



## Brief to the House of Commons Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA)

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### Introduction

The MS Society of Canada provides services to people with MS and their families, and funds research to find the cause and cure for this disease. We are pleased to provide this brief to the HUMA committee and applaud the federal government and this committee for showing leadership and engaging with Canadians about poverty reduction. This 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.

There are considerations in discussing poverty particularly 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.

### MS is Canada's Disease

MS is a chronic, often disabling, disease of the central nervous system. 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.

***Canada has the highest rate of MS in the world!***

## Making Work...Work!

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,”*, 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.”*<sup>5</sup>

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. The occurrence of episodic conditions among Canadians is significant. The recent IRPP report states 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>7</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>8</sup>

## Recommendations for Change

- ***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.***

## Making Ends Meet

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 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>9</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>10</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.

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.

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 who incur costs associated with their disability yet aren’t eligible because of the restrictive criteria and lack of understanding.

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

### Meet Alex

Alex, diagnosed with primary-progressive MS 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.”*

with the DTC. 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. Making it refundable would see “*a majority, 56.4 % receiving benefits.*”<sup>11</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)*

### Recommendations for Change

- ***We recommend as proposed 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.***
- ***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;***
- ***Change eligibility criteria (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to ensure people with episodic conditions have access 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.***

### Conclusion

Reducing poverty for Canadians is necessary. We look forward to seeing the national poverty reduction strategies 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.

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<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> Meredith and Chia, *Leaving Some Behind*

<sup>8</sup> Furrie, A. (2010). *Towards a better understanding of the dynamics of disability and its impact on employment*. Ottawa: Adele Furrie Consulting Inc.

<sup>9</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>10</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>11</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.