



Senate of Canada
Standing Committee on Social Affairs, Science & Technology

Briefing Note for presentation by Jean Lewis, of Vancouver, BC

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Today, according to the world renowned *US Centers for Disease Control*, there is an epidemic of staggering proportion sweeping North America: it is called autism and it's stealing our children. According to this authoritative institution, one in 166 children in Canada and the United States is today being diagnosed with an autism spectrum disorder. While the US Senate has recently passed, unanimously, the "Combating Autism Bill", a measure designed to pour literally hundreds of millions of dollars into the fight against this devastating neurological ailment, the non-response to date of our own national government is not only inexplicable, it is morally shameful and it's economically stupid.

We have a Medicare system in our country that purports to be universal, yet it excludes from coverage children with autism, some of Canada's most vulnerable. This is simply wrong. A judge of the BC Court of Appeal, in ruling on the *Auton* case, had it exactly correct in stating: "The failure of the health care administrators [to provide funding for autism treatment] is a statement that their [the infant complainants before the court] mental disability is less worthy of assistance than is the transitory medical problems of others. It is to say the community was less interested in their plight than the plight of other children needing medical care and adults needing mental health therapy. **This is a socially constructed handicap.**" [emphasis added]

The failure to provide medically necessary treatment is also, all things considered, more costly than it would be to do so. Currently, effective treatment costs, on average, roughly \$60,000. per year for each child. Not to provide such treatment costs infinitely more. By adolescence, the vast majority of autistic children require institutionalization. Reliable estimates indicate that, as of 2000, providing treatment will save taxpayers \$1.5 million per person with autism, assuming a normal lifespan which most such people will live. Those autistic children who are "higher functioning" will, in all likelihood, end up as part of the growing legions of the mentally-ill homeless people wandering the mean streets of urban Canada. Yet more costs, financial and spiritual, to be absorbed by society.

Then there are the indirect, but all too real, costs associated with the failure to treat autistic children: marriage break-downs, estimated at a 75% chance, when an untreated autistic child is



being raised in the family home; the emotional, and often financial, impact on siblings, and other close relatives such as grandparents, aunts and uncles; and, last but very important, the opportunity cost [potentially enormous] to Canadian society generally when these children, through a conscious and myopic failure to provide them with available and proven to be effective treatment, are prevented from becoming the best they can be. Their potential contribution to their families, their communities and to the common good of Canada is being denied, and for reasons that are simply unacceptable.

As far as cost is concerned, why is it that nobody asks how much it costs to treat breast cancer, HIV/AIDs, diabetes or prostate cancer, to name but a few, high profile ailments that plague adult Canadians. Why ask this question when it is autistic children who need our help? Could it be because these children can't voice their demands, can't organize among themselves, can't vote? In other words, because they, and their parents, most often exhausted physically, emotionally, and financially, have little or no political efficacy?

Two years ago, on November 17, 2004, an infamous day to parents of autistic children in Canada, as well as to all who care about equality rights in our country, seven members of the Supreme Court of Canada [hereinafter "SCC"], in its grotesquely mis-guided decision in the *Auton* case, over-turned two lower court rulings, and, by applying a restrictive interpretation of the law, have, in the words of Mary Eberts, a prominent advocate for equality rights in Canada, "torn the guts out of the Charter's section 15(1) guarantee of 'equal benefit of the law without discrimination'".

In essence, the SCC told parents of autistic children to "get political". FEAT-BC took this advice to heart and participated, to a small extent, in the last federal general election. We, together with allies elsewhere in Canada, particularly in Ontario, intend to be much more active in the next and every subsequent federal election until Medicare coverage is extended to medically necessary treatment for our children. Despite the SCC's decision in *Auton*, autistic children have the right to this treatment, without the associated costs that potentially may destroy their families financially and imperil the future for themselves, their parents and their siblings, if any.

It is beyond debate that ABA/IBI [applied behavioural analysis and intensive behavioural intervention] is both the only effective treatment for children who suffer from autism spectrum disorder and it is medically necessary. After having heard evidence from experts in the field, on both sides of the argument and often at great length, trial judges in each of British Columbia and Ontario have so found as a fact. The BC Court of Appeal has agreed. An extensive study conducted by York University professors, and released only a week or so ago, again supports this position. Further discussion is not helpful.



Whether autistic children get the medically necessary treatment that is, or ought to be, their right as Canadians, comes down to political will. First the Liberals, and now the Conservatives, take their advice respecting this public policy decision from the same blinkered and obdurate bureaucracy. The existence of a so-called "professional civil service" in our country, like the notion of free Canadian citizens being considered as mere "subjects" of the Crown, is long overdue for reconsideration. In the meantime, their nominal political masters can save the disingenuous lectures about federal-provincial jurisdictional issues being an impediment to federal government action respecting Medicare coverage for the treatment of autism. Fewer and fewer Canadians are gullible enough to believe them. They know this is nothing but a smoke-screen, one that will evaporate like an autumn morning fog over Vancouver's English Bay as soon as the opinion polls show there are sufficient votes in play in crucial electoral battlegrounds. Otherwise, why would the federal government have a "Minister of Infrastructure and Communities", whose principal function apparently is to travel the country spreading federal tax-dollars in areas of clear provincial jurisdiction. Let's get real here.

The parents of autistic children are no longer prepared to appear before our government as supplicants. Those days are over. Our question is: will our myopic MPs, governed as they are by the political oestrus cycle, discover in themselves the moral courage and summon the necessary will-power to over-rule the entrenched health technocrats and do the right thing by our children? Will this Senate committee, exercising as it may a sober second thought, encourage the federal government to do what is right? If not, then we have a problem. The solution will be to elect some new MPs.

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