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Submission to the public consultation on inclusion and accessibility leading to a Canada Disability Act

on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM)

The Government of Canada has announced its commitment to promoting equality of opportunity and increasing the inclusion and participation in society for Canadians who have disabilities or functional limitations. The government has announced a public consultation process leading to the introduction of new legislation.

The National ME/FM Action Network is very familiar with disability issues.

The National ME/FM Action Network is a registered charity that has been working on behalf of Canadians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and/or Fibromyalgia (FM) since 1993. We have many accomplishments to our credit including spearheading the development of diagnostic and treatment protocols for ME/CFS and FM, publishing a guide to applying for CPP-Disability, publishing a sourcebook for teachers of young people with ME/CFS or FM, and publishing statistics on the illnesses. We keep in contact with the ME/FM community by newsletter, website, email, facebook, twitter, phone and personal contact.

ME/CFS and FM are chronic disabling illnesses that impact many Canadians.

We know from our contacts with the ME/CFS and FM community that people are experiencing very serious issues. This has been confirmed by Statistics Canada's Canadian Community Health Survey. The 2014 cycle found over 800,000 Canadians with a diagnosis of ME/CFS, FM or both. These Canadians are predominantly female and of working age. Among people with ME/CFS and FM, the survey found:

- high rates of disability,
- high rates of unmet health care and home care needs,
- high rates of poverty,
- high rate of food insecurity.

Very importantly for this consultation, the survey found <u>a weak sense of community belonging</u>. This is a key measure of the lack of inclusion and needs to be addressed

The ME/FM community brings an important perspective to disability discussions – having a disability that is not well-established.

Our community experiences many of the same barriers that the traditional disability community experiences. There are, however three interrelated barriers which strongly affect the ME/FM community:

- lack of health services and supporting research
- lack of awareness and understanding of the conditions and, often, misinformation and stigma
- incomplete incorporation into disability programs.

Other groups have been in this situation in recent times - autism and mental illness jump to mind.

People should not be disadvantaged because their disability is not a traditional or well-established one. The new disability legislation should address the needs of traditional, well-established disabilities, but the needs of people with non-traditional disabilities must be addressed as well.

The CRPD provides a definition of disability, but putting too little emphasis on participation restrictions and too much emphasis on impairments can be exclusionary.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes disability as resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

While people with ME/CFS and FM often encounter major participation restrictions, the physical mechanisms causing ME/CFS and FM are not well understood. In the absence of a biological explanation, society tends to downplay the disability or to blame the person for the problems. Health professionals shy away from helping, disability benefits are hard to obtain, and even friends and families can be judgmental.

The obvious solution is for research to find an explanation. Unfortunately, the research system is uncomfortable in less-established stigmatized areas like this and is not aggressively searching for answers. The disability system needs to recognize this phenomenon and focus less on medical explanations and more on observational evidence of the restrictions in participation.

The discussion paper uses other disability legislation as the main models for moving forward. Much can be learned from experiences around building inclusion for other excluded groups.

The discussion paper looks to previous disability experience for models of moving forward. The Americans with Disability Act and the Accessibility for Ontarians with Disabilities Act are two models suggested. Our suggestion is to look more widely at inclusion initiatives. Examples include minority official languages, women, visible minority groups, indigenous people, and the LGBTQ community. Many initiatives have been undertaken to overcome the outsider status experienced by these groups.

The discussion paper seems to be defining accessibility in a very narrow sense, the way it is used in article 9 of the CRPD. All rights within the CRPD need to be considered, not just article 9.

Section 9 of the CRPD states that people with disabilities have the right of access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public. Other provisions within the CRPD are extremely important to our community such as Article 8 awareness-raising, Article 24 education, Article 25 health, and Article 28 adequate standard of living and social protection.

Our experience is that federal government employees know little about disability issues. A key priority of the new legislation should be building federal competency.

I have personally been bringing forward issues to the federal and Ontario governments for 15 years. I find that I am giving the introductory speech over and over and over. Conversations rarely get beyond a very basic level. Federal government employees need to know much more about disabilities and disability issues.

Every government job has a linguistic profile – saying what language skills the incumbent is required to have. Every government job should have a disability profile. Senior management jobs, jobs in the disability area, and certain human resource jobs should require a high level of disability competency. Supervisory jobs, policy jobs and public contact jobs should require a reasonable level of disability competency. All employees should receive basic training.

Further, there should be a disability coordinator in every federal department and agency to facilitate the government/public interface, and the disability coordinators should be meeting at regular intervals to ensure up-to-date information.

The federal government should be taking leadership on disability issues as there are many stakeholders.

People with ME/CFS and FM have very poor access to health care, one of the rights in the CRPD. Stakeholders include several federal departments and agencies, the provinces and territories, and numerous professional groups. When we discuss our issues with government, the attitude is typically "Thank you for telling us about it. You should be talking to someone else. Good luck sorting it out." One senior government official commented to us on how hard it would be to sort out the health care issue with so many players involved. If it is hard for government, think how much harder it is for a little-known all-volunteer organization dependent on memberships and donations, with donations hard to raise because the cause is unknown and stigmatized. A better answer would be "Thank you for telling us about it. There is obviously a public issue here. We need to be part of sorting it out. How can we work together? Who else do we need to bring into this discussion?"

The federal government needs to understand the value of disability organizations like ours.

The National ME/FM Action Network is providing a very valuable service to Canadians, as are ME/FM organizations at the provincial and local levels. We understand the problems in the community. have knowledge, credibility and infrastructure to connect to the community. We understand the culture and sensitivities.

We have seen what happens when government ignores the needs of the community. We have seen what happens when government jumps in without understanding the culture or sensitivities.

Amendments to the Disability Tax Credit provisions should be included in the new legislation.

In a February meeting with the Minister, we focused on five existing federal programs – Canada Pension Plan-Disability, Disability Tax Credit (which is a benefit but also a gateway to other benefits), home care, accommodation at work and voting in elections from home.

It appears that most issues in these programs can be sorted out within the current legislative framework. In the case of the DTC, legislative change is needed because the eligibility criteria spelled out in the Income Tax Act are selective and non-inclusive.

Statistics and evaluation are extremely important.

We will know that the new legislation is working when our communication with government improves and our community reports improved experiences. We will be looking to the Canadian Community Health Survey for confirmation. In particular, we will be looking for the ME/CFS and FM communities to have:

- greater sense of community belonging
- lower rates of unmet health care needs
- lower rates of unmet home care needs
- lower rates of poverty
- lower rates of food insecurity

Note that many of these indicators are not included on the Canadian Survey on Disability. The survey needs to be reviewed.

We see the need for a holistic disability statistical program rather than a single survey. There needs to be surveys on participation, experiences and attitudes. There need to be evaluations of the various programs. There need to be studies of issues like the adequacy of disability benefits.

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Thank you for this opportunity to contribute to the dialogue around accessibility and inclusion. <u>We hope to be invited for more discussions as the consultations progress.</u>

We will be sharing this document with our community and making it available on our website. We give you full permission to post and share this document.

Margaret Parlor
President
National ME/FM Action Network