

Parents launch provincial fight for autistic kids

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A group of York Region parents would like you to imagine this:

You've just been diagnosed with cancer. To get chemotherapy you'll have to go on a waiting list — behind 1,400 others. To move up the list, someone ahead of you has to die or get better - three years or longer. The more you wait, the less likely your chemo will work, and there's a good chance you'll only get a portion before the government pulls it away.

Would you put up with it?

Sharon Aschaiek is guessing no. And yet, she says that's what children with autism do in Ontario because the government does not provide enough funding for the therapy that will help them.

Like a cancer diagnosis, discovering your child has autism is devastating enough. But in Ontario, parents face an agonizing choice: wait for years for the therapy that can help their child communicate with the world — possibly missing the window of opportunity because that therapy works best in the early years — or re-mortgage the house, go into debt, even face bankruptcy to pay out of pocket and save their child's future.

Ms Aschaiek, whose three-year-old son Jaiden has autism, says the government has abandoned autistic children and the Thornhill resident has organized an advocacy group to fight back.

DENIED VITAL HELP

Autism Resolution Ontario is a network of families with autistic children who believe their children are being denied vital Applied Behavior Analysis (ABA) therapy that would allow them to be functioning members of society.

ABA is a proven therapy of rewards and repetition. To be effective, young children require 20 to 40 hours per week of one-on-one instruction (called Intensive Behavioral Intervention, or IBI) costing \$40,000 to \$80,000 per year.

But while there's a provincially funded program in place to provide this therapy, Ms Aschaiek says families face significant obstacles, such as waiting for years to receive IBI, having it prematurely cut off, not qualifying despite an autism diagnosis and not being able to access it at school.

"Our children face discrimina-



STAFF PHOTO/STEVE SOMERVILLE

Jerry Meirovich works with therapist Kathryn Kiely outside his Richmond Hill school. He normally travels to her home office, as he can't receive the help he needs in his school.

tion at every turn," she says.

Ms Aschaiek says she was forced to move back in with her parents to pay for her son's IBI.

As of December, the Ministry of Children and Youth Services says there were more than 1,400 children in Ontario waiting for subsidized autism treatment and almost 400 waiting to be assessed.

Queen's Park insists it's not ignoring the issue.

Ten years ago, there was no funding for autism, says ministry spokesperson Anne Smith. McGuinty's government removed the age six cut-off, more than tripled autism spending from \$44 million to \$158 million and more than doubled the number of kids getting IBI.

But parents say it's not enough. They point to the growing number of kids being diagnosed and are threatening civil disobedience if there's no action by World Autism Awareness Day on April 2, 2010.

This fall, the group is launching "ARO Caravan", travelling around the GTA to spread the word.

Leah Kalvari can't wait.

"The years are just flying past. My child's early years are gone," says Mrs. Kalvari, who worries that her six-year-old son will never reach his full potential.

She has seen glimpses of that

potential on the rare occasions Mendy receives IBI. On those days, he seems to break free from the shell that encloses him. He is calmer and starts to reach out to others.

Like the other day at bathtime.

"Water is cold," he said — and his parents rejoiced.

That is what three hours of IBI on a Saturday can do, says Ms Kalvari. But, unfortunately, it's not sustainable. The Kalvaris can only occasionally afford to pay for private therapy and Mendy's frustration with not being able to communicate grows. A simple need for a drink can spiral into a biting, screaming, pushing fit.

At age two Mendy began obsessively lining up blocks, closing doors and throwing tantrums.

"He'd freak out, be scared, crying, uncontrollable."

She was forced to quit her day job as a social worker because no one could handle him; her husband took shorter work hours to bring relief at the end of the day.

Now, with money a constant struggle, they purchase IBI when they can. But he needs more; it's time to get him out of the house and interacting with others.

They've almost maxed out their \$27,000 line of credit. If her parents can manage to secure a \$50,000 line, maybe they can enroll him in

a daily half-day program. If not, "then he gets nothing. Two and a half hours in a public school" she says is akin to babysitting.

"It's like having a child who is sick and taking away the medicine that makes him better."

SOME FAMILIES MOVE

She admits her family could move from Thornhill.

"If I lived in Toronto, my son would be getting treatment now."

People are doing that, moving to where the waiting list is shorter.

She could move to her parent's home in Calgary. "He'd be getting as many hours as he needs."

But her husband can't work there and she's reluctant to uproot her other children from the Jewish community they've grown to love.

The Kalvaris are 66th on the waiting list for government funding and don't hold out much hope. Friends with a same-aged boy were called to say their name was finally coming up; funding would start soon. Those friends haven't heard back. That was in April 2008.

And yet, these friends are more fortunate than most, Ms Kalvari says. They've been able to remortgage the house to spend \$80,000 a year on IBI. So while Mendy languishes without therapy, she's watched her friend's son progress

HELP IN SCHOOLS

In York Region, two classrooms provide ABA-based teaching to help children transition from IBI into the regular school system. Located at Carrville Mills P.S. in Vaughan and James Robinson P.S. in Markham, the classes provide individualized programming for 13 students aged 7 to 10.

It's not "classic IBI" says Frances Donovan, program director for autism services with the central east autism program at Kinark. "But generally children don't need IBI beyond a certain point."

Ms Donovan agrees there's a "huge demand" for IBI services in a booming area, which includes Durham, Simcoe, York Region and four adjoining counties.

"We'd like to service as much as we can as quickly as we can," she said, "and we're doing the best we can with the resources we have."

For more information, contact Kinark Child and Family Services, 1-888-454-6275 or www.kinark.on.ca, or www.autismresolutionontario.com

to where he can be integrated into a regular school — although that family has hired a lawyer to fight for IBI in the school.

"Imagine hiring a lawyer just to get your child the only therapy that helps him learn."

Neil Meirovich can imagine. He's been fighting for years for his son Jerry, 8. Jerry's IBI therapist is not allowed in his Richmond Hill school, while others — speech therapists, for example — are.

According to Ministry of Education spokesperson Patricia MacNeil, all school boards are required to provide ABA instruction for students on the autism spectrum. However, the more intensive form, IBI, is not suitable for schools because "they just don't have the one-on-one space."

But the parents say the classroom-based ABA approach doesn't work because autistic children lose focus in a group. The key is to customize the therapy.

Thornhill MPP Peter Shurman and Newmarket-Aurora MPP Frank Klees agree the system does not work. Mr. Klees has made the issue part of his leadership platform for the PC Party of Ontario.

Ms Aschaiek warns: "Children with autism who receive insufficient IBI go on to cost taxpayers millions of dollars more."

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