DEMENTIA IN CANADA:
RECOMMENDATIONS FROM PEOPLE LIVING WITH DEMENTIA

Brief prepared for the Senate Standing Committee on Social Affairs, Science and Technology

May 2016
INTRODUCTION

The Ontario Dementia Advisory Group (ODAG), is a group of individuals with dementia living in Ontario. It formed in the Fall of 2014.

Members of ODAG presented as Witnesses to the Standing Senate Committee on Social Affairs, Science and Technology on the Study on the issue of dementia in Canadian society in May 2016.

There is much discussion on the needs of the those who have dementia. But, it is primarily from a medical not a social perspective. Furthermore, discussions are driven predominantly by those who believe they are experts – not by people with dementia, who are the true experts.

We believe that the real-life experience of someone living with dementia is the best way for researchers and practitioners to find ways to listen to, and to communicate with, us in order that our voices are heard in shaping our lives and services we receive. Work of this kind has demonstrated that when people with dementia are enabled to communicate, we have important things to say about how dementia affects us, about what we consider important about our present and future lives, including how our health and social care needs should be met.¹

It is critical that government policies are based on input from those who have the disease not just the medical, research and educational communities.

A PARADIGM SHIFT IS NEEDED

When we talk about the rights of people with dementia, we are not legal counselors, but merely, a group of people trying to understand and work through how people with dementia can and should be treated within our society, and as such, our discussion about rights is based on experiential understandings and perceptions of the laws that we have in Canada and in Ontario.

The time has come to rethink and re-position dementia, to shift our ways of seeing and treating people with dementia. This shift is happening, despite resistance, but the activism of people with dementia is emerging across the world and here in Canada.

A bio-medical model currently informs dementia care. In this model we look to "fix" the disease and "fix" the person. Medications, pathology, diagnostic tests and medical care are indicative of a medical model, where people's expressions, communications, and behavior are interpreted through a lens of
In the social model, people with dementia are at the center of our own care, and are recognized as equal citizens with rights. Disabling barriers such as attitudinal, social, architectural, physical and institutional have led to our marginalization and exclusion.

**BACKGROUND**

**DEMENTIA AS A DISABILITY**

The rethinking of dementia includes positioning dementia as a disability. The UN Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 but is only now beginning to be used by the dementia community. Its ratification by the European Union and 163 countries commits their governments in international law to implement each of its General Obligations, General Principles and 37 Articles.

Article 1 of CRPD includes people with dementia as: "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

Canada's governments at all levels are responsible for implementing the Convention. The federal structure allows governments to work together and to adopt policies and programs designed to local needs and circumstances.

**Canada Reporting to the CRPD Committee – Aug 2016**

The government of Canada will be submitting a detailed report on implementation of each of its General Principles and Articles to the CRPD Committee in August 2016. This will be an excellent opportunity for people with dementia to use their right to submit parallel reports to the CRPD Committee.

In addition, it will enable the Government of Canada's Office for Disability Issues (ODI) to provide leadership on disability for people with dementia at the federal level.

ODAG welcomes to work in partnership with ODI to help strength outcomes for persons with dementia. In particular, to focus on:

- "Developing and administrating programs designed to remove barriers and promote inclusion;
- Developing principled and evidence-based policy options that respond to existing and
emerging issues; and

• Working to improve awareness and horizontal management of disability issues across the Government of Canada and its public servants.”6

Following the international lead of Dementia Alliance International, the global voice of dementia, ODAG has three key topics of significant importance:

1. We have the human right to a more ethical pathway of care.
2. Being treated with the same human rights as everyone else, under the UN Convention on the Rights of Persons with Disabilities.
3. That research focuses on care as much as cure.7

RECOMMENDATIONS

1. Dementia-Friendly Communities (DFC)8

The concept of dementia-friendly communities is simply to work for the common better life for people with dementia.

Alzheimer’s Disease International (ADI) suggests that there are four essential elements needed to support a dementia friendly community; people, communities, organizations and partnerships.

People

DFC’s should be shaped by the needs and opinions of people living with dementia, together with input from their care-partners. This provides us with a sense of respect, dignity and purpose we seek.

The Alzheimer Society of Ontario is moving forward in the right direction with its Dementia Friendly Communities Program Advisory Group. The Program Manager works directly with ODAG in the development of its strategy. This is an excellent example of a strategy that is working. The Alzheimer Societies have much to learn from each other.

Communities

There is a critical need to provide supports for the needs of people living with dementia in both physical and social environments.
The majority of people living with dementia wish to remain safely in their own home. Canada must create strategies and polices to support persons with dementia to live where and with whom on an equal basis. The goal is to prevent segregation and isolation from the wider community.

Transportation can be a great challenge due to revoking of a drivers license which results in loss of independence and potential financial constraint. Article 20 of the CRPD states that the nations must facilitate the personal mobility of person in the manner and at the time of their choice and affordable costs.

**Organizations**

An important aspect of DFC is how people within communities respond to people with dementia. Ontario is well on its way with five local Alzheimer Societies being a part of "The Blue Umbrella" program. It trains local businesses on how to interact with someone who has dementia. This forces the breakdown of stigma and supports "reasonable accommodation." Assistance with shopping or banking is a simple yet significant way to help someone with dementia. Like many other programs, The Blue Umbrella program is just that – a program. The challenge is to ensure sustainable funding resources for this movement to continue across Canada.

A timely diagnosis of dementia and early treatment is a critical component of a DFC. There is a need to respond to the unique needs of people with dementia at the right place at the right time.

Rural areas of Canada are particularly hard hit when it comes to accessing health care. Research into technology (i.e. Video conferencing) may help in alleviating this stress.

**Partnerships**

Issues arise from multi-sector involvement providing funding and services in silos, and structures that focus on one part of the life span, on single health issues, and on either chronic or acute care; all failing to address the complexity of the disease.

Canada needs to continue to look for opportunities of creating and nurturing partnerships across all sectors and agencies.

2. **DEVELOP A NATIONAL DEMENTIA STRATEGY**

According to a Nanos survey, 83% of Canadians believe that Canada needs a national dementia plan, a comprehensive workable dementia strategy that dramatically improves the lives of people living with dementia. Canada trails the United States, France, Australia, the UK and other countries that already have dementia strategies.⁹
Due to the lack of a national strategy, provinces are working on developing their own dementia plans; Nova Scotia already has a plan. The Ontario Ministry of Health and Long-Term Care has begun the process of gathering information that will guide the development of a comprehensive Ontario Dementia Strategy to address the needs of Ontarians with dementia, and their care-partners. This project team has done a good job on moving to a model where people with dementia have the opportunity to be actively involved in decision-making processes about its policies and programs, including those directly concerning us.

When the decision to develop a Canadian national dementia strategy is agreed upon, all government agencies and organizations should actively encourage participation of people with dementia at the stakeholder levels of the project, and at the center for the development of polices. Having one or two persons with dementia is tokenism and does not meet the intention of the CRPD.

Like many other organizations, ODAG believes the time is now for the federal, provincial, and territorial, and municipal governments to recognize their roles in the creation of a national strategy.

3. **FOCUS RESEARCH ON CARE OVER CURE**

Canada has much to be proud about in its international role of dementia research. It brings together over 20 research teams (over 350 researchers) across Canada. The Canadian Institutes of Healthy Research (CIHR) Dementia Research Strategy supports research on the latest preventive, diagnostic and treatment approaches to Alzheimer's disease and related dementia. Its ambitious goal is to find a cure or disease-modifying treatment for dementia by 2025 – only 10 years away.

The goals of the strategy fall under three themes: Primary Prevention, Secondary Prevention and Quality of life.

As more people are diagnosed with dementia, international dialogue by people with dementia is active on the topic of "care over cure." Of course we want to have a cure. However, people with dementia need to live in the here and now. We want for this time to be the best in can be. This presents a dilemma as where you want your research funding to go towards.

For ODAG members, we prioritize the quality of our life over a cure. For instance we promote research and development of, and to promote the availability of new technologies, including information and communication technologies, mobility aids, devices and assistive technologies, giving priorities to technologies at an affordable cost.

The Canadian government will need to have timely public polls on the prioritization of funding. It must be able to address a change in public opinion on this important topic.
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ENDNOTES

¹Cantley, C., Steven, K., Smit, M. 2003.
⁴Swaffer, K. 2016.
⁶Consideration of reports submitted by States parties under article 35 of the Convention Canada February 2014.
⁸ADI 2016