

Myalgic Encephalomyelitis-Chronic Fatigue Syndrome (ME) and/or Fibromyalgia (FM)

Submission to the

UN Committee on the Rights of Persons with Disabilities

Review of Canada's implementation of the

Convention on the Rights of Persons with Disabilities - 2025

on behalf of Canadians with

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME)

and/or Fibromyalgia (FM)

November, 2024

Summary:

According to the Office of the United Nations High Commissioner for Human Rights:

The Convention on the Rights of Persons with Disabilities, which was adopted in 2006 and entered into force in 2008, signaled a 'paradigm shift' from traditional charity-oriented, medical-based approaches to disability to one based on human rights.

<https://www.ohchr.org/en/disabilities/about-human-rights-persons-disabilities>

The overriding message of this submission is that Canada is still using traditional approaches to disability and has not made the paradigm shift called for by the High Commissioner for Human Rights.

The National ME/FM Action Network has been working on behalf of Canadians with ME, FM or both since 1993. ME and FM were not traditionally considered to be disabling. ME and FM can cause reduction in physical, cognitive and emotional activity that can significantly affect our people's ability to participate in society. The paradigm shift is important for our people.

We have identified five initiatives that would go a long way toward implementing the paradigm shift:

- 1) Increase disability literacy in government.
- 2) Address gaps in the health care system for ME and FM.
- 3) Review the content, accessibility, use and messaging of disability statistics.
- 4) Update the Disability Tax Credit criteria.
- 5) Ensure the availability of special education for young people with ME and/or FM.

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About ME and FM

The National ME/FM Action Network is a registered charity working on behalf of Canadians with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia or both. A key impairment with these conditions is a reduction in the overall amount of physical, cognitive and emotional activity people can handle. Generally, people with reduced activity levels cut back their social and recreational activities first, then work or education, then family and household activities, then self-care. Cutting back activities reduces participation in society.

The Canadian Community Health Survey (CCHS) shows that there are around a million Canadians diagnosed with ME, FM or both. Most are of working age and most are women. The ME and FM cohorts show high levels on measures such as unemployment, poverty, food insecurity and social isolation.

https://www.mefmaction.com/docs/CCHS_2005-2014_Tables.pdf

Even though our people's participation in society is reduced because of long-term impairment, ME and FM were not traditionally considered as disabling. There are several explanations. Reduction in overall activity is a more difficult concept than reduction in specific activities. The impact of activity reduction on participation has been seriously underestimated. And ME and FM baffle the medical profession which, rather than tackling the problem, has fallen back on a myth that ME and FM are due to personal failings. The social sector has gone along with the medical sector's hands-off approach to ME and FM. This leaves our people with both inadequate health care and inadequate social support.

We have identified five initiatives which would go a long way towards implementing the paradigm shift for ME and FM.

1) Increase disability literacy in government.

Over many years, we have tried to build communication with public servants. We have found that disability literacy in government is very low. We find that we have to contact them – they rarely contact us. We find that we have to start from basics – what are ME and FM, what is disability. We find that they do not understand that they have responsibilities.

A few years ago, we were told by a high-ranking public servant in the disability area that ME and FM would be accepted as disabilities when the traditional disability community decides to accept them as disabilities. This illustrates the lack of government understanding of their responsibilities and the depth of the challenges we face. And yes, we have tried working with the traditional disability community. They have their own needs and have not shown interest in ME or FM issues.

The federal government assigns language requirements to each position in the public service, stating how much capability the employee must have in English and French. We would like to see disability requirements assigned to each position as well. All employees should have basic disability literacy. Those in supervision and those having public interaction should have more. Those who design, manage and deliver services to people with disabilities should have a high level. It might be an idea to offer training to disability organizations as well.

2) Address gaps in the health care system for ME and FM

CRPD Article 25 calls on governments to provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.

Currently, it is hard for people with ME and/or FM to find any health services at all for these conditions. This is obviously frustrating for the patients. Less obviously, this is frustrating for the health care system since patients keep coming back for help. The health care system needs to recognize that using a better care model would reduce strain on the health system itself. Further, better health services could minimize or prevent further disabilities and that would benefit society.

3) Review the content, accessibility, use and messaging of disability statistics

CRPD Article 31 calls on governments to collect appropriate information to enable them to formulate and implement policies to give effect to the CRPD and to assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Issue 1 is data content. Disability statistics are supposed to enable the formulation and implementation of policies to implement the CRPD. The current disability statistics program misses the mark in two key ways. Firstly, it focuses on traditional disability. Secondly, it focuses on counting people and not on exploring the range of social issues that people with disabilities face.

Issue 2 is data accessibility. ME and FM have been included on the Canadian Community Health Survey from time to time. To protect confidentiality, the government controls who can see what data. Unfortunately, very little information on ME and FM has been made available to the public in recent years.

Issue 3 is use of the information. We see little evidence that governments are actively using the data. We also have seen little evidence that governments paid attention to information we compiled, at great effort, when public use microdata files were available.

Issue 4 is messaging. When the government conducts the Canadian Survey on Disability and when it publishes the results, it is making a statement to the public about what disability means to government. The current survey is perpetuating the traditional model of disability.

4) Update the Disability Tax Credit criteria

The DTC is a federal program which provides a reduction in income tax for those who qualify. It is also the gateway into a number of disability programs, including the proposed income supplement for low-income working-age people with disabilities. The eligibility criteria are based primarily on a list of self-care activities. The application form must be signed by an eligible medical practitioner. Our people have difficulty qualifying for the DTC because people with ME and FM are generally severely disabled before their self-care activities are affected and because it can be difficult to find a medical practitioner to sign the form.

Like the Canadian Survey on Disability, the DTC is sending out a message about what the government considers disability to be.

This initiative should be combined with a review of eligibility criteria for disability income support programs across the country to identify issues and best practices.

5) Ensure the availability of special education for young people with ME and/or FM

CRPD article 24 deals with education and calls on governments to ensure that reasonable accommodation of the individual's requirements is provided.

Ontario is Canada's most populous province and has 2 million students in its public education system. Eligibility for special education is based on specific impairments. Energy impairment is not included and there is no catch-all category like the US's "other health impaired". Therefore, the types of education a young person could benefit from – notably part time or homebound schooling – are not necessarily available.

This initiative should be combined with a review of special education provisions in all jurisdictions to identify issues and best practices.

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These five initiatives cover a range of issues and affect different levels of governments in Canada. We think that these discussions would build a stronger understanding of disability issues, would build stronger relationships between public servants and disability organizations, and would uncover other disability issues that need to be addressed.

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Thank you for the opportunity to put forward our observations and ideas. We will report back the next time that Canada's implementation of the CRPD is reviewed describing what progress has been made.