# UNDERSTANDING **158** | October 2011 | **Parents**



hen he was a toddler, Donald didn't seem to care whether his parents came or went. Before turning 2, he'd already memorized Psalm 23 ("The Lord is my shepherd...") and could recite the catechism from memory, but never paid attention to a fully costumed Santa Claus during the winter holidays. He soon became obsessed with watching spinning objects and would have explosive temper tantrums if he was interrupted. Worried, Donald's father sent a 33-page typed letter recounting these and other unusual behaviors to a young psychiatrist named Leo Kanner at Johns Hopkins Hospital, in Baltimore.

The year was 1938, and Donald would later become the first American child ever diagnosed with autism. For decades afterward, it was believed that the condition was rare. Times have certainly changed. Today, according to the Centers for Disease Control and Prevention, roughly 1 in 110 children are diagnosed with autism spectrum disorders, or ASDs, and it's four to five times more likely to occur in boys than in girls.

The almost fivefold jump in schoolchildren diagnosed with autism between 1993 and 2003 has prompted some authorities and politicians to proclaim that we're in the midst of an "autism epidemic." Bombarded with news about autism (as I write this, Google reports that 4,470 new stories mentioned the condition in the past 24 hours), parents of babies and

## Some of the questions on autism screenings can freak out parents needlessly. If you feel uneasy as you answer them, try not to panic.

toddlers are understandably alarmed and confused. I've been there myself. As a pediatrician and first-time father, I followed my son Jake's growth and development with anticipation, and eagerly awaited his first smile and steps. But when he was almost 2, back in 2003, he was saying only a few words. According to a checklist known as the Denver Scale that was used at the time, he should have known more words. Naturally, my wife and I were very worried.

One reason that autism frightens mothers and fathers so deeply is because its cause is unclear. Parents also fear that a diagnosis of autism virtually guarantees a difficult life—not only for their child, but for their entire family. But researchers are more encouraged than ever about early intervention, which can be enormously beneficial. "We can do so much to help children manage their challenges," explains Patricia Wright, Ph.D., M.P.H., national director of autism services for Easter Seals, which provides support for people with disabilities. "Wherever your child is now, he or she can make significant progress over time."

# WHAT DO WE KNOW ABOUT THE CAUSES?

Simply put, autism is a defect of brain development that impairs social skills. The condition can occur on a spectrum from mild to severe. Experts still don't know the cause, but there are many theories. "We are sure that genetics plays a role," says *Parents* advisor Philip Landrigan, M.D., M.Sc., a pediatrician and director of the Children's Environmental Health Center at Mount Sinai Medical Center, in New York City. In fact, a new study in *Pediatrics* of babies who have an older sibling with autism found that nearly 19 percent of them were diagnosed with the disorder by age 3. The link was almost three times stronger for boys: Twenty-six percent of the male infants developed autism, compared with only 9 percent of female infants.

Many scientists, including Dr. Landrigan, also suspect a direct connection between a child's exposure to certain industrial chemicals, particularly in utero, and the risk of brain disorders including autism. Another possible cause: a parent's age. A study in *Autism Research* in 2010 found that while mothers have a steadily increasing risk of having a child with autism as they get older, the age of the fathers only seems to contribute to that risk when the mother is younger than 30. But it's possible that older parents are just more attuned to the warning signs of developmental problems in their children.

Vaccines are incorrectly believed by many to be another risk factor. A full 25 percent of parents think that some immuniza-

tions can cause autism in otherwise healthy infants, found a 2010 survey from the University of Michigan. (That may explain why nearly 10 percent of kids ages 19 to 35 months are not up to date on their immunizations.) However, at least two dozen studies in medical journals have refuted any connection between autism and vaccines—particularly the MMR vaccine protecting against measles, mumps, and rubella.

Beyond the cause, researchers also aren't entirely sure why there seems to have been such a rise in the prevalence of the condition. But changes in how it is defined are certainly a factor. Between 1980 and 1994 the American Psychiatric Association defined three new forms of autism, including pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger's syndrome. These changes essentially expanded the criteria. What's more, the Individuals With Disabilities Education Act of 1990 clarified the already existing federal law and specifically named autism as a category for special education, which caused an apparent jump in rates. Many kids who may previously have been labeled as learning disabled or mentally retarded are now diagnosed with autism.

# THE (SUBTLE) SCREENING PROCESS

Autism can't be diagnosed with a brain scan, a biopsy, or another medical test. It's usually first suspected by a concerned parent or doctor. In 2007, the American Academy of Pediatrics

BY KRISTENPETLISKI, GROOMING BY SUSAN DONOGHUE FORENNIS, INC. OPPOSITEPAGE: HUDOBAAND DAUGHTER, COURTESY OF LARRY ROY.

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(AAP) recommended that every healthy 18- and 24-month-old should be screened specifically for autism. (A handful of states, like Massachusetts and New Jersey, now mandate this.) As a result, pediatricians are much more attuned to autism and developmental delays than ever before. And yet there's still room for improvement: In a recent *Pediatrics* study, only 48 percent of pediatricians surveyed said they use formal screening tools to identify developmental delays, including autism.

The tools are fairly simple questionnaires that take parents only a few minutes to complete. Perhaps the most common one is the Modified Checklist for Autism in Toddlers (M-CHAT), which can be used on children starting at 18 months of age. It consists of two dozen Yes/No questions such as "Does your child ever use his finger to point, to ask for something?" If two or more answers indicate problems, the test usually is considered positive. (You can download it at www2.gsu.edu/~psydlr.)

A relatively new tool, the Infant-Toddler Checklist, helps determine whether a child from 6 months to 24 months is at risk for autism or a developmental or language delay. Its reliability hasn't been studied as extensively as other tools. As with M-CHAT, it does not diagnose; it's meant to help pediatricians decide whether they should refer a child for further evaluation. (See the tool at brookespublishing.com.Checklist.pdf.)

Some of the questions might freak out parents needlessly. For example, the M-CHAT asks if a child seems "oversensitive to noise" or wanders "with no purpose," which are both normal behaviors for many toddlers. But for the purposes of the screening test, it doesn't count if the action has happened only once or twice—it needs to happen regularly. If you feel uneasy as you answer the questions, try not to panic. But do talk to your pediatrician, who will help determine what you should do next.

Always remember: A positive test doesn't necessarily mean your child has autism, just as only a fraction of women with a positive mammogram will go on to have an abnormal breast biopsy. "It's very likely, though, that a child who tests positive has some kind of delay that can benefit from early intervention," says Geraldine Dawson, Ph.D., chief science officer of Autism Speaks, the country's largest autism science and advocacy group. This was the case with my son Jake. When his scores indicated an increased risk for autism back in 2003, he underwent a more detailed developmental test from our state's early-intervention program and was diagnosed with a mild speech delay, not autism. I was thankful the problem was found. He had speech therapy for a year, and soon met all his milestones. He's now a typical fourth-grader.

### MAKING THE DIAGNOSIS

Depending on the results of a child's screening test, the next step is a more definitive diagnosis process, like the one I recently observed at the University of Massachusetts Medical School, where I work. From behind a one-way mirror, I watched developmental pediatrician Jo Ann Carson, M.D., while she performed the Autism Diagnostic Observation Schedule (or ADOS) on young kids suspected of having autism. The evalu-



# One Family's Story

Monday, October 24, 2005, was a beautiful fall day. I was stopped at an intersection not far from my house when I had a sudden and certain realization: My 18-monthold daughter has autism.

Audrey was in the back, flipping through books in her car seat. Nothing had changed about her in those few seconds, but suddenly my perception of her was completely different. The fact that she was barely mobile wasn't because she was a late bloomer. Her poor speech and inability to answer to her name didn't mean she was an introvert. Our doctor had spoken of developmental delays and was very careful to not use the word autism, but I knew that's what Audrey had, and that she might never recover.

From then on, I passed through each stage of grief several times over, often in the course of a single day: denial, pain, anger, bargaining, shock, guilt, depression, and finally acceptance. The Holy Grail of the stages was acceptance. But even that doesn't sound all that great: Okay, I've accepted

it... now what? What about happiness? What about joy? What about laughter? That's the real Holy Grail.

It's been a long journey, but we've finally gotten beyond acceptance. And humor has had more than a little to do with what has brought us to where we are today. At first it seemed almost forbidden to laugh at our situation. But it's hard not to sometimes, like when you're faced with things such as the clueless reaction of an elderly relative who says she always knew that her grandchild was "artistic."

My daughter doesn't act the same way as a typically developing 7-year-old. She can't ride a bike or make friends like other children her age can. Nor can she converse with you as you might expect her to. But she is sweet and funny, warm and affectionate, adorable and endlessly endearing. Autism may bring me to my knees on occasion, but Audrey is always there to lift me up, bring a smile to my face, and show me all the joy to be had in this life of ours. —Lynn Hudoba, blogger, Autism Army Mom

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ation looks something like a structured playdate, where the doctor and child might blow bubbles, talk about a birthday party, read a story, and do other fun projects over 45 minutes.

After each activity, Dr. Carson recorded a child's responses and assigned a score for 11 key skills (making gestures and recognizing facial expressions, for example). A zero meant that the child was normal, and higher numbers indicated a cause for concern. Dr. Carson then tallied the scores. This is essentially how doctors diagnose autism spectrum disorders: A total score of less than 4 means the child is probably developing typically, 4 or 5 implies a milder form of autism, and 6 or more points means the child has more severe autism.

As I watched the children, I realized that some preschoolers

seemed clearly affected. They failed to make any eye contact, did not speak to share their feelings, and seemed not to notice people at all. Other children's symptoms didn't strike me as worrisome. One kindergartner who read, spoke, and appeared to be quite pleasant was diagnosed as having Asperger's syndrome, the form of autism characterized by peculiarities in speech and language and an inability to interact appropriately with peers,

among other things. Later, Dr. Carson explained that she had been struck by the child's monotonous speech, inability to look directly at anyone, and, based on a report from his teacher, serious problems making friends.

Catherine Lord, Ph.D., director of the new Institute for Brain Development at New York-Presbyterian Hospital, Weill Cornell Medical College, and Columbia University Medical Center, in New York City—who developed ADOS—explains that in severe cases "you know within five minutes that the child has autism." Such children seem truly lost in their own world. But for other very young children, their behavior isn't definitive enough after several hours of testing to warrant an immediate diagnosis. The good news is that those children usually qualify for the same types of educational and support services they'd get if they were found to have autism—and they are nearly certain to benefit. "All early intervention focuses on helping children develop social and communication skills, which are the keys to life," says Dr. Wright. Such services range from speech therapy (like my son Jake got) as infrequently as once a month to intensive oneto-one daily behavioral sessions from a specialized therapist.

### THE CASE FOR EARLY TREATMENT

Autism experts believe that the earlier the treatment, the better the outcome. The best-studied technique, applied behavior analysis (ABA), can require 20 to 25 hours of one-on-one time each week with a trained parent or therapist. Although there is no "cure" for autism, decades of data suggest that ABA (and possibly other intensive behavior therapies) help kids achieve better language and social skills and higher intelligence levels.

The New England Center for Children, in Southborough, Massachusetts, provides ABA therapy in homes and a special-

ized school for children from preschool to young adulthood. When I visited the center, I was struck by how much attention the staffers paid to each child. In one classroom, for example, each preschooler had a full-time teacher who sat with him or her and provided continuous guidance for literally every task in the day. Bill Ahearn, Ph.D., the center's research director, explained that this intensive teaching can be too pricey for most families to pay for themselves. In some states local school districts are responsible for these costs; in other states, parents and school districts split the costs. Insurance coverage is also available in some states to fund ABA therapy outside of school hours.

Still, there is controversy over whether intensive treatment away from mainstream preschools is right for all children on the

Even when children evaluated for autism aren't definitively diagnosed, they can still qualify for services that are likely to benefit them.

autism spectrum. "If my child had mild autism, I wouldn't do 25 hours per week of ABA," admits Dr. Lord. That kind of therapy may take those children away from important opportunities to socialize with typical kids, and may not be critical to their development, she explains. It may be better for them to join a classroom in a regular preschool and have occasional therapy.

### **BRIGHTER DAYS AHEAD**

Despite all the questions that surround the condition, enough is now known about autism to help children have a promising future. "If parents find out that their child has autism, there's every reason to be hopeful that he or she can respond to treatment," says Dr. Dawson. "By starting early, many children, especially ones along the mild end of the spectrum, go on to attend a regular classroom and develop friendships. We want parents to follow their instincts, bring concerns to their pediatrician, and get early intervention as quickly as possible so their child has the best chance at a positive outcome."

Many parents say that they have come a long way since the grief-filled days when their child was diagnosed. Susan Senator, of Brookline, Massachusetts, is one of them. Her oldest son, Nat, now 23, was diagnosed with autism at age 3. "Autism is not the end of the world; just the end of one kind of world," she says. Senator went on to write two acclaimed books about all she's learned: Making Peace With Autism and The Autism Mom's Survival Guide. "Nothing is the way I once dreamed it would be," she admits. "And yet things are very much all right."

Shannon Des Roches Rosa, of San Francisco, whose 10-year-old, Leo, has autism, feels the same. There are many hard days, she says. "But Leo is more capable of pure joy than any child you'll meet. Our family has made our own kind of happiness."