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'THEY'RE GOING TO BANKRUPT FAMILIES'

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MUSKOKA - Jennifer Grubwinkler is concerned about her son's future.

"How can our children fully participate in society, if they don't get the services they need?" asked the Utterson resident.

Her son, Josef, 7, after a parade of medical tests and professional observations early in life was diagnosed with a rare genetic disorder called Sotos syndrome - which affected physical, mental and emotional development - while also being diagnosed with attention deficit hyperactivity disorder and autism spectrum disorder.

And now Jennifer is concerned about the provincial government's intention to end financial transfers to publicly funded autism service providers. Instead, the government will offer cash on a sliding scale to families, who would then directly pay providers for services, as of April 1.

"The government is making a big mistake, but they seem to have dug in their heels," she said. "They are going to bankrupt families."

The amended Ontario Autism Program would offer eligible families up to \$20,000 a year for children under six, with a lifetime maximum of \$140,000. Older children could access up to \$5,000 a year to age 18 with a lifetime maximum of \$55,000.

See FUNDING, page 27



Alison Brownlee/Metroland

Utterson resident Jennifer Grubwinkler says her son, Josef, deserves the best opportunity to meet his potential as an individual and community member.

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FUNDING OVERHAUL FOR AUTISM WILL HAVE PROFOUND EFFECT

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But only families with an income of less than \$55,000 would qualify for the full amounts.

Jennifer said she and her husband expected their family would need to spend roughly \$23,000 a year on behaviour therapy, but estimated they would be eligible for only \$2,000 to \$3,000, annually.

She described her son as a sweet, affectionate, playful and funny child, who loved to snuggle and watch movies. Her face broke into a smile as she remembered cradling her son in her arms, at his request, on Valentine's Day or listening to him joyfully mimic the sound of trains and his beloved Transformers.

"I could see him going into voice acting or something," she mused.

And then a pause.

"A lot of people don't get to see that sweet side of his," she added. "And when it's bad, it's bad."

Josef's medical conditions lead to struggles, like an inability to effectively communicate with others or adapt well to changes in routine. The changes in routine cause him frustration, which triggers restlessness, outbursts or tantrums that sometimes dramatically escalate.

She noted that, in addition to collaborative support from faculty and staff at Watt Public School, her son had also benefited from occupational and speech therapy offered until age five by One Kids Place in Huntsville.

And then, at age six, Josef was put on wait lists for applied behavioural analysis and intensive behavioural interventions therapy offered by Hands TheFamilyHelpNetwork.ca in Bracebridge.

Jennifer said therapy and services have helped Josef make gains, but more time was needed if he was to have the most possible independence and integrate effectively into the community as he reached adulthood.

She added that, rather than a program that arbitrarily determined benefit based on age and household income, she wanted a pro-

THE ISSUE:
ONTARIO AUTISM PROGRAM

LOCAL IMPACT:
PARENTS, PROVIDERS UNEASY ABOUT RURAL SERVICE ACCESS IN NEW MARKET-DRIVEN MODEL

gram that assessed each child individually and provided behavioural service hours based on severity of need.

Premier Doug Ford, on a whirlwind tour of Muskoka on March 1, told this newspaper that autism program funding shortfalls had ballooned wait lists, which forced an overhaul of the autism program.

"Talking to these families, and the challenges that they're facing, it's the most difficult file I've ever handled in politics," said Ford. "They were told to wait in a line, ba-

sically."

The program, he said, had run out of funds by the time his government came to power.

"As soon as we got there, we found out the system was bankrupt," he said. "We had to add emergency funds from the treasury. An additional \$100 million."

The proposed program changes, he said, would eliminate the wait list by offering funds to families so they could immediately access services.

"We've increased the funding as well from \$256 million up to \$321 million. We're pouring the money back in, doubling the therapists and allowing people to have choice," he said.

But will it work in rural communities?

Hands TheFamilyHelpNetwork.ca and One Kids Place Children's Treatment Centre provide autism services, in partnership, for children and youth in north-east Ontario, which includes

about 300 children and youth in Muskoka.

Neither had been able to offer behavioural services to wait listed families since September, as the province directed providers to wait while it reviewed the autism program and its financial situation. And both have now either reduced staff or planned to forgo renewals of some contract staff as a result of the province's new direction for autism services.

Jeffrey Hawkins, executive director for Hands, said families here seemed to prefer publicly funded agencies for autism services.

"There has been the option, historically, to take money and buy services privately, under a fair amount of regulation and based on severity of diagnosis, or to use a public provider," said Hawkins. "All the families in Muskoka have chosen to use a public provider."

Reasons for that, he said, could include the economic realities of rural and remote

communities.

"There's not a lot of choice out there for private providers," he said. "You move into rural and remote communities, it's going to be a struggle to have private providers who can make a business model work."

Hawkins noted the agency was now working on its own business model to continue to offer behavioural services to families within the new program, and it wanted to shape that plan based on feedback from families.

So, too, was One Kids Place. Denis Filiatrault, executive director for One Kids Place, said behavioural services would still have to be provided by qualified professionals under the new model.

But he, too, noted concerns about creating cost-effective and affordable op-

tions for behavioural services, especially in rural or remote communities where issues such as travel expenses added to service costs.

"We're really going to continue to work with the ministry in terms of trying to provide a solution for those rural-remote areas," he said.

Families interested in discussing autism service needs in Muskoka could contact Hands TheFamilyHelpNetwork.ca at 1-800-668-8555 ext. 1333 or One Kids Place at 1-866-232-5559.

(With files from Roland Cilliers)

STORY BEHIND THE STORY

A family reached out to our newspaper amid concerns in the community about the province's plans to change the funding model for the Ontario Autism Program as of April 1. We wanted to know what the changes could mean for families and providers in Muskoka.



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