

Council of Canadians with Disabilities

Why PWD Want Access to UN CRPD

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Dec. 1. 2016



My name is Mary Beth Wighton. I am 50 years old with a diagnosis of probable frontotemporal dementia. I am the Chairperson for the Ontario Dementia Advisory Group, otherwise known as ODAG. ODAG is a group of people with dementia living in Ontario. We are involved in policy-making strategies, research projects and education initiatives. We work with organizations at all levels from local up to and including the international community.

I am 1 of 564,000 Canadians who will die from dementia. When I was diagnosed at the age of 45, I was told to get my affairs in order, that I had about five to eight years to live and that I would eventually live in long-term care.

My partner was told she would be responsible for my welfare and that it would eventually become totally time-consuming. The doctor then revoked my licence on the spot as she told me I did not have the capacity to drive any longer. My loss of licence was done without any kind of due process. What is frightening is that my story is like most other people living with dementia in Canada.

Today, I have been asked to speak on why PWD want access to the CRPD. I feel this is somewhat a rhetorical question. Why is it that you, representatives of disability organizations in Canada want access to CRPD? PWD, like you, want to utilize any and all tools and strategies that may help in making our lives better.

The definition in Article 1 of the CRPD it indicates that "persons with disabilities include 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." Dementia is a chronic, progressive health condition that causes damage to the brain. This damage slowly impairs a person's memory, thinking, language skills and their ability to carry out everyday tasks. There is no cure. Unfortunately, people with dementia are included in the broad definition of disability in Article 1 of the Convention, but have not been included in its implementation by the Government of Canada. Clearly, dementia is a disability.

It is interesting to note, that the Council of Canadians with Disabilities does not have representation from the dementia population. The very group that should be inclusive is exclusive to those with dementia. We hope this will change with continuing dialogue.

People in Canada living with dementia face many challenges including:

1. Accessibility. Transportation is a major issue as we are routinely denied it because we pass the necessary physical tests. Cognitive impairment is rarely considered.
2. Disproportionate use of antipsychotic drugs and restraints in LTC and nursing homes.
3. Segregation from the community through locked wards in LTC.
4. Lack of dementia-specific care pathways.
5. Lack of appropriate post-diagnostic support services. In particular – rehabilitation.
6. Stigma
7. Social isolation
8. Lack of early detection and intervention
9. Obstacles to participate in political life, cultural life, recreation, leisure and sport.

And the list goes on.

I'm sure this list must resonate with many of you. Not only can you surmise but you know that one of the strongest strategies to overcome this list is by using the CRPD. And this is exactly what we would like to do – with your help.

In a matter of a few minutes, I have touched on a number of CRPD Articles relevant to persons with dementia, including:

Article 1 – Purpose

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 16 – Freedom from Exploitation, Violence & Abuse

Article 19 – Living Independently in the Community

Article 26 – Rehabilitation

Article 29 & 30 – Participation in Political and Public life, Cultural life, Recreation, Leisure & Sport

The CRPD is important, as it helps to spell out practical steps to ensure persons with dementia enjoy the human rights on an equal basis with others. In particular, we recommend that Canada take action, first, regarding equality and non-discrimination, including providing reasonable accommodation and accessibility. This may include unlawful discrimination by health care, driving licence authorities, insurance companies and employers. In a nutshell, this means to make changes so that we can continue to participate and we have access to anything and anywhere, the same as anyone else has.

Second, introduce the Dementia-Friendly Communities, DFC, model. It has goals of reducing stigma, ensuring early diagnosis, having consistent and reliable travel options, practical support and community-based solutions, including helping us to live independently and safely in our own homes. There are many benefits of this model, including empowerment for people with dementia and the financial benefit to less time needed in costly residential or hospital care.

Third, reduce the disproportionate use of antipsychotic drugs, physical restraints and being detained in psychiatric institutions.

You may be aware of the excellent news that The Standing Committee on Health is examining Bill C-233, an Act respecting a national strategy for Alzheimer's disease and other dementias. It has gone through its second reading in parliament. We are truly excited for the possibilities of the implementation of a national dementia plan. The only problem is that the government of Canada does not see PWD as important enough to actually participate in providing witness. We are grateful for the many members of parliament who have stood up and declared its necessity and the 6 individuals on the Witness list. But, for PWD it is the "same old same old" as we have not been asked to participate and requests from ODAG 2 weeks ago has gone unanswered.

If our own government does not feel the need to include us in the actual discussion of a national dementia strategy plan, then our efforts to date has failed to convince them they must as it is our right. And this is why PWD living in Canada need access to the UN CRPD.

Thank you.