

Subject: Breaking Down Barriers - Thank you!

To: Chair, Deputy Chairs, Members and staff of the Standing Senate Committee on Social Affairs, Science and Technology
July 3rd, 2018

The National ME/FM Action Network is a Canadian charity working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), or both.

We would like to thank the Standing Senate Committee on Social Affairs, Science and Technology for looking at Disability Tax Credit and Registered Disability Savings Plan issues. Your report paves the way for important discussions around the DTC eligibility requirements. We hope to use this opportunity to make the DTC programs more fair and inclusive for Canadians with ME/CFS and/or FM and to increase Canada's understanding of different forms of disability.

People with ME/CFS and FM have impairments of energy production and/or pain signalling which reduce the quantity of physical and mental activities they can undertake. People with relatively mild cases have to cut back on some of their activities, people with more severe cases are partly or completely homebound, while people with the most severe cases are bedridden. In other words, the ability of people with ME/CFS and/or FM to participate in society is reduced to some degree due to impairment. This is the essence of disability as described by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

One of our organization's key concerns has been the eligibility requirements of the DTC. Eligibility for the DTC is the entry point for income support programs like the RDSP. The purpose of these programs is to recognize the additional expenses and loss of earning capability that come with disabilities. The DTC also signals to the public what the federal government means by disability.

The DTC eligibility requirements focus on specific activities. Many of our people, even some who are homebound and unable to work or study, can technically do each of the activities on the list if they have to. However, doing an activity means setting other activities aside. Further, people may experience repercussions from the effort of doing the activity. The DTC criteria, including the cumulative provisions, were written without serious consideration of this scenario. As a result, people may be very disabled and still not apply or qualify for the DTC.

The Canadian Community Health Survey (2014) showed that over 800,000 Canadians had a diagnosis of CFS, FM or both. Most people who are affected are women and of working age. People diagnosed with CFS and/or FM showed high rates of unemployment, poverty, food insecurity and social isolation. This shows that social programs are not adequately reaching the ME/FM community You can see the statistics here:

English: http://mefmaction.com/docs/CCHS_Stats_2014.pdf

French: http://mefmaction.com/docs/CCHS_Stats_2014_Fr.pdf

The CRPD describes disability as an evolving concept. We hope that the DTC criteria will evolve to recognize impairments in energy production and pain signalling so that people with these impairments will receive the social and financial support they badly need.

Thank you again.

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President

National ME/FM Action Network

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