

# Ontario parents forced to wage pricy fights for access to autism care

By Hattie Klotz | Jun 2, 2014 4:59 am | 1 comment |



Anne Jovanovic takes her Autistic son Mica for wagon ride outside of their in Ottawa on Friday, May 9, 2014. iPolitics/ Matthew Usherwood

Ontario's quiet settlement of a human rights complaint over access to treatment for autistic children has left parents in the province with a difficult decision: either launch their own expensive cases or accept their children won't get potentially life-changing treatment.

David Hurd agreed to drop his Ontario Human Rights Tribunal complaint against the Children's Hospital of Eastern Ontario and the Ministry of Children and Youth Services for alleged discrimination against his autistic son last month.

Hurd had alleged that his son suffered discrimination due to a disability because, in 2011, he was booted from the Intensive Behavioural Intervention (IBI) program provided by CHEO, due to his secondary diagnosis of global development delay.

The case was being closely watched by other parents concerned that their own kids could not get access to the expensive treatment option. But with details of the settlement confidential and no tribunal ruling to set a precedence, the highly anticipated case failed to resolve the question of access, said Autism Ontario Executive Director Margaret Spoelstra.

“Legal action such as cases like this one bring attention to a topic that is otherwise difficult to get, but it may not have the impact that everyone hopes,” she said. “It highlights for us who gets services, when they get them, under what conditions, how and for how long, but it doesn't address the problems here. Right now, we are not fair about this in this province.”

IBI is individualized therapy, designed to help children towards the more severe end of the autism spectrum. It teaches language, social interaction, play, fine motor skills and self-help skills, taught through constant repetition and reinforcement to create pathways in the child's brain to support normal functioning.

Ontario's youth services ministry funds IBI for some children through the Autism Intervention Program's \$191.7-million annual budget. The program is administered by regional service providers across the province, CHEO in Eastern Ontario.

According to a recent report by Ontario's auditor general, there are between 30,000 and 35,000 children with autism in the province. About half of all kids with autism are not eligible for IBI services, says Spoelstra, "but there are a ton of these children who are exactly the ones who could benefit."

Governments point to budget restrictions for strict requirements on who gets funded access, but Spoelstra says IBI needs to be available to all autistic kids, based on individualized, on-going assessment.

When he came to a last-minute settlement after two days of private mediation in Ottawa in May, Hurd, CHEO and the MCYS avoided a public discussion of the funding and diagnostic process for access to treatment in Ontario. By doing so, they have avoided setting a precedent that might have forced the province's hand.

All the involved parties will say is that "the matter has been amicably resolved," and lawyers familiar with the details are bound by confidentiality agreements. Other parents of children with autism can only speculate about the settlement and weigh the expensive option of launching their own cases.

Already, advocates within the autism community in Ottawa say that there are at least four other cases now pending. With a potential cost of \$50,000 in a case with several expert witnesses, a protracted legal fight is not something everybody can afford .

The prospect of more parents turning to the courts worries Anne Jovanovic, mother to a severely autistic six-year-old boy.

“My fear is that settlements via the courts will become the trend for parents with the knowledge and resources to fight for their kids. Mr. Hurd did what was in the best interests of his own child. Of that, I have no doubt. But who is doing what is in the best interests of all of our kids?”

Others, like Meg Kirby Friedman, mother to a five-year-old autistic girl, put blame squarely at the ministry’s feet.

“If the ministry truly valued all Ontarians, it would commit to funding Intensive Behavioural Intervention for all children with autism. Instead, the ministry has set very narrow guidelines for eligibility,” she explained.

The ministry aggravates the problem by allowing regional providers to establish benchmarks that effectively require children to “nearly overcome or lose their diagnosis in a very short period” in order to keep their funding, she added. “So, while most children will make important progress through IBI, most parents would say vital, life-changing progress, almost all will fail to make ‘the grade.’ ”

This is where the buck stops for Lisa Prasuhn. Funding for her daughter’s IBI treatment is to be phased out in the period leading to December this year, ignoring her pleas to extend the time over her daughter’s transition to high school, a matter of weeks. The end to funding also comes despite recommendations from her psychologist, “who still believes that Carlyne can continue making progress,” she said.

Prashun says she might have little choice but to pursue the legal course.

“I anticipate looking at filing my own human rights claim, because it might be the only way to ensure that my daughter gets access to what she needs, to get the support for continued learning to reach her full potential. It’s that simple,” she said.

“I’d also like to change the system. It needs to stop. It hasn’t changed over the years, and there doesn’t seem to be a will to deal with this.”

Minister of Children and Youth Services Teresa Piruzza was not available for comment on this issue.

## Ontario autism care access in balance as human rights case opens

By Hattie Klotz | May 12, 2014 5:02 am | 7 comments |



Anne Jovanovic takes her Autistic son Mica for wagon ride outside of their in Ottawa on Friday, May 9, 2014. iPolitics/ Matthew Usherwood

The Ontario Human Rights Tribunal is considering the case of an eight-year old Ottawa boy with severe autism whose plight could drastically alter access to and quality of care for autistic Ontarians.

D.H. the “next friend” of the boy, M.B. (“next friend” is a legal term used to refer to someone who acts on behalf of another person, unable to act for themselves) alleges that M.B. suffered discrimination in his access to Intensive Be-

havioural Intervention because he also suffers from global developmental disability. IBI is individualized therapy, designed to help children towards the more severe end of the autism spectrum. It teaches language, social interaction, play, fine motor skills and self-help skills, taught through constant repetition and reinforcement to create pathways in the child's brain to support normal functioning.

While M.B. did receive 18 months of funding for IBI through the service provider, the Children's Hospital of Eastern Ontario, D.H. feels that the therapy was terminated, "as a result of his secondary diagnosis of GDD, which affected his ability to meet certain learning goals." This, his complaint asserts, amounts to discrimination due to a disability.

Access to services for Ontario children who fall on the autism spectrum, both health and educational, vary so widely across the province and in some cases fall so far behind that some families are moving to Alberta – the gold standard – simply to access that province's approach to funding therapies for autism spectrum disorders and other special needs services.

The whole system is a mess, says Anne Jovanovic, mother to a 6-year old boy on the severe end of the autism spectrum, who was essentially non-verbal. It pits parents against other parents, each fighting the case for their own child, each fighting for funding so that their child can have access to the best therapies for their needs.

The Autism Intervention Program is funded by the Ministry for Child and Youth Services, has an annual budget of \$191.7-million and is administered by CHEO in Eastern Ontario. According to a recent report by Ontario's auditor general, there were between 30,000 and 35,000 children with autism in the province in 2013.

“There’s an ethical dimension that’s not about politics here, too,” says Jo-  
vanovic, who lives in Ottawa, “which is that there’s a research agenda at play  
as well, whereby those who are administering the programs are constantly  
looking for kids that will give them better success.”

This means that children who don't meet developmental and learning targets are discharged from IBI, a program that was originally designed to help children with more severe problems. "The way they are going about their research is ethically wrong," says Jovanovic.

Anne and Mica. iPolitics/ Matthew Usherwood

Mica, Jovanovic's son, will have been in IBI for three years when his funding is re-assessed in June this year.

"But that's by sheer force of my will," says Jovanovic. "He'll have had at least six months more than most children because we've taught him to the benchmarks in order to meet the funding position."

Teaching to the benchmarks means that Mica's therapists have worked hard to see that he meets the benchmarks necessary for him to continue to receive funding for IBI, even if it has not been in his best therapeutic interests.

For 2012-2013 there were 210 children receiving IBI treatment at CHEO and there are currently 165 children on the waiting list, while a further 700 are receiving other, less intensive therapies.

In some regions of Ontario, children can receive funding for as long as four years, while in others, such as Eastern Ontario, the average amount of time funded for IBI therapy is 15 months, despite the fact that the auditor general's report found that children who received therapy for two years or more did markedly better than those who received less.

Dr. Lise Bisnaire, director of the autism program at CHEO, explains the statistics for the region by way of good tracking.

“We track our patients’ progress carefully and every child is assessed for who they are,” she says. “There’s a standardized way to do this and it’s done systematically so that we aim to serve the right child at the right time for the right amount of therapy.”

For Lisa Prasuhn, who lives north of Toronto, the right amount of therapy for her daughter, now 14, has been seven years.

“IBI therapy has changed her life. Upon entering the program aged 7, she was assessed to have language functioning below a six-month old level and her diagnosis was considered severe. Through the years, and with intervention, she has learned to communicate with technology, developing language skills that no one thought possible,” says Prasuhn.

Even so, Prasuhn feels that the system, which will discharge her daughter in December 2014, does not take into account the individual needs of each child. “There’s so much more she could learn and gain, including a smooth transition to Grade 9.”

Lisa Prasuhn and her daughter Carolyn, 14.

“She can sign with some fluency and she will graduate from Grade 7 with her classmates. She will probably never speak a single word in her life but her ability with technology is astounding. Nobody can put a price on the quality of life that has been afforded her through IBI therapy.”

The important point, says Prasuhn, is that her daughter would never have reached her potential if benchmarks had been in place at the outset of her programming. “The province is not justified to write these kids off and cycle them

through the system quickly because they don't reach the impossible benchmarks they have set out. Children with a diagnosed developmental disability are expected to make gains at the same rate as a normal child, and worse, they are being deemed ineligible for IBI.”

According to Prasuhn, this is, “a system that is failing children in so many ways.”