



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)

COMPLETE REPORT/ 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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RECOGNITION, EQUALITY, EQUITY

THE TIME IS NOW

PERSPECTIVES OF ONTARIANS LIVING WITH

ES/MCS, ME/CFS and FM

PART ONE - OVERVIEWS

CELCs IN ONTARIO SNAPSHOT 2010

PATIENT VISION FOR THE MODEL OF CARE

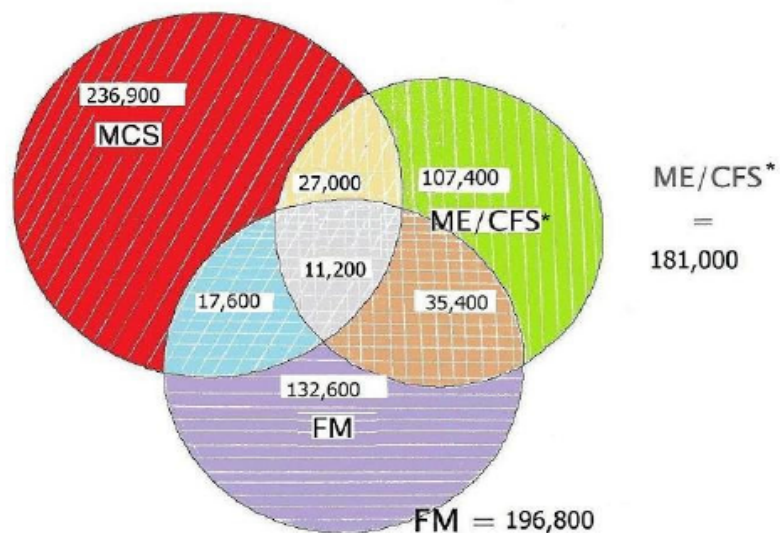
INTRODUCTION

EXECUTIVE SUMMARY OF KEY FINDINGS AND RECOMMENDATIONS

1 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



Total reporting one or more diagnoses = 568,100



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

Notes: Canadian Community Health Survey (CCHS) results rounded

This diagram created February 17, 2012 by MM

2 AN OPENING WORD FROM OUR COMMUNITY

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 Sensitivity (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.

3 INTRODUCTION

WELCOME to this report about key issues in the lives and needs of Ontarians living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Environmental Sensitivities/Multiple chemical Sensitivity (ES/MCS) and Fibromyalgia Syndrome (FM). These are three serious chronic environmentally-linked health conditions ('CELCS') that have been on the rise everywhere, including in Canada and in Ontario for a long time. Much of this report is dedicated to explaining them, illuminating their impact on people's lives and addressing multiple issues in how to meet their needs for care and support.

According to Statistics Canada's Canadian Community Health Survey (CCHS), as of 2010 over 568,000 Ontarians had been diagnosed with one or more of the three conditions – approximately five percent of Ontario's population. That number had grown from 439,000 in 2005 . We have reason to believe that this represents an underestimation of numbers, due to lack of awareness and knowledge among health professionals. But even with these figures we can say that these conditions are very widespread and display 'an illness burden similar to that of heart disease and greater than that of cancer.'

Ontario began the process of investigating how to respond to the needs of those with one of these conditions - 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.¹ It took eleven years for government to digest and then to fund the initial Environmental Health Clinic situated at Women's College Hospital, along with a productive but short-lived research program. It was expected that from that base many of the other recommendations of the Ad Hoc Committee would be implemented. **The report urged that numerous steps be taken to provide an adequate and appropriate system of care** - a number of which have been gathered in Appendix 2. Indeed the Committee 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.

However - 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

¹ 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.

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. This report, combined with *'Complex Chronic Conditions: Academic and Clinical Perspective,'*² 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.

HISTORY OF THE OCEEH BC PROJECT

This report, *'Recognition, Inclusion and Equity: The Time is Now'* has been written to represent the patient perspective within a broader Steering Committee process guiding the Ontario Centre of Excellence Business Case project (OCEEH BCP). It is one of four supporting appendices. We believe these different 'lenses' will truly help readers to see the many sides and possible approaches to both broad and narrower issues involved in thinking through the challenges and the solutions of helping our community.

Two parallel streams of work from patient representatives and physicians came together in 2012 to develop and launch this project and the complete submission.

The first stream began five years ago with initiatives with the Minister and Ministry of Health and Long Term Care. The originators of that effort were two then-board members of the Environmental Health Association of Ontario (EHAO, 2008), ES/MCS representatives, who were then joined by Ted Ball as pro bono consultant (2009). Late that year, they sought the support of physicians from the EHC. These efforts eventually resulted in a 6-part proposal for services for people with ES/MCS, ME/CFS and FM. Successive drafts of this were submitted to the Minister and senior officials in the winter and spring of 2011. MEAO came on board at that time in actively supporting these proposals and winning key allies.

Important elements of that original proposal were informed by many sources including EHAO policy recommendations, operating clinics in other jurisdictions, and two 'centre of excellence' proposals, including the 2008 Ontario College of Family Physicians 'vision document' and a 2009 proposal prepared by Dr. Alison Bested's patients, as well as the most pressing needs articulated by the EHC physicians.

By June 2011, an Assistant Deputy Minister had been assigned the file. In July, she asked for a business case proposal for a Centre of Excellence with a hub and spoke model - a model that would aggregate the 6 components of the pre-existing request. In November 2011, the partnership between the patient advocate-physician collaborative and the Association of Ontario Health Centres (AOHC) was initiated with the purpose of assembling that business case proposal and moving forward to envision the described centre of excellence.

In parallel developments, the second stream began with MEAO board volunteers in 2009. They commenced work to develop a major grant proposal to the Ontario Trillium Foundation (OTF). Submitted in 2011, it was for a multi-component study whose objectives were embodied in its title: *'Improving the Quality of Care and Support for People Living with ME/CFS, ES/MCS and FM'*. MEAO was

² 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., a staff physician of the Environmental Health Clinic, currently situated at Women's College Hospital in Toronto.

awarded the grant in late 2011. The MEAO team met the OCEEH team in early 2012, and with overlapping goals and components to the OCEEH BC proposal, the MEAO/OTF project was launched in Spring 2012, with the intention to merge the two projects should Ministry funding arrive in time. Ministry funding for the OCEEH business case proposal was received in October 2012 and delivered to AOHC to administer. The two projects were then merged, and a full steering committee was constituted to lead the project.

The unified project has a Steering Committee (SC) that oversees the OCEEH BCP, guided by the OCEEH vision statement. It consists of eight members with a majority of patient/client representatives. The SC includes representation from MEAO, AOHC and two physician representatives from the Medical Advisory Committee (MAC), who are also on staff at the EHC. It also includes a long-time patient advocate with ES/MCS.

The Myalgic Encephalomyelitis Association (MEAO) is a charitable organization that has been primarily focused on supporting individuals with ME/CFS, and their families, since 1990. In more recent years, in large part due to a growing understanding of the co-occurrence of ME/CFS with FM and ES/MCS, MEAO has sought to become more responsive to the needs of individuals with all three conditions, a mandate it has now fully taken on board. In 2011, through the OTF grant and for the purposes of creating new health care supports, it sought to engage individuals living with these three conditions in order to better understand the impacts on their lives, their assessment of the current state in care and support and to integrate their recommendations with those emerging from other study components to present a plan to ‘improve the quality of care and support.’

The results of this community consultation, reported in detail in Part Three of this report and also woven into other sections of this document, was a project entirely of MEAO’s. But the results were reported on at length and in depth throughout the OCEEH business case Steering Committee process, informed all SC deliberations and were utilized by the whole project to identify unmet needs and barriers to care, and to develop a cohesive and systemic proposal for care for the communities.

For this reason, we are confident that the patients’ collective experience has fully and deeply informed the model of care and of service delivery, as well as multiple needs for barrier-removing policy shifts, elaborated below and codified in the OCEEH business case as such. We believe the words of our community are remarkable in their eloquence, their insight, and even their wit, and hope readers can find time to learn from and enjoy them.

IN THIS REPORT

In the world of today’s health care system, ever-increasing importance has been placed on ‘person-centred’ and ‘patient led’ care. But such care can only take shape if the patient voice is clear, strong and articulate. So we have taken very seriously our mission to represent our heretofore largely invisible patient community, its experiences and its knowledge. The **‘patient perspective’ is truly the lens through which we have presented the material offered in this report.** And because so little is known about, or established for, our communities, we had many pieces we felt it worthy to address.

The overarching objective that emerged from this long process of study and discussion can be summed up in one word: ‘normalization’. This catch-up, future state goal can be further broken down into the components of ‘recognition, inclusion and equity,’ which we have chosen as the title for this report. And

these three terms in turn **can 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)

Parts 1 through 4 present and analyze issues that related to the challenge of creating normal care and support for the three conditions. Having to cover three distinct syndromes/disabilities that are still relatively unknown, presenting the compelling results of our rich patient survey/community consultation and extracting out a number of special issues for our populations meant there was a lot of territory to cover.

Part 5 is concerned with recommendations. Broadly speaking and across a number of subject areas, (we have made two types of recommendations:

(a) For direct services (generally corresponding to ‘Pillar 1’ in the OCEEH BC)

(b) Barrier-removing ‘strategic enablers’ to effect and accelerate access and equity (generally corresponding to ‘Pillar 2’ in the OCEEH BC).

The proposed Ontario Centre of Excellence in Environmental Health - described in structure, function, roles and mandate in Chapter 26 - embodies all the recommendations made in previous chapters, and brings together both of these types of recommendations.

Descriptions of the OCEEH proposal are contained both in the business case as such, and, with respect to clinical practice, in John Molot’s report. Our report has avoided duplicating these two documents, but has rather been written as a resource book for those looking for **a more comprehensive explication of the many factors motivating the recommendations for the OCEEH**. We are sure readers will have questions about those factors; we hope they can find many of these answers here.

As a result, as much as we would have liked to provide the proverbial ‘few pithy pages’ to busy readers, this was not possible. Instead, we ended by opting to create **a report that** is not only a narrative from start to finish, but also **has discrete components that are usable as resources for readers with different interests and different purposes**. To that end, we have taken care to **provide a very detailed table of contents**, and, within each chapter, many headings, subheadings and other means of highlighting different types of information that we hope will make different kinds of readings possible.

We have also provided a stand-alone **‘Highlights’ report** that summarizes the whole project and covers all the recommendations.

We welcome you to our report and hope you will find much that is enlightening and helpful in the pages to come.

4 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 to... similar to what Dr. B.'s going out and starting up in BC. ... 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**

5 EXECUTIVE SUMMARY OF REPORT AND RECOMMENDATIONS

OVERVIEW OF REPORT AND RECOMMENDATIONS

THIS report is about the lives and needs for care and support of Ontarians living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS) and Fibromyalgia Syndrome (FM). These are three serious chronic environmentally-linked health conditions ('CELCS') that have been on the rise everywhere, including 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.

In Ontario in 2010 those diagnosed with one or more of these conditions numbered just over 568,000 persons. In this study, we conclude that these conditions display 'an illness burden similar to that of heart disease and greater than that of cancer.'

Ontario began the process of investigating how to respond to the needs of those with ES/MCS in 1985, and a system of care was recommended. In the intervening period - nearly 30 years - no such system of care was established, only one very small assessment and diagnosis clinic.

As far as our current state is concerned, our community consultation and our environmental scanning processes for several years have revealed what we have called a '**void in service with a few tiny islands of assistance.**' So now is the time to take the steps needed to bring about recognition, inclusion and equity **of people living with the CELCs.**

To put our overarching corrective objective in one word, our community is calling for the 'normalization' of care and support. This in turn can 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.'

These comparator groups include people living with the effects of a stroke, with cancer and receiving chemotherapy, with heart disease, with late-stage HIV-AIDs, diabetes and/or arthritis

Broadly speaking, in Part Four and Part Five we make recommendations for:

Direct services - through a new and dedicated hub-and-spoke network of service delivery. These recommendations generally correspond to 'Pillar 1' in the OCEEH business case proposal.

Barrier-removing policy shifts - 'strategic enablers' in the MOHLTC, broader health care system and in relevant and related government ministries to accelerate change and remove barriers - these generally correspond to 'Pillar 2' in the OCEEH business case proposal.

The proposed Ontario Centre of Excellence in Environmental Health (**OCEEH**) - the culmination of the research and analysis process - **brings together both of these types of recommendations.** The clinical components of the hub and spokes are designed to deliver a number of new and urgently needed services, to support both client health and the social determinants of health. The OCEEH research,

education and policy departments have been designed to effect both a continual improvement in services, and to provide support for policy shifts needed to bring about broader government and public changes, thus removing barriers to our goal achievement.

PRINCIPLES FOR CHANGE AND FOR CARE

Two types of principles emerged in setting out recommended changes.

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 system, social determinants of health supported, community development model.

NATURE AND IMPACT OF THE 3 ‘CELCs’

Clear links between most common chronic conditions and common chemicals are now established in the scientific and medical literature. These conditions include: Cardio-vascular illnesses, cardiac birth defects, low birth weight, obesity, type 2 diabetes, Parkinson’s, developmental neurotoxicity, cancer: breast, prostate, testicular, respiratory disease, many other cancers.

Such links are very strong to the CELCs.

Those with one or more of the CELCs in Canada numbered 1,135,500 in 2005 and 1,415,000 in 2010. It is very common for persons to have more than one of these conditions at the same time.³ 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.

- **Environmental Sensitivities/Multiple chemical sensitivity (ES/MCS):** ‘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.’ **Think ‘toxic injury that does not resolve’.**
- **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS):** **Think ‘infection that does not resolve.’** Debilitating fatigue, swollen lymph nodes, pain, neurological dysfunction.
- **Fibromyalgia (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 bad that it makes normal existence impossible, resulting in disability and severely compromised quality of life.

³ Quantitative data derived from the CCHS 2005 and 2010 studies are found in relevant sections throughout this report. Those wishing to refer to prevalence data immediately are directed to Chapter 6, section 6.7.

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

The level of disability was comparable with a number of comparator groups. 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.

LESSONS FROM THE ENVIRONMENTAL SCAN - TIME FOR CHANGE IS NOW AND CHANGE NEEDS 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 three different attempts by patient organizations to get service 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.

HIGH HEALTH SERVICES UTILIZATION AND VERY HIGH SOCIAL COSTS

The population-based Canadian Community Health Survey (CCHS), which includes cases across the severity gradient, 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.

Although we do not have data that make it possible to accurately calculate the social costs and their burden on the public purse, 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 so forth - we

believe these costs are very high, likely in the billions of dollars, and represent a major economic motivator to establish appropriate care to minimize these costs.

FINDINGS OF THE COMMUNITY/PATIENT CONSULTATION

DEVASTATING IMPACTS ON WELLBEING AND SOCIAL DETERMINANTS OF HEALTH

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. Isolation sets in. For those who are single and/or very sick, the isolation and physical hardship can be absolute and crushing.

For most, though not all, participants the onset of symptoms occurs 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) their economic realities grow much worse. Therefore the economic impact of these conditions is generally devastating.

Economic insecurity was seen as a major, overarching issue linked to lack of recognition: 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* 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 with accommodation.

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 *The Quantitative Data*.)

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

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**

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. **Shan 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 as sufferers, or related to those living with them) they provided excellent care. In other words, models of good care do exist, and they can be provided. We are not starting from zero.

NEGATIVE FINDINGS ON HEALTH CARE AND PARTICIPANT RECOMMENDATIONS FOR CHANGE

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 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 a system 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 the summary of PART FIVE, below.

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

CHILDREN 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;⁴ and impressionistically (EHCD, patients' organization reports, physician reports), there are also many with ES/MCS.⁵ As schools are equipped with Wi-Fi, the number of children with ES seems to be increasing. Ontario has no way of tracking or treating these children. No education and training for pediatricians or family physicians exists. 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.

WOMEN who suffer from these conditions outnumber men by a rough ratio of 3:1 (though estimates range higher in some studies). At the same time, a pronounced sexist bias exists among many service providers, as a result of which women's claims to illness (pain, fatigue, chemical reactions) are discounted and disrespected. The discounting behavior was most frequently expressed as women's 'tendency to complain' or because the women were 'hormonal'. These findings are in keeping with similar findings with respect to women with overlapping and separate conditions, well established in the medical literature and across health care provision. The lack of services and lack of research reflect systemic sexism. Research dollars should be apportioned relative to prevalence of disorders.

STIGMA AND INSTITUTIONAL DENIAL At this time many care providers still treat the conditions as psychogenic or forms of hypochondria. The great majority of community informants described very negative attitudes linked to tangible stigmatization, discrimination and active hostility, in every social sphere, including in the health and social support systems. These attitudes were identified as a fundamental barrier to care. They derive from obsolete and incorrect ideas, including regarding types of stress (including biophysical), mind/body divisions and the actual injurious agents involved. A brief look at institutional resistances to their reality in the experience of Gulf War Related Illnesses (GWRI), which includes the three CELCs, shows that factors other than science can drive denial and stigmatization. (See Chapter 16.6 for further discussion of the treatment of GWRI.)

SPECIAL MEDICAL HOUSING ISSUES FOR ES/MCS The need for air quality that is free of most 'everyday chemicals' now ubiquitous in the built environment presents a level of challenge with respect to housing - be it ordinary residential, supportive and assisted, or long-term care and palliative - 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.

MAIN RECOMMENDATIONS

Currently, no dedicated services are in place to assist sufferers except for a small, over-burdened assessment clinic in downtown Toronto for adults. There are no programs for children. Overall and

⁴ National Health Service (NHS), UK, 'Chronic fatigue syndrome'. Quote: "Anyone can get CFS, although it is more common in women than in men. It usually develops in the early 20s to mid-40s. Children can also be affected, usually between the ages of 13 and 15." <http://www.nhs.uk/conditions/chronic-fatigue-syndrome/Pages/Introduction.aspx> (Accessed October 20, 2013.)

⁵ British Society for Ecological Medicine, 'Multiple Chemical Sensitivity,' February 11, 2009. Quote: "The genuine nature of MCS has been recognized by officially commissioned reports from independent scientists in the USA and the UK, who have concluded that it is a valid diagnosis and a sometimes disabling condition, although all have stressed the need for further research." <http://www.ecomed.org.uk/publications/reports/multiple-chemical-sensitivity> (Accessed October 21, 2013.)

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 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 is urgent and imperative. Two types of recommendations are involved.

(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) **Policy shifts in the MOHLTC, broader health care system and in relevant and related government ministries - to accelerate change and remove systemic barriers.** *These 'strategic enablers' generally correspond to 'Pillar 2' in the OCEEH business case proposal.*

DIRECT SERVICES

➤ 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
- 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.

‘STRATEGIC ENABLERS’: SYSTEM- AND GOVERNMENT-WIDE ALIGNMENT TO REMOVE SYSTEMIC BARRIERS

The hub and spokes of the proposed OCEEH cannot provide services to all Ontarians, nor can it alone undo many of the more damaging attitudes and deficiencies faced by sufferers of these conditions. As well, if the OCEEH network provides system navigation to assist clients in searching for appropriate supports, but those supports are not available to clients beyond the OCEEH network itself, clients will come to a dead end, causing outcomes to suffer. Certain key policy shifts across government - ‘strategic enablers’ - are therefore critical companion pieces to changes in service provision through the OCEEH.

These ‘strategic enablers’ identify the Ministry of Health and Long Term Care, Ontario Human Rights Commission, Ministry of the Attorney General, Ministry of Community and Social Services, Ministry of Education, Ministry of Training, Colleges and Universities, Ministry of Labour, Ministry of the Environment, Ministry of Finance as key sites for change.

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 rights, benefits, 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**.

Within the purview of the **MOHLTC**, these would include: recognize the three conditions as chronic health disorders, ensure diagnostic and billing codes for ES/MCS are added, require education for all health care practitioners, diffuse clinical guidelines for all conditions, revise the drug benefit program, include funding and policy for relevant services into provincial, LHIN level, CDMP and other program envelopes. Public health programs to begin prevention efforts (linked to the Ministry of Environment) are urgent. Emergency and hospital services are high danger zones for those with ES/MCS: policies to train all providers in emergency protocols and safe reception; measures to accommodate for acute care, elective surgeries and diagnostic procedures are needed, and central policy from the ministry and from the OHA is required. Resting rooms and condition recognition for those with ME/CFS and FM are also needed.

It will be especially important to revise and align **MCSS** programs. The ODSP and assistive device program require revision to include and normalize assistance for the CLCs. Supplementation of medically required food and water and for safe housing is needed. Integration into employment programs is needed. Extra coverage for medically needed organic food and filtered water; extra funds for chemically-safe, supportive housing are needed to achieve equity with comparator groups. As well, integration into all other disability related programs and services is required.

Two fronts are involved with respect to **education**. Government should require and assist all health education facilities to adequately train health professionals as appropriate to their scopes of practice; and require agencies and facilities to develop condition-competence and appropriate care - in other words, require, and lead in the development of professional capacity. Government should also ensure central policy changes enabling accommodation of students with the conditions in schools, colleges and universities.

Equity in accommodation (including in tax incentives to employers to hire or maintain employees with the conditions), in public and private insurance benefits and in occupational health and safety standards are needed, involving the **Ministry of Labour** and the **Ministry of Finance**. Change is especially urgent at the **Workers Insurance and Safety Board**.

Awareness campaigns are needed for four audiences to create recognition, acceptance and vigilance (prevention): health professionals, public and para-public servants, the general public and patients and families.

Prevention is key to halting the rising suffering and social costs of these conditions, and others linked to the environment. Government should ensure that enlightened and effective regulatory regimes are created to radically reduce the common usage of hazardous chemicals. Effective public awareness campaigns, co-driven by the **Ministry of the Environment and the MOHLTC**, are equally needed to reduce the widespread health harms of many chemicals in every day use.

KEY ELEMENTS OF THE ONTARIO CENTRE OF EXCELLENCE IN ENVIRONMENTAL HEALTH ‘PYRAMID’

Four main functions or ‘departments’ are recommended for the OCEEH: **direct health and social support services to clients, education, research and policy**.

The main hub is to provide specialist care for complex and/or difficult cases, research, and policy development, and educational services to support the four target groups: health professionals, public and para-public servants, patients and families and the general public. Care includes assessment, diagnosis and treatment, case conferencing with specialists, state of the art diagnostic methods and treatment modalities. A **lodge for chemically sensitive patients** staying for any length of time is to provide safe shelter. Research should be both epidemiological and evaluative in nature. Policy should seek to ensure that ongoing needs for systemic barrier removal, new or changed services, and extensive and enduring partnership building are well met.

The spokes, based in selected CHCs across the province, eventual number to be determined, are to provide condition-competent, integrated and comprehensive primary and secondary care, including support for the social determinants affecting sufferers, including patient outreach and community development.

On-site spoke services include assessment, diagnosis and on-site treatment, self-management/peer group activities; family support activities, appropriate exercise and mind-body support programs, legal and advocacy assistance with workplace accommodation, disability benefits, WSIB, ODSP.

Health and social supports are to be facilitated beyond the OCEEH itself by dedicated system navigation, and worked toward by OCEEH policy and education departments. These supports include: homecare and other personal support services (health care, personal hygiene, physiotherapy, massage, other therapy if housebound, OT ergonomic, mobility assistance, food shopping, prep, cleanup, assistance with feeding, assistance with travel to health and social destinations (re isolation), ES/MCS assistance with finding safe housing, housekeeping and laundry); assistance with transportation.

Additionally and crucially, primary **care providers beyond the CHC-located spokes must be recruited to the network** and its educational activities, to expand the base of the 'pyramid' - perhaps with an OCEEH 'associate' or 'affiliate' status. This can ensure that patients find appropriate care in key issues (e.g., sleep management, hormonal balance, infection control, pain management, toxicity, diet and appropriate exercise) close to home. If the policy shifts indicated above are enacted, such primary care providers will be able to link patients to many appropriate supports even in the absence of CHC teams. Given the size of Ontario and the inevitable length of time it will take to bring new building sites on-line, this is a very important part of the OCEEH network.

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 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.

APPENDICES

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), detailing pro-active initiatives to frame ES/MCS as fictitious.

PART TWO - THE CELCs TODAY

DESCRIPTIONS AND QUANTITATIVE DATA

KEY LESSONS FROM THE ENVIRONMENTAL SCAN

NEGATIVE VALUE FOR HEALTH CARE DOLLARS IN THE CURRENT STATE

6 THE THREE CELCs: DESCRIPTIONS AND QUANTITATIVE DATA

6.1 THE RISE OF ENVIRONMENTALLY-LINKED ILLNESS

THE expression ‘canary in a coal mine’ dates back to the nineteenth century, to the use of these delicate birds in British coal mines to detect harmful gases, and to give miners a chance to escape before they too succumbed to noxious, but undetectable, hazards. The canaries’ signaled danger through obvious signs of physical distress, including death, their songs stilled forever. The miners knew how important canaries were to their survival. They knew that when a canary was distressed they were all in danger, so they listened to their canaries and heeded their warnings.

From the 1940s to the turn of the 21st century, more than 80,000 new chemicals have been introduced into our environment through the manufacture of both industrial and everyday products.

- More than 82,000 chemicals introduced in commerce in U.S. and Canada since WW II
- 2,863 in U.S. are high production volume (HPV) chemicals, i.e., 1 million pounds or more per year, produced or imported
- Basic toxicity information exists for less than 50% of HPV chemicals
- Information on developmental toxicity exists for less than 20% HPV chemicals ⁶

Chemicals have proliferated into every environment of our daily lives. From the cars we drive and fuel, to the materials we use to build our houses and workplaces, to the chemicals we use in industrial production, in offices and in retail networks, to the products we use for our laundry or to store our food, to the cosmetics and personal grooming products in our bathrooms, bedrooms and beauty salons, we have created a ‘chemical coalmine’ where we all now live and breathe. And more and more we understand that this chemical coalmine is making a lot of us very sick.

How sick? The ‘*Early Exposures to Hazardous Chemicals/Pollution: A Scoping Review*’⁷, a scoping study published in 2011 by the Canadian Environmental Law Association (CELA), the Ontario College of Physicians and Surgeons and the Environmental Health Institute of Canada, reviewed the extensive evidence linking the powerfully harmful effects of many everyday chemicals to true epidemics of illness and developmental problems. These include some of the best-known health challenges of our times:

- Cardio-vascular illnesses
- Cardiac birth defects

⁶ Philip J. Landrigan, 'The unique vulnerability of children to toxic chemicals, Implications for science and policy', *Presentation to Canadian Partnership for Children's Health and the Environment's 5th National Policy Consultation Workshop "Toxic Substances in Consumer Products"*, Montreal, P.Q., 25 September, 2007.

⁷ K. Cooper, L. Marshall, L. Vanderlinden, and F. Ursitti, 'Early Exposures to Hazardous Chemicals/Pollution and Associations with Chronic Disease: A Scoping Review.' *A report from the Canadian Environmental Law Association, the Ontario College of Family Physicians and the Environmental Health Institute of Canada*, 2011. Find at www.healthyenvironmentforkids.ca.

- Low birth weight
- Obesity
- Type 2 diabetes
- Parkinson's
- Developmental neurotoxicity
- Cancer: breast, prostate, testicular
- Respiratory disease
- Many other cancers

A whole literature, both scientific and popularized, now exists on these health harms. The 1996 groundbreaking book *Our Stolen Future: Are We Threatening Our Fertility, Intelligence, and Survival? A Scientific Detective Story* first brought these issues into the public arena.⁸ Several excellent books have followed, including the more recent, and perhaps more accessible, Canadian bestseller, *Slow Death by Rubber Duck*. Two other accessible and excellent books are Nena Baker's *The Body Toxic* and Nancy Nichols' *Lake Effect*.⁹ The World Health Organization and the United Nations Environment Program monitor these developments and issue regular briefings to the scientific and medical communities.¹⁰

These chronic conditions and developmental problems are the result of long-term exposure by generations of parents and children, living and reproducing in our 'chemical coal mine.' And so we see that we are all affected by chemical proliferation. **As a society, therefore, we have the strongest possible motivation to positively address the hazards this coalmine is generating.**

6.2 THE THREE CELCs - 'CANARY CONDITIONS'

WITHIN that framework, we also have urgent motivation to heed and help our own 'human canaries'.

The majority of us are experiencing what has been dubbed a 'slow death' by chemicals - an accretion of chemicals, identified in our bloodstreams but not felt by us, manifesting in epidemics of chronic disease. But some of us are also experiencing a 'fast death.' These are the people who are suffering from the three conditions with which this report is concerned. For **these conditions often result in immediate and devastating consequences linked to toxic overload, as well as several other critical co-factors, that are 'canary-like' in their import.**

This is why we describe ES/MCS, ME/CFS and FM as chronic, co-morbid, *environmentally-linked* conditions.

⁸ Theo Colborn, Dianne Dumanoski, and John Peterson Myers, *Our Stolen Future: Are We Threatening Our Fertility, Intelligence, and Survival? A Scientific Detective Story*. (New York: Dutton, 1996) 306 pg. [Forward by Vice President Al Gore.]

⁹ Rick Smith, Bruce Lourie, and Sarah Dopp, *Slow Death by Rubber Duck: How the Toxic Chemistry of Everyday Life Affects our Health*. (Canada: Vintage, 2010) 352 pg. Nena Baker, *The Body Toxic: How the Hazardous Chemistry of Everyday Things Threatens Our Health and Well-Being*. (New York: North Point Press, 2008). Nancy Nichols, *Lake Effect: Two Sisters and a Town's Toxic Legacy*. (Washington, London: Shearwater Books, 2008).

¹⁰ A. Bergman, J.J. Heindle, S. Jobling, K. Kidd, R.T. Zoeller, eds. 'State of the Science of Endocrine Disrupting Chemicals - 2012,' *Inter Organization Programme for the Sound Management of Chemicals*. (United Nations Environment Program and World Health Organization Collaborative, 2012).

While all these conditions exist on a gradient from mild to severe (and can go completely undiagnosed until greater severity sets in), all three often produce devastating symptoms that can lead to total disability¹¹ and, in the case of ES/MCS and ME/CFS, are life threatening at severe levels. More difficult still, many people have two or three of the conditions at once.

6.3 WHAT THE CONDITIONS HAVE IN COMMON

CHRONIC: BECAUSE THEY ARE JUST THAT

- Once established, they must be treated and managed over time, often a lifetime.

CO-MORBID: BECAUSE THEY GENERALLY APPEAR WITH OTHER CHRONIC PROBLEMS

- They affect the central nervous system, which in turn affects the entire 'body-mind'.
- Many other organs or body systems can be affected; as severity increases, there is generally more co-morbidity.
- Many people have two or three of the conditions simultaneously.

MANY PEOPLE HAVE TWO OR THREE OF THE CONDITIONS SIMULTANEOUSLY

'I was just 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**

ENVIRONMENTALLY-LINKED¹²

- Rise of conditions is linked to wide proliferation of industrial and 'everyday' chemicals.
- Evidence of compromised ability to detoxify is found in people with the conditions, with genetic and epigenetic factors as part of this picture.
- High levels of oxidative stress are present and require reduction through specialized avoidance strategies and specialized treatment.

¹¹ M.R. Lavergne, D.C. Cole, K. Kerr, L.M. Marshall, 'Functional impairment in chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity,' *Canadian Family Physician*, February 2010, 56: e60-1.

¹² See John Molot, MD, FCFP, 'Chronic Complex Conditions: Academic and Clinical Perspectives' (Sept. 13, 2013). See also Appendix 4 for excerpts.

- Damage to and poor function of cellular organelles and lack of power in the mitochondria are found.
- Systemic inflammation is common - affecting both the central nervous system and potentially other organ systems, including cardiovascular, lung, digestive, kidney and urinary tract, skin or any system in the body. Co-morbidities are common as a result of this.

LINKING DIVERGENT CHRONIC CONDITIONS AND THE ENVIRONMENT FROM 'CHRONIC, COMPLEX CONDITIONS: ACADEMIC AND CLINICAL PERSPECTIVES'

John Molot, M.D.

Biologically, these chronic illnesses and conditions are distinct, but there are common, overlapping pathological mechanisms. These include a burden to detoxification systems, damage to cellular organelles, oxidative stress, changes in cell function, and systemic inflammation.

Detoxification

The liver is a major organ for detoxification. It breaks down toxic agents and converts oil soluble products into more water soluble metabolites, which can be efficiently eliminated from the body by the kidneys. This degradation, or biotransformation, is primarily accomplished by two liver enzyme systems called Phase I and II. Waste products can be eliminated from the body through bile and stool, urine, and sweat.

Every cell is naturally equipped with a detoxification system to deal with internal wastes, and that same system is used to detoxify and eliminate foreign chemicals (xenobiotics) which are potentially harmful. Xenobiotics are encountered by humans on a daily basis and undergo metabolism and detoxification to produce numerous metabolites, some of which also have the potential to cause toxic effects.²⁰² Waste that cannot be completely degraded or easily eliminated by the cell must be altered in order to remove it from the body. When the cell is unable to rapidly detoxify waste or toxic foreign substances, damage can occur.

Cellular Organelles

Cells obtain energy by combining glucose with oxygen. This critical role in energy metabolism is performed by cell organelles (cell subunits that perform specific functions) called mitochondria. Mitochondria are specialized subunits which are fundamental to cell life and cell death. They consume about 98% of the oxygen we inhale. That we must breathe oxygen to stay alive is simply the consequence of the demand of our mitochondria for oxygen.

Mitochondria are the source of the energy, strength and vitality for every cell. As the powerhouse of cells, they provide energy for cell division, production or destruction of proteins and other substances, cell signalling, and transportation of large molecules across the cell membrane. Depending on the cell's energy requirements, there are hundreds or thousands of well-functioning mitochondria traveling around the cell, distributing readily available energy wherever it is needed. Metabolically, this is where the action is inside a cell. The by-products of this metabolism are toxic waste products, to be destroyed or eliminated, but unfortunately, the mitochondria sit in the middle of it all.

These by-products are called reactive oxygen species or oxidants or free radicals. They are electronically unstable molecules capable of stripping electrons from any other molecules they meet in an effort to achieve stability. Doing so creates more unstable molecules which can then attack their neighbours in domino-like chain reactions.

Free radicals are produced in small amounts under normal physiological conditions, derived from essential

metabolic processes. They are the waste products of the energy produced by mitochondria. When their production is increased, or their detoxification is inadequate, molecular damage occurs inside cells. This damaging process is called oxidative stress.

Oxidative Stress

Oxidative stress represents an imbalance between the production of reactive oxygen species and the ability to neutralize or detoxify them. It refers to any of the resulting various pathologic changes seen in living cells in response to excessive levels. We can observe the imbalance directly by measuring the levels of oxidants or free radicals, or we can assume it is occurring by finding low levels of antioxidants.

We know oxidative stress is occurring when we find evidence of damage and destruction inside cells. Oxidative stress damages DNA, especially mitochondrial DNA, lipids from cell and organelle membranes and various proteins, and we can measure the resulting by-products of this damage in blood or urine.

Changes in Cell Function

Oxidative stress and DNA damage can cause significant changes in cell function. The mitochondria are most likely to be damaged because they produce free radicals as waste products of their production of energy, and are immersed in them, making them highly vulnerable to attack. In research labs, we can assess mitochondrial function by stimulating cell activity and measuring the levels of substances normally used by working mitochondria. When the mitochondria are activated, and are functioning well, there is a marked reduction in these substances as they get used up.

Systemic Inflammation

The literature robustly demonstrates pollution leads to oxidative stress and systemic inflammation, which in turn contributes to the onset and exacerbation of cardiovascular disease, chronic obstructive lung disease, and neurodegenerative disorders, such as Alzheimer's and Parkinson's diseases. It worsens symptoms, increases medication use, decreases function and increases health care utilization and mortality. Those with an abnormal genotype for detoxification tend to be more susceptible to developing such chronic illnesses.

6.4 ENVIRONMENTAL SENSITIVITIES/MULTIPLE CHEMICAL SENSITIVITY

THINK TOXIC INJURY THAT DOES NOT RESOLVE

'I lived and worked in an environment next to a dry cleaner, and there was a perchloroethylene leak, and that is when I first went blind in one eye. It came back, but not for nine months. From that time on the chemical sensitivities just mushroomed. Actually, domino affects more, not that you're allergic, you are reactive to this, reactive to that - Petro-chemicals, the broad umbrella - and then, these are things I never expected or even heard of.' **Claire MCS**

- “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.” (United State Environmental Protection Agency.) *And* to touch or oral ingestion of substances.
- Central nervous system dysfunction can affect any and every organ and body system - and often does.
- Symptoms occur when exposed to multiple unrelated chemicals.
- Symptoms improve or resolve when trigger chemicals are removed - therefore not an affective disorder.

POTENTIALLY DISABLING TOXIC SUBSTANCES FOR THOSE WITH ES/MCS MAY INCLUDE ANY QUANTITY OF...

pesticides secondhand smoke formaldehyde fresh paint candles fragrances food preservatives flavor enhancers aerosols tap water cosmetics personal care products new carpets petroleum products solvents paints and stains newspaper ink cleaning compounds moulds artificial dyes outdoor pollutants (diesel, gasoline, oil smoke, laundry product emissions) printing and office products... and other synthetically derived chemicals

ES/MCS CAN BE PROFOUNDLY DISABLING, PAINFUL AND LIFE THREATENING

- Living in today’s chemically-saturated environment is like living in a mine-field for those with ES/MCS. Symptoms range from minor annoyances (headache, runny nose) to devastating, life-threatening reactions (seizures, anaphylaxis). Severe ES/MCS is profoundly disabling and can be excruciatingly painful.
- Without treatment, sufferers with severe ES/MCS must live in almost total physical isolation, in environments that are completely free of chemical ‘incitants’, profoundly disrupting all networks - familial, friendship, work, community.¹³

‘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**

¹³ Pamela Reed Gibson, Ph.D., Lauren G. Sledd, BS, MA, William H. McEnroe, BS, and Abby P. Vos, BA, ‘Isolation and lack of access in multiple chemical sensitivity: A qualitative study,’ *Nursing and Health Sciences*, 2011: 13, 232–237. Quote: ‘We ... planned to focus on the impact of MCS on relationships, but found that difficulty with accessing safe spaces at times prevented relationships by limiting access to personal interactions. Thus, persons with MCS either lost or were unable to cultivate new relationships as a result of lack of spatial access. Others’ lack of understanding and refusal to make accommodations at times denied spatial access to those with MCS. In this way, relationships (relationality) and spatial access (spatiality) interacted with one another to keep persons isolated.’

A LONG TRAIL OF LOSS OFTEN ACCOMPANIES THIS DISEASE

- Marriages fall apart; friends and family often pull away, especially when they do not understand the reality of the conditions, life savings are depleted as people move from place to place seeking safe shelter. This leads to tremendous hardship and extreme deprivation for those without private means, including severe, heartbreaking isolation.

6.5 MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE SYNDROME

THINK INFECTION THAT DOESN'T RESOLVE 'I HAD THE SHOTS AND I WAS SICK...'

My doctor thought that right from the first, when many other doctors denied that it was probably related to the flu shot, because she's known me for 25 years and she's known that I was always healthy. And I had the shot and I was sick.' **Theresa ME**

DEBILITATING FATIGUE, SWOLLEN LYMPH NODES, PAIN, NEUROLOGICAL DYSFUNCTION

ME - CFS is a serious debilitating physical illness

- Accepted as a physical illness by the Centers for Disease Control, National Institutes of Health in the USA, Chief Medical Officer in Britain, World Health Organization.
- Scientific and medical evidence: highly complex physical illness, involving multiple factors.
- There is chronic immune activation. While certain infectious agents have been associated with triggering ME/CFS, no particular agent has been identified which explains the ongoing symptoms. The question is whether there is such an agent or whether the immune system cannot regulate itself properly.

PRIMARY AND SECONDARY FACTORS IN ME/CFS

Primary factors

**immune system endocrine system mitochondria brain dysfunctions nervous system
dysfunctions and abnormalities**

Symptoms

reduced activity levels	post-exertional malaise	sleep dysfunction	cognitive issues
neurological issues	autonomic issues	neuroendocrine issues	immune issues

'I'M JUST TRYING TO LIVE WITHIN MY ENERGY ENVELOPE...'

'I'm just trying to live within my energy envelope because I know if I push too much or if I go for so many hours, I start crashing and then it's worse. Like, I can't function the next day type of thing. ... I met somebody I hadn't seen for a number of years and I started telling him about it, and then he'd go into, 'yeah, well, you know, at the end of the day I get tired too and I know what it's like.' And it's, like, no, you don't... I don't want to get into arguments with these people, I want to tell them "you really don't know what it's like." It's just... you're totally burned out. You crash; you can't function.' **Frank ME FM**

SOME PEOPLE ARE BEDRIDDEN AND HOUSEBOUND: 'I CALL IT THE LONELY DISEASE'

- Weakness and fatigue can undermine all functions, and can lead to an inability to perform the basic necessities of life.
- Loss and isolation can result, especially when family and friends do not understand reality of the condition.

6.6 FIBROMYALGIA SYNDROME

THINK PHYSICAL INJURY THAT DOES NOT RESOLVE

'This condition was as an onset of a motor vehicle accident, which I had in 2003, so the first symptoms appeared towards the end or the middle of 2005, and while the doctor is confident that it was the motor vehicle accident ... he ... was not willing to conclusively say, or be held liable to, to the fact that it's because of the accident that I have this condition.' **Peter FM ME**

FM IS A DISEASE PROCESS CHARACTERIZED BY ...

chronic widespread musculoskeletal pain non-restorative sleep fatigue headache morning stiffness poor memory difficulty concentrating paresthesia (numbness and tingling) gastrointestinal problems overall impaired functioning in both social and occupational settings

NEUROINFLAMMATION CAN CREATE SEVERE PAIN

Such pain ...

- is more constant than other forms of pain
- may come and go rapidly
- may move around to various parts of the body
- may worsen with touch
- FM is not managed well by many standard pain medications and requires specialized treatment.

FM CAN BE DISABLING AND DESTROY QUALITY OF LIFE

When I was first diagnosed I was told it was a soft tissue disease, I wasn't told anything about nerves or anything like that. With it I get a lot of numbness, if my back is hurting then my thigh will go numb. When it first happened in a theatre, I thought I was having a stroke, it was very scary. I can't sit too long, lay too long, nighttime is hard, I lay on my side, it falls asleep, I lay on my other side, it falls asleep, I lay on my back, and everything goes numb. ... I don't give up; I keep going, if people tell me, slow down, because if I am in pain you should be resting, I don't. I'll still go places with my daughter, I don't want to just lie in the bed, and everything just falls asleep. **Pearl FM**

FM CAN BE DISABLING AND DESTROY QUALITY OF LIFE

- Pain occurs on a gradient: from nuisance-type symptoms to severe pain so bad that it makes normal existence impossible, resulting in disability and severely compromised quality of life.
- Fibromyalgia is the 2nd most common disorder seen by rheumatologists.
- **An Iceland study estimates the prevalence of children affected by fibromyalgia at from 1.2% to 6.2%.**
- Onset of FM syndrome is often associated with **a physical injury**, whether past or recent. The question is: why does the pain not resolve after 'normal' periods of recovery.

To learn more about what all these definitional issues mean for those with the conditions, readers are referred to Part Three of this document.

6.7 THE QUANTITATIVE DATA - '...AN ILLNESS BURDEN SIMILAR TO THAT OF HEART DISEASE AND GREATER THAN THAT OF CANCER.'

FROM 'THE QUANTITATIVE DATA'

PREVALENCE * BURDEN OF ILLNESS * AGE * GENDER

In 2010, the number of Canadians with one or more of ES/MCS, FM or ME/CFS surpassed 1.4 million. This figure represents an increase of almost 300,000 cases since 2005 (Table 1). The prevalence of one condition or more increased from 4.2% in 2005 to 4.9% in 2010. Although increases were observed for each of the

conditions individually, the rise in the number of cases of ES/MCS from under 600,000 in 2005 to just over 800,000 in 2010 is most notable.¹⁴

When examining the number of Canadians reporting a diagnosis of various chronic conditions by a health professional, those with ES/MCS, FM and/or ME/CFS outnumber those living with the effects of a stroke, Alzheimer's disease and other dementias, Multiple Sclerosis and Parkinson's disease (Table 2). When the three conditions are combined, they represent an illness burden similar to that of heart disease and greater than that of cancer.¹⁵

The prevalence of the conditions by age groups reveals that for ES/MCS and FM, the prevalence peaks at age 45 (3.9% and 2.5%, respectively), while for ME/CFS the prevalence peaks at age 65 and older (2.2%) (Table 3). For FM, there is even a slight decrease in the prevalence in those aged 65 and older. Prevalence is higher in women for all three conditions. Among those with FM, women had four times the prevalence of men (2.4% vs. 0.6%).¹⁶

An examination of the age distribution for those with ES/MCS, FM and/or ME/CFS demonstrates that the majority of those affected are aged 45-64 (Table 4). Younger people (aged 12-24) are also affected, in particular with ES/MCS (8%) and ME/CFS (6%). The age distribution is similar for all three conditions. The gender distributions show that by far, the majority of those living with these conditions are women; the range varies from 66% of those with ME/CFS to 79% of those with FM.¹⁷

A breakdown of the number of cases in Ontario shows that the 2010 prevalence of one condition or more is 5.0% (Table 5), similar to the national value of 4.9% reported in Table 1. There were only slight variations in the prevalence estimates of the individual conditions when compared to the national values. The greatest number of cases was observed for ES/MCS (n=292,660 in 2010), which is consistent with the results for Canada. The growth in one or more of the conditions from 2005 was also similar between Ontario and Canada, but slightly greater growth was observed for ME/CFS and for FM in particular, in Ontario.¹⁸

ESTABLISHING THE LEVEL OF IMPAIRMENT WITH COMPARATOR GROUPS

CCHS DATA (2005/2010)

Being permanently unable to work is a well-known measure indicating level of disability. Those with chronic conditions in general experience higher levels of being permanently unable to work than the total population (Table 7). Although there are overlaps among the chronic conditions groupings, when evaluating the proportion of Canadians permanently unable to work according to their chronic health condition, the results are telling. Canadians with ME/CFS in particular experience high levels of being permanently unable to work (24.0%), which is similar to the finding for those living with the effects of a stroke (23.6%). Those with FM also

¹⁴ See *The Quantitative Data*, Table 1: Prevalence of ES/MCS, FM and ME/CFS among Canadians aged 12 and older, 2005 and 2010, pg. 11.

¹⁵ See *The Quantitative Data*, Table 2: Number of Canadians with Chronic Conditions based on their Reported Diagnosis by a health Professional, 2010, pg. 12.

¹⁶ See *The Quantitative Data*, Table 3: Prevalence of ES/MCS, FM and ME/CFS according to Age and Gender, Canada 2010, pg. 12.

¹⁷ See *The Quantitative Data*, Table 4: Age and Gender Distributions of Canadian Population aged 12 and older with ES/MCS, FM and/or ME/CFS, 2010, pg. 13.

¹⁸ See *The Quantitative Data*, Table 5: Prevalence of ES/MCS, FM and ME/CFS among Ontarians aged 12 and older, 2005 and 2010, pg. 14.

have a high rate and followed closely behind (20.6%). Further, those with ES/MCS have a similar level to those with cancer and diabetes.¹⁹

Needing help with activities of daily living is a routine measure of functional status and extent of disability. An overall summary measure for needing help with tasks indicates that those living with the effects of a stroke (51.9%) and those with ME/CFS (47.2%), followed by those with FM (37.7%) require very high levels of assistance with activities of daily living (Table 8). Those with ES/MCS require a similar level of assistance as those with cancer and diabetes, and the rates are greater than those for the total population.²⁰

For individual tasks of daily living such as needing help with housework, preparing meals and running errands, the proportions of people living with the effects of a stroke and with ME/CFS that require assistance consistently remained the highest. Housework is cited most often as the task people with chronic conditions including ES/MCS, FM and ME/CFS need help with.

(Tasks queries were housework, meals, getting to appointments/errands, personal care, moving about inside the house and looking after personal finances.)

An analysis with 2003 CCHS data by Park and Knudson (2007) [6] also found high percentages of people with ES/MCS, FM and/or ME/CFS needing help with activities of daily living. For instrumental activities of daily living (defined as housework, preparing meals and getting to appointments/errands), those with ME/CFS (43%), FM (37%) and ES/MCS (22%) had significantly higher rates ($p < 0.05$) than those in the general population without the conditions (7%). Similarly for other activities of daily living (such as personal care and moving about inside the house), those with ME/CFS (15%), FM (11%) and ES/MCS (6%) had significantly higher rates ($p < 0.05$) than those without the conditions (2%). They further adjusted for socio-demographic factors and found the associations remained statistically significant.

Severe functional impairment – specific indicators of severe functional impairment based on cognition, mobility and pain for people with the three conditions are listed in Table 9. The sample sizes for cognition and mobility estimates are small and should be interpreted with caution, but the pattern indicates that a sizeable proportion of people with the conditions have severe cognitive or mobility issues. Pain prevents most activities in over one quarter of people with ME/CFS. The proportions are lower for FM (21.4%) and ES/MCS (10.1%), but are still substantive.²¹

SUMMARY - CCHS: UNABLE TO WORK * ACTIVITIES OF DAILY LIVING * SEVERE FUNCTIONAL IMPAIRMENT

Overall these results 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 findings that the levels of impairment for certain disability measures in people affected with ME/CFS are akin to or approach those for people living with the effects of a stroke are most notable. It is important to note that several chronic conditions such as stroke and cancer are commonly associated with older age, which is also a time when needing help for tasks increases. People with ES/MCS, FM and/or ME/CFS are on average middle-aged and yet, still require high rates of assistance with activities of daily living.

The levels of disability among people with ES/MCS, FM and/or ME/CFS are also substantially elevated in

¹⁹ See *The Quantitative Data*, Table 7: Canadian Population who are Permanently Unable to Work According to their Chronic Health Condition, 2010, pg. 19.

²⁰ See *The Quantitative Data*, Table 8: Canadian Population who Need Help with Activities of Daily Living According to their Chronic Health Condition, 2010, pg. 20.

²¹ See *The Quantitative Data*, Table 9: Indicators of Functional Impairment among Canadians with ES/MCS, FM and/or ME/CFS, 2010, pg. 22.

comparison to the general population. Despite slight differences in groupings of activities of daily living, a similar range in proportions of those requiring assistance were found between the previous analysis conducted with the 2003 CCHS [6] and the present analysis with more recent 2010 data. This demonstrates the consistency in findings from different samples over time. The additional analysis with adjustment for socio-demographic factors in the 2003 study further strengthens the findings.

Much of the functional impairment among people with ES/MCS, FM and ME/CFS can be due to severe fatigue, sleep dysfunction, chronic headaches, neurological and neuro-muscular manifestations, plus a host of other multi-system symptoms that are not captured in the available measures of disability. This may be particularly true for ES/MCS, where serious reactions to symptom triggers are not captured in the questions. Such exposures can sometimes render individuals incapacitated for days or weeks at a time, or even provoke deterioration into a more severe state of the condition. Lack of relevant information makes it difficult to understand the needs of people with these conditions and can serve to understate the extent of the problem.

The high levels of those permanently unable to work likely reflect significant impairment experienced by people with chronic conditions; but could also reflect less than adequate workplace accommodations which may prevent some from participating in the workforce.

ENVIRONMENTAL HEALTH CLINIC (WOMEN'S COLLEGE HOSPITAL, TORONTO) DATA (2005-2006)

Data from a chart review of 128 patients attending the Environmental Health Clinic (EHC) in Toronto, Ontario between January 2005 and March 2006 were analyzed for demographic factors and functional status based on the Short Form (SF)-36 [8]. **Patients were on average 44.6 years of age and mostly female (86.7%). The majority had stopped work (68.0%), and the average number of years between symptom onset and discontinuing work due to their health was three years.** A breakdown of diagnoses of these patients in comparison to the breakdown in the Canadian population is shown in Table 10. These results indicate that the EHC is more likely to assess patients with multiple diagnoses and in particular, those diagnosed with both FM and ME/CFS.²²

The EHC patient population was found to have lower scores for functional status according to the eight SF-36 subscales (bodily pain, energy and fatigue, emotional well-being, general health perceptions, physical functioning, emotional role limitations, physical role limitations and social functioning) than the average scores of Canadians with comparable age and sex [8]. This was particularly true when patients had multiple diagnoses. In multivariate regression analysis, FM was found to be significantly associated with poorer functional status on the majority of SF-36 subscales, while ME/CFS was significantly associated with lower physical functioning and emotional wellbeing.

The EHC in Toronto, Ontario is the only government-funded clinic assessing patients with ES/MCS, FM and ME/CFS in the province. Those patients referred to the EHC may be more likely to have greater severity of symptoms and prolonged duration of illness. This notion is supported by the finding of a greater proportion of patients diagnosed with one or more of the conditions, which are known to be more severe cases, than in the general Canadian population. The general pattern of middle aged, mostly female cases with a high proportion that are unable to work and have high levels of functional impairment are consistent with findings observed on the CCHS.

²² See *The Quantitative Data*, Table 10: Diagnoses of the EHC patient population, 2005-2006, pg. 24.

7 KEY LESSONS FROM THE ENVIRONMENTAL SCAN

FROM MEAO's environmental scan and the historical experience of two patients organizations, in this chapter we want to speak to two broad areas. The first has to do with positive changes in understanding of the environmental links to chronic illnesses more broadly, and of the CELCs more specifically. The second has to do with hard lessons learned through attempts by patient organizations to obtain key health supports from CCACs, hospitals and schools - attempts that have largely failed in the absence of central policies and mechanisms for accommodation. The first area shows that the time for change has truly arrived. The second area shows that change will have to be driven and supported by enabling pro-active policy shifts, new programs and new incentives if it is to succeed.

7.1 NEW RECOGNITION OF LINKS BETWEEN CHRONIC ILLNESSES AND ENVIRONMENTAL FACTORS - PARADIGMS ARE SHIFTING

AS noted, 568,000 Ontarians were diagnosed with the CELCs in 2010 (undoubtedly an under-reported figure). Therefore many, many individuals and families are touched by the conditions, and many health personnel are confronted with this reality. **Myths about the CELCs as fictitious are simply not accepted by many health professionals, as well as rejected by patients. Many health providers want assistance in helping people living with the CELCs. A survey of CHC physicians conducted in the winter and spring of 2013 showed great lack of confidence in assessing and treating, but a very enthusiastic response to the possibility of learning how to assist with these populations.**²³

Medicine and public health are changing. Environmental impacts are now understood by an ever-increasing number to be powerful drivers of chronic illness, so the long-standing claims of those who have treated and theorized the CELCs are not alone as paradigm challengers any longer.

Major new departments at leading universities in many jurisdictions have established programs in health and the environment in the last decade. Advances in toxicology, diagnostic imaging, neurology, immunology, genetics and epigenetics all contribute to these changes. Signaling a new institutional comprehension of the importance of environmental factors to health, the University of Toronto recently appointed the distinguished expert in environment and health, Dr. Howard Hu, to the position of dean of the Dalla Lana School of Public Health, and a new department of clinical environmental medicine has been established. **Scientists and teaching clinicians - the ones at the forefront of this sea change in understanding the links between environment, health and chronic illness - know these conditions are real and serious,** for individuals, for families and for society as a whole.

Newer programs in environmental health issues among children (U.S.) target endocrine disruption, immunity disorders and cognitive deficits due to small, ubiquitous doses of many types of everyday chemicals, as well as the older identified industrial chemical hazards linked to cancers, for example. Until

²³ Survey conducted of Community Health Centre (CHC) physicians by Dr. Dona Bowers, Ottawa/Somerset West physician and OCEEH BCP consultant, Winter/Spring 2013, for the OCEEH Business Case Project. Available from the Association of Ontario Health Centres (AOHC) <http://www.aohc.org/>

recently, however, these programs have not included our three conditions - though this is beginning to change. Problematically, it takes time for new science to be expressed in clinical practice, and many of these children's programs do not yet have clinical components beyond assessment and advice.²⁴

The process of shifting paradigms can be slow and frustrating because there are many commercial and institutional factors that create a drag on the translation of research into practice. Phil Brown is Professor of Sociology and Environmental Studies, and founder of the *Contested Illnesses Research Group*, at Brown University, Providence, Rhode Island. In his retrospective evaluation of Gulf War related-illnesses (GWRI), which include symptom clusters identical to multiple chemical sensitivity, chronic fatigue syndrome and fibromyalgia, he writes:

Revisiting the case of Gulf War-related illnesses shows that the evolution of a dominant epidemiological paradigm is not simply a function of advancing scientific knowledge. ... Obstacles to advancing the science originate from a variety of sources: not only the quality and availability of data but also the political and personal motivations of different actors and the complicated relationships among them. When the science on a contested illness is in disarray and unable to advance toward a shared understanding of a disease or condition, other forces may steer the evolution of the dominant epidemiological paradigm²⁵

It has taken a long time for the advances in discreet fields to cohere **with respect to the CELCs, but this has been ongoing and the needed syntheses are now strong enough to move forward.** (Chapter 16 explores this in greater detail). Today, in short, the notion that these conditions are either fictitious or psychogenic has lost its hegemonic status; challengers to this 'received wisdom' are many and distinguished.

Indeed, a new period is opening up in which innovative solutions to complex, chronic conditions are combining with a greater awareness of environmental factors in health - a context in which the proposed model of care for services for the three CELC, **in this report and the OCEEH business case it is supporting, can play a positive role in achieving much better value (outcomes) for the health care dollar, not only for these groups, but for many others.**

²⁴ For example, Dr. Philip J. Landrigan and his work at the Childrens' Environmental Health Center, Mt. Sinai Hospital, New York. <http://www.mountsinai.org/patient-care/service-areas/children/areas-of-care/childrens-environmental-health-center>. See also <http://healthychild.org/about-us/philip-j-landrigan-md-msc/>. The appointment of Dr. Howard Hu as Dean of the Dalla Lana School of Public Health at the University of Toronto signals a major step forward in the larger trend to understand and include environmental impacts in 21st century health and health care.

²⁵ Phil Brown, Rachel Morello-Frosch, Stephen Zavestoski, and the Contested Illnesses Research Group eds. *Contested Illnesses: Citizens, Science, and Health Social Movements* (Berkeley, Los Angeles, London: University of California Press, 2012); and Steve Kroll-Smith, Phil Brown, and Valerie J. Gunter, eds. *Illness and the Environment: A Reader in Contested Medicine* (New York and London: New York University Press, 2000) pg. 98. Phil Brown is also the author of *No Safe Place: Toxic Waste, Leukemia and Community Action* (University of California Press, 1990). He is editor of *Perspectives in Medical Sociology* and co-editor of *Social Movements in Health and Illness and the Environment: A Reader in Contested Medicine*. For discussions of other such 'contested illnesses' in relation to environmental hazards, and their evolution, see Phil Brown, *Toxic Exposures: Contested Illnesses and the Environmental Health Movement* (New York: Columbia University Press, 2007).

‘CONTESTED ILLNESSES’: THE NEED TO PROVIDE ACADEMIC AND CLINICAL PERSPECTIVES FOR THE CELCs

At some point along the way, every person who has ever attempted to advocate for the CELCs has encountered claims that there is no scientific basis for diagnosis and treatment. This is an obsolete view that has also dogged many other conditions initially linked to environmental problems.²⁶ It has, nevertheless, hung on in the culture of health care in the absence of system initiatives and incentives for correction. Therefore **being able to refute this view becomes a critical aspect of reversing the current state.**

In 2010, Dr. Lynn Marshall, in collaboration with other staff physicians at the Environmental Health Clinic in Toronto, wrote *The ES/MCS Status Report* to assist the Ministry of Health and Long Term Care to have access to up-to-the-minute understandings of ES/MCS.

The OCEEH BC project has made it possible to support the writing of a ‘next-step’ state-of-the-art literature survey and bibliography for all three conditions, authored by Dr. John Molot, another staff physician at the Environmental Health Clinic.²⁷ His **‘Complex chronic conditions: Academic and clinical perspectives’ supports a developing paradigm that addresses etiology, symptomatology, diagnosis, treatment and support (best and promising practices) of the three conditions within a framework of chronic disease and systems and cellular medicine** – the innovative, cutting-edge approach.

The many recommendations for clinical treatment made by participants in the patient study/community consultation, found in Parts Three, Four and Five of this report, are aligned with and strongly support the recommendations for service provision by Dr. Molot.

We hope both the patient and physician perspectives can assist with the evidence needed to support the business case.

7.2 KEEPING COMPANY WITH NEW INITIATIVES IN OTHER JURISDICTIONS

THE cumulative effect of these improved understandings has been to prompt major changes in a number of Canadian and international jurisdictions. Many governments are beginning to register this knowledge and respond in a number of ways.

In 2011, for example, the Norwegian government issued a public apology to ME/CFS patients. Through the serendipitous results of a drug trial for Rituximab in cancer treatment, it was found that though the drug did little for the cancer patients, those in the study with ME/CFS benefited from it because of its positive effect on immune function - long held, by knowledgeable practitioners, to be negatively

²⁶ Ibid. This report is available has been added as an appendix to *Chronic, complex conditions: Academic and Clinical Perspectives*, by Dr. John Molot, soon to be available at the MEAO website (www.MEAO.ca).

²⁷ J. Molot, MD, *Chronic complex conditions: Academic and clinical perspectives* (Ontario Centre of Excellence in Environmental Health, 2013); the clinical submission to the Ministry of Health and Long Term Care, supporting the Ontario Centre of Excellence Business Case Proposal.

affected in ME/CFS. Norway changed its categorization of the illness from an affective to a biophysical disorder, and changed its attitude to sufferers and their needs.²⁸

Literally as we complete this report, a new report, *'The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis'* has been issued by the United States Center for Drug Evaluation and Research.²⁹ Its results are completely in line with our own findings (Part Three of this report) on the devastating impact of ME/CFS on many lives. This study is part of an initiative to research new drug therapies.

New initiatives to create care facilities are taking place in the UK, in Europe, and in Canada too. In British Columbia, for example, a new clinic for ME/CFS and Lyme disease (a frequent co-factor with all three conditions) opened its doors in March 2013 and was inundated with new patients. Two-thirds of the OCEEH BCP has been funded by Ontario's Ministry of Health. The funding for that study was supported in 2012 by then Transport Minister, now Premier Kathleen Wynne. The Ontario Trillium Foundation supported MEAO's project, 'Improving the Quality of Care and Support', with a generous grant.

In fact, the proposed OCEEH initiative that the complete OCEEH submission motivates - to create a delivery system for care and support to assist our three populations initially, and later to use that network to help much larger populations with environmentally-linked health challenges - is the most far-reaching, ambitious and exciting of any new initiatives on any drawing board in any jurisdiction.

The great advantage we now have is that we can learn from other jurisdictions, both with respect to the types of services required for our communities, and how to create those services. Most especially, we feel privileged to be able to participate in creating new services within the emerging framework of true person-centred and patient-led care. With a number of patients' organizations (Patient Destiny, Patients Canada) we have been truly excited by the 'Nuka Model', for example, developed by First Nations Alaskans to develop a fully integrated health care and social support services delivery system that holds as its core philosophy and mission to reflect that the people who come to its services are both 'patients' and 'owners' of these services.

²⁸ There are currently two other clinics in Canada that provide services for individuals with environmental health related conditions: the Complex Chronic Disease Program (CCDP) at the BC Women's Hospital and Health Centre in Vancouver, British Columbia and the Nova Scotia Environmental Health Centre (NSEHC) in Fall River, Nova Scotia. The CCDP opened in 2012 to provide services to individuals with FM, ME/CFS, and tick borne illnesses such as Lyme disease. The clinic provides clinical care, research and surveillance, education and health promotion, and scientific evidence synthesis and knowledge transfer. The clinic was provided funding of approximately \$2M by the BC Ministry of Health to establish the program and related research activities. The NSEHC was opened in 1996 and provides clinical care and research; it is now known as the Integrated Chronic Care Service (ICCS). The ICCS provides services for individuals with ME/CFS, chronic pain conditions, environmental illnesses, FM/ES, MCS, multiple chronic conditions, and functional neurologic and gastrointestinal syndromes. It serves a population of approximately 54,500 who are living with one or more of ME/CFS, FM and/or ES/MCS, has an annual operating budget of approximately \$1.3M and recorded 5,386 visits in 2011.

²⁹ Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration (FDA), *The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis*. (Silver Spring, MD, September 2013). See Appendix 3 for summary of key themes.

7.3 LESSONS FROM PATIENT EXPERIENCES PRIOR TO COMMUNITY CONSULTATION

7.3.1 EHAO AND THE CHRONIC DISEASE PREVENTION AND MANAGEMENT PROGRAM

WHEN an Environmental Health Association of Ontario (EHAO)-based patient initiative to seek new services for those with ES/MCS began in late 2008 (inclusion of those with ME and FM occurred early in 2011), EHAO approached the office of Ontario's Minister of Health and Long Term Care with a request to be linked to the ministry's senior staff in charge of the chronic disease prevention and management program. Prevention and management of chronic illness was a major priority for the Ministry, and it made perfect sense to the EHAO board members to renew efforts for service provision, last attempted in the 1980s and 1990s, at this location. At that time, no official in the Ministry had carriage of the file, so this seemed like a good place to start.

When a meeting with senior officials eventually took place in September 2009, the EHAO representatives found that ES/MCS (and ME) were neither part of the program, nor even on its radar screen. However, the officials agreed to explore whether a proof of concept and business case proposal could be developed. Six months later, after a lot of work on the part of the volunteers and what turned out to be a problematic and poorly framed investigation of the area by ministry staff, the EHAO board members were informed that there was no research to show that a clear diagnosis could be made or that anything helpful could be done for the condition. At that time (April 2010), therefore, they were informed there would be no further collaboration to seek to create the proof of concept and business case.

Three lessons were learned from this reception. First, virtually nothing of the new research on ES/MCS had filtered to those assigned to prepare the exploratory 'vignette'. Second, the conditions were so unknown that even director-level officials would require permission and safe conduct from higher levels to take on the work. Third, that the CDMP as it was constituted may in the abstract have provided an important framework to provide services, but in practice lacked key pieces to address critical factors in our target conditions, and vice versa. The lack of codified and diffused clinical guidelines - though linked to lack of funding of services - was a problem for that program. Clearly work had to be started on different fronts.

These lessons guided the approach of the patient advocates, who had been joined by several other experts, including physicians from the Environmental Health Clinic. The expanded team then developed material that assisted more senior officials to feel comfortable in eventually (2012) funding a business case proposal. **However a major lesson learned remains highly relevant today: unless there is policy directing the provision of services of services from the top and the centre of the health care system, those at lower or more local levels will not feel able to step up to fulfill their roles.**

The community consultation, in which more than fifty people spoke about their experiences in seeking care and support, eventually corroborated this impression.

7.3.2 EHAO AND INDIVIDUAL PATIENT EFFORTS TO OBTAIN ASSISTANCE AT THE LHIN AND CCAC LEVELS

To date, people living with the CELCs have not done well with seeking health support. As patients can report, the list of physicians serving the CELC populations has always been small, but now, even as the

numbers of those in need grows, physician numbers have been diminishing. As well, countless attempts by individuals to obtain CCAC supports for local service and for hospital reception have generally failed.

With a view to setting positive precedents for others, between 2008 and 2010 a number of EHAO members (in Peterborough, Picton, Thunder Bay, and the GTA, among other locations), including several very experienced and articulate members conversant with human rights and health entitlements, worked in their different locales to try to obtain CCAC and hospital services for themselves, and, by extension for others with ES/MCS. Each story is instructive, but the aggregate result was poor to complete failure in terms of permanent outcomes. At the same time the efforts depleted the health and finances of the people involved. The information-gathering consultation with the CELC respondents in this report confirms many others have had similar negative experiences, with all three conditions.

In response to failures to obtain local assistance, a then-VP of EHAO, Lin Grist, met with the CCAC provincial CEO Margaret Mottershead to discuss the possibilities of province-wide directives from Ms. Mottershead's office, only to hear another version of a recurring refrain: with no billing code, no practice guidelines, no funding, no local physicians conversant in the condition and, above all, no Ministry policy, there would be no specialized CCAC services made available. **Once again, it was clear that unless the most senior decision makers at the ministry were engaged and persuaded to take policy initiatives from the top to direct and fund local services, individual attempts would largely founder.**

This has also been the experience of MEAO members and of members of patient organizations across the province. **The key conclusion from this experience is that the shotgun approach – individual patients fighting for services at individual locales, replicating their struggles over and over again, with no precedent setting power – is extremely difficult, time consuming and ineffective, be these efforts to persuade providers directly, or to compel them via human rights procedures.** Full court proceedings might be more successful, but the costs of these have put them out of reach of people living with the CELCs. As well, an adversarial struggle is extremely stressful, and the least possible attractive option in securing services.

7.3.3 MEAO AND EFFORTS TO ENSURE SCHOOLING FOR YOUNG PEOPLE WITH ME/CFS AND FM.

In a survey of UK school boards in the UK in the mid-1990's, researchers found that ME was the leading cause of student absences of two months or more. Students were more likely to be absent for extended periods because of ME than because of mental illness, physical trauma, or any other reason. The study came up with a rate of long-term absence for ME at 70 per 100,000 students, which would convert to several thousand young people in Ontario missing significant periods of school because of ME at any one time.

In 2002, the National ME/FM Action Network published the *Teach-ME Sourcebook for Teachers of Students with ME/CFS and FM*.

Based on the UK study, the Sourcebook, and the terrible experiences of several young Ontarians with ME/CFS or FM who went without public education, **MEAO looked at the policies and procedures regarding education for students who were dealing with reduced activity levels.** These students required programs that were designed around their functional capabilities. For those mildly affected, this could involve strategies like being excused from physical education, being given reduced homework assignments, or being allowed to take rest breaks. For those more seriously affected, it could include part-time or home-based instruction. **What MEAO found was a gaping hole.**

By way of background, the US and UK approach this issue in different ways. The US has a Special Education system with categories of exceptionality (autism, hearing impairment, etc.). One of the categories is 'Other Health Impaired.' Young people with ME/CFS or FM can qualify for special education under this category. In the UK, there are special policies put out by the Ministry of Education to School Boards covering student with medical needs.

Ontario has a special education system, but there is no category of exceptionality equivalent to 'other health impaired' that directly covers students with attendance challenges. There are two main consequences. First, students have a hard time qualifying for special education – it is really at the discretion of the school board whether they interpret another category sufficiently broadly. Second, the categories are instructions to school boards to have programs in place. Because attendance limitation is not a category on the special education list, many or most school boards do not have systems to serve these students.

Ontario has special policies in place for students in institutions, but it does not have special policies for young people sick at home. MEAO approached the Ministry of Education on numerous occasions asking that the policies and procedures be updated to include these students who had been overlooked. Despite great efforts by MEAO, this issue has never been resolved. For the young people affected even today, they do not have the 'right' to an education. It is at the discretion of the system.

It is hard to understand why the Ministry of Education has not fixed this problem, which has denied disabled young people their education. One possibility is that the resistance was based on the fear of the costs of providing the services. Another possibility is a fear that by offering students reduced or home-based instruction, other students would want it. (Equivalent to saying that no students should be allowed to use wheel chairs because other students would rather ride than walk between classrooms.) A third possibility is the fear that resolving issues in the education area could lead to demand for similar policy changes in other areas.

Two lessons can be drawn from this experience. First, the lack of awareness and possibility for accommodation for children and young people in education in this province is very troubling. Second, as with so many issues and needs identified in this report, centralized government policy directives and aligned initiatives across areas are urgently needed.

8 NEGATIVE VALUE FOR HEALTH CARE DOLLAR IN THE CURRENT STATE

THE range of impacts of these conditions on the people who live with them is taken up in a number of ways throughout this report, especially in Part Three. Ameliorating the hardships those living with the CELCs face is what this project is all about.

However, at the same time as we examine the plight of those affected, we are very conscious of the fiscal constraints that public services face and the need in these times to get excellent value for the health care dollar.

In this context, we wish to deliver several critical messages with respect to **addressing the needs of society as a whole, in assessing costs and impacts on both the health care budget, and on the larger public purse.**

Three major sets of issues delineate the territory.

8.1 ENVIRONMENTAL HARMS IMPOSE SIGNIFICANT BUT NON-TRANSPARENT COSTS

EVEN a cursory glance at the involvement of harmful chemicals in epidemics of chronic illness leads inevitably to a common-sense understanding that these **chemicals hazards are increasing the burden of suffering and the burden of public payment on a massive social scale.**

In their paper, *‘Environmental influences on healthcare expenditures: an exploratory analysis from Ontario, Canada,’* M. Jerrett, J. Eyles, C. Dufournaud, and S. Birch set out to ‘explore the relation between healthcare expenditures (HCEs) and environmental variables in Ontario, Canada.’ Even ten years ago...

The results show that, after control for other variables that may influence health expenditures, both total toxic pollution output and per capita municipal environmental expenditures have significant associations with health expenditures.

And they concluded:

Counties with higher pollution output tend to have higher per capita HCEs, while those that spend more on defending environmental quality have lower expenditures on health care.³⁰

The implications of our findings are twofold. Firstly, sound investments in public health and environmental protection have external benefits in the form of reduced HCEs. Combined with the other benefits such as recreational values, investments in environmental protection probably yield net social benefits. Secondly, health policy that excludes consideration of environmental

³⁰ M. Jerrett, J. Eyles, C. Dufournaud, S. Birch, ‘Environmental influences on healthcare expenditures: an exploratory analysis from Ontario, Canada.’ *Journal of Epidemiological Community Health* 2003: 57, 334-338; doi:10.1136/jech.57.5.334.

quality may eventually result in increased expenditures. These results suggest a need to broaden the cost containment debate to ensure environmental determinants of health receive attention as potential complements to conventional cost control policies.

Much of the research collected in the 'Early Exposures'³¹ report, already cited, has been conducted subsequent to the Jerret et al. study. From the results of that 'Early Exposures' it is necessary to conclude that the **cost implications of environmental influences have only increased.** (Better assessing the actual financial costs of environmental impacts is a field begging for research funds and projects. In this day and age, such research needs to inform all government policy including all aspects of economic development.)

Therefore, **the policy shifts and services outlined in the recommendations that follow later in this document (the 'strategic enablers'),** with respect to the role of government in better regulating harmful chemicals, with respect to public health priorities and programs, and with respect to including environmental health in clinical practice through education of physicians and incorporation of medical surveillance into everyday practice, **are of major importance to Ontario society as a whole.**

8.2 NEGATIVE VALUE FOR HEALTH CARE DOLLARS IN INAPPROPRIATE CARE FOR THE CELCs

At the same time, major fiscal issues are also involved in the current state of void in care for the three 'canary conditions' - the CELCs. **Exceptionally high utilization costs by people with the CELCs have been noted by many observers.** These include Statistics Canada, the Environmental Health Clinic (Toronto), the Nova Scotia Environmental Health Centre, and U.S. scholars.³² In Ontario, the EHC found that by the time patients arrived for assistance at the clinic - patients who, on average, had stopped working three years after onset of symptoms - they were consulting both specialists and family physicians at roughly eight times the rate of average Canadians (see directly below). At the same time, **they had received little to no help, and many had deteriorated over the time they waited for diagnosis and appropriate care.**

³¹ Cooper, 'Early Exposures...'.

³² J. Park and S. Knudson, 'Medically unexplained physical symptoms,' *Health Reports* Vol. 18, No 1, February 2007, Statistics Canada; Roy A. Fox, M.D., M.E.S., F.R.C.P.C., Michel R. Joffres, M.D., Ph.D., Tara Sampalli, M.Sc., and Jill Casey, M.Sc., 'The Impact of a Multidisciplinary, Holistic Approach to Management of Patients Diagnosed with Multiple Chemical Sensitivity on Health Care Utilization Costs: An Observational Study,' *The Journal of Alternative and Complementary Medicine* Vol. 13. No. 2, 2007, pg. 223-229; Pamela Reed Gibson, Amy Nicole-Marie Elms, and Lisa Ann Ruding, 'Perceived Treatment Efficacy for Conventional and Alternative Therapies Reported by Persons with Multiple Chemical Sensitivity,' *Environmental Health Perspectives* Volume 111, Number 12 September 2003, p1498 (Quote: 'Participants had consulted a mean of 12 health care providers and spent over one-third of their annual income on health care costs'); M.R. Lavergne, D.C. Cole, K. Kerr, L.M. Marshall, 'Functional impairment in chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity,' *Canadian Family Physician*, February 2010; 56: e60-1.

By contrast, however, we have examples even in our own consultation of people who had high costs on onset of illness, and ongoing, but who received timely and appropriate care *plus* responsive accommodation at work (just as important), and were therefore returned to productivity. Investment in such care tips the balance sheet of the public purse into the black as a result of restored productivity.

AMY'S STORY

FINANCIAL RESOURCES NEEDED TO RETURN TO WORK AND REMAIN PRODUCTIVE

Everything that I've needed, I've had the financial resources and the family support to get for myself. So today, I had my \$100 a week physiotherapy appointment, which is really helpful. It keeps me going so I can get into work three days a week. On Tuesday, I have my hour and a half massage appointment. The physiotherapy, fortunately I have private benefits that take care of. The massage, not so much. So that's \$125 a week that I pay in order to function. If I don't go, I find that things tend to flare up and it interrupts with my ability to work.

So it's pretty much a locked in cost that I have to pay. But I have the money to pay it, so that's not an unmet need, being with the physiotherapy. My drug costs, quite substantial. I take an array of wonderful pharmaceuticals that help me greatly. I'm part of a generous healthcare plan, and so is my husband. I have 100 percent drug coverage, thank God. A lot of people don't. So that's another expense. Let me see, oh, I can't clean my house. I can't both clean my house and work, so I have a cleaning team that comes in. I opted to get a team that comes in, which is more expensive than one person, because it's so exhausting to have someone there in my house for five hours cleaning my house. So they come in and it's, ... like a flurry of activity. I kind of hunker down and try not to get in their way and then off they go. But that's another expense each month that I'm dealing with.

You know, there are just so many things. Oh, supplements, you had mentioned supplements earlier, and I'm on a bunch of supplements that help me very well again. That's probably, I'm going to say between \$200 and \$300 every couple of months. No help for that. I sleep on a very nice, very comfortable Tempurpedic mattress that cost \$4,000. ... I feel uncomfortable actually disclosing how lucky I am and how fortunate I am that I don't have unmet needs because I'm sure that there are people in the group who are thinking, 'Damn, she's lucky.' Well, I am, but that's a financial burden. My husband and I are both highly educated, he has a master's degree. I have a law degree. We're people who should be able to afford everything. And even for us, it's a struggle.

We went through a lot of money getting me rehabilitated. I went from needing a wheelchair to get around, to now working three days a week and being able to do things like go on vacation and have a little bit of a social life. And thank God that I was able to find the resources to pay for that stuff. ... Just to put it all in perspective, our first cost for the first year that I was ill, was over \$10,000 in medical expenses. And that was with both my husband and I having what I would consider to be a generous healthcare benefit plan. Still \$10,000. That's *on top* of the benefits, and that's just healthcare stuff that we could claim with CRA. Not even the house cleaning, convenience services, the cost of having to have someone pump gas for me because my hands are too sore, all on down the line. **Amy FM**

In terms of health costs, narrowly defined, neglect of the CELCs is a big story of short-sighted waste as well as patient neglect. Impressionistically again, it seems that **possibly hundreds of millions of dollars are being paid out for useless and inappropriate treatment to physicians that do not understand the conditions and provide useless or even harmful interventions - all because no appropriate system is in place.** The outcomes for patients are terrible. The cost to society is very high.

8.3 LACK OF CARE PERPETUATES HIGH SOCIAL COSTS

PERHAPS equally importantly in calculating the costs of the CELCs, it is important to understand that **those who do not receive appropriate care and support are likely to generate a series of social costs that are also very burdensome for society. In the current state, these social costs are not transparent and not being tracked.** Nevertheless, impressionistically and analogously to other conditions, we know a number of things that we need to consider, both in moving forward immediately, and in setting up studies and tracking mechanisms that can help us to calculate those social costs. We know that:

- When people stop working, they stop paying income tax and reduce all types of consumption - affecting public and private revenues.
- When people lose their livelihoods, they must rely on social assistance and ODSP, on the assistive devices and drug benefit programs - all of which are costly to society.
- When adults are affected in the prime of life, their ability to save for their senior years is undermined, and they are much more likely to draw on public resources sooner and at greater volume.
- When parents are affected during the middle years, their ability to pay for higher education for their children is compromised, affecting their children's life chances.
- When parents are affected during their twenties and thirties, children suffer through both parenting deficits and fewer educational and recreational resources, which then show up in poorer economic and (physical and mental) health outcomes - therefore costs are handed along to the next generation.³³
- When adults are affected, elder care for their own parents is often compromised, creating a greater burden on public resources.
- When children are affected, productivity of parents, and health and well-being of the whole family are negatively affected;
- When those able to contest the denial of their rights to accommodation and public services take their complaints to Human Rights Tribunals, the costs of these many public processes mount up, year after year and drain the public purse.

When health and social costs are added up, the lack of appropriate care and support for Ontario as a whole - for its citizens, its families and its communities - is nothing short of tragic.

³³ Centers for Disease Control and Kaiser Permanente, *The Adverse Childhood Experiences Study* (Atlanta, GA, and San Diego, CA: ongoing). Quote: 'The ACE Study is ongoing collaborative research between the Centers for Disease Control and Prevention in Atlanta, GA, and Kaiser Permanente in San Diego, CA. The Co-principal Investigators of the study are Robert F. Anda, MD, MS, with the CDC; and Vincent J. Felitti, MD, with Kaiser Permanente. Over 17,000 Kaiser patients participating in routine health screening volunteered to participate in the study. Data resulting from their participation continues to be analyzed; it reveals staggering proof of the health, social, and economic risks that result from childhood trauma. [The Centers for Disease Control and Prevention](http://www.cdc.gov/ncj126204/20140110.pdf) provides access to the peer-reviewed publications resulting from The ACE Study.' <http://acestudy.org/>

The OCEEH BCP, then, and this report supporting it, is proposing a system of care that can both provide appropriate care to patients to re-align and re-invest health dollars into services that give value, improve outcomes and improve chances for an overall lower draw on the public purse.

The recommendations in this report and in the OCEEH BCP are in line with Ministry policies that seek to reduce the high cost of the top 5% of health care users, both at present, and in preventing people from becoming such users. We are convinced that if government reinvests money currently being wasted in inappropriate care into a system with ‘the right service, at the right time, in the right place’ literally everybody will win. The findings of our survey of the quantitative data, as well as our patient study and community consultation, strongly validate these concerns.

FROM ‘THE QUANTITATIVE DATA’

CCHS SHOWS HIGH BUT INEFFECTIVE HEALTH CARE UTILIZATION

In 2010, the majority of Canadians (77.3%) consulted with their family doctor/GP within the previous 12 months (Table 11). People with chronic conditions were more likely to have consulted with their family doctor than the general population, but there was not much variation according to health condition.³⁴

When examining the proportions of people consulting their family doctor/GP 10 or more times, among those who had a consultation, people with chronic conditions had more consultations than the general population, and more variation according to health condition was evident. Those with ME/CFS, FM, living with the effects of a stroke and ES/MCS had the greatest proportions (>20%) having 10 or more consultations with a family doctor/GP.

People with chronic conditions were more likely to have consulted with a specialist or other physician than the general population, and among the chronic conditions, those with cancer were most likely to have had a consultation (72.8%). Those with ME/CFS (30.4%), FM (29.5%) and cancer (29.1%) had the greatest rates having 5 or more specialist/other physician consults (among those who had a consultation), while those with ES/MCS (21.3%) had a similar proportion to those living with the effects of a stroke (22.3%).

The previous analysis with 2003 CCHS data also noted high rates of medical consultations. Specifically, 33% of those with ME/CFS, 29% of those with FM and 17% of those with ES/MCS consulted their family doctor/GP 10 or more times within the previous 12 months [6]. This was in comparison with 11% of those with other chronic conditions (consisting of a mixed group of 15 other diseases including the four comparators in this report as well as additional conditions such as asthma, back problems and high blood pressure), and with 7% of those in the general population without the conditions. Those with ME/CFS (53%), FM (47%) and ES/MCS (43%) were also more likely to have consulted with a specialist versus those with other chronic conditions (33%) and those without the conditions (26%). The differences in rates of consultations between those with ES/MCS, FM and/or ME/CFS and the comparison groups were statistically significant ($p < 0.05$).

GREATEST NUMBER OF CONSULTATIONS WITH OTHER HEALTH PROFESSIONALS

People with ES/MCS, FM and/or ME/CFS consistently demonstrated the greatest proportions having a consultation with other health professionals. The pattern indicates that a greater proportion of those with FM tended to have consultations with chiropractors, physiotherapists and massage therapists. Consultation rates

³⁴ See *The Quantitative Data*, Table 11: Consultations with Medical Doctors in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010, pg. 26.

with acupuncturists and homeopaths or naturopaths were lower overall than for the other health professionals.³⁵

EHC PATIENTS AND COMMUNITY SURVEY - EXTREMELY HIGH UTILIZATION

For patients of the Environmental Health Clinic, the mean number of visits to family physicians in the previous 12 months was 10.7, while for other physicians (including specialists) it was 13.7. This is in comparison to 2.9 and 0.79 for the general population, respectively (Table 12). Multivariate regression analysis found that higher numbers of visits to family physicians was significantly associated with lower scores on general health, while higher numbers of visits to other physicians was associated with lower scores on physical function [8].³⁶

A community-based survey of 875 people with ME/CFS in Ontario conducted in 1996 reported extensive use of hospitals, medical specialists, medical and alternative therapies and emotional counseling [10]. Because this study did not report the exact numbers found on the survey, they cannot be included, but the overall finding is consistent with those reported from other sources.

TIME TO DIAGNOSIS INCREASES UTILIZATION

An unpublished survey of over 600 respondents conducted by the MEAO [11] found that for the majority of people, several years elapsed before they received a diagnosis of ES/MCS, FM and/or ME/CFS (Table 13). For greater than 50% of the respondents, it took four or more years for a diagnosis to be reached, and for an astounding 19.0%, the time to diagnosis was greater than 10 years. Further to this, the vast majority of people (76.6%) visited three or more physicians prior to receiving their diagnosis, with 12.4% requiring visits to 10 or more physicians.³⁷

THE NOVA SCOTIA ENVIRONMENTAL HEALTH CENTRE (NSEHC) - DECLINE IN MEAN PHYSICIAN VISITS TO PROVINCIAL AVERAGE AFTER TREATMENT

The Nova Scotia Environmental Health Centre (NSEHC) uses a multidisciplinary holistic approach of care to treat those with ES/MCS. Data from a prospective cohort study (with three cohorts enrolled in 1998, 1999 and 2000) conducted at the NSEHC showed a decrease in physician visits after consultation at the clinic [9]. The overall yearly decline from the year prior to initial consultation until end of follow-up in 2002 ranged from 8.0%-10.6% for the three cohorts (Table 14), and the decline in mean physician visits per person per year dropped close to the provincial average in 2000. A decrease in the mean number of physician visits was found for all levels of symptom severity, but was greatest among those with the highest severity scores (31% for the 1998 cohort). These decreases in health care utilization were naturally associated with decreases in health care costs.³⁸

³⁵ See *The Quantitative Data*, Table 15: Consultations with Health Professionals in the Previous 12 Months among Canadians according to their Chronic Health Condition, 2010, pg. 30.

³⁶ See *The Quantitative Data*, Table 12: Mean Number of Visits to Medical Doctors in the Previous 12 Months by Patients of the Environmental Health Clinic (EHC) in Toronto, Ontario, 2005-2006, pg. 28.

³⁷ See *The Quantitative Data*, Table 13: Health Care Utilization Related Variables from a Survey by the Myalgic Encephalomyelitis Association of Ontario (MEAO), 2011, pg. 29.

³⁸ See *The Quantitative Data*, Table 14: Percentage Decline in Physician Visits by Patients with ES/MCS Following Consultations at the Nova Scotia Environmental Health Centre, pg. 29.

SUMMARY OF THESE ISSUES

The high number of consultations with physicians (both family doctor/GP and specialists) as found with the CCHS and EHC populations may reflect the complexity of ES/MCS, FM and ME/CFS, as well as their associated co-morbidities. Family physician visits are sometimes restricted to one reason per visit, and therefore people with complex chronic conditions may require numerous follow-ups. These conditions also affect multiple systems, and as a result, patients may be referred to several specialists. The results suggest that people with ES/MCS, FM and ME/CFS require medical support, but might not be receiving appropriate care for their conditions. The long times to diagnosis and large number of physicians visited prior to diagnosis found on the MEAO survey are suggestive of the lack of awareness and knowledge in diagnosing the conditions, and may also indicate that people with ES/MCS, FM and ME/CFS are, in fact, receiving ineffective care. High utilization will result in increased health care costs. The 1996 community-based survey conducted among Ontarians with ME/CFS concluded that due to 'the extensive use of all medical services, CFS is a substantial drain on our health care system with little, if any, benefit in return for such costs' [10].

In contrast, the results from the NSEHC for ES/MCS are indicative of the effect that a multidisciplinary holistic approach can have in reducing health care utilization rates. The observed decreases in health care utilization directly translated into decreases in health care costs as documented in the study. The NSEHC has been in operation nearly twenty years, is well-known in the province and is well-integrated into the health care system.

The high number of consultations with other health professionals among those with ES/MCS, FM and ME/CFS suggests that people with the conditions are looking for effective care and therapies outside of the conventional medical profession. The higher consultations with chiropractors, physiotherapists and massage therapists among those with FM are consistent with a condition of widespread pain. The fact that the majority of the costs for other health professionals are out-of-pocket suggests that the motivation for patients to find help is great. In light of what we know about the financial hardship faced by people with long-term chronic health conditions, financial barriers likely reduce ongoing access to these treatments, accounting for lower overall consultation rates observed with certain professionals such as acupuncturists and homeopaths or naturopaths. Participants in the qualitative study reported these modalities as helpful and also indicated that high costs for these treatments are in fact, an issue.

PART THREE - COMMUNITY VOICES

INTRODUCTION

IMPACTS

SOCIAL DETERMINANTS

PHYSICIANS AND HEALTH SERVICES

9 INTRODUCTION TO THE COMMUNITY INFORMATION-GATHERING INITIATIVE

9.1 METHODOLOGY AND QUESTIONS

IN order to 'improve the quality of care and support' for our communities - the original mandate of MEAO's Ontario Trillium Foundation-funded project - we needed to know, and to communicate to decision makers, what our community members experienced as the most important impacts of the conditions, what were their unmet needs and perceived 'gaps in services,' what they experience as the chief barriers to access and equity, and what recommendations, in their view, would be most helpful in creating a future state of appropriate, responsive, adequate and accessible care.

A detailed explanation of our methodology can be found in the full-length '*Community Consultation-Needs Gaps Barriers Access*' to be released as a separate document by MEAO in the Fall of 2013. In the interests of brevity, here we can summarize the key points behind our approach to this component of the project.

Existing resources identifying needs for the CELCs in any jurisdiction were limited. MEAO had performed a limited, if enlightening survey, in 2011, which helped to clarify issues for exploration.³⁹ Another paper strictly in relation to ME/CFS from the UK in 2009 was also helpful but only to limited extents.⁴⁰ One article on an ME/CFS survey in Ontario (1996) dealing with health and social support needs, was reviewed - helpful but very limited.⁴¹ The Environmental Health Clinic had done suggestive and concerning analysis of its patients in 2010, which implied many unmet needs. Finally, the major issues raised by the quantitative data from Statistic's Canada's Canadian Community Health Surveys in 2005 and 2010 (cited at length in various sections of this document, and gathered together for easy reference in 'The Quantitative Data', also being submitted as supporting documentation for the OCEEH business case) begged exploration.⁴² **So it was clear from the outset that a much deeper information-gathering exercise was needed in which the community was given a real opportunity to feed back at length and in depth their experiences, their needs and their own visions for solutions.**

³⁹ Myalgic Encephalomyelitis Association of Ontario (MEAO). 2011. [Patient survey] Unpublished raw data. http://www.meao.ca/files/Reaching_Out_2011_Spring.pdf. See *The Quantitative Data*, OCEEH BCP Steering Committee submission of the Ministry of Health and Long Term Care, 2013.

⁴⁰ Maria de Lourdes Drachler, Jose Carlos de Carvalho Leite, Lee Hooper, Chia Swee Hong, Derek Pheby, Luis Nacul, Eliana Lacerda, Peter Campion, Anne Killett, Maggie McArthur and Fiona Poland, 'The expressed needs of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A systematic review,' *BMC Public Health* 11 December 2009, 9:458 doi:10.1186/1471-2458-9-458.

⁴¹ G. Stirling, D.W. Reid, J. Pollard, M. Ondrack, 'Symptoms and characteristics of CFS: A survey of 875 Ontario residents,' *The CFIDS Chronicle* Summer 1996; 2-5.

⁴² *Canadian Community Health Survey*: <http://www.statcan.gc.ca/survey-enquete/household-menages/3226-eng.htm> See *The Quantitative Data*, OCEEH BCP Steering Committee, 2013, appendix to the OCEEH BCP, and charts from that study throughout this report.

We therefore settled on a qualitative approach to a combined patient survey/community consultation, with a very ambitious agenda for inquiry. Unfortunately, due to lack of resources and need for a robust sample, we had to restrict the project to adults. A study on children is urgently needed.

A criteria-based sampling method was used to select participants from among those who completed an initial questionnaire. The goal was to select participants from a broad range of circumstances, seeking representation from:

- As many parts of the province as possible and from both urban and rural areas
- All adult ages
- Men in addition to women as they experience the conditions less frequently
- The three conditions based on their relative proportions among the Ontario population according to the 2010 Canadian Community Health Survey³
- Individuals with varying levels of disease severity, and
- Individuals experiencing the conditions for varying lengths of time
- Caregivers, who were eligible to participate on behalf of individuals with the conditions.

We did have imperfections (addressed in the full-length compilation). But we can say with confidence that we were successful enough to generate a wealth of valid, illuminating themes and findings.

THE QUESTIONNAIRE

The development of the questionnaires went through a collaborative and iterative process among the researchers, a member of the Institute for Social Research at York University (John Pollard) and the President of the National ME/FM Action Network (Margaret Parlor). In addition, the interview and focus group questions were pre-tested with seven individuals from the target population. This allowed individuals affected by the conditions under study an opportunity to provide feedback on the survey tools and methods. Further modifications to the questions and format were made based on their feedback before the protocols were finalized. The final interview questionnaire is shown here.

MEAO PATIENT QUALITATIVE INTERVIEW QUESTIONS

About You

1. Tell me about yourself, your experience of being ill, your main diagnosis and other health problems. Probe: What has been difficult or challenging for you?
2. How long have you been ill, who made your diagnosis, where and when?
3. What have you done to get yourself better? Probe: What types of health care and other supports and services have you used?

Health and Social Supports

4. Can you describe any supportive or positive experiences you've had while seeking health care or social or legal supports since your illness, at onset and currently? Probe: Any experiences with your physician, specialists, with social workers, insurance or disability?
5. Can you describe any unpleasant or unsupportive experiences you have had while seeking health care social, legal and other services since your illness, at onset and currently? Probe:

Any experiences with your physician, specialists, with social workers, insurance or disability?

6. Have you had any unmet needs while seeking health care, social, legal or other services since your illness, at onset or currently? Probe: Unmet needs would be services that you would have liked to have available to you but found that they were not
7. How much of an understanding did your various physicians and other health professionals have of your condition?
8. Has your employer/workplace been supportive of you during your illness?
9. What impact has your illness had on your family and caregivers?
10. What impact has your illness had on your relationships with your friends and social support networks?
11. Have your health care providers, or the social, legal and other services assisted or made it easier for your family and care-givers to support you? Probe: Have they made it more difficult for them to do so? How so?
12. How has being a woman [or a man] affected your experience of your illness and of seeking health care?
13. Have you felt any prejudice, lack of respect and/or discrimination within the health care system, social, legal and other services? Probe: If yes, can you elaborate on your experience.

Solutions and Changes

14. Do you have any suggestions about what could be changed in terms of health care and the health care system to improve your life and your health and make life better for your family and caregivers?
15. Do you have any suggestions about what could be changed in terms of social, legal, insurance, disability, workplaces, and any other services to improve your life and your health and to make life better for your family and caregivers?
16. If you were designing an ideal system of care that would address most your illness related needs and the needs of your family and caregivers, what would that system include?

9.2 CHALLENGES IN REPORTING AND IN READING THE RESULTS - HOW TO BALANCE THE NEGATIVE WITH THE POSITIVE

As it turned out, one of our greatest challenges emerged not before, but rather after our informants had shared their lives and thoughts with us. In compiling their words, we discovered we had more than 300 pages of rich, compelling and highly enlightening data on everything from impacts to recommendations for the future. Even for a stand-alone report or book, these data were copious. But clearly the quantity exceeded the possibilities of this present report, and so presentation of themes and findings here had to be radically condensed.

Within this rich pool of material we encountered another challenge, however, which has given us some considerable pause for thought. We want now to draw it to the attention of readers and ask them to keep it mind as they proceed through this section. Bluntly put: **the number of negative experiences with health and social supports reported by informants vastly outnumbered the number of positive experiences**. In the longer report, we included every single positive and mostly positive experience

reported and were able to fill not more than 20 pages. In recording representative negative experiences, by contrast, we winnowed out at least 50% of the data as repetitive, but still filled more than 100 pages. Counting the original number of both types of experiences, we came up with 200 pages of negative to about 20 of positive.

The greatly unbalanced ratio of negative to positive experiences presented us with a real dilemma: how could we accurately reflect this ratio here without sinking what we believe should be an optimistic, constructive report with the overwhelming weight of negative experience? Because despite this sea of negative experience - tragically striking to read and to contemplate - our findings from the positive side were full of hope, enlightenment and direction.

Nothing can substitute for the encounter with the experience of people as patients and clients described in the full compilation. For this reason, if for no other, we encourage readers to skim or dip into it or read the full-length compilation *in total*. But for the purposes of focusing on clear steps with which to move forward, for the sake of brevity and of accentuating what we can build on, in the chapters of this section that follow, **we have chosen to radically condense the negatives and to present at greater length the findings on impacts, and on positive experiences.**

9.3 HOW THIS STUDY APPROACHED THE ‘SOCIAL DETERMINANTS OF HEALTH’

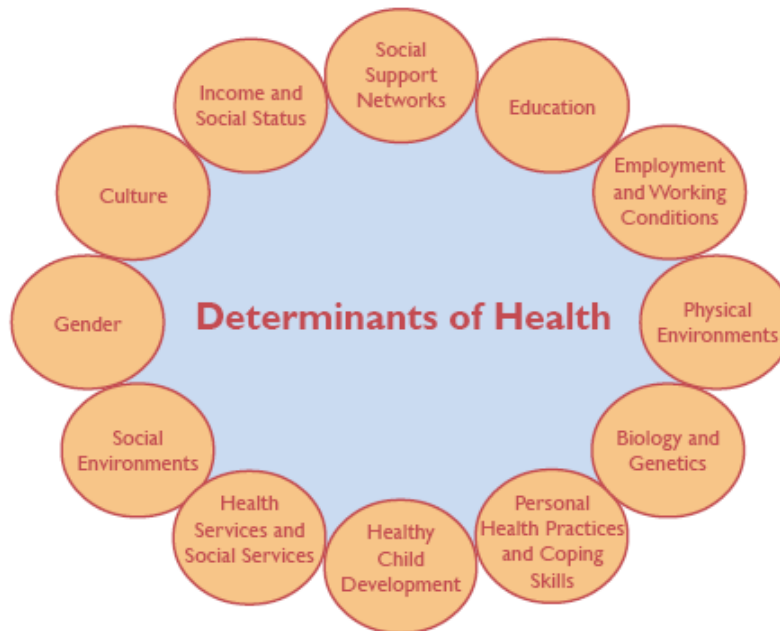
In framing our questions, we were guided by several factors including the model of health defined by the World Health Organization (WHO) as ‘a state of complete physical, mental and social wellbeing and not merely the absence of disease.’⁴³ WHO defines environmental health as follows:

- Environmental health addresses all the physical, chemical, and biological factors external to a person, and all the related factors impacting behaviours.
- It encompasses the assessment and control of those environmental factors that can potentially affect health.
- It is targeted towards preventing disease and creating health-supportive environments.⁵

The ‘determinants of health’ used as a basis for crafting our questionnaire and analyzing our answers are those identified by the WHO, depicted here.⁴³

⁴³ *Preamble to the Constitution of the World Health Organization* as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100); and entered into force on 7 April 1948. Accessed April 6, 2013: http://www.who.int/topics/environmental_health/en/ .

The Determinants of Health identified by the World Health Organization



Source: World Health Organization, 2013⁶

This oft-cited WHO diagram condenses the cumulative wisdom of decades, and illustrates that health is the result of multiple dimensions. If even one of these is badly damaged, there may be negative health outcomes. If some or many of these dimensions fare poorly, there will almost certainly be negative outcomes. And if most of these dimensions are in trouble, so will be the populations who endure that trouble. Such is the population of people with the CELCs, at this time.

In Ontario, the 'Community Health Centre' model and network, working with populations with many socio-economic and cultural challenges, has led the way in integrating social services that address the social determinants of health into a care setting that also provides health services as such. Studies by the Institute for Clinical Evaluative Sciences (ICES)⁴⁴ reveal that where health care services *per se* are integrated with services supporting social determinants, outcomes are optimal. This has further confirmed the conviction that social services are, in a very direct sense, also health services.

The main WHO determinants have been ordered in this report to better identify the social determinants that most affect our populations - and to the extent possible, their priority or dependencies, though these are dynamic, complex and intertwined. These are the issues we queried our community about, and address in the findings and subsequent recommendations.

⁴⁴ Institute for Clinical Evaluative Sciences (ICES), numerous articles, including: 'Developing a balanced scorecard for public health' (2004), 'Improving health care data in Ontario' (2005), and 'The impact of not having a primary care physician among people with chronic conditions' (2008). Available from <http://www.ices.on.ca/> *

- Disability (having it; societal recognition through accommodation, law, custom)
- Income security, employment and social status
- Food insecurity
- Housing insecurity
- Health services
- Social safety support networks - involve services that address:
 - family and social inclusion/exclusions
 - friendships
 - community involvement
 - isolation
 - emotional/psychological wellbeing
- Gendered issues
- Physical environment
- Education

The dimensions of biology and genetics and early childhood development were not addressed by this study, but are discussed by John Molot in *Chronic complex conditions: Academic and clinical perspectives*.⁴⁵ Participants were encouraged to speak about their experiences in terms of gender, and the larger social/environmental context.

9.4 ANALYSIS

THE interviews and focus group discussions were transcribed from the recordings. Four experienced researchers with varied backgrounds independently reviewed the transcripts, each bringing unique skills and perspectives to the evaluation. One had a science and participatory action research background (M. Ann Phillips), the second an epidemiology background (Erika Halapy), the third an environmental and women's health and health policy background (Varda Burstyn) and the fourth a health and social action research background (Paula McKweon). Emerging themes were identified by each researcher, compared and contrasted and later compiled. Quotations relating to each theme were selected and presented in the report.

We have attempted to find an overarching story from among the contributions of the participants, their experiences and the narratives of their illnesses, and to give the participants a voice through the analysis process.

9.5 THE INFORMANTS

Demographic characteristics of the 56 patient informants: Most participants were middle-aged (ages 40-69), with the majority (41.1%) being aged 50-59. The sample included some participants aged 30-39 and aged 70 and older, but did not capture anyone younger than age 30. The large majority of participants were women (85.7%), although 8 males did participate in the study. All regions of Ontario

⁴⁵ J. Molot, MD, *Chronic complex conditions: Academic and clinical perspectives* (Ontario Centre of Excellence in Environmental Health, 2013). The clinical submission to the Ministry of Health and Long Term Care, supporting the Ontario Centre of Excellence Business Case Proposal.

were represented with most participants residing in Toronto and Central Ontario (53.6%) followed by Eastern Ontario (32.1%). Those residing in urban settings represented the majority of the sample (92.9%).

Characteristics associated with people's diagnoses of ES-MCS, FM and/or ME-CFS: The majority of consultation participants had a main diagnosis of ME-CFS (44.6%) followed by FM (32.1%) and then ES-MCS (23.3%). Almost half of the participants in this study (48.2%) had multiple diagnoses. Only one participant in the sample had been suffering for less than five years, while 37.5% had experience symptoms for 20 years or more. The majority of participants (55.4%) rated the present severity of their main diagnosis somewhere in the moderate range (5-7 on a scale of 1-10). When rating their severity when they felt their worst, there was a shift towards the severe range (8-10 on a scale of 1-10) with the vast majority (91.1%) with a rating in this range. Only one participant rated their worst severity in the milder category of 1-4.

Connections to organizations and the broader ES-MCS, FM and ME-CFS communities: Participants were asked if they belonged to an organization such as the MEAO, National ME/FM Action Network or the Environmental Health Association of Ontario. Over half of participants (57.1%) belong to such an organization. Similarly, over half (58.9%) of participants belonged to a support group, either in person or online, that is related to one of the conditions. The proportion of those who did not belong to a related organization or support groups (approximately 40%), is still sizable. When asking participants how many other people they know with these conditions, almost half (44.6%) indicated they knew 20 or more people; 3.6% did not know anyone else, while 17.9% knew only 1 or two other people. The vast majority of people have access to internet at home, which can facilitate connectedness to health related information, organizations and communities.

9.6 NEW US GOVERNMENT QUALITATIVE STUDY ON ME/CFS CORROBORATES OUR FINDINGS

Literally as we complete this report, a new report, 'The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis' has been issued by the United States Center for Drug Evaluation and Research.⁴⁶ **Its results completely corroborate the findings of our consultation on the devastating impact of ME/CFS on many lives, and give us confidence that our study's findings with respect to ES/MCS and FM are equally valid.**

⁴⁶ Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration (FDA), *The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis*. (Silver Spring, MD, September 2013). See Appendix 3 for summary of key themes.

10 IMPACTS ON WELLBEING, FAMILY LIFE, FRIENDSHIPS AND SOCIAL INTEGRATION

'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...'

BY 2010 in Ontario 586,000 people had been diagnosed with one, two or three of the three conditions that form the subject of this report.

The opening chapter of this section presents the voices of people living with the conditions as they recount the impact on their lives. Our community informants explain the effects on their physical and emotional wellbeing, on their ability to earn a living (in more detail in the following chapter), on their spouses, parents, siblings and children, and on their ability to be social beings, with friends and in their communities. They discuss the negative attitudes and discrimination they have faced. Their voices are clear and compelling.

We hope that for readers who have not yet had an opportunity to learn about these illnesses, these voices will provide a meaningful and helpful introduction. We have included some lengthy quotations as well as briefer ones, for it is only with these longer stories that the true physical and social complexity of life with these conditions can really be understood.

10.1 ONSET, IMPACT, COPING WITH A DEVASTATING 'NEW NORMAL'

MOST PARTICIPANTS SAID THEY LIVED A NORMAL LIFE BEFORE ONSET OF THESE CONDITIONS AND WERE ACTIVE AND HEALTHY.

FOR MOST LIFE WAS GOOD BEFORE ONSET

Well, I was a healthy young woman, and very strong and fit, and in high school I was a majorette and on several sports teams, so that shows you level of activity I took part in. **Nancy ME FM MCS**

Once upon a time, I was a Critical Care Nurse and full of dreams and very active in my community, and volunteering with kids on the street and the homeless, and driving our seniors to Church, had a boyfriend - just living life in the fast lane, I guess. **Mary Lou ME FM MCS**

In my old life I used to be marathon runner and triathlete at one point of my life, I worked out every day of my life, I was knowledgeable about yoga and stretching. Since I have lost weight, I have got back into yoga but every yoga class or social gathering I find it typically starts at 7pm at night and I am in bed usually prior to that - so there is not much out there - I can go play cards with old people but that is about it. **John ME FM**

I actually feel like I'm still grieving. I'm grieving for colleagues. I'm grieving for friends. Financial hardship: I had to sell a house and move. Of course, there's also isolation problems -- depression, frustration -- also the family dynamics change. **Joanne ME FM**

The extent of the impact of these conditions/illnesses on the daily life of sufferers varies. But overall:

INFORMANTS CONFIRMED THESE ILLNESSES TO BE CHRONIC, COMPLEX, DEBILITATING AND DISABLING, NEGATIVELY AFFECTING EVERY ASPECT OF LIFE

When these illnesses set in, everything changed. **Informants confirmed these illnesses to be chronic, complex, debilitating and disabling and often last a lifetime.** They can affect any, many and even all systems in the body. So the process of becoming ill, especially when diagnosis and treatment were not available, was often described as a downward spiral, with many cascading events and developing co-morbidities.

Those with ES/MCS must deal with the painful and debilitating impacts of chemical exposures on their bodies - both at onset, and ongoing. This effect is not visible to others, yet it is powerful, painful and disabling to those who live with it.

AT THE SEVERE END OF THE GRADIENT, THE IMPACTS OF THESE CONDITIONS CAN BE COMPARED TO EFFECTS OF STROKE, TO THE EFFECTS OF CHEMOTHERAPY, TO LATE STAGE HIV-AIDS OR SEVERE ARTHRITIS

With multiple disorders involved, all aspects of life can be affected. Work, livelihood, family life, socializing and community involvement, and most activities of daily living, including mobility, physical functions (e.g., going to the bathroom) and cognition can all be involved and negatively affected.

THE CONDITIONS ARE CHRONIC, COMPLEX, DEBILITATING, DISABLING...

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 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**

Initially when it was MCS and the petrochemicals, any socialization involved perfume and I was and [still] am very reactive to perfume and aftershave, those kind of chemicals. I remember when the environmental doctor, [when] I first saw him, and I thought I was 'healthy'. I just thought I was having an episode of something I didn't know about. He said, 'You're an allergic person'. And I never thought I was an allergic person. He said that this is what it was and he said, 'oh you can't be around perfume, or no,' he said, 'you can't wear perfume.' I said, 'That's okay I can give up perfume.' Then he said, 'You don't really understand, you won't be able to be around people with perfume or you'll get symptoms' and he was right. **Claire MCS**

DURATION IS OFTEN LONG, EVEN LIFE-LONG, AND SEVERITY OF ILLNESSES IS OFTEN EXTREME.

This study confirmed that these conditions are chronic and serious. It also confirmed that **symptoms could occur for years - up to 17 years in our study - before diagnoses were made.** A few participants noted that eventual diagnosis of one or more conditions helped them to make sense of long-standing health problems that were caused by the condition but were attributed by unaware physicians to other causes.

DURATION IS OFTEN LIFE-LONG AND SEVERITY IS OFTEN EXTREME

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. That was the major issue for me was getting a diagnosis. **Bill ME**

I've been a teacher since 1972 and it was in a teaching situation that the MCS showed up full-blown and became chronic. In '82 I was typesetting when I came back from overseas in the summer, and it was a new method of photo typesetting, where they used the chemicals for photography. And that machine was right in the middle of the room. There was no special air venting at all, and in that situation, after a few months, I had two seizures and a stroke, and I never knew the reason for it. Now when I think back, I think it has to do with the chemicals. And that stroke did cause damage on the brain where you can still see scar tissue. **Betty MCS**

FOR MANY, CLEAR TRIGGER EVENTS WERE EVIDENT...

These included toxic exposures, flu or other infections and physical injuries. ES/MCS participants identified that chemical events in their work places and personal spaces, including offices, dwellings and cars, were triggers for symptoms. For others, the illnesses presented slowly with increased fatigue, increased reactions to chemicals and/or various pains - the 'downward spiral' already mentioned, but with unknown causes.

ONSET TRIGGER EVENTS ARE SOMETIMES EVIDENT ...

This condition was as an onset of a motor vehicle accident, which I had in 2003, so the first symptoms appeared towards the end or the middle of 2005, and while the doctor is confident that it was the motor vehicle accident ... he ... was not willing to conclusively say, or be held liable to, to the fact that it's because of the accident that I have this condition. **Peter FM ME**

It all happened as a result of exposure to incorrectly mixed adhesive chemical to repair a windshield in my vehicle. I started getting symptoms within about fifteen minutes of being in my vehicle. Things started to go weird and life ... went to hell in a hand basket ... It wasn't until I saw Dr. B. that she diagnosed the FM and chemical sensitivity and the toxic brain injury. **Sandra MCS FM**

I had the flu and then bingo, I couldn't hold my hands up to type. I couldn't drive my car. I couldn't stand. I still had to work. Had a pillow that I laid my arms on so I could type, because I was agency and agency people don't ever get time off. **Janepher FM MCS**

...FOR OTHERS, ONSET WAS SLOWER AND MORE MYSTERIOUS

...TRIGGER EVENTS ARE SOMETIMES MYSTERIOUS

I noticed I became ill probably in the spring of 2001. I was a computer technician. I felt very fatigued. I had to drag myself to work. I saw my doctor, and he ran some blood tests. And they all came back okay, but I was still feeling very, very tired. And I pushed on during the summer and fall, but I felt like something got broken in my body. Something wasn't working properly. **Frank ME**

It's been about half my life that I have had chemical sensitivities, multiple chemical sensitivities. I don't really know how it started to happen, but I think what happened was when I was young I had a major inner ear infection. Then I went to the hospital; I had surgery; I had tubes put in and I had them taken out. Then I started having the asthma attacks in the fall. Then when I was in my early 20s – I was in nursing school actually – that's where it started. I started to have reactions to chemicals and perfumes and things around – the cleaners and stuff. I couldn't even continue in the class. I had moved to Montreal and there I found out that it could be this multiple chemical sensitivities. **Petra MCS**

I was diagnosed in 2005. But much earlier than that, I have had experiences that now make sense, but didn't make sense until I was diagnosed. I went back to college when I was 31 and can remember wearing a neck brace for 6 months and I could not understand what was going on. All the doctors said it was some kind of pain in my neck, and the tests came back negative, nothing showed up. But even back farther than that, when my first husband died, I had bursitis like a few days after the funeral and that lasted for 20 days. **Phylis FM ME**

PHYSICAL AND EMOTIONAL CHALLENGES OF DAY-TO-DAY LIFE CAN BE STAGGERINGLY DIFFICULT AS PEOPLE STRUGGLE TO DEAL WITH THEIR 'NEW NORMAL'.

Here are informant reports on that struggle. **Keep in mind that many people live with two or three of these conditions at once.**

NEW NORMAL FM

At home, I literally have to crawl up the stairs to get to the washroom. This all depends on the pain. ... I don't even have a bedroom, I am sleeping in the living room. ... Any stress makes the fibro worse, any kind of normal daily stress makes the pain worse, makes you really scatter-brained, really forgetful, can't remember. ... You don't get better, you just learn to deal with it, you take medications and do therapy, and you are always trying to move. I ride a bike sometimes, but sometimes it hurts too much to put a leg over the bar to get on. If I'm able to, we walk. If I am too sore we take the bus. I don't drive. My two adult daughters live with me, thank God, I would be in trouble otherwise, one helps with money, other helps around the house with the chores I can't do anymore. ... I loved volunteering at school, but I can't hold a pen long now, and if I do too much cutting my hands hurt. I used to be very organized, now I get mixed up. ... I used to be able to five things at once, now I am lucky if I can do one and a half. (laughs) Guaranteed I forget everything, I have notes everywhere, I have a tack board, I have magnets all over fridge, and I am really forgetful. It is really ridiculous. ... **Pearl FM**

NEW NORMAL ES/MCS

You can't have what other people take for granted, like family, friends, socialization, clothing. Lately I order most of my clothing from the Sears catalogue. I guess it's not so lately that everything comes through China and it is soaked in formaldehyde. ... With my current partner we've taken cotton clothing and washed it in everything and soaked it in vinegar, just washing and washing and washing. Then we even buried this pair of jeans hoping the earth would eat away some of it. Actually, after about a year of washing and washing and soaking, then you can wear something. ... I moved to the country on the advice of my doctor. Then the air quality has deteriorated over [there during] the time I've been unwell so that, you really can't go anywhere. ... I'm more polluted now, than in my house in the city, cause you have the wind off the water. It's really a Catch-22. **Claire MCS**

I can't eat food from a supermarket because that's all contaminated with fragrances and laundry product residue. So I need non-supermarket sources of organic food. I must prepare my own food. Mixed, packaged foods have too many sources of contamination, even at the farmers' market, I bought organic cabbage rolls because, you know, their vegetables were really good for me. I'm eating the cabbage rolls and I can taste dish detergent in them, so I asked, 'Well, what do you wash your dishes with?' 'Oh, we use Palmolive.' I said, 'Well it's in your cabbage rolls. **LMS MCS**

NEW NORMAL ME/CFS

I had requested to my doctor to give me some time off. I was basically falling asleep in her office waiting for her to see me. I remember not having the energy to even be able to hold up my head, resting it on the wall. My doctor had no proof or diagnosis of anything wrong. She agreed to put me part-time [at work]. By May, I begged my doctor to take me off work because I felt I was no longer safe to practice with my extreme fatigue. I would wake up every morning at three o'clock, unable to return to sleep. I was exhausted. I was saying 'good morning' when it was afternoon. I had issues with time of day, remembering people's names and triple checking my medication administration. It was like there was some faulty wiring in the brain that was misfiring, causing delays in my thinking, my movement and alertness. ... At that time, I lived on a second floor apartment with about twenty-five steps. On bad days, by the time I got to the top of the stairs, my legs were aching – plus, plus on bad days – and I was very short of breath. I was so tired. No matter how much I slept, I still felt exhausted. I lived alone at the time. Just getting up was a chore. ... having a shower, making a meal, doing dishes – I had no energy for nothing.' **Joanne ME**

And just the frustration of really wanting to do things and having to constantly plan your life around: What can I do? It's the limitations. And then even if you carefully plan, you still find you're so sick you can't enjoy it or you can't do it. **Kathryn ME FM**

There are times when my illness is really bad, that I can't even make a meal. If it weren't for my husband, I would not eat. I wouldn't be able to eat. **Sharon ME FM**

SOME PEOPLE ARE ABLE TO WORK, BUT WITH DIFFICULTY. OTHERS ARE TOO DISABLED.

You know, going to work just about does me in everyday. I don't have much energy at the end of the day, you know, coming home, making supper, doing the domestic duties. The fatigue and the brain fog have been most difficult and the emotional aspect. Dealing with, coming to terms with, the fact that this is the way it is, when intellectually I am somewhere else and my body kind of betrays me. I think of all the things I could be doing if I did not have this limitation and that causes incredible despair for me. **Hope MCS**

WITH ALL THE CHALLENGES, MOST INFORMANTS SAID THEY EXPERIENCED GREAT EMOTIONAL AS WELL AS PHYSICAL HARDSHIP

The most ordinary life events can trigger setbacks if they involve certain types of stressors, making it difficult simply to live in the world as it is now. It is not uncommon for sufferers to seriously consider, and sometimes commit suicide. Many who survive and endure the trauma of these severe illnesses said they felt as though they and their lives are discontinuous with their previous selves.

EMOTIONAL TRAUMA IS OFTEN PART OF THE EXPERIENCE

The main diagnosis, I don't know what is worse; I have been diagnosed with toxic brain injury, MCS and FM. ... I couldn't work and I couldn't stand all the smells and everything in Stouffville so I had to sell my home – I was living in a little cottage that belonged to some friend of mine up here and then they let me live in it and were trying to help me with research and stuff. ... in November of 2002 ... I was probably so suicidal because I thought that the rest of my life was going to be spent in a little cottage by the river where it was freezing cold with a composting toilet, by myself in pain, which wasn't an option. ... The whole experience changed me psychologically so much, I lost myself, I died. The real Sandy basically died with this and this person that is left now is a totally new invention, I don't even recognize myself in the mirror. **Sandra MCS FM**

10.2 UNCARING, DISMISSIVE AND DISCRIMINATORY SOCIAL ATTITUDES PERVASIVE

PARTICIPANTS NOTED VERY WIDESPREAD NEGATIVE SOCIAL ATTITUDES THAT ARE UNCARING, DISMISSIVE AND DISCRIMINATORY.

Almost all participants experienced significant discrimination, dismissal, lack of belief, lack of compassion and lack of respect, including from certain physicians, friends, family, co-workers, employers, insurers and health and social service providers. This theme - perhaps the single most important finding of the whole study, for it provides the larger explanation for a context in which sufferers have to live without health and social support - is taken up throughout the following chapters, and addressed in greater depth in Chapters 15 and 16.

ALMOST ALL PARTICIPANTS IN THE STUDY DESCRIBED A FEELING OF BEING INVISIBLE, TO COMMUNITY AND SOCIETY, AND TO HEALTH AND SOCIAL SERVICE PROVIDERS.

In the case of service providers, this invisibility was linked to the lack of legitimacy of their conditions. (See 'discussion' at the end of this chapter.) Invisibility was described as profoundly disturbing and anomic.

Only one participant in the study did not share the experience of these negative attitudes in some aspect of health care provision.

LACK OF RESPECT, EXCLUSION AND DISCRIMINATION IN THE HEALTH AND SOCIAL SUPPORT SYSTEMS SET THE STAGE AND THE TONE FOR THE TREATMENT OF SUFFERERS IN WORK AND SOCIAL LIFE.

Professional attitudes encourage social ignorance. In turn this sets up negative attitudes and behaviors from others in every aspect of life. Negative attitudes are not confined to ignorance and insensitivity. The vast majority of participants in this study noted a strong stigma attached to having these conditions.

MANY STUDY PARTICIPANTS DESCRIBED SHUNNING BEHAVIOR FROM PEERS AND FAMILY. MANY PEOPLE FEAR THIS STIGMA SO INTENSELY THAT THEY HIDE THEIR ILLNESS FROM FAMILY AND PEERS.

SOME SUFFERERS EXPERIENCE SHUNNING FROM PEERS AND FAMILY MANY HIDE THE TRUE NATURE OF THEIR CONDITIONS

Even though I live in the country, on my street a lot of IT people are moving in, and last year my neighbour had a router going through my bedroom window. I had to get a professional in to do a reading on it, and forward it to my neighbor and it was a really bad feeling. I used to be friendly with this neighbour and no longer. You become, you become isolated and worse than isolated, you actually become hated. ... What I would like to see is publicity, that this is real, so that I would have a family, that I wouldn't be shunned. Shunning was an old fashioned method of really killing people. It was kind of like with voodoo. If your whole tribe is against you, you die. The only way shunning wouldn't be so prevalent would be through the media. **Claire MCS**

A friend and I talk on the phone, we sometimes say we should tell people we have MS and even as disrespectful as that is, we would not have to deal with the prejudice and dismissal. ... She is of a similar age and she has been sick a similar amount of time as well. We are both normal people ... but we are at a similar place in life. Her husband is a post doc and they have a group of friends that they hang out with, and she does not tell anyone because of the prejudice. I try to hide the fact that I have ME and I will say that I have a disability or a chronic illness. I hear a lot of things as well because they do not know I have it. **Gayle ME**

WITHOUT MEDICAL ASSISTANCE, AFFECTED BY STIGMA AND IN FEAR OF HAVING THESE DIAGNOSES, PEOPLE RESIST THEIR DIAGNOSES.

As a result of these attitudes, many informants reported resisting their diagnosis and continuing to 'push through' - with many harmful effects resulting.

FEAR AND STIGMA CAN LEAD TO DENIAL AND DETERIORATION

At the beginning I didn't believe there was such a thing as chronic fatigue. I just thought those people were lazy. ... When my doctor first told me that was what I had, I said, 'That's yuppie flu.' And I said, 'There's no such thing and I haven't got it and there's no way I'm taking time off.' **Joan ME FM MCS**

I noticed I became ill probably in the spring of 2001. I was a computer technician. I felt very fatigued. I had to drag myself to work. I saw my doctor, and he ran some blood tests. And they all came back okay, but I was still feeling very, very tired. And I pushed on during the summer and fall, but I felt like something got broken in my body. Something wasn't working properly. **Frank ME**

I am a 45-year-old female. I got sick with ME/FM early on but didn't realize what it was. I spent a lot of years in denial. I first started having symptoms as I was leaving high school and then it has gradually gotten worse over time. Between high school and succumbing to my symptoms I held down a job as a teacher for five years, which was a highlight of my life. **Sharon ME FM**

10.3 FINANCIAL IMPACTS - see next chapter.

WITHOUT PRIVATE MEANS, AFFECTED INDIVIDUALS AND THEIR FAMILIES SUFFER SIGNIFICANT, ONGOING, FREQUENTLY DEVASTATING, FINANCIAL IMPACTS.

Informants raised this difficult and sad issue in relation to every aspect of life with these conditions, and negative financial impacts informed every unmet need. This theme was so pervasive, it could not be treated as a sub-section. Therefore it is addressed in more detail in the following chapter.

10.4 PARENTS, SPOUSES, SIBLINGS, CHILDREN - THE OTHER CASUALTIES

IN the context of professional and societal misinformation and stigmatization, families often find the realities of the conditions difficult to understand, accept, and cope with. Lack of understanding by family members is deeply stressful for sufferers and family members alike.

Even for families that do fully accept the diagnoses, dealing with the consequences is often very difficult. Some participants felt the need to protect loved ones by not disclosing the full extent of their illnesses. Few participants reported positive impacts with families, but those who did first identified a long process of learning and adjusting before a positive outcome.

These conditions place serious strains on most marriages and terminal strains on many.

Many partners take on responsibilities and household duties that participants can no longer carry out. These are often life-saving or life-changing supports for sufferers, but they exact a high price for caregivers. For many people, family life is multigenerational, and adults have challenges with taking care of themselves, their children and their parents' at the same time. It is a juggling act that works more or less well, depending on illness levels and human and financial resources.

Numerous participants noted how critical the help of spouses and family is; and how difficult it is to cope with these conditions on one's own. Living with these conditions leads to marriage breakdown for significant numbers.

MARRIAGES ALWAYS STRESSED AND OFTEN BROKEN

Strains ... in terms of my life, obviously: I have to spend many, many hours looking after my wife. Weekend and after-hours care pretty much falls to me. So that means that 9:30 every evening I need to be at home, unless I'm out-of-town working; but if I'm not out-of-town I will be at home at 9:30 to look after her bedtime routine. I will be home to do her breakfast. On the weekends, I have certain fixed times during the day on Sunday and Saturday, when I need to be home. All of that very severely restricts my social life. My community involvements were relatively high; they have fallen off to almost nothing. The number of friends ... I see regularly has dropped off. **Thomas, caregiver for wife with ME**

My primary caregiver is my husband, and I could not even begin to measure the sacrifices that he has made. ...When we are invited over to a friend's house and I can't go he is forced to go alone, or deny himself the socializing and stay home with me. Those are the more obvious things. ...He [also] has to curtail all his activities down to my level of energy, or else be forced to be alone to do them.

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**

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**

It was really hard to raise three sons ... and have a relationship with a husband who left me after 20 years of marriage for another woman. I basically went to live with my girlfriend in an attic and traded places with the woman that my husband chose. She moved into the house that I built with him and I lost everything. **Judy ME FM**

LACK OF SUPPORTS FOR FAMILY CAREGIVERS IS A SERIOUS PROBLEM AND A MAJOR GAP IN SERVICE

There's no information directed to the caregiver or at least I haven't come across it. ... At no point in time were family members made to sit down and have explained to them either the diagnosis or the change in the quality of interactions that's going to happen as a result of this diagnosis. When you have a heart attack or something like that and the whole family is involved, the doctor explains how this is going to impact the whole family, and that kind of interaction has never happened... **Peter FM ME**

... I think 2007 was the last time I had a vacation that was greater than a week. And for the other times since then, my vacations have tended to be somewhere between two days and four or five days maximum, because I just can't get away. That clearly is not healthy, but nevertheless that's the current situation. The unavailability of any kind of reasonable respite care is a big factor in that. **Thomas, caregiver**

These conditions create serious problems for parenting of children. One participant only spoke positively of her experience while raising children. The other parent participants indicated that they were not able to parent their children as they would have liked to. For some parents, children became caregivers who carried burdens disproportionate to their years or capacities.

CHILDREN SUFFER WHEN PARENTS SUFFER

My younger son lived with me all that whole time. He is seriously affected (cries) because, for instance, he couldn't have his friends over. All his friends wore Axe or something that is definitely a no-no. I can't be exposed to that. So his social life was definitely changed.... He had to worry about his mother a lot more, because his mother was in pain, because his mother was fatigued, he didn't know if his mother was going to die. Don't forget he was maybe twelve when I was disabled. ... most of his teenage years I've been in arbitration and human rights so ... he was [not] immune to that, he had to get the side effects. These are very serious emotional and physical demands on our family. **Elva MCS FM ME**

Relationships with parents and siblings of sufferers are often stressed. These conditions often make it challenging or impossible to stay connected to extended family members. Some participants even felt they were not able to properly care for their pets, which were the only assistance in reducing isolation.

DIFFICULT TO STAY CONNECTED TO PARENTS AND SIBLINGS

I've lost touch ... even family that lives a two-hour drive away. I can't attend those events because of the driving. I can only drive myself about 15, 20 minutes. But to be in a car for an hour is my max before it interferes with the rest of the week. So I haven't seen certain family members for a long time. **Sophie FM ME MCS**

The loss of a close relationship with a sister of mine. ... largely because really, right from the beginning, in fact, in the late '70s when I got my real sensitivity diagnosis ... because some of the symptoms I had that affected my nervous system and therefore my behavioural systems also, that confused the picture considerably for anyone looking on, including her. I think ... there was a great tendency to attribute things to psychological causes quite often. And she was certainly part of that mindset, as I was too, mainly at the beginning. **Rob ME**

LACK OF AVAILABLE SUPPORTS FOR FAMILY MEMBERS IS A SERIOUS PROBLEM AND A MAJOR GAP IN SERVICE.

Lack of homecare, respite care, child care, caregiver care - especially when these services cannot be purchased privately - puts a major stress on caregivers as well as on those living with the conditions. Taken up again in the following chapter, this problem was identified as extremely serious by many participants. Lack of supports to sick parents, or to parents of sick kids, was another major deficit identified by participants (see Chapter 14).

MANY GENDER ISSUES WERE IDENTIFIED AS DIFFICULT.

Identities and gender roles are strained in family and social life and sexist attitudes are evident. A number of women spoke about the difficulties of dependency caused by the conditions. Some women face the possibility of not being able to have children.

Many women spoke about the sexist perception that their illnesses were not real or serious, but rather a result of women's physiology or tendency to complain. Chapter 14 is devoted to this frequently repeated theme.

WOMEN EXPERIENCED STRAINS FROM INCREASED DEPENDENCE

I was never that type of woman before this illness. I was very strong and capable and it's been a real learning experience being the dependent, because this wasn't my personality nor how I felt about myself or anything. **Claire MCS**

A number of men spoke about the strains on their gender identity of being sick. Losing the ability to be the breadwinner featured centrally in their comments. Some also identified strains in having what was perceived as a 'woman's condition.' Some women spoke about the way in which the perception of the conditions as 'women's problems' created sexist perceptions of male sufferers.

MEN EXPERIENCED STRESS REGARDING THE 'BREADWINNER' ROLE

As a man ... you don't want to lose your job because you are the breadwinner, and you come down with this, and it's very hard on a man. ... Most men, losing their job, that's a big thing because they're the ones who are supposed to be supporting the family. That's got to be very hard. **Doug FM**

It kind of emasculates me in the sense that this is an illness that usually affects women, and guys are expected to be macho and push through. I think part of my problem was that in the earlier stages, I pushed through when I shouldn't have pushed through. Maybe a woman would have sought medical attention a little earlier and really pushed the doctors. I kept thinking that this would kind of go away and I could just kind of work through it. But it didn't. It never did. But yeah, in our CBT groups, it's typically all women. I and another gentleman usually would show up, but as a man, yeah, it's kind of embarrassing. Because we're taught to kind of, like, push through on everything. Suck it up... but they don't understand when I've got the pedal to the metal and there's nothing there. ... It's very difficult being a man and having this disorder. **Frank ME FM**

For those who did not already have a partner, dating or finding a mate was made very difficult with these conditions.

A number of participants, all women, noted that some female family members seemed to have the same condition and some wondered to what extent there was a genetic component to it.

10.5 FRIENDSHIPS AND COMMUNITY LIFE - A DISAPPEARING ACT

Friendships and social support networks are always negatively affected. Isolation is the norm.

WITHIN a larger picture of rejection and isolation, a few participants told of positive social experiences. Some good friendships did survive the onset and duration of illness, but were stressed. By a very wide margin, however, the great majority of participants reported that social and community life as a whole had been strongly negatively impacted, and in many cases completely eliminated. Isolation, including severe isolation, has been the frequent result. One participant, with ME/CFS & FM, said: **'I call this the lonely disease.'** This sentiment was echoed by every participant in the study. A lack of belief in the reality of the conditions and an absence of compassion is part of the loss of friendships for some. Isolation affects couples and families, not just those directly afflicted.

FRIENDS LOST TO DISBELIEF

I lost a lot of friends that I used to be really, really close with. One in particular, last time that we really had any association, she called me and I wasn't feeling well. And at any rate, her remark was, 'I think the idea of your illness ... is interfering with us. Give me a call sometime when you have nothing better to do.' So that was the end of that. **Joan ME FM MCS**

- ES/MCS participants have social lives restricted by the ubiquitous presence of everyday chemicals. Some felt that because of their needs, people experienced them as an imposition. Some felt their needs were not perceived as legitimate. For many, being social in 'normal' circumstances is impossible, or exacts a very heavy price. It is not uncommon for ES/MCS sufferers to experience hostile behavior from friends or acquaintances who reject the reality of MCS.
- ME sufferers may have very limited energy or even be completely bedridden.
- FM sufferers may have difficulty leaving their homes due to pain and mobility issues and accessibility requirements. FM and ME participants described difficulties going to homes where bathrooms were located on the second floor or difficulties in being able to reliably host people, causing frustration for others and anguish for them.

Many participants said they learned who their true friends were when they become ill with these conditions. Friends who did understand and continued to care become very precious.

'I CALL THIS THE LONELY DISEASE'

Friends who are well, the topic of conversation is: what's everybody doing? And you often feel you don't have anything to contribute because you just can't do much. I've noticed that. Like, they don't know what to ask you, because, 'well, I'm sitting.' **Kathryn ME FM**

I had friends that don't bother with me anymore because it takes too much effort to be with me because there are a lot of rules attached to what you can smell like, what you have to do for two or three days before you come and see me. They fell by the wayside. ... I don't have a social life. **Sandra MCS FM**

Many have found new friendships through support groups of others living with the conditions thanks to mutual respect and understanding. For a number of participants, needed support came only via a group sponsored by a knowledgeable ME/CFS specialist physician. Many participants found local support groups and associations to be helpful and good sources of information. Social media provide support to

some people. A few participants were able to find support in their faith, some when no other support was available. However, only one participant noted positive *practical* support from their faith community (above) while others noted its absence.

NEW FRIENDSHIPS THROUGH SUPPORT GROUPS THANKS TO MUTUAL RESPECT AND UNDERSTANDING

One positive thing that came out from my illness is that when I was with Dr. Bested, the CBT [cognitive behavioural therapy] group, we have a few of us that became quite good friends, and we try to set a date for lunch or something, and hopefully when the day comes we can all show up. So that's a positive part, the social aspect of it in spite of being sick. **Cecilia FM ME**

I have just started on Facebook. There is a severe ME page. I have just started chatting on there, and they have been giving me virtual hugs. That's great from someone you don't really know, but you understand that they are facing the same things **TJ FM ME MCS**

This illness has taught me that life is so beautiful, a gift of God, and God is the only support for me. **Bina FM**

10.6 From *THE QUANTITATIVE DATA*

PROFILE OF SOCIAL IMPACT

Experiencing difficulty in social situations is a summary measure which encompasses difficulty making new friends and maintaining friendships, difficulty dealing with unknown people and difficulty starting and maintaining conversations. Those with ME-CFS and living with the effects of a stroke experienced the greatest degree of difficulty in social situations (27.0% and 26.0%, respectively) (Table 24). Among those with FM, 17.8% experienced difficulty in social situations, followed by 11.8% of those with ES-MCS.⁴⁷

People with chronic conditions expressed a greater sense of very weak community belonging than the total population (Table 25). Similar to patterns throughout this report, those with ME-CFS in particular expressed that they felt a very weak sense of community belonging, followed by those with FM and ES/MCS.⁴⁸

In 2005, Canadians reporting a reduction in activity due to long-term health problems (approximately 8 million Canadians) were asked if they had ever experienced discrimination or unfair treatment due to their health problem as shown in Table 26. Those with ME-CFS (27.5%) and FM (25.3%) and ES-MCS (23.3%) reported the highest proportions experiencing such treatment by far. Interestingly, people suffering from cancer reported a lower level of discrimination or unfair treatment than the total population.⁴⁹

SUMMARY

Experiencing difficulty in social situations highlights the social impact these illnesses have in addition to the significant physical impairments previously discussed. Participants in the qualitative study reported difficulty maintaining friendships after becoming ill. Social difficulties could be due to the high levels of disability and resulting in an inability to engage in regular activities, but could also be due to the lack of understanding and awareness surrounding these conditions and the special needs they necessitate. As a result, experiencing a very weak sense of community belonging as observed for those with ES/MCS, FM and/or ME/CFS is not surprising. The qualitative study has illustrated that in their most severe forms, all three of the conditions are isolating.

Reports of discrimination and unfair treatment are suggestive of the lack of understanding and accommodation provided to people with these conditions. It is not known from the available CCHS data in what circumstance (medical, workplace or social) the reported discrimination was experienced, but our qualitative research has suggested that it occurred in all of these realms. Experiencing discrimination or unfair treatment could further contribute to a weak sense of community belonging and isolation.

⁴⁷ See *The Quantitative Data*, Table 24: Canadian Population Experiencing Difficulty in Social Situations according to their Chronic Health Condition, 2005, pg. 42.

⁴⁸ See *The Quantitative Data*, Table 25: Canadian Population who have a Very Weak Sense of Community Belonging according to their Chronic Health Condition, 2010, pg. 43.

⁴⁹ See *The Quantitative Data*, Table 26: Canadian Population Experiencing Discrimination or Unfair Treatment due to their Health Problem among those reporting a Reduction in Activities according to their Chronic Health Condition, 2005, pg. 43.

11 FINANCIAL IMPACTS AND OTHER SOCIAL DETERMINANTS OF HEALTH

HEALTH and wealth are positively correlated across all societies. Indeed, many of the social determinants of health are either subsets of economic security or directly affected by it. Affluence permits both the avoidance of exposures to undermining health conditions (poor nutrition, toxic and overtiring work, polluted neighbourhoods, lack of time for parenting, familial and social relationships, decreased span of control at work and so forth); and, when needed, also permits access to good health care and related social supports. Those with sufficient means are able to purchase these services privately - and they do as needed. Those without such means are profoundly disadvantaged. So when health and social support services are provided through public systems, this fundamental inequality is much improved. This understanding is the bedrock of Canada's commitment to Medicare and our 'social safety net.'

For most adults, financial well-being is tied directly to adequate employment supported by a social safety net that provides individuals and families with the ability to meet extraordinary needs - such as those arising from illness - with supports that compensate for extraordinary burdens and costs. **Social supports for our identified comparator groups are delivered through a complex and interdependent web of rights, benefits, programs, policies and facilities, in government, in the para-public sector, and even, with respect to some rights and benefits, in the private sector.**

When there are fundamental deficiencies in all of these areas, as for those with the CELCs, as our community consultation dramatically demonstrated, the stresses from illness are massively exacerbated.

Informants identified these deficits and spoke to remedies. They also stressed - given the myriad fronts on which assistance is both required and so difficult to obtain - **the key need for system navigators (social workers, for example) to assist individuals so that the search for support does not actually make people worse. This is covered at the end of this chapter, but in importance ranks close to the top of unmet care needs.**

First, though, **we begin with a positive tale - an example of how severe illness can still resolve into functionality, productivity and a quality of life worth having.** We then cover a number of economically-related issues with which so many struggle. We look at lack of disability recognition and its relationship to job and insurance related matters, to deficiencies in government programs, then move on to food insecurity, housing insecurity and a set of issues relating to personal and family support.

11.1 A POSITIVE STORY

ADEQUATE INCOME AND BENEFITS MAKE FOR A GOOD OUTCOME

We want to begin this section by recalling 'Amy's story,' first recounted in Chapter 8 for the purposes of demonstrating the type of costs involved for an FM patient within a context of addressing inappropriate

utilization and high costs to taxpayers. Had we had even one more positive story from our community, we would present it at this point. The lack of such stories is a testament to the overall situation in itself. However, 'Amy's Story' has is so illuminating with respect to the key issues covered in this chapter that we believe it is worth repeating here. With respect to the **nexus of issues involved with respect to income support, four emerged as central:**

- **Having and keeping a job is critical for most people's economic wellbeing.**
- **Often the income from even a middle-class job is not enough to cover all health costs.**
- **A health plan with adequate benefits is a critical income support in times of ill-health.**
- **The recognition of the disability and a responsive accommodation by the employer is a critical income support, for it permits the sick person to continue working when honoured by the employer; and, when illness prevents continued employment, opens the door to a system of benefits that help to survive.**

AMY'S STORY - TAKE TWO

DISABILITY RECOGNITION, COVERAGE OF COSTS (BENEFITS) AND DISABILITY ACCOMMODATION AS ECONOMIC DETERMINANTS

Everything that I've needed, I've had the financial resources and the family support to get for myself. So today, I had my \$100 a week physiotherapy appointment, which is really helpful. It keeps me going so I can get into work three days a week. On Tuesday, I have my hour and a half massage appointment. The physiotherapy, fortunately I have private benefits that take care of. The massage, not so much. So that's \$125 a week that I pay in order to function. If I don't go, I find that things tend to flare up and it interrupts with my ability to work.

So it's pretty much a locked in cost that I have to pay. But I have the money to pay it, so that's not an unmet need, being with the physiotherapy. My drug costs, quite substantial. I take an array of wonderful pharmaceuticals that help me greatly. I'm part of a generous Healthcare Plan, and so is my husband. I have 100 percent drug coverage, thank God. A lot of people don't. So that's another expense. Let me see, oh, I can't clean my house. And so that's a bit of an issue. I can't both clean my house and work, so I have a cleaning team that comes in. I opted to get a team that comes in, which is more expensive than one person because it's so exhausting to have someone there in my house for five hours cleaning my house. So they come in and ... they're amazing. They come in; it's like a flurry of activity. I kind of hunker down and try not to get in their way and then off they go. But that's another expense each month that I'm dealing with.

You know, there are just so many things. Oh, supplements, you had mentioned supplements earlier, and I'm on a bunch of supplements that help me very well again. That's probably - I'm going to say between \$200 and \$300 every couple of months. No help for that. I sleep on a very nice, very comfortable Tempurpedic mattress that cost \$4,000. It's... I feel uncomfortable actually disclosing how lucky I am and how fortunate I am that I don't have unmet needs because I'm sure that there are people in the group who are thinking, 'Damn, she's lucky.' Well, I am, but that's a financial burden. My husband and I are both highly... he has a master's degree. I have a law degree. We're ... we're people who should be able to afford everything. And even for us, it's a struggle.

We went through a lot of money getting me rehabilitated. I went from needing a wheelchair to get around, to now working three days a week and being able to do things like go on vacation and have a little bit of a social life. And thank God that I was able to find the resources to pay for that stuff. ... Just to put it all in perspective, our first cost for the first year that I was ill, was over \$10,000 in medical expenses. And

that was with both my husband and I having what I would consider to be a generous healthcare benefit plan. Still \$10,000. That's *on top* of the benefits, and that's just healthcare stuff that we could claim with CRA. Not even the house cleaning, convenience services, the cost of having to have someone pump gas for me because my hands are too sore, all on down the line. **Amy FM**

11.2 POVERTY - OFFICIAL AND ACTUAL - AMONG THOSE WITH THE CELCs

AS the CCHS data show, and as the data from the Environmental Health Clinic, indicating patients stop work about three years after onset of illness confirm, there is a lot of poverty in our communities. A significant number report incomes under \$15,000 a year. But, as our study confirmed, while more may have incomes above the poverty line, indeed have jobs considered 'middle-class,' **many do not have sufficient resources to adequately meet their health needs - ranging from food and housing to essential treatments. For all too many, even middle-class incomes cannot take care of personal and family needs when the CELCs strike.**

EVEN MANY EMPLOYED INDIVIDUALS 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**

Honestly right now, I don't have enough money this month to buy the rest of my supplements. I have to wait for another eight days until my cheque comes in, but for those eight days I am going to be without my cough pill. If I had money I could follow my regimen more and that has been a problem for me, running out of money to follow what I need and that causes inconsistency in my body. **Hope MCS social worker**

Indeed, the informants in our study reported that **the financial challenges of these conditions, combined with an absence of publicly-funded care and support, ranged from very considerable to crippling.**

11.3 INCOME INSECURITY AND DISABILITY ISSUES

INFORMANTS raised this difficult and sad issue in relation to every aspect of life with these conditions because...

AFFECTED INDIVIDUALS AND THEIR FAMILIES SUFFER SIGNIFICANT, ONGOING, OFTEN DEVASTATING FINANCIAL IMPACTS. NEGATIVE FINANCIAL IMPACTS INFORMED EVERY UNMET NEED.

These impacts cause significant stress and worry for all involved.

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**

At the same time I lost my income, my husband was let out of work. ... Contracts weren't renewed for him. He was mid-40s, trying to get a job. And one income from two. My daughter was in university at the time, going through teacher's college and my son was in a northern college. At that point, my husband had sought employment in Alberta. That's just to keep a roof over our heads, right? **Wendy ME FM**

We've used all of our savings because I've been on disability. ...It depleted our savings, so we really have no savings. We still have our house, but that's all that we have left, really. **Jane ME, FM**

JOB LOSS DUE TO ILLNESS ONSET AND/OR LACK OF DISABILITY ACCOMMODATION WAS A CENTRAL FEATURE OF LIFE FOR THE MAJORITY OF INFORMANTS.

UNEMPLOYMENT, INCOME LOSS, DISCRIMINATION ON THE JOB, LACK OF ACCOMMODATION COMMON FOR PEOPLE WITH THE CELCs

I was laid off last year. For four years I had a couple of managers who were very supportive. I was allowed to work from home because my kind of work was project-based ... As long as the work got done, extremely supportive. And then there was a new manager, she turned things around. And the various accommodations that were provided for the past years she felt were affecting business and that this could no longer be provided. So even reasonable accommodations were denied. **Peter FM ME**

- Some participants' employers would not accommodate them because they did not believe their employees were really sick.
- Some employers took actions that isolated and undermined their employees and made it impossible for them to continue working.
- A number of study informants had succeeded in continuing to work but faced major and complex obstacles that remain ongoing and are not easily resolved.
- Some participants expressed the desire to continue to work but were unable to, due to lack of provision of supportive accommodations to suit the needs of their conditions.
- Some participants got sick because of hazards in the workplace, but lost their jobs anyway, sometimes for punitive reasons, often with no compensation.
- A number of people reported unrealistic pressures for re-employment due to lack of understanding of the conditions.

JOB LOSS DURING WORKING YEARS WITHOUT INCOME PROTECTION AND HEALTH BENEFITS AFFECTS FUTURE INCOME (PENSIONS) AS WELL AS PRESENT INCOME.

Participants expressed dismay at the costs of being sick. ‘Amy’ - self-identified as a person with good financial resources who had returned to work, benefited from her husband’s salary and had excellent health coverage benefits at work - was still challenged financially. She questioned the justice and rationality of individuals having to pay the costs of socially (environmentally) induced illnesses.

Extreme financial difficulties combined with lack of social supports result in great stress, including emotional distress, for many people. (This theme was a constant in all areas surveyed.)

INABILITY TO OBTAIN INSURANCE BENEFITS DUE TO LACK OF RECOGNITION COMMON FOR PEOPLE WITH THE CELCs - HIGH STRESS ADDS TO ILLNESS

It has been incredibly difficult financially, because the insurance company that will end up settling with me has denied any kind of responsibility for the toxic injury. So I had just been on my own trying to muddle through and operating on CPP disability for a number of years, and now with CPP and old age. If the legal system didn’t let the guilty party drag things out for so long, that too would be helpful. **Sandra MCS FM**

My biggest challenge was the insurance companies. The short-term disability insurance and the long-term disability insurance, they just don’t recognize fibromyalgia as a case for even a short-term disability. Forget the long-term, the long-term is not even in their radar, at least FM is not even in their radar for long-term. ... Just before I got laid off, I was on a three-month short-term disability. The doctor had said, ‘he needs to take rest and be at home.’ But the short-term people sent me to their own specialist. They sent me to many other places. They had my doctor write out so many reports. By the time all the reporting and everything got done it was three months and in the trauma of getting these things done, I didn’t get that break that I could have used and really be rested. But at the end of three months I had to get back to work, and so they put me on an accelerated return to work, or had me back to the five days that I was supposed to work, and I was still not well. **Peter FM ME**

INSURANCE BENEFITS ARE EXTREMELY DIFFICULT TO OBTAIN FOR MANY AND THE PROCESS OF SEEKING THEM OFTEN BECOMES INJURIOUS TO THOSE ALREADY VERY SICK.

Some insurers exhibited bullying, discriminatory and other harmful behaviours. In many cases, insurance companies that did not recognize these conditions as illnesses or disabilities put the onus on people who were ill to prove that they deserved insurance, or compelled them to take medication or perform physical ‘therapies’ that were very harmful. **In these ways insurers exacerbated illness instead of assisting sufferers.**

Some participants were cut off prematurely from disability payments.

INSURANCE BENEFITS ARE EXTREMELY DIFFICULT TO OBTAIN AND SEEKING THEM OFTEN BECOMES INJURIOUS

The one that really got me was when my family doctor said, ‘well, Joanne, you have to go on traditional medication in order for your insurance to cover you. If you don’t, then your insurance will not cover you.’ Therefore, I feel I’m forced to go onto antidepressants and gain weight due to side effects. **Joanne ME**

The CPP suggested that I couldn’t go back to my old job but they suggested that I could do seasonal or part-time work. I don’t know whether they thought I was going to pick fruit or what they thought I had to

do. [laughs] But, you know, I couldn't put my head down to work at a computer for very long and I have to rest twice a day and I can only walk for three minutes and I can only concentrate for 15 minutes. So what kind of part-time work, where are you going to get it? **Theresa ME**

My insurance company at the time, from work, sent me to a personal fitness trainer for three months, three times a week. And if I didn't do that, I was totally cut off from my insurance ... Now, that just about killed someone in my condition **Wendy ME FM**

When I finally couldn't work, I had to go on disability and the insurance company, they sent me to the IME, and she wrote a 13-page report to the insurance company saying, 'this is an overweight lady who doesn't want to go back to work.' [laughs] I managed to get a copy of that report sent to my family doctor. That's how I read it. ... Anyway, they denied my claim, and I was... in so much depression at that time because trying to deal with my illness, I didn't know how to respond to that. **Cecilia FM ME**

INFORMANTS PROTESTED PAYING INTO INSURANCE PLANS FROM WHICH THEY WERE UNABLE TO RECEIVE BENEFITS

INDIVIDUALS PAY INTO INSURANCE BUT CANNOT BENEFIT

They made it more difficult for people such as myself to benefit from the premium that we're paying in, you know, five years we've been paying the short-term benefit premium and the long-term benefit premium, but we never get to take advantage of it even though disability exists. **Peter FM ME**

11.4 LACK OF COVERAGE FOR ESSENTIAL NEEDS RESULTS IN EXTREME HARDSHIP AND MAJOR INEQUITIES

Onset of these conditions often results in disability and income loss. At the same time, most treatments must be paid for privately - not the case for the comparator groups. This was identified as a crushing burden for many; and for all, a barrier to necessary care and a major inequity.

ESSENTIAL TREATMENTS AND NEEDS NOT COVERED BY PUBLIC INSURANCE

The major issue that I have, is that what I get from OHIP is very minimal in terms of what I need. And I do work, and I pay taxes and I would like to go back to the pre-Dalton McGuinty days of physiotherapy being something that's considered to be a benefit that should be available to everybody. **Amy FM**

Why are only the pharmaceutical company medications subsidized? My \$200 worth of supplements a month isn't. The next person on ODSP who takes \$200 worth of pharmaceuticals, doesn't have to pay for them. **LMS MCS**

I need a wheelchair lift at my front door. The occupational therapist recommended it a year and half ago. I still

don't have it. **Sharon ME FM**

A common issue for many working people is an inability to afford uninsured medical necessities. Most of the standard treatment needs for the CELCs are uninsured. A significant number of pharmaceuticals are uninsured, including by the Ontario Drug Benefit Program. For those who are completely unemployed and on social or disability assistance, the situation is even worse.

PUBLICLY-PROVIDED DISABILITY PROGRAMS ARE VERY DEFICIENT WHEN IT COMES TO COVERING THE NEEDS OF PEOPLE WITH THE CELCs.

These programs have never been revised to include coverage for the special needs of people living with the CELCs. As a result, many people go without essential medical supports, and experience tremendous inequality relative to comparator groups.

Many physicians understand how important nutritional supplementation is, yet most people find it very difficult if not impossible to afford what is needed.

ESSENTIAL NUTRITIONAL SUPPORTS NOT COVERED BY DISABILITY PROGRAMS

My doctor, he isn't one for pushing a lot of pain medication. ... I have to have medication for my heart. ... But other than that, he has more [emphasis] on vitamins, and then any kind of a supplement that he finds that he thinks will help this disease... He's saying that the supplements that he knows really help, they should be covered. **Joan ME FM MCS**

Informants spoke about urgent needs for:

- **ODSP:** rent/housing supplements for housing modifications or rental of appropriate housing particularly for those with MCS/ES; employment services that are geared to the needs of the people with the CELCs
- **ASSISTIVE DEVICES PROGRAM:** essential devices for those with ES/MCS (water and air filtration) and for those with FM and ME/CFS (mobility-related)
- **ONTARIO DRUG BENEFITS PROGRAM:** coverage for a number of anti-infective and pain medications and all compounded drugs, commonly prescribed by expert physicians, currently not covered in the Ontario formulary, need to be included as insured medications.
- **NEW COVERAGE FOR 'NEUTRACEUTICALS':** Over and over again, informants said that their need for nutritional supports - understood by all expert physicians to be critical to living with these condition - were more onerous even than their needs for prescription drugs. These are medically necessary therapeutic substances, and they must be insured and included in ODSP to give people with the CELCs who do not have private means an equal chance to improve their health.

ASSISTIVE DEVICES AND DRUG BENEFIT PROGRAMS SERIOUSLY DEFICIENT IN MEETING THE NEEDS OF PEOPLE WITH THE CELCs.

The ADP [Assisted Device Program] that pays for things like wheelchairs and walkers and so on needs to be expanded. When I first got my first scooter, it was covered. When I needed a replacement, it wasn't covered. ... If I had MS, I could get it funded. If Worker's Comp had told me that I couldn't work, it would have been covered. But because they told me to work sitting down, it's not covered. I have to get to the desk. **Sheila FM**

PHYSICIAN ASSISTANCE IS REQUIRED TO OBTAIN PUBLIC BENEFITS, BUT IS OFTEN DIFFICULT OR IMPOSSIBLE TO OBTAIN.

Many informants reported lack of support from physicians, ranging from procrastination to refusal to assist.

GOVERNMENT TAX AND OTHER BENEFITS DIFFICULT AND STRESSFUL TO OBTAIN, SOMETIMES IMPOSSIBLE

I am on ODSP, I got turned down the first two times, and I didn't have much help at all with my ODSP application. The GP I had, I only had her for a few months and she made it sound that there was not much wrong with me. **Gayle ME**

I had applied to Canada tax benefits, I had to go to the GP up here ... She started reading [the form] and she said, 'you are not disabled,' and I said, 'yes I am disabled. I cannot do other things that people can do.' And she rambled on and on, then I got upset and I said, 'I do not need this. I will tell you right now that when I get up in the morning it takes me an hour to get up, get dressed ... just to do my exercises to loosen up so I can get out of bed. Sometimes I need help to get out of bed.' Here she was giving me this whole thing: 'you are not disabled.' **Phylis FM ME**

Qualifying for ODSP may be successful in the end for some, but it takes a long time and is very stressful. Some make it; some don't. Dealing with federal government disability programs was very difficult for many who reported on the process. **Trivialization of illness and disrespect were common.**

11.5 LEGAL SERVICES ARE CRITICAL BUT NOT FINANCIALLY OR PHYSICALLY ACCESSIBLE

Legal services are not available without private means - means that generally disappear with job loss. And without educated legal services, at the moment these services are most needed many patients are too sick to do what is required of them, even to write or follow normal procedures. This 'gap' is a serious strategic gap in enabling people to obtain what they need in order to survive and make it possible to 'get back in the game.'

LEGAL SERVICES ARE CRITICAL YET NOT ACCESSIBLE

They told me to go to Legal Aid, but I couldn't write. ... I'm left-handed and I had a pain in my arm. Even touching buttons on the phone was too much. And so anyway, so she sent me to a social worker, she said maybe a social worker would be good. After ten minutes, the social worker threw up her hands and said, 'no, I can't do this.' And she sent me to a lawyer again. Now the lawyer's all ... 'we're busy.' And so I left my name, and he phoned me back and wanted me to fill out all the forms. I couldn't damn well write!

Sharon MCS ME

Funding for a social worker on staff at the WCH Environmental Health Clinic to facilitate access to legal as well as other services was urged.

11.6 HOUSING

HOUSING INSECURITY IS A MASSIVE PROBLEM FOR MANY; FOR THOSE WITH ES/MCS IT HAS EXTRA, CRITICAL DIMENSIONS.

Housing insecurity is a big problem in general for economically disadvantaged people. The shortage of healthy and health-condition-adapted public housing is an important problem in Ontario as a whole.

ME/CFS AND FM: SPECIAL REQUIREMENTS RELATED TO PAIN AND LACK OF MOBILITY THAT ARE NOT BEING ADDRESSED OR MET.

Single-level dwellings, ramps, adjustment of counters and other ergonomic needs are generally not provided for people with ME/CFS. For those who have severe mobility issues, these deficits have a fundamental impact on quality of life and the ability to care for self and others.

ES/MCS: CHEMICALLY-SAFE SUPPORTIVE HOUSING IS A MEDICAL NEED REQUIRING MULTIPLE MOVES AND MAJOR EXPENDITURES IN HOUSE FURNISHINGS AND ALTERATIONS TO CREATE A SAFE ENVIRONMENT

Because of the needs of those with ES/MCS for a safe dwelling, most have histories of multiple moves. These moves are very expensive because they involve repeated moving and repairing costs, and not infrequently, the repeated loss of equity in property. Many people with ES-MCS are bankrupted by this process, and their health fundamentally compromised.

There is no access to 'safe housing' for this group - be it in emergency shelters, market value housing, supportive housing, assisted living or long term care and palliative facilities. This creates a nightmare scenario for many, one that can repeat many times over years. This, therefore, represents a massive gap, barrier and glaring inequity for this group.

For those with ES/MCS, the issue of housing insecurity ranks as the single most urgent need of all; and also as the greatest inequity and barrier to accessing health supports, among them many grave

inequities and barriers documented in this study. **This issue is addressed in detail in Chapter 20, as well as briefly here.**

HOUSING INSECURITY IS AN ISSUE FOR ALL 3 CONDITIONS, WITH CRITICAL DIMENSIONS FOR THOSE WITH ES/MCS

That was a terrible journey. ...It progressively became worse as I deteriorated. But ... the City of Toronto Housing, when they got letters from my doctor saying I needed to be transferred, and even to the point where the doctor said I was concerned even about my life, that I could die in ... the available housing ... Because I didn't fit into their criteria that was, like cancer, they said the only thing they could do was put me on the waiting list which is ten years, that I couldn't get special consideration for transfer. ... I was ... being kept in relapse because I couldn't get to a place where I could be stable. So that was psychologically really awful, being in relapse and knowing that you don't have to be. ... It's been very sad. Almost every avenue where I've needed support or help, the initial and continued response was no response that helped me get a foot up. **MaryLou ME FM MCS**

ES/MCS 'AVOIDANCE': THIS CRITICAL STRATEGY IS COMPLICATED, DEMANDING AND EXPENSIVE.

ES/MCS 'AVOIDANCE' OF CHEMICALS

A COMPLICATED, DEMANDING, NON-OPTIONAL AND EXPENSIVE WAY TO LIVE

The water filtration installed here wasn't sufficient for me to use the kitchen sink to wash my clothes in, so I had to do them in the bathroom through the double shower filter, and the bending ruined my back. After a year, they finally put in a second carbon for the whole house filter (instead of a pre-filter,) so now I can wash my clothes standing up.. However, after I wash my facemask, my skin felt like it was burned. It just went red for about a week from using it. I'm still going to have to use the drinking water filter, which has an extra filter, to wash my facemask. ... I had to use bottled water before moving here. ... I couldn't wash the clothing off my back except for with the bottled water. I had to drink and cook with it too. I couldn't afford to get water filtration installed. One of the women at the spring water filtration place gave me a couple of dollars off the bottles, she was really helpful and supportive with my orders, but it was insanely expensive and prevented me from doing many things I needed to be able to do (like have clean clothing and bedding). **LMS MCS**

11.7 FOOD INSECURITY

FOOD INSECURITY IS A VERY SERIOUS ISSUE FOR MANY IN THE COMMUNITY; MEASURES TO ADDRESS IT ARE URGENTLY REQUIRED.

Food insecurity may be comprised of one or more elements:

- Not being able to afford food at all
- Not being able to obtain or afford medically-indicated food or medically-tolerated food (such as organic and gluten free)

- Not being able to access food by shopping because of disability
- Not having any consistent support to prepare and serve meals, and clean up afterward
- Not being able to perform the physical function of eating unassisted
- For many with ES/MCS, supermarket environments where chemicals from everyday products make every shopping excursion an illness-inducing episode.

The Canadian Community Health Survey of 2010 showed high levels of food insecurity among our three groups. In previous chapters, and at the beginning of this one, we learned how difficult it is for people with severe ME to actually shop for and prepare food. In fact, difficulties with food are generally part of a larger picture of serious unmet needs for a variety of social supports.

Since many have severe food allergies and sensitivities, and/or are not considered eligible for food assistance, they are not able to utilize Meals on Wheels.

Since poverty is high among sufferers, many do not have the private means to purchase healthy food or food services.

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, cold soup 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 two years because the delivery guys carrying eggs with date stamps and the dye gets into the eggs and affects me. There's some basic foods that I can't get delivered now. **Linda MCS**

11.8 SOCIAL SAFETY AND PERSONAL SUPPORT SERVICES

CCAC-PROVIDED, CONDITION-COMPETENT PERSONAL SUPPORT SERVICES FOR COMPARATOR GROUPS ARE URGENTLY NEEDED AND WERE UNANIMOUSLY RECOMMENDED

Most informants said they have experienced a need for home support and/or anticipate needing such support in the future. Most informants said they were unable to pay for such support out of their own

resources. For a significant number, lack of such supports involved fundamental hardships with the basic necessities of life, and reinforced extreme isolation. Participants called for sufficient personal support worker hours by CCACS. The lack of such care can create nightmarish lives for sufferers. Many informants pointed to the need for PSWs to be trained in the special needs of the conditions, for example in being scent-free or in understanding energy and pain limitations.

PERSONAL SUPPORT SERVICES FOR BASIC NEEDS DIFFICULT OR IMPOSSIBLE TO OBTAIN

Right now, I am totally stuck in bed. ... My family doctor and I are frustrated with CCAC – they don't really listen to what I need. They only give ten hours for someone that has no family support and is bed-ridden. Basically I get a diaper changed every 24 hours -- I am going to try not to cry here. I have to sit in my urine, which is very uncomfortable to sit in urine for 24 hours and wait for someone to come and change me. For eating I get one meal a day. ... That is basically what my life looks like now. I keep telling people I need fourteen hours but they say no, that ten is the limit. **TJ FM ME MCS**

The first visit has to be in the office, then they'd decide if they can do a home visit after. They're not open to Skype or anything like that. They don't have a fragrance-free office, and they said they can't guarantee safety for a home visit, and they won't even do the home visit unless I come into the office. 'What we can offer you is an appointment to come in to see us where we'll discuss it.' I said, 'so you're offering me a chance to become completely disabled and possibly not be able look after myself ... you're offering me a chance to be assaulted, basically.' **LMS MCS**

So life has become extremely difficult for me, trying to get food in here and trying to manage. I tried to get home help, you know, through CCAC, and I was interviewed over the phone about a year and a half ago – it totally exhausted me. And they said, yeah, there'd be a social worker calling you... I think it was six to eight months later, she called. And she came for an interview to my home... So yep, she interviewed me, and I said, 'well, do I qualify for some home healthcare? Like, I need somebody to help do my laundry or do something around here for me.' And she said, 'oh yeah, you qualify, but there's a waiting list of 1000 people.' Can you imagine? **Nancy ME MCS FM**

SOCIAL SUPPORT WORKERS CAN INJURE CLIENTS (ME/CFS AND FM RE EXHAUSTION, PAIN AND MOBILITY, ES/MCS RE TOXICS)

Many important services are not provided in ways that people who are home bound or chemically isolated can take advantage of. People with two or more of the conditions are especially challenged. Some informants reported misinformed and hurtful comments, even abusive ones from CCAC personnel or workers.

Lack of recognition of existence and needs of the CELCs by CCACs, combined with the absence of social supports overburdens family caregivers and puts serious strains on family members and family relationships.

Trained, competent and adequate homecare and other personal support services are needed for:

- Health care, personal hygiene
- Physiotherapy, other therapy if housebound

- OT ergonomic, mobility issues
- Food shopping, prep, cleanup, assistance with feeding
- Assistance with travel to health and social destinations (isolation)
- ES/MCS assistance with finding safe housing
- Housekeeping and laundry (laundry a major challenge for ES/MCSers)
- Respite care

TRAINED, COMPETENT AND ADEQUATE PERSONAL SUPPORT SERVICES ARE BADLY NEEDED

My PSW - it's more exhausting with them, because I have to tell them exactly what to do. It is not a service where I can just go to be bed and so, you are here make me dinner, I will go and sleep some more. No you have to be up with them to tell them to chop the celery. It is still very exhausting I am trying to find ways to work around that. **TJ FM ME MCS**

The first thing has got to be the fragrance-free home visits. Without access to other places, that would be the first thing. You know, and also fragrance-free and education about what that is. **Linda MCS**

TRANSPORTATION and TRAVEL SUBSIDIES

Quite a few informants spoke about a variety of challenges with transportation, ranging from lack of eligibility to air quality problems. Transportation that was condition-friendly was identified as an important unmet need.

SAFE TRANSPORTATION AND ELIGIBILITY NEEDED

I just could mention one other thing, is Wheel-Trans. I've never actually tried to get it. I'm kind of assuming that I'm not eligible ... **Kathryn ME FM**

- To attend appointments and get necessities of life
- For ME/CFS and FM - responsive to mobility and pain issues
- For ES/MCS - Clean, fragrance free
- Safe residence hunting - critical for those with ES/MCS

11.9 LACK OF SUPPORT SERVICES FOR FAMILY MEMBERS AND FAMILY CAREGIVERS

MANY needs were identified (see previous and next chapter, plus Chapter 13) for adults in families - for assistance for spouses with care of their sick partner, for parents with care of children and for adult children for assistance with elder are. Lack of such support when it is available to people with conditions of comparable severity was seen as a major gap and inequity.

ASSISTANCE TO ADULTS IN FAMILIES LACKING AND NEEDED

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. **Judy ME FM**

Then there needs to be much better education. There probably needs to be some counseling, talking about the kinds of changes that are going to come to their lives – both for the patient and the social system in which the patient is... and that probably means mostly family, but it may mean more than just family. **Thomas, caregiver for wife with ME**

You need things like childcare and elder parents care ... And support groups for families. **Chris ME FM**

And education groups for families. **Kathryn ME FM**

Yeah, because they really don't know how to deal. When I first got sick, I remember my husband and my kids didn't know how to deal with it. An active person all of a sudden couldn't do anything, so it was a real change for them as well as for myself. **Cecilia FM ME**

Family caregivers need:

- Education and ongoing medical and peer support
- Respite care
- Assistance in advocating for sick family members (system navigation)
- Support to take impaired patients to appointments,
- Direct support to sick family members at home so that economic productivity, parenting and some kind of social and family life can be maintained.

11.10 SYSTEM NAVIGATION AND ADVOCACY CRITICAL

A SOCIAL WORKER AS SYSTEM NAVIGATOR AND ADVOCATE FOR INDIVIDUALS AND FAMILY CAREGIVERS WAS REPEATEDLY URGED BY MANY INFORMANTS AS AN ESSENTIAL SERVICE

Being too sick to access a variety of difficult-to-find care and support services, including services related to income issues, and being treated badly and/or dismissed by service providers were very common experiences that severely stressed and undermined informants. Family caregivers trying to wrestle supports from a non-responsive system were often reported as being completely overburdened. **Having a qualified and recognized professional, paid and provided by the public system, to assist with these aspects was a frequent and insistent theme.**

In corroboration of the importance of this form of support, the one informant that had had a responsive social worker assisting him reported positive experiences with individual support providers and described his social worker as a 'godsend.'

SOCIAL WORKERS NEEDED FOR SYSTEM NAVIGATION AND ADVOCACY

OFTEN NOT ACCESSIBLE AND/OR REJECTING

When I got to a point where I couldn't help myself anymore and I needed help. I asked the doctor if I could see a social worker. ... That is a really hard step to take, because you're admitting ... you're really sick and as hard as you're trying you can't get it together. What's important in life is people and you can't get to the people because the basics of life are taking what you have ... You finally get the courage to go to a social worker and then ... how humiliating it was and how I was spoken to! ... This happened with three different social workers so I'm not just saying one. I had to have somebody with me for the social worker to be nice. I don't know what else to say - to be professional - maybe that's a better word. **MaryLou ME FM MCS**

WHEN ACCESSIBLE, 'A GODSEND'

The other person that was very positive was my social worker with York Support Services. She was a godsend. She helped me navigate through filling out forms, my CBT forms, dealing with ODSP. I also went through bankruptcy and she also helped me and would go to all the meetings that I had to go to. I told Katherine she had to be my second brain because my brain wasn't working too well. ... When I went to ODSP, they seemed to talk very fast and they would go through all the details and I would just - I couldn't keep up with what was going on. I just became overloaded with whatever they were telling me. If they told me something, I would forget five minutes later what was it they were telling me, because I have difficulty absorbing new information. It was very... it was good to have [my social worker] along. **Frank ME**

11.11 From *THE QUANTITATIVE DATA*

PROFILE OF SOCIOECONOMIC DISADVANTAGE

Food security is a measure of reliable access to healthy food in adequate quantities. Canadians with ME/CFS reported the highest levels of moderate or severe household food insecurity (20.4%). This finding was almost three times that of the general population. Those with ES/MCS (14.7%) and FM (12.9%) also had high levels of moderate or severe household food insecurity (Table 22). The pattern indicates that those with heart disease and cancer had similar or possibly lower levels of moderate or severe household food insecurity compared to the general population.⁵⁰

Less variation among chronic health conditions is seen when examining households with income less than \$15,000 annually (Table 23). People with any chronic condition had a greater rate of low income than the total population, with the exception of those with cancer, who had a similar level as the total population. The

⁵⁰ See *The Quantitative Data*, Table 22: Canadian Population Experiencing Moderate or Severe Household Food Insecurity according to their Chronic Health Condition, 2010, pg. 40.

pattern shows that those with ME/CFS, ES/MCS, FM and living with the effects of a stroke tended to have the highest proportions with lower income.⁵¹

POSSIBLE REASONS FOR FOOD INSECURITY

High rates of household food insecurity and a substantive amount of people (approximately 10%) with household income below \$15,000 among people with ES/MCS, FM and ME/CFS may be due to reduced employment income or the inability to work altogether due to high levels of disability as discussed in section 2.2. Results from the EHC patient population found that people with the conditions could only work 9.4 hours/week on average, and this was reduced for those with multiple diagnoses [8].

Other reasons for low income include difficulties in obtaining and retaining long-term disability, or the low monthly benefit of provincial support such as ODSP. Lower income may have also contributed to onset of the conditions in the first place. Food insecurity may be perpetuated by intolerances to particular foods and expensive costs of alternative ingredients. There may also be practical challenges for those requiring assistance with grocery shopping and meal preparation not receiving the services they need.

The EHC study showed that patients living in areas with higher socioeconomic status had better scores for physical function, bodily pain and general health [8]. This suggests that people with more access to financial resources may be able to afford helpful treatments (such as those with other health professionals), needed home care services (such as groceries and housework), and other health and social services that may not be accessible to those with lower income.

⁵¹ See *The Quantitative Data*, Table 23: Canadian Population who have Household Income less than \$15,000 according to their Chronic Health Condition, 2010, pg. 41.

12 PHYSICIANS AND HEALTH SERVICES - POSITIVE EXPERIENCES

EXPERTISE, CAPACITY AND A WILL TO HELP MAKE A LIFE-CHANGING DIFFERENCE

PERHAPS the most important and over-arching recommendation to emerge from this study is the need for what several participants termed the 'normalization' of care and support for people with the CELCs. **Normalization refers to three critical elements: recognition, inclusion and equity.**

PEOPLE WANT TO BE TREATED WITH COMPETENCE, COMPASSION AND DIGNITY

I felt nobody was putting me in time, so it was okay to say, 'come back in three weeks', 'come back in four weeks, 'Come back in three weeks', 'come back in four weeks' and on and on and on. ... I used the word 'dehumanize[d]' in a little speech I said recently. And I guess that's the most important thing that wasn't met as a priority. Because when the healthcare [system] treats you like it matters, then the journey for better health is easier. **Mary Lou ME FM MCS**

POSITIVE EXPERIENCES

"...a miracle in my books."

The participants in this consultation were queried at some length about their positive and their negative experiences with health care and social service providers and the health and social service systems, and they answered in detail. Positive experiences were infrequent - indeed for many rare and for some nil - relative to negative experiences.

However, **a significant number of informants did have positive experiences, some even wonderful experiences, and the patterns that characterized these experiences are clear and meaningful for policy-makers seeking to provide better care in the future.** We want to begin our study reportage on experiences with physicians and the health care system as such with the positive, and emphasize that **we have a body of experience, knowledge and practice to guide us going forward.**

Patient participants have had excellent experiences with expert physicians who were trained in the three CELCs. This finding rings out in the voices of the study participants. Equally, participants reported excellent support from non-specialist physicians and other health professionals who already had, either competence in the conditions when patients sought them out, or who obtained education on their own when presented with patients who needed this expertise. Patients had very good experiences with providers who have personal experience with the CELCs, even when these providers had no special training. Participants had positive experiences with providers who, although knowing little or nothing about the CELCs, still treated patients with respect and compassion, and attended to information brought to them by their patients.

Some participants who never found help in the medical system did find assistance with other health professionals - naturopaths, chiropractors, physiotherapists, acupuncturists and massage therapists were among those mentioned repeatedly by participants.

The overarching pattern of which the above themes are subsets is this: when positive encounters with health care providers have occurred, study participants have reported that they have been *enormously beneficial* - specialists have been dubbed 'a miracle,' 'an angel' and other such superlatives; and words of praise and appreciation nearly as strong were used to describe other providers who showed care, compassion, respect and competence. **Expert and supportive care has improved the quality of life for all who reported receiving it; and for a significant number, helped them to regain productivity and an important measure of wellness.**

These findings show that the education and training both of specialized and primary and secondary care providers delivers excellent value for the health care dollar in assisting patients, families and communities and is well worth future investment.

RARE BUT POSITIVE EXPERIENCES FROM AN INFORMANT WHO REGAINED HER PRODUCTIVITY

I have had, for the most part, very positive responses from all of my attempts to seek care within the healthcare system. Now I say that with full awareness that probably who I am and some other things in my life, might maybe help me present a certain way to professionals. My husband was a great advocate for me. My onset of illness happened very abruptly. I went from hiking one weekend to having some undetermined viral illness, to that going away and me being left unable to perform personal care activities. And I think that the suddenness and the severity of the onset, coupled with the fact that there were quantitative measures that showed that something had happened to me, as well as the fact that I had an existing positive relationship with my family doctor - really all came together to help me access care in a very effective way. **Amy FM**

12.1 PARTICIPANTS WHO WERE ABLE TO CONSULT EXPERTS HAD EXCEPTIONALLY POSITIVE EXPERIENCES

THESE ENCOUNTERS MADE MAJOR, LIFE-CHANGING AND LIFE-SAVING DIFFERENCES IN THEIR HEALTH AND WELLBEING.

Physicians with training in the field were consistently named, highly praised and deeply appreciated for their help by many participants who had had such assistance.

SPECIALIZED CARE IS LIFE CHANGING AND LIFE SAVING

I've had a few positive experiences with health care people. Notably, first of all, Dr. M., the environmental physician. **Robert ME FM**

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.

Shan ME MCS

By about late 2006, I was still unable to work and I was pretty much close to being destitute. At one point, I ended up calling 310-COPE, they had the stress centre in York region. And I got a referral to York Support Services, and I told them about my story and they referred me to Dr. B. And I was finally able to get in to see her, and she diagnosed me with ME. And we eventually got me on ODSP and rent [subsidy for low income housing, which I am on now. So basically I'm saying that Dr. B. saved my life because at that time that I saw her, I was pretty much suicidal. She was very thorough in the testing, as opposed to my other doctors who would just do, like, a CBC. She got into a lot of in depth-testing.

Frank ME

I went to the LAMP occupational health program... It's the Lakeshore Area Multiservice Project. It's the only Community Health Centre that has an occupational component, and there was a new addition built on designed specifically for people with chemical sensitivity. So the docs there are excellent, and the program is excellent. I also came to the clinic when Dr. F. was here, and so my diagnosis was confirmed. **Hillary MCS**

I found somewhere, a place ... in Nova Scotia. There's an environmental health centre there. Ten years it took me [to find it]. ... It was a really good place to go, to go and talk to people who had the same sort of issues that I do and what not. But it took so long for my country to send me there and I had no idea why. I think that's way too long, when the doctor there – the specialist there – is saying that I need to be seen yesterday. ... But I did get to go there and I was not disappointed when I went there.

Petra MCS

And the other part, too: I was feeling very guilty. Did I do this to myself? How did I do this to myself? And I was really angry for a long time, and I just didn't accept my illness. But I felt a little bit better. I said, 'Oh, I can do this.' And then I crashed for a week, and I said, 'Okay, what happened?' So it's only after I met up with Dr. B. that she sort of slowly helped me figure things out for myself as to what to do. **Cecilia FM ME**

I would say when my GP sent me to this pain specialist, and he knew quite a bit about fibromyalgia, and they had set up a self pain management course. This was at Providence Healthcare. And they were very supportive down there for people with fibromyalgia and a lot of the other problems people have. This particular specialist, pain specialist, he was very supportive. **Doug FM**

Dr. A. is a miracle in my books. She tells you the truth in the first place, and in the second place, she gives you alternatives that, if you got on the internet, you can find them. **Sharon MCS ME**

Dr. B. was fantastic ... she was up to date. She knew it was an illness. She helped write the definition. She was great and compassionate. **Gayle ME**

I've been in pool therapy for about five or six years. I[t] has been going on six years since I have been seeing a specialist. He's ... the[e] one [that] signed me up for therapy. **Pearl FM**

It maybe was six months later and I went to Dr. B. again. That is when she did all the -- what I call 'outside the box' – test[s] that my family doctor didn't do or wouldn't do.... It wasn't until I saw Dr. B. that she diagnosed the FM and chemical sensitivity and the toxic brain injury. **Sandra MCS FM**

I think I've been extremely fortunate with the people I've had to deal with ... The best time was a

fellow who's in Kingston. Client pain management was really his thing. His ... doctorate was in ME, and I learned so much from him. And he was able to come and speak to my support group on the scatter pattern, on an MRI. And it's that sort of thing, how that differs and how it's often mistaken for MS, and he's just incredibly supportive that way. **Elizabeth ME**

THE GREATEST PROBLEM WITH EXPERT CARE WAS HOW HARD IT WAS TO FIND, TO ACCESS AND TO KEEP.

SPECIALIZED CARE AVAILABILITY IS VERY LIMITED OR NON-EXISTENT

I had one doctor who really had a firm grasp on [my condition and] basically tore a strip off the insurance company person ... She was an incredible advocate, and she had incredible knowledge. It was rather stunning, but unfortunately she was only my doctor for not quite a year. **Ottawa Focus Group participant**

12.2 SUPPORTIVE FAMILY PHYSICIANS WERE VERY HELPFUL

WHETHER IN PRIVATE PRACTICE OR IN CHCS, PCPs WHO ALREADY HAD, OR WHO AGREED TO OBTAIN, ADDITIONAL EXPERTISE TO ASSIST PATIENTS, WERE SINGLED OUT AS EXCEPTIONALLY HELPFUL BY PARTICIPANTS.

CARING FAMILY PHYSICIANS WITH EXPERTISE HAD A MAJOR POSITIVE IMPACT

I have got a lot of support from my GP, who is part of the Kingston family health team. In the team there are various professionals and one is a social worker who has lots of experience and qualifications – he has been involved since day one and has been instrumental in helping me build my life to what is it today.

John ME FM

He has been so supportive. He says to me, 'what can I do for you?' Through his help I have been able to get aids, an OT and a PT, like an OT for aids around the house like a stair glide, and a walker and a PT, for teaching me how to breathe better and things like that. My family doctor is just amazing. He's so good. He listens and he researches and he is great. **Sharon ME FM**

My initial GP, she didn't know anything ... From then on I had my own shelf on the bookcase in her office. [I would] take every single piece of information that I could for her. ... By the end of our time together, she was really good and she was thrilled because she actually was able to diagnose somebody else... **Elizabeth ME**

My family doctor ... was doing home visits for me for a few months, just before the surgery, because she knew how hard it was and how exhausted I was feeling, getting to see her. That has been very supportive. I find that she is amazing. I call her an angel. She does things I wouldn't expect a family doctor to do, like home visits and bringing me salad when I don't have enough PSW [personal support work] hours. **TJ FM ME MCS**

12.3 PRACTITIONERS WITH PERSONAL EXPERIENCE OF THE CONDITIONS PROVIDED ASSISTANCE AND RESPECT

ONE MCS participant, whose physician was among those rated as exceptionally helpful, had a positive experience with requesting chemical reduction in ambient air at her physician's offices. Being able to get good medical care was sometimes dependent on the conditions or attributes of the patient and her/his relationship with his GP and other health providers.

PROVIDERS WITH PERSONAL EXPERIENCE OF THE CONDITIONS WERE SUPPORTIVE AND COMPASSIONATE

I didn't get decent treatment until I found a psychologist who had it. And all of a sudden she's, like, 'Oh, you need to do this. You overdid it there by about two hours, so this is how to stabilize your energy. This is how to stabilize ...' She taught me how to live with it. And so finally ... I was validated and I was seriously helped. I mean, she turned me around with it within a couple of months. **Annabella FM ME MCS**

12.4 MANY PARTICIPANTS REPORTED BETTER ASSISTANCE FROM COMPLEMENTARY CARE THAN FROM M.D.s

NATUROPATHY, CHIROPRACTIC/PHYSIOTHERAPY, MASSAGE AND ACUPUNCTURE WERE FREQUENTLY AFFIRMED AS VERY HELPFUL

A significant number reported more assistance from such professionals than from M.D.s. However, it should be noted that such care is privately paid and outside the financial means of many people.

Having a psychological health provider who is knowledgeable and can direct participants to the services appropriate for their condition was also seen as positive.

MANY PARTICIPANTS HAD CONSULTED COMPLEMENTARY/ALTERNATIVE HEALTH PROFESSIONALS

Going to an osteopath, you know, who moves the plates in the head, fantastic! I have never felt so good with my fibromyalgia as I did when I was going to see this person. Yeah, I was actually pain-free for a while. **Janepher FM MCS**

Essentially, the medical system didn't offer me any explanation. I was told I had arthritis. I was told I had lupus. I don't know how many different things I have been told and I have tried different things, like medical things that were of no use to me and didn't really help me. I have gone to naturopaths since age 24. I did get good help [from naturopaths] to a certain extent. **Hope MCS**

PSYCHOLOGICAL SERVICES WERE IDENTIFIED BY SEVERAL PARTICIPANTS TO BE VERY HELPFUL IN COPING WITH THE MAJOR STRESSES OF LIVING WITH THE CONDITIONS.

(Note, however, that no participants attributed recovery or major remission of conditions symptoms as such to these services.) Numerous participants noted that the assistance of a psychologist was an important factor in promoting their wellbeing. Several ME/CFS patients noted that mindfulness-based approaches taught in self-management groups were helpful to them in coping.

PSYCHOLOGICAL SERVICES WERE IDENTIFIED BY SEVERAL PARTICIPANTS TO BE VERY HELPFUL

Our psychologist started running a course recently, especially for caregivers. Part of her mindfulness programs, which were hugely helpful for us. **Annabella FM ME MCS**

Other sources of helpful health support were cited.

SEVERAL PARTICIPANTS SINGLED OUT THEIR DENTISTS FOR THEIR UNDERSTANDING AND SUPPORT.

SUPPORTIVE DENTISTS ARE IMPORTANT AND APPRECIATED

My dentist's office, I went in there when they first opened because I wanted to know what kind of building materials they had used. The dentist himself actually sat down with me, and he understood about chemical sensitivity. I can go to his office very safely. It is only occasionally that I will smell something. If I do the educating, people are quite receptive. **Sandra MCS FM**

Her dentist has been very supportive. When she goes to the dentist, they take one of their spare rooms and we can set up a cot or a mattress there and she rests for an hour. Then she sees the dentist. Then she rests for an hour. And then she comes home again. **Thomas, caregiver for wife with ME**

ADDITIONAL POSITIVE CONTRIBUTIONS TO PATIENT HEALTH CARE EXPERIENCES WERE ATTRIBUTED TO MASSAGE THERAPISTS, PHYSIOTHERAPISTS, SOCIAL WORKERS AND HAVING ACCESS TO CLINICS SUCH AS YORK SIMCOE BRAIN INJURY SERVICES.

ONE PARTICIPANT GAVE GOOD MARKS, WITHIN VERY LIMITED PARAMETERS, TO HIS WIFE'S CCAC.

WHERE AVAILABLE, CCAC SUPPORT WAS RATED AS VERY IMPORTANT

TO PATIENT AND CAREGIVER

We have had mostly positive support from the CCAS within their limitations, which are pretty severe. The case workers have been understanding and open to being educated about [my wife's] disease, and they've been quite good about making sure that she has what care they can provide. The flip side of that is that

the care they can provide is very, very limited. But it does allow someone to come in and look after her toes and her showers, and that sort of thing – washing her hair once a week. It also will occasionally provide an Occupational Therapist to come in and make some suggestions about how we can better arrange the home and her room, etc. for her benefit. **Thomas, caregiver for wife with ME**

FOR MANY PARTICIPANTS, A PATIENT ORGANIZATION PROVIDING PATIENT INFORMATION AND CONNECTING THEM WITH PEERS WAS A POSITIVE EXPERIENCE, IN SOME CASES, THE ONLY POSITIVE EXPERIENCE THEY HAVE HAD. For a discussion of the importance of this issue, see Chapter 27 -‘Helping patients to help themselves’.

13 PHYSICIANS AND HEALTH SERVICES - DEFICITS AND COMMUNITY RECOMMENDATIONS

‘...A very disempowering and horrible experience’

‘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.’

THE new diagnostic tools and the codification of assessment and treatment regimes that have been put to use in select clinical settings over the last forty years have now reached the stage where, despite the continued absence of agreed biological diagnostic markers for these syndromes, clear clinical approaches and care pathways have been established and can be taken into the main stream.⁵² So far, however, this material is not yet taught in most medical schools, and has not formed part of the training of the vast majority of physicians, nurses and other health care system personnel. Consequently, our system fundamentally lacks the capacity to identify and assist the half-million-plus people in Ontario who suffer from these conditions.

Physicians are the key decision makers, the ‘legitimizers’ and the gatekeepers to the larger, publicly-funded health care system. Their ability to understand and assist with the three CELCs, and their attitudes towards the people who suffer with them, is absolutely central to, and determining of, the experiences of people within the larger health system as well as the social support systems.

In the first part of this chapter (NEGATIVE EXPERIENCES) and in contrast to the positive experiences of our participants reported above, the great majority reported having multiple negative and unsupportive experiences with physicians - their main interface with the health care system - and other health professionals much or all of the time. There is no overlooking the depth of this negativity. For a number of participants, it has included both physical and emotional trauma. ‘This can be a very disempowering and horrible experience,’ said one informant.

Needs are further identified and recommendations tabulated in the second part of this chapter (PATIENT-IDENTIFIED SOLUTIONS). Some repetition has been unavoidable, but we hope that the constructive information contained makes up for it.

⁵² For a comprehensive discussion of these matters, with up-to-the minute definitions, case criteria, diagnostic and treatment measures, and for a bibliography that addresses all these issues and their evolution, see John Molot, MD, *Ontario Centre of Excellence in Environmental Health: Academic and Clinical perspectives*, companion appendix supporting material to the OCEEH BCP (Toronto: 2013). To see the distance we have come between what was known in 1985, when Ontario conducted its first enquiry into ES/MCS (then known as environmental illness or chemical hypersensitivity), and today, see 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) and contrast it with Dr. Molot’s report. For the prescience of the Ad Hoc Committee regarding health care system recommendations, see Appendix 2 for (unimplemented) recommendations from the Committee.

NEGATIVE EXPERIENCES

13.1 NEGATIVE EXPERIENCES WITH PHYSICIANS AND THE HEALTH CARE SYSTEM OUTNUMBERED POSITIVE EXPERIENCES BY A WIDE MARGIN

Virtually all participants affirmed a number of consistent and recurring patterns of negative interactions and experiences with health care professionals. Their full dimensions are conveyed most comprehensively by the longer compilation of patient voices. However, it is possible to summarize the patterns of negative experience that were emerged as the norm and the usual context in the medical system.

'I WOULD SAY NINETY PER CENT OF MY EXPERIENCES WITH ALL OF THOSE HAVE BEEN UNPLEASANT OR UNSUPPORTIVE.'

I would say ninety per cent of my experiences with all of those [physicians] have been unpleasant or unsupportive. Dismissal too, like if I said, 'I can't take this medication' or 'I can't do that,' ... my doctor called me non-compliant once, because I knew I reacted to what they had prescribed. So finally I said 'okay, I will take that,' and I broke out into an angry raised body rash. And I went to her office, and I said, 'I took your medication.' And she looked at me and panicked. Because she wasn't listening to me, I finally I took the medication, knowing what was going to happen to me, just to show her that what I was saying was the truth and was real. **Hope MCS**

So the one doctor I went to had a sign on the door that she definitely would not even see patients that had fibromyalgia. **Wendy ME FM**

THE CURRENT STATE OF MISTAKEN BELIEFS AND LACK OF SERVICES WAS PERCEIVED BY MOST PARTICIPANTS AS A PUBLIC WRONG, A FAILURE IN THE HEALTH CARE SYSTEM AND ON THE PART OF GOVERNMENT IN THEIR DUTY OF CARE.

For some, this failure constitutes a form of abuse.

THE CURRENT STATE REPRESENTS A PUBLIC WRONG AND A FAILURE BY GOVERNMENT IN ITS DUTY TO CARE

Every one of us has a non-evident, or invisible, disability. You can't say, 'my arm is broken. Please stop hitting my broken arm.' And that's very important for lawyers and health care providers. They have a responsibility, doctors have a responsibility, to become knowledgeable about things that are difficult, things that are not curable. ... Refusal to do that is negligence. It is abuse. **Hilary MCS**

13.2 LACK OF EDUCATION AND TRAINING SEEN AS RESPONSIBLE FOR NEGATIVITY, DISCRIMINATION AND NEGLECT

THE GREAT MAJORITY OF CONSULTATION PARTICIPANTS WERE CLEAR: THE ABSENCE OF GOOD EDUCATION IS RESPONSIBLE FOR BELIEFS AMONG PHYSICIANS THAT THE CELCs ARE MENTAL ILLNESSES AND/OR HYPCHONDRIA IN TURN RESPONSIBLE FOR THE NEGATIVE PERCEPTIONS OF PHYSICIANS.

This belief/perception combination was reported as so common and so frequently distorting of the doctor-patient relationship that it emerged as a perhaps the most fundamental overall barrier to care. We flag it now as critically important and take it up briefly again later in this chapter. However, this central theme- and its accompanying finding, that women are not believed or taken seriously by many physicians due to negative gender bias – c McCampbellot be covered in this chapter alone. So each of these themes is reported and analyzed in detail in dedicated chapters, women’s issues in Chapter 15, and broader stigmatization and denial, in Chapter 16.

LINKED TO THESE BELIEFS, INFORMANTS REPORTED THAT COMMON PHYSICIAN ATTITUDES INCLUDED DISRESPECT, DISMISSAL, SPOKEN DISBELIEF AND EXPLICIT DISPARAGEMENT; EVEN, ON A FEW OCCASIONS, BEHAVIORS IDENTIFIED BY PATIENTS AS PHYSICALLY HARMFUL AND/OR INTENTIONALLY PERFORMED.

Some participants pointed out a general culture of dismissal and prejudice among physicians and medical schools.

A CULTURE OF DISMISSAL AND PREJUDICE IN THE MEDICAL PROFESSION

It is a culture of dismissal and prejudice. **Gayle ME**

I find that in the medical system there is a de-legitimization of this condition ES/MCS and there is a dismissal, and you are pathologized in a negative sense and psychologized. ... They need to understand that this is a legitimate condition, and disability, because that was one of the most disparaging experiences for me when I reached out for help. **Hope MCS**

Participants were refused referrals to other physicians, letters to employers and insurance companies, explanations to family members and other caregivers - all behaviors with which patient support organizations were familiar with prior to this study. As well, when such practices and attitudes prevailed among physicians, they were also prevalent among other providers (e.g., nurses, other health and social support providers).

From the point of view of providing appropriate services - the most important objective in both client outcomes and cost efficiency - **three sets of greatest failure included:**

- **Failure to diagnose in a timely fashion, or at all, or in a fashion that assisted the development of a helpful treatment and care plan;**
- **Lack of treatment, or erroneous treatment, or refusal to take the CELC into account in addressing co-morbid conditions; and**

- Refusal to accommodate chemical sensitivity, a life-threatening condition, in providing safe medical treatment, safe air quality in facilities or safe air quality with patients through changing personal grooming habits.

13.3 A FUNDAMENTAL LACK OF FAMILIARITY AND COMPETENCE ENCOUNTERED BY ALL INFORMANTS AT ONE TIME OR ANOTHER

THE GREAT MAJORITY OF PARTICIPANTS ASCRIBED NEGATIVE EXPERIENCES WITH HEALTH CARE SERVICES TO A FUNDAMENTAL LACK OF FAMILIARITY WITH, AND COMPETENCE IN, THE CONDITIONS.

A FUNDAMENTAL LACK OF FAMILIARITY WITH, AND COMPETENCE IN, THE CONDITIONS

Every doctor. Every professional. Even a naturopath, chiropractor, nurses, you name it. When I talk about it, they have no idea what you're talking about. I try to avoid the term 'chronic fatigue syndrome,' and I just go with my myalgic encephalomyelitis now, and I just -- they have no idea. They have never heard of it. They don't know what it is. **Frank ME FM**

The other doctors have been pretty bad. They look in their little patient care website and it says in there to treat patients with counseling and exercise. But they have no idea what exercise means in the context with someone with ME. ... They do not know about the illness or how to treat it. **Gayle ME**

Practitioners other than those who 'get it' don't get how invasive these disabilities are in families. [They] can barely deal with you as patient, let alone think about dealing with extended family, like children, husband, or wife, it doesn't even come into their mind. **Elva MCS FM ME**

FOR THE GREAT MAJORITY, GETTING AN ACCURATE DIAGNOSIS WAS VERY DIFFICULT AND TOOK YEARS OF CONSULTING MULTIPLE FAMILY AND SPECIALIST PHYSICIANS.

The process undermines patients and has many negative consequences, including deterioration that cannot be reversed.

GETTING A DIAGNOSIS IS VERY DIFFICULT AND UNDERMINING

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. That was the major issue for me was getting a diagnosis. **Bill ME**

Well considering that I was sick from -- I married in 1994 and moved to Marathon right away. I was seeing doctors all the time for various complaints. I have a right leg weakness that I have had all that time and the sore throats and all the different things. Yet, I did not have my diagnosis until 2003. I think the level of understanding was very poor in that sense. **Sharon ME FM**

LONG WAIT TIMES BETWEEN TESTS AND TO SEE SPECIALISTS, AS WELL AS THE NEED TO CONSULT MANY DIFFERENT SPECIALISTS, WERE COMMON AND FRUSTRATING EXPERIENCES.

Participants confirmed that it is extremely difficult, often impossible, to be referred out of province or country for treatment even when such treatment is available in other jurisdictions, but not accessible in Ontario. A number of participants reported experiences of prolonged and severe symptoms followed by a reluctant diagnosis and the announcement that there is no medical help for the problem.

‘I’M AFRAID THAT THERE IS NOTHING THAT MEDICAL SCIENCE CAN DO FOR YOU.’

I made an appointment with my doctor again. This time, instead of ad-libbing and going in and just talking to her, I decided to sit down and write down my symptoms from my perspective and the ways that it was affecting my life - socially, economically and in other ways. ... When she came in ... she said, ‘well, I really believe that you have chronic fatigue syndrome. I’m afraid that there is nothing that medical science can do for you.’ She gave me some recommendations to go and see a naturopath, which was economically not feasible at the time. **Sharon ME FM**

CO-MORBIDITY IS VERY COMMON. AS A RESULT, PARTICIPANTS TYPICALLY CONSULTED MANY SPECIALISTS FOR DIAGNOSTIC PURPOSES ABOVE AND BEYOND THEIR CELC SYMPTOMS, BUT WITHOUT GOOD OUTCOMES.

The vast majority of these consultations were with untrained physicians and not helpful. MDs often failed to make diagnostic links to the three conditions, and thereby failed to provide assistance to patients

MANY UNTRAINED SPECIALISTS CONSULTED FOR MANY SYMPTOMS, VERY POOR OUTCOMES FOR PATIENTS

I've seen a lot of specialists that are just like... not negative, it was just nothing – a waste of time more or less. **Theresa ME**

In 2001 I went to teach students with eating disorders 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**

FAILURE TO DIAGNOSE IS FREQUENT AND OFTEN LEADS TO THE WORSENING OF CONDITIONS.

Above and beyond the conditions themselves, chronic infections were mentioned as frequently missed by Ontario physicians, and very consequential to overall health. Diagnoses were made by GPs and by specialists and sometimes by nurse practitioners. Often GPs have no idea what their patients are dealing with.

DIAGNOSTIC FAILURES LEAD TO WORSENING OF CONDITIONS AND DEMORALIZATION

I was diagnosed in the States through Dr. S. with a blood infection and was treated for that on a long-term antibiotic course. And lo and behold, my fibromyalgia, which wasn't even responding to narcotics, started minimizing. **Mary Lou ME FM MCS**

Rheumatology is the one medical specialty that has officially been charged by government with caring for people with one of the conditions - FM. Yet only a few participants reported effective support. Several participants reported very negative experiences even with these specialists, ranging from neglect to verbal abuse.

VERBAL ABUSE FROM SOME DOCTORS, INCLUDING RHEUMATOLOGISTS

The most challenging is the attitude of doctors, especially my first GP, he wasn't very supportive: 'here is Tylenol - take Tylenol.' I was telling him it wasn't doing anything for me, so I was suffering with the pain for months. Then he sends me to ... this rheumatologist, who basically yelled at me for being in a wheel chair. I was very distrustful of doctors. **TJ FM ME MCS**

EVEN WITH AN ACCURATE DIAGNOSIS, INDIVIDUALS DO NOT HAVE ACCESS TO APPROPRIATE HEALTH SERVICES. NOT INFREQUENTLY, THIS RESULTS IN HARM TO PATIENTS.

Lack of physician knowledge frequently led to harmful interventions. Lack of established system-wide clinical guidelines and familiarity by physicians creates deficiencies in treatment, and not uncommonly, conflicting messages to patients.

EVEN WITH AN ACCURATE DIAGNOSIS, INDIVIDUALS DO NOT HAVE ACCESS TO APPROPRIATE, EFFECTIVE HEALTH SERVICES

Negative problems: my doctor not wanting to order enough pain medication. **Jane ME/FM**

My doctor told me to go to the gym too. And I went for a month and the muscle pain was so abnormal. You know what normal pain is. So I had to quit going. **Judy ME FM**

We have an international primer that came out. There are really no excuses for doctors to not go online and see what is out there and there is a treatment program out there. **TJ FM ME MCS**

Even now I get conflicting messages from doctors, all of whom I consider to be very good physicians. ... You know - different doctors with different theories because they don't really know. So here I am with no medical background trying to sort out which is the best advice. **Kathryn ME FM**

The doctors are not really good where I go at the Community Health Centre. The doctors are switching all the time. I don't even discuss my fibromyalgia now. The doctor just says, 'keep up what you are doing.' I get no extra support. I am not even sure that doctor really understands it. **Pearl FM ME**

VERY FEW PHYSICIANS UNDERSTAND THAT FOR MANY, ES/MCS INCLUDES PROBLEMS IN METABOLIZING PHARMACEUTICAL SUBSTANCES; THEY ARE RELUCTANT TO BELIEVE PATIENTS WHEN THEY EXPLAIN.

FEW PHYSICIANS UNDERSTAND THAT ES/MCS MAY INCLUDE PROBLEMS IN METABOLIZING PHARMACEUTICAL SUBSTANCES AND CAUSE HARM AS A RESULT

I had three or four mini strokes and went to a local GP who I had seen now and then, but he had no clue of any of this. And he gave me a prescription for Lipitor, saying, 'oh well, you'll have to be on this now, because of the strokes.' Well, I think after one or two pills at the most, I had a very extreme reaction that attacked all my muscles. I could barely walk, and I wasn't feeling like I couldn't walk at that time. I was pretty strong at that time. **Nancy ME FM MCS**

Participants suggested that physicians' lack of knowledge about their conditions makes the physicians focus on treating the symptoms rather than addressing the underlying causes.

FOR SOME PARTICIPANTS THE ABSENCE OF SPECIFIC AND KNOWLEDGEABLE TREATMENT BY EXPERTS IN THE CONDITIONS HAS MEANT THEY HAVE RECEIVED NO HELP AT ALL FROM HEALTH PRACTITIONERS.

SOME HAVE RECEIVED NO HELP AT ALL FROM HEALTH PRACTITIONERS

I have tried all the different type of medicines - homeopathic, naturopathic, chiropractic, exercise and all sorts of diets and I have seen different specialists over the years. Pretty much, nothing has worked to get me better. I can keep myself from getting a lot worse just by doing very little. **Gayle ME**

I've kind of taken responsibility for my disorder onto myself because I realized that the knowledge isn't out there. So I'm trying to figure it out by myself. It's very complicated. **Frank ME**

13.4 NEGATIVE EFFECTS OF DIAGNOSIS AS MENTAL ILLNESS OR HYPOCHONDRIA

As already noted:

ALMOST UNIVERSALLY, PARTICIPANTS' ENCOUNTERED PHYSICIANS AND OTHER HEALTH PROFESSIONALS WHO DIAGNOSED AND TREATED THE CONDITIONS AS AFFECTIVE OR NON-EXISTENT DISORDERS, WITH VERY NEGATIVE CONSEQUENCES FOR PATIENTS.

The vast majority of participants have encountered the belief among health practitioners that their health problems are 'in their head' in the sense of a psychological or affective disorder, either depression or somatization, or, indeed, a *form of hypochondria*; all were treated inappropriately, often harmfully as a result. This central problem is addressed in detail in the Chapter 16.

HEALTH PROFESSIONALS DIAGNOSED AND TREATED THE CONDITIONS AS PSYCHOGENIC DISORDERS WITH VERY NEGATIVE CONSEQUENCES FOR PATIENTS

I said [with] chronic fatigue syndrome [to] my GP that I need to see some good doctor. Because I know I've been diagnosed with this fibromyalgia, and I have the reports and all. But he doesn't want to believe. He says, 'Go and find your own doctor.' Can you imagine that? And then ... saying that it is all you. 'You are quite an attention-seeking person, and you are non-compliant.' I said, 'I don't need that therapy because I can't get up in the morning. Yes, I'm not able to go to work, and if I would be able to, I would love to go to work rather than coming for hours there. And I have no energy and strength ... and since you're giving me all these depression medicines ... I don't like to take medicines, but now I have to.' So it was giving me a lot of dizziness and everything. So then he also says that it's psychosomatic, and I didn't understand the word. I went and discussed with my social worker, what does it mean?' She says, 'this is not good for you because it is re-traumatizing you again and again by doing all these things.' ... Then I just went to my psychologist, psychiatrist. He says, 'You know what? It is all in your head.' So I was so upset, I said, 'Okay. If it is in my head, is there any way to get it out of my head?' **Bina FM**

IGNORANCE LEADS TO HARMFUL PHYSICIAN BEHAVIOUR

I did have to go and see a psychiatrist - as part of my legal proceedings, a psychiatrist for the defendant. ... I had sat across from him for several hours, answering his questions and at the end he got to his feet as I did. And as he was adjusting his clothing and tucking his clothes in, he put his hands in his pockets and all of a sudden I smelled laundry detergent. I don't know why I knew that it was laundry detergent but there is something in my brain that can compartmentalize what type of smell I am smelling, and I remember saying something to him, 'I have been sitting in the same room as you all these hours and now I am just smelling something.' **Sandra MCS FM**

A VERY SIGNIFICANT NUMBER OF INFORMANTS FELT THAT GENDER BIAS PLAYS AN IMPORTANT PART IN MEDICAL DISMISSAL OR 'PSYCHOLOGIZATION' OF THE ILLNESSES.

A number of informants expressed that these conditions were not adequately researched and funded because they are primarily women's diseases.

SIGNIFICANT GENDER BIAS LEADS TO ASCRIPTION OF CONDITIONS TO 'FEMALE HORMONES' OR WOMEN'S 'TENDENCY TO COMPLAIN'

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**

DESPITE THE FREQUENT BELIEF AMONG PHYSICIANS THAT THESE CONDITIONS ARE CAUSED BY PSYCHOLOGICAL DISORDERS, THERE ARE NO DEDICATED, CONDITION-APPROPRIATE PSYCHOLOGICAL SERVICES.

Participants noted they have no support to cope with an unrecognized condition that is physiological in nature but affects cognitive function and mimics mental illness stemming from affective disorders and that creates monumental stress in daily life, including from disbelief and lack of compassion.

LACK OF TRAINED COUNSELLORS/PSYCHOLOGISTS A SIGNIFICANT HARDSHIP FOR PEOPLE

The stress! The crises that one goes through and so on, result in a lot of stress. Through some of those crisis periods I wanted to get some support, counseling, somebody to talk to, but I didn't have anyone. And the efforts that I made to do that were for the most part frustrating and fruitless. ... Even though counseling agencies sometimes say that they deal with all kinds of issues and so on, they largely are uneducated and uninformed. **Rob ME**

MANY PARTICIPANTS SIMPLY EXPRESSED A DEEP DISTRUST, EVEN A FEAR, OF PHYSICIANS.

In this larger context where lack of capacity, stigmatization and a failure to demonstrate compassion often occur simultaneously, patients often expressed lack of trust in both physicians and the medical system.

PHYSICIAN IGNORANCE AND DISRESPECT LEADS TO A FEAR OF DOCTORS BY PATIENTS

I try to avoid MD's in general. I have had that experience over and over. I was in a walk-in clinic and I tried lying about my diagnosis, I was having some discomfort breathing. The deeper I would breathe the more it would be painful. I said something to him, my throat is always quite blistered and swollen, so he asked about me having a cold, I had to tell him that it was always like that, I had to tell him my diagnosis and after that he was treating me very poorly. **Gayle ME**

The only positive one in the healthcare field is, if doctors are specialized in this field, it's positive ... they get it. Anybody else is deficient in their understanding, in their motivation to understand, in their training, in their general acceptance, in their understanding of law and their duty. On a scale 1 to 10 I put a zero. ... I am not coming to a medical service unless I'm going to get better and not more injured. **Elva MCS FM ME**

INFORMANTS WITH ES/MCS SAID THAT THEY FEARED MEDICAL SERVICES AND AVOIDED TRYING TO ACCESS EVEN CRITICALLY-NEEDED EMERGENCY AND ACUTE CARE SERVICES.

Because of the physical dangers posed to patients by a lack of knowledge about and safety for **ES/MCS** in medical settings, and lack of knowledge of care protocols, those with this condition were extremely aversive to health providers and health sites.

THOSE WITH ES/MCS FEAR HARM IN HOSPITALS

I actually was in touch when I was in Toronto with EMS, because the thought of having to call an ambulance scared the hell out of me, because if the people are scented or there's scent whatever, then I would just be sicker and then I couldn't speak for myself, which is the most frightening thing to think about, or that I'd go irritable and impossible and then I experience what other people have experienced in hospitals, which is being put in a psych ward. In Toronto I got sick... from truck exhaust under my

window, I ended up a couple days later with a kind of stroke called timed blindness, and there was no way I was going into a hospital because any of the hospitals that I'd been to in Toronto, there's always a problem along the way. They spout the scent-free line but it isn't. **Betty MCS**

13.5 HEALTH SYSTEM STRUCTURAL PROBLEMS ACT AS BARRIERS TO ACCESS

MANY INFORMANTS COMMENTED ON SYSTEM-WIDE OR 'STRUCTURAL' PROBLEMS IN THE SET-UP OF SERVICE PROVISIONS THROUGHOUT THE HEALTH CARE SYSTEM THAT MAKE IT VERY DIFFICULT, IF NOT IMPOSSIBLE, FOR THOSE IN NEED TO ACTUALLY GET HELP.

Debilitating fatigue and cognitive impairment are across-the-board problems for all three conditions when providers have no understanding of what patients are experiencing. For those with ES/MCS, exterior or interior air quality problems often mean that people do not even seek services when needed for fear of greater harm being done. A significant number of informants voiced the theme that the system effectively shuts out those who need it most. A lack of understanding of the CELCs makes communication difficult or impossible, while often feeding into the erroneous and negative perceptions held by care providers.

'YOU CAN'T GET THERE FROM HERE' ... STRUCTURAL PROBLEMS INTERFERE WITH ACCESSING HELP FOR THOSE WHO NEED IT MOST

'It is not a patient-centred system'

It is not a patient-centred system. It is a system-centric system... Something what really disadvantages people who have fatigue, cognitive issues and many of the symptoms ... is that the system's set up in a way that you have to be able to go to a doctor. You have to be able to physically make it in there and then not be too exhausted by the time you get there to provide the information that the doctor needs. The doctor may ask you questions. ... [I]t's all about getting the evidence of your situation to the right people in the right way. And that's a structural problem ... embedded in how the healthcare system works and how we are forced to engage with it. Then you have to manage to provide the information to the doctor in a fashion that allows the doctor to learn what the doctor needs in order to help you ... and you're forced to do all of these active things to help access care at a time when you're uniquely unprepared and unable to put the energy and resources into doing it. **Amy FM**

I've had a lot of trouble accessing language for many years now, so there were more than a few misunderstandings ...and I couldn't clear them up because I couldn't find the words and I didn't have the energy. It took so much energy to move my hand where it needed to go and to merely think, to come up with a complete sentence, to find words which I often got wrong, when people made assumptions it was impossible to try and correct it. I just gave up and waited, hoping for a better opportunity to arise. Now I'm starting to get more language back. **Linda MCS**

AN EXPERIENCE CONSISTENTLY SHARED BY INFORMANTS WAS THE ABSENCE OF ADVOCATES AND THE NEED TO EDUCATE PHYSICIANS, AS WELL AS OTHER TYPES OF HEALTH CARE PROVIDERS, THEMSELVES.

A few physicians responded well to patients' offers of educational material. Others rejected such collaboration. As patients, participants found this difficult, exhausting and frustrating when ill.

PATIENTS HAVE TO EDUCATE PHYSICIANS AND ADVOCATE FOR THEMSELVES

One of the big negatives for me was that my GP had no idea what was happening with me. And I came to her, and she kept trying some alternatives, saying, 'Oh, is it thyroid? Is it iron or whatever?' We looked at a number of things, and basically what happened was, I had to look on the Internet and figure out what my diagnosis was and check with her. And she said, 'well, yes, it's probably got to be this because we've ruled out everything else.' So I basically came down with the diagnosis after having been sick for months and months. **Benita ME**

13.6 MANY TRIED A WIDE VARIETY OF TREATMENTS AND SUPPORTS - ALL PRIVATELY PAID.

ALL expenses were privately borne.

MANY SEEK 'COMPLEMENTARY' AND PRIVATE M.D. CARE AND PAY FOR SERVICES PRIVATELY

First, I was sent to a psychologist. I went and took hydrotherapy, acupuncture, and massage therapy. Anyway, I went to a chiropractor, took laser therapy, and all these things, of course, [payment] came out of my pocket... And many, many blood tests and EKGs and CT scans, you go on forever. **Wendy ME FM**

PATIENT-IDENTIFIED SOLUTIONS

Almost all informants in the consultation identified a great many unmet health care needs throughout the health care system. As already noted, the term '*gaps in service*' is appropriate when an imperfect network of services and programs is in place and it is useful to identify what services or programs need to be filled in. When no such network exists - as is the case with the CELCs - it becomes less productive to speak of 'gaps'. As well, in such a context, there is an overlap between the non-existence of services ('needs' and 'gaps') and 'barriers.' For example, the lack of training and knowledge of physicians, which so many participants identified as the absolute primary 'need' for achieving system-wide change, is also a 'gap' and a 'barrier' at the same time. Therefore we have paid less attention to categorizing deficits as gaps or barriers as such, and more to presenting identified needs and suggested ways to address them.

13.7 RECOGNITION, INCLUSION AND EQUITY: NORMALIZATION URGENTLY NEEDED

URGENT NEED FOR RECOGNITION AND NORMALIZATION

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**

NORMALIZATION REFERS TO THREE CRITICAL ELEMENTS: RECOGNITION, INCLUSION AND EQUITY.

In this framework, the most important and over-arching recommendation to emerge is the need for what several participants termed the 'normalization' of care for people with the CELCs.

DEVELOPING SYSTEM CAPACITY INVOLVES PUTTING INTO PLACE THE SAME TYPES OF CARE AND SUPPORT SERVICES THAT OUR SOCIETY MAKES AVAILABLE TO PEOPLE WITH ILLNESSES AND DISABILITIES OF COMPARABLE SEVERITY - A POINT MADE OVER AND OVER BY PARTICIPANTS.

NORMALIZATION REFERS TO THREE CRITICAL ELEMENTS: RECOGNITION, INCLUSION AND EQUITY

We need the same funding as other people have, like cancer. If somebody says, 'you've got cancer? Oh, well, poor you.' But if somebody says, 'oh, you've got chronic fatigue syndrome? Oh, I'm tired, too.' The general public has no idea what it is. It's an invisible disease... If you have cancer, you can have the Cancer Society to help. But there doesn't seem anywhere to be any help for people with chronic fatigue syndrome or fibromyalgia. **Jane ME FM**

One doctor told her, 'I know exactly the right program for you, but it's only open to cancer patients above the age of 60.' ...If you're having a disease that isn't one of the favourite diseases, then even where programs exist that might be just right for you, you don't get to participate in those programs. That's definitely a problem. **Thomas, caregiver of wife with ME**

I mean ... if I had cancer then I would be treated. Why not this? That's what kind of bothers me. ... [W]hy can't I get treated for it, especially since I know what can help me. **Petra MCS**

My sister in law has lupus and has four kids and she works full-time and shops on the weekends and that illness gets funding, help and a specialist. I am bedbound and I get squat. **Gayle ME**

How best to move from a current state of a total void in services to a future state where normalized services are in place is a challenging question. Many informants had very helpful recommendations with respect to both the types of care and methods of organization and delivery. These insights are reflected and embodied in the recommendations that flow from the study, gathered together in Part Five. [Here is a selection of comments from the consultation participants about 'deficits and needs in health care.'](#)

13.8 MEDICAL EDUCATION IDENTIFIED AS NUMBER 1 NECESSITY FOR CHANGE

MEDICAL EDUCATION WAS RANKED BY MOST AS THE NUMBER 1 NEED.

Patients unanimously identified the lack of knowledge, training and education of physicians as a central and pivotal gap and a fundamental barrier to accessing care.

LACK OF MEDICAL EDUCATION THE PIVOTAL GAP AND NUMBER 1 NEED

In the medical schools ... since the last ten years, there have been people, patients, with this fibromyalgia, chronic fatigue ... come to speak to all the medical students. But there are not enough clinics, specialists, family doctors, rheumatologists, that are available who have the knowledge to help mentor these students. And it's not in the medical school system in the list of interests that the medical students can click on and say, 'okay, this week I'm going to try and shadow this doctor.' ... So that part of it is not there, the linkage is not there. And then that way when ... they finish and they have to select which area they want to go to, where do they go and do the residency? So that part is not there for the students, the medical students who come out and do a residency there. **Cecilia FM ME**

Many participants identified the same deficits and needs in education and training with respect to nurses. Numerous participants drew on other health professions and pointed to the need for better integration of and coverage for their practitioners (see below) and better education for them.

PROVISION OF NEW COHORT OF EXPERT (SPECIALIST) PHYSICIANS SEEN AS CRITICAL

Informants identified services provided by environmental physicians as critically important.

They identified many unmet needs in health care services that are normally provided by expert physicians other jurisdictions (Nova Scotia, various sites in the U.S.) as fundamental gaps in care and as barriers to equity in care.

SERVICES PROVIDED BY ENVIRONMENTAL PHYSICIANS IDENTIFIED AS CRITICALLY IMPORTANT

One ME specialist in the province and that person leaves. ... A specialist [laughs] would be good. I would probably have taken my life if it hadn't been for her, just being so alone with this illness and so sick. Knowing there was one person who got it and was willing to try stuff. I don't know how people survive without one caregiver. **Gayle ME**

I honour and appreciate the work of the environmental health clinic [at Women's College Hospital]. But I feel that the government needs to provide more funding to this area so it can be an ongoing service. Right now you go in and essentially what is provided is assessment and diagnostic services, not ongoing support. **Hope MCS**

THERE IS A MASSIVE NEED FOR AN EXPANSION OF THE ENVIRONMENTAL HEALTH CLINIC AND FOR SIMILAR CLINICS THROUGHOUT THE PROVINCE.

- The limit of three appointments per patient at the Environmental Health Clinic in Toronto was seen as a major gap in service, and a barrier to accessing appropriate health care.
- The limitation of the EHC to assessment and diagnosis only - the absence of treatment on site - was seen as a serious deficit.
- Lack of availability in Ontario and at the EHC of treatments used in well-known clinics with good outcomes for these conditions in other jurisdictions was identified as a serious gap.

- Numerous treatments were specifically identified (see Chapters 21, 22 and 23 for recommendations).
- Safe air quality for ES/MCS patients at the EHC was seen as a critically important. Its absence was described as gap that clearly constitutes a barrier to access for the ES/MCS client base.
- Lack of more fully-specialized environmental physicians and more specially-trained primary care physicians and physicians in other specialties is seen as major need, a major gap and a major barrier in accessing health care.

13.9 LACK OF OHIP CODES FOR ES/MCS SEEN AS GROSSLY DISCRIMINATORY AND A TOP PRIORITY FOR CHANGE

Refusal to-date by government to provide codes for, and to fund treatment for ES/MCS and to provide safe sites for care is experienced by many as a massive barrier that constitutes blatant discrimination over and above the considerable deficits experienced by sufferers with ME/CFS and FM.

LACK OF CARE AND SAFE SITES FOR ES/MCS 'HIGHLY DISCRIMINATORY WITHIN THE MEDICAL SYSTEM'

Right now people aren't getting access to treatment, and that is highly discriminatory within the medical system. I am not talking about doctors now. I am talking about the government who makes the decisions. It is highly discriminatory and denies access to treatment to all of us ... people with MCS particularly because it is highly underserved. **Elva FM ME MCS**

13.10 PRIMARY CARE NEEDS

Informants were unanimous in stating the need for well-informed and responsive primary care providers.

INFORMED AND RESPONSIVE PRIMARY CARE PROVIDERS ESSENTIAL

What was great for me was having my husband take me to all of these things and basically what my doctor did was tell my husband: 'this is the care and feeding instructions of fibromyalgia patients. Basically take her home; this is what you need to do with her. Make sure that she does these things and you're doing these things.' ... If you have a good doctor, then it's kind of not coming from you. Like, 'I need, I need, and I need.' It's more, like, the medical professional has announced that you henceforth shall do all the housework, right? [laughs] So that was really, for me that was great because I didn't have to ask for anything. We just got told. **Amy FM**

I just wish that at the beginning I had a more supportive doctor – it would have been nice to know that I was not going crazy. **TJ FM ME MCS**

My family doctor, it turned out when I needed proofs [for disability insurance] ... he had not done any documentation, so that left me with no proof but to start again. ... That was really sad. **Mary Lou ME FM MCS**

Participants identified urgent needs for the following features of *primary and secondary care provision*.

- Respect and support for patients (see all patient survey chapters) - understanding of effects of chemical exposures on those with ES/MCS and understanding that those with ME/CFS and FM are not lazy, cannot keep up, are unmotivated or are bad role models.
- Physician/medical education and support for families and caregivers.
- Competent physician screening, earlier diagnosis and preventive measures as per other conditions (e.g., strokes, see previous chapters).
- Physicians showing more trust in patients' assessment of their own health and working with patients to find solutions.
- Physicians' recognition of conditions as disabilities with appropriate responses (see above, previous and following chapters).
- Physicians supporting patients in their insurance claims in a responsive, comprehensive and timely manner.
- More local support groups; Community Health Centres suggested as venues.

In addition, participants repeatedly pointed to the need for case managers and system navigators to find responsive and appropriate providers, to link clients and providers, and to act as advocates and legitimizers for client needs.

13.11 APPROPRIATE INTEGRATED INTERPROFESSIONAL CARE PROVIDED BY THE HEALTH CARE SYSTEM NEEDED FOR CHRONIC, COMPLEX CONDITIONS

A holistic approach and training of professionals along the continuum of care as part of comprehensive and integrated care is needed, including for specific types of complementary care, is needed with *a publicly insured system*. The Nova Scotia Environmental Health Centre, a centre providing a significant number (though not all) of the services along that continuum was cited as one example to emulate.

HOLISTIC, APPROPRIATE, COMPREHENSIVE AND INTER-PROFESSIONAL CARE WITH ADEQUATE HEALTH AND SOCIAL SUPPORTS IS NEEDED AND ENVISIONED

There is not a holistic approach, a mind, body, soul and environmental – that is what is lacking in the medical field. It is too concentrated on fixing body parts, rather than looking at the whole person and their life and their world and treating the person like a human being in a world and not a body part to be dissected and analyzed and fixed. ... There needs to be more money put into this for increased coverage for alternative and complementary services – reflexology, chiropractors, naturopaths, what have you, because with this condition, you need a holistic approach. **Hope MCS**

This theme - as expressed in the words of informants early in this report - was a major preoccupation of participants. **Many had experienced improvements with modalities beyond the medical and pharmaceutical but found themselves unable to afford this care, and/or to access it geographically.** Several non-MD professions were specifically mentioned by participants as beneficial in the management of these illnesses (see previous chapter; recommendations).

CASE MANAGEMENT AND SYSTEM NAVIGATION NEEDS WERE IDENTIFIED AS URGENT (see previous chapter).

MULTI-SYSTEM CONDITION REQUIRES GOOD CASE MANAGEMENT AND SYSTEM NAVIGATION ACROSS SERVICES

Because it's a multi-system disease, you probably need to have some good coordination between various specialists – that doesn't always happen. The specialist doesn't always report back to the primary physician, the specialists tend to look at their own little piece of the puzzle in isolation – that doesn't work very well. There's not a whole lot of coordination on that end. Also, on the care-giving end, we could use a little more coordination. It's a little better. [But] it needs to be counselling and physiotherapy, and occupational therapy and whatever else – a bit at a time. **Thomas, caregiver for wife with ME**

13.12 ISSUES RELATED TO REMOTENESS OR SMALL SIZE OF COMMUNITY NEED ADDRESSING

PARTICIPANTS were clear on the **need for appropriate care - including of the comprehensive and integrated type - close enough to home to be able to access it**. Inability to travel far due to illness is a major problem for many. Accessible, high-expertise regional satellites to a central hub were recommended frequently to address lack of care beyond the Greater Toronto Area. Patients repeatedly referred to extremely long wait times; lack of knowledge resources and knowledge transfer, lack of patient information for education and self-help.

TREATMENT CENTRES NEEDED IN FOUR QUADRANTS OF PROVINCE

I've been thinking a lot since I've been sick that, you know, it's high time they should have three, four treatment centres in the east, west, north, and south where it is a holistic, integrated approach because there are some medicinal approaches like naturopathic, homeopathic, they do have treatment for fibromyalgia. They say that. But it's not covered, again. **Bina FM**

As far as my support group, I am in a small town outside the area of the support group, so in order for me to participate with the support group, I have to travel. The cost of gas and not having any money coming in that was a big barrier. It would have been better to have something closer. **Phylis FM ME**

Study participants called for home visits by physicians and other providers, and prescription renewal by nurses for people who are housebound. Severity of illness can prevent many from accessing in-office health care, either because the distance is prohibitive (more than twenty or thirty minutes away from home) or due to debilitation or reactions to chemicals (e.g., smog, car exhaust). Informants called for appropriate transportation services, travel subsidies and transportation vehicles that are MCS-safe, as well as home visits.

13.13 TRAINED MENTAL HEALTH PROFESSIONALS PROVIDING SERVICES IN SAFE SITES ARE MISSING, AND NEEDED

COUNSELING services developed specifically for patients with ME/CFS, ES/MCS and FM, similar to those assisting sufferers with other chronic illnesses, were identified as urgently needed. Given the extreme stress involved in living with these conditions, the lack of trained mental health professionals - often available through programs for other types of conditions that create great stress in people's lives - is considered a major gap and a barrier to accessing supports available to others.

APPROPRIATE AND COMPETENT MENTAL HEALTH SUPPORT IS NEEDED

I started abusing alcohol ... to help me cope with the pain. And of course that ran into more problems, so that was not a positive experience at all. That certainly isn't the way to go. But I ended up having a counselor through that, and that helped a lot. It at least gave me somebody to vent to. **Jane ME/CFS FM**

13.14 UNIQUE NEEDS OF ES/MCS

SAFE CARE

ES/MCSers have special needs in addition to the ones they share with people with ME/CFS and FM. Unaddressed, the lack of safety for these needs constitutes a fundamental barrier to accessing care and instituting self-management at every level of the system.

ES/MCS ACCOMMODATION CRITICAL AND IMPOSSIBLE TO GET FOR MOST

The main thing about unmet needs is not getting accommodation so that you can actually attend or be there at the health facility without getting exposure to chemicals. So I have to say generally it's not available. Just accessing medical hospitals for different things is very difficult. You have to make so many arrangements, and even then, it's very difficult. ... A big part of all of this is the fear and anxiety about doing anything. **Betty MCS**

For those with ES/MCS to have equity in accessing the health care system, a number of fundamental changes are needed.

- Destigmatization and receptivity is needed so that sufferers with ES/MCS are able to explain their needs to competent and responsive providers.
- Special types of detoxification treatments and safe exercise sites.
- Safe sites for self-management and peer support groups are needed, and those with ES/MCS need to be able to participate in the planning and governance of care and support services, as others do.
- Hospitals must be made safe for people with ES/MCS. A range of measures are required, detailed in chapter 19. Lack of policy in this regard constitutes a barrier, par excellence, to care.

- Health system personnel must stop wearing fragranced personal care products, both in facilities and while providing homecare.
- Emergency services with well-trained, fragrance-free paramedics and emergency shelters for people experiencing MCS ‘crashes’ or other emergency episodes are needed.

THE SPECIAL CASE OF HOUSING - See Chapter 17

As previously noted, for ES/MCS sufferers, chemically safe housing is a critical *medical* need, above and beyond its status as a basic social determinant of health. The vast majority of health care providers have no awareness of this fact. The lack of safe emergency shelters, affordable safe housing, assisted living and long term care facilities constitutes a massive barrier to the stabilization of health and self-management, and a major inequity in provision of, and access to health and social services available to others. This issue arose with respect to every question put to those with ES/MCS in the consultation process. It is taken up in detail in Chapter 17.

13.15 GOVERNMENT AND ACADEMIC RESPONSIBILITIES

THE need for funding for research was identified as urgent. The lack of such funding was seen as inexplicable given the widespread incidence of the conditions and their high costs.

RESEARCH PRIORITIES SHOULD BE LINKED TO PREVALENCE AND COST REDUCTION

[I]f you take various ailments and you measure the impact that they have economically, I think the research funds should be doled out on that basis - meaning the most prevalent and the most pressing problem should have some money thrown at it. The early diagnoses of such things would be helpful, rather than have people like myself run ragged and spend *five years* trying to rebuild something that resembles a life. So earlier diagnosis of such ailments would be helpful. When I was speaking with Dr. K. she mentioned something about the funding for the [EHC] and it was pathetic. ... [I]f you took cancer research it would be a fraction of a fraction of a fraction . And yet apparently so many Canadians suffer from FM and ME. More money put into research into what I am diagnosed with would be very nice. ...

John ME FM

MEDICAL RESEARCH NEEDS IDENTIFIED BY COMMUNITY PARTICIPANTS

- Finding bio-markers for these conditions
- Better understanding of causes
- Better understanding of treatments and cures
- New and better ways to assess and evaluate disability
- New ways to assist with pain

A number of participants pointed out the extremely high costs to society of deficits in care for the three conditions (cited previously). **With respect to research, the economic argument was made to apportion research funds relative to the prevalence of the conditions in society.**

EPIDEMIOLOGICAL RESEARCH NEEDS IDENTIFIED BY COMMUNITY PARTICIPANTS

Informants spoke to a massive need for governments, from provincial to local, to have knowledge of incidence, prevalence and needs of the conditions, including the creation of a registry.

GOVERNMENT STRATEGIES FOR RECOGNITION, AWARENESS AND VIGILANCE

Informants spoke to a massive need for governments to institute a broad range of measures and strategies to create awareness, vigilance and acceptance (see also Chapter 21.)

‘MINISTRY OF HEALTH GETTING MORE INFORMATION OUT THERE’

Having people believe what I am saying! Education. People coming out and talking, the Ministry of Health getting more information out there [by] printing up pamphlet[s] and having them in doctor’s offices [warning] about the toxics in your children life, [by] making people aware. More information coming out has made it easier for everyone in my world to understand my problems better. **Sandra MCS FM**

Several participants called for increased vigilance in ensuring that links to the pharmaceutical and chemical industries - commercial interests - do not affect health policy in the public sector. (See Chapter 16 for a fuller discussion of this issue.)

PUBLIC INTEREST IN ADDRESSING CONFLICTS OF INTEREST

It's a conflict of interest when the oil, gas and petrochemical industries are making toxic substances that are harming us, while simultaneously making pharmaceutical and medical supplies to supposedly treat people for the health problems their pollutants cause. **Linda MCS**

13.16 From *THE QUANTITATIVE DATA*

WE have already addressed the high to very high rates of physician utilization tracked for these groups. Our informant sample corroborates a high utilization-poor outcome scenario, and explains the reasons for it. Here are the relevant findings from ‘*The Quantitative Data*’ for unmet health needs, unmet home care needs, consultations with complementary practitioners and a brief discussion of these findings vis a vis those for our comparator groups.

FROM ‘THE QUANTITATIVE DATA’

PROFILE OF UNMET HEALTH AND HOME CARE NEEDS AND CONTRAST WITH COMPARATOR GROUPS

(According to the CCHS, 2010), there is a wide range in self-perceived unmet health care needs in the previous 12 months among those with chronic health conditions (Table 16). Unmet health care needs were clearly the highest among those with FM (30.7%), ME/CFS (29.4%) and ES/MCS (25.5%) followed by those living with the effects of a stroke (21.1%). Those with FM were more than two and a half times as likely as to report unmet

health care needs as the general population. Interestingly, those with diabetes had a similar level of unmet health care needs as those in the general population.⁵³

A recently published analysis of 2005 CCHS data by Williams et al. (2011) [7] examined consultations with alternative health care providers (including massage therapists, acupuncturists and homeopaths or naturopaths) among Ontario women aged 18 and older living with ES/MCS, FM and ME/CFS according to their self-perceived unmet health care needs (Table 17). For all three conditions, women who reported having unmet health care needs were significantly more likely to consult with an alternative care provider than women who did not report having unmet health care needs.⁵⁴

An examination of self-perceived unmet home care needs in the previous 12 months among Ontarians (in 2010 home care questions were only asked of Ontario residents) reveals a similar pattern as that for unmet health care needs (Table 18). Some of the 2010 numbers should be interpreted with caution, but those living with ME/CFS and the effects of a stroke in particular, reported the highest rates of unmet health care needs in both in 2005 and in 2010.⁵⁵

Those living with the effects of a stroke and with cancer had the greatest proportion of people receiving home care services in both 2005 and 2010 (Table 19). Although there is some overlap in the chronic condition groupings, those living with the effects of a stroke were more than twice as likely as those with ME/CFS to receive these services in 2005, and more than one and a half times as likely in 2010. A further examination of home care services funded in whole or in part by the government indicates that those living with the effects of a stroke or with cancer continued to receive the greatest proportion of home care services.⁵⁶

SUMMARY

The findings indicate that people with ES/MCS, FM and ME/CFS are most likely to report unmet health care needs. This is despite the high physician consultation rates described in the previous section, further contributing to the view that people with these conditions are receiving inappropriate care or are experiencing barriers to and deficits in care. The finding that Ontario women with unmet health care needs were more likely to consult with an alternative care provider supports the idea that patients are willing to look outside of conventional medicine when they are not satisfied with their care, where they are able to assume the costs themselves.

The disability measures in section 2.2 indicated that, in some ways, those with ME/CFS can be as disabled as those living with the effects of a stroke, and that those with FM or ES/MCS are at least as disabled as those with other chronic conditions including cancer. Nonetheless, the pattern indicates that people with cancer and living with the effects of a stroke are most likely to receive home care services and, furthermore, they are more likely to have the services paid for. One reason for this could be that the health delivery models for cancer and stroke include home-based care such as nursing, physiotherapy, occupational therapy, nutritional counseling and housekeeping, and that these models of care have been accepted for government funding. A

⁵³ See *The Quantitative Data*, Table 16: Canadians reporting Unmet Health Care Needs according to their Chronic Condition, 2010, pg. 34.

⁵⁴ See *The Quantitative Data*, Table 17: Proportion of Women with ES/MCS, FM and/or ME/CFS who consulted an Alternative Care Provider according to their Unmet Health Care Needs, Ontario 2005.

⁵⁵ See *The Quantitative Data*, Table 18: Ontarians reporting Unmet Home Care Needs according to their Chronic Condition, 2005 and 2010, pg. 35.

⁵⁶ See *The Quantitative Data*, Table 19: Ontarians Receiving Home Care in the Past 12 Months according to their Chronic Health Condition, 2005 and 2010, pg. 36.

model of care including a home-based component for people with ES/MCS, FM and/or ME/CFS has not been accepted at the governmental level, but could have many benefits. In addition, ES/MCS, FM and ME/CFS are poorly recognized and understood chronic conditions; their seriousness may be underestimated when home care services are allocated. Finally, since many people with ES/MCS, FM and/or ME/CFS needing these services may have to assume the costs of care privately, lower rates of home care overall could also be due to financial barriers. Various possible explanations combined with expressed unmet home care needs in Table 18 indicate that the findings around home care services require further investigation.

PART FOUR - SPECIAL ISSUES

CHILDREN AND YOUTH

WOMEN'S SPECIAL CHALLENGES

STIGMA AND DENIAL

SPECIAL NEEDS OF ES/MCS

14 CHILDREN AND YOUTH - MORE VULNERABLE YET STILL INVISIBLE

14.1 PREVALENCE AMONG CHILDREN

ONE of the most troubling findings of this project is that in Ontario we have no mechanisms for tracking or for treating children with these conditions. **It is imperative that we catch up on this score because we know that illness in childhood, especially when combined with all the associated problems discussed below, is traumatic, and an ‘adverse childhood experience’ or ACE. As such, it will have negative consequences on education, physical and emotional health, earning potential and overall wellbeing in later life.**⁵⁷ So in this chapter, we look briefly at issues of prevalence and vulnerability, and address policy issues that flow from these.

We begin with an assessment of children’s vulnerability to environmental factors - chemicals and electromagnetic frequencies - and there is **consensus across the board that children are much more vulnerable than adults to these insults.**⁵⁸ As John Molot writes,

Children, from embryo to the completion of adolescence, are often at a different and increased risk from environmental contaminants compared to adults because of differences in behavior and physiology. They have greater exposures relative to adults, immature detoxification systems, and still-maturing organ systems.⁵⁹

With respect to prevalence, let us utilize Dr. John Molot’s summaries on ME/CFS and FM.

PREVALENCE OF ME/CFS AND FM IN CHILDREN

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. ...

⁵⁷ See footnote 33, re Centers for Disease Control and Kaiser Permanente, *Adverse Childhood Experiences Study* (Atlanta, GA, and San Diego, CA: ongoing).’ <http://acestudy.org/>

⁵⁸ Philip J. Landrigan, *The unique vulnerability of children to toxic chemicals, Implications for science and policy, Presentation to Canadian Partnership for Children’s Health and the Environment’s 5th National Policy Consultation Workshop ‘Toxic Substances in Consumer Products’*, Montreal, P.Q., 25 September, 2007. See H. Hu, MD, MPH, ScD., ‘Human Health and Heavy Metals Exposure,’ Michael McCally (ed.) *Life Support: The Environment and Human Health* (Cambridge, MA: MIT Press, 2002) 65-82. See also Varda Burstyn and Gary Sampson, ‘Techno-Environmental Assaults on Childhood in America,’ *Childhood Lost: How American Culture is Failing our Kids*, ed. Sharna Olfman (Westport, Connecticut; London: Praeger, 2005) 155-184; Varda Burstyn and David Fenton ‘Toxic World, Troubled Minds,’ *No Child Left Behind*, ed. Sharna Olfman (Westport, Connecticut; London: Praeger, 2005) 49-72; Varda Burstyn, ‘A World Fit for Children,’ *Child Honoring*, ed. Raffi Cavoukian and Sharna Olfman, foreword by the Dalai Lama (Westport, Connecticut; London: Praeger, 2006) 211-222.

⁵⁹ Molot, 2013.

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.

Dr. 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 in several books,⁶⁰ give the impression that prevalence is as great with ES/MCS among children and youth as with the other two conditions.

The rise of the three CELCs is linked with a general increase in childhood illness of the chronic, complex type. John Molot:

INCREASE IN CHRONIC OMPLEX CONDITONS IN CHILDHOOD

There has been a significant rise in chronic complex conditions in childhood. The number of children with developmental disabilities has increased by 17% over the last decade so that now one child in six is being diagnosed with one of attention deficit hyperactivity disorder (ADHD), cerebral palsy, autistic spectrum disorder, seizures, stammering or stuttering, mental retardation, moderate to profound hearing loss, blindness or learning disorders.

The Environmental Working Group did two small studies of 10 American, Canadian and Dutch newborn babies in 2005 and 2009, in which they measured the chemicals found in cord blood. In both studies, they found well over 200 chemicals in the newborn babies' circulation.

More than 400 publications are available in the U.S. National Library of Medicine which confirms the presence of pollutants in newborn children. Sources of contaminants include outdoor and indoor air, food, water and consumer products.

In 2011, the Canadian Environmental Law Association, the Ontario College of Family Physicians and the Environmental Health Institute of Canada published an extensive scoping review of the literature.⁵³⁷ Their main findings were that there is increasing scientific confirmation for the role of early life (in utero and peri-natal) exposures to environmental contaminants and a lifelong vulnerability to chronic disease.

Children are particularly vulnerable to the effects of outdoor air pollution. Those living in urban areas exhibit higher rates of allergy and asthma compared with those from rural areas. There are several studies showing adverse effects of outdoor air pollutants on lung development in children of all ages. The more time kids spend outdoors and the closer they live to major roadways, the more likely they are to have reduced lung function growth by age 18 with a genetic predisposition to poor detoxification are more likely to have their pulmonary function growth affected by air pollution.

⁶⁰ Doris Rapp, MD, *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).

Several studies have also associated autism and prenatal and early life exposure to air pollution from traffic. Children with autism have shown a decreased ability to detoxify as well as an elevated body burden of xenobiotics.⁵⁵³ Furthermore, there may be an epigenetic predisposition inherited from the mother.⁶¹

14.2 CONSEQUENCES FOR CHILDREN AND FAMILY

The first set of consequences for children is, of course, **the experience of illness itself**: the debilitation, the pain, the fatigue and learning challenges, the multi-system symptoms - the actual chronic, recurring physical distress of the conditions. Such distress **greatly mars childhood and is difficult to bear in and of itself**.

The second set of consequences has to do with how these illnesses impact on normal developmental activities and stages, and here we have a **long list of serious psychosocial consequences**. John Molot:

In children and adolescents, ME/CFS occurs at a developmentally vulnerable time, which adds to the disability. It affects self-concept, autonomy, body image, socialization, sexuality and academic problems, which have a significant psychosocial impact. Those affected report difficulty explaining their illness to peers and being believed, and they experience bullying. ... 45% report more than 50% school absences with a mean time out of school estimated at more than one academic year.⁶²

Generally speaking, the other two conditions bring about the same type of consequences for young people.

The problems of bullying, disbelief, isolation and loneliness are not trivial. 'Adolescents seem particularly sensitive to rejection,' writes Lisa Raffensberger in *New Scientist*, reporting on a dozen neuroscience research initiatives in Canada, the United States and Europe now **explicating the physiological impact on the brain of hurtful words and behaviors** - which turns out to be as powerful as the impact of physical insult. This sheds light on the scarring experiences of bullying and other forms of rejection or derision.

The brain's pain network is still developing at their age and, compared to the adult brain, it tends to show a more exaggerated response to small slights and insults. On the positive side, social support during this period can carry lasting benefits. For instance, young adults who enjoyed tighter social networks in their late teens show more muted reactions to the sting of rejection than those who had felt lonelier in the past, perhaps because memories of past acceptance subconsciously sooth their feelings (*Social Cognitive Affective Neuroscience*, vol. 7, p 106).⁶³

As previously noted (see Chapter 7: Key lessons from the environmental scan)⁶⁴ MEAO reported failure in obtaining appropriate accommodation for children in Ontario schools. This experience is part of a larger problem of lack of care and support for children and parents.

⁶¹ Molot, 2013.

⁶² Molot, 2013.

⁶³ Lisa Raffensberger, 'Why words are as painful as sticks and stones', *New Scientist* 04 December 2012 36-39. Quote: 'Rejection and heartbreak can have effects every bit as physical as cuts and bruises.'

⁶⁴ Molot 2013; see also Chapter 7, section 7.2.

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.⁶⁵

Parents with children with all three conditions are familiar with the blaming by physicians of their parenting for their children's illnesses. Margaret Parlor, president of the ME FM National Action Network says, 'no-one with children with ME should be surprised to see Children's Aid at their door.'

From narratives conveyed to us by parents and advocates, it is clear that children with ES/MCS have great challenges in schools where toxic cleaning materials, pesticides, molds and, increasingly, very significant amounts of EMF (as schools bring in Wi-Fi) abound. Physicians who tend to frame the condition as psychogenic in adults do the same with ES/MCS children, commonly suggesting the problems originate with bad parenting and/or strains on the child due to strains in the parental relationship.

14.3 HOW A FULL-SERVICE ENVIRONMENTAL HEALTH CENTRE WORKS WITH CHILDREN AND FAMILIES

GROWING awareness of the effects of environmental insults on children has led to a body of research and, increasingly, clinical programs that provide assessment and advice to parents and physicians. As yet, however, there are very few full clinical programs that actually treat children - in this area, as with adults, the scope of clinical practice and understanding lags behind research.

HOW THE ENVIRONMENTAL HEALTH CENTRE- DALLAS APPROACHES CHILDREN'S AND FAMILY HEALTH

Since 1974, the Environmental Health Center – Dallas has invested in the future. We have seen and treated hundreds of children and their families, and we know that early intervention and a healthy lifestyle for a child can lead to a healthier and happier adult. Our expanded EHC-D services include children with:

- Autism – The center has worked with autistic children over the years. New innovations, including secretin therapy are being used.
- Allergies/Sensitivities
- Attention Deficit Hyperactivity Disorder
- Learning Disorders, Tourette Syndrome
- Chronic Ear Infections
- Asthma

⁶⁵ Molot, 2013.

- Behavior Problems
- Other Chronic Problems of Childhood including Arthritis, Cardiomyopathy, and Vascular Dysfunction
- Vasculitis, Cardiac Arrhythmia, Raynaud's phenomena

Our goal is to provide children with compassionate care and high quality treatment and services. Our competent team of health professionals offers a warm and thorough approach to treating children, while including the family in every aspect of the child's care. Ultimately, our objective is for each child to reach his or her optimal level of health.

Just as every child has his or her own fingerprint, so each has individualized medical needs. At the Environmental Health Center – Dallas, we work closely with parents to develop an effective treatment regimen for each child. Because we realize that many health traits are inherited, the Environmental Health Center – Dallas is also geared toward treating the entire family.

Often parents will identify with symptoms experienced by their child or may want other family members to utilize EHC-D services. The EHC-D is a full-service facility that can treat most of the entire family's medical needs.

Though a child may receive a specific diagnosis, there are usually compounding factors that must also be addressed in order for the child to obtain optimal health. We use advanced diagnostic techniques to determine the child's needs, then we coordinate a specially designed multi-faceted program for that child, often integrating some of the following services: Complete Medical Examinations and Evaluations

- Preventive Medicine
- Environmental Medicine
- Nutritional Counseling
- General Laboratory Blood Tests
- Sensitivity Skin Testing
- Immunotherapy
- Physical Therapy
- Psychological Testing and Counseling
- Toxic Chemical Detoxification/Sauna Program
- Eye-lens Manipulation
- Sealton Therapy

The family health program at the Environmental Health Centre - Dallas <http://www.ehcd.com/children-services/>, is an, if not, the outstanding exception. It provides an exemplary program that fully assesses and treats children, and supports their families.

Ontario is very far behind with its most precious resources - its children. Now is the time to bring our care and support for these young people fully into the 21st century, so that they can survive and thrive in this most environmentally challenged time of all.

14.4 MULTIPLE NEGATIVE CONSEQUENCES FOR CHILDREN OF SICK PARENTS

The lack of support for sick parents, and the great difficulties for their children stemming from their parent's illness, was frequently raised by consultation participants. Problems arise and persist at all

ages and stages of life and can become multi-generational in impact. For many families, the current situation results in real tragedy.

LACK OF SUPPORTS AND RECOGNITION MEANS HARDSHIP FOR CHILDREN AND PARENTS ALIKE

I wish there was a caregiver because 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 much money on disability. And I just felt so bad not making the meals and driving my kids the places that they wanted to be. I couldn't drive because I figured I'd kill me and them too, being so exhausted. And I felt like a bad mother. **Judy 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**

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, my oldest daughter had a baby in June of 2001, which was the year I was injured. I know that we had words and I left her a message or sent her an email that if they couldn't be supportive of me and what was going on in my life at that time, then I did want to have anything to do with them. ... I wasn't allowed to babysit this child which was extremely, incredibly hurtful at the time but I later came to understand that I was not capable of looking after this child. I could not have done it. **Sandra MCS FM**

[My wife] agonizes. We just had a grandson born in June and she finally saw the grandson for the first time in September, because she is at a stage where if she overdoes it, she's afraid of a serious relapse. She's had three serious relapses since 2002 and she's, at the moment, not recovered to the level she was in 2006, 2007. She's afraid of getting an even lower level of functioning, when at the moment she can hardly do anything. Which, as you can imagine, causes a grandmother a great deal of grief and distress? She feels horrible for not seeing her son and her grandson when they're in the house and at the same time she's afraid that if she does it'll have drastic consequences. She could certainly use some help, but I don't know who's available to provide that kind of help. **Thomas, caregiver for wife with ME**

14.5 RECOMMENDATIONS REGARDING CHILDREN

RECOMMENDATIONS REGARDING CHILDREN

1. Ontario's new should place a high priority on developing a full range of care and support policies and programs for sick children and their families; and for children with sick parents.
2. OCEEH staffing must include expertise in children - from services to policy.
3. Inter-ministerial mechanisms (e.g. 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.
4. 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 children with the CELCs are also worthy - indeed overdue - for inclusion in their initiative and programs.

15 WOMEN'S SPECIAL CHALLENGES

IN many places in this report we have noted the preponderance of women among those who have the three conditions, and in this chapter we will look a little more closely at why this might be the case. We have also mentioned that a great many of our women community informants perceived a pronounced sexist bias against them by physicians and health care providers, in their discounting and dismissal as credible individuals with real and serious health problems.

This particular and perverse coupling of issues - the preponderance of women with the CELCs plus a gender bias against them in belief and in treatment approaches - represents a sad and apparently very trenchant complex of problems to solve. Here we want to assist in the effort by surfacing these issues, analyzing them briefly and making some preliminary recommendations.

15.1 DISCOUNTING AND PSYCHOLOGIZATION OF WOMEN'S ILLNESS NOT UNIQUE TO CELCS

TO begin, it is important to note that **anti-woman gender bias is not unique to these conditions. It can be found in the most recognized and most 'heroic' areas of medicine.** In Canada, it has been documented in various fields, including with respect to coronary syndromes.

GENDER BIAS IN CANADIAN EMERGENCY DEPARTMENTS DEALING WITH CORONARY SYNDROMES

In 2007, Canadian researchers reported: "Among 50,000 patients presenting to an emergency department with a main ambulatory care diagnosis of acute myocardial infarction, unstable angina, stable angina or chest pain, we found that women were more likely than men to be discharged home and less likely than men to undergo cardiac catheterization or revascularization."⁶⁶ A recent study of emergency patients with similar presenting symptoms found paramedics gave morphine to men reporting pain, but did not provide morphine to treat pain in women.⁶⁷

From: *Chronic Pain in Women: Neglect, Dismissal and Discrimination*, 2010, Mary Lou Ballweg & Carol Drury, The Endometriosis Association. Terrie Cowley The TMJ Association. K. Kim McCleary CFIDS Association of America. Christin Veasley National Vulvodynia Association. www.endwomenspain.org

In a review of many different studies relating to a variety of medical fields, with a view to addressing matters of legal and ethical concern, Diane Hoffman and Anita Tarzian conclude their

⁶⁶ P. Kaul, W.C. Chang, C.M. Westerhout, et al, 'Differences in admission rates and outcomes between men and women presenting to emergency departments with coronary syndromes,' *Canadian Medical Association Journal* 2007: 177(10): 1193-9.

⁶⁷ B. Lord, J. Cui, A.M. Kelly, 'The impact of patient sex on paramedic pain management in the prehospital setting,' *American Journal of Emergency Medicine* 2009: 27(5): 525-529.

excellent paper in this way:

'THE GIRL WHO CRIED PAIN: A Bias Against Women in the Treatment of Pain,' *Journal of Law, Medicine and Ethics* 2001

Research Findings in Pain Response and Treatment of Women and Men⁶⁸

- While women have a higher prevalence of chronic pain syndromes and diseases associated with chronic pain than men, and women are biologically more sensitive to pain than men and respond differently to certain analgesics, women's pain reports are taken less seriously than men's, and women receive less aggressive treatment than men for their pain.
- Although women have more coping mechanisms to deal with pain, this may contribute to a general perception that they can put up with more pain and that their pain does not need to be taken as seriously.
- Although women more frequently report pain to a health-care provider, they are more likely to have their pain reports discounted as "emotional" or "psychogenic" and, therefore, "not real."
- Women, being socialized to attend more to their physical appearance, are more likely than men to have health-care providers assume they are not in pain if they look more physically attractive.
- Men with chronic pain are more likely to delay seeking treatment, but generally receive a more aggressive response by health-care providers once they enter the health-care system.
- Both men and women are more likely to have the emotional or psychological component of their pain experience suppressed due to Western medicine's tendency to separate mind and body and to view objective, biological "facts" as more credible than subjective feelings.

- Diane E. Hoffman and Anita J. Tarzian

It is clear from this 'check-list' of findings that women still face major challenges in achieving equal respect, concern and care throughout the healthcare system. In this regard, women with the CELCs are not alone. But there is a convergence of factors for such women that exacerbate these problems to extreme degrees.

⁶⁸ Diane E. Hoffman and Anita J. Tarzian, 'The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain,' *Journal of Law, Medicine and Ethics* (29) 2001: 13-27.

To understand better what is at stake, let us look at the hypotheses regarding the reasons for women's greater affliction with these conditions.

15.2 WOMEN AFFECTED BY THE THREE CONDITIONS MORE THAN MEN

While a significant number of men - adults and boys - do suffer greatly from these conditions (and from their discounting and neglect), and while there may be under-diagnosis of the conditions in males, still the prevalence of the CELCs among women is striking. **The 2010 CCHS data suggest a ratio of 4:1 women to men for FM, 3:1 for ES/MCS and 2:1 for ME/CFS. Other studies, cited by John Molot, for example, suggest even greater preponderance. Higher estimates for FM, for example, range from 6:1 to 9:1.**

In the United States, a coalition of women's patient organizations - the **Chronic Pain Research Alliance (CPRA)** - has come together to work in common on a set of conditions that include and overlap with ME/CFS and FM, though not, unfortunately, ES/MCS. These conditions are: chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular (TMJ) disorders and vulvodynia (persistent pelvic and vulvovaginal pain).

In their policy document, *Chronic Pain in Women: Neglect, Dismissal and Discrimination* (2011), they state:

Chronic pain – defined as pain persisting more than six months – is all too common. It is estimated to affect 25 percent of Americans and account for more than 20 percent of all physician office visits. Unfortunately, women bear the brunt of inadequate care and suffering experienced by chronic pain sufferers. **As many as 50 million American women live with one or more neglected chronic pain disorders. For the majority, our health care system offers frustratingly little help. In fact, most face neglect, dismissal and discrimination.** [Our emphasis.]

Borrowing from the same document, with thanks, we present a chart of all of the conditions involved. Each has its distinct symptoms, but as a group they also share a common factor - some form of neurological disorder - and are very often co-morbid ('overlapping') with one another.

□ SUMMARY OF COMMON PAIN CONDITIONS DISPROPORTIONATELY AFFECTING WOMEN

Disorder	Description / Symptoms	Prevalence (US Pop)	Prevalence in Women	Symptom Onset	Misdiagnosed-Undiagnosed	Economic Cost (US, Annual)
Chronic Fatigue Syndrome	Chronic, debilitating fatigue and other characteristic symptoms. Symptoms: Chronic fatigue. Sleep difficulties. Problems with concentration and short-term memory. Flu-like symptoms. Pain in joints and muscles. Tender lymph nodes. Sore throat. Headache. Postexertional relapse.	Up to 4 million ¹⁶	Four times more common in women ¹⁷	Highest between 40-59 ¹⁸	More than 80% have not been diagnosed ¹⁹	\$17-24 billion (direct & indirect) ²⁰
Endometriosis	Chronic pelvic pain due to growth of endometrial tissue outside of the uterus. Symptoms: Pelvic pain before and/or during menstruation. Pain during/after sexual activity. Fatigue. Infertility. Heavy bleeding. Intestinal upset, painful bowel movements and/or low back pain with periods.	6.3 million ²¹	Affects women (extremely rare in men)	66% before the age 20 ²²	50% of women with endometriosis see at least five providers before receiving a diagnosis and/or referral ^{23, 24}	\$22 billion (direct & indirect) ²⁵
Fibromyalgia	Fibromyalgia is a chronic condition characterized by widespread soft tissue pain, as well as accompanying comorbidities such as disturbed sleep, fatigue and cognitive difficulties.	6 million ²⁶	Nine times more common in women ²⁷	Between 20-50 ²⁸	Has not been studied	\$20 billion (direct & indirect) ²⁹

Interstitial Cystitis	Pelvic pain, pressure, or discomfort related to the bladder typically associated with urinary frequency and urgency, in the absence of infection or other pathology. Symptoms: Pressure, pain or tenderness in the bladder and/or pelvis. Chronic pelvic pain. Urinary frequency and urgency. Pain during/after sex. Increased pain as bladder fills.	8 million ^{30, 31, 32}	70% women ^{33, 34, 35}	Between 28-67 ³⁶	38% misdiagnoses rate ³⁷	\$66 million (direct & indirect) ³⁸
TMJ & Muscle Disorders	Group of conditions that cause chronic pain and dysfunction in the jaw joint and muscles that control jaw movement. Symptoms: Dull aching pain in the face, jaw, neck, or shoulders. Jaw muscle stiffness. Limited movement or jaw "locking." Painful clicking, popping or grating in the jaw joint when opening or closing the mouth. A change in the way the upper and lower teeth fit together or bite that feels "off."	35 million ³⁹	90% of the most severe cases are women in childbearing years ⁴⁰	Between teens and 50 ⁴¹	4 years from symptom onset to diagnosis ⁴²	\$32 billion (direct & indirect for orofacial pain) ⁴³
Vulvodynia	Chronic vulvar pain without an identifiable cause. Symptoms: Pain or discomfort with sexual intercourse, tampon insertion or sitting. Burning or other painful sensations in the vulva (area surrounding the vaginal opening). Redness/swelling of the vulvar tissue.	6 million ⁴⁴	Only affects women	Highest between 18-25/teens ^{45, 46}	40% remain undiagnosed after 3 medical consults ⁴⁷	Is currently being studied.

While so much research on the higher rate of prevalence among women remains to be done - in fact the underfunding of research is a direct consequence of the gender bias - still, a number of factors have been hypothesized, in relation to the prevalence of our CELCs, overlapping (co-morbid) conditions with each other as well as with the other conditions named above.⁶⁹

SOME REASONS FOR PREVALENCE OF CONDITIONS AMONG WOMEN

JOHN MOLOT, MD FCFP

One common denominator of these three conditions is limbic system sensitization. **There are sex differences in how the limbic system responds.** Functional brain scans reveal that, when challenged, men and women activate different limbic structures following the same provocative stimuli. There are sensory differences which are related to limbic system function. **Women have a higher prevalence of several pain-related conditions,** including migraine headaches, temporomandibular joint disorders, carpal tunnel syndrome, Raynaud's disease, chronic widespread pain, osteoarthritis (OA), irritable bowel syndrome and pain related to autoimmune disorders (rheumatoid arthritis and other collagen vascular diseases). **On**

⁶⁹ Chronic Pain Research Alliance, *Chronic Pain in Women: Neglect, Dismissal and Discrimination* (May, 2010); PDF available from <http://www.overlappingconditions.org/>

average, women are more responsive to painful stimuli, and women also tend to have a heightened inflammatory response compared to men.

Statistics gleaned from the National Health and Nutrition Environmental Survey (NHANES) in the US suggests that **environmental pollution exposures affect women more than men**. Women biologically handle chemicals differently compared to men. The enzyme systems for detoxification are more active than men. Normal kidney clearance of chemicals is lower in females compared to males. Also, women retain more inhaled volatile organic compounds than men. This is likely because women have a higher percentage of body fat which affects the distribution of chemicals that are not easily eradicated.

Given the higher domestic responsibilities relative to men, **women also have greater exposure to chemical cleaners, detergents and fabric softeners. Women also use more cosmetics, skin care and scented products.**

In summary, the prevalence of environmentally linked illnesses, as seen particularly well in ES/MCS, are more common in women because they are more responsive to their environment via both the limbic and immune systems have a greater body burden of chemical exposures and less efficient detoxification systems compared to men. [Our emphasis]⁷⁰

These factors are critically important in setting up women's susceptibility to the CELCs. Yet the vast majority of physicians and other health care providers still have no awareness of them. **Once again, we see the consequences of the gap between research results and clinical practice.**

15.3 FINANCIAL AND SOCIETAL COSTS

The costs of this level of illness among women should be considered unacceptable to society. We are not aware of corresponding Canadian figures, but these US figures are worth showing for what they suggest:

While chronic pain exacts a heavy personal toll on millions of women, it imposes a staggering financial burden as well. Our **country's failure to support an adequate research effort and train medical professionals in the appropriate diagnosis and treatment of just six of these conditions – chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular (TMJ) disorders and vulvodynia - adds as much as \$80 billion a year in direct and indirect costs to American taxpayer's health care bill.**⁷¹

Given this preponderance of women with these conditions, given the burden of suffering involved, and given the financial burden to society, **one fundamental question begs an answer: Why are so many women getting so sick?** And if, as we who support the OCEEEH initiative believe, the reasons have to do with women's even greater susceptibility to chemical exposures, and if we now know that women's bio-accumulated body burden of toxins is passed on to babies during gestation and nursing, then the question that must follow is this: **what are we doing to the very viability of our society by permitting so many harmful chemicals to continue in circulation?**

⁷⁰ Molot, 2013.

⁷¹ Chronic Pain Research Alliance, 2010.

15.4 GENDER BIAS AGAINST WOMEN PLAYS A SIGNIFICANT PART IN MEDICAL DISMISSAL AND LACK OF RESEARCH OF THE CELCs

In the reportage of our informants, as in the literature, this negative bias against women expresses itself in the discounting and psychologization of their ailments and in the dismissing, in many cases reported in our study, of their suggestions of diagnosis or offerings of expert materials to assist unaware physicians. The figure below, again borrowed with thanks, was developed for the CPRA, but is very useful for our conditions, two out of three of which are included in that coalition. The factors illustrated here are even more striking with respect to ES/MCS, which properly belongs with these other conditions.

The Perfect Storm of Women's Pain Policy: How discrimination impacts women with chronic pain



The women members of our community expressed great frustration and dismay at explicit or strongly implicit messages that what they were reporting was not real and/or not important because of their sex (physiology - 'hormones') and gender (cultural norms - 'women complain a lot').

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. I don't know, but that was my feeling. **Elizabeth ME**

There is a definite perception that's sexist. I think if it was men primarily who were in this much pain; we'd see more funding, more positive reinforcement. ... But it's just women in pain. **Sheila FM**

As women with any illnesses that have come up over time, we're always treated as if it's all in our heads... 'You're just being a hypochondriac,' and all these things ... This whole area is probably not recognized as much because it's mainly women getting it. I think it's about how women are treated in society... So when anything's wrong with you, if you're depressed or whatever, it's your own fault as opposed to society, the way the world is set up. ... And, 'you're too sensitive,' and all of that stuff, especially being an older woman too. Also women have less money, and a lot of women go into poverty with this. ... **Betty MCS**

Some of our participants observed that these conditions were not adequately researched and funded because they are primarily women's diseases.

LACK OF FUNDING FOR RESEARCH SEEN AS TIED TO PREPONDERANCE OF WOMEN AFFECTED

Well, the way I interpret some of the behaviour of care providers by immediately going to, 'well, it must be depression'- when you share that information, it's mostly women that get that comment. And the mere fact that there is so little awareness and practically zero funding for research and awareness, to me speaks volumes about the fact that a large percentage of the people that have ME/FM are female. In my opinion. **Sophie FM ME MCS**

This concern about research echoes a strong conviction of the CPRA, backed up with evidence:

Despite their enormous personal and financial burden, the National Institute of Health's (NIH) research investment in the six conditions has been glaringly shortchanged. **In 2010, the NIH's research investment in these six disorders totaled only \$64 million – about two-tenths of one percent of its total budget. This is an average of just \$1.36 for every affected woman and represents less than one-tenth of one percent of the annual estimated cost of these conditions.** Also, what little research that has been conducted to date has lacked sufficient coordination, interdisciplinary collaboration and direction. As a result, the disorders' underlying causes are unknown, diagnostic protocols are lacking and there are very few, if any, scientifically proven treatments. Health care professionals are therefore left without adequate knowledge to appropriately diagnose and treat chronic pain sufferers. [Emphasis in original.]

Finally, literature on the discounting of women's experiences of illness and pain consistently reports that where conditions are perceived by physicians to be 'unreal' due to women's 'hormonal status'

and their ‘tendency to complain,’ (hypochondria) the conditions become more broadly stigmatized in the medical profession. This is an important factor in the overall stigmatization of the conditions, the larger phenomenon and mechanisms of which, are the topics for the next chapter.

15.5 CONCLUSION AND RECOMMENDATIONS

Many issues are posed by women’s special challenges, many beyond the scope of this report to address. What can be said, however, is this:

RECOMMENDATIONS FOR THE OCEEH RE WOMEN’S CHALLENGES

A key mission of the OCEEH, both in its direct services, and in its research, policy and education priorities, must be to integrate the issues involved and to take up the various ‘gendered’ pieces of this field *as priorities*.

With respect to direct services, it is important to recruit physicians and other health professionals who are experts in women’s health and psychosocial issues to services staff.

On a broad scale, the extent of women’s chronic, environmentally related illness is truly staggering, yet it seems as if **there is no locus in our guardian systems where the toll is being measured, the implications taken on board and relevant policy generated**. Successive governments have defunded women’s bureaus, and no centralizing agencies have replaced them. Yet, **the extent of women’s illness should be ringing loud and repeated alarms with respect to the health and viability of our society in the immediate future**.

Therefore we make the following recommendations

RECOMMENDATIONS FOR SYSTEM WIDE ACTION RE WOMEN’S CHALLENGES

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; to local and regional offices, through the spokes, to devise initiatives addressing indicated issues.

RELEVANT MULTIPLES MOHLTC BRANCHES AND PROGRAMS whose policies and services bear on or can help to change the systemic features of bias against women in the CELCs.

THE MINISTRY OF THE ENVIRONMENT - particularly those offices and individuals who are familiar with the types of chemicals implicated in women’s conditions - to prompt timely policy change, including regulation of women’s work sites and chemicals at use in the domestic environment.

ENVIRONMENTAL ORGANIZATIONS IN THE NON-PROFIT SECTOR - which have, in fact, led in

raising issues of pollution and regulation of chemicals in women's lives, 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.

These recommendations are as important for children as they are for women, since women and children are unified biologically through gestation and lactation, as well as inter-dependent during growth and development.

16 INSTITUTIONAL DENIAL, STIGMATIZATION AND DISCRIMINATION

PROFESSIONAL IGNORANCE LEADS TO DISBELIEF, DENIAL AND STIGMATIZATION

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**

I find that in the medical system there is a de-legitimization of this condition ES/MCS and there is a dismissal, and you are pathologized in a negative sense and psychologized. And that is what the medical system needs to work on. They need to understand that this is a legitimate condition, and a disability, because that was one of the most disparaging experiences for me when I reached out for help. **Hope MCS**

NEW understandings of the CELCs have arrived among those on the forefront, but institutional culture changes more slowly. The community consultation showed that prejudice leading to denial and stemming from obsolete views continues to strongly degrade the experience of people with the CELCs as they encounter health and social services. Given the centrality of this to our communities' negative experiences - and given that we know from many other historical experiences vis a vis other marginalized groups how important it is to purposefully and constructively find ways to dissolve prejudice in effecting system change - we provide here a better understanding of the mechanisms of this stigmatization. Once these are understood, constructive means to dissipate them and their consequences can be undertaken.

The need for systemic dissipation of stigmatization and for recognition of the conditions is a key driver behind the set of system- and government-wide policy shifts we are recommending as 'Strategic Enablers,' (Chapters 19, 23, 24 and 25) and which the OCEEH business case has cast as the second of its two 'pillars'. This need is also a driver behind recommendations for a patients' organization to be co-located with services, and to be funded to develop peer support programs in conjunction with trained experts, delivered in safe sites (Chapter 27).

16.1 HOW INVISIBILITY WORKS

THREE framing themes emerged from the community consultation: 'invisibility' 'exclusion' and 'stigmatization.' Taken together, and in the framework of public rights, benefits, programs, policies and services for comparator groups, these are attitudes embodied in views held by professional personnel, but also in a set of norms and rules that stand on their own. **These realities constitute institutional denial, which in turn results in discrimination. And, as we have repeatedly noted, professional norms set institutional norms, and both set the prevailing views in society.**

PEOPLE WITH CELCs EXCLUDED FROM INFORMAL AND FORMAL SUPPORT SYSTEMS

I just wanted to comment on the fact that there is no social convention to bring casseroles to people with Fibromyalgia, chronic fatigue and multiple chemical sensitivities. ... A close friend of mine got sick shortly before I did. She was diagnosed with breast cancer and was unable to work because she had to go through chemotherapy, fairly bad chemotherapy. She had the community just draw close around her. It was unbelievable the support that her diagnosis mobilized. I got sick months later and who came to take me out for coffee? The cancer patient. And in her words, 'you know you're screwed when a cancer patient undergoing chemotherapy, has to take you out for coffee.' So, I thought, yeah, I am pretty screwed. **Amy FM**

The exclusion experience seems to be grounded in invisibility and denial, in turn informed and exacerbated by stigmatization. So let us **begin the deconstruction of the ultimate problem - discriminatory exclusion - by identifying the characteristics of this 'invisibility.'**

The people who live with these conditions are virtually 'invisible,' in three important senses:

- **Those who are most sick are literally invisible to others because they are profoundly isolated in their own dwellings and therefore out of the public sphere and out of the public eye.** This isolation is the result of physical debilitation or mobility-restricting pain or extreme sensitivity to ubiquitous everyday chemicals, or two or three at once. Sufferers are often simply missing from social, family and community events, from educational institutions and workplaces, and even from health facilities. So literally: *out of sight, out of mind* is the adage that rings true. This leads to lack of awareness of the conditions and the numbers of people afflicted.
- **People with the CELCs do not bear any visually recognizable markers, unlike people who are wheelchair-bound or face other mobility or sensory limitations that are visually evident because of the presence of assistive devices or physical signs.** This means that sufferers are generally not visibly sick or disabled 'on the outside' even when they are extremely unwell 'on the inside'. Absent public awareness and understanding, this form of 'invisibility' often translates into disbelief - and the many consequences that flow from such an attitude. However, people with other disabling conditions that are not visually evident still do not encounter the negation of their experience that is universal to those with ES/MCS, ME/CFS and FM.
- **The predominating notion of 'unreality' among physicians feeds into invisibility and denial in public consciousness.** Even though most people know of someone who lives with one or more of the CELCs, there is a way in which such knowledge does not register as important with respect to community and societal health or social responsibility - hence sufferers and their maladies become 'invisible'.

16.2 STIGMATIZATION IS UBIQUITOUS AND AN OVERARCHING BARRIER TO ACHIEVING INCLUSION AND EQUITY

In the collective wisdom of patient's organizations, support-groups and on-line support communities it is a truism that those with the CELCs will encounter a combination of ignorance and what are euphemistically described as 'negative attitudes' among health and social support providers. **The community consultation found that, in effect and despite all the new knowledge available, stigmatization of, and discrimination against patients with the CELCs remains both broad and deep.**⁷²

In physician's culture, for decades physicians who treated patients with CELCs were considered professionally irresponsible ('quacks' 'doing harm') by some influential peers, and suffered significant penalties, ranging from shunning to prosecution by various colleges to loss of license. In medical anthropologist Tarryn Phillips's 2010 publication, *'I didn't want to grow up to be a quack'*, these realities are presented within the Australian context.⁷³ Her article is a chilling explication of the severity of penalties for professionals who have swum against the current with respect to ES/MCS.

PHYSICIANS WHO WORK WITH THE CELCs ALSO STIGMATIZED BY SOME PEERS

I have an online friend now with two young children. She has to move. ... She's on Ontario Works because she can't work. She's trying to get the official diagnosis so she can get ODSP papers. She's in a small town in Ontario and the doctors at the local clinics don't believe in MCS. They say ... that the Environmental Health clinic is encouraging mass hysteria with people, that she just needs to expose herself more and develop a tolerance for these chemicals again. This is what she's being told now. I think doctors like that should be charged for causing harm. Didn't they take a vow to cause no harm? **LMS MCS**

When stigma extends from the perception of patients to their doctors, many harmful outcomes result. Most important is that **the stigma becomes a powerful counter-incentive that has discouraged all but a handful of brave souls from taking on these conditions.** That number has been shrinking in Ontario, even where it has grown in less restrictive jurisdictions - the United States for example, where need and a market system have combined. Neighbouring Michigan has more than 20 physicians who list care of these diseases in the services they provide. **Hence our current state of 'void of services with a few tiny islands of support.'**

In short, **stigmatization is a form of stereotype that embodies a damaging type of prejudice.** When institutionalized, it underlies neglect or even shunning of patients, inappropriate treatment and iatrogenesis and professional disrespect to physicians. **It is the factor that most accounts for the status of the conditions as 'unwanted orphans'.**

⁷² This stigmatization phenomenon has been reported elsewhere. See Juliene G. Lipson, 'Multiple Chemical Sensitivities: Stigma and Social Experiences', *Medical Anthropology Quarterly*, Vol. 18, Issue 2 (2008), pp. 200–213, ISSN 0745-5194, online ISSN 15481387.

⁷³ Tarryn Phillips, 'I Never Wanted to Be a Quack! The Professional Deviance of Plaintiff Experts in Contested Illness Lawsuits: The Case of Multiple Chemical Sensitivities,' *Medical Anthropology Quarterly*, Vol. 24, Issue 2 (2010), pp. 182–198.

PATIENTS DISBELIEVED AND SHUNNED IN MEDICAL SETTINGS

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**

This in turn explains why norms to accommodate people with these conditions in workplaces, in educational and in other institutional site, have not yet been established *and* why those who attempt to seek such provisions on their own are often met with refusal. The Canadian Human Rights Tribunal and the Ontario Human Rights Tribunal are both sites where struggles for accommodation unfold, not always to good effect. One study that would be useful in the very near future, outside the scope of this project, is to survey the number of such cases in the OHRC in the last decades, and estimate the cost of these both for the public purse and for the sick individuals who have bravely persisted with them.

Let us move on now to understand the fundamental core belief that leads to stigmatization.

16.3 ERRONEOUS 'PSYCHOLOGIZATION' AND ITS CONSEQUENCES

'... If it is in my head, is there any way to get it out of my head?'

OXFORD ENGLISH DICTIONARY DEFINITION OF 'STIGMA' AND 'STIGMATIZE'

- Stigma: A mark of *disgrace* associated with a particular circumstance, quality, or person
- Stigmatize: verb [*with object*]: describe or regard as worthy of *disgrace* or *great disapproval*

Helping professions, health and social support agencies and philanthropic organizations exist to assist people in need, not people who are 'disgraceful' and 'worthy of great disapproval'. **In the case of the CELCs, the disgraceful and unworthy behavior is to be found in what many physicians, hence others, still believe is a false claim of illness, and hence a disgraceful and unworthy call for support. '**

In the community consultation, participants noted that some physicians (primary and specialist) explained to them that they (the doctors) simply did not understand the origin and nature of the ailments - that from this place of neutral lack of awareness, they could offer no assistance. Such attitudes were not helpful, but they were also not destructive.

However, **far too frequently, family and specialist physicians took a different approach. Commonly they framed the symptoms of the conditions incorrectly and approached them as the result of some form of emotional disturbance, which marked the patient as problematic and unworthy.**

FILL IN 'KOOKY UNIMPORTANT ILLNESS' THERE. THAT HAS BEEN BEYOND DISCOURAGING

I have lupus as well, and when my lupus is active, doctors take me a whole heck of a lot more seriously

than when it's the other... when it's FM, CFS or whatever. And I mean, you can almost see the change on their faces as they open the lab results and go, 'Hmm, hmm, oh, you must be depressed. You must be - fill in 'kooky unimportant illness there.' And that has been beyond discouraging. **Annabella FM ME MCS**

'Annabella' was articulating an experience that most people encountered: to a lesser or greater extent many of their physicians saw them as kooky or 'crazy' - though this is not a term that was precise or helpful in their contexts. The technical way to express this would be to say that **physicians perceived the conditions to be 'psychogenic' - originating in unowned emotional disturbances rather than bio-physical causes.**

For physicians who do not 'believe in' the existence of some or all these conditions, **three types of psychogenic explanations are generally implied or expressed.** In patients' experience, physicians were confused and uncaring about precision in this respect, so that often they attributed one, two or all three of these possible explanations to the patient's symptoms.

1. The patient is depressed or anxious or even psychotic, and physical symptoms are being directly produced by the depression or anxiety or psychosis: Therefore, the patient is refusing to recognize the real problem, refusing to deal appropriately with that problem by refusing appropriate medical attention (anti-depressants and other psychotropic drugs, usually) and causing distress to others - hence a 'non-compliant' and 'irresponsible' patient. Doctors don't like such patients for understandable reasons. Alas, in addition to countless inappropriate and even harmful prescriptions, this attitude has led to far too many forced committals of patients to psychiatric wards, with catastrophic consequences, including suicide.

PATIENTS REPEATEDLY SENT TO PSYCHIATRISTS BY MISINFORMED SPECIALISTS

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**

2. The patient is somatizing or has a conversion disorder: An unconscious emotional problem has actually created a physical symptom that will disappear when the unconscious problem disappears. Psychotherapy (talk therapy) is usually indicated for this type of problem. However, the patient is caught in a bind. By insisting on the physical etiology of the condition (e.g. toxic exposure, infection, physical injury), the patient 'proves' to the physician that s/he is evading or denying the underlying neurosis/psychosis. Again, by refusing to accept mental illness as the cause of the condition the patient is seen to be refusing help, being non-compliant with appropriate treatment and, again, is choosing to prolong the disorder at the cost of others (children, parents, health care providers). The 'denial' itself is both proof of mental illness and a form of non-compliance. This is a no-win situation for the patient.

'There ain't no distress here to somatize.'

I think the worst thing about it was that I even could think it through afterwards and I knew what I wanted to say to him, which is: I am familiar with the somatization of distress because I took some medical anthropology courses. I know what you're talking about. There ain't no distress here to somatize. It's not that I have a problem that's being worked out physically here. I was really healthy and now I'm sick and I'm having a bit of an issue adjusting, to going from having, what I would consider to be a fairly acute legal reasoning mind to pudding that has to have my husband advocating for me. It was horrible. **Amy FM**

3. The patient is actually a hypochondriac and/or a malingerer, and essentially there is nothing wrong: The disorder(s) as reported by the patients are basically fictitious - hence the patient is basically lying ('exaggerating'), has high and misplaced needs for attention, is a parasite on the system and a burden to her/his family. In the case of ME/CFS and FM, such patients are constructed as 'lazy crazy' ('too tired' or 'too much pain' is construed as 'doesn't want to work or carry their responsibilities'); in the case of ES/MCS, they are construed as 'crazy crazy' (hallucinating non-existent harm in small doses of chemicals in order to sever normal human relationships and avoid dealing with emotional problems). **This view is very prevalent and exceptionally harmful to sufferers.** Almost all participants in the study encountered it repeatedly.

'There's nothing wrong with you.'

CONTEMPT AND DERISION FROM MISINFORMED DOCTORS

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**

It is these attitudes that caused one informant to say to her doctor: 'If it is in my head, is there any way to get it out of my head?' People do not want to have these conditions. They do want effective treatment, and they would be more than willing to take medications and undertake psychotherapy if these modalities were effective. **Alas, to date, psychopharmacology and talk therapy have not been effective in eradicating symptoms. So patients experience many negative consequences - including depression and anxiety - when confronted with such attitudes by physicians.**⁷⁴

These provider attitudes are personal beliefs, not scientifically valid positions. They are a product of previous hypotheses prior to current knowledge. They underlie almost all negative experiences in health

⁷⁴ See discussion in Molot, 2013.

and social service systems and they function as fundamental disincentives for physicians to assist patients, even more powerful than lack of billing codes.

The extent of the tragedy of these views persisting is that, as neuroscience is dramatically showing, **denial and derision by physicians actually increases the bio-physical load of pain and suffering.** This has to do with the fact that, as discussed in Chapter 14, there turns out to be no wall at all between the physiological impacts of ‘emotional’ and ‘physical’ insults in the brain. **In fact, the same regions of the brain experience hurtful words and gestures in the same physiological ways that they experience physical pain.**⁷⁵ We pick up this issue below.

Again, however, here **we see the urgent need to close the gap between relevant research and clinical practice, so that physicians stop harming patients through behaviours grounded in erroneous views and attitudes. And again, we must stress how powerfully these views within the medical profession shape views outside it, including among employers, friends and family.**

THERE'S NO SUCH THING, YOU JUST HAD A LITTLE BIT OF BURNOUT'

I had an executive director that looked me right in the face and said, ‘there's no such thing. Dr. So-and-so, he wants to tell you, you've had a nervous breakdown. There's no such thing. And the only way you're going to get better is come back to work tomorrow.’ And I mean, you know, ‘til the day he left Peterborough, he did not believe. ... He said, ‘you look great. You just got to get in here and get going.’ ... Even when the board said they'd hold my position for three years, he still kept bugging me every day to come back and telling me, ‘there's no such thing, you just had a little bit of burnout.’ **Joan ME FM MCS**

Such obsolete medical myths create a context in which many families reject sick members, change is very difficult to achieve and - another destructive outcome- patient's organizations have an impossible time raising significant funds or support.

16.4 GENDER BIAS DISCOUNTS REALITY AND SERIOUSNESS OF CONDITIONS

As previously noted, **women who have the three conditions outnumber men by wide margins. Estimates vary; the CCHS data show a 4:10 ratio for FM, and a 3:10 ratio for the other two conditions. Among the most troubling findings in the community consultation was the extent to which informants experienced the discounting of the reality and severity of conditions as a gendered, sexist phenomenon.** As detailed in the previous chapter, a great many women spoke to negative and diminishing attitudes linked to spoken or strongly implicit assumptions that women complain a lot and/or that they are ‘hormonal’. Similar gender bias has been documented with respect to women's

⁷⁵ Raffensperger, *New Scientist*, 04 December 2012, 36-39. Quote: ‘Extroverts have been shown to have a higher pain tolerance than introverts, and this is mirrored by their [greater tolerance for social rejection](#). Eisenberger, meanwhile, has found that people who feel more pain when a hot electrode touches their arm are also more sensitive to hurt feelings ... These diverse reactions may be partly genetic. Eisenberger's team has shown that people with a small mutation to the gene OPRM1, which codes for one of the body's opioid receptors, are more likely to slip into depressed feelings after rejection than are those without the mutation. This same mutation also makes people more sensitive to physical pain, and they typically need more morphine following surgery.’

reporting of other types of symptoms as well. Readers are referred to the previous chapter for an analysis of this issue.

16.5 CO-MORBIDITY OF DEPRESSION AND ANXIETY DO NOT EQUAL PSYCHOGENESIS OF CONDITIONS

THE quantitative data from the 2010 CCHS report that Canadians with ME/CFS and with FM were most likely of the groups surveyed to experience depression for two or more weeks in a row in the previous 12 months.⁷⁶ Those with ES/MCS and living with the effects of a stroke followed behind. People living with cancer and diabetes were least likely to experience depression for two weeks in a row in the previous 12 months.

We draw attention to these data because we do not wish them to be misinterpreted or mobilized for misguided purposes. Since the stigmatization of patients seems to rest on the ascription by physicians of these conditions to psychological causes, it is important to address this finding.

In John Molot's paper, accompanying this report as supporting documentation for the OCEEH business case, readers can find a clinical critique of the theory and literature that advances a psychogenic causation for the conditions. Readers who wish to learn more about this issue in the medical literature are referred to that report and its bibliography.⁷⁷ For ease of reference, the pages in which Dr. Molot addresses this issue are provided as Appendix 4, below.

Here we are concerned to present the perceptions of people living with the conditions, who know their own bodies and their own emotions and can feel the consequences of these conditions and perceive the relationship between their condition and their emotions; and to offer new research in support of what sufferers claim and explain.

Our community participants were very clear that even when affective symptoms - depression, anxiety, despair, panic - accompany the conditions *these symptoms do not cause the conditions*. Several reasons explain why these symptoms accompany the conditions.

a) LIFE IS OVERWHELMINGLY DIFFICULT AND DEMORALIZING: Depression and related feelings are natural feelings to have about the impacts on people of what has happened in their lives - the loss of jobs, of loved ones including family, friends and community, loss of ability to pursue interests and exercise, often great isolation, rejection and worse from health providers, repeatedly and on an ongoing basis, and, very often, gnawing and ceaseless anxiety about economic survival. These concerns, expressed by the majority of our informants, were **also recently expressed by participants in a spring, 2013 forum sponsored by the Center for Drug Evaluation and Research (U.S. Food and**

⁷⁶ Statistics Canada, *Canadian Community Health Survey*, Public Use Microdata File, (2009/2010, Released November 7, 2011). <http://www5.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=82M0013X&chropt=1&lang=eng> (accessed July 26, 2013). All computations, use and interpretation of these data are entirely those of the author.

⁷⁷ Molot, 2013, pp. 44-47.

Drug Administration), on the impacts of ME/CFS. Here are some quotes from the report on that event, just released in September 2013.⁷⁸

THE VOICE OF THE PATIENT: A SERIES OF REPORTS FROM THE U.S. FOOD AND DRUG ADMINISTRATION'S PATIENT-FOCUSED DRUG DEVELOPMENT INITIATIVE

'CHRONIC FATIGUE SYNDROME AND MYALGIC ENCEPHALOMYELITIS'

A few participants described depression, fear and anxiety, not as a symptom, but as a consequence of the devastating impact of the disease and its symptoms. As one web participant put it, 'anxiety is NOT a symptom - anxiety is a by-product [of this disease.]'

Having deep personal feelings of hopelessness, emptiness and despair. As one participant commented, 'all my work and career plans went down the drain. I think I'm just waiting my turn for heaven.'

A patient representative shared this experience of another, 'I'm living a life of lowered expectation and I feel like this is a living death.'

b) SERIOUS STRESS IS OFTEN A CO-FACTOR WITH THESE CONDITIONS: Sometimes before onset, always after, due to the issues addressed in detail above, people with the CELCs live with great stress, including from the stress caused by their stigmatization. However, stress is a co-factor with many other chronic conditions as well. Our system has recognized the value of mindfulness meditation and other stress relief modalities, including psychotherapy, for almost all health conditions because it is now known that reducing stress improves health status. However, such modalities cannot fully, sometimes even partially, compensate for the multi-frontal stresses our community informants have described.

Crucially, **stress is not a mental illness and we do not ignore the biophysical issues people with comparable conditions face because they endure stress in their lives.** We do not treat their conditions as psychogenic or, worst of all, fictitious.

ABOUT THE WHITEHALL STUDY

STRESS A COMMON FACTOR IN ALL DISEASE - LINKED TO SOCIAL GRADIENT AND SOCIAL FACTORS

Stress is thought to be a common factor in nearly all disease processes. The famous Whitehall Study of British civil servants, now into its third decade, has shown the extremely close coupling between stress, especially on the job (high responsibility-low authority, unsupportive managers and colleagues, effort/reward imbalance and job insecurity are major disease-related stressors) but also in family and community life. Consistently these stressors appear on a social gradient along with the well-known chronic illnesses. Those at the top have the least stress, because they have the most authority, affirmation from

⁷⁸ Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration (FDA), *The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis*. (Silver Spring, MD, September 2013). Respectively, pp. 8, 10 and 10.

colleagues, financial and other rewards and job security. They are also the healthiest, despite often heavy workloads. The thousands of people at the bottom of that gradient suffer from lack of control and they show much greater incidence of major indices of poor health. Exercises, smoking cessation and good nutrition have been found to help people deal with the effects of stress; but not to overcome them completely. Furthermore, having the conditions to pursue such behaviours is also socially determined. Therefore, **policy recommendations to reduce these different socioeconomic stress-producing factors have been the key outcomes of the Whitehall study. The study has not recommended that stress be treated as a mental illness or as an individual responsibility than can be solved by individual action.**

c) INTERDEPENDENCE AND BI-DIRECTIONALITY OF MIND-BODY PROCESSES: The longstanding Western paradigm of an impermeable division between the mind and the body as two distinct and independent entities has been dissolving under the weight of many types of research over the last decades, not least neuroscience. **Now we know that cognitive and affective processes can be affected by many types of phenomena in an interdependent and bi-directional manner. Stress can come in a number of biophysical forms - chemical toxins, biological infective agents, hormonal imbalances and nutritional deficiencies are all stressors par excellence - that may manifest as or mimic affective disorders.**

For example:

- **Chemical toxins** can provoke depression, anxiety and panic. With ES/MCS sufferers, chemicals can and often do trigger what appear to be affective symptoms in the central nervous system (crying, depression, anxiety), but as well cognitive symptoms (inability to speak or write, read or handle normal inputs) and neuromuscular symptoms (pain, loss of mobility). When such symptoms are provoked, they resemble affective symptoms but they are not psychogenic. Rather they are biophysical reactions that lift when the incitant is removed. **When incitants are ubiquitous - and this is the case if people continue to work and live in the world - such symptoms may recur and persist for weeks at a time or simply be ongoing.**
- **Electromagnetic frequencies** can provoke all the same symptoms as chemical toxins.
- **Biotoxins** produced by infections of various types can have similar effects -- many types of dysfunction can be provoked, including symptoms that are affective in appearance but not psychogenic in causation, and duration of affective symptoms is also linked to the duration of the infection. A viral or bacterial infection of the nervous system can create depressive and anxious symptoms in significant numbers of people.
- **Hormonal imbalances and nutritional deficiencies can cause affective symptoms.** Restoration of thyroid and adrenal levels, for example, can much improve depression when these levels are low; many vitamins, but especially B-vitamins, are needed for healthy affect. **Nutritional deficiencies undermine detoxification and good immune functioning,** and so forth.
- **Neuro-inflammation**, produced by free radicals and oxidative stress can provoke affective-like symptoms. And the research on 'words that hurt,' - cited above - is showing that hurtful,

rejecting behaviours (think, for example, of the negative behaviors of physicians vis a vis patients) **can cause neuro-inflammation as directly as biophysical insults.**⁷⁹

‘FIBRO IS NOT A MENTAL ILLNESS, BUT EVENTUALLY IT AFFECTS YOU THAT WAY’

Fibro is not a mental illness, but eventually it affects you that way. You’re forgetful. You’re nervous. I used to be very organized, now I’m not. I used to be able to do five things at once. Now I’m lucky if I can do one and a half. ... You can’t go into a mental health organization and say, ‘I have fibro. Help me’. You can’t. It’s not recognized like other things. **Pearl FM ME**

Those who do not understand this interdependence and ‘bi-directionality’ of effects - and unfortunately this still seems to be true of the majority of our physicians - can mistake affective symptoms for affective causes. When they additionally prescribe psychotropic medications that do not help, and can actually be toxic to metabolize, this misunderstanding can add additional harm to that of their rejecting behaviors. In the worst-case scenario, which still takes place too often, people are mistakenly committed to psychiatric institutions (the environments of which can be akin to physical torture for those with ES/MCS) and compelled to take heavy anti-psychotic medication. In these cases, the consequences are truly catastrophic, leading even to suicide or death.

Hence a new paradigm for stress, not only for the CELCs as such, but for other conditions, requires a multi-factorial approach to understanding the multiple causes of stress and, hence, of illness - and, therefore, to the treatment of both.

16.6 INSTITUTIONAL INTERESTS, DENIAL AND STIGMATIZATION OF RELATED ILLNESSES (‘GWRI’)

In 1990 the United States went to war in the Persian Gulf (Gulf War 1) and concluded the war early in 1991. About 700,000 personnel served. Ninety-three percent of the soldiers deployed were male. **Fully one quarter of those came back with a frightening legacy of health problems, which they soon began to report, and continued to report over the ensuing years - a legacy that sounds astoundingly familiar to those who know about the CELCs.**

Phil Brown is Professor of Sociology and Environmental Studies, and founder of the Contested Illnesses Research Group, at Brown University, Providence, Rhode Island. He has been writing about environmental health since the mid-1980s, beginning with *No Safe Place: Toxic Waste, Leukemia and Community Action*. He has **chronicled the evolution of the struggle of Gulf War 1 veterans for recognition of their illnesses and for compensation.** In his 2012 retrospective evaluation of this evolution, ‘*A Narrowing Gulf of Difference? Disputes and Discoveries of Gulf War-Related Illnesses*’, commenting on the symptoms soldiers that soldiers reported in the early and mid-1990s, he writes:

Symptoms of what has come to be called Gulf War-related illness include nausea, loss of concentration, blurred vision, fatigue, lack of muscle control and coordination, irritable bowels,

⁷⁹ For an explication of the phenomenon of bi-directionality, see J. Molot, *12,000 Canaries Can’t Be Wrong*, (October 2013, ISBN: 9780992041014). See also Raffensperger, *New Scientist*, 04 December 2012, 36-39.

headaches, respiratory problems, rashes, and other ailments that the affected individuals had not experienced prior to service in the Gulf.⁸⁰ ... 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.**"⁸¹

Sound familiar? Indeed, Phil Brown writes: 'Some symptom clusters resemble chronic fatigue syndrome, fibromyalgia or multiple chemical sensitivity, all of which are themselves poorly understood and subject to dispute.'⁸²

Here is a circumstance in which a very large majority of a group afflicted with the CELC syndromes are males. How did this come about?

Soldiers have gone to war and come home with health problems since time immemorial. From physical maiming and scarring to post-traumatic stress disorder to the teratogenic effects from pesticides such as Agent Orange in Vietnam, the legacy of war is a dreadful one.

Yet no other combat experience has ever produced the cluster of symptoms and number of victims that Gulf War 1 produced. Three distinct chemical circumstances were present in that war.

1. **Ingestion of pyridostigmine bromide (PB):** Everyone who was deployed to the theatre was ordered to ingest PB on a regular and supervised basis ostensibly to prevent injury from chemical warfare agents. This medication had been given before, apparently safely, because it was thought not to cross the blood-brain barrier. However, as was later learned, under stress conditions, it did breach that barrier and became a toxic agent in its own right.
2. **Exposure to chemical warfare agents per se:** Many combatants were exposed to said chemical warfare agents, originally in the hands of the Iraqi regime, as these were being destroyed by US forces. The make-up of these chemical weapons was known to the US.
3. **Massive ambient mixture of chemical hazards:** Many combatants were exposed to an incredible cocktail of ambient chemical pollutants at unprecedented levels. In addition to the PB and the ambient chemical warfare materials, this **included fumes and particulates from oil wells that burned for months and pesticides and insect repellants that were used liberally and repeatedly at all camps.**

Other studies have confirmed the relevance of a variety of environmental factors, notably a 1997-2002 study of a Fort Devens cohort of 2949 US Army soldiers who were Gulf War veterans. According to the study, sixty percent of respondents met criteria for multisymptom illness, and "ingestion of anti-nerve

⁸⁰ 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.

⁸¹ Ibid, p. 89.

⁸² Ibid, pp. 87-88.

gas pills (pyridostigmine bromide), anthrax vaccination, tent heaters, exposure to oil fire smoke, and chemical odors were significantly related to multisymptom illness in logistic regression analyses."⁸³

Arguably this war imposed **certain new types of physical and emotional stress** on top of the more 'conventional' stressors. In no war before had the **chemical alert sirens gone off so often** - often daily or even more frequently - **repeatedly provoking fear of annihilation. This was accompanied by the requirement for all personnel to suit up in chemical warfare gear for extended periods of time. 'Discomfort' does not begin to capture the harsh physical reality involved with this gear. Soldiers regularly passed out when dressed in it, even in practice drills on US soil** when there was no threat whatsoever, simply from the hardships created by the masked helmets, full suit, gloves and boots. **Severe claustrophobia was regularly reported by soldiers in the gear, in addition to ordinary difficulty with breathing, overheating and exhaustion.**⁸⁴ So all combatants experienced a very high degree of **constant stress -- even when not in combat as such.**

The story of what happened to the claims of illness made almost entirely by young people, a majority male, who were strong and fit when they deployed is fairly well known. **The vast institutional apparatus of the US military and government moved into defensive posture and, for a long time, denied environmental exposures as responsible and minimized the symptomatology. The institutional counter response relied essentially on a psychogenic notion of stress.** Implicit in that model was a characterization of the victims as psychologically weak or deficient, and therefore prone to breakdown - which then encouraged stigmatization of victims. In keeping with this approach, treatment, such as it was, attempted to fix the victim's 'mind' or 'psyche, generally to no effect other than frustration.

'For many veterans,' Phil Brown writes, **'the reliance on a stress model, with the VA's accompanying cognitive behavioral treatment trial, represented a form of delegitimization.'**⁸⁵ **This strategy is very familiar to civilians with the CELCs.**

It is beyond the scope of this report to explore at length the great diagnostic strides that have been made in attempting to understand what caused - and what can ameliorate - this GWRI syndrome, and the ways in which **these advances point to environmental exposures as the explanatory culprit.** Suffice to say that in the last ten years especially, discoveries related to detoxification abilities and genetic polymorphisms regarding enzymatic capacities, brain damage that can be seen only with the most advanced forms of imaging, and a series of other **diagnostic techniques tracking parameters all familiar to us from the study of the CELCs** have come to light.⁸⁶

⁸³ J. Wolfe, S.P. Proctor, D.J. Erickson, H. Hu, 'Risk factors for multi-symptom illness in US Army veterans of the Gulf War,' *Journal of Occupational and Environmental Medicine* 44, no.3 (2002): 271-81.

⁸⁴ USAF Major (Ret.) David S. Fenton to Varda Burstyn, personal communication, 2013.

⁸⁵ Brown, 2012, p. 94.

⁸⁶ A small sample of recent work: 'Increased Brain White Matter Axial Diffusivity Associated with Fatigue, Pain and Hyperalgesia in Gulf War Illness,' <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058493>). And 'Gulf War Illness and Pyridostigmine Bromide, Neurological Effects and Detoxification,' from <http://www.antipersonnel.net/links/R003.html> (Accessed September 20, 2013). And University of Texas Southwestern Medical Center, 'Gulf War illness symptoms persist, new imaging shows,' from <http://www.utsouthwestern.edu/newsroom/center-times/year-2012/march/haley-gulf-ct-march.html>, reporting on a study run by Dr. Robert Haley, Chief of Epidemiology and the U.S. Armed Forces Veterans Distinguished Chair for Medical Research (accessed September 20, 2013). And 'Brain Abnormalities in Gulf War Syndrome: Evaluation with 1H MR Spectroscopy,' *Radiology* 215 (2000, June), 807-817. <http://radiology.rsna.org/content/215/3/807.long> (Accessed September

Yet the types of epidemiological paradigms brandished by institutional deniers have consistently challenged the exposure model. This has been done, despite the well-known fact that, as one researcher interviewed by Brown said, **'we are never going to get the exposure models down because I think the exposures are too diverse. I mean, I've just never seen a public health study where you could have possibly multiple exposures.'**⁸⁷ Another researcher added: 'You know, war, like any other social experience, is very complex and it's hard to deal with complexity in a fashion that we're familiar with.'⁸⁸

In the process of learning about GWRI, **a shift in the definition of 'stress'** has taken place for many of those genuinely seeking to understand and support the sick veterans, rather than to protect institutions or industries from criticism or liability. As in parallel fields, stress has increasingly been understood to **fully encompass physical hardship and environmental exposures, as well as 'psychological' (emotional) issues. Further, 'emotional' stressors issues have been tied to overwhelmingly social factors** (e.g. fear of chemical warfare, fear of closed spaces), rather than to mental weakness or illness. Thus a clearer picture emerges with respect to how certain physical defenses, such as the blood-brain barrier, can be weakened at stressful times. **But it is also very clear that psychological stress alone does not produce these three symptom clusters. It may have been a critical co-factor - we stress 'may'. But the many form of extreme emotional stress in other wars demonstrate that without the chemical exposures, these illnesses would not have developed.**

Significant numbers of **Gulf War veterans, as well as first responders sickened in the 2001 World Trade Centre attack and during the BP oil spill off Louisiana in 2010, exhibiting similar symptoms,** have all concluded the same thing. They **have sought the assistance of environmental physicians (for example, Dr. William Rea and Dr. Grace Ziem, among others) for treatment that has helped to improve their health status** - treatment that is predicated on detoxification and other supports for a damaged central nervous system and other co-morbidities.

Still **'[t]he dominant epidemiological paradigm ... persists in multiple locations of science, government, academia, and the media, all of which contribute to maintaining the status quo,'** as Phil Brown observes. 'Hence, proposals of alternative paradigms incorporating environmental causes or other explanations must take on many different actors.'⁸⁹ Again, this is a familiar reality in the civilian world too. **Stigmatization of the sick comes along with denial of environmental causes.**

Before returning to Ontario and the issue of stigmatization of our three CELCs, let us attend to the words of **James Binns, chair of the Research Advisory Committee (struck by the US government to deal with contentious issues of GWRI)** regarding the difficulty in landing on a definition that all government agencies accept. As Brown notes, 'Binns continues to challenge the notion that the absence of a definition somehow makes the condition imaginary.' In his 2008 report, Binns writes: **'This is a real condition, which affects at least one-fourth of the 700,000 veterans who served in the 1991 war. It differs fundamentally from the trauma and stress related syndromes that had been described after other wars.'**⁹⁰

21, 2013).

⁸⁷ Ibid, p. 99.

⁸⁸ Ibid, p. 99.

⁸⁹ Ibid, pp. 95-96.

⁹⁰ Ibid, p. 103.

There are many lessons in this experience, beyond the scope of this report to explore. However, **the notion that the CELCs are ‘only’ dangers to women should now be completely dispelled.** Under the right circumstances of high enough exposure anyone is susceptible. Many men in civilian life are exposed to environmental stressors and there is a great distribution of detoxification capacities among men. Some are blessed with better, some worse. Additionally, given gender norms that expect men to override fatigue and pain, and to ‘suck it up’, as previously hypothesized, the CELCs may well be under-reported and under-diagnosed in men.

For public policy most broadly speaking, the GWRI experience has clear implications: Crucially, we must enact policies and production practices that reduce chemical exposures, because many of us who are strong and fit in other ways do not have the detoxification capacity to deal with the overload in our modern environments.

For our CELCs specifically, we need to understand that stigmatization arising from denial, and anchored by a theory of psychogenic etiology, can come from institutional forces that do not represent the public or patient interest. We need to be vigilant about the interests driving this psychological account of the conditions, even if this account may come from ‘official’ sources (e.g. military and governmental). And we need to ensure that those branches of government especially charged with health and wellbeing fulfill their special responsibility to ensure that people who are sick are believed and cared for, not abandoned and sacrificed.

16.7 COMMERCIAL VERSUS HEALTH INTERESTS - THE CASE OF ES/MCS

A number of participants in the community consultation raised similar concerns relating to the role that the chemical industry has played in denying that ES/MCS is a biophysical condition incited by everyday chemicals. **They have expressed concerns, long held by patients, advocates and physicians in that filed, that chemical industries, linked through corporate ownership to pharmaceutical industries, personal and homecare product industries, and, indeed, defense industries, have aggressively propounded the view that ES/MCS (also known as EI, ‘environmental illness’) is the result of unresolved and projected emotional disturbances.**

COMMERCIAL VERSUS HEALTH INTERESTS

THE CHEMICAL MANUFACTURERS ASSOCIATION’S AGGRESSIVE CAMPAIGN, PROPAGATED BY THEIR ‘ENVIRONMENTAL ILLNESS BRIEFING PAPER’, 1990

‘The impact [of recognizing ‘EI’], however, would not be restricted to the chemical industry. Commonly used chemicals are found everywhere, in the home, the workplace, outdoors, shopping malls, and even hospitals. Potentially affected industries include the textiles, clothing, lawn care products, household cleaners, dry cleaners, paints and solvents, perfumes, hair treatment products, plastics, paper and many other consumer goods industries.’

‘Environmental illness patients generally lead troubled lives and have genuine problems in coping with family, work and life-style pressures. They often eagerly accept environmental illness as the explanation for their condition...’

‘Forming Coalition: Because it has the potential to impact many segments of society, many groups have an interest in placing environmental illness in its proper perspective [i.e. opposing its recognition, and

framing it as an emotional and fictive conditions]. Among them: medical associations; manufacturers and applicators of agricultural and pesticide products; personnel, labor relations, etc.; food dealers; restaurants; insurance companies; self-insurers; soap and detergent manufacturers; chambers of commerce; lawn care services; homebuilders; aerospace industry; retailers; and automobile manufacturers.'

'Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary.'

- For the full paper, see Appendix 6b

This concern stems from an accurate perception on the part of informants and is not a paranoid account. For more than 25 years, driven by corporate concerns for liability, the costs of implementing new chemical processes, and for major losses in market share, such views have been actively promulgated in a variety of ways, including in the financing of 'scientific' 'research' organizations whose mission is to discredit ES/MCS and in non-disclosed or transparent financial support to certain physicians to represent these views within the medical profession and public arena (think tobacco, asbestos and coal industries). **Appendix 6a and 6b reprint two informative documents with respect to the conflict between commercial and health interests.**

- **Appendix 6a: 'Multiple chemical sensitivities under siege',⁹¹ by Ann McCampbell, MD, Chair, Multiple Chemical Sensitivities Task Force of New Mexico, 2001.** Much of the analysis of this issue - including the names of the corporate actors and their lobbying, public relations and faux science organizations - provided by Dr. McCampbell is still current.
- **Appendix 6b: A 1990 'briefing paper' circulated by the Chemical Manufacturers' Association** (now the **American Chemistry Council**), is a virtual playbook from the chemical industry in how to discredit those with 'EI' and their physicians with all the social actors and agencies that have been identified in this report as needing to be reached for recognition purposes.

Skeptics would benefit greatly from reading both of these documents. A quick summary of the main points is contained in footnote 92, below. Patients say they are up against a well-funded campaign of disinformation, and need much stronger public-interest advocates.⁹² They believe that as the myriad and

⁹¹ Ann McCampbell, MD, 'Multiple Chemical Sensitivities Under Siege,' *Townsend Letter for Doctors and Patients*, January 2001, Issue #210; reprinted with permission, www.townsendletter.com. For a wealth of information on MCS, chemicals and the chemical industry, see <http://annmccampbell.com/publicationswritings/publication-1/>

⁹² Molloy, *Best of the Reactor*, 1990. Quote from The Chemical Manufacturer's Association's 'Environmental Illness Briefing Paper': 'Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary.' And a further quote from Dr. McCampbell on the Environmental Sensitivities Research Institute (ESRI) (full text and references in Appendix 5a): 'Several nonprofit organizations and trade associations sponsored by the chemical industry are particularly active in opposing MCS. For example, lobbyists for RISE (Responsible Industry for a Sound Environment), a pesticide trade association, and the Cosmetic, Toiletry, and Fragrance Association, testify against MCS each year in the New Mexico legislature. The Chemical Specialties Manufacturing Association, which represents companies who manufacture and distribute home, lawn and garden pesticides, antimicrobial and disinfectant products, automotive specialty products, waxes, floor finish products, and many types of cleaners and detergents, has also submitted anti-MCS comments to the NM legislature. And individuals from a lesser-known organization calling itself the Advancement of Sound Science Coalition published an opinion-editorial in two New Mexico newspapers several years ago that was critical of the positive steps being taken by the New Mexico legislature on MCS.'

far-reaching health hazards of so many ‘everyday’ chemicals are coming to light, **it is increasingly important for government to put health needs ahead of commercial interests; and for government to become aware of the various issues at stake in this area and provide responsible, pro-active leadership.**

We share those concerns and support this view very strongly. We further believe that the denial of the reality of ES/MCS and the stigmatization those who have developed it as delusional by commercial interests, society has a whole has been deceived with respect to the safety of many ordinary chemicals, and the fight for regulation of these chemicals has lost a powerful and highly compelling mascot.

16.8 HOW ME/CFS HAS BEEN MISCONSTRUED

MECHANISMS of stigmatization regarding ME/CFS are linked to trivialization and basic misunderstanding. One of the key frustrations among ME/CFS patients is the term ‘chronic fatigue syndrome’ itself. This was introduced in 1988 by the US Centres for Disease Control against strong objections, even though the term ‘Myalgic Encephalomyelitis’ had been introduced in the UK many years before. The fact is that **‘fatigue’ does not begin describe the activity limitations experienced by patients. Nor does it convey the range of symptoms associated with the illness.** Unfortunately, because of the term, **many people confuse ‘Chronic Fatigue Syndrome’ with chronic fatigue, i.e. being tired all the time.** There can be many reasons for chronic fatigue, including working shifts and having young children. But that is not the same thing as ME/CFS. (See Chapter 6 for a definition, Chapter 10 for impacts).

A psychiatric model for chronic fatigue syndrome was developed by psychiatrists in the UK. The model was based on the concept that chronic fatigue syndrome is not a physical illness and the **symptoms experienced by patients are the result of distorted illness beliefs.** The solutions proposed were cognitive behaviour therapy and graded exercise therapy (incrementally forcing a return to normal activity levels). **Studies of CBT and GET were conducted using a loose definition** of chronic fatigue syndrome. The studies showed that about half of people with fatigue, loosely defined, responded to CBT and GET. These **findings were then interpreted by the media and many uneducated physicians, to say that everyone experiencing fatigue benefited from CBT and GET.** A number of articles and studies supporting CBT and GET for ME/CFS patients have been published in peer-review journals.

Yet, over time, a number of physical dysfunctions have been identified in ME/CFS patients. This means that CBT, in the sense of convincing people that their illness is not real, is absolutely

The leading opponent of MCS, however, is unquestionably the Environmental Sensitivities Research Institute (ESRI). This corporate-financed nonprofit organization was founded in 1995 specifically to combat MCS. According to MCS Referral and Resources, ESRI was founded “to serve the needs of industries affected by MCS litigation.” But since ESRI tends to be secretive about its membership, board members, and activities, it is hard to know exactly who is involved with ESRI and what the organization does. However, it is known that ESRI is primarily supported by its member companies and trade associations, who pay \$5000 or \$10,000 a year in annual dues. It is also known that the past board of directors have included representatives or employees of DowElanco, Monsanto, Procter and Gamble, RISE, the Cosmetic, Toiletry and Fragrance Association, and other chemical companies and trade associations. Although ESRI has in the past claimed to be a scientific and educational organization dedicated to the open exchange of scientific information, this is belied by its decidedly anti-MCS views. ESRI’s bias against MCS is evident in its fact sheet that claims that MCS is a “phenomenon” that “defies classification as a disease.” It appears that this organization’s main work consists of disseminating anti-MCS literature, holding anti-MCS conferences, intervening in legal and government affairs, and otherwise trying to impede progress on MCS.’

inappropriate. Post-exertional malaise has been found to be a hallmark, if not the hallmark, of ME/CFS. Post-exertional malaise means that forced exercise can cause real harm. This implies that GET, while it may be appropriate for some people with fatigue, is definitely not appropriate for ME/CFS patients. **Despite the later findings, the psychiatric model lives on, especially in peer-reviewed journals, and ME/CFS patients are constantly forced to defend themselves against it.** For example, as we have seen, the model repeatedly arises in the disability insurance context where insurers use the idea or threat of CBT and GET to delay or deny benefits, often harming patients in the meantime.

The definitions developed in the US for 'CFS' (Holmes 1988, Fukuda 1994) were vague (example: fatigue and four of eight additional symptoms). This has brought imprecision to parameters for diagnosis and research. With a broad and heterogeneous cohort, it has been difficult to find patterns, leaving open the possibility that CFS is psychological or behavioural.

The introduction of the 'Canadian' definition of ME/CFS in 2003, by contrast, was a watershed. Over time its value has been recognized and strong support internationally has developed for its use in diagnosis and research. This was emphasized in September 2013 when over 30 of the world's leading clinicians and researchers recommended to the United States Secretary of Health and Human Services that the Canadian definition be adopted for research and clinical use.⁹³

16.9 FIBROMYALGIA ENTERING A DIFFICULT PERIOD

With the publication of criteria for Fibromyalgia by the American College of Rheumatology in 1990, Fibromyalgia avoided many of the issues of lack of credibility and definitional vagueness that have plagued ES/MCS and ME/CFS. This may have been temporary. The ACR has recently introduced a suggested optional definition for Fibromyalgia that is less specific. Rheumatologists in Canada have pressed for its acceptance. At the same time, **rheumatologists have suggested that Fibromyalgia is *not* a rheumatological illness and that rheumatologists should withdraw their services.** Concurrently, there have been new drugs introduced in the marketplace for Fibromyalgia pain. One argument is that family doctors can administer the drugs. The counter argument is that it takes time and expertise to find the best drugs and dosages for the individuals. **In the confusion, the rate of unmet needs for Fibromyalgia jumped between 2005 and 2010. In 2010, the rate was the highest of the illnesses surveyed.**

16.10 NEW NOMENCLATURE NEEDED

A number of patients suggested that the misleading nomenclature for the conditions needs changing so that names express the true nature and seriousness of the conditions, and that does not lead to confusion of these with more ordinary states such as being tired, or having allergies or feeling muscular pain after physical exertion or injury.

⁹³ 'Case Definition Letter' re Canadian Consensus Criteria (CCC): Open letter to Kathleen Sebelius, US Secretary of Health and Human Services, September 23, 2013. Signed by thirty-five US and international signatories. The letter can be found here: <https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%2023%202013.pdf>

COUNTERPRODUCTIVE NOMENCLATURE

One thing is the name Chronic Fatigue Syndrome. Before I got sick if I had been told chronic fatigue I would have immediately thought it would say that you are tired all the time. I know they are trying to change the name but it has been ten years since I got sick and this is still what they call it. **Gayle ME**

16.11 CONCLUSION

There are many conclusions to be drawn from the material addressed in this chapter. **Clearly, the stigma attached to these illnesses must be removed. Ontario's Ministry of Health and Long Term Care must now recognize the CELCs as chronic health conditions (illnesses) and disabilities - that is, it must end their invisibility, exclusion and the inequity these cause.** From that vantage point, now is the time to bring about inclusion of care and support for those with the conditions into all the rights, benefits, programs, policies and facilities that make up our health care and social supports systems, and that protect people in public and in the workplace. **Recommendations for all of these steps follow in Part Five.**

RECOMMENDATION: STRATEGIC AND LEVERAGED ACTION BY GOVERNMENT FOR THE MEDICAL PROFESSION

There are some very important steps that the medical profession as a whole needs to take - steps that, given institutional resistance, will require directed support and incentives from government.

Every physician in practice has a duty of care to his or her patients. That duty requires acquiring basic knowledge in prevalent health problems, and in treating patients with respect, compassion and intelligence.

Requiring physicians to acquire knowledge, and supporting them through various measures to do so, becomes a strategic and leveraged action that can both heal the physician-patient relationship, and set off positive dynamics throughout society.

TWO HELPFUL GUIDES FOR PHYSICIANS WORKING WITH ME/CFS PATIENTS

Eleanor Stein, MD FRCP (C), an experienced Calgary-based psychiatrist who works extensively with patients with the three conditions, has produced two helpful guides to assist in improving the physician-patient relationship.⁹⁴

⁹⁴ Eleanor Stein, MD, FRCP(C): 'How to improve therapeutic encounters between patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Health Care Practitioners,' 2013, and 'Assessment and Treatment of Patients with ME/CFS:

For psychiatrists who have patients with ME/CFS: **Assessment and Treatment of Patients with ME/CFS: Clinical Guidelines for Psychiatrists;**

For a wider range of health care providers: **How to improve therapeutic encounters between patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Health Care Practitioners.**

Both are available at <http://www.eleanorsteinmd.ca/>

17 THE SPECIAL NEEDS OF ES/MCS

‘HOUSING IS OFTEN A NIGHTMARE FOR THOSE WITH ES/MCS’ DR. ANN MCCAMPBELL, CHAIR, NEW MEXICO TASK FORCE ON MCS

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.

17.1 AIR QUALITY AND THE BUILT ENVIRONMENT - A DISTINCT ADDITIONAL DIMENSION

Those struggling with ES/MCS have a number of similar needs to those with ME/CFS and FM, especially when they have multiple diagnoses. However they also have needs that are unique, urgent and chronic, but very poorly understood by those who do not have this condition, including the vast majority of health service providers and planners.

The poor quality of indoor air has received a great deal of attention in recent years and rightly so. With energy-saving building techniques making houses and offices ever more air tight, and with increasing proliferation of unhealthy chemicals in everything from building materials to food containers to make-up, studies show clear correlations between poor indoor air quality and health status for the population as a whole. The American Lung Association provides a good summary of key AQI issues.⁹⁵ They state that **‘The Environmental Protection Agency lists indoor air quality as the fourth largest environmental threat to our country.’** An online booklet from the EPA, ‘The Inside Story: A guide to Indoor Air Quality,’ introduces its subject as follows:

In the last several years, a growing body of scientific evidence has indicated that the air within homes and other buildings can be more seriously polluted than the outdoor air in even the largest and most industrialized cities. Other research indicates that people spend approximately 90 percent of their

⁹⁵ American Lung Association, *Indoor Air Quality*, accessed September 15, 2013.
<http://www.lung.org/associations/charters/mid-atlantic/air-quality/indoor-air-quality.html>

time indoors. Thus, for many people, the risks to health may be greater due to exposure to air pollution indoors than outdoors.⁹⁶

So one **major conclusion of this body of research is that better indoor air quality should become a public health issue in its own right.** This is an area where clinical public health needs to develop a presence and a practice.

However, for those living with ES/MCS, our most sensitive ‘canaries,’ poor air quality creates truly terrible problems because most indoor spaces are full of chemicals that they experience as immediately painful and disabling, indeed as toxic miasmas permeating every interior space. The resultant *biophysical* pressures on them to withdraw from all such laden spaces and, indeed, from all persons who use such chemicals in personal grooming, isolates those with severe ES/MCS to degrees simply not imaginable by most people.

17.2 SAFE HOMES ARE A MEDICAL REQUIREMENT FOR THOSE WITH ES/MCS

WHEN sufferers do not have adequate economic resources to create safe spaces to live - safe oases, in effect - it is common for them to live in a state of homelessness, in tents, cars, on balconies or in stripped-down trailers in remote areas, or to remain very unwell in unsafe dwellings. Social relationships and belonging in familial, friendship and community contexts are undermined, not to speak of the ability to seek and access health and social support services.⁹⁷

WITHOUT SAFE HOUSING THOSE WITH ES/MCS DETERIORATE

That was a terrible journey. ... It progressively became worse as I deteriorated. But ... the City of Toronto Housing, when they got letters from my doctor saying I needed to be transferred, and even to the point where the doctor said I was concerned even about my life, that I could die in ... the available housing ... Because I didn't fit into their criteria that was, like cancer, they said the only thing they could do was put me on the waiting list which is ten years, that I couldn't get special consideration for transfer. ... I was ... being kept in relapse because I couldn't get to a place where I could be stable. So that was psychologically really awful, being in relapse and knowing that you don't have to be. ... It's been very sad. Almost every avenue where I've needed support or help, the initial and continued response was no response that helped me get a foot up. **MaryLou ME FM MCS**

⁹⁶ United States Environmental Protection Agency (EPA), *The Inside Story: A Guide to Indoor Air Quality*, accessed September 15, 2013. <http://www.epa.gov/iaq/pubs/insidestory.html>

⁹⁷ Julienne G. Lipson, 'Multiple Chemical Sensitivities: Stigma and Social Experiences,' *Medical Anthropology Quarterly*, Vol. 18, Issue 2, pp. 200–213, ISSN 0745-5194, online ISSN 1548-1387. Quote: 'Multiple Chemical Sensitivity (MCS), an intolerance to everyday chemical and biological Substances in amounts that do not bother other people, is a medically contested condition. In addition to symptoms and the ongoing difficulties of living with this condition, this hidden and stigmatized disability strongly impacts social relationships and daily life. Based on an ethnographic study, this article introduces the context of MCS in terms of cultural themes, the media, and the economic power of industries that manufacture the products that make people with MCS sick. Participants' experiences with family members and friends, in work and school settings, and with physicians exemplify the difficulties of living with MCS.'

Therefore **the issue of air quality, in all its multiple aspects and applications, is a truly critical dimension that must be factored in at the centre of care and support for this condition, not at the margins. It is not an optional add-on.**

For those who are acutely sensitive to electromagnetic frequencies (EMF sensitivity) - whose symptoms are exactly like those of people with chemical sensitivities and often overlap those sensitivities - life these days can be equally nightmarish. Being in an environment, both built and outdoors, pulsing with unseen waves that make one sick, and being surrounded by people who never turn off their electronic devices brings on severe symptoms of disorientation, body pain, weakness, shortness of breath and so on. Sweden has constructed a micro-wave and device-free village for such people so they can achieve 'avoidance' and stay well in an environment that has all such frequencies removed. As with the chemically sensitive, removal of the incitant leads to restoration of normal physical and mental function.

Among specialist physicians, it has become axiomatic that the first line of medically prescribed treatment for those with ES/MCS is 'avoidance' of incitants - at least to a level where symptoms disappear and stability is possible.⁹⁸ The word 'avoidance' is so easy to say, and yet the reality is extremely difficult to achieve. It is a basic corollary of the avoidance axiom that ES/MCS sufferers cannot stabilize or improve unless they can practice avoidance in their homes. **A safe home for a person with ES/MCS must be conceptualized even more as an assistive breathing device than as a shelter from the elements.**

The central problem for the majority of people seriously afflicted with ES/MCS is that at the very moment in time when income generally drops or disappears, the costs of finding and/or creating a safe home escalate greatly. In the US, in 2003, the average costs for this were estimated at \$57,000, when post-onset income levels dropped to below \$20,000 per year.⁹⁹ It is usual for people to move multiple times in search of a safe place, and to lose life savings as a result of financial penalties due to those moves. Homelessness is far too frequently the result.¹⁰⁰

⁹⁸ Pamela Reed Gibson, Amy Nicole-Marie Elms, and Lisa Ann Ruding, 'Perceived Treatment Efficacy for Conventional and Alternative Therapies Reported by Persons with Multiple Chemical Sensitivity,' *Environmental Health Perspectives*, Vol 111, Number 12, (September 2003): 1498-1504. (Note: Participants had consulted a mean of 12 health care providers and spent over one-third of their annual income on health care costs.) Quote: 'This study examined self-reported perceived treatment efficacy of 101 treatments used by 917 persons with self-reported MCS. Treatments examined included environmental medicine techniques, holistic therapies, individual nutritional supplements, detoxification techniques, body therapies, Eastern-origin techniques, newer therapies, prescription items, and others. ... **Both creating a chemical-free living space and chemical avoidance were rated by 95% of respondents as helpful.** Results for most therapies were mixed.' [Emphasis added]. See also Molot, 2013.

⁹⁹ Ibid.

¹⁰⁰ See for example: Rhonda Zwillinger (Photographer), *The Dispossessed - Living With Multiple Chemical Sensitivities*, (Photo documentary, 1998). Available from <http://www.rhondazwillinger.com/dispossessed.php?n=8> . Excerpts at <http://thechemicaledge.com/section-2-the-song-of-the-canary-mcs/mcs-the-new-homeless/>

SAFE HOUSING SHOULD BE BY Rx AND SAFE SHELTERS ARE NEEDED

Safe housing should be by prescription, too. It's a medical need. CERA [Centre for Equality Rights in Accommodation] has done a post on the medical need for housing. We also need to be able to get away. There's no safe shelter for us to go for two or three days. What almost did me in was asphalt on the road, four times, on Bloor Street when I was living there. I had no place else to go. The roof repairs, again, very toxic materials in asphalt. It almost killed me, but there was no place to go. We need to have places like safe shelters. **LMS MCS**

17.3 SAFE HEALTH FACILITIES AND SCHOOLS ARE CRITICALLY IMPORTANT

BY the same token, health facilities, in order to help and not harm must also be places where air quality is safe. Many people with ES/MCS do not seek primary care when they should because they must risk feeling very sick simply to consult their doctor. It is a cruel irony of modern life that hospitals are very dangerous sites for those with ES/MCS. A combination of poor air quality and poor-to-no understanding of the need for safe reception protocols can create a minefield of terrifying proportions. Many people with ES/MCS do not even seek specialist and hospital care when they need these because they are not prepared to risk their health in hospital environments.

For children and youth schools must be places where they are safe enough to learn and develop and come home healthy every night. This is not the case at this time. Above all, the use of no-toxic cleaning products, the banning of pesticides and the vetting of new equipment and furnishings for off-gassing of chemicals in schools would create an 'equal opportunity breathing environment'. Such measures would benefit all children too, for children are much more vulnerable than adults to chemical hazards and deserve to study in a safe place. **For chemically sensitive children, if the school is not safe, then a safe home becomes overwhelmingly important.**

Hence, for those with ES/MCS, from the point of view specifically of health and social supports, living in a safe dwelling is a first-line health requirement.

WHEN SAFE OASES CAN BE ACHIEVED AND OTHER EXPOSURES MANAGED, WONDERFUL THINGS HAPPEN.

- People at mild levels of chemical sensitivity need never 'crash' into more severe stages, or can recover quickly from early 'crashes' when safe shelters exist to allow for safe short-term and emergency housing.
- Those who are already more seriously affected may recover to more mild levels and return to full productivity; or may be able to feel well enough that they can earn a living working from home; and certainly will have a quality of life that is bearable, even with severe ES/MCS when their dwellings support, not harm, them.
- Those who experience symptoms in more toxic environments beyond the home can still be functional parents and spouses at home, minimizing the cascade of negative consequences to families such a disability would otherwise bring.
- Children can recover from exposures in other contexts, or, if needed, have a place where schooling can proceed and a life built despite the condition.

- For elderly or more seriously disabled people, safe supportive/assisted living, long-term care and palliative care facilities - of which there is not one unit or bed at present - mean that daily life can be made bearable, possibly even enjoyable. Those with ES/MCS who live in facilities not adapted to their condition now suffer immensely. Life is shortened either through health stresses or suicide.

In all these ways, assisting ES/MCS sufferers to achieve healthy housing is the most health-effective and, eventually, cost-effective preventive or supportive measure that can be taken. At this time, however, only seven units of safe social housing (in Barrhaven, Ottawa) have ever been constructed in Ontario (or Canada, for that matter). Turnover is very slow and the waiting list very long, indicating a great need for such housing. Such housing should be understood within the same frameworks as both supportive housing (mental illness, physical disabilities) and as medical housing (safe breathing envelope.)

Finally, it would be impossible for **persons ES/MCS at a certain level of severity to come for extended services at the proposed OCEEH hub unless a safe lodge is created for them.**¹⁰¹ Most cannot stay at hotels or even the houses of friends, and cannot respond to treatment if they are not stable in a safe residence.

Recommendations arising from the issues addressed in this chapter are incorporated into the various chapters of Part Five, immediately following.

¹⁰¹ For the importance of special housing, both for residence and for the OCEEH Lodge, see Environmental Health Centre Dallas's page on housing available at <http://www.ehcd.com/ehc-d-patient-less-toxic-housing-services/>

PART FIVE - SYSTEM RECOMMENDATIONS

INTRODUCTION VISION

COMPONENTS FOR A MODEL OF CARE

PATIENT RECOMMENDATIONS FOR CLINICAL SERVICES

SPECIAL NEEDS STRATEGIC ENABLERS

THE PROPOSED OCEEH PATIENTS' ORGANIZATIONS

18 INTRODUCTION TO PART FIVE

ALL the chapters of Part 5 seek to further motivate, identify and cluster the key recommendations coming out of the long process in which we have been involved.

A major and central part of our effort to present action recommendations was grounded in our community consultation, and our community consultation has, in turn, grounded all of our final recommendations.

At the same time, however, **we had several other knowledge streams informing our deliberations.**

- **Our environmental scan** (Chapter 7) - particularly lessons learned with respect to the need for central policy directives to HSPs as a precondition of local responsiveness; and for a similar need in order to effect change in the ministry departments per se.
- Our perhaps informal but still focused **consideration of the public costs** associated with the inappropriate care of the current state.
- A review of the services and experiences of the **Nova Scotia Environmental Health Centre (NEHC)**, the **Environmental Health Center-Dallas (EHC-D)**, and the approach and services of a network of dedicated centres, the **'Fibromyalgia and Fatigue' network** in the United States.
- Focused research with respect to **key pieces in the literature illuminating the issues faced by our communities** in general and as they have been revealed to us in our own province.
- A **six-part proposal for new and integrated services submitted to the Hon. Deb Matthews, February 2011.**
- A report on the Ontario College of Family Physicians sponsored process: **'Results of the Research Project to Determine the Feasibility of Establishing a "Centre of Excellence in Environmental Health in the Great Lakes Basin,"** 2008.¹⁰²
- A **'Top 10 Recommendations for services and programs'** as developed for the Minister of Health and Long Term Care and the Chronic Disease Management Program by the **Environmental Health Association**, 2009.

¹⁰² Ontario College of Family Physicians, *Results of the Research Project to Determine The Feasibility of Establishing a "Centre of Excellence in Environmental Health In the Great Lakes Basin* (Toronto: Ontario College of Family Physicians, May 26, 2008), 24 pages.

- A **proposal for a Centre of Excellence for ME/CFS** developed by **a patient group, working with Dr. A. Bested**, Toronto, 2009.

With all these sources contributing to our thinking, and in collaboration with the OCEEH BCP Steering Committee, we now present our recommendations for a **model of care, a proposed delivery system, and a specification of the additional rights and benefits needed for our populations to achieve a level of support equal to that which we have in place for our comparator groups.**

We also wish to flag for readers that, inherent in the detailed presentation of the measures needed to achieve ‘recognition, inclusion and equity’ from several different agencies, in the following chapters there is some measure of overlap. We regret any tedium resulting from this overlap, but hope, nevertheless, that readers will find matters of real interest in each of the chapters that follows.

19 THE VISION FOR THE OCEEH

AS ORIGINALLY ADOPTED, WINTER 2012, BY MEAO, AOHC AND THE PHYSICIANS OF THE ENVIRONMENTAL HEALTH CLINIC



Ontario Centre for Excellence in Environmental Health Business Case Project

WE will create a leading edge, patient-centred health care delivery system for over 500,000 Ontarians with chronic, complex environment-associated illnesses* who are currently receiving sub-optimal care while spending many times the average Ontarian in physician utilization costs.

This world-class CENTRE OF EXCELLENCE will be composed of a hub that will include, and expand on, the Environmental Health Clinic, and spokes delivering primary care, that could begin with a patient-population-based selection of Community Health Centres.

The independent, self-governed hub, affiliated with the University of Toronto and other academic health centres, will provide teaching, research, health promotion, and policy analysis as well as both primary and secondary clinical services. It will operate as a referral resource for primary care providers, and support the spokes in the delivery of best and promising practices - including those for continuum of care support services - based on evidence from research and leading clinics, and from the findings of patient-centred needs assessments.

The Centre of Excellence for Environmental Health Steering Committee will work collaboratively with the AOHC, LAMP CHC, MEAO and other patient organizations, knowledgeable health professionals, MOHLTC and the Toronto Central LHIN to realize our vision and accomplish our mission.

** Including but not limited to: environmental sensitivities/multiple chemical sensitivities (ES/MCS), myalgic encephalomyelitis-chronic fatigue syndrome (ME/CFS), and fibromyalgia (FM).*

DELIVERABLE

The key deliverable for this project is the development of a Business Case for an Ontario Centre of Excellence for Environmental Health *(as described in paragraph 3 of the vision)*.

20 COMPONENTS NEEDED FOR ‘NORMALIZATION’

THE **overall objective sought by people living with the CELCs** as articulated in the community consultation process is the **‘normalization’** of care and support, which we have further specified as achieving **‘recognition, inclusion and equity.’**

The components of support Ontario provides to its sick and disabled, the way the province delivers these, and the ways in which it has developed entitlements to these come through many different ministries, agencies, programs, rights and laws. It is useful to identify these in order to get a sense of where interventions are needed to create a comparable model of care and delivery system for our communities.

20.1 MINISTRY OF HEALTH AND LONG TERM CARE

Crucially, **when speaking of health services *per se*, we are speaking of a continuum of care** mostly overseen by the:

1. **Health promotion** activities: By public health and primary care providers - public awareness campaigns and prevention programs in many social sites; in-office patient-provider screening and vigilance; intra- and inter-ministerial cooperation on issues of concern.
2. **Disease prevention** activities: Physicians screen by regular examinations, questioning, testing, history-taking and counseling.
3. **In-clinic and hospital care:** From birth to death, on-going and as needed treatments of many kinds, including many types of hospital care.
4. **Drug Benefit Program - Assistance for prescriptions:** A program that seeks to ensure people get the prescribed medications and other support the need.
5. **Home-based care:** Including nursing, physiotherapy, occupational therapy, nutritional counseling, housekeeping, assistance with transportation, respite care.
6. **Family supports:** Education of family members re needs of patients, resources to family members for extra support, often within clinical programs.
7. **Chronic disease management:** Self-management and peer support: local, accessible and condition-relevant programs of self-management, including peer support groups.
8. **Medical emergency shelter (hospital admissions) supportive living and long term care:** Facilities where those whose health needs require on-site care can live with as much support as they need.
9. **System navigation services:** Increasingly, whether hospital- or CCAC-based, or primary care-based, assistance with identifying and mobilizing the right care at the right time in the right place.

THE FUNDAMENTAL STEP:

MOHLTC TO RECOGNIZE THE CELCs AS CHRONIC HEALTH CONDITIONS

If you go to the website of the government, Ontario Government Health, they don't list ME or CFS as a chronic disease. That needs to be there. **Frank ME FM**

This report **recommends that appropriate care be instituted for the CELCs in all these areas and sites.** Detailed recommendations for this follow.

In addition, however, and very importantly, **multiple other relevant ministries, agencies and systems throughout our public and para-public sectors are aligned to recognize the comparator conditions (and others) as illnesses and as disabilities**, and to deliver their services or benefits accordingly. But as a rule **at this time they do not recognize the CELCs as chronic disease/health conditions or as disabilities, and do not support the special needs of the conditions.**

20.2 MINISTRY OF COMMUNITY AND SOCIAL SERVICES

PROVIDES services that support disabled persons and have the following programs and services,

- **Ontario Disability Support Program** - provides eligible people with disabilities with **Income Support** for those who are in financial need to pay for living expenses, like food and housing; and **Employment Supports** (finding a job) helping people with disabilities who can and want to work prepare for and find a job.
- **Assistive Devices Program** - Consumer centered support and funding to Ontario residents who have long-term physical disabilities and to provide access to personalized assistive devices appropriate for the individual's basic needs.
- **Making Ontario accessible** - Creating a province where every person who lives or visits can participate fully makes good sense — for our people, our businesses and our communities.
- **Community services** - Community services and supports help people recover from hardship and regain control of their lives.
- **Developmental services** - People with a developmental disability today want to be active participants in their communities. To do that, they rely on a variety of local programs and services that promote inclusion and involvement.
- **Tax credits and benefits** - Benefit and tax credit programs for people with a disability.
- **Social and Supportive Housing** - Housing provided for those who need assistance with the costs of shelter and with special health needs (i.e. mental health, mobility challenges, etc.).

None of these fully or, in many cases even partially, **integrates care and/or support for the CELCs** and their specific needs.

ACCESSIBILITY FOR ONTARIANS WITH DISABILITIES OFFICE ON ES/MCS:

'WE CAN'T HAVE EVERY DISABILITY'

The AODA (Accessibility for Ontarians with Disabilities), I tried to work with them; I tried to get on committees. I talked to the director about including ES/MCS under customer service as one of the things, along with service dogs and all ... the four or five different subtitles. They would not. They said, 'well, we can't have every disability.' **Betty MCS**

20.3 ONTARIO HUMAN RIGHTS COMMISSION and the MINISTRY OF THE ATTORNEY GENERAL

- **Laws and precedents** that recognize the comparator illnesses have been developed in these sites, and have responsibility for **systems for enforcing violations of human rights or laws**.
- **Legal aid lawyers and programs are familiar with the comparator groups; not with the CELCs**; it is very difficult to get informed assistance, compassionate treatment, and physical accommodation by staff and others involved in disputes.
- **The Ontario Human Rights Commission is specifically entrusted with addressing the rights of minority or marginalized groups, including the disabled.**
- At this time, **any recognition of the human rights of those with the CELCs is strictly theoretical, and is not expressed in practice. This can and does prevent equitable treatment in all areas of life**; for those with ES/MCS it can be life threatening.

WHEN HAVING HUMAN RIGHTS CAN MEAN LIFE OR DEATH

Having a safe hospital or medical situation, I think, would mean the world to people with this. ... It would be the recognition of MCS as a disability as it has been recognized in Human Rights and to do the right thing. And there are lots of materials out there where hospitals can have a list of things that they need to do when someone has MCS, as well as accepting that person's personal list of what they need as far as accommodation. **Betty MCS**

20.4 MINISTRY OF EDUCATION and MINISTRY OF TRAINING, COLLEGES AND UNIVERSITIES

1. **Education is the most important predictor of socio-economic wellbeing. Education is a right we protect for many disabled people.** Accommodation for those with ME/CFS, FM and ES/MCS is not included in these protections. Some institutions do better than others.
2. **Schools, colleges and universities shape the curriculum of the health professions, who shape perception and behavior throughout society.** Curriculum on the comparator conditions is an integral part of what is taught. Not so with the CELCs.

3. **Schools, colleges and universities provide health services to students** and, in the latter case, faculty and very **important sites of public education** for students and families with respect to the comparator groups. The CELCs are missing on both fronts.

TWO STUDENT EXPERIENCES - ME/CFS and ES/MCS

I did this master's degree] from bed over a long period of time and then I got accommodation for classes. I ended missing quite a bit. I would do just one three-hour class per semester. So the university has been a very positive experience for accommodations overall. **Gayle ME**

I wanted to go back to school but I can't because when I go into a classroom I get sick, so I did my master's online. But I was so lonely and isolated that whole time. I wanted to go to the class. I would like to pursue my doctorate degree but I don't know how I am going to do it with my limitations. **Hope MCS**

20.5 MINISTRY OF LABOUR

THERE are a number of critical social determinants of health affected by the provinces labour laws and norms, and regulated and adjudicated by the Ministry of Labour.

1. **Norms for workplace accommodations of persons with disabilities, complete with tax incentives for willing employers**, are in place for many recognized disabilities. These do not include people with ME/CFS, FM and ES/MCS who are able to work; and to prevent deterioration so as to keep these people in the workforces
2. The **Workers Safety and Insurance Board** is crucial to positive resolution of many job-related issues. The WSIB recognizes the comparator conditions, and this lessens the stress of procedures before that board. This is not the case with the CELCs.

TWO EXAMPLES OF WORKPLACE ACCOMMODATION ISSUES - ME/CFS AND ES/MCS

I have something actually quite positive to say about my current employer. ... I have speech to text software. I have a special keyboard. I had an ergonomic assessment done. My desk has been lowered. I'm smaller than the standard. They really were very willing and it was almost sort of a non-issue, that this all needed to go on and happen. That kind of accommodation I find is fairly simple. **Amy FM**

I work in a job that involves exposure to smoke, moulds and other health risks in the field. I expressed concerns about these exposures to my employer and noted the importance of being able to come back to an office that was environmentally safe. What unfolded was a discussion that was geared towards my capacity to do my job versus the need for workplace accommodations. What I found was that there is a big disparity between having rights and practicing them. **Hope MCS**

20.6 MINISTRY OF THE ENVIRONMENT

1. The MOE is 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. At present **many 'everyday chemicals' that have been shown by medical research to be harmful** (a major lag between science and public policy) **are still ubiquitous, and impossible to escape.**
2. Alignment is needed to bring about recognition of the CELCs as illnesses and resulting disabilities involving harms, including from 'everyday' chemicals. **Action to protect those with the CELCs would benefit every single citizen of this province (much better regulation, 'share the air' campaigns, etc.).**

COMMERCIAL FRAGRANCE EMITTING DEVICES SHOWN TO BE HARMFUL¹⁰³

NOT REGULATED IN PRIVATE OR IN PUBLIC

People complain about the cost of buying a fragrance-free product... Consider it from a health standpoint. You are spending a bit more money on a product that has good ingredients that are not going to accumulate in your body or your children's' body and cause health problems. ... We are all sucked in by the major marketing companies. And if SC Johnson, a 'family' company -- I see those adds for Glad plug-ins, I think, how the hell can you be a family company when you are putting all these toxic chemicals into all the products? ... The government does not really care. Nothing is regulated. Things like the toxic chemicals that they are using need to be more closely regulated. **Sandra MCS FM**

20.7 MINISTRY OF FINANCE

1. REGULATES insurance companies. **Medical and work-related insurance policies have categories for the comparator conditions, and benefits are administered accordingly.**
2. **Tax incentives for employers with disabled workers increase employment, but also awareness, compassion and respect,** and expectations on all societal actors to provide necessary supports, services or accommodation as appropriate. Those with the CELCs are not included.

With these components in mind, therefore, **the recommendations that follow address two broad but distinct types of action needed.**

- Components that can and should be provided in-house in the hub and spokes of the proposed Ontario Centre of Excellence in Environmental Health (OCEEH) - **a health services delivery**

¹⁰³ Anne C. Steinemann, PhD., 'Fragranced consumer products: Chemicals emitted, ingredients unlisted,' *Environmental Impact Assessment Review*, Vol. 31, Issue 3 (2011, April) 328-333; and 'Fragranced consumer products and undisclosed ingredients,' *Environmental Impact Assessment Review*, Vol. 29, Issue 1 (2009, January) 32-38.

system, based in primary care, with specialized care - corresponding to 'Pillar 1' of the OCEEH business case proposal.

- Intra- and inter-ministerial components needed beyond the OCEEH system, both within MOHLTC-funded programs and facilities; and in other parts of the public and para-public sectors - **'strategic enablers' corresponding overall to Pillar 2 of the business case proposal.**

Patients are aware that **the accomplishment of the efforts involved in implementing the recommendations** that follow will take time. It is understood that this **will happen in a phased process**, in which the establishment of the OCEEH as a lead agency on both these broad fronts is a critical condition. We have not addressed phase-out. The sequencing of the efforts is being addressed initially in the OCEEH business case proposal; and will also be the work of the pre-operational phase of the OCEEH in partnership with the MOHLTC and LHINS.

However, **this province has many sick people who have no appropriate care**, among whom is a large and non-affluent aging cohort that has serious needs for supportive, and soon, assisted, housing. So while dependencies and sequencing must be worked out, **we must emphasize the urgency of moving forward quickly, and, therefore, of addressing the 'strategic enablers' as well as the recommendations for direct services.**

21 PATIENT RECOMMENDATIONS FOR OCEEH HEALTH PROMOTION, DISEASE PREVENTION, DIAGNOSIS AND TREATMENT

DR. John Molot and the Medical Advisory Committee to the OCEEH BC Steering committee has set out the components that will be needed to create a full clinical program.

However, certain repeating issues with respect to clinical practice emerged in the community consultation, and from the collective experience of patients' organizations, that we would like additionally to provide here.

21.1 MEDICAL EDUCATION IDENTIFIED AS NUMBER 1 PRIORITY FOR SYSTEM CHANGE

THE nature of the conditions combined with the dominant views of them makes it very difficult for patients to educate their physicians. Yet patients unanimously identified **the lack of knowledge, training and education of physicians as a central and pivotal gap and a fundamental barrier to accessing care**. Developing capacity in Ontario medical and other health professional corps is therefore a top priority, and virtually every other service delivery recommendation is linked to or dependent on this process moving forward. Therefore,

RECOMMENDATION - PHYSICIAN EDUCATION

1. Government should take steps needed with the College of Physicians and Surgeons, the OMA, the Ministry of Training, Colleges and Universities to **require and provide education and training of physicians in diagnosis and treatment/management of conditions**.
2. The MOHLTC should **require competence in these conditions of HSPs** in hiring primary care and specialist physicians in government-funded facilities and programs.

21.2 DISEASE PREVENTION AND HEALTH PROMOTION ARE NEEDED AS PART OF OCEEH MANDATE

Our patient survey/community consultation demonstrated virtually no prevention strategies in place in our health care system. Yet it was evident that **early and effective intervention - to prevent worsening at every place along the severity gradient - is very important**. The following recommendations emerged.

RECOMMENDATIONS DISEASE PREVENTION AND HEALTH PROMOTION

1 Government should lead in a radical reduction in the number of harmful chemicals, both industrial and 'everyday,' in circulation and linked to the conditions - as well as many other documented chronic health problems - with respect to both general circulation and occupation-specific materials. Action with respect to unregulated materials in women's occupations, domestic and grooming products is urgently needed.¹⁰⁴

2 Excellent primary care screening protocols to be developed; conditions for applying them (e.g. more time in physician appointments) to be taught to health providers.

3 Client education by primary care givers on how to live a healthy chemical life-style and on stress reduction is essential; education is needed for the educators to be capable of this.

4 Active and ongoing public health initiatives - including effective public campaigns - to be mounted, to create awareness and vigilance, and support primary care providers.

5 Government-funded, OCEEH-developed broad health, social service and educational ('para-public') sector educational programs to be developed and delivered, to create awareness and capacity to identify and assist individuals, families and institutions (such as schools) to consider warning symptoms and take appropriate actions.

21.3 COMPREHENSIVE AND SIMULTANEOUS APPROACH TO DIAGNOSIS AND TREATMENT IS URGENTLY NEEDED

Our patient study showed that **diagnosis usually takes years**, sometimes even decades. It showed that people generally deteriorated over this time, had quality of life harmed, experienced severe stressing of families, and found it more difficult to get better when diagnosis finally did take place.

This record of protracted and inaccurate diagnoses (until the right one was found) had **profoundly negative consequences for patients**. Equally, years and decades went by for many patients in which treatment was either non-existent or partial and ineffective.

It may be stating the obvious, but in the current context, and a desired future state, **the link between a good prognosis and appropriate treatment is a critical one, and correct diagnosis, the precondition to appropriate treatment, must therefore be seen as of exceptional importance both to the patient and to the health care system and budget as a whole** (see chapter 7).

¹⁰⁴ Burstyn and Phillips, 'Women's Health and Chemicals...', 2009. See Appendix 4 for the complete presentation.

FROM 'ACADEMIC AND CLINICAL PERSPECTIVES,' JOHN MOLOT, M.D., 2013

EARLY INTERVENTION AND PROGNOSIS FOR ME/CFS, FM AND ES/MCS

Many patients with FM and ES/MCS are at least partially disabled and unable to work, as are most patients with ME/CFS. Reduced physical functioning, which is common in all three of these conditions, is a predictor of work disability. The more time missed from work, the greater the likelihood of long-term disability. The present inadequacies in being able to provide early diagnoses and the paucity of available treatments in the general medical community underline the need for more education and earlier interventions to preserve or even restore the ability to work. Patients with one of these conditions are more likely to develop one or both of the others, increasing disability. Both the number of comorbidities and disability are strongly associated with cost. Earlier diagnosis can reduce referral costs and investigations, and interventions may prevent the onset of comorbidity, all of which can lead to a net savings for the healthcare sector, and a better quality of life for the individual.

These informant experiences combined with previous research discussions with many physicians (including at the Environmental Health Center - Dallas clinic and in the Fibromyalgia and Fatigue Centers),¹⁰⁵ identify a **critical issue for clinical strategies for positive outcomes: an aggressive approach in providing comprehensive, state-of-the-art testing followed by comprehensive, simultaneous treatment.**

The simultaneous treatment approach is critical to address all co-morbidities so that they do not act as a drag on recovery. Addressing, for example, sleep, hormonal imbalances, infections, nutrition and toxicity at the same time allows the patient to move forward. Neglecting any of these, as well as additional other issues, often means that other interventions are ineffective.

As well, patients who had been able to receive good specialized care regularly reported that **testing for certain issues (thyroid levels, infections, toxicity) by standard OHIP-insured procedures had produced incorrect results while more accurate testing, paid privately, had revealed important problems, which, when treated, greatly accelerated improvements. The pattern for treatment was the same.**

Therefore the OCEEH, and eventually other care providers, need to incorporate both a simultaneous approach to testing and treatment, and methods for both that are effective and adequate to need.

ENVIRONMENTAL HEALTH CENTRE - DALLAS APPROACH TO COMPREHENSIVE AND
SIMULTANEOUS DIAGNOSIS

People may develop chemical sensitivity, debilitating fatigue and painful fibromyalgia as a result of a variety of causes (toxicity, infection, physical injury and others). However, it is also possible

¹⁰⁵ With Dr. Wm. J. Rea and Dr. Katherine Henry, EHCD, and Dr. Wm. Marcus Spurlock, Fibromyalgia and Fatigue Center, Dallas, 2008 - personal communications with Varda Burstyn.

that a primary factor is causing the three types of symptom clusters or preventing them from improving. For example, ES/MCS and a high body burden of chemicals can provoke all three conditions. At the EHC-D the premier clinic that specializes in chemical sensitivity - patients with fatigue/debilitation and pain are always tested for chemical body burdens and chemical sensitivities. For a significant number of patients, when these issues are identified and treated, the symptoms of fatigue/debilitation and pain improve or resolve. Here is a list of toxics tests performed at the EHC-D in this regard.¹⁰⁶

Blood, urine, adipose tissue for xenobiotics; pesticides – organophosphates, organochlorides, – solvents, aromatic volatile hydrocarbons, ketones, aldehydes and metabolites, [mold and mycotoxins](#), polychlorinated biphenyls, pentachlorophenol, pyrethroid metabolites, heavy metals, and chlorophenoxy herbicides; Breath Air Analysis for volatile organic compounds derived from the blood by passive diffusion across pulmonary alveolar membrane.

By the same token, however, chemical sensitivity, as well as ME/CFS and FM, may be caused by, or may be prevented from ameliorating by the persistence of certain types of microbial infections and/or biotoxins - viral, fungal, bacterial and parasitical. Therefore, at EHCD, it is considered critical to cover this territory for ES/MCS as well as for ME/CFS patients, both in testing and treating for infectious agents, and for impaired immune response associated with chronic infection. State of the art diagnostic tests as well as immune enhancing therapies may all be needed simultaneously to achieve a qualitative improvement that raises the patient to a platform from which more incremental gains may then be made.

Ensuring this comprehensiveness and simultaneity involves **a strategy of up-front investment**, first in diagnostic measures and then in a commitment to timely and complete treatment follow-up. **This is of paramount importance to patients and their families.** It has implications for measuring outcomes, so for research at the OCEEH. It has implications for funding, and for the attitude of funders to clinical strategies.

RECOMMENDATION ON SIMULTANEOUS AND COMPREHENSIVE DIAGNOSTIC AND TREATMENT MEASURES

In order to ensure timely diagnosis and effective treatment outcomes:

- 1 Ensure comprehensive, simultaneous, state-of-the-art testing, and indicated treatment is funded and adopted as normative in all the clinical programs of the OCEEH.
- 2 Ensure this approach is addressed and explained in educational material for primary and specialist physicians beyond the OCEEH network.
- 3 Provide a chemically-safe lodge with appropriate building standards and rules for product

¹⁰⁶ To explore the web site of the EHCD, see <http://www.ehcd.com/>

usage by residents to enable those with ES/MCS to receive care at the OCEEH hub.

22 RECOMMENDED TREATMENTS AND MODALITIES BY HEALTH PROFESSIONALS IDENTIFIED BY PATIENT INFORMANTS - 'AT A GLANCE'

TREATMENT/MODALITY	PROVIDER/SITES
Nutritional and Immune IV treatments	MDs, NPs and NDs (naturopathic doctors) to prescribe; nurses, phlebotomists to administer; in-clinic or at home
Oxygen for ES/MCS	MDs to prescribe, on-site intensive; home therapy
Pain management Pharmaceutical, massage, physio/chiro, exercise	MDs, NPs, PTs, RMTs, fitness professionals See below
Massage - detoxification, pain and stress management	Registered massage therapists trained in FM, ME/CFS and lymphatic drainage; on-site and/or at home
Detoxification treatments - Sauna - IV (chelation, Vitamin C, glutathione, B & other vitamins) - Dietary -herbal	Sauna - full program, naturopath or MD to devise; technicians to assist/monitor. IV chelation - MDs and NDs to prescribe; nurses, phlebotomists to administer Dietary-herbal - NDs, nutritionists, MDs
Naturopathy : detoxification, nutritional supports, non-pharmaceutical anti-infection/immune building therapies	NDs Overlapping with integrative medicine: MDs
Chiropractic, Osteopathy, Physiotherapy, Cranial-sacral therapy	Chiropractors, osteopaths, physiotherapists, cranial sacral therapists; on-site or at home
Massage	Registered massage therapists trained in FM, ME and lymphatic drainage; on-site or at home
Occupational therapy	OTs - at home
Acupuncture	Traditional or classical Chinese medicine practitioners, trained MDs, trained chiropractors; on-site or at home
Homeopathy	Homeopaths, NDs

Psychotherapy	Psychologists, psychiatrists, social workers, trained family physicians; on-site or at home
Mindfulness mediation and other mind-body modalities	Psychologists, psychiatrists, social workers, trained family physicians; also yoga and other eastern mind-body discipline instructors; generally on-site; in some cases, at home.
Individual and condition- specific exercise regimes	Various health professions including fitness professionals; training for needs of the conditions is critical to avoid harm and effect improvement; generally on-site (safe site); sometimes at home
Trained paramedics	

23 RECOMMENDATIONS FOR SPECIAL NEEDS AND ADAPTATIONS OF SERVICES FOR THE CELCs IN HEALTH AND SOCIAL SUPPORTS

PEOPLE living with the three CELCs require the same treatment as others. At the same time, obviously our system recognizes that different illnesses or diseases require dedicated and expert support for the unique features of the respective conditions. **In this context, therefore, capacity means adequately providing the same rights, benefits, programs, policies and services as those for comparator groups, adapted in appropriate ways.**

The three conditions share a number of features. Moreover many people have more than one of the conditions concurrently. Nevertheless, **each of the conditions creates specific challenges that require specific services and accommodations. It is important to understand what these are in order to make sure that new policies and programs cover these in a comprehensive way.**

To this end, we now provide **a check-list of recommendations for special needs.** In each category, we first list those that are common for all three conditions; then those that are condition-specific.

23. 1 RECOGNIZE THE CELCs AS CHRONIC HEALTH CONDITIONS (ILLNESSES) AND AS DISABILITIES

RECOGNIZE the CELCs as both chronic health conditions and as disabilities - this is a precondition to all other change. It can be enacted immediately and publicized to all government and government funded sectors.

When people are extremely sick and losing income along with physical and cognitive abilities and/or when they have developed serious chemical sensitivities, having to wage protracted fights for services or economic benefits due to lack of recognition causes deterioration and retards stabilization and recovery. Policy change, as indicated by the 'Strategic Enablers' would greatly reduce this illness-exacerbating stress, the private expenditure of precious financial resources and perverse efforts to maintain a negative service or benefit environment in the relevant locations.

Set appropriate policies in place (see Chapters 24 and 25) so that individuals who are sick do not have to contest their rights and needs with service providers, with insurers, with Human Rights Commissions. The current state creates an unconscionable drain both on personal resources and public funds.

Provide competent, trained legal assistance to obtain services from employers, insurers, service providers, government agencies, schools and Human Rights Commission as long as rights and benefits are so difficult to obtain.

23.2 SYSTEM NAVIGATION BY TRAINED PROFESSIONALS

ME/CFS and FM are poorly understood or recognized by system personnel. Social workers and others trained to assist with these specific challenges are needed as keys agents to unlocking care and support for people so affected through coordination, advocacy, planning of service provision (safe reception at hospitals and other settings, for example).

ME/CFS and FM create mobility and exhaustion problems due weakness/fatigue and/or pain, cognitive difficulties, including problems in speech and expression; all these make accessing care and support very difficult without assistance.

ES/MCS, with many similar symptoms from different a different cause, requires safe air quality on site so sufferers can access basic and essential health and social support services; whole-sector policy with respect to air quality issues would make a tremendous positive difference and cut down on needs for system navigation for each individual.

23.3 INCOME SUPPLEMENTS FOR THE NECESSITIES OF LIFE

COVERAGE via ODBP is needed for all prescriptions not on the formulary and for physician required nutritional supplementation; revise plans accordingly.

- Included here are pain medications, anti-infective agents, compounded hormones and other medications, and immune supports.
- Also needed - inclusion of medically-necessary nutritional supplementation.

Revise ODSP to provide income supplements for special needs of those with the CELCs and for inclusion into employment programs (including ergonomic modifications, safe-air dwellings).

Revise assistive devices programs to cover specific needs of the conditions.

- For ME/CFS and FM - mobility and pain related devices.
- For ES/MCS - air and water quality filtering devices, safe laundry facilities.

Require all insurers to cover the CELCs, and ensure appropriate needs are included.

Require employers of a certain size/type to accommodate those still able to work- protocols to be developed with stakeholders and required to guide WSIB.

Provide access to specially trained legal aid lawyers for the purposes of obtaining work-income benefits and service-related entitlement.

23.4 MEDICAL CARE

REQUIRE and provide training in diagnosis and treatment/management of conditions, including in understanding the injurious nature of common chemicals and certain drugs.

Provide house calls by condition-competent, fragrance-free medical professionals to those too chemically sensitive or too physically disabled for office attendance.

Provide state of the art education for pain management, infection control, sleep assistance, endocrinological balance, toxicity and appropriate exercise or physicians and nurse practitioners.

Require all medical facilities to be fragrance-free and sensitive to pain/weakness/fatigue needs of patients; educate physicians and NPs in reasons for this in their personal practice and with staff.

23.5 INTERPROFESSIONAL CARE

REQUIRE and provide training in special needs, at home and/or on-site in a health centre facility.

- Massage therapy
- Physiotherapy, chiropractic, osteopathy, cranial sacral therapy
- Occupational Therapy
- Warm-water therapy (FM)
- Custom designed for paced exercise for FM and ME
- Acupuncture for energy, pain management
- Oxygen therapy
- Detoxification therapies including sauna-with-exercise- and-massage
- Chiropractic, physiotherapy, osteopathy
- Condition-competent nutrition counseling
- Yoga and aerobic exercise in safe location with scent-free trainers (health, isolation)
- Counseling/psychotherapy by trained professionals with expertise in special features of this condition, offered in safe locations.

Ensure cadre of specialists for co-morbidities are trained, available and geographically accessible.

23.6 BUILT ENVIRONMENT FOR HEALTH CARE FACILITIES RECEPTION

REQUIRE that only non-toxic cleaning and building maintenance materials may be used in health, social services and educational facilities ('green the indoor air quality').

FOR ME/CFS AND ME

Quiet resting places to be created throughout system, at offices and in health centres and hospitals, to permit those with ME/CFS to be able to attend in person.

Require and provide training to health and social services system staff to recognize weakness, pain and cognitive problems and assist when needed.

FOR ES/MCS

Standard and enforced fragrance-free policies for all staff in public and para-public sectors, including in use of fragrance free laundry products. 'Scent' is not only found in perfume.

Government campaign for ‘share the air’ - similar to ‘smoke free’ campaign to establish standards with posters in all health facilities; rigorous enforcement in health and educational facilities.

Green hospitals and medical sites: only non-toxic cleaning and building maintenance products and strict care to contain medical chemicals and gases in designated areas; non-toxic and fragrance free laundry products.

Require and provide training of facility staff (medical, nursing, other) to provide safe care, recognize symptoms and assist when needed; **emergency staff a top priority.**

Require a ‘clean room,’ with excellent ventilation and oxygen available in hospital emergency rooms and for admission purposes; surgical and other procedures by condition-competent providers in safe spaces.

Designated special sites (OCEEH ‘spokes’) for safe rooms for specialized treatments and safe activities (e.g., self-management groups, participation in governance).

23.7 SOCIAL SERVICE SITES AND EDUCATIONAL FACILITIES

Require and provide training for service professionals and education professionals in understanding, recognizing and responding to symptoms of ME/CFS, FM and ES/MCS and assist when needed.

Ensure accessibility of sites for those with mobility issues.

Provide assistance as needed to clients to negotiate multi-stair sites.

Require use of only non-toxic cleaning and building maintenance (‘green air quality in offices and schools’).

‘Quiet room’ and ‘clean-air room with oxygen’ available for emergencies in sites where large numbers of people work and/or attend school.

23.8 HOUSING

23. 8.1 FOR ME/CFS AND FM

RESIDENTIAL

Assist with subsidies in providing single floor dwellings or those with mechanized assistance, with other ergonomic adjustments (kitchens, bathrooms).

Make personal support workers available to assist in dwelling search, if needed.

Ensure provincial tax-deductibility of all dwelling alteration costs as medical costs; including with measures to ensure a quiet dwelling if noise hypersensitivity is diagnosed.

SUPPORTIVE AND ASSISTED LIVING

Provide supportive housing for those in need of specially-adapted premises, as for other physical handicaps.

Employ only non-toxic cleaners and low-VOC building maintenance, no pesticides or other toxic chemicals for management and residents.

Create sensory (sound) protection when needed.

Require and provide training of on-site care providers in special features and needs of the conditions.

Provide single floor dwellings or mechanized assistance, other ergonomic adjustments (kitchens, bathrooms); provide subsidy if needed.

LONG-TERM CARE and PALLIATIVE CARE

Require and provide training of care providers in special features and needs of the conditions.

Single floor or mechanized assistance, other ergonomic adjustments (kitchens, bathrooms) - subsidy if needed.

Sensory (sound) protection when needed.

23.8.2 FOR ES/MCS

RESIDENTIAL - EXISTING SITES

Train social workers or PS Workers to provide assistance in residential search and for automobile search (typically processes that set individuals back months or years if on their own).

Provide allowance for environmental building experts to assist with safe home construction or alterations.

Allow provincial tax-deductibility of all safe-home costs as medical costs.

Legal support to residents of multiple dwellings in negotiating accommodation

HOUSING - NEW SITES

Create new safe shelters, supportive housing, market value residences, assisted living and long-term care facilities for medical needs - urgent and critical

Residence in publicly-funded sites to be available by physician recommendation only.

Strict policies re non-toxic cleaners and low-VOC building maintenance, no pesticides or other toxic chemicals, no Wi-Fi installed: design prototypes exist in Ottawa, Quebec, Dallas, Sweden. In addition strict rules with respect to scented and/or toxic personal space cleaning, laundry and grooming products as a condition for residence in the facilities, for clients and for staff.

Supportive housing for those in need of especially-adapted premises.

SHELTERS

Create regional emergency safe-housing shelters to assist those developing ES/MCS symptoms or experiencing 'crashes,' and provide safe haven for those who need shelter due to more common reasons (e.g. domestic abuse, poverty and homelessness)

SUPPORTIVE AND ASSISTED LIVING

Require and provide training of care providers in special features and needs of the conditions.

Legal support to residents of multiple dwellings in negotiating accommodation if residence not dedicated for ES/MCS.

LONG-TERM CARE and PALLIATIVE CARE

Require and provide training of care providers in special features and needs of the conditions.

Provide legal support to residents of multiple dwellings in negotiating accommodation if residence not dedicated for ES/MCS.

23.9 FOOD SECURITY - 'THREE MEALS A DAY'

When poverty is an issue: ensure food security by income supplementation.

Provide income supplements, for obtaining safe foods - these are not a luxury or option.

When energy/mobility problems and/or unsafe air on grocery stores are issues: provide assistance in obtaining food.

When energy/mobility in preparing and cleaning up after meals, provide PSW to assist.

Provide sufficient hours to assist with all needed tasks.

Ensure meal preparation programs can deliver food for those with special needs; or provide personal meal assistance income or PSW supplement.

Training of personal support workers in ES/MCS needs and in arriving for work completely fragrance and smoke free.

23.10 SELF-MANAGEMENT, PEER AND FAMILY SUPPORTS

Develop self-management programs with communications materials, including peer support activities, ongoing and emergency

Provide these in safe on-site locations and via social media

Use these to assist in all aspects of self-care, and to attenuate social isolation

Develop family support programs and communication materials for family caregivers of adults, including peer support, ongoing and emergency

Develop family support programs and communication materials for family caregivers of children, including peer support, ongoing and emergency

Support materials to include assistance in all service needs and system navigation resources
Provide respite care for family caregivers

Provide income supports for in-need families with sick children

Co-locate patients' organization with safe service sites to work on and with all of the above

23.11 PERSONAL SUPPORT SERVICES

CREATE policy to ensure inclusion of those with CELCs as eligible for personal support services ('homecare'); ensure that CCAC care is easily accessed by primary care providers.

Require of, and train personal support workers in ES/MCS needs and to arrive for work completely fragrance and smoke free.

Require of, and train personal support workers in ME/CFS and FM needs and ability to work in ways that are minimally demanding or energy from clients.

Appropriately provide personal support services relating to

- Health care, including home blood draws
- Personal hygiene and dressing
- Physiotherapy, other therapy if housebound
- OT ergonomic, mobility issues
- Assistance with travel to health and social destinations,
- Housekeeping and laundry, including for ES/MCS special laundry needs. A clean, dust-free home is critical to those with ES/MCS; washing clothes tens of times before wearing is critical, but often the client is too sick to do it; therefore extra PSW hours for ES/MCS clients to do laundry are needed.

23.12 TRANSPORTATION and TRAVEL SUBSIDIES

FOR ME/CFS and FM - mobility issues and fatigue issues - provide wheel-trans transportation to treatment and/or travel subsidies, including caregiver payment or trained drivers.

Safe transportation - no diesel, no toxic cleaners, no scented passengers or drivers.

Transportation to treatment and/or travel subsidies if safe transport not available; including caregiver payment.

24 REMOVING BARRIERS: KEY ISSUES FOR SIMULTANEOUS LEVERAGED ACTIONS ACROSS GOVERNMENT

THROUGHOUT this report, we have pointed to many interacting factors that perpetuate the current unacceptable state. We have also stated that our overall objective can be expressed as securing the same rights, benefits, services, programs and policies that others with conditions of comparable severity have. In other words, **we need to remove all barriers across government and government-funded sectors.**

In this chapter we present **arguments for taking simultaneous leveraged action on a number of fronts** because such an approach can have remarkable and synergistic positive effects in bringing about this overall objective. The following chapters provide a concise list of these actions, which we are calling our 'strategic enablers.' This chapter motivates those actions.

We are concerned that failure to align key sites or policies may permit various types of inertia and even prejudice to slow down or limit the effects of positive actions taken in, for example, setting up the proposed OCEEH.

24.1 SHIFT HUMAN RIGHTS FOR THESE DISABILITIES FROM 'THEORETICAL' TO REAL

DESPITE the theoretical recognition of these conditions as disabilities by the Ontario Human Rights Commission, the community consultation clearly demonstrated that it is extremely difficult - often, simply impossible - for people living with these conditions to benefit from norms, rights and benefits that have been developed for people comparably disabled by better-known disorders.

We have noted that there is no meaningful recognition of the conditions as *chronic health conditions* (as illnesses) on the ground at any level in public health and social service systems, and that this ripples all the way through the systems and results in lack of appropriate care and services.

We have noted that there is no meaningful recognition of the conditions as *disabilities* at any level in public health and social service systems ripples all the way through systems and results in lack of accommodation and services.

Systemic refusal to enforce disability norms abandons sufferers to extremely negative health and economic consequences. It dooms individuals either to struggle alone for facility-by-facility accommodation, which is expensive and often fails, and sometimes even sets negative precedents; or to abandon their rights altogether.

Central policy directives, even legislation if need be, to bring about the formal recognition of the conditions as chronic diseases and as disabilities, would be the first step. These directives would need to include all health providers and facilities, but also social services, specific disability programs (as listed

above), business and labour agencies (e.g. WSIB) and educational institutions, and the Ontario Human Rights Commission.

These directives must be accompanied by pro-active, relevant educational initiatives that target health professionals, the public and para-public sectors and the general public. Otherwise widespread lack of awareness and prejudice will work as a counterforce to all the changes sought.

24.2 TRACK TRUE COSTS OF THE CONDITIONS INCLUDING AMONG CHILDREN

Because the health care system has not yet integrated care for the CELCs, government as a whole has not yet measured their true costs to Ontario. Still, **certain utilization statistics, already discussed, show that the medical costs are very high while the outcomes are very poor.**

The social costs are extremely high, likely in the billions of dollars. At present we lack data to show the impact of these conditions on the health, well-being, productivity and sustainability (providing the necessities of life, saving for education and retirement) of families. But we do know from our collective body of knowledge about the social determinants of health that when a family member is chronically sick and disabled, and there are no supports for that person or her/his family, consequences to that family have a grave impact on all the measures just mentioned. **These are present and future costs that are growing and real, but remain hidden.**

One of the most disturbing features of this picture is that *children with these problems have been 'invisible' to the system.* When society registers that its children are being affected by a serious disorder (e.g., childhood cancers) societal alarm bells ring, and rightly so. But because we have no capacity in our primary or pediatric systems to spot or diagnose such children, or to screen for risk factors for these conditions, afflicted children remain largely invisible to the system. Chemical sensitivity is generally perceived as 'allergy' or 'emotional disturbance.' ME/CFS and FM are perceived as fatigue and/or pains ascribed to emotional problems. This arises because there is little or no training to pay attention to, identify, refer or treat in family medicine or pediatrics.

So, to date, Ontario has not yet taken social account of the warnings for future health and health expenditures implicit in the spread of conditions. **Leadership by the MOHLTC, in partnership with the proposed OCEEH, in creating initiatives to identify and track these costs is needed** - an immediate task for the new OCEEH research department, and in building partnerships with appropriate departments in related ministries.

24.3 ASSIST MEDICAL PRACTICE TO CATCH UP TO MEDICAL KNOWLEDGE

The CELCs continue as 'invisible' and 'unreal' for many, if not most, practicing physicians, even as those living with them number in the hundreds of thousands, and increase year by year. And because physicians are the gatekeepers, the standard setters and granters of legitimacy in the whole system, when they resist supporting the CELCs, inertia and negative bias are maintained everywhere.

Yet, **there are many interventions, clinically and through social supports, that make a huge positive difference in patients' lives and can reduce both health and social costs. By adopting these, physicians working with people living the CELC would also increase their own sense of work satisfaction, making their own effort/reward ratio much higher.**

Central MOHLTC policy decisions are needed to require medical and other health professional schools to engage specialist experts to develop and include excellent curriculum material and to make this material a mandatory learning component in education, as is required with respect to other diseases, disorders and conditions that have been fully recognized. Also needed is the creation of an OHIP diagnostic code for ES/MCS. Provision of clinical guidelines, clinical pathways, and accepted protocols - a priority task of the proposed OCEEH - would assist the integration of the CELCs into the Chronic Disease Management and Prevention Program.

Devising positive incentives and rewards for physicians who practice responsive and innovative care would help to counteract the perverse incentives now in place.

24.4 FUND AND CREATE INCENTIVES FOR INNOVATIVE NEW SERVICES THROUGHOUT THE HEALTH AND SOCIAL SERVICE SYSTEMS

Health and social services need key supports to effect change - funding, help with innovation, extension of services with special adaptations. Cross-silo cooperation needs support and reward, as exemplified in the Health Links program. Change at the local level clearly depends on policy change and enabling actions from the centre - be it the MOHLTC itself, the LHINS, the OHA, the CCACs and so forth. The following steps would be helpful in this regard:

- Central policy directives to all HSPs regarding needed changes or adaptations to their services and facilities
- Funding the changes required
- Supporting these through provision of education and training of all staff involved
- Creating ongoing incentives for new and/or different ways of doing things.

The proposed OCEEH research department can assist in thinking through such actions, but the MOHLTC itself will have to enact them in the final analysis.

24.5 ALIGN POLICY AND PRACTICE IN PUBLIC AND PRIVATE INSURANCE AND IN OTHER BUSINESS AND LABOUR SERVICES AND SITES

THE record of awards and findings for people with these conditions at the WSIB has not been a positive one. This requires attention by government, with leadership from the Ministry of Health and Long Term Care in collaboration with the Ministry of Labour. It is helpful to recognize some of the issues and pressures.

- ES/MCS invokes liability for injury and chemical regulation, including for regulation of substances that have been acceptable in the past.
- ME/CFS invokes/overlaps with problems of stress and burnout - massive problems, on the rise due to lengthening work weeks and fewer union protections; retards needed policy and decisions.
- FM invokes repetitive strain injuries, other physical injuries.

All these issues are real, and all require thoughtful social policy on a broad scale. Were working conditions better in these respects, it is likely we would see fewer work-related incidences of the CELCs

as well as less intensive disorders. Agencies such as the WSIB need central government guidelines, policy and encouragement to make enlightened decisions, so that individuals and taxpayers do not have to carry the off-loaded costs of unacceptable business practices.

Decisions supportive of those with the conditions would be an important step in making the societal costs of poor working conditions transparent, thus building social and electoral support for improving them.

24.6 REVISE ONTARIO DISABILITY PROGRAMS

WHILE all the disability programs noted in Chapter 17 are important, change to some is more urgent than others. The Ontario Disability Support Program and the Assistive Devices Program deserve special mention. People disabled by the CELCs have special housing needs that are not covered by ODSP and they rarely receive disability accommodation from employers. We look forward to the day that this changes. Regulations need revision to equitably accommodate the specific needs of the three conditions. The same is true for the ADP and for drug benefits. For a person with ES/MCS, water and air filtration devices can be as or more important than, say, a wheelchair is to a person with mobility problems.

However, **the time is now also for a full integration of people with these conditions - and understanding of these conditions - in all the disability-related programs of the MCS.**

24.7 REQUIRE INSURANCE COMPANIES TO PROVIDE COVERAGE

Insurance companies are a very influential force in medical-health nexus, and they are constitutionally resistant to taking on new, chronic and complex conditions. Nevertheless, we do regulate insurance companies, and it is time to include the CELCs as part of what is required of them.

The remedy at hand is for the Ministry of Finance to enforce equitable treatment of the CELCs by insurance companies, with their recognition as diseases and disabilities.

24.8 INVOLVE THE MINISTRY OF THE ENVIRONMENT FOR RECOGNITION AND PREVENTION

Prevention is key, and at this time, almost non-existent. The first step in prevention is reducing the causes of illness. Policy and legislation lag *seriously* behind science and medicine in this regard, and the toll is growing steeper every day. Inter-ministry mechanisms to identify a host of harmful 'everyday' chemicals are urgently needed and new regulatory regimes are long overdue. This is not the place to specify standards, but at a minimum the European R.E.A.C.H.¹⁰⁷ protocols would be a good starting point; and special attention to unregulated chemicals in women's work and domestic environments must

¹⁰⁷ Registration, Evaluation, Authorisation and Restriction of Chemicals (R.E.A.C.H.) is a European Union Regulation of December 18, 2006. It addresses the production and use of chemical substances and their potential impacts on both human health and the environment.

come under scrutiny and control.¹⁰⁸ Government should ensure that effective public awareness campaigns, co-driven by the **Ministry of the Environment** and the MOHLTC are implemented to reduce widespread health hazards and clearly link them to serious negative health outcomes in chronic disease and in disorders of the reproductive, respiratory and cognitive systems.¹⁰⁹

24.9 ESTABLISH MECHANISMS FOR POLICY ALIGNMENT AND REMOVAL OF BARRIERS ACROSS GOVERNMENT ON THE CELCs

To condense the recommendations that flow from these broader descriptions, three ‘at a glance’ charts for the barrier-removing Strategic Enablers follow.

However, when all these recommendations - for services and for policy shifts - are taken together, it certainly appears that a coordinating body is needed to bring these about. So, in addition to supporting the proposed OCEEH, along with its research, policy and education functions, we also wish to recommend that mechanism be established, anchored by the OCEEH but including senior public service officials as indicated by the scope of the measures needed.

MECHANISMS NEEDED FOR MULTI-MINISTRY ALIGNMENT

In addition to establishing the OCEEH and in recognition of the many sites in which alignment is needed to bring about normalized care and support for the CELCs, MEAO recommends the establishment authoritative mechanisms to identify needed action beyond the establishment of the OCEEH and coordinate efforts to effect the changes needed for government-wide alignment.

¹⁰⁸ Burstyn and Phillips, 'Women's Health and Chemicals...', 2009. See Appendix 4 for the complete presentation.

¹⁰⁹ See previous references in Chapter 6, sections 6.1 and 6.2 in particular.

25 THE STRATEGIC ENABLERS – RECOMMENDATIONS AT A GLANCE

25.1 RECOGNIZE CELCs AS CHRONIC HEALTH CONDITIONS (ILLNESSES)

ONTARIO MINISTRY OF HEALTH AND LONG TERM CARE

- Add diagnostic and service code for ES/MCS to existing codes for ME/CFS and FM.
- Require (and support) adequate education for physicians and other health care practitioners.
- 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.

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.

25.2 RECOGNIZE CELCs AS DISABILITIES

Systemic policy alignment for recognition of the three conditions as disabilities

ONTARIO MINISTRY OF HEALTH AND LONG TERM CARE

- As above, and central policy directives to HSPs to provide safe reception (air quality, resting spaces, trained staff) in all facilities.

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.

25.3 PROFESSIONAL, PUBLIC SERVICE AND GENERAL PUBLIC CAMPAIGNS

PUBLIC AND PROFESSIONAL RECOGNITION OF 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.

Would have rapid normalizing function at every level; 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.

26 PRINCIPLES FOR CHANGE

IN investigating the current state of services, identifying unmet needs, gaps in and barriers to care, and in setting forth a set of recommendations for the future, **two sets of principles emerged.**

The first set was developed in order to guide selection and implementation of new services, programs, facilities and initiatives.

The second set reflects the fundamental principles to which most of Ontario health service providers are committed and further, guide the model of care practices in Ontario's Community Health Centres.

26.1 PRINCIPLES FOR CREATING NEW CAPACITY AND ACCESS

RECOGNITION OF THREE CONDITIONS AS CHRONIC DISEASES AND AS DISABILITIES

- Meaningful recognition by MOHLTC and OHRC of CELCs as illnesses and as disabilities, with all the benefits and rights this confers enforcement of norms as per comparator groups
- OHIP diagnostic and service codes for ES/MCS added to those for ME/CFS and FM
- Expression of recognition in policy directives to HSPs and other service providers.

INCLUSION OF PEOPLE LIVING WITH THE CONDITIONS - IN HEALTH AND SOCIAL SUPPORT SYSTEMS, RIGHTS, BENEFITS, PROGRAMS AND POLICIES

- 'Keep Ontarians Healthy' - 'Excellent Care For All Act' - key priorities of the Minister and Ministry of Health and Long Term Care - principles put into practice for these groups
- Inclusion into major programs, e.g., chronic disease management and prevention program, others
- Inclusion into health promotion, primary, secondary and tertiary care facilities
- Inclusion of children as well as adults
- Inclusion of sufferers in all parts of the province
- Inclusion into disability programs and networks and all other rights and benefits for comparable conditions across government and the public sector.

EQUITY FOR PEOPLE LIVING WITH THE CONDITIONS - IN HEALTH AND SOCIAL SUPPORT SYSTEMS, RIGHTS, BENEFITS, PROGRAMS AND POLICIES

A) SIMILAR LEVEL OF CARE TO COMPARATOR GROUPS

- Implements policy intent of Excellent Care for All Act vis a vis 3 conditions
- Put in place basket of services (types and levels of care) for CELCs similar to those for comparator groups (those with diabetes, effects of a stroke, undergoing chemotherapy, late stage HIV-AIDS) similar to/as part of CDMP
- Create system that makes these services accessible (physically, geographically, through knowledgeable referral process)

- Provide liveable supportive living, assisted-living and long-term care facilities for those with the CELCs in need now and in the near future.

B) SPECIAL NEEDS ADDRESSED

- Ensure that services, programs and initiatives achieving a comparable level of care are adapted to special needs of CELCs
- Services delivered in 'condition-competent' ways by staff trained in special needs
- Sites made safe for those with ES/MCS
- ODSP and other disability programs revised to take special needs into account
- Ensure that shelter and supportive housing are addressed as a medical issue for ES/MCS.

NORMALIZATION OF CARE AND SUPPORT

- Broad government, para-public and legal profession awareness campaigns to explain and normalize CELCs, including schools, colleges and universities.

INNOVATION FOR THESE AND OTHER CHRONIC COMPLEX CONDITIONS

- For chronic, complex conditions/diseases - a model that can be applied to others of comparable impact
- For environmentally linked conditions/diseases - specifically addressing chemical and other environmental impacts - modalities that can be useful in treating other diseases with similar underlying or co-morbid factors
- For marginalized, low-mobility, high-fragility populations - a model that can be applied to others.

ENVIRONMENTAL HEALTH

A) HEALTH PROMOTION AND DISEASE PREVENTION

- Develop patient education and screening protocols and implement these throughout primary care system to enable identification of risk and for early intervention
- Partner with education and public health systems in campaigns for public awareness; set up programs for disease prevention and health promotion to reach para-public sector, families, workplaces
- Create active links at senior levels between MOHLTC and MOE to develop, implement and enforce chemical and air quality standards to improve public health generally, and specifically support those with CELCs.

B) NEW EDUCATION AND TRAINING

- Develop and require basic education and training for all health care professionals, prior to licensing and ongoing
- Fund immediate curriculum development for medical schools in recognition of role MDs play in care, and as system leaders
- Approve and fund immediate implementation of provisions (EHC fellowships, AOHC network training) to boost number of primary care providers and specialists within OCEEH framework

- Create education programs for MOHLTC and HSP administrative and program staff to create basic familiarity and capacity relating to given work role
- Provide major increase in funding and support for clinical environmental health programs.

THE RIGHT CARE, AT THE RIGHT TIME, IN THE RIGHT PLACE

A) VALUE FOR HEALTH CARE DOLLARS

- Providing appropriate care in these three ways produces good outcomes and reduced costs by comparison with current state of inappropriate care
- Addresses high system users (5%), and prevents people from becoming part of that group
- Hub for complex cases, treatment with a lodge for residential care, thereby accelerating rapid accurate diagnosis, jump-starting improvement, providing expertise to the whole health care system for faster diagnosis and treatment across the province.

B) AS CLOSE TO HOME AS POSSIBLE

- 'Faster access and a stronger link to family health care'
- Local family physicians educated to screen, assess, diagnose and do basic treatment with clients so fewer specialists are used
- Regional CHC-based 'spokes' for more in-depth assessment, diagnosis and treatment while addressing 'whole person's' social determinants, and access to other health and social services: CHC model both cost and outcome effective

26.2 PRINCIPLES FOR CARE

PERSON AND PATIENT CENTRED

- Incorporates patient empowerment, peer support, self-management - clients are active participants in their care
- Shared decision-making model is employed between the clients and their provider team with an individualized care management plan as an outcome of this model.

COMPREHENSIVE INTERPROFESSIONAL TEAM OF PROVIDERS

- Incorporates a range of professionals and their perspectives working in collaboration to provide health and social services
- Key professions are chosen according to clinical knowledge and patient perspectives as most helpful to the three conditions
- Health professionals on-site in the OCEEH are educated and trained in assisting people with the CELCs.

INTEGRATED ACROSS SYSTEM

- Provides case management, system navigation and advocacy to achieve and integrate services
- Proactively engages with system partners to educate and train on impacts, characteristics and needs of people with three conditions, to assist partners to develop capacity to serve these groups

- Health professionals, including specialists in other areas across the system, are educated and trained in assisting people with the CELCs.

SOCIAL DETERMINANTS OF HEALTH SUPPORTED

- Understands and addresses importance of social determinants of health (economic, environmental, familial, social/community, employment and income, food and housing security, psycho-social, etc.)
- Seeks to provide as many services as possible within the OCEEH
- Provides excellent system navigation and advocacy for services beyond the OCEEH
- Supportive housing, especially for those with ES/MCS, as most important element of care.

COMMUNITY DEVELOPMENT MODEL

- Includes clients in planning of programs and in governance of own care
- Provides community outreach activities to break isolation and create links
- Provides safe physical sites for gathering and activities of clients
- Encourages broader community planning processes to address community needs.

27 THE OCEEH EVOLVING MODEL

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 propose 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, that has fundamentally informed the OCEEH business case proposal.**

27.1 PURPOSE, OBJECTIVES AND PRINCIPLES OF THE OCEEH

PURPOSE

- To serve the health and social needs of Ontarians with complex, chronic environmentally-linked conditions with a focus on:
 - ME/CFS
 - FM
 - ES/MCS
- 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.
- To serve all ages including pre-pregnancy; **children's services integrated into care.**

OBJECTIVES

These correspond to the **'TWO PILLARS'** in the business case.

- To provide **direct services to clients**, and link to others where they exist (corresponds to Pillar 1 of the business case - 'A System of Care with its Foundation in Primary Care').
- To accelerate 'recognition, inclusion and equity' by **assisting in the removal of systemic barriers** (corresponds to Pillar 2 - 'Driving Systemic Level Change').

FROM THE OCEEH BUSINESS CASE PROPOSAL, OCTOBER 2013-10-23

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.

27.2 STRUCTURE

GOVERNANCE

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

FACILITIES AND NETWORK - see below.

27.3 OCEEH FUNCTIONS OVERVIEW

- 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.

27.4 THE OCEEH 'PYRAMID'

➤ 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 plans, on site and/or with PCPs
- Treats cases needing specialist care levels on-site
- **ES/MCS-safe site and ME/CFS & FM-friendly lodge for those who need residential accommodation**

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

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

- Provide trained primary and secondary care providers for day to day care - physicians, nurses, other health professions
- Assess, diagnose, case manage and provide system navigation for clients
- Refer to and collaborate with hub specialists to develop and implement monitor care plan; refer to more local health and social support resources
- Hands-on, on-site treatment with best and promising practices for clients in specially-designed spaces.
- 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 PROVIDERS: REFERRALS AND RESOURCES

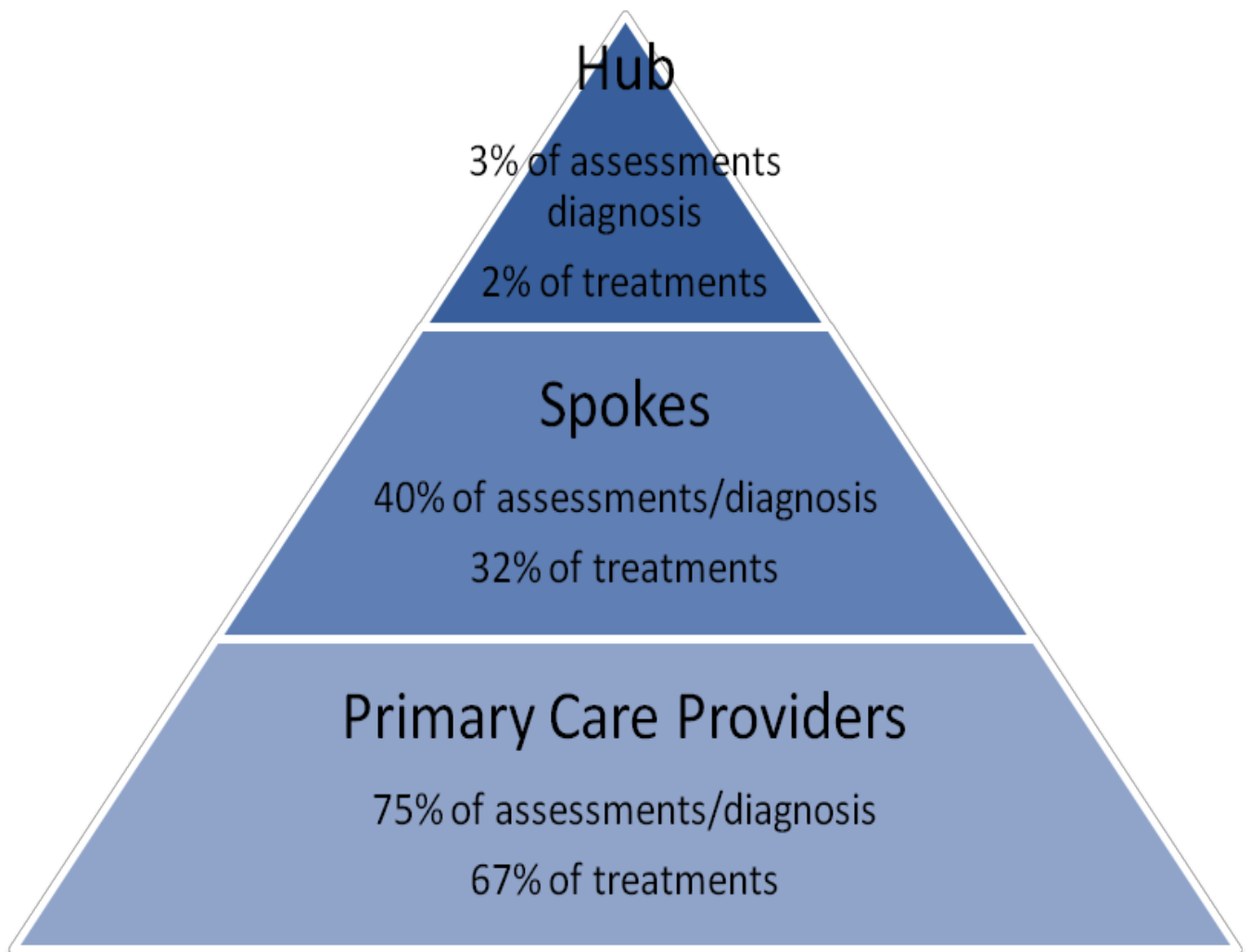
The spokes will become referral and resource centres for health and social service providers in the region

- Communications initiatives, including with partners such as public health, the relevant LHIN and main HSPs to spread the work 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 close to home that all PCPs have a foundation in the conditions
- Phasing in of OCEEH should include targeting of selected PCPS (those who have shown an interest in environmental health to begin) into the CHC educational program so that the PCP pyramid is complete with a larger network at its base.



27.5 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.

27.6 RESEARCH AND EVALUATION

LEAD through 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

27.7 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 for the purposes of promoting recognition, accommodation and vigilance
- Partner with provincial and local public health agencies

➤ 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

27.8 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.

27.9 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.

28 HELPING PATIENTS TO HELP THEMSELVES

ANALYSIS AND KEY RECOMMENDATIONS

NEEDED:

ROBUST PATIENT ASSOCIATION CAPABLE OF MAJOR PUBLIC EDUCATION INITIATIVES

I think if we even had awareness -- doctors have to get to know about the illnesses. HIV had a lot of rallies, because of the discrimination of people who were gay. ME and FM are different from people who have cancer or MS. There are many runs or rides for cancer. If we had a walk for ME -- I was going to suggest this to MEAO, that we have a fundraising. One idea was to have someone dedicate a song for someone who had ME -- a lot of awareness in the media. **TJ FM ME MCS**

We need to decrease the stigmatism with these illnesses to the public -- through media campaigns or have a chronic fatigue, fibromyalgia, multi-chemical sensitivity awareness days or week every year. Information sessions with speakers with these illnesses from out of town, to let people see the real face of these illnesses and reality of it and how it's affecting a lot of the middle-aged people that should be in the prime of their life and working, and how it's affected a big part of the workforce. And especially political action; making aware our MPs and MPPs... of the statistics in this area or in Canada ... and to voice their concern by hopefully getting more funding -- like what we're doing right now -- and to get research done. And for the MEAO to be more made aware of as support; I think that's a huge issue. **Joanne ME**

28.1 ROBUST AND CAPABLE PATIENTS' ORGANIZATION IDENTIFIED AS MAJOR NEED BY COMMUNITY CONSULTATION

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 association like those in place for other, better-recognized, disorders**. Such an organization was seen as corollary and partner to government initiatives and provider services. Yet at this time, such an organization on such a scale and with similar capabilities does not exist.

For over forty years, in a number of jurisdictions in Ontario, across Canada and internationally, there have been attempts to grow patient associations for the CELCs so that they can take their place with other such organizations in the health care nexus and public arena. With very few funds historically, remarkable and far-reaching projects have been undertaken. Some organizations have specialized in centralizing and making accessible research in the CELCs. Others have created print and web-based health, treatment and self-help information projects for sufferers. Many have attempted to reach and work with politicians and public officials to advance the cause of 'improved quality of care and support' - the key purpose of this project.

Yet, though these organizations have stretched their funds to the maximum, drawn on dedicated and skilled volunteer efforts and produced amazing results, **none 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. Patients’ organizations:

- Raise public awareness and create conditions for health promotion and disease prevention.
- Compete for funds for programs, research, bricks and mortar facilities.
- Innovate programs and win the attention of key opinion leaders and decision makers.
- Work hand in hand with experts to provide peer support programs, which are often more effective in self-management than any other type of assistance.
- Are indispensable agents in speaking for groups of people as our systems become more patient-focused and patient led?

Therefore the lack of a robust organization results in deficits on all these levels and fundamentally disadvantages people with the CELCs. Strengthening patients’ organizations, then, becomes another critical factor to overcome in achieving the larger agenda of ‘improving quality of care and support.’

The following key factors play a big role in this current state.

28.2 WHY IS IT SO DIFFICULT TO GROW CELC PATIENT ORGANIZATIONS?

FACTORS INTERNAL TO THE ‘COMMUNITY’

Many of the people who have these conditions are too sick to become active volunteers or take on staff positions, when these are available. **The combination of extreme weakness, fatigue and pain and isolation due to air quality and spatial issues makes it nearly impossible for sufferers alone to sustain and expand organizational efforts.** Since the chronicity of the conditions may be life long, this is a major limiting factor.

In the absence of health and social supports for the vast majority of sufferers, families are often overburdened with care, physically and financially. **Family members who would want to work in patients’ organizations are generally not able to,** or can only participate for very limited hours or periods - not, then, as ongoing volunteers, certainly not as effective substitutes for staff.

Individuals and families with these conditions often face extremely **serious financial challenges, and cannot donate sufficient funds to achieve major program funding,** or even more modest sustaining contributions.

FACTORS EXTERNAL TO THE COMMUNITY - THE CHALLENGE OF STIGMATIZATION

However, these reasons alone, while very significant, cannot explain persistent, cross-jurisdictional failure to raise adequate funds to achieve qualitative growth. There are wealthy people afflicted with these conditions whose resources would allow for donations; there are philanthropic foundations whose mandate should cover support for the CELCs; and there are public sources for non-profit organizations that should be providing support.

Yet that support has not been there.

Our contention is that this is due primarily to the effects, already discussed with respect to health and public service provision, of stigmatization.

The heart of the matter re funding supports is this: no helping organization wants to waste precious resources on people it perceives as - to speak candidly - hypochondriacs, fakers, scammers, malingers or persons who refuse to acknowledge their mental illness - i.e., on 'unworthy' and 'disgraceful' people (definition of stigma). This is also true for individual major donors, who may support many other associations for better-recognized conditions (e.g., cancer, arthritis, MS, HIV-AIDS, autism spectrum disorder).

No prestige or other social benefits accrue to people in working to support stigmatized groups. As a result:

- We have poster-people for breast cancer, mental illness, and even, recently, Lyme disease, but none for the CELCs.
- Some families even abandon sick members because of the stigma.
- Professionals who grant legitimacy, prestige, expertise and funding connections do not step up to do board, fundraising or other support work.
- Advertising agencies do not undertake pro bono campaigns.
- **Affluent patients purchase services where they can and stay deep in the closet - do not 'come out', do not support patients associations, and do not work with opinion leaders and decision makers.**
- Most doctors run the other way because legitimacy is hard to win and professional reputations and even licenses may be on the line.

People are also more likely to give to charity when they are pleased with the service they receive.

Good cancer care likely translates into increased giving to the Cancer Society, for example. People are more likely to give to charity when they have contact with charity staff - so, a volunteer from the diabetes society speaks at a workshop; attendees are more likely to donate to diabetes. Lack of any public services therefore seriously weakens a key motivator in donating.

Heretofore the unbreakable conundrum for patient organizations has been that the patients organizations needed to compete for health care resources so better care is provided, and to be able to provide contact with the public, depend on the disappearance of this stigmatization, which has not been within their own power to effect. Fundamentally, such a change depends on the legitimacy that can only come when the health care system itself recognizes and includes the CELCs. When that happens, perception of causes championed by the organizations of those afflicted will shift. We hope that this will be augmented by a wider recognition among funders of links between chronic, complex health conditions and the environment. However the basic point remains true: the conferral of such legitimacy is entirely dependent, in a public system with physician gatekeepers, and given the history of these conditions, upon the actions of government, specifically and catalytically, the Ministry of Health and Long Term Care.

28.3 CONCLUSION and RECOMMENDATIONS

THERE is a negative entanglement of internal and external reasons that have kept patients' organizations for the CELCs too small to meet societal needs; and that have overburdened volunteer

boards and led to burnout of many teams every few years - a feature of this community. One crucial reason for this burnout is the wall of funding limitation, including major funding rejection, which board teams hit, over and over again. Lack of major funding makes it impossible to move from 'working board' status, good for start-up groups, to 'policy board' status with paid staff, needed for ongoing work and to develop self-sustaining funding.

To reverse this situation, the perception of the CELCs needs to change from 'disgraceful' to 'worthy.' In the Canadian and Ontario context, this requires major shifts in government policy and action. **Funding of the proposed OCEEH and effecting the policy changes suggested by the Strategic Enablers will fundamentally change the landscape, but this will take some time to unfold in full.**

In the meantime, because of the public interest in ensuring organized and informed patient leadership for this population in developing policy and programs and in developing major awareness campaigns, and because of experience in the superior effectiveness of peer support and peer community outreach in connecting with and assisting our target populations, **we recommend:**

RECOMMENDATIONS TO SUPPORT THE DEVELOPMENT OF ROBUST PATIENTS' ORGANIZATIONS

1. Co-locate provincial patient organization with the OCEEH hub and in a number of spokes. Office space and group space should be made available to it.
2. LHINs funding provision, through the OCEEH hub and spokes to commission this organization, in collaboration with experts, to design and hold peer support activities, self-management groups and community engagement initiatives.
3. Include a funding allotment for policy development at the OCEEH to support the patient organization (or organizations) to provide ongoing input into program planning and governance.
4. Include segments delivered by patients' organization representatives in training initiatives undertaken for various health professions to ensure the patient perspective and experience is part of this process.
5. MOHLTC and TC LHIN funding a central partnership with the OCEEH and the patients' organization to help develop government, para-public, professional and public education awareness campaigns of the kinds specified elsewhere in this document.

29 CONCLUSION

WE now conclude our report on a journey that began almost five years ago as a patient-initiated project. It was then joined by physicians and, in the last two years, was partnered with the AOHC with the objective of bringing about a major change and improvement in the quality of care and support for the 586,000 Ontarians living with ES/MCS, ME/CFS and FM - to achieve the normalization our communities are seeking.

It has been an honour and a privilege to work with these partners, to bring together so much important research, and to inform a set of recommendations that, taken together, can move our communities from 'invisibility, exclusion and discrimination,' to 'recognition, inclusion and equity.' None of this would have been possible without the support of the Ontario Trillium Foundation and the Ministry of Health and Long Term Care.

Broadly speaking, we have made recommendations for:

- **Direct services** - through a new and dedicated hub and spoke network of service delivery. These generally correspond to 'Pillar 1' in the OCEEH business case proposal.
- **Policy shifts in the MOHLTC, broader health care system and in relevant and related government ministries** - to effect the complementary delivery of services, benefits and rights, in other parts of the larger health system overseen by the MOHLTC and to remove barriers to care and equity so as to make change effective and meaningful. These generally correspond to 'Pillar 2' in the OCEEH business case proposal.

The proposed **Ontario Centre of Excellence in Environmental Health** brings together both of these types of recommendations.

- **OCEEH hub and spokes have been designed to deliver a number of new and urgently needed services**, to support both client health and the social determinants of health, as much as this is possible; and to act as major resource of expertise with respect to the CELCs to other health and social service providers across the province.
- **OCEEH research, education and policy departments have been designed to effect both a continual improvement in services, and to provide support for policy shifts** needed to bring about broader government and public changes, thus removing barriers to our goal achievement.

We respectfully submit this report, expressing the perspectives and recommendations of patients, in support of the OCEEH business case, with unprecedented hope for the future. We are confident that the steps involved in realizing these goals - steps that involve establishing ways of delivering care and support that will be helpful to many people with other chronic and environmentally-related illness not long into the future - will generate many, many benefits for our citizens, our families, our communities and our province. We know that these steps can strengthen our collective ability to be healthy and productive, now and in the decades to come.

ACKNOWLEDGEMENTS

MANY of the informants whose words paint the vivid and helpful pictures of current-state realities, and whose remarkable wisdom and insights have provided such inspiring visions for change, made heroic efforts to contribute to MEAO's information gathering initiative, despite their poor health. They were full of hope that their experiences, their needs and their ideas would be catalysts for change. MEAO would like to express its gratitude to the people with serious health challenges who made such a major effort to contribute to this important undertaking.

MEAO (meao.ca) is a charitable organization that has been primarily focused on supporting individuals with ME/CFS, and their families, since 1990. In more recent years, in large part due to a growing understanding of the co-occurrence of ME/CFS with FM and ES/MCS, MEAO has sought to become more responsive to the needs of individuals with all three conditions. In 2011, it sought funding from the Ontario Trillium Foundation to prepare a report to 'improve the quality of care and support' for people living with these conditions, and, in the process, to consult them in order to better understand their experiences, so as to make recommendations to improve their health and quality of life. This report is largely the result of OTF's generous funding, linked to Ontario Ministry of Health and Long Term Care's financial support to develop a business case for these solutions.

MEAO would therefore like to express its profound gratitude to the Ontario Trillium Foundation, whose funding made this groundbreaking project possible. Through the team of volunteers and consultants that OTF funding assembled, assisted by OCEEH business case support, Ontarians with the CELCs, numbering more than 560,000 in 2010, have been to provide leadership in ending their exclusion from our health care and social support services.

MEAO's profound and heartfelt thanks, then, also go to the Association of Ontario Health Centres (AOHC), who partnered with MEAO in this project. Executive director Adrianna Tetley embraced the cause of these orphan conditions with a generosity, commitment and expertise that have been truly breathtaking, enriching the depth and quality of the undertaking in countless important and inspiring ways. Sophie Bart and now Leah Stephenson have lent their expertise in developing health and social support organizations, and their impressive project management skills to the undertaking. Dr. Dona Bowers similarly put her decades of experience and indefatigable energy to work for the project, assisting both the Medical Advisory Committee and the Steering Committee of the project to advance the planning of clinical and related services.

MEAO would equally like to express its thanks to the staff physicians of the Environmental Health Clinic - John Molot, Lynn Marshall, Riina Bray, Kathleen Kerr - who constituted the Medical Advisory Committee to the OCEEH business case Steering Committee and provided critical expertise for this groundbreaking effort. Long ago they listened to their patients when others would not and acted on the accumulating evidence of environmental health harms.

MEAO would also like to thank Ian Brunskill, Signy Franklin and Karen Singh of MNP LLP for the remarkable way in which they took a vision, helped the Steering Committee to clarify it and then so skillfully developed the business case that our government needs in order to make our aspirations come to life.

The work to initiate, carry and conclude this project was additionally sustained by a dedicated group of remarkable volunteers without whom it would never have come to pass or to succeed. Ted Ball, a senior health policy consultant who lent his unwavering support to patient advocate efforts as early as 2009, contributed invaluable knowledge, insight, vision, perseverance, political skills and moral support, and facilitated partnerships with AOHC and project funding from the Ministry of Health and Long Term Care. With years of senior, public-sector project development experience, Arvinder Bindra Singh led in the development of the OTF application process and helped to set an astute and prescient agenda for the project. With amazing perseverance and good will, MEAO president Keith Deviney and MEAO Vice President Denise Magi carried the myriad, constantly emerging tasks of an ambitious project that demanded enormous effort and dedication under very challenging circumstances. MEAO board member Erin Deviney lent her considerable editing skills. Eleanor Johnston brought a sense of corporate history to the project. Finally, though not with the project now, in the critical years of work that led up to its official launch Lin Grist gave of her great store of health sector and environmental health expertise in extraordinarily generous ways, and helped to shape the vision of services and model of care.

The mandate and purpose of MEAO's project was to investigate the health and social support needs of Ontarians suffering with the three CELCs, to identify gaps and barriers to care, and from this to craft detailed recommendations, including a model of care and of service delivery, and then to feed this work into the OCEEH business case process. With my own background in environmental health, women's health and health policy, I was hired by MEAO in June 2012 to lead this effort on the patient side. It has been an extraordinary experience working with so many talented and dedicated individuals to bring the project to completion.

In addition to those just mentioned, I would like to thank the team of people who worked on the community consultation process that launched the project and continued for many months into it. M. Ann Phillips, Ph.D. with a background in genetics and participatory action research as well as in environmental and women's health, Erika Halapy epidemiologist, and social documentarist and researcher Paula McKeown all played major roles. Kristine Peruzzi, MEAO's office manager, juggled the many tasks of logistical coordination and data processing with skill, good humour and patience, and contributed many insights into analysis of the results. Margaret Parlor, statistician and President of the National ME/FM Action Network helped in designing the research questionnaire. John Pollard of the York Institute for Social Research provided guidance, and MEAO is very grateful for this assistance.

As for this larger report of which the consultation is a part, I want to thank Erika Halapy, Margaret Parlor and Rohini Peris, president of the Environmental Health Association of Quebec, in particular, for their readings and comments. This report has presented many of the important findings of another of appendix to the OCEEH business case, *The Quantitative Data*, assembled by Erika Halapy in collaboration with Margaret Parlor, and I want to acknowledge those contributions as well. Once again, Kristine Peruzzi's skills and patience in report production were invaluable. And thanks go to my partner, David Fenton, who brought his science research skills and knowledge of environmental issues to the project and strengthened it in innumerable ways.

I would also like to acknowledge Linda Nolan-Leeming, past president of the Environmental Health Association of Ontario (EHAO) and Mary de Bassecourt, its former executive director. The first initiatives to get this project started in late 2008 were made with their blessing and support, and I hope they, along with the current board, will be happy and proud of that most germinal contribution.

One of the key breakthroughs of this project is the understanding of, and commitment to the urgent special needs of those with ES/MCS for safe environments in which to seek health care and social support. The project was very fortunate to have the assistance of David Fujiwara, the principal of Main Street Studio, with his exceptional expertise in truly green design, working on this aspect of the OCEEH business case.

Finally, I want to acknowledge and thank four brilliant, courageous and dedicated physicians - Dr. Wm. J. Rea, founder and director of the Environmental Health Centre- Dallas, Dr. Katherine S. Henry and Dr. Wm. Marcus Spurlock, also of Dallas, Texas, and Dr. Jennifer Armstrong, of Ottawa. Five years ago, these physicians not only helped me survive my darkest hours but also provided the shining example of what could, and what should be possible for those struggling with similar challenges. These physicians exemplify the most remarkable combination of expertise and compassion it has ever been my privilege and good fortune to encounter.

Blazing new trails is always difficult and always asks more than is easy to give. Few take it on. Ontarians suffering from the three conditions, their families and communities, and, indeed, their elected representatives, owe a true debt of gratitude to the organizations and the people who made this project possible.

Varda Burstyn, Paradigm Consultants

October 30, 2013

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APPENDICES

APPENDIX 1 - PARTICIPANTS IN THE DEVELOPMENT OF THE OCEEH BC

The project has a Steering Committee (SC) that oversees the OCEEH BC, guided by the OCEEH BC vision statement. Its purpose is to provide strategic guidance to the project team to ensure the business case meets the requirements of the funder (the MOHLTC) and serves the needs and objectives of the patient/client community and caregivers.

The SC consists of 8 members with a majority of patient/client representatives. The SC includes representation from MEAO, AOHC and two physician representatives from the Medical Advisory Committee (MAC), who are also on staff at the EHC. It also includes a long-time patient advocate with ES/MCS.

The MAC has guided the development of the clinical, research, education and health promotion report by an EHC physician. Members include all the other physicians from the Environmental Health Clinic at Women's College Hospital and a CHC physician in the role of advisor and Chair. In addition, two physicians from Ottawa and Vancouver are advisors.

The OCEEH BC project also has a series of consultants and a project management team. In addition, the project has academic, policy, medical and patient support organization experts providing advice on different aspects of the OCEEH BC. The project team has selected a wide range of advisors to ensure the best possible report is prepared.

Steering Committee

Ted Ball, Co-Chair, MEAO representative
Adrianna Tetley, Co-Chair, Project Executive, AOHC Executive Director
Arvinder Bindra, MEAO representative
Dr. Riina Bray, MAC Liaison, Environmental Health Clinic Medical Director
Keith Deviney, MEAO President
Eleanor Johnston, Patient representative
Denise Magi, MEAO Vice-President
Dr. Lynn Marshall, MAC Liaison, Environmental Health Clinic Staff Physician and Education Liaison

Medical Advisory Committee

Dr. Dona Bowers, CHC Physician, Physician Co-Project Manager, MAC Chair
Dr. Riina Bray, MAC Liaison to the Steering Committee, Medical Director, EHC
Dr. Kathleen Kerr, Staff Physician and Research Liaison, EHC
Dr. John Molot, Staff Physician and Medico-Legal Liaison, EHC
Dr. Lynn Marshall, MAC Liaison to the Steering Committee, Staff Physician and Education Liaison, EHC

Project Advisors (Confirmed)

Dr. Howard Hu, Director of the Dalla Lana School of Public Health, University of Toronto
Mary Catherine Lindberg, Former Assistant Deputy Minister, MOHLTC and Executive Director, Ontario Council of Academic Hospitals
Margaret Parlor, President, National ME/FM Action Network

Dr. Jennifer Armstrong, Medical Director, Ottawa Environmental Health Centre
Dr. Alison Bested, Medical Director, Complex Chronic Disease Clinic, British Columbia

Project Consultants

Varda Burstyn, Paradigm Consultants, Lead Consultant MEAO/OTF project; Consultant/Writer OCEEH model development and final report
Ian Brunskill & Karen Singh, MNP, Healthy Policy Analysts
Signy Franklin, MNP, Business Analyst
Susan Mowbray, MNP, Economic Analyst
Dr. John Molot, Physician preparing clinical report
David Fujiwara, Architect
Erika Halapy, Epidemiologist
Arron Service, CHC Decision Support Specialist

Project Management Team

Leah Stephenson, AOHC Co-Project Manager
Dr. Dona Bowers, Physician Co-Project Manager
Erika Halapy, Project Coordinator
Wendy Banh, AOHC Administrative Assistant

APPENDIX 2 - 1985 ONTARIO REPORT OF THE AD HOC COMMITTEE ON ENVIRONMENTAL HYPERSENSITIVITY DISORDERS

PRESCIENT YET UNIMPLEMENTED RECOMMENDATIONS

SUBMITTED TO THE HON. MURRAY ELSTON, MINISTER OF HEALTH, 1985

Judge G. M. Thomson, J.H. Day M.D., S.E. Evers Ph.D., J.W. Gerrard D.M., D.R. Mccourtie M.D., W.D. Woodward Ph.D. 1985

Recommendation 3: We recommend that research be undertaken to establish the prevalence of environmental hypersensitivity and to determine which of the current tests and treatments being used by clinical ecologists are demonstrably useful.

Recommendation 4: To provide an estimate of the prevalence of environmental hypersensitivity and in the absence of clear diagnostic criteria, we recommend a cross-sectional survey be undertaken using the definition set in chapter two. Because subsequent investigation may prove our definition inadequate, it should be used to identify persons with environmental hypersensitivity for the purposes of this study only. Such a survey would require the cooperation of those Ontario physicians who are members of the Society for Clinical Ecology and Environmental Medicine.

Recommendation 6: The Committee recommends that the research be carried out in a multi-disciplinary investigative and therapeutic environmental unit, established for a defined period of time, for the assessment of environmental hypersensitivity disorders. We recommend that funding for three years be provided, because this is sufficient for completion of the initial investigations; after three years, it might be reasonable to expect that such an environmental unit would sustain itself through other funding sources, e.g., grants obtained in open competition.

Recommendation 12: The Committee recommends that vitamin and mineral supplements and uncontaminated food and water not be included as insured health services. We do, however, recommend that they be included in health care plans that provide coverage for drugs and other treatments when they have been prescribed by a physician, subject to defined financial limits. Moreover, those who receive social assistance should be eligible for payment through the associated drug or food supplement plans.

Recommendation 13: The Committee recommends that Nystatin should be financially supported when prescribed for proven Candida infections. Long-term use of Nystatin should not be supported until it has been demonstrated to be effective and safe.

Recommendation 17: Both the cost per test and the maximum number of tests per year should be established.

Recommendation 18: That the environmental unit undertake production of easily understood pamphlets on the more controversial issues related to environmental hypersensitivity; that it consider issuing a version of the Committee's report that is easily understood by members of the public; that it ensure adequate involvement in conferences, meetings, etc. sponsored by various advocacy and information bodies recently established in Ontario; that it offer assistance in ensuring that documents prepared by school boards, public health units, etc. are accurate and balanced.

Recommendation 19: In view of the special role that can be played by the public health system, by medical officers of health and, in particular by public health nurses, we recommend that special efforts be made to educate and prepare public health nurses to function as a source of current information on environmental illness in general and on environmental hypersensitivity in particular. These nurses are often the first and most accessible source of information for the patient who is confused by conflicting reports elsewhere. Moreover, this role is consistent with the accent on prevention established in the new Health Protection and Promotion Act.

Recommendation 20: We recommend that programs of continuing education be developed to provide practitioners with the scientific information, which is increasing, that both supports and questions recent, highly publicized theories and beliefs in the field of environmental hypersensitivity. As an example of why this is needed, we note that there is a general lack of understanding of the possibility that indoor air can be a contributory factor in illness.

Recommendation 21: All basic social assistance programs, particularly those administered under the Family Benefits Act, should be reviewed to ensure that they recognize how disabled some of these patients are. They should not be deprived of minimal levels of support because of disagreement within the medical profession regarding the causes of their conditions.

Recommendation 22: Because administrators of social assistance programs have wide discretion, the environmental unit should provide expert assistance to appeal bodies such as the Social Assistance Review Board, and to those groups, such as the Community and Social Services Medical Advisory Board, that provide appeal bodies with expert advice.

Recommendation 23: In view of the important role of the individual physician to whom a person seeking social assistance, Worker's Compensation, etc. is referred, those physicians must have current information about environmental hypersensitivity. And must be willing to assess the patient's condition irrespective of any diagnosis attached to it. Here, too, the environmental unit should be involved in selecting such physicians and, in particular cases, should be available to bodies seeking expert advice.

Recommendation 24: Private insurers need to be encouraged to take the same approach in situations where there is a clear disability but some debate as to causation. This is true for those programs that provide payments as replacement for lost income as well as for those that provide assistance for the costs of drugs, extracts and other interventions.

Recommendation 25: At least a portion of the costs associated with special diets and prescribed vitamin and mineral supplements should be claimable through existing food supplement programs and drug plans. Controls would have to be placed on what would otherwise be an extremely open-ended level of support. However, we are satisfied that these measures, when prescribed by a physician after careful investigation and diagnosis, should not be denied those who are simply unable to afford them.

Recommendation 26: In cases of genuine financial need, (i.e., people receiving social assistance) rent supplements or discretionary payments should be available for those seeking to make modest environmental changes.

Recommendation 27: We recommend that the environmental unit collaborate with and assist those involved in the development of special housing programs. Consideration should be given to establishing a nearby apartment, modified for patients who are participants in the environmental unit's research program and are able to reside outside the unit. The unit might also assist some hospitals in making changes to one or two rooms so that patients diagnosed as environmentally hypersensitive would feel less concerned about being hospitalized when they become seriously ill and required emergency admission.

Recommendation 28: That, in the near future, an interdisciplinary conference be held to discuss this report and its recommendations and that conferences of this type should be held regularly as part of the environmental unit's vital educational role.

Recommendation 29: That the Ontario Medical Association consider establishing an environmental health subsection to bring together practitioners interested in this field.

Recommendation 30: The Committee recommends that the environmental unit develop recommendations for curriculum review committees regarding possible curriculum changes in medical schools to ensure that issues relating to environmental illness are part of medical education.

APPENDIX 3 - 'VOICE OF THE PATIENT' USA: ME/CFS IMPACTS

CENTER FOR DRUG EVALUATION AND RESEARCH U.S. FOOD AND DRUG ADMINISTRATION (FDA),
September 2013

The Voice of the Patient: A series of reports from the U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative - Chronic Fatigue Syndrome and Myalgic Encephalomyelitis. (September 2013) Center for Drug Evaluation and Research (CDER), U.S. Food and Drug Administration (FDA).

Key themes: The input FDA received through the meeting and the public docket underscore the chronic and serious nature of CFS and ME. Several key themes emerged from the meeting and submitted docket comments:

- Many patients can pinpoint a specific time in their life when they contracted the disease. Prior to contracting CFS and ME, many patients were highly productive and successful professionals or students. They now struggle with even the simplest aspects of day-to-day living.
- *• Patients struggle daily with their symptoms. Of over 50 symptoms identified, the most frequently mentioned included severe fatigue or exhaustion, impairments in cognitive functioning (e.g., concentrating or processing information), chronic pain, sleep difficulties, blood pressure drops and dizziness, sensitivity to light, sound and temperature and susceptibility to infection. The type, nature and severity of symptoms can vary from patient to patient.
- Post-exertional malaise or PEM (which participants believe is more aptly termed a “crash” or “collapse”) is a severe exacerbation of those cognitive and physical symptoms. A crash can result from even minimal mental or physical exertion, can happen without warning, and can last for days, weeks, months, or even years.
- Patients use or have tried a complex regimen of drug and non-drug therapies to treat their disease and manage their symptoms. *Appendix 4* lists the therapies mentioned during this meeting or in comments submitted to the docket. These treatments have been met with varying degrees of effectiveness, and for some, none is effective. These treatments are often associated with bothersome side effects, which can, for example, exacerbate other symptoms of their disease (e.g., by causing drowsiness).
- CFS and ME takes a devastating toll on the lives of many patients and their families, including loss of careers, decreased quality of family life, social isolation, and feelings of hopelessness.
- Patients are desperate for research and development of treatments that can: (a) better relieve their most significant symptoms and (b) address the underlying cause(s) of their disease.

APPENDIX 4 - WOMEN'S HEALTH AND CHEMICALS: POLICY IMPLICATIONS

Varda Burstyn & M. Ann Phillips, PhD, submitted to

Conference on Women's Health and Environmental Problems, convened by Health Canada and Environment Canada for university and NGO researchers, Feb. 26, 2009, Ottawa

WOMEN'S HEALTH AND CHEMICALS: POLICY IMPLICATIONS

THE CHALLENGES

IN considering the impact of chemicals on women's health, we must recall that to achieve good health a complex number of factors need to be in balance in women's bodies, their lives and their world. These factors come into play even during gestation, because a baby is not a *tabula rasa* and the womb is not a pristine environment. A baby's mother's and father's state of health, the state of the environments they live in and have lived in, and the chemicals they have been exposed to will influence the genetic makeup of their children, the epigenetic expression of their genes and the future health of their children in profound ways. From an ever-growing body of evidence, we know that low doses of many ubiquitous everyday chemicals now found even in the womb, in cord blood, and in breast milk, are having serious and permanent effects on the sexual, neurological and immunological development of fetuses and babies, as well as on other health-related developmental aspects.

Important research, accumulating for more than twenty years shows that almost all previously established "safe" levels of exposure to many everyday chemicals can no longer be considered valid. The levels considered safe were generally determined by testing chemicals one by one in laboratory animals (often adult animals), or by surveying their effects in occupational cohorts of adult males. The idea of 'safe' levels does not take into account the fact that low-level exposures during critical windows of vulnerability can have irreversible developmental and even long term health consequences, or that low doses of certain chemicals can function as hormone-mimickers, nor does it consider the powerful synergistic effects of many chemicals acting together.

Toxicity tests and the resulting establishment of 'safe' levels of exposure, do not take into account the fact that, just as children are more vulnerable to chemical harms than adults, women are in some important ways, more vulnerable than men, with girls and women of child-bearing age being specifically vulnerable. Biologically speaking, women have thinner skin, more chemical-loving body fat and more estrogen receptors that bind to xeno-estrogens, which are becoming widespread in the environment. As individuals, women have different genetically determined abilities to metabolize specific chemicals. We may yet discover that some differences may, to a certain extent, correlate with sex. Metabolic differences are strongly affected by socio-economically shaped physiological factors such as stress, nutritional status, physical activity, chronic chemical exposures, chronic/acute infections and amount of sleep/rest.

Natural and synthetic chemicals do not stay in the mines and factories where they are extracted, produced or processed. Instead they become a part of a web of production and consumption and spread, through indoor and outdoor air, water, soil, food and consumer products to every corner of

communities - the houses, offices, schools and workplaces around the globe. Aboriginal women and working class women living in polluted communities experience significant health problems related to environmental exposures. Women experience greater exposures to the chemicals used in gendered sectors of the labour force, where women are concentrated as workers and which, as a rule, tend to be under paid and less regulated or not at all regulated. These include factories, sweatshops, farms and industrial worksites, where many immigrant women work and are exposed to chemicals about which they have little or no knowledge and no informed consent; offices full of synthetic furnishings with toxic-emitting business machines; retail stores full of chemical dyes, formaldehyde, latex, dry-cleaning and many other chemicals; health care institutions, with a wide array of chemicals including anesthetics, solvents, disinfectants; and cleaning services. Standards of feminine beauty and a mammoth beauty industry have led to the daily application of many very toxic chemicals to the skin, nails and hair of chemicals. This is still a “mostly women” hazard.

Women are also the main housekeepers and family caregivers. They are the ones who work with harsh household cleaners, polishes, drain cleaners and toxic fragranced products, marketed as healthy and wholesome and signs of their love for their families. Women are the ones who primarily take care of children, partners and parents when illness, including environmentally-linked illness, becomes an acute or chronic issue. Research has shown that this role is a major stressor for women, particularly for those with low income and/or employment outside the home, and pre-disposes them to health problems.

Recent research shows that chemicals are directly implicated in virtually all the major “diseases of civilization” both “established” and “new”: diabetes, heart, lung and upper respiratory disease, gastrointestinal diseases, obesity, endocrine disorders (thyroid, adrenal, pituitary, pancreatic, ovarian, testicular), rheumatoid arthritis, lupus and fibromyalgia, Alzheimer’s and Parkinson’s diseases, autism spectrum disorders and other neurological problems including attention deficit hyperactivity disorder (ADHD), depression, anxiety and panic disorders, multiple sclerosis, ME-CFS and multiple chemical sensitivities. Of particular interest when considering chemical exposures and the health of reproductive and post-menopausal women are multisystem and overlapping diseases like sick building syndrome, ME-CFS, fibromyalgia and multiple chemical sensitivities or, as its officially called in Canada, environmental Sensitivities (MCS-ES).

Without question, the sexist bias of medicine is demonstrated by the fact that for a long time gendered environmental illnesses fell outside the accepted boundaries of biomedical illness. Many are still unrecognized or contested, which means that women not only suffer from them, but cannot achieve quality care for their ailments. Statistics Canada estimates that at least 2.5 per cent of Canadians have been diagnosed with MCS-ES – about one million people -- a disability classed by the World Health organization as a disease of toxic poisoning. Roughly 80 per cent are women. Yet provincial health care systems do not have a billing code for this illness, nor standardized treatment or safe facilities for treatment. Sick building syndrome also deserves special mention as an illness in which women's experience of poor health has been downplayed and psychologized. As with these other illnesses, acknowledging their link to chemicals points urgently to the need for government to revise occupational hygiene standards set by business and supported by government. There is a need to review and revise ambient air standards for non-industrial workplaces, including all government workplaces (federal, provincial and municipal).

Chemically induced health problems in women are so widespread, particularly among Aboriginal and low-income women that we have not yet even begun to truly tally them. There is no longer any way to hive off chemical illness from illness in general, no way to minimize the devastating effect of our

“chemical life” and no way to avoid the need to act rapidly and comprehensively to protect women and their families.

POLICY RECOMMENDATIONS

IDENTIFICATION AND REGULATION OF PRODUCTION AND UTILIZATION OF CHEMICALS

Objectives: Rapidly develop mechanisms to identify and reduce the overall chemical footprint to address the ubiquitous nature of women’s exposure to chemicals and expand and improve the knowledge base and make it accessible to women:

- Increase funding and personnel quotas within the appropriate agencies responsible for the identification and assessment of potentially harmful chemicals including the health effects related to low-dose exposures, compound effects of multiple exposures to different chemicals. Chemicals such as endocrine disruptors and those that are capable of reproductive, neurological, immunological, multigenerational and disease-specific effects should be clearly identified in the assessment process.
- Ensure that industry supplies as complete as possible a dataset on a substance when the substance is nominated for use in the Canadian market. This would allow government assessors to better assess the toxicity of chemicals through their independent process, recommend necessary changes hopefully with regulations and not voluntary actions. Government must be aware of potential hazards to human health and the environment even at low levels of usage and exposures.
- Ensure that air and water borne chemicals present in women-dominant arenas, including workplaces, are given priority in this process.
- Require the *compulsory, full disclosure labeling of all chemicals in consumer and commercial products*, including those used by women at work and at home. Full disclosure means technical name of product and its health risks, e.g. ‘cancer, lung disease, endocrine disruptors, neuro-developmental toxins, gastrointestinal disorders.’ Ensure full compliance to these regulations and that any deviations such as misleading labeling, whether by omission or commission, are punishable with fines high enough to act as effective incentives to honesty.
- In addition to Health Canada’s current website on chemicals and health, create a comprehensive, user-friendly government website for information on chemicals and health that would include basic general knowledge on chemicals in everyday usage and associated risks and a guide to reading full-disclosure labeling, in plain language and organized in every day categories, enabling women access to chemical information, so informed decisions are possible.
- Update federal and provincial standards for air and water quality to reflect the current knowledge of health impacts of air and water contaminants i.e. stricter emissions standards, better and more frequent testing, better filtration methods, stricter point source protection regulations to reduce pollution at the point of production and stricter regulations regarding the use of the resultant sludge on agricultural lands. Strict standards should be set for levels of radionucleotides in drinking water and mandatory warnings and advice should be given to the public where levels

exceed these standards, particularly in Aboriginal communities in proximity to uranium mines and communities in proximity to nuclear power plants. Monitoring for radionuclides should occur daily for drinking water locations near nuclear power stations and alternative water supplies should be provided when radionuclides are detected in excess of standard. More stringent air monitoring of local industries in proximity to Aboriginal communities with high levels of exposures to toxic chemicals e.g. Aamjiwnaang First Nations.

- Rapid completion of Canadian Environmental Protection Act (CEPA) evaluation of the 4,300 industrial substances on the domestic substances list identified as requiring further assessment, in particular the 500 high priority and 2,600 medium priority items.
- Revision of the Pest Control Products Act to include reproductive and developmental health and women-protective measures. Through a “Healthy Pest Control” website, publications and social marketing campaign, Health and Environment Canada in partnership ensure the public is equally informed of alternative pest control practices.
- Revision of the Hazardous Products Act to be proactively protective and preventive rather than reactive; special emphasis on products often used by women so that the standards that are devised to protect us are reflective of the best available standards with reduced exposure limits or levels. This initiative would require a comparison to European Union standards (revised upwards where better ones exist).
- Require that determination of toxicity status under CEPA prevents use of a chemical in consumer products, especially cosmetics, personal care, cleaning and air ‘freshening’ products and when in use in an industrial or commercial setting, safe substitution for such substances be investigated and employed. Also, occupational health and safety as well as best management practices appropriate for these substances must be followed, including appropriate venting and/or containment
- At the local level, augment monitoring and enforcement of anti-smoking, anti-idling and pesticide by-laws; institute anti-smoking guidelines for multi-unit dwellings and commercial /residential buildings.

Initiate programs to proactively remove toxic chemicals and replace with healthy alternatives:

- Adopt ‘healthy products procurement policies’ in all government offices and agencies (women are the majority workforce) – e.g. non-toxic cleaning and VOC- free building materials, soy-based inks, chlorine free paper, organic food, etc. Many schools and daycares have adopted such policies, with great immediate health outcomes.
- Create tax and direct subsidy incentives for enterprises in the private sector to institute such policies, across all economic sectors including manufacturing, commercial, agricultural, resource extraction and energy production. Devise system of economic disincentives for enterprises employing unhealthy chemicals.
- Fast-track economic incentives for ‘green chemistry’ businesses to develop benign alternatives to chemicals associated with health harms, with priority funding for chemicals that women are

specifically exposed to; and to ensure that green chemistry includes the process as well as the actual product. Develop a social marketing campaign to educate consumers about health benefits of reducing their chemical footprint, using non-toxic products and buying green.

HEALTH AND SOCIAL SUPPORTS TO THOSE HARMED BY CHEMICALS

Objective: Facilitate the development of a paradigm shift to reduce chemical exposures through alliances across government departments and sectors, build capacity in health and social services and communities to respond to chemically-linked health problems and improve women's health.

- Institute and support 'Community Right to Know' laws and capacities, particularly in Aboriginal communities. Improve labeling of products and other information available to consumers regarding chemicals in products. Improve information available to residents regarding domestic and commercial indoor air quality, small point source and larger industrial sources of environmental contamination in their communities – create meaningful full disclosure with respect to air and water quality, include lowering of levels for releases and mandatory reporting use and release for some substances used at lower levels, which still pose risks to women's health.
- Empower women and health professionals by publicizing the user-friendly government website for health-related chemical information (see above) through all health, social service and public education agencies, offices, universities and institutions.
- Health Canada fund a registry for all environmentally-related illnesses, including cancers, 'birth defects', fertility issues, endocrine disorders, and mental health issues.
- Improve and increase information on environmental health effects and reduction strategies among physicians, nurses and allied health professionals; mandate creation or expansion of environmental health programs, with gender-specific content, in medical and nursing education, and in the curriculum of the regulated health professions.
- Establish capacity within health-care systems to identify and treat chemically related illnesses, ensuring full funding and high priority for women-dominant health conditions and diseases; create capacity in public health systems to identify and respond to air and water pollution, and take aggressive preventive action; establish better programs to support women who are chronically ill from chemical harms, or are providing care to such people.
- To supplement WHMIS with information so that workers can easily relate to chemical hazards, their health effects and effective exposure reduction strategies; create educational programs for officials in charge of programs such as worker's compensation, disability pensions and other relevant labour-management issues. To be aware of the subtle yet meaningful effects of toxic chemicals as a result of chronic low-level exposure and that the 'science-based approach' to quantify occupational illness is often exclusive of some illnesses that are apparently outside of the government's radar of occupationally-linked illnesses.
- Workplace exposures: Workers live in Communities Too! Adjust/reduce/ban levels of permissible exposures to chemicals that are known to have reproductive, developmental, mutagenic, carcinogenic or other health effects. Regulate women's workplaces (such as nail salons and

cleaning businesses) diligently. Institute permissible exposure limits to reflect toxicity of exposure to the mixtures of chemicals used in workplaces rather than to individual chemical exposures. Regulators must be made more aware that multiple exposures to the same substance as well as exposure to mixtures are common in a workday and assessments need to reflect these situations in a meaningful manner. For nail salons, these toxic substances need to be listed on Health Canada's Cosmetic Ingredient Hotlist as prohibited substances.

- Ensure safe public housing is available as a preventative and proactive measure and priority for such housing be given to those injured by exposure to chemicals.
- Address issues of environmental justice whereby the intersection of gender, race, class and culture makes it more likely that Aboriginal women, low-income women, immigrant women and women of colour, live in communities with exposure to higher levels of environmental contaminants and work in places that often do not see the need to abide with regulations, instead focusing on the bottom line – profit.

APPENDIX 5 - EXCERPTS ON 'PSYCHOLOGIZATION' OF THE CELCs, JOHN MOLOT MD FCFP, OCEEH ACADEMIC AND CLINICAL PERSPECTIVES

- **Psychologization**

Opinion articles still appear in respected medical journals in support of the psychogenesis of ME/CFS, FM and ES/MCS, despite the fact that the citations frequently used to support the argument are outdated.

Significant methodological errors also persist. For example, studies which positively demonstrate the efficacy of graduated exercise for ME/CFS often use case definitions which capture other fatigue-related conditions, such as depression and unexplained chronic fatigue. These latter conditions respond somewhat favorably to exercise, but ME/CFS does not.

ME/CFS patients do have an increased prevalence of current mood disorders, primarily major depression, but it is unclear whether the patients had these conditions before or after they became ill with ME/CFS. Some doctors use this fact to insist that ME/CFS is primarily a psychiatric illness.

Mood disorder has been added by the Canadian Fibromyalgia Guidelines Committee to the latest diagnostic criteria for FM with scant evidence from a tertiary care sample.

Because there are currently no generally recognized biological markers for ES/MCS and the pattern of sensitivities does not match the traditional toxicology paradigm, psychological theories to explain ES/MCS and psychotherapeutic treatments have been suggested since the 1980s. They were roundly criticized for poor methodology. For example, one early study of 50 cases concluded that because at least half the patients were still symptomatic even when avoiding chemical pollutants, ES/MCS cannot exist.

Studies report associations of ES/MCS with panic disorder and major depression. However, association does not mean that there is a cause and effect relationship. In fact, mood disorders are also more likely to be comorbid with other physical diseases such as allergy asthma, diabetes and cardiovascular disease.⁷²³ Nevertheless, the theories of psychogenic etiology due to false attribution, i.e., panic disorder, chemical phobia and agoraphobia, continue to be offered in the medical literature. Some authors have opined that ES/MCS "is a belief characterized by an over-valued idea of toxic attribution of symptoms and disability, fulfilling criteria for a somatoform disorder and a functional somatic syndrome." These same authors postulate that to work with ES/MCS patients, "one must understand the dynamics of brainwashing, including the effects of iatrogenic influence and the individual's predisposition and susceptibility to it."

Another recently published article refers to these patients as hermits. The authors claimed to have conducted a "literature review" of case reports of ES/MCS and compared their "recluse-like behaviour" resulting from environmental sensitivities to the behaviour of ancient hermits. The bias in this report is reflected by their "literature review", which only searched media articles, blog posts, and online books and forums in order to generate the following quotes: "This is not a lifestyle I choose", "I have no choice", "Nobody would live like this if they had a choice", and, "Do you think I would have given up a satisfying life ... if I had a choice?" Unfortunately, the authors used these quotes to conclude, without

any substantiation, that ES/MCS patients have a compulsion to flee, like hermits. What was actually expressed in these case reports is the absence of choice due to symptom provocation in certain environments, and the subsequent negative impact on quality of life in order to maintain health.

If one wishes to study how individuals experience their own problems in the life situation in which they find themselves, interviews can offer a method to obtain such information. They are used as a means of understanding how people experience their world and to gain insight into their perceptions, experiences and emotions. However, the goal of the interview is to obtain nuanced descriptions of various aspects of the interviewee's life-world, and to analyze the data according to qualitative research protocols. Qualitative content analysis of interview data should follow a set procedure: (a) audio review, (b) reading through transcriptions, (c) discussions among investigators regarding key elements of participants' perceptions, (d) determination of conceptual themes, and (e) assignment of relevant responses to appropriate thematic constructs.

In comparison to the lack of science and open bias apparent in the above article comparing ES/MCS patients to hermits, consider the results of a published interview study, in which ES/MCS subjects were first identified objectively by capsaicin inhalation challenge. The interviews were analyzed using qualitative content analysis, which revealed the following themes and suitable quotes:

Limitations in one's life situation

- *I simply can't enter that shop, my eyes smart ...I have to leave immediately.*
- *We have someone who uses ... it's the smell that makes me feel so bad and I avoid her ever since she got that perfume.*
- *We have relaxation exercises in that room in the morning and it ended up with me leaving; I couldn't take part because we were supposed to lie down on the wall-to-wall carpet and my throat started to catch and I felt bad.*

Lack of understanding from others

- *You can be sitting at a meeting where people reek of strong perfume and an undertone of sweat. And it attracts a bit of attention when you have to inhale and all that and, well...I know that people have thought that I was being fussy.*
- *The staff come back from their breaks and smell of smoke and coffee and what-not and it's...I haven't told anyone that they're causing me any problems...you'd just look like a whiner.*

In support of the psychogenic theory is the argument that we are in support of the psychogenic theory is the argument that we have been unable to demonstrate chemical sensitivity with double blind challenge studies. However, blinding the chemical challenge is impossible, without using another chemical to mask it. Nevertheless, a published, systematic review of all the challenge studies concluded that MCS cannot exist. There was no transparency of authors' financial involvements in this systematic review. Furthermore, there was no explanation as to why several previously published challenge studies using capsaicin to demonstrate chemical sensitivity were not considered.

Based on a reductionist, psychogenic model, published suggestions for treatment have included cognitive behavioral therapy, relaxation therapy with deconditioning and psychotherapeutic

medications. However, the level of evidence demonstrating any efficacy of these treatments for ES/MCS is almost non-existent since only a few case reports of improvement have been published in the past 30 years. Furthermore, the fact that relaxation therapies may possibly have a biological impact on patients with ES/MCS does not verify that it is a psychiatric illness. These techniques also have a positive effect on biological entities, such as asthma, hypertension and migraine, and can significantly lower blood glucose, cholesterol and hypertension.

While skeptics and proponents often frame the debate in a dualistic or reductionist manner, claiming that chemical intolerance is either completely psychogenic or completely toxicogenic, accumulating data strongly suggests that a multifactorial process underlies these conditions. The Nova Scotia Environmental Health Center integrates relaxation therapies with avoidance of chemical triggers, elimination diet for food sensitivities, low dose allergen therapy, intravenous therapy, and pacing and energy management strategies when necessary. This is consistent with the systems medicine model.

Although there is no objective evidence of direct psychogenesis, some people disbelieve patients reporting of symptoms of ME/CFS, FM or ES/MCS, diminish the significance of their symptoms and experiences, and dismiss even the possibility of the existence of the conditions.

Thus far, treatments routinely used for ME/CFS and ES/MCS are consistent with their definitions. Patients with ME/CFS have fatigue that is exacerbated with minimal exertion, with prolonged recovery. Therefore, the patients are instructed how to pace, with reported improvement in quality of life. Patients with ES/MCS have symptoms exacerbated by chemical exposures, which are relieved after they are no longer exposed. Treatment is the provision of support and education to maintain environmental control and avoidance, which seems to provide the highest patient satisfaction. There are more treatments available for fibromyalgia, but they are highly variable, and long-term prospective observational studies have found that patient outcomes are typically poor. Almost half the patients with fibromyalgia are likely to be dissatisfied with treatment.

The basic requirements for care of patients with ME/CFS, FM and ES/MCS is the same as those with other chronic diseases; to provide support, improve outcome and quality of life, increase function and independence, and decrease their use of the healthcare system other than periodic monitoring. If patients avoid physicians, they may neglect to get timely treatment for other significant treatable conditions.

APPENDIX 6a - COMMERCIAL VERSUS HEALTH INTERESTS: 'MULTIPLE CHEMICAL SENSITIVITIES UNDER SEIGE'

MULTIPLE CHEMICAL SENSITIVITIES UNDER SIEGE¹¹⁰

Ann McCampbell, MD

Chair, Multiple Chemical Sensitivities Task Force of New Mexico

Movies like *Erin Brockovich* and *A Civil Action* depict the true stories of communities whose members became ill after drinking water contaminated with industrial waste. Their struggles clearly show how difficult it is for people to hold corporations responsible for the harm they have caused. Whether individuals are injured by exposures to contaminated air or water, silicone breast implants, cigarettes, or other chemicals, their quest for justice is usually a David versus Goliath battle that pits average citizens against giant corporations.

When confronted with the harm they have caused, corporations typically blame the victims, deny the problem, and try to avoid responsibility for the harm caused. The corporate response to people with multiple chemical sensitivities (MCS) has been no different. People with MCS are made sick from exposures to many common products, such as pesticides, paints, solvents, perfumes, carpets, building materials, and many cleaning and other products. But the manufacturers of these products would rather silence the messenger than acknowledge the message that their products are not safe.

To that end, the chemical manufacturing industry has launched an anti-MCS campaign designed to create the illusion of controversy about MCS and cast doubt on its existence. What has been said about the tobacco industry could easily apply to the chemical industry regarding MCS, that is, "the only diversity of opinion comes from the authors with ... industry affiliations (1)."

It is a credit to the chemical industry's public relations efforts that we frequently hear that multiple chemical sensitivities (MCS) is "controversial" or find journalists who feel obligated to report "both sides" of the MCS story, or attempt to give equal weight to those who say MCS exists and those who say it does not. But this is very misleading, since there are not two legitimate views of MCS. Rather, there is a serious, chronic, and often disabling illness that is under attack by the chemical industry.

The manufacturers of pesticides, carpets, perfumes, and other products associated with the cause or exacerbation of chemical sensitivities adamantly want MCS to go away. Even though a significant and growing portion of the population report being chemically sensitive, chemical manufacturers appear to think that if they can just beat on the illness long enough, it will disappear. To that end, they have

¹¹⁰ <http://annmccampbell.com/publicationswritings/publication-1/>. Published in *Townsend Letter for Doctors and Patients*, January 2001, Issue #210. Reprinted with permission from *Townsend Letter*, www.townsendletter.com

launched a multipronged attack on MCS that consists of labeling sufferers as “neurotic” and “lazy,” doctors who help them as “quacks,” scientific studies which support MCS as “flawed,” calls for more research as “unnecessary,” laboratory tests that document physiologic damage in people with MCS as “unreliable,” government assistance programs helping those with MCS as “abused,” and anyone sympathetic to people with MCS as “cruel” for reinforcing patients’ “beliefs” that they are sick. They also have been influential in blocking the admission of MCS testimony in lawsuits through their apparent influence on judges.

Like the tobacco industry, the chemical industry often uses non-profit front groups with pleasant sounding names, neutral-appearing third party spokespeople, and science-for-hire studies to try to convince others of the safety of their products. This helps promote the appearance of scientific objectivity, hide the biased and bottom-line driven agenda of the chemical industry, and create the illusion of scientific “controversy” regarding MCS. But whether anti-MCS statements are made by doctors, researchers, reporters, pest control operators, private organizations, or government officials, make no mistake about it – the anti-MCS movement is driven by chemical manufacturers. This is the real story of MCS.

CHEMICAL INDUSTRY

In 1990, the Chemical Manufacturers Association (now the American Chemistry Council) vowed to work to prevent the recognition of MCS out of concern for potential lost profits and increased liability if MCS were to become widely acknowledged (2). It specifically committed to work through physicians and medical associations to accomplish this, stating that it was critical to keep physicians from legitimizing MCS. Unfortunately, this plan has been relatively successful. The industry has enlisted the aid of vocal anti-MCS physicians who promote the myths that people with MCS are “hypochondriacs,” “hysterical,” “neurotic,” suffer from some other psychiatric disorder, belong to a “cult,” or just complain too much. Most of these physicians work for industry as high-paid expert witnesses although their financial ties are usually not disclosed in their journal articles, interviews, or speaking engagements. Therefore, many people, including those in the health care profession, are often led to believe that these physicians’ opinions reflect an honest appraisal of MCS rather than the chemical industry’s agenda. At least one industry expert witness has authored two anti-MCS position papers for prominent medical associations. It is easy to see why these papers are biased against MCS and how by helping to combat MCS in the courts, these position statements are quite lucrative for industry and expert witnesses alike.

PHARMACEUTICAL INDUSTRY

The pharmaceutical industry is also involved in the effort to suppress MCS. Drug companies, which usually work with the medical profession to try to help patients, are working to deny help for those with MCS. This is extraordinary, but can be explained by the fact that the pharmaceutical industry is intimately linked to the chemical industry. That is, many companies that make medications also manufacture pesticides, the chemicals most implicated in causing MCS and triggering symptoms in people who are chemically sensitive. For example, Novartis (formerly Ciba-Geigy and Sandoz) is a pharmaceutical company that makes and sells the widely used herbicide atrazine (3). This helps explain why a Ciba-Geigy lobbyist submitted material to a New Mexico legislative committee in 1996 opposing all legislation related to MCS and declaring that the symptoms of people with MCS “have no physical origins” (4). The legislation being proposed would have, among other things, funded a prevalence study of MCS, an information and assistance program and “800” telephone number, hospital accommodation guidelines, and an investigation of housing needs of people with MCS (5).

Novartis is also a large manufacturer of the organophosphate insecticide diazinon (3), a neurotoxic pesticide currently being reviewed for its safety by the U.S. Environmental Protection Agency (6). The EPA recently banned a related organophosphate pesticide, chlorpyrifos (commonly sold as Dursban), from household uses because of concern about its toxicity, especially to children (7). The pharmaceutical company Eli Lilly used to be a part of DowElanco (now Dow Agrosience), the primary manufacturer of chlorpyrifos (8). Aventis (formerly Hoeschst and Rhone-Poulenc) manufactures the allergy medicine Allegra as well as the carbamate-containing insecticide Sevin (active ingredient carbaryl) (9). Monsanto, known for making Roundup and other herbicides, is a wholly owned subsidiary of a pharmaceutical company called Pharmacia (10, 11). Zeneca manufactures pesticides (12) and pharmaceuticals (AstraZeneca), including drugs to treat breast and prostate cancer, migraine headaches, and epilepsy (13) — illnesses whose cause or exacerbation have been linked to pesticide exposures.

Pfizer and Abbott Laboratories make both pharmaceuticals (14) and pesticides (15), while BASF makes pharmaceutical ingredients and pesticides (16). Even Bayer, famous for making aspirin, manufactures the popular neurotoxic pyrethroid insecticide Tempo (active ingredient cyfluthrin) (17). Novartis, Ciba, Dow, Eli Lilly, BASF, Aventis, Zeneca, and Bayer are all members of the American Chemical Council (formerly the Chemical Manufacturers Association), as are other pharmaceutical manufacturers, such as Dupont, Merck, Procter & Gamble, and Roche (18).

The pharmaceutical industry has been able to spread misinformation about MCS and limit the amount of accurate information received by physicians and other health care providers through its financial influence over medical journals, conferences, and research. It is well known that magazines containing cigarette ads are less likely to publish anti-smoking articles. Similarly, because medical journals rely on pharmaceutical advertisements for funding, they are not likely to publish positive MCS articles. In fact, researchers supportive of MCS have long complained that it is very difficult to get their studies published in the medical literature. Pharmaceutical companies may also influence medical organizations such as the American Medical Association, whose funding relies in large part on the sales of drug advertisements in its journals (19), and the American Academy of Family Physicians, whose major donors are drug companies (20).

Corporate financing of medical conferences has also been shown to bias the information presented (21). Since continuing medical education is becoming increasingly reliant on corporate sponsorship, industry influence over physician education is a growing concern in the medical community (22). Other ways the pharmaceutical industry can influence physicians are also of concern. In a 2000 Journal of the American Medical Association article (23), the author states that “physicians have regular contact with the pharmaceutical industry and its sales representatives, who spend a large sum of money each year promoting to them by way of gifts, free meals, travel subsidies, sponsored teachings, and symposia” (p. 373). The study concludes that “the present extent of physician-industry interactions appears to affect prescribing and professional behavior and should be further addressed ...” (p. 373). This is especially true regarding the effect that the pharmaceutical and chemical industries have had on physicians’ professional behavior in response to MCS. Because they do not receive appropriate and accurate information on MCS during their training or from medical journals and continuing education courses, physicians have been largely unprepared to deal with chemically sensitive patients. As a result, their responses to MCS patients have tended to range from dismissive to blatantly hostile.

One example of the pharmaceutical industry’s direct attempt to present anti-MCS information at a medical conference was at the 1990 meeting of the American College of Allergy and Immunology. Sandoz (now Novartis) was scheduled to sponsor a one day workshop that characterized people with

MCS as mentally ill (24). This company was a large manufacturer of pesticides and pharmaceuticals (25), including anti-psychotic, anti-depressant, and sedative medications (14). Therefore, Sandoz stood to benefit both from pesticides being exonerated as the cause of MCS and from people with MCS being treated with psychiatric drugs. As it turned out, people with MCS outraged by the workshop risked their health to protest the event and were able to shut it down (26).

The pharmaceutical industry also influences research on MCS. First and foremost, it is not pursuing research on MCS (other than to perhaps fund a few studies to try to discount it), despite being a major source of funding for medical research to help those with other diseases. Secondly, as was evident when the Ciba-Geigy lobbyist opposing funding for MCS research in New Mexico, the industry is not only refraining from doing research on MCS itself but is attempting to block research by others as well.

A recent editorial in the New England Journal of Medicine outlined a myriad of ways that financial ties with the pharmaceutical industry may influence physicians (27). “The ties between clinical researchers and industry include not only grant support, but also a host of other financial arrangements. Researchers serve as consultants to companies whose products they are studying, join advisory boards and speakers’ bureaus, enter into patent and royalty arrangements, agree to be the listed authors of articles ghost written by interested companies, promote drugs and devices at company-sponsored symposiums, and allow themselves to be plied with expensive gifts and trips to luxurious settings” (p. 1516). In fact, some industries, including the tobacco industry, have paid authors up to \$10,000 to publish letters in high-profile scientific journals (28, 29). The author of another New England Journal of Medicine article wrote, “The practice of buying editorials reflects the growing influence of the pharmaceutical industry on medical care” (30). Since these conflicts of interest are increasingly encroaching on the medical profession in general, it is highly likely that some of them apply to physicians opposed to MCS as well.

ENVIRONMENTAL SENSITIVITIES RESEARCH INSTITUTE

Several nonprofit organizations and trade associations sponsored by the chemical industry are particularly active in opposing MCS. For example, lobbyists for RISE (Responsible Industry for a Sound Environment), a pesticide trade association, and the Cosmetic, Toiletry, and Fragrance Association testify against MCS each year in the New Mexico legislature. The Chemical Specialties Manufacturing Association, which represents companies who manufacture and distribute home, lawn and garden pesticides, antimicrobial and disinfectant products, automotive specialty products, waxes, floor finish products, and many types of cleaners and detergents, has also submitted anti-MCS comments to the NM legislature (31). And individuals from a lesser-known organization calling itself the Advancement of Sound Science Coalition published an opinion-editorial in two New Mexico newspapers several years ago that was critical of the positive steps being taken by the New Mexico legislature on MCS (32, 33).

The leading opponent of MCS, however, is unquestionably the Environmental Sensitivities Research Institute (ESRI). This corporate-financed nonprofit organization was founded in 1995 specifically to combat MCS. According to MCS Referral and Resources, ESRI was founded to “serve the needs of industries affected by MCS litigation” (34). But since ESRI tends to be secretive about its membership, board members, and activities, it is hard to know exactly who is involved with ESRI and what the organization does. However, it is known that ESRI is primarily supported by its member companies and trade associations, who pay \$5000 or \$10,000 a year in annual dues (35, 36). It is also known that the past board of directors have included representatives or employees of DowElanco, Monsanto, Procter

and Gamble, RISE, the Cosmetic, Toiletry and Fragrance Association, and other chemical companies and trade associations (36).

Although ESRI has in the past claimed to be a scientific and educational organization dedicated to the open exchange of scientific information (37), this is belied by its decidedly anti-MCS views. ESRI's bias against MCS is evident in its fact sheet that claims that MCS is a "phenomenon" that "defies classification as a disease" (38). It appears that this organization's main work consists of disseminating anti-MCS literature, holding anti-MCS conferences, intervening in legal and government affairs, and otherwise trying to impede progress on MCS. And despite its name as a research institute, ESRI has only recently begun to award small MCS research grants. It will be a great surprise, however, if the majority of these studies do not support a psychological basis for MCS.

Besides lacking objectivity, some of ESRI's activities demonstrate questionable ethics. For example, ESRI published an "advertorial," advertisements made to look like legitimate news stories, in newspapers around the country that stated that MCS "exists only because a patient believes it does and because a doctor validates that belief." Then, according to Albert Donnay of MCS Referral in Resources, ESRI anonymously tried to get the American Academy of Family Physicians Foundation (AAFPF) to endorse its anti-MCS brochure (36). Fortunately, the AAFPf withdrew its support for the brochure when ESRI would not put its name on it.

One of the more flagrant misrepresentations in the brochure (39) was the answer "No" to the question, "Is MCS listed as a disability under the Americans with Disabilities Act?" One might consider this an honest mistake if it were not for the fact that an article published at almost the same time by ESRI's then executive director clearly demonstrated he knew better. In the article, he states that "although not categorically noted to be a disability in the body of the law, the ADA [Americans with Disabilities Act] does allow for the consideration of MCS as a disability on a case-by-case analysis that is applied to all other physical and mental impairments" (40). And he also writes that "in 1991, the Department of Housing and Urban Development stated that people suffering from MCS can seek protection under federal housing discrimination laws." It appears that ESRI was attempting to mislead physicians and the public into believing that MCS is not a covered disability, while its executive director was warning an industry-oriented audience that MCS was a covered disability and offering suggestions for how to defend themselves against a claim.

New Mexico has had direct experience with ESRI representatives and tactics. In 1996, ESRI mailed anti-MCS literature to a state disability agency that was developing a report to the legislature on MCS. Among other things, this material included advice on how to avoid accommodating chemically sensitive employees (41). Then, ESRI staff visited New Mexico in person. The ESRI manager attended a Town Hall Meeting on MCS at which she offered to help the state epidemiologists develop a prevalence study protocol. Shortly thereafter, however, she reportedly told another member of the prevalence study working group that MCS can't be studied because it doesn't exist. This circular reasoning, that you can't prove MCS exists without more study and you can't study it because it doesn't exist, is commonly used by industry lobbyists. A corollary to this is the lobbying strategy of calling for more research on MCS while attempting to block it at the same time.

ESRI's then executive director also visited Santa Fe in 1996. Among other things, he went to a Medicaid Advisory Committee meeting and urged that Medicaid benefits be denied for the diagnosis and treatment of chemical sensitivities, spoke against MCS at a continuing medical education (CME) conference for physicians where he failed to disclose his industry affiliations as required by CME

guidelines, and berated the staff at an independent living center for providing a support group for people with MCS.

Another ESRI project involved paying a medical journal to publish the proceedings of an anti-MCS conference in its supplement (42). This conference was organized, in part, by a consulting firm that was owned by ESRI's then executive director and supplied expert witnesses to testify against MCS. Later these papers were cited as references to support anti-MCS statements in material ESRI gave to the Ciba-Geigy lobbyist, which she submitted to the legislature. In keeping with its attempts to keep a low profile, however, ESRI did not put its name on the documents that were submitted.

A ROSE BY ANY OTHER NAME

Even though MCS has gone by that name for over a decade, industry associates would have you believe that it goes by a myriad of other names, so many that it must not be describing anything legitimate. In fact, if an article starts out with a long list of possible names for MCS, you can be almost positive it is going to be critical of MCS. Referring to MCS as a "phenomenon" rather than an illness and using the term "multiple chemical sensitivity syndrome" also tend to be code for "it doesn't really exist" or if it does, "it's all in people's heads." Articles using these names are usually accompanied by other myths and put-downs, such as MCS has no definition, no objective findings, and no known prevalence, and is "only symptom-based," a "belief system," or "chemophobia." People with MCS are also frequently dismissed as having an "unexplained illness," as if they, rather than their physicians, were to blame for not adequately "explaining" it.

Since 1996, however, the chemical industry has taken a bold new approach to the name for MCS. It has made a concerted effort to rename MCS "idiopathic environmental intolerances (IEI)." It is quite clear that its motivation is to get the word "chemical" out of the name. This would be analogous to the tobacco industry trying to change the name of "smokers cough" to "idiopathic respiratory paroxysms." Anything to try to distance the disease from its products.

But despite frequent claims to the contrary by its users, the term IEI has not replaced the name for MCS. Its use, however, has slowly increased over the years in anti-MCS journal articles, industry propaganda, and medical association position papers. Fortunately, the use of the term IEI is like a tracer dye that immediately alerts the reader, patient, or constituent that the person or organization using the term is biased against MCS. The most frequent users of the name IEI are doctors who work for industry as expert witnesses or allegedly "independent" medical examiners, industry-sponsored organizations, and allergy or occupational medicine organizations that have long been critical of environmental doctors who treat people with MCS. While there may be some individuals who innocently use the term IEI, the overwhelming majority who use it appear to be connected to industry in some way.

One of the more outrageous claims that the chemical industry and its associates make is that the World Health Organization (WHO) supports the name change from MCS to IEI. The WHO was one of the sponsors of an International Programme on Chemical Safety (IPSC) workshop on MCS held in Germany in February 1996. This workshop was dominated by industry-associated participants and had no representatives from environmental, labor, or consumer groups. Instead, the non-governmental participants were individuals employed by BASF, Bayer, Monsanto, and Coca Cola (43). It was at this meeting that the decision was made to try to change the name of MCS to IEI.

Besides getting the word “chemical” out of the name, the workshop participants chose to add the term “idiopathic,” apparently because they thought it meant the illness was “all in someone’s head” rather than of unknown etiology (cause) (44). But lots of “real” illnesses are considered idiopathic, such as idiopathic epilepsy (i.e., epilepsy not resulting from trauma, surgery, infection, or other obvious cause). Still, implying that MCS has no known cause helps the industry. They do not want to be held responsible for their products causing MCS, or for that matter, triggering symptoms in people sensitized to them. It’s hard to understand, however, how IEI is much of an improvement over MCS, since the term MCS does not address the cause of the illness either. It is just a good description of the condition, that sufferers are sensitive to multiple chemicals, which is not that different from having multiple “environmental intolerances.”

In any case, the WHO issued a statement to the workshop participants after the meeting to try to put a stop to claims that WHO supported the name change from MCS to IEI. It stated that “A workshop report to WHO, with conclusions and recommendations, presents the opinions of the invited experts and does not necessarily represent the decision or the stated policy of WHO.” It goes on to say that “with respect to ‘MCS,’ WHO has neither adopted nor endorsed a policy or scientific opinion” (45). Despite this explicit disclaimer, claims that the World Health Organization supports IEI continue to be made by MCS opponents.

MCS IN COURT

Perhaps the area where the chemical industry is most aggressively fighting MCS is in the courts. This is not surprising considering the fact that ESRI was founded to assist industries involved in MCS litigation. MCS cases commonly involve workers compensation, social security, toxic tort, disability or health insurance, and disability accommodations. MCS can also arise in divorce proceedings, child custody battles, and landlord-tenant and other disputes. In lawsuits where chemical manufacturers are directly involved, for example, when they are being sued for harm caused by their products, it is clear that attacks on the plaintiff’s credibility and medical condition, including MCS, come from the manufacturers. It is often unrecognized, however, how much the chemical industry is also involved in suppressing MCS in other lawsuits, through filing of briefs, supplying “expert” witnesses, and distributing anti-MCS literature to attorneys and witnesses.

The chemical industry also seems to have been influential in convincing many judges that MCS testimony should not be allowed in court. They argue that MCS does not satisfy the Daubert criteria for the admission of scientific testimony established by the U.S. Supreme Court in 1993. This ruling eliminated the requirement that expert testimony be “generally accepted” in the scientific community to be admissible and replaced it with the requirement that the reasoning or methodology underlying any proposed testimony merely be scientifically reliable and relevant (46). Thus, the intent of the ruling was to allow testimony on emergent theories of disease even if they had not yet been generally accepted by the medical community. But in the case of MCS, this has backfired. The Daubert ruling, which was intended to make it easier to admit scientific testimony in court, has increasingly been used to block testimony on MCS.

Some judges have ruled that MCS does not satisfy the Daubert criteria, despite the fact that it clearly satisfies at least three of the four factors specified in the Daubert ruling to assess proposed testimony. The Daubert ruling states that the following considerations will bear on admissibility of expert testimony: 1) whether the theory or technique in question can be (and has been) tested, 2) whether it has been subjected to peer review and publication, 3) whether the reasoning or methodology has a

known or potential error rate, and 4) whether it has widespread acceptance within a relevant scientific community (46). According to these criteria, testimony on MCS should be admitted because, it “can” and “has” been tested (47), has been subjected to extensive peer review and publication (48), and is widely accepted in the environmental medicine community. The factor regarding potential error rates is largely irrelevant because MCS is a clinical diagnosis that does not rely on tests.

But whether an illness or theory satisfies the Daubert criteria is obviously in the eye of the beholder. A judge in New Mexico, for example, ruled there was not enough published literature on MCS to fulfill the Daubert criteria (49). Yet there are over 600 articles on MCS and related conditions in the published literature, the majority of which support a physiological rather than psychological basis for MCS in a ratio of two to one (48). The judge rejected testimony on MCS even though he thought there would be enough literature in 5 to 10 years for it to satisfy the Daubert requirements. But if a judge is convinced MCS will be well established in the future, then testimony on MCS is credible and ought to be admitted now. After all, the intent of the Daubert rule is to admit testimony on just such valid emerging theories of disease as this one. In addition, it is unclear how much this judge was swayed by the anti-MCS opinions of the defendant’s expert witness, who admitted she relied on material sent by ESRI for her testimony and did not know who funded the organization (50). It is, indeed, unfortunate that the subjective nature of the Daubert criteria has allowed judges to misinterpret them in favor of the chemical industry. This has resulted in many people with MCS being denied disability benefits, compensation for toxic injuries, and reasonable accommodations under the ADA, among other things.

A case in point is a recent ruling by the Massachusetts Supreme Court that rejected MCS testimony in a work-related injury case because the physician’s testimony was not based on “reliable methodology,” that is, because he did not use a test to diagnose MCS (51). This conclusion was reached even after stating that “a new theory or process might be so ‘logically reliable’ that it should be admissible, even though its novelty prevents it from having attained general acceptance in the relevant scientific community” and that “in many cases personal observation will be a reliable methodology to justify an expert’s conclusion.” This is another example of a biased interpretation of the law against MCS. And again we find the chemical industry involved. Though not a defendant in the case, the American Chemical Council (formerly the Chemical Manufacturers Association) filed a “friend of the court” brief against the worker and expressed delight with the court’s anti-MCS decision (52).

Finally, there are growing attempts to get medical licensing boards to revoke the licenses of physicians who diagnose and treat chemically sensitive patients. One physician is in a legal battle with the California Medical Board to keep his license, in part, for this reason (53). In an anti-MCS booklet, an author who is known as an industry sympathist, has called for state licensing boards to “scrutinize” the activities of doctors who treat MCS patients. He also stated that he thought “most of them should be delicensed” (54). Trying to put physicians who treat MCS out of practice or harassing them until they quit on their own is an extremely insidious way of trying to get rid of MCS. It is also a threat to the independent practice of medicine by everyone.

IMPACTS OF MCS

The impact of MCS on individuals and society is huge, both in terms of its potential severity and the number of people affected. 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.

The impact on society is no less severe. An increasing number of physicians, lawyers, teachers, computer consultants, nurses and other skilled workers who were once productive members of society can no longer support themselves or contribute their skills to society. Their loss of earning power also translates into less money spent in the marketplace and less tax revenues. Deputy state epidemiologist Ron Voorhees of New Mexico estimated in a letter to the governor that the state may be losing 15 million dollars a year in tax revenues due to the decreased earning capacity of those with MCS (55).

And this medical condition is not rare. Prevalence studies in California (56) and New Mexico (57) found that 16% of the respondents reported being chemically sensitive. Additionally, in New Mexico 2% of the respondents reported having been diagnosed with MCS — the more severe form of chemical sensitivities — and in California, 3.5% reported having been diagnosed with MCS and being chemically sensitive. Although women report being chemically sensitive twice as often as men, which contributes to its “hysteria” label, those reporting chemical sensitivities are otherwise evenly distributed with respect to age, education, income, and geographic areas. Chemical sensitivities are also evenly reported among ethnic and racial groups, except for Native Americans, who reported a higher prevalence in both studies.

It should be of great concern to everyone that this devastating and potentially preventable illness is affecting an increasing percentage of the population and disabling a significant portion of the work force. It is affecting people in all walks of life throughout the country and around the world. It is vitally important, therefore, that MCS be squarely addressed and not swept under the rug as the chemical and pharmaceutical industries are trying to get the medical profession and government to do. But ignoring MCS is not only ill-advised, it is inhumane.

CONCLUSION

MCS is under siege by a well-funded and widespread disinformation campaign being waged by the chemical and pharmaceutical industries. Their goal is to create the illusion of controversy about MCS and cast doubt on its existence. These industries feel threatened by this illness, but rather than heed the message that their products may be harmful, they have chosen to go after the messenger instead. While corporations are only beholden to their stockholders, medicine and government need to be responsive to the needs of their patients and citizens. Unfortunately, industry has convinced many in the medical and legal professions, the government, the general public, and even loved ones of people with MCS, that this illness doesn't exist or is only a psychological problem. As a result, people whose lives have already been devastated by the illness itself frequently are denied appropriate health care, housing, employment opportunities, and disability benefits. On top of this, people with MCS often have to endure hostility and disrespect from the very agencies, professionals, and people who are supposed to help them.

For example, an elderly woman with MCS was forced out of public housing and became homeless when staff insisted on remodeling her apartment, even though she warned them ahead of time that the new

carpet and cabinets would make her too sick to continue living there. The physician of a woman, hospitalized because she was having anaphylactic reactions to all foods, tried to transfer her to the psychiatric ward for “force feeding.” A school district fired a chemically sensitive teacher for excessive absenteeism after it failed to provide her with the accommodations she had requested and needed in order to work. A former airline attendant had to camp in the desert and a mother and her small child had to live in their car because they could not find housing that did not make them severely ill. And a man disabled with MCS is unable to obtain vocational rehabilitation services even though he wants to work.

Countless others have failed to find tolerable housing, including a former marathon runner who has lived in her car for 7 years and struggles to fight off frostbite every winter. In another case, a chemically sensitive woman living in her trailer was forced to leave a state park when hostile staff insisted on spraying pesticides while she was there. The park supervisor said that he had seen a television show on MCS which convinced him that he did not have to make accommodations for people claiming to have MCS because it did not exist. The show had featured ESRI’s then executive director and portrayed people with MCS as freeloaders and misfits.

Despite the chemical industry’s disinformation campaign, however, and its influence over doctors, lawyers, judges, and government, incremental progress is being made with respect to MCS. This is a testament to the strength, courage, dedication, and sheer numbers of people with MCS. In fact, there are so many people becoming chemically sensitive that attempts to ignore or silence them are ultimately doomed to fail. But even though it is just a matter of time before MCS gets the recognition it deserves, each day it is delayed prolongs the suffering of millions of people with MCS and puts millions more at risk of developing it. Therefore, it is essential that those in medicine, government, and society begin to see past the industry disinformation campaign in order to recognize the true nature of MCS and the urgent need to address this growing epidemic.

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APPENDIX 6b - COMMERCIAL VERSUS HEALTH INTERESTS: THE CHEMICAL MANUFACTURER'S ASSOCIATION'S 'ENVIRONMENTAL ILLNESS BRIEFING PAPER', 1990¹¹¹

"Environmental illness patients generally lead troubled lives and have genuine problems in coping with family, work and life-style pressures. They often eagerly accept environmental illness as the explanation for their condition..."

"Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary."

Our society now has long experience with the intervention of commercial interests when the evidence of illness from their products threatens their profits. Whether the issue is smoking or pesticide use, or any number of other substances or practices that clearly have proven harmful to humans and fellow creatures, commercial interests have often intervened in ways geared to powerfully undermine the credibility of those who suffer from the products of their commercial practice. These battles are major and ongoing every day, fought by scientists and environmentalists against corporations with profits to lose.

ES/MCS (originally called 'Environmental Illness') has been no exception. The difficulty is that the commercial propaganda promoted by the then-Chemical Manufacturers' Association, (now, American Chemistry Council) left a harmful lasting legacy - the myth that people with ES/MCS are emotionally troubled, not physically sick - while the vast majority of those who have adopted this belief have no notion of its origin. It is our opinion that by denying the harms suffered by ES/MCS 'canaries' - harms that, unlike the slow and hidden progression of hidden cancers, for example, are acute and immediate and excruciating - the chemical industry effectively succeeded in whitewashing many of the chemicals that today have either been banned, or are under siege by those fighting for the interests of future generations and the biosphere. Some of the most ubiquitous of those chemicals have been documented in popular books such as *Slow Death by Rubber Duck* and *The Body Toxic*.¹¹²

For those interested in understanding how this has taken place in the ES/MCS case, we include this historic document.

¹¹¹ Reprinted in **BEST of the Reactor**, edited by Susan Molloy, 1990, pages 171 - 181. Discussed in **Illness and the Environment: A Reader in Contested Medicine**. Ed Steve Krohl-Smith, Phil Brown and Valerie J. Gunter New York University Press, New York (1997).

¹¹²

In 1990 CMA lobbied for approximately 175 member companies, and supported twenty full-time lobbyists in Washington, DC. The CMA was in the process of establishing a Political Action Committee to enable contributions to the campaigns of political candidates. The paper below was circulated to physicians associations, insurers, governments and other businesses. Today, the CMA has a new name - the American Chemistry Council.

Executive Summary

Known variously by more than 20 names, among them, chemical hypersensitivity syndrome, total allergy syndrome and 20th century disease, "environmental illness" is a subject of controversy within the field of medicine and an object of considerable public attention. For many patients, environmental illness has become the explanation for a combination of symptoms for which they've found no other acceptable explanation.

According to a small group of clinicians from a medically unrecognized specialty called "clinical ecology" or "environmental medicine," millions of people in this country suffer from environmental illness. Practitioners of environmental medicine report that the medical cause of their patients' conditions is a depressed immune system. These clinicians attribute their patients' symptoms which typically include headaches, fatigue, depression, anxiety and digestive problems primarily to exposure to trace amounts of virtually all synthetic chemicals found in food, water, air, clothing and everyday surroundings. In short, environmental medicine specialists believe their patients are severely "allergic" to the world they live in to the extent that many of them cannot function in society.

There is no doubt that these patients are ill and deserving of compassion, understanding and expert medical care. However, nationally known experts in the fields of allergy, immunology and internal medicine say the assertion that environmental illness is a legitimate disease is unproven. Elaborate testing of the immune systems of these patients almost always indicates normal immune functions, and they rarely have increased infections.

And only rarely are their symptoms supported by physical findings or laboratory tests. In addition, review of both the methods of diagnosis and treatment used by environmental medicine specialists have shown no convincing evidence that their patients have unique, recognizable symptoms or that their treatment procedures are any more effective than placebo treatment.

Environmental illness patients generally lead troubled lives and have genuine problems in coping with family, work and life-style pressures. They often eagerly accept environmental illness as the explanation for their condition and undertake the costly life-style changes including moving to new environments and eliminating all synthetic agents from their homes that are part of treatment.

Despite unsubstantiated evidence, environmental medicine specialists and their patients persistently advocate that environmental illness exists. What they have failed to prove in the scientific arena, they are attempting to legitimize in the media, in the legislature, and in the courts. The important elements of human interest stories, human suffering, controversy, testimonials, and novelty, have provided natural stories for the media.

Legislative initiatives have so far failed to legitimize environmental illness, but it would not be difficult for legislators to misperceive the goals of environmental medicine as medically legitimate. And lawsuits, of which several are currently pending, could multiply.

The label of environmental illness is a misdiagnosis and condemns these patients to the life of an outcast with little hope of cure. It is essential that their described symptoms be taken seriously. These patients deserve the best medical evaluation and treatment consistent with established medical principles.

It is not the legitimacy of the patients that is in question, but the alleged environmental cause. Failure to recognize this critical difference can result in enormous costs to the patient, to industry and to society.

"Environmental Illness" Background "Environmental illness" has no single, accepted definition. However it may be described as a diagnosis that ascribes a broad range of common substances in the environment. Proponents allege that these symptoms are triggered particularly by contact with trace amounts of chemicals in our food, water, air and daily surroundings.

Symptoms are typically multiple, subjective and unsupported by physical findings or laboratory tests. Headaches, fatigue, depression, anxiety and digestive problems are some of the common initial complaints.

Those physicians who diagnose environmental illness call themselves "environmental medicine specialists." (Formerly they called themselves "clinical ecologists.") Environmental medicine is very controversial. There is no residency training in environmental medicine and the certifying board for its practitioners is not recognized by the American Board of Medical Specialties.

Furthermore, the American Academy of Allergy and Immunology, the California Medical Association and the American College of Physicians have taken the position that the tenets of environmental medicine are unproven (Refer to Appendix D).

Diagnosis and Treatment

Practitioners of environmental medicine generally diagnose environmental illness by performing "provocation testing," which consists of exposing subjects to various mixtures of test substances at progressively higher concentrations. The testing is variously done by inhalation, injection or placing the test solution under the patient's tongue. If any symptoms occur, the test is positive.

Subsequently, part of the subject's therapy consists of injection of the offending agents in lower concentrations. This "neutralization therapy" has no proven or even logical medical or scientific rationale to support it, according to the medical community. Provocation testing and symptom neutralization bear some superficial resemblance to skin testing for allergies and allergy shots for desensitization but are actually quite different. (Refer to section on Allergic Diseases, p. 9.) No reputable medical organization accepts provocation testing combined with neutralization therapy as having scientific meaning.

Independent "provocation testing" of environmental illness patients, for example, has resulted in equal numbers of positive tests from placebo solutions and from solutions of substances to which they allegedly were sensitive. [Terr, A. I., 1987. In *Allergy: Clinical Ecology. Insights in Allergy*. 2(5).]

Another part of an environmental illness patient's treatment is to avoid the common substances that purportedly make them ill. This could include living in environments totally free of modern synthetic materials, such as rooms or trailers with metal or porcelain surfaces; elaborate air filtration; and diets free of all additives, preservatives, or contaminants. This approach obviously renders the individual unemployable.

In short, there is no consensus on the proper diagnosis, treatment or even existence of environmental illness as a single, proven medical condition. The hypotheses of environmental medicine practitioners are medically unproven and have been rejected by professional medical organizations. In addition, the treatments, which are extremely expensive, have not verifiably helped patients any more than placebo therapy would.

"Environmental Illness" Impacts

Environmental medicine specialists and other advocates are well organized and effective at representing environmental illness as a recognized medical condition affecting millions of people in this country. These advocates are working hard to legitimize environmental illness. Environmental illness already affects the patients who accept it as a legitimate disease. Should environmental illness advocates succeed in their efforts, it would also impact society and many industries.

For the patients, the unproven tests used to diagnose environmental illness may in fact lead to misdiagnosis of a true medical illness. Because environmental illness cannot be clearly diagnosed by clinical criteria, environmental illness specialists use the history of presumed environmental exposure as the basis for diagnosis.

This belief in itself can be psychologically crippling. Indeed, some patients view themselves in a hostile world, surrounded by chemicals that make them chronically ill and physicians who do not care. Often, their life becomes centered totally around their disease. Coping becomes stressful and living needs become costly as these individuals change their life-styles to avoid all chemicals. They are determined to consume only organic foods grown without insecticides, sprays and fertilizers.

They may use only items made of glass, porcelain, stainless steel and untreated animal or plant fabrics (cotton, linen, silk, wood and leather). Often, this results in social isolation, difficulty within the community and unemployment.

The primary impact on society would be the huge cost associated with the legitimization of environmental illness. Up to now, environmental illness and the associated testing and therapy have not been eligible for coverage under such programs as medical insurance plans, Social Security disability, Medicare and Workers' Compensation. But proponents of environmental illness are now trying to legislate the legitimacy of environmental illness.

Although they have not been successful, it would not be difficult for legislators to misperceive environmental illness as medically legitimate and fail to recognize the potentially enormous cost that could accrue. Environmental illness advocates believe they are entitled to a number of sources of financial support. Among them:

- monetary damage for increased illness resulting from exposure;
- monetary damages for existing fear of contracting future illness;
- disability benefits from private insurance policies and Social Security;
- reimbursement for medical costs;
- Workers' Compensation payments;
- a variety of workplace protections (from termination, demotion, pay cuts, etc.);
- rehabilitation services; and
- financial assistance for alteration of living space.

Environmental illness forces nearly succeeded in accomplishing their goal in Maryland in 1988. They proposed legislation and it came close to being passed before informed health professionals became aware of it and managed to transform a bill legitimizing the diagnosis of environmental illness into a resolution to study the issue. The resulting study basically called environmental illness an unresolved issue; however, further actions by the legislature in Maryland on this issue seem unlikely in the near future.

Proponents of environmental illness have drafted "fill-in-the-blank" model legislation in an attempt to accomplish their aims. Such legislation could pop up in any state at any time. A carbon copy measure in California passed, but Governor Deukmejian vetoed it after the California Medical Association intervened.

The impact, however, would not be restricted to the chemical industry. Commonly used chemicals are found everywhere, in the home, the workplace, outdoors, shopping malls, and even hospitals. Potentially affected industries include the textiles, clothing, lawn care products, household cleaners, dry cleaners, paints and solvents, perfumes, hair treatment products, plastics, paper and many other consumer goods industries.

There is also the threat of lawsuits. Litigants seeking redress for personal injury allegedly resulting from exposure to toxic substances are numerous now. Should environmental illness be recognized by legal or judicial decree, these suits would only multiply. Toxic torts create special problems for the defendant in the best of circumstances. It is scientifically impossible to ever prove a negative, the nonexistence of something.

Plaintiffs typically allege effects at very low exposure levels that are only known to be caused at much higher exposure levels. Often, only the presence of nearby chemicals, rather than true exposure, is documented. Or they allege that health effects were caused by substances not known to cause those effects.

Suits involving environmental illness are further complicated by the lack of a definition of environmental illness. In the eyes of environmental medicine practitioners and their patients, almost any symptom could be caused by exposure to almost anything. But most physicians do not agree with the environmental illness advocates. For example, Dr. Abba Terr, an immunologist at Stanford University Medical School, summarizes environmental illness in a chapter of a recent book reviewing multiple chemical hypersensitivity:

The concept of multiple chemical hypersensitivities as a disease entity in which the patient experiences numerous symptoms from numerous chemicals and foods caused by a disturbance of the immune system lacks a scientific foundation. Published reports of such cases are anecdotal and without proper controls. There is no convincing evidence for any immunologic abnormality in these cases. Diagnostic methods have been shown to be unreliable. Diagnosis, treatment and theoretical concepts underlying the purported disease are not consistent with current immunologic knowledge and theory. As defined and presented by its proponents, multiple chemical hypersensitivities constitutes a belief and not a disease.

[Terr, A. I., 1987. Multiple Chemical Sensitivities: Immunologic Critique of Clinical Ecology Theories and Practices. In "Occupational Medicine State of the Art Reviews: Workers with Chemical Sensitivities", ed. M. R. Cullen, Vol. 2(4):693. Philadelphia, Hanley and Belfus.]

Supporting Material: Theories of Etiology

Proponents of "environmental illness" ascribe many symptoms to exposure to numerous common substances in the environment. Although these can include natural chemicals, more often the symptoms are attributed to low level chronic exposure to synthetic chemicals. Most recently, environmental illness proponents have postulated that exposure to such chemicals causes a malfunction of the immune system that results in sensitivities not only to the chemicals to which the patient has been exposed but also to chemicals he may encounter in the future.

In the eyes of its advocates, almost any symptom can be attributed to environmental illness. But laboratory tests on patients who believe they are suffering from environmental illness have shown normal or inconsistent results.

Some of the patients who believe they have environmental illness also have symptoms characteristic of psychosomatic illness. [Terr, A. I. 1986. Environmental Illness: A Clinical Review of 50 Cases. "Archives of Internal Medicine". 146:145- 149. Stewart, D. E. et. al. 1985. Psychiatric Assessment of Patients with "20th Century Disease" in "Canadian Medical Association Journal". 133:1001 - 1006.]

Others have a variety of symptoms that do not fit any known medical disease. These latter patients should be investigated further with well designed scientific studies rather than being stigmatized by unproven illness that might hinder further medical investigation.

Allergic Diseases

Environmental illness advocates have borrowed much of their terminology from the fields of allergy and immunology. This can be very confusing since there are legitimate allergic diseases that are well accepted and documented by the medical profession.

Environmental illness advocates claim that sensitization to one chemical may cause a spreading phenomenon in which the patient becomes allergic to many chemicals. True allergies do not behave this way. If a patient is sensitized to one chemical, they are sensitized only to that chemical and perhaps to a few other chemicals that are structurally almost identical. New sensitizations must occur before the patient will react to different chemicals.

Documented allergic diseases are caused when an individual develops an exaggerated IgE response to environmental, drug or microbial antigens. IgE is an immunoglobulin protein that circulates in the blood and brings about allergic responses; other immunoglobulins are involved less frequently. Typically, allergies do not affect everyone exposed to the substance. Minute amounts of the offending agent may cause symptoms in a person who is sensitized or allergic to the substance. But not all chemicals are capable of causing allergies.

Allergic individuals characteristically give rapid responses in skin testing, have high sum IgE levels and often have increased blood and tissue concentrations of eosinophilic leukocytes; an eosinophilic leukocyte is a specific type of white blood cell.

Symptoms are subjective changes perceived and described by the patients while signs are objective physical findings observed by the physician. Allergic symptoms typically involve the skin, the respiratory tract or the gastrointestinal tract. The following statements are generally true:

- Food allergies may cause vomiting, cramps and diarrhea.
- Skin reactions cause hives, which are large blisters or red, itchy rashes.
- Respiratory allergies are either of the hay fever type which involves the nose causing sneezing or nasal congestion, or the asthma type, which involves the lungs and the lower respiratory tract causing difficulty in breathing.
- A severe generalized allergic reaction known as anaphylactic shock may have symptoms of a drop in blood pressure and spasm of the larynx leading to shock and suffocation.

The location and type of symptoms most often depends on the type of contact with the agent to which the patient is sensitized. For example, contact with poison oak or with poison ivy usually involves the skin and results in a red, itchy rash with small blisters. Firefighters who are exposed to smoke from burning oak or ivy, however, inhale and ingest the smoke and may have symptoms in the lungs, nose and gastrointestinal tract as well. [Hood, L. E. ed. 1984, Immunology, 2d. ed. 460-462. California: Benjamin/Cummings.]

In contrast to environmental illness, the symptoms of allergic reactions are reproducible. Usually a person who is allergic to an agent has the same type of contact and the same symptoms on each subsequent contact.

Problems with Medical Testing

The specialty of immunology is one of the newest and most rapidly changing medical specialties. Laboratory tests used to measure a person's immune system function are also relatively new and still evolving. Some of the laboratory tests proponents of environmental illness use to support their position are well established in the medical repertoire. Other tests are new and not accepted by the general medical profession. A few, such as

cytotoxic testing, have been declared invalid by federal agencies [Fed. Reg. Vol. 48, No. 162, August 19, 1983-Notices.] which will not reimburse for performance of these tests.

Environmental medicine specialists often do a large number of screening tests on their patients. Inevitably, one or two tests are abnormal. Individual laboratory results are often compared with ranges of numbers rather than one absolute number. By chance alone, five percent of people tested with no clinical disease will have either "abnormally" high or low laboratory values.

The more tests that are done, the more often the result will be abnormal, simply because of the mathematics involved. Proponents of environmental illness use these abnormal tests as proof that the patient has environmental illness.

The nonstandard test most often conducted by environmental medicine specialists is provocation with neutralization. In provocation testing, subjects are exposed to concentrations of suspected substances either by inhalation, injection under the skin, or placement under the tongue. The occurrences of any symptoms within a short period of time are noted; any symptom is interpreted as a positive test.

Lower concentrations are then given until no symptoms occur. The concentration resulting in no symptoms is termed the "neutralizing dose." Provocation testing is not an accepted practice within the medical community.

Any patient has the right to expect that a qualified person is managing the laboratory in which tests of immune function are being conducted. The patient also has the right to expect that the physician interpreting the test results is qualified. Both the American Board of Pathology and the American Board of Internal Medicine, in conjunction with the American Board of Pediatrics and the American Board of Allergy and Immunology, now have examinations to assess the competence of clinical pathologists, internists and pediatricians conducting diagnostic immunologic tests.

"This certification process was developed to ensure that clinical immunology laboratories are directed by the persons who know the most about conducting such tests, properly applying them in diagnosis, and interpreting the results." [1988. Certification in Diagnostic Laboratory Immunology, "Annals of Internal Medicine". 108: 458-459.]

Why "Environmental Illness" is Not Science or Medicine

"Environmental illness" lacks credible medical specificity. The symptoms, which are changes perceived by the patients, reported are neither substantiated by clinical signs, which are objective physical indications of illness, nor by laboratory testing of a wide array of body functions. The breadth of isolated symptoms is exceeded only by the number of purported chemical and environmental causes.

Indeed, there is no medical precedence to suggest that any syndrome or disease can be brought on by numerous separate and distinct agents.

Proponents of environmental illness assert that environmental illness exists because they have repeatedly observed patients with multiple, non specific symptoms, conceivably arising after a variety of exposures to numerous chemical substances. The heart of the problem lies in their reasoning process and the validity of the data they use to support a causal link.

The basic fallacy in their reasoning is that the observed symptoms may be induced by many other causes. An equivalent example of such erroneous reasoning is that if a rooster crows every morning before sunrise, then the sun rises because roosters crow.

Because a case of environmental illness cannot be defined objectively, control individuals (those without both the "disease" and exposure to the "agent") cannot be defined in order to perform traditional scientific studies. This fact is confirmed by the current scant medical literature on the subject, which only emphasizes collections of cases. Such case studies without controls cannot prove the valid existence of environmental illness but can only assert its existence.

Such hypotheses by environmental medicine practitioners are unfocused and scientifically unfounded, and have been rejected by main-stream professional medical organizations.

The data used by the proponents of environmental illness is largely invalid. [California Medical Association Scientific Board Task Force on Clinical Ecology. 1986. Clinical Ecology - A Critical Appraisal. "Western Journal of Medicine", 144:239-245.] Their principle data consists of uncontrolled and unblinded observations of alleged patients improving after therapy. Simply stated, they have not considered classical placebo effect, whereby a small percent of treated individuals will always improve regardless of whether effective therapy was used or not (the good effects of sugar tablets have been known for 2000 years).

Other problems with their information are that appropriate epidemiology cannot be applied, their patient history questionnaires are overly simplistic and biased, and high quality psychological testing of patients is generally avoided.

The scientific dilemma is that well conducted studies (with controls) cannot prove the nonexistence of the "disease" because true science can not prove a negative. Advocates can only assert the existence of a theoretical condition while assailing traditional clinicians and scientists for not having the ability to disprove their theory.

People who have received the label of environmental illness clearly merit the compassion and understanding of the medical and social communities. Emphasis should be placed on proper psychological diagnosis and treatment rather than upon false labels and therapy that can ultimately prolong their impairment.

Because the role of true science is inherently limited, it is the responsibility of reputable scientists and clinicians to emphasize that environmental illness has not been proven to exist.

Responding to the Media

Because environmental illness is a health issue, its debate is best left primarily to physicians; the chemical industry, for example, should not get overly involved in such debates. Nonetheless, a ready response for media queries is a prudent precaution. Should reporters, editors, news directors or other media question industry about environmental illness, it would be appropriate to respond in a limited way. Steps best taken are:

- Monitor media coverage of the issue.

- Gather relevant background and reference material.

- Identify medical personnel familiar with environmental illness who can speak as experts.

- Informally offer guidance and background materials to reporters, based on their degree of knowledge.

Workers' Compensation Trends

Legislation already introduced by environmental illness support groups is designed to legitimize environmental illness for disability purposes. Given this thrust, more and more workers' compensation claims are expected. Presently, no state recognizes environmental illness on its list of workers' compensation diagnoses.

Each case would be considered on an individual basis. Since proponents of environmental illness advocate that patients suffering from environmental illness avoid all contact with synthetic chemicals, a diagnosis of active environmental illness could preclude return to work in many jobs.

Cost Impact

Once workers' compensation claims are settled, the plaintiff often files a toxic tort claim based on product liability theory. At the present time, it is estimated that to defend an average case of this type through a jury trial costs in excess of \$200,000 to \$300,000. No figures are available on the number of environmental illness cases filed nationwide.

Expert Testimony

Proof of causation varies greatly from jurisdiction to jurisdiction. For this reason it is impossible to give a short definition that would be accepted by most jurisdictions. However, in each case the plaintiff bears the burden of proof on the issue. Often the plaintiff needs a person accepted by the court as an expert who will testify that there is a cause and effect relationship to a reasonable degree of medical certainty.

The qualifications for being an expert vary from jurisdiction to jurisdiction and even from judge to judge, as does the meaning of "reasonable degree of medical certainty." While there have been a few exceptions, in most cases environmental illness proponents have not been excluded from giving expert testimony.

State Legislative Summary: History of Legislative Initiatives in Environmental Illness

California: Legislative activity in California began with a bill (AB 3587) introduced in 1981 to primarily set up a "chemical hypersensitivity syndrome advisory committee." It also made provisions for educating those who believed they were environmentally ill about treatment and life-style changes, public education for prevention, and workshops to facilitate exchange between researchers and proponents of environmental illness. The bill passed in both Houses of the California Assembly but was vetoed by Governor Deukmejian.

A second bill (SB 1177) was introduced in 1985. It requested funding for a pilot project to identify those allegedly affected by this syndrome, to develop a clearinghouse for information and advocacy, to provide legal, financial, medical and support services and to conduct and coordinate interdisciplinary conference and research activities on environmental illness. This bill was also defeated.

Connecticut: A public health committee House bill (5191) was defeated in Connecticut in 1987. It would have established a program to study and treat environmental illness at the University of Connecticut Health Center in Farmington.

Maryland: The Maryland Senate drafted and both chambers passed Joint Resolution 32 (1988), which directed the Maryland Department of Environment to conduct a study on the alleged "chemical hypersensitivity syndrome." [Bascom, R., M.D., M.P.H. 1986. "Chemical Hypersensitivity Syndrome Study." University of Maryland School of Medicine.] While there is no single definition of environmental illness or the problems it is alleged to pose, the study group's mission was to determine if people could be classified as suffering from allergic reactions.

When the study was finished, Maryland's Secretary of the Department of Environment, Martin Walsh, sent an

advisory letter to Governor William Donald Schaeffer. In his closing summary of the environmental illness study, Walsh dictated that "...a great deal more research is needed before there will even be a consensus on a definition of chemical hypersensitivity. It is, in my view, premature to classify environmental illness as a purely environmental problem in the classic sense." (Refer to Appendix E.)

A copy of the Maryland Department of Environment's Report on chemical hypersensitivity syndrome can be ordered from the Maryland Department of the Environment, 2500 Broening Highway, Baltimore, MD 21224 (Fee: \$25).

Florida: In 1989, Florida passed a bill creating a registry of people believing they have multiple chemical sensitivities. Creation of such a registry implies that the disease listed is accepted as proven. In this case, this is not true.

Because environmental illness lacks clear definition, the issue could be considered in various state legislative committees. Depending upon the intent of an environmental illness bill, it could be forwarded to Health and Welfare, Labor, Judicial, or Environmental committees. If the proposal focused on alleged allergic reactions, it would be considered by Health related committees; if the purpose of the bill were to review workers' compensation claims rising out of alleged environmental complications, it would be reviewed in Labor or Judicial committees; and, if the proposal asserts environmental concerns then the bill would be sent to Environmental committees.

Legislators and respective staff should be wary of legislation attempting to review and redress the issue of environmental illness or related themes. (The topic is not easily recognizable as it is not consistently addressed by the popular names of environmental illness or chemical hypersensitivity syndrome.) Environmental illness bills should be thoroughly critiqued by members of the medical and legal community prior to legislative action. When considering a bill, legislators should remember that environmental illness is a grey area, one which has not proven its existence in the medical arena and one which has no precedence in state statutes.

Legislative and Social Goals

Dr. Linda Lee Davidoff, representing the Environmental Illness Support Group, stated in her testimony to the Environmental Affairs Committee of the Maryland Senate, on May 8, 1988, that if Senate Joint Resolution 32, titled "Chemical Hypersensitivity Syndrome" was enacted, "chemically sensitive" people would benefit from:

- access to insurance coverage;
- social services;
- financial assistance;
- vocational rehabilitation; and
- alternate housing.

E.J. Davis, J.D., M.P.H., editor of "Ecological Illness Law Report", Vol. 2(6): p. 3, revealed several specific legal goals of his agenda, several of which follow:

- preventing "improper" employee dismissals and demotions;
- securing and maintaining a "safe" work environment;
- securing financial assistance for the rehabilitation of living space;
- securing coverage under Medicaid or Medicare and various state and federal assistance programs;
- securing workers' compensation payments;

- securing assistance under federal and state protections for disabled;
- securing compensation from companies and individuals responsible for chemical exposures that cause disabling illness;
- securing proper income tax deductions for expenses associated with ecological illness, especially excess costs of remodeling or changing heating systems and organic foods; and
- securing safe environments and food in prisons, mental hospitals, hospitals, and other public and private institutions.

Overlap With Indoor Air Pollution

Indoor air pollution or "tight building syndrome" is currently a major topic in several regulatory agencies and environmental advocacy groups. Symptoms often resemble those attributed to environmental illness. Among them: headaches, dizziness, drowsiness, nausea, irritations of the skin and upper respiratory tract, anxiety, irritability and other nervous system disorders.

Insufficient provision of fresh air in a building's heating, ventilation and air conditioning system, resulting in a buildup of air contaminants, formaldehyde, pesticides, cleaning materials and others, most often is cited as the cause. However, rarely is a specific agent indicated.

Environmental illness advocates would like society to believe that "sufferers" in indoor air pollution have a form of environmental illness because this would significantly increase the victim population and further legitimize their cause.

Forming Coalition

Because it has the potential to impact many segments of society, many groups have an interest in placing environmental illness in its proper perspective. Among them:

- medical associations;
- manufacturers and applicators of agricultural and pesticide products;
- personnel, labor relations, etc.;
- food dealers;
- restaurants;
- insurance companies;
- self-insurers;
- soap and detergent manufacturers;
- chambers of commerce;
- lawn care services;
- homebuilders;
- aerospace industry;
- retailers; and
- automobile manufacturers.

Because environmental illness is a health issue, the only people who can legitimize it are physicians, and they have not. Should environmental illness arise as an issue, a coalition with the state medical association is absolutely necessary.

Appendix A Synonyms for Environmental Illness Allergic Toxemia, Cerebral Allergy, Chemical AIDS, Chemical Hypersensitivity Syndrome, Chemical Induced Immune Dysregulation, Complex Allergy, Ecological Illness, Environmental Hypersensitivity Disorder, Environmentally induced Illness, Immune System Dysregulation, Multiple Chemical Hypersensitivity, Total Allergy Syndrome, Twentieth Century Disease.

Appendix B Environmental Illness Organizations American Academy of Environmental Medicine The American Academy of Environmental Medicine (AAEM) was founded in 1965 as an international association of physicians interested in clinical aspects of environmental medicine. Prior to 1984, they were called the Society for Clinical Ecology (Environmental Medicine). This group changed its name after 1984. The position paper of the Society for Clinical Ecology states that the organization is made up of physicians, who are board certified in a clinical specialty and interested in newer concepts utilizing diagnostic and treatment modalities in treating environmental illness. The 1988 position statement of the AAEM is included in Appendix D of this paper. [AAEM, 10 E. Randolph St., New Hope, PA 18933 (215) 862-4544 or Fax (250) 862-2418]

American Board of Environmental Medicine, Inc. Formal residency training is required for board certification. The board, however, is not recognized by the American Board of Medical Specialties, which is the umbrella organization overseeing specialty board certification of medical doctors in the United States. The American Board of Environmental Medicine, founded in 1988, offers its own examination in the field of environmental medicine. Executive director: Dr. Clifton R. Brooks, M.D., M.P.H., 2114 Martingale Dr., Noran, OK 73072; phone (405) 329-8437

Appendix C Editorial Statement "Clinical Ecology: Environmental Medicine or Unsubstantiated Theory?" Reproduced with permission from the Annals of International Medicine, Kahn, Ephraim; Letz, Gideon, 1989 July; 111(2): 104-106).

Appendix D Position Statements: California Medical Association Scientific Task Force on Clinical Ecology, Clinical Ecology -- A Critical Appraisal [Information], reproduced with permission from the "Western Journal of Medicine", 1986 Feb.; 144:239-245)

American Academy of Allergy and Immunology (<http://www.aaaai.org/>)

American College of Physicians (<http://www.acponline.org/>)

American Academy of Environmental Medicine (<http://www.aaem.com/>)