

# Inside Autism

## By Miriam Falco, CNN

Autism. It's a word more often heard these days. But what autism actually is is probably less understood by the average person. For someone who may not have met a child with autism, the closest reference to what it is may come from the 1988 movie "Rain Man," where Dustin Hoffman is rocking and counting toothpicks.

However, when you meet some of the children who have autism, that's not what you see.

Wendy Stone, a longtime autism researcher, says autism is "really the absence of behaviors. It's not the presence of unusual behaviors, like spinning or hand flicking ... which a lot of people look for."

Moreover, there's no one type of autism. There's no one treatment to help a child with autism -- no pill, no cure.

The cause is still a mystery, but one that scientists have been unraveling more in recent years.

### **What is autism?**

So what is autism? Autism falls under an umbrella of disorders called "pervasive developmental disorders" (PDD) or autistic spectrum disorders (ASD).

"Autism spans a range of symptoms ... a range of degrees of symptoms so that one child with autism, or an autism spectrum disorder can be very different from another child," says Stone from Vanderbilt University's Kennedy Center for Research on Human Development.

According to the U.S. Centers for Disease Control and Prevention, 1 in 166 children is born with autism. Boys outnumber girls 4 to 1. Most experts, doctors, therapists and researchers believe children are born with ASD, a brain disorder that leads to difficulties in social interaction, communication and behavior. Parents are experts, too, because they live with autism every day, for the rest of their lives. Chicago speech therapist Sharon Rosenbloom, also the mother of 18-year-old son Joey with autism, puts it this way: "People with autism do not experience the world as others do."

If you don't have a child with autism, it may be difficult to imagine.

A 12-minute video, posted on the Web site of organization Autism Speaks will give you a glimpse into that world. (Autism Speaks )

One mother describes her situation: "I didn't choose this. I was drafted. I have an autistic child."

Other mothers describe how people with "typical" children don't understand what families with autism go through.

"They have no idea," says another mother in the video. Another says she knows she can't live forever, but fears "what happens when I'm not here?"

Researchers have broken pervasive developmental disorders or autism spectrum disorders into five categories.

The most common diagnoses are autism, Asperger syndrome and pervasive disorder-not otherwise specified (PDD-NOS). The two other disorders: Rett syndrome and childhood disintegrative disorder (CDD), are more rare.

According to the National Institute of Mental Health "autism spectrum disorders are more common in the pediatric population than are some better known disorders such as diabetes, spina bifida or Down syndrome." National Institute of Mental Health

### **Getting the diagnosis**

Parents of children with autism are experts too because they live with the disorder 24 hours a day.

They are also usually the first to notice something's wrong. Often parents are told to wait.

Getting the diagnosis is difficult. Jessica Bates from Prattville, Alabama, has two children with ASD.

Her first child's diagnosis, she says, "was probably the most devastating thing I've ever been through in my entire life."

For Cindy Pike of Lawrenceville, Georgia, learning that her child had autism was hard, but getting the diagnosis was almost a relief.

"It was so obvious to me for so long that there was something wrong... To have a name for it so that I could help. Then the frustrating part of 'What do you do next?'"

Cindy's not alone. When parents learn their child has autism, they have to figure out how to help him or her.

Tommy Bates describes trying to find a treatment for his child: "There was so much information -- it was so hard to process all the information, so I was dizzy and I remember being shocked by all that."

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## **What's a parent to do?**

Most everyone will agree that the best way to help a child is through early intervention because it can change the way the brain develops.

That means getting a diagnosis as early as possible is essential, so a child can begin therapy early.

However, there's still no test for autism. The child will need therapy, but what kind? What works for one child doesn't necessarily work for the next. And, what may be most surprising to outsiders, a child with a behavioral and brain disorder gets the majority of his treatment via the education system, not the medical system.

What does that mean? In most cases, the school system is responsible for providing the necessary behavioral therapy for the child. That's where the parents' search for their child gets more difficult. Some schools don't have the ability to provide many different types of services. Experts say children with autism need to be given proven therapies to serve their needs. Too often, children have to take what they can get.

Susan Smith, who has a son with severe autism, moved from one county in Georgia to another, so her child would get better care. She believes her son "shouldn't be penalized for having a disability."

Parents of children with autism often have to look for outside resources to get their child's needs met.

In some parts of the country, there just aren't enough therapists to help the growing number of children with autism. When parents do find someone who can help their child, insurance often doesn't cover it, so they have to pay for it themselves.

## **The search for more information**

No two children with autism are the same. Sadly, many parents share common experiences when trying to find the proper services. When ordinary services fail, they find their own ways and their frustration leads to sharing what worked for their child with others, in the event it may help another child.

Susan Ellis from Marietta, Georgia, is just one of many such parents. Her son Ryan couldn't learn how to write.

Along with his occupational therapist, Marnie Danielson, Ryan's mom created a video using chants and it worked for him. Like many parents, she shares her success because it may work for another child with autism. She's made her videos commercially available via her Web site. (Alpha Beats)

Robert and Suzanne Wright are the grandparents of a boy with autism. They, like many other families coping with autism, were frustrated with the options for their grandson and the many other children with ASD.

Not everyone has the resources and clout to reach a lot of people. But Robert Wright is the chairman and CEO of NBC Universal. He and his wife founded Autism Speaks in 2005 for the purpose of finding a cure for autism, according to the Web site. The video on the Web site provides a unique perspective of the difficulties families face when coping with autism. The site also provides a lot of information for those eager to learn more about autism.

## **What's next?**

The U.S. Senate passed the "Combating Autism Act" late Thursday. The House is expected to take up the measure in the fall, and if signed into law could provide \$900 million over five years to fund more research and provide state grants to help families with children with autism.

Researchers are studying children with autism as well as their siblings to learn more about the genetic component.

They are learning more about what parts of the brain are not communicating as well as they do in "typical" children.

More needs to be learned about what environmental factors may influence or trigger autism.

And if children are born with autism, how can they be tested for it?

Many questions are still unanswered. More funding is needed for the research and new therapies to help these children.