

# Ontario backs off controversial autism changes, boosts services after parents protest <sup>[1]</sup>

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## EXCERPTS

For the last three months, a group of Ontario parents vowed they would never stop fighting for their children's right to autism services. On Tuesday, their protests and headlines paid off as the province announced it is fixing some of the most contentious parts of the new autism program introduced in March.

Most significantly, the Liberal government backed away from the move that has caused the most havoc - a decision that children age 5 and older would no longer be eligible for intensive treatment and to start taking them off wait lists they'd been on for years.

Instead, all kids with an autism diagnosis can now count on the treatment when they need it, regardless of age, Children and Youth Services Minister Michael Coteau said at Queen's Park.

"The new program will provide all children, no matter how old they are with the level of intensity they require," he told reporters.

"Every single child will receive the services they need, period."

News of the age cap in March came under immediate fire from many parents, therapists, teachers and advocates who mounted an unrelenting campaign to overturn the move. It sparked a vocal grassroots backlash known as #AutismDoesntEndAt5 and fierce lobbying by the advocacy group Ontario Autism Coalition.

Coteau's revisions amount to "a massive victory" even though the minister doesn't call it a reversal, said Laura Kirby-McIntosh of Thornhill, coalition founder and mother of two teenagers on the autism spectrum.

"I think what we've seen today is somebody pressing restart," she said Tuesday. "This is how it should have come the first time."

Under the changes, about 2,200 children ages 5 and up being transitioned off wait lists for intensive behavioural intervention (IBI) and given a spot in the new autism program will come out ahead.

First, they won't have to wait as long for the new autism program. Previously scheduled for rollout in two years, it will now be bumped up to a June 2017 launch and will provide varying intensities of behavioural therapy for all children but tailored to each child's needs.

In addition, those children coming off wait lists will get significantly more funds during the transition period. They had been promised a one-time payment of \$8,000 to tide them over, which most parents said was barely enough to cover two months of private therapy.

But under the new plan, those families will get successive payments of \$10,000 to spend over 10 weeks until their child has a spot in the new program next June. That amount was designed to be enough to pay for intensive private treatment and could potentially amount to \$50,000 over the year for children currently off the wait lists.

Coteau said the package of revisions will be financed by new autism funding of \$200-million over the next four years, on top of the \$333 million announced when the program launched in March. The money is primarily aimed at reducing wait times that can be years long and creating more treatment spots.

While the changes were greeted as good news by parents, advocates and opposition politicians, many families were wary of hailing it as a triumph until they see the fine print and how the new program actually works for their children.

"I'm thrilled but I'm cautious, I want to see it roll out," said Marguerite Schabas of Toronto, whose four-year-old son, Peter, started IBI this week after almost two years on a wait list.

She noted a big part of the problem over the last three months has been "the utter chaos" and confusion as government autism providers started putting new rules in place, often inconsistently, according to parents.

At Queen's Park, Linda Galvao quietly wiped away tears as she listened to the news conference. She and her husband, David, have two

sons with autism and came from Georgetown to hear the news in person.

"It's emotional," said Galvao, whose son Toby, 8, is receiving IBI and is about to lose his spot because of the age cap. Luke, 6, has been on a wait list for almost three years. She was still trying to grasp the news that they can expect transition funding for private therapy.

"The amount of stress . . . I can't even be excited," said Galvao.

Coteau has been in his job for only two weeks since replacing Tracy MacCharles in a cabinet shuffle, and said the changes to his predecessor's plan were made because "supports that were put in place were not adequate."

The new program reflects "the collective voice" of parents, advocates and MPPs, added Coteau, who started meeting with parents soon after his appointment.

Opposition leaders were quick to congratulate parents for their unremitting pressure on the government, which included protests outside the legislature, ejections from public galleries in side the legislature, a massive social media campaign and aggressive lobbying of MPPs that even resulted in one Liberal calling the police on a mother who had planned to picket outside his constituency office.

Progressive Conservative Leader Patrick Brown tweeted that he is "pleased" that Coteau "listened to what we've been saying all along, that autism doesn't end at 5."

The changes are "a victory for families" and proof that speaking up and protesting can pay dividends, said NDP Leader Andrea Horwath.

"Parents and children across Ontario living with autism stood up to fight for the services they need," she said. "While this is an important win, there is more work to do so that Ontarians with autism can succeed throughout their lives."

Coteau also announced five regional hubs aimed at providing families quicker access to diagnosis, considered essential for starting intervention early and improving a child's long-term prospects.

The province will also beef up school supports for children with autism, including programs to help them transition into classrooms, and after-school sessions aimed at helping them build skills.

#### Tears of a different kind

A month ago, Melanie Palaypayon was in tears after her MPP called police on her. The Mississauga mother had planned a solo protest against the new autism program outside his office and he wasn't pleased. On Tuesday, her tears were happy ones after learning that Xavier, 6, is now eligible for funding for private autism treatment. "I'm so happy beyond words, not only for Xavier but all the kids," Palaypayon said in an interview from Maryland, where she watched a live webcast of the announcement while travelling. "I feel so strong that we got the government to do the right thing."

#### A sigh of relief

Sandra and Jerry Pimentel went to the bank recently, bracing themselves to borrow for the private autism therapy their son needs. In April they found out that after a two-year wait, Vincent, 5, was suddenly too old for treatment covered by Ontario. "I'm not going to lie, there have been a lot of tears over the last few months," says Sandra. Then on Tuesday came news the province had backtracked and kids like Vincent would get funds for therapy until they land a spot in the new autism program. "I'm feeling a lot better," said the relieved Brampton mother. "My son has a better chance at a future."

#### Seeking school supports

It wasn't front and centre of the autism changes but better school supports are key and should be the next focus, said Barkaat Ahmad of King City. His son, Amaar, 7, is social and plays well with other kids. But without proper support, he struggled in a regular classroom and moved to an autism class, where he regressed socially. The province's plan to invest in diagnosis "is crucial," and would have benefitted Amaar, who waited almost two years, says his father. "I do not want other parents to have to go through that."

#### Feeling aftershocks

It has been three months of anger, worry and no idea what kind of autism treatment Kristen Ellison could manage for her son Carter, 5. He started therapy in April but then became part of the cohort who aged out. Prolonged uncertainty is one reason Ellison, a single parent from Cobourg, isn't ready to jump for joy over the latest fixes to Ontario's autism plan. "It's a good day, but I'm apprehensive," she said. The confusion among parents and treatment providers has made it "like the wild west" trying to get services, she added. "I wanted an apology."

#### Mom has questions

Spring has been a roller coaster for Janet Asher's family. After a two-year wait, Benjamin got an autism treatment spot in April. Two weeks later, he turned 5 and hit the age cut-off. Now he can count on one year's funding and a spot in the new streamlined service. "In the long run, I think it's a win for Benjamin and everyone in Ontario," says Asher. But still, she has many questions, such as who decides on the level of treatment each child needs under the new program and will they really get it.

#### 'Thrilled but cautious'

Marguerite Schabas wishes the province had nailed the autism program the first time and saved families months of anxiety. The Toronto mother is "thrilled but cautious" about how it will unfold and glad the transition time has been cut in half. "I hope that long-term this is going to get kids the help they need when they need it," said Schabas, whose son, Peter, 4, got an intensive treatment spot this week. The changes are aimed at giving kids under 5 shorter wait times than the two years he faced. Schabas, an active advocate, said the whole thing "has been

draining and emotionally exhausting."

-reprinted from The Toronto Star

**Region:** Ontario <sup>[3]</sup>

**Tags:** funding <sup>[4]</sup>

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