A Snapshot of Autism Spectrum Disorder in North Carolina

The North Carolina Autism and Developmental Disabilities Monitoring (NC-ADDM) Project helps determine the number of children with autism spectrum disorder (ASD) in the central part of North Carolina, the characteristics of those children, and the age at which they are first evaluated and diagnosed.

1 in 39
or 2.5% of 8-year-old children in central North Carolina were identified with ASD by the NC-ADDM Project in 2016.

**Black children were 1.4x More likely to be identified with ASD than Hispanic children**

**Boys were 4.7x More likely to be identified with ASD than girls**

By 38 months half of children identified with ASD were diagnosed.

IQ data available for 91% Of children identified with ASD by the NC-ADDM Project

62% of children Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years.

57% of children Identified with ASD had a documented ASD diagnosis.

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between Hispanic and white children or white and black children.
What are the key take-away messages?
• Many children with ASD need services and support, now and as they grow into adolescence and adulthood.
• Hispanic children are less likely to be identified with ASD than white or black children in North Carolina. This may reflect cultural or socioeconomic factors that impact access to services compared to other groups in North Carolina.
• Among the areas where CDC tracks ASD across the United States, central North Carolina had the highest percentage of children identified with ASD who had received a comprehensive developmental evaluation by age 3 years. This is good news, but there is still more to be done to ensure that all children are evaluated as soon as concerns about their development are identified.
• Evaluating and diagnosing all children with ASD as early as possible can help them get connected to the services they need.

How can this information be useful?
The NC-ADDM Project’s latest findings can be used to:
• Promote early identification of ASD;
• Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
• Guide future ASD research; and
• Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Stakeholders in North Carolina might consider different ways to increase awareness of ASD among Hispanic families and identify and address barriers to evaluation and diagnosis in order to decrease the age at which Hispanic children are evaluated and diagnosed.

How and where was this information collected?
This information is based on the analysis of data collected from the health and special education records of children who were 8 years old and living in one of four counties in central North Carolina in 2016.

Tracking area
Alamance, Chatham, Orange, and Wake counties

8-year-old children in tracking area: 19,291
• 55% white
• 21% black
• 12% Hispanic
• 7% Asian or Pacific Islander

What else does NC-ADDM do besides tracking ASD among 8-year-olds?
The NC-ADDM Project collaborates with the North Carolina Department of Health and Human Services and investigators from the University of North Carolina at Chapel Hill to track the number and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability. The NC-ADDM Project works with the North Carolina Autism Alliance and other interdisciplinary partners to continually identify ways the data can help improve our understanding of the needs of families in North Carolina.
North Carolina Autism & Developmental Disabilities Monitoring Network

NC ADDM has been part of a national effort to estimate the number of children with autism spectrum disorders (ASD) funded by the Centers for Disease Control and Prevention (CDC). NC ADDM has reviewed health and education records to provide the most accurate data possible on the prevalence of ASD in central NC to inform programmatic and fiscal planning that supports the education and health of affected children.

The March 2020 reports\textsuperscript{1,2} present the prevalence of ASD for the ADDM Network, including the ASD prevalence among 17,545 children who were 4 years old (born in 2012) and 19,291 children who were 8 years old (born in 2008) and resided in central North Carolina (NC) in 2016. The central NC counties included in NC ADDM are Alamance, Chatham, Orange, and Wake counties. This brief summary is for our NC stakeholders, the complete report, including methods and results, can be found in the CDC publications\textsuperscript{1,2}

**Highlights of the 2016 Autism Spectrum Disorders Prevalence Estimates**

| 2016 Prevalence among children born in 2008, 8-year-old children\textsuperscript{1}: |
| NC 4-central counties: | 25.3 per 1,000 children* or 1 in 40 |
| CDC’s 11 participating sites: | 18.5 per 1000 children* or 1 in 54 |

| 2016 Prevalence among children born in 2012, 4-year-old children\textsuperscript{2}: |
| NC 4-central counties: | 11.8 per 1,000 children* or 1 in 84 |
| CDC’s 6 participating sites: | 15.6 per 1000 children* or 1 in 64 |

**Among both 4-year old and 8-year old NC children:**

- ASD Prevalence was nearly 5 times higher among boys than girls.
- ASD Prevalence was similar among non-Hispanic black and white children, but lower among Hispanic children. Getting a diagnosis is often key to getting timely support, which emphasizes the need to improve identification of ASD among Hispanic children in NC.
- 63% of 8 year-olds and 93% of 4 year-olds identified with ASD in NC received a comprehensive evaluation before 3 years of age, earlier than much of the ADDM Network.
Trends over time 2002-2016:
Over time, ASD prevalence among 8-year-old NC children has consistently tracked slightly higher, but generally similar to the CDC estimates. Yet, in this report, the 2016 ASD estimate among 8-year-olds in NC is notably higher than the CDC pooled estimate and higher than previous NC estimates. Importantly, the 2016 estimate reflects a smaller geographic region that is known to have favorable access to services for children with developmental disabilities.

Considerations for interpreting North Carolina’s 2016 estimates relative to previous estimates:
CDC’s standardized criteria for ASD was operationalized from DSM5 criteria. Compared to previous reports, this NC Report reflects a smaller geographic area (fewer counties), but adds information for 4 year old children. The counties included was based on both geography and availability of data. The density and number of records requiring review was higher this cycle than in previous cycles. Anecdotally, these counties have a number of resources for children with ASD, which might impact both the age at evaluation and the overall prevalence estimates. For 4-year-olds, data from educational sources was not available for all four counties. This may contribute to the comparably lower prevalence estimate for 4-year-olds in NC.

We will work with our regional partners to further analyze the data from this initial report and explore factors (real and artifactual) that may impact the estimates for 2016.

Collaborating agencies in NC:
This project reflects collaborations among the University of North Carolina at Chapel Hill (the NC Autism and Developmental Disabilities Monitoring Project and the TEACCH Autism Program), The Early Intervention Program of the Children’s Developmental Service Agencies at the Department of Health and Human Services, and the Exceptional Children’s Division of the Department of Public Instruction.

References & Additional Resources:
*Denominator from CDC’s National Center for Health Statistics vintage 2018 bridged-race population estimates.
1. Maenner MJ, Shaw KA, Baio J, et al. Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disability Monitoring Network, 11 sites, United States, 2016. MMWR Surveill Summ 2020;69(No. SS-4). [https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w](https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w)
2. Shaw KA, Maenner MJ, Baio J, et al. Early identification of autism spectrum disorder among children aged 4 years—Early Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2016. MMWR Surveill Summ 2020;69(No. SS-3). [https://www.cdc.gov/mmwr/volumes/69/ss/ss6903a1.htm?s_cid=ss6903a1_w](https://www.cdc.gov/mmwr/volumes/69/ss/ss6903a1.htm?s_cid=ss6903a1_w)
- CDC Act Early Campaign [www.cdc.gov/ActEarly/HealthCare](http://www.cdc.gov/ActEarly/HealthCare)
- CDC Milestone Tracker App [https://www.cdc.gov/milestonetracker](https://www.cdc.gov/milestonetracker)