

REPORT NEEDS MEANINGFUL GOVERNMENT ACTION

Good but inadequate: Interim Report of Ontario's Environmental Health Task Force

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Few Ontarians have any idea of the numbers of people in Ontario afflicted with the debilitating, painful, often co-occurring and even life-threatening conditions of Environmental Sensitivity/Multiple Chemical Sensitivities, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and Fibromyalgia. But it turns out there are a whopping 550,000 of them (Statistics Canada 2014). Consider that this is nearly nine times the number of people living with Alzheimer's disease. These sufferers and their families carry a huge burden of illness because in addition to the physical punishments they endure, they also face neglect, inappropriate treatment and great stigmatization in Ontario's health and social services systems. These in turn are the results of ignorance, obsolete ideas, inertia and lack of capacity.

For the province as a whole, this whole situation creates a phenomenal, but unseen drag on the provincial economy and public purse. For it turns out that Ontario pays hundreds of millions of dollars in wasted revenue *every year* for what's known as "inappropriate utilization" (aka ignorant, wasteful and even harmful treatment) - money that badly needs to be redirected to do good instead of harm.

A new report released on Sept. 28, under pressure from patients and opposition parties, by the Ministry of Health and Long Term Care's Task Force on Environmental Health begins to make the invisible people living with these

conditions visible - at least to the ministry, if not yet to the public, since there was no announcement or other media to publicize the event. The report begins to explain the black hole in care, social support and human rights that patients with these three conditions face. The task force was established to recommend key measures on recognition, education and care to the health minister to address this black hole. It began meeting in June 2016 (again, under near-stealth conditions) and given a three-year mandate. Another report will be submitted in 2019, a long way off, and well past the next election.

The recommendations in this interim report were good, but they were also insufficient, numbering only eight. First up, the task force recommended “the Minister of Health and Long-Term Care make a statement recognizing ME/CFS, FM and ES/MCS,” one that “should reinforce the serious debilitating nature of these conditions and dispel the misperception that they are psychological; and it should include a commitment to improve care and education, develop a system of care for people.” This one deserves a mighty cheer, since it is decades overdue and has so many other important consequences.

The report further recommended the government fund three academic chair positions, one for each of the conditions, in clinical environmental health at leading Ontario universities. It advised the modernization of the Ontario Health Insurance Program (OHIP) fee code system to ensure all three conditions are recognized (they are not at present). It said the province needs to fund a process of expert conferral to develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care. More loud cheers for each of these. The fact is - and this fact is well known and no surprise - these are *pre-conditional measures* without which nothing will move or change.

Further the task force recommended immediate policies to make hospitals and long term care facilities safe for people with these conditions (astoundingly,

they are not, and are especially dangerous for the chemically sensitive). And finally it recommended the province continue to fund the only two fellowships in care for these conditions, at the modest, diagnosis-only Environmental Health Clinic at Women's College Hospital, until further recommendations can be delivered regarding health provider education. Amen to that.

Every single one of these recommendations is urgent and important.

Indeed, taken together, they are analogous to the measures that paramedics take when called to rescue and keep alive a very badly injured patient for a few moments, until more extensive - and adequate - help can be administered. The Hon. Dr. Eric Hoskins, Ontario's minister of health and long term care, should therefore receive overwhelming messages to get that oxygen to the patient without the delay of days, let alone months or years, to keep the patient alive. And the task force should certainly be approved for telling him to do it.

However, the patient has suffered terminal injury to every single organ system - to keep the analogy going - and only comprehensive, intensive care on all fronts - which is to say at all points along the normal continuum of care - will keep that patient alive for any length of time, and eventually heal the patient. So a few emergency measures, though critical now, will mean nothing if the full menu of needed acute care is not provided in a very timely fashion.

For patients, then, the report is good as far as it goes, but it does not go nearly far enough to stop the damage and reverse course.

As well, though beyond the scope of this brief commentary, a striking and important problem with the *motivating text* for the recommendations and the recommendations themselves is that they utterly "fail" on the very "environmental health" dimensions the task force bears in its name. The report shows disturbing inadequacies analytically, and in terms of measures needed by patients with severe chemical sensitivity. Yet the chemically sensitive patients

and expert advocates have driven the quest for government recognition and action since 1983. The severely chemically sensitive suffer the greatest forms of societal isolation and most dangerous lack of access to care, by far. It was for them that the original, if exceedingly modest, Environmental Health Clinic at Women's College Hospital was first set up in 1996 by New Democratic and, following on, the Conservative governments.

Now, a 2013 plan for how to provide the needed comprehensive care is actually immediately to hand in an extensively researched and documented business case proposal, funded in 2012 by the health ministry. This plan provides an overarching, systemic plan with a proposed model of care and care delivery system, phased and costed at \$26 million dollars (about \$50 per person) for implementation over five years. For this modest, up-front investment, the province could save hundreds of millions of dollars every year. (You can find the documents at <http://recognitioninclusionandequity.org/resources/>.)

It is a very black mark indeed on the Wynne government that it did not validate and implement these recommendations when they were first submitted, even after promises for fast-track action had been made. Instead, the health ministry delayed any action by three years, and then it struck yet another investigative body to begin from square one. Only this time, it did so without giving it a budget or expert staff, and reduced and fragmented its mandate dramatically.

The government did this despite the fact that both the Conservative and NDP health critics strongly and repeatedly voiced their support for the 2013 recommendations, in the legislature, in public meetings at Queen's Park and in letters to the health minister.

So the takeaway for the moment is clear: the "small-start" recommendations of this Interim Report are all good and absolutely necessary, as

far as they go, and they should be strongly supported and anyone who reads this assessment is urged to write to the minister and the Premier with this message. But 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 based on the 2013 business case recommendations, is now needed to show good faith and, indeed, competence. Voters will be looking for both.

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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 develop a business case proposal to establish an Ontario Centre of Excellence in Environmental Health in 2012 and 2013.