



The Legal Rights and Challenges Faced by Persons with Chronic Disability Triggered by Environmental Factors

*Report prepared by ARCH Disability Law Centre and the Canadian
Environmental Law Association*

September 2019

Acknowledgements:

ARCH and CELA gratefully acknowledge the following people in the preparation of this report.

Authors: Dianne Wintermute, Lawyer (ARCH) and Kathleen Cooper, Senior Researcher and Paralegal (CELA)

Legal and Research Assistants: Joshua Patlik and Erica Stahl

We are particularly indebted to the participants in our focus groups for their invaluable contributions to our research.

The authors also acknowledge the expertise of physicians with the Environmental Health Clinic, particularly Dr. Lynn Marshall and Dr. John Molot, as well as board members of the Environmental Health Institute of Canada. Any errors or oversights are the responsibility of ARCH and CELA.

Suggested citation:

Wintermute, D and Cooper, K, *The Legal Rights and Challenges Faced by Persons with Chronic Disability Triggered by Environmental Factors*. ARCH Disability Law Centre and Canadian Environmental Law Association, Toronto. July, 2019.

ARCH Disability Law Centre (ARCH) is a specialty legal aid clinic whose mandate is to provide services to persons with disabilities who also have low incomes in the Province of Ontario. ARCH promotes and defends the rights of persons with disabilities by providing free legal advice and representation to persons with disabilities or the organizations that support them in test case and systemic litigation at all levels of courts and tribunals. ARCH writes briefs and submissions to government on policies or laws that affect the rights and interests of persons with disabilities. ARCH provides public legal education to persons with disabilities and continuing legal education to the legal profession.

The Canadian Environmental Law Association (CELA) is a specialty community legal aid clinic. It was established in 1970 to use existing laws to protect the environment and to advocate for environmental law reforms. CELA provides services to low income individuals and disadvantaged communities across Ontario in matters of environmental law and public health. CELA services include representation before a variety of courts and tribunals, assistance to individuals representing themselves and summary advice. CELA also conducts extensive public interest law reform and legal education with a dual focus on access to environmental justice and pollution prevention, public health and safety.

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I. Introduction

This report addresses challenges faced by persons with chronic disabilities that are triggered by environmental factors. It is informed by communities of people with lived experience and by specialist physicians in this field who conduct research, provide educational programs for other health service providers and develop treatment models for persons with environmental health (EH) disabilities. It is also informed by the work of Ontario's Task Force on Environmental Health, and by legal intake, casework, one-on-one and group consultations with persons with environmental health disabilities, and research conducted by the ARCH Disability Law Centre (ARCH) and the Canadian Environmental Law Association (CELA).

EH disabilities are highly complex and, although they are far from being fully understood, are supported by extensive scientific evidence. They typically encompass the following: myalgic encephalomyelitis (ME) also referred to as chronic fatigue syndrome (CFS), fibromyalgia (FM), and Environmental Sensitivities (ES), also referred to as Multiple Chemical Sensitivities (MCS). The evidence base is much stronger for ME/CFS and FM than for ES/MCS.¹ For convenience, this report refers to all three of these conditions under the more generalized heading of environmental health disabilities (EH disabilities) unless more specificity is needed. We discuss the legal rights of persons with EH disabilities in Ontario, the barriers they encounter, and make recommendations for change.

1.1 Characteristics of EH Disabilities

EH disabilities are often characterized by one or more of the following: chronic and disabling fatigue and/or pain, weakness, problems with memory/concentration, and

¹ Hu, Howard, et al 2017. Current State of Recognition and Scientific Understanding of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Fibromyalgia (FM) and Environmental Sensitivities/Multiple Chemical Sensitivities (ES/MCS). A White Paper for the Ontario Task Force on Environmental Health. Appendix 4 to Phase 1 Report of the Task Force on Environmental Health. Online at: http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx

symptoms related to respiratory, skin or other sensitivities. These and additional symptoms may be recurrent, nonspecific, and heterogeneous.^{2,3} A common element across all of ME/CFS, FM, and ES/CFS is that symptoms arise from environmental triggers. Such triggers can include extreme sensitivity to low doses of various, often unrelated, chemicals⁴ or toxic substances,⁵ and often include sensitivity to moulds. Bright lights, physical trauma, and infectious agents may also be environmental triggers.

1.2 Contextual Survey of Persons with EH

Very large numbers of people are affected – more than 740,000 Ontarians live with one or more of ME/CFS, FM, or ES/MCS.⁶ This large number is reflected in a consistently high volume of requests for legal assistance at ARCH and CELA from people with EH disabilities. A deeper look at the numbers reveals that poverty is a constant problem. In addition, women are disproportionately affected, often during the years that might otherwise provide their most productive employment earning potential.

² Environmental Health Clinic – Women’s College Hospital, “Medical Description: How a person develops ES,” online: <<http://www.womenshealthmatters.ca/health-centres/environmental-health/environmental-sensitivities/medical-description/>>

³ Busby, Laurie Dennison. 2017. “A Comparison of Multiple Chemical Sensitivity with Other Hypersensitivity Illnesses Suggests Evidence and a Path to Answers.” *Ecopsychology* 9 (2):90–98. <https://doi.org/10.1089/eco.2017.0003>.

⁴ “Multiple chemical sensitivity: a 1999 consensus” (1999) 54 Arch Environ Health 147 [MCES Consensus].

⁵ This report refers to “toxic substances” as those exposures that cause irritation or worse symptoms in people diagnosed with EH disabilities whereas others without such sensitivity may not react. However, it is well-established in the scientific literature that there is an indoor burden of multiple contaminants arising from diverse sources such as consumer products, cleaning products, etc., that are measurable in indoor air, on surfaces, and in house dust, including many that are known to be associated with animal or human toxicity at varied levels of exposure. See, e.g., Mitro, Susanna D., Robin E. Dodson, Veena Singla, Gary Adamkiewicz, Angelo F. Elmi, Monica K. Tilly, and Ami R. Zota. 2016. “Consumer Product Chemicals in Indoor Dust: A Quantitative Meta-Analysis of U.S. Studies.” *Environmental Science & Technology*, September. doi:10.1021/acs.est.6b02023; and Roberts, John W., Lance A. Wallace, David E. Camann, Philip Dickey, Steven G. Gilbert, Robert G. Lewis, and Tim K. Takaro. 2009. “Monitoring and Reducing Exposure of Infants to Pollutants in House Dust.” In *Reviews of Environmental Contamination and Toxicology* Vol 201, edited by David M. Whitacre, 201:1–39. Boston, MA: Springer US. http://link.springer.com/10.1007/978-1-4419-0032-6_1.

⁶ This figure includes Ontarians age 12 years and older. Canadian Community Health Survey (CCHS), 2016, Ministry of Health and Long-Term Care Share File, Statistics Canada. As cited in Care Now, Final Report of the Task Force on Environmental Health, December, 2018. http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/task_force_on_environmental_health_report_2018.pdf

The Canadian Community Health Survey reports that the proportion of women diagnosed with EH regularly outnumbers men by a margin of more than two to one.^{7,8} Likewise, earlier Statistics Canada data from 2005 shows that the prevalence of EH increases with age, particularly after age 45.⁹ On average, persons with EH stopped working within three years of symptom onset.¹⁰ In 2010, the Canadian Community Health Survey showed that 14.7% of Canadians with EH disabilities experience moderate or severe household food insecurity, a little over twice the rate of food insecurity in the total population (7.2%).¹¹ Furthermore, a significant number of persons with EH disabilities (approximately 10%) have a household income below \$15,000.¹²

Similar evidence of disproportionate impact on this community comes from research done in support of a business case for an Ontario Centre of Excellence in Environmental Health. Recognizing that EH disabilities and their symptoms occur on a spectrum, individuals with EH disabilities are significantly more likely to have unmet health needs, experience much greater life stress, have poorer health and a weaker sense of community belonging. Persons with EH disabilities also encounter greater rates of unemployment and poverty, as compared to the general population.¹³

In the focus groups held by ARCH and CELA, the individuals we consulted described their personal experiences with marginalization, stigmatization, isolation, and loneliness,

⁷ Statistics Canada, *Canadian Community Health Survey, 2014*, online: Statistics Canada <<http://www.statcan.gc.ca/daily-quotidien/150617/dq150617b-eng.htm>> [StatsCan].

⁸ For a more detailed summary of the 2014 Canadian Community Health Survey prevalence and profile data of Canadians affected by ME/CFS, FM and ES/MCS, see Appendix 2 of the Environmental Task Force Report. July, 2017. *Op.cit.*

⁹ Environmental Health Clinic 2011, *supra* note 9 at p 21.

¹⁰ MR Lavergne, DC Cole, K Kerr, LM Marshall, "Functional impairment in chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivity" (2010) 56:2 *Can Fam Physician* 57 at 61 [Lavergne et al]. The chart review was conducted for 128 consecutive patients with one or more diagnoses of MCES, chronic fatigue syndrome, or fibromyalgia.

¹¹ Erika Halapy, *Quantitative Data Report*, online: Myalgic Encephalomyelitis Association of Ontario (MEAO) <http://www.meao.ca/files/Quantitative_Data_Report.pdf> at 40.

This number does not include data from NB or PEI (question was not asked)

¹² *Ibid* at 41.

¹³ For detailed documentation of challenges faced by affected individuals see the report developed in support of a business case for an Ontario Centre of Excellence in Environmental Health: Varda Burstyn, Recognition Inclusion and Equity – the Time is Now: Perspectives of Ontarians Living With ES/MCS, ME/CFS and FM. (Toronto: Myalgic Encephalomyelitis Association of Ontario MEAO) 2013.

loss of employment, poverty and declining health. These lived experiences are a call to greater action, and ignoring them comes at a high cost. Disregarding those with EH disabilities, who may be warning us all of the need for reducing exposure to toxic substances more generally, tends to impede development of practical, preventative and cost-saving public health strategies.¹⁴

1.3 Lack of Specialized Health Services

There are very few physicians in Ontario who are qualified to address EH disabilities. They face a serious shortage of resources to treat persons who require complex, long-term, and specialized health services. There is also a lack of time and resources to assist with much-needed primary research and to pass on expertise by training other physicians.

There is only one specialized clinic in Ontario – the Environmental Health Clinic based at Women’s College Hospital in Toronto. When people contact either ARCH or CELA, we cannot make a direct referral to the clinic and must advise clients to ask their family physician for a referral. While such physician referrals are generally forthcoming, or may have already been made, the Clinic has a waiting list of approximately one year.¹⁵

Physicians at the clinic are experts in their field. A detailed intake and assessment protocol is followed. Clinic physicians can typically only do the initial appointment and one or two follow-up appointments and then need to spend significant time in sending detailed instructions to family physicians.

Such person-centred services are time consuming and occur within constant pressure to reduce the Clinic waiting list. The Environmental Health Clinic needs more resources

¹⁴ Environmental Health Clinic Women’s College Hospital, Toronto, “Environmental Sensitivities-Multiple Chemical Sensitivities Status Report Advances in Knowledge, and Current Service Gaps,” (updated 2 June 2011) at p 18 [Environmental Health Clinic 2011]. Online at:

<<http://www.womenshealthmatters.ca/assets/legacy/wch/pdfs/ESMCESStatusReportJune22011.pdf>>
Can also be downloaded from: <<http://www.womenshealthmatters.ca/health-centres/environmental-health/environmental-sensitivities/>>

¹⁵ <https://www.womenscollegethospita.ca/programs-and-services/environmental-health-clinic/referrals>

and more doctors. The latter is a significant challenge as these are among the few physicians in Ontario able to train other physicians in a very demanding area where per-patient billing and time availability can make a person with a sprained ankle equivalent to a person with a complex, chronic, and debilitating condition.

These factors underpin the significant challenge of obtaining evidence for legal proceedings on behalf of clients who experience EH disabilities. When ARCH or CELA staff are approached with legal inquiries, the first question is often to ask about medical evidence. It is rarely available.

1.4 The Task Force on Environmental Health

Public health perspectives often reflect high priority areas where a large number of people are affected. However, for the community of persons affected by EH disabilities in Ontario, such prioritizing is not the case. This situation may change if Ontario acts upon the recommendations of the Task Force on Environmental Health.

Established in 2016 by the Ministry of Health and Long Term Care, the Task Force on Environmental Health was asked to provide recommendations and advice in four areas:

- guidance or policy to support persons with EH disabilities;
- increasing public and health care providers' knowledge;
- identifying gaps in evidence, knowledge transfer and care of individuals who are impacted by EH disabilities; and
- person focused actions to improve health outcomes.¹⁶

The Phase 1 Report¹⁷ focuses on improving the recognition and understanding of EH disabilities. It establishes the groundwork for a person-centred system of health

¹⁶ Details about the Task Force mandate and membership are on-line here:

<http://www.health.gov.on.ca/en/public/programs/environmentalhealth/>

¹⁷ Task Force on Environmental Health, 2017. Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS. Online at:

services, and increasing the number of knowledgeable healthcare providers. This interim report makes a strong case for necessary action in multiple areas.

The Phase 1 Report concludes that despite ongoing gaps in knowledge, (a situation severely hindered by both inadequate research and great difficulty in diagnosis), a substantial body of scientific evidence exists for each of the three conditions (ME/CFS, FM, and ES/MCS). Research supports the fact that EH disabilities are not primarily psychological as is often assumed. The Task Force also notes that evidence confirms that psychological approaches to treatment are rarely successful.

Related findings, noted in both the Phase One and Final Report,¹⁸ describe the serious problem of stigma associated with EH disabilities, having negative consequences for this community, and resulting in serious barriers to increased research and involvement by clinicians providing support and services. This stigma and skepticism extends to all aspects of people's lives including family, friends, employers and the general public. The associated lack of recognition of EH disabilities results in people being denied insurance benefits, social services and supports, and other benefits. Related problems often include often not being able to obtain letters from physicians or other specialists necessary to be eligible for assistance. Stigma is reflected by an inability to work, find housing, visit hospital emergency departments, or function in diverse public locations.

The Task Force also describes the profound shortage of specialized doctors, a lack of academic and research leadership, and a lack of timely and appropriate treatments. At present, there is no "cure" for those with EH disabilities.

The eight recommendations in the Phase One report are divided into four areas:

http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx

¹⁸ Care Now - An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS). Final Report of the Task Force on Environmental Health, December, 2018.

http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/task_force_on_environmental_health_report_2018.pdf

- increasing understanding and recognition of these conditions;
- developing common definitions and practice guidelines via an expert panel;
- laying the groundwork for a person-centred system of health services; and
- increasing the number of knowledgeable health providers.

The Task Force's Final Report discusses several of the Phase One recommendations, and adds considerable detail. The Final Report makes ten recommendations, organized across diverse aspects of: improving; integrating; and evaluating health services.

Recommendations for improving health services include:

- raising awareness and reducing stigma across the board;
- establishing priority groups within the general public that would benefit from public campaigns, like employers and landlords;
- priority areas for improving treatment in healthcare settings, including hospitals, long-term care homes, and key home care providers;
- greater awareness about the availability of clinical tools and information across all primary health care settings.

Additional recommendations for improving health services highlight the increasing capacity across the system to develop and disseminate clinical tools and information, and to address training needs and related supports. Associated recommendations speak to how this developing capacity must occur by creating a coordinated strategy that increases the pool of both primary and specialized health providers to confront a health services field that demands a high degree of interdisciplinary integration.

Building on the interdisciplinary demands of improving health services, the second set of recommendations address the need to integrate those services. Two recommendations are made: to create and support a network of enhanced primary health programs across the province; and to support this with a shared planning tool.

The third group of recommendations is about evaluating health services. These form the majority of the Report's recommendations. The recommendations seek to address many gaps in knowledge and the lack of funding for primary research. They include a centre of excellence for EH research and outcomes, as well as measures to ensure leadership in transitional implementation of the action plan and the provision of regular updates and progress reports.

The two Task Force Reports and recommendations focus only on the health sector, albeit noting this emphasis is only a first step. However, with a mandate to support persons with EH disabilities, increasing public knowledge of environmentally-triggered conditions and actions to improve health outcomes, the Task Force could have gone further. For example, both reports note the reality and far-reaching consequences of stigma associated with EH disabilities, and the many challenges of access and accommodation. The Task Force also notes associated legal challenges and states that it "believes strongly that Ontario must seize the opportunity provided by the [Ontario Human Rights] Code and the [*Accessibility for Ontarians with Disabilities Act*] AODA to fully recognize and address the disabilities arising from ME/CFS, FM and ES/MCS."¹⁹ Yet, the Task Force chose, in both the interim and final reports, to focus recommendations only on access and accommodation in the health system. While extremely important, the Task Force mandate was framed broadly enough to make recommendations about access and accommodation more broadly for society at large.

While the recommendations provide important signposts for necessary change in the health system, very limited recognition is given to key funding issues and constraints. It is implied that increased funding is necessary to implement the recommendations but explicit mention would have been welcomed. Also implied, but not explicitly mentioned in either the interim or final reports, is recognition of the complexity and length of health services necessary for persons with EH disabilities. The long waiting list at the Environmental Health Clinic has as much to do with complexity as with the clinic's very

¹⁹ Task Force on Environmental Health, 2017. *Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS.* at page 25.

small budget and the shortage of specialized doctors in Ontario. Nevertheless, the Task Force makes a valuable contribution to improving understanding of EH disabilities and recommending a detailed path forward for urgently needed improvements in Ontario's health system.

2. The Law

2.1 Introduction

EH has been legally recognized as a disability for many years. The Ontario Human Rights Commission and Tribunal have accepted EH as a disability since 2000,²⁰ and the Canadian Human Rights Commission has had a policy on EH since 2007.²¹

While laudable, legal recognition is not enough. The narratives we heard from persons with EH disabilities indicate that there is a gap between legal rights and lived experience. They still face many barriers finding adequate housing and participating in the essential activities of daily life. Taking public transit can be impossible; renovating one's home to make it accessible can consume savings; attendance at school or the workplace becomes dependent on implementing and enforcing accommodation plans and policies.

The following legal inquiry will consider some of the challenges faced by persons with EH disabilities through a human rights lens. It starts with the discrimination analysis and is followed by issues experienced in housing; employment; and transportation. This

²⁰ Ontario Human Rights Commission, *Policy and guidelines on disability and the duty to accommodate* (2000), online: Ontario Human Rights Commission <http://www.ohrc.on.ca/sites/default/files/attachments/Policy_and_guidelines_on_disability_and_the_duty_to_accommodate.pdf> at 7 [OHRC 2000].

²¹ Canadian Human Rights Commission, *Policy on Environmental Sensitivities*, online: Canadian Human Rights Commission <http://www.chrc-ccdp.gc.ca/sites/default/files/policy_sensitivity_0.pdf> [CHRC]. See also Wilkie, Cara and David Baker, "Accommodation for Environmental Sensitivities: Legal Perspective," report prepared for the Canadian Human Rights Commission (May 2007), online: <http://www.chrc-ccdp.gc.ca/sites/default/files/legal_sensitivity_en_1.pdf>

section concludes with a discussion of the *Accessibility for Ontarians with Disabilities Act*²² (AODA).

Importantly, there are other tribunals that address EH disabilities in employment (for example, the Workplace Safety and Insurance Board²³) or housing (for example, the Landlord and Tenant Board²⁴). This paper does not discuss proceeding under other pieces of legislation or before tribunals other than the Human Rights Tribunal of Ontario (HRTO) or the Canadian Human Rights Tribunal (CHRT).

2.2 Disability Discrimination Analysis

The Ontario *Human Rights Code*²⁵ (Code) applies to public and private actors in the Province of Ontario. The *Canadian Human Rights Act*²⁶ (Act) applies to public and private actors in the federal sphere.

Disability is defined very broadly in both pieces of legislation. It is an inclusive definition that adopts the social model of disability and covers not just existing, but also new or emerging, disabilities.

In order to prove disability discrimination, a person must show that they have a disability; that they are treated differently because of disability; and that they experience an adverse impact.

Discrimination can be any form of unequal treatment that results in disadvantage, whether by imposing extra burdens or denying benefits. It may be intentional or unintentional. It can involve direct actions that are discriminatory on their face, or the application of rules, practices or procedures that appear to be neutral but have the

²² Accessibility for Ontarians with Disabilities Act 2005, S.O. 2005, c. 11

²³ Workplace Safety and Insurance Act 1997, S.O. 1997, c.16

²⁴ Residential Tenancies Act 2006, S.O. 2006, c. 17

²⁵ Ontario Human Rights Code, R.S.O. 1990, c. H. 19

²⁶ Canadian Human Rights Act, R.S.C. 1985, c.H-6

effect of disadvantaging people with disabilities. Discrimination can be obvious, or it may occur in very subtle ways.

The Code prohibits discrimination in five social areas: housing; employment; services (which include education, transportation and healthcare); trade unions and vocational associations; and contracts.

Once a person establishes a *prima facie* case of discrimination, then the duty to accommodate to the point of undue hardship is considered. *Prima facie* means providing enough evidence to support the allegations of discrimination. The duty to accommodate means the steps and solutions taken to provide equal access, opportunity or benefits to the person with a disability. Accommodation must be provided in a manner that most respects the dignity of the person with a disability and promotes their inclusion and full participation in society.

The only three defenses to the undue hardship test are: health and safety; the availability of outside sources of funding; and cost and the availability of other sources of funding.²⁷ The test for cost is a high one. The cost must be so great that it will alter the essential nature of, or substantially affect the viability of the organization or person responsible for the accommodation.²⁸

Accommodation must respond to the characteristics of each individual. This means that each person with a disability must be considered, assessed, and accommodated within the context of their own unique circumstances.²⁹ There can be no cookie cutter approach to accommodation.

²⁷ Code s.11(2) and Act s. 15(2)

²⁸ *B.C. (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, 181 DLR (4th) 385 — 249 NR 45 — [2000] 1 WWR 565 — 70 BCLR (3d) 215 — 131 BCAC 280 — 36 CHRR 129 — AZ-50068485 — EYB 1999-15531 — JE 2000-43 — [1999] SCJ No 73 (QL) — [1999] ACS no 73 — 47 MVR (3d) 167 — 93 ACWS (3d) 524

²⁹ *Ibid*

In addition, the accommodation process is a two-way street, involving the service provider or the employer and the person with EH disabilities, to ensure that individual accommodation needs are explored and met. It is important to recognize that the person with EH disabilities may not get exactly what he or she wants as an accommodation. As long as the proposed accommodation meets the person's support and service needs, then an alternative and less costly solution may be sufficient to meet the Code or Act standard of undue hardship.

An application under the Code or complaint under the Act must be filed within one year of the date the discrimination occurred, unless there are exceptional circumstances that prevent a person from meeting that deadline. The HRTO takes a strict approach to the one year limitation period³⁰. Additionally, the HRTO not accept general assertions of not feeling well to be an exceptional circumstance. There is a high threshold to meet the test for exceptional circumstances³¹

Both the Code and the Act take precedence over all other provincial or federal laws unless expressly excluded.³² Hence, human rights legislation is a powerful, quasi-constitutional law that requires all legislation to be read in a way that promotes human rights.

Persons with EH disabilities are entitled to equal opportunities without discrimination. However the legal process can create challenges in securing their rights.

The following sections review published case law. There may be other complaints or applications that have been mediated or settled and are subject to confidentiality clauses. It should be noted that in many instances, the Applicant or Complainant are self-represented. We cannot stress enough the importance of getting legal advice before filing a disability discrimination complaint with either Tribunal.

³⁰ See, for example, *Biondic v. Ontario*, 2019 HRTO 833 CanLii

³¹ See *Davlik v Leach* 2019 HRTO 509 CanLii

³² Code s. 47; Act s.66

2.3 Housing

In focus groups, participants with EH disabilities voiced significant concerns about the barriers they experience in finding and maintaining accessible and affordable rental housing. Some of the issues experienced include EH triggers in response to: strong fumes caused by laundry facilities; dust; carpeting; cleaning products in common areas; mould; and cigarette smoke.

The 2014 decision of *Noe v Rane Management*³³ deals with a housing complaint filed at the HRTO by a person with EH disabilities.

In this case, Ms. Noe had provided a medical report to her landlord confirming an EH disability. The report included the types of environmental factors that caused her health to deteriorate. At the HRTO hearing, the Parties accepted that Ms. Noe had an EH disability.

Prior to the hearing, Ms. Noe had asked the landlord for the following accommodations:

- she be allowed to move temporarily to another unit while the neighbouring unit was being painted and re-varnished;
- the landlord notify her before doing work on apartments on her floor; and
- the landlord use less-toxic chemicals when cleaning or working on neighbouring units or common areas.

The landlord did not provide any of the requested accommodations. The HRTO determined that the landlord's failure to accommodate Ms. Noe's disability was discriminatory. Importantly, it held that the landlord's breach of Ms. Noe's rights was serious because it made it impossible for her to live without discomfort in her own home. The HRTO awarded Ms. Noe \$5,000 as compensation for injury to dignity, feelings and self-respect and ordered the landlord's managerial employees to complete the OHRC's

³³ *Noe v Rane Management* 2014 HRTO 746 (CanLii)

Human Rights 101 e-learning module.³⁴ It is important to note that the HRTO was restricted in the remedies it could award because Ms. Noe did not attend the remedial portion of the hearing. No evidence of the impact of the landlord's failure to accommodate Ms. Noe was presented. In order to achieve meaningful remedies, there must be evidence of both the discriminatory conduct and its impact on the Applicant.

Other housing cases before the HRTO have not been as successful this decision.

In *Silverberg v. Lau*³⁵, the tenant applicant failed to provide sufficient evidence to establish, on the balance of probabilities, that she had an EH disability. As a result, she could not prove that there was a need for the landlord to implement any accommodation measures. The tenant failed to link her medical condition with the environmental exposures she complained of. Moreover, she did not provide the Tribunal with expert reports, nor did she call any experts who could testify on her behalf. The HRTO only heard the tenant's testimony. The tenant failed to prove that the conditions in her apartment triggered her EH disability. The HRTO also found that the tenant did not participate in the accommodation process. The application was dismissed. The important issue raised in this case is the need for persons with EH disabilities to provide evidence of disability and accommodation needs, sometimes requiring medical or other expert opinion.

*Creary v. Bajaj*³⁶ also highlights evidentiary problems in tenant complaints before the HRTO. In this case, the particular rental housing had been constructed to be smoke and pet free. The tenant testified that despite the landlord's measures, she could still smell smoke and other irritants in her apartment. She asked the landlord to reseal the windows and doors in her apartment. She also asked the landlord to provide her with an air purifier. The Parties and the HRTO accepted that the tenant had an EH disability.

³⁴ *Ibid.*

³⁵ *Silverberg v. Lau*, 2016 HRTO 1368 (CanLii)

³⁶ *Creary v. Bajaj*, 2017 HRTO 411 (CanLii)

Evidence was tendered showing that when the landlord first received the tenant's complaints, he sent technicians to inspect the sealant on the windows and doors. Inspections were performed intermittently thereafter. There was no evidence of the windows and doors being improperly sealed. Additionally, during cross-examination, the tenant admitted that she did not follow all of her doctor's recommendations for limiting exposure to environmental triggers. For example, she did not wear air filter mask when she was outdoors. The tenant also testified that she had recently purchased a car. The HRTO held that if she had been concerned about environmental triggers affecting her health, the tenant should have purchased an air purifier instead of a car. The HRTO determined that, although there was no doubt that the tenant had a disability, she had not proved that she was treated adversely. Therefore the landlord did not have a duty to accommodate her. Expert evidence from inspectors was critical in showing that the landlord had taken all precautionary measures that he could.

In *XY v. Housing Connections*³⁷ the tenant proposed very specific accommodations for the landlord to address her EH related needs. Her requests included:

- being housed in a particular location;
- being temporarily housed in a less suitable apartment until a more appropriate one could be found;
- being placed in a two bedroom townhouse although she was the sole occupant;
- qualifying for a special needs program designed specifically for persons with EH disabilities;
- creating a local priority housing program for persons with EH disabilities; and
- having the landlord purchase housing that would specifically meet the needs of persons with EH disabilities.

The HRTO addressed each of the proposed accommodations and held:

- the tenant had unnecessarily restricted her accommodation options;

³⁷ *XY v. Housing Connections*, 2013 HRTO 1094 (CanLii)

- housing her in an inferior apartment would detract from her accommodation needs;
- she was the only person to occupy the premises, so did not require a two bedroom living unit;
- the likelihood of needing a second bedroom in the future was remote;
- there were many tenants on the waitlist for housing who required housing appropriate to their needs immediately;
- the tenant met the eligibility criteria for a special needs program (domestic violence) and there was no special needs program for persons with EH disabilities;
- there was no obligation on the landlord to create a local housing priority for persons with EH disabilities;
- there was no requirement for landlords to purchase a building specific to a particular disability related need;
- the tenant failed to cooperate with the landlord in the accommodation process by limiting her options; and
- asking for remedies that were not connected to her specific circumstances. In other words, the remedies asked for were remote and not connected to the facts of the tenant's specific case.

This case clearly demonstrates the necessity of asking for accommodations or remedies that can be connected to the impact of disability on a person.

Other barriers to accessible housing for persons with EH disabilities include, but are not limited to: financial constraints; lack of emergency shelters that are universally accessible and free of chemical or other environmental triggers; exposures in poorly maintained housing and/or shared housing, particularly those from common areas and neighbouring units.

In each of the cases discussed above, the tenant was self-represented. We strongly recommend getting legal information or advice before filing an HRTTO application or

CHRT complaint. Legal staff from ARCH or CELA are available for consultations on these, and other EH related, issues.

Applicants to the HRTO must be prepared to adduce sufficient evidence to link their EH disability with the accommodations sought. In some cases, the Applicant's own testimony may not be sufficient to establish this connection. Applicants must also think about whether there are experts they can call to provide objective evidence, or whether there are reports from experts to bolster their case. Applicants must cooperate in the accommodation process and be flexible when doing so. Finally, accommodations must be connected to the facts of each case and cannot be overly broad or remote.

However, Applicants can be creative in fashioning remedies that respond to their individual case, as long as they are connected to the facts of each case. These might include, but are not limited to requesting: air filters, cleaners or purifiers; shower filters; the use of alternative cleaning products; being housed in a different apartment (if one is available) when renovations near to the applicant's unit are being performed; and advance notice of any work being done in the building. However, it is important for the remedies to reflect the actual accommodation needs of the tenant.

Home owners with EH disabilities can incur substantial expenses in making their homes more accessible to them. Some expenses may be eligible for medical expense tax credits under the *Income Tax Act*.³⁸ The Canada Revenue Agency (CRA) publishes a list of eligible medical expenses that specifically relate to housing, which include: an air filter; cleaner, or purifier; furnace; and renovation or construction expenses.³⁹ Although not included in the CRA's list, shower filters have also been recognized in case law as allowable medical expenses under s. 118.2(2) of the *Income Tax Act*.⁴⁰

³⁸ *Income Tax Act*, RSC 1985, c 1 (5th Supp), <<http://canlii.ca/t/52lhj>>.

³⁹ Canada Revenue Agency, "List of eligible medical expenses," online: Canada Revenue Agency <http://www.cra-arc.gc.ca/medical/#mdcl_xpns>

⁴⁰ See for example, *Tall v Canada*, 2008 TCC 677, TCJ No 532.

For renovation or construction expenses to be eligible for medical tax credits, a person must first prove that their disability is severe and prolonged. Next the person must show that the amounts claimed were spent on changes that permit greater access to (or greater mobility or functioning within) a dwelling⁴¹.

In *Pawlychka v Canada*,⁴² the Tax Court of Canada expanded the interpretation of “mobility” under the *Income Tax Act*. The Court stated that a mobility impairment is not restricted to “not having normal use of limbs”. The Court accepted the claimant’s EH disability as a severe and prolonged mobility impairment and allowed renovation expenses to be claimed as a medical expense tax credit because they enabled greater access, mobility, and/or functionality within the home.⁴³

2.4 Employment

Persons with EH disabilities want to work. In focus groups, participants told us of the barriers they experience in the workplace, ranging from scented products worn by co-workers to office renovations. The Environmental Health Clinic at Toronto’s Women’s College Hospital found that on average, persons with EH disabilities stopped working within three years of symptom onset.⁴⁴ This represents a tremendous amount of lost income and productivity that could be regained with appropriate accommodations for employees with EH disabilities.

Focus group participants said that one of the most difficult barriers to overcome in employment was the attitude of others, making the stigma associated with EH disabilities very impactful. Some employers and co-workers expressed doubt that EH disabilities are a “real” disability, which led to the perception that the person with EH disability was malingering, being unreasonable in requesting accommodation for their

⁴¹ *Supra* ft. 37

⁴² *Pawlychka v Canada*, [1999] TCJ No 886; [2000] 1 CTC 3005 ⁴³ *Ibid.*

⁴³ *Ibid.*

⁴⁴ Lavergne et al, *supra* note 14.

disability, or being unreasonable in requesting the implementation or enforcement of an agreed-upon accommodation plan and office policies.

The employer's duty to accommodate may be triggered if they are aware that an employee needs supports and services related to their disability.⁴⁵ However, the duty to identify disability and the need for accommodation rests on the employee.⁴⁶ Importantly, the employee is rarely required to disclose their actual diagnosis. The fact that they are a person with a disability, supported by a note from a health practitioner attesting to this, and including a description of necessary accommodations, is generally accepted.

The need for both parties to participate in the accommodation process was highlighted in *Kovios v Inteleservices Canada Inc.*⁴⁷ the Applicant disclosed her fragrance and scent sensitivity to her employer, but failed to disclose the need for her to avoid fragrances not detectable by others. The HRTO determined that if the employer had known of the applicant's need to avoid scents unnoticed by others, then it would have had to provide accommodation beyond a fragrance-free policy. However, since the employer was not aware that undetected scents were part of the employee's disability, they did not have a duty to accommodate them. This case highlights the importance of telling an employer about the very specific accommodation needs of a person with EH disabilities.

An individual cannot be deemed unable to perform their essential job requirements ("bona fide occupational requirements" or "BFOR") until appropriate accommodation is provided.⁴⁸ This could involve reassigning non-essential tasks to another employee, or an independent and objective assessment of the employee's ability to perform the essential tasks of their job.⁴⁹ If the employee is unable to perform an essential duty of their own job after accommodations are provided, the employer must still accommodate

⁴⁵ OHRC 2000, *supra* note 2 at p 20.

⁴⁶ 2012 HRTO 1570, [2012] OHRTD No 1553 (QL).

⁴⁷ 2012 HRTO 1570, [2012] OHRTD No 1553 (QL).

⁴⁸ *Entrop*, *supra* note 29 at para 75.

⁴⁹ Ontario Human Rights Commission, "The Duty to Accommodate" (nd), *Policy and guidelines on disability and the duty to accommodate*, online: <<http://www.ohrc.on.ca/en/policy-and-guidelines-disability-and-duty-accommodate/4-duty-accommodate>> [OHRC].

up to the point of undue hardship. This may involve modifying productivity targets or performance standards or modifying job descriptions.

The duty to accommodate persons with EH disabilities in the workplace was the central issue in *Toronto District School Board v Ontario Secondary School Teachers Federation, District 12*.⁵⁰ This was a labour arbitration case that applied a human rights analysis. In this case, there were two findings that triggered the employer's duty to accommodate. First, the employee self-identified as a person with EH disabilities. Second, she provided evidence to show that the school environment prevented her from fully functioning as a teacher.⁵¹

Prior to the commencement of arbitration, the employer and the employee had agreed to a detailed accommodation plan that would reduce the employee's exposure to environmental triggers in the workplace. The Arbitrator found that the extent of the employee's required accommodations, and the work conditions of the secondary school where she was teaching, meant that accommodation of her EH disabilities would be very difficult, if not impossible, to achieve.⁵² Furthermore, the Arbitrator concluded that even the full implementation of the accommodation plan would likely not have resulted in the employee being able to perform the core job duties of a teacher.⁵³ However the arbitrator held that the employer did not fully implement the agreed-upon plan. In particular, the proposed accommodations fell short of undue hardship.⁵⁴ In the end, the determination of what more could or should have been done became moot as a result of the employee's decision to retire. The Arbitrator awarded the employee two weeks of sick leave credits, as well as damages totaling \$30,000 for the failure of the School Board to adequately accommodate her.

⁵⁰ *Toronto District School Board v Ontario Secondary School Teachers Federation, District 12*, [2011] OLA No 461, 2011 CarswellOnt 10662 (WL Can) [TDSB].

⁵¹ *Ibid* at paras 220-222.

⁵² *Ibid* at para 263.

⁵³ *Ibid* at paras 247-248

⁵⁴ *Ibid* at para 256.

An employer has the responsibility to facilitate the accommodation process. The HRTO has stipulated that an employer is required to:

- accept the employee's accommodation request in good faith (unless there are legitimate reasons to do otherwise);
- maintain confidentiality;
- limit requests for medical information to those reasonably related to any limitations or accommodations in question;
- take an active role in ensuring accommodations are provided or exploring alternative approaches;
- grant accommodation requests (including those that do not use specific, formal language) in a timely manner;
- bear the cost of required documentation; and
- maintain a record of the process used to reach the actual accommodations.⁵⁵

However, it is not up to an employer to guess the nature of the accommodations required by an employee. The employee has a positive obligation to self-identify as a person with a disability, describe their accommodation needs, and work alongside the employer to engage in and manage the accommodation process.⁵⁶ The employer can request medical documentation to link the disability with accommodations.

In *Central Okanagan School District No. 23 v. Renaud*⁵⁷, the Supreme Court of Canada clarified that when an employer has proposed a reasonable solution that fulfils their duty to accommodate, the applicant must consider it. If the proposal meets the employee's accommodation needs, they should accept it. The complainant cannot expect a perfect solution. If a reasonable proposal that addresses the employee's circumstances is turned down, the employer's duty to accommodate may be discharged.

These cases show the importance of medical evidence to link disability with accommodations requested. They demonstrate the importance of both parties

⁵⁵ OHRC, *supra* note 52 at "4.4 Duties and responsibilities in the accommodation process."

⁵⁶ *Supra* footnote 28

⁵⁷ *Central Okanagan School District No. 23 v. Renaud*, [1992] 2 SCR 970, 1992 CanLii 81 (SCC)

participating in the accommodation process. Finally they illustrate that a person with an EH disability might not get the exact accommodations they want. It is sufficient if the employer provides alternative supports or services that may be more cost-effective or have less impact on the workplace as long as they meet the employee's disability-related needs.

2.5 Transportation

Accessible transportation promotes independence and the ability to travel to places of employment, education, recreation and social activities. Public transportation promotes community participation and inclusion, and helps relieve loneliness and isolation. In addition, because many individuals with EH have lower incomes, access to public transportation is essential. Persons with EH disabilities have the right to public transportation services others take for granted.

We could not find provincial or federal human rights cases that investigate the issues affecting persons with EH and public transportation. However, it is likely that the predominant issues will engage issues of enforcement of EH policies and undue hardship for transportation service providers.

Public transportation providers can and should post signs alerting the public to the impact of EH triggers. They can and should have scent or fragrance free policies. Conducting public campaigns about "share the air" are important public reminders and should be broadly implemented across the provision of all services in Ontario, including transportation providers.

We must find creative ways of ensuring public understanding, respect and adherence to providing the least toxic environment for all Ontarians. It may be trite to say everyone will benefit from living in the least toxic environment, but that is the task going forward.

2.6 Accessibility for Ontarians with Disabilities Act (AODA)

2.6.1 Introduction

The AODA was unanimously passed by all members of the provincial government and took effect in 2005. The purpose of the AODA is to remove barriers that prevent persons with disabilities from fully participating in society and in their communities. Barriers are identified and removed by Regulations, called Standards, under the AODA. The groups who develop and amend the Standards are called Standards Development Committees (SDCs). The goal of the AODA is to have a fully accessible Ontario by 2025.

Like the *Human Rights Code*, the definition of disability under the AODA is forward looking. While the AODA specifically lists a number of disabilities, it also includes emerging disabilities. The Standards apply to persons with EH disabilities.

Presently there are five social areas covered by AODA Standards: Customer Service; Employment; Transportation; Public Spaces, and Communication and Information.⁵⁸ In 2017, the government established SDCs for two new areas: Health Care and Education.

Every five years an Independent Reviewer is appointed to review the Standards, their on-going development and impact, and to determine whether the AODA is effective in meeting its target date of full accessibility by 2025. There have been three Independent Reviewers to date. Each one has noted that the AODA lacks both complaint and enforcement mechanisms. The most recent review by the Honourable David Onley is a scathing commentary on the failure of successive governments to realize and implement actual change in Ontario. Both Mr. Onley and the other two reviews emphatically state that Ontario will not be accessible by 2025. Unfortunately, governments have not implemented the significant recommendations of the reviewers.

⁵⁸ ARCH Disability Law Centre, along with the AODA Alliance, has made submissions on many Standards and has also made submissions to the Independent Reviewers. You can find our submissions at: <https://archdisabilitylaw.ca/resources/law-and-policy-submissions/>

Because of this, it is often said that the AODA is aspirational, but lacks the ability to promote real change to accessibility in Ontario.

Presently, there is no tribunal to hear complaints under the AODA or its Standards. It is important to note that the HRTO cannot enforce or make decisions based solely on the AODA and its Standards. However, it is often possible to turn an accessibility complaint under the AODA into an Application alleging disability discrimination under the Code or the Act.

2.6.2 Customer Service Standard

This Standard has the greatest potential impact on persons with disabilities. Everyone is entitled to access goods, services, and facilities that respect independence and dignity.

The Customer Service Standard requires all service providers covered under the AODA to identify and remove barriers that prevent customers with disabilities from accessing the services they use. Under the Standard, identified barriers include:

- Physical obstacles
- Technology
- Information and communication
- An organization's practices or procedures
- Attitudes of staff

In order to meet the mandate of this Standard, service providers must take actions that include: develop and implement customer service policies; provide policies in accessible format upon request; welcome support persons and service animals; train staff to interact appropriately with persons with disabilities. In addition, a process must be established for receiving and responding to the concerns of customers with disabilities.

2.6.3 Employment Standard

This Standard requires employers to make their work places and employment practices accessible to persons with disabilities. The issues considered under this Standard are:

- Recruiting and hiring
- Employee accommodation
- Training
- Retention
- Performance management
- Workplace emergency response

This Standard is intended to address all facets of the employment cycle. As noted, many of the above issues can also form the basis for a human rights application based on disability discrimination. The HRTO can order significant individual and systemic remedies. The AODA standard can be a guide to best practices.

2.6.4 Transportation Standard

The Transportation Standard does not directly assist many persons with EH disabilities. However under this Standard, all public transportation providers in Ontario are required to hold a public forum for review and comment on their accessibility plans. This is an important opportunity for persons with EH to raise issues that are of particular interest, and to suggest potential solutions. You can ask the public transportation provider in your community when their annual event will be held. You can encourage people who share your concerns to attend and make their voices heard.

2.6.5 Health Care Standard

The Ministry of Health and Long-term Care, along with the Accessibility Directorate, held pre-consultations on a Health Care Standard in 2017. ARCH was one of the participants in this pre-consultation and provided input on the kinds of issues this new Standard should address. The SDC commenced work on drafting a new Standard in 2017. However, following the 2018 provincial election, the activities of the SDC were

suspended. The Health Care SDC was reconvened in April 2019 although they have yet to meet to continue their work on drafting a Health Care Standard.

We understand that the Standard may be limited in its scope and apply only to the hospital sector. However, it is important to note that many healthcare providers have developed their own practices and policies, including scent-free policies. For example, hospitals in Toronto who are members of the University Health Network (UHN) acknowledge scent-related sensitivities and outline steps that should be taken to accommodate persons with EH disabilities. The UHN policy states the following:

Scented products can affect our staff, patients and visitors who are sensitive or have allergies. All individuals are asked to refrain from wearing or using scented personal products while in any UHN buildings. Scented personal products may include shampoos and conditioners, hairsprays, deodorants, colognes and aftershaves, and fragrances and perfumes.

In addition, wherever possible, we use scent-free cleaning products.

In cases of extreme sensitivity, patients may request that specific cleaning and/or other supplies be used. Please speak to your care team if you are experiencing scent-related sensitivities.⁵⁹

To assist organizations in the development of scent-free policies, the Canadian Coalition for Green Health Care publishes a fragrance-free implementation kit. The Coalition models the approach of the Environmental Health Clinic at Women's College Hospital. Other pioneers of scent-free policies include "We Share the Air" policy at Dalhousie University (which has been in effect since 1995), and the Peter Lougheed Centre's "We Share the Air Scent-Free Awareness Campaign" in Alberta.⁶⁰ These policies advocate the following phases for community engagement:

⁵⁹ UHN, *Smoke-Free and Scent-Free*, online: UHN <http://www.uhn.ca/corporate/AboutUHN/OurHospitals/Pages/smoke_scent_free_UHN.aspx>.

⁶⁰ The Canadian Coalition of Green Health Care, *Fragrance Free Implementation Kit for Health Care Facilities*, at 3, online: <<http://www.greenhealthcare.ca/images/projects/FragranceFreeImplementationKit.pdf>> [Green Health Care].

Step 1: Build awareness and encourage voluntary participation, with the following components:

- Program announcement
- Fragrance-free program web page content
- Fragrance-free alternatives
- Fragrance-free campaign Q&A document
- Corporate signage

Step 2: Fragrance Free Policy:

- Develop formal corporate fragrance free policy
(the Canadian Centre for Occupational Health and Safety has a sample Scent-Free Policy⁶¹)
- Fragrance-free policy phone messaging
- Fragrance-free policy brochure and webpage content⁶²

These steps are a useful guide for organizations that want to develop scent-free policies. They are also a basic first step towards achieving the more detailed recommendations on the Environmental Task Force.

3. Conclusion

While there has been significant research and study into barriers to include persons with EH disabilities, critical obstacles remain. Seeking help in the health system, trying to find and/or retain adequate housing or employment, entering public spaces, shopping, or using public transportation, limit the inclusion of persons with EH disabilities in our communities. Much more needs to be done to acknowledge the significant hurdles faced by persons with EH disabilities.

⁶¹ Canadian Centre for Occupational Health and Safety, *OSH Answers Fact Sheets*, online: Government of Canada <http://www.ccohs.ca/oshanswers/hsprograms/scent_free.html>.

⁶² *Ibid.*

There are nearly 750,000 Ontarians affected by EH disabilities. A disproportionate number of them live in poverty and poor health. They face stigmatization and are marginalized. They often live in inadequate housing or are unable to work, often in the prime of their lives. Ontario is clearly failing to address a serious problem.

The work of the Task Force on Environmental Health and this overview of legal rights and challenges faced by people with EH disabilities demonstrate a serious lack of access to adequate medical care and access to justice. These medical and legal challenges are closely linked to the evidentiary burden placed on people who must fight for legal rights. Human rights obligations may be strong on paper but are often weak in practice.

The Task Force on Environmental Health makes an important contribution. In a comprehensive package of recommendations, the Task Force encourages a holistic approach that would see more health care practitioners become specialists in environmental health who will generate better treatment models. The recommendations include a much-needed public awareness campaign and a comprehensive research agenda. The Task Force's initial focus on the health care system is limiting, given the much broader range of challenges across society as a whole. Nevertheless the Task Force recommendations are an essential first step. If implemented, they will assist persons with EH disabilities in producing expert or other reports that can support legal challenges, through human rights tribunals or other forums. More specialists available throughout the province will also reduce wait times for receiving appropriate health care. A person-centred approach will assist in providing individualized accommodation plans. Existing case law also demonstrates the importance of legal representation in navigating the legal system and having the best chance of obtaining successful results in the courts and before tribunals. Finally, educating the public at large will help address the stigma that is often associated with EH disabilities and bring about lasting change across all public spaces to reduce environmental triggers.

We hope that this paper will encourage and support the work that is already being done, and provide some ideas for moving forward.

4. Recommendations

ARCH and CELA want to acknowledge the important recommendations made in the Final Report of the Task Force on Environmental Health. We adopt those recommendations and repeat them here for easier reference.⁶³ We have also added other recommendations informed by our research and the input of focus group participants.

4.1 Summary of Task Force on Environmental Health Recommendations

Recommendation 1

Develop a one-to-three year awareness campaign that targets the general public, health care facilities and providers and primary care settings.

Recommendation 1.1 – Develop awareness materials that target the general public and specifically engage priority groups, starting with employers and landlords.

Recommendation 1.2 – Create materials and tools designed to promote awareness of ME/CFS, FM and ES/MCS and explain how to accommodate patients with these chronic conditions in priority health care settings, starting with hospitals, long-term care homes and key home care providers.

Recommendation 1.3 – Increase awareness of ME/CFS, FM and ES/MCS, clinical tools and information, and the need for accommodation, in all primary care settings in Ontario.

Recommendation 2

Develop and disseminate clinical tools and information that support evidence-informed treatment and management.

Recommendation 3

Establish a system to develop and support a cadre of primary health care and specialized providers skilled in managing ME/CFS, FM and ES/MCS.

⁶³ Summary transcribed from pages 8-9 of: Care Now - An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS). Final Report of the Task Force on Environmental Health, December, 2018.
http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/task_force_on_environmental_health_report_2018.pdf

Recommendation 3.1 – Establish a community of practice to provide training and support the network of primary care clinics that will provide chronic disease management for people with ME/CFS, FM and ES/MCS across the province.

Recommendation 3.2 – Fund a comprehensive strategy to increase the pool of skilled, specialized providers to reflect the high demand for interdisciplinary care.

Recommendation 4

Create and support a network of enhanced primary care programs throughout Ontario.

Recommendation 5

Develop a shared care planning tool.

Recommendation 6

Modernize the OHIP K037 fee code to include all three conditions and use it to help gather data on their prevalence.

Recommendation 7

Support research to fill critical gaps in knowledge about the pathogenesis, prevention and treatment of ME/CFS, FM and ES/MCS.

Recommendation 7.1 – Leverage the Health System Research Fund (HSRF) to fund priority research into patients' experience with the health system and improve care and efficiency.

Recommendation 7.2 – Work with funding organizations such as the Canadian Institutes of Health Research (CIHR) and the US National Institutes of Health (NIH) to support funding research projects that explore questions related to the pathogenesis and prevention of ME/CFS, FM and ES/MCS.

Recommendation 8

Create a centre of excellence in ME/CFS, FM and ES/MCS care, education and research in Ontario.

Recommendation 9

Establish a transitional implementation committee to provide the leadership in the initial phases of putting this plan into action.

Recommendation 10

Provide regular updates and progress reports on the implementation of the proposed action plan.

Task force members all agreed with and support these recommendations. The task force also discussed in detail another recommendation on additional funding for the Environmental Health Clinic at the Women's College Hospital,

but did not reach agreement. Some members wanted to see an immediate increase in funding for the Environmental Health Clinic as a way to reduce wait times and improve access to specialized care while the action plan is initiated. Other members were concerned that approach would simply maintain the status quo and potentially delay the much needed investment in developing a centre of excellence and for the enhanced system of primary care proposed in the report. This underscores the challenge ahead to provide immediate and sustainable health care for people with ME/CFS, FM and ES/MCS.

4.2 Recommendations from ARCH and CELA

1. Accepting the leadership offered by the Task Force on Environmental Health to address the health care system, proactive change can begin immediately at all levels of society including federal, provincial, and municipal governments and public departments and agencies. These would include, but are not limited to, public transportation providers, school boards, and the private sector. For example:
 - a. All provincial ministries should consult on and revise their Statements of Environmental Values (as required under Ontario's *Environmental Bill of Rights*) to achieve procurement policies, workplace scent-free policies, and other means to reduce environmental triggers in their workplaces, with particular focus on addressing front-line/public-facing departments and services.
 - b. Likewise, all municipal governments should consult on and finalize comparable policies to address procurement, workplace scent-free policies, and other means to reduce environmental triggers in municipal workplaces, and particularly in front-line/public-facing services and departments.
 - c. Similarly, both public and private transit and transportation services (buses, trains, taxis, etc.) should also develop scent or fragrance free policies.

2. A corporate challenge is needed to address environmental triggers in the private sector in three major respects: workplaces, consumer product pricing and housing:
 - a. As described in Recommendation 1 above, corporate workplace policies should be developed to address procurement, scent-free policies, and other means to reduce environmental triggers in workplaces, particularly in front-line/public-facing services and departments,
 - b. In light of the frequent high price differential for scent-free products, to achieve consumer choice, a much broader range of scent-free products is needed in the marketplace at comparable pricing to frequently used products.
 - c. Public transportation providers need to listen to the concerns of persons with EH disabilities and work collaboratively to find solutions.

5. Selected Resources

- Task Force on Environmental Health, 2017. Time for Leadership: Recognizing and Improving Care for those with ME/CFS, FM and ES/MCS. Online at: http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/default.aspx
- Care Now - An Action Plan to Improve Care for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM), and Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS). Final Report of the Task Force on Environmental Health, December, 2018. http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2018/task_force_on_environmental_health_report_2018.pdf

- Environmental Sensitivities and Rental Housing: A Toolkit for Community Workers, 2019. Centre for Equality Rights in Accommodation, Toronto.
<http://www.equalityrights.org/wp-content/uploads/2019/02/Environmental-Sensitivities-and-Rental-Housing-Toolkit-1.pdf>

See detailed list of Resources listed on pages 28-30.

- Unlocking the AODA: Obligations of Housing Providers Under the Accessibility for Ontarians with Disabilities Act, A Guide for Housing Providers in Ontario, undated. Centre for Equality Rights in Accommodation, Toronto.
http://www.equalityrights.org/wp-content/uploads/2019/02/unlocking_the_AODA_final.pdf