

The Standing Senate Committee on Social Affairs, Science and Technology

Final Report on:

The Enquiry on the Funding for the Treatment of Autism

PAY NOW OR PAY LATER

AUTISM FAMILIES IN CRISIS

Chair

The Honourable Art Eggleton, P.C.

Deputy Chair

The Honourable Wilbert Joseph Keon

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SUMMARY OF RECOMMENDATIONS

Section in Part III	RECOMMENDATIONS	PAGE
I	The federal government, in collaboration with the provinces and territories, establish a comprehensive National ASD Strategy;	19
	All stakeholders, including individuals with autism, be consulted on the components that should be part of the Strategy, such as treatment, research, surveillance, awareness campaigns, community initiatives, education, respite care for families, etc.; and,	20
	The Strategy include child, adolescent and adult treatments and supports.	20
A	The federal government convene a federal/provincial/territorial ministerial conference to examine innovative funding arrangements for the purpose of financing autism therapy;	14
	The conference establish an appropriate level of funding by the federal government;	14
	The conference identify measures of accountability in the use of federal funds for autism treatment;	14
	The conference recommend listing of essential services for ASD; and,	14
	The conference also define the feasibility of introducing measures such as supports for caregivers, including respite, family training and assistance, assisted living support as well as career and vocational training.	14
B	Health Canada, in consultation with autistic individuals and other stakeholders, implement a national public awareness campaign to enhance knowledge and understanding about ASD; and,	15
	Health Canada use its dedicated webpage as one component of a public awareness campaign.	15

Section in Part III	RECOMMENDATIONS	PAGE
C	The federal government provide funding for the creation of an Autism Knowledge Exchange Centre;	15
	The Centre include an Internet-based web portal for access to reliable data and credible links for those seeking autism information;	15
	The Centre be at arm's length to government; and,	15
	The Centre be mandated with the dissemination of best practices based on authoritative research and scientific consensus.	15
D	The federal government create an Autism Research Network and provide substantial new funding for this through CIHR; and,	16
	The Autism Research Network work collaboratively with all stakeholders, including individuals with ASD, to develop a research agenda.	16
E	The federal government work collaboratively with the provinces and territories to address the human resource issues including training standards and inter-provincial mobility in the field of ASD.	17
F	The federal government, in implementing the recommendations of the Minister of Finance's Expert Panel on Financial Security for Children with Severe Disabilities, ensure that autism qualifies as an eligible disability.	18
G	The Department of Finance and the Revenue Canada Agency study the implications of income splitting for ASD families and issue a report to the Minister of Finance by June 2008.	18
	These departments issue the results of the tax measures review no later than 31 December 2007 and that these include a clear set of tax benefits for ASD individuals and their families.	18
H	Health Canada invite autistic individuals to attend the symposium and be given the opportunity to contribute as equal partners in an exchange with other participants and,	19
	Health Canada ensure that the symposium is conducted with a clear set of goals and defined outcomes and is based on consensus building.	19

ORDER OF REFERENCE

Extract from the *Journals of the Senate* of Thursday, June 22, 2006:

Resuming debate on the inquiry of the Honourable Senator Munson calling the attention of the Senate to the issue of funding for the treatment of autism.

After debate,

The Honourable Senator Moore moved, seconded by the Honourable Senator Banks:

That the Inquiry on the issue of funding for the treatment of autism be referred to the Standing Senate Committee on Social Affairs, Science and Technology for study and report; and

That the Committee submit its final report no later than November 30, 2006.

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

Extract from the *Journals of the Senate* of Monday, November 6, 2006.

The Honourable Senator Fraser moved, seconded by the Honourable Senator Cook:

That, notwithstanding the Order of the Senate adopted on Thursday, June 22, 2006, the Standing Senate Committee on Social Affairs, Science and Technology which was authorized to examine and report on the issue of funding for the treatment of autism, be empowered to extend the date of presenting its final report from November 30, 2006 to May 31, 2007.

After debate,

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

Paul C. Bélisle
Clerk of the Senate

SENATORS

The following Senators have participated in the study on the issue of funding for autism treatment of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Art Eggleton, P.C., Chair of the Committee

The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck

Andrée Champagne

Ethel M. Cochrane

Joan Cook

Jane Mary Cordy

Joyce Fairbairn, P.C.

Jim Munson

Nancy Ruth

Lucie Pépin

Marilyn Trenholme Counsell

Ex-officio members of the Committee:

The Honourable Senators: Marjory LeBreton (or Gerald J. Comeau) and Céline Hervieux-Payette, P.C. (or Claudette Tardif)

Other Senators who have participated from time to time on this study:

The Honourable Senators: Gustafson, Mercer, Peterson, Rompkey, St-Germain and Watt.

PAY NOW OR PAY LATER: AUTISM FAMILIES IN CRISIS¹

INTRODUCTION

Families with autistic children in Canada are facing a crisis. When a child is diagnosed with autism and therapy is prescribed by a health professional, publicly funded health care insurance does not pay for the cost of the therapy. As a result, families must often pay out of their own pockets for a very large portion of expensive autism therapy – whose cost may reach \$60,000 per year – because provincial and territorial jurisdictions offer only limited financial assistance. Families with autistic children across the country are therefore calling on the federal government to take a leadership role with respect to autism. As a matter of comparison, they point to the *Combating Autism Act of 2006* in the United States which authorizes the federal government to spend \$US 945 million over five years for autism research, screening, intervention and education.

Autism is a complex, lifelong, developmental disability which is 3 to 4 times more prevalent among boys than girls. Children and adults with autism may find it hard to communicate with others and to relate to the outside world. Autism can result in severe problems in social interaction, communication, and behaviour. A generation ago, the vast majority of the people with autism were eventually placed in institutions, while many others were misdiagnosed. Today, however, the picture is brighter. There is evidence to suggest that some people who have autism can improve significantly with proper therapy. When provided with appropriate support, training and information, families can often ensure that their son or daughter can enjoy a good quality of life.

Autism therapy, along with autism-specific programs and services, provide the opportunity for individuals to be taught skills, which allow them to reach their fullest potential and contribute positively to society. Many individuals with autism eventually become more responsive to others as they learn to understand the world around them. They can learn to function at home and in the community and to develop skills that will enable them to secure and retain employment. Families with autistic children and autistic individuals themselves insist that governments must pay now for autism therapy, services and supports in order

(...) if you pay for it now, look at the return you will get on your investment. The people with autism will get out in the real world and get jobs, and that will stimulate the economy. Or you can pay later, which means they will go into group homes and it will cost the taxpayers a lot of money in the long run to keep them there.

*Jason Oldford, Fredericton,
New Brunswick (12:32)*

¹ In this report, the testimony received by witnesses printed in the *Minutes of Proceedings and Evidence of the Standing Committee on Social Affairs, Science and Technology* will be hereinafter referred to only by issue number and page number within the text.

to obtain the greatest return on investment. Otherwise, they will pay later in terms of much higher costs in future years for welfare, social services and institutional care.

It is not the first time that the Standing Senate Committee on Social Affairs, Science and Technology has heard about the challenges of autism. Between 2003 and 2006, during its study on mental health, mental illness and addiction, the Committee had an opportunity to hear and learn from persons living with autism, their families and experts. We were made aware that autism is an extraordinarily complex issue that is also very controversial. At the time, however, we heard from some that autism should not be considered as a mental illness and accordingly decided that a more thorough investigation was required before taking a public position. For this reason, when the Committee released *Out of the Shadows at Last* in May 2006, the report did not contain recommendations with respect to autism. Nonetheless, our report did state that we hoped to undertake a thematic study on autism.

Within this context, in June 2006, the Committee received a mandate from the Senate to undertake an inquiry and to report on the issue of funding for the treatment of autism and on the need for a national autism strategy. In response to this mandate, the Committee held nine meetings and heard from 53 witnesses including autistic individuals, parents of autistic children, advocacy groups, health professionals, autism researchers, and selected federal department representatives, as well as one provincial minister. Witnesses also had the opportunity to discuss the announcement made on 21 November 2006 by the Honourable Tony Clement, Minister of Health, regarding a set of federal initiatives related to autism, and to share their views on recent parliamentary business related to autism, including:

- Bill C-211. This bill, which was introduced on 6 April 2006 by Peter Stoffer, Member of Parliament from Sackville-Eastern Shore (Nova Scotia) and is at first reading, calls on the federal government to include autism therapy under the *Canada Health Act* to ensure uniform and equitable access for all children with autism.
- Bill C-304: This bill, which was tabled on 17 May 2006 by Shawn Murphy, Member of Parliament for Charlottetown (Prince Edward Island), but was defeated on 21 February 2007, proposed, like Bill C-211, to include autism therapy under the *Canada Health Act*. In addition, it required the Minister of Health to convene a conference of all provincial and territorial ministers of health for the purpose of working together to develop a national strategy for the treatment of autism.
- Motion M-172: This motion was introduced on 27 October 2006 by Andy Scott, Member of Parliament for Fredericton (New Brunswick) and adopted on 5 December 2006. The motion calls on the federal government to create a national autism strategy that would include: the development of evidence based standards for the diagnosis and treatment of autism; the implementation of innovative funding methods for the care of those with autism; the provision of additional federal funding for autism research; and, the implementation of a national surveillance program for autism.

In this report, the Committee summarizes the testimony heard during these hearings, highlights issues raised by witnesses and identifies action needed by the federal government in response to these issues.

PART I: AUTISM:

A COMPLEX ISSUE WITH SEVERAL DIFFERING VIEWS

The Committee heard many different points of view on the complex issue of autism. Contrasting views were presented with respect to the definition of autism, its prevalence, the effectiveness of various autism interventions, and the need for treatment. Sometimes, divergent opinions were highlighted among autistic individuals, advocacy groups and families. This makes it very difficult to achieve consensus and to identify potential options for policy considerations. For this reason, it is clear that any set of recommendations will not please everyone. At the same time however, this reinforces the call for a strong foundation of autism research and underscores the need for unbiased, accurate information through education, knowledge exchange and public awareness. This also suggests that consultations with all stakeholders including, perhaps most importantly, autistic individuals, are essential to policy decision-making.

A. Definition of Autism

The Committee was given two distinct definitions of autism. The first one, which was provided by numerous witnesses including researchers, health professionals, advocacy groups, parents and autistic individuals, refers to the *Diagnostic and Statistical Manual of Mental Disorders*, 4^{ed} (DSM-IV). According to this definition, autism or “Autistic Disorder” is a mental illness and one of a group of five “Pervasive Developmental Disorders” (PDD). The other four include Asperger’s Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Rett’s Syndrome, and Childhood Disintegrative Disorder (CDD). The Committee was also told that, in practice, reference is often made to “Autism Spectrum Disorders” (ASD) which encompass Autistic Disorder, Asperger’s Syndrome, and PDD-NOS. It is interesting to note, however, that ASD is not a term that is officially defined in any international medical classification codes. The DSM-IV indicates that individuals with these disorders exhibit qualitative impairment in social interaction; restricted repetitive and stereotyped patterns of behaviour, interests, and activities; and qualitative impairment in communication. Autism is described according to a spectrum with varying degrees of pervasive impairment that range from mild to severe.

The second definition presented to the Committee was provided by other autistic individuals and researchers in the field. In their view, autism (or ASD) is not a mental disorder; it is rather a neurological difference classified as a developmental disability that begins in early childhood and persists throughout adulthood. They explain that while autism may affect behaviours in three crucial areas of development – social interaction, communication, and restricted interests or repetitive behaviours – it also presents measurable and admirable differences in perception, attention, memory, intelligence, etc. In their view, autistic individuals have strengths and traits not seen in the general population, just like “non-autistics” have strengths and weaknesses of their own. Like non-autistic people, individuals with autism may suffer from mental health problems and illnesses, including for example depression, self-hate and suicidal ideation. Those mental health problems may be exacerbated by the lack of knowledge about and appreciation of autism among non-autistic individuals.

Despite these different definitions, the two groups acknowledge that no two individuals with autism are alike and that a wide range of approaches and interventions must be considered. In addition, they both acknowledge that no one knows the exact causes of ASD. The first group insists on the need for early and intensive behavioural intervention, while the second argues that autistic individuals should receive the assistance, accommodation, acceptance, and respect they need to succeed in society as autistic people. They all insist that treatment and support services must be provided throughout the lifespan of the individual.

(...) there is no universal guide to autism. There are countless different degrees of autism and different kinds of autism spectrum disorders. To truly get a universal understanding of autism, you would have to talk to thousands of individuals and families. (...) all Canadians with autism spectrum disorders are unique individuals with different strengths, skills, abilities and needs.

Kristian Hooker, Selkirk, Manitoba (12:22)

B. Prevalence of Autism

Another area of contrasting opinion that arose during the Committee hearings relates to the prevalence of autism. Numerous witnesses suggested that there is an autism “epidemic”. Others argued that the increased prevalence is due to better identification of ASD and not to an increase in the actual incidence. The Committee heard that increased sensitivity to ASD, more accurate diagnoses as well as significant changes to diagnostic criteria may have contributed to the higher numbers.

It is unclear whether the actual prevalence of ASD is changing over time, but the number of diagnoses has been on the rise. Currently, the rate often cited for ASD in Canada is 6 per 1000, or 1 in 166 and is consistently detected 3 to 4 times more often in boys than in girls. This translates to about 48,000 autistic children aged 0 to 19 and 144,000 adults within Canada. Those who support the view of an increase in prevalence insisted that action must be taken now in providing publicly funded autism therapy, while others pointed to the need to invest more government funding into research to determine more adequately the prevalence and to assess the effectiveness of autism therapy.

C. Effectiveness of Interventions

Another area of disagreement which was also evident among the various advocacy groups/parents relates to the choice of autism interventions. Some witnesses argued that the only intervention options that should be made available to autistic children are Applied Behavioural Analysis (ABA) or Intensive Behavioural Intervention (IBI), while others favoured an integrated, multi-disciplinary approach, combining biomedical and nutritional treatments in addition to various forms of behavioural interventions. Still, others felt that there is no one approach that can be universally applied to all and that it should be left to the ASD professionals, in consultation with the family, to determine the best treatment option. The Committee heard that some treatment options have little, or no, scientific evidence of their efficacy and that some others have even been found harmful. Many witnesses, including some individuals with ASD, emphasized that funding should only be provided for treatments with a solid evidence-base. Again, this raises the question as to whether more funding should be devoted to research to improve knowledge about treatments and their effectiveness.

D. Need for Treatment

The Committee also heard differing opinions between autistic adults and the parents of autistic children with respect to the need for treatment. Parents want their children to receive intervention as soon as diagnosis is made, for as long and as intense as needed. Some autistic individuals, however, do not believe that early, intensive intervention is required. They explained that autism is not a degenerative condition and that, accordingly, autistic people do not inherently deteriorate or die in the absence of specific autism treatments. They also pointed out that many autistic individuals are able to learn and to communicate without intensive interventions. Moreover, they told the Committee that the nature of the treatment itself can deny or hamper particular abilities, strengths and traits of autistic individuals. Therefore, in establishing public policy, decisions about the nature and needs of autistic individuals should be made in consultation with autistic individuals and their families.

(...) autistics should receive the assistance, accommodation, acceptance, and respect we need in order to succeed in society as autistic people.

*Michelle Dawson, Montréal Quebec,
Brief to the Committee, p. 9.*

PART II:
ISSUES OF CONCERN RAISED BY
INDIVIDUALS WITH AUTISM, THEIR FAMILIES,
ADVOCACY GROUPS AND RESEARCHERS

A. Access to Autism Treatment

The Committee was told that access to autism treatment is problematic for different reasons. For one, ABA/IBI, the most intensive form of intervention, is very expensive and can cost parents as much as \$60,000 per year if no public funding is provided. These interventions are not exclusively “health services” but include a wide range of psychological, social and educational services. In addition, there is the jurisdictional aspect to consider when discussing the funding and provision of services. Witnesses stressed that provinces and territories have jurisdiction over the provision of autism interventions (either through the health, education, social and community service sectors), but they noted that the federal government has more ability to finance them through its spending power.

ABA is an expensive treatment. You have probably heard the figure \$60,000 per year per child. It is derived from 52 weeks a year at 40 hours a week at \$30 an hour. Parents put themselves on the verge of bankruptcy when they have to pay for that treatment out of pocket. I certainly understand the situation they are in. I am amazed they can cover the treatment they need for their child and still pay the bills. How they do it, I do not know. Somehow, they get it done.

Jason Oldford, Fredericton, New Brunswick (12:28)

Currently, all provinces and territories, with the exception of Nunavut, provide some funding for autism therapy, most notably for ABA/IBI. There is, however, no national program that would ensure uniform and equitable access to therapy by autistic individuals. As a result, autism therapy is funded under a variety of approaches and the number of hours of therapy allowed and the amount of funding provided per child vary greatly from one jurisdiction to another. Witnesses urged that equitable and uniform access to treatment should be made across the country regardless of the individual’s ability to pay.

Witnesses spoke of the need for flexibility in treatment options as different approaches are needed for different individuals. There was a strong consensus that all available treatment approaches should be monitored for effectiveness and that treatment regimens should be provided based on scientific evidence. It was suggested that some treatments that are currently offered for ASD do not meet the rigors for scientific validation. For this reason, they stressed the need for properly designed, randomized and controlled clinical trials to evaluate the spectrum of therapies. It was also indicated that the individuals themselves who are being treated should be regularly monitored for progress and that ineffective therapy either be stopped or redesigned. In any case, harmful therapies should be discredited or even prohibited.

Numerous witnesses noted that autism treatment requires the participation of a multidisciplinary team. For example, medical practitioners, psychologists, psychiatrists, speech-language pathologists, occupational therapists and special education providers all have a vital role to play in ASD therapy. For many witnesses, early intervention is critical, regardless of the approach taken for treatment. The Committee also heard that another consideration is access to these services in both English and French and that the shortage of trained professionals is even greater for the francophone community living outside the province of Quebec.

Witnesses noted that the recent announcement by the Minister of Health is only a “very modest first step” as it does not include any initiative related to the funding of autism therapy. This is despite the fact that the burden associated with the cost of autism therapy is the most pressing issue facing families with autistic children. For many witnesses, only a federal funding program would allow access to universal, equitable and uniform treatment in Canada.

B. Wait Time for Assessment, Diagnosis and Treatment

The Committee was told that access to autism treatment is not only impeded by its high cost and a lack of public funding, but that it is also significantly affected in some areas within Canada by a shortage of professional service providers. Witnesses explained that, in turn, this shortage has produced waiting times for assessment and diagnosis as well as for treatment. The Committee was made aware of the common, but unacceptable, experience of parents being unable to access timely assessment and diagnosis of their children. Witnesses spoke of the frustration of waiting months, if not years, to obtain the ASD diagnosis, only to find the child was now too old to qualify for publicly funded treatment. Witnesses also spoke of the irony of placing children in the privately funded stream due to the long waits in the public queue, only to be turned down for public funding later as the treatment produced such advances in the child that they now no longer qualified.

Another factor associated with longer waiting times relates to the expansion of eligibility for autism therapy to an increasing number of children. For example, the Committee was told that when Ontario decided to continue public funding for IBI therapy beyond age six, waiting lists for IBI therapy in that province grew substantially. The Committee was told that in Alberta, despite parents obtaining direct public funding for therapy, children cannot access treatment because there is a shortage of service providers. It heard that in contrast, Ontario has invested in increasing service provider capacity and does not have a shortage at this time, but the provincial government currently lacks the money to fund the therapy. The Committee was told that there is a fear that those who received autism training in Ontario may be enticed to move to Alberta.

Therefore, in some jurisdictions, like Ontario, additional federal funds could help alleviate some of the wait for publicly funded treatment. In other jurisdictions, such as Alberta where there is a shortage of providers, adding more public funding would have no immediate impact. After all, additional funds for treatment will not be helpful if there is no one to provide the therapy. In this case, there must be sustained capacity-building to attract, train and retain specially trained professionals, such as, but not limited to, child psychologists, speech-language pathologists, occupational therapists and special educators. Witnesses saw a role for the federal government in such an endeavour in terms of developing appropriate guidelines and standards for professional training.

Witnesses also stressed that mainstream medical practitioners are often too busy and not adequately trained about autism or the available therapy options. They also talked about teachers and assistants who are not properly trained to accommodate autistic children. Where training is made available for educators, it is not mandatory. Witnesses suggested that care of some autistic children in the hands of untrained personnel may create a dangerous scenario.

C. Stresses on Families

The Committee heard from many parents and advocacy groups about the tremendous emotional stresses and financial challenges faced by families with autistic children. Witnesses spoke of the devastation for parents and siblings who struggle to find ways to best accommodate the special needs of an individual with ASD. The Committee was told that families must often adapt their whole lifestyle to the needs of their ASD child. Witnesses frequently reported that there needed to be one stay-at-home parent to provide the necessary comfort and consistency, not to mention added support and intervention. Moreover, it is often necessary to have extra help within the home or at school. The Committee was also told that in the course of hiring treatment providers, who often provide treatment in the home setting, parents suddenly discover that they have become employers and are essentially operating a clinic.

Some witnesses stated that families “are bleeding” and that help is needed right now, not just for autistic children, but for parents and siblings as well. Needed supports are varied and include such things as respite care and home-care aid.

D. Insufficient Disability Supports

The Committee was told that the federal government offers a variety of financial supports that are applicable to individuals with ASD or their parents. In 2004-2005, the federal government invested \$7.6 billion in income support, tax measures and programs for people with disabilities. Income support is primarily available through the Canada Pension Plan Disability Benefits. As well, there are tax measures such as the Disability Tax Credit, the Medical Expense Tax Credit and the Child Disability Benefit. In the 2006 budget, the government increased the annual Child Disability Benefit from \$2,044 to \$2,300 and the medical expense supplement was increased to \$1,000 from \$767. In addition, the Committee was told that additional federal funding for disability supports and services is provided under the Canada Health Transfer and the Canada Social Transfer. However, numerous witnesses shared the view that this support is insufficient given the diverse and substantial needs they have, and that ASD is not always eligible for tax credits or deductions intended for disability or medical expenses.

E. Lack of Accurate Information on Autism and its Prevalence

Several witnesses told the Committee that many Canadians do not understand what autism is; this makes it difficult for them to know how to interact with and accommodate autistic individuals and their families. An awareness campaign was suggested in order to enhance the public understanding of autism. Lack of understanding may also extend to professionals who would benefit from ongoing education to ensure that

children are not mislabelled and improperly assessed. Minister Clement recently announced that Health Canada will create a dedicated page on its website to guide the public to ASD information available through the Canadian Health Network and other resources. Given the contrasting views and opinions about ASD and autism therapy, it will be crucial for the department to consult all interested parties to ensure that ASD information is presented in an unbiased fashion.

Witnesses also signalled the poor data on prevalence. They suggested that there are inadequate surveillance systems to obtain the required data. They discussed the National Epidemiological Database for the Study of Autism in Canada (NEDSAC), which aims to determine whether the prevalence is increasing.

This project conducts surveys only within various regions of Canada however, and therefore cannot be expected to supply comprehensive surveillance data. Minister Clement informed the Committee that his recent announcement includes the launch of a consultation process on the feasibility of developing an ASD surveillance program through the Public Health Agency of Canada. This was also suggested in Motion 172 by Andy Scott, M.P. Witnesses welcomed this initiative.

Numerous witnesses complained that there is currently no dedicated, central source of information on autism and autism therapy. A vast body of information exists but it is not being made readily available in terms that are clear and concise that the general public can appreciate. Witnesses frequently stated that the parents of autistic children are forced to navigate through a very complex web of information with little

A big problem with people facing ASD in society is that others often have a stereotype of how a person with ASD is supposed to look or behave. Many people with ASD could eliminate that stereotype but rarely get that opportunity, especially with a large group of people. The one thing that people should realize about people with ASD is that we are really no different from anyone else. We may have traits or abilities that seem unique or different but so does everyone else.

Kristian Hooker, Selkirk, Manitoba (12:24)

The first requirement of any website on autism should be that a person be in charge of keeping it up to date. Given the speed with which knowledge is moving forward in this day and age, this is a must. It is essential to take every precaution before disseminating information. Sources must be verified, in order to avoid having statements such as autism is a mental illness or some other qualifier such as that which I heard earlier and which I will attempt to forget. It is important that all sources be verified. I could never repeat this often enough: It is essential to go through autistic people themselves and not just those surrounding them, observing them and basing their reactions on their fears.

Brigitte Harrisson, Quebec (12:35-36)

Generally speaking, autism-related sites lag way behind what is really happening. They contain a lot of obsolete information, which but adds to the confusion of parents and adults. Adults come to us, at the association, with all kinds of explanations that simply do not hold water. This is due to the fact that the information posted on sites is not updated.

Brigitte Harrisson, Quebec (12:35)

help. They suggested that there is an abundance of inaccurate information as well as considerable accurate information with no way for individuals to distinguish between them. This can be particularly harmful since families impacted by autism are willing to soak up any and all information they can find. As such, they emphasized that there is a need for a centralized, unbiased and credible source for information, a need for knowledge exchange and for effective communication of research findings.

F. Need for Research

Research has a vital role to play in the provision of reliable information. According to the Canadian Institutes of Health Research (CIHR), funding for autism-specific research has increased from just over \$1 million in 2000-2001, to \$3.5 million 2005-2006. In total, CIHR invested some \$15 million during this period. The Committee also heard that Genome Canada, the Canadian Foundation for Innovation and Health Canada invest federal funds into autism research. Witnesses commented on the excellence of the Canadian autism research community, highlighting the collaborative spirit and collegiality. They insisted, however, that additional resources are necessary so that promising theories and hypotheses can be tested. It was also explained that autism research is not an area that lends itself to industry investment and that private donations to charitable organizations that fund research, though generous and vital, are not sufficiently stable from one year to the next. For these reasons, witnesses suggested that funding by the federal government in a substantial and on-going manner is imperative.

The Committee heard of promising programs such as that funded jointly by the CIHR, the National Alliance for Autism Research (now called Autism Speaks) and the *Fonds de recherche en santé du Québec* which will train the next generation of autism researchers. Despite this promising initiative, witnesses stressed that much more is needed in the way of training more researchers as well as promoting a multidisciplinary approach to research.

The announcement by Minister Clement, in contrast to Motion 172 which calls for additional federal funding on autism research, only includes the possibility of establishing a new research chair focusing on effective treatment and intervention for ASD. The research community welcomed this government decision but, much like the advocacy groups, they insisted on the need for additional autism research funding for areas such as the incidence, causes, effective screening tools, and treatment development including psychopharmacological and psychosocial interventions. Witnesses stressed the importance of distinguishing between short-, medium- and long-term needs when establishing research priorities.

PART III:

ACTION NEEDED BY THE FEDERAL GOVERNMENT

The Committee is encouraged by recent steps taken by the federal government to address autism concerns. However, it also heard the frustration expressed by many witnesses that both the recent announcement of Minister Clement and the private motion (M-172) by Andy Scott, M.P., regarding the creation of a National Autism Strategy do not commit to specific actions. The Committee wants to recommend a number of urgent initiatives that the federal government should implement over the next two years in response to the challenges faced by ASD individuals and their families. These initiatives will reduce the stresses for those affected by ASD as well as increase our knowledge base for this developmental disability.

A. Mechanism for Funding Autism Therapy

The Committee's primary focus was federal funding for autism treatment. Many witnesses stressed the urgent need to immediately provide extra financial resources for families who insist they need to access very costly ASD therapy. Some suggested that the government in fact had a moral obligation to do so.

The provision of health care, education and social services, including those relevant to ASD, are provincial/territorial responsibilities with federal funds being provided for these in the forms of the Canada Health Transfer and the Canada Social Transfer. Although federal funds make up a substantial portion of the budgets in these areas, the provinces and territories have the sole authority to decide how the money is spent. Numerous witnesses supported the private member bills C-211 (Peter Stoffer, M.P.) and C-304 (Shawn Murphy, M.P.) and suggested that ABA/IBI should be included as medically necessary services under the *Canada Health Act* in order to ensure universal and free access to autism therapy across the country. However, the Committee recognizes that the Act is not an appropriate mechanism to ensure federal funding for ABA and IBI therapies. The reality is that the Act does not refer to any specific disease, condition or treatment. Moreover, the medically necessary services defined under the *Canada Health Act* are those provided by physicians or other health care practitioners either in hospitals or doctors' offices, which is not the case for autism therapy.

If the federal government truly became the leader, while still intending to transfer the program to the provinces later on, it would be worthwhile for it to set the example and to keep autistic people involved in the treatment protocols. Allow me to repeat myself: It is really important that those autistic persons who are autonomous, who are capable of helping, do so. The need is an urgent one. This is what we are seeing. Therefore, if you are able to launch something, if you set the tone, then the provinces will obviously be able to jump on board afterwards.

Brigitte Harrisson, Quebec (12:20)

The Committee considered other funding mechanisms to assist the provinces and territories in financing autism treatment. The proposed catastrophic prescription drug insurance program, recommended by this Committee in October 2002 in its report entitled *The Health of Canadians – The Federal Role, Volume 6: Recommendations for Reform*, which aims to ensure that families do not suffer undue financial hardship for required drug therapy provides one model. Families with autistic

children, because of the extremely high cost of ABA/IBI therapies, could benefit from a similar program that provides financial assistance when costs exceed a pre-determined proportion of the family income. Witnesses, however, did not comment on the potential benefits of such a proposal.

Therefore, the pressures and challenges experienced by families coping with the demands of caring for a child or children with ASD result in considerable stress. The Committee believes that the financial burden on these families and caregivers is excessive and a solution must be found.

Another issue that was raised during the hearings was the need for additional supports such as supports for caregivers, including respite, family training and assistance, and assisted living support. There is a need to study the feasibility of introducing such measures. Witnesses also underscored that the needs of autistic adults must be taken into consideration when it comes to education, vocational training and employment (currently done by Social Development Canada with Opportunities Fund for People with Disabilities).

In developing a funding policy for autism, it is important that adults are an integral part of the equation and that more able is not translated to mean less need of supports and services. Children with autism grow up to be adults with autism.

*Daniel Hatton, Hamilton, Ontario
Brief to the Committee, p. 1.*

Witnesses suggested that concerns over funding arrangements could be initially addressed at a federal/provincial/territorial ministerial conference. This was suggested under the private motion by Andy Scott that was recently passed. This motion also states that innovative funding methods should be developed. The need for a federal/provincial/territorial ministerial conference is also acknowledged in Shawn Murphy's private member bill C-304. Therefore, the Committee finds that it is urgent that the federal government assume a leadership role and recommends that:

The federal government convene a federal/provincial/territorial ministerial conference to examine innovative funding arrangements for the purpose of financing autism therapy;

The conference establish an appropriate level of funding by the federal government;

The conference identify measures of accountability in the use of federal funds for autism treatment;

The conference recommend listing of essential services for ASD; and,

The conference also define the feasibility of introducing measures such as supports for caregivers, including respite, family training and assistance, assisted living support as well as career and vocational training.

B. Public Awareness Campaign

Throughout the course of the hearings on this difficult subject, witnesses identified a clear need for a national public awareness campaign. The Committee agrees that there is a general lack of understanding among Canadians about autism and its spectrum of disabilities and feels that a greater

understanding of ASD by all Canadians could help to reduce the stress experienced by these individuals and their families. The general population should be made aware of the associated early signs and symptoms in order that parents might pursue assessment of their child at the youngest possible age. Such a campaign could also serve as a tool to promote the Knowledge Exchange Centre (discussed below). The Committee therefore recommends that:

Health Canada, in consultation with autistic individuals and other stakeholders, implement a national public awareness campaign to enhance knowledge and understanding about ASD; and,

Health Canada use its dedicated webpage as one component of a public awareness campaign.

C. Knowledge Exchange Centre

There was a consensus among witnesses about the need to consolidate areas of education, clinical expertise and research endeavours to enhance and facilitate collaborative efforts. The Committee sees a need for a clearinghouse of “best practices” (including international experiences) which would allow each province or territory to develop or enhance its own services. It would also serve as the means to provide families with an unbiased source of accurate information including current research findings. Families affected by ASD are already under considerable stress and the Committee asserts that it is unfair to make them spend their precious resources and what little time they have wondering what to do, where to go for help, what help to get, whom to trust and whom to believe. A focal point for ASD information, provided by a trusted source, would save individuals from navigating the current confusing and unreliable maze and could sort out the accurate from inaccurate information.

As a corollary, there is a need to provide the centralized infrastructure for the dissemination of information that is helpful, accurate and supportive and to put scientific findings into plain language. The Committee heard that the university setting might be most appropriate as it is often viewed as unbiased and trustworthy.

Thus, the Committee recommends that:

The federal government provide funding for the creation of an Autism Knowledge Exchange Centre;

The Centre include an Internet-based web portal for access to reliable data and credible links for those seeking autism information;

The Centre be at arm’s length to government; and,

The Centre be mandated with the dissemination of best practices based on authoritative research and scientific consensus.

D. Research

The Committee sees a need for a significant investment in research into autism. Although there has been considerable work in the research community there are still many areas that need to be more fully explored. The Committee believes that there is a clear role for the government to fund research that will explore the causes of autism, develop treatment models, establish new treatment methods, determine treatment suitability, refine treatment approaches for older children and adults and develop appropriate evaluation tools so that treatment effectiveness can be properly measured.

The Committee is aware that CIHR is prepared to take the lead in a federal autism research program and work with all partners and stakeholders in order to define the priorities. It is important for CIHR to work inclusively with such partners as the Autism Society Canada, Autism Speaks and the Canadian Autism Intervention Research Network to develop a comprehensive research agenda. The development of this agenda should: include multidisciplinary research teams; encourage more programs that train autism researchers; provide the long-term, randomized, controlled trials required to properly measure treatment effectiveness; facilitate collaboration; and, include public policy research. Moreover, CIHR must also consult with autistic individuals in identifying priorities.

As such, the Committee recommends that:

The federal government create an Autism Research Network and provide substantial new funding for this through CIHR; and,

The Autism Research Network work collaboratively with all stakeholders, including individuals with ASD, to develop a research agenda.

E. Human Resources Initiative

The Committee heard repeatedly that shortages exist across Canada in various specialty fields. In addition, witnesses indicated that teachers and medical practitioners should be better trained to spot signs and symptoms of ASD in order that an assessment can be ordered in a timely fashion. Witnesses contended that the need for a multi-disciplinary approach to autism assessment, diagnosis, treatment, training, education and research cannot be overstated. Some suggested that the multi-disciplinary teams should be supervised by a regulated health care professional. Others indicated that more of the professional groups involved should be certified by a regulatory body. Further, the Committee heard that more must be done to increase enrolment for the training of all relevant social services and education professionals (including supports for special training for teachers/aides, life skills programs, mental health services professionals), to encourage recruitment, and to optimize retention of these individuals, including perhaps improved remuneration.

The shortage of human resources is of paramount concern in the context of extending autism therapy. Some witnesses spoke of the need to establish a national training centre for autism therapy. Although it is not an area that lends itself easily to federal intervention, the Committee understands that this needs to be resolved before additional funds for treatment would be optimally beneficial.

While respecting the jurisdictional constraints in this area, the Committee recommends that:

The federal government work collaboratively with the provinces and territories to address the human resource issues including training standards and inter-provincial mobility in the field of ASD.

F. Mechanism to Ensure the Future Financial Security of Autistic Children

Although the main focus of the Committee's study was on today's needs of autism families, parents also expressed their concern about the future of their autistic children when they will no longer be there to care for them. The issue regarding the future financial security of children with severe disabilities was addressed in a recent report commissioned by the Minister of Finance. The report, entitled *A New Beginning*, recommended one new fiscal measure under the *Income Tax Act* – the Registered Disability Savings Plan – and two related new legislated programs – the Disability Savings Grant and the Canada Disability Bond Program. The Registered Disability Savings Plan would be modelled after the current Registered Education Savings Plan and would involve no restrictions on who could contribute to the plan (families, friends and strangers); it would have a lifetime contribution limit of \$200,000. The Disability Savings Grants would be modelled after the existing Canada Education Savings Grant. It would be equivalent to 20% of the annual amount contributed to the Registered Disability Savings Plan, for the first \$2,000 per year of contributions. Finally, the Canada Disability Bond would be broadly modelled after the Canada Learning Bond provisions currently in effect; it would provide low income families with at least \$1,000 per year for the first 20 years of the registration under the Registered Disability Savings Plan.

Parents of autistic children welcome these three measures. They explained that other family members and friends often provide financial assistance to pay for autism therapy and that making them eligible as contributors under the Registered Disability Savings Plan was a sound recommendation. Some witnesses expressed concern about the lifetime contribution limit set at \$200,000 and recommended that this ceiling be removed. However, Mr. James Barton Love, Chair of the Expert Panel, explained that this limit had been recommended to ensure that contributors would not benefit from excessive income referral. Another issue related to the treatment of the contributions under the Registered Disability Savings Plan by provincial social assistance plans. It was explained these contributions could disqualify a person with disabilities from receiving provincial benefits or could reduce the payments to be made under social assistance programs. To address this concern, it is essential that federal and provincial negotiations be initiated with a view to having contributions under the Registered Disability Savings Plan entirely exempted from the asset test in provincial social assistance programs.

The Committee welcomes the recommendations of the Expert Panel and is pleased that the government accepted them and announced the Registered Disability Savings Plan in Budget 2007. It supports the federal government in this attempt to enable parents to set aside funds today to financially support children with disabilities when they are no longer able to provide support. Moreover, the Committee feels that the report of the Expert Panel responds particularly well to the concerns of parents about the future of their autistic children. Therefore, the Committee recommends that:

The federal government, in implementing the recommendations of the Minister of Finance's Expert Panel on Financial Security for Children with Severe Disabilities, ensure that autism qualifies as an eligible disability.

G. The *Income Tax Act* as a Means to Reduce the Financial Burden of ASD families

Another option that was explored during our autism study included tax breaks to families with autistic children. The Committee acknowledges that the federal government does currently offer tax credits or deductions to benefit those affected by ASD, such as the Disability Tax Credit and the Medical Expense Tax Credit. Although Committee members heard little testimony as to the extent that these tax credits are available to ASD families, they did hear that the tax treatment of expenditures related to autism under the federal *Income Tax Act* does little in alleviating the enormous financial burden faced by families due to the cost of autism therapy. This is particularly true for those with low or no taxable income.

In addition, the Committee heard repeatedly during its hearings that ASD families often have a single income earner because the second parent must stay home to care for the affected child or children. Frequently, the earning parent must also take on a second job in order to pay the high cost of ASD care and treatment. Witnesses explained that this results in pushing the income earner into a higher tax bracket, reducing the effect of the medical expense tax credit. The Committee heard that income splitting would be one way of assisting these struggling families. Therefore, the Committee recommends that:

The Department of Finance and the Revenue Canada Agency study the implications of income splitting for ASD families and issue a report to the Minister of Finance by June 2008.

The Committee also heard about current restrictions that prevent the roll over of RRSPs and RRIFs of family members into absolute discretionary trusts for individuals with ASD. These trusts are designed to protect the assets of the individual as well as their disability benefits and entitlements. Members feel strongly that any tax, or other financial relief, that is created for persons with ASD and their families, should not have a negative impact on their disability benefits and entitlements. This position was taken, in the context of all persons living with disabilities, in the report *Disability Tax Fairness*. This report was submitted to the Ministers of Finance and National Revenue in December 2004 by the Technical Advisory Committee on Tax Measures for Persons with Disabilities. The Committee applauds the government for having implemented all of the policy recommendations made in this report, but we are concerned that no action has yet been taken with respect to allowing an RRSP or RRIF roll over into a discretionary trust for a disabled person. The government indicated in early 2005 that it would “conduct a review of the tax rules in this area with a view to providing more flexibility where appropriate”. This review is still on-going.

Therefore, the Committee also recommends that:

These departments issue the results of the tax measures review no later than 31 December 2007 and that these include a clear set of tax benefits for ASD individuals and their families.

H. Consulting with Autistic Individuals and Others

The Committee appreciates that the complexity of this issue cannot be efficiently and effectively resolved without extensive consultation with all stakeholders. The diversity of opinions about the nature of autism, its prevalence, the effectiveness of treatments and interventions, etc., requires considerable consensus building in order to identify priorities and achieve common goals. Consensus building can be achieved only through ongoing consultations with all interested parties. In particular, the perspective of autistic individuals needs to be included.

In his announcement, the Minister of Health stated that Health Canada will sponsor an ASD stakeholder symposium in 2007 to “encourage the development and sharing of ASD knowledge among health care professionals, researchers, community groups, teachers, individuals and families.” The Committee welcomes this announcement, however would like to reiterate the need for input from all stakeholders, including autistic Canadians. We insist that this symposium must take place sooner rather than later.

At that national symposium I would like nothing better than to see people with autism being invited to speak.

*Jason Oldford, Fredericton, New Brunswick
(12:33)*

Therefore, the Committee supports the symposium announced by the government and recommends that:

Health Canada invite autistic individuals to attend the symposium and be given the opportunity to contribute as equal partners in an exchange with other participants and,

Health Canada ensure that the symposium is conducted with a clear set of goals and defined outcomes and is based on consensus building.

I. Need for a National Autism Strategy

Finally, and most importantly, the Committee wants to see the recommendations described above implemented as part of a National Autism Strategy. Autism is a very complex issue and it is extremely difficult to efficiently and completely address all of the parameters involved. Members of the Committee agree that the solution does not exist in a tidy policy package and that whatever approach is taken should be done within a forum that has a clear authority to effect change and that avoids inter-departmental and inter-governmental “turf-wars.” No matter how a National Autism Strategy is structured, witnesses were clear that individuals with ASD must be included in the consultation and play a role within the Strategy itself, that it receive adequate ongoing funding, that it span the lifetime of affected individuals and that it strive to achieve consistency across the country in terms of information dissemination, assessment, treatments and supports. Therefore, the Committee recommends that:

The federal government, in collaboration with the provinces and territories, establish a comprehensive National ASD Strategy;

All stakeholders, including individuals with autism, be consulted on the components that should be part of the Strategy, such as treatment, research, surveillance, awareness campaigns, community initiatives, education, respite care for families, etc.; and,

The Strategy include child, adolescent and adult treatments and supports.

CONCLUSION

Members of the Standing Senate Committee on Social Affairs, Science and Technology are profoundly aware of the challenges facing those with autism and their families. We are encouraged by recent events such as the motion in Parliament to explore autism treatment funding, the government's announcement regarding autism initiatives, and the establishment of the Mental Health Commission in Budget 2007. However, all members agree that the federal government must act now to assist these Canadians. The Committee fully supports the view expressed by families with autistic children and autistic individuals themselves that governments must pay now; otherwise, they will pay later. We believe that the latter is simply not an option.

APPENDIX 1 – LIST OF WITNESSES

ORGANIZATION	NAME, TITLE	DATE OF APPEARANCE	ISSUE NO.
As Individuals	Barton Love ,James, Past Chair, Expert Panel on Financial Security for Children with Severe Disabilities.	Feb. 1, 2007	16
	Bateman, Carolyn	Dec. 7, 2007	12
	Borbey-Schwartz, Anne	Dec. 7, 2006	12
	Dawson, Michelle	Nov. 22, 2006	11
	Erb, John	Dec. 6, 2006	12
	Gibbons, Laurel	Dec. 7, 2006 Dec. 8, 2006	12 13
	Harrisson, Brigitte	Dec. 6, 2006	12
	Hatton, Daniel	Dec. 6, 2006	12
	Hooker, Kristian	Dec. 6, 2006	12
	Kavchak, Andrew	Dec. 6, 2006	12
	Laredo, Dr. Sheila	Dec. 6, 2006	12
	McVicar, John, Retired Expert in Field of Estate and Tax Planning	Feb. 1, 2007	16
	Oldford, Jason	Dec. 6, 2006	12
	Pope, Kenneth, Tax Expert	Feb. 1, 2007	16
	Simmerson, Lisa	Dec. 6, 2006	12
Autism Canada	Laurie Mawlam, Executive Director	Nov. 23, 2006	11
Autism Canada	Wendy Edwards, Director	Dec. 8 2006	13
Autism Society of Canada	Jo-Lynn Fenton, President	Nov. 23, 2006	11
	Louise Fleming, Executive Director	Dec. 8 2006	13

ORGANIZATION	NAME, TITLE	DATE OF APPEARANCE	ISSUE NO.
Autism Speaks Canda	Suzanne Lanthier, Greater Toronto Regional Director	Nov. 23, 2006	11
Autism Treatment Services of Canada	Davis Mikkelsen, Executive Director	Nov. 23, 2006	11
Canada Revenue Agency	Daphne Fraser, Manager, Disability Tax Measures Initiative	Feb. 1, 2007	16
Canada Revenue Agency	Michel F. Cloutier, Director, Special Programs and Partnerships	Feb. 1, 2007	16
Canadian Academy of Child and Adolescent Psychiatry	Pippa Moss, Dr., Clinical Psychiatrist in Nova Scotia	Nov. 9, 2006	10
Canadian Association of Occupational Therapists	Mary Law, Associate Dean and Director, School of Rehabilitation Science, McMaster University	Nov. 9, 2006	10
Canadian Association of Speech-Language Pathologists and Audiologists	Tracie L. Lindblad, Director and Speech-Language Pathologist	Nov. 9, 2006	10
Canadian Autism Intervention Research Network, McMaster University	Peter Szatmari, Faculty of Health Science, McMaster University, Head of Division of Child Psychiatry	Nov. 22, 2006 Dec. 8, 2006	11 13
Canadian Institutes of Health Research	Rémi Quirion, Dr., Scientific Director, Institute of Neurosciences, Mental Health and Addiction	Nov. 2, 2006	9
Canadian Paediatric Association	S. G. Wendy Roberts, Dr., The Hospital for Sick Children of Toronto	Nov. 9, 2006	10
Canadian Psychiatric Association	Blake Woodside, Dr., Chairman of the Board	Nov. 9, 2006	10
Canadian Psychological Association	Karen Cohen, Dr., Associate Executive Director	Nov. 9, 2006	10
Children and Youth Services of Ontario	The Honourable Mary Anne Chambers, Minister	Nov. 8, 2006	10

ORGANIZATION	NAME, TITLE	DATE OF APPEARANCE	ISSUE NO.
Dalhousie University, Department of Pediatrics, Autism Research Centre	Susan Bryson, Dr.	Dec. 8 2006	13
Department of Finance Canada	Annik Bordeleau, Tax Policy Officer, Personal Income Tax Division	Feb. 1, 2007	16
Department of Finance Canada	Katherine Rechico, Chief, Charities, Personal Income Tax Division, Tax Policy Branch	Feb. 1, 2007	16
Families for Early Autism Treatment	Jean Lewis, Director	Nov. 23, 2006	11
Health Canada	Gigi Mandy, Acting Director General of Intergovernmental Affairs Directorate	Nov. 2, 2006	9
Health Canada	Serge Lafond, Acting Director of the Canada Health Act Division	Nov. 2, 2006	9
Hospital for Sick Children	Stephen Scherer, Dr., Senior Scientist, Genetics and Genome Biology	Dec. 8 2006	13
Human Resources and Social Development Canada	Caroline Weber, Director General, Office for Disability Issues	Nov. 2, 2006	9
McGill University	Eric Fombonne, Dr., Director of Child Psychiatry	Nov. 22, 2006 Dec. 8, 2006	11 13
Queen's University	Helene Ouellette-Kuntz, Associate Professor, Departments of Community Health and Epidemiology and Psychiatry	Dec. 8 2006	13
Queen's University – Cytogenetics and DNA Research Laboratory	Jeanette Holden, Co-Director of Research	Dec. 8, 2006	13
Société franco-ontarienne de l'autisme	Bernard Delisle, Member	Dec. 7, 2006	12

ORGANIZATION	NAME, TITLE	DATE OF APPEARANCE	ISSUE NO.
Université du Québec à Montréal	Dr. Ridha Joobar, Researcher	Dec. 8 2006	13
Université du Québec à Montréal	Normand Giroux, Dr., Associate Professor, Douglas Hospital Research Centre	Dec. 8 2006	13
University of Alberta – Glenrose Rehabilitation Hospital	Lonnie Zwaigenbaum, Dr.,	Dec. 8 2006	13
University of British Columbia	Suzanne Lewis, Dr., Department of Medical Genetics, BC Children’s and Women’s Health Centre	Dec. 8 2006	13
University of Manitoba	C.T. Yu, Dr., Director of Research, St-Amant Research Centre	Dec. 8 2006	13
University of Manitoba	Tammy Ivanco, Dr., Associate Professor of Psychology	Dec. 8 2006	13
University of Montreal	Laurent Mottron, Dr. , Researcher, Faculty of Medecine, Psychiatry	Dec. 8 2006	13
University of Toronto	Marianne Ofner, Department of Public Health Science	Nov. 22, 2006	11
Walk-on	Barbara Beckett, Canadian Institutes of Health Research, Institute of Mental Health and Addiction	Dec. 8 2006	13
York University	Adrienne Perry, Dr., Department of Psychology	Dec. 8 2006	13