Part 3:
Community Voices (the qualitative needs identification study)

Part 4:
Special Issues (to emerge from the study)

Excerpted from

RECOGNITION INCLUSION AND EQUITY THE TIME IS NOW: PERSPECTIVES OF ONTARIANS LIVING WITH ES/MCS, ME/CFS AND FM

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Note: page numbers differ from the original document, but accurately reflect order and length in this excerpt.

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.[1] Another paper strictly in relation to ME/CFS from the UK in 2009 was also helpful but only to limited extents.[2] One article on an ME/CFS survey in Ontario (1996) dealing with health and social support needs, was reviewed - helpful but very limited.[3] 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.[4] 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.**

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[1] 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.

[2] 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.

[3] 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.

[4] *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 Survey[3]
- 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.’[4] 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.[5]

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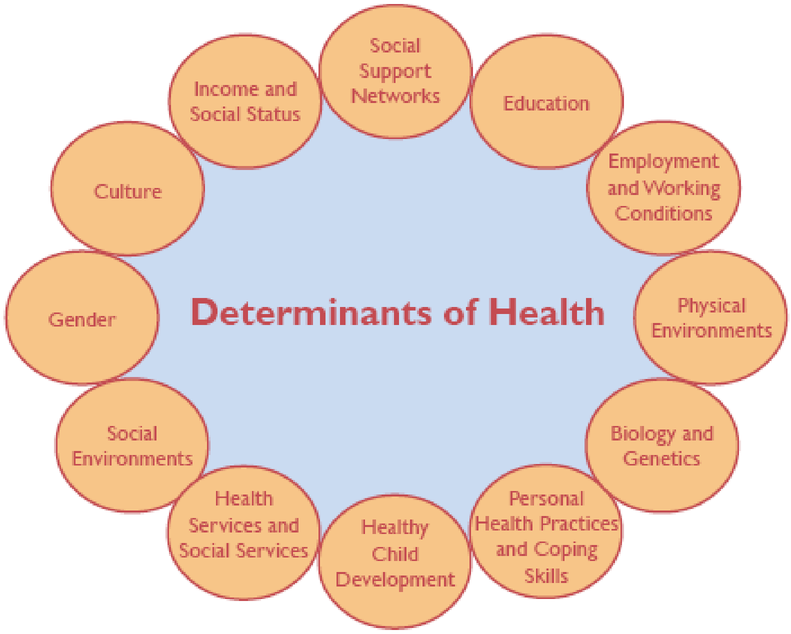
[5] *Preamble to the Constitution of the World Health Organization* as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100); and entered into force on 7 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, 2013[6]

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)[6] 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.

- Disability (having it; societal recognition through accommodation, law, custom)

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[6] 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/ *

- 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*.[7] 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 were represented with most participants residing in Toronto and Central Ontario (53.6%) followed by

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[7] 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.

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.[8] **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.**

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[8] 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 EVDIENT …

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 PHYSICIAL 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 for wife with ME**

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.[9]

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.[10]

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.[11]

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.

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

[10] 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.

[11] 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 piont. 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.

PUBLICILY-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 I 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 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, buy 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 ... K**athryn 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 and 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 NOTACCESSIBLE 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.[12]

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 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.[13]

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

[13] 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.

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.

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 CONDIITIONS 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/PHSIOTHERAPY, 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. [14] 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 the. 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.

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[14] 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 HYPCHONDIRA 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 THETHE 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 PYSYCHOGENIC 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 breath 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]why 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 underserviced. **Elva FM ME MCS**

13.10 PRIMARY CARE NEEDS

Informatnts 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 CONDTIONS

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 CONDTION 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 provides.
- 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.[15]

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.[16]

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.[17]

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.[18]

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 model of care including a home-based component for people with ES/MCS, FM and/or ME/CFS has not been

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

[16] 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.

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

[18] 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.

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.**[19] 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.**[20] 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.[21]

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. …

In children, [FM] is more common in prepubertal or adolescent girls, and estimates for the prevalence of

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[19] 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/

[20] 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.

[21] Molot, 2013.

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,[22] 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 CONDTIONS 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.

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

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[22] 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).

of xenobiotics.553 Furthermore, there may be an epigenetic predisposition inherited from the mother.[23]

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.[24]

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 or 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).’[25]

As previously noted (see Chapter 7: Key lessons from the environmental scan)[26] 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.

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[23] Molot, 2013.

[24] Molot, 2013.

[25] 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.’

[26] 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.[27]

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
- Behavior Problems

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[27] Molot, 2013.

- 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.”[28] 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.[29]

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 excellent paper in this way:

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[28] 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.

[29] 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.

'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 Men[30]

- 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.

To understand better what is at stake, let us look at the hypotheses regarding the reasons for women's greater affliction with these conditions.

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[30] 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.

15.2 WOMEN AFFECTED BY THE THREE CONDITIONS MORE THAN MEN

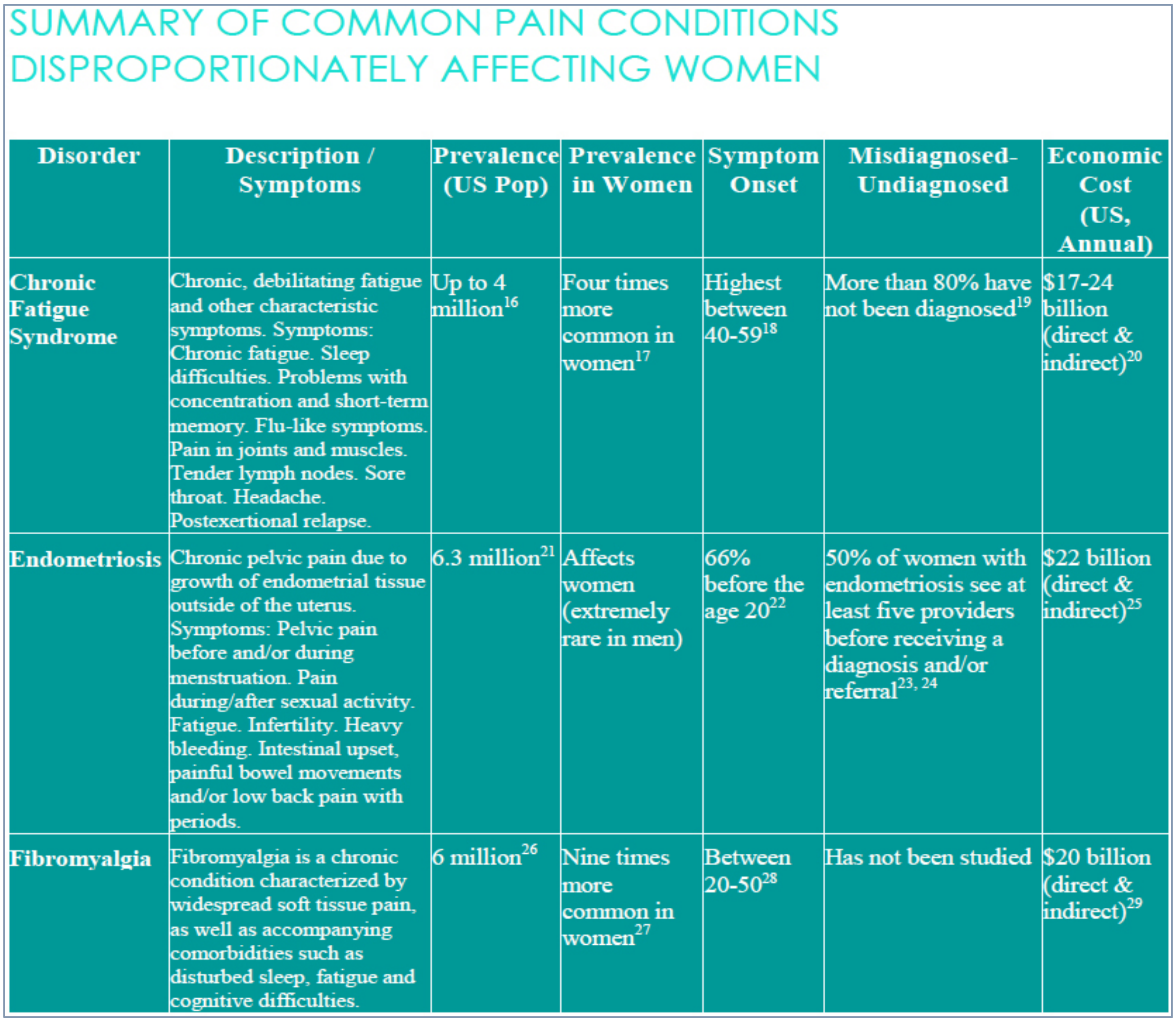
While a significant number of men - adults and boys - do suffer greatly from these conditions (and from their discounting and neglect), and while there may be under-diagnosis of the conditions in males, still the prevalence of the CELCs among women is striking. **The 2010 CCHS data suggest a ratio of 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 he jaw joint and muscles that control jaw movement. Symptoms: Dull aching pain in he 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 ower teeth fit together or bite hat 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.[31]

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 average, women are more responsive to painful stimuli, and women also tend to have a heightened**

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[31] Chronic Pain Research Alliance, *Chronic Pain in Women: Neglect, Dismissal and Discrimination* (May, 2010); PDF available from http://www.overlappingconditions.org/

> **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][32]

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**.[33]

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?**

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[32] Molot, 2013.

[33] 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 it 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.**[34]

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.[35] 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'.**

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[34] 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.

[35] 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.**[36]

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[36] See discussion in Molot, 2013.

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 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.**[37] 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

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[37] 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 hat 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.[38] 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.[39] 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**

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[38] 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&chropg=1&lang=eng (accessed July 26, 2013). All computations, use and interpretation of these data are entirely those of the author.

[39] 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.[40]

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 colleagues, financial and other rewards and job security. They are also the healthiest, despite often heavy

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[40] 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.

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.**[41]

‘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, headaches, respiratory problems, rashes, and other ailments that the affected individuals had not

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[41] 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.

> experienced prior to service in the Gulf.[42] … 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**."[43]

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.'[44]

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 gas pills (pyridostigmine bromide), anthrax vaccination, tent heaters, exposure to oil fire smoke, and

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[42] 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.

[43] Ibid, p. 89.

[44] Ibid, pp. 87-88.

chemical odors were significantly related to multisymptom illness in logistic regression analyses."[45]

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.**[46] 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.’**[47] **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. [48]

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[45] 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.

[46] USAF Major (Ret.) David S. Fenton to Varda Burstyn, personal communication, 2013.

[47] Brown, 2012, p. 94.

[48] 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 21, 2013).

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.**[49]' 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.' [50]

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.' [51]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.'**[52]

There are many lessons in this experience, beyond the scope of this report to explore. However, **the**

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[49] Ibid, p. 99.

[50] Ibid, p. 99.

[51] Ibid, pp. 95-96.

[52] Ibid, p. 103.

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.**

COMMERICAL VERSUS HEALTH INTERESTS

THE CHEMICAL MANUFACTURERS ASSOCATION'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',[53] 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.[54] They believe that as the myriad and

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[53] 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/

[54] 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. 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

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 tim**e. 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 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**

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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.'

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.[55]

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.

COUNTERPRODUCTIVE NOMENCLATURE

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[55] '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

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.[56]

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[56] 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: Treatment Guidelines for Psychiatrists,' 2006. Both are available for download at http://www.eleanorsteinmd.ca/publications/

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.[57] 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 time indoors. Thus, for many people, the risks to health may be greater due to exposure to air pollution indoors than outdoors. [58]

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[57] American Lung Association, *Indoor Air Quality*, accessed September 15, 2013. http://www.lung.org/associations/charters/mid-atlantic/air-quality/indoor-air-quality.html

[58] 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

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. [59]

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 I 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**

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**.

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[59] Juliene 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.'

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.[60] 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.[61] 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.[62]

SAFE HOUSING SHOULD BE BY Rx AND SAFE SHELTERS ARE NEEDED

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[60] 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.

[61] Ibid.

[62] 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 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.** [63] 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.

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[63] 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/