in this article

Autism Now

For the families who live with autism, life can never be the same
John Hoffman

Michelle and Craig McNair, of Barrie, Ont., are letting me spend part of a day with them so I can get a glimpse of what life is like for parents of autistic children. The McNairs have two. Kieran was diagnosed in March, not long after his second birthday.

Michelle says opening doors — Jonah particularly likes pushing the buttons on automatic doors — is one way he helps himself to feel a bit in control, or at least more OK, in the many situations he finds overwhelming. “If someone else opens a door, Jonah has a meltdown.”

Once inside, Jonah and Kieran start tearing around the perimeter of the playroom, another of Jonah’s rituals, while Michelle hurries to put his things away so she can get back to keep an eye on her boys. They are the only two running around like this. With Kieran, you mightn’t think much of it. He’s only two and he seems to be revelling in the silliness of copying his big brother. In fact, at first glance Kieran seems quite typical. He talks fairly well. He looks at me when I speak to him. He does little that seems out of the ordinary — until I see him with other kids at his gym and swim program.

“OK. Everybody pick one of the coloured dots, put it on the black line,” the instructor says. “Then get a ball and go stand on your dot.” The preschoolers scramble to pick their dots, eagerly anticipating the next instruction, which they seem to know will be something fun.

Except Kieran. He’s not having any of it. He was fine during the free-play period as the kids tore around the gym kicking balls into little soccer nets or shooting them into baskets. But as soon as the instructor introduced some structure, Kieran was suddenly out of sorts.

After unsuccessful attempts to get her boy to select a dot, Michelle picks one and tries to get Kieran to stand on it. You’d think it was a patch of dog poop. He whines to be picked up. Michelle tries to draw Kieran into the game. He stamps his feet and crumples to the ground.

Michelle attends to Kieran with the deliberate carefulness of someone who knows she’s being watched. She admits she wonders what the other parents are thinking. “I get the feeling that they think the problem is bad parenting.” Sometimes, Michelle wears her Autism Ontario T-shirt in hopes people will be more understanding. That might help. These days most parents know at least something about autism. It’s the most commonly diagnosed developmental or psychological disorder of childhood. But for something so common, the amount of uncertainty surrounding autism is striking, even when it comes to the definition.

What is autism?

“The simplest way to put it is that autism is a neurologically based developmental disability in which children process information, particularly sensory information, differently from other people,” says Susan Bryson, a clinical-developmental psychologist at the IWK Health Centre in Halifax. “This leads to difficulties with communication and social interaction, repetitive behaviours, restricted interests and unusual responses to sensory stimuli. But within that definition there is tremendous variability in specifics and severity of symptoms and levels of impairment in individual children.” Symptoms can include unusual eye contact, speech delay, unusual play patterns (lining toys up or focusing on certain parts of a toy rather than playing with it), difficulty with transitions and extreme sensitivity to sound, touch and other sensory stimulation, such as textures in clothing or foods.

Autism spectrum disorders (ASDs) are broken down into subtypes, the main ones being autistic disorder (classic autism), Asperger’s syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS — autism with fewer or less severe symptoms).

No one can say exactly how many kids have autism. Today’s most-cited figure for all ASDs combined (including autistic disorder, Asperger’s syndrome and PDD-NOS) is one in 165. These disorders are diagnosed in boys four times more often than in girls. This puts the prevalence in males as high as one in 100.

Few Canadian statistics are available. One study in BC shows that the prevalence of autistic disorder alone (not including Asperger’s syndrome and PDD-NOS) among children between four and nine years of age has gone from one in 813 in 1996 to one in 232 in 2004.

This large increase is in part due to the number of kids previously diagnosed with another disorder, who were later diagnosed with an ASD, or borderline kids who would not have been diagnosed with autism back in 1996.

What we know about causes

More uncertainty. The exact cause of autism remains unknown, although two things seem likely: that there is no one single cause and that genetics (though not one single gene) plays a major role. Beyond that, there are lots of theories. Gastrointestinal abnormalities, environmental toxins, brain abnormalities, prenatal factors and postnatal neurological injuries have all been proposed, with varying degrees of credibility, as causing or contributing to the development or severity of autism. Concerns have been raised about vaccines, but studies have shown that unvaccinated children have similar rates of ASDs as vaccinated children.

The predominant, though not universal, view among autism experts is that genetics is the most important factor, and that symptoms or behaviours develop because children with autism have difficulty processing sensory information. Behaviours such as Jonah’s door opening, repetitive hand flapping or limited interests may be the child’s attempts to cope with stimuli and calm situations he finds overwhelming and confusing.

One intriguing research question right now centres on how the neurobiological deficits that children with autism are born with might influence the interactive experiences they seek out or are receptive to, which, in turn, could fundamentally alter their emotional, social and cognitive development.

For example, the biological vulnerability could affect a child's ability to engage in typical early childhood learning. "The most important way babies learn is by interacting with people," says Bryson. "But that kind of learning requires the parent and baby to be in sync in terms of how they process information and relate to each other." Because certain babies process sensory, social and emotional information differently, it's hard for them to be in sync with their parents and participate in the typical back-and-forth interaction that drives normal development. Another difference is that these vulnerable babies and toddlers orient more toward objects than people, says Lonnie Zwaigenbaum, co-director of the Autism Research Centre at the Glenrose Rehabilitation Hospital in Edmonton. As a result, he says, "they won't be actively creating opportunities to experience social interaction the way typical children do."

How treatments can help

There are many treatments for autism, but one clearly dominates the public consciousness. That's the class of treatment generally referred to as ABA or IBI.

The terms are used interchangeably by parents, though they don't mean exactly the same thing. ABA stands for applied behaviour analysis, a systematic approach to designing ways to teach children and change their behaviour using principles of learning derived from behavioural psychology. IBI, or intensive behavioural intervention, is the application of those teaching strategies with a time-intensive treatment program. In autism treatment, this usually means one-on-one sessions (at least 25 hours a week) where a therapist teaches skills (matching colours and shapes, times tables, etc.) and behaviours (sitting still, paying attention) in small incremental steps using lots of prompting, repetition and rewards.

ABA/IBI has often been billed as the only evidence-based therapy for autism, apart from speech and language intervention, says Zwaigenbaum. Certainly it is the most highly researched and it's the one that provincial governments tend to fund (see The Cruel Politics of Autism Treatment). However, as time goes on, more people are saying that ABA/IBI does not work for all kids, nor can it address all the problems and deficits of autism. Still, ABA is an important basis for many autism therapies. "We're seeing a paradigm shift in Nova Scotia," says Bryson. "We are using the principles of ABA to teach in more natural settings. Instead of sitting a child at a table and teaching colours with flash cards, we might teach colours in a play setting using toys of different colours."

Other key autism treatments include speech therapy to address problems in verbal communication; occupational therapy to cope with sensory issues and teach daily living skills; physical therapy to improve motor and mobility skills; social skills therapy, which can improve children's ability to relate socially; and play therapy to help children engage in more typical types of play that are important to early childhood learning and development.

One very interesting and relatively new approach to autism therapy is DIR (developmental, individual differences, relationship-based), developed by US child psychiatrist Stanley Greenspan and clinical psychologist Serena Wieder. DIR is often referred to as Floortime because much of it is about parents getting down on the floor and playing with children. Unlike ABA/IBI, in which instruction is adapted to the way the autistic mind works, DIR seeks to actually *change* the way a child's mind works, so he can learn and develop more like a typical child. Floortime has been used as an autism treatment for more than 10 years, but is not widely available and is still being tested. Jonah McNair and his parents are subjects in a study at York University's Milton and Ethel Harris Research Institute in Toronto that Greenspan and Wieder hope will help build for Floortime some of the research-based credibility now enjoyed by ABA/IBI.

“Wheerrrrre’s Jonah?” the therapist calls out with an exaggerated amount of feeling and facial expression, much the way people talk to babies. But Jonah is four. He’s hiding in a play tunnel while his mom and the therapist act out a charade of not being able to find him. “Is he under the pillows?” Jonah waits under his pillows with excited anticipation. When the adults find him, there are more exaggerated exclamations.

These affected responses are part of a strategy to teach parents how to engage with children who don’t respond in typical ways. The goal is to get and keep the child’s attention so he can participate in and learn to initiate the socially based interactions which form the foundation for much of early childhood learning. Parents and kids come for weekly videotaped therapy sessions where they learn play-based interaction techniques, which they employ at home for at least 20 hours a week. Children’s brain activity is assessed with special equipment before treatment, and then again after one and two years of Floortime sessions, to see if the therapy leads not only to improvements in behaviour but to an actual “wake up ” so to speak of certain emotional and social areas of the brain to him, but he never answers or looks at her.

Contrast that with the excited Jonah in today’s session, who is a willing participant in the give-and-take of imaginative play. It’s clear Michelle has learned how to engage him. She’s more demonstrative, speaks louder and more often, and essentially doesn’t accept Jonah’s lack of interest. She works harder to get it, and succeeds.

“Before, if Jonah was playing with his Brio train, he’d just move it back and forth over and over and watch the wheels,” Michelle explains.” If I spoke to him or tried to play with him, he’d just ignore me and keep playing. But now I’ll get another train, bring it up close to him and make it do something really silly, like knock the train over or pretend my hand is stuck.”

After 13 months of therapy, Michelle sees great improvements. “A year ago, I couldn’t have imagined him being able to cope at nursery school. But he sits in circle time and plays with another boy sometimes.”

But Michelle doesn’t believe Floortime, or any other single therapy, has all the answers. “I want to do some IBI as well. I want to take a little something from lots of different therapies,” she says. “My kids have a lot of needs and that’s the way it’s going to be for a long time.”

What does autism look like?

Rocking, twirling, rejecting affection, struggling to communicate. These are behaviours often associated with autism. But the truth is that symptoms vary widely, and it can be difficult to discern a typical behaviour from one that might indicate autism.

Thanks to the online ASD Video Glossary, parents and health professionals can see what key behaviours actually look like. The tool features hundreds of free video clips, which show registered users common warning signs.

Nancy D. Wiseman, founder and president of First Signs, which developed the tool with the Florida State University First Words Project, stresses the glossary is not a diagnostic tool; its main goal is to increase awareness and help families catch autism at its critical earlier stages, when there’s a better chance of treatment making a positive long-term impact on their child’s development.

“A picture is worth a thousand words,” Wiseman says. “A video is worth even more.”

View the tool at autismspeaks.org. Click on Autism Video Glossary. – *Frances Olimpo*

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