

## Canadian Poverty Reduction Strategy Consultation Submission by the Multiple Sclerosis (MS) Society of Canada May 2017

---

### About the 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.

### Introduction

The MS Society of Canada is pleased to provide this submission to the consultation underway regarding the Canadian Poverty Reduction Strategy. We applaud the federal government for showing leadership and engaging with Canadians about poverty reduction. This leadership, coupled with the consultation, is a positive step forward to improving the lives of Canadians struggling to make ends meet.

MS impacts all Canadians - not only the affected individuals, but also their families. The MS Society heard directly from 6000 Canadians affected by MS through our *Listening to People Affected by MS Quality of Life Initiative* in 2013. The data-based conclusions:

- If you live in Canada with MS, you may face the reality that you will no longer be able to work because of the unpredictability of your disease, and the barriers that exist in our support systems.
- Your quality of life will be lower due to a lack of access to financial support and not easily accessible employment and income programs.
- Your family may also be your caregivers.
- And if you live with progressive MS, there are currently no disease-modifying treatments.<sup>1</sup>

The unpredictability and episodic yet progressive nature of MS makes it particularly challenging in maintaining an adequate quality of life. This along with the challenges of living with a disability which has both visible and invisible symptoms and the barriers in our support programs across all levels of governments creates immense financial challenges for Canadian families who struggle to manage the realities of living with MS.

### MS is Canada's Disease

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. MS is three times as likely to occur in women as in men. The unpredictable effects of MS are physical, emotional, and financial and last for the rest of their lives.

***Canada has the highest rate of MS in the world, and consequently, it is often referred to as "Canada's Disease."***

There are considerations in discussing poverty and in particular relating to living with a disability that is both episodic and progressive. The MS community is particularly qualified to advise in this regard, as many of the issues encompassing poverty are everyday experiences for people living with MS and their families. While we understand that poverty is influenced by many factors and this is true for people affected by MS we provide commentary below on issues relating to employment, income and support programs.

### **Making Work...Work! (MS and Employment)**

Employment is a key factor in maintaining adequate income and reducing poverty. However, 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 indicates 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 Conference Board of Canada earlier this year published a report, *MS in the Workplace* and found that: *“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>4</sup>

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>5</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>6</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>7</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>8</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>9</sup>

## Make Work...Work! Recommendations for Change

- 1. 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.**
- 2. Extend the duration of EI benefits (from 15 weeks to 26 weeks to match compassionate care benefits), reduce/eliminate the clawback, and create a flexible work-sharing program so that a person can reduce work hours while receiving EI income.**
- 3. 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.**

### Make Ends Meet! (MS and Income/Support Programs)

Lack of secure, adequate income intensifies the hardship caused by MS and keeps people affected by the disease from participating fully in their communities.

This situation is amplified if you are a woman with a disability. In the MS population, there are more women with MS as MS is three times as likely to occur in women as in men. When looking at the distribution of gender of working age Canadians with severe or very severe disabilities “women outnumber men both in absolute number and incidence (i.e., the percentage of the population with disabilities) among those with severe/very severe disabilities and those with mild/moderate disabilities.” They also have on average lower incomes and earnings thus making them most susceptible to poverty.<sup>10</sup>

Accessing financial support and managing the high costs of MS is a challenge. This is consistent with research that shows MS seriously affects the economic life of those diagnosed, even within a few years of onset.<sup>11</sup> We heard of challenges of paying for medication, services, equipment, treatment and transportation. Many indicate that they need more money and have difficulty navigating the system to find financial support, be it for medications, income replacement, or claiming tax deductions related to disability.

### Meet Alex

Alex was diagnosed with primary-progressive MS in 2011. He was forced to leave his career because of his disease and now relies on income support to provide for himself, his wife, and three children. Alex and his family went months without any income while trying to access disability benefits.

*“You have to jump through hoops to access employment insurance, social assistance and disability supports. It takes many hours and lots of visits to doctors, health professionals and government offices just to apply for the financial help you need. The process takes many months, and while you are doing this you have to go without a diagnosis, income, medications and at times, even food on the table.”*

Qualifying for these programs is challenging for people with MS due to the episodic nature of the disease. Complicated application processes, requirements for numerous verified medical forms, and strict eligibility criteria pose significant problems. Additionally, 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.

### Meet Geeta

Geeta, a woman living with MS, is likely to have MS for the rest of her life but her symptoms may only be severe for 6 months in a year or they may become severe and stay that way for several years. Geeta must regularly rely on a network of supports and services to maintain her health and avoid exacerbating her illness. These supports include things such as help cleaning her home, assistance with child care, and taxis to and from appointments and work. When her MS flares up Geeta may be completely unable to leave her home and must rely on additional supports to help get herself dressed, prepare food and use the bathroom. Even when relatively asymptomatic Geeta still retains a permanent restriction in her activities of daily living due to the unpredictable and episodic nature of MS. She also incurs additional expenses related to her disability and should therefore be entitled to the disability tax credit.

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>12</sup>

The added costs associated with having a disability are an important factor contributing to poverty for people with disabilities. While the Disability Tax Credit (DTC) is designed to provide equity to compensate at least roughly for the added non-itemizable and non-reimbursable costs of disability as noted above qualifying for the credit is challenging for people with a progressive and episodic disability. See Geeta’s story in the side-bar.

And for those that qualify for the DTC in order to benefit from it an individual must have an adequate amount of income. Many Canadians with episodic disabilities, and in particular, women with disabilities, cannot work enough to generate the minimum income required to be able to enjoy any benefit associated with the DTC. A refundable tax credit that even those with the lowest incomes may access would offer a solution to this problem.

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

*“The poorest families with incomes below the LICO receive a refundable tax credit worth an average of \$511 compared to \$29 for the same families under the current non-refundable DTC. This represents an increase of 4.1 per cent of total income of tax filers living in low-income families. Much of this improvement in benefits is an improvement in coverage, since 56.4 per cent of families below the LICO would receive the refundable credit compared to only 0.2 per cent of families under the current non-refundable scheme. In other words, the refundable credit brings benefits for a majority of the poorest families who had insufficient taxes owing to benefit from the current credit.”*<sup>13</sup>

People with MS who can't work have trouble getting by on the limited financial assistance offered under current government programs. As one respondent from our Listening Initiative explained:

*"You can't live off of the CPP-D amount. And you can't really work because they take the little they are giving you away if they find out you are earning money somewhere else. So you get stuck in a bad cycle that you can't get out of." (Respondent, Listening Initiative, 2013)*

## Make Ends Meet! Recommendations for Change

### **Long Term:**

5. ***We recommend as published in report by the Caledon Institute of Social Policy, that the federal government, in close cooperation with other governments, give serious consideration to a basic income program that would replace provincial/territorial social assistance for most working-age persons with severe disabilities. The Basic Income program would be a close model of the Old Age Security (OAS) and Guaranteed Income Supplement (GIS) programs for seniors.***

### **Short Term:**

6. ***Make disability tax credits fully refundable and increase them to put much needed income directly in the hands of low-income people with MS and other disabilities;***
7. ***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;***
8. ***Harmonize the EI sickness benefits duration of 15 weeks to match the 26 weeks duration of compassionate care benefits.***

## Conclusion

Reducing poverty for Canadians is necessary. We look forward to seeing the Canadian Poverty Reduction Strategy include the recommendations contained within this submission to ensure that all Canadians including those with episodic and progressive disabilities have adequate income to participate fully and equally in our Canadian society.

### **For Further Information, Contact:**

#### **Benjamin Davis**

National Vice-President, Government Relations

MS Society of Canada

[Benjamin.davis@mssociety.ca](mailto:Benjamin.davis@mssociety.ca)

1-109 Ilsley Ave, Dartmouth, NS B3B 1S8

P: 902.468.8230 ext. 1003 Toll Free: 1.800.268.7582

---

<sup>1</sup> MS Society of Canada. *Listening to People Affected by MS*. 2013. (accessed 8 December 2016) available from <http://mslistening.ca/>

<sup>2</sup> Schiavolin, S., and others. "Factors Related to Difficulties With Employment in Patients With Multiple Sclerosis: A Review of 2002–2011 Literature." *International Journal of Rehabilitation Research* 36, no. 2 (2013):105–111.

<sup>3</sup> Sweetland, J., Howse, E., & Playford E. A systematic review of research undertaken in vocational rehabilitation for people with multiple sclerosis. *Disability & Rehabilitation*, 2012; 34(24): 2031-2038.

<sup>4</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>5</sup> Meredith, T., and Chia, C. *Leaving Some Behind: What Happens When Workers Get Sick*. Institute for Research on Public Policy, 2015.

<sup>6</sup> Brisbois, Richard. *Business Benefits of Accessible Workplaces*. Ottawa: The Conference Board of Canada, 2014.

<sup>7</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>8</sup> Meredith, T., and Chia, C. *Leaving Some Behind: What Happens When Workers Get Sick*. Institute for Research on Public Policy, 2015.

<sup>9</sup> Furrie, A. (2010). *Towards a better understanding of the dynamics of disability and its impact on employment*. Ottawa: Adele Furrie Consulting Inc.

<sup>10</sup> Mendelson, M., Battle, K., Torjman, S., and Lightman, E. *A Basic Income Plan for Canadians with Severe Disabilities*. Ottawa: Caledon Institute of Social Policy, 2010.

<sup>11</sup> Pflieger, C., Flachs, E.M. and KochHenrikson, N. *social consequences of multiple sclerosis: early pension and temporary unemployed – a historical prospective cohort study*. *Multiple Sclerosis* 2010; 16:121. Originally published online 9 December 2009.

<sup>12</sup> Furrie, A. (2010). *Towards a better understanding of the dynamics of disability and its impact on employment*. Ottawa: Adele Furrie Consulting Inc.

<sup>13</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.