

Ensuring Bill C-81, An Act to ensure a barrier-free Canada, Is Inclusive of Canadians Living with Brain Conditions

SUBMISSION TO THE HOUSE OF COMMONS STANDING COMMITTEE ON HUMAN RESOURCES, SKILLS AND SOCIAL DEVELOPMENT AND THE STATUS OF PERSONS WITH DISABILITIES

BY NEUROLOGICAL HEALTH CHARITIES CANADA

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Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions). We are providing input to the Committee's review of Bill C-81, *An Act to ensure a barrier-free Canada*, on behalf of the millions of Canadians living with brain conditions.

Brain conditions are the largest cause of disability worldwideⁱ, and one in three Canadians will be affected by a brain or nervous system illness, disorder or injury, including mental health conditions, within their lifetimes. Disabilities that develop as the result of a brain condition can occur at any point along the life course. Some examples are:

- **At birth** – Cerebral palsy, characterized by the loss or impairment of motor function, results from brain damage caused by injury or abnormal development while a child's brain is still developing — before birth, during birth or immediately after birth. Cerebral palsy is the most common childhood disabilityⁱⁱ;
- **Childhood** – Rett's syndrome is a neurodevelopmental condition. It has a devastating impact: loss of spoken language, gross motor and fine motor skills and many other medical complications. There is currently no cureⁱⁱⁱ;
- **Adulthood** – Diseases such as Huntington's and multiple sclerosis (MS) occur most frequently in midlife (from 30 to 55). In addition, dystonia, MS and other conditions such as depression and other mental illnesses are often episodic in nature, resulting in periods of disability that can vary in severity and duration, and persist for the rest of the lifespan^{iv};
- **Older adults** – Neurodegenerative conditions like Parkinson's disease and various types of dementia most typically occur in adults over 60 with the incidence rising with increasing age^v;
- **Entire lifespan** – Traumatic brain injury (TBI) can occur across the entire lifespan from young children to older adults, and ranges from concussion to severe impairment. TBI occurs frequently in males between 15 and 25 years of age, often as the result of bicycle, motorcycle or motor vehicle collisions or sports-related injuries; and in older adults because of falls^{vi}.

We provide these examples to make the point that flexibility in the legislation is paramount to meet the objective of improving accessibility and making Canada barrier-free for individuals living with disabilities. How individuals live with and deal with their disability will vary greatly depending upon the kind of disability and where individuals are along their life courses.

Strengths of the current bill

NHCC is encouraged that Bill C-81 does recognize to some extent that disability is not the same for all, or is static in nature, and limitations arise because of barriers that prevent the full and equal participation of people who have a disability. This language is similar to that of the preamble to the UN Convention on the Rights of Persons with Disabilities, which recognizes that disability is an evolving concept, and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others^{vii}.

Of particular note is the specific inclusion within Bill C-81's definition of disability of a limitation *whether that limitation is permanent, temporary or episodic in nature*. NHCC applauds the inclusion of this language since episodic periods of improvement or worsening in some brain conditions (as well as other conditions such as arthritis) occur occasionally but have not always been recognized by Canada Revenue Agency, for example, when adjudicating eligibility for the Disability Tax Credit.

NHCC supports Bill C-81's principles (6. A-e) which provide excellent aspirational objectives for the Government of Canada. The creation of a new Accessibility Commissioner, a federal Canadian Accessibility Standards Development Organization charged with creating model accessibility stands and a Chief Accessibility Officer also appear to be useful innovations.

How Bill C-81 could be improved

NHCC is hopeful that the Committee's review of Bill C-81 will result in improvements to the bill in key areas. We are grateful to the AODA Alliance for its thorough analysis of the proposed legislation and support the seven recommendations it has provided to the Committee to amend the bill. The following amendments NHCC suggests are crucial to the success of making Canada barrier-free in the areas of federal jurisdiction.

Recommendations

1. Bill C-81 must contain realistic timelines for implementation. Currently, the bill includes language such as "progressive realization" of barrier removal. This is not satisfactory. The Committee could look at the example of the Province of Ontario's accessibility legislation which set out timelines for the various standards.

2. The complaints process appears to be needlessly complicated with currently too many avenues for complainants to take depending upon the nature of the complaint. Instead, a single intake point for complaints, perhaps overseen by the Accessibility Commissioner or a similar clearly-designated ombudsman function, would make the process more user friendly. For example, to report a violation of the Accessibility for Ontarians with Disabilities Act (AODA) to the Government of Ontario, complainants can use a toll-free number. While that system still needs improvement, the single intake point is one that this legislation should adopt.
3. Consider the creation of an independent Ombudsman for Disability Issues to monitor application of the legislation, enforcement and the complaints process.
4. Currently, the Accessibility Commissioner, the Canada Accessibility Standards Organization and the Chief Accessibility Officer report to the Government of Canada. Consideration should be given to having these entities report directly to Parliament to avoid the appearance of conflicts of interest, given the federal government has the obligation to abide by the legislation. Government should not police itself on effective implementation and achievement of objectives.
5. The legislation should recognize that there is a continuing need for better data about accessibility in Canada and provide ongoing funding for accessibility research. This is particularly important for brain conditions and the disabilities that arise since not enough is known about how they impact key demographics such Indigenous peoples, women and more vulnerable socio-economic groups. Ideally, this research should be undertaken through well recognized peer-reviewed processes.

Who We Are

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions). Brain health is essential to the overall health of Canadians and their productivity, and brain conditions impact every aspect of life. They affect mobility and dexterity, while impairing memory and the ability to think. These conditions can make it hard to see, speak and communicate; and tend to be painful and debilitating.

Member organizations are: Brain Injury Canada, Brain Tumour Foundation of Canada, Canadian Epilepsy Alliance, Canadian Neurological Sciences Federation, Dystonia Medical Research Foundation of Canada, Huntington Society of Canada, Hydrocephalus Canada, March of Dimes Canada, Mood Disorders Society of Canada, Ontario Federation for Cerebral Palsy, Ontario Neurotrauma Foundation, Ontario Rett Syndrome Association, Parkinson Canada. See more information at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

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- ⁱⁱ Accessed at <https://www.ofcp.ca/about-cerebral-palsy>
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- ^{iv} Accessed at <http://episodicdisabilities.ca/home.php>
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