

GOOD BUT TOO LITTLE: THE INTERIM REPORT OF ONTARIO'S TASK FORCE ON ENVIRONMENTAL HEALTH

By Varda Burstyn
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On Sept. 28, the Interim Report of the Task Force on Environmental Health was released. This task force is a body with a three-year mandate, first assembled by Ontario's Ministry of Health and Long Term Care in June 2016 to make recommendations with respect to the 550,00+ Ontarians living with three serious, chronic, often co-occurring and potentially life-threatening conditions: Environmental Sensitivity/Multiple Chemical Sensitivities (ES/MCS), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FM).

The eight recommendations in this Interim Report are certainly correct and worthy of support as far as they go. But I am deeply concerned that as few, minimal and piecemeal as they are, they might perversely be used to justify slowing and diminishing a process of extensive reform that has lagged spectacularly behind and needs to be much more rapid and fulsome. An immediate public statement from Ontario's health minister accepting these recommendations, committing funds to implement them in an expedited fashion, and committing to much more extensive actions in the immediate future would put this fear to rest. It would also bring the Liberal government into line with the stated positions of the New Democrats and Conservatives.

Now, it is probable that many people will have no idea that this task force even exists. It's formation in June 2016 was accomplished practically by stealth, and the public website it maintains provides only one page of anodyne information. Still less will many people know much about the conditions that the task force was created to address.

This is because ES/MCS, ME/CFS and FM, though very widespread and debilitating, are almost invisible except to sufferers and their families. Decades of erroneous framing of these conditions within the medical system as psychologically-driven malingering or, at best, somatization - an issue well presented by the Interim Report - has led to deep stigmatization of those who live with them. It has also resulted in shockingly inappropriate treatment in health care and disability-related social services, and gross neglect.

In 2014, more than 550,000 Ontarians (Statistics Canada, 2014, excluding children) were living with these notoriously underdiagnosed conditions. Note that this is nearly *nine times the number of people living with with Alzheimer's Disease*. Yet between 1985 and today, six Liberal ministers of health have steadfastly turned their back on them. By contrast, the NDP and Conservative governments at least established

a small clinic and funded some important research when they formed governments at Queen's Park in the 1990s.

To the question, then, of how Ontarians should react to this report, there are three broad answers.

First, Ontarians should proactively and vociferously urge their government to implement every single one of the recommendations of the Interim Report, and do so immediately, as a prelude to much expanded action. Not one more day, let alone two more years, should elapse before health minister Eric Hoskins announces implementation of these recommendations, and steps up to implement a host of others.

Second, Ontarians should take a little time to learn about the huge but invisible group of sufferers whose profoundly inappropriate treatment actually costs Ontario taxpayers hundreds of millions of wasted healthcare dollars (estimates in 2013 sat in the \$150 million per year range) and even more in preventable social service costs (estimates topped a billion dollars).

They should know, for example, that, in theory, Ontario's Human Rights Commission formally recognizes people with these conditions as having "non-evident disabilities." In practice, however, the ignorance, denial, stigmatization, neglect and exclusion of people with these conditions from normal health and social service entitlements and supports, render this recognition only marginally meaningful. In fact, the physical punishments of these often co-morbid illnesses, combined with our systems' incapacity to prevent, diagnose, treat and support them, make it nearly impossible for people to keep jobs (disability accommodation is nearly impossible to win) or to obtain disability compensation, thus guaranteeing a worsening of illness and a steep descent into poverty and isolation.

Exclusion and discrimination are then mirrored in compromised human rights and justice, environmental health, access to education, housing and food security. Children, youth, women and the elderly are especially hard-hit. And families of sufferers carry a huge burden of illness alone. This has profound adverse consequences for the productivity, mental and physical health of other family members, with resultant costs in suffering, economic status and health and social service expenditures that are transgenerational. (For an introduction to these conditions, the challenges and the solutions this province needs is to go to the website of the Campaign for an Ontario Centre of Excellence in Environmental Health [<http://recognitioninclusionandequity.org/>], explore the site and follow the links.)

Better the first two times

With respect to the third broad response, Ontarians also need to understand something of the history of the Interim Report recommendations, a 32-year history that has now been entirely lost to growing ranks of senior executives at the ministry of health. This history reveals where these recommendations sit on a trend line of Liberal-led health ministries, and shows why many people in the field wonder whether the new

recommendations represent a real step forward or yet another turn of the hamster wheel. Through this historical lens, big concerns come into focus.

To begin with, this lens reveals that, the call for chairs in the conditions in Ontario universities aside, the “new” recommendations, are, alas, much more limited and scaled-down repeats and do-overs of many more comprehensive recommendations that emerged from two other major study processes previously funded by the health ministry.

The first of these - the extensive *1985 Report of the Ad Hoc Committee on Environmental Hypersensitivity Disorders* - was submitted a generation ago to Liberal health minister Murray Elston. It dealt broadly with what was then an emerging and confounding problem: the increasing numbers of Ontarians who were presenting as intensely chemically sensitive. [The second sidebar shows what was recommended long before more advanced forms of diagnosis and treatment were developed.] Together, its recommendations suggested a *system* - not just one or two measures - of care.

The second, much more recent study process was funded in 2012 to the tune of \$250,000 by the Hon. Deb Matthews, after six years of renewed advocacy, study and collaboration. The then-Minister did this on the recommendation of an assistant deputy minister who was the last senior official with history in the ES/MCS file. The study was specifically tasked with designing a system of care for all three conditions on a multi-site “centre of excellence” model, addressing needs for multiple functions and multiple locations that were clearly apparent to all involved at that time.

The project was guided by a multi-stakeholder collaborative, which oversaw the study and report writing process. The results were summarized in the 2013 reports of the Steering Committee for an Ontario Centre of Excellence in Environmental Health. Four major supporting reports were produced. They included quantitative analysis (*The Quantitative Data, Erika Halapy*) and an in-depth qualitative study and extensive analysis (*Recognition, Inclusion and Equity: The Time is Now - Perspectives of People Living in Ontario with ES/MCS, ME/CFS and FM, Varda Burstyn*) that assessed lived experience, needs, gaps in service and barriers to care, concluding the current state was “a void in care, with a few islands of support,” within a cross-system reality of denial, exclusion and discrimination. The *Perspectives* document then explained in great detail the proposed model of care and system of care delivery recommended to respond most efficiently and effectively to these needs.

Another report presented the status of medical/scientific knowledge (*Chronic, Complex Conditions: Academic and Clinical Perspectives, John Molot, MD, FRCFP*) and finally architect David Fujiwara produced a report on how to meet the special needs of the chemically sensitive when creating safe-care sites.

Then the Steering Committee produced a business case proposal (*Recognition, inclusion and equity: Solutions for people living in Ontario with ES/MCS, ME/CFS and FM – The Business Case Proposal*) that phased and costed the proposed system of care, as embedded in the larger health system. This centre of excellence system included a specialist centre, a series of regional clinics and large numbers of local primary care

providers across the province. It had a capacity for curriculum development for health education faculties; capacity to work with and ensure the practical application of human and disability rights in all sectors; and measure for the special needs of the chemically sensitive over and above the other two conditions in all areas, a crucial component for meaningful inclusion. It contained extensive recommendations for support measures to families and children; and for civil service, public sector and patient education campaigns to fundamentally change awareness and capacity.

But the wisdom of the business case proposal lay as much in the overarching logic as in any specifics in its co-related parts. It argued that a modest investment of \$26 million dollars upfront over five years for a leveraged, co-ordinated and synergistic system of care (less than \$50 per person) would not only alleviate needless suffering and support families, it would also save the public purse hundreds of millions of dollars in inappropriate and ineffective expenditure every year.

The centre of excellence project reports reports can be found at <http://recognitioninclusionandequity.org/>.

How the comprehensive recommendations got buried

Originally, the supervising Assistant Deputy Minister had promised a short and rapid evaluation and planning phase to follow the submission of the report, to be followed immediately by the implementation of the tweaked and finalized Phase 1.

But what actually happened when she left her position and a dizzying succession of new, unschooled officials took carriage of the file, is that the health ministry and the Premier ignored the reports.

The Minister did make a couple of vague promises “to recognize” the conditions - so far unfulfilled. But one year after the report was submitted, a completely unqualified adviser to the Premier decided the whole proposal had to be questioned all over again. This initiated another two-year interregnum, with the file bouncing around to new, non-expert officials every few months, each time moving it farther and farther away from the people and collective memory of all that had been achieved before.

In stark contrast to this abdication, both the Conservative and NDP health critics strongly and repeatedly voiced their support for the centre of excellence recommendations in the legislature, in public meetings at Queen’s Park and in letters to the health minister.

Tragically, the outcome of these three years was not a final “tweak and implement” process for the business case proposal, but the announcement of yet *another* investigative body, the current Task Force on Environmental Health. Only this time, this body was staffed by civil servants with no background in the condition or its history. It was given a reduced and fragmented mandate, and not one cent of funding for expert support. Only four of its members had any history in the previous phase, and two of these (including me) left well before the end of the first year.

The task force was, astoundingly, instructed to begin from square one. So though the many people who had worked in the trenches to bring about change for so many years - some for decades - still hoped fervently that good would come from the task force, many also felt betrayed by this move, and saw it as a yet another delaying tactic for effective action, enacted in bad faith.

To understand this fear, consider, for example, the Interim Report's second recommendation, "that the ministry establish an expert panel to reach consensus on clinical case definitions and clinical practice guidelines for each of the three conditions."

This recommendation was first made, in effect, 32 years ago. In the late 1990s, an expert panel was assembled under New Democrat and Conservative ministers. But the file was retired, the panel was not renewed, and the Liberals never created another one. Indeed, when a new wave of advocacy in 2009 begged for the re-establishment of such a panel and funding to create guidelines, it did so to deaf Liberal ears.

Then this recommendation was put forward as a pre-conditional recommendation in 2013, this time with very detailed specifics, costs and fast-track timelines. Everyone knew - and still knows - that without case definitions and clinical guidelines nothing moves in the health system; and without leadership from health, nothing shifts in other sectors.

Had the recommendation been implemented in 2014, we would already have the definitions and guidelines in place, and a panel of experts convened, and the whole system, as well as any additional task force, would already have been working with these, moving the entire project forward.

But even this basic recommendation was not implemented.

Not surprisingly, then, when the terms of reference for the current task force were originally being drawn up, patient representatives fought mightily with civil servants for agreement that the task force would build on the systemic scope and logic, as well as the specific recommendations, of the centre of excellence proposals, in order to maximize results and minimize time and expense in implementing solutions.

Clearly, this did not happen. So though all the individual 2017 task force Interim Report recommendations had been part of the 2013 recommendations and all should be adopted immediately, as disaggregated as they now are, they fail to reflect the components, insights and strategic leveraging of the proposals that came of that process.

Poor content on chemical sensitivity

In addition, it also needs to be noted that without outright prevarication, the Interim Report has distorted or even disappeared some key information through understatement or omission. This is especially true vis à vis the chemically sensitive (those with ES/MCS), and is especially egregious in this respect. ES/MCS advocates have repeatedly played the leading role in forcing government to address the issues since 1983. ES/MCSers have special needs, and experience unique forms of suffering and

societal exclusion. They constitute the single largest group of the aggregate number of the three conditions. And finally, though terribly underfunded, research and response at official levels has truly taken hold with respect to the ME/CFS and FM over the past decade, but zero dollars and zero recognition have been devoted to ES/MCS, the most contested by far of all the conditions.

Indeed, reading the Interim Report, one could easily form the impression that there is no research available on ES/MCS, that it is monumentally difficult to diagnose and that there is a “lack” of treatment, and treatment models of any interest to Ontario. These implications occlude the extant body of research, including in peer-reviewed journals; and a whole network of physicians and clinics in the U.S. and other countries, who have been helping the chemically sensitive everyday, some of them for more than forty years.

The oldest, largest and most prestigious of these clinical facilities, which treats all three conditions and was referenced at length in the 1985 report, is the Environmental Health Center, Dallas. We believe it should serve as a model for at least the most advanced clinical centres we need here, as it has done for several centres in Japan, for example. Yet this centre is not referenced at all in the Interim Report, nor is the network of which it is a part. (To learn more about the American Academy of Environmental Medicine and their accredited educational courses, visit <https://aaemonline.org/community.php> [resources] and https://aaemonline.org/online_ed.php [education].

It is impossible in this space to address these deficiencies, or to catalogue and explain the complex dynamic of professional inertia, cost-resistant insurers and even strong sexist bias with respect to all three conditions; nor the powerful, well-documented and well-funded chemical industry resistance to recognizing ES/MCS. But the important point is that this Interim Report, while seeming to shine a light on the three conditions, also casts some shadows, and, again, on the chemically sensitive more than on others.

So the takeaway is clear: the “small-start” recommendations are all good and absolutely necessary, as far as they go, and they should be supported. But they should be supported along with this message to the Liberals: the neglect, whittling down and slowing-rolling for which they and their senior civil servants are responsible with respect to more than half a million Ontarians and their families are not invisible anymore, and not acceptable. It is more than time to demonstrate through immediate announcements, funding and accelerated implementation the kind of actions that will provide *real* recognition, inclusion and equity.

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Varda Burstyn was the major policy speech writer for the Hon. Frances Lankin, Ontario’s Minister of Health in 1992, and has written and consulted extensively on environmental

health. She was the initiator, then lead consultant of the project to establish an Ontario Centre of Excellence in Environmental Health and a member of the Task Force on Environmental Health from June 2016 to February 2017. Visit vardaburstyn.com for more information

SIDEBARS AND/OR BACKGROUND INFORMATION

RECOMMENDATIONS FROM THE INTERIM REPORT TASK FORCE ON ENVIRONMENTAL HEALTH 2017

1. Change the Conversation

Recommendation #1.1 Make a formal public statement recognizing ME/CFS, FM and ES/MCS: The task force recommends the Minister of Health and Long-Term Care make a statement recognizing ME/CFS, FM and ES/MCS. The statement should reinforce the serious debilitating nature of these conditions and dispel the misperception that they are psychological. It should also include a commitment to improve care and education, develop a system of care for people living with ME/CFS, FM and ES/MCS, and provide support for caregivers.

Recommendation #1.2 Establish academic chairs focused on ME/CFS, FM and ES/MCS The task force recommends that the Ministry of Health and Long-Term Care (ministry) fund academic chair positions in clinical environmental health focused specifically on ME/CFS, FM and ES/MCS. The chairs should be located at three different academic health science centres across the province. A key criterion in selecting/awarding these chairs should be a demonstrated commitment to champion improved care for those affected by these conditions.

Recommendation #1.3 Modernize the K037 fee code to include all three conditions The task force recommends that the ministry re-initiate the process to modernize the Ontario Health Insurance program (OHIP) fee code K037 in collaboration with physician and patient experts to ensure it recognizes all three conditions.

2. Develop a Common Understanding of ME/CFS, FM and ES/MCS

Recommendation #2.1 Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care. The task force recommends that the ministry establish an expert panel to reach consensus on clinical case definitions and clinical practice guidelines for each of the three conditions. The expert panel, which should include people with lived experience as well as input from expert advisors outside Ontario, should meet periodically to review updates in the science on each condition, evaluate the evidence and assess progress in managing the three conditions.

3. Lay the Groundwork for a Person-Centred System of Care

Recommendation #3.1 Establish detailed clinical care pathways to support the development of an evidence-based system of care. The task force recommends that the ministry provide funds to support the development of clinical care pathways for people with ME/CFS, FM and ES/MCS and map out an appropriate patient-centred system of care for Ontario.

Recommendation #3.2 Make hospitals safe for people with ME/CFS, FM and ES/MCS The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure hospitals comply, as quickly as possible, with relevant accessibility and accommodation legislation. As a starting point, the ministry should work with the Ontario Hospitals Association (OHA) to build on relevant prior work, including the Quinte Healthcare Corporation policy on Multiple Chemical Sensitivities and the guidance for hospital staff contained in *Marshall, LM, MacLennan JG. Environmental health in hospital: A practical guide for hospital staff. Part I Pollution prevention, Part II Environment-sensitive care (2001).*

Recommendation #3.3 Make long-term care homes safe for people with ME/CFS, FM and ES/MCS. The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure long-term care homes comply, as quickly as possible, with relevant accessibility and accommodation legislation. The MOHLTC should work with long-term care provider associations to build on opportunities within the long-term care home renewal process to improve accessibility and accommodation in existing homes and in the homes of the future.

4. Increase the number of knowledgeable providers

Recommendation #4.1: Continue to fund the Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health. The task force recommends that the ministry continue to fund this program until the task force makes further recommendations for advanced education specializing in ME/CFS, FM and ES/MCS.

SELECTED RECOMMENDATIONS FROM THE 1985 ONTARIO REPORT OF THE AD HOC COMMITTEE ON ENVIRONMENTAL HYPERSENSITIVITY DISORDERS 1985

Judge G. M. Thomson, J.H. Day M.D., S.E. Evers Ph.D., J.W. Gerrard D.M., D.R. McCourtie M.D., W.D. Woodward Ph.D. 1985

Recommendation 3: We recommend that research be undertaken to establish the

prevalence of environmental hypersensitivity and to determine which of the current tests and treatments being used by clinical ecologists are demonstrably useful.

Recommendation 4: To provide an estimate of the prevalence of environmental hypersensitivity and in the absence of clear diagnostic criteria, we recommend a cross-sectional survey be undertaken using the definition set in chapter two. Because subsequent investigation may prove our definition inadequate, it should be used to identify persons with environmental hypersensitivity for the purposes of this study only. Such a survey would require the cooperation of those Ontario physicians who are members of the Society for Clinical Ecology and Environmental Medicine.

Recommendation 6: The Committee recommends that the research be carried out in a multi-disciplinary investigative and therapeutic environmental unit, established for a defined period of time, for the assessment of environmental hypersensitivity disorders. We recommend that funding for three years be provided, because this is sufficient for completion of the initial investigations; after three years, it might be reasonable to expect that such an environmental unit would sustain itself through other funding sources, e.g., grants obtained in open competition.

Recommendation 12: The Committee recommends that vitamin and mineral supplements and uncontaminated food and water not be included as insured health services. We do, however, recommend that they be included in health care plans that provide coverage for drugs and other treatments when they have been prescribed by a physician, subject to defined financial limits. Moreover, those who receive social assistance should be eligible for payment through the associated drug or food supplement plans.

Recommendation 17: Both the cost per test and the maximum number of tests per year should be established.

Recommendation 18: That the environmental unit undertake production of easily understood pamphlets on the more controversial issues related to environmental hypersensitivity; that it consider issuing a version of the Committee's report that is easily understood by members of the public; that it ensure adequate involvement in conferences, meetings, etc. sponsored by various advocacy and information bodies recently established in Ontario; that it offer assistance in ensuring that documents prepared by school boards, public health units, etc. are accurate and balanced.

Recommendation 19: In view of the special role that can be played by the public health system, by medical officers of health and, in particular by public health nurses, we recommend that special efforts be made to educate and prepare public health nurses to function as a source of current information on environmental illness in general and on environmental hypersensitivity in particular. These nurses are often the first and most

accessible source of information for the patient who is confused by conflicting reports elsewhere. Moreover, this role is consistent with the accent on prevention established in the new Health Protection and Promotion Act.

Recommendation 20: We recommend that programs of continuing education be developed to provide practitioners with the scientific information, which is increasing, that both supports and questions recent, highly publicized theories and beliefs in the field of environmental hypersensitivity. As an example of why this is needed, we note that there is a general lack of understanding of the possibility that indoor air can be a contributory [sic] factor in illness.

Recommendation 21: All basic social assistance programs, particularly those administered under the Family Benefits Act, should be reviewed to ensure that they recognize how disabled some of these patients are. They should not be deprived of minimal levels of support because of disagreement within the medical profession regarding the causes of their conditions.

Recommendation 22: Because administrators of social assistance programs have wide discretion, the environmental unit should provide expert assistance to appeal bodies such as the Social Assistance Review Board, and to those groups, such as the Community and Social Services Medical Advisory Board, that provide appeal bodies with expert advice.

Recommendation 23: In view of the important role of the individual physician to whom a person seeking social assistance, Worker's Compensation, etc. is referred, those physicians must have current information about environmental hypersensitivity. And must be willing to assess the patient's condition irrespective of any diagnosis attached to it. Here, too, the environmental unit should be involved in selecting such physicians and, in particular cases, should be available to bodies seeking expert advice.

Recommendation 24: Private insurers need to be encouraged to take the same approach in situations where there is a clear disability but some debate as to causation. This is true for those programs that provide payments as replacement for lost income as well as for those that provide assistance for the costs of drugs, extracts and other interventions.

Recommendation 25: At least a portion of the costs associated with special diets and prescribed vitamin and mineral supplements should be claimable through existing food supplement programs and drug plans. Controls would have to be placed on what would otherwise be an extremely open-ended level of support. However, we are satisfied that these measures, when prescribed by a physician after careful investigation and diagnosis, should not be denied those who are simply unable to afford them.

Recommendation 26: In cases of genuine financial need, (i.e., people receiving social

assistance) rent supplements or discretionary payments should be available for those seeking to make modest environmental changes.

Recommendation 27: We recommend that the environmental unit collaborate with and assist those involved in the development of special housing programs. Consideration should be given to establishing a nearby apartment, modified for patients who are participants in the environmental unit's research program and are able to reside outside the unit. The unit might also assist some hospitals in making changes to one or two rooms so that patients diagnosed as environmentally hypersensitive would feel less concerned about being hospitalized when they become seriously ill and required emergency admission.

Recommendation 28: That, in the near future, an interdisciplinary conference be held to discuss this report and its recommendations and that conferences of this type should be held regularly as part of the environmental unit's vital educational role.

Recommendation 29: That the Ontario Medical Association consider establishing an environmental health subsection to bring together practitioners interested in this field.

Recommendation 30: The Committee recommends that the environmental unit develop recommendations for curriculum review committees regarding possible curriculum changes in medical schools to ensure that issues relating to environmental illness are part of medical education.