



Autism Findings Little Surprise to Parents

Research Suggests Autism More Common Than Thought, Additional Funding Needed

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Feb. 9, 2007 - More than half a million children in the United States have an autism spectrum disorder.

This was the finding reported Thursday by the U.S. Centers for Disease Control and Prevention, which also views the new data as "confirming the upper end of estimates" from recent U.S. and non-U.S. studies.

In short, the findings from the Autism and Developmental Disabilities Monitoring study suggest roughly one in 150 American children have autism -- many more than previously thought.

But some parents of autistic children say the finding of an increased prevalence is no surprise.

Jeff Sell, who lives in Texas, is a 45-year-old father of two children with autism. Both of his children were born in 1994, but were diagnosed at different times in 1996.

"From a certain perspective, this is big news, but it is something that parents of these children have already known," Sell says. "But for a few years, everybody has been going through these more or less academic-type arguments [about the prevalence rate]."

"Call it what it is, I have two autistic children in my house, and at the neighborhood school there are also very many."

Catriona Johnson, 43, of Columbia, Md., has a son with autism who was diagnosed in 1995 at the age of 2. "This didn't surprise me, particularly in terms of where I come from in my state because our numbers are consistent with this," she says.

A True Increase?

The higher prevalence in these latest findings begs another question: Is the number of autism cases growing, or are more existing cases simply being detected?

"That's one of the challenging questions, and there is no way to answer this for sure, for the time being," says Catherine Rice, a behavioral scientist with the National Center on Birth Defects and Developmental Disabilities and a leader of the study. "That's one of the reasons that we developed the network, so we can answer this."

The true answer may lie somewhere in between better detection and an actual increase. There is little doubt that detection of existing cases of autism has improved.

Also, the classification of the disorder has expanded over the years to include cases that may have been categorized differently in past decades.

But even taking these factors into account, some autism experts say the leap from a working figure of four to five cases per 10,000 children a few decades ago up to one in 150 today is too significant to be attributed to these factors alone.

"I think that certainly accounts for some of the increase in prevalence, but I don't think that we, as professionals in the field, can feel totally comfortable that this can account for all of it," says Cynthia Johnson, director of the Autism Center at the Children's Hospital of Pittsburgh.

The suspicions that autism is on the rise in the United States are echoed by Catriona Johnson, who says she and other parents of autistic children -- as well as many of the physicians she has consulted -- have seen an increase in autism incidence in recent years.

"We have seen these huge increases over the last decade," she says. "We have been talking to medical professionals, and every professional I've spoken to is saying that there is a real increase; they say they've never had to handle so many kids with autism."

Discrepancies Between States

Another new question raised by the data concerned the wide variation in prevalence between certain states.

New Jersey, for example, was found to have a nearly 1 percent prevalence of autism among children. In Alabama, on the other hand, autism appeared to be roughly one-third as common.

"It may be in part due to differences in how things were sampled," says Cynthia Johnson. "Even though this was a good study by the CDC, there were differences in terms of the records that could be accessed from state to state."

She says the difference may also be attributed to parents who move to other states to take advantage of medical and support services.

Still, Rice says, further research could reveal other factors present in individual states that would have an effect on the prevalence of autism.

A Growing Public Health Concern

Last year, Congress allocated \$945 million to fight autism. Today, advocacy groups are calling for more and the recent findings could support this appeal.

Autism organizations say additional funds may come not a moment too soon.

As growing numbers of those with autism reach the age of 21 -- the age at which they will no longer be eligible for services provided through the educational system -- many parents worry that they will not be able to provide all of the care and support their children need.

"The adults who care for these children are not ready to deal with that," says Catriona Johnson. "This study may help us sort of think forward in terms of the services that will be needed to care for those with autism into adulthood."

One option may be to fund programs that allow those less profoundly affected to live as independently as possible. Many, with adequate support, have shown that they are able to hold a job and otherwise become productive members of society.

The alternative, Sell says, is an expensive one.

"If we don't start providing them a little support, they will continue to be a drain on society, and that could end up bankrupting the health care system," he says.

Findings Offer Hope

Even though the study confirms a higher prevalence of autism, parents and advocacy groups are hopeful that the new findings will prompt additional research and services to deal with autism.

"I think this is what the autism community has been struggling with for the last five to 10 years getting enough public awareness in order to get services in place," Catriona Johnson says.

And the CDC findings could spur both the public and the government to act quickly to find new ways to deal with this growing public health issue.

"My hope is that this will generate conviction," Cynthia Johnson says. "If you think about it, one in 150 children, that's petrifying for families. We need to work even harder to understand autism."

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