addiction characterized by a dynamic collaboration among all levels of government and all stakeholders ranging from individuals with mental illness and addiction to data collectors. Several databases, including those provided by an expanded CCHS survey, could be used to lay the base of such an information system. This basic system could be expanded over time into a well-organized database which could be used by policy makers and researchers both inside and outside of government with the addition of new indicators and new sources of data.

Who should take the lead in facilitating the development of such a national information database system?

Who should take the lead in facilitating the development of such a national information database system? What role should Statistics Canada, Health Canada, the Canadian Institute for Health Information and the Canadian Institutes of Health Research and provincial/territorial governments play in the establishment and maintenance of the system? Are there countries or provinces/territories that could be considered as a potential model for the development of a nationwide database? How much funding would be necessary to establish a comprehensive, well-managed national information database system for mental health, mental illness and addiction?

6.3 RESEARCH

6.3.1 Level of Funding

The Canadian Institutes of Health Research (CIHR), through its Institute of Neurosciences, Mental Health and Addiction (INMHA), is the primary federal funding agency for research into mental health, mental illness and addiction. For the 2003-2004 fiscal year, CIHR has allocated $93 million to INMHA from its total base budget of $623 million. Some $33

million from the INMHA budget goes to mental health and addiction research, or 5.3% of the total envelope of CIHR health research funding.[48]

Several witnesses presented the view that the proportion of health research dollars allocated to mental health, mental illness and addiction is too small. They claimed that the funding dedicated to research into mental health, mental illness and addiction does not reflect the burden of mental illness and substance use disorders on the Canadian economy. Estimates suggest that if funding were to be provided in relation to the economic burden of disease, then CIHR's support for mental illness and addiction would have to increase from its current base of $33 million to at least $80 million per year. The Committee was also told that CIHR's proportional investment in mental health, mental illness and addiction (5.3%) is relatively low in comparison to other countries (6.5% in the United Kingdom and 10% in the United States).[49]

The funding dedicated to research into mental health, mental illness and addiction does not reflect the burden of mental illness and substance use disorders on the Canadian economy. Estimates suggest that if funding were to be provided in relation to the economic burden of disease, then CIHR's support for mental illness and addiction would have to increase from its current base of $33 million to at least $80 million per year.

What measure should be used to determine the appropriateness of the proportion of research funds spent on research into any given disease? Should it be prevalence rates, morbidity and mortality, disability, or the economic burden associated with the disease? Is such an approach to measurement appropriate at all? What should be the role, if any, of international comparisons? Should research funding be decided solely or predominantly on the basis of merit and promise among all applications submitted to the granting agency concerned? Or, should it be determined after consideration of a combination of all of the measures and factors referred to above?

If more funding is required for INMHA, where should it come from – a reallocation within CIHR's budget or an increase in INMHA's total budget? Should a dedicated fund be established to support research into mental health, mental illness and addiction? Should a new institute dedicated to mental health, mental illness and addiction be created by CIHR and, if so, how should it relate to INMHA? The Committee welcomes opinions and suggestions on the options to increase federal funding for research into mental health, mental illness and addiction.

If more funding is required for INMHA, where should it come from – a reallocation within CIHR's budget or an increase in INMHA's total budget?

Other research funding questions include: is the research funding from provincial governments sufficient? What about the level of research funding from mental health organizations? Are pharmaceutical companies investing sufficient funds in this area?

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[48] First Report, Chapter 10, Section 10.1.
[49] First Report, Chapter 10, Section 10.2.

6.3.2 Knowledge Translation

The Committee has also considered the issue of knowledge translation – bringing the outcomes of research to the provider/institution/community where services and supports are delivered. All too frequently, published research discoveries in mental health, mental illness and addiction (medications, psychotherapies, etc.) remain with researchers in their laboratories and have too limited an impact on service delivery and patients' outcomes.

This situation is not unique to Canada. In the United States, a report estimated that there is a 15 to 20 year lag between discovering effective forms of treatment (medications, therapies, new ways of delivering care, etc.) and incorporating them routinely into patient care. The same report also showed that when discoveries become routinely applied at the community level, actual clinical practices remain highly variable and are often inconsistent with the treatment model shown to be most efficacious.[50] At the same time, the Committee was told that, in the United Kingdom, the National Institute for Mental Health in England (NIMHE) has played an important role in making the most advanced research available to mental health providers on the ground.[51]

All too frequently, published research discoveries in mental health, mental illness and addiction (medications, psychotherapies, etc.) remain with researchers in their laboratories and have too limited an impact on service delivery and patients' outcomes.

What are the reasons behind the resistance to adopting evidence-based state-of-the-art medications and therapies? How can this resistance be overcome?

What are the reasons behind the resistance to adopting evidence-based state-of-the-art medications and therapies? How can this resistance be overcome?

What incentives will work to encourage the early and universal adoption of new beneficial evidence-based research results by mental health and addiction service providers? Should the federal government put in place an innovation fund to encourage innovation in service delivery and accelerate the adoption of research results in the mental health/addiction system? How big should this fund be? What conditions should be attached to projects supported by the fund?

What incentives will work to encourage the early and universal adoption of new beneficial evidence-based research results by mental health and addiction service providers?

Should the federal government consider the possibility of establishing a body similar to NIMHE in the United Kingdom in order to facilitate knowledge translation? Or, should this task be the responsibility of CIHR's Institute of Neurosciences, Mental Health and Addiction (INMHA)? If so, what can be done to enhance INMHA's capacity to bring the outcomes of research into practice settings?

The Committee welcomes the views of readers on ways that could accelerate the application of research results with beneficial impacts on treating patients in mental health, mental illness and addiction.

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[50] First Report, Chapter 10, Section 10.4.
[51] Second Report, Chapter 3, Section 3.6.

6.3.3 Research Involving Human Subjects

As mentioned in the first report, there has been an acceleration of clinical research into mental illness and addiction in the last two decades that has produced significant advances in treatment. Much of this important research requires the participation of research subjects who suffer from mental disorders themselves.[52]

Special precautions are needed in research involving individuals with mental illness and addiction. While all subjects of clinical research are vulnerable to some degree, the vulnerability of individuals participating in clinical mental illness/addiction research is of particular concern because such disorders, particularly if they affect cognition or are severe, often impair their decision-making capacity. The capacity to give a valid consent is, of course, an essential condition for research involving human subjects. Therefore, keen vigilance must be applied when assessing the decision-making capacity of potential subjects and when determining and informing alternative decision-makers for the patient, especially when participation in a study may not directly benefit the patient/subject concerned.[53]

While all subjects of clinical research are vulnerable to some degree, the vulnerability of individuals participating in clinical mental illness/addiction research is of particular concern because such disorders, particularly if they affect cognition or are severe, often impair their decision-making capacity.

Recognizing the particular vulnerability of individuals participating in clinical mental illness/addiction, the Committee attaches paramount importance to the protection of the rights and well-being of those who participate as research subjects. Research advances should only be pursued in the most ethically responsible way and never at the expense of human rights and dignity. But neither should the protections be so stringent as to exacerbate existing social stigma associated with mental illness and addiction and exclude this vulnerable population from participating in vitally important research with the potential to improve scientific knowledge about their conditions, and sometimes, benefit them as individuals. Are the guidelines currently governing the conduct of research involving human subjects adequate to protect the special vulnerabilities of individuals with mental illness and addiction? Are the safeguards applied with sufficient stringency in clinical trials conducted outside teaching centres?

Are the guidelines currently governing the conduct of research involving human subjects adequate to protect the special vulnerabilities of individuals with mental illness and addiction? Are the safeguards applied with sufficient stringency in clinical trials conducted outside teaching centres?

6.3.4 A National Research Agenda

Those who addressed issues related to mental health and addiction research agreed unanimously on the need for a national research agenda. In their view, such an agenda should build on current Canadian expertise, coordinate the currently fragmented research

[52] First Report, Chapter 11, Section 11.6.
[53] First Report, Chapter 11, Section 11.6.

activities performed by a variety of actors (governments, non-governmental organizations, pharmaceutical companies, universities, etc.) and ensure a balance between biomedical, clinical, health services and population health research related to mental health, mental illness and addiction.[54] Who should have the responsibility of developing, implementing and coordinating such a national research agenda – INMHA, CIHR or another entity entirely? What research topics should claim initial priority?

6.4 INFORMATION AND COMMUNICATIONS TECHNOLOGY

6.4.1 Electronic Health Records

As explained in the Committee's October 2002 health care report, a system of electronic health records (EHRs) provides each individual with a secure, private and comprehensive lifetime record of his/her health history and care within and by the health care system, including visits to family physicians and specialists, hospital stays, prescription drugs, laboratory tests, etc. That record is available electronically anywhere, anytime, to its individual owner and those health care providers authorized by him or her to access it in support of high quality care.

Not only would such an EHR system greatly improve the quality and timeliness of health care delivery, it would also enhance health care system management, efficiency and accountability. The data collected from an EHR system would also be invaluable for the purposes of health research.[55]

All levels of government in Canada have recognized the importance of developing and deploying a system of EHR. In fact, on September 11, 2000, the First Ministers agreed to work together to develop an EHR system over the next three years and to work collaboratively to develop common data standards to ensure the compatibility and interoperability of provincial health information networks and the stringent protection of personal health information. In support of that agreement, the federal government established Canada Health Infoway Inc. (or *Infoway*) in 2001 with a budget of $500 million to support and accelerate the development and adoption of interoperable electronic health records solutions throughout the country.

The Committee believes that the effective health information management made possible in substantial part by an EHR system can improve effectiveness and efficiency of the provision of mental health services and the treatment of addiction.

In its report of October 2002, the Committee expressed strong support for the deployment of a national EHR system. In particular, we stressed that the work undertaken by *Infoway* represented a major step towards the full integration of the several provincial and territorial health infostructures. We recommended that the federal government provide *Infoway* with $2 billion over a five-year period for the development of a national system of electronic health records (EHRs) to support the Canadian hospital and doctor

[54] First Report, Chapter 10, Section 10.5.
[55] *Recommendations for Reform*, October 2002, Chapter 10, Section 10.2.

system insured under Medicare.[56] In 2003, the federal government increased *Infoway*'s capitalization to $1.1 billion.

The Committee believes that the effective health information management made possible in substantial part by an EHR system can improve effectiveness and efficiency of the provision of mental health services and the treatment of addiction. First, as in physical health care, an EHR is a necessary prerequisite to a truly patient-oriented mental health and addiction system. Second, it offers tremendous opportunities to support integration of the different components of the mental health service system and the addiction treatment system that currently work in silos. Third, exchanging health information through secure means makes important data available at the right times and places to support optimal mental health care and recovery for all patients/clients. And finally, EHR can dramatically reduce the need to repeatedly provide personal and family health history every time an individual with mental illness and addiction encounters a different mental health/addiction professional.

The Committee wants to know if the EHR system now being developed by Canada Health Infoway Inc. raises particular concerns among and with respect to patients/clients with mental illness and addiction. For example, do psychiatric records differ materially from other types of medical records and, if so, how? Should information about mental illness and addiction be dealt with differently than other personal health information under the EHR? We invite the views of mental health providers, addiction specialists, patients/clients and their families.

The Committee wants to know if the EHR system now being developed by Canada Health Infoway Inc. raises particular concerns among and with respect to patients/clients with mental illness and addiction. Should information about mental illness and addiction be dealt with differently than other personal health information under the EHR?

Issues related to the privacy, confidentiality and protection of personal health information are perhaps the most sensitive ones raised in relation to an EHR system. We address this question in detail in section 6.5 below.

6.4.2 Tele-Mental Health Services

As explained in the Committee's April 2002 report, telemedicine makes use of videoconferencing and related equipment to provide health care at a distance. As such, it can greatly improve the quality and timely access to care, particularly in rural and remote areas. Videoconferencing equipment can also be used for other purposes such as providing the continuing education and training of health care providers located in remote communities.[57]

Mental health services and supports are unevenly distributed geographically in Canada. They are specially lacking in rural and remote areas of the country, including in most Aboriginal communities/reservations. The result is that individuals with mental disorders living in rural

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[56] *Recommendations for Reform*, October 2002, Chapter 10, Section 10.2.
[57] *Principles and Recommendations for Reform*, April 2002, Chapter 4.

and remote regions and in Aboriginal settings are forced to travel far from their homes for needed services. This hardship, ironically dubbed "Greyhound Therapy", is doubly stressful for someone affected by mental illness and addiction.[58]

When removed from their communities, individuals are separated from their natural support systems and informal care networks, those things that provide the kind of financial, emotional and social supports essential for recovery but not found in the formal treatment system. Although for some the anonymity of the city may be a welcome respite from stigma and shame, removal from the home community can have a significant negative impact on treatment interventions and outcomes.

The Committee was told that transplanting urban mental health workers into rural settings, even if they would be willing to relocate, would not necessarily do much good. The transplanted professionals would still not be qualified to deal with distinctive rural culture and the myriad of related issues.

What is the potential for telemedicine in the field of mental illness and addiction? What are the challenges? Is the current investment by the federal government in telemedicine adequate in the field of mental illness and addiction?

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The Committee wants to hear the view of Canadians on the need for expanded telemedicine applications in mental health service delivery and in mental health/addiction education and training.

6.4.3 Internet-Based Health Information Network

Individuals with mental illness and addiction and their families want up-to-date information about the mental disorders with which they are dealing, together with information on effective treatments, services and supports. But despite the quickly growing availability of communications via the Internet, reliable information is not always available when and how people need it most; certainly it is not readily or universally accessible to all Canadians. Moreover, most times it is difficult for individuals to assess the accuracy and objectivity of information available and whether or not it can be trusted.

The Canadian Health Network, a collaborative effort by the federal government and some health organizations across Canada, is considered by many to be among the best in the world. It provides in-depth health promotion and disease prevention information to Canadians on 26 key health topics, including mental health and substance use/addiction.

There are also provincial websites devoted to mental illness and addiction; an example is www.heretohelp.bc.ca, a website developed by a group of seven provincial non-profit agencies dealing with mental health and addiction in British Columbia and funded by the provincial government.

[58] First Report, Chapter 8, Section 8.2.3.

In its April 2002 report, the Committee recommended the creation of a national portal for the Canadian public that would provide comprehensive, trusted health-related information to support self-care decision-making. We stressed that the portal should build on the success of the Canadian Health Network and be linked strategically to provincial and territorial website services to ensure the consistency of health-related information. We also indicated that the national portal should allow better access by specific populations that currently have only restricted access to health-related information of assured high quality (e.g. Aboriginal Canadians, rural and remote communities, etc.).[59]

In its April 2002 report, the Committee recommended the creation of a national portal for the Canadian public that would provide comprehensive, trusted health-related information to support self-care decision-making. We stressed that the portal should build on the success of the Canadian Health Network and be linked strategically to provincial and territorial website services to ensure the consistency of health-related information.

Is the Canadian Health Network well positioned to become a universally trusted website in the field of mental health, mental illness and addiction? How could the Network build on successful provincial information websites and, at the same time, avoid resource-wasting duplication?

Is the Canadian Health Network well positioned to become a universally trusted website in the field of mental health, mental illness and addiction? How could the Network build on successful provincial information websites and, at the same time, avoid resource-wasting duplication?

6.5 PRIVACY

In its final report on health care (October 2002), the Committee discussed the need to protect the privacy of electronic health records and their use in research.

With respect to EHRs, we noted the significant variation in privacy laws and data access policies across the country. To address this concern, the Committee recommended ongoing federal/provincial/territorial efforts to develop a harmonized approach to protecting personal health information.

We also raised the issue of the large number of players involved in the collection of personal health information which would be included in a common EHR. We recommended that state-of-the-art security safeguards be implemented to protect personal health information and that the various custodians accessing EHRs be accountable for the use of those records.[60]

With respect to research, the Committee acknowledged the need to permit restricted access to personal health information for health research purposes while preserving the confidentiality of such information. We recommended that the federal government initiate a public awareness program to foster a better understanding of the benefit of using personal

[59] Principles and Recommendations for Reform, April 2002, Chapter 4, Section 4.7.
[60] Recommendations for Reform, October 2002, Chapter 10.

health information for health research purposes. We also recommended that the federal government, together with CIHR and other relevant stakeholders, examine the control and review mechanisms needed to ensure the adequate protection of personal health information.[61]

In the first report, the Committee noted that some people argue that considerations of privacy are perhaps of greater concern in mental health, mental illness and addiction than they are in the physical health care system. The testimony we heard compels us to ask if Canada's current legal and policy frameworks on privacy and confidentiality, which are acknowledged to serve the mentally competent well on the whole, nevertheless act against the best interests of those who, because of the nature and pervasiveness of mental illness and addiction, become partially or completely dependent on a series of providers along the whole continuum of care.[62]

The testimony we heard compels us to ask if Canada's current legal and policy frameworks on privacy and confidentiality, which are acknowledged to serve the mentally competent well on the whole, nevertheless act against the best interests of those who, because of the nature and pervasiveness of mental illness and addiction, become partially or completely dependent on a series of providers along the whole continuum of care.

In the context of an EHR system, the Committee is well aware that any erosion of privacy and confidentiality protections can have serious negative consequences on an affected individual's trust in his or her mental health providers. Witnesses have told us, however, that rigid adherence to privacy and confidentiality rules in certain circumstances works against the interests of individuals whose mental health is compromised. This particular challenge must be recognized when developing, interpreting and applying rules of privacy and confidentiality so as not to prevent health care providers from providing patients/clients with the much needed support they require.[63]

The Committee wants to obtain the views of Canadians on whether more safeguards are required under a system of EHRs for protecting mental illness and addiction information or whether more flexibility is needed to allow for the flow of information to provide better mental health care and greater continuity of care. In addition, we need to know whether amendments to existing provincial legislation are required to permit the sharing of patient information among providers.

Concerns relating to the strict observation of current privacy and confidentiality rules extend also to the family of individuals with mental illness and addiction. Without the patient's permission, which those with mental illness/addiction may not be competent to give at times, a physician cannot currently share personal information with the involved caregivers, parents, siblings or children.[64]

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[61] *Recommendations for Reform*, October 2002, Chapter 12.
[62] First Report, Chapter 11, Section 11.3.
[63] First Report, Chapter 11, Section 11.7.
[64] First Report, Chapter 11, Section 11.3.

Are there mental health systems that have better, clearer procedures and consent forms for releasing information to families? What changes are required in Canada to facilitate the sharing of information about a patient's/client's condition with his or her family? Should there be greater consistency and standardization of information sharing practices in Canada with respect to patients with mental illness and addiction?

What changes are required in Canada to facilitate the sharing of information about a patient's/client's condition with his or her family? Should there be greater consistency and standardization of information sharing practices in Canada with respect to patients with mental illness and addiction?

CHAPTER 7:
THE ROLE OF THE FEDERAL GOVERNMENT

The federal government has both a direct and an indirect role in the field of mental health, mental illness and addiction. Its direct role stems from its constitutional responsibility for First Nations living on reserves and the Inuit populations, inmates of federal penitentiaries, veterans and serving members of the Canadian forces, the RCMP, and certain landed immigrants and refugee claimants. Through its direct role, the federal government is also a major employer with management of a large workforce with particular health-related concerns. Its indirect role derives from its broad responsibility to oversee the national interest of all Canadians and encompasses: funding transfers to provinces/territories, data collection, funding research, drug approval process, income support and disability pension benefits, social programming such as housing initiatives, criminal justice, and ongoing work to promote overall population health and well-being. Therefore, the range of federal programs and services relevant to mental health, mental illness and addiction is large.[65]

7.1 DIRECT ROLE

In its first report, the Committee noted that the federal approach to mental health, mental illness and addiction for the specific population groups who fall under its responsibility is highly fragmented: services and supports are provided by different departments, or various departmental directorates or divisions, all without much collaboration. We also commented on the lack of collaboration between federal and provincial governments with respect to programs targeted at First Nations, Inuit people and federal inmates. In addition, we noted gaps in services in many of the programs reviewed.[66]

The federal approach to mental health, mental illness and addiction for the specific population groups who fall under its responsibility is highly fragmented.

Overall, we concluded that there is little evidence to suggest that the federal government is following specific population-targeted strategies for the groups for which it has direct responsibility, let alone a broad all-encompassing strategy for all Canadians. There is no evidence of any effort to develop an overall coordinated federal framework or to elicit the collaboration of all involved departments or agencies. Neither is there apparent any initiative to develop a comprehensive population specific strategy to address the mental health needs of any of the groups under federal responsibility.[67]

There is no evidence of any effort to develop an overall coordinated federal framework or to elicit the collaboration of all involved departments or agencies.

What can be done to coordinate and better integrate the federal approach to mental illness and addiction for Canadians falling under its responsibility? For example, should Health

[65] First Report, Chapter 9, Section 9.1.
[66] First Report, Chapter 9, Section 9.2.
[67] First Report, Chapter 9, Section 9.3.

Canada work in partnership with the Department of Indian and Northern Affairs, Human Resources Development and other relevant departments to improve the effectiveness and efficiency of the delivery of mental health services and addiction treatment to First Nations and Inuit communities? How can such inter-ministerial collaboration be fostered? Or should a single department be responsible for the delivery of mental health/addiction services? Or should responsibility be transferred to the provinces with the federal government paying the cost of the services provided?

What can be done to coordinate and better integrate the federal approach to mental illness and addiction for Canadians falling under its responsibility?

Similarly, how can the access to, and quality of, needed services and supports be improved for inmates of federal penitentiaries? What can the federal government do to enhance Correctional Service Canada's response capacity for those in need of mental health services and addiction treatment?

How can inter-jurisdictional collaboration be enhanced in the delivery of mental health services and addiction treatment for First Nations and Inuit people and federal inmates? For example, with respect to the inmates of federal penitentiaries, what relevant federal and provincial policies and programs should be harmonized (e.g.: Criminal Code and provincial mental health legislation)?

Veterans, members of the Canadian Forces and RCMP are excluded from the definition of "insured persons" under the *Canada Health Act*. Health care, mental health services, suicide prevention and addiction treatment are the responsibility of Veterans Affairs Canada, the Department of National Defence and Health Canada. How should the programs and activities of these departments be better coordinated?

7.2 INDIRECT ROLE

In addition to its direct role, the federal government has an indirect role in the field of mental health, mental illness and addiction with broad responsibility to oversee the national interest of Canadians. The Committee was told that traditionally the federal government has made use of its constitutional spending power to influence broad national initiatives in the area of health and social policy. As a matter of fact, that spending power forms the basis for the *Canada Health Act*, the Canada Health Transfer and the Canada Social Transfer.[68]

A major issue raised during the Committee's hearings with respect to the indirect federal role relates to the apparent ambivalence over the last 55 years about the place of mental health services in the publicly funded health care system.[69] Today, the *Canada Health Act* expressly excludes from its definition of comprehensiveness services provided by psychiatric institutions. Many mental health services provided in the community by non-

A major issue raised during the Committee's hearings with respect to the indirect federal role relates to the apparent ambivalence over the last 55 years about the place of mental health services in the publicly funded health care system.

[68] First Report, Chapter 9, Section 9.4.
[69] First Report, Chapter 9, Section 9.4.2.

physician providers are not covered under the *Act*; this is true for the counselling services provided by psychologists, for example.[70]

Currently, no specific amount of federal transfers is dedicated to mental health care and addiction treatment. While the Canada Health Transfer includes funding for acute community mental health care, no portion of the transfer is expressly designed for this purpose.[71]

How can the federal government correct what is described as its "ambivalent approach" taken over the years about the place of mental health in its broad national policies and programs? Is it appropriate at this point in time to re-open the *Canada Health Act* to include under its publicly insured services those provided by psychiatric institutions and by psychologists? Should the federal government devote a specific portion of its transfer payments to mental illness and addiction? Would this require passage of a "Canada Mental Health Act"? Should the Prime Minister appoint a Minister of State for mental health, mental illness and addiction?

How can the federal government correct what is described as its "ambivalent approach" taken over the years about the place of mental health in its broad national policies and programs?

Or, should the federal government provide funding for the support of mental health, mental illness and addiction under a new funding mechanism? Should conditions be attached to any federal transfers to the provinces/territories for the purpose of mental illness and addiction and, if so, what should they be? If the federal government is to develop a set of incentives to ensure that individuals with mental illness and addiction get universal and equitable access to needed services and supports, what should they be and how best could this objective be achieved?

If the federal government is to develop a set of incentives to ensure that individuals with mental illness and addiction get universal and equitable access to needed services and supports, what should they be and how best could this objective be achieved?

Access to prescription drugs and home care is also an issue identified during the Committee's hearings. What role can the federal government play to ensure that individuals with mental illness and addiction have access to the drug therapy they need? Will the catastrophic prescription drug plan envisioned by the Committee[72], and included in the First Ministers' *10-Year Plan to Strengthen Health Care* (September 2004), ensure that individuals with mental illness and addiction get the prescription drugs

Access to prescription drugs and home care is also an issue identified during the Committee's hearings. Will the catastrophic prescription drug plan envisioned by the Committee[1], and included in the First Ministers' *10-Year Plan to Strengthen Health Care* (September 2004), ensure that individuals with mental illness and addiction get the prescription drugs they need?

[70] First Report, Chapter 9, Section 9.5.1.
[71] First Report, Chapter 9, Section 9.5.2.
[72] *Recommendations for Reform*, October 2002, Chapter 7.

they need? Do affected individuals have specific concerns with respect to such a plan?

Similarly, what form of home care program (short-term acute care, needs assessment, or long-term care in the home) is needed in the field of mental illness and addiction? Is the September 2004 First Ministers' agreement, which provides first dollar coverage for some home care services, particularly short-term acute community mental health home care for two-weeks and for the provision of case management and crisis response services, sufficient or is a more comprehensive program needed?

What form of home care program (short-term acute care, needs assessment, or long-term care in the home) is needed in the field of mental illness and addiction?

7.3 INTERGOVERNMENTAL COLLABORATION

While traditionally the federal government has used its fiscal capacity to influence health and social policies at the national level, some have claimed that this is not sufficient. Witnesses told the Committee that a high degree of intergovernmental consultation and collaboration is essential to achieve uniformity, to develop and maintain standards, bring harmonization and establish a national mental health initiative across the country. The provinces and territories have major responsibility for the delivery of services for mental illness and addiction in their particular jurisdictions. Any consideration of a federal role in mental health, mental illness and addiction, however, cannot displace or reduce the primary provincial/territorial responsibility for the design and delivery of programs for individuals with mental illness and addiction. Therefore, to restructure and reform the mental health/addiction system, a great deal of effort must be devoted to intergovernmental consultation, partnerships and collaboration.

A high degree of intergovernmental consultation and collaboration is essential to achieve uniformity, to develop and maintain standards, bring harmonization and establish a national mental health initiative across the country.

To restructure and reform the mental health/addiction system, a great deal of effort must be devoted to intergovernmental consultation, partnerships and collaboration.

Currently, however, few resources are devoted to the intergovernmental work in this area. A formal structure – the Federal/Provincial/Territorial Advisory Network on Mental Health – was established on 17 April 1986 to advise the Conference of Deputy Ministers of Health on cooperation among federal, provincial and territorial governments on mental health issues. In the late 1990s, however, the Council of Deputy Ministers of Health withdrew its support for the F/P/T Advisory Network on Mental Health. As a result, there is now insufficient funding available even to bring together mental health policy makers from across the country to share information and develop coherent policies and plans. A

Currently, there is not enough funding available to bring together mental health policy makers from across the country to share information and develop coherent policies and plans.

number of provinces still continue to participate in the F/P/T Advisory Network, but their work is limited by the small amount of funding they provide.[73]

What could the federal government do to encourage intergovernmental coordination, collaboration and partnerships in the field of mental health, mental illness and addiction?

What could the federal government do to encourage intergovernmental coordination, collaboration and partnerships in the field of mental health, mental illness and addiction? Should the F/P/T Advisory Network be re-established with a broader mandate to encompass both mental health and addiction? Or should another entity, either a new body (such as the Mental Health Commission in New Zealand[74], the National Institute of Mental Health in England[75] or the former Mental Health Commission in New Brunswick) or an existing one (like the Canadian Public Health Agency) take over such a mandate?

What could the federal government do to assist the provinces and territories in their efforts to reform and renew their mental health and addiction systems?

What could the federal government do to assist the provinces and territories in their efforts to reform and renew their mental health and addiction systems? Is there a province, region or country whose mental health delivery system and addiction treatment system can be used as a model? Would the position of a Minister of State responsible for mental health and addiction, as in British Columbia, be helpful in other jurisdictions, including the federal government?

7.4 NATIONAL ACTION PLAN

Canada needs to develop a comprehensive national action plan on mental health, mental illness and addiction to ensure successful reform and restructuring. Canada lacks national leadership in mental health, mental illness and addiction, a serious deficiency that, in the view of many, has left a very large void.

The Committee was told that, in addition to intergovernmental collaboration, Canada needs to develop a comprehensive national action plan on mental health, mental illness and addiction to ensure successful reform and restructuring. Australia, New Zealand and the United Kingdom have already adopted such a national mental health strategy or action plan. Canada lacks national leadership in mental health, mental illness and addiction, a serious deficiency that, in the view of many, has left a very large void: there is no focus on mental illness and addiction within national and provincial/territorial health care reform initiatives; there is no clear delineation of the roles and responsibilities of the various stakeholders; troublesome inequities are the result of different provinces and territories being at various stages in the reform of their mental health care and addiction treatment systems.

Many recommended to the Committee a strong leadership role for the federal government in the development of a national action plan. They believe that the lack of such leadership

[73] First Report, Chapter 9, Section 9.4.
[74] Second Report, Chapter 2, Section 2.1.1.
[75] Second Report, Chapter 3, Section 3.1.1.

has contributed to the piecemeal approach to addressing mental illness and addiction, has led to the development of potentially conflicting models in different provinces, and resulted in unnecessary duplication and a waste of resources.

Many recommended a strong leadership role for the federal government in the development of a national action plan.

Witnesses argued that the national framework must set standards for service delivery covering all aspects of mental health from prevention, promotion and advocacy through community-based services to inpatient and specialty services. It must also apply to services provided throughout every affected individual's lifespan. It must provide a stronger focus on children and adolescents, Aboriginal peoples, senior Canadians, federal inmates, women and landed immigrants.

Many stressed that a national action plan for mental health, mental illness and addiction can only be developed out of the collaboration among the federal government, provincial and territorial jurisdictions, NGOs and other stakeholders, together with individuals with mental illness/addiction.

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In September 2000, the Canadian Alliance on Mental Illness and Mental Health (CAMIMH), an organization representing some 20 NGOs, released a discussion paper calling for the development of a national action plan that would lead to a fundamental shift in how Canada deals with mental health, mental illness and addiction. This discussion paper was intended to be the first step toward the development of consensus for a national action plan on mental health, mental illness and addiction. It was seen as a tool to facilitate discussion, stimulate ideas and build a strong national coalition to promote its implementation by all levels of government. It was not intended to be a policy discussion document nor a guide to systemic reform. What has been achieved at the federal, provincial and local levels since the release of CAMIMH's call for action? Have any of the goals or the vision put forward by CAMIMH been adopted in any regions of the country? Should the NGOs represented by CAMIMH go a step further and develop a more concrete proposal for restructuring the mental health/addiction system?

More generally, what are the current obstacles to the development of a national action plan on mental health, mental illness and addiction? How should such a plan be developed and implemented? Should it be by an incremental approach or through the simultaneous reform of several large scale systems? Should Canada have a single, national, action plan? Or, should each province/territory have its own action plan but with a common vision?

Should the national action plan be developed by an incremental approach or through the simultaneous reform of several large scale systems? Should Canada have a single, national, action plan? Or, should each province/ territory have its own action plan but with a common vision?

In addition to articulating a common, clear vision, should governments develop detailed goals, objectives and standards for mental health, mental illness and addiction? Would this

help to properly assess patient/client outcomes and in reporting on the system's performance?

What elements should be included in a national action plan?

What elements should be included in a national action plan: public and professional awareness and education; mental illness and suicide prevention, dissemination of information and/or guidelines on best practices, human resource planning (including training and education), research funding, incentives to encourage systemic integration and collaboration? What should the priorities be?

How can we ensure that individuals affected by mental illness and addiction and their families participate fully in the development of a national action plan?

How can we ensure that individuals affected by mental illness and addiction and their families participate fully in the development of a national action plan?

CHAPTER 8: FINANCING REFORM AND FOSTERING PERFORMANCE AND ACCOUNTABILITY

Concerns have been expressed about the total amount of funding available for mental health services supports and addiction treatment. Another issue relates to the need for a financing approach that distributes funding for mental health services and addiction treatment equitably across Canada.

The Committee heard that successful restructuring of the mental health/addiction system depends not only on ensuring that there are sufficient resources to provide the necessary services and supports. It also depends on the establishment of effective performance monitoring and evaluation tools and structures an information management infrastructure, and a funding framework which would allocate funds equitably.

8.1 LEVEL OF FUNDING

Funding for mental health services and addiction treatment is the subject of intense debate in Canada, as it is in many other countries. Provincial reports document the historical under-funding of mental health services and addiction treatment. Many believe that those with severe and persistent mental disorders have been badly served by insufficient funding. Those who have suffered particularly negative impacts have been individuals from different ethnocultural communities, individuals who are homeless, and those with concurrent disorders.[76]

Many witnesses told the Committee that the proportion of overall government health care spending devoted to mental health services and addiction treatment in Canada is very low in relation to the prevalence and economic burden of mental illnesses and substance use disorders and in comparison with physical illnesses. Others claimed that not enough public funding has been allocated to ensure a successful shift from institutional care to more community-based services and supports.[77]

Many witnesses told the Committee that the proportion of overall government health care spending devoted to mental health services and addiction treatment in Canada is very low in relation to the prevalence and economic burden of mental illnesses and substance use disorders and in comparison with physical illnesses.

Unfortunately, there is no simple answer to the question: "What is the right amount to spend on mental health, mental illness and addiction?" There is currently no comprehensive information on current levels of spending on mental health services and addiction. But the

There is no simple answer to the question: "What is the right amount to spend on mental health, mental illness and addiction?

[76] First Report, Section 8.2.1.
[77] First Report, Chapter 7.

Committee heard repeatedly that there are serious gaps in services and in meeting the needs and improving outcomes for individuals with mental illness and addiction. Additional resources are likely to be required over time. To answer the question "what is the right amount to spend", there must first be a thorough review of how current resources are used to meet the mental health needs of Canadians and the development of a plan on the most effective ways to best use existing resources.

The question of best use raises many issues. For example, can sufficient changes to the mental health/addiction system be made so that the resulting efficiencies will generate enough money to pay for needed mental health services and addiction treatment? Is more public funding needed? If so, how much? If more funding for mental health services and addiction treatment is needed, how should it be obtained – from a reallocation of existing resources or from increased taxation?

What, if any, should be the relationship between the funding for mental illness and addiction and the prevalence and economic burden of these illnesses? What should be the level and form of the federal government's contribution to mental health services and addiction treatment? Should it be within current transfer payment mechanisms (under the CHT and CST) or should it be provided as part of a new, different funding envelope?

What, if any, should be the relationship between the funding for mental illness and addiction and the prevalence and economic burden of these illnesses?

The Committee noted with interest that the government of New Zealand has developed very detailed national targets to build capacity in the field of mental illness and addiction (such as the number of inpatient beds, community mental health workers, detoxification beds, methadone treatment places, etc.) and to calculate national funding levels and service development requirements.[78] Should Canada develop resource targets as New Zealand has done? If so, should these targets then form the basis for federal and provincial/territorial mental illness/addiction budgets? If not, how should budgets be set in this sector and by whom?

Currently, the mental health and addiction system relies on multiple sources of funding. Like its several services and supports, funding is fragmented across many different programs. Should public funding continue to reflect the fact that numerous departments are involved in mental health, mental illness and addiction? Or, should governments establish an inter-ministerial funding pool, or initiate inter-ministerial projects and initiatives with shared program costs and benefits?

Should governments establish an inter-ministerial funding pool, or initiate inter-ministerial projects and initiatives with shared program costs and benefits?

The Committee also feels that questions need to be raised about whether funding needs to emphasize the treatment of signs and symptoms of mental disorders, or the remediation of root causes. Similarly, it is crucial to determine what to fund and, perhaps even more importantly, what to stop funding.

[78] Second Report, Chapter 2, Section 2.1.1.

8.2 DEDICATED FUNDING

Many witnesses have advocated the need for a separate, protected funding envelope for mental health, mental illness and addiction. They cited Australia's experience with increased transfer payments to the states/territories earmarked for the purpose of mental health reform; In Australia, intergovernmental agreements were signed committing the states/territories to protect or maintain their level of funding. In other words, transfer payments were clearly additional or incremental to existing funding.[79] Should a comparable "ring fencing" approach to mental health funding be established in Canada? Or, should funding for mental health, mental illness and addiction be provided in a separate funding envelope? Would dedicated funds better ensure that funding for mental health, mental illness and addiction is predictable, sustainable and equitably allocated?

Should a "ring fencing" approach to mental health/addiction funding be established in Canada?

What would be the drawbacks of dedicated funding for mental health, mental illness and addiction? For example, is there a risk that funding would be directed primarily to treatment and care and away from broader social supports?

8.3 PERFORMANCE AND ACCOUNTABILITY

Numerous provincial reports and witnesses have pointed out to the Committee that there is a significant lack of accountability mechanisms in the current mental health/addiction system. The respective roles and responsibilities of the various levels of government and the multiple service providers are not clearly set out. A performance evaluation system is needed to monitor the quality and effectiveness of the services provided and the productivity of the overall system.[80]

There is a significant lack of accountability mechanisms in the current mental health/addiction system. The respective roles and responsibilities of the various levels of government and the multiple service providers are not clearly set out.

In its October 2002 report on health care, the Committee recommended the establishment of a National Health Care Council to improve accountability in the health care system and to measure and report on system performance (cost-effectiveness, efficiency, quality and patient outcomes).[81] We also recommended that both levels of government share accountability for the use of public health care funds.[82]

How can Canadians become well informed on the progress being made by governments in reforming the mental health/addiction system? In implemen-

How can Canadians become well informed on the progress being made by governments in reforming the mental health/addiction system?

[79] Second Report, Chapter 1, Section 1.2.
[80] First Report, Chapter 8, Section 8.2.1.
[81] *Recommendations for Reform*, October 2002, Chapter 1, pp. 5-21.
[82] *Recommendations for Reform*, October 2002, Chapter 14, pp. 255-264.

ting provincial and national plans? In reducing stigma and discrimination? In meeting human resource needs?

Should quality assurance programs be put in place? How should quality be defined and, equally importantly, how should it be measured? What is the process by which a quality assurance program should be developed?

Should quality assurance programs be put in place? How should quality be defined and, equally importantly, how should it be measured?

Accountability and performance indicators are as important in the field of mental illness and addiction as they are in health care everywhere. In 2000, the F/P/T Advisory Network on Mental Health released a document containing a resource kit of performance indicators to facilitate ongoing accountability and evaluation of mental health services and supports. This very detailed resource kit, which was prepared for the provinces and territories, provides indicators for tracking performance at the system, program and client level. Have these indicators of accountability and performance been utilized by any jurisdictions? Should the federal government encourage the use of these indicators? If so, how?

Have the indicators of accountability and performance developed in 2000 by the F/P/T Advisory Network on Mental Health been utilized by any jurisdictions? Should the federal government encourage the use of these indicators?

Is the National Health Care Council envisioned by the Committee, and subsequently established as the National Health Council, the appropriate structure to assess, and report on, the performance of the mental health/addiction system and to improve accountability? Or, given that the mental health/addiction system requires services from a much broader range of programs and sectors than the health care system, should another entity – such as the Canadian Public Health Agency or a new federal-provincial-territorial organization – take on this responsibility?

Is the National Health Council, the appropriate structure to assess, and report on, the performance of the mental health/addiction system and to improve accountability?

CONCLUSION

The Committee recognizes that the set of issues, questions and options presented in this report, while extensive, is far from being exhaustive. Some readers of this paper may want to add to the issues list and others will feel that our set of options in not complete and will want to add new options of their own. We will welcome these additions to our work. We believe strongly that the input of Canadians will help to inform the public policy debate on the broad range of issues related to mental health, mental illness and addiction.

We acknowledge that the real experts in the field of mental illness and addiction are those individuals confronted with these disorders and their families/caregivers. We understand that, because stigma is so strong, you may hesitate to speak openly about your concerns and suggestions for reform. But we need your input! We have developed a short set of questions which are available on the Committee's website. We would like you to respond to them either directly through the internet or by regular post as the questionnaire is available in printed format.

The Committee needs the input of individuals confronted with mental illness and addiction and their families.

In addition to individuals with mental illness and addiction, their families and caregivers, we strongly invite mental health and addiction professionals, other providers of health services, representatives from nongovernmental organizations, and officials from federal and provincial/territorial governments and departments, and members of the general public to take the time to review the Issues and Options paper and its two companion reports and write to the Committee with their views on which options for reform they prefer, and why. We very much look forward to receiving the guidance of all Canadians as we prepare our final report and our set of recommendations. Please write to:

The Standing Senate Committee on Social Affairs, Science and Technology

The Senate

Ottawa, Ontario

K1A 0A4

soc-aff-soc@sen.parl.gc.ca

fax: (613) 990-6666

APPENDIX A:
LIST OF WITNESSES
THIRD SESSION OF THE 37TH PARLIAMENT
(FEBRUARY 2, 2004 – MAY 23, 2004)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alzheimer Society of Canada	Steve Rudin, Executive Director	June 4, 2003	17
As individuals	Thomas Stephens, Consultant	March 20, 2003	11
	Nancy Hall, Mental Health Consultant	May 28, 2003	16
	J. Michael Grass, Past Chair, Champlain District Mental Health Implementation Task Force	June 5, 2003	17
	Loïse David Murray Ronald	February 26, 2003	9
Canadian Academy of Psychiatric Epidemiology	Dr. Alain Lesage, Past President	March 19, 2003	11
Canadian Academy of Psychiatry and the Law	Dr. Dominique Bourget, President	June 5, 2003	17
Canadian Coalition for Senior Mental Health	Dr. David K. Conn, Co-Chair; President, Canadian Academy of Geriatric Psychiatry	June 4, 2003	17
Canadian Institute for Health Information	Dr. John S. Millar, Vice-President, Research and Analysis	March 20, 2003	11
	Carolyn Pullen, Consultant	March 20, 2003	11
	John Roch, Chief Privacy Officer and Manager, Privacy Secretariat	March 20, 2003	11
Canadian Institutes of Health Research	Bronwyn Shoush, Board Member, Institute of Aboriginal Peoples' Health	May 28, 2003	16

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Institutes of Health Research	Jean-Yves Savoie, President, Advisory Board, Institute of Population and Public Health	June 12, 2003	18
	Dr. Rémi Quirion, Scientific Director, Institute of Neurosciences, Mental Health and Addiction	May 6, 2003	14
Canadian Mental Health Association – Ontario Division	Patti Bregman, Director of Programs	June 12, 2003	18
Canadian Paediatric Society	Dr. Diane Sacks, President-Elect	May 1, 2003	13
	Marie-Adèle Davis, Executive Director	May 1, 2003	13
Centre for Addiction and Mental Health	Jennifer Chambers, Empowerment Council Coordinator	May 14, 2003	15
	Rena Scheffer, Director, Public Education and Information Services	May 28, 2003	16
Centre hospitalier Mère-enfant Sainte-Justine	Dr. Joanne Renaud, Child and Adolescent Psychiatrist; Young Investigator, Canadian Institutes of Health Research	April 30, 2003	13
Children's Hospital of Eastern Ontario	Dr. Simon Davidson, Chairman, Division of Child and Adolescent Psychiatry	May 1, 2003	13
CN Centre for Occupational Health and Safety	Kevin Kelloway, Director	June 12, 2003	18
Douglas Hospital	Eric Latimer, Health Economist	May 6, 2003	14
	Dr. James Farquhar, Psychiatrist	May 6, 2003	14
	Dr. Mimi Israël, Head, Department of Psychiatry ; Associate Professor, McGill University	May 6, 2003	14

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Douglas Hospital	Myra Piat, Researcher	May 6, 2003	14
	Ampara Garcia, Clinical Administrative Chief, Adult Ultraspecialized Services Division	May 6, 2003	14
	Manon Desjardins, Clinical Administration Chief, Adult Sectorized Services Division	May 6, 2003	14
	Jacques Hendlisz, Director General	May 6, 2003	14
	Robyne Kershaw-Bellmare, Director of Nursing Services	May 6, 2003	14
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, President and Chief Executive Officer, Warren Sheppell Consultants	June 12, 2003	18
Hamilton Health Sciences Centre	Venera Bruto, Psychologist	June 4, 2003	17
Health Canada	Tom Lips, Senior Advisor, mental Health, Healthy Communities Division, Population and Public Health Branch	March 19, 2003	11
	Pam Assad, Associate Director, Division of Childhood and Adolescence, Centre for Healthy Human Development, Population and Public Health Branch	April 30, 2003	13
Laval University	Dr. Michel Maziade, Head, Department of Psychiatry, Faculty of Medecine	May 6, 2003	14
Louis-H. Lafontaine Hospital	Jean-Jacques Leclerc, Director, Rehabilitation Services and Community Living	May 6, 2003	14
	Dr. Pierre Lalonde, Director, Clinique jeunes adultes	May 6, 2003	14

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
McGill University	Dr. Howard Steiger, Professor, Psychiatry Department; Director, Eating Disorders Program, Douglas Hospital	May 1, 2003	13
Province of British Columbia	Patrick Storey, Chair, Minister's Advisory Council on Mental Health	May 14, 2003	15
	Heather Stuart, Associate Professor, Community Health and Epidemiology	May 14, 2003	15
Queen's University	Dr. Julio Arboleda-Florèz, Professor and head, Department of Psychiatry	March 20, 2003	11
Registered Nurses of Canada	Margaret Synyshyn, President	May 29, 2003	16
Statistics Canada	Lorna Bailie, Assistant Director, Health Statistics Division	March 20, 2003	11
St.Joseph's Health Care London	Maggie Gibson, Psychologist	June 4, 2003	17
St. Michaels Hospital	Dr. Paul Links, Arthur Sommer Rothenberg Chair in Suicide Studies	March 19, 2003	11
Université du Québec à Montréal	Henri Dorvil, Professor, School of Social Work	May 6, 2003	14
	Dr. Michel Tousignant, Professor, Centre de recherche et intervention sur le suicide et l'euthanasie	May 6, 2003	14
University of British Columbia	Dr. Charlotte Waddell, Assistant Professor, Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, Faculty of Medecine	May 1, 2003	13

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Calgary	Dr. Donald Addington, Professor and Head, Department of Psychiatry	May 29, 2003	16
University of Manitoba	John Arnett, Head, Department of Clinical Health Psychology, Faculty of Medicine	May 28, 2003	16
	Robert McIlwraith, Professor and Director, Rural and Northern Psychology Program	May 29, 2003	16
University of Montreal	Laurent Mottron, Researcher, Department of Psychiatry, Faculty of Medicine	May 6, 2003	14
	Dr. Richard Tremblay, Canada Research Chair in Child Development, Professor of Pediatrics, Psychiatry and Psychology, Director, Centre of Excellence for Early Childhood Development	May 6, 2003	14
	Dr. Jean Wilkins, Professor and Paediatrics, Faculty of Medecine	May 6, 2003	14
	Dr. Renée Roy, Assistant Clinical Professor, Department of Psychiatry, Faculty of Medecine	May 6, 2003	14
University of Ottawa	Tim D. Aubry, Associate Professor; Co-Director, Centre for Research and Community Services	June 5, 2003	17
	Dr. Jeffrey Turnbull, Chairman, Department of Medicine, Faculty of Medicine	June 5, 2003	17

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
University of Toronto	Dr. Joe Beitchman, Professor and Head, Division of Child Psychiatry, Department of Psychiatry; Psychiatrist-in-Chief, Hospital for Sick Children	April 30, 2003	13
	Dr. David Marsh, Clinical Director, Addiction Medicine, Centre for Addiction and Mental Health	May 29, 2003	16

APPENDIX B:
LIST OF WITNESSES
THE SECOND SESSION OF THE 37TH PARLIAMENT
(SEPTEMBER 30, 2002 – NOVEMBER 12, 2003)

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Alberta Mental Health Board	Ray Block, Chief Executive Officer	April 28, 2004	7
Alberta Mental Health Board	Sandra Harrison, Executive Director, Panning, Advocacy & Liaison	April 28, 2004	7
Anxiety Disorders Association of Canada	Peter McLean, Vice-President	May 12, 2004	9
As individuals	Charles Bosdet	April 29, 2004	7
	Pat Caponi		
	Don Chapman		
Australia, Government of (*by videoconference)*	Dermot Casey, Assistant Secretary, Health Priorities and Suicide Prevention Branch, Department of Health and Ageing	April 20, 2004	6
	Jenny Hefford, Assistant Secretary, Drug Strategy Branch, Department of Health and Ageing		
British Columbia Ministry of Health Services	Irene Clarkson, Executive Director, Mental Health and Addictions	April 28, 2004	7
Canadian Association of Social Workers	Stephen Arbuckle, Member, Health Interest Group	March 31, 2004	5
Canadian Medical Association	Dr. Sunil Patel, President	March 31, 2004	5
	Dr. Gail Beck, Acting Associate Secretary General		
Canadian Mental Health Association	Penny Marrett, Chief Executive Officer	May 12, 2004	9

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Canadian Nurses Association, the Canadian Federation of Mental Health Nurses and the Registered Psychiatric Nurses of Canada	Nancy Panagabko, President, Canadian Federation of Mental Health Nurses	March 31, 2004	5
	Annette Osten, Board Member, Canadian Nurses Association	March 31, 2004	5
Canadian Psychiatric Association	Dr. Blake Woodside, Chairman of the Board	March 31, 2004	5
Canadian Psychological Association	John Service, Executive Director	March 31, 2004	5
Centre for Addiction and Mental Health	Christine Bois, Provincial Priority Manager for Concurrent Disorders	May 5, 2004	8
	Wayne Skinner, Clinical Director, Concurrent Disorder Program		
	Brian Rush, Research Scientist, Social Prevention and Health Policy		
Centre for Suicide Prevention	Diane Yackel, Executive Director	April 21, 2004	6
Cognos	Marilyn Smith-Grant, Senior Human Resources Specialist	April 1, 2004	5
Correctional Service of Canada	Larry Motiuk, Director General, Research	April 29, 2004	7
	Françoise Bouchard, Director General, Health Services	April 29, 2004	7
Douglas Hospital	Dr. Gustavo Turecki, Director, McGill Group for Suicide Studies, McGill University	April 21, 2004	6
House of Commons	The Honourable Jacques Saada, P.C., M.P., Leader of the Government in the House of Commons and Minister responsible for Democratic Reforms	April 1, 2004	5

Human Resources and Skills Development Canada	Bill Cameron, Director General, National Secretariat on Homelessness	April 29, 2004	7
Human Resources and Skills Development Canada	Marie-Chantal Girard, Strategic Research Manager, National	April 29, 2004	7
Institute of Neurosciences, Mental Health and Addiction	Richard Brière, Assistant Director	April 21, 2004	6
McGill University (*by videoconference)*	Dr. Laurence Kirmayer, Director, Division of Social and Transcultural Psychiatry, Department of Psychiatry	May 13, 2004	9
Mood Disorder Society of Canada	Phil Upshall, President	May 12, 2004	9
Native Mental Health Association of Canada	Brenda M. Restoule, Psychologist and Ontario Board Representative	May 13, 2004	9
New Zealand, Government of (*by videoconference)*	Janice Wilson, Deputy Director General, Mental Health Directorate, Ministry of Health	May 5, 2004	8
	David Chaplow, Director and Chief Advisor of Mental Health		
	Arawhetu Peretini, Manager of Maori Mental Health		
	Phillipa Gaines, Manager of Systems Development of Mental Health		
Nova Scotia Department of Health	Dr. James Millar, Executive Director, Mental Health and Physician Services	April 28, 2004	7
Ontario Federation of Community Mental Health and Addiction	David Kelly, Executive Director	May 5, 2004	8
Ontario Hospital Association	Dr. Paul Garfinkel, Chair, Mental Health Working Group	March 31, 2004	5

ORGANIZATION	NAME	DATE OF APPEARANCE	ISSUE NO.
Privy Council Office	Ron Wall, Director, Parliamentary Operations, Legislation and House Planning	April 1, 2004	5
Privy Council Office	Ginette Bougie, Director, Compensation and Classification	April 1, 2004	5
Public Service Alliance of Canada	John Gordon, National Executive Vice-President	April 1, 2004	5
	James Infantino, Pensions and Disability Insurance Officer		
Schizophrenia Society of Canada	John Gray, President-Elect	May 12, 2004	9
Simon Fraser University (*by videoconference)*	Margaret Jackson, Director, Institute for Studies in Criminal Justice Policy	April 29, 2004	7
Six Nations Mental Health Services	Dr. Cornelia Wieman, Psychiatrist	May 13, 2004	9
Treasury Board Secretariat	Joan Arnold, Director, Pensions Legislation Development, Pensions Division	April 1, 2004	5
U.S. Campaign for Mental Health Reform	William Emmet, Coordinator	April 1, 2004	5
U.S. President's New Freedom Commission on Mental Health (*by videoconference)*	Michael Hogan, Chair	April 1, 2004	5
United Kingdom, Government of (*by videoconference)*	Anne Richardson, Head of the Mental Health Policy Branch, Department of Health	May 6, 2004	8
	Adrian Sieff, Head of the Mental Health Legislation Branch		

APPENDIX C:
LIST OF INDIVIDUALS WHO RESPONDED TO A LETTER FROM THE COMMITTEE ON PRIORITIES FOR ACTION

CANADIAN RESEARCH GROUP

CancerCare Manitoba	Harvey Max Chochinov, MD, PhD, FRCPC, Canada Research Chair in Palliative Care, Director, Manitoba Palliative Care Research Unit, CancerCare Manitoba, Professor, Department of Psychiatry, Community Health Sciences and Family Medicine(Division of Palliative Care) University of Manitoba
Carleton University	Dr. Hymie Anisman, Canadian Research Chair in Neuroscience, Ontario Mental Health Foundation Senior Research Fellow
Douglas Hospital Reseach Centre	Ashok Malla, MD, FRCP Canada Research Chair in Early Psychosis, Professor of Psychiatry, McGill University, Director, Clinical Research Division
McGill University Health Centre	Eric Fombonne, MD, FRCPsych, Canada Research Chair in Child Psychiatry, Professor of Psychiatry, University McGill, Director, Montreal Children's Hospital
University of Alberta	Glen B. Baker, PhD, DSc, Professor and Chair, Canada Research Chair in Neurochemistry and Drug Development
University of Manitoba – Faculty of Medecine	Brian J. Cox, Ph.D., C. Psych., Canada Research Chair in Mood and Anxiety Disorders, Associate Professor of Psychiatry, Adjunct Professor, Departments of Community Health Sciences and Psychology

DEANS OF MEDICAL SCHOOLS

Kingston General Hospital	Samuel K. Ludwin, M.B.B., Ch., F.R.C.P.C., Vice-President, (Research Development)
McGill University Health Centre	Joel Paris, M.D., Professor and Chair, Department of Psychiatry
University of Alberta	Dr. L. Beauchamp, Dean, Faculty of Eduction
University of Sherbrooke	Pierre Labossière, P. Eng., Ph.D., Associate Vice-Rector, Research
University of Western Ontario	Dr. Carol P. Herbert, Dean of Medicine and Dentistry

ILLNESS RELATED GROUP

Canada's Research-Based Pharmaceutical Companies	Murray J. Elston, President
Eli Lilly Canada Inc.	Terry McCool, Vice-President, Corporate Affairs
GlaxoSmith Kline	Geoffrey Mitchinson, Vice-President of Public Affairs
Merck Frosst Canada	André Marcheterre, President
NSERC	Thomas A. Brzustowski, President
Ontario Mental Health Foundation	Howard Cappell, Ph.,D. (C.Psych) Executive Director
Roche Pharmaceuticals	Ronnie Miller, President & C.E.O.
Schizophrenia Society of Canada	Fred Dawe, President

MENTAL HEALTH ETHICS GROUP

Centre for Addiction and Mental Health	Paul E. Garfinkel, MD, FRCPC, President and CEO
McGill University – Douglas Hospital Research Centre	Maurice Dongier, Professor of Psychiatry

Parkwood Hospital, St.Joseph's Health Care London	Maggie Gibson, Ph. D., Psychologist, Veterans Care Program
Queen's University	J. Arboleda-Florèz, Professor and Head, Department of Psychiatry
Salvation Army – Territorial Headquarters Canada and Bermuda	Glen Shepherd, Colonel, Chief Secretary
St-Paul's Hospital	Mark Miller, C.S.s.R., Ph.D. Ethicist
University of Alberta	Wendy Austin, RN, Ph. D., Canada Research Chair, Relational Ethics in Health Care, Faculty of Nursing and John Dosseter Health Ethics Centre
University of Alberta, Faculty of Nursing	Genevieve Gray, Dean and Professor, Faculty of Nursing
University of British Columbia	Peter D. McLean, Ph.D. Professor and Director, Anxiety Disorders Unit
University of Western Ontario	Nancy Fedyk, Executive Assistant to the Dean
Winnipeg Regional Health Authority	Linda Hughes, Chair, WRHA Mental Health Ethics Committee
York University	David Shugarman, Director

PRESIDENT OF UNIVERSITY

Institute of Mental Health Research – University of Ottawa	Zul Merali, Ph. D., President and CEO
McGill University	Heather Munroe-Blum, Professor of Epidemiology and Biostatistics
University of Lethbridge	Lynn Basford, Dean, Health Sciences

GOVERNMENT RESPONSIBILITY

Canadian Coalition for Seniors	J. Kenneth Le Clair, MD, FRCPC, Co-Chair, Canadian Coalition for Seniors Mental Health, Professor and Chair, Geriatric Division, Department of Psychiatry, Queen's University, Clinical Director, Specialty Geriatric Psychiatry Program
Canadian Coalition for Seniors Mental Health	David K. Conn, MB., FRCPC, Co-Chair Canadian Coalition for Seniors Mental Health, Psychiatrist-in-Chief, Department of Psychiatry, Baycrest Centre for Geriatric Care, Associate Professor, Department of Psychiatry, University of Toronto, President, Canadian Academy of Geriatric Psychiatry
Canadian Institute of Health Research	Dr. Jeff Reading, PhD, Scientific Director – Institute of Aboriginal Peoples's Health
Canadian Mental Health Association	Bonnie Pape, Director of Programs & Research, Canadian Mental Health Association – National Office
Dalhousie University – Department of Psychology	Patrick J. McGrath, OC, PhD, FRSC, Co-ordinator of Clinical Psychology, Killam Professor of Psychology, Professor of Pediatrics and Psychiatry, Canada Research Chair, Psychologist IWK Health Centre
Dalhousie University, Faculty of Medicine	David Zitner, D. Ph., Director, Medical Informatics
Department of Health and Wellness New-Brunswick	Ken Ross, Assistant deputy Minister
Douglas Hospital Research Centre	Michel Perreault, Ph. D., Researcher, Douglas Hospital, Professor, Department of Psychiatry McGill University
Douglas Hospital Research Centre - Institute of Neurosciences, Mental Health and Addiction	Rémi Quirion, Scientific Director, (INMHA)

Faculty of Medicine – University of Ottawa	Jacques Bradwejn, MD FRCPC, DABPN, Chair of the Department of Psychiatry, Psychiatris-in-Chief, Royal Ottawa Hospital, Head of Psychiatrist, The Ottawa Hospital
Family Council: Empowering Families in Addictions and Mental Health	Betty Miller, Coordinator, The Family Council
Global Business and Economic Roundtable on Addiction and Mental Health – Affiliated with the Centre for Addiction and Mental Health	Bill Wilkerson, Co-Founder and Chief Executive Officer
Human Resources Development Canada	Deborah Tunis, Director General, Office for Disability Issues
McGill University Health Centre	Juan C. Negrete, MD, FRCP(C) Professor of Psychiatry, McGill University, Chair, Addictions Section, Canadian Psychiatric Association
McMaster University	Dr. Richard P. Swinson, MD, FRCPC, Morgan Firestone Chair in Psychiatry, Psychiatry & Behavioural Neurosciences, McMaster University, Chief, Department of Psychiatry, St.Joseph's Healthcare
NAHO National Aboriginal Health Organization	Judith G. Bartlett, M.D. CCFP, Chairperson
Ottawa Hospital	Paul Roy, MD, FRCPC, Assistant Professor of Psychiatry, University of Ottawa, Director, Ottawa First Episode Psychosis Program
Royal Ottawa Hospital	J. Paul Fedoroff, M.D., Associate Professor of Psychiatry, University of Ottawa, Research Director, Forensic Unit, Institute of Mental Health Research
Six Nations Mental Health Services	Cornelia Wieman, M.D., FRCPC, Psychiatrist
Syncrude	Eric P. Newell, Chairman & Chief Executive Officer

University of British Columbia – Mental Health Evaluation & Community Consultation Unit, Department of Psychiatry	Elliot Goldner, MD, MHSc, FRCPC, Head, Division of Mental Health Policy & Services
University of Ottawa – Office of the Vice-President, Research	Yvonne Lefebvre, Ph.D., Associate Vice-President, Research
University of Ottawa- School of Psychology	John Hunsley, Ph.D., C. Psych., Professor of Psychology
University of Toronto – Sunnybrook & Women's College Health Sciences Centre	Nathan Herrmann, M.D., F.R.C.P. (C)

SENATE SÉNAT
CANADA

RAPPORT 3

Santé mentale, maladie mentale et toxicomanie:

Problèmes et options pour le Canada

Rapport provisoire du
Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

L'honorable Michael J.L.Kirby, *président*
L'honorable Wilbert Joseph Keon, *vice-président*

Novembre 2004

TABLE DES MATIÈRES

ORDRE DE RENVOI

Extrait des *Journaux du Sénat* du jeudi 7 octobre 2004

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Losier-Cool,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système des soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale ;

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la trente-septième législature soient déférés au Comité ;

Que le Comité présente son rapport final au plus tard le 16 décembre 2005 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 mars 2006.

La motion, mise aux voix, est adoptée.

Le greffier du Sénat,

Paul C. Bélisle

SÉNATEURS

Les sénateurs suivants ont participé à l'étude du Comité sénatorial permanent des affaires sociales, des sciences et de la technologies sur l'état du système de soins de santé (plus particulièrement sur la santé mentale):

L'honorable Michael J. L. Kirby, president du Comité
L'honorable Wilbert Joseph Keon, vice-président du Comité

Les honorables sénateurs:

Catherine S. Callbeck
Ethel M. Cochrane
Joan Cook
Jane Mary Cordy
Joyce Fairbairn, P.C.
Aurélien Gill
Janis G. Johnson
Marjory LeBreton
Viola Léger
Yves Morin
Lucie Pépin
Brenda Robertson (retraitée)
Douglas Roche (retraité)
Eileen Rossiter (retraitée)
Marilyn Trenholme Counsell

Membres d'office du Comité:
Les honorables sénateurs: Jack Austin P.C. (ou William Rompkey) et Noël A. Kinsella (ou Terrance Stratton)

Autres sénateurs ayant participle de temps à autre à cette étude:
Les honorables sénateurs Di Nino, Forrestall, Kinsella, Lynch-Staunton, Milne et Murray.

SANTÉ MENTALE, MALADIE MENTALE ET TOXICOMANIE: PROBLÈMES ET OPTIONS POUR LE CANADA

INTRODUCTION

Nous allons passer brièvement en revue les grands problèmes que posent la prestation des services de santé mentale et les traitements contre la toxicomanie au Canada, proposer des pistes de solutions pour certains d'entre eux et lancer un débat public qui permettra aux Canadiens de donner leur opinion sur la façon de les régler.

Deux autres rapports résumant les données dont nous nous sommes servis viennent compléter ce document qui présente les problèmes et les solutions. Le premier, intitulé *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, donne un aperçu des politiques et des services au pays en matière de santé mentale, de maladie mentale et de toxicomanie.[1] Le second, intitulé *Politiques et programmes de certains pays en matière de santé mentale*, décrit les politiques et programmes en vigueur dans quatre pays – l'Australie, la Nouvelle-Zélande, le Royaume-Uni et les États-Unis – et en tire des conclusions applicables à la réforme du domaine de la santé mentale au Canada.[2] Le Comité incite ardemment les intéressés à lire attentivement les deux rapports complémentaires avant de préparer leurs interventions.

Les problèmes, principes, questions et solutions que nous exposons ci-dessous sont en partie le produit de ce que le Comité a appris aux audiences publiques qu'il a tenues entre février 2003 et mai 2004. Il en entendu 104 témoins en 24 séances publiques qui ont duré 55 heures en tout. De plus, le Comité a reçu 43 lettres et 114 mémoires, commandé deux études (l'une sur la recherche et l'autre sur les questions d'éthique) et fait librement usage des publications des théoriciens autant que des praticiens sur la santé mentale, la maladie mentale et la toxicomanie.

Le Comité est impatient de savoir quelles politiques gouvernementales, tant au palier provincial/territorial que fédéral, les Canadiens privilégient pour résoudre les problèmes soulevés ci-après. Il tiendra des séances publiques dans tout le pays de février à juin 2005 avant de publier, en novembre 2005, ses recommandations sur la meilleure façon de régler les problèmes et questions traités.

Le Comité tiendra des séances publiques dans tout le pays de février à juin 2005 avant de publier, en novembre 2005, ses recommandations sur la meilleure façon de régler les problèmes et questions traités.

1 Ci-après le « Premier rapport ».
2 Ci-après le « Deuxième rapport ».

Le présent document Problèmes et options peut être considéré comme un sommaire des constatations et observations présentées dans les deux rapports complémentaires. Il ne saurait en être dissocié et il renvoie d'ailleurs constamment à ceux-ci. **Par conséquent, le Comité encourage instamment les lecteurs à consulter les sections pertinentes des premier et deuxième rapports à mesure qu'ils examinent les problèmes, questions et options présentés ci-après.**

Le plan du rapport reflète le parti pris de notre étude pour la perspective du patient/client. Ainsi, les problèmes de prestation des services sont analysés du point de vue de la personne qui bénéficie du service ou moyen de soutien plutôt que de celui de l'établissement ou organisme qui le fournit. Par ailleurs, les problèmes sont traités en fonction des besoins propres à certains segments de la population – enfants et adolescents, personnes âgées, Canadiens autochtones, patients au cas complexe – et non du type de trouble mental.

Nous traitons aussi des services et des moyens de soutien nécessaires pour répondre adéquatement aux besoins du patient/client et soulevons des questions à propos des politiques gouvernementales à adopter compte tenu des problèmes de ressources humaines en santé mentale, de la réforme des soins de santé primaires, de la recherche en santé mentale et de l'usage de la technologie (p. ex. dossiers électroniques des patients et télésanté).

Enfin, nous présentons en conclusion une série de questions sur le rôle que les gouvernements fédéral, provinciaux et territoriaux devraient être appelés à jouer pour améliorer le réseau canadien des services en santé mentale et en toxicomanie. Par exemple, quels devraient être les éléments clés des plans d'action fédéraux et provinciaux pour la santé mentale, la maladie mentale et la toxicomanie? Comment faudrait-il contrôler la mise en œuvre de ces plans? Comment et à qui les gouvernements devraient-ils rendre compte de la mise en œuvre de leurs plans? Comment devrait-on financer l'amélioration des services en santé mentale et du traitement de la toxicomanie? S'il faut augmenter les budgets, comment obtenir les montants supplémentaires et de quelles sources?

Le Comité est conscient que s'il est bien de faire des recommandations, encore faut-il que celles-ci soient mises en œuvre pour que tout son travail sur la santé mentale, la maladie mentale et la toxicomanie soit vraiment utile.

Le Comité presse tous ceux et toutes celles qui s'intéressent à la santé mentale, à la maladie mentale et à la toxicomanie de participer à la phase consultative prochaine, soit en venant témoigner entre février et juin 2005, soit en faisant parvenir une lettre ou un mémoire exposant votre opinion. La qualité de notre rapport final et de nos recommandations, voire le bien-être de tous ceux qui sont aux prises avec la maladie mentale ou la toxicomanie au Canada dépendent de la libre discussion des problèmes, des questions et des options exposés ci-dessous et de l'abondance des commentaires qui nous seront transmis.

Le Comité comprend parfaitement qu'il ne pourra y avoir progrès que lorsqu'une très forte proportion de ceux qui s'occupent de santé mentale, de maladie mentale et de toxicomanie seront disposés à contribuer tangiblement au changement, notamment en modifiant, à leur niveau, leur participation au « système ».

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CHAPITRE 1:
PRESTATION DES SERVICES ET DES MOYENS DE SOUTIEN

Le système envisagé par le Comité pour la santé mentale et le traitement de la toxicomanie a deux caractéristiques clés : il est axé sur le patient et sur son rétablissement. Il adapte ses services pour qu'ils répondent aux besoins du patient/client dans le respect de ses sensibilités culturelles. Il assure le diagnostic et le traitement précoces du patient dès les premiers signes de maladie mentale ou de toxicomanie.

C'est aussi un système parfaitement intégré dans lesquels les services et moyens de soutien sont accessibles, de grande qualité et bien coordonnés. Nous rejetons dès lors carrément l'actuelle approche du cloisonnement des services en santé mentale et en toxicomanie (également appliquée dans une trop grande partie du réseau des services de santé en général).

1.1 SYSTÈME AXÉ SUR LE PATIENT/CLIENT ET ORIENTÉ SUR LE RÉTABLISSEMENT PAR LE BIAIS DE PLANS D'INTERVENTION PERSONNALISÉS

L'une des principales critiques formulées à l'endroit des services et des moyens de soutien en santé mentale et en traitement de la toxicomanie au Canada, tient à ce que le système s'organise surtout autour du fournisseur (et souvent pour sa commodité à lui) plutôt qu'autour du patient/client. Au lieu de s'adapter aux besoins des patients/clients atteint de maladie mentale ou de toxicomanie, on demande à ces derniers de s'adapter au système et de se contenter des services et des moyens de soutien qu'il est en mesure de leur fournir.[3]

L'une des principales critiques formulées à l'endroit des services et des moyens de soutien en santé mentale et en traitement de la toxicomanie au Canada, tient à ce que le système s'organise surtout autour du fournisseur (et souvent pour sa commodité à lui) plutôt qu'autour du patient/client.

Voilà une constatation assez accablante, d'autant plus qu'elle est confirmée par plusieurs études provinciales ayant reconnu qu'il faut recentrer sur l'individu la prestation des services et des moyens de soutien en santé mentale et en toxicomanie. Pour améliorer la qualité de vie des patients/clients, il faudrait offrir sans délai des traitements, des services et des moyens de soutien sûrs et efficaces qui s'articuleraient autour des besoins des personnes ayant une maladie mentale ou une toxicomanie.[4]

Fournir des services et des moyens de soutien conçus expressément pour le patient est essentiel à son rétablissement.

Notre analyse internationale comparée montre que, dans les autres pays, on a précisément recentré le

[3] Premier rapport, chapitre 8.
[4] Premier rapport, chapitre 8, section 8.2.1.

système sur le patient/client dans le domaine de la maladie mentale et de la toxicomanie.[5] Ainsi, dans certains pays, chaque patient atteint de graves troubles mentaux fait l'objet d'un plan d'intervention personnalisé résolument orienté sur le rétablissement.

Fournir des services et des moyens de soutien conçus expressément pour le patient est essentiel à son rétablissement. Le plan d'intervention personnalisé fournit une description détaillée des services et des moyens de soutien dont un malade mental ou un toxicomane a besoin pour se rétablir définitivement; il s'ajuste aux besoins du patient/client qui évoluent en fonction de sa maladie et de son âge.[6] Le financement de la réalisation des plans d'intervention personnalisés est habituellement rattaché au patient lui-même. Les patients qui ont besoin de services ou de moyens de soutien multiples et leurs familles ne devraient pas avoir à en faire la coordination eux-mêmes (comme c'est presque toujours le cas à l'heure actuelle); ce fardeau devrait être partagé avec les fournisseurs des services et moyens de soutien nécessaires.

Le Comité est maintenant convaincu que le statu quo est inacceptable. Alors, comment faut-il procéder pour recentrer le système des services en santé mentale et en toxicomanie sur le patient/client?

Le Comité est maintenant convaincu que le statu quo est inacceptable. Alors, comment faut-il procéder pour recentrer le système des services en santé mentale et en toxicomanie sur le patient/client? Faudrait-il aller jusqu'à l'adoption de plans d'intervention personnalisés et, dans l'affirmative, à quels types de patients/clients cette méthode serait-elle applicable? Quels types de renseignements ces plans devraient-ils contenir; autrement dit, que devraient-ils prévoir? Que faut-il changer à la structure actuelle de prestation des services pour offrir des plans d'intervention personnalisés aux malades mentaux et toxicomanes? Qui devrait coordonner la mise en œuvre du plan d'intervention personnalisé de chaque patient/client?

Quels incitatifs sont envisageables et comment parvenir à les introduire dans le système pour provoquer les changements qui favoriseront un recentrage sur le patient/client?

Si l'on modifiait le mode de rémunération des professionnels et des établissements au profit d'un financement rattaché au patient/client, cela aurait-il un effet incitatif assez puissant pour que les services et moyens de soutien en maladie mentale et toxicomanie se recentrent véritablement sur le patient/client? Dans l'affirmative, quelles modifications s'imposent pour permettre l'implantation de ce nouveau mode de financement/rémunération? Dans le cas contraire, quels incitatifs sont envisageables et comment parvenir à les introduire dans le système pour provoquer les changements qui favoriseront un recentrage sur le patient/client? De façon générale, quelles seraient les implications d'un budget rattaché au patient?

En outre, le Comité fait remarquer dans son premier rapport que la faculté décisionnelle de ceux qui souffrent d'une maladie mentale ou de toxicomanie peut être affaiblie à degrés divers et irrégulièrement dans le temps.[7] En conséquence, comment un système centré sur le

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5 Deuxième rapport, chapitre 5, section 5.7.

6 Premier rapport, chapitre 4, section 4.9.

7 Premier rapport, chapitre 8 (section 8.3) et chapitre 11 (section11.2).

patient/client peut-il mettre en équilibre les droits individuels des personnes atteintes de graves troubles mentaux et le rôle que doit jouer la société en s'occupant d'elles avec compassion tout en se protégeant? Y a-t-il lieu d'entreprendre une révision des lois des diverses provinces et territoires concernant la santé mentale en vue de supprimer les disparités qui s'observent actuellement, pour arriver à un cadre légal national et uniforme?

1.2 PRESTATION DE SERVICES ET DE MOYENS DE SOUTIEN COMPATIBLES AVEC LA CULTURE DES PATIENTS/CLIENTS

Certains segments de la population canadienne éprouvent des difficultés d'accès particulières et reçoivent des services de qualité inférieure à cause de barrières culturelles, linguistiques ou géographiques. Ce sont les Autochtones, les personnes de culture ou de langue différente de celles de la majorité, et les résidents de régions rurales ou éloignées. En fait, le manque de services et de moyens de soutien adaptés aux cultures dessert bien des gens.

Un nombre croissant de Canadiens proviennent de milieux culturels et linguistiques différents. De quels mécanismes faut-il se doter pour offrir des services et des moyens de soutien qui respectent la culture du patient/client?

Un nombre croissant de Canadiens proviennent de milieux culturels et linguistiques différents. De quels mécanismes faut-il se doter pour offrir des services et des moyens de soutien qui respectent la culture du patient/client? Le gouvernement fédéral a-t-il un rôle à jouer à cet égard, puisqu'il lui incombe de promouvoir la diversité culturelle? De plus, que pensent les Canadiens appartenant à une minorité de langue officielle, de leur accès au réseau des services en santé mentale et en toxicomanie? Que peut faire le gouvernement fédéral pour qu'aucune barrière linguistique n'empêche un patient de recevoir les soins dont il a besoin? [Le rôle du gouvernement fédéral dans la prestation des services en santé mentale et en toxicomanie en milieu autochtone est traité en détail au chapitre 2 (section 2.2) et au chapitre 7 (section 7.1) ci-après.]

1.3 COORDINATION ET INTÉGRATION DU SYSTÈME PRIVILÉGIANT UNE PRESTATION COMMUNAUTAIRE

Comment faire pour répartir équitablement le fardeau de la coordination et de l'intégration des services et moyens de soutien entre le système, d'une part, et les patients et leurs familles, d'autre part?

Les gens atteints d'une maladie mentale ou d'une toxicomanie sont souvent désemparés et se sentent dépassés lorsqu'ils doivent non seulement trouver des services et des moyens de soutien, mais aussi faire l'intégration des soins psychiatriques, des traitements contre la toxicomanie, des services d'aide (logement, éducation, etc.) et d'un régime de prestations d'invalidité qui relèvent d'une foule de programmes, tout à fait indépendants les uns des autres, ressortissant à d'organismes fédéraux, provinciaux et régionaux, ainsi qu'à diverses organisations non gouvernementales.[8] Comment faire pour répartir équitablement le fardeau de la coordination

[8] Premier rapport, chapitre 8, section 8.2.1.

et de l'intégration des services et moyens de soutien entre le système, d'une part, et les patients et leurs familles, d'autre part?

Pour abandonner l'approche du cloisonnement qui prédomine actuellement dans le monde de la santé mentale et du traitement des toxicomanies et assurer une prestation intégrée des soins, il faudrait que les nombreuses organisations qui offrent des services renoncent à leur autonomie. Quels outils employer pour mettre sur pied un système intégré regroupant les services et moyens de soutien en santé mentale et le traitement de la toxicomanie? Quels incitatifs permettraient de surmonter les obstacles qui empêchent les organismes en place de travailler de concert, en abandonnant leur autonomie au profit de l'interdépendance? Il semble y avoir un sérieux dédoublement et chevauchement entre la multitude d'ONG qui dispensent des services et des moyens de soutien aux malades mentaux et aux toxicomanes; comment peut-on éliminer ce problème?

Quels incitatifs permettraient de surmonter les obstacles qui empêchent les organismes en place de travailler de concert, en abandonnant leur autonomie au profit de l'interdépendance?

Quel est le meilleur moyen d'intégrer les services et programmes en toxicomanie pour composer un véritable réseau de services en santé mentale? Comment améliorer la coordination entre les services en santé mentale et en toxicomanie et les autres « silos » au sens large du secteur social (logement, éducation, emploi, soutien du revenu, etc.)? Si nous ne voulons pas « imposer » de formule, à quels incitatifs pourrions-nous avoir recours pour accélérer les changements qui s'imposent dans le système des services en santé mentale et en toxicomanie? Peut-on envisager de resserrer les liens entre les différents programmes et structures administratives uniquement en entretenant de bonnes relations ou faut-il conclure des protocoles d'entente ou des conventions de services pour y parvenir? Quand on entreprend une intégration structurelle, à quels services et moyens de soutien communautaires faut-il accorder la priorité? Est-ce une bonne idée de mettre sur pied des projets pilotes locaux?

Une foule d'autres questions demeurent sans réponse pour le moment. Comment le Canada peut-il établir un énoncé clair des rôles et des responsabilités des divers organismes qui prodiguent des services et des moyens de soutien en santé mentale et en toxicomanie? En particulier, quels devraient être le rôle et les responsabilités du gouvernement fédéral, des gouvernements provinciaux et territoriaux, des régies régionales de la santé, des divers ministères et organismes provinciaux (santé, éducation, services sociaux, logement, justice, assistance sociale, etc.), des fournisseurs de soins de santé mentale, des organisations non gouvernementales, des groupes d'entraide, etc.?

Comment allouer le financement public de façon à encourager la collaboration à l'intérieur des secteurs de la santé mentale et de la toxicomanie et entre eux? Quelle forme de financement conviendrait le mieux et aurait l'effet incitatif le plus efficace pour atteindre cet objectif? Quel

Comment allouer le financement public de façon à encourager la collaboration à l'intérieur des secteurs de la santé mentale et de la toxicomanie et entre eux? Quelle forme de financement conviendrait le mieux et aurait l'effet incitatif le plus efficace pour atteindre cet objectif?

type de financement ou de mécanisme aiderait à établir une meilleure coordination entre le réseau en santé mentale et en toxicomanie et le grand système social? [Le financement est traité en détail au chapitre 8 (sections 8.1 et 8.2) ci-après.]

1.4 DÉPISTAGE ET INTERVENTION PRÉCOCES

Une intervention précoce est fondamentale pour tuer dans l'œuf une maladie naissante; il est aussi important de maîtriser les symptômes et d'améliorer les pronostics. Or, plus le bon traitement commence tôt et meilleur est le pronostic du patient/client.[9]

L'intervention précoce est importante quel que soit le groupe d'âge, mais elle est primordiale chez les enfants et les adolescents. La plupart des troubles mentaux des adultes apparaissent à l'adolescence et au début de l'âge adulte, justement quand une intervention précoce peut atténuer sensiblement la perturbation des études, de la vie professionnelle et du développement social du malade. Les gains réalisés à ce moment là se font souvent sentir toute la vie durant.

Que faut-il faire pour qu'on en vienne à accorder encore plus d'importance au dépistage et à l'intervention précoces dans les cas de troubles mentaux chez les enfants et les adolescents? Recourir à des programmes pour la santé mentale dans les écoles? À un dépistage systématique des troubles mentaux chez les élèves du secondaire? Au dépistage du diagnostic mixte et des troubles concourants?

Que faut-il faire pour qu'on en vienne à accorder encore plus d'importance au dépistage et à l'intervention précoces dans les cas de troubles mentaux chez les enfants et les adolescents? Recourir à des programmes pour la santé mentale dans les écoles? À un dépistage systématique des troubles mentaux chez les élèves du secondaire? Au dépistage du diagnostic mixte et des troubles concourants? Quels changements faut-il apporter aux systèmes de santé, de santé mentale et de toxicomanie, d'éducation et de service social en général pour faciliter la précocité d'intervention? [Les questions touchant les enfants et les adolescents sont traitées en détail au chapitre 2 (section 2.1) ci-après.]

Le dépistage et l'intervention précoces devraient aussi être envisagés du point de vue de la santé publique en général. Il est essentiel d'améliorer les conditions sociales que nous savons essentielles à une bonne santé mentale (p. ex., un milieu physique et social sain, de bonnes aptitudes à l'adaptation, etc.) pour assurer non seulement le rétablissement des patients ayant des troubles mentaux mais aussi leur bonne santé mentale par la suite. Par conséquent, il faut s'attaquer aux racines mêmes de la maladie mentale et de la toxicomanie an adoptant des politiques ciblant la pauvreté, l'itinérance, le manque d'instruction, etc., et développer la capacité communautaire de s'occuper de ces questions.

Quel rôle le gouvernement fédéral devrait-il jouer dans la conception et la mise en œuvre d'une stratégie de santé publique concernant la santé mentale des Canadiens? Quels ministères fédéraux devraient y participer? Comment le gouvernement fédéral pourrait-il

[9] Premier rapport, chapitre 8, section 8.2.7.

amener les provinces et territoires et les autres parties prenantes à coopérer étroitement aux initiatives ciblant les racines de la maladie mentale et de la toxicomanie?

1.5 AMÉLIORATION DE L'ACCÈS

Malgré les efforts déployés par toutes les provinces et tous les territoires pour améliorer la prestation des services et des moyens de soutien en santé mentale et en toxicomanie, la majorité des Canadiens ayant des troubles mentaux ne consultent pas et ne sont pas traités. L'Enquête sur la santé dans les collectivités canadiennes (ESCC), réalisée récemment par Statistique Canada, a montré que 32 p. 100 seulement des personnes souffrant d'une maladie mentale ou de toxicomanie ont consulté, en personne ou autrement, un professionnel de la santé (psychiatre, médecin de famille, médecin spécialiste, psychologue, travailleur social ou infirmier) dans les 12 mois ayant précédé l'enquête.[10]

Que pourrait-on faire pour améliorer la situation? Il serait possible d'établir une charte du patient qui fixerait les normes d'accès aux services de santé mentale, que ce soit les soins de santé primaires, les services de santé mentale spécialisés ou les soins actifs. En Ontario, le Groupe d'étude sur la mise en œuvre de la réforme du système de santé mentale du district de Champlain (2002) a recommandé l'adoption d'une charte provinciale des droits des patients des services de santé mentale. D'autres groupes ont suggéré une forme de loi équitable, destinée à combler le fossé qui sépare les pathologies physiques des troubles mentaux, sur le plan des services offerts et du financement public. D'autres encore préconisent la nomination de défenseurs de la santé mentale, des fonctionnaires auxquels pourraient s'adresser les personnes ayant de la difficulté à obtenir les services de santé mentale et les moyens de soutien dont elles auraient besoin. Il y a eu un tel défenseur en Colombie-Britannique durant un temps, mais le poste a été supprimé à la création du ministère d'État de la Santé mentale et de la toxicomanie.[11] Le Comité sollicite le point de vue des lecteurs sur ces solutions ou d'autres suggestions qui seraient envisageables.

Compte tenu de la situation actuelle, est-il nécessaire d'établir des normes nationales régissant les délais d'attente pour les services de santé mentale et le traitement de la toxicomanie?

Dans son rapport d'octobre 2002, le Comité a recommandé que l'on accorde une garantie de soins de santé et qu'un délai d'attente maximum soit fixé en fonction des besoins pour les consultations en soins primaires, la première consultation d'un spécialiste, les tests diagnostiques et la chirurgie.[12] Compte tenu de la situation actuelle, est-il nécessaire d'établir des normes nationales

Le gouvernement fédéral et chacun des gouvernements provinciaux et territoriaux devraient-ils former un comité consultatif sur la santé mentale et la toxicomanie, qui serait représentatif d'un large éventail d'individus ayant une maladie mentale ou une toxicomanie pour faciliter la conception d'un système centré sur le patient?

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10 Premier rapport, chapitre 8, section 8.2.6.

11 *Ibid.*

12 *Recommandations en vue d'une réforme*, octobre 2002, chapitre 6.

régissant les délais d'attente pour les services de santé mentale et le traitement de la toxicomanie?

De toute évidence, il faudra obtenir le point de vue des patients/clients au sujet des changements apportés au système de santé mentale et de toxicomanie et de leur mise en application. Dans l'intervalle, le gouvernement fédéral et chacun des gouvernements provinciaux et territoriaux devraient-ils former un comité consultatif sur la santé mentale et la toxicomanie, qui serait représentatif d'un large éventail d'individus ayant une maladie mentale ou une toxicomanie pour faciliter la conception d'un système centré sur le patient? Un autre mécanisme serait-il préférable?

CHAPITRE 2:
GROUPES ET SOUS-GROUPES CONCERNÉS

Il n'existe pas, dit-on, de modèle universel et le Comité s'en est laissé convaincre. Les malades mentaux et les toxicomanes ne forment pas un groupe homogène. Ce sont des êtres humains ayant leur spécificité propre qu'il faut respecter. On peut tout de même les classer grosso modo en sous-groupes chacun confrontés à leurs propres obstacles et ayant besoin de services particuliers : les enfants et adolescents, les Autochtones, les personnes âgées et les individus aux besoins particulièrement complexes, pour n'en mentionner que quelques-uns.

2.1 ENFANTS ET ADOLESCENTS

Comme nous l'avons indiqué dans notre premier rapport, la prévalence générale de la maladie mentale chez les enfants et les adolescents au Canada oscille en permanence aux environs de 15 p. 100. Cela signifie qu'à n'importe quel moment donné, on dénombre quelque 1,2 million d'enfants et d'adolescents qui sont atteints d'une maladie mentale ou d'une toxicomanie suffisamment grave pour occasionner chez eux une grande détresse et une altération fonctionnelle. Les maladies mentales les plus fréquentes chez les jeunes sont les troubles anxieux (6,5 p. 100), les troubles de comportement (3,3 p. 100), le trouble déficitaire de l'attention (3,3 p. 100), le trouble dépressif (2,1 p. 100), les troubles liés à la consommation de substances psychoactives (0,8 p. 100) et l'autisme ou tout autre trouble envahissant du développement (0,3 p. 100).[13]

Les services et les moyens de soutien en santé mentale pour ce groupe ont été qualifiés de « parent pauvre du parent pauvre » du système de santé, étant donné qu'on dit souvent de la santé mentale qu'elle est le parent pauvre du système de santé du Canada.

Dans la plupart des provinces et des territoires, on note actuellement un énorme mécontentement au sujet de la prestation des services aux enfants et aux adolescents. Les services et les moyens de soutien en santé mentale pour ce groupe ont été qualifiés de « parent pauvre du parent pauvre » du système de santé, étant donné qu'on dit souvent de la santé mentale qu'elle est le parent pauvre du système de santé du Canada.

Quelle est la meilleure façon de constituer un réseau intégré et bien coordonné des services et des moyens de soutien pour lutter contre la prévalence des troubles mentaux chez les enfants et les adolescents?

Du côté des provinces et des territoires, la prestation des services de santé mentale aux jeunes est extrêmement morcelée et mal coordonnée, puisqu'une foule de ministères et d'organismes différents (p. ex., santé mentale, soins de santé primaires, hôpitaux, aide à l'enfance, écoles, jeunes contrevenants, services de lutte contre la toxicomanie, services d'éducation spécialisée) s'en occupent habituellement. Le pire, c'est que la plupart des politiques et des programmes en santé mentale visent d'abord la population adulte. Par

[13] Premier rapport, chapitre 5, section 5.1.2.

conséquent, les services pour enfants et adolescents se sont développés lentement et uniquement en marge des programmes pour adultes.

Quelle est la meilleure façon de constituer un réseau intégré et bien coordonné des services et des moyens de soutien pour lutter contre la prévalence des troubles mentaux chez les enfants et les adolescents, à partir des multiples couches de programmes obéissant à de bonnes intentions mais sans la moindre coordination? Quelles mesures précises faut-il adopter pour veiller à la santé mentale des jeunes? Faudrait-il d'abord que les divers ministères et organismes gouvernementaux conçoivent en collaboration avec les autres intervenants, une stratégie interministérielle pour la santé mentale des jeunes? Par la suite, devrait-on établir des protocoles qui seraient mis en application pour assurer l'efficacité de la collaboration et de la communication entre les divers protagonistes? Est-ce que chaque province devrait mettre sur pied un organisme ou un ministère consacré à la santé mentale des enfants et adolescents?

Plusieurs provinces, notamment l'Alberta, la Colombie-Britannique et l'Île-du-Prince-Édouard, ont mis en œuvre des stratégies visant exclusivement la santé mentale des enfants. Quelle leçon tirer de ces initiatives provinciales? Y a-t-il des modèles provinciaux/territoriaux ou régionaux que le Comité devrait examiner?

Quels services et moyens de soutien pourrait-on prodiguer d'une manière efficiente et économique dans le système scolaire?

D'instinct, on trouve évident qu'il est essentiel de fournir des services de santé mentale à l'école puisqu'elle constitue un environnement familier qui permet d'intervenir auprès des jeunes ayant des ennuis de santé mentale. D'ailleurs, dans bien des ressorts, l'école est considérée comme un intervenant clé du réseau de prestation des services de santé mentale et moyens de soutien. Quels services et moyens de soutien pourrait-on prodiguer d'une manière efficiente et économique dans le système scolaire?

Les chercheurs en santé mentale devraient-ils consacrer plus de temps et de ressources à l'étude des problèmes qu'éprouvent les enfants et les adolescents?

Il est difficile, presque partout, d'obtenir des services de santé mentale et des moyens de soutien pour les enfants et les adolescents. Là où de tels services sont offerts, les listes d'attente sont généralement longues. Il apparaît donc qu'il faudra presque partout augmenter la capacité pour qu'un minimum de services soient accessibles. Le Comité a compris que, dans la mesure du possible, les services devraient être offerts là où les jeunes et leur famille passent le plus clair de leur temps (p. ex., à l'école ou à la maison) et dans des plages horaires commodes. Voilà qui soulève une série d'autres questions. Combien coûterait un accroissement de la capacité? Quelle est la gravité de la pénurie de professionnels dans le domaine des soins de santé mentale pour enfants et adolescents? Faudrait-il donner aux fournisseurs des soins de santé primaires et au personnel enseignant une formation plus complète sur le dépistage précoce des troubles mentaux chez les enfants et les adolescents? Les chercheurs en santé mentale devraient-ils consacrer plus de temps et de ressources à l'étude des problèmes qu'éprouvent les enfants et les adolescents?

Faudrait-il concevoir de nouveaux programmes et services pour faciliter la transition aux services de santé mentale pour adulte?

Le Comité a entendu des exposés sur les besoins particuliers des adolescents, dans le domaine de la santé mentale, au moment de leur passage à l'âge adulte. Certains ont soulevé notamment la question générale de la jonction entre les systèmes et services organisés pour les jeunes et ceux qui s'adressent à une clientèle adulte. D'une part, il est probable qu'un adolescent continue d'avoir besoin de services de santé mentale et de moyens de soutien au lendemain de son 18e anniversaire, mais c'est à cette date qu'il cesse d'avoir droit aux services réservés aux jeunes. D'autre part, la transition entre l'adolescence et l'âge adulte peut être une période difficile et il est vraisemblable que les services et les moyens de soutien soient plus nécessaires que jamais auparavant durant cette phase importante du développement. Comment les divers systèmes pourraient-ils collaborer pour offrir un service intégré aux adolescents qui en sont au passage à l'âge adulte? Faudrait-il concevoir de nouveaux programmes et services pour faciliter la transition aux services de santé mentale pour adulte?

2.2 AUTOCHTONES

Comme nous le soulignons dans notre premier rapport complémentaire, selon la définition à l'article 35 de la *Loi constitutionnelle de 1982*, l'expression « peuples autochtones » désigne les « Indiens, les Inuits et les Métis du Canada ». Malgré cette définition assez large, le gouvernement fédéral assume actuellement l'entière responsabilité des Indiens qui vivent dans les réserves et de certaines populations inuites. Santé Canada et Affaires indiennes et du Nord Canada sont aujourd'hui les deux principaux ministères fédéraux chargés de fournir des services de santé physique et mentale, des traitements contre la toxicomanie, des services sociaux et des moyens de soutien aux Premières nations dans les réserves et aux Inuits.[14]

Les gouvernements provinciaux et territoriaux sont responsables des Autochtones qui vivent en dehors des réserves, y compris les Métis et les Indiens non inscrits qui ont accès aux programmes et services au même titre que les autres résidents. L'hétérogénéité de la population autochtone conjuguée au partage des compétences au Canada a dressé d'imposantes barrières contre l'établissement d'un régime complet pour la santé mentale, la maladie mentale et la toxicomanie chez les Canadiens autochtones.[15]

L'hétérogénéité de la population autochtone conjuguée au partage des compétences au Canada a dressé d'imposantes barrières contre l'établissement d'un régime complet pour la santé mentale, la maladie mentale et la toxicomanie chez les Canadiens autochtones.

Malgré le peu de données sur la prévalence des troubles mentaux chez les Autochtones, les auteurs s'entendent sur le fait que les communautés autochtones sont affligées de taux de maladie mentale, de toxicomanie et de comportement suicidaire sensiblement plus élevés que la population en général. En outre, les taux de prévalence du syndrome d'alcoolisation fœtale et des effets de l'alcool sur le fœtus (SAF/EAF) dans

Si bien des causes de la maladie mentale, de la toxicomanie et du comportement suicidaire sont les mêmes chez les Autochtones que chez les non-Autochtones, il s'ajoute dans les collectivités autochtones des facteurs culturels qui jouent sur la prise de décisions et l'idéation suicidaire chez l'individu.

14 Premier rapport, chapitre 9 section 9.2.1.
15 *Ibid.*

certaines de ces communautés sont supérieurs à la moyenne nationale.[16]

Les experts du domaine croient que, si bien des causes de la maladie mentale, de la toxicomanie et du comportement suicidaire sont les mêmes chez les Autochtones que chez les non-Autochtones, il s'ajoute dans les collectivités autochtones des facteurs culturels qui jouent sur la prise de décisions et l'idéation suicidaire chez l'individu. Parmi ces facteurs culturels, on retrouve les anciennes politiques gouvernementales, la création des réserves, le passage d'une vie active à un mode de vie sédentaire, les séquelles de la vie dans les pensionnats, le racisme, la marginalisation et la projection d'une image de soi négative.[17]

Plusieurs problèmes influent directement sur l'offre de services de santé mentale et de traitements contre la toxicomanie dans les collectivités autochtones :

- Premièrement, le système est extrêmement morcelé. Les services et les moyens de soutien sont fournis par une foule de directions et de divisions de différents ministères appartenant à divers ordres de gouvernement qui ne coopèrent pas. Ce morcellement est illustré par la pratique actuelle qui consiste à isoler les problèmes symptomatiques – toxicomanie, suicide, SAF/EAF, logements insalubres, chômage, etc. – et à concevoir des programmes autonomes pour essayer de les gérer chacun séparément.
- Deuxièmement, les habitudes que crée la dépendance sont entretenues depuis longtemps. Les ministères doivent déléguer aux collectivités autochtones le pouvoir de personnaliser les services et de les adapter en tenant compte des facteurs locaux. Autrement dit, les Autochtones devraient être épaulés pour concevoir leurs propres solutions au lieu de s'en faire imposer. Un tel changement favoriserait l'implantation de services et moyens de soutien plus conformes à leur culture et, partant, plus efficaces.

Les Autochtones devraient être épaulés pour concevoir leurs propres solutions au lieu de s'en faire imposer. Un tel changement favoriserait l'implantation de services et moyens de soutien plus conformes à leur culture et, partant, plus efficaces.

- Troisièmement, on constate une pénurie critique de professionnels autochtones en santé mentale et en toxicomanie. Par exemple, seulement quatre psychiatres au Canada sont d'origine autochtone.
- Quatrièmement, certaines provinces ont établi leur stratégie universelle pour la santé mentale en tenant compte des besoins des Autochtones. Dans les provinces où tel est le cas, les programmes fédéraux de santé mentale destinés aux Autochtones vivant dans les réserves ou en dehors devraient être harmonisés avec les régimes provinciaux pour la santé mentale et leurs stratégies d'application.

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16 Premier rapport, chapitre 5, section 5.3.1.

17 *Ibid.*

Quelles devraient être les principales priorités du gouvernement fédéral lorsqu'il commencera à réformer la manière dont les services de santé mentale et les traitements contre la toxicomanie sont offerts aux Canadiens autochtones? Quelles seraient les structures idéales pour que les Autochtones puissent participer réellement à la conception des services dont ils ont besoin? Comment le gouvernement fédéral pourrait-il s'organiser pour fournir ces services avec le plus d'efficacité possible? Le gouvernement fédéral devrait-il offrir des incitatifs monétaires aux Canadiens autochtones pour les encourager à suivre une formation de travailleur en santé mentale?

La question sans doute la plus importante, compte tenu du dédoublement inutile et dispendieux des programmes non coordonnés, consiste à savoir qui devrait assumer la responsabilité d'analyser le milieu en vue de dresser l'inventaire des programmes actuels pour déterminer s'il y a dédoublement d'un gouvernement, ministère et organisme à l'autre, s'il y a des lacunes flagrantes et quelle serait la meilleure utilisation des ressources disponibles?

Quelles devraient être les principales priorités du gouvernement fédéral lorsqu'il commencera à réformer la manière dont les services de santé mentale et les traitements contre la toxicomanie sont offerts aux Canadiens autochtones?

2.3 PERSONNES ÂGÉES

Selon des experts de la question, la croissance accélérée de la population âgée entraînera une demande sans précédent étant donné la capacité que possède actuellement le système pour répondre aux besoins des personnes âgées en santé mentale. La dépression, la démence, les troubles délirants et le delirium sont les maladies mentales les plus courantes parmi les Canadiens âgés. L'incidence des troubles mentaux chez ceux qui se trouvent dans un établissement de soins prolongés ou en centre d'hébergement est beaucoup plus élevé que dans la population en général. Le taux de suicide chez les hommes de 80 ans ou plus est le plus élevé de tous les groupes d'âge.[18]

Les personnes âgées atteintes d'une maladie mentale ou de toxicomanie forment un segment de la population qui est particulièrement vulnérable et dont les besoins en santé sont uniques.

Les personnes âgées atteintes d'une maladie mentale ou de toxicomanie forment un segment de la population qui est particulièrement vulnérable et dont les besoins en santé sont uniques. Nombre d'entre elles croient à tort que les problèmes de santé mentale tels que la dépression ou une déficience cognitive font partie du processus normal du vieillissement et qu'il n'y a donc aucun traitement efficace. Les maladies mentales chez les personnes âgées peuvent être confondues avec d'autres en cas de comorbidité ou masquées par des troubles concourants, ce qui complique énormément

On peut aussi de demander s'il n'y aurait pas lieu de réviser les programmes d'études des facultés de médecine et de nursing pour y offrir des cours et des stages supplémentaires en gérontopsychiatrie.

[18] Premier rapport, chapitre 5, section 5.1.3.

leur diagnostic et leur traitement.

Tout cela fait ressortir la nécessité de recruter des professionnels spécialisés dans les soins aux personnes âgées ayant des troubles mentaux, y compris celles qui sont institutionnalisées. On peut aussi se demander s'il n'y aurait pas lieu de réviser les programmes d'études des facultés de médecine et de nursing pour y offrir des cours et des stages supplémentaires en gérontopsychiatrie.

Le Comité a appris que les actuels modèles de prestation ne répondent pas aux besoins complexes et très changeants des personnes âgées en santé mentale. Là encore, le manque de coordination entre les fournisseurs de services fait obstacle aux méthodes correctes et efficaces d'évaluation, de traitement et de prévention de la maladie mentale. Y a-t-il des problèmes particuliers qui empêchent la coordination et l'intégration des services et des moyens de soutien dont les personnes âgées ont besoin?

Y a-t-il des problèmes particuliers qui empêchent la coordination et l'intégration des services et moyens de soutien dont les personnes âgées ont besoin?

Peu d'études ont été publiées sur les pratiques exemplaires en santé mentale pour les personnes âgées ou sur l'urgence de rédiger des lignes directrices éclairées, applicables et validées pour aider les professionnels à adopter des pratiques exemplaires lorsqu'ils doivent traiter des patients chez qui on trouve simultanément de multiples maladies mentales et des problèmes de santé corporelle physique. Qui devrait assumer la responsabilité d'établir ces lignes directrices?

Il faut aussi assurer aux aidants naturels des personnes âgées atteintes de troubles mentaux une gamme de moyens de soutien bien coordonnés, puisque les services qu'ils rendent ont une valeur économique considérable. À l'heure actuelle, le soutien apporté aux aidants naturels est très limité et il est habituellement insuffisant au point de ne pas aider vraiment. De toute façon, ce soutien vise surtout à répondre aux besoins de la personne malade, pas à ceux de l'aidant naturel.

Que pourrait faire le gouvernement fédéral pour alléger le fardeau qui retombe maintenant sur les épaules de milliers d'aidants naturels?

Que pourrait faire le gouvernement fédéral pour alléger le fardeau qui retombe maintenant sur les épaules de milliers d'aidants naturels? De quels services de soutien les aidants naturels ont-ils besoin? Le gouvernement fédéral devrait-il envisager de réviser le Régime de pensions du Canada, le programme d'assurance-emploi et le Code canadien du travail pour tenir compte des besoins de ceux qui abandonnent le marché du travail pour prendre soin d'un membre de leur famille atteint d'une grave maladie mentale? Combien coûteraient les nouvelles dispositions? Les dispositions actuelles de la loi de l'impôt fédérale permettent-elles de dédommager correctement les aidants naturels pour le temps et les ressources qu'ils consacrent au malade?

Quels sont les besoins des parents âgés qui sont les principaux soignants de leurs enfants adultes atteints d'une maladie mentale ou de toxicomanie?

De même, quels sont les besoins des parents âgés qui sont les principaux

soignants de leurs enfants adultes atteints d'une maladie mentale ou de toxicomanie? De quel type de soutien (monétaire, répit) ces aidants naturels âgés ont-ils besoin?

2.4 CAS COMPLEXES

Parmi les Canadiens ayant des besoins complexes, il y a ceux qui souffrent de troubles concourants (maladie mentale et toxicomanie) et d'un diagnostic mixte (maladie mentale et déficience développementale), ainsi que certains sans-abri et des détenus. Des démarches systématiques et de bons outils d'évaluation pour mieux dépister cette population font défaut. D'ailleurs, parce que ces personnes sont souvent mal diagnostiquées, elles sont mal soignées.

Ceux qui ont des troubles concourants et un diagnostic mixte ont besoin de l'aide et des services de plusieurs secteurs : santé mentale, toxicomanie, santé, éducation et services sociaux. Rappelons qu'il faut absolument intégrer, d'une part, services de santé mentale et de traitement des toxicomanies et, d'autre part, le secteur de la santé mentale et celui des troubles développementaux. Le Comité a hâte de connaître l'opinion des Canadiens sur les problèmes et les solutions concernant les troubles concourants et le diagnostic mixte, sur lesquels il faut se pencher.

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Les maladies mentales et les troubles liés à une substance psychoactive sont plus fréquents chez les sans-abri et les détenus que dans la population en général. De plus, leur prévalence est en hausse dans ces deux segments de la population canadienne. L'accès aux services et aux moyens de soutien pour ces personnes ne pourra s'améliorer sans coopération intergouvernementale.

En ce qui concerne les besoins en santé mentale des sans-abri, nous voulons connaître le point de vue des Canadiens sur les problèmes et solutions auxquels il faudrait s'intéresser.

Dans le chapitre 7 ci-après, le Comité traite des problèmes et des solutions concernant les besoins en santé mentale des détenus sous responsabilité fédérale. En ce qui concerne les besoins en santé mentale des sans-abri, nous voulons connaître le point de vue des Canadiens sur les problèmes et solutions auxquels il faudrait s'intéresser. Par exemple, quel rôle le gouvernement fédéral peut-il jouer dans le contexte de l'Initiative nationale pour les sans-abri?

CHAPITRE 3:
MILIEU DE TRAVAIL

Deux grands facteurs font de la maladie mentale et de la toxicomanie un problème critique en milieu de travail. Premièrement, les troubles mentaux frappent généralement les jeunes travailleurs et, deuxièmement, comme de nombreuses maladies mentales sont à la fois chroniques et cycliques, elles nécessitent des traitements répétés pendant des années. Compte tenu des coûts économiques découlant de ces troubles – notamment ceux de l'absentéisme et de la perte de productivité – il est essentiel que les employeurs et les gouvernements unissent leurs efforts pour s'attaquer sans délai à ce problème.

3.1 EMPLOYEURS

Les employeurs ont un rôle capital à jouer auprès des travailleurs aux prises avec une maladie mentale ou la toxicomanie puisqu'ils ont à gérer l'invalidité, à appliquer une politique d'accommodement et à offrir des programmes de retour au travail.

Les employeurs ont un rôle capital à jouer auprès des travailleurs qui sont aux prises avec une maladie mentale ou la toxicomanie, puisqu'ils ont à gérer l'invalidité, à appliquer une politique d'accommodement et à offrir des programmes de retour au travail. L'économie mondiale, dans laquelle l'information et l'innovation sont la clé du succès, exige des travailleurs compétents, motivés et assidus. Le capital humain et sa motivation, ses connaissances, son opinion, son jugement, son talent pour la communication, les échanges d'idées, l'établissement de relations solides sont le moteur de la compétitivité dans cette économie mondiale.[19]

En ce qui concerne les régimes d'assurance-invalidité proposés par l'employeur, le Comité est préoccupé par trois éléments précis. Premièrement, toutes les grandes entreprises devraient analyser les demandes de prestations d'invalidité de courte et de longue durée dont elles sont saisies afin de mesurer la prévalence de la maladie mentale et de la toxicomanie en leur sein. Deuxièmement, les employeurs devraient réexaminer le type et l'étendue de la couverture pour invalidité ainsi que son incidence sur la durée des prestations en sorte de concevoir un régime d'assurance-invalidité de l'employeur qui soit d'une efficacité optimale. Troisièmement, les employeurs, cadres et assureurs doivent apprivoiser la maladie mentale et la toxicomanie.[20]

Les gros employeurs parrainent habituellement des programmes d'aide aux employés (PAE) qui paient aux travailleurs un certain nombre de séances de thérapie. Ces programmes sont conçus pour aider l'employé à affronter divers problèmes en milieu de travail. Le Comité a appris qu'il fallait revoir les PAE parce qu'ils ne répondent pas bien aux besoins des employés aux prises avec une maladie mentale ou un problème de toxicomanie. En effet,

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19 Premier rapport, chapitre 6, section 6.5.

20 Premier rapport, chapitre 6, section 6.4.1.

ceux-ci n'offrent pas assez de séances de thérapie pour bien traiter la maladie mentale et la toxicomanie.[21]

Le Comité a aussi appris qu'il faudrait amener les employeurs à prendre des mesures pour accommoder les travailleurs souffrant d'une maladie mentale ou de toxicomanie. L'accommodement consiste à aménagemer des lieux de travail ou des procédures de travail pour permettre à une personne ayant des besoins spéciaux d'accomplir ses tâches. Par exemple, le fait d'accorder un horaire de travail variable à un employé ayant un trouble mental serait équivalent à construire une rampe d'accès pour un travailleur en fauteuil roulant. Un employé qui revient au travail après un épisode de maladie mentale peut avoir des besoins passablement différents de ceux d'un travailleur qui revient après une opération au dos. Il faut réviser les programmes de retour au travail actuels de façon qu'ils répondent à ces besoins variés.[22]

La culture d'une organisation peut tout changer dans la façon dont la maladie mentale et la toxicomanie sont considérées au travail. Comment les employeurs peuvent-ils contribuer à hausser le degré de sensibilisation à la maladie mentale et à la toxicomanie dans toute l'entreprise? Plus important encore, que peut-on faire pour augmenter les connaissances des employeurs et des cadres sur la maladie mentale et la toxicomanie et leur capacité de venir en aide aux employés qui en souffrent?

Que peut-on faire pour augmenter les connaissances des employeurs et des cadres sur la maladie mentale et la toxicomanie et leur capacité de venir en aide aux employés qui en souffrent?

Le Comité a appris que certaines grandes entreprises et institutions – comme Alcan Inc., la Banque Canadienne Impériale de Commerce et Dofasco Inc. pour n'en nommer que quelques-unes – consacrent, avec beaucoup de succès d'ailleurs, plus d'attention à la santé mentale et aux problèmes de toxicomanie en milieu de travail. Y a-t-il d'autres réussites que le Comité devrait connaître? Que devrait-on faire pour diffuser les connaissances et l'expérience de ces chefs d'entreprise?

Bien des Canadiens bénéficient d'un régime d'assurance-maladie complémentaire de l'employeur qui comporte un volet santé mentale. Les niveaux de couverture de ces régimes privés sont-ils suffisants? Faudrait-il étendre la couverture et, le cas échéant, quels services de santé mentale ont le plus besoin d'une meilleure couverture? Quelles modifications précises faut-il apporter aux règles pour que l'assurance-invalidité ne dissuade pas un malade mental ou un toxicomane de retourner au travail? Qu'est-ce qui parviendrait le mieux à inciter les employeurs à améliorer leur PAE pour faciliter l'accès des travailleurs à des traitements et à des services de réadaptation?

Qu'est-ce qui parviendrait le mieux à inciter les employeurs à améliorer leur PAE pour faciliter l'accès des travailleurs à des traitements et à des services de réadaptation?

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21 Premier rapport, chapitre 6, section 6.5.1.

22 Premier rapport, chapitre 6, section 6.5.2.

Quel est le meilleur moyen pour amener les employeurs à accorder à leurs employés atteints d'un trouble mental un horaire variable ou un véritable accommodement? Quelles mesures devraient-ils prendre pour résoudre les problèmes en milieu de travail qui ont un effet préjudiciable sur tous les employés, en particulier sur ceux souffrant d'une maladie mentale ou de toxicomanie?

Pourrait-on formuler certaines idées ou politiques visant à encourager les entreprises à engager des malades mentaux et des toxicomanes, ne serait-ce qu'à temps partiel? En particulier, existe-t-il des programmes axés sur les adolescents désavantagés par un manque d'instruction et de compétence particulière qui s'ajoute à leur maladie mentale, pour leur permettre de se trouver un emploi?

Existe-t-il des programmes axés sur les adolescents désavantagés par leur manque d'instruction et de compétence particulière qui s'ajoute à leur maladie mentale, pour leur permettre de se trouver un emploi?

Le Global Business and Economic Roundtable on Addiction and Mental Health a proposé un programme en douze temps pour lutter contre la maladie mentale et la toxicomanie en milieu de travail.[23] Est-ce un programme éprouvé? Dans l'affirmative, que peuvent faire les gouvernements pour encourager les entreprises à l'implanter? Le gouvernement fédéral devrait-il constituer un groupe de travail mixte avec cet organisme pour encourager l'adoption du programme?

3.2 COMMISSIONS DES ACCIDENTS DU TRAVAIL

Comment parvenir à uniformiser les règles des CAT applicables aux cas de maladie mentale et de toxicomanie? Faudrait-il réviser les règles des CAT applicables aux demandes de prestations pour maladie mentale et qui devrait le faire?

Dans toutes les provinces et tous les territoires, les commissions des accidents du travail (CAT) reçoivent de plus en plus de demandes d'indemnisation pour cause de maladie mentale (appelée « stress professionnel ») et, de plus en plus souvent, l'indemnisation est accordée. Le principal problème de ces demandes tient au fait qu'il est plus difficile de faire la preuve de la genèse d'un trouble mental que d'une maladie physique. Par conséquent, certaines CAT hésitent à accorder des prestations d'invalidité pour cause de maladie mentale. Les travailleurs concernés et ces CAT doivent donc se débattre seuls avec la question de savoir si les prestations d'invalidité pour troubles mentaux devraient être versées par la commission des accidents du travail ou par le régime d'assurance-maladie.[24] Comment parvenir à uniformiser les règles des CAT applicables aux cas de maladie mentale et de toxicomanie? Faudrait-il réviser les règles des CAT applicables aux demandes de prestations pour maladie mentale et qui devrait le faire? Quel rôle l'Association des commissions des accidents du travail du Canada peut-elle jouer pour donner à la recherche nécessaire une envergure nationale et uniformiser les règles de prestations?

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23 Premier rapport, chapitre 6, tableau 6.3.

24 Premier rapport, chapitre 6, section 6.4.2.

3.3 PROGRAMMES FÉDÉRAUX DE LA SÉCURITÉ DU REVENU

Le Comité a été informé de la nécessité de réviser le Programme de prestations d'invalidité du Régime de pensions du Canada (RPC-I) et le programme de l'assurance-emploi (AE) pour qu'ils tiennent compte de la nature imprévisible et souvent cyclique des troubles mentaux.[25]

En ce qui concerne le RPC-I, certaines personnes atteintes de troubles mentaux peuvent ne pas y avoir droit parce qu'elles n'ont pas travaillé assez longtemps (il faut avoir cotisé au Régime durant quatre des six années précédentes). Le Comité a appris que les demandeurs doivent accepter d'être désignés « inapte au travail de façon permanente » pour avoir droit aux prestations du RPC-I. Or, bien des personnes atteintes de troubles mentaux peuvent travailler, mais souvent, seulement à temps partiel. En outre, la première demande de plus de 66 p. 100 des malades mentaux et toxicomanes est rejetée pour défaut d'admissibilité et les deux tiers de ces demandeurs ne font pas appel de la décision et ne présentent plus d'autre demande.

Le gouvernement fédéral devrait-il réviser le RPC-I pour prévoir des prestations partielles ou tronquées afin de permettre à ceux qui ont des troubles mentaux de toucher une partie de leurs prestations tout en travaillant à temps partiel?

Le gouvernement fédéral devrait-il réviser le RPC-I pour prévoir des prestations partielles ou tronquées afin de permettre à ceux qui ont des troubles mentaux de toucher une partie de leurs prestations tout en travaillant à temps partiel? Le personnel du RPC-I devrait-il recevoir une formation pour être mieux renseigné sur la maladie mentale et la toxicomanie? Quelles autres modifications s'imposent pour que le RPC-I puisse être plus équitable envers les travailleurs ayant une maladie mentale ou une toxicomanie?

En ce qui concerne l'AE, les employés qui sont congédiés pour « inconduite » ou qui démissionnent « sans motif valable » n'ont pas droit aux prestations de l'AE. Par crainte d'être stigmatisés, les employés ayant une maladie mentale taisent leur état au travail. Lorsqu'ils ont des difficultés, ils se font congédier ou démissionnent sous l'effet de leur maladie, mais ils ne peuvent pas demander de prestations d'AE parce qu'ils n'ont pas révélé leur maladie avant. De plus, lorsqu'une personne demande des prestations de maladie de l'AE, elle est tenue de se procurer un certificat médical indiquant la durée probable de sa maladie. Étant donné l'imprévisibilité de la maladie mentale, un médecin peut difficilement fournir un tel renseignement.

Quelles modifications y aurait-il lieu d'apporter à l'AE pour mieux protéger les travailleurs souffrant d'une maladie mentale ou de toxicomanie?

Quelles modifications y aurait-il lieu d'apporter à l'AE pour mieux protéger les travailleurs souffrant d'une maladie mentale ou de toxicomanie? Par exemple, ceux dont la maladie mentale ou la toxicomanie est diagnostiquée après qu'ils ont laissé leur emploi devraient-ils être exemptés de

[25] Premier rapport, chapitre 6, section 6.4.3.

l'obligation d'avoir accumulé le nombre d'heures d'emploi assurables dont dépend actuellement l'admissibilité à l'AE? Quelles autres modifications le gouvernement fédéral devrait-il envisager?

Certains ont suggéré au Comité de recommander que le gouvernement fédéral trouve des moyens de partager plus équitablement avec les employeurs les coûts associés à la maladie mentale et à la toxicomanie en milieu de travail.[26] Quels mécanismes pourrait-on utiliser pour déterminer le partage de ces coûts et le mettre en application?

3.4 GOUVERNEMENT FÉDÉRAL, EMPLOYEUR DE TAILLE

Le gouvernement fédéral est un employeur d'importance. Dans son rôle d'employeur de la fonction publique fédérale, le Conseil du Trésor supervise l'application des avantages auxquels les fonctionnaires ont droit en vertu du Régime de soins de santé de la fonction publique et du Régime d'assurance-invalidité. Ces deux régimes garantissent aux fonctionnaires un niveau de revenu acceptable durant les périodes où ils luttent contre une maladie physique ou mentale de longue durée. En outre, Santé Canada est chargé de fournir aux fonctionnaires fédéraux des services de santé et de sécurité au travail, notamment les programmes d'aide aux employés.[27]

Le Comité sollicite le point de vue des fonctionnaires fédéraux et de leurs représentants sur la qualité et l'efficacité des efforts de promotion de la santé mentale et de prévention d'une incapacité d'ordre mental chez les fonctionnaires par le gouvernement fédéral.

Le gouvernement fédéral est-il un bon employeur au chapitre de l'accommodement des fonctionnaires ayant une maladie mentale ou une toxicomanie? Ses politiques de retour au travail sont-elles bonnes? Que doit-il améliorer pour être un employeur exemplaire?

Le gouvernement fédéral est-il un bon employeur au chapitre de l'accommodement des fonctionnaires ayant une maladie mentale ou une toxicomanie? Ses politiques de retour au travail sont-elles bonnes? Que doit-il améliorer pour être un employeur exemplaire?

[26] Premier rapport, chapitre 6, section 6.6.
[27] Premier rapport, chapitre 9, sections 9.2.9 et 9.2.10.

CHAPITRE 4:
PROBLÈMES PARTICULIERS

4.1 COMBATTRE LA STIGATISATION ET LA DISCRIMINATION

Le Comité juge extrêmement important le problème de la stigmatisation des personnes atteintes d'une maladie mentale ou de toxicomanie et aussi celui de la discrimination à leur endroit.

La stigmatisation et la discrimination touchent les malades mentaux et les toxicomanes de multiples façons. D'abord, ceux-ci sont régulièrement mis à l'écart de la société et peuvent même être privés d'une foule de droits fondamentaux que le reste du monde considère comme allant de soi. On les prive souvent de leurs droits élémentaires dans les secteurs du logement, de l'emploi, du revenu, des assurances, des études postsecondaires, de la justice pénale et de la responsabilité parentale.

Les personnes souffrant de maladie mentale ou de toxicomanie sont aussi victimes de discrimination et de rejet par les fournisseurs de services tant dans le réseau de la santé mentale que dans le réseau de la santé en général, et elles sont aussi victimes de discrimination de la part des décideurs et des médias. Pour de nombreux malades mentaux et toxicomanes, la stigmatisation et la discrimination peuvent être une source de détresse aussi importante que le trouble lui-même.[28]

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La stigmatisation de la maladie mentale affligeant à ce point les malades mentaux et les toxicomanes dans leur vie quotidienne, ne faudrait-il pas plutôt la qualifier de ce qu'elle est vraiment : de la discrimination? C'est certainement de la discrimination lorsqu'une personne atteinte d'une maladie mentale est systématiquement traitée différemment d'une autre qui en est exempte. Le mot stigmatisation serait-il devenu une façon polie de parler de discrimination?

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Le Comité a longuement discuté de la meilleure façon d'atténuer la stigmatisation et de lutter contre la discrimination. Pour y arriver, il faut un effort concerté et soutenu sur une longue période, notamment une éducation et une action communautaires permanentes, des campagnes de presse, des tribunes où les personnes atteintes peuvent échanger avec la population pour la renseigner sur la problématique, et des campagnes de sensibilisation

Plusieurs témoins ont souligné l'importance d'élaborer une stratégie nationale contre la stigmatisation. Son adoption signifierait aux Canadiens que les gouvernements fédéral, provinciaux et territoriaux attachent tous autant d'importance à la promotion de la santé mentale de la population qu'à celle de sa santé physique.

[28] Premier rapport, chapitre 3, section 3.3.

auprès des professionnels pour diminuer la discrimination structurelle dans le réseau de la santé et dans le réseau de la santé mentale.[29]

À noter que plusieurs témoins ont souligné l'importance d'élaborer une stratégie nationale contre la stigmatisation. Ils ont dit au Comité qu'une telle stratégie devait résolument attirer l'attention du public sur les problèmes de santé mentale et de toxicomanie. Son adoption signifierait aux Canadiens que les gouvernements fédéral, provinciaux et territoriaux attachent tous autant d'importance à la promotion de la santé mentale de la population qu'à celle de sa santé physique.[30] Pourtant, de nombreux témoins ont dit juger important de cibler soigneusement les efforts contre la stigmatisation et que, selon certaines études, les campagnes de sensibilisation trop générales ne donnent pas les résultats escomptés.

Après avoir étudié les campagnes menées dans des pays étrangers pour faire la promotion de la santé mentale, le Comité a conclu que, pour réussir, les campagnes de sensibilisation contre la stigmatisation et la discrimination doivent faire l'objet d'un financement continu, d'une planification à long terme et d'une évaluation constante. De plus, à en juger d'après les campagnes menées jusqu'ici, en particulier en Australie et en Nouvelle-Zélande, mieux vaut, semble-t-il, les adapter aux situations, aux groupes de population et aux communautés visées. Notre examen de ce qui se fait dans le monde fait aussi ressortir la nécessité d'entreprendre au départ une vaste consultation auprès des divers ordres de gouvernement, des fournisseurs, des ONG et, surtout, des personnes atteintes et de leur famille.[31]

Les médias ont-ils aussi un rôle à jouer pour amener les Canadiens à changer d'attitude à l'endroit des personnes ayant une maladie mentale ou une toxicomanie?

Outre les campagnes gouvernementales, les médias ont-ils aussi un rôle à jouer pour amener les Canadiens à changer d'attitude à l'endroit des personnes ayant une maladie mentale ou une toxicomanie? Dans l'affirmative, quel devrait être ce rôle? Y a-t-il des stratégies de sensibilisation qui ont eu particulièrement de succès au Canada pour diminuer la stigmatisation et la discrimination (p. ex., la Stratégie canadienne sur le VIH/sida) et dont on pourrait tirer des leçons?

Le Royaume-Uni a établi une brigade d'ambassadeurs composée d'une quarantaine de personnes souffrant d'une maladie mentale ou de toxicomanie qui ont appris à rencontrer la presse et les employeurs pour parler de leur vécu[1]. Le Canada devrait-il constituer une équipe comparable?

Le Comité s'est aussi fait dire que la stratégie la plus efficace contre la stigmatisation et la discrimination consiste à multiplier les contacts avec les personnes atteintes d'une maladie mentale ou de toxicomanie. À ce propos, il a appris que le Royaume-Uni a établi une brigade d'ambassadeurs composée d'une quarantaine de personnes souffrant d'une maladie mentale ou de toxicomanie qui ont appris à rencontrer la presse et les employeurs pour parler de leur vécu.[32] Cette initiative a permis

29 Premier rapport, chapitre 3, article 3.4.
30 Premier rapport, chapitre 3, section 3.4.1.
31 Deuxième rapport, chapitre 5, section 5.5.
32 Deuxième rapport, chapitre 3, section 3.4.1.

d'associer des visages à la campagne contre la stigmatisation. Le Canada devrait-il constituer une équipe comparable?

De même, les autorités australiennes ont lancé une stratégie nationale pour la santé mentale dans les écoles de journalisme afin de montrer aux étudiants comment faire leurs reportages sans stigmatiser les personnes atteintes de troubles mentaux et pour encourager la presse à transmettre des messages positifs sur la santé mentale.[33] Le gouvernement fédéral devrait-il, en collaboration avec les médias, se doter d'une stratégie semblable au Canada? Combien coûterait une telle stratégie et comment serait-elle financée?

Enfin, il faut sensibiliser les professionnels de la santé à cette difficulté, puisque les intervenants en santé mentale et en toxicomanie ne sont pas non plus à l'abri de l'influence de la stigmatisation que vivent leurs patients/clients. Quelle est la prévalence de cette forme de stigmatisation structurelle? Faudrait-il réviser les programmes d'études des facultés de médecine et de nursing pour ajouter des cours et des stages en santé mentale et en toxicomanie? Est-ce un champ de compétence provinciale? Le gouvernement fédéral a-t-il un rôle à y jouer? Quelles autres mesures ciblant les professionnels de la santé pourraient diminuer la discrimination?

De façon générale, que peuvent faire les gouvernements pour faire prendre conscience à tout le monde que la santé mentale est aussi importante que la santé physique pour le bien-être des Canadiens et que, en corollaire, la prestation des services et des moyens de soutien en santé mentale et en toxicomanie est aussi capitale que la prestation des services de santé pour les affections physiques?

De façon générale, que peuvent faire les gouvernements pour faire prendre conscience à tout le monde que la santé mentale est aussi importante que la santé physique pour le bien-être des Canadiens et que, en corollaire, la prestation des services et des moyens de soutien en santé mentale et en toxicomanie est aussi capitale que la prestation des services de santé pour les affections physiques?

4.2 PRÉVENTION DU SUICIDE

Chaque année, quelque 3 700 Canadiens se suicident. C'est la première cause de décès chez les hommes de 25 à 29 ans et chez les femmes de 30 à 34 ans. En outre, on recense annuellement un grand nombre de tentatives de suicide. En 2002, environ 4 p. 100 des Canadiens de 15 ans et plus ont eu des pensées suicidaires.[34]

Dans son premier rapport, le Comité signale que, sans être défini comme un trouble mental, le comportement suicidaire est souvent en corrélation avec la maladie mentale et la toxicomanie; plus de 90 p. 100 des suicidés souffrent d'une maladie mentale diagnosticable ou d'un trouble lié à une substance psychoactive. Le suicide est la première cause de décès prématuré chez les schizophrènes et il est responsable de 15 à 25 p. 100 de tous les décès chez les personnes souffrant de troubles de l'humeur graves. La toxicomanie prédispose

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33 Deuxième rapport, chapitre 1, section 1.5.

34 Premier rapport, chapitre 5, section 5.2.

souvent une personne à avoir un comportement suicidaire en accentuant une humeur dépressive et en atténuant la maîtrise de soi.[35]

Contrairement à l'Australie, la Finlande, la France, les Pays-Bas, la Nouvelle-Zélande, la Norvège, la Suède, le Royaume-Uni et les États-Unis, le Canada n'a pas de stratégie nationale pour la prévention du suicide. Selon le Centre de prévention du suicide, deux provinces seulement – le Nouveau-Brunswick et le Québec – ont mis en œuvre des stratégies de prévention exclusivement pour le suicide. Beaucoup voudrait que le gouvernement fédéral se concerte avec les provinces, les territoires et les intéressés pour élaborer une stratégie nationale.

Contrairement à l'Australie, la Finlande, la France, les Pays-Bas, la Nouvelle-Zélande, la Norvège, la Suède, le Royaume-Uni et les États-Unis, le Canada n'a pas de stratégie nationale pour la prévention du suicide.

Cette stratégie nationale pour la prévention du suicide pourrait incorporer les programmes et activités suivants, entre autres :

- Campagnes de sensibilisation populaire pour lutter contre la stigmatisation du comportement suicidaire.
- Stratégies pour l'amélioration de la santé de la population visant les déterminants de la santé, notamment le logement, la sécurité du revenu, l'éducation, l'emploi et les attitudes de la société envers ceux ayant une maladie mentale ou une toxicomanie.
- Programmes de prévention pour les adolescents, pour les personnes à risque élevé d'avoir un comportement suicidaire et pour les familles dont un membre s'est suicidé ou a fait une tentative.
- Accès équitable à des services intégrés et bien coordonnés, y compris à des services de counseling par téléphone pour les personnes en crise et de traitement des maladies mentales et de toxicomanies.
- Mesures de restriction de l'accès à des moyens de se suicider comme les armes à feu, les médicaments, les ponts accessibles et d'autres endroits.
- Formation des fournisseurs de services et des éducateurs sur le dépistage précoce des comportements suicidaires et sur la gestion de crise.
- Recherche et évaluation pour contribuer à l'élaboration de programmes efficaces de prévention du suicide et pour évaluer le succès des services de santé et des services sociaux dans la prévention du suicide.

Lesquels parmi les gouvernements fédéral, provinciaux et territoriaux et les organisations non gouvernementales devraient participer à l'élaboration d'une stratégie nationale pour la prévention du suicide? Quels devraient être les objectifs précis d'une telle stratégie? Quels programmes et activités devraient faire partie d'une stratégie nationale de prévention du suicide?

[35] Premier rapport, chapitre 4, section 4.5.

Lesquels parmi les gouvernements fédéral, provinciaux et territoriaux et les organisations non gouvernementales devraient participer à l'élaboration d'une stratégie nationale pour la prévention du suicide? Quels devraient être les objectifs précis d'une telle stratégie? Quels programmes et activités devraient faire partie d'une stratégie nationale de prévention du suicide? Combien celle-ci devrait-elle coûter et comment devrait-elle être financée? Devrait-il y avoir une seule stratégie nationale ou chaque ordre de gouvernement devrait-il en implanter une?

CHAPITRE 5:
RESSOURCES HUMAINES

Des professionnels de diverses disciplines prodiguent des services de santé mentale, des moyens de soutien et des traitements contre la toxicomanie. On trouve notamment des médecins qui dispensent les soins primaires, des psychiatres, des spécialistes en toxicomanie, des psychologues, des infirmiers psychiatriques, des travailleurs sociaux, des infirmiers praticiens, des ergothérapeutes, des gestionnaires de cas, des intervenants en toxicomanie, des éducateurs en soins spéciaux, etc. Le Comité s'est fait dire que, comme dans d'autres secteurs du système de santé, il y a un manque criant de fournisseurs. La mauvaise répartition géographique des professionnels de la santé mentale et de la toxicomanie est aussi préoccupante.[36] D'autres pays sont aux prises avec le même casse-tête de ressources humaines dans le domaine de la santé mentale et de la toxicomanie.[37] Le Comité a aussi appris que le secteur des soins de santé primaire a cruellement besoin d'une réforme en vue d'améliorer l'accès aux services de santé mentale et de multiplier les initiatives partagées en santé mentale dans tout le pays.

Comme dans d'autres secteurs du système de santé, il y a un manque criant de fournisseurs.

5.1 OFFRE DE RESSOURCES HUMAINES

Bien que le Comité ait entendu parler maintes fois des pénuries de fournisseurs,[38] il n'existe actuellement aucune base de données nationale capable de fournir des données générales sur l'offre de ressources humaines en santé mentale et en toxicomanie, et encore moins une ventilation détaillée. À l'heure actuelle, on ne sait pas s'il y a vraiment pénurie de fournisseurs de services en santé mentale et en toxicomanie au Canada ni, s'il y en a effectivement une, quelle en est la gravité. Voilà qui montre aussi que les données sur la santé en général au Canada ne sont pas fiables.

La pénurie est-elle pire dans certaines catégories de fournisseurs? Certaines provinces ont-elles réussi mieux que les autres à corriger le manque de professionnels en santé mentale et en toxicomanie?

Le manque d'information nuit très sérieusement à une bonne planification des ressources humaines, en particulier à la mise en œuvre d'une stratégie nationale des ressources humaines en santé mentale, en maladie mentale et en toxicomanie.[39]

Comment peut-on produire des estimations réalistes et dignes de foi des ressources humaines actuellement sur le marché du travail et de celles qui seraient nécessaires après la réforme du système de santé mentale et de traitement de la toxicomanie? Quel rôle le

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36 Premier rapport, chapitre 8, section 8.2.5.
37 Deuxième rapport, sections 1.3.2, 2.3.2, 3.3.1, 4.3.1, 4.3.2 et 4.3.3.
38 Premier rapport, chapitre 8, section 8.2.5.
39 *Ibid.*

gouvernement fédéral devrait-il jouer pour aider les provinces et les territoires à assurer une offre suffisante de professionnels de la santé dans tout le pays? Comment le gouvernement fédéral peut-il se mêler de la planification des ressources humaines dans le secteur de la santé mentale et de la toxicomanie sans empiéter sur les compétences provinciales et territoriales?

Quels devraient être les éléments d'une stratégie nationale de ressources humaines (planification, formation, réexamen des champs d'activité)? Quels programmes et incitatifs faudrait-il instaurer pour encourager les gens à choisir une carrière en santé mentale et en toxicomanie? Le Comité sollicite les opinions sur les écueils et les possibilités de l'élaboration et de la mise en œuvre d'une telle stratégie.

Une stratégie des ressources humaines devrait avoir pour objet de veiller à ce qu'on offre les bonnes compétences et les services utiles en tenant compte de la culture du patient, par la bonne personne et au moment opportun. Comment pourrait-on élargir et valoriser l'instruction et la formation des professionnels et travailleurs de la santé mentale et de la toxicomanie afin d'atteindre cet objectif?

Quel rôle le gouvernement fédéral devrait-il jouer pour aider les provinces et les territoires à assurer une offre suffisante de professionnels de la santé dans tout le pays?

Il est évident que la mauvaise répartition géographique des professionnels de la santé mentale et de la toxicomanie a pour effet de restreindre l'accès aux services et moyens de soutien nécessaires dans les régions rurales et les endroits reculés du Canada.[40] Comment faire pour contrer le manque de services? Le Comité veut connaître l'opinion des Canadiens sur les types d'incitatifs qu'on pourrait établir pour lutter contre le manque de personnel dans les régions rurales et reculées.

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5.2 SECTEUR DES SOINS PRIMAIRES

Le secteur des soins primaires est celui où s'établit généralement le premier contact entre le système de santé et les patients, que ceux-ci consultent pour une maladie, une blessure, une maladie mentale ou une toxicomanie. Pourtant, le Comité s'est fait dire que les fournisseurs des soins primaires n'ont peut-être pas les connaissances, ni les compétences pour répondre aux besoins des patients ayant une maladie mentale ou une toxicomanie, pour diagnostiquer correctement les troubles mentaux, ni pour aider les patients à s'y retrouver dans les méandres des services plus spécialisés vers lesquels ils sont aiguillés. Ils ne sont pas non plus rémunérer pour le

Si les fournisseurs de soins primaires doivent débuter le traitement de la maladie mentale ou de la toxicomanie des patients, que faut-il faire pour améliorer les soins de santé mentale à ce stade?

40 Premier rapport, chapitre 8, section 8.2.3.

faire.[41] Si les fournisseurs de soins primaires doivent débuter le traitement de la maladie mentale ou de la toxicomanie des patients, que faut-il faire pour améliorer les soins de santé mentale à ce stade? Comment y parvenir, compte tenu du terrible manque de médecins de famille, d'infirmiers et d'autres professionnels de la santé au Canada en ce moment?

Il faut mieux sensibiliser les professionnels de la santé à la santé mentale et à la toxicomanie. Quelle devrait être l'ampleur de la formation à donner aux médecins de famille, aux infirmiers praticiens et aux autres professionnels de la santé sur la maladie mentale et la toxicomanie, durant leurs études? Les programmes d'études des écoles de soins infirmiers et des facultés de médecine devraient-ils être révisés pour y ajouter plus de cours sur la maladie mentale et la toxicomanie?

Certains ont recommandé au Comité de réclamer une modification des tarifs des services médicaux afin d'accorder aux médecins de famille une prime pour les inciter à consacrer plus de temps aux patients souffrant d'une maladie mentale ou de toxicomanie quand ceux-ci en ont besoin.[42] C'est ce qu'ont fait l'Alberta et le Québec après le lancement d'un programme très réussi en Australie il y a trois ans. Les médecins de famille qui doivent passer plus de temps avec les patients atteints de troubles mentaux pour répondre à leurs besoins devraient avoir droit à une hausse du tarif en guise d'indemnité.[43] Les provinces qui n'ont pas encore modifié leur tarif de la sorte devraient-elles le faire?

D'autres ont recommandé au Comité l'établissement d'un plus grand nombre de projets pour des soins de santé mentale partagés au pays. Il s'agit de coopération entre psychiatres et fournisseurs de soins primaires. Ces projets de soins partagés sont très axés sur la clinique et ils intègrent les services de santé mentale dans un cadre de soins de santé primaires. Le Comité s'est fait dire que le gouvernement fédéral pouvait jouer un rôle majeur en continuant à financer les projets qui réussissent et en veillant à ce que les pratiques exemplaires soient implantées et incorporées dans les politiques et programmes permanents de l'ensemble des provinces et territoires.[44]

Comment peut-on encourager la collaboration clinique entre les fournisseurs de soins primaires et les professionnels de la santé mentale?

De nombreuses provinces sont en train de réformer leur secteur des soins primaires. Comment peut-on encourager la collaboration clinique entre les fournisseurs de soins primaires et les professionnels de la santé mentale? Par exemple, les psychiatres devraient-ils agir comme consultants auprès des équipes pluridisciplinaires de soins primaires ou en faire partie directement? Quels services spécialisés ou institutionnels en santé mentale et toxicomanie pourraient être avantageusement relogés avec les soins primaires? Quels sont les principaux obstacles à l'implantation de services de soins de santé mixtes? Quels sont les obstacles financiers? Faudra-t-il modifier les règles de pratique actuelles pour permettre le partage des soins de santé mentale? Le gouvernement fédéral devrait-il encourager explicitement le

41 Premier rapport, chapitre 8, section 8.2.4.
42 *Ibid.*
43 Deuxième rapport, section 10.3.2.
44 Premier rapport, chapitre 8, section 8.2.4.

partage des soins de santé mentale dans le cadre de la réforme des soins primaires qu'il soutient? Combien d'argent faudrait-il pour généraliser cette organisation des soins?

Comment les psychologues et les travailleurs sociaux peuvent-ils être intégrés à une équipe de soins de santé mentale?

Comment les psychologues et les travailleurs sociaux peuvent-ils être intégrés à une équipe de soins de santé mentale? D'où viendrait l'argent nécessaire pour les rémunérer puisque, n'étant pas médecins, ils ne peuvent pas facturer leurs services sous le régime de la *Loi canadienne sur la santé* parce que leurs services ne sont pas assurés par le régime d'assurance-maladie financé par l'État?

5.3 TRAVAILLEURS COMMUNAUTAIRES ET POLICIERS

Toute une gamme de travailleurs apportent un soutien de type communautaire aux personnes ayant une maladie mentale ou une toxicomanie. Il s'agit de de membres ou d'employés de diverses organisations non gouvernementales ainsi que de nombreux organismes sociaux (assistance sociale, soutien du revenu, emploi, etc.).

Il y a cinq ans, la Nouvelle-Zélande a implanté un programme de formation qui procure une qualification aux travailleurs communautaires en santé mentale. Quels types de formation obligatoire sont actuellement offerts à ces travailleurs communautaires au Canada?

Il y a cinq ans, la Nouvelle-Zélande a implanté un programme de formation qui procure une qualification aux travailleurs communautaires en santé mentale.[45] Quels types de formation obligatoire sont actuellement offerts à ces travailleurs communautaires au Canada? Devrait-on uniformiser les études et la formation de ces travailleurs? Faudrait-il mettre sur pied des programmes de formation comme ceux offerts en Nouvelle-Zélande? Dans l'affirmative, quels établissements devraient offrir cette formation? Faudrait-il confier à des organismes provinciaux et nationaux assimilables aux corporations chargées de l'autoréglementation des professionnels de la santé le soin de réglementer ces travailleurs? Le gouvernement fédéral devrait-il soutenir financièrement le lancement d'un tel programme de formation?

Que faudrait-il faire pour améliorer la formation des policiers de façon qu'ils puissent intervenir plus efficacement auprès des personnes ayant une maladie mentale ou une toxicomanie? Que faire pour augmenter la sécurité de ceux qui participent à l'intervention et aider les policiers à employer le moins de force possible lorsqu'ils appréhendent une personne en crise?

Le Comité sait aussi que, de plus en plus souvent, les policiers, et non pas les fournisseurs de soins de santé mentale, sont les premiers à entrer en contact avec une personne en crise. Il arrive fréquemment que les personnes atteintes de graves troubles mentaux n'aient nulle part où aller quand elles sont en crise et, lorsque cela se produit, on appelle les policiers pour qu'ils interviennent. Le Comité a appris que, malheureusement, les policiers n'ont généralement pas la formation voulue et ne disposent pas non plus de lignes

[45] Deuxième rapport, chapitre 2, section 2.3.2.

directrices sur lesquelles s'appuyer pour intervenir auprès des personnes en crise. Que faudrait-il faire pour améliorer leur formation de façon qu'ils puissent intervenir plus efficacement auprès des personnes ayant une maladie mentale ou une toxicomanie? Que faire pour augmenter la sécurité de ceux qui participent à l'intervention et aider les policiers à employer le moins de force possible lorsqu'ils appréhendent une personne en crise?

5.4 SOUTIEN DES AIDANTS NATURELS

Les familles sont souvent la principale ressource et le seul soutien disponible pour les individus souffrant de maladie mentale ou de toxicomanie. À cause des ressources limitées du système de santé et de la communauté, ce sont les parents qui hébergent leurs enfants malades, prennent soin d'eux, les surveillent et les aident financièrement.

Les familles qui vivent avec une personne ayant une maladie mentale ou une toxicomanie ont-elles un accès adéquat aux ressources dont elles ont besoin pour aider leurs proches?

Selon plusieurs études, outre qu'elle est une source d'énormes tensions et de stress affectif, cette situation draine les ressources financières des proches des personnes ayant une maladie mentale ou souffrant de toxicomanie. Les familles qui vivent avec une telle personne ont-elles un accès adéquat aux ressources dont elles ont besoin pour aider leurs proches? Les familles sont-elles bien outillées pour s'occuper de leurs proches qui ont une maladie mentale ou une toxicomanie?

Les familles font partie intégrante du traitement des personnes atteintes de maladie mentale ou de toxicomanie. Elles constituent des alliés efficaces et bienveillants pour limiter la douleur et la souffrance du patient. Les aidants naturels devraient-ils être davantage mis à contribution dans le traitement des patients? De quelle façon devrait-on encourager leur participation au système de soins pour la santé mentale et contre la toxicomanie?

CHAPITRE 6: BANQUE D'INFORMATION NATIONALE, RECHERCHE ET TECHNOLOGIE

Le Comité est convaincu que, pour parvenir à des services de santé mentale et de traitement des toxicomanies de grande qualité, il faudra nécessairement établir une banque d'information nationale, encourager la recherche sur la gestion de l'information en matière de santé en général, mais plus particulièrement de santé mentale et de toxicomanie, et exploiter judicieusement les technologies de l'information et des communications. Si des mesures en ce sens étaient prises, il serait possible de prendre des décisions mieux éclairées, d'établir des priorités et des politiques bien pensées et d'améliorer les résultats pour les personnes souffrant de troubles mentaux ou de toxicomanie.

6.1 ENQUÊTE SUR LA SANTÉ DANS LES COLLECTIVITÉS CANADIENNES

Le cycle 1.2 de l'Enquête de Statistique Canada sur la santé dans les collectivités canadiennes (ESCC) de 2002, qui portait sur la santé mentale et le bien-être, a permis de calculer pour la première fois des taux de prévalence de certaines maladies mentales, des troubles liés à l'usage de substances psychoactives, des idées suicidaires et du jeu pathologique. L'enquête ne portait cependant pas sur le vaste éventail des troubles affectifs de l'humeur et des troubles anxieux couverts par l'enquête nationale sur la santé mentale et le bien-être réalisée en Australie en 1997. Cette même enquête australienne se distingue également en ce sens qu'elle établissait une distinction entre la consommation excessive d'alcool et de drogue et la toxicomanie et qu'elle permettait d'évaluer aussi les troubles concomitants et la comorbidité. Le gouvernement australien envisage de réaliser une enquête sur la prévalence de la maladie mentale chez les enfants et les adolescents, de même qu'une enquête sur les troubles psychotiques moins répandus comme la schizophrénie.[46]

L'Enquête sur la santé dans les collectivités canadiennes devrait être répétée à intervalles réguliers et il serait utile d'en élargir la base pour couvrir un plus grand éventail de troubles mentaux, de groupes d'âges et de sous-groupes démographiques.

L'Enquête sur la santé dans les collectivités canadiennes devrait être répétée à intervalles réguliers et il serait utile d'en élargir la base pour couvrir un plus grand éventail de troubles mentaux, de groupes d'âges et de sous-groupes démographiques. Le Canada ne recueille pas régulièrement de données sur la prévalence des maladies mentales et des toxicomanies chez les Autochtones, les sans-abri et les détenus – groupes qui semblent présenter un risque de maladie mentale plus élevé que la population en général.[47]

Est-ce que Statistique Canada devrait effectuer une enquête sur les enfants et les adolescents comme l'Australie entend le faire? Doit-on demander à Statistique Canada d'élargir la portée

46 Premier rapport, chapitre 5, section 5.1 et 5.2.

47 Premier rapport, chapitre 5, section 5.3.

de la prochaine Enquête sur la santé dans les collectivités canadienne pour y inclure des questions permettant d'évaluer les troubles concomitants et la comorbidité, comme le fait l'enquête australienne? Que peut-on faire pour améliorer l'information sur la prévalence de la maladie mentale parmi les Autochtones, les sans-abri et les détenus? À quelle fréquence devrait-on administrer l'Enquête sur la santé dans les collectivités canadiennes? Devons-nous communiquer notre méthodologie d'enquête à d'autres pays pour permettre des comparaisons internationales valables et utiles?

Que peut-on faire pour améliorer l'information sur la prévalence de la maladie mentale chez les Autochtones, les sans-abri et les détenus?

6.2 BANQUE D'INFORMATION NATIONALE

Actuellement, le Canada n'a pas de banque d'information sur la prévalence des maladies mentales et des toxicomanies dans la population. Nous n'avons pas non plus de système d'information permettant de mesurer la situation des Canadiens sur le plan de la maladie mentale et d'évaluer les politiques, les programmes et les services dans les domaines de la santé mentale, de la maladie mentale et de la toxicomanie. Bien difficile dans ces conditions de déterminer les besoins et la qualité des services dans les provinces et les territoires.

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L'Alliance canadienne pour la maladie mentale et la santé mentale prône l'établissement d'un système national d'information sur la santé mentale, la maladie mentale et la toxicomanie reposant sur une collaboration dynamique de tous les paliers de gouvernement et de toutes les parties concernées, des personnes atteintes aux services de collecte de données. Plusieurs bases de données, dont celles que procurerait une enquête élargie sur la santé dans les collectivités canadiennes, pourraient servir de point de départ. Ce système initial pourrait être transformé en une banque de données bien organisée – à mesure qu'on y ajouterait de nouveaux indicateurs et de nouvelles sources de données – qui serait mise à la disposition des chercheurs et décisionnaires du secteur public et d'ailleurs.

Qui doit prendre l'initiative de faciliter la mise sur pied d'une telle banque d'information nationale? Quels seraient les rôles respectifs de Statistique Canada, de Santé Canada, de l'Institut canadien d'information sur la santé, des Instituts de recherche en santé du Canada et des administrations provinciales et territoriales dans l'établissement et la gestion de ce système? Les réalisations de certains pays ou de certaines provinces peuvent-elles servir de modèle? Combien coûterait l'établissement d'une banque nationale d'information sur la santé mentale, la maladie mentale et la toxicomanie?

Qui doit prendre l'initiative de faciliter la mise sur pied d'une telle banque d'information nationale?

6.3 RECHERCHE

6.3.1 Le financement

Ce sont les Instituts de recherche en santé du Canada qui, par la voie de l'Institut des neurosciences, de la santé mentale et des toxicomanies (INSMT), sont la principale source fédérale de financement de la recherche sur la santé mentale, la maladie mentale et la toxicomanie. En 2003-2004, les IRSC ont alloué 93 millions de dollars à l'INSMT, dont le budget de base totalise 623 millions de dollars. Sur ce total, quelque 33 millions de dollars vont à la recherche sur la santé mentale et la toxicomanie, soit 5,3 p. 100 du budget total de recherche en santé des IRSC.[48]

Pour beaucoup de témoins, la part du budget total de recherche en santé consacrée à la santé mentale, à la maladie mentale et aux toxicomanies est trop faible et ne reflète pas le fardeau que font peser les troubles mentaux et la toxicomanie sur l'économie. D'après certaines estimations, si le niveau de financement était en rapport avec le coût économique de la maladie, les IRSC devraient porter de 33 à au moins 80 millions de dollars par an les crédits consacrés à la recherche sur la maladie mentale et la toxicomanie. Le Comité a par ailleurs appris que la part du budget total des IRSC consacrée à la santé mentale, à la maladie mentale et à la toxicomanie (5,3 p. 100) est relativement faible par rapport à ce qui se fait dans d'autres pays comme le Royaume-Uni (6,5 p. 100) et les États-Unis (10 p. 100).[49]

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Sur quoi faut-il se fonder pour déterminer la proportion des budgets de recherche à consacrer à telle ou telle maladie? Sur sa prévalence? Sur la morbidité et la mortalité? Sur le coût économique de la maladie? Est-ce bien la bonne façon de procéder? Les comparaisons internationales sont-elles utiles? Les allocations de fonds de recherche doivent-elles être déterminées exclusivement ou surtout en fonction de l'intérêt que présente chaque projet de recherche par rapport à toutes les demandes de financement soumises à l'organisme subventionnaire ou doivent-elles être déterminées en tenant compte de tous les chiffres et facteurs abordés plus haut?

S'il faut allouer davantage de crédits à l'INSMT, comment faut-il s'y prendre? En distribuant différemment le budget des IRSC ou en augmentant le budget total de l'INSMT?

S'il faut allouer davantage de crédits à l'INSMT, comment faut-il s'y prendre? En distribuant différemment le budget des IRSC ou en augmentant le budget total de l'INSMT? Doit-on instituer un fonds spécial consacré à la recherche sur la santé mentale, la maladie mentale et la toxicomanie? Les IRSC doivent-ils créer un nouvel institut voué à la santé mentale, à la

48 Premier rapport, chapitre 10, section 10.1.
49 Premier rapport, chapitre 10, section 10.2.

maladie mentale et aux toxicomanies? Dans l'affirmative, qu'est-ce qui le distinguerait de l'INSMT? Le Comité veut connaître votre avis et vos suggestions quant à l'augmentation du financement, par le gouvernement fédéral, de la recherche sur la santé mentale, la maladie mentale et la toxicomanie.

D'autres questions encore nous préoccupent : les autorités provinciales accordent-elles suffisamment d'argent à la recherche? Et les organisations de santé mentale, financent-elles suffisamment la recherche? Et les sociétés pharmaceutiques?

6.3.2 Le transfert du savoir acquis

Le Comité s'est aussi intéressé à la question du transfert du savoir, c'est-à-dire à la façon de permettre aux fournisseurs de services, aux établissements et aux collectivités locales (soit l'échelon de la prestation des services et des moyens de soutien) d'appliquer les résultats de la recherche. Il arrive en effet trop souvent que les découvertes issues de recherches publiées sur la santé mentale, la maladie mentale et la toxicomanie (médicaments, psychothérapies, etc.) ne sortent pas des laboratoires, privant ainsi les malades et les autres parties concernées de services utiles.

Il arrive en effet trop souvent que les découvertes issues de recherches publiées sur la santé mentale, la maladie mentale et la toxicomanie (médicaments, psychothérapies, etc.) ne sortent pas des laboratoires, privant ainsi les malades et les autres parties concernées de services utiles.

La situation du Canada à cet égard n'est pas unique. D'après un rapport américain, aux États-Unis, il s'écoule de 15 à 20 ans entre la découverte de formes de traitement efficaces (médicaments, thérapies, nouveaux modes d'administration des soins, etc.) et leur généralisation dans les soins aux malades. On précise dans le même rapport que, même quand les résultats des découvertes se répandent dans l'usage, on continue d'observer une grande variabilité dans les pratiques cliniques, dont certaines sont même incompatibles avec le modèle de traitement dont la supériorité est avérée.[50] En revanche, le Comité a appris qu'au Royaume-Uni, le National Institute for Mental Health in England (NIMHE) contribue énormément à diffuser les résultats de recherches les plus poussées jusqu'aux praticiens en santé mentale.[51]

Pourquoi est-il si difficile d'intégrer à la pratique courante les médicaments et thérapies modernes dont l'utilité est avérée? Comment peut-on surmonter cette résistance?

Pourquoi est-il si difficile d'intégrer à la pratique courante les médicaments et thérapies modernes dont l'utilité est avérée? Comment peut-on surmonter cette résistance?

Quelles mesures pourrait-on prendre pour encourager l'adoption rapide et universelle, par les fournisseurs de services en santé mentale et en toxicomanie, des résultats prometteurs de la recherche obtenus par l'expérience clinique? Le gouvernement fédéral doit-il établir un fonds pour l'innovation afin d'encourager l'innovation dans la prestation des services et

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50 Premier rapport, chapitre 10, section 10.4.

51 Deuxième rapport, chapitre 3, section 3.6.

d'accélérer la mise en pratique des résultats de la recherche ? De quel ordre de grandeur ce fonds devrait-il être? À quelles conditions devait être subordonné le financement de projets?

Le gouvernement fédéral doit-il envisager de créer un organisme analogue au NIMHE du Royaume-Uni pour faciliter l'application des connaissances ou cette tâche relève-t-elle de l'Institut des neurosciences, de la santé mentale et des toxicomanies? Dans l'affirmative, comment faciliter sa tâche?

Quelles mesures pourrait-on prendre pour encourager l'adoption rapide et universelle, par les fournisseurs de services en santé mentale et en toxicomanie, des résultats prometteurs de la recherche obtenus par l'expérience clinique?

Le Comité souhaite connaître l'avis des Canadiens sur la manière d'accélérer l'application des résultats de la recherche dans le traitement des personnes souffrant de maladie mentale ou de toxicomanie.

6.3.3 La recherche sur des sujets humains

Comme nous l'avons signalé dans notre premier rapport, la recherche clinique sur la maladie mentale et la toxicomanie s'est accélérée depuis une vingtaine d'années, ce qui a grandement fait progresser les thérapies. Or, ces importants travaux de recherche exigent souvent la participation de sujets de recherche souffrant eux-mêmes de troubles mentaux.[52]

La recherche sur des personnes atteintes de maladie mentale ou souffrant de toxicomanie exige des précautions particulières. En effet, si tous les sujets qui participent à des recherches cliniques sont vulnérables jusqu'à un certain point, ceux qui prennent part à des travaux sur la maladie mentale ou la toxicomanie le sont encore plus du fait que les troubles dont ils souffrent, surtout s'ils affectent leurs facultés cognitives ou sont particulièrement graves, compromettent souvent leur capacité de prendre des décisions en toute connaissance de cause. Or, la capacité de donner un consentement valable est évidemment une condition essentielle de la recherche sur des sujets humains. En conséquence, la vigilance s'impose quand il s'agit d'évaluer, chez les sujets potentiels, la capacité de prendre des décisions et de faire un choix, et d'informer les personnes pertinentes

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Les lignes directrices qui régissent la recherche sur des sujets humains sont-elles suffisantes pour protéger les personnes qui souffrent de maladie mentale ou de toxicomanie, particulièrement vulnérables? Sont-elles appliquées avec suffisamment de rigueur dans les essais cliniques menés en dehors des établissements d'enseignement?

52 Premier rapport, chapitre 11, section 11.6.

capables de prendre ces décisions à leur place, particulièrement lorsque la recherche en question ne présente pas nécessairement d'avantages directs pour le sujet concerné.[53]

Cela étant posé, le Comité considère primordial de protéger les droits et le bien-être des sujets de recherches en santé mentale et en toxicomanie. La recherche doit absolument respecter les normes d'éthique les plus élevées et ne jamais porter atteinte aux droits et à la dignité de la personne. Par contre, il faut se garder d'imposer des règles à un point restrictives qu'elles exacerbent la stigmatisation sociale associée à la maladie mentale et à la toxicomanie et empêchent ce segment de population vulnérable de participer à des recherches d'une importance vitale qui pourraient améliorer les connaissances scientifiques sur les troubles qui les affectent et parfois même leur être personnellement bénéfiques. Les lignes directrices qui régissent la recherche sur des sujets humains sont-elles suffisantes pour protéger les personnes qui souffrent de maladie mentale ou de toxicomanie, particulièrement vulnérables? Sont-elles appliquées avec suffisamment de rigueur dans les essais cliniques menés en dehors des établissements d'enseignement?

6.3.4 Un programme de recherché national

Les témoins qui ont parlé de la recherche sur la santé mentale et la toxicomanie ont tous insisté sur la nécessité de disposer d'un programme de recherche national qui ferait fond sur le savoir-faire canadien actuel, qui coordonnerait les activités de recherche actuellement fragmentées menées par divers acteurs (gouvernements, organisations non gouvernementales, sociétés pharmaceutiques) et qui assurerait un équilibre entre la recherche biomédicale, la recherche clinique, la recherche sur les services de santé et la recherche sur la santé de la population dans le grand domaine de la santé mentale, de la maladie mentale et de la toxicomanie.[54] À qui doit-on confier la responsabilité d'élaborer, de mettre en œuvre et de coordonner un tel programme de recherche : à l'INSMT, aux IRSC ou à une toute autre organisation? Quels sujets de recherche doivent initialement avoir la priorité?

6.4 TECHNOLOGIE DE L'INFORMATION ET DES COMMUNICATIONS

6.4.1 Les dossiers de santé électroniques

Comme le Comité l'a expliqué dans son rapport d'octobre 2002 sur les soins de santé, l'établissement d'un système de dossiers de santé électroniques fournirait à chaque personne un dossier sûr, privé et complet relatant ses antécédents médicaux, à savoir les visites à des médecins de famille et des spécialistes, les hospitalisations, les prescriptions de médicaments, les tests de laboratoire, etc. Ce dossier pourrait être consulté en tout temps et en tout lieu par son titulaire et par les fournisseurs de soins de santé autorisés par lui.

Un tel système de dossiers de santé électroniques permettrait d'améliorer non seulement la qualité et l'opportunité des soins, mais aussi la gestion du système de santé et son efficience,

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53 Premier rapport, chapitre 11, section 11.6.

54 Premier rapport, chapitre 10, section 10.5.

de même que la reddition de comptes. Les données extraites d'un tel système seraient par ailleurs extrêmement utiles à la recherche sur la santé.[55]

Tous les ordres de gouvernement du Canada sont bien conscients de l'utilité d'un système de dossiers de santé électroniques. En fait, le 11 septembre 2000, les premiers ministres s'étaient donné trois ans pour établir un tel système et étaient convenus de collaborer à l'élaboration de normes communes pour assurer la compatibilité et l'interopérabilité des réseaux provinciaux d'information sur la santé et garantir l'inviolabilité des renseignements médicaux personnels. C'est à la suite de cette entente que le gouvernement fédéral a, en 2001, établi Inforoute Santé du Canada Inc., organisme doté d'un budget de 500 millions de dollars, pour soutenir et accélérer l'élaboration et l'adoption de systèmes de dossiers de santé électroniques interfonctionnels dans tout le pays.

Le Comité estime que l'amélioration de la gestion de l'information sur la santé, en grande partie grâce à l'application du dossier de santé électronique, peut avoir un effet sur l'efficacité et l'efficience des services de santé mentale et du traitement des toxicomanies.

Dans son rapport d'octobre 2002, le Comité s'était dit tôt à fait en faveur de l'établissement d'un système de dossiers de santé électroniques. Nous avions souligné en particulier les travaux d'*Inforoute*, qui marquaient une étape importante vers l'intégration des infostructures de la santé provinciales et territoriales existantes. Nous avions alors recommandé que le gouvernement fédéral accorde à *Inforoute* deux milliards de dollars sur cinq ans pour l'élaboration d'un système national de dossiers de santé électroniques à l'appui du système hospitalier et médical qui relève de l'assurance-maladie.[56] En 2003, le gouvernement fédéral a porté le capital d'*Inforoute* à 1,1 milliard de dollars.

Le Comité estime que l'amélioration de la gestion de l'information sur la santé, en grande partie grâce à l'application du dossier de santé électronique, peut avoir un effet sur l'efficacité et l'efficience des services de santé mentale et du traitement des toxicomanies. Premièrement, comme dans le cas des soins de santé physique, le dossier de santé électronique est une condition préalable nécessaire à l'instauration d'un système de santé mentale et de traitement de la toxicomanie véritablement axé sur la personne. Deuxièmement, il présente un potentiel extraordinaire d'intégration des divers éléments du système de services de santé mentale et du système de traitement de la toxicomanie, lesquels fonctionnent actuellement en vase clos. Troisièmement, le fait de pouvoir échanger des renseignements sur la santé par des moyens sûrs, où et quand on en a besoin, permet d'optimiser les soins de santé mentale et d'accélérer le rétablissement des malades. Enfin, le dossier de santé électronique permet d'éviter de redemander les antécédents personnels et familiaux en matière de santé mentale chaque fois qu'une personne rencontre un nouveau professionnel de la santé mentale ou de la toxicomanie.

Le Comité voudrait savoir si le système de dossiers de santé électroniques en cours d'élaboration par Inforoute Santé du Canada Inc. suscite des inquiétudes particulières parmi les personnes souffrant de maladie mentale ou de toxicomanie. Par exemple, les dossiers

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55 *Recommandations en vue d'une réforme*, octobre 2002, chapitre 10, section 10.2.

56 *Ibid.*

psychiatriques sont-ils vraiment différents des autres types de dossiers médicaux et, dans l'affirmative, en quoi? L'information sur la santé mentale et la toxicomanie doit-elle être traitée différemment des autres données personnelles sur la santé contenues dans le dossier de santé électronique? Nous aimerions connaître les vues des fournisseurs de soins en santé mentale, des spécialistes de la toxicomanie, des malades et de leur famille.

Les questions les plus délicates que soulève le dossier de santé électronique concernent la confidentialité et la sécurité des renseignements personnels sur la santé. Nous traitons de ces questions en détail à la section 6.5 ci-dessous.

Le Comité voudrait savoir si le système de dossiers de santé électroniques en cours d'élaboration par Inforoute Santé du Canada Inc. suscite des inquiétudes particulières parmi les personnes souffrant de maladie mentale ou de toxicomanie. L'information sur la santé mentale et la toxicomanie doit-elle être traitée différemment des autres données personnelles sur la santé contenues dans le dossier de santé électronique?

6.4.2 Les services de télésanté mentale

Comme le Comité l'a expliqué dans son rapport d'avril 2002, la télémédecine exploite le matériel de vidéoconférence et les appareils connexes pour fournir des soins de santé à distance. Elle permet donc d'améliorer grandement la qualité des soins et l'accès aux soins en temps opportun, en particulier dans les régions rurales et éloignées. Le matériel de vidéoconférence peut, par ailleurs, servir aussi à la formation permanente et au perfectionnement des fournisseurs de soins de santé dans les collectivités éloignées.[57]

Les services de santé mentale et les moyens de soutien connexes sont très inégalement distribués entre les régions. Ils font particulièrement défaut dans les régions rurales et éloignées, surtout dans les communautés et les réserves autochtones où les personnes qui en ont besoin sont souvent forcées de parcourir de grandes distances pour se les procurer. Nul doute que cela ajoute au stress déjà grand des personnes atteintes de troubles mentaux ou de toxicomanie.[58]

Quand ils sont forcés de quitter leur localité, les gens se trouvent privés de leurs systèmes naturels de soutien et de leurs réseaux de soins informels qui leur apportent l'aide financière, psychologique et sociale dont ils ont besoin pour se rétablir mais que n'offre pas le système médical. Si, pour certains, l'anonymat de la ville est un répit bienvenu qui les libère de la stigmatisation et de la honte, dans bien des cas, l'éloignement peut avoir des répercussions fâcheuses importantes sur les thérapies et leurs résultats.

On a dit au Comité que de transplanter des travailleurs de la santé mentale habitués à la ville en milieu rural – en admettant qu'il y en ait qui acceptent de le faire – ne donnerait pas nécessairement de bons résultats, car ceux-ci ne seraient pas qualifiés pour composer avec les particularités de la culture rurale et la myriade d'enjeux connexes.

Quelles sont les perspectives de la télémédecine dans le domaine de la santé mentale et de la toxicomanie? Quels sont les problèmes à surmonter? Le gouvernement fédéral investit-il

57 Principes et recommandations en vue d'une réforme, avril 2002, chapitre 4.
58 Premier rapport, chapitre 8, section 8.2.3.

suffisamment dans la télémédecine pour les besoins du secteur de la santé mentale et de la toxicomanie?

Le Comité voudrait connaître l'avis des Canadiens sur l'expansion possible de la télémédecine en matière de prestation de services de santé mentale et de formation et de perfectionnement en santé mentale et en toxicomanie.

Quelles sont les perspectives de la télémédecine dans le domaine de la santé mentale et de la toxicomanie? Quels sont les problèmes à surmonter? Le gouvernement fédéral investit-il suffisamment dans la télémédecine pour les besoins du secteur de la santé mentale et de la toxicomanie?

6.4.3 Un réseau d'information sur la santé accessible sur internet

Les personnes atteintes de maladie mentale ou de toxicomanie et leur famille veulent de l'information à jour sur les troubles mentaux qui les frappent et sur les thérapies, services et moyens de soutien qui pourraient leur être utiles. Cependant, malgré l'essor des communications par Internet, les gens continuent d'avoir du mal à se procurer une information fiable quand ils en ont le plus besoin; à coup sûr, cette information n'est pas toujours accessible, ni à la portée de tous les Canadiens. En outre, la plupart du temps, il est bien difficile pour les personnes concernées de savoir si l'information qu'elles trouvent est juste et objective et si elles peuvent s'y fier.

Le Réseau canadien de la santé, établi conjointement par le gouvernement fédéral et certaines organisations du secteur de la santé, est considéré par beaucoup comme un des meilleurs du monde. Il offre à la population une information utile sur la promotion de la santé et la prévention de la maladie dans 26 domaines clés, dont la santé mentale et la toxicomanie.

Certaines provinces ont aussi établi des sites Web consacrés à la maladie mentale et à la toxicomanie. Citons à titre d'exemple le site www.heretohelp.bc.ca, établi par un groupe de sept organismes provinciaux sans but lucratif de la Colombie-Britannique et financé par le gouvernement provincial.

Dans son rapport d'avril 2002, le Comité recommandait la création d'un portail national public donnant accès à une information sur la santé qui soit complète, fiable et propre à faciliter la prise des décisions liées à la santé. Nous avions recommandé que l'on s'appuie pour cela sur le succès du Réseau canadien de la santé et que le portail assure l'intégration des portails provinciaux et territoriaux de manière à garantir la cohérence de l'information. Nous avions aussi précisé que le portail national devrait faciliter

Dans son rapport d'avril 2002, le Comité recommandait la création d'un portail national public donnant accès à une information sur la santé qui soit complète, fiable et propre à faciliter la prise des décisions liées à la santé. Nous avions recommandé que l'on s'appuie pour cela sur le succès du Réseau canadien de la santé et que le portail assure l'intégration des portails provinciaux et territoriaux de manière à garantir la cohérence de l'information.

l'accès des populations mal desservies (Autochtones, collectivités rurales et éloignées, etc.) à une information de haute qualité.[59]

Le Réseau canadien de la santé est-il bien placé pour devenir un site Web de confiance dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie? Comment le Réseau peut-il exploiter les forces de ses homologues provinciaux sans cependant faire double emploi?

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6.5 PROTECTION DES RENSEIGNEMENTS PERSONNELS

Dans son dernier rapport sur les soins de santé (octobre 2002), le Comité a traité de la question de la protection des dossiers de santé électroniques et de leur exploitation pour les fins de la recherche.

Pour ce qui est des dossiers de santé électroniques, nous avons noté d'importantes différences entre les lois sur la protection des renseignements personnels et les politiques d'accès aux données des provinces. Nous avons recommandé que le gouvernement fédéral et les provinces et territoires se concertent pour harmoniser la protection des renseignements personnels sur la santé.

Nous avons aussi abordé la question du grand nombre d'intervenants dans la collecte des renseignements personnels sur la santé qui figureraient dans un dossier de santé. Nous avons recommandé que l'on institue des mesures de sécurité de pointe pour protéger les renseignements personnels sur la santé et que les divers dépositaires, qui ont accès aux dossiers, rendent compte de l'utilisation qu'ils en font.[60]

En ce qui concerne la recherche, le Comité s'était rangé à la nécessité d'autoriser un accès limité aux renseignements personnels sur la santé à des fins de recherche tout en préservant la confidentialité de cette information. Nous avons recommandé que le gouvernement fédéral mène une campagne de sensibilisation du public pour faire valoir les avantages de l'exploitation des renseignements personnels sur la santé pour les fins de la recherche sur la santé. Nous avons recommandé aussi que le gouvernement fédéral, en collaboration avec les IRSC et les autres parties concernées, étudie les mécanismes d'examen et de contrôle nécessaires pour protéger les renseignements personnels sur la santé.[61]

Dans son premier rapport, le Comité faisait remarquer que, selon certains personnes, la protection des renseignements personnels est peut-être encore plus préoccupante dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie que dans celui de la santé physique. Les témoignages que nous avons entendus nous forcent à nous demander si les politiques et les lois qui régissent la confidentialité et la protection des renseignements

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59 Principes et recommandations en vue d'une réforme, avril 2002, chapitre 4, section 4.7.

60 Recommandations en vue d'une réforme, octobre 2002, chapitre 10.

61 Recommandations en vue d'une réforme, octobre 2002, chapitre 12.

personnels – qui, en règle générale, servent assez bien les personnes mentalement compétentes – ne desservent en fait pas les intérêts des personnes qui, en raison de la nature et du caractère envahissant de la maladie mentale et de la toxicomanie, sont partiellement ou entièrement dépendantes de multiples prestataires de soins.[62]

Les témoignages que nous avons entendus nous forcent à nous demander si les politiques et les lois qui régissent la confidentialité et la protection des renseignements personnels qui, en règle générale, servent assez bien les personnes mentalement compétentes, ne desservent pas en fait les intérêts des personnes qui, en raison de la nature et du caractère envahissant de la maladie mentale et de la toxicomanie, sont partiellement ou entièrement dépendantes de multiples dispensateurs de soins.

Dans le contexte d'un système de dossiers de santé électroniques, le Comité est bien conscient que toute érosion des mesures de protection des renseignements personnels aurait de graves conséquences sur la confiance que les patients ont envers ceux qui leur dispensent des soins. Cependant, des témoins nous ont déclaré que, dans certaines circonstances, la stricte observance des règles relatives à la protection des renseignements personnels et à la confidentialité va à l'encontre des intérêts des personnes dont la santé mentale est compromise. Il faut reconnaître ces difficultés particulières lorsqu'on élabore, interprète et applique les règles en matière de protection des renseignements personnels et de confidentialité, afin que les dispensateurs de soins de santé puissent apporter aux patients l'aide dont ils ont besoin.[63]

Le Comité voudrait connaître les vues des Canadiens à ce sujet. L'établissement d'un système de dossiers de santé électroniques exige-t-il l'ajout de mesures de sécurité additionnelles pour protéger l'information sur la santé mentale et la toxicomanie ou faut-il au contraire prévoir des assouplissements pour que l'information circule mieux et que l'on puisse dispenser des soins de santé mentale de meilleure qualité avec une plus grande continuité? Nous aimerions savoir aussi s'il faut modifier les lois provinciales pour permettre la communication de renseignements sur les malades entre fournisseurs de soins.

Quels changements faudrait-il apporter aux règles pour faciliter la communication des renseignements concernant un malade à sa famille? Faut-il normaliser et uniformiser davantage les usages quant à la communication de renseignements personnels sur des personnes atteintes de troubles mentaux ou de toxicomanie?

L'observation rigoureuse des règles courantes de confidentialité et de protection des renseignements personnels peut avoir des conséquences fâcheuses. En effet, actuellement, un médecin ne peut communiquer aucune information personnelle aux soignants, parents, frères et sœurs ou enfants d'une personne atteinte de troubles mentaux ou de toxicomanie sans le consentement de celle-ci. Or, les personnes concernées ne sont pas toujours aptes à donner ce consentement.[64]

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62 Premier rapport, chapitre 11, section 11.3.
63 Premier rapport, chapitre 11, section 11.7.
64 Premier rapport, chapitre 11, section 11.3.

Existe-t-il des systèmes de santé mentale comportant des procédures et des formulaires de consentement meilleurs et plus clairs pour la divulgation d'informations aux familles? Quels changements faudrait-il apporter aux règles pour faciliter la communication des renseignements concernant un malade à sa famille? Faut-il normaliser et uniformiser davantage les usages quant à la communication de renseignements personnels sur des personnes atteintes de troubles mentaux ou de toxicomanie?

CHAPITRE 7:
LE RÔLE DU GOUVERNEMENT FÉDÉRAL

Le gouvernement fédéral a un rôle direct et un rôle indirect dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie. Son rôle direct tient à ses responsabilités constitutionnelles envers les membres des Premières Nations qui vivent dans des réserves, les détenus des pénitenciers fédéraux, les anciens combattants et les membres des Forces canadiennes, la GRC, et certains immigrants reçus et demandeurs du statut de réfugié. Le gouvernement fédéral est, par ailleurs, un gros employeur qui gère des effectifs considérables. Son rôle indirect tient à ce qu'il lui incombe de veiller à l'intérêt public au niveau national, ce qui couvre notamment les transferts aux provinces et territoires, la collecte de données, le financement de travaux de recherche, l'homologation des médicaments, les mesures de soutien du revenu et les pensions d'invalidité, certains programmes sociaux comme les mesures relatives au logement, la justice pénale et la promotion de la santé et du bien-être de la population. En conséquence, il existe un vaste éventail de programmes et de services fédéraux qui touchent la santé mentale, la maladie mentale et la toxicomanie.[65]

7.1 RÔLE DIRECT

Dans son premier rapport, le Comité signale la façon extrêmement fragmentée dont le gouvernement fédéral aborde les questions de santé mentale, de maladie mentale et de toxicomanie relativement aux divers groupes qui relèvent de lui : les services et moyens de soutien sont offerts par plusieurs ministères ou plusieurs direction ou divisions ministérielles, sans grande collaboration. Nous avons aussi fait état du manque de coopération entre le gouvernement fédéral et les provinces au sujet des programmes qui visent les Premières Nations, les Inuits et les détenus des pénitenciers fédéraux. Nous avons en outre signalé de nombreuses lacunes au niveau des services dans de nombreux programmes.[66]

La manière dont le gouvernement fédéral aborde les questions de santé mentale, de maladie mentale et de toxicomanie relativement aux divers groupes qui relèvent de lui est très fragmentée.

Dans l'ensemble, le gouvernement fédéral ne semble pas s'être donné de stratégie à l'égard des groupes dont il est directement responsable, et encore moins une stratégie globale visant l'ensemble de la population. Nous n'avons observé aucun effort ayant pour objet d'élaborer un cadre fédéral global intégré ou d'obtenir la collaboration de tous les ministères et

Nous n'avons constaté aucun effort ayant pour objet d'élaborer un cadre fédéral global intégré ou d'obtenir la collaboration de tous les ministères et organismes concernés.

65 Premier rapport, chapitre 9, section 9.1.
66 Premier rapport, chapitre 9, section 9.2.

organismes concernés. On ne semble pas non plus chercher à concevoir une stratégie pour répondre aux besoins, en matière de santé mentale, des divers groupes qui relèvent du gouvernement fédéral.[67]

Que peut-on faire pour mieux coordonner et intégrer les mesures fédérales en matière de santé mentale et de toxicomanie à l'égard des groupes qui relèvent des autorités fédérales?

Que peut-on faire pour mieux coordonner et intégrer les mesures fédérales en matière de santé mentale et de toxicomanie à l'égard des groupes qui relèvent des autorités fédérales? Par exemple, faudrait-il que Santé Canada collabore avec le ministère des Affaires indiennes et du Nord, le ministère du Développement des ressources humaines et les autres ministères concernés pour améliorer l'efficacité et l'efficience de la prestation des services de santé mentale et des traitements de la toxicomanie dans les communautés de Premières Nations et les collectivités inuites? Comment s'y prendre pour favoriser ce type de collaboration interministérielle? Vaudrait-il mieux confier à un seul ministère la prestation de tous les services concernant la santé mentale et la toxicomanie? Ou encore faudrait-il céder cette responsabilité aux provinces, le gouvernement fédéral se contentant d'assumer le coût des services fournis?

De même, que peut-on faire pour améliorer l'offre et la qualité des services et des moyens de soutien dont les détenus des pénitenciers fédéraux ont besoin? Que peut faire le gouvernement fédéral pour que le Service correctionnel du Canada soit mieux en mesure de répondre aux besoins sur le plan des services de santé mentale et du traitement de la toxicomanie?

Comment pourrait-on améliorer la collaboration entre les divers ordres de gouvernement en ce qui à trait à la prestation des services de santé mentale et au traitement de la toxicomanie pour les Premières Nations et les Inuits ainsi que les détenus des pénitenciers fédéraux? Dans le cas de ces derniers, par exemple, quelles politiques et quels programmes fédéraux et provinciaux faudrait-il harmoniser (par ex., le Code criminel et les lois provinciales sur la santé mentale)?

Les anciens combattants, ainsi que les membres des Forces canadiennes et de la GRC sont exclus de la définition de « personne assurée » aux termes de la *Loi canadienne sur la santé*. Dans leur cas, les soins de santé, les services de santé mentale, la prévention du suicide et le traitement de la toxicomanie relèvent du ministère des Anciens combattants, du ministère de la Défense nationale et de Santé Canada. Comment pourrait-on mieux coordonner les programmes et les activités de ces ministères?

7.2 RÔLE INDIRECT

Outre un rôle direct, le gouvernement fédéral a aussi un rôle indirect dans le secteur de la santé mentale, de la maladie mentale et de la toxicomanie dans la mesure où il doit voir à l'intérêt public d'un point de vue national. Des témoins ont fait remarquer au Comité que le gouvernement fédéral se sert régulièrement du pouvoir de dépenser que lui confère la

[67] Premier rapport, chapitre 9, section 9.3.

Constitution pour influer sur de vastes initiatives nationales qui relèvent de la politique de santé et de la politique sociale. En fait, ce pouvoir de dépenser est à la base de la *Loi canadienne sur la santé* et du Transfert canadien en matière de santé et de programmes sociaux.[68]

Il a beaucoup été question, durant les audiences du Comité, de l'ambivalence qui persiste depuis 55 ans quant à la place des services de santé mentale dans le système public de soins de santé.[69] Actuellement, la *Loi canadienne sur la santé* exclut expressément de la définition de l'*intégralité* les services dispensés par des établissements psychiatriques. De nombreux services de santé mentale dispensés par des fournisseurs de soins autres que des médecins ne sont pas couverts par la *Loi;* c'est le cas par exemple des services des psychologues.[70]

Il a beaucoup été question, durant les audiences du Comité, de l'ambivalence qui persiste depuis 55 ans quant à la place des services de santé mentale dans le système public de soins de santé.

Actuellement, aucune portion spécifiée des transferts fédéraux n'est expressément vouée à la santé mentale et au traitement de la toxicomanie. Le Transfert canadien en matière de santé prévoit des fonds pour les services communautaires actifs de santé mentale mais aucun montant précis n'est réservé à cet usage.[71]

Que peut faire le gouvernement fédéral pour dissiper l'ambivalence quant à la place de la santé mentale dans ses politiques et programmes d'envergure nationale?

Que peut faire le gouvernement fédéral pour dissiper l'ambivalence quant à la place de la santé mentale dans ses politiques et programmes d'envergure nationale? Serait-il opportun de modifier la *Loi canadienne sur la santé* pour inclure dans les services assurés les services dispensés par les établissements psychiatriques et par les psychologues? Le gouvernement fédéral doit-il vouer une partie donnée de ses paiements de transfert à la maladie mentale et à la toxicomanie? Faudrait-il pour cela adopter une loi sur la santé mentale? Le premier ministre doit-il nommer un ministre d'État à la santé mentale, à la maladie mentale et à la toxicomanie?

Si le gouvernement fédéral décidait d'adopter des mesures incitatives propres à faire en sorte que les personnes souffrant de troubles mentaux ou de toxicomanie aient un accès universel et équitable aux services et aux moyens de soutien dont elles ont besoin, de quelle nature doivent être ces mesures et comment pourra-t-on le mieux atteindre l'objectif visé?

Vaudrait-il mieux que le gouvernement fédéral institue un nouveau mécanisme de financement axé spécifiquement sur la santé mentale, la maladie mentale et la toxicomanie? Faut-il subordonner les transferts aux provinces et aux territoires à certaines conditions relativement à la maladie mentale et à la toxicomanie et, dans l'affirmative, lesquelles? Si le

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68 Premier rapport, chapitre 9, section 9.4.
69 Premier rapport, chapitre 9, section 9.4.2.
70 Premier rapport, chapitre 9, section 9.5.1.
71 Premier rapport, chapitre 9, section 9.5.2.

gouvernement fédéral décidait d'adopter des mesures incitatives propres à faire en sorte que les personnes souffrant de troubles mentaux ou de toxicomanie aient un accès universel et équitable aux services et aux moyens de soutien dont elles ont besoin, de quelle nature doivent être ces mesures et comment pourra-t-on le mieux atteindre l'objectif visé?

Une autre question a été abordée durant les audiences du Comité : celle des médicaments de prescription et des services à domicile. Que peut faire le gouvernement pour que les personnes souffrant de maladie mentale ou de toxicomanie bénéficient des pharmacothérapies dont elles ont besoin? Le régime d'assurance contre les frais exorbitants de médicaments de prescription – envisagé par le Comité[72] et qui figure dans le *Plan décennal pour consolider les soins de santé* des premiers ministres (septembre 2004) – permettra-t-il que les personnes atteintes de troubles mentaux ou de toxicomanie obtiennent les médicaments de prescription dont elles ont besoin? Ces personnes ont-elles des réserves au sujet de ce régime?

Le régime d'assurance contre les frais exorbitants de médicaments de prescription – envisagé par le Comité et qui figure dans le Plan décennal pour consolider les soins de santé des premiers ministres (septembre 2004) – permettra-t-il que les personnes atteintes de troubles mentaux ou de toxicomanie obtiennent les médicaments de prescription dont elles ont besoin?

De même, de quelle forme de programme de soins à domicile (soins actifs de courte durée, évaluation des besoins ou soins de longue durée) a-t-on besoin dans le domaine de la maladie mentale et de la toxicomanie? L'entente des premiers ministres de septembre 2004 prévoyant la couverture intégrale de certains services de soins à domicile, notamment deux semaines de soins actifs communautaires de santé mentale fournis à domicile pour la gestion du cas et des services d'intervention d'urgence, est-elle suffisante ou faut-il envisager un programme plus complet?

De quelle forme de programme de soins à domicile (soins actifs de courte durée, évaluation des besoins ou soins de longue durée) a-t-on besoin dans le domaine de la maladie mentale et de la toxicomanie?

7.3 COLLABORATION INTERGOUVERNEMENTALE

Le gouvernement fédéral se sert depuis longtemps de son potentiel fiscal pour influer sur les politiques nationales en matière de santé et de programmes sociaux, mais certains affirment que cela ne suffit pas. Des témoins ont dit au Comité qu'il est essentiel de resserrer très nettement la consultation et la collaboration intergouvernementales pour assurer l'uniformité, élaborer et faire respecter des normes, harmoniser les mesures et lancer une initiative nationale en santé mentale. Cependant, c'est aux provinces et aux territoires qu'il incombe d'assurer la prestation des services liés à la santé mentale et à la toxicomanie sur leur territoire, et toute initiative fédérale doit en tenir compte. En

Il est essentiel de resserrer très nettement la consultation et la collaboration intergouvernementales pour assurer l'uniformité, élaborer et faire respecter des normes, harmoniser les mesures et lancer une initiative nationale en santé mentale.

[72] Recommandations en vue d'une réforme, octobre 2002, chapitre 7.

conséquence, toute tentative de restructuration et de réforme du secteur de la santé mentale et de la toxicomanie passe nécessairement par la consultation et la collaboration intergouvernementales.

Que peut faire le gouvernement fédéral pour encourager la coordination, la collaboration et les partenariats entre les divers ordres de gouvernement dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie?

Or, bien peu de ressources sont consacrées aux activités intergouvernementales dans ce domaine. Une structure a été certes été établie le 17 avril 1986 – le Réseau consultatif fédéral-provincial-territorial sur la santé mentale – pour conseiller la conférence des sous-ministres de la santé sur la coopération entre les administrations fédérale, provinciales et territoriales dans le domaine de la santé mentale. Cependant, à la fin des années 90, la Conférence des sous-ministres de la santé a cessé de financer le Réseau, si bien qu'on n'a plus les moyens de réunir les décisionnaires en santé mentale de tout le pays pour leur permettre d'échanger des informations et d'élaborer des politiques et des plans cohérents. Quelques provinces continuent de participer au Réseau consultatif, mais le financement plutôt restreint qu'elles fournissent limite l'envergure des travaux.[73]

Toute tentative de restructuration et de réforme du secteur de la santé mentale et de la toxicomanie passe nécessairement par la consultation et la collaboration intergouvernementales

Que peut faire le gouvernement fédéral pour encourager la coordination, la collaboration et les partenariats entre les divers ordres de gouvernement dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie?

Que peut faire le gouvernement fédéral pour encourager la coordination, la collaboration et les partenariats entre les divers ordres de gouvernement dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie? Faut-il révisiter le Réseau consultatif fédéral-provincial-territorial sur la santé mentale pour lui donner un mandat plus vaste qui engloberait à la fois la santé mentale et la toxicomanie? Vaudrait-il mieux soit établir un tout nouvel organisme (sur le modèle de la commission de la santé mentale de la Nouvelle-Zélande[74], du National Institue for Mental Health in England[75] ou de l'ancienne Commission de la santé mentale du Nouveau-Brunswick), soit confier ce mandat à un organisme existant (comme l'Agence de santé publique du Canada)?

Que peut faire le gouvernement fédéral pour faciliter la tâche aux provinces et aux territoires qui tentent une réforme et un renouvellement de leur système de traitement de la maladie mentale et de la toxicomanie?

Que peut faire le gouvernement fédéral pour faciliter la tâche aux provinces et aux territoires qui tentent une réforme et un renouvellement de leur système de traitement de la maladie mentale et de la toxicomanie? Existe-t-il, au Canada, des modèles à émuler? Est-ce que la création d'un ministère

73 Premier rapport, chapitre 9, section 9.4.
74 Deuxième rapport, chapitre 2, section 2.1.1.
75 Deuxième rapport, chapitre 2, section 3.1.1.

d'État à la santé mentale et à la toxicomanie, comme il en existe en Colombie-Britannique, serait utile dans les autres provinces et territoires, voire au niveau fédéral?

7.4 PLAN D'ACTION NATIONAL

On a fait valoir au Comité qu'en plus d'une bonne collaboration intergouvernementale, le Canada a besoin d'un plan d'action national complet en matière de santé mentale, de maladie mentale et de toxicomanie pour garantir la réussite de la réforme et de la restructuration. L'Australie, la Nouvelle-Zélande et le Royaume-Uni se sont déjà dotés d'une stratégie ou d'un plan d'action national en santé mentale. De l'avis de beaucoup, le Canada souffre de l'absence de leadership au niveau national dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie, ce qui a des conséquences non négligeables : les mesures de réforme du secteur de la santé, qu'il s'agisse de celles du gouvernement fédéral ou de celles des provinces et des territoires, ne traitent pas spécifiquement de la maladie mentale et de la toxicomanie; les rôles et responsabilités des parties concernées sont mal définis; le fait que les provinces et les territoires en soient chacun à des étapes différentes de réforme de leur système de soins relativement à la maladie mentale et à la toxicomanie entraîne des inégalités ennuyeuses.

Beaucoup ont dit au Comité que le gouvernement fédéral devrait assumer un rôle de chef de file dans l'élaboration d'un plan d'action national. Ils estiment que c'est l'absence de leadership fédéral qui est à l'origine de l'approche fragmentée de la maladie mentale et de la toxicomanie, de l'apparition de modèles divergents voire incompatibles dans les diverses provinces et de doubles emplois inutiles et d'un gaspillage de ressources.

Le Canada a besoin d'un plan d'action national complet en matière de santé mentale, de maladie mentale et de toxicomanie pour assurer la réussite de la réforme et de la restructuration. De l'avis de beaucoup, le Canada souffre de l'absence de leadership au niveau national dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie, ce qui a des conséquences non négligeables.

Pour de nombreux témoins, le cadre national doit fixer des normes de service pour tous les aspects de la santé mentale (prévention, promotion de la santé, services communautaires aux malades hospitalisés et services spécialisés). Ces normes doivent aussi s'appliquer aux services dispensés durant toute la vie de chaque personne concernée. Le plan d'action doit faire une bonne place aux enfants et aux adolescents, aux Autochtones, aux personnes âgées, aux détenus des pénitenciers fédéraux, aux femmes et aux immigrants reçus.

Beaucoup ont recommandé que le gouvernement fédéral assume un rôle de chef de file dans l'élaboration d'un plan d'action national.

Beaucoup de témoins ont insisté sur le fait qu'un plan d'action national en matière de santé mentale doit être le fruit d'une collaboration faisant intervenir le gouvernement fédéral et les gouvernements des provinces et des territoires, les ONG et les autres organisations concernées, de même que les malades eux-mêmes.

En septembre 2000, l'Alliance canadienne pour la maladie mentale et la santé mentale, organisation qui représente une vingtaine d'ONG, a fait paraître un document de discussion dans lequel elle réclamait l'élaboration d'un plan d'action national qui susciterait une transformation fondamentale de la manière dont on aborde la santé mentale, la maladie mentale et la toxicomanie au Canada. Ce document de travail se voulait la première étape d'un processus qui devait mener à un consensus sur un plan d'action national. Il s'agissait d'un outil permettant de faciliter la discussion, de susciter des idées et d'établir une coalition nationale forte pour promouvoir la mise en œuvre du plan d'action par tous les paliers de gouvernement. Il n'était pas conçu comme un document de discussion politique ni comme un guide de réforme systémique. Quels progrès ont été réalisés aux échelons fédéral, provincial et local depuis la parution de ce document de l'Alliance? Les objectifs ou la conception prônés par l'Alliance ont-elles été adoptés dans certaines régions? Les ONG représentées par l'Alliance doivent-elles aller plus loin et élaborer une proposition concrète de restructuration du système de traitement de la maladie mentale et de la toxicomanie?

De manière plus générale, qu'est-ce qui empêche actuellement l'élaboration d'un plan d'action national en matière de santé mentale, de maladie mentale et de toxicomanie? Comment ce plan devrait-il être élaboré et mis en oeuvre? Faudrait-il procéder par étapes ou mettre en œuvre simultanément plusieurs grands systèmes? Faut-il un seul plan d'action pour l'ensemble du Canada ou des plans d'action par province et par territoire fondés sur une conception commune?

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Outre qu'ils leur faut élaborer une démarche commune claire, les gouvernements devraient-ils définir des objectifs et normes détaillés en matière de santé mentale, de maladie mentale et de toxicomanie? Cela contribuerait-il à une meilleure évaluation des résultats obtenus auprès des malades et à une meilleure appréciation du rendement du système?

Le plan d'action national doit-il être élaboré par étapes ou faudrait-il mettre en œuvre simultanément plusieurs grands systèmes? Faut-il un seul plan d'action pour l'ensemble du Canada ou des plans d'action par province et par territoire fondés sur une conception commune?

Quels éléments doivent figurer dans un plan d'action national : sensibilisation et éducation du public et des professionnels; prévention de la maladie mentale et du suicide; diffusion d'informations ou de lignes directrices sur les pratiques exemplaires; planification des ressources humaines (formation et perfectionnement); financement de la recherche; mesures propres à encourager l'intégration systémique et la collaboration? Quelles doivent être les priorités?

Quels éléments doivent figurer dans un plan d'action national?

Comment devons-nous nous y prendre pour faire en sorte que les personnes touchées par la maladie mentale et la toxicomanie et leur famille puissent participer pleinement à l'élaboration d'un plan d'action national?

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CHAPITRE 8: FINANCEMENT DE LA RÉFORME, RENDEMENT ET REDDITION DE COMPTES

Le montant total du financement consacré aux services et moyens de soutien en matière de santé mentale et de traitement des toxicomanies suscite des préoccupations. IL a aussi beaucoup été question de la nécessité de trouver une formule de financement qui permette de distribuer équitablement dans tout le pays les fonds destinés aux services de santé mentale et au traitement des toxicomanies.

Le Comité a entendu dire que l'aboutissement de la restructuration du système de santé mentale et de traitement de la toxicomanie dépend non seulement d'une suffisance de ressources pour offrir les services et moyens de soutien nécessaires, mais aussi de la mise en place d'outils et de structures efficaces de contrôle et d'évaluation du rendement, d'une structure de gestion de l'information et d'un cadre de financement pour assurer une distribution équitable des fonds.

8.1 NIVEAU DE FINANCEMENT

La question du financement des services de santé mentale et de traitement de la toxicomanie est l'objet d'un intense débat au Canada, comme dans bien d'autres pays d'ailleurs. Des rapports provinciaux illustrent le sous-financement chronique des services de santé mentale et de traitement de la toxicomanie. Beaucoup de gens estiment que les personnes atteintes de troubles mentaux graves et persistants pâtissent de ce manque de financement. En particulier celles qui appartiennent à une minorité ethnoculturelle, les sans-abri et celles atteintes de troubles multiples.[76]

De nombreux témoins sont d'avis que les dépenses publiques consacrées à la santé mentale et à la toxicomanie au Canada sont bien faibles en regard de la prévalence et du fardeau économique de la maladie mentale et des toxicomanies, comparativement aux affections physiques

De l'avis de nombreux témoins, les dépenses publiques consacrées à la santé mentale et à la toxicomanie au Canada sont bien faibles en regard de la prévalence et du fardeau économique de la maladie mentale et des toxicomanies, comparativement aux affections physiques. D'autres ont affirmé que les budgets sont insuffisants pour permettre une transition réussie des soins en institution à des soins et des moyens de soutien permettant la vie dans la collectivité.[77]

Il n'est pas facile de savoir combien d'argent exactement il faut consacrer à la maladie mentale.

Malheureusement, il n'est pas facile de savoir combien d'argent exactement il faut consacrer à la maladie mentale, à la santé mentale et à la toxicomanie. Il est actuellement impossible d'obtenir des données globales sur les

76 Premier rapport, section 8.2.1.
77 Premier rapport, chapitre 7.

dépenses au titre des services de santé mentale et de traitement de la toxicomanie. Il reste que beaucoup de témoins ont dénoncé les grandes lacunes des services et le fait qu'on répond mal aux besoins des personnes atteintes. Il faudra vraisemblablement augmenter les ressources consacrées à ce segment du système de santé. Pour déterminer les investissements nécessaires, il faudra d'abord se livrer à un examen en profondeur de la manière dont sont employées les ressources actuelles et élaborer un plan exploitant les façons les plus efficaces de faire un usage optimal des ressources courantes.

L'usage optimal des ressources soulève de nombreuses questions. Par exemple, est-il possible de modifier le système de traitement de la maladie mentale et de la toxicomanie pour obtenir des gains d'efficience et générer des économies suffisantes pour financer les services nécessaires de santé mentale et de traitement de la toxicomanie? Les pouvoirs publics doivent-ils consacrer davantage d'argent à ces services? Dans l'affirmative, combien? Et d'où doivent venir les crédits additionnels nécessaires : de la réaffectation de ressources courantes ou d'une augmentation des impôts?

Doit-on lier le montant des fonds destinés à la maladie mentale et à la toxicomanie à la prévalence de ces troubles et au fardeau qu'ils font peser sur l'économie? Quels doivent être le niveau et la forme de la contribution du gouvernement fédéral à cet égard? Doit-elle demeurer à l'intérieur du système actuel de transferts (TCMS et TCMPS) ou doit elle relever d'une enveloppe nouvelle distincte?

Doit-on lier le montant des fonds destinés à la maladie mentale et à la toxicomanie à la prévalence de ces troubles et au fardeau qu'ils font peser sur l'économie?

Le Comité a noté avec intérêt que le gouvernement de la Nouvelle-Zélande s'est fixé des objectifs très détaillés (comme le nombre de lits d'hôpital, de travailleurs communautaires en santé mentale, de places de traitement à la méthadone, etc.) qui lui permettent de calculer le financement requis au niveau national et les besoins en matière de développement des services.[78] Le Canada doit-il suivre l'exemple de la Nouvelle-Zélande et se donner des objectifs en matière de ressources? Dans l'affirmative, ces objectifs doivent-ils ensuite servir de base au calcul des budgets du gouvernement fédéral, des provinces et des territoires en matière de maladie mentale et de toxicomanie? Dans la négative, comment les budgets de ce secteur doivent-ils être calculés et par qui?

Le système actuel de traitement de la maladie mentale et de la toxicomanie dépend de multiples sources de financement. Comme les services et les moyens de soutien, le financement est fragmenté entre de nombreux programmes. Le financement public de ce secteur doit-il continuer de provenir des divers ministères concernés ou vaudrait-il mieux que les gouvernements instituent un fonds interministériel ou des programmes ou mesures interministériels dont les coûts et les avantages seraient partagés?

Vaudrait-il mieux que les gouvernements instituent un fonds interministériel ou des programmes ou mesures interministériels dont les coûts et les avantages seraient partagés?

[78] Deuxième rapport, chapitre 2, section 2.1.1.

Le Comité estime qu'il serait important d'aborder aussi la question de savoir si les fonds doivent viser surtout le traitement des signes et symptômes des troubles mentaux ou s'il faut également chercher à s'attaquer aux causes du mal. Il est également crucial de déterminer les activités à financer et, peut-être plus important encore, celles qu'il faut cesser de financer.

8.2 FINANCEMENT DISTINCT

Beaucoup de témoins ont recommandé un financement distinct réservé au secteur de la santé mentale, de la maladie mentale et de la toxicomanie. Ils s'appuient en cela sur l'exemple de l'Australie qui a consenti aux États et territoires une augmentation des transferts réservée à la réforme du secteur de la santé mentale; des ententes intergouvernementales ont été signées dans lesquelles les États et territoires s'engagent à maintenir ou à protéger leur niveau de financement. Autrement dit, ces transferts étaient en sus du financement courant.[79] Doit-on adopter une approche analogue au Canada ou vaudrait-il mieux que le financement du secteur relève d'une enveloppe séparée? Est-ce que la création de fonds réservés permettrait mieux de faire en sorte que le financement du secteur soit prévisible, durable et équitable?

Faut-il réserver une part des transferts à la santé mentale et à la toxicomanie?

Quels seraient les inconvénients de cette formule? Par exemple, court-on le risque que les fonds servent essentiellement à financer de soins primaires au détriment des moyens de soutien à caractère social?

8.3 RENDEMENT ET REDDITION DE COMPTES

De nombreux rapports provinciaux et des témoins ont fait état du manque criant de mécanismes de reddition de comptes dans le système actuel de traitement de la maladie mentale et de la toxicomanie. Les rôles et responsabilités des divers paliers de gouvernement et des multiples fournisseurs de services ne sont pas clairement définis. On a aussi besoin d'un système d'évaluation du rendement pour contrôler la qualité et l'efficacité des services offerts et la productivité globale du système.[80]

On observe un manque criant de mécanismes de reddition de comptes dans le système actuel de traitement de la maladie mentale et de la toxicomanie. Les rôles et responsabilités des divers paliers de gouvernement et des multiples fournisseurs de services ne sont pas clairement définis.

Dans son rapport d'octobre 2002 sur le régime de santé, le Comité avait recommandé la création d'un conseil national des soins de santé pour améliorer la responsabilisation dans le secteur de la santé et faire rapport sur le rendement du système (rentabilité, efficience, qualité et résultats des soins).[81] Nous avions aussi recommandé que les deux paliers de

Comment doit-on tenir les Canadiens au courant des progrès des gouvernements sur le plan de la réforme du système de traitement de la maladie mentale et de la toxicomanie?

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79 Deuxième rapport, chapitre 1, section 1.2.

80 Premier rapport, chapitre 8, section 8.2.1.

81 *Recommandations en vue d'une réforme*, octobre 2002, chapitre 1, p. 5-21.

gouvernement rendent compte de l'usage des fonds publics destinés à la santé.[82]

Comment doit-on tenir les Canadiens au courant des progrès des gouvernements sur le plan de la réforme du système de traitement de la maladie mentale et de la toxicomanie? De la mise en œuvre des plans nationaux et provinciaux? De la réduction de la stigmatisation et de la discrimination? De l'offre de ressources humaines?

Faut-il instituer des programmes d'assurance de la qualité? Comment définir la qualité et, tout aussi important, comment la mesurer? Suivant quel processus doit-on élaborer un programme d'assurance de la qualité?

Faut-il instituer des programmes d'assurance de la qualité? Comment définir la qualité et, tout aussi important, comment la mesurer?

La reddition de comptes et les indicateurs de rendement sont tout aussi importants dans le domaine de la maladie mentale et de la toxicomanie qu'ils le sont dans celui des soins de santé en général. En 2000, le Réseau consultatif fédéral-provincial-territorial sur la santé mentale a publié un document contenant une trousse d'indicateurs de rendement pour faciliter la reddition de comptes et l'évaluation permanentes des services et moyens de soutien en santé mentale. Cette trousse très détaillée, préparée à l'intention des provinces et des territoires, propose des indicateurs permettant de suivre le rendement au niveau du système, du programme et du client. Ces indicateurs sont-ils utilisés dans une province ou un territoire? Le gouvernement fédéral devrait-il encourager l'utilisation de ces indicateurs? Dans l'affirmative, comment?

Les indicateurs de rendement élaborés en 2000 par le Réseau consultatif fédéral-provincial-territorial sur la santé mentale sont-ils utilisés dans une province ou un territoire? Le gouvernement fédéral devrait-il encourager l'utilisation de ces indicateurs? Dans l'affirmative, comment?

Le Conseil national des soins de santé proposé par le Comité et qui, une fois établi, s'est appelé le Conseil national de la santé, est-il l'organe approprié pour évaluer le rendement du système de traitement de la maladie mentale et de la toxicomanie, faire rapport à ce sujet et améliorer la reddition de comptes? Ou est-ce que, comme ce système a besoin de services provenant d'un bien plus vaste éventail de programmes et de secteurs que le système de soins de santé, il ne vaudrait pas mieux confier ces responsabilités à un autre organe, comme l'Agence de santé publique du Canada ou une nouvelle organisation fédérale-provinciale-territoriale?

Le Conseil national des soins de santé est-il l'organe approprié pour évaluer le rendement du système de traitement de la maladie mentale et de la toxicomanie, faire rapport à ce sujet et améliorer la reddition de comptes?

82 *Recommandations en vue d'une réforme*, octobre 2002, chapitre 14, p. 255-264.

CONCLUSION

Le Comité sait que si la liste des sujets abordés et des solutions proposées dans le présent rapport est assez longue, il est encore loin d'avoir fait le tour de la question. Certains lecteurs auront d'autres sujets à proposer ou nous suggéreront de nouvelles solutions. Nous nous réjouissons d'avance de leur contribution. Nous sommes convaincus que leur participation contribuera à rehausser le débat sur toutes les questions qui touchent le secteur de la santé mentale, de la maladie mentale et de la toxicomanie.

Le Comité a besoin de l'opinion des personnes atteintes de maladie mentale ou de toxicomanie et de leur famille.

Nous savons parfaitement que les vrais experts de la maladie mentale et de la toxicomanie sont les personnes atteintes et leur famille ou ceux qui s'en occupent. Vous hésitez peut-être à parler ouvertement de vos préoccupations et de vos propositions de réforme par peur du qu'en-dira-t-on. Nous avons pourtant bien besoin de vous! Nous avons donc dressé une liste abrégée de questions qui se trouve sur le site Web du Comité. Nous aimerions que vous y répondiez, soit directement par courriel, soit par la poste, puisque le questionnaire est disponible en format imprimable.

Outre les personnes souffrant de troubles mentaux ou de toxicomanie, leur famille et leurs soignants, nous invitons vivement les professionnels de la santé mentale et du traitement de la toxicomanie, les autres fournisseurs de services de santé, les représentants d'organisations non gouvernementales et les porte-parole des gouvernements et ministères fédéraux, provinciaux et territoriaux, ainsi que le grand public à prendre le temps de lire le document *Questions et options* et les deux rapports qui l'accompagnent et de nous faire part de leurs vues sur les solutions de réforme qu'ils préfèrent en nous indiquant les raisons de leur choix. Nous comptons sur l'aide de tous les Canadiens et de toutes les Canadiennes dans la préparation de notre rapport final et de nos recommandations. Veuillez faire parvenir vos commentaires à l'adresse suivante :

Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

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ANNEXE A:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
TROISIÈME SESSION DE LA 37E LÉGISLATURE
(2 FÉVRIER AU 23 MAI 2004)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	David Loïse Murray Ronald	26 février 2003	9
	J. Michael Grass, président sortant, Groupe de mise en oeuvre en santé mentale du district de Champlain	5 juin 2003	17
	Nancy Hall, conseillère en santé mentale	8 mai 2003	16
	Thomas Stephens, expert-conseil	20 mars 2003	11
Académie canadienne d'épidémiologie psychiatrique	Dr Alain Lesage, président sortant	19 mars 2003	11
Académie canadienne de psychiatrie et de droit	Dre Dominique Bourget, présidente	5 juin 2003	17
Association canadienne de la santé mentale de l'Ontario	Patti Bregman, directrice des programmes	12 juin 2003	18
Association des infirmières et infirmiers psychiatriques du Canada	Margaret Synyshyn, présidente	29 mai 2003	16
Centre hospitalier pour enfants de l'est de l'Ontario	Dr Simon Davidson, Chef, Section de psychiatrie de l'enfant et de l'adolescent	1er mai 2003	13
Centre hospitalier universitaire Mère-enfant Sainte-Justine	Dre Joanne Renaud, pédopsychiatre; chercheuse boursière, Instituts de recherche en santé au Canada	30 avril 2003	13

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Centre de toxicomanie et de santé mentale	Jennifer Chambers, coordonnatrice du Conseil d'habitation	14 mai 2003	15
	Rena Scheffer, directrice, Services d'informations et d'éducation du public	28 mai 2003	16
CN Centre for Occupational Health and Safety	Kevin Kelloway, directeur	12 juin 2003	18
Coalition canadienne pour la santé mentale des personnes âgées	Dr David K. Conn, coprésident; president, Académie canadienne de psychiatrie gériatrique	4 juin 2003	17
Colombie-Britannique, Province de la	Patrick Storey, président, Conseil consultative du minister sur la santé mentale	14 mai 2003	15
	Heather Stuart, professeure agrégée, Santé communautaire et épidémiologie		
Global Business and Economic, Roundtable and Addiction and Mental Health	Rod Phillips, président et directeur général, Les Consultants Warren Sheppell	12 juin 2003	18
Hamilton Health Sciences Centre	Venera Bruto, psychologue	4 juin 2003	17
Hôpital Douglas	Eric Latimer, économiste de la santé	6 mai 2003	14
	Dr James Farquhar, psychiatre		
	Dre Mimi Israël, chef, Département de psychiatrie; professeure agrégée, Université McGill		
	Myra Piat, chercheuse		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Hôpital Douglas	Amparo Garcia, chef clinico-administratif, Division des Services ultraspécialisés pour adultes	6 mai 2003	14
	Manon Desjardins, chef clinico-administratif, Division des Services sectorisés pour adultes		
	Jacques Hendlisz, directeur général		
	Robyne Kershaw-Bellmare, directrice des soins infirmiers		
Hôpital Louis-H. Lafontaine	Jean-Jacques Leclerc, directeur, Services de réadaptation et d'hébergement dans la communauté	6 mai 2003	14
	Dr Pierre Lalonde, directeur, Clinique des jeunes adultes		
Hôpital St. Michaels	Dr Paul Links, titulaire de la chaire Arthur Sommer Rothenberg d'études sur le suicide	19 mars 2003	11
Institut canadien d'information sur la santé	Dr John S. Millar, vice-président, Recherche et analyse	20 mars 2003	11
	Carolyn Pullen, expert conseil		
	John Roch, gestionnaire principale, Protection de la vie privée, Secrétariat de la protection de la vie privée		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Instituts de recherche en santé du Canada	Dr Rémi Quirion, directeur scientifique, Institut des neurosciences, de la santé mentale et des toxicomanies	6 mai 2003	14
	Bronwyn Shoush, commissaire, Institut de la santé des Autochtones	28 mai 2003	16
	Jean-Yves Savoie, président, Conseil consultatif, Institut de la santé publique et des populations	12 juin 2003	18
Santé Canada	Tom Lips, conseiller principal, Santé mentale, Division de la santé des collectivités, Direction générale de la santé de la population et de la santé publique	19 mars 2003	11
	Pam Assad, directrice déléguée, Division de l'enfance et de l'adolescence, Centre de développement de la santé humaine, Direction générale de la santé de la population et de la santé publique	30 avril 2003	13
Société Alzheimer du Canada	Steve Rudin, directeur exécutif	4 juin 2003	7
Société canadienne de pédiatrie	Dre Diane Sacks, présidente élue	1er mai 2003	13
	Marie-Adèle Davis, directrice exécutive		
Statistique Canada	Lorna Bailie, directrice adjointe, Division des statistiques sur la santé	20 mars 2003	11
St.Joseph's Health Care London	Maggie Gibson, psychologue	4 juin 2003	17

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Calgary	Dr Donald Addington, professeur et chef, Département de psychiatrie	29 mai 2003	16
Université de la Colombie-Britannique *(par vidéoconférence)*	Dre Charlotte Waddell, professeur adjointe, Unité d'évaluation de la santé mentale et des consultations communautaires, Département de psychiatrie, Faculté de médecine	1er mai 2003	13
Université Laval	Dr Michel Maziade, directeur, Département de spychiatrie, Faculté de médecine	6 mai 2003	14
Université du Manitoba	John Arnett, chef, Département de santé psychologique clinique, Faculté de médecine	28 mai 2003	16
	Robert McIlwraith, professeur et directeur, Programme de psychologie en milieu rural et nordique	29 mai 2003	
Université McGill	Dr Howard Steiger, professeur, Départment de psychiatrie; directeur, Clinique des troubles alimentaires, Hôpital Douglas	1er mai 2003	13
Université de Montréal	Laurent Mottron, chercheur, Département de psychiatrie, Faculté de médecine	6 mai 2003	14

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Montréal	Dr Richard Tremblay, titulaire, chaire de recherche du Canada sur le développement des enfants, professeur de pédiatrie, psychiatrie et psychologie, directeur, Centre d'excellence pour le développement des jeunes enfants	6 mai 2003	14
	Dr Jean Wilkins, professeur titulaire et pédiatre, Département de pédiatrie, Faculté de médecine		
	Dre Renée Roy, professeure adjointe de clinique, Département de psychiatrie, Faculté de médecine		
Université d'Ottawa	Tim D. Aubry, professeur associé; co-directeur , Centre de recherché sur les services communautaires	5 juin 2003	17
	Dr Jeffrey Turnbull, directeur, Département de médecine, Faculté de médecine		
Université du Québec à Montréal	Henri Dorvil, professeur, École de travail social	6 mai 2003	14
	Dr Michel Tousignant, professeur et chercheur, Centre de recherche et intervention sur le suicide et l'euthanasie		
Université Queen's	Dr Julio Arboleda-Florèz, professeur et chef du Département de psychiatrie	20 mars 2003	11

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Université de Toronto	Dr Joe Beitchman, professeur et directeur, Division de la psychiatrie de l'enfant; psychiatre en chef, Hospital for Sick Children	30 avril 2003	13
Université de Toronto	Dr David Marsh, directeur des services cliniques, Médecine des toxicomanies, Centre de toxicomanie et de santé mentale	29 mai 2003	16

ANNEXE B:
LISTE DES TÉMOINS AYANT COMPARUS DEVANT LE COMITÉ
DEUXIÈME SESSION DE LA 37E LÉGISLATURE
(30 SEPTEMBRE 2002 – 12 NOVEMBRE 2003)

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
À titre personnel	Charles Bosdet Pat Caponi Don Chapman,	29 avril 2004	7
Alberta Mental Health Board	Ray Block, directeur général	28 avril 2004	7
	Sandra Harrison, directrice exécutive, Planification, défense des droits et liaison		
Alliance de la Fonction publique du Canada	John Gordon, vice-président executive national	1er avril 2004	5
	James Infantino, agent des pensions et assurances d'invalidité		
Association canadienne des travailleuses et travailleurs sociaux	Stephen Arbuckle, membre, Groupe d'intérêt lié à la santé	31 mars 2004	5
Association canadienne des troubles anxieux	Peter McLean, vice-président	12 mai 2004	9
Association canadienne pour la santé mentale	Penny Marrett, chef de la direction	12 mai 2004	9
Association des infirmières et infirmiers du Canada, la Fédération canadienne des infirmières et infirmiers en santé mentale et l'Association des infirmières et infirmiers psychiatriques du Canada	Nancy Panagabko, présidente, Fédération canadienne des infirmières et infirmiers en santé mentale	31 mars 2004	5
	Annette Osten, membre du Conseil d'administration, Association des infirmières et infirmiers du Canada		
Association médicale canadienne	Dre Gail Beck, secrétaire générale adjointe intérimaire	31 mars 2004	5
	Dr Sunil Patel, président		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Association des psychiatres du Canada	Dr Blake Woodside, président du Conseil d'administration	31 mars 2004	5
Australie, Gouvernement d' *(par vidéoconférence)*	Dermot Casey, secrétaire adjoint, Direction des priorités sanitaires et de la prévention du suicide, ministère de la Santé et de la Vieillesse	20 avril 2004	6
	Jenny Hefford, secrétaire adjointe, Direction de la stratégie contre la drogue, ministère de la Santé et de la Vieillesse		
Bureau du Conseil Privé	Ron Wall, directeur des relations parlementaires, Planification de la législation et des travaux de la Chambre/avocat	1er avril 2004	5
	Ginette Bougie, directrice, Rémunération et classification		
Centre for Suicide Prevention	Diane Yackel, directrice exécutive	21 avril 2004	6
Centre de toxicomanie et de santé mentale	Christine Bois, gestionnaire des priorités provinciales en matière de troubles concourants	5 mai 2004	8
	Wayne Skinner, directeur clinique, Programme de troubles concourants		
	Brian Rush, chercheur, Politique de prévention sociale et de santé		
Chambre des communes	L'honorable Jacques Saada, C.P., député, leader du gouvernement à la Chambre des communes et ministre responsable de la Réforme démocratique	1er avril 2004	5

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Citoyenneté et de l'Immigration, Ministère de la	Patricia Birkett, directrice générale par intérim, Direction générale de l'intégration	22 avril 2004	6
Cognos	Marilyn Smith-grant, spécialiste en ressources humaines	1er avril 2004	5
	Sean Reid, gestionnaire principal, Communication corporatives		
Fédération canadienne des contribuables	Bruce Winchester, directeur de recherche	22 avril 2004	6
Fédération des programmes communautaires de la santé mentale et du traitement des toxicomanies de l'Ontario	David Kelly, directeur exécutif	5 mai 2004	8
Hôpital Douglas	Dr Gustavo Turecki, directeur, Groupe McGill d'études sur le suicide, Université MGill	21 avril 2004	6
Institut des neurosciences, de la santé mentale et des toxicomanies	Richard Brière, directeur adjoint	21 avril 2004	6
Justice, Ministère de la	Manon Lefebvre, conseillère juridique	22 avril 2004	6
Mercer consultation en resources humaines	Bernard Potvin, conseiller principal	22 avril 2004	6
Native Mental Health Association of Canada	Brenda M. Restoule, psychologue et représentante du conseil de l'Ontario	13 mai 2004	9
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	Janice Wilson, directrice générale adjointe, Direction générale de la santé mentale, ministère de la Santé	5 mai 2004	8

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Nouvelle –Zélande, Gouvernement de la *(par vidéoconférence)*	David Chaplow, directeur et conseiller principal en santé mentale	5 mai 2004	8
	Arawhetu Peretini, gestionnaire, Santé mentale des Maoris		
	Phillipa Gaines, gestionnaire, Développement des systèmes de santé mentale		
Ontario Hospital Association	Dr Paul Garfinkel, président, Groupe de travail sur la santé mentale	31 mars 2004	5
Ressources humaines et Développement des compétences Canada	Bill Cameron, directeur général, Secrétariat national pour les sans-abri	29 avril 2004	7
	Marie-Chantal Girard, gestionnaire de la recherche stratégique, Secrétariat national pour les sans-abri		
Royaume-Uni, Gouvernement du *(par vidéoconférence)*	Anne Richardson, chef de la Direction des politiques en santé mentale, ministère de la Santé	6 mai 2004	8
	Adrian Sieff, chef de la Direction de la législation en matière de santé mentale		
Santé, Ministère de la de la Nouvelle Écosse	Dr James Millar, directeur exécutif, Santé mentale et services aux médecins	28 avril 2004	7
Secrétariat du Conseil du Trésor	Joan Arnold, directrice, Élaboration de la législation, Division des pensions	1er avril 2004	5
Service correctionnel du Canada	Larry Motiuk, directeur général, Recherches	29 avril 2004	7
	Françoise Bouchard, directrice générale, Services de santé		

ORGANISMES	NOM	DATE DE COMPARUTION	FASCICULE
Services de santé de la Colombie-Britannique, Ministère des	Irene Clarkson, directrice exécutive, Santé mentale et toxicomanie	28 avril 2004	7
Six Nations Mental Health Services	Dre Cornelia Wieman, psychiatre	13 mai 2004	9
Société canadienne de psychologie	John Service, directeur exécutif	31 mars 2004	5
Société canadienne de schizophrénie	John Gray, président élu	12 mai 2004	9
Société pour les troubles de l'humeur du Canada	Phil Upshall, président	12 mai 2004	9
Université McGill *(par videoconférence)*	Dr Laurence Kirmayer, directeur, Division de la psychiatrie sociale et transculturelle, Département de psychiatrie	13 mai 2004	9
Université Simon Fraser *(par vidéoconférence)*	Margaret Jackson, directrice, Institut d'études en politiques de justice pénale	29 avril 2004	7
U.S. Campaign for Mental Health Reform	William Emmet, coordonnateur	1er avril 2004	
U.S. President's New Freedom Commission on Mental Health *(par videoconférence)*	Michael Hogan, président	1er avril 2004	5

ANNEXE C:
LISTE DES INDIVIDUS QUI ONT RÉPONDU À UNE LETTRE DU COMITÉ AU SUJET DES PRIORITÉS POUR LA RÉFORME DANS LE SECTEUR DE LA MALADIE MENTALE

GROUPE CANADIEN DE RECHERCHE

Action cancer Manitoba	Harvey Max Chochinov, MD, PhD, MCRMC, titulaire d'une chaire de recherche du Canada en soins palliatifs, directeur de la Manitoba Palliative Care Research Unit d'Action cancer Manitoba
Hôpital Douglas, Centre de recherche de l'	Ashok Mall, MD, MCRMC, titulaire d'une chaire de recherche du Canada pour l'étude des premiers stades de la psychose, professeur en psychiatrie à l'Université McGill
Université Carleton	Dr Hymie Anisman, titulaire d'une chaire de recherche du Canada en neuroscience, chercheur supérieur attaché à la Fondation ontarienne de santé mentale
Université de l'Alberta	Glen B. Baker, PhD, DSc, professeur et titulaire d'une chaire de recherche du Canada en neurochimie et en développement de médicaments
Université du Manitoba, Faculté de médecine de l'	Brian J. Cox, docteur en psychiatrie, titulaire d'une chaire de recherche du Canada sur les troubles de l'humeur et sur les troubles anxieux, professeur agrégé de psychiatrie
Université McGill	Eric Fombonne, MD, MCRMC (Psych.), titulaire d'une chaire de recherche du Canada en psychiatrie de l'enfance et de l'adolescence, professeur de psychiatrie à l'Université McGill, directeur du Département de pédopsychiatrie de l'Hôpital pour enfants de Montréal

DOYEN D'UNIVERSITÉ

Centre universitaire de santé McGill	Joel Paris, MD, professeur titulaire et directeur du Département de psychiatrie
Hôpital général de Kingston	Samuel K. Ludwin, MBB, Ch., MCRMC, vice-président du développement à la recherche
Université de l'Alberta	Dr L. Beauchamp, doyen de la Faculté d'éducation
Université de l'Ouest de l'Ontario	Dr Carol P. Herbert, doyen de la Faculté de médecine et d'art dentaire
Université de Sherbrooke	Pierre Labossière, ing., PhD, vice-recteur adjoint à la recherche

GROUPE RELATIF À LA MALADIE

CRSNG	Thomas A. Brzustowski, président
La Fondation ontarienne de la santé mentale	Howard Cappell, PhD, c. psych., directeur exécutif
Société canadienne de schizophrénie	Fred Dawe, président

INDUSTRIE

Eli Lilly Canada Inc.	Terry McCool, vice-président des Affaires générales de la société
GlaxoSmith Kline	Geoffrey Mitchinson, vice-président des Affaires publiques
Les compagnies de recherche pharmaceutique du Canada	Murray J. Elston, président
Merck Frosst Canada Ltée	André Marcheterre, président
Roche Pharmaceutiques	Ronnie Miller, président-directeur général

GROUPE D'ÉTHIQUE EN SANTÉ MENTALE

Armée du Salut - Territoire du Canada et des Bermudes	Glen Shepherd, colonel et secrétaire en chef
Centre de recherche de l'Hôpital Douglas de l'Université McGill	Maurice Dongier, professeur en psychiatrie
Centre de toxicomanie et de santé mentale	Paul E. Garfinkel, MD, FRCP, président-directeur général
Hôpital St-Paul	Mark Miller, éthicien
Office régional de la santé de Winnipeg	Linda Hughes, présidente du Comité d'éthique en santé mentale de l'ORSW
St-Joseph's Health Care Centre du Parkwood Hospital de London	Maggie Gibson, PhD, psychologue du Programme des soins aux anciens combattants
Université de l'Alberta	Genevieve Gray, doyenne et professeure de la Faculté en soins infirmiers
Université de l'Alberta, Faculté des sciences infirmières et Centre John Dossetor d'éthique en santé de l'	Wendy Austin, inf. aut., titulaire d'une chaire de recherche du Canada
Université de la Colombie-Britannique	Peter D. McLean, PhD, professeur et directeur de l'Unité des troubles anxieux
Université de l'Ouest de l'Ontario	Nancy Feduk, adjointe exécutive au doyen de la Faculté de médecine et d'art dentaire
Université Queen's	J. Arboleda-Florèz, professeur et chef du Département de psychiatrie
Université York	David Shugarman, directeur

PRÉSIDENT D'UNIVERSITÉ

Institut de recherches en santé mentale de l'Université d'Ottawa	Zul Merali, PhD, président-directeur général
Université de Lethbridge	Lynn Basford, doyenne de la Faculté en sciences de la santé
Université McGill	Heather Munroe-Blum, professeure d'épidémiologie et de biostatistiques

RESPONSABILITÉ GOUVERNEMENTALE

Association canadienne de la santé mentale	Bonnie Pape, directrice des programmes et de la recherche au Bureau national de l'Association canadienne de la santé mentale
Cabinet du vice-recteur à la recherche de l'Université d'Ottawa	Yvonne Lefebvre, PhD, vice-présidente associée à la recherche
Centre de recherche de l'Hôpital Douglas	Rémi Quirion, directeur scientifiques de l'INSMT
Centre universitaire de santé McGill	Juan C. Negrete, MD, MCRMC, professeur de psychiatrie à l'Université McGill, président de la Section des toxicomanies, de l'Association des psychiatres du Canada
Coalition canadienne pour la santé mentale des personnes âgées	David K. Conn, MB, MCRMC, coprésident de l'Académie canadienne de psychiatrie gériatrique, professeur agrégé du Département de psychiatrie de l'Université de Toronto, président de l'Académie canadienne de psychiatrie gériatrique
Coalition canadienne pour la santé mentale des personnes âgées	J. Kenneth Le Clair, MD, MCRMC, coprésident de la Coalition canadienne pour la santé mentale des personnes âgées, professeur et directeur de l'Unité de gériatrie du Département de psychiatrie de l'Université Queen's, directeur clinique du Programme spécialisé de psychiatrie gériatrique
Développement des ressources humaines Canada	Deborah Tunis, directrice générale du Bureau de la condition des personnes handicapées

The Family Council : Empowering Families in Addictions and Mental Health	Betty Miller, coordonnatrice du Family Council
Global Business and Economic Roundtable on Addiction and Mental Health, affiliée au Centre de toxicomanie et de santé mentale	Bill Wilkerson, cofondateur et directeur général
Hôpital d'Ottawa	Paul Roy, MD, MCRMC, professeur adjoint en psychiatrie à l'Université d'Ottawa, directeur du programme « Premier épisode pour les maladies psychotiques » d'Ottawa
Hôpital royal d'Ottawa	J. Paul Fedoroff, MD, professeur agrégé de psychiatrie à l'Université d'Ottawa, directeur de recherche au Service médico-légal de l'Institut de recherche en santé mentale
Institut des neurosciences, de la santé mentale et des toxicomanies du Centre de recherche de l'Hôpital Douglas	Michel Perreault, PhD, chercheur à l'Hôpital Douglas
Instituts de recherche en santé du Canada	Dr. Jeff Reading, PhD, directeur scientifique de l'Institut de la santé des Autochtones
Ministère de la Santé et du Mieux-Être du Nouveau-Brunswick	Ken Ross, sous-ministre adjoint
ONSA : Organisation nationale de la santé autochtone	Judith G. Bartlett, MD, CMFC
Six Nations Mental Health Services	Cornelia Wieman, MD, MCRMC, psychiatre
Sunnybrook & Women's College Health Sciences Centre de l'Université de Toronto	N. Herrmann, médecin, MCRMC
Syncrude	Eric P. Newell, président-directeur général
Unité de l'évaluation de la santé mentale et des consultations communautaires du Département de psychiatrie de l'Université de la Colombie-Britannique	Elliot Goldner, MD, MScS, MCRMC, chef de la Division de la politique et des services de santé mentale

Université Dalhousie, Département de psychologie de l'	Patrick J. McGrath, OC, PhD, MSRC, titulaire de la chaire Killam de psychologie, professeur de pédiatrie et de psychiatrie, titulaire d'une chaire de recherche du Canada, psychologue au IWK Hospital
Université Dalhousie, Faculté de médecine de l'	David Zitner, PhD, directeur en informatique médicale
Université d'Ottawa, École de psychologie de l'	John Hunsley, PhD, c. psych., professeur en psychologie
Université d'Ottawa, Faculté de médecine de	Jacques Bradwejn, MD MCRMC, DABPN, président du Département de psychiatrie
Université McMaster	Docteur Richard P. Swinson, MD, MCRMC, titulaire de la chaire Morgan Firestone de psychiatrie et de neurosciences du comportement à l'Université McMaster, chef du Département de psychiatrie du St. Joseph's Healthcare Centre

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