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## **RECOGNITION, INCLUSION AND EQUITY THE TIME IS NOW**

Perspectives of Ontarians Living with Environmental Sensitivities/  
Multiple Chemical Sensitivity (ES/MCS), Myalgic Encephalomyelitis/  
Chronic Fatigue Syndrome (ME/CFS), and Fibromyalgia (FM)

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Report Highlights/Appendix to  
**The Ontario Centre of Excellence in  
Environmental Health Business Case Proposal**

*With funding from*  
**MINISTRY OF HEALTH AND LONG TERM CARE ONTARIO TRILLIUM FOUNDATION**  
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**Compendium 1/4 of the Business Case for an OCEEH**

**September 30, 2013**

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Reference as: Varda Burstyn, *Recognition Inclusion and Equity - the Time is Now: Perspectives of Ontarians Living With ES/MCS, ME/CFS and FM*. (Toronto: Myalgic Encephalomyelitis Association of Ontario MEAO) 2013.

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## A PREFACE FROM OUR COMMUNITY

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### WHAT OUR COMMUNITY INFORMANTS SAID ABOUT THIS PROJECT

It helps that there are people out there doing something like this. They're actually putting it together. We all need to work together on this, I think, to make it better for all of us. ... God didn't give this to me for nothing. It's not to sit around and stare at it. This is to help out with something in the future. I hope it does. **Petra MCS**

I am really glad that this [research] is happening because I am hoping that with this information we can send this to the Ministry of Health: these are the needs, this is what we are asking for and we have doctors backing up what we say. **TJ FM ME MCS**

We need systems that treat us with compassion and empathy instead of feeling as if we're a minority and put as a lower standard of the health care priority list. We are people like anybody else. ... And to be able to talk about these three illnesses out in the open and be believed and not feel as if it doesn't exist, instead of having to fight everyone in the system and even ourselves. We just want to be treated like anybody else. Just because you can't see it outright, doesn't mean it doesn't exist and it is real. ... Just being able to go into a health care facility and be like anyone else and be received in the hospital or health care setting – like a clinic or family health team or community health centre – to be accepted as an illness or a diagnosis ... like anything else. That it's not stigmatized, that it's not associated with a mental health issue. **Joanne ME**

I've just come out of a horrible, horrible pit, but I've still got my attitude . . . and I thank you very, very much for this opportunity to make me feel that I can help. One day ... those politicians are going to see that ME is like a constant dripping. You know they tell us, 'when you have a hot water tap dripping every day, if you would just fix your tap you would save this much money.' ME is like a constant dripping, and the Government and the supports and the medical system, they've got to wake up. Because that constant dripping is money... With ME and FM and multiple chemical sensitivities, it's a constant dripping and dollar, dollar, dollar, dollar. They've got to sit up and they they've got to hear it because that's some mountain of cash and it's not going anywhere. People [health care providers] are getting paid but... They're getting paid for time and not results. I'm just...full of emotion. **MaryLou ME FM MCS**

Many people living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS) and Fibromyalgia Syndrome (FM) made heroic efforts to contribute to MEAO's information gathering initiative, despite their poor health. They did so, as they often told us, because they were so happy to finally have the opportunity to make their voices heard by health care system and government decision makers. Throughout this report their words paint a vivid picture of current-state

realities, provide astute insights into identifying ‘needs, gaps and barriers,’ and spell out with remarkable breadth and precision a set of recommendations for a ‘future state’. These are now embodied in both the Ontario Centre of Excellence in Environmental Health Business Case Proposal as such, and in a number of proposed ‘strategic enablers’ for key policy shifts.

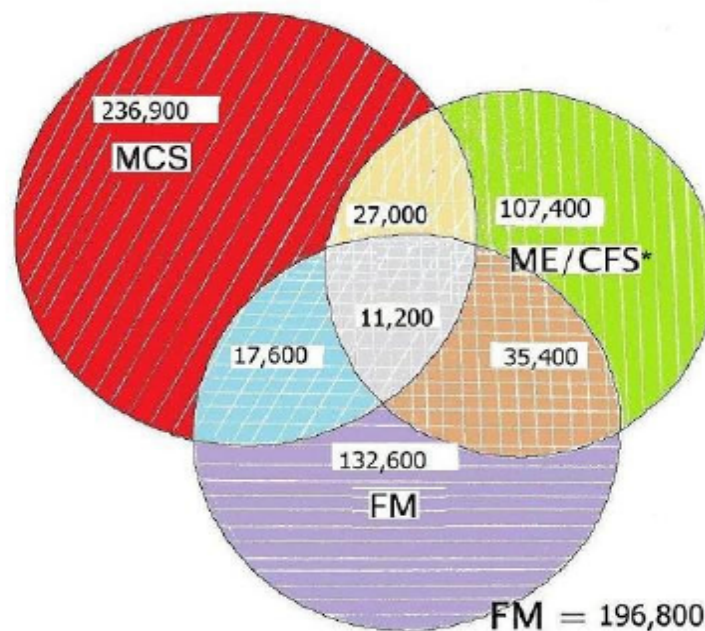
The community members who contributed so much wisdom expressed the hope that their experiences, their needs and their ideas for a better future would be catalysts for change. MEAO would like to express its profound gratitude to these remarkable people for making the study and this report possible, and for incomparably enriching the final proposal for services in the OCEEH BCP.

We dedicate this study to them and to all those for whom they spoke.

## THE CELCs IN ONTARIO - A SNAPSHOT IN 2010

### Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)\* Fibromyalgia (FM) and Multiple Chemical Sensitivities (MCS) in Ontario (2010)

MCS = 292,700



ME/CFS\*  
=  
181,000

FM = 196,800

Total reporting one or more diagnoses = 568,100



ME/CFS, FM and MCS **ONTARIO** Canadian Community Health Survey

Note: Canadian Community Health Survey (CCHS) results rounded

This diagram created February 17, 2012 by MM

# PART ONE: THE CONDITIONS, THE CONSULTATION, EMERGING ISSUES, RECOMMENDATIONS

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*'By far, the most important finding for future state planning was this: where study participants did find expert health professionals who were familiar with their conditions, they had exceptional, life-changing, often life-saving positive support which raised their quality of life, and in significant cases, restored productivity and ability to function in many social spheres.'*

## 1 WELCOME - WHAT YOU WILL FIND IN THE 'HIGHLIGHTS'

WELCOME to the highlights and recommendations from **RECOGNITION INCLUSION AND EQUITY: THE TIME IS NOW - Perspectives of Ontarians Living with ES/MCS, ME/CFS AND FM**, a report written to support the business case for a proposed Ontario Centre of Excellence in Environmental Health (OCEEH), and submitted to the Ontario Ministry of Health and Long Term Care in November, 2013. The OCEEH's intended initial focus is to serve the needs of those living with three chronic, complex environmentally-linked conditions ('CELCs'): Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS) and Fibromyalgia Syndrome (FM). These serious health conditions have been on the rise in Canada and in Ontario for a long time. Between 2005 and 2010 alone, they rose by 23 percent, 34 percent, and 13 percent respectively.

The first item up in these 'Highlights' is an invitation to read the full report, which this shorter one summarizes. The full report explains the three chronic, environmentally linked conditions (CELCs) in laymen's terms and presents an analysis of some of the most striking features in today's changing landscape with respect to new knowledge and changing paradigms of health, especially as linked to the environment, affecting new possibilities for care. As well, the full-length report presents a rich and remarkable array of voices from the groundbreaking community consultation that we conducted during 2012, along with our closer analysis of a number of key emergent issues from that consultation and from the ways our findings overlapped with and were corroborated by the literature in the field. In Part One of these 'Highlights,' we have summarized this material.

In Part Two of this document, we provide summaries of the motivation, explication and enumeration of the extensive, in-depth, on-the-ground recommendations of our report - those meant to implement the overarching objective that emerged from this long process. In one word, that objective can be summed up as the 'normalization' of care and support for our community. This catch-up, future state goal can be further broken down into the key components of 'recognition, inclusion and equity' - our report title. And these terms can in turn be conceptualized as establishing for people living with the CELCs the same rights, benefits, policies, services and programs that Ontario provides to those living with conditions of



comparable severity - in other words, achieving equality with those we have identified as our 'comparator groups.'

**OUR COMPARATOR GROUPS: PEOPLE LIVING WITH CONDITIONS OF COMPARABLE SEVERITY**

**Effects of a stroke   Cancer and receiving chemotherapy   Heart disease**

**Late-stage HIV-AIDs   Diabetes   Arthritis**

**(These groups are derived from a combination of quantitative data reports, assessments of expert physicians and patient informants)**

For us, the proposed Ontario Centre of Excellence in Environmental Health (OCEEH) is the strategic solution to put these aspirations into practice. It is the culmination of the long process we have been through, both as a patient organization and as a partner in the OCEEH business case Steering Committee.

## **2 BACKGROUND TO THIS PROJECT**

Ontario began the process of investigating how to respond to the needs of those with ES/MCS in 1985. At that time, the *Ad Hoc Committee of Inquiry into Environmental Hypersensitivity* tabled its report to then-Minister of Health, the Hon. Murray Elston.<sup>1</sup> It took eleven years for government to digest and then to fund both the initial Environmental Health Clinic situated at Women's College Hospital, and a productive but short-lived research program. It was expected that from that base many of the other recommendations would be implemented. The report urged that numerous steps be taken to provide an adequate and appropriate system of care. Indeed it argued that Ontario could not morally or medically refuse patients funds to travel to obtain care in the United States if the province did not provide such care here. In 1998, with a budget of only \$250,000, the clinic was also given the provincial mandate to care for those with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Fibromyalgia, a frequent co-morbidity with both conditions, came along with the package.

In the intervening period - nearly 20 years - no such system of care was established. Indeed, Ontario lost a significant number of physicians who used to care for people living with these conditions, even as the numbers of those afflicted increased at alarming rates. As a result, individuals living with the CELCs and their families have experienced invisibility, exclusion and discrimination in our health and social services systems, resulting in great suffering and hardship.

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<sup>1</sup> George M. Thomson, J.H. Day, M.D., S.E. Evers, Ph.D., J.W. Gerrard, D.M., D.R. Mcourtie, M.D., W.D. Woodward, Ph.D., *Report of the Ad Hoc Committee on Environmental Hypersensitivity Disorders* (Ontario Provincial Court, Family Division, Toronto: 1985). For the prescience of the Ad Hoc Committee regarding health care system recommendations, see Appendix 2 for (unimplemented) recommendations from the Committee.

But - and this is the great news that we want to celebrate as a basis for moving forward in this report - in a number of jurisdictions, in multiple practices and research programs in key fields of medicine and epidemiology, in parallel and in interaction with major knowledge accumulation about the links between the environment and health, **huge strides have been made in understanding what lies behind the conditions and what can be done to help those who have them. Our full report, combined with ‘Complex Chronic Conditions: Academic and Clinical Perspectives,’<sup>2</sup> by Dr. John Molot, presents these positive findings and argues that the time is now to take the steps needed to bring about recognition, inclusion and equity.**

### 3 OVERVIEW OF THE FULL REPORT AND RECOMMENDATIONS

The full report is about key issues in the lives and needs for care and support of Ontarians living with ME/CFS, ES/MCS and FM. In Ontario in 2010 those diagnosed with one or more of these conditions numbered just over 568,000 persons. In our study, we conclude that these conditions display ‘an illness burden similar to that of heart disease and greater than that of cancer.’

As far as our current state is concerned, our community consultation and our environmental scanning processes over several years revealed what we have called a ‘void in service with a few tiny islands of assistance.’ It also revealed a body of knowledge and practice that, when Ontarians with the conditions have been able to access it, makes an extraordinary, life-changing difference for the better in their lives. So we feel confident in saying that now truly is the time to take the steps needed to bring about the implementation of our goals and aspirations.

### 4 BRIEF DEFINITIONS OF THE 3 ‘CELCs’

Clear links between most common chronic conditions and common, ‘everyday’ chemical, including heavy metals, are now established in the scientific and medical literature. These conditions include but are not limited to: cardio-vascular illnesses, cardiac birth defects, low birth weight, obesity, type 2 diabetes, Parkinson’s, developmental neurotoxicity, cancers (breast, prostate, testicular and others) and respiratory disease.

Such links to chemicals are exceptionally strong in the CELCs.

Those with one or more of the CELCs in Canada numbered 1,135,500 in 2005 and 1,415,000 in 2010. These are large numbers by any reckoning, and we have good reason to suppose that at least ES/MCS is under-diagnosed and that possibly ME/CFS and FM are as well. While all these conditions exist on a gradient from mild to severe (and can go completely undiagnosed until greater severity sets in), all three produce devastating symptoms that can lead to total disability. ES/MCS and ME/CFS are life threatening at severe levels.

It is very common for persons to have more than one of these conditions at the same time.

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<sup>2</sup> Detailed and medically-keyed definitions of the conditions, as well as an explication of best-practices for diagnosis and treatment, and a proposed, detailed plan for clinical services, are contained in ‘Appendix 5’ by John Molot, M.D.,

### **MANY PEOPLE HAVE TWO OR THREE OF THE CONDITIONS SIMULTANEOUSLY**

‘I [was] just was an ordinary person and then things started slowing down. I was getting fatigued and I was not able to remember a thousand things without writing them down anymore. I found I was writing notes to [remember] simple things ... I started reacting to the cleaners in the hospitals, and in the centres where I would be, to their cleaning things, where I was noticing them but I never noticed them before. Then I got the flu and that was the end. That was the beginning of an incredible journey that I’m still on.’ **MaryLou ME FM MCS**

### **ENVIRONMENTAL SENSITIVITIES-MULTIPLE CHEMICAL SENSITIVITIES (ES/MCS)**

The US Environmental Protection Agency defines what we call ES/MCS as ‘a diagnostic label for people who suffer multi-system illnesses as a result of contact with, or proximity to, a variety of airborne agents and other substances.’ To which we add, also to substances when ingested. Think ‘toxic injury that does not resolve’. Central nervous system dysfunction can affect any and every organ and body system. Symptoms can be excruciating and completely disabling. The need to escape ordinary, everyday chemical ‘incitants’ can drive people into homelessness and total isolation.

#### **ES/MCS ‘NOBODY CAN SEE WHAT IS HAPPENING IN MY BODY’...**

‘When I am exposed to perfumes and other chemicals ... nobody can see what is happening in my body, they don’t understand. So my body is burning. My eyes are burning. My throat is burning. I think I am going to throw up. I get migraines. I get shaky and then those other symptoms that I describe, I am also dealing with as well. It is kind of like a package deal that feels like every system in your body is going into hyper-drive and you don’t feel a sense of control of your body and of your life.’ **Hope MCS**

### **MYALGIC ENCEPHALOMYELITIS-CHRONIC FATIGUE SYNDROME (ME/CFS)**

Think ‘infection that does not resolve.’ Debilitating fatigue, swollen lymph nodes, pain, neurological dysfunction are typical symptoms. Flu-like weakness and fatigue can undermine all functions, can involve a great deal of pain, and can lead to an inability to physically perform the basic necessities of life. Isolation and disability can result from these symptoms.

### ME/CFS SOME PEOPLE ARE BEDRIDDEN AND HOUSEBOUND

My wife's] symptoms include what the old consensus definition used to call 'post-exertional malaise.' Malaise is not really a good description. She says it's more like having the flu and PMS at the same time, and it's pretty miserable. She also has ... a lot of sensitivity to noise, so she wears ear-plugs a good deal of the time; she can't have music on. She also is very sensitive to light, so she wears a visor even in the house to keep some of the bright lights off her eyes. She still has her irritable bowel and various gut upsets, although it's not as painful as it was. She [also] has some cognitive dysfunction – sometimes trouble finding words. But also, any time that there's sort of mental multi-processing going on, conversations are difficult. Any time she needs to follow something that's moving – visual as well as auditory at the same time, so watching movies – can be very difficult. **Thomas, caregiver for wife with ME**

### FIBROMYALGIA SYNDROME (FM)

Think 'physical injury that does not resolve'. Onset of FM syndrome is often associated with a physical injury, whether past or recent. Symptoms occur on a gradient from nuisance-type symptoms to severe pain so intense that it makes normal existence impossible, resulting in disability and severely compromised quality of life.

### FM CAN BE EXCRUCIATING AND DISABLING AND DESTROY QUALITY OF LIFE

FM - I think I've had it since a teenager. I have always had muscular problems but it was not diagnosed properly. I got sick with the flu and I couldn't walk. I went to see the family doctor who sent me to the rheumatologist and diagnosed me with FM. I got sicker and sicker and symptoms popping up. Today I have a good family doctor and PSW's that come almost every day. I could walk, but I couldn't carry stuff -- I couldn't walk very far, only to the park across the street. When winter came and it gets cold, I also have nerve pain whenever I get cold or even a fan, my muscles would freeze up. I can tell when my FM is acting up -- when it is raining outside my neck gets really stiff and I can't move because my shoulders get as hard as rock and that is how I know the FM is acting up, not the others. **TJ FM ME/CFS ES/MCS**

Along with the qualitative data gathered by our community consultation/patient survey, a quantitative data project was also conducted. This can be accessed independently in the stand-alone document<sup>3</sup>, and its results are also summarized in the full '*Recognition, Inclusion and Equity*' report. The quantitative data illuminated many issues: The CELCs are widespread. They are most common among the middle-aged during a time in people's lives when they are usually at their peak earning potential and contributing most to the economy and the public purse, (whereas other chronic conditions tend to strike at a later age.) ES/MCS, FM and ME/CFS also occur among younger children and teenagers, and the conditions thus have the potential to impact people's lives from a very early age. The majority of people with the conditions are women, a finding that has further implications regarding issues of parenting, family

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<sup>3</sup> E. Halapy, *The Quantitative Data*. 2013. Toronto: MEAO

cohesiveness, poverty and respect from health care professionals, among others. However, a significant number of men (roughly 20 to 30 percent of patients) also have the conditions.

Measures of functional impairment indicate that people with ES/MCS, FM and/or ME/CFS are at least as disabled and in some cases more disabled than people with other well-known chronic conditions. The levels of unmet health care needs were greater than for our comparator groups. These findings combined with unmet home care needs and less than ideal proportions receiving home care services may indicate people with these conditions are receiving ineffective care or are experiencing barriers to or deficits in care. People with these conditions are experiencing socioeconomic disadvantage as demonstrated by high levels of moderate or severe food insecurity and sizeable proportions with low annual household income.

**The qualitative data from our community consultation, reported below, corroborated and augmented all these findings.**

## **5 LESSONS FROM THE ENVIRONMENTAL SCAN - TIME FOR CHANGE IS HERE; CHANGE REQUIRES CENTRAL POLICY SHIFTS**

The full report draws on MEAO's environmental scan to address two broad areas. The first of these is scientific and academic: today, the growth of understanding between environmental factors, notably chemical harms, to chronic illnesses more broadly, and to the CELCs more specifically, has been very widespread. We note some of the ways in which these advances have been expressed in other jurisdictions and in Ontario. The result of these changes means that the time is right for moving ahead to support those living with the CELCs.

The second of these areas is comprised of hard lessons learned from a number of attempts by patient organizations to get assistance and accommodation in key health and social services (CCACs, hospitals and schools) for members - attempts that have largely failed in the absence of central policies and mechanisms for accommodation. These experiences show that change in service delivery will have to be driven by central, pro-active policy shifts, new programs and new incentives if they are to succeed.

## **6 HIGH HEALTH SERVICES UTILIZATION AND VERY HIGH SOCIAL COSTS**

The population-based Canadian Community Health Survey (CCHS), which includes cases across the severity gradient and which was the primary source of our quantitative study, found that the three groups used the services of family doctors/GPs and specialists at higher rates and more frequently than the general public. The Environmental Health Clinic found that by the time patients got to them, their utilization rates were roughly *8 times the national average* - a very high figure that speaks to tremendous patient distress and to great cost inefficiencies due to inappropriate and inadequate care. In the current state of high utilization for inappropriate care, neither sufferers nor taxpayers win.



### **MULTIPLE PHYSICIAN CONSULTATIONS GIVE POOR VALUE FOR HEALTH CARE DOLLAR AND POOR OUTCOMES FOR PATIENTS**

In 2001 I went to teach students with eating disorder at a Toronto Hospital. By February of 2002 I was having all kinds of symptoms. I was getting more migraines. I had within a couple months put on 25 pounds. I had stomach problems. I was very achy. ...My doctor, who is very good and very understanding, had me go to maybe a dozen specialists, a neurologist, a gastrointestinal specialist, another neurologist for fibro, my dentist. ...Everybody, each of the specialists had their take of what was wrong with me, but none of them connected it to MCS... I was diagnosed at the Environmental Health Clinic. **Betty MCS**

I've seen a lot of specialists - it was just nothing, a waste of time more or less. **Theresa ME**

Although we do not yet have data that make it possible to accurately calculate the social costs and their burden on the public purse (we recommend such data be collected) when tallying what we do know about the conditions - lost wages and taxes from high earning years, pressures on family caregiver productivity, high ODSP costs, and problems with parenting that will show up in health care and other problems in the next generation - we believe these social costs are very high, likely in the billions of dollars, and represent a major economic motivator to establish appropriate care.

## **7 FINDINGS OF THE COMMUNITY/PATIENT CONSULTATION**

### **7.1 IMPACTS: DEVASTATING ON WELLBEING AND SOCIAL DETERMINANTS OF HEALTH**

*'I call this the lonely disease ...' 'it really is devastating to all parts of your life. It is just so debilitating.' 'I lost my job, my marriage and my friends...'*

The CELCs are challenging conditions at mild degrees of severity and devastating and disabling at more severe levels. The conditions are chronic, often co-morbid, and once acquired must generally be managed for a lifetime. Impacts are felt in every sphere of life. Marriages are strained or broken, parenting of children is difficult to impossible, elder care for parents is compromised, friendships and community involvement melt away because of debilitation, pain, and/or chemical reactivity. Financial challenges can be devastating. Isolation sets in. For those who are single and/or very sick, the isolation and physical hardship can be absolute and crushing.

### **MARRIAGES ARE STRAINED OR BROKEN, PARENTING OF CHILDREN IS DIFFICULT TO IMPOSSIBLE...**

He has to do jobs around the house that I would have to do or would be my job. He is my sole financial support. If I didn't have him, I'd be penniless. He does the laundry because I cannot walk down the stairs sometimes. He does the cooking because I can't make a meal. Often I can't hold my head up to eat. I'm too weak to hold my head up or sit at the table. We have to eat apart. I'm lying on the couch

with my plate on my chest, eating, and he is sitting at the table. It has impacted him in every way, socially, financially, physically. Not only does he have to go out and work to provide, but then he has to come home and do all the things that I should be doing here at home. Like make the meals, do the dishes, do laundry, walk the dog, everything .... Yeah, it's impacted him. He is my family and he is my support. He's impacted in every way. **Sharon ME FM**

It was hard on my kids, because I had to take all these breaks all the time, to lie down and recharge. So they were kind of, like, on their own in a way and it got so bad. ... My wife and I were separated, and I simply said to her, 'you need to take a couple of the kids back.' One of them didn't want to go. He stayed with me. He was the oldest. But I didn't feel that I was able to take care of them. So I asked my wife to look after the other two. **Frank ME**

My husband left. ... As he told my father, when he married me, he didn't realize I was going to get sick. We didn't take the same vows as everyone else, obviously. [Laughter] **Elizabeth ME**

I wish there was a caregiver when you're in bed for five years and you're trying to look after two sons who want meals made. [laughs] I just wish there was some caregiver that even would come in once or twice a week to help you .... because we don't have any money. And I just felt so bad not making the meals and driving your kids the places that they want to be. I couldn't drive because I figure I'd kill me and them too, being so tired. And I felt like a bad mother. **Judy ME FM**

There was one day that I saw my son off to high school, went back to bed, and then he came home from high school at the end of the day, came into the bedroom and said, 'Mom, I'm home.' And I said, 'Oh, you're going to be late for school.' I'll never forget that. ... Their expectations do not change because they're not ill, which is wonderful. But you are. So you're still not only dealing with your income loss and your career, you still have to maintain a household ... because there is no support that could come in. There is nothing. **Wendy ME FM**

It almost destroyed us in the beginning because they thought I was crazy and that I was making it up. It has been a really long process. A long road ... **Sandra MCS FM**

For most, though not all, participants in our study the onset of symptoms occurred during the highest-earning and saving years, not in senior years. Such a time of onset has many negative economic consequences for individuals and families, in present and in future time. Costs for care are not insured and are almost entirely privately borne. They are too high for ordinary Ontarians, even those with middle-class jobs, to bear on their own. Because so many people stop working after onset (especially absent appropriate care and support and accommodation of disability at work), finances plummet. Therefore the economic impact of these conditions is generally devastating.

#### **ONGOING, OFTEN DEVASTATING FINANCIAL IMPACTS**

The most challenging part was losing my job and not having any income for ten years, is watching my savings just be depleted. I'm at a point right now I'm being forced to sell my house just to get the money out of it to live. **Chris ME FM**

Now eight years down the line, I have salary loss or wage loss on a yearly basis, and I'm only 47. If I were to live even to 75, I don't know how the future is going to play out. **Peter FM ME**

Economic insecurity - including food and housing insecurity and many unmet health needs - was seen as a major, overarching issue linked to lack of recognition and supports: loss of jobs and income due to disabling health conditions is extremely common and causes great hardship. Lack of recognition of these conditions *as disabilities* is a fundamental problem that makes it very difficult to obtain workplace accommodation and disability coverage, through either private or public insurance systems, even when sufferers wanted to continue working.

#### **FOOD INSECURITY LINKED TO POVERTY AND DISABILITY: A SERIOUS UNMET NEED**

For eating I get one meal a day and the rest of my meals are on Ensure or water. I ran out of Ensure so I have a banana for breakfast and have water for lunch and at night I have a dinner. That is basically what my life looks like now. I keep telling people I need fourteen hours [of personal support work] but they say no, that ten is the limit. That is the very unpleasant part. ... I am shocked, that even my family doctor doesn't have the power to convince them that I need convalescent care or higher care. Even one hour with the PWS is not enough for all the eating, changing and the cleaning. It just runs out. I have 15 minutes to eat and she has to sometime hand-feed me because I am too weak or it is too painful to eat. **TJ FM ME MCS**

Jim would have to leave me a sandwich, and we lived in ... a side split. But he had to leave me my sandwich for lunch at my bedside and make sure I had enough to drink until he got home because the chances of me getting down stairs were slim to none. **Jane ME FM**

I had no idea how to access any help for grocery shopping or phone counseling, because sometimes I would go ten to twelve days without seeing or talking to a human being and not well enough to leave my house to drive or walk. **Gayle ME**

I haven't been able to get eggs for a year because these guys are carrying eggs with date stamps and the stuff gets into the eggs and I can't eat them. There's basic food things I can't get. **Linda S MCS** working with accommodation.

#### **EVEN INDIVIDUALS STILL EMPLOYED CANNOT SUPPORT COSTS ON THEIR OWN**

I earn too much money to get social support from the government or to benefit from any government programs, but I don't have enough money to pay for all of what I have to pay for, especially when I'm on medications that cost \$600 a month and Trillium doesn't cover it. So I'm stuck in the middle and don't have any social support for, you know, things like: I need orthotics. I need the dentist. I need,

you know, because I have dizzy spells and I can be unsteady on my feet, I get a little bit of support for the walker for ADP, but I don't get support for the shower [pole], which is really something that I need support for. And getting on a list for any kind of community housing is not something that I'm a priority for. So even though I have to support myself with no other income than what I'm getting, I don't qualify for any other support financially. **Connie FM ME nurse**

Community informants identified a number of social determinants that are especially affected by their condition and the current deficits in care and support. These include disability benefits (societal and service recognition through accommodation, law, custom); income security, employment and social status; food security; housing security; social safety support networks (personal support services, family and social inclusion/exclusion, friendships, community involvement, isolation); emotional/psychological wellbeing; gender equality; physical environment and education.

### THE QUANTITATIVE DATA AND THE QUALITATIVE DATA ('COMMUNITY CONSULTATION') CORROBORATE ONE ANOTHER

'Despite [study limitations], a consistent pattern in relation to ES/MCS, FM and ME/CFS clearly emerged across a variety of factors related to measures of disability, socioeconomic status, health care utilization and unmet health care needs. There was also consistency in results between the other sources of data included in this report and the population-based CCHS. Collectively the findings show that those living with ES/MCS, FM and/or ME/CFS represent a very large, disabled and disadvantaged cohort, that have specific health care needs that are not being met. Resultant impacts are likely far reaching and significantly affect families/caregivers, communities and society.' (From E. Halapy, *The Quantitative Data*, 2013)

## 7.2 POSITIVE EXPERIENCES WITH HEALTH PROVIDERS: EXPERT CARE IS LIFE-CHANGING

By far, the most important finding for future state planning was this: where study participants did find expert health professionals who were familiar with their conditions, they had exceptional, life-changing, often life-saving positive support which raised their quality of life, and in significant cases, restored productivity and ability to function in many social spheres.

### SPECIALIST CARE FOUND TO BE LIFE-CHANGING AND LIFE-SAVING

There was that understanding and my life started to change. ... The thing that really helped me was Dr. Bested's book that she wrote and the therapy as far as measuring your activity. I did that two years ago, and now I actually have good days. I have had more days that I could even go back to work. **Jane ME FM**

It [Dr. A's treatment] worked. ... After the IV I could talk. I wasn't slurring my words anymore. ... Also, she impressed me because she asked me how I felt. ... In my experience with doctors, I've never met a doctor [before] that really cared about the patient. ... She's a wonderful person, a wonderful doctor. **Gabrielle FM MCS**

Another highly noteworthy finding is that even where health professionals were not experts, but compassionate and willing to learn about the conditions, participants reported major positive impacts. Likewise, when health professionals had personal experience with the conditions (either living with them, or related to those living with them) they provided good care. In other words, models of good care do exist, and they can be provided. We are not starting from zero.

## 7.3 NEGATIVE FINDINGS ON HEALTH CARE AND PARTICIPANT RECOMMENDATIONS FOR CHANGE

### YEARS OF SUFFERING BEFORE DIAGNOSIS IS THE NORM

My main issue from the start was the diagnosis. I had it for almost 17 years before [a physician] did a diagnosis on it. I went through all kinds of testing and this, that and everything else ... to find out what was wrong with me. **Bill ME**

Participants also provided detailed information about negative experiences with physicians and health care providers, per se, and gave their recommendations for improvement and change. Negative experiences were the norm, and featured doctors' lack of knowledge about the conditions with inability to diagnose or treat correctly. This resulted in neglect or iatrogenesis, lack of compassion and respect and persistent and widespread stigmatization of patients as either emotionally disturbed or hypochondriacs, or both. This was very damaging to patients and very damaging to their families and made their overall situation much worse. Participants identified the fundamental cause of this complex of problems as a lack of medical education. They identified physicians as gatekeepers and legitimizers within the system as a whole, and repeatedly spoke of the need for both a medical and systemic shift. They noted the stigmatization of physicians who were expert in and cared for these patients.

The participants' recommendations for changes in health care and social service provision are folded into Part Two, below.

## 8 FOUR SPECIAL ADDITIONAL ISSUES EMERGED - CHILDREN, WOMEN, INSTITUTIONAL DENIAL, ES/MCS HOUSING

### 8.1 CHILDREN

**Children and youth** are also afflicted with these conditions. UK and European studies suggest children with ME/CFS and FM suffer in the same numbers as their older counterparts; and impressionistically (EHCD, patients' organization reports, physician reports), there are also many with ES/MCS.



#### PREVALENCE OF ME/CFS AND FM IN CHILDREN<sup>4</sup>

ME/CFS also occurs in children, especially adolescents. ME/CFS is relatively common in young people (prevalence 0.4% to 2.0%)... [though] lower than among adults and the prognosis is better. However, they report significantly more illness impairment, especially in school attendance, than those with other chronic conditions such as juvenile idiopathic arthritis and emotional disorders. ...

In children, [FM] is more common in prepubertal or adolescent girls, and estimates for the prevalence of juvenile fibromyalgia range from 1.3-6.2 percent. Juvenile fibromyalgia is similar to the adult presentation and is characterized by persistent and widespread musculoskeletal pain, sleep difficulty, fatigue, and mood disturbance. Patients with juvenile fibromyalgia experience substantial impairment in physical, school, social, and emotional functioning and the majority of them continue to have ongoing symptoms and functional disability into late adolescence and early adulthood.

- John Molot, MD, FCPC, *Chronic, Complex Conditions: Academic and Clinical Perspectives*, 2013

John Molot cites no figures for ES/MCS. Nevertheless, the significant numbers of children with the conditions who are seen by the Environmental Health Centre - Dallas's children's health program, as well as the many cases documented over decades by board-certified environmental medical specialist and pediatric allergist Doris Rapp, documented in several books,<sup>5</sup> give the impression that prevalence is as great with ES/MCS among children and youth as with the other two conditions.

As schools are equipped with Wi-Fi, the number of children with ES seems to be increasing yet Ontario has no way of tracking or treating these children. Pediatricians and family physicians lack for education and training. Not only are parents with sick children not supported in any way; they frequently find physicians blaming their 'bad parenting' for their children's 'psychosomatic' conditions. Children with sick parents also suffer in many ways that can affect them for life. Accommodation at school for children with the disabilities is needed; support to parents is needed.

#### PARENTS FEEL ABANDONED AND DISRESPECTED

One recent study assessed the impact of adolescent ME/CFS on the parents. They described anger and frustration as consequences of struggling to access health care for their child. The anger and frustration was attributed to their interactions with the medical profession, feeling helpless and not knowing where to turn to for support and practical advice. Furthermore, the parents described problems with judgmental blaming attitudes by physicians, which made them feel abandoned and disrespected. They specifically described doctors as blaming their parenting.<sup>6</sup>

<sup>4</sup> John Molot, MD, FCPC, 'Chronic, Complex Conditions: Academic and Clinical Perspectives, 2013. Dr. Molot is a staff physician of the Environmental Health Clinic, situated at Women's College Hospital in Toronto.

<sup>5</sup> Doris Rapp, MD, (board-certified environmental medical specialist and pediatric allergist): *Is This Your Child?* (New York: William Morrow & Co., 1991); *Is This Your Child's World?: How You Can Fix the Schools and Homes That Are Making Your Children Sick* (New York: Bantam, 1997); *Our Toxic World - A Wake Up Call* (Buffalo: Environmental Medical Research Foundation, 2004).

<sup>6</sup> Molot, 2013.

## RECOMMENDATIONS REGARDING CHILDREN

- Ontario's new initiatives (OCEEH, aligned efforts with the MOHLTC and health care system) should place a high priority on developing a full range of care and support policies and programs for children and their families.
- OCEEH staffing must include expertise in children - from services, through to policy.
- Inter-ministerial mechanisms (MOHLTC, MCSS, MCYS, MOE) to align rights, benefits, policies, programs and supports so as to make them comparable to those available to children and parents in the comparator groups should be established, led by the OCEEH.
- The OCEEH should build on partnerships already begun by the Environmental Health Clinic, with organizations dedicated to children's health and environmental health. It is important for such organizations to understand that the CELCs are also worthy - indeed overdue - for inclusion in their initiatives and programs.

## 8.2 WOMEN

**Women** have a number of physiological features that make them more susceptible to these disorders under everyday conditions. They outnumber men by a rough ratio of 3:1 (though estimates range higher in some studies of FM). At the same time, a pronounced sexist bias against women exists among many service providers, as a result of which women's claims to illness (pain, fatigue, chemical reactions, multi-system ailments) are repeatedly discounted and disrespected. The discounting behavior in our communities was most frequently expressed as women's 'tendency to complain' (hypochondria) or because the women were 'hormonal'. These findings are in keeping with similar findings with respect to women both with these and overlapping conditions, and better-recognized health problems (e.g. coronary syndromes), well established in the medical literature across health care provision in other areas. The lack of services and lack of research reflect systemic sexism. Research is urgent, and dollars should be apportioned relative to prevalence of disorders in the population.

### PHYSICIAN DISCOUNTING BEHAVIOURS TIED TO SEXIST PERCEPTIONS OF WOMEN

There have been two particular doctors that, when I mentioned that I had ME ... they kind of ... gave me the look: here's another hysterical woman, post-menopausal type, going mmm. **Elizabeth ME**

I have been told twice by a doctor, one recently, that it is an issue of chemicals in my brain and my period. Is this the 1800s here or what! Women's illnesses get less money for research and less respect and a lot of times, women's illnesses, if they have not found what is wrong with people, they are

considered to be psychosomatic in some way. **Gayle ME**

## RECOMMENDATIONS REGARDING WOMEN

- The OCEEH should seek meaningful partnerships and joint projects with key actors who have the interest and capacity to effect change, from the front lines of care to the broad arena of consumer protection and pollution regulation. Partnerships should be sought with:
- PUBLIC HEALTH - from the central provincial departments, through the hub and to local and regional offices, through the spokes, to devise initiatives addressing indicated issues.
- THE MINISTRY OF THE ENVIRONMENT - particularly those offices and individuals who are familiar with the types of chemicals implicated in women's conditions, and found in women's workplaces and in domestic use - to prompt timely policy change.
- ENVIRONMENTAL ORGANIZATIONS IN THE NON-PROFIT SECTOR - which have, in fact, led in raising issues of pollution and regulation, including in harms of 'everyday chemicals' but have not fully integrated the gender dimension, or understood the CELCs as legitimate and environmentally -related conditions.
- WOMEN'S HEALTH AND BROADER ADVOCACY ORGANIZATIONS - both academic and popular - to assist them to incorporate these issues into their understandings and their mandates.

## 8.3 STIGMA AND INSTITUTIONAL DENIAL

The most troubling and most common finding of the community consultation was that the level of professional ignorance, reflected in persistence in assessing the CELCs as emotional disturbance or forms of hypochondria, is exceedingly widespread, and affects men as well as women. The great majority of community informants described resultant very negative attitudes linked to tangible stigmatization, discrimination and even active hostility at times, in every social sphere, including in the health and social support systems. These attitudes were identified as a fundamental barrier to care.

### PROFESSIONAL IGNORANCE LEADS TO DISBELIEF, DENIAL AND INAPPROPRIATE TREATMENT...

I had a specialist. I looked into his face and I said, 'you think that I'm making all this up, that I'm crazy.' And he looked at me and he said, 'yeah'. This was a specialist at St. Michael's... It really is shocking. As a nurse, it's shocking. It's just shocking. **MaryLou ME FM MCS**

When I went to see the endocrinologist, he would simply say I'm probably depressed. If I've got some kind of family problems, I should see a psychiatrist or I should get on the antidepressants. And if the antidepressants don't seem to be working, well, I should take them longer or I should be trying something else. He didn't see anything beyond that little box that he's taught to think within. ... And they're [specialists] both in the assembly-line type of medicine, but they allow you so many minutes

and then they kick you out the door. So anytime I went to any other specialist, I mean ... Dr. H. sent me to a respirologist and he did all his [tests] ... they always come up with, 'see the psychiatrist'. ... [I]f you don't fall within some bad ranges within their particular blood testing that they send you out for, then their assumption is that you're fine and they just lose interest, 'see a psychiatrist,' type of thing. **Frank ME FM**

### ...AND CONTEMPT, DERISION AND SHUNNING

I am considered one of the crazy people - it is akin to having old friends of mine cross the street so that they don't have to bump into me. You get the same sort of treatment in some medical settings. **John ME FM**

I was so sick once I went to the hospital emergency because I thought I was having a heart attack, I had so much pressure in the top half of my body. And the doctor there laughed at me ... and you know, you just want to hit him. **Theresa ME**

Before my diagnoses, when I was going in [to doctors] constantly for complaints of sore throat[s], swollen lymph nodes and the feeling that I'm coming down with something, it was such a frequent complaint that one of my doctors sent me to a throat specialist. It was a very quick visit. It was about five minutes. He took a lighted thing and looked down my throat and said in disgust, his tone was full of disgust, and he said, 'there's nothing wrong with you,' and he sent me home. **Sharon ME FM**

The persistence of the psychogenic explanation for the CELCs derives from obsolete and incorrect ideas, including misunderstanding of the nature of different types of stress, mind/body divisions and the actual injurious agents involved. However, the strength of institutional denial and resistance to acceptance of new understandings in these fields displays features that discount science and patient/public interest in favour of a host of other factors. A case study of such factors, in play with a patient population that is 93% male and that experienced extreme environmental (toxic chemical) exposures, can be found in the evolution of those showing symptoms of what has come to be called Gulf War-related illness (GWRI) stemming from 1991, and these include CELC type syndromes. These were ailments that the affected individuals - primarily fit, young males, fully 25 percent of the 700,000 fighting force, but also and disproportionately, women - had not experienced prior to service in the Gulf,<sup>7</sup> and have not been produced in cohorts from other wars in which these chemical exposures were not present.

### THE CELCs EMERGED AS SYMPTOMS CLUSTERS IN GULF WAR RELATED ILLNESS

... Veterans' claims were supported by studies showing an excess of self-reported symptoms among deployed versus non-deployed troops, including chronic diarrhea, other gastrointestinal symptoms, memory loss, concentration difficulty, trouble finding words, fatigue, depression, PTSD, bronchitis, asthma, alcohol trouble, sexual discomfort, and anxiety."<sup>8</sup>

<sup>7</sup> Phil Brown, et al, 'A Narrowing Gulf of Difference? Disputes and Discoveries of Gulf War-Related Illnesses,' *Contested Illnesses: Citizens, Science, and Health Social Movements*, eds. Phil Brown, Rachel Morello-Frosch, Stephen Zavestoski, and the Contested Illnesses Research Group (Berkeley, Los Angeles, London: University of California Press, 2012) 79-80. The chapter is a discussion of the evolution of GWRI issues from 1995-2011.

<sup>8</sup> Ibid, p. 89.

The GWRI experience holds a number of important lessons. Most important: a) Given intense enough toxic exposures, anyone can develop the conditions; and b) official and institutional denials cannot be accepted at face value. When patients report symptoms, these must be taken seriously and addressed appropriately.

#### RECOMMENDATIONS REGARDING PHYSICIANS AND OTHER HEALTH CARE PROFESSIONALS

- Rapidly develop curriculum in the CELCs for physicians and other health care professionals.
- Require competence in the conditions during professional training and/or in continuing education, as for comparator health conditions.
- Require competence in the conditions, as appropriate to the profession, for employment by the public health care system, as for comparator health conditions.

### 8.4 SPECIAL ISSUES FOR ES/MCS

The need for air quality that is free of most 'everyday chemicals' now ubiquitous in the built environment presents a staggering level of challenge with respect to housing - be it ordinary residential, supportive and assisted, or long-term care and palliative - for those living with ES/MCS that has not been understood or addressed by any health or social service providers. It represents a major, ongoing and developing crisis for those with the condition. Good residential air quality supports stabilization and improvement; bad air quality creates suffering and deterioration. For this group, housing is a medical need, per se.

#### HOUSING IS OFTEN A NIGHTMARE FOR THOSE WITH ES/MCS

##### DR. ANN McCAMPBELL, CHAIR, NEW MEXICO TASK FORCE ON MCS<sup>9</sup>

'Many people with MCS have lost everything – including their health, homes, careers, savings, and families. They are chronically ill and struggle to obtain the basic necessities of life, such as food, water, clothing, housing, and automobiles that they can tolerate. Finding housing that does not make them sicker, that is, housing that is not contaminated with pesticides, perfume, cleaning products, cigarette smoke residues, new carpets or paint, and formaldehyde-containing building products, is especially difficult. Many people with MCS live in cars, tents, and porches at some time during the course of their illness. In addition, people with MCS usually have financial difficulties. One of the most unjust aspects of the anti-MCS movement is that many expert witnesses are paid \$500 per hour to testify against people disabled with MCS who are seeking that much money to live on per month.'

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<sup>9</sup> Ann McCampbell, MD, 'Multiple Chemical Sensitivities Under Siege,' *Townsend Letter for Doctors and Patients*, January 2001, Issue #210; reprinted with permission, [www.townsendletter.com](http://www.townsendletter.com). For a wealth of information on MCS, chemicals and the chemical industry, see <http://annmccampbell.com/publicationswritings/publication-1/>



## 9 TWO BROAD TYPES OF RECOMMENDATIONS

Currently, no dedicated services are in place to assist those living with the CELCs except for a small, over-burdened assessment clinic in downtown Toronto for adults only. There are no programs for children. Overall and taken as a whole, there is virtually no capacity in the public health care system to deal with these conditions. The current state is a void in support with only a few tiny islands of assistance, most privately paid, for those who can reach them.

Small or piece-meal initiatives alone are unlikely to solve this 'void in service'. Instead, a whole-system strategy for the 'normalization' of these conditions - for recognition, inclusion and equity - is urgent and imperative. Two broad types of recommendations are proposed in the full report.

(1) **Direct services** - through a new and dedicated network of service delivery, based in primary care, comprising the OCEEH hub, its regional spokes, and, eventually the whole primary care system in the province. Direct service recommendations generally correspond to 'Pillar 1' in the OCEEH business case proposal.

(2) **Barrier-removing policy shifts in the MOHLTC, broader health care system and in relevant and related government ministries** - to accelerate change and secure gains. These 'strategic enablers' generally correspond to 'Pillar 2' in the OCEEH business case proposal.

## 10 DIRECT SERVICES

The community consultation above all, fundamentally in keeping with a number of other key sources, clearly established a set of recommendations for direct services. These recommendations were also in keeping with issues emerging from the literature and from the experience of patient organizations. For how these are to be provided for, see below, 'Part Two: The Proposed Ontario Centre of Excellence in Environmental Health 'Pyramid''. Tightly summarized, they are:

### ➤ **HEALTH PROVIDERS and SYSTEM NAVIGATORS**

Trained physician and nurse practitioner care for assessment, diagnosis and treatment; trained supports from other health professionals to create comprehensive and integrated care; outreach to PCPs in the community to support patients; outreach to other HSPs in community to create appropriate reception for clients.

### ➤ **MODALITIES OF HEALTH CARE**

Medical diagnostics and treatments, including prescription pharmaceuticals and nutraceuticals for management of sleep, hormonal imbalances, infections, toxicity, nutrition and exercise; physiotherapy, chiropractic, massage, acupuncture, nutrition; detoxification supports; oxygen therapy; nutritional and immune enhancing IVs; mind-body modalities; self-management activities; safe hospital reception for ES/MCS; quiet resting rooms for ME/CFS and 'clean rooms' for ES/MCS in all major para-public sites and health care facilities; condition-competent hospital services for all conditions - emergency, acute, elective needs; training for para-medics and system navigation/advocacy with other HSPs, notably hospitals and CCACs.

### ➤ **SOCIAL SUPPORTS ADDRESSING SOCIAL DETERMINANTS OF HEALTH**

Condition-competent, fragrance-free, trained personal support workers for personal hygiene and health (e.g., blood draws), mobility needs, laundry, cleaning, shopping and maintenance; services for food security; services for transportation (appointments, necessities, social needs - isolation reduction); support services to family caregivers: education, peer-group, respite support services to sick parents with children; support services to parents with sick children income support services (social assistance, ODSP, WSIB, etc.); legal assistance to access these; psychological supports; advocacy for workplace, daycare and educational institutions, legal support services; advocacy for ES/MCS safe housing - shelters, residential, supportive- assisted, long-term care, palliative; advocacy for ME/CFS & FM competent and friendly social housing assisted living and long term care; personals support services for residence search; advocacy and legal assistance with landlords when needed.

## 11 'STRATEGIC ENABLERS' TO REMOVE SYSTEMIC BARRIERS

The hub and spokes of the proposed OCEEH will not be able to provide all needed direct services to its clients, even at full strength some years into the future. Some other needed providers are the CCACs, MCSS disability programs, legal aid, WSIB. Certainly, the spokes will not be able to service all Ontarians. Nor will the OCEEH on its own be able to undo many of the more damaging attitudes and systemic barriers faced by those living with the CELCs. As well, if the OCEEH network provides system navigation to assist clients in searching for these appropriate supports as it wishes to do, but those supports are not available to clients beyond the OCEEH network itself, clients will come to a dead end, causing outcomes to suffer. Therefore, certain key policy shifts across government - 'strategic enablers' - are critical companion pieces to changes in direct service provision through the OCEEH.

Overall, and to enable all other policy shifts, government should ensure that adequate recognition of the CELCs as chronic health conditions and as disabilities is instituted, supported and enforced in all appropriate arenas - be it in the provision of health and social services or in developing norms and regulations with respect to employment and income related issues, across the public and para-public sectors; and in the private sector and society more generally. Shifts in human rights policies and in law need to be identified and enacted, involving the Ontario Human Rights Commission and the Ministry of the Attorney General. Initiatives to promote health and prevent illness must involve the Ministry of the Environment as well as the MOHLTC and MCSS. At a glance, here are the key policy changes recommended.

### 11.1 RECOGNIZE CELCs AS CHRONIC HEALTH CONDITIONS AND AS DISABILITIES

#### ***SYSTEMIC POLICY ALIGNMENT FOR RECOGNITION OF THE THREE CONDITIONS AS CHRONIC HEALTH DISORDERS***

##### **ONTARIO MINISTRY OF HEALTH AND LONG TERM CARE**

- Add diagnostic and service code for ES/MCS to existing codes for ME/CFS

and FM.

- Establish Clinical guidelines and pathways, other medical requirements established.
- Officially include ES/MCS, ME/CFS AND FM in chronic disease management program (CDMP) and mandate of CCAS; educate, train and fund accordingly.
- Implement key ministry priorities re CELCs in all relevant sites and include in all relevant policies.
- Develop and issue centralized policy directives to all ministry bodies, LHINS and HSPs re need to develop capacity, respect human rights disability needs of three populations.
- Provide public assistance to OCEEH to include peer support services and patient-led patient outreach, community building, patient involvement in program planning and governance to launch and sustain strong presence for development of patient-centred care throughout system.
- As above, and central policy directives to HSPs to provide safe reception (air quality, resting spaces, trained staff) in all facilities.

#### **MINISTRY OF THE ENVIRONMENT**

- Establish and implement new standards banning and/or regulating harmful everyday chemicals - minimal standards: EU R.E.A.C.H. protocols - in all appropriate sites and products.
- Regulate air quality in workplaces previously unregulated, predominantly women's workplaces (e.g., dry-cleaning, nail salons, cleaning services) to prevent everyday poisoning.
- Provide financial support to OCEEH's epidemiological and basic research.

#### ***SYSTEMIC POLICY ALIGNMENT FOR RECOGNITION OF THE THREE CONDITIONS AS DISABILITIES***

#### **ONTARIO HUMAN RIGHTS COMMISSION AND MINISTRY OF THE ATTORNEY GENERAL**

- Develop Commission policy to be deployed in evaluating all cases prior to proceeding with mediations and tribunals; consolidate all cases according to primary diagnoses and needs; communicate policies to all relevant agencies and the public.
- Develop and *enforce* laws and precedents that recognize the CELCs as illnesses (chronic health conditions); ensure inclusion of three conditions in all laws pertaining to illness and disability norms, rights and benefits.

#### **MINISTRY OF COMMUNITY AND SOCIAL SERVICES and MINISTRY OF CHILDREN AND YOUTH SERVICES**

Integrate care and/or support for the CELCs and their specific needs in

- Ontario Disability Support Program: provide rent supplement for ES/MCS; develop employment support.
- Assistive Devices Program: Revise to include specific needs of CELCs.
- Making Ontario Accessible: Develop accommodation guidelines for workplaces, schools, all government services.
- Community services: Ensure all such services recognize, include and create equity for people with the 3 CELCs.
- Tax credits and benefits: Benefit and tax credit programs for people with these disabilities.
- Social Housing: provide shelters, social and assisted-living housing for those with the CELCs who need assistance with the costs of shelter, addressing special mobility and air quality needs.

#### **MINISTRY OF EDUCATION and MINISTRY OF TRAINING, COLLEGES AND UNIVERSITIES**

Schools, colleges and universities shape the curriculum of the health professions, which needs to be aligned. They also provide health services to students and, in the latter case, faculty, so these also need to be aligned. These institutions are also very important sites of public education for students and families.

#### **MINISTRY OF THE ENVIRONMENT**

A critical actor in addressing issues of public health and safety with respect to environmental problems, among which pollution of many kinds is a very important component. Alignment is needed to bring about recognition of the CELCs as illnesses and resulting disabilities involving harms from many 'everyday' chemicals.

#### **MINISTRY OF FINANCE**

Regulates insurance companies. **Medical and work-related insurance policies** have categories for the comparator conditions, and benefits are administered accordingly.

#### **MINISTRY OF LABOUR**

- Establish standards for workplace accommodation as feasible ('undue hardship' test) for each of the conditions/disabilities; enforcement of these through consistent decisions
- Inclusion of conditions in disability incentives for employers.
- Workplace Safety and Insurance Board (WSIB) - same entitlements and benefits as for other conditions/disabilities; equity of ease of claiming benefits.
- Implement regulation of toxic chemicals in women's workplaces.

## 11.2 PROFESSIONAL, PUBLIC SERVICE, GENERAL PUBLIC AND PATIENTS AND CAREGIVERS EDUCATIONAL CAMPAIGNS

### **PUBLIC AND PROFESSIONAL AWARENESS OF THE CELCs AS CHRONIC DISEASES, AS DISABILITIES AND AS HEALTH PROBLEMS REQUIRING VIGILANCE AND ACCEPTANCE**

MOHLTC-led, government-supported awareness campaigns for public and para-public sectors, for health and other professionals, for Ontario's citizens and for patients and their caregivers need to be initiated and maintained, as for other health conditions. These would have a rapid normalizing function at every level and create societal and professional vigilance.

- Public-interest awareness campaigns, mounted by government in collaboration with patient organization(s) to kick-start and maintain momentum of changing ideas and to establish public vigilance and acceptance.
- Assist individuals, families, primary care providers, specialists, educators and so forth to learn about conditions and take appropriate action.
- Models: ongoing campaigns on heart disease & stroke, diabetes, dementia, cancer.

## 12 THE OCEEH EVOLVING MODEL

[See Part 2, page 28, immediately following.](#)

## 13 THE NEED TO SUPPORT ROBUST PATIENTS' ORGANIZATIONS

In the community consultation, the need for greater public, government, health professional and media awareness was raised and related by many to the need for a strong patient association like those in place for other, better-recognized, disorders. Such an organization was rightfully seen as a corollary and partner to government initiatives, provider partners and as a key need in competing for resources. Yet due to a number of factors combining levels of illness and poverty in the community with the profound effects of stigmatization, no patient organization has succeeded in achieving the size or influence of patients' organizations for people with conditions of comparable severity and established recognition.

As a factor negatively affecting the progress of help for the CELCs, this permanent 'stunting' cannot be underestimated. Strengthening patients' organizations, then, is another critical factor to overcome in achieving the larger agenda. Recommendations for co-location of patients' organizations with the hub and spokes, for funding to them to develop peer and family support programs and to assist them to participate as key partners in public awareness campaigns are included in the full report.

## PART TWO: THE PROPOSED ONTARIO CENTRE OF EXCELLENCE IN ENVIRONMENTAL HEALTH

### 14 PATIENT VISIONARIES PRESENT THE MODEL OF CARE

#### TORONTO FOCUS GROUP EXCHANGE ON A VISION FOR CARE AND SUPPORT

I've got the image. It's an old school that has two or three floors, and you can have it all there. You would have team meetings with the person so that if I was the patient coming in and these were my symptoms and I had been referred to do so, so, and so and I had done so, so, and so, then we would sit down with those practitioners and say with the client, 'How did that work for you? What else do we need to do?' Have access to community care through that program, and have volunteers who are willing to do things like transportation. Like, Senior Link has transportation that's free to the seniors. The majority of it would be covered by the government, and that we would get private funding somehow that's non-pharmaceutical. One of the floors could be a place where people could actually be admitted for respite care. That's my dream. **Connie FM ME**

I would add to that, ... because a lot of people don't have access to go to a central place, you have satellite, neighbourhood things where you have a tai chi class, you have a swimming pool, you have right in the neighbourhoods. And so it builds community, but it also is easier for people who have trouble getting from one place to another. **Kim MCS**

They should have an aqua fit pool there so that we can do exercises through water. I have been for that, but by the time I come home, I'm exhausted, but it's really great. And, plus, they should have a legal clinic there. ... I don't know disability tax credit. ... So it should have a perfect building and a place to live and relax and a library there and music there. **Bina FM**

If you listen to a lot of people, it took them ten years, 40 doctors before she was diagnosed. If we had a treatment centre where we can go to, right, we don't have to visit those 40 doctors. We just go there. And that 40 doctors of fees is set off, so it's realigned. The money is realigned into a treatment centre where people can go to seek help. **Cecilia FM ME**

I know people are talking about realigning funds. ... I think it's half a million dollars a year that's available for the environmental health clinic and research. That's it. **Sophie FM ME MCS**

What we need is a Centre of Excellence of some sort. ... Within the centre, well, sort of an expanded MEAO, with Meals on Wheels type programs and lists of names and phone numbers for all the services that we might require, including legal, social workers, social assistance, transportation, that type of thing. And almost like assisted living, something similar to CCAC. **Frank ME FM**

Actually, the model at the Wasser Pain clinic is not a bad one because they integrate traditional medicine with complementary medicine and various other cognitive techniques. ... There is no sort of integrated seamless access to ongoing treatment, especially for MCS issues, so it really becomes just a patchwork of whatever you can pull together, which is totally unacceptable. I don't have access to OHIP drugs that would support my treatments, because these are not approved by the government as being in the non-experimental category. I don't even consider that I have access to the OHIP system unless I have a traditional problem that has arisen out of the disabilities. **Elva MCS FM ME**

THE most important deliverable for MEAO's OTF funded 'Improving quality of care and support project' was to design a model of care, and a delivery system for that care. Fundamentally, this objective overlapped so substantially with that of the MOHLTC funded project to create a new 'Ontario Centre of Excellence in Environmental Health' (OCEEH), that it was decided to merge the two projects and proceed eventually to unified objectives. Here **is the model that emerged from the overlapping OTF and BCP processes, and the several years of patient-physician collaboration that preceded these.**

## 15 TWO TYPES OF PRINCIPLES - FOR CHANGE AND FOR CARE

Two types of principles emerged in setting out recommended changes in the broader process.

**Principles to create new capacity and equalize access:** recognition, inclusion, equity, normalization, innovation, environmental health (health promotion and disease prevention and new education and training), 'the right care, at the right time, in the right place' ('value for health care' dollars and 'as close to home as possible').

**Principles to guide how care should be delivered:** person-centred and patient-led, comprehensive, inter-professional, integrated across the health and social services systems, social determinants of health supported, community development model.

## 16 PURPOSE AND OBJECTIVES OF THE OCEEH 'PYRAMID'

### PURPOSE

- To serve the health and social needs of Ontarians of all ages with complex, chronic environmentally-linked conditions with a focus on:

- ME/CFS
- FM
- ES/MCS

This corresponds to Pillar 1 of the business case - 'A System of Care with its Foundation in Primary Care'.

- To advance the goals of 'recognition, inclusion and equity' in rights, benefits, services, programs, policies and facilities in the public and para-public sectors, and in society. To serve the whole province.

This corresponds to Pillar 2 of the business case - 'Driving Systemic Level Change'.

### **FROM THE OCEEH BUSINESS CASE PROPOSAL, OCTOBER 2013**

#### **IN THE OCEEH SYSTEM...**

- Environmental health conditions are 'normalized' and recognized as a chronic disease with



supports equitable to other major chronic conditions.

- People receive holistic, appropriate, comprehensive interprofessional primary health care with appropriate health and social services; and, when necessary, have access to trained specialists as well.
- Services are available at the right place at the right time from the right provider. All health professionals receive formal training, integrated into their foundational education, and all primary care providers are trained to assess, diagnose and treat.
- Treatment for more complex conditions is available closer to home in safe facilities.
- Appropriate and safe housing and treatment facilities, including supportive housing, long-term care homes and hospitals, are available.
- A spirit of enquiry, innovation and evaluation pervades.

## 17 STRUCTURE AND FUNCTIONS

### GOVERNANCE

- **The Hub** is self-governed, though affiliated to teaching hospital and medical schools.
- The **Spokes** are located inside CHCs; with a commitment to recruit clients and/or family members into governance structures to be represented at that level.

### FUNCTIONS OF THE WHOLE CENTRE/NETWORK

- Health and social services
- Research and evaluation
- Education, professional, public sector, general public, patient outreach and community development
- Policy development

Communications needs for each of these will require support.

### FACILITIES AND NETWORK

#### ➤ TOP LEVEL - HUB - SPECIALIST CLINICAL SERVICES

**Affiliated to University of Toronto medical school and the Dalla Lana Faculty for Public Health; in partnerships with other health professional schools; affiliated to a teaching hospital, yet to be designated; accountable to the TC LHIN**

- Referral centre for patients across the province; travel grants subsidized
- Assess, diagnose, case manage complex and difficult patients, including with extensive inter-professional team of affiliated specialists
- Develops care plan, on site and/or with PCPs
- Treats cases needing tertiary care levels on-site

- ES/MCS-safe site and ME/CFS & FM-friendly lodge for those who need residential accommodation

➤ **MIDDLE LEVEL - SPOKES - PRIMARY AND SECONDARY SERVICES - SELECTED REGIONS**  
**FOR CLIENTS: DIRECT SERVICES**

**Situated in selected CHCs with special alterations to make spaces ES/MCS-friendly; affiliated to local health education facilities (colleges and universities). The spokes:**

- Provide trained primary and secondary care providers for day-to-day care - physicians, nurses, other health professions with best and promising practices
- Assess, diagnose, case manage and provide system navigation for clients
- Refer to and collaborate with hub specialists to develop and implement monitor care plans, refer to local health and social support resources
- Provide placements for residents and other students in regional health professional colleges and universities
- ES/MCS-friendly sites for treatment and programs

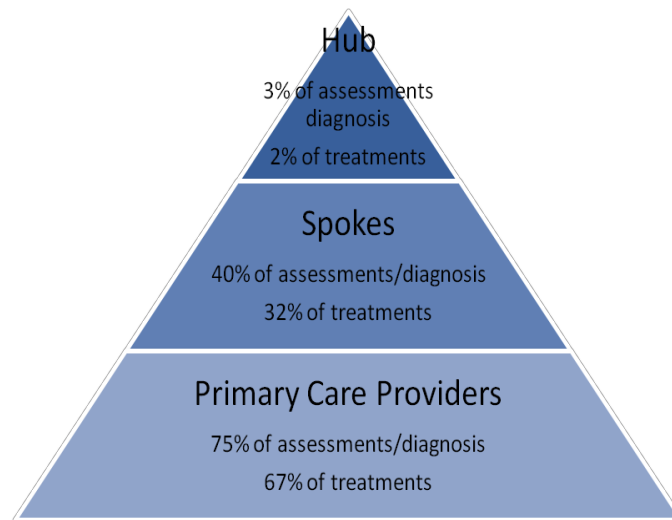
**FOR REGIONAL AND LOCAL HEALTH AND SOCIAL SERVICE PROVIDERS: REFERRALS AND RESOURCES**

- Communications initiatives, including with partners such as public health, the relevant LHIN, main HSPs and PCPs to spread the word about the availability of 'main hub' services
- Ongoing referral centres and health provider education resources for the region

➤ **BASE LEVEL: PRIMARY CARE PROVIDERS - THROUGHOUT THE PROVINCE**

**A key objective of the OCEEH, through its own educational activities, and by enabling the province and health professional schools to provide excellent curriculum, is to rapidly develop expertise among physicians, especially primary care providers, with respect to the three conditions.**

- Even at full capacity the OCEEH network will not be able to reach all in need; Ontario is a vast province and the nature of the chronic conditions make travel difficult; therefore PCPs need to 'fill the spaces' between spokes
- Critical for early detection and intervention that all PCPs have a foundation in the conditions
- Phasing in of the OCEEH should include targeting of selected PCPS ( beginning with physicians who have shown an interest in environmental health) into the CHC educational program so that the PCP pyramid is complete with a larger network at its base



## 18 COMPENDIUM OF CLINICAL SERVICES PROVIDED BY THE SPOKES - FROM A PATIENT PERSPECTIVE

To be provided either on-site in the spokes or obtained through system navigation and advocacy at the regional and local levels.

### ➤ HEALTH-RELATED TREATMENT MODALITIES AND TREATMENT-RELATED SERVICES

- Physiotherapy, chiropractic, massage, acupuncture, nutrition
- Detoxification supports
- Psychological supports
- Mind-body modalities
- Self-management activities
- Family support activities
- Safe hospital reception for ES/MCS
- Condition-competent hospital services for all conditions - emergency, acute, elective needs

### ➤ SOCIAL SUPPORTS ADDRESSING SOCIAL DETERMINANTS OF HEALTH

- Condition-competent, fragrance-free, trained personal support workers for personal hygiene and health (e.g., blood draws), mobility needs, laundry, cleaning, shopping and maintenance
- Services for food security
- Services for transportation (appointments, necessities, social needs - isolation reduction)
- Support services to family caregivers: education, peer-group, respite
- Support services to sick parents with children; support services to parents with sick children
- Income support services (social assistance, ODSP, WSIB, etc.)
- Advocacy for workplace, school accommodation, legal support services
  - Advocacy with day care and educational institutions
- Advocacy for ES/MCS safe housing - shelters, 'medical', assisted, long-term care

- Advocacy for ME/CFS & FM competent and friendly social housing assisted living and long term care; personal support services for residence search; advocacy with landlords when needed.

## 19 RESEARCH AND EVALUATION

**Lead by the HUB in partnership with the spokes (CHCs) and other primary care providers.**

### ➤ **CLINICAL RESEARCH PRIORTIES FROM PATIENT PERSPECTIVE**

- Assessment and diagnostic modalities - identify, evaluate
- Treatment modalities, treatment programs - identify, evaluate
- Partnership with medical schools for basic research: etiology, biological markers, genetic/epigenetic components
- Develop best practice guidelines and identification of promising practices

### ➤ **EPIDEMIOLOGY RESEARCH**

- Prevalence, incidence, regional variations, occupational variations, age variations, clusters
- Sex/gender factors, age factors, special issues for children, socio-economic variables
- Data as they relate to costs, cost-benefits and to systemic policy shifts needed to remove barriers to equity, care and support

## 20 EDUCATION

**Led by the HUB in partnership with CHCs and interested others. Recognize this is an urgent and major priority for whole-system change as well as for staffing the OCEEH.**

### ➤ **PROFESSIONAL**

- Develop and maintain curriculum for primary care providers, allied health providers, and the spokes
- Provide professional training to the spokes and through fellowships
- Manage and provide elements of professional training for primary care providers and residents, allied health providers and undergraduates

### ➤ **PUBLIC AND PARA-PUBLIC SERVICE**

- Develop and maintain educational initiatives and supporting materials to accelerate systemic change (pro-active service provision, removal of barriers, alignment of rights, benefits, policies, programs)
- Target sites identified in and/or funded by ministries of health, community and social services, children and youth services, education, training, colleges and universities; attorney general and Ontario Human Rights Commission, labour and WSIB, finance

### ➤ **GENERAL PUBLIC**

- Lead development of major campaigns to raise awareness of the three conditions to promote recognition, accommodation and vigilance purposes
- Partner with provincial and local public health

### ➤ **PATIENTS AND FAMILIES - PATIENT OUTREACH AND COMMUNITY DEVELOPMENT)**

- Client and family outreach to advise of availability of services
- Peer support activities (self-management, crisis support, etc.)

- Family support activities, for those with sick family members
- Mechanisms to integrate client input into program development

## **21 COMMUNICATIONS/STAKEHOLDER ENGAGEMENT AND PARTNERSHIP DEVELOPMENT**

OCEEH is a network of facilities and services, however:

- Many new partnerships will be needed to achieve all objectives identified by OCEEH project (e.g., public health, United Way, schools and universities, environmental agencies, children's environmental health projects, government and not-for-profit disability organizations)
- Knowledge translation/communication initiatives and tools needed to effect such partnerships; especially important given lack of any existing materials and lack of awareness or understanding
- Adequate staffing for communications purposes a critical part of the OCEEH to facilitate all other objectives

## **22 POLICY DEVELOPMENT**

- Develop and inform public policy and knowledge translation to accelerate equitable provision of services and to reduce systemic barriers to health equity in identified sites (ministries of health, community and social services, children and youth services, education, training, colleges and universities; attorney general and Ontario Human Rights Commission, labour and WSIB, finance)
- Generate policy and collaborate with all education efforts as indicated
- Dedicate one full-time senior staff to developing a system of safe housing (shelters, supportive housing, assisted housing and long term care) especially for ES/MCS population, also for ME/CFS and FM clients who wish to be included in these facilities

## **23 APPENDICES TO THE FULL REPORT**

To provide extra insight into, or support for, issues we have addressed in the report we have included: the participants in the OCEEH BC project; a remarkable set of prescient but not yet implemented recommendations from the 1985 Ad Hoc Commission of Inquiry into Environmental Hypersensitivity - demonstrating that many of our recommendations were prefigured nearly thirty years ago; excerpts from an FDA study on ME/CFS released in Sept. 2013, corroborating our findings in our consultation; two pieces related to the commercial interest by chemical companies in discrediting the reality of ES/MCS, one by a New Mexico physician, the other a 1990 'briefing paper' from the Chemical Manufacturers' Association (now American Chemistry Council).