



**SUBMISSION TO THE SENATE STANDING COMMITTEE ON
SOCIAL AFFAIRS, SCIENCE AND TECHNOLOGY**

***Bill C-233: An Act respecting a national strategy for
Alzheimer's disease and other dementias***

APRIL 2017

INTRODUCTION

The Dementia Justice Society of Canada appreciates the opportunity to comment on Bill C-233: *An Act respecting a national strategy for Alzheimer's disease and other dementias*.

Dementia Justice is a federally incorporated non-profit society dedicated to advancing the rights, needs and dignity of people with dementia who are, or are at risk of becoming, involved with the criminal justice system. We strive to achieve our objectives through public advocacy, awareness-raising, education and research.

We are largely supportive of the proposed legislation; however, in our view, it is too narrow in scope. Bill C-233 rightly focuses on health care, but people with dementia are not just patients. They are rights-bearing subjects that participate in all aspects society. Sometimes this includes contact with the criminal justice system.

In this submission, we recommend changes to Bill C-233 that recognize the rights and dignity of people with dementia, and underscore their position as full and equal participants in society.

Under this inclusive umbrella, we then recommend changes that specifically recognize the potential impact dementia may have on people's relationship with the criminal justice system.

We have also included a minor recommendation regarding the outdated statistic provided in the preamble.

As one of the last G7 countries without a national dementia strategy, Canada urgently needs to develop and implement a coordinated plan. By making these proposed amendments, our aim is not to slow down that process. But we believe that our recommendations will enhance Bill C-233, and ultimately, improve the lives of people affected by dementia.

1. RIGHTS-BEARING SUBJECTS

The dominant narrative has traditionally viewed people with dementia as patients. Given that dementia is a medical condition, this perspective is understandable. However, modern approaches recognize people with dementia as rights-bearing subjects that participate in all aspects of society.

Scotland's national dementia strategy (2013-2016), for example, is underpinned by a rights-based approach, and commits to taking more action in relation to human rights, dignity and respect.¹

Alzheimer's Disease International (ADI) and Dementia Alliance International (DAI) have also called for a rights-based approach to dementia advocacy.² ADI is the international federation of 85 Alzheimer associations around the world, and DAI is a collaboration of people diagnosed with dementia who seek to represent, support and educate others living with the disease, as well as the wider community.

The World Health Organization has also recognized the importance of addressing dementia through a rights-based approach, and specifically, the PANEL framework.³ PANEL stands for Participation; Accountability; Non-Discrimination; Empowerment; and Legality. These are important elements in dementia advocacy.

Incorporating a rights-based approach in Bill C-233 is also consistent with Canada's commitments under the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD).⁴ The treaty came into force on May 3, 2008, and Canada ratified it on March 11, 2010.

The purpose of the CRPD is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."⁵ More specifically, Article 5(1) recognizes that all persons, including those with disabilities, are equal before and under the law, and are entitled to equal benefit of the law without discrimination.

Therefore, we recommend changes to the preamble of Bill C-233 which reflect a modern and rights-based approach to dementia advocacy. In the section below, we have underlined these proposed amendments.

¹ Scotland's National Dementia Strategy 2013-2016, online: <<http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>>.

² Alzheimer's Disease International, News Release, "A new landmark for people with dementia" (26 August 2016), online: <<https://www.alz.co.uk/media/160825>>.

³ World Health Organization, "Ensuring a Human-Rights Based Approach for People Living with Dementia", online: <http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf>.

⁴ UN GAOR, 61st Sess, 76th Mtg, UN Doc GA/10554 (2006), online: <<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>>.

⁵ *Ibid*, art 1.

RECOMMENDATION 1: Incorporate a rights-based approach.

Preamble

Whereas it is important to recognize, promote and respect the rights and dignity of people with Alzheimer’s disease and other forms of dementia;

Whereas people with Alzheimer’s disease and other forms of dementia participate in all aspects of society;

...

Whereas research, collaboration and partnerships remain the key to improving the lives of people with any form of dementia, and finding a cure, and early diagnosis and support for treatment and social inclusion can lead to positive health and well-being outcomes for people with any form of dementia and can have a positive impact on the family and friends who support or provide care for them;

2. CRIMINAL JUSTICE

Most people with dementia will not commit a crime. They are more likely to be victims. However, some will become entangled with the criminal justice system.

Transgressions in the community may be relatively minor, such as shoplifting from the local pharmacy. Indeed, research suggests that impulsive and disinhibited behaviour may be an early sign of dementia, namely, behavioural variant frontotemporal dementia.⁶

Less commonly, people with dementia may be charged with a serious crime, such as assault or murder. While rare, several high-profile cases in recent years have captured the public’s attention. To-date, these tragedies have most often occurred in care homes as resident-to-resident aggression.

There have also been incidents in domestic settings, where a person with Alzheimer’s disease, for example, may strike a spouse. Given that people with dementia are living at home longer, it seems reasonable to expect that, if nothing changes, there may be an increase in such violence.

The responsive behaviours associated with dementia can often be managed with appropriate supports. But we cannot prevent every incident of disinhibition or aggression.

⁶ Madeleine Liljegen et al, “Criminal Behavior in Frontotemporal Dementia and Alzheimer Disease” (2015) 72:3 JAMA Neurol 295.

Despite best efforts, some people with dementia will come into conflict with the criminal law. Therefore, it is imperative that we have a criminal justice system which is prepared to deal with this vulnerable population.

Our prison population is also aging, and dementia among inmates is an increasing concern.⁷

Yet, criminal justice and dementia has received very little attention. For instance, while we commend this Committee on its 2016 report, *Dementia in Canada*, we note that the recommendations do not specifically address criminal justice.

Further, our review of provincial, national and international dementia plans across many parts of the globe found that criminal justice is largely overlooked. In this sense, dementia strategies lag mental health initiatives. The Mental Health Commission of Canada, for example, specifically identifies criminal justice as a priority in its national mental health strategy.⁸ In our view, dementia strategies must also recognize criminal justice as a priority.

To be sure, there is already some good work being done. For instance, the Guelph Police and the Alzheimer Society Waterloo Wellington partnered on an initiative to reduce the number of people with dementia who come into conflict with the criminal law.⁹

Bill C-233 and the envisioned national strategy provides an excellent opportunity for Canada to establish itself as a leader on improving how criminal justice systems manage people with dementia. It is also important to note that Article 13(1) of the CRPD provides that State Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others.

To be sure, a generous reading of Bill C-233 envisions a comprehensive strategy that addresses all aspects of dementia. But given its current wording, there is a considerable risk that criminal justice—and justice matters generally—will not receive due attention.

For example, the bill states that the National Dementia Strategy advisory board’s role would be to advise “on any matter related to the health care” of persons with dementia. In our view, this scope is too limited. Dementia has the potential to affect every aspect of people’s lives, including their relationship with the criminal law.

Therefore, we recommend changes to Bill C-233 which encourage the creation of an advisory board that is more comprehensive in scope and composition. In particular, we recommend the addition of legal professionals and criminal justice advocates to the non-exhaustive list of possible advisory board members. Our proposed amendments are underlined below.

⁷ The Correctional Investigator Canada, Annual Report 2010-2011 (29 June 2011), online: <http://www.cpa.ca/docs/File/Practice/OCI_annrpt_20102011-eng.pdf> at 20 & 23.

⁸ Mental Health Commission of Canada, “Changing Directions, Changing Lives: The Mental Health Strategy for Canada” (2012), online: <<http://strategy.mentalhealthcommission.ca/pdf/strategy-images-en.pdf>>.

⁹ Alzheimer Society Waterloo Wellington, *Safe Pathways*, online: <<http://www.alzheimer.ca/en/ww/Safe-Pathways>>.

RECOMMENDATION 2: Include legal professionals and criminal justice advocates on the advisory board.

Role of advisory board

(3) The board is to advise the Minister on any matter related to the health care, well-being, rights, or dignity of persons living with Alzheimer’s disease or other forms of dementia.

Representation

(4) The Minister may appoint any person with relevant knowledge or expertise to the advisory board, including

(a) representatives from the federal, provincial and territorial governments responsible for public health;

(b) representatives from Alzheimer advocacy groups and other dementia advocacy groups;

(c) health care professionals; ~~and~~

(d) people living with Alzheimer’s disease or other forms of dementia or their caregivers;

(e) legal professionals; and

(f) criminal justice professionals or advocates.

3. DEMENTIA PREVALENCE

Lastly, we recommend a minor change to the outdated prevalence statistic in the preamble.

The estimate of 747,000 not only includes those with dementia, but also people with other cognitive impairments. An expert panel recently assembled by the Alzheimer’s Society of Canada studied dementia prevalence, and estimated that in 2016 there were 564,000 persons in Canada living with dementia.¹⁰ Therefore, we recommend that Bill C-233 be amended to reflect this more accurate and up-to-date number.

¹⁰ Larry W Chambers, Christina Bancej & Ian McDowell, eds, *Prevalence and Monetary Costs of Dementia in Canada* (Toronto: Alzheimer Society of Canada, 2016), online: <http://www.alzheimer.ca/~media/Files/national/Statistics/PrevalenceandCostsofDementia_EN.pdf> at 27.

RECOMMENDATION 3: Use the most recent prevalence estimate provided by the Alzheimer Society of Canada.

Preamble

...

Whereas there are more than ~~747,000~~ 564,000 Canadians living with Alzheimer's disease and other forms of dementia;

CONCLUSION

Bill C-233 represents an important step forward in improving the lives of Canadians affected by dementia. However, it is out-of-step with the modern approach of recognizing people with dementia as rights-bearing subjects that participate in all aspects society.

In our submission, Bill C-233 should be amended to acknowledge the importance of recognizing, promoting and respecting the rights and dignity of people with dementia.

More specifically, Bill C-233 should be amended to acknowledge that dementia has the potential to impact all aspect of people's lives, including their relationship with the criminal law.

By incorporating our recommendations, Canada will be at the forefront of recognizing dementia as a criminal justice issue. Most importantly, we believe that our recommendations will improve the lives of people affected by this terrible disease.

For questions or further information, please contact:

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