

# New Jersey has highest rate ever documented in U.S.

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One in every 94 children in New Jersey has autism -- the highest rate ever documented in the United States. For boys, the rate is one in every 60.

New Jersey's rate, based on 2002 data, should "be understood as a public health crisis," said the principal researcher for the study in New Jersey, Walter Zahorodny, of the University of Medicine and Dentistry of New Jersey. His work was part of a multistate study by the federal Centers for Disease Control and Prevention.

"The burden of autism is much more than people estimate," he said.

Zahorodny traveled to Washington, D.C., on Thursday to brief members of Congress on his part of the report, which provided the first broad look at the prevalence of autism here and in other states.

Overall, the rate in 13 other states studied was one in 150 children. While that is higher than the previous estimate of one in 166, it is unclear whether autism is increasing or the studies have simply improved.

"We do know, however, that these disorders are affecting too many children," said Dr. Julie Gerberding, director of the CDC.

Even veterans of the autism world were stunned. "One in 100? Oh my Lord. I'm shocked," said Diane Lento, who helped to found a private school for children with autism a decade ago. Her daughter, Kate, who has autism, is now 15.

"It's really frightening," said Barbara Strate of Palisades Park, the mother of an 11-year-old girl with autism and manager of an Internet community for North Jersey families affected by autism. "If I were having children in this day and age, I'd be really scared."

The new research raised as many questions as it answered.

"We don't know why the rates are higher in New Jersey," said Marshalyn Yeargin-Allsopp, chief of the CDC's developmental disabilities branch. "We need to continue working toward figuring out what's causing the range of autism to answer that question."

Autism is a complex disability that affects the brain's development in early childhood, and interferes with a person's ability to communicate, learn and form relationships. Behavior is often focused and repetitive. Symptoms vary in their combination and intensity: Some people with autism have higher-than-average intelligence and appear quirky and socially inept, while others are completely unable to speak, sometimes bite, scratch and hit themselves, and require constant supervision.

The studies published on Thursday include the entire spectrum of autism disorders. They were based on a review of health and educational records for 8-year-olds in 2000 and 2002. In New Jersey, the records of nearly 30,000 children -- all the 8-year-olds -- in Hudson, Essex, Union and Ocean counties were culled, yielding 295 children with autism in 2000 and 316 in 2002. These counties are "very likely to be representative of the entire New Jersey-New York metropolitan region," Zahorodny said.

The New Jersey Autism Study found a rate of one in 101 in 2000, and one in 94 in 2002 -- a difference that was not statistically significant, he said. The rate for boys went from one in 68 in 2000, to one in 60 two years later, while for girls it went from one in 233 in 2000, to one in 250.

A new study, funded by the New Jersey Council on Autism, is to examine the rate in 2006.

The high rate of autism in New Jersey was not caused by families moving to the state, Zahorodny said. Researchers checked birth certificates and found that 84 percent of the children with autism were born here, a higher rate than in other states.

The higher rate among boys -- found in all states studied -- confirmed previous studies. The difference in the rates among whites, blacks and Hispanics was not significant, Zahorodny said.

Among other states, Georgia reported the lowest rates in 2000, with one in 222. Alabama was the lowest in 2002, with one in 300. Zahorodny attributed the comparatively high numbers here to greater public awareness of autism and sensitivity by educators and physicians to the disorder.

Suzanne Buchanan, head of clinical services for the New Jersey Center for Outreach and Services for the Autism Community (COSAC), said, "New Jersey ... is much more knowledgeable about autism than other states. You're working with professionals in the educational system here who are much more aware of autism than professionals in other states."

The study should be an impetus for more research into the causes of autism, said Dr. Joseph Holahan, chief of the child development center at St. Joseph's Children's Hospital in Paterson.

"What used to be considered a very rare condition is actually a very common one," he said.

U.S. Rep. Chris Smith, R-N.J., is co-chairman of Congress's Coalition on Autism Research and Education, said: "You can't combat any disease until you start chronicling it. This information, disturbing as it is, is necessary. We need to know the truth."

His district includes Brick Township, site of a 1998 CDC investigation to determine whether the incidence of autism was abnormally high. The new studies show that, in fact, there was no cluster of autism in Brick Township.

While it was not designed to gauge the effects of childhood immunization on autism, the study shed some light on the issue: Immunization rates in the study states were similar, though autism rates were not, Zahorodny said. Future data may reveal the effect, if any, of removal of mercury from most vaccines in the late 1990s.

The study underscores the enormous need for resources, not only for early diagnosis and treatment, but to provide jobs and homes for people with autism as they become adults and grow out of the educational system, educators and researchers said.

"I hear these numbers and I think all these children need to be educated," said Dawn Townsend, director of the Institute for Educational Achievement, a private school for children with autism. "Where are we going to do that?"

The 8-year-olds counted in this study are now 15. "We need to provide opportunities," so they may participate as fully as possible in jobs and housing and cultural activities, said Linda Walder Fiddle, who started a foundation that funds programs for adolescents and adults with autism.

Mary Beth Walsh, whose son, Ben, 8, attends Reed Academy in Garfield, said the results are "a cry for greater funding of services."

"There's a tremendous need for more training, for more people to do the interventions that make such a difference in these kids' lives," she said. Ben did not use his vocal cords before he began therapy, but now counts the steps as he climbs them and enjoys telling his mother, "Come on, Mom," she said.

Brendan Gilfillan, a spokesman for Governor Corzine, said New Jersey is at the forefront of identifying and treating those with the disorder, and the state's fiscal 2007 budget contains \$15 million for special-education programs, including one for autism. "The governor is committed to doing more to address the complex issues associated with autism." he said.

The CDC figures may lead to a surge in funding proposals, said Judah Zeigler of Leonia, a member of the Governor's Council on Autism, which distributes millions of dollars for in-state research.

"The study shows what the autism community and what researchers have been saying for a long time," he said.

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### **Some facts about autism in New Jersey**

- New Jersey's rate is the highest among 14 states studied. Researchers don't think that necessarily means more children here are born with autism. Rather, there is more awareness, better identification and better record keeping.
- More children in New Jersey are categorized as "severely impaired" (classic autism) than "less-impaired" (Asperger's syndrome and pervasive developmental disorder-not otherwise specified).
- The rates were the same among ethnic groups and races.
- Boys are three to four times more likely than girls to have autism.
- The rates didn't vary much by county, which may mean that specific local environmental factors are not a cause.
- Some 14,000 New Jerseyans ages 3 and 21 have autism.
- Future state-funded studies will determine the rate for 2006, and analyze the data for correlations with socioeconomic class and maternal and paternal age.

- The study is published in the Feb. 9 issue of the CDC's Morbidity and Mortality Weekly Report, available online at [CDC.gov/mmwr](http://CDC.gov/mmwr). Details on the New Jersey data from the study are available at [njcosac.org](http://njcosac.org).