

## **Accessibility Legislation: What does an Accessible Canada mean to you?** *Submission by the Multiple Sclerosis Society of Canada to the Government of Canada*

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### **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 Society (MS) of Canada is pleased to provide this submission to the federal accessibility legislation consultation. We applaud the federal government for showing leadership and engaging with Canadians about accessibility legislation. This leadership, coupled with the multiple vehicles for consultation, is a positive step forward to improving awareness and attitudes about accessibility and disability in Canada, and to ensuring that the final legislation be broad-based and comprehensive.

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:

- timely and flexible access to employment and income supports;
- quality medical care and treatments;
- reliable public transportation;
- education and counselling;
- support for family members and caregivers;
- workplace accommodations; and
- advancements in MS research leading to better symptom management and quality of life – avenues to ultimately reduce reliance on disability support systems.

## Proposals for Inclusion in Legislation

### **1. Inclusive, Broad Definitions of “Disability” and Barrier”**

The legislation should establish clear, broad, inclusive definitions of “disability” and “barrier.” The legislation should include and protect all Canadians 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.

**The legislation 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.**

Below we explore the barriers listed in the introduction as well as some suggested solutions that are relevant to Canadians affected by MS.

### **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 of 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 another area that presents gaps for Canadians 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.<sup>1</sup>

**“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.”**

Additionally, these 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.<sup>1</sup>

All of 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.”*<sup>1</sup>

### **3. Access to Timely and Flexible Income and Employment Supports**

The recently published report, *MS in the Workplace* by the Conference Board of Canada, states: *“The unpredictability and episodic nature of MS make it particularly challenging in the workplace. As symptom types and severity vary greatly, individuals with MS can find it difficult to manage their treatments, let alone maintain a daily routine and meet work commitments within the traditional employment space.”*<sup>2</sup> This aligns with the MS Society’s findings from the Listening to People Affected by MS Initiative, where we heard from thousands of Canadians affected by MS about factors that impact their quality of life which included employment

A review of literature published between 2002- 2011 estimated that the average unemployment rate for individuals with MS is almost 60 per cent.<sup>2</sup> Data from the US indicate that people with MS experience some of the highest unemployment rates among groups of individuals with severe and chronic disabilities and have disproportionately high unemployment rates given their educational and vocational histories.<sup>3</sup> Yet people with MS want to work and struggle to continue to work.

The Institute for Research on Public Policy (IRPP) report *“Leaving Some Behind: What Happens When Workers Get Sick,”* cited as the Mowat Centre’s top public policy paper in 2015, asks how Canada is doing in supporting Canadians who experience a major health issue with their employment and income needs. It points to the “need for a comprehensive re-examination of how Canadians are able to balance work and income during periods of receiving or giving care.” The report notes that each year, six per cent of the Canadian workforce adjust its work status for some length of time in order to deal with a health condition.<sup>4</sup>

In general, people with disabilities face barriers in the employment context. Research conducted by the Conference Board of Canada identifies Canadians with disabilities as an under-represented group in the Canadian labour force.<sup>5</sup> There are, however, substantial numbers of Canadians with disabilities that are willing and able to work. If not full-time, then at least on an intermittent basis. Certain conditions, including but not limited to, Multiple Sclerosis, arthritis, HIV, and some mental health conditions, have symptoms that are considered “episodic” – periods of good health interrupted (often unpredictably) by periods of illness or disability that affect one’s ability to work.<sup>6</sup>

The occurrence of episodic conditions among Canadians is significant. The recent IRPP report notes the estimate that 1.2 million working-age Canadians in 2012 reported one or more of the twenty conditions considered episodic. This represents slightly more than half of the 2.3 million working-age Canadians living with a disability.<sup>4</sup> Often policies and programs targeted at income or employment support focus narrowly on “disability,” assuming a health condition that is either continuous or progresses linearly through time.<sup>7</sup>

A study conducted on behalf of HRDC recommended that *“federal and provincial governments should continue to make eligibility rules for income support programs less restrictive and more flexible to reflect the fact that many people experience disability and work capacity as variable, episodic, and intermittent.”*<sup>7</sup>

People with MS who can’t work have trouble getting by on the limited financial assistance offered under current government programs. Many Canadians 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.

In a recent paper, *“The Disability Tax Credit: Why It Fails and How to Fix It,”* researchers Wayne Simpson and Harvey Stevens calculated that 301,458 of the 499,302 adult Canadians who qualify for the credit cannot receive any benefit from it because they don’t have enough income. To turn this around the authors suggest *“turning this non-refundable credit into a refundable credit, would increase the average benefit for Canada’s poorest families with a disabled person from \$29 to \$511, increasing their total income by a meaningful 4.1 per cent. Just as importantly, where a meagre 0.2 per cent of these families now get any benefit at all from the credit, a refundable credit would now see a majority, 56.4 per cent, receiving benefits.”*<sup>8</sup>

**There are solutions to remove barriers and improve accessibility for employment and income support programs which need to be a part of the legislation to ensure changes ensue. In terms of employment supports these include changes to:**

- **improve the coordination of basic definitions and program parameters across the disability support system and enhance the breadth and quality of disability insurance coverage within the labour market.**
- **extend the duration of EI benefits (from 15 weeks to 26 weeks to match compassionate care benefits), reducing/eliminating the clawback, and creating a flexible work-sharing program so that a person can reduce work hours while receiving EI income.**
- **create a system for the expert dissemination of information and hands-on support to employers on roles, best practices and resources when an employee or family member is diagnosed with a chronic or episodic illness, and requires time away from work.**

**And for income supports:**

- **Make disability tax credits fully refundable to put much needed income directly in the hands of low-income people with MS and other disabilities;**
- **Change eligibility criteria (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to ensure people with episodic conditions have access to public insurance and tax credit systems for those unable to work or who can only work on an intermittent basis;**
- **Harmonize the EI sickness benefits duration of 15 weeks to match the 26 weeks duration of compassionate care benefits.**

#### 4. **Quality Medical Care and Treatment & Transportation**

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. These realities make particularly challenging in accessing services and supports throughout one's life. We heard during the Listening to People Affected by MS Initiative/Survey as we described above regarding quality of life that accessing doctors, specialists, tests, treatment and services in a timely and convenient manner is difficult for many.

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.<sup>1</sup>

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 ensure that Canadians living with MS have access to all currently approved disease-modifying therapies (DMTs) approved for multiple sclerosis (MS) as they appear to work by blunting the destructive autoimmune response that targets tissues in the central nervous system (CNS). For many individuals living with MS, DMTs offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. Access to these medications is key to maintaining quality of life including employment and income.

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

**We need to look at including solutions in the 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. This includes:**

- **Increasing investments in comprehensive home care for people with long-term chronic health conditions such as MS. Through negotiations of the Health Accord, ensure provinces and territories are accountable to deliver measurable improvements for those who need home care because of a long-term chronic disease and not only to those whose access to homecare is for short period of time as is the case for those requiring post-acute or palliative care at home.**
- **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. This includes access to immunoablation and autologous hematopoietic stem cell transplantation (IAHSCT) at the Ottawa Hospital for those who meet the eligibility criteria. Additionally, medical facilities across the country need to utilize these findings in order to work together to offer this treatment locally – to provide the benefit of this procedure to as many people as possible.**

Canadians. There are many gaps in daily transportation services in cities and regions across the country. 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 in and between many cities across the country. In many cities across Canada 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.<sup>1</sup>

### **5. Caregiver Support**

Multiple sclerosis affects the entire family. Many find it very difficult to keep full-time jobs while they carry out their vital duties as caregivers – and government support is not adequate or flexible enough to cover their basic living costs.

The Family Caregiver Tax Credit is providing necessary recognition and support of caregivers. However, because the credit is non-refundable, it does not provide adequate support to low income families. Supporting caregivers in Canada is vital to strengthening the social infrastructure of communities across our country to meet the needs of their residents.

### **6. Accelerating Research**

Canadians need increased investment in research to speed up research to develop effective disease-modifying therapies for progressive MS, to reduce attrition, reduce sick-leave costs, and reduce workplace volatility through better treatments. People diagnosed with progressive MS currently face an extremely difficult and precarious future. Approximately 85% of people with MS are diagnosed with a relapsing-remitting course, but half of them will go on to develop secondary progressive MS. Around 15% of people with MS are diagnosed with primary progressive MS, meaning their disease declines steadily from onset – a slow, devastating accumulation of neurological damage and disability.

Better treatments for progressive MS would mean increased mobility, less pain and fatigue, improved productivity (i.e. fewer lost work days), lower health care costs, and full and active participation in many spheres of social and economic life by people affected by MS. It’s time to focus additional scientific and financial resources on progressive MS so that we can accelerate the search for and hence access to disease-modifying treatments and cures.

**Accessibility legislation needs to include recognition of the vital role of caregivers in creating accessibility in our Canadian society. This can include changes such as:**

- **Making caregiver tax credits (family caregiver and caregiver tax credits) fully refundable to help provide essential income for people sacrificing time and income to care for people with MS and other disabilities;**
- **Increase the caregiver tax credit amounts (family caregiver and caregiver tax credits) to help alleviate the immense financial burden faced by Canada’s caregivers;**
- **Expand the “gravely ill” criteria in the Compassionate Care Benefits to include caregivers of people with progressive diseases such as MS.**

## **Additional Recommendations – Underlying Principles and Measurement**

The federal accessibility legislation's purpose should be to ensure that the federal government will lead Canada to become fully accessible to people with disabilities by a deadline the legislation sets, as far as the federal government can.

It should ensure that all federally-reachable organizations, including all organizations that receive federal funds, have accessible environments, buildings, goods, services and jobs for example. The procurement process of the federal government should include a disability lens in all of its interactions.

It should also ensure the accessibility of all courts within federal authority, and federal elections that are fully accessible to voters and candidates with disabilities.

The legislation should create a new independent federal office, the Canada Accessibility Commissioner. The Commissioner should lead the legislation's implementation and enforcement. The Commissioner should be Canada's national accessibility champion and independent watchdog.

The legislation should also require the federal government to create all the mandatory, enforceable accessibility standards needed to lead Canada to full accessibility. It should create a prompt, effective, open process for developing and reviewing accessibility standards. Government 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. Any federal accessibility standards should at least rise to the level of accessibility that the Charter of Rights and the Canada Human Rights Act set. Accessibility plans for each government department as well as other organizations within the federal jurisdictions 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.

In order to be successful there must be resources to accompany the legislation. It must be a timely legislation with set timelines for implementation and enforcement 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 process and measures developed and implemented while the legislation is being developed to promote accessibility.

Core to this accessibility legislation is the relationship with the provinces and territories. The legislation should mandate the federal government to assist and encourage provincial and territorial governments to enact comprehensive accessibility legislation. It should mandate the federal government to create national model accessibility standards which provinces, territories and other organizations can adopt.

## Conclusion

Improving accessibility is needed to create an equitable and fair playing field for Canadians living with disabilities. We look forward to seeing the creation of this comprehensive and broad-based legislation which includes the proposals contained within this submission. This legislation along with effective implementation and enforcement will improve awareness and attitudes about accessibility and disability in Canada, and be inclusive of all people with disabilities including episodic which is key for people affected by MS.

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

<sup>2</sup> Thy, Dinh, Philip Astles, and Karen Turpin. *Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences*. Ottawa: The Conference Board of Canada, 2016.

<sup>3</sup> Sweetland, J., Howse, E., & Playford E., *Disability & Rehabilitation*, 2012; 34(24): 2031-2038.

<sup>4</sup> Meredith, T., and Chia, C. *Leaving Some Behind: What Happens When Workers Get Sick*. Institute for Research on Public Policy, 2015.

<sup>5</sup> Brisbois, Richard. *Business Benefits of Accessible Workplaces*. Ottawa: The Conference Board of Canada, 2014.

<sup>6</sup> Smith Fowler, H., *Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?* (accessed 1 October 2016) available from [http://www.srdc.org/uploads/IntermittentWork\\_report\\_EN.pdf](http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf)

<sup>7</sup> Furrie, A. (2010). *Towards a better understanding of the dynamics of disability and its impact on employment*. Ottawa: Adele Furrie Consulting Inc.

<sup>8</sup> Simpson, W., and Stevens, H. *The Disability Tax Credit: Why It Fails and How to Fix It*. University of Calgary, School of Public Policy, 2015.