

## State with one of highest rates of autism turns out to be in normal range

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When New Jersey reported one of the nation's highest rates of autism last year - doubling in six years to one in 49 children - researchers described it as "beyond an emergency." But a federal study released this past week indicated that the high rate appears to be the norm nationally. Autism spectrum disorder now affects one in every 50 children, well above the one in 88 previously reported by the Centers for Disease Control and Prevention.

"The good news is that the increase in autism isn't special to New Jersey," said Walter Zahorodny, an autism researcher at the University of Medicine and Dentistry of New Jersey. "The bad news is that it's a significant increase and it's registering everywhere."

The findings released this past week by the U.S. Health Resources and Services Administration and the <u>CDC</u> are spurring debate: While experts attribute the increase to better reporting, it also suggests that the disorder is being diagnosed more frequently in children with milder symptoms.

According to the study, 1 million children nationally are diagnosed with autism, a complex disorder that affects <u>brain development</u> and a person's ability to communicate, learn and form relationships.

"The feeling all along wasn't that New Jersey has more cases of autism - New Jersey was just more rigorous in ascertaining the incidence," said Dr. Joseph Holahan, medical director of the child development center at St. Joseph's Children's Hospital in Paterson. "It's still one of the most



common serious developmental disorders we see."

The varying counts can be attributed to many factors - whether information is obtained from a telephone survey or a more rigorous accounting that relies on education and <u>medical records</u>. Some surveys counted children as old as teenagers with milder symptoms that may have been missed in their younger years. Other federal research only counts the number of 8-year-olds diagnosed - the age by which most children are seeking <u>specialized care</u>.

However the rates are determined, advocates say there are still too many children left undiagnosed and too few federal dollars channeled into research and specialized treatment and education.

"We still think one in 50 is an underestimate," said Michael Rosanoff, associate director for public health research and scientific review for the advocacy group Autism Speaks.

"The real issue is we need to meet the demands of this public health crisis," said Rosanoff said. "This should be a wake-up call."

Even worldwide, higher rates of the disorder are evident, Rosanoff noted. A study in South Korea, led by Yale experts and published in the *American Journal of Psychiatry* in 2011, estimated that one in 38 South Korean children have some form of autism. That study included research by clinicians evaluating children previously undiagnosed. Experts say the research team may study 8,000 children in South Carolina to better determine rates of the disorder in the U.S.

Some experts have questioned the methodology used in the latest federal report - a national phone survey of 95,000 parents from 2011 and 2012, compared with more rigorous population-based research the CDC relied on when it estimated the 1-in-88 rate. Fewer than a quarter of the



parents contacted agreed to answer questions in the general health survey, which included the questions about autism.

The survey focused on children ages 6 to 17, and the CDC attributed much of the increase to reported cases in adolescents ages 14-17. These children were more likely to have milder symptoms and therefore were not diagnosed until later, CDC experts concluded.

"This is a good study, done with a large U.S. sample, and it correctly reflects the magnitude of increase in <u>autism spectrum disorder</u> over the past years," Zahorodny said.

But he urged caution. As a telephone survey, he said, "it may be biased from the perspective of who responds."

More complete counts are expected in coming months when the CDC releases its population-based studies of 8-year-olds from 14 areas in the country. Over the last decade, that CDC data have shown a sharp rise in prevalence, from one in 150 children in 2000 to one in 88 in 2008, the last year information was complete.

Zahorodny was the principal researcher in New Jersey for the federal study released last year that identified the 1-in-49 rate. The study was based on a survey of educational and medical records for more than 7,000 children who turned 8 in Union County in 2008. New Jersey has an average of eight to 10 records for each child, compared with three or four in other states.

Eighty percent of the <u>children</u> with autism in the New Jersey study were identified as having the most severe form of the disorder. Boys were more than five times as likely to be diagnosed as girls, both in New Jersey and in the rest of the country.



The symptoms of autism, which is believed to have genetic and environmental causes, vary in combination and intensity. While some people have normal or higher-than-average intelligence, they may be socially inept. Others are unable to speak or care for themselves.

If anything has changed in North Jersey pediatric neurology practices, it's the number of parents seeking a diagnosis for more moderate symptoms that are frequently discussed in the media.

"I've been in practice for 15 years, and right from the beginning I had a large number of cases," said Dr. Peter L. Heilbroner, a pediatric neurologist in Ridgewood.

"We're seeing more parents coming in asking about mild symptoms, which aren't always autism," he said. Is a speech delay truly autism? Is a teen's behavioral problem or lack of social connections a sign of Asperger's syndrome? Is a child suffering from depression or anxiety, which can mimic autism?

"Labeling a child with any of these disorders should be done very carefully," he said. "It's not a diagnosis that should be thrown around lightly."

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