

Ford's Deceptively Cruel Autism Plan Must be Stopped

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The Ford government's demolition of the Ontario Autism Program is deceptively cruel to parents, children and professionals. Clothed in the sheep's wool of "equality" and "clearing waitlists", the wolf inside cruelly irreparably harms children, families, and Ontario's world-class autism system built over 20 years.

The Ford government has lied to parents, threatened our professional organization, ONTABA, misquoted parents and professionals as if they support the plan, gagged public programs while directing them to "pause" admissions, and misconstrued the waitlist numbers.

It must be stopped before it is too late!

As someone who has been involved in designing autism services, delivering clinical services, and researching treatment effectiveness in Ontario's program, here are some of the major issues with the Ford autism plan announced in February 2019.

One-size-fits-all is wrong clinically and not sensible economically!

Any proper treatment (whether medical, psychological, etc.) should be individualized based on a clinical assessment. Kids with autism vary a great deal from one another and deserve an individualized approach based on their needs. Some have intellectual disabilities, mental health and behavioural challenges, as well as autism. Research (including our own research on the Ontario program) clearly demonstrates that a lot of kids (though not necessarily all) will benefit from highly intensive (i.e., 25-40 hrs/wk) behavioural intervention for 2-3 years in the preschool period, after which a good percentage will be OK in school (if they have a decent education program) and a smaller amount of ASD-specific service.

But some kids (and adults as well) with autism will always need a high level of service. These more severe kids will be extremely negatively impacted by this new plan. Apart from human compassion considerations, this is a very short-sighted plan economically, as these children and adolescents will end up costing society far more later in the psychiatric system, justice system, residential care system, etc.

To use a medical analogy, autism spectrum conditions can be likened to heart conditions. In the case of heart conditions, qualified professionals (e.g., cardiologists) conduct various tests and give prescriptions or recommendations for appropriate treatment on a case-by-case basis. Some people may need a heart transplant, heart bypass surgery, a pacemaker, medication, or an aspirin a day. One size does not fit all. Heart patients receive what they need, regardless of income. What this proposed autism program will do is akin to giving everyone an aspirin.

The Income-based approach will rob most families of what their children need.

While "up to \$140,000" per child may sound good initially, it is a pitiful amount really. Guidelines have now been presented that allow for construction of scenarios. It turns out that virtually **no child will receive the \$140,000** number that has been flouted as the "Childhood Budget". Only families whose child was diagnosed before age 2 (which is possible but rare) and who have an income below \$55,000 would potentially receive that full amount. Families with a moderate income (say \$100,000; who receive about 75% funding) with a child diagnosed at age 4 (more realistic) would receive a maximum of **\$66,000 for the child's entire childhood from age 4 to 18** (i.e., 2 years [age 4 and 5] @ \$15,000/year and 12 years [age 6-18] at \$3,000/year). That is not even enough for one year of IBI (at \$80,000)!!

Combining the one-size-fits-all approach with the income-testing approach yields scenarios like this. Take two different children with autism. **Child A** has a child with severe needs (e.g., nonverbal, not toilet trained, constant repetitive behaviour (e.g., spinning and hand flapping), aggressive when needs not met or can't communicate). Child A clearly needs Intensive Behavioural Intervention (IBI), the comprehensive form of evidence-based behavioural services. The real cost would be about \$80,000/year. Families with low incomes would receive a maximum of \$20,000/year while the child is under 6. Yes, your mental arithmetic is correct: that means only one-quarter of the actual cost!! But, remember, that's only if the family has an income below \$55,000! Most families will receive **less than one-quarter of the real cost**, only a "proportion of a pittance".

On the other hand, consider **Child B** who has mild difficulties, needs some focused behavioural intervention to assist with social skills, but is able to learn in the regular school system. This child does not need IBI and may only need 3 or 4 hours/week of intervention (say \$10,000/year). That child's parents would receive \$20,000 as well, even though their child might not need that much. What is espoused as being "fair" and "equal" is simply an inefficient and irresponsible use of public funds. And it makes no sense clinically.

This represents the Loss of Evidence-based Autism Treatment in Ontario.

Autism has always been a magnet for fad treatments. I was a co-author on an extensive review of what interventions are evidence-based for autism (<http://www.ontaba.org/pdf/ONTABA%20OSETT-ASD%20REPORT%20WEB.pdf>). Applied Behaviour Analysis (ABA) based interventions generally, whether intensive/comprehensive (25-40 hrs/wk targeting many areas of skill development and behaviour problems, otherwise known as IBI) or focused ABA programs (fewer hours, one or a few specific target areas) have, by far, the greatest body of evidence. I was also lead author on the largest community effectiveness studies of IBI in the research literature, studies conducted in the Ontario program showing that the majority of children showed measureable gains.

Ontario used to be a world leader in providing Intensive Behavioural Intervention in a publicly funded program where parents could choose public or private service delivery. If this Ford plan goes forward, no child in Ontario will receive this any more. No family will receive enough funding to pay for this therapy. **This is the death of IBI in Ontario!** Families will receive only a "proportion of a pittance" and very few will be in a position to pay the other 75% or more of the cost themselves.

Furthermore, this plan leaves open the possibility that parents would use the money to buy things they hope might help but which have no solid research evidence behind them. The range of services that will

be allowed is unclear but "technology" and respite care have been mentioned as examples. Consider a 14-year-old with severe behaviour problems who is repeatedly sent home from school because of the difficult behaviour, and whose mother does her best to look after him but is physically and emotionally exhausted. She could choose to spend her allocation of \$3,000 or \$4,000/year on respite care because she is so stressed -- and who could blame her? Meanwhile, the child receives no behavioural treatment whatsoever! Giving kids an iPad, without training and programming in how to use it to teach skills, is useless or maybe even detrimental, as iPADS that are treated as toys or reinforcers can lose their potency as communication tools, virtually "stealing" one of the few communication systems available for some of the most profoundly affected children.

This will cause a major crisis for the School System.

Recent media attention has focused on the impact of children with autism (who were receiving IBI) now attending school. There will be many children, possibly thousands (no one seems to know how many....), coming to school as of April 1 (or coming full-time who used to be part-time). There is a high level of panic among families and schools alike. There will inevitably be impacts on the kids with autism, the teachers and educational assistants, and the other kids in the schools.

Transitions are difficult for many kids with autism and an abrupt transition without proper planning in place is a recipe for disaster. Parents are very worried about this, not knowing whether their children will be properly resourced or even that the school will be able to keep their kids safe. A recent study showed that half of the children with autism are "flight risks". It is only a matter of time before a child with autism darts out of the classroom or the playground and something really bad happens! The timing couldn't have been worse for the school system, who have already had cuts to the Special Education budget and now have been given a sort of hiring freeze with more cutbacks anticipated. Schools apparently had no warning and it is pretty much impossible for them to plan and be able to give assurances to parents that resources will be available to meet the children's needs.

There will be a major impact on Employment in Behavioural Services.

It remains unclear what the impact will be on the public programs that have been doing IBI for the past 20 years. We still don't know for sure whether they will be able to offer services on a fee-for-service basis. If they can't, there will be major lay-offs. If they are allowed, they will have a major challenge shifting their whole business model with very little time to do so.

In the private programs, as well, there is a great deal of uncertainty. If families currently in intensive service have their funding cut completely on April 1 and cannot pay privately, they will have to withdraw from service at the private centre and send their child to school. So there may be little or no work for staff in these private centres, especially as there will necessarily be gaps before other families from the waiting list get their "proportion of a pittance" beginning at some unknown point over the next 18 months.

The system is certain to lose a lot of highly trained behaviour analysts and therapists, capacity that Ontario has built up over the past 20 years. There may, eventually, be more families with some funding but, since the funding won't be any where near enough to pay for the evidence-based intensive services needed by some children, service providers who do survive will be in the no-win situation of not being able to provide what children really need. To use the heart analogy above, it is like asking a heart

surgeon to prescribe everyone an aspirin when, in fact, she determines that heart surgery is indicated. In that scenario, not only do professionals face serious ethical dilemmas, but lives are at stake!

Implementation & Logistics.

There are very few details on the obviously very complex transition process from the old to new program. What is proposed sounds completely inadequate and unrealistic. It is set to begin April 1. They say they will establish a new agency to administer the program but provide no details on how that could be possibly be done for the whole province in such a short time. It seems unlikely that any family will receive any funding on April 1 since there is no information whatsoever on the new agency that is supposed to administer the program, which is beyond absurd! This will, not coincidentally, result in cost savings for the government, on the backs of these vulnerable children and families.

There will, inevitably, be extensive chaos for quite some time, for families and public programs and private providers. Parents and professionals are scared and confused and will likely remain so for some time.

The bottom line is that we need to get this plan stopped! The children of Ontario deserve better.

It's time for real, meaningful consultation with parents and professionals to ensure that children with autism in Ontario can access the high quality evidence-based behavioural treatment they deserve. We must replace Ford's plan with one that makes things better, not worse.

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