

## PARENTS' PRIMER

# Autism Spectrum Disorders

What you need to know about this set of developmental conditions

By **Melissa Taylor**

**I**n the U.S., one child in 88 has an autism spectrum disorder (ASD). The hallmark of ASD is poor social interaction, according to the National Institutes of Health.

**WHAT ARE THESE DISORDERS?** Included in the spectrum are autistic disorder, Asperger's syndrome, and pervasive development disorder-not otherwise specified (PDD-NOS). As early as infancy, children with an ASD may be unresponsive to people or focus intently on one thing for a long time. Sometimes children with an ASD appear to develop normally and then withdraw from social interaction. Children with an ASD often avoid eye contact, don't understand social cues such as tone of voice, and lack empathy.

**WHAT CAUSES ASD?** No one knows exactly what causes autism or related disorders, but research points to both genetic and environmental factors.

**HOW CAN ASD BE TREATED?** The children who do best are the ones who have early intervention—think 14 months to 3 years of age. Therapy needs to be individually tailored and can focus on everything from speech to social skills to physical therapy.



## AUTISTIC DISORDER

**CHILDREN WITH AUTISTIC DISORDER** start to show delays in their social and communication abilities between the ages of 1 and 3, says Rebecca Landa, director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute. Autistic disorder is low emotional intelligence, explains nurse practitioner Petique Oeflein, whose 10-year-old son, Max, was diagnosed with the disorder. "It is part of Max's compromised neurological make-up that he does not look Grandma in the eye and walks away without saying 'hi' or 'thank you,'" Oeflein says. "It looks really rude, but Max is not a bad kid who wasn't taught how to be polite. He is autistic."

Children with autistic disorder have problems with communication, sensory processing, and social skills and show repetitive behaviors, such as flapping their hands or repeating sounds. Each child presents unique challenges. "In the autism community, we like to say that if you've met one child with autism, you've met one child with autism," says Ellen Notbohm, a parent of autistic sons.

Treatment may include behavioral consulting, speech therapy, and occupational therapy. "Children with autism require direct teaching of social skills," Notbohm says. They "are visual, concrete thinkers, who have a hard time generalizing," says Robin Gabriels of Children's Hospital Colorado.

### AUTISTIC DISORDER

#### What to watch for

*Look for these early signs of autistic disorder*

- › Speaks few words
- › Doesn't like back-and-forth social exchanges, like peek-a-boo
- › Doesn't play appropriately with toys. For example, a child may line the trains up by color instead of pushing them on a train track.
- › Doesn't imitate adults
- › Doesn't smile back
- › Makes strange squealing sounds
- › Flaps arms



### AUTISM SPECTRUM BY THE NUMBERS

**1 in 88**  
children in the U.S. has an autism spectrum disorder

**40%**  
OF CHILDREN WITH AN AUTISM SPECTRUM DISORDER DON'T SPEAK AT ALL

Autism spectrum disorders are almost **5 times** more common among boys (**1 in 54**) than girls (**1 in 252**)

**4**

THE MEDIAN AGE OF DIAGNOSIS

## ASPERGER'S SYNDROME

**CHILDREN WITH ASPERGER'S SYNDROME** vary in their degrees of clumsiness, obsessive behavior, and social and emotional delays. "Every Asperger child looks so different," says Ryan Plosker, executive director and founder of New England Academy, which focuses on children with Asperger's syndrome. "One Asperger's kid is sensitive to smells; one isn't. One kid is gifted in math; another isn't. It's such a specialized population of kids whose quirks are all different."

Asperger's syndrome is usually not diagnosed before elementary school, says Landa, because Asperger's does not result in delayed speech and children with Asperger's do not have a lower IQ.

While children with Asperger's don't always have academic issues, they do struggle with social and emotional delays. "It doesn't matter if you have a 140 IQ. If you're not being taught communication skills, you're going to struggle as an adult," Plosker says. Children with Asperger's also need to feel connected. "So many kids that I work with have never had a friend because they have such special interests and are developmentally behind," Plosker says.

Mary-Francis Main, whose

9-year-old son, Alec, has Asperger's, says, "Alec has a completely different way of processing things. He's not lazy; he's just totally and completely focused on his passion of becoming a director." Like others with Asperger's, Alec has found his singular interest: movies.

"Before the diagnosis, we got so frustrated with Alec because he was always off in his head. We were constantly wrestling to have even the most basic conversation with him," Main says.

Diagnosis has brought new understanding and resulted in serious improvements. Today, Alec goes to occupational therapy and a social skills group and is on a waiting list for speech therapy. "Our house is full of checklists and little notes to help Alec keep focused," Main says. "Once he has a checklist, he loves it and follows it completely."

At school, a child with Asperger's needs support when it comes to social skills and learning styles. "Schoolwork is a challenge," Main says. "Alec has always wanted to think about his own things rather than schoolwork. If he sees a benefit to him, he'll learn, but it's not a priority." Alec's school accommodates his needs. "They keep a special eye on him," Main says.

### ASPERGER'S SYNDROME

#### What to watch for

Look for these early signs of Asperger's syndrome

- › Prefers to be isolated
- › Shows obsessive interest in one object or subject
- › Talks about interest exclusively
- › Doesn't interact with peers in play or conversation
- › Experiences a high sensitivity in one or more senses

**"Our house is full of checklists and little notes to help keep Alec focused. Once he has a checklist, he loves it and follows it completely."**

**Mary-Francis Main, parent of a child with Asperger's syndrome**



## Scrambled senses

### MANY CHILDREN WITH AN AUTISM SPECTRUM DISORDER

also have sensory processing disorder (SPD). They get heightened or decreased sensory input from the world around them, making processing information difficult. They may be over-responsive or under-responsive in one or more senses, have difficulty discriminating between senses, or have problems planning and coordinating their motor skills. For example, they may have trouble with handwriting or struggle with jumping or balancing.

Children trying to "calm overloaded senses or alert under-responsive ones" often exhibit unusual behaviors, says Ellen Notbohm, who has a son with autistic disorder and SPD. "Such behaviors are informally called stims (self-stimulating behaviors) and may include repetitive actions like hand flapping, rocking, hair twirling, humming, spinning, pacing, toe-walking, licking, sniffing, and chewing or mouthing objects."

Sensory processing disorder can be treated by occupational therapists, who train parents in home therapy solutions, such as lightly brushing the child over his entire body with a small plastic-bristle brush or doing activities such as jumping and hugging.

## PERVASIVE DEVELOPMENT DISORDER NOT OTHERWISE SPECIFIED

**PERVASIVE DEVELOPMENT DISORDER-NOT OTHERWISE SPECIFIED**, or PDD-NOS, is a catchall term for "a category with some of the same impairments [as autism] but in a different presentation," explains Zachary Warren, director of the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders. While doctors see many of the same social and behavioral issues as with autistic disorder, the child's symptoms do not quite warrant a diagnosis of autism. For this reason, parents sometimes describe PDD-NOS as "autism light."

As with other autism spectrum disorders, each child with PDD-NOS faces a unique set of challenges, and symptoms can vary from mild to severe.

"My son, Brady, was 2½ when

he got the diagnosis of PDD-NOS," Emily Venek says. "He cannot talk, struggles socially, and often doesn't respond to his name. He is obsessed with lights and fans. He will point out to anyone who cares, or is nearby, where the fans and lights are in any given room."

Therapies are individualized according to a child's specific needs. Treatment for Brady, now 4, includes speech therapy, occupational therapy, and physical therapy. Many children with PDD-NOS learn social and communication skills through play therapy.

Children with PDD-NOS thrive on routines and schedules both at home and at school. Smaller class sizes, communication support, and modified curriculum are all essential for their success.

### PDD-NOS

#### What to watch for

*Look for these early signs of PDD-NOS*

- › Doesn't babble by 12 months and doesn't say two-word phrases by age 2
- › Doesn't point or gesture at 1 year of age
- › Doesn't make eye contact
- › Doesn't respond to name
- › Obsessive interest in one toy or object
- › Flaps hands or rocks body
- › Prefers to play alone
- › Repeats words or phrases over and over
- › Gets upset with minor changes in schedule