

A Deeper Dive: Frequently Asked Questions about the ADDM Network Data

How was this information collected?

As discussed in greater detail on page 6, the ADDM Network uses a systematic record review method. Specifically, this information is based on the analysis of data collected from the health and special education records (if available) of 8-year-old children who lived in one of 11 different areas throughout the United States in 2012.

Where was this information collected? Which children does it include?

- Tracking area: Specific areas of Arkansas, Arizona, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin (see state pages for more information)
- Children in tracking area: 346,978 8-year-olds
 - 53% white
 - 21% black
 - 20% Hispanic
 - 5% Asian or Pacific Islander
 - Less than 1% American Indian or Alaska Native

What are the key take-away messages?

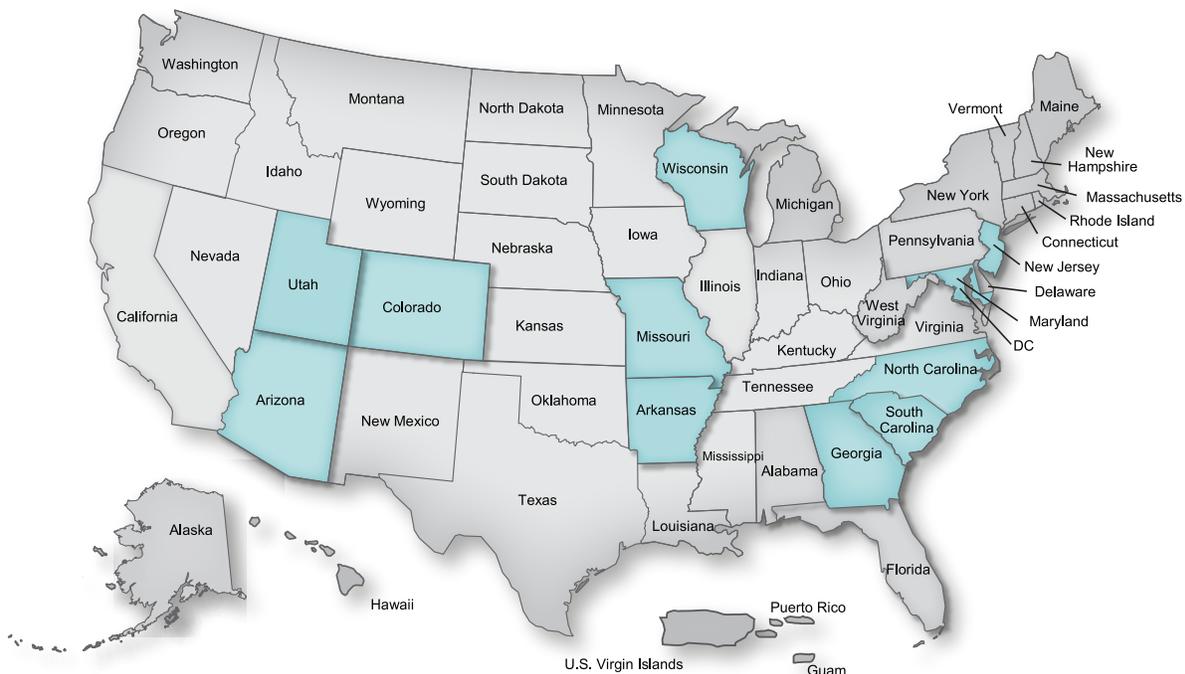
There continue to be many children living with ASD who need services and support, both now and as they grow into adolescence and adulthood. More needs to be done to ensure that all children with ASD are evaluated and diagnosed as early as possible so that they can be connected to the services they need.

Why did the percentage of children with ASD stay the same between 2010 and 2012?

The ADDM Network estimates that about 1 in 68 or 1.5% of 8-year-old children in multiple communities across the United States were identified with ASD. This means that the percentage of children identified with ASD did not change significantly between 2010 and 2012. It is too soon to tell if the percentage of children identified with ASD over time is stabilizing. There are two main reasons why it is too soon to tell:

- While the average percentage of children identified with ASD in all geographic areas stayed the same, in two individual areas, the percentage of children identified with ASD increased significantly between 2010 and 2012.

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites



- The percentage of children identified with ASD ranged widely by geographic area— in areas where both health and education records were reviewed, estimates ranged from a low of 1.2% in parts of South Carolina to a high of 2.4% in parts of New Jersey.

CDC will continue to track ASD over time to help better understand if the percentage of children identified with ASD is staying the same or increasing. Regardless, it is clear that there are many children with ASD who need services and support, now and as they grow into adolescence and adulthood.

Why did the percentage of children identified with ASD increase in some areas but not in others?

There were significant increases in the percentage of children identified with ASD in areas of New Jersey and Wisconsin, while the percentage stayed the same in other areas. Currently, research does not show that living in certain communities puts children at greater risk for developing ASD. These geographic differences could be related to how the ADDM Network identifies children—for example, access to health versus both health and special education records. It could also be due to changes in how children are identified and served in their local communities—for example, variations across communities in insurance coverage for ASD services. Continuing to track ASD over time will help us monitor future changes.

These data show that black and Hispanic children are less likely to be identified with ASD and are, on average, being evaluated later than white children. Why is that?

The exact reasons are not known, but research into this trend is ongoing. Research does not show that black or Hispanic children have a lower risk of developing ASD than white children. It is possible that black and Hispanic children face socioeconomic or other barriers resulting in a lack of or delayed access to evaluation, diagnosis, and services. Previous studies have shown that stigma, lack of access to healthcare services due to non-citizenship or low-income, and language barriers are potential factors that may influence ASD identification among Hispanic children. Targeted strategies are needed to increase awareness of ASD among black and Hispanic families, and identify and address barriers in order to decrease the age at which black and Hispanic children are evaluated and diagnosed.

How many children in the United States have ASD?

Currently, there is not a full count of all individuals with ASD living in the United States. However, it is estimated that there are currently between 500,000 and 1 million children aged 6-17 years living with ASD in the United States.

How does the ADDM Network estimate compare to other estimates that as many as 1 in 50 or 1 in 45 children have ASD?

Estimates from the ADDM Network, the National Survey on Children's Health (NSCH), and the National Health Interview Survey (NHIS) cannot be directly compared because they use different methods to collect their information and look at different age groups. NSCH and NHIS, based on national surveys of parent experiences, can provide insight into how many children have been diagnosed with ASD and other developmental disabilities. The ADDM Network findings further enrich our understanding of ASD by working with communities across the United States to collect information on specific characteristics of children with ASD, and tracking changes in those communities and within different subgroups over time. Overall, however, the ADDM Network and the surveys produce similar estimates of the percentage of children identified with ASD. For example, 2011-2012 data from the NSCH found that about 1.8% of 6-9-year-olds were identified by parent-report as having ASD. Similarly, 2012 data from the ADDM Network found that about 1.7% of 8-year-olds were identified by information found in both special education and health records as having ASD. The bottom line is that the ADDM Network and the surveys are complementary and help us understand ASD from different vantage points.

“CDC's latest autism surveillance report underscores the magnitude of need for personalized treatments, therapies, and educational supports for children across the entire autism spectrum in every neighborhood throughout the country. We know that these services and improved medical care can make a lifetime of difference – not only for these children and their families – but for a society that will be richer for their inclusion in employment, post-secondary education and community life.”

**- Angela Geiger
President/CEO, Autism Speaks**