



F-P/T Consultations on Federal Labour Transfer Agreements Submission by the Multiple Sclerosis Society of Canada

Introduction

The Multiple Sclerosis Society (MS) of Canada is pleased to provide this submission to the F-P/T Consultations on Federal Labour Transfer Agreements. Our perspective is founded in the voices of Canadians affected by MS as Canada has the highest rate of multiple sclerosis in the world.

About MS and the MS Society of Canada

Canada is a world leader in hockey, maple syrup, and unfortunately, MS. MS is truly Canada's disease. As Canadians, our risk of developing MS is two times greater than if we lived in France, 13 times greater than if we lived in Argentina and 27 times greater than if we lived in Pakistan.

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.

The MS Society hosted a quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. We heard that 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 may be lower than that of your friends and other Canadians 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.¹ This feedback was echoed in 2015 during our advocacy campaign during the federal election.

The Consultation

One of the purposes of the labour market transfer agreement is "*Promoting access to employment and skills training programs and services to support the successful participation of underrepresented groups in the labour market, including persons with disabilities, youth, immigrants and Indigenous Canadians, while promoting broader economic and social inclusion;*" People living with multiple sclerosis (MS), a chronic, often disabling disease of the central nervous system, and their caregivers, are part of this underrepresented group in the labour market. There is an on-going struggle to remain employed while having a disease whose effects are physical, emotional, financial, and unpredictable and lasts for the rest of their lives. It is particularly salient in Canada as we have the highest rate of MS in the world, and it is one of the most common neurological disease affecting young adults in Canada, with most people diagnosed between the ages of 15-40 -- their prime family and career building years.

Overall, the labour market transfer agreements need to be more inclusive to support people living with episodic conditions such as MS remain in the workforce. Job retention needs to be a key pillar in these agreements so as to better support the employee who lives with an episodic condition like MS as well as their employer to achieve the outcome of increased workforce participation.

Background

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.*”² 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.¹

A recent review of literature published between 2002- 2011 estimated that the average unemployment rate for individuals with MS is almost 60 per cent.³ Numbers 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. Yet people with MS want to work and struggle to continue to work.⁴

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.⁵

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.⁶ 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.⁷

The occurrence of episodic conditions among Canadians is significant. The recent *Institute for Research on Public Policy (IRPP) report*, notes the estimate that 1.2 million working-age Canadians in 2012 reported one or more of the twenty conditions considered episodic.⁴ This represents slightly more than half of the 2.3 million working-age Canadians living with a disability.⁸ 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.⁹

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.*”⁶

Discussion Guide Commentary

Key Discussion Themes - Impact

Supporting the potential of underrepresented groups such as persons with disabilities and in particular Canadians living with episodic disabilities needs to be a shared priority with governments to enable their full social inclusion in Canadian society.

Job retention is a key concept and needs to be a focused priority of the federal labour transfer agreements moving forward. As discussed above in the background, there are millions of Canadians with health conditions and episodic conditions who need employment supports to enable their workforce participation. In particular people living with MS have some of the highest unemployment rates given their vocational and education backgrounds. The types of support they need to remain working are unique to them given their work and educational histories. A program that focuses on workplace and job accommodations and awareness building amongst employers and their staff are important.

Flexibility is a key feature of any employment supports program as well as any training and specifically with respect to the concept of job retention. Training can also include awareness building amongst employees, employers, and the general public of the job accommodations including flexible work arrangements that can support people to maintain their employment.

Key Discussion Themes – Innovate

Innovative ways to support Canadians living with disability including those living with episodic disabilities is imperative. As noted in the discussion guide, establishing centres of excellence to support this to help them get the best support, encourage research, and share best practices is a great step forward. Sherri Torjman of the Caledon Institute recently remarked in the article *“Innovation: Counting What Counts”* how innovation can be undertaken as a way to tackle societal challenges such as accessibility and inclusion, not just bring in innovative new products.¹⁰ Looking at innovation in this perspective challenges us to address the issues such as underrepresentation of people with disabilities and in particular people with episodic disabilities in the workforce. The federal labour market transfer agreements can underscore the importance of innovation as a lever to support the inclusion of people with disabilities in the workforce. Questions such as how can innovation be used to support job retention and flexible work arrangements as tools to support workforce attachment need to be addressed.

Key Discussion Themes – Inform

As mentioned in the discussion guide there is immense value in engaging relevant stakeholders to inform decision-making, identify priorities and designing and evaluating programs. One of the inherent difficulties is determining who are relevant stakeholders. To ensure broad engagement this process needs to be communicated widely in multiple realms to inform and engage these stakeholders. Also of value is involving stakeholders from the outset and all the way through the process as described above. There is a need for engagement with those Canadians these agreements impact. For example, for the Labour Market Agreements for Persons with Disabilities, involving people with all types of disabilities in the discussions of how they work and how they can improve the workplace attachment for example is critical.

In terms of the types of information, there is a need for statistics around the number of people with disabilities in the labour force as well as their type of disability. Also important are the reasons why people with disabilities are unemployed and if there were ways for them to remain in the workforce.

For employers general awareness and information on the types of accommodations that can be made to support job retention is needed. The IRPP report highlights the role employers can play but notes that effective awareness is needed: *“In addition to supports provided by a private insurance carrier or a public benefit program, employers also have an important role to play in helping accommodate workers. Often these accommodations, which can include such things as flexible work hours or assistive devices, are relatively inexpensive to implement. What is required is effective awareness of potential needs, understanding of the types of job accommodations that might be beneficial, and a commitment to practice.”*⁵

The study further notes that *“Providing active employment supports for both employers and workers earlier on in the course of an illness may help improve the well-being of workers as they recover from an illness, enhance earnings capacity, raise long-term employment retention, and, as a result, potentially reduce the need for future claims.”*⁵

For both employees and employers navigation support is needed to locate information, resources, and support specific to employment supports and in particular for Canadians living with episodic conditions.

Conclusion

We applaud the federal, provincial and territorial Labour Market Ministers for consulting with Canadians about Federal Labour Transfer Agreements. The MS Society believes this is an important program that needs to be more inclusive of persons with episodic disabilities to remain in the workforce. A clear focus on job retention supports for both the employee and employer as a key pillar in the programs that these agreements fund is essential to improve the underrepresentation of persons with disabilities, and in particular Canadians with episodic conditions like MS in the workforce.

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¹ MS Society of Canada. *Listening to People Affected by MS*. 2013. (accessed 14 July 2016) available from <http://mslistening.ca/>

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

³ 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.

⁴ Sweetland, J., Howse, E., & Playford E., *Disability & Rehabilitation*, 2012; 34(24): 2031-2038.

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

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

⁷ Smith Fowler, H., *Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?* (accessed 17 March 2016) available from

http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf

⁸ Statistics Canada (2013). "Disability in Canada Initial Findings from the Canadian Survey on Disability." *Fact Sheet*. Catalogue 89-654-X no. 002. Ottawa: Statistics Canada

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

¹⁰ Torjman, S. (2016). *Innovation: Counting What Counts*. (accessed 20 July 2016) available from <http://www.caledoninst.org/Publications/PDF/1099ENG.pdf>