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Province bumps older autistic children from therapy wait list

by Michael Gregory

Burlington Post Staff

The families of two Halton four year olds are devastated after learning their children are among 2,200 in Ontario no longer eligible for publicly-funded intensive autism therapy.

"I think it's disgusting and I think it's a disgrace," said Burlington single mother Crystal Campbell, whose son Casey was diagnosed with autism at age 18 months.

"It's one thing for the government to make this change but it should owe something to the children."

Ontario Autism Program changed

The province announced \$333 million in funding last week that will help revamp the Ontario Autism Program and set a wait list target of six months or less by 2021 for Intensive Behavioural Intervention (IBI) and Applied Behavioural Analysis (ABA).

As part of the changes, families of children on the more comprehensive IBI wait list — who are turning five between May 1, 2016 and March 31, 2018 — will be given one-time funding of \$8,000 and be dropped from that therapy's wait list.

"Why should my son, and everyone else's child, be discriminated against now because they've decided to change their standards?" Campbell asked.

According to the Ministry of Children and Youth Services, clinical evidence has shown that children with Autism Spectrum Disorder (ASD) benefit the most from intensive services such as IBI at an earlier age.

"This means that children who are five and older, who are currently waiting for more intensive therapy, are not in the right development window for this service," said ministry spokesperson Peter Spadoni.



Crystal Campbell, a single mom trying to raise her autistic son Casey in Burlington, believes the Ontario government's recent decision to remove children five and older from a waiting list for IBI therapy is 'disgusting' and 'a disgrace.' She says a one-time lump sum payment of \$8,000 isn't enough. | photo by Nikki Wesley - Burlington Post (Follow on Twitter @halton_photog)

In Halton Region, ErinoakKids Centre for Treatment and Development administers the wait lists for IBI and ABA.

To make matters worse, both Campbell and Oakville mother Athena Yu had recently received

uation is tougher than others," said Yu, who is also a single mother and currently pays a behavioural therapist \$40 an hour to work with her daughter Sofia, who will turn five in August.

"I feel like the government promised us so much. This is not fair. I'm going to fight for this for my child," she said.

“

I feel like a bad parent because I can't afford to put him (in IBI) the way I should be able to

”

Crystal Campbell
Casey's mother

Yu's parents helped her pay \$50,000 for her daughter to receive private ABA therapy instead of holding out on the wait list for public care.

Sofia, who had previously been non-verbal, benefitted immensely from consistent therapy and can now pick out which dress she'd like to wear to school at St. James in Oakville.

"It's a huge, huge difference — she can do every class, she can read. It is this amazing journey," Yu said. "This is the whole point I'm trying to tell the government is consistency."

Similarly, Campbell's son Casey has only come up for ABA therapy once, last summer, and had

see Older on p. 9

letters from the organization saying their children would be eligible for IBI in the coming months after both families waited more than two years.

"I'm speechless. I cannot even think about what I'm going to do with my kids because our family sit-

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Oakville's Athena Yu intends to fight the province in order to get IBI therapy for her autistic daughter Sofia, above, who turns five this summer. A new provincial program has decided that children ages 2-4 should be given priority on a provincial list for the one form of intensive therapy. | Photo Special to Burlington Post

Older autistic children taken off IBI wait list

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been on the wait list since he was diagnosed.

"With the ABA I can now get him to put his shoes on all the time by himself, but in general his autism is getting worse and so are his behaviours," Campbell said.

Queen's Park representatives in Burlington and Oakville say they have received around a half dozen calls and emails about the new autism program.

Burlington MPP Eleanor McMahon said the government's investment will mean families will be eligible for ABA services that are "more intensive, available for a longer period of time and tailored to children's individual needs."

IBI therapy is generally up to two years, depending on the individual, and costs upwards of \$50,000 privately, according to Campbell.

see He's on p. 10



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'He's a very active kid that never stops': mom of autistic son

continued from p. 9

Casey attended, and benefited from, a March Break program at Canoe Therapy in Burlington, but the \$8,000 cheque from the province will only pay for a few hours a week over the short term.

"I feel like a bad parent because I can't afford to put him (in IBI) the way I should be

able to," said Campbell, who quit her job as a nurse at Oakville-Trafalgar Memorial Hospital to care for her son.

"We were told we wouldn't need to worry about that when he was diagnosed, that we just had to wait until he came up on the wait list."

While also reducing wait times, the gov-

ernment plans to create space for 16,000 additional children to receive critical intervention and individualized intensive supports.

McMahon said because clinical evidence has shown intensive intervention is most effective for children between 2-4 years old, the \$8,000 in funding helps families right now.

"Instead of continuing to wait, these children will have immediate access to services," McMahon said.

Families will work hand in hand with their local service providers to determine the best treatment path for this funding that is responsive to the child's personal needs."

Casey for his part has plenty of energy, and according to Campbell can sometimes act out: hitting, screaming or even darting out into the street.

The city has even placed signs near the family's house letting motorists know that a child with autism lives in the neighbourhood

and to drive with care.

"That's why this IBI was going to be so good for him, because they were going to work with him for 21 hours a week (on his behaviour)," Campbell said. "The benefits would be him listening, doing, what he's being asked to do, not being so violent...his social communication skills are (also) lacking."

Casey currently attends junior kindergarten at Frontenac elementary school in Burlington. Some of his favourite things include superheroes, art, the outdoors and jumping on a trampoline in his backyard.

He also has a black lab therapy dog, Neville, who will accompany him to school next year.

"He's a very active kid that never stops," Campbell said. "He has all of these needs and I don't even have words to say how I feel that he's going to be discriminated against and removed off that wait list."



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