Socio-Economic Impacts of Environmental Illness in Canada

Prepared for:
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November 15, 2000

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Acknowledgements

The authors are pleased to acknowledge the important contribution made by participants in the Experts Panel (see list in Appendix 1), and those who peer-reviewed portions of the report including Nancy Bradshaw, Dr. Lynn MarshaIl, Yolande Mennie, Ian Morton, John Sankey, Bruce Small, Professor Tang Lee, and Steven Rowat.

1. Executive Summary

Millions of Canadians suffer tremendous physical, emotional and financial hardship as a result of Environmental Illness. In addition, tax revenues could increase by over a billion dollars and government spending could be reduced by billions of dollars each year, if appropriate medical tests and treatments for the illness were instituted in a timely manner. Productivity could be increased by over ten billion dollars a year. That makes Environmental illness one of the most expensive health care conditions in Canada, along with cardiovascular disease, musculosekeletal disease, injuries and cancer (based on Health Canada's cost estimates for these other diseases at $13 billion to $19 billion a year, each.)

For the purposes of this paper, Environmental illness has been defined to include Multiple Chemical Sensitivity (MCS), Chronic Fatigue Syndrome (CFS), Fibromyalgia (FM), Gulf War Syndrome (GWS), Porphyria, and environmental hypersensitivity including reactivity to microbiological exposures. The EISC includes asthma and allergies as Environmental Illnesses, and many of those who suffer other symptoms of the disease also have asthma and/or allergies. However the data for asthma and allergies have not been included in this study in order to highlight the suffering and impact of the other forms of Environmental Illness that are less accepted and more poorly understood.

Because most Canadian medical bodies do not recognize Environmental Illness, and because the disease is therefore seldom diagnosed in this country, it is difficult to determine accurately how many Canadians have the illness and what the impacts are. There is relatively little prior research on this topic and almost no 'hard data' available. Nonetheless, it is critical that both the incidence and impact of the illness be measured in some way in order to rationalize the spending of additional resources to better understand the illness, and to better diagnose and treat those afflicted.

Therefore, the authors of this paper have chosen to compile and synthesize the best, most relevant data available, in order to see what sort of a picture emerged. Most of the studies we found involved self-reporting and/or self-diagnosis. We have therefore confined our conclusions to orders of magnitude (i.e. the big picture), in order to favor accuracy over unwarranted precision.

The data from researchers across North America paint a remarkably consistent image. Based on the available data, we estimate the following.

Incidence

- About one in eight (several million) adult Canadians suffer significant symptoms, increased absenteeism, and measurably impaired abilities at work due to 'normally safe' exposures to some of the common chemicals and molds found in their homes and at work.
- About one in 50 (about half a million) adult Canadians are unable to do paid work due to a disability associated with Environmental Illness.

Impacts on Society

- Over ten billion dollars a year in lost productivity
- Over 1 billion each year eroded from the tax base
- Over 1 billion dollars each year in health care costs, much of which could be avoided if the illness were diagnosed and treated in a timely manner
- Over 1 billion dollars each year in avoidable disability payments
- Avoidable costs to private health plans (not measured)
- Avoidable suicides (not measured)
- Erosion of personal rights and universality of healthcare

Impacts on Individuals and their Families

- One million Canadian adults are less productive or underemployed, and are needing to renovate their homes

- Half a million Canadian adults are
    - unable to do paid work,
    - isolated,
    - facing additional costs such as organic foods and uncovered medications, medical services and assistive devices – which can easily total $10,000 a year, and are
    - depleting their RRSPs and other savings

- Hundreds of thousands of Canadian adults are relatively homeless, and thousands are absolutely homeless
- Failed marriages and family tension
- Suicide

Additional research is certainly warranted in the area, in order to better understand and treat the illness. At the same time, the magnitude of these impacts begs for action that will have a more immediate effect on prevention, diagnosis and treatment of the illness. It would be prudent to immediately begin integrating complementary approaches that have been proven to be cost-effective. This would mean training physicians and other health care practitioners to diagnose potential cases of the illness and to refer afflicted patients to specialists, including doctors trained in complementary medical approaches (for example, vitamin and mineral supplementation.)

An education program for public and private insurers is also needed, along with guidelines for identifying or ruling out any organic basis for the illness. It is also critical that those who are currently suffering from the disease be better accommodated, so that they are less isolated and better able to continue contributing to society. A multi-pronged social marketing / education campaign is recommended that would address the needs of suffers, and also the responsibilities of employers, and public facilities such as schools, hospitals and recreation facilities. Campaigns targeted at family members, and the general public are also advised.

2. Background, Methodology, Limitations of this Study

The Environmental Illness Society of Canada (EISC) retained the services of Cullbridge™ Marketing and Communications to investigate the socio-economic impacts of Environmental Illness in Canada.

Paradigms are slow to change. A sound body of scientific, medical knowledge on Environmental Illness has been developed over the past fifty years, and is gradually becoming more widely known and accepted by physicians and other mainstream healthcare practitioners. However, because most Canadian medical bodies do not yet recognize Environmental Illness, and because the disease is therefore seldom diagnosed in this country, it is difficult to determine accurately on a small budget how many Canadians have the illness and at what cost. There is relatively little prior research on this topic and almost no 'hard data' available (i.e. based on Canadians who have been diagnosed by a qualified medical professional as having Environmental Illness.)

Nonetheless, it is critical that both the incidence and impact of the illness be measured in some way in order to rationalize the spending of additional resources to better understand the illness, and to better diagnose and treat those afflicted.

Walters et. al. (1995, p 8), based on the work by Shrecker (1986) and Murray (1998) distinguishes between "the standards of proof required by conventional science and the standards appropriate to the formulation of public or corporate policy." As she notes, "science demands strict standards – the amount and type of evidence required to support a hypothesis. The response to uncertainty is further data collection. But theses standards may not be appropriate in the realm of policy making (though appeals to scientific rigor have been used to block policy changes). The issues are different and the need to act is greater because the costs of not correcting a problem may be high; lives may be lost or the quality of life impaired … (for example) with respect to environmental hazards and other causes of ill health where the evidence is relatively persuasive."

Therefore, the authors of this paper have chosen to compile and synthesize the best, most relevant data available, in order to see what sort of a picture emerged. Most of the studies we found involved self-reporting and/or self-diagnosis. We have therefore confined our conclusions to orders of magnitude (i.e. the big picture), in order to favor accuracy over unwarranted precision.

The data from researchers across North America paint a remarkably consistent image. The Canadian studies include: a Province of Nova Scotia Health Survey (1996), Judge Thomson's report of Ontario's Ad Hoc Committee on Environmental Hypersensitivity Disorders (1985), a survey by Canada Mortgage and Housing Corporation (1997), and a yet-to-be published needs assessment by The Environmental Health Clinic, Sunnybrook and Women's College Health Sciences Centre. (2000). Readers who are aware of additional relevant studies are requested to notify the authors.

In the U.S., Dr. Pam Gibson and her students of James Madison University have been studying a group of over 300 Americans with multiple chemical sensitivities (MCS) since 1992 (Gibson et al, 1996). Some other relevant surveys have also been conducted in United States (e.g. Bell et al., 1996 and 1998; Kreutzer et al., 1999; Meggs et al., 1996; and Voorhees et al., 1998).

In addition to a literature review, we conducted interviews with a panel of thirteen experts working in the area (doctors, engineers, architects, advocates, and researchers; c.f. the list of names in Appendix 1). This allowed for discussion and elaboration of points raised.

Our findings are presented below, including actual examples from our Experts Panel.

3. Environmental Illness in Canada

Definition of Environmental Illness

For the purposes of this study, environmental illness has been defined to include Multiple Chemical Sensitivities (MCS), Chronic Fatigue Syndrome (CFS, or ME – myalgic encephalomyelitis), Fibromyalgia (FM or fibrositis), environmental hypersensitivity including reactivity to microbiological exposures, Porphyria, and Gulf War Syndrome (GWS), and to exclude cancer, Parkinson's Disease and Alzheimer's Disease. While the EISC includes allergies and asthma as Environmental Illnesses, the data for asthma and allergies have not been included in this study in order to highlight the suffering and impact of the other forms of Environmental Illness that are less accepted and more poorly understood.

Our definition for MCS is based on the top five consensus criteria first identified in a 1989 multidisciplinary survey of 89 clinicians and researchers with extensive experience in, but widely differing views of MCS (multiple chemical sensitivities). A decade later, these criteria are still unrefuted in published literature. (MCS Referral and Resources, 1999)

According to these criteria, Environmental illness is:

1) a chronic condition
2) with symptoms that recur reproducibly
3) in response to low levels of exposure
4) to multiple unrelated chemicals and
5) that improve or resolve when incitants are removed.

After ten more years of experience, the group added a 6th criterion:

6) with symptoms occurring in multiple organ systems.

Chronic Fatigue Syndrome (CFS / ME) is defined as "an illness characterized by persistent fatigue, neurocognitive symptoms, and a variety of multi-system symptoms…The core symptoms include excessive fatigue, general muscular and joint pain, mental fogginess, and often gastrointestinal problems. Other symptoms include fatigue following stressful activities,

headaches, sore throat, sleep disturbances, low-grade fever and depressed mood. The symptoms fluctuate in severity and persist for a prolonged period." (Panjwani, 1999)

Fibromyalgia syndrome (FM) is defined as "a painful muscle disorder in which the thin film or tissue (myofascia) holding muscle together becomes tightened or thickened, causing pain. It shares many of the same symptoms as CFS"." (Panjwani, 1999)

How Many Canadians Have Environmental Illness?

Because most Canadian medical bodies do not recognize environmental illness, and because the disease is therefore seldom diagnosed, it is difficult to know how many people actually suffer from it. Nonetheless, the few existing North American studies provide a relatively consistent picture that enables us to provide a rational estimate. Here is what these studies say:

- Nearly one third (32%) of Canadians think that environmental pollution has affected their health either very much (8%) or a fair amount (24%), according to Health Canada's Canada's Health Promotion Survey 1990. (1993, p 79).

- One third of randomly selected adults in United States thought they were "*especially* sensitive to everyday chemicals", consistently over three studies. (Bell et al., 1996 and 1998; and Meggs et al., 1996).

- About 16% of adults in California and New Mexico reported being "*unusually* sensitive to everyday chemicals"[1] (Kreutzer et al., 1999; Voorhees et al., 1998).

- About 15% of Canadians are likely affected by Environmental Illness to the degree that their productivity at work, school, or home is significantly reduced (unable to perform regular tasks, or get to school or work, at least one day a month), according to most members of our Experts Panel.

- 6% of the adults in California and 2% of the adults in New Mexico indicate that they had already been diagnosed with MCS or Environmental Illness[2] (Kreutzer et al., 1999; Voorhees et al., 1998).

- About 3% of citizens in Nova Scotia reported in a 1995 provincial health survey that a health professional had told them they have environmental illness[3] (Province of Nova Scotia, 1996).

[1] Based on statewide telephone surveys of randomly selected adults, conducted by state health departments between 1995 and 1997. The question was "Compared to other people, do you consider yourself allergic or unusually sensitive to everyday chemicals like those in household cleaning products,paints, perfumes, detergents, insect sprays and things like that?"

[2] Based on statewide telephone surveys of randomly selected adults, conducted by state health departments between 1995 and 1997. The question was " Have you ever been diagnosed with multiple chemical sensitivities, which is also known as environmental illness?"

[3] The question was "Do you have any of the following long-term conditions that have been diagnosed by a health care professional?…t.) Environmental illness"

- 57% of those who had been diagnosed with Environmental Illness in one Ontario study were off work due to their disability. (The Environmental Health Clinic, Sunnybrook and Women's College Health Sciences Centre, 2000).

- 55% of the environmentally ill participants studied by Gibson and her students reported having either severe (39%) or totally disabling (16%) symptoms (Gibson et al., 1996).

- According to our Experts Panel, 1-3% of Canadians are likely affected to the degree that they are not able to work (on disability pensions, report being unable to work, or were employed prior to illness and have not been able to return to work).

	At Risk:
% adults	Based on the above information, it is reasonable to estimate that:
33%[4]	• About one in three Canadian adults are perceptibly *more sensitive than average* to environmental pollution – indoors and out. This does not necessarily mean that they have Environmental illness – just that they are more sensitive than average.
10-15%[5]	• About one in eight (several million[8]) suffer significant symptoms, increased absenteeism, and measurably impaired abilities at work[9] due to 'normally safe' exposures to some of the common chemicals[10] found in their homes and at work. Almost all of these individuals would meet the criteria for having Environmental Illness.
2-6%[6]	• About one in 25 (about a million) have been 'diagnosed' (self-diagnosed, or by a health care practitioner) as having Environmental Illness.
1-3%[7]	• About one in 50 (about half a million) adult Canadians are unable to do paid work due to a disability associated with Environmental Illness.

[4] Based on Health Canada (1993); Bell et al., (1996 and 1998); and Meggs et al. (1996).
[5] Based on our Experts Panel, and Kreutzer et al. (1999)
[6] Based on Province of Nova Scotia (1996); Kreutzer et al. (1999); and Voorhees et al. (1998).
[7] Based on our Experts Panel, Gibson (1996), and Sunnybrook and Women's College Hospital (2000).
[8] These calculations are based on 2000 population data from Statistics Canada for those aged 15 and over (www.statcan.ca/english/Pgdb/People/Population/demo31a.htm).
[9] Including paid work, housework, volunteer service, and school studies.
[10] Including naturally occurring substances like mold toxins.

The vast majority of sufferers are female. For example, between 80% and 86% of participants were women, in the studies conducted by Gibson, CMHC, and The Environmental Health Clinic at Sunnybrook and Women's College Health Sciences Centre.

4. Costs to the Public Health Care System

As mentioned above, Canadian medical licensing bodies do not recognize environmental illness, and it is therefore seldom diagnosed. The result is that health care resources are 'wasted' on unnecessary visits and treatments, as our health care systems try to cope with patients who are misdiagnosed and improperly treated by a chain of physicians and specialists as their conditions spiral into full-blown disabilities.

Judge Thomson found that in Ontario "many very expensive, fully insured interventions had been tried and found not to be helpful." (1985, p131) In the USA, Gibson's study participants saw a mean of 8.6 medical practitioners each; of these practitioners, only 27% were described as being helpful. (1996)

Ballpark Figures – What Does it Cost? Billions.

Jim Cotter, a member of our Experts Panel, is Chair of EISC's War Veterans' Committee. Based on his experience with war veterans, he estimates that each chronic sufferer of Environmental Illness costs Medicare about $3,000 each year. Based on our estimate that a half million Canadian adults are unable to work because of their disability, we calculate that Medicare must spend over a billion dollars each year on chronic suffers. And this estimate does not even take into account the medical expenses of the remaining millions of Canadians who suffer significant symptoms but are still able to work.

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	At Risk:	*Examples from our Experts Panel*
% Adults	Costs	One panel member reviewed his Ontario Health Insurance Plan (OHIP) files this year to find that from 1987 to 1994 he saw 22 doctors, was diagnosed with 53 different illnesses and had incurred 700 charges against OHIP. Physician visits are estimated to cost OHIP between $17 (GP) and $50 (specialists) per visit. 700 visits at an average charge of $33.50, costs OHIP $23,450 over 7 years.
10-15%	?	
1-3%	over $1 billion	

It Would Likely Cost Less, If Covered By Medicare

It would likely cost the public health care system less if Environmental Illnesses were addressed straight on. According to Dr. Ross, a specialist in diagnosing and treating Environmental Illness, early intervention often stops the illness in its tracks. According to Ross, the chronic cases we see now are a result of improper treatment and diagnosis.

Further, the longer a patient goes without proper diagnosis and treatment, the worse the symptoms grow to be and the more chronic a patient's condition is likely to become.

> "The cost of undetected environmental sensitivities is huge. A simple allergy to mold could be remediated so quickly and cheaply by assessment and remediation. Instead, $1,000 to $10,000 dollars or more are spent on failed treatments (per person)… If the medical establishment were properly trained, we would see much less long-term disability." (Panel member, Bruce Small)

In addition, some complementary approaches are proving more cost-effective than traditional medical approaches. For example, a study of 75 asthmatic patients showed 73% savings in hospital bed/day cost using environmental medicine treatments. (Brostoff, 1981).

As Cynthia Ramsay of the Fraser Institute points out, the current situation also artificially increases the costs of covered treatments.

> "From a pure cost perspective, irrespective of the argument for free choice, the medical licensing bodies are keeping the demand for health care services at an artificially high level by restricting the supply of services available to consumers. They are creating an additional inefficiency in the health care system; a price which *everyone* has to pay in the end" (Ramsey 1995, p12)

5. Costs to Private Health Insurance Plans

Private health insurance plans are currently caught in a double bind. They have to pay out needlessly large amounts of money to cover treatments (e.g. medicines and the services of alternative health care providers) that might be unnecessary if Environmental Illness were better diagnosed and treated. They also stand to incur increased costs in the short run if they allow claims for a long-term, still-controversial illness that is rarely covered by the public health care system.

The result is that, as Judge Thomson found in Ontario “in general, it seems that the position of private insurers has become more restrictive in recent years as the number of claims has grown and the controversy over clinical ecology has become more public.” (Thomson, 1985, p134) "If one looks at the situation from an insurer's perspective, environmental illness is a bane to their existence - liability with no end in sight and no consistent objective findings to help in following the course of illness" - according to Dr. Lynn Marshal a the Environmental Health Clinic at Sunnybrook and Women's College Health Sciences Centre in Toronto. "Some insurance plans have a clause limiting the insurer's liability to 2 years for applicants with psychiatric diagnoses. In such a situation, the insurer may naturally prefer a psychiatric diagnosis."

The *Diagnostic Statement* working group at Health Canada’s 1992 workshop on *Multiple Chemical Sensitivities and their Relevance to Psychiatric Disorders* noted that “the diagnosis that is proffered often depends on the part of the health care system the patient accesses. Patients may seek help because of psychosocial distress resulting from (biological) illness, and thus be more likely to receive a psychiatric diagnosis.” (Health Canada, 1992, p16) Similarly, if public and private insurers preferentially send sufferers for a psychiatric assessment, the diagnosis – today - is more likely to be psychiatric.

This may be a financially costly mistake and it is one that could lead to the worsening of patient health because treatment aimed at correcting organic problems may be delayed. And sufferers who do not have their biological illnesses properly diagnosed and treated may well require more long-term disability support (as well as public health care and social support services) than would otherwise be the case.

Given the wide variety of private health insurance plans available and the uncertainty of how many Environmental Illness sufferers actually belong to plans, we have not attempted to estimate the costs of Environmental Illness to these companies.

6. Costs to 'Safety Net' Systems

To date there have been few successful claims to workers' compensation relating to environmental illnesses. Judge Thomson found that "some received coverage. Most did not." (Thomson, 1985, p.135)

Ashford and Miller report a similar situation in the USA:

> "Only about 1 percent of severely affected chemically sensitive workers will file a workers' compensation claim because they do not want to be labeled as psychiatric cases. In addition, many workers leave jobs because of chemical sensitivity only to find themselves unable to tolerate a new job and unable to file a claim against either the new or old employer" (Ashford, 1991, p. 56,)

However, many Canadian sufferers do receive disability compensation of some sort. A large number of disability claims may actually be Environmental Illness disguised under a legitimate claim such as arthritis, migraines, or back pain, according to panel members. In a recent study by the Sunnybrook and Women's College Hospital Environmental Health Clinic, 29% of those surveyed (about half of those who reported being off work due to disability) depended on disability payments as their "main income." (The Environmental Health Clinic, Sunnybrook and Women's College Health Sciences Centre, 2000)

.3% to 1% of Canadian adults	*At Risk:* Disability benefits related to environmental illness likely cost in the ballpark of hundreds of millions of dollars a month, or over a billion dollars a year[11].

Welfare

We were not able to find any data on cost to welfare, except for the following comment by one panel member.

[11] This assumes that disability payments are being received by 1/3 of the 500,000 Canadian adults who are unable to work due to a disability associated with environmental illness, and that these payments average the same as for other Canadians receiving CPP disability benefits ($676.33 per month in January 2000 according to HRDC (www.hrdc-drhc.gc.ca/isp/cpp/disabi_e.shtml)

7. Reduced productivity at work, school, and home

As people become ill, their ability to function decreases across a wide debilitation spectrum. This inevitably results in lost productivity through decreased hours/wages or loss of job, declining ability to perform on the job, impaired learning at school and its consequences, and a struggle to perform household duties. Compared with other chronic diseases, the decline in productivity among chronic suffers is particularly great. Gibson (1999) used the Sickness Impact Profile developed by Berger et. al. (1976) to measure illness-engendered dysfunction among her MCS study participants. She compared her data with those collected by Patrick and Deyo (1989) who summarized the literature on the use of the indicator with a number of chronic illnesses. The only conditions showing more dysfunction were non-responding chronic pain and amyotrophic lateral schlerosis.

Paid Work

Health Canada (1997) has identified lost productivity due to long-term disability as the largest single cost of illness in Canada. This loss is particularly high for Environmental Illness, because large numbers of sufferers remain unable to do paid work. Estimating that a half million adult Canadians can't do paid work, and if they would otherwise earn at least $20,000 a year each, then the lost revenue is over ten billion dollars annually.

Furthermore, our expert panel estimated that Environmental Illness costs Canadian employers additional 100s of millions of dollars each year in lost productivity from decreases in attendance rates and on–the-job efficiency.

These numbers are more than mere conjectures. The U.S. EPA (1989) estimates that in the U.S. each year indoor air pollution alone is responsible for:

- $4.7 to $5.4 billion in productivity losses associated with major illnesses, and
- as much as $60 billion in productivity losses on the job and increased leave time.

Sunnybrook and Women's College Hospital Environmental Health Clinic (2000) found in their not-yet-published study of 487 environmentally ill participants, that the vast majority had changed their working situation to accommodate their disability:

89% - had experienced a decreased ability to work
42% - had reduced their hours of work
57% - were off-work due to disability
29% - were receiving disability payments that represented their main income

Similarly, Gibson (1996) found that of her study participants:

77%- had had to quit or had lost a job because they were unable to tolerate the chemicals in their workplace
<33% - worked outside of the home
22%- of those who worked, worked in conditions they considered safe for their health

Note that productivity is not always measured in lost hours or decreased production. Work in our society is knowledge work not just factory work. Further costs may hide within the decreased brain function of employees.

Panel members believed that all Environmental Illness sufferers can return to full productivity. Dr. Gerry Ross said he could attest to that by his treatment of thousands of patients. Professor Tang Lee said, "If we can clean up the environment, remove the chemicals, then these people can and are willing to be 100% productive. A healthy population facilitates a healthy economy."

This lost productivity costs our governments an enormous amount in lost taxes. Every person who is unemployed or underemployed because of environmental illness is not contributing his or her maximum in taxes. Over ten billion in lost revenue represents over a billion dollars of lost taxes.

% Adults	*At Risk:*
1-3% up to 12%	• Over ten billion dollars in lost productivity of those unable to work • Hundreds of millions of dollars in lost productivity of those who work and who display significant symptoms • Over one billion dollars eroded from the tax base

School

Sick schools and/or sick students are frighteningly common. This threatens future productivity by arresting crucial development. Almost all of our panel experts knew of children or young adults who either dropped out of school or were struggling to attend school due to their illness.

Expert Panel member Bruce Small details three categories of impairment:

1) Attendance: Were they able to attend class?
2) Ability: Were they able to learn?
3) Confidence: Long term impairment to their self-esteem around learning because they had difficulty. Do they feel confident that they can learn?

Insufficient data were uncovered to estimate the dollar value of this loss.

Home

While there is certainly a tremendous productivity loss associated with 'home' work, insufficient data were uncovered to estimate the dollar value of this loss.

8. Costs to People with the Disability and their Families

> "There are serious economic implications of environmental hypersensitivity. As the condition worsens, medical expenses and expenses for modifications to homes increase at the same time as their ability to earn a living decreases. Therefore, there could be tremendous changes in the economic status of environmentally hypersensitive individuals over the course of their illness." (CMHC, 1997, p50)

Lost Income

A study conducted by Canadian Mortgage and Housing Corporation examined the total household incomes of environmentally ill Ontario residents. The majority of survey respondents (53%) reported that their household income had decreased as a result of their condition. It remained the same for 40 % and increased for 7%" (CMHC, 1997, p.20)

Similarly, Gibson (1996) found that "most persons suffered a drastic decline in income since becoming chemically sensitive, and the mean reported decline in annual income was roughly $27,000."[12]

[12] Translated into Canadian dollars at a conversion rate of $1 US = $1.5 CDN

	At Risk:	*Examples from our Experts Panel*
<u>% Adults</u> 2-6% 1-3%	<u>Costs</u> One million Canadian adults less productive, underemployed Half a million Canadian adults unable to do paid work	• One panelist lost $100,000 over 10 years in potential earnings. • Another lost $240, 000 over 10 years in potential earnings ($30,000/yr, 4yrs part-time) • Another lost $900,000 over 15 years in potential earnings ($60,000/yr). • Yet another had his/her income reduced to 1/25th of before and is only now starting to recover.

Depletion of Personal Savings

Increased expenditures coupled with a loss in income usually results in a depletion of personal savings, including RRSP's. As Gibson notes "participants attempted avoidance of chemical exposures through (changes to their homes.) But, for many, income decline accompanied the growing perception that living conditions were unsafe. Consequently many respondents reported either continuing to live in unsafe conditions, or spending their life savings to redo their homes and purchase air purifiers or other necessities." (Gibson, 1996, p.70)

	At Risk:	*Examples from our Experts Panel*
<u>% Adults</u> 1-3%	<u>Costs</u> Half a million Canadian adults unable to do paid work, depleting their RRSPs and other savings	• One panelist was not able to accumulate savings as a result of lost income. • Another said he/she can never make enough to give to RRSPs. He/she hasn't contributed in 13 years. • Another lost almost all of his / her RRSPs at $30,000. • Another substantially depleted his/her savings. • Yet another had been living on savings for 5 years. "They are dwindling down rapidly."

Safe Home / Renovations

Creating a safe home environment can be expensive. According to our panel of experts, sufferers often spend $25,000 or more on renovations or upgrading to a new home.

The CMHC study found that "77% had made changes to their current dwelling in order to alleviate some of their symptoms. (1997, p.34) Financial limitations were indicated to be the main factor that prevents the realization of housing needs.

Gibson's study participants reported spending a mean of $42,000 to redo their homes [13]

	At Risk:	*Examples from our Experts Panel*
<u>% Adults</u> 2-6%	<u>Costs</u> One million Canadian adults with significant symptoms, needing to renovate their homes	• One panelist paid for: a new ventilation unit with air exchanger, a home addition, removal and installation of carpet and flooring, special paints, removal and treatment of mold, and construction of a new home office so that a government job could be done in a healthy environment away from the workplace." (at a cost of around $60,000) • Another bought a house, and pays the monthly mortgage and other bills out of his/her dwindling savings. If he / she weren't sick "I would be in a cheap little apartment."

Other Costs

According to our Experts Panel, chronic sufferers of Environmental Illness often face many of the costs outlined in the chart below. These can easily total $10,000 a year.

Examples from our Experts Panel
Medications (not covered) Typically includes vitamin and mineral supplements as well as herbal and homeopathic remedies. • One panel member: $2000/yr. • Another panel member: $3000/yr. • Another panel member: $1200/yr. *Physician Services (not covered)* • One panel member: $4500 over 10 yrs. This includes clinical ecologist treatments: allergy treatment, and tests in states. • Another panel member: $2000/yr. *Other Treatments* • One panel member: $1000/yr. • Another panel member: $1000 yr. • Another panel member: $1000/yr *Continued….*

[13] US$ 27,816 translated into Canadian dollars at a conversion rate of $1 US = $1.5 CDN.

Assistive Devices

- One panel member: $4000 for portable air unit, oxygen tank, mask for outside, and unit in car.
- Another panel member: $800 for oxygen equipment plus $240/yr for oxygen.

Organic Foods

- One panelist: food bills now 1.5 times as much as before
- Another: it adds upwards of 8-10% more to your food bill
- Another: organic foods cost twice as much as regular foods
- Another: it has added $3000 extra a year

9. Social costs

All facets of the life of an environmentally ill person are disrupted. The CMHC study documents this decreased quality of life. "When asked to provide an overall assessment of the extent to which their environmental hypersensitivity has limited their experience of a "normal life", fully 41 % responded to a great extent (by selecting 5 on a 5-point scale)… and 32% selected 4 on the 5 point scale)" (CMHC, 1997, 24).

Absolute Homelessness

The absolutely homeless Environmental Illness sufferers don't have homes. "They live on the street, in parks, shelters, cars, trailers, tents, and even igloos", according to panel member, Bruce Small. "They may move from place to place, escaping from the illness that the last shelter evoked." Dr. Len Levine, another panel member who is trained to diagnose the disease, estimates that around 1% of Environmental Illness sufferers are absolutely homeless. That would be thousands of Canadian adults (for example, 1% of the million Canadians who have been diagnosed with Environmental Illness represents 10,000 people). Levine says "A whole subculture of the environmentally ill live on the streets. Of the 40,000 people homeless in Toronto, I believe a large portion of them suffer environmental hypersensitivities."

According to Small, some could afford a house but are too hypersensitive for any indoor environment and prefer the outdoors. Others simply can't afford to live indoors. Low-income rental accommodation almost always exacerbates Environmental Illness symptoms. They commonly have sick ventilation systems, frequent insecticide sprayings, oil-based paints, cheap carpets and glues, and many other aggravators of Environmental Illness. This is compounded by the fact that low-income housing is often found in areas of town that suffer poor air quality due to their proximity to industry or highways.

% Adults	*At Risk:* Costs	*Examples from our Experts Panel*
.05%	Thousands of homeless adult Canadians	

Relative Homelessness

Those who are *relatively homeless* have homes – but they are not able to live in them without endangering their health. According to our panel, most of the environmentally ill who are 'seriously affected' probably fall into this category. Sixty-six percent of Gibson's study participants reported living in highly unusual conditions (e.g. cars, recreational vehicles, tents) at some point in order to avoid chemical exposures. Only 40% reported that their current living conditions were "very safe"(5%) or "mostly safe." (35%) (Gibson et al., 1996, p. 70)

Those who cannot afford to buy or build a safe house remain vulnerable to relative homelessness because in almost every rental situation there is the risk of activities by the landlord or other tenants that could compromise their health. For example, one woman in Kingston reportedly rents a room for her belongings, yet sleeps in a tent in the backyard – because her landlord (who lives in the same house) refuses to stop using scented products. Other commonly used and potentially problematic goods include pesticides, cigarettes, cleaning products, and building / renovation materials.

We have conservatively estimated the number of relatively homeless Canadians at half of the half million Canadian adults who are unable to do paid work – or hundreds of thousands of Canadian adults.

% Adults	*At Risk:* Costs	*Examples from our Experts Panel*
1%	Hundreds of thousands of 'relatively homeless' Canadians	• Dr. Gerald Ross, who is trained to diagnose Environmental Illness, knows of 50 individuals who live in their car. • One panelist was homeless for 6 months before his/her parents helped buy him/her a house. • Another has had to move every 8 months over the last 25 years.

Failed Marriages and *Family Tension*

According to our expert panel, marriages are usually strained and often threatened, when one or more family members have environmental illness. Primary relationships often break down, since those who are closest to sufferers become suspicious that they are malingering, hypochondriac or mentally ill. The others in the family often do not understand and /or are not willing to have their life revolve around accommodating the environmentally ill.

Gibson concurs. She found that almost three quarters of those who suffered break-ups believed that their illnesses contributed to ending the relationship (p. 71). About one in seven (14%) of all women participants said that their chemical sensitivity had been a factor in deciding not to have children (p. 69).

Isolation

Family members are not the only ones who have difficulty understanding and accommodating the needs of the environmentally ill. According to our panel, many environmentally ill end up making friends only with other environmental ill patients. One of the most painful social costs is that of losing contact with both family members and friends. It can be quite an isolated and lonely life.

Eight percent of Gibson's study participants reported being totally housebound. Many reported that they had to avoid church (11%), malls (25%), movies (8%), and restaurants (19% could not go at all and 23% went rarely and with extreme care). They said that they had lost access to continued education (24%), involvement in hobbies (e.g. painting) (33%), travel (22%), socializing (17%), and visiting family (9%). (Gibson et al., 1996) "Participants needed but were prevented from receiving support for personal difficulties due to their limited public access, their need for chemical avoidance including fragrances, and others' lack of information and negative attitudes regarding chemical sensitivities." (Gibson et al., 1998, Abstract)

The half million adult Canadians who are not able to do paid work because of Environmental Illness would all qualify as being 'isolated', although it is likely that there are more who are able to work but suffer a significant loss of access.

	At Risk:	*Examples from our Experts Panel*
% Adults	Costs	
2%	Over half a million isolated Canadian adults	One panelist said "I went from being extremely active, extremely social, and traveling a lot…. to doing virtually none of this. It has had a huge impact on every aspect of my life."

Suicides

A number of our Experts Panel members knew three 3 or 4 environmentally ill patients who had committed suicide. One fifth of Gibson's study participants had seriously considered suicide, 8% had made a plan, and 3% had attempted suicide. (Gibson, 1996, p. 72)

Examples from our Experts Panel

"One woman kept calling me up at the end of her rope. She was diagnosed with cancer and had to move near a cancer clinic with no support for her Environmental Illness. She thought that there was no place for her. So she plotted to kill herself and succeeded."

Erosion of Rights

The fact that Environmental Illness is currently not covered by the public health care system raises issues about fairness and universal availability. Bruce Small illuminates this controversy: "If someone can get treatment covered for pain in their hands under the name arthritis, an environmental sensitivity symptom that is identical should be covered. You have the right to restore your function no matter what the source of your function impairment."

Ashford and Miller argue that:

> "Recognition of diagnosis and treatment of chemical sensitivity for insurance purposes is necessary on grounds of fairness and, in the case of some patients, to enable them to receive adequate care. For traditional medical practitioners to throw up their hands and not be able to help these patients and, at the same time, to lobby vigorously to deny them therapies that sometimes, if not often, relieve their suffering cannot be justified." (Ashford, 1991, p.156).

Cynthia Ramsay of the Fraser Institute says:

> "Provincial medical licensing bodies exceed and abuse their mandate when they investigate and harass licensed medical doctors who practice complementary medicine with the informed consent of their patients and in the absence of demonstrable harm to their patients. Such actions coupled with the fact that alternative therapies generally are not covered by provincial health insurance plans indicate that freedom of choice in health care does not exist in Canada, neither for those who are supplying it nor for those who are demanding it." (Ramsey, 1995, p12)

This situation also compromises the ability of physicians to meet their obligations under the World Medical Association's Declaration of Helsinki, which states that "the physician must be free to use a new diagnostic and therapeutic measure, if in his or her judgment it offers hope of saving life, reestablishing health or alleviating suffering" (1989, p3).

The fact that so few sufferers are accommodated (e.g. at work and school) or awarded disability payments for their Environmental Illness can also be seen as a rights issue. The Individual's Rights Protection Act of Canada (R.S.A. 1980, c. 1-2) requires accommodations for those with a disability that "withholds or limits access to opportunities, benefits, and advantages available to other members of society" (Andrews vs. Law Society of B.C.[1989] IS,C.R. 143). The act apparently covers those with physical and mental disabilities and those with respiratory related problems.

Similarly, the United Nations Convention on the Rights of the Child protects children's rights to health care (article 24), education (article 28) and "to participate fully in cultural and artistic life" (article 31). It also protects the rights of mentally or physically disabled children to live in conditions which "facilitate the child's active participation in the community." (article 23) (Heritage Canada, 1991)

10. Conclusion

In conclusion, there are enormous economic and social consequences of not recognizing and thus not treating those with Environmental Illness. Millions of Canadians and their families suffer tremendous physical, emotional and financial hardship as a result of the illness. Those who are unable to heal from the illness are less able to contribute to society and are likely to require costly medical and social support. Tax revenues could increase by over a billion dollars, and government spending could be reduced by billions of dollars each year, if appropriate medical tests and treatments were instituted in a timely manner. Productivity could be increased by over ten billion dollars a year. That makes Environmental illness one of the most expensive health care conditions in Canada, along with cardiovascular disease, musculosekeletal disease, injuries and cancer (based on Health Canada's estimates for these other diseases at $13 billion to $19 billion a year.) (Health Canada, 1997)

Specifically we have estimated the following based on the available data (please note the limitations on this study, discussed in section 2).

Incidence

- About one in eight (several million) adult Canadians suffer significant symptoms, increased absenteeism, and measurably impaired abilities at work due to 'normally safe' exposures to some of the common chemicals and molds found in their homes and at work.
- About one in 50 (about half a million) adult Canadians are unable to do paid work due to a disability associated with Environmental Illness.

Impacts on Society

- Over ten billion dollars a year in lost productivity
- Over 1 billion each year eroded from the tax base
- Over 1 billion dollars each year in health care costs, much or which could be avoided if the illness were diagnosed and treated in a timely manner
- Over 1 billion dollars each year in avoidable disability payments
- Avoidable costs to private health plans (not measured)
- Avoidable suicides (not measured)
- Erosion of personal rights and universality of healthcare

Impacts on Individuals and their Families

- One million Canadian adults are less productive or underemployed, and are needing to renovate their homes

- Half a million Canadian adults are
    - unable to do paid work,
    - isolated,
    - facing additional costs such as organic foods and uncovered medications, medical services and assistive devices – which can easily total $10,000 a year, and who are
    - depleting their RRSPs and other savings

- Hundreds of thousands of Canadian adults are relatively homeless, and thousands are absolutely homeless
- Failed marriages and family tension
- Suicide

Recommendations

1. Additional Research

While it is difficult to find 'hard data' on these impacts, the studies referenced in this report paint a consistent picture: that the prevalence and impact of Environmental illness is great. Additional research is certainly warranted in the area, in order to better understand and treat the illness.

2. Improved Diagnosis and Treatment

At the same time, the magnitude of these impacts begs for action that will have a more immediate effect on preventing, diagnosing and treating the illness. Currently, health care dollars are often wasted on many, often-expensive services and treatments that have not been helping those with the illness, while some unrecognized complementary treatments and paradigms are

proving to be more cost-effective than traditional medical approaches. Furthermore, the longer a patient goes without proper diagnosis and treatment, the worse the symptoms grow to be and the more chronic a patient's condition is likely to become. It would be prudent to begin immediately to integrate those complementary approaches that have been proven to be cost-effective. This would mean training physicians and other health care practitioners to diagnose potential cases of the illness and to refer afflicted patients to specialists, including doctors trained in complementary medical approaches (for example, vitamin and mineral supplementation.)

3. Provide Insurers with Education and Guidelines

An education program aimed at private and public insurers is needed so that those who are charged with assessing pension and treatment claims are well versed in the illnesses, the clinical definitions, and current testing and treatment practices. In addition, guidelines are needed to assure that suffers have the benefit of a biological assessment, in order to identify or rule out any organic basis for the illness.

4. Increased Accommodation

Finally, it is also critical that those who are currently suffering from the disease are better accommodated, so that they are less isolated and better able to continue contributing to society. A multi-pronged social marketing / education campaign is recommended that would address the needs of suffers, and also the responsibilities of employers, and public facilities such as schools, hospitals and recreation facilities. A campaigns targeted at family members is particularly needed. In addition, one for the general public would help develop broader social support for those afflicted with the illness.

Appendix One – Expert Panel Members

Bradshaw, Nancy

Cotter, Jim

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Donnay, Al

Ferrie, Helke

Lee, Professor Tang

Levine, Dr. Len

Maslo, Wendell

Marshall, Dr. Lynn

Mennie, Yolande

Proctor, Cathy

Rowat, Steven

Ross, Dr. Gerry

Small, Bruce

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