



## **“Increasing Autism Prevalence in Metropolitan New Jersey.”**

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### *KEY POINTS*

**Autism prevalence in the New Jersey metropolitan area is approaching 2%.** The high rate of autism underscores the need to address the significant needs of affected children and their families. New Jersey has been a leading indicator of autism prevalence for the past decade, due to completeness of autism case-finding in our region. It is likely that autism prevalence is underestimated in other US regions and that with continued monitoring autism rates will approach 2% elsewhere. Continued autism monitoring in New Jersey is likely to reveal future trends in autism prevalence.

**Autism prevalence increased significantly between 2002 and 2006.** The observed increase was broad, affecting children of all backgrounds, across the region. The rise in autism prevalence in New Jersey is consistent with the magnitude of increased prevalence reported by the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network, indicating that the rise in autism is not unique to New Jersey.

Boys are more likely than girls to have autism. In the metropolitan area, approximately 1 in 35 boys have autism. The preponderance of autism among males is not understood and calls for further research.

Consistent autism definitions and autism case-finding procedures were implemented by this investigation, in order to increase the validity of study findings. Additional analyses were conducted to evaluate the influence of factors reflecting better awareness on prevalence.

Additional studies are needed to identify autism risk factors. The New Jersey investigators are conducting case-control studies that may shed light on the interaction of genetic and environmental risk factors for autism.

An effective screener is needed to detect children with autism earlier and maximize opportunities for early intervention.

## *Questions and Answers*

- **How many children in our region have autism?**

This study found that 1-in-57 8-year old children (17.4 per 1,000) living in our region had autism. The findings are based on comprehensive review and analysis of information contained in health and special education records of children born in 1998 and living in four New Jersey counties in 2006. We estimate that nearly 28,000 New Jersey children between the ages of 3 and 18 have autism.

- **How does the New Jersey Autism Study determine autism prevalence?**

This study tracked autism prevalence by using an active case-finding strategy developed by the Centers for Disease Control and Prevention (CDC). The method is based on review and analysis of information contained in existing health and special education records of children living in a four-county New Jersey metropolitan region (Essex, Hudson, Union and Ocean counties). By this approach, we were able to identify children that showed the defining characteristics of autism regardless of whether they had been diagnosed with the disorder by a community provider.

- **The 2006 prevalence estimate shows a 63% increase in autism prevalence in the New Jersey metropolitan region between 2002 and 2006. What accounts for this increase?**

We do not know why more children than ever before are being identified with autism. Some of the increase may be due to better awareness and access to services. However, it is also possible that environmental factors may be influencing autism prevalence.

- **Do most of the children identified by this study have a mild form of autism?**

No, we found that 80-85% of the children who were identified with autism satisfied the criteria for Autistic Disorder, the more severe form of autism.

- **What is the Autism and Developmental Disabilities Monitoring (ADDM) Network?**

The ADDM Network is a group of programs funded by the CDC to estimate the number of children with autism spectrum disorders and other developmental disabilities living in different areas of the United States (US). Each ADDM Network site uses the same autism definitions and process for tracking autism prevalence. That way, the prevalence for each site can be combined to produce an overall US prevalence estimate. Information on the number and characteristics of children with autism from the Network can be used by to inform planning and service delivery. The New Jersey Autism Study has been funded by CDC as an ADDM Network site to track autism prevalence for the 2000, 2002, 2008, 2010 and 2012 surveillance years (MMWR, 2007a, 2007b, 2009, 2012). 2006 autism monitoring by the New Jersey Autism Study was supported by the *New Jersey Governor's Council on Biomedical Research and Treatment of Autism*.

- **Why is autism prevalence higher in New Jersey than in other states?**

We can't say for sure. The health and special education records that we review contain more detailed information than in other ADDM Network sites. This may increase the accuracy of New Jersey prevalence estimates. However, we cannot rule-out the possibility that other factors may be at play. The New Jersey investigators are looking at a number of demographic and environmental factors that may contribute to higher levels of autism prevalence.

- **The method used to determine how many children have autism relies on analyzing information from existing health and education records, not by direct clinical evaluation of children. Isn't it likely that the study is over-identifying autism and overstating the prevalence of the disorder for that reason?**

That is not likely. A recent validation study of the method (Avchen et al., 2011) included direct clinical evaluation of cases identified by the surveillance method. This study found that while the method for tracking autism prevalence developed by CDC and used by the New Jersey Autism Study is very specific in identifying autism, it may under-estimate the prevalence of the disorder.

- **Are boys still disproportionately affected by autism?**

Yes. Boys in New Jersey are about 5 times more likely to be identified with autism than girls. In 2006, about 3% of 8-year old boys in our region had autism. More research is needed to understand why boys are more frequently affected.

- **Are children of different races and ethnicities equally-likely to have autism?**

Children of all race and ethnicities have autism. However, it is not clear whether autism prevalence varies by race or ethnicity. New Jersey autism prevalence findings for 2000 showed equivalent rates of autism across race groups. On the other hand, the 2006 results showed that white children had higher rates of autism, in comparison to black and Hispanic children.

- **Why do the prevalence reports focus on 8-year old children, rather than all children and why is autism monitoring in New Jersey conducted in four counties, rather than in the entire state?**

The method we use for tracking autism is very labor-intensive and time-consuming. We chose to determine prevalence among 8-year old children because it is very likely that most children with autism would have come to the attention of health and education providers by that age. To produce reliable autism estimates every two years, the New Jersey Autism Study must restrict itself to a specific region with an annual birth population between 20,000 and 40,000. We chose to track autism prevalence in Essex, Hudson and Union counties because they are geographically contiguous and because they represent the diverse urban-suburban demographic of the metropolitan region. We added Ocean County to our surveillance region because Ocean County is a high-growth area and because the first autism surveillance in New Jersey was conducted in Brick Township (Ocean County) (Bertrand et al., 2001).

- **The study found that 1.7% of 8-year olds living in the four-county surveillance area, in 2006, had autism. How confident are you that the overall rate of autism is that high across the New York metropolitan region or throughout New Jersey?**

Autism prevalence is likely to be similar throughout the New York and New Jersey metropolitan area. It is very unlikely that there is something special or atypical about the 4 counties we studied that would make for higher levels of autism. All the counties included in our investigation are suburban or urban, however. Since the region does not include a large rural population, autism prevalence may be different in rural areas, like Cumberland, Sussex or Burlington counties.

- **What can be done to figure out why autism prevalence is increasing?**

Much more research is needed to identify risk factors for autism and to define specific autism subtypes.

- **What do we know about the causes and risk factors for autism?**

Today, most scientists agree there are multiple causes of autism. While genetics may play a role in whether a child will have autism, other non-genetic factors such as parental age, premature birth and the use of medications during pregnancy may also play a role. The search for potential risk factors and causes is a prominent, rapidly-growing, field of research, and our tracking data helps to direct this research.

- **How does the estimate of children identified with autism compare with other childhood disabilities?**

About 17% of US children are estimated to have a developmental disability (Boyle et al., 2011). Autism is among the most common serious developmental disabilities, but Attention Deficit Hyperactivity Disorder (7.6%), learning disabilities (7.24%) and communication disorders (6.3%) occur more frequently.

- **Do the results from this study shed light on the vaccine theories of autism?**

This investigation was not designed to look at whether vaccines play a role in the occurrence of autism. However, many studies have looked at whether there is a relationship and, to date, none have proven an association between vaccines and autism. With regard to the thimerosal theory of autism, since thimerosal was largely eliminated from vaccines by 2000, if that preservative was a substantial risk

factor for autism, we would expect decreasing ASD prevalence, over time. So far, autism prevalence has increased, however.

- **How will proposed changes to the definition of autism in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) affect future autism prevalence estimates?**

In general, it is hard to predict what effects DSM-5 will have on autism estimates. However, because we collect information on a comprehensive range of symptoms, the New Jersey Autism Study is well-positioned to adopt any new (DSM-5) definition since our ongoing tracking system and to also get comparison estimates based on the current (DSM-IV) definitions. We have already started exploring the New Jersey data to see how the proposed changes might affect our current estimates, and will continue to prioritize these comparisons so we can better understand autism trends, over time. This information will be essential to our growing knowledge of this complex spectrum of behaviors.

- **What should parents do if they suspect their child might have autism?**

The best thing parents can do is monitor their child's development and talk to their pediatrician. We found that many children are not diagnosed until after age 4. It is important to act early if you have any concerns. Talk to your child's doctor about your concerns. Call your local early intervention program or school system for an assessment. Remember, it's never too early or too late to get help for your child. You can learn more about developmental milestones and get free milestone checklists on CDC's website at [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly).

- **How can New Jersey parents access their Early Intervention Program (EIP) system?**

The EIP system in New Jersey serves all children under age 3. Concerned parents can request diagnostic services for their child by contacting: (<http://nj.gov/health/fhs/eis/index.shtml>) (NJDOH, 2012) or calling 1-888-653-4463.

- **What if parents are concerned about a child that is older than age 3?**  
Children over the age of 3 years are served by their local school district. Parents should contact the child study team in their town to request evaluation of their child. The school-based diagnostic services and any needed educational interventions are provided without cost to the family.
- **In March 2012, the ADDM Network autism prevalence estimates for 2008 were published. The study findings included autism estimates from 14 sites, including New Jersey. However, the New Jersey surveillance estimates were based on one county (Union County), rather than four counties. Why was autism surveillance for 2008 only conducted in Union County?**

In 2009, CDC provided funding to the New Jersey ADDM Network site to track autism prevalence in only one county. We chose Union County because of the diversity of the county and our excellent access to health and special education records there. The 2008 ADDM Network prevalence report, including the New Jersey findings can be reviewed at:

(<http://www.cdc.gov/ncbddd/autism/addm.html>) (MMWR, 2012).

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