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Olympic track and field medalist, coach, commentator for hockey
right in Canada and mom to one daughter, 2 VJs

MY CHILD HAS



October is Autism Awareness month in Canada. Find out what's happening in your community at

AutismSocietyCanada.ca.

AUTISM. Now what?



As autism rates increase, the medical and parenting communities continue to put together the pieces of this puzzling condition.

By Julie M. Green

"Check out what Deckard made!" Farida Peters holds out her smartphone to show me her three-year-old's latest drawing. It's no more than a stick figure, yet she's agog at her son's achievement. She has reason to be proud. A few short months ago such a feat scarcely seemed possible.

At age one, Deckard needed an operation to remove fluid from his ears. To help him communicate, the Peters took their son for speech therapy. What they ultimately received was a referral to a specialist and an unexpected diagnosis: autism.

"I wasn't surprised, but I was very upset," recalls the Toronto mom. "The developmental pediatrician initially made me feel that I wasn't doing the right things to teach my son. I cried all the time. It was hard for me to be around people. I thought they wouldn't understand if he freaked out. They'd think he was a brat. It was really isolating for me."

Farida's experience echoes that of many – one in 94, in fact. That's the number of Canadian children, predominantly boys, currently estimated to have autism, a neurological disorder that affects communication, behaviour and social interaction. And that figure is steadily rising.

As the government pours money into research, families like the Peters struggle to help their son face everyday challenges. Deckard's play is rigid and repetitive, his speech limited, his meltdowns intense.

Autism is a scarcely understood disability with no singular known cause. Everyone, it seems, has a theory, none of which is conclusive. Over a decade ago, British medical researcher Andrew Wakefield infamously posited a correlation between the measles-mumps-rubella (MMR)

vaccine and autism. (Even though any MMR-autism link has since been thoroughly disproven, immunization rates continue to plummet worldwide, leading to a recent resurgence in measles.)

Other theories behind the cause of autism point to genetic variables, environmental toxins, and physiological influences – including gastrointestinal, hormone, and immune differences.

Yet some believe the rise in autism is merely perceived, a result of heightened awareness and a broadening of the inclusionary criteria over time. What previously might have been diagnosed as a developmental or learning delay is now referred to as autism.

And the path to diagnosis is rarely clear-cut, as Lyanne Lavigne of Gatineau, Que., knows too well. When her son Zachary failed to hit developmental milestones within the widely accepted timeframe, she suspected something was wrong. He only started walking at 20 months, and his speech was delayed. He didn't engage with other children and became obsessed with things like vehicles and music. Zac was diagnosed with severe ADD and developmental delays, but his mom suspected the diagnosis was wrong. She insisted he see a specialist. Her gut instinct was right.

Whatever its cause – or causes – autism is the epidemic of our children's generation, creating a ripple effect that spreads from families to schools and to the workplace beyond. As a society, we can't afford *not* to do something about it.

Does your little one have special needs?
Find out 10 common misconceptions about learning disabilities at ParentsCanada.com/10-misconceptions

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EARLY ACTION

While there is no ‘cure’ for autism, if treatment begins early (ideally under the age of four), many children can make great gains. It’s therefore vital that parents and professionals pick up on early signs of the disorder. With autism, the wait-and-see approach can actually do more harm than good.

“Early intervention is absolutely critical,” insists Nancy Freeman, a psychologist and Clinical Director of the Toronto Partnership for Autism Services (TPAS). “There is such a huge body of literature that clearly supports the efficacy and effectiveness of behavioural therapies. We are finding that 40 to 50 percent of very young children can really take off.”

Funded by the Ministry of Children and Youth Services, Surrey Place Centre is a Toronto-based agency that offers specialized clinical services for children with developmental disabilities and/or autism spectrum disorders, including Intensive Behavioural Intervention (IBI) and Applied Behaviour Analysis (ABA). Finding the right intervention for each child at the right time is pivotal. Unfortunately, there is no one-size-fits-all approach.

For Deckard, weekly speech therapy proved invaluable. “When we started going, it was hard,” admits Farida. “He would be screaming and wouldn’t sit still. I hated it at first. But then I saw how much he was improving... He started making eye contact and saying more words.”

Parenting kids on the autism spectrum is no easy road. After Deckard was subjected to various medical tests, the Peters were sent home with a heaving file of resources and forms, and ostensibly told ‘good luck.’ The diagnosis came as an emotional blow to his mother, who spent a month mourning and trying to process what it would mean for her family, before she sprang

into action. She purchased various folders in which she logged every phone call, appointment and follow-up. Being her son’s advocate and project manager quickly became a full-time job, forcing her to abandon her cake design business.

“There are a lot of services,” says Nancy. “Trying to navigate the system successfully is exhausting because it turns out you have a kid with autism, and that takes up much of your time and energy.” Her advice to parents is to contact the agency that meets the bulk of the child’s needs as the first port of call. Speak to a central intake worker to coordinate services. Fill in the forms and get on waitlists immediately. Depending on the area, the wait times for some programs can span two years – time that these children simply do not have to waste.

While awaiting funded services, many parents wind up paying for treatment out of pocket. Few therapies are covered by private medical health plans, though disability tax credits do offset some of the costs, which can be exorbitant. Speech-language pathology and occupational therapy average \$120 per hour, while full-time IBI can cost upwards of \$50,000 per year.

By the time Zac was diagnosed with autism at four-and-a-half, he was too old for an ABA-

not know a single other parent of a child with autism. In addition to feelings of isolation and hopelessness, she went through a phase of intense introspection. “Did I eat well enough during pregnancy? Did the oxytocin/epidural I had during the labour process damage his brain?” She questioned whether she had done enough to help him. “Though I knew these thoughts were irrational, I couldn’t help but feel guilty.”

Though well-meaning and sympathetic, friends and relatives simply do not understand what it’s like to parent a child on the spectrum. That’s where parent education groups come into play. Often with shorter waiting times, the groups bring together families experiencing similar issues. As they learn strategies to support their children, parents usually end up supporting each other. They form networks, swap tips, and trade valuable insider information.

“The groups are great for forging relationships and helping people cope,” says Suzanne Robertson, supervisor of Toronto Autism ABA Services. “It’s interesting how quickly an intimacy forms. We facilitate that because we want people to come and feel safe to share [their experiences].”

Now 11, Zachary is a charming boy with a

Hope or HYPE?

A groundbreaking and controversial study from New York University’s Langone Medical Centre recently revealed that oxytocin, administered as a nasal spray, may prove helpful to people with autism who have lower than normal levels of the naturally occurring neurohormone. Known as the “love hormone,” oxytocin is said to boost trust and cooperation among social circles, and minimize background noise.

Is oxytocin a treatment for autism? It’s tempting to think so, but researchers insist the hormone may not prove effective over the long term. Different and opposing interpretations of this study continue to surface in the mainstream media.

based daycare program. His parents paid for private speech and occupational therapy to the tune of \$600 to \$800 a month, only half of which was subsidized. His mother still questions whether such therapies, though beneficial, were worth getting in debt for.

Some families go to extremes – re-mortgaging their homes to pay for therapy while their children are still young and their brains are still malleable and responsive. For many others, private therapy simply isn’t an option.

PARENTAL STRESS

Aside from the financial burden, the strain of having a child on the spectrum can be considerable. At the time of Zac’s diagnosis, his mom did

great passion for music. This summer he attended a special summer camp run by Trait d’Union Outaouais Inc. (TUO), a not-for-profit organization that provides respite to parents and specialized services to integrate autistic children into society. His mother, who serves on the TUO board, has a newfound sense of perspective. “Today, I don’t feel as guilty or powerless. I’ve learned to live with autism and accept it as my new normal. I’ve also learned – and am still learning – to accept Zac’s limitations while focusing on his strengths.”

Farida Peters is also starting to see a silver lining. Deckard is a sweet little boy who enjoys painting. Approved for TPAS’s IBI program, he is finally nearing the top of the wait list. His mom takes each day as it comes, never knowing whether it will bring sunshine or thunder. “I ended up being burnt out and angry at the process. But everything we’ve done for him has paid off. He’s not magically someone else; it was a lot of work.” ○

Julie M. Green is a Toronto-based writer and frequent contributor to ParentsCanada. She has one son, a wonderful five-year-old who happens to have autism.



KEEPING WATCH

Children with autism occasionally wander astray, sometimes being lost overnight. A GPS such as iLoc Technologies’ TRILOC Personal Locator can be worn like a watch and gives parents a bit of added security. iloctech.com