



- Phone 613-829-6667 • Fax 613-829-8518
- 512-33 Banner Road
- Ottawa, ON K2H 8V7 Canada
- mefminfo@mefmaction.com
- (BN) 89183 3642 RR0001

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

Hearings on M-192 Episodic Disabilities

Disability due to chronic or episodic activity reduction

The HUMA committee is tackling the topic of episodic disabilities. At the November 29, 2018 committee meeting, the question was raised whether Fibromyalgia (FM) fit within the episodic framework. We do not consider FM or its companion Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) to be episodic. However, we do think that the key issue before the committee is whether people can be considered disabled when they can function some of the time. In the case of episodic conditions, people can have periods of illness that are frequent, long and unpredictable enough to lead to disability. In the case of ME/CFS and FM, there is chronic activity reduction due to impairment in energy production and pain signalling which can have enough impact to be disabling. The broad context needs to be considered, not simply whether people have listed impairments or can do listed activities at a point in time. We hope that the committee will agree that activity reduction, whether chronic or episodic, can be disabling. We will discuss our reasoning, then point out several areas which need to be reviewed to ensure that the needs of people disabled through chronic and episodic activity reduction are addressed.

Disability is often thought of as a list of impairments (eg. vision impaired, developmental delays) or as a list of activity limitations (e.g. difficulty walking, difficulty dressing oneself). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and Bill C-81 Accessible Canada Act emphasize that disability should focus on participation restrictions (difficult participating in the economy and the community).

There are many reasons that someone could have difficulty participating in the economy or the community which can be missed when using lists of impairments or activities. This is the point that the episodic disabilities community is making. Their people may be able to function normally and do activities some of the time, but the times that they cannot function normally can affect their ability to participate in society to such an extent as to render them disabled.

The National ME/FM Action Network is a Canadian charity working on behalf of Canadians with ME/CFS, FM or both since 1993. ME/CFS and FM are associated with impairment in energy production and pain signalling. People with relatively mild cases have to cut back on some of their activities, people with more severe cases are largely or completely homebound, while people with the most severe cases are bedridden. The Canadian Community Health Survey 2014 found that over 800,000 Canadians had a diagnosis of ME/CFS, FM or both. This group of Canadians showed high rates of unemployment, poverty and social isolation, indicating clearly that they were experiencing difficulty participating in the economy and the community.

While we recognize that the symptoms in people with ME/CFS and FM can vary over time, we have resisted the application of the episodic model to ME/CFS and FM. The episodic model emphasizes the ups and downs of a condition. In the management of ME/CFS and FM, it is far more important to emphasize the trend line than the variations. Pacing is the primary technique for managing these

conditions, which means that people adopt a level of functioning that is sustainable, then adjust that level of functioning if health improves or deteriorates over time. An often used expression is “save me from my good days”, referring to the tendency of people to overexert themselves on days when they feel well, which can lead to “crashing”. This is why we concentrate on stability in functioning rather than variability in functioning.

In the same way that episodes of illness can restrict participation in society and the economy to the point of disability, chronic activity reduction can lead to disability as well. What complicates matters is that people with chronically reduced activity levels have choice around what activities they do, as long as the sum of the activities does not exceed their limit. Thus, they could give almost everything up and still not qualify under programs like the Disability Tax Credit which is based on a selective list of priority activities.

We hope that the committee will confirm that both chronic and episodic activity reduction can be disabling. Some action should be taken in light of this enhanced view of disability. These items below relate to actions needed around disability programs and do not include actions needed in the health sector.

There needs to be greater public awareness that disability includes people with chronic and episodic activity reductions.

Public service training on disability should be reviewed to ensure that chronic and episodic activity reduction issues are covered. Government policy analysts should verify that they have the information they need to reflect chronic and episodic disabilities. For instance, an academic researcher found no studies anywhere on the experience of people with ME/CFS in the workplace. How can policy analysts make recommendations about employment and unemployment issues without this information?

The statistics collected on disability need to be reviewed. The 2017 Canadian Disability Survey was designed around types of impairment. Activity reduction was not referenced.

The Disability Tax Credit legislation is a patchwork of disability concepts. A review is needed to link the program's qualification criteria to the program's purpose.

The legislation for the Canada Pension Plan-Disability is indeed participation based. The manager of CPP-D assured the committee that people with episodic disabilities can qualify and we know that people with chronic activity reduction can qualify as well. Problems do arise at the administration level. It can be difficult for applicants to document their disability and for adjudicator to decide reduced activity cases. This needs discussion.

A review should be undertaken of services to people with episodic and chronic activity reductions. For instance, we are not aware of any job counsellors in the ME/FM field. A review should be undertaken around funding of disability organizations to ensure fairness across disabilities.

Thank you for the opportunity to raise these issues.



Margaret Parlor, President