

Bill No. 59: An Act Respecting Accessibility in Nova Scotia

*Submission by the Multiple Sclerosis Society of Canada, Atlantic Division
to the Government of Nova Scotia - Law Amendments Committee
February 13, 2017*

About the Multiple Sclerosis (MS) Society of Canada

The MS Society provides services to people with multiple sclerosis and their families, and funds research to find the cause and cure for this disease. We have a membership of 17,000 and are the only national voluntary organization in Canada that supports both MS research and services. Since our founding in 1948, the core support of the MS Society has been from tens of thousands of dedicated individuals, companies and foundations in communities across Canada.

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance, and mobility. It is the most common neurological disease affecting young adults in Canada. Most people with MS are diagnosed between the ages of 15 and 40. The unpredictable effects of MS are physical, emotional, and financial and last for the rest of their lives. MS impacts all Canadians - not only the affected individuals, but also their families who come together to manage the realities of MS. Canada has the highest rate of MS in the world, and consequently, it is often referred to as "Canada's Disease."

Introduction

The Multiple Sclerosis (MS) Society of Canada is pleased to provide this submission to the Government of Nova Scotia's Law Amendments Committee on behalf of Nova Scotians living with and affected by multiple sclerosis. We thank the committee for allowing us to be consulted and to the government for showing leadership and engaging with Nova Scotians regarding accessibility legislation. We believe this proposed bill is a positive step forward to improving awareness and attitudes about accessibility and disability in Nova Scotia, and to ensuring that detailed legislation will be well researched, thought-out, deliberate in its capabilities, and enforced.

There are considerations in discussing accessibility and determining what the proposed legislation should include. The MS community is particularly qualified to advise in this regard, as many of the issues surrounding the broader themes of accessibility and disability are everyday experiences for people living with MS and their families. First, as noted above, the unpredictability and episodic yet progressive nature of MS makes it particularly challenging not only in accessing the built environment, but also in accessing care and supports and more specifically access to quality medical care and treatments; reliable public transportation; education and counselling; workplace accommodations; and general everyday things that many of us take for granted.



Proposals for Inclusion in Legislation

We see this Bill as a good beginning and hope that detailed and distinct regulations will be developed and that the regulations and standards will be readily adopted and, most importantly, enforced. Below are some of the issues that are important to people living with MS in relation to this proposed Bill.

1. Inclusive, Broad Definitions of "Disability" and Barrier"

The proposed bill has established inclusive definitions of "disability" and "barrier." We want to ensure the Committee understands that any regulations born out of this bill should include and protect all Nova Scotians with disabilities whether they are visible or invisible, and whether they are permanent or episodic (periods of wellness followed by periods of disability). This definition needs to include the notion of the changing dynamic of disability which is the case for individuals living with progressive neurological diseases like MS.

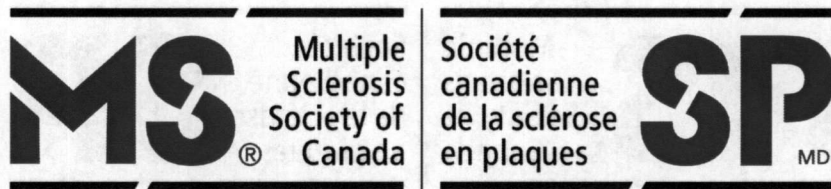
"Accessibility" means "barrier-free." An accessible workplace or goods or services are ones in which people with disabilities can fully participate to the extent of their individual abilities. "Barrier" should mean anything that prevents a person with a disability from fully participating in all aspects of society because of a disability.

New regulations should address all kinds of accessibility barriers, such as physical barriers in the built environment inside and outside buildings, communication barriers, technology barriers, information barriers, transportation barriers, attitude barriers, legal barriers, and policy or bureaucratic barriers in health, income, employment and disability programs.

2. Built Environment

MS is a complicated disease that has a major impact on quality of life of all those affected by it. The day-to-day uncertainty that many people with MS experience often causes a significant loss to quality of life. To maintain independence, people affected by MS must be able to participate fully in their communities and have access to public buildings, housing and transportation. Accessibility issues are a significant factor in maintaining and ensuring a positive quality of life for people affected by MS.

The MS Society hosted a quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. We heard that accessible buildings, particularly for programs and services such as restaurants, fitness programs, and recreation centres, is an area that presents gaps for people affected by MS. This issue was discussed by the focus group participants who indicated that many of these programs/services are not available to them because the buildings are not fully accessible.



Additionally, building codes only apply to new buildings and larger renovations, leaving many existing structures inaccessible. Considerations such as the use of interlocking brick, uneven walkways, and poorly designed stores create daily challenges for those with restricted mobility.¹

“Our environmental scan as part of the Listening to People Affected by MS initiative found that many buildings and spaces are not accessible to people with disabilities. Building codes govern this accessibility through minimum standards that are not highly specific so many issues ‘fall through the cracks’ such as the height of sinks, towel and soap dispensers, and the location of wheelchair accessible doors and ramps which may not be convenient.”

These issues have a significant impact on a person's daily life, their ability to get around and stay active in their community; ultimately, having a negative impact on their quality of life. As one participant stated *“These architects do not really know what accessible means. It is about more than the size of the stall in the bathroom.”*¹

3. Access to Quality Medical Care

As stated above, the unpredictability of MS means that people living with the disease can face physical, emotional, and financial challenges for most of their lives. MS impacts all Canadians - not only the affected individuals, but also their families who come together to manage the realities of MS. These realities make it particularly challenging in accessing services and supports throughout one's life. We know that a person's quality of life is affected by access to doctors, specialists, tests, treatment and that services in a timely and convenient manner is difficult for many.

People with MS who can't work have trouble getting by on the limited financial assistance offered under current government programs. Many people with MS cannot qualify for disability-related public or private insurance programs because eligibility is obtained through employment or is a workplace benefit, and many people impacted by MS in the prime of their lives are no longer able to maintain employment.

Finding information about programs and services is also consistently problematic. We also heard that people with MS want to live at home and not be a burden on family and friends. They want to be active participants in their communities. However, we heard that accessing services to maintain this independence can be difficult. There were many barriers. Home care services and assistance with personal care vary significantly by region, have long wait times, and often limited access. There are few age-appropriate long-term care facilities for people with MS and life is very difficult for those living in facilities that do not provide the mental, recreational and social stimulation required to maintain good physical, mental, emotional and social health.¹



Quality healthcare in the community for people with complex disabling chronic disease such as progressive MS is woefully inadequate. The current system offers community-based care to those who are terminally ill in the form of palliative care, but leaves people with diseases like MS struggling to get support.

We need to look at including solutions in accessibility legislation so that people with MS and people with disabilities can have equitable access to a continuum of appropriate, high-quality housing, care and treatment options. This includes:

- **Increasing investments in comprehensive home care for people with long-term chronic health conditions such as MS;**
- **Creating a range of age-appropriate housing and care options for people who cannot remain at home;**
- **Funding rehabilitation services in the community (e.g. physiotherapy, occupational therapy, vocational rehabilitation) for people living with MS;**
- **Ensuring people with MS have timely access to affordable treatments.**

4. Transportation

Based on our survey results, we heard that finding transportation services to allow people to function independently and participate in their communities is also a challenge for some Nova Scotians. There are many gaps in daily transportation services. Although the nationally-regulated systems such as air and train travel are usually manageable, daily travel on municipally-run transit systems can be very challenging throughout the province. In many cases, these systems are fraught with issues such as inaccessibility for those with mobility restrictions, inconvenient booking requirements (i.e. having to book days or weeks in advance), limited service availability, constant delays in service provision, and limited hours of operation. For those in rural areas, accessible transportation is non-existent.

This lack of day-to-day transportation has a significant impact on people's abilities to attend medical appointments, maintain employment, volunteer and participate socially in their communities, thus, directly affecting their quality of life.¹

Conclusion

This Bill should require the provincial government to create all the mandatory, enforceable accessibility standards needed to lead Nova Scotia to full accessibility. It should create a prompt, effective, open process for developing and reviewing accessibility standards. Government departments and organizations and private companies must be told in clear, specific terms what to do, and when, to tear down barriers and to avoid creating new ones.



Accessibility plans should be developed in consultation with the wider disability community. Examples of what these plans should include are: regular reporting on the measures taken to identify, prevent and remove barriers that disable people; measures that will be taken in the period covered by the plan to identify, prevent and remove barriers; and measures that are in place to assess the effect on accessibility for persons disabled by barriers when new policies, activities or initiatives are undertaken.

To be successful, there must be resources to accompany the Bill. It must set out timelines for regulations, guidelines for implementation and strict enforcement protocols, as well as required periodic independent reviews of progress. There should not be delays in implementation and enforcement while educating the public on accessibility. There should be interim processes and measures developed and implemented while the regulations are being developed to promote accessibility.

Improving accessibility is needed to create an equitable and fair playing field for all Nova Scotians living with disabilities. We look forward to seeing the creation of comprehensive and detailed regulations that will improve the quality of life for those living with any form of disability. This legislation along with effective implementation and enforcement will improve awareness and attitudes about accessibility and disability in Nova Scotia, and be inclusive of all people with disabilities including episodic which is key for people affected by MS.

1 MS Society of Canada. Listening to People Affected by MS. 2013. (accessed 1 October 2016) available from <http://mslistening.ca/>

Respectfully submitted,

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