Attachment to SDPP-D Application

for the National ME/FM Action Network

A Canadian registered charity serving Canadians with ME/CFS and/or FM

Our organization

The National ME/FM Action Network is a national not-for-profit registered charity that has been working since 1993 to increase the social inclusion of a large group of sick, disabled and socially isolated Canadians. This group of over 800,000 Canadians currently receives very little recognition in the disability arena, far less than it deserves.

The Need for Conversation

This application process provides the opportunity to open a conversation about important disability issues that our organization and our community have encountered and expect to encounter moving forward. The issues include the following:

- The Government of Canada has being using a narrow concept of disability focusing discussions on traditional topics and involving traditional groups. Is the government committed to reaching out based on the broader concept found in the UN Convention on the Rights of Persons with Disabilities (CRPD)?
- The Government of Canada does not fully recognize the disabling consequences of having reduced capacity for physical and mental activity. How can this be corrected?
- The health system has a problem – it has not succeeded in explaining the mechanism around ME/CFS. A cop-out has been to suggest that ME/CFS is not a medical condition at all; poof the problem disappears. This suggestion has influenced health policy in Canada and around the world for decades. The results have been catastrophic. With little infrastructure to support the community and little understanding or sympathy, people are dealing with unmet health care needs, unmet home care needs, unemployment, poverty, food insecurity and social isolation.. Why was this allowed to happen in the first place and what can be done to correct the situation as quickly as possible?
- How will “primary mandate” (as in “your organization has a primary mandate that promotes the social inclusion of persons with disabilities”) be interpreted? ME/CFS and FM are medical conditions which are disabling. Some of our work in promoting social inclusion involves sorting out problems with the health system. Would we therefore be considered a health organization rather than a disability organization? That would imply that SDPP-D recognizes disabilities only after their medical issues have been resolved, even though health care is an article in the UN CRPD.
- How will “partnering” be interpreted in our context? We have limited capacity and are working in an area with little infrastructure. Our community gets little recognition and is

highly stigmatized. We have to work exceedingly hard even to get someone to talk with us.

- How will financial statements be interpreted? Will our relatively low income be seen as a sign of lack of capacity to handle new funding or as a sign of a need for a big infusion?
- What other programs besides SDPP-D are in place to help address the ME/FM situation?

Our community

ME stands for Myalgic Encephalomyelitis, a British term. The US adopted the term Chronic Fatigue Syndrome (CFS). Our organization generally uses the combined term ME/CFS. Diagnostic criteria include reduced physical and mental activity levels, post-exertional malaise (meaning that symptoms flare after people exert themselves), sleep dysfunction (meaning that more sleep is not the solution), pain, cognitive difficulties and other symptoms, together lasting six months or more.

FM stands for Fibromyalgia. FM is associated with widespread pain, reduced activity levels, cognitive difficulties, unrefreshing sleep and other symptoms lasting six months or more.

As you can see, the criteria for ME and FM overlap to a large extent. The boundaries between ME and FM are no longer clear. They were assigned to separate silos by the medical system. We have always felt that they are very closely related, with many people experiencing both. The medical system now seems to be moving them closer together.

Statistics Canada's Canadian Community Health Survey has given us a big picture. The 2014 survey showed over 400,000 Canadians with a diagnosis of Chronic Fatigue Syndrome and over 500,000 with a diagnosis of FM. Removing overlap, there were over 800,000 Canadians with one or both diagnoses. They are primarily women. They are primarily of working age. The survey went on to show that these Canadians have very high levels of unmet health and home care needs despite frequent contacts with the health system. **The survey also showed that these Canadians have very high rates of inability to work, disability, poverty, food insecurity, and social isolation. See** http://mefmaction.com/docs/CCHS_Stats_2014.pdf

How ME/CFS and FM are disabilities

ME/CFS and FM are medical diagnoses, but are they disabilities? Under the UN CRPD, “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The two key concepts are participation and long-term physical impairment.

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In discussions of ME/FM disability, the symptom of activity reduction is central. A young person with relatively mild ME/CFS or FM may have enough energy to attend school full time if he is driven to and from school, is excused from physical education classes, has little or no homework, and drops evening and weekend activities. A young person with more pronounced symptoms may be able to attend school on a part time basis if she is driven back and forth and if she does minimal activity for the remainder of the day. A young person with even more pronounced symptoms may not have the energy to get to school at all but may be able to do some lessons at home. Some young people cannot even manage that.

For adults, relatively mild cases can mean cutting back some activities, and more severe cases can range from part time work through not working at all through being housebound and even bedbound. The Canadian Community Health Survey tells us that almost a quarter of working aged adults with ME/CFS or FM were permanently unable to work. Looking from another direction, a fifth of working aged Canadians who said they were permanently unable to work reported having a diagnosis of ME/CFS, FM or both.

Activity reduction implies participation reduction. How severe the illness is and what other factors are at play determines the degree of participation restriction and the kinds of accommodations and supports required.

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Reduced participation is not enough to qualify as disabled under the UN CRPD. The participation restriction must be related to a long-term physical, mental, intellectual or sensory impairment.

Two models have been proposed to explain ME/CFS. The good model is based on a long-term physical impairment while the bad model is not. A similar dichotomy exists for FM but more subtly.

The National ME/FM Action Network has always believed the long-term physical impairment model is correct. We hesitate to draw your attention to the bad model. However, the bad model has dominated public policy for two or three decades and has done a huge amount of harm. To understand the frustration and under-service experienced by Canadians with ME/CFS and FM, you have to understand that model and its serious implications.

The bad ME/CFS model assumes that people are de-conditioned and afraid of doing more activity. Therefore, they should be coaxed or prodded to increase their activity levels. Sympathy and support are seen as counter-productive. Under this model, patients are seen as not credible and are told to push themselves even if this makes them feel worse. Health and social system officials, family, friends and organizations who support patients are seen to be enabling a behavioural problem. Research is not necessary because the illness is explained. Patients don't qualify as disabled under the UN CRPD because their participation restrictions are due to personal failings, not long-term physical impairment.

The good model says that ME/CFS is indeed due to a long-term physical impairment, that activity has to be carefully managed to respect the individual's “energy envelope”, that the health and social systems play key roles because early diagnosis and proper supports can have long term benefits, and that research is badly needed. In this model, patients would be considered disabled under the UN CRPD criteria because their participation restrictions are due to long term physical impairment.

The international ME/CFS community has fought the bad model. Scientific research (often privately funded) has found that people with ME/CFS have genuine dysfunctions, notably impaired energy production, while the main study used to support the bad model has been shown to be fundamentally flawed and manipulated. The leading medical organization in the

US has unequivocally rejected the bad model. Key organizations (such as the US NIH, the US CDC, the Australian MRC and the Canadian Institutes of Health Research are adopting the long-term physical impairment model. It is time for everyone, including the disability system, to follow suit.

Our activities and partnering

Over the years, our organization has been doing what we can to help individuals deal with their individual situations, to give them the sense that they are not alone, to help official understand that this area needs a different model and to fix what can be fixed.

Our whole raison d'etre is connecting with the ME/FM community. We listen to the community to understand what is important to them. We monitor developments in Canada and elsewhere. We publish a newsletter outlining developments and giving hope. The newsletter is distributed across the Canada and around the world. We maintain a website and Facebook page, and we respond to requests for help. We provide resource material. We collaborate with other ME/FM groups as well as with groups representing people with related illnesses and disabilities.

Our community tells us that it is unhelpful and socially isolating to go to health professionals who do not understand or respect their medical situation and it is helpful and socially affirming to go to health professionals who do. To build understanding and respect for ME/CFS and FM patients, we spearheaded the appointment and supported the work of expert panels which developed diagnostic and treatment protocols to guide medical professionals. We hosted an international research and clinical conference. We have pointed out the lack of research and have done our best to encourage research in Canada. We have supported the development of the complex chronic disease program in British Columbia and have a representative on the community advisory committee. We have funded the translation of several key medical documents into French.

Our community tells us that it is unhelpful and socially isolating not to have the supports they need or to have to fight unduly for the supports. We have identified changes needed to to make federal programs like CPP-D, DTC and elections more inclusive of people with reduced functional capacity. We have published a sourcebook for teachers with young people with ME/FM (bilingual). We have two representatives on a CPP-Disability advisory committee. We have intervened in several court cases dealing with disability issues, including a case that went to the Supreme Court of Canada. (The Supreme Court does consider ME/CFS, FM and chronic pain to be disabilities.)

We are very proud of the fact that our founder and current CEO, Lydia Neilson, was awarded the Meritorious Service Medal by the Governor-General of Canada for her work with our organization.

We do our very best to meet the needs of the ME/FM community with the few resources that we have available. We work with ME/FM groups that have sprung up in Canada and elsewhere. You might be interested to know that there is an international ME/CFS network. We work with supportive health professionals, researchers and lawyers. We collaborate with groups in related areas (e.g. Lyme, Ehlers-Danlos, chronic pain, Multiple Chemical Sensitivities) though we find that these groups are as under resourced as we are. Our cause is little known, complex and stigmatized so partners can be hard to find. Partnering sometimes is and sometimes is not be a good use of our limited resources. We always have to ensure that partnerships do not conflict with our commitment to our community.

Looking forward

With the acceptance of the physical impairment model of ME/FM, we are looking forward to a new era, but we also know that there is much work to be done to implement the shift. The old model has left Canada with little infrastructure to help the people affected. There are few doctors and allied professionals knowledgeable about ME/FM, these illnesses have been excluded from medical education, there is little research underway, disability supports have not been designed with ME/FM in mind, there are few support groups, and misinformation and stigma are rampant.

Change is starting to happen here in Canada and around the world. The US National Institutes of Health is investing in research and the Center for Disease Control has changed its treatment recommendations. The medical research council in Australia has appointed an advisory committee and the UK has called for a change to their clinical guidelines which were based on the old model. The Canadian Institutes of Health Research has just funded a ME/CFS research conference to take place in May 2018 – our organization is involved. The government of BC established a clinical and research program several years ago – we are represented on the community advisory committee. Ontario commissioned a study several years ago and now has an implementation task force.

There is so much that our organization expects to be doing in the upcoming years. We will be providing input to officials implementing changes and informing the community about what is happening. A major undertaking will be building peer support programs that are desperately needed.

Your questions

The SDPP-D qualification process centers around four themes: scope, principal activities, reach, and partnering. We have also been asked to submit financial statements. Here are key points for each.

<u>Scope:</u> Our organization works on behalf of Canadians with ME/CFS and or FM. The 2014 Canadian Community Health Survey found that there were over 800,000 Canadians with one or both diagnoses. Most are women and most are of working age. The survey also shows that these Canadians have very high rates of inability to work, disability, poverty, food insecurity, and social isolation.

This is not a traditional area of disability, but the UN CRPD emphasizes that disability is an evolving concept and defines persons with disability in terms of long-term impairment and reduced participation in society. Reduced participation comes with the reduced activity levels that are inherent to these illnesses. Meanwhile, public policy has marginalized people for many years. There is new recognition that ME/CFS and FM are genuine long-term impairments.

<u>Principal Activities</u>: As stated above, our organization has been on the front line of promoting social inclusion since 1993. Our principal activity, described in detail above, has been working with the ME/FM community. Based on what they have said, we have identified the health, disability, and peer-support systems as areas that need attention.

Reach: We have directors and members from across the country. We focus on Canada-wide issues such as health-care, CPP-D and DTC. We network with other associations, notably the four provincial associations that currently exist (BC, MB, ON, QC). There have been suggestions of forming a national association with provincial branches, but we do not have the capacity at this time to support this. We would like to make more information available in French but again capacity is an issue.

Partnering: Our focus is on serving the needs of the ME/FM community. We work with others wherever possible to accomplish this.

Financial statements: In the early 1990's, our organization received some federal funding. Since then, we have financially supported our work through memberships and donations. We were turned down for a SDPP-D grant in 2012 – we were unsuccessful in developing a feasible project that met both our community's needs and the competition requirements. Our organization carried on, but a grant would have allowed us to do more for our community.

We rely on grass-roots support and are very appreciative of our supporters. Our income last year was a $42,981 which covered our operating expenses. We have no paid employees but we do pay for bookkeeping, webmaster and accounting services. Rent, printing and postage are other major expenditures.

The latest financial statements show a year-end deficit. We received a bequest in the previous year which allowed us to fund several special projects such as document translation and travel, so the deficit should not be considered an indication of overspending of financial instability.

Thank you for reviewing our application. We hope you have a better appreciation of the needs of our community, the services we have been providing, and the important activities for the years ahead.