Community Report on Autism

2016

From the Autism and Developmental Disabilities Monitoring Network

National Center on Birth Defects and Developmental Disabilities
Division of Congenital and Developmental Disorders

CS263934

Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network

A Snapshot of Autism Spectrum Disorder among 8-year-old Children in Multiple Communities across the United States in 2012

Funded by the Centers for Disease Control and Prevention (CDC),
United States Department of Health and Human Services

This community report summarizes the main findings from the following published report:

Christensen DL, Baio J, Van Naarden Braun K, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. MMWR Surveill Summ 2016;65(No. SS-3): 1 -23.

To read the full scientific report, please go to www.cdc.gov/mmwr

To read more about autism spectrum disorder, please visit CDC's Autism Homepage at www.cdc.gov/autism

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Table of Contents

Executive Summary iv

What Is Autism Spectrum Disorder? 1

What is the ADDM Network? 5

Key Findings from the ADDM Network: A Snapshot of Autism Spectrum Disorder 9

A Deeper Dive: Frequently Asked Questions about the ADDM Network Data 11

Data for Action: How Can You Use the ADDM Network Findings? 13

State by State: Key Findings and Resources 15

- Arizona 17
- Arkanas 19
- Colorado 21
- Georgia 23
- Maryland 25
- Missouri 27
- New Jersey 29
- North Carolina 31
- South Carolina 33
- Utah 35
- Wisconsin 37

What Else Do I Need to Know? 39

Where Can I Get More Information? 40

Glossary 42

References 43

Executive Summary

Introduction

Findings from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network show that the estimated percentage of children identified with autism spectrum disorder (ASD) remains high. About 1 in 68 or 1.5% of 8-year-old children were identified with ASD based on tracking across multiple areas of the United States. These findings indicate that there continue to be many children living with ASD who need services and support, now and as they grow into adolescence and adulthood. Knowing how many children have ASD is just part of the picture. Findings also show that more can be done to ensure that children are evaluated as soon as possible after developmental concerns are identified. We urge those who work with or on behalf of children—from healthcare providers to educators to community advocates—to join forces to ensure that all children with ASD are identified and connected to the services they need as early as possible.

What is the purpose of this report?

This is the 6th Community Report from the ADDM Network, which tracks the number and characteristics of children with ASD and other developmental disabilities in diverse communities throughout the United States. The purpose of this Community Report is to highlight the ADDM Network's most recent scientific findings on ASD and empower those living in the ADDM Network communities—from public health agencies to healthcare organizations to school systems and beyond—to use these data for action.

What are the key findings?

These findings are based on the analysis of information collected from the health and special education (if available) records of 8-year-old children who lived in areas of Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin in 2012.

- ✓ The estimated percentage of children identified with ASD remains high, but 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.
- ✓ Children identified with ASD are not receiving comprehensive developmental evaluations as early as they could be.
- ✓ Black and Hispanic children are less likely to be identified with ASD. Those who *are* identified with ASD receive comprehensive developmental evaluations later than white children.
- ✓ Schools play a vital role in evaluating and serving children with ASD.

For a more in-depth look at the Key Findings, please go to page 9.

Why is this information important and how can it be used?

For over a decade, CDC's ADDM Network has been at the forefront of documenting the changing number and characteristics of children with ASD. Findings from the ADDM Network have laid the foundation for research into who is likely to develop ASD, why ASD develops, and how best to support individuals, families, and communities affected by ASD. Service providers (such as healthcare organizations and school systems), researchers, and policymakers can use ADDM Network findings to support service planning, guide research on the factors that put a child at risk for ASD and which interventions can help, and inform policies that promote improved outcomes in health care and education. In particular, targeted strategies are needed to

1. Lower the age of first evaluation by community providers, and
2. 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.

CDC will continue tracking the number and characteristics of children with ASD, researching what puts children at greater risk for ASD, and promoting early identification, the most powerful tool we have now for making a difference in the lives of children with ASD.

NUMBER OF CHILDREN IDENTIFIED WITH ASD

What Is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) is a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. Signs of ASD begin during early childhood and usually last throughout a person's life (1).

Previously, the term "ASD" collectively referred to the following three conditions that were diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger disorder (2). ASD now encompasses a single diagnosis of "autism spectrum disorder" (see pg. 7 for more information on this change). The term "spectrum" in ASD means that each person can be affected in different ways, and symptoms can range from mild to severe. People with ASD share some similar symptoms, such as difficulties with social interaction, difficulties with communication, and highly focused interests and/or repetitive activities. How the symptoms affect a person's functioning depends on the severity and combination of those symptoms.

Developmental Monitoring

Developmental monitoring is important for all young children from birth to age 5 years. Caregivers, such as parents, healthcare providers, and early educators, should be aware of developmental milestones—how children grow, move, communicate, interact, learn, and play. This information helps caregivers know what to expect, get ideas on how to promote positive development, and be aware of potential concerns about development as early as possible. Developmental monitoring is an ongoing process, and CDC's "Learn the Signs. Act Early." program has tools and information to help at www.cdc.gov/ActEarly.

Screening, Evaluation, and Diagnosis

Screening, evaluating, and diagnosing children with ASD as early as possible is important for ensuring that these children access the services and support they need. At this time, there is no medical test, such as a blood test or brain scan, to diagnose ASD. Instead, ASD is diagnosed by qualified professionals who conduct comprehensive psychological and behavioral evaluations.

A Developmental Screen is a short test to tell if a child is learning basic skills, and can help identify if there might be a delay. The American Academy of Pediatrics recommends that all children be screened for developmental delays and disabilities during regular well-child doctor visits at 9 months, 18 months, and 24 or 30 months of age. They also recommend that children be screened specifically for ASD at 18 and 24 months of age (3-4).

A Comprehensive Developmental Evaluation is a thorough review of the child's behavior and development. These evaluations can include clinical observation, parental reports of developmental and health histories, psychological testing, and speech and language assessments. A range of professionals can conduct comprehensive evaluations, including teachers, social workers, nurses, psychologists, doctors, and speech-language pathologists.

Diagnosis occurs when a developmental pediatrician, child neurologist, child psychiatrist, or child psychologist uses the results of the comprehensive evaluation to determine if a child has ASD based on the criteria in the *Diagnostic and Statistical Manual of Mental Disorders* (1). Also, neurologic and genetic testing can be used to rule out other disorders and to check for genetic or neurological problems that sometimes co-occur with ASD.

"CDC data continue to show that schools are vital in evaluating and serving children with ASD. Children, especially those with developmental delays or special needs, spend large portions of the day at school, working with educators and therapists. This supports that a partnership between the medical and educational community is vital."

-Susan Levy, MD, MPH
Chair, Autism Subcommittee, Council on Children with Disabilities, American Academy of Pediatrics

Signs and Symptoms

A child with ASD might

- ✓ Avoid eye contact and want to be alone.
- ✓ Have trouble understanding other people's feelings or talking about his or her own feelings.
- ✓ Have delayed speech and language skills (for example, use words much later than siblings or peers or not use words to communicate).
- ✓ Repeat words or phrases over and over.
- ✓ Give unrelated answers to questions.
- ✓ Get upset by minor changes in routine (for example, getting a new toothbrush).
- ✓ Have obsessive interests (for example, having a very strong interest in trains that is difficult to interrupt).
- ✓ Flap his or her hands, rock his or her body, or spin in circles.
- ✓ Have unusual ways of playing with or using objects, such as spinning or lining them up repeatedly.
- ✓ Have unusual reactions to the way things sound, smell, taste, look, or feel.

A child with ASD might not

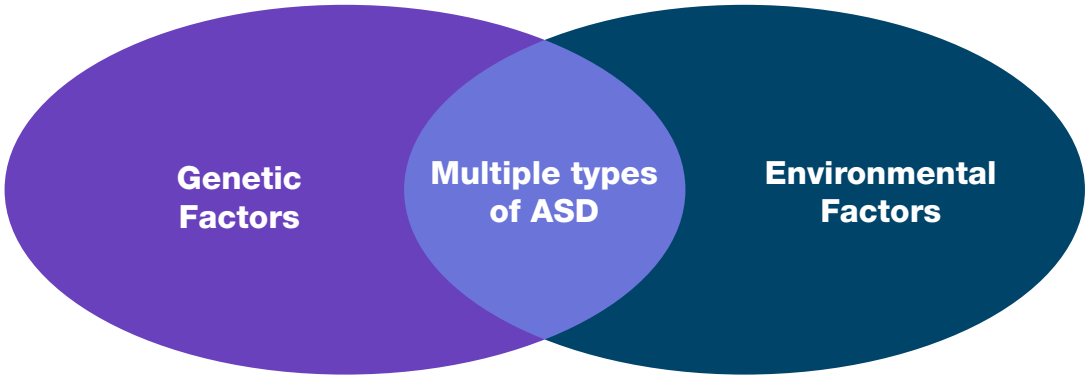
- ✓ Respond to his or her name by 12 months of age (for example, appear not to hear).
- ✓ Point at objects to show interest by 14 months of age (for example, point at an airplane flying over).
- ✓ Play "pretend" games by 18 months of age (for example, pretend to "feed" a doll).

To access downloadable checklists of developmental milestones for children from 2 months to 5 years of age, and to watch real-life examples of ASD symptoms, please visit www.cdc.gov/ActEarly.

Risk Factors and Causes

ASD is a complex disorder, and most scientists who study ASD believe that there is no single cause. We have learned that there are likely many causes for multiple types of ASD. There may also be many different factors, including environmental and genetic factors, which make a child more likely to have ASD. Understanding more about these factors will help us learn about the causes of ASD. The table below highlights some of the factors which have been found to have strong evidence for putting children at greater risk for ASD and some which are suspected of putting children at greater risk. It is important to remember that no single risk factor leads to ASD, and many of these risk factors are outside of an individual's control.

Currently, CDC is working on one of the largest studies in the United States to try to identify the factors that might make a child more likely to develop ASD. This study, called the Study to Explore Early Development (SEED), is examining many factors—from genes to characteristics of the pregnancy, birth, and newborn period. SEED is unique because it includes a large sample of children that allows for complex evaluation of how child characteristics and environmental and genetic factors all interact to increase a child's risk for ASD (25).



Strong Evidence	Suspected
Family history of ASD, such as having siblings or a twin with ASD (5 -7)	**Family history of immune-associated conditions**, such as thyroid disease or rheumatoid arthritis (11)
Older age of mother and/or father (8 - 9)	**Genes, genetic mutations, and epigenetic processes** (changes in how a gene is expressed without changes to the DNA), including complex interactions between genes and environmental factors before, during, and immediately after pregnancy (12-14)
Select single gene disorders, such as fragile X syndrome, Rett syndrome and tuberous sclerosis complex (10)	**Various factors related to pregnancy**, such as extremely preterm delivery, very low birthweight, maternal infection, use of infertility treatments, maternal exposure to environmental pollutants, obstetric complications, use of certain medications during pregnancy, and maternal diabetes or obesity (15 – 24)

"The CDC's prevalence data are essential because they inform our efforts to build out the infrastructure -- schools, and later adult housing and services -- that people with autism need and deserve. The insights we glean from these data, including information about disparities in diagnosis along racial and ethnic lines, also impact the direction of autism science and advocacy. None of us can ever forget that our children, our sons and daughters, are not just numbers. We have to be relentless in our fight for more research and services."

- Alison Singer
Co-Founder and President, Autism Science Foundation

Economic Costs

Caring for a child with ASD can place a heavy economic burden on families and communities and can extend beyond paying for a child's services and supports.

- The total costs per year for children from birth to 17 years old with ASD in the United States were estimated to be between $11.5 billion - $60.9 billion in 2011 US dollars. This significant economic burden can represent a variety of direct and indirect costs, from medical care to special education (26-27-21).
- Some parents report having to stop work to care for their child with ASD (28-29-23).
- Mothers who maintain employment end up working about 7 hours less per week and earn 56% less than mothers of children with no major health issues (30).

Staying Healthy with ASD

Children with ASD need health care and health programs for the same reasons anyone else does—to stay well and active, and to be able to participate in their community. Some conditions have been found to be more common among children with ASD such as anxiety, attention deficits, Down syndrome, depression, epilepsy, fragile X syndrome, gastrointestinal problems, hearing loss, intellectual disability, obesity, sensory-processing difficulties, sleep problems, tuberous sclerosis, and vision impairment (31-34). It is important to recognize these conditions and treat them accordingly. Regular medical and dental examinations are essential components of a child's care plan, as are preventive measures, such as routine childhood immunizations and flu shots.

What is the ADDM Network?

The Autism and Developmental Disabilities Monitoring (ADDM) Network is the only collaborative network to track the number and characteristics of children with ASD in multiple communities in the United States. Since the launch of the ADDM Network in 2000, CDC has funded 14 sites in areas of Alabama, Arizona, Arkansas, Colorado, Florida, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Tennessee, Utah, West Virginia, and Wisconsin. The ADDM Network sites are selected through a competitive award process and are not intended to form a sample that represents the nation as a whole. The ADDM Network sites all collect and analyze information using the same tracking method, which is modeled after CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP). MADDSP represents the Georgia ADDM Network site.

The ADDM Network's goals are to

- Obtain as complete a count as possible of the number of children with ASD in each ADDM Network area and identify changes in that count over time.
- Provide information on the characteristics, including sex, race/ethnicity, co-occurring intellectual ability, and age of evaluation and diagnosis, of children with ASD.
- Determine whether ASD is more common in some groups of children (for example, among boys versus girls) than among others, and if those differences are changing over time.
- Understand the impact of ASD and related conditions upon children, families, and communities in the United States.

What is prevalence?

The ADDM Network tracks the prevalence of ASD among children. Prevalence is a scientific term that describes the number of people with a disease or condition among a defined group at a specific period in time. For example, CDC estimated the prevalence of ASD among 8-year-olds in 2012 in metropolitan Atlanta, Georgia, by counting all of the 8-year-olds in metropolitan Atlanta who were identified with ASD, and then dividing that number by the total number of 8-year-olds living in metropolitan Atlanta during 2012. The resulting number is usually expressed as a percentage or proportion of the defined group.

What are the different ways of estimating the number of children with ASD?

There are several different ways to estimate the number of children with ASD, and each method has its advantages and disadvantages.

Method	What Is It?	Advantages and Disadvantages
Population-based screening and evaluation	Screening and evaluating a sample of all children in a population.	Can provide high accuracy, but can be costly and time-consuming, and might produce skewed results based on who agrees to participate.
National surveys	Collecting information via standardized instruments such as telephone interviews or self-completed questionnaires.	Is representative of national characteristics, but might reflect bias based on who participates and how ASD is defined and reported.
Registries	Collecting information on children and families who voluntarily include themselves on a list of people affected by ASD.	Relatively low cost, but time-consuming and includes only individuals with a clear diagnosis and families who know about the registry and are willing to be on the list.
Administrative data	Looking at codes for services in records from Medicaid and agencies such as the U.S. Department of Education.	Relatively low cost, but can underestimate prevalence because not all children with ASD are receiving services for ASD or have been diagnosed with ASD.
Systematic record review (ADDM Network's Method)	Reviewing health and special education records to identify children with ASD behaviors.	Relatively cost-effective and uses multiple data sources to identify children who might not have a clear ASD diagnosis already, but relies on the quality and quantity of information in records and, because data collection is retrospective, it is not always timely.

What is the ADDM Network's method?

The ADDM Network estimates the number of children with ASD using a record review method. Trained abstractors review records at sources in the community that educate, diagnose, treat, and/or provide services to children with developmental disabilities. It is important to note that this review does not only rely on a child having an ASD diagnosis, but also includes review of records for children with documented behaviors that are consistent with ASD. Abstracted information from all sources for a child is then reviewed by trained clinicians who determine if the child meets the definition of ASD using the *DSM-IV-TR* criteria.

Community partnerships are the key.

What are the advantages of the ADDM Network method?

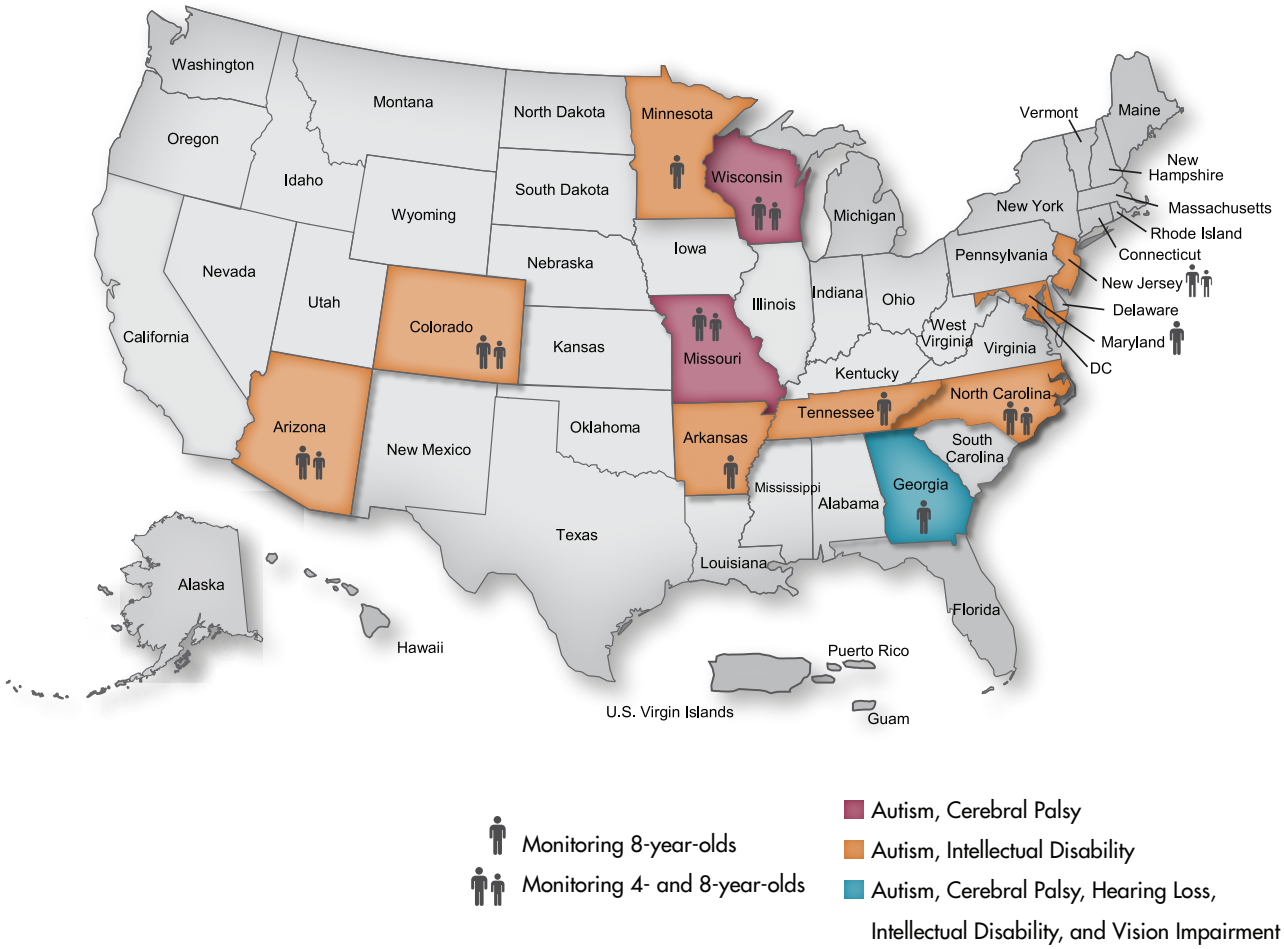
There are several major advantages to using the ADDM Network method for tracking the number and characteristics of children with ASD. For example, the ADDM Network

- Is the largest, ongoing ASD tracking system in the United States.
- Uses a method that is population-based, which means we try to identify all the children with ASD from the entire population of children in a defined geographic area (or multiple geographic areas).
- Can track changes over time within different communities and within different groups (such as racial/ethnic groups)
- Collects information from multiple sources in the community where children are served, including schools and local clinics.
- Uses expert reviewers to make a decision about whether a child has ASD based on review of symptoms documented in multiple records This means children with ASD are included in the total count even if they did not have an ASD diagnosis in their records.

DSM-5 and the ADDM Network

In May 2013, the American Psychiatric Association released a new edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), which is what doctors and other service providers use to diagnose mental disorders and conditions among children and adults. This new edition, also known as DSM-5, includes new criteria for diagnosing children and adults with ASD. **It important to note that the findings in this Community Report are based on information collected in 2012 before the DSM-5 was being used by doctors and other service providers to diagnose ASD.** This means that the information in this report reflects the ASD criteria in the previous edition, DSM-IV-TR.

Current ADDM Network Sites, Tracking Years 2014–2016



The exact impact that *DSM-5* will have on estimates of the number of children identified with ASD is unknown. An initial analysis using information from the ADDM Network found that estimates of the number of children identified with ASD might be lower using the current *DSM-5* criteria than using the previous *DSM-IV-TR* criteria (35). As doctors and other service providers start using the *DSM-5* criteria, they might diagnose ASD using new or revised tools or they might document symptoms differently. These changes in everyday community practice could alter the *DSM-5*'s effect on estimates of the number of children with ASD. Because of the way that it collects information, the ADDM Network is uniquely positioned to track these changes. The ADDM Network will be able to use both the previous *DSM-IV-TR* and the current *DSM-5* criteria to estimate the number of children with identified ASD from tracking year 2014 and onward. CDC will continue to evaluate the effect of using the *DSM-5* on trends in how doctors diagnose ASD. CDC will also continue to examine how other service providers, such as educators, evaluate and document symptoms as they transition to using the *DSM-5* criteria.

What else is the ADDM Network doing?

Ongoing tracking is essential to our understanding of ASD. Since 2000, the ADDM Network has continued to collect and analyze information to produce estimates every two years of the number and characteristics of children with ASD among 8-year-old children. In 2010 and 2012, the Early ADDM Network, a subset of the ADDM Network, tracked ASD among 4-year-olds in areas of Arizona, Missouri, New Jersey, Utah, and Wisconsin. Beginning with the 2014 tracking year, the Early ADDM Network tracked ASD among 4-year-olds in areas of Arizona, Colorado, Missouri, New Jersey, North Carolina, and Wisconsin. Some ADDM Network sites also track the number and characteristics of children with other developmental disabilities including cerebral palsy, intellectual disability, hearing loss, and vision impairment.

The ADDM Network continues to analyze ADDM Network findings to answer questions about potential risk factors for ASD and characteristics of children with ASD, and to understand more about changes in ASD over time. In 2011, CDC brought together a diverse group of professionals and community stakeholders to develop a plan to better understand changes in ASD prevalence over time. The summary of the "Workshop on U.S. Data to Evaluate Changes in the Prevalence of Autism Spectrum Disorders" is a valuable resource that can help researchers and others better understand the changes in the number and characteristics of children with ASD. A full list of publications and reports based on CDC's work in ASD can be found on our website at www.cdc.gov/autism.

"The Autism Society and our 100 affiliates strongly rely upon CDC's autism-related data for our strategic planning and policy development. We value our partnership with CDC as a national leader helping guide us and others as we address the growing needs of all impacted by autism."

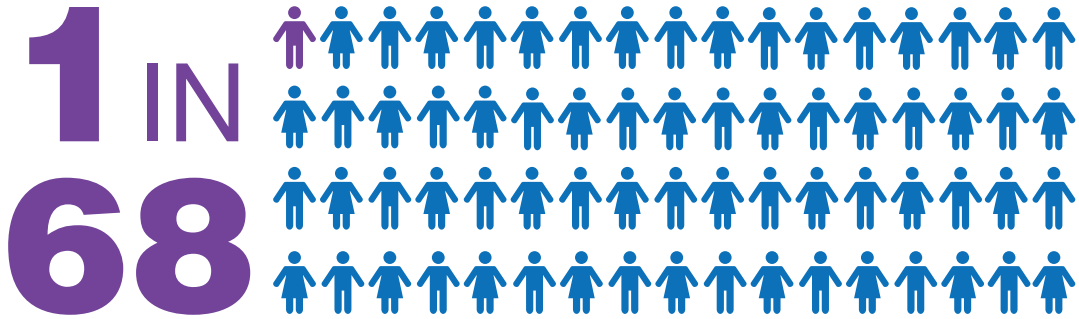
-Scott Badesch
President/CEO, Autism Society of America

Key Findings from the ADDM Network: A Snapshot of Autism Spectrum Disorder

Data from the Autism and Developmental Disabilities Monitoring (ADDM) Network help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD across the ADDM Network.

How many children were identified with ASD?

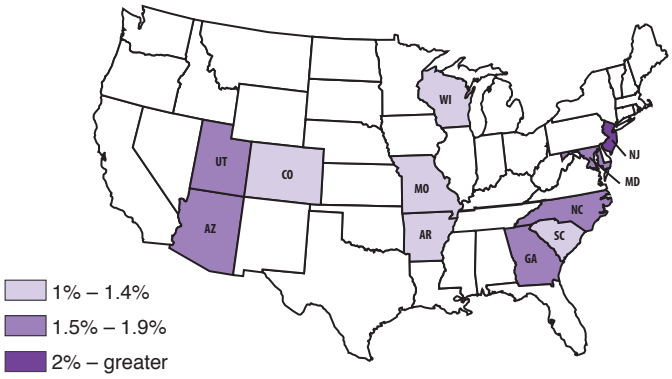
About 1 in 68 or 1.5% of 8-year-olds were identified with ASD by the ADDM Network.



How did the percentage of children identified with ASD range across geographic areas?

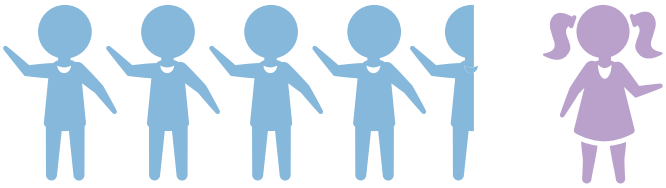
The percentage of children identified with ASD ranged widely across geographic areas.

For example, in the areas where the ADDM Network reviewed both health and special education records, the percentage of children who were identified with ASD ranged from a low of 1 in 81 or 1.2% in areas of South Carolina to a high of 1 in 41 or 2.5% in areas of New Jersey.



Which children were more likely to be identified with ASD?

Boys were 4.5 times more likely to be identified with ASD than girls.



White children were more likely to be identified with ASD than black or Hispanic children. Black children were more likely to be identified with ASD than Hispanic children.

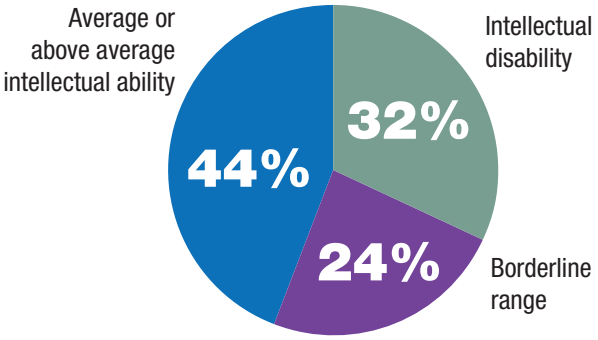
1.2x MORE LIKELY among white vs black children

1.5x MORE LIKELY among white vs Hispanic children

1.3x MORE LIKELY among black vs Hispanic children

What was the intellectual ability of the children identified with ASD?

Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.



* Based on information from the 9 ADDM Network sites that had intelligence quotient (IQ) scores available for at least 70% of children identified with ASD. Intellectual disability defined as IQ score ≤70.

When were children evaluated and diagnosed?

- **About 43% of children identified with ASD were evaluated for developmental concerns by age 3 years. This percentage is lower than the goal set by Healthy People 2020 that 47% of children with ASD have a first evaluation by age 3 years.**
- **Black and Hispanic children were less likely to be evaluated for developmental concerns by age 3 years than white children.**

- **Even though ASD can be diagnosed as early as age 2 years, most children were not diagnosed with ASD by a community provider until after age 4 years.**

ASD Subtype	Median* Age of Diagnosis
Autistic disorder	3 years, 10 months
Pervasive developmental disorder-not otherwise specified (PDD-NOS)	4 years, 1 month
Asperger disorder	6 years, 2 months

* Median is the number in the "middle" within a sorted list of number from highest to lowest.

- **About 82% of children identified with ASD either had an**
  - **Eligibility for autism-specific services within the special education program at school, or**
  - **ASD diagnosis from a community provider.**
- **The remaining 18% of children were identified as having ASD by the ADDM Network based on ASD symptoms documented in their health and/or special education records, but had not yet been recognized by a community provider as having ASD.**

What role do schools play in the identification of children with ASD?

- **A greater percentage of children were identified with ASD when combining all ADDM Network sites that reviewed both health and special education records than when combining all ADDM Network sites that reviewed only health records.**
- **ADDM Network data continue to highlight the pivotal role schools play in evaluating and serving children with ASD.**

Health-Only Sites

= 1 in 93 (or 1.1%)

Health and Special Education Sites

= 1 in 58 (or 1.7%)

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

Data for Action: How Can You Use the ADDM Network Findings?

There are many children and families living with ASD across the United States. The ADDM Network's information on the number and characteristics of children with ASD provides data for action. These findings can be used in local communities and nationwide to move forward initiatives, policies, and research that help children with ASD.

The federal government is using this information to

- ❏ Measure progress toward goals.
  - o ADDM Network findings are used to measure progress toward the Healthy People 2020 goals of increasing the proportion of children with ASD with a first evaluation by 36 months of age and enrolled in special services by 48 months of age (36).
- ❏ Guide our research and the research of other scientists across the country.
  - o ADDM Network findings have helped inform the Interagency Autism Coordinating Committee's Strategic Plan for ASD research (37).
- ❏ Promote early identification efforts.
  - o ADDM Network findings on average age of diagnosis support CDC's "Learn the Signs. Act Early." program, which aims to lower the average age of diagnosis by promoting developmental monitoring among parents, childcare providers, and healthcare providers.

Service providers, such as healthcare organizations and school systems, can use this information to

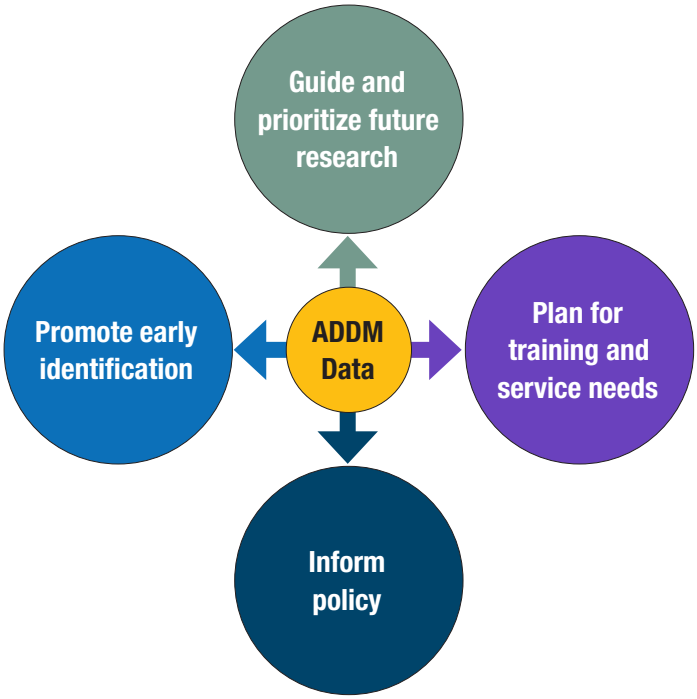
- ❏ Promote early identification efforts in order to lower the age when children are first evaluated for developmental concerns, diagnosed with ASD, and enrolled in community-based support systems.
- ❏ Improve recognition and documentation of symptoms of ASD.
- ❏ Plan and coordinate service delivery.
- ❏ Target outreach to under-identified groups of children, such as black and Hispanic children.

Policymakers and community leaders can use this information to

- ❏ Promote awareness of ASD and bring the community together to address the growing needs of families living with ASD.
- ❏ Develop policies and promote early identification and equity in access to services and supports so that all children get the help they need.
- ❏ Serve as the basis for the creation of a task force or commission, focused on the coordination of ASD activities in local communities.

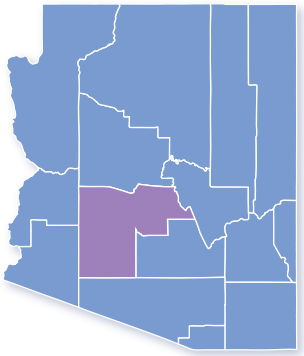
Researchers can use this information to

- ❏ Document the need for accelerated ASD research.
- ❏ Guide future research projects.
- ❏ Examine more closely why and how ASD affects children differently by sex, race/ethnicity, intellectual ability, and community.
- ❏ Support the creation of ASD community research consortia in local communities.
- ❏ Develop standard tools for measuring and documenting severity and functioning among children with ASD.



State by State: Key Findings and Resources

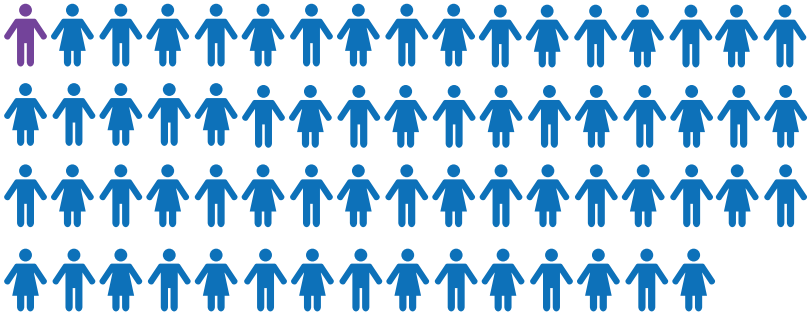
A Snapshot of Autism Spectrum Disorder in Arizona



Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Arizona and how this important information can be useful to you.

About 1 in 66 or 1.5% of 8-year-old children were identified with ASD by ADDSP in 2012. This percentage is about the same as the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

1 IN 66



Boys were more likely to be identified with ASD than girls. White and black children were more likely to be identified with ASD than Hispanic children.

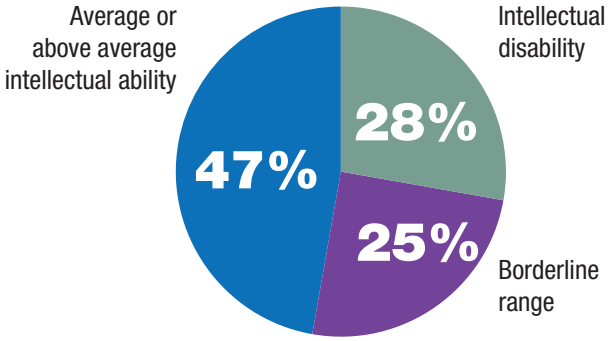
4.2x MORE LIKELY among boys vs girls

1.5x MORE LIKELY among white vs Hispanic children

1.7x MORE LIKELY among black vs Hispanic children

* No significant differences between white and black children

Among children identified with ASD who had IQ test scores available, less than a third also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by ADDSP. Intellectual disability defined as IQ score ≤ 70.

About 90% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 39% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 7 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Differences between the percentage of boys and girls identified with ASD continue. It may be that boys are at greater risk for ASD and/or it may be that girls are under-identified due to other factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- Hispanic children are less likely to be identified with ASD than white or black children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in Arizona.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

ADDSP's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Arizona might consider different ways to

1. Lower the age of first evaluation by community providers.
2. Increase awareness of ASD among Hispanic families, and identify and address barriers 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 part of Maricopa County in metropolitan Phoenix in 2012. Overall, the tracking area included 32,615 8-year-olds (48% white, 6% black, 40% Hispanic, 4% Asian or Pacific Islander, 2% American Indian or Alaska Native).

What else does ADDSP do besides tracking ASD among 8-year-olds?

ADDSP is a collaboration between Arizona Department of Health Services, Arizona Department of Education, and investigators from the University of Arizona to track the percentage and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability. In addition, ADDSP is involved in extensive ASD and developmental disabilities-related outreach and training of students, parents, educators, and clinicians. Training and outreach also extends to minority communities and rural service providers in Arizona.

"I use the information from ADDSP daily as I talk with families and professionals about what we are seeing in our community and across the state. The ADDM data are intrinsic to our understanding of the context of individuals with autism in the greater community of our state and nation."

-Sydney Rice, MD
Arizona Developmental Pediatrician

Get Resources and Connect Families to Services and Support in Arizona

Arizona Autism Coalition
azautism.org

Arizona Early Intervention Program
602-542-4446 des.az.gov/services/disabilities/developmental-infant

AZ Find
800-352-4558
www.azed.gov/special-education/az-find/

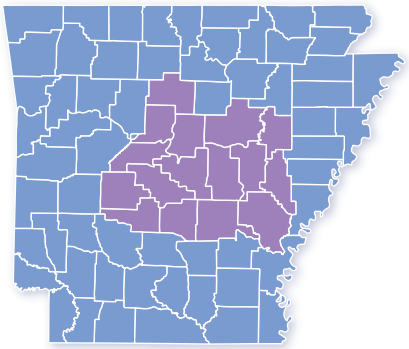
AZA United
602-773-5773
www.azaunited.org/

Southwest Autism Research and Resource Center (SARRC)
602-340-8717
www.autismcenter.org/

Connect with ADDSP
Sydney Pettygrove, PhD
Margaret Kurzius-Spencer, PhD

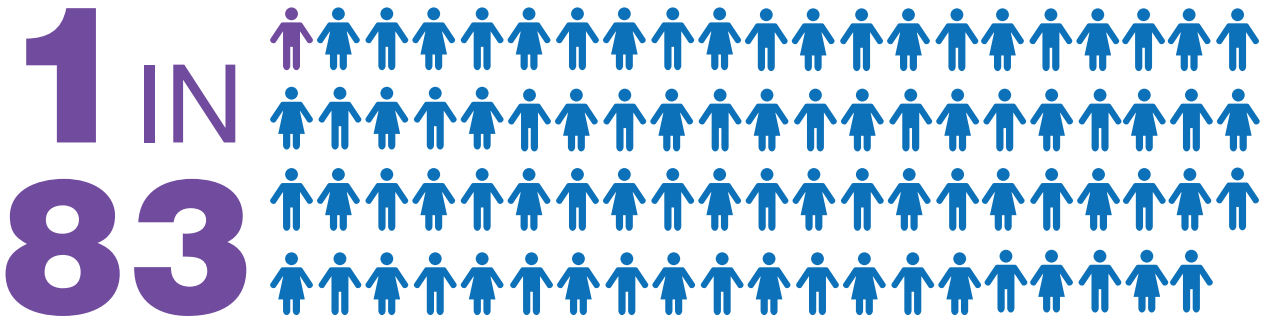
University of Arizona Health Sciences Center
PO Box 245073
Tucson, AZ 85724
sydneyp@u.arizona.edu
mkurzius@email.arizona.edu

A Snapshot of Autism Spectrum Disorder in Arkansas

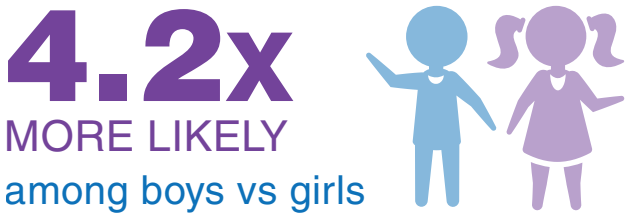


Findings from the Arkansas Autism and Developmental Disabilities Monitoring (AR ADDM) Program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Arkansas and how this important information can be useful to you.

About 1 in 83 or 1.2% of 8-year-old children were identified with ASD by AR ADDM in 2012. This percentage is lower than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

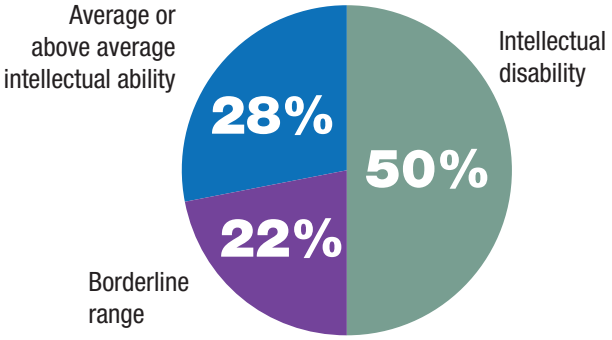


Boys were more likely to be identified with ASD than girls. No significant differences were found in the percentage of white and black children identified with ASD.



* No data available on Hispanic children with ASD

Among children identified with ASD who had IQ test scores available, half also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by AR ADDM. Intellectual disability defined as IQ score ≤ 70.

About 88% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 24% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 5 years.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Differences between the percentage of boys and girls identified with ASD continue. It may be that boys are at greater risk for ASD and/or it may be that girls are under-identified due to other factors, such as how providers diagnose and document ASD symptoms among boys versus girls.

How can this information be useful?

AR ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Arkansas might consider different ways to lower the age of first evaluation by community providers.

How and where was this information collected?

This information is based on the analysis of data collected from the health records of children who were 8 years old and living in one of 16 counties (Arkansas, Conway, Faulkner, Garland, Grant, Hot Spring, Jefferson, Lonoke, Monroe, Perry, Prairie, Pulaski, Saline, Van Buren, White, Woodruff) in central Arkansas in 2012. Overall, the tracking area included 14,153 8-year-olds (64% white, 26% black, 7% Hispanic, 2% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does AR ADDM do besides tracking ASD among 8-year-olds?

AR ADDM collaborates with the Arkansas Department of Health and investigators from the University of Arkansas for Medical Services (UAMS) to track the number and characteristics of 8-year-olds with ASD and/or intellectual disability. In addition, AR ADDM offers individualized presentations on the number and characteristics of children with ASD and partners with UAMS Department of Pediatrics and Arkansas Children's Hospital to provide training to physicians and staff. AR ADDM also co-sponsors educational events for families and educators (such as TeamUP), and collaborates on developmental disabilities awareness events such as Walk Now for Autism Speaks.

"For the Arkansas Legislative Task Force on Autism, having current prevalence data for this developmental disorder is of primary importance in offering guidance to legislative efforts to parcel resources efficiently and appropriately. I am certain that the AR ADDM data will fuel the Task Force's sense of the 'fierce urgency' of addressing needs now, and planning for lifelong needs for Arkansas families."

-Tyra Reid, MD
Member, Arkansas Legislative Task Force on Autism

Get Resources and Connect Families to Services and Support in Arkansas

First Connections
1-800-643-8258
www.arkansas.gov/dhs/ddds/FirstConn

Department of Education's Special Education Unit
1-800-482-8437
arksped.k12.ar.us

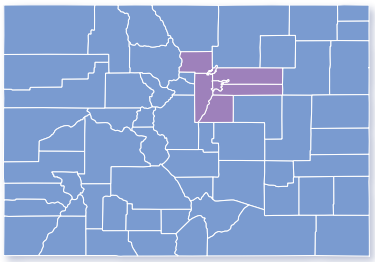
Arkansas site of Autism Treatment Network
Stefanie Jernigan
501-364-4665

Arkansas Autism Resource and Outreach Center
1-800-342-2923
aaroc.org

The Dennis Developmental Center
501-364-1830
www.uams.edu/ddc

Connect with AR ADDM
Allison Hudson
University of Arkansas for Medical Sciences
1 Children's Way, Slot 512-41, Little Rock, AR 72202
501-364-3612
aehudson@uams.edu

A Snapshot of Autism Spectrum Disorder in Colorado



Findings from the Colorado Autism and Developmental Disabilities Monitoring (CO-ADDM) Project help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Colorado and how this important information can be useful to you.

About 1 in 92 or 1.1% of 8-year-old children were identified with ASD by the CO-ADDM Project in 2012. This percentage is lower than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

Boys were more likely to be identified with ASD than girls. White and black children were more likely to be identified with ASD than Hispanic children.

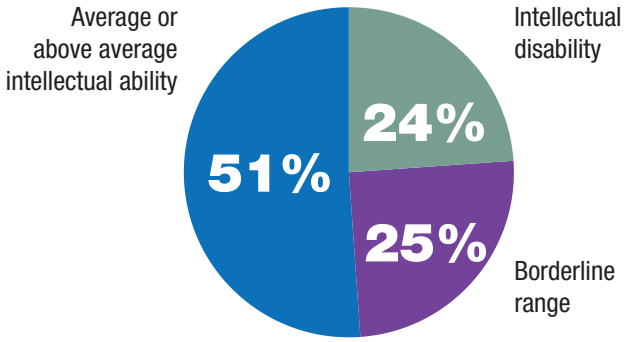
4.1x MORE LIKELY among boys vs girls

1.9x MORE LIKELY among white vs Hispanic children

1.6x MORE LIKELY among black vs Hispanic children

* No significant differences between white and black children

Among children identified with ASD who had IQ scores available, about a quarter also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by the CO-ADDM Project. Intellectual disability defined as IQ score ≤ 70.

About 86% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 41% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 7 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who 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. Research does not show that being Hispanic makes a child less likely to develop ASD. This difference in identification may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

The CO-ADDM Project's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Colorado might consider different ways to

1. Lower the age of first evaluation by community providers.
2. Increase awareness of ASD among Hispanic families, and identify and address barriers 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 some special education records of children who were 8 years old and living in one of 7 counties (Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, Jefferson) in Colorado in 2012. Overall, the tracking area included 40,538 8-year-olds (55% white, 6% black, 33% Hispanic, 5% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does the CO-ADDM Project do besides tracking ASD among 8-year-olds?

The CO-ADDM Project is a collaboration between the Colorado Department of Public Health and Environment and JFK Partners at the University of Colorado-Denver to track the number and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability. The CO-ADDM Project offers tailored presentations on the number and characteristics of children with ASD and links families and community partners with resources to improve collaboration across the ASD community.

"We are learning more about autism and how to be a better community for those affected because we are getting better data. We aren't there yet; we need to scale up the services and supports to meet the demand, but we also understand that is the next step. Knowing is half the task, and that comes from having good data."

- Kathryn Dran, PMP
Colorado Parent

Get Resources and Connect Families to Services and Support in Colorado

Autism Society of Colorado
720-214-0794
www.autismcolorado.org

Department of Education's Office of Special Education
www.cde.state.co.us/cdesped

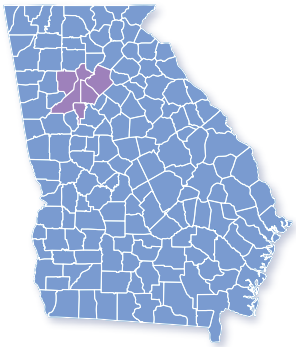
Early Intervention Colorado
1-888-777-4041
www.eicolorado.org/

JFK Partners/Developmental Pediatrics at the University of Colorado School of Medicine
720-777-6630 (clinical line)
303-724-5266 (general line)
www.jfkpartners.org

The Arc of Colorado
303-864-9334
www.thearcofco.org

Connect with CO-ADDM
Kelly R. Kast, MSPH
Colorado Department of Public Health and Environment
4300 Cherry Creek South Drive
Denver, CO 80246
303-692-2680
kelly.kast@state.co.us

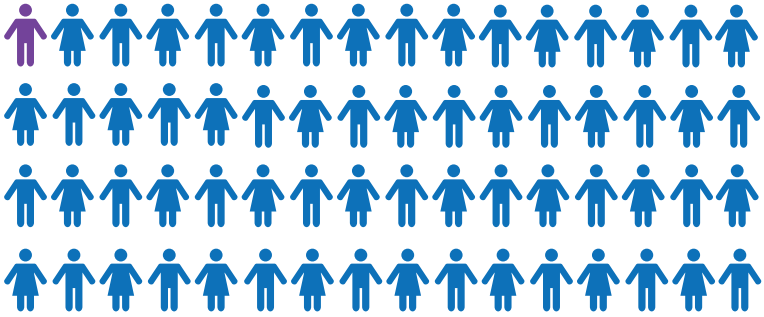
A Snapshot of Autism Spectrum Disorder in Georgia



Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Georgia and how this important information can be useful to you.

About 1 in 64 or 1.6% of 8-year-old children were identified with ASD by MADDSP in 2012. This percentage is about the same as the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

1 IN 64



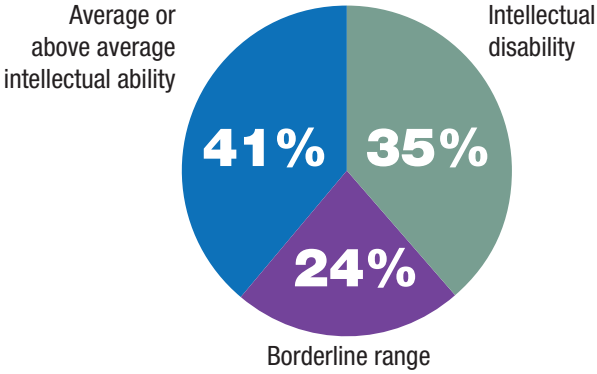
Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than black and Hispanic children.

4.9x MORE LIKELY among boys vs girls

1.3x MORE LIKELY among white vs black children

2.0x MORE LIKELY among white vs Hispanic children

Among children identified with ASD, slightly more than a third also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by MADDSP. Intellectual disability defined as IQ score ≤ 70.

About 88% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 41% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 3 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Hispanic and black children are less likely to be identified with ASD than white children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to white children in Georgia.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

MADDSP's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Georgia might consider different ways to

1. Lower the age of first evaluation by community providers.
2. 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 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 5 counties (Clayton, Cobb, DeKalb, Fulton, Gwinnett) in Georgia in 2012. Overall, the tracking area included 49,720 8-year-olds (33% white, 41% black, 18% Hispanic, 7% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does MADDSP do besides tracking ASD among 8-year-olds?

MADDSP is an intramural program administered by the Centers for Disease Control and Prevention (CDC). MADDSP collaborates with state agencies that serve children with developmental disabilities and their families to track the number and characteristics of 8-year-olds with ASD, cerebral palsy, hearing loss, intellectual disability, and/or vision impairment in select areas of Georgia. MADDSP also partners with community organizations to host annual ASD awareness month events. Upon request, MADDSP offers trainings for local professionals and provides tailored data reports and presentations on the number and characteristics of children with developmental disabilities.

"CDC's ADDM Network provides essential information on the numbers of children with ASD from multiple areas in the U.S. Knowing that 1 in 64 children in metro Atlanta have been identified with ASD really hits home in Georgia, and makes it clear that everyone has a stake in improving the lives of people affected by ASD."

-Catherine Rice PhD
Director, Emory Autism Center

Get Resources and Connect Families to Services and Support in Georgia

Atlanta Autism Consortium
www.atlantaautismconsortium.org/

Autism Society of Georgia
1-844-404-ASGa
www.autismsocietyga.org

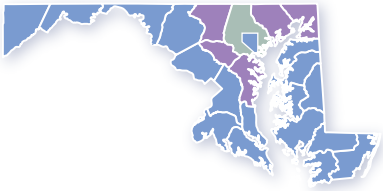
Autism Speaks
770-451-0570
georgia@autismspeaks.org

Babies Can't Wait
1-888-777-4041
dph.georgia.gov/Babies-Cant-Wait

Department of Education's Special Education Services and Supports
404-656-3963
www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/default.aspx

Connect with MADDSP
Kim Van Naarden Braun, PhD
Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities
404-498-3860
KVanNaarden@cdc.gov

A Snapshot of Autism Spectrum Disorder in Maryland



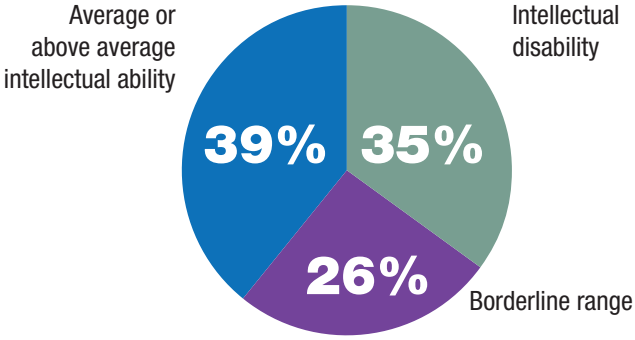
* Green = health + special education
* Purple = health only

Findings from the Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) Project help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Maryland and how this important information can be useful to you.

About 1 in 55 or 1.8% of 8-year-old children were identified with ASD by MD-ADDM in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

Boys were more likely to be identified with ASD than girls. No significant differences were found in the percentage of white, black, and Hispanic children identified with ASD.

Among children identified with ASD who had IQ scores available, over a third also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by MD-ADDM. Intellectual disability defined as IQ score ≤ 70.

About 95% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 55% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 3 years and 9 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- The percentage of children with ASD is high in this area of Maryland.
- Differences between the percentage of boys and girls identified with ASD continue. It may be that boys are at greater risk for ASD and/or it may be that girls are under-identified due to other factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- Despite the developmental concerns noted in many of the children's records by age 3 years, only slightly more than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

MD-ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Maryland might consider different ways to lower the age of first evaluation by community providers.

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 Baltimore County in 2012. Overall, the tracking area included 9,577 8-year-olds (52% white, 33% black, 7% Hispanic, 7% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

MD-ADDM also collected information from the health records of children who were 8 years old and living in Anne Arundel, Carroll, Cecil, Harford, and Howard counties in 2012. To read more about that data, please access the full scientific publication at www.cdc.gov/mmwr or contact MD-ADDM.

What else does MD-ADDM do besides tracking ASD among 8-year-olds?

MD-ADDM partners with the Maryland Department of Health and Mental Hygiene and investigators from Johns Hopkins University to track the number and characteristics of 8-year-olds with ASD and/or intellectual disability in select areas of Maryland. MD-ADDM offers presentations on the number and characteristics of children with ASD in Maryland and across the ADDM Network for stakeholders, state and local agencies, partnering institutes, and parent groups. MD-ADDM also participates in and organizes annual autism awareness month events in the community.

"We are very appreciative for the wonderful work MD-ADDM provides to and on behalf of the autism community in Maryland. Their work in advancing our collective efforts at providing families and individuals with greater access to diagnosis and early intervention efforts is impressive and very much needed."

-Scott Badesch
President/CEO, Autism Society of America

Get Resources and Connect Families to Services and Support in Maryland

AutismConnect
www.autismconnectmd.org

Autism Society of Baltimore-Chesapeake
www.baltimoreautismsociety.org

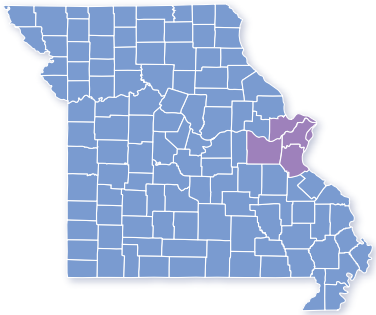
Center for Autism and Related Disorders at Kennedy Krieger Institute
www.card.kennedykrieger.org

Department of Education's Division of Special Education and Early Intervention Services
www.marylandpublicschools.org/MSDE/divisions/earlyinterv

Pathfinders for Autism
www.pathfindersforautism.org

Connect with MD-ADDM
Li-Ching Lee, PhD, ScM
Johns Hopkins University
615 N. Wolfe St., Suite E6032
Baltimore, MD 21205
410-502-0605
llee38@jhu.edu

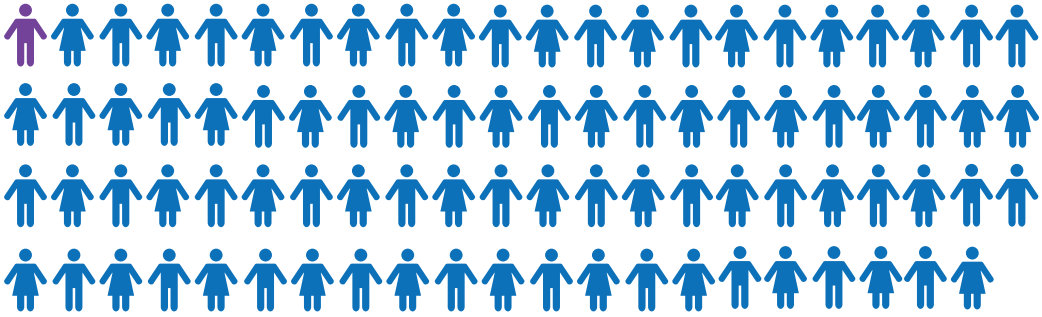
A Snapshot of Autism Spectrum Disorder in Missouri



Findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) Project help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Missouri and how this important information can be useful to you.

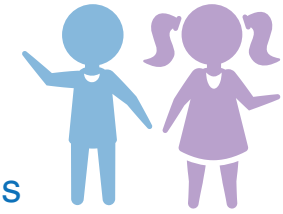
About 1 in 87 or 1.2% of 8-year-old children were identified with ASD by MO-ADDM in 2012. This percentage is lower than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

1 IN 87



Boys were more likely to be identified with ASD than girls. No significant differences were found in the percentage of white, black, and Hispanic children identified with ASD.

5x
MORE LIKELY
among boys vs girls



About 83% of children identified with ASD had concerns about their development noted in their health records by age 3 years.

About 41% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 10 months. The table includes median ages of first diagnosis by subtype.

ASD Subtype	Median* Age of Diagnosis
Autistic disorder	4 years, 2 months
Pervasive developmental disorder-not otherwise specified (PDD-NOS)	4 years, 3 months
Asperger disorder	6 years, 6 months

* Median is the number in the "middle" within a sorted list of numbers from highest to lowest.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- Differences between the percentage of boys and girls identified with ASD continue. It may be that boys are at greater risk for ASD and/or it may be that girls are under-identified due to other factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

MO-ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Missouri might consider different ways to lower the age of first evaluation by community providers.

How and where was this information collected?

This information is based on the analysis of data collected from the health records of children who were 8 years old and living in one of 5 counties (Franklin, Jefferson, St. Charles, St. Louis, St. Louis City) in Missouri in 2012. Overall, the tracking area included 25,870 8-year-olds (67% white, 25% black, 4% Hispanic, 4% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does MO-ADDM do besides tracking ASD among 8-year-olds?

MO-ADDM collaborates with the Missouri Department of Health and Senior Services and investigators from Washington University in St. Louis to track the number and characteristics of 8-year-olds with ASD and/or cerebral palsy. MO-ADDM also tracks the number and characteristics of 4-year-olds with ASD. In addition, MO-ADDM conducts various ASD-related public health, research, and clinical activities to inform various stakeholders (such as clinicians, educators, and families) on the latest science around ASD, best practices for early intervention, and clinical care for children with ASD.

"In St. Louis County, MO-ADDM is linking the opportunity to contribute to epidemiologic surveillance with the provision of services for young, ASD-affected children. This effort creates the dual opportunity to monitor the prevalence of early-diagnosed cases and track children's progress as a function of the interventions they receive."

-Donald McCary
Director of Special Education, St. Louis County Special School District

Get Resources and Connect Families to Services and Support in Missouri

Department of Elementary and Secondary Education's Office of Special Education
573-751-5739
dese.mo.gov/special-education

Department of Mental Health's Division of Developmental Disabilities
dmh.mo.gov/dd/

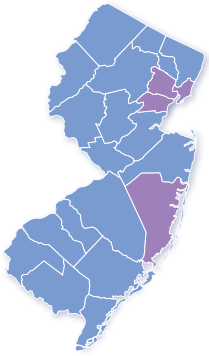
First Steps
1-866-583-2392
www.mofirststeps.com/

Missouri Families for Effective Autism Treatment
877-275-8988
www.mo-feat.org/

Navigating Autism Services
dmh.mo.gov/dd/autism/docs/navigationguide.pdf

Connect with MO-ADDM
Robert Fitzgerald, PhD, MPH
Washington University in St. Louis
314-286-0151
fitzgeraldr@wustl.edu

A Snapshot of Autism Spectrum Disorder in New Jersey



Findings from the New Jersey Autism Study (NJAS) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in New Jersey and how this important information can be useful to you.

About 1 in 41 or 2.5% of 8-year-old children were identified with ASD by NJAS in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

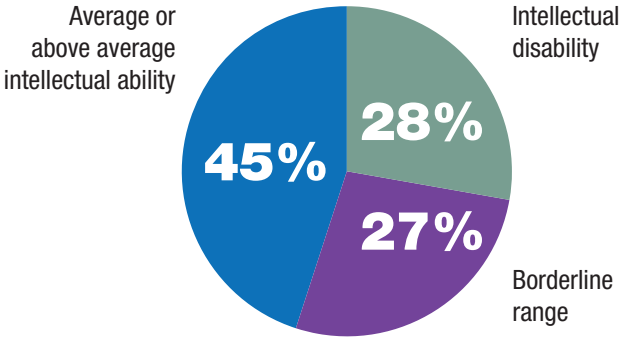
Boys were more likely to be identified with ASD than girls. White and black children were more likely to be identified with ASD than Hispanic children. No significant differences were found between the percentage of white and black children with ASD.

4.2x MORE LIKELY among boys vs girls

1.5x MORE LIKELY among white vs Hispanic children

1.3x MORE LIKELY among black vs Hispanic children

Among children identified with ASD who had IQ scores available, less than a third also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by NJAS. Intellectual disability defined as IQ score ≤ 70.

About 82% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 43% of children identified with ASD received comprehensive developmental evaluations by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 3 years and 11 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- The percentage of children with ASD increased in this area, from about 2.1% in 2010 to about 2.5% in 2012.
- The percentage of children with ASD continues to be higher in this area compared to other areas in the United States where CDC tracks ASD—it is not known exactly why, but it could be related to how children are identified and connected to services in their local communities.
- Differences between the percentage of boys and girls identified with ASD continue—almost 4% of boys in the area were identified with ASD compared to about 1% of girls. It may be that boys are at greater risk for ASD and/or it may be that girls are under-identified due to other factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

NJAS' latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in New Jersey might consider different ways to lower the age of first evaluation by community providers.

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 4 counties (Essex, Hudson, Union, Ocean) in New Jersey in 2012. Overall, the tracking area included 32,581 eight-year-olds (42% white, 22% black, 30% Hispanic, 6% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does NJAS do besides tracking ASD among 8-year-olds?

NJAS collaborates with the New Jersey Departments of Health and Education and local agencies and organizations that serve children with developmental disabilities and their families to track the number and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability in select areas of New Jersey. NJAS offers information and training on the identification and diagnosis of ASD, sponsors presentations and workshops on ASD topics, and promotes innovative approaches to the detection of ASD.

"NJAS is essential to understanding the true scope of autism."

-Cherie Castellano
Mom2Mom Program Director

Get Resources and Connect Families to Services and Support in New Jersey

Autism Family Services of New Jersey
877-237-4477
www.autismfamilyservicesnj.org

Autism New Jersey
800-4-AUTISM
www.autismnj.org

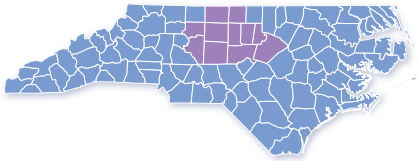
Department of Education's Office of Special Education Program
www.nj.gov/education/specialed/

Early Intervention System
www.nj.gov/health/fhs/eis/

Governor's Council for Medical Research and Treatment of Autism
www.state.nj.us/health/autism/

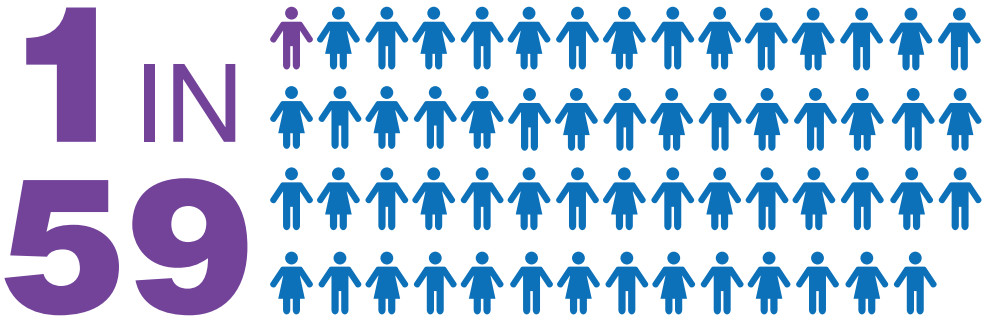
Connect with NJAS
Walter Zahorodny, PhD
Rutgers-New Jersey Medical School
185 South Orange Avenue, F570
Newark, New Jersey 07101
973-972-9773
zahorodn@njms.rutgers.edu

A Snapshot of Autism Spectrum Disorder in North Carolina



Findings from the North Carolina Autism and Developmental Disabilities Monitoring (NC-ADDM) Project help understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in North Carolina and how this important information can be useful to you.

About 1 in 59 or 1.7% of 8-year-old children were identified with ASD by NC-ADDM in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.



Boys were more likely to be identified with ASD than girls. White and black children were more likely to be identified with ASD than Hispanic children.

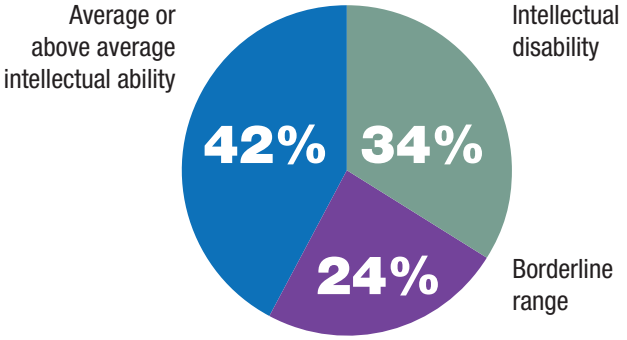
4.6x MORE LIKELY among boys vs girls

1.2x MORE LIKELY among white vs black children

2.1x MORE LIKELY among white vs Hispanic children

1.7x MORE LIKELY among black vs Hispanic children

Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by NC-ADDM. Intellectual disability defined as IQ score ≤ 70.

About 92% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 60% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who 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. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in North Carolina.
- Among the areas where CDC tracks ASD across the United States, the area in 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.

How can this information be useful?

NC-ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, 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 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 11 counties (Alamance, Caswell, Chatham, Davison, Durham, Forsyth, Guilford, Orange, Randolph, Rockingham, Wake) in central North Carolina in 2012. Overall, the tracking area included 38,913 eight-year-olds (53% white, 25% black, 17% Hispanic, 5% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does NC-ADDM do besides tracking ASD among 8-year-olds?

NC-ADDM 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. NC-ADDM 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 and opportunities of families in North Carolina.

Get Resources and Connect Families to Services and Support in North Carolina

Autism Speaks
888-288-4762
www.autismspeaks.org

Autism Society of North Carolina
800-442-2762
www.autismsociety-nc.org/

Learn the Signs. Act Early.
www.ncactearly.com

North Carolina Infant-Toddler Program
919-707-5520
www.beearly.nc.gov/

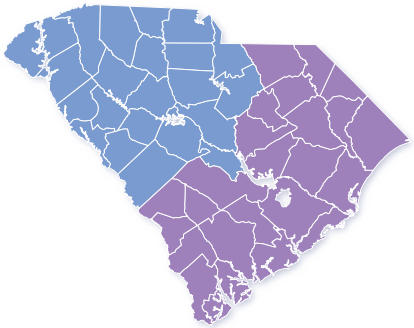
TEACCH Autism Program
www.teacch.com/

Connect with NC-ADDM
Julie Daniels, PhD
University of North Carolina at Chapel Hill
919-966-7096
Julie_Daniels@unc.edu

"These prevalence data are essential to helping us to predict the need for adult services in North Carolina and around the country. The first cohort of 8-year-olds is now 22 years of age; we can anticipate that the increase from 1 in 150 to 1 in 59 will be paralleled in the demand for adult services in the next 12 years."

-Laura Klinger, PhD
Director of TEACCH

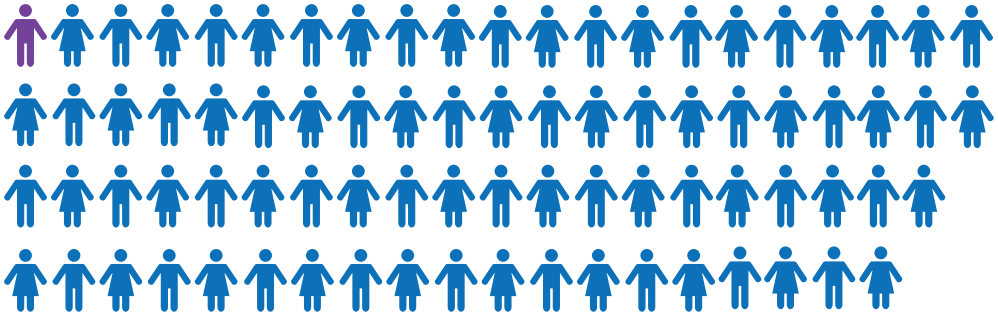
A Snapshot of Autism Spectrum Disorder in South Carolina



Findings from the South Carolina Autism and Developmental Disabilities Monitoring (SC-ADDM) Program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in South Carolina and how this important information can be useful to you.

About 1 in 81 or 1.2% of 8-year-old children were identified with ASD by SC-ADDM in 2012. This percentage is lower than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

1 IN 81



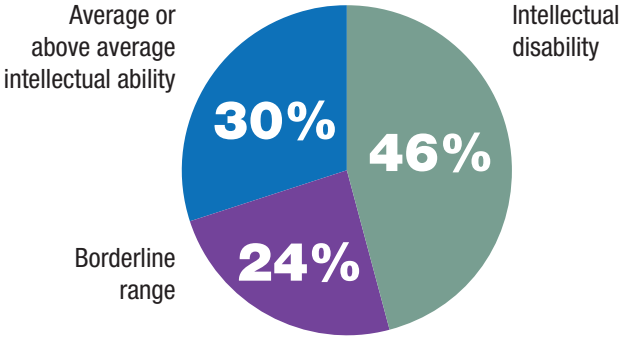
Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than Hispanic children.

4.3x MORE LIKELY among boys vs girls

1.9x MORE LIKELY among white vs Hispanic children

* No significant differences between white and black children or black and Hispanic children

Among children identified with ASD who had IQ scores available, almost half also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by SC-ADDM. Intellectual disability defined as IQ score ≤ 70.

About 92% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 39% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who 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 children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in South Carolina.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

SC-ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in South Carolina might consider different ways to

Lower the age of first evaluation by community providers.

Increase awareness of ASD among Hispanic families, and identify and address barriers 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 23 counties (Allendale, Bamberg, Barnwell, Beaufort, Berkeley, Charleston, Chesterfield, Clarendon, Colleton, Darlington, Dillon, Dorchester, Florence, Georgetown, Hampton, Horry, Jasper, Lee, Marion, Marlboro, Orangeburg, Sumter, Williamsburg) in 2012. Overall, the tracking area included 24,356 eight-year-olds (51% white, 38% black, 8% Hispanic, 2% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else did SC-ADDM do besides tracking ASD among 8-year-olds?

SC-ADDM collaborated with the South Carolina Department of Health and Environmental Control and investigators from the Medical University of South Carolina to track the number and characteristics of 4-year-olds and 8-year-olds with ASD and/or intellectual disability. SC-ADDM presented programs and hosted conferences for healthcare providers, educators, and the community to increase awareness, screening, diagnosis, and early intervention efforts.

"Adequate planning for intervention and related services can only be accomplished if there are sufficient data to indicate the extent of the disability. SC-ADDM has provided, and will continue to provide, valuable information to policymakers, state agency personnel, disability advocates, and family members in South Carolina."

-Beverly McCarty
Executive Director Family Resource Center for Disabilities and Special Needs

Get Resources and Connect Families to Services and Support in South Carolina

BabyNet
877-621-0865
scfirststeps.com/babynet/

Family Resource Center for Disabilities and Special Needs
843-266-1348
frc@frcdsn.org

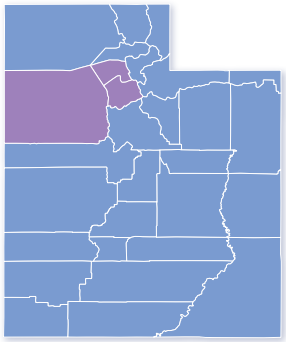
South Carolina Autism Society
www.scautism.org

South Carolina Department of Education
801-538-7587
ed.sc.gov/districts-schools/special-education-services/

South Carolina Department of Disabilities and Special Needs
803-898-9600
www.ddsn.sc.gov

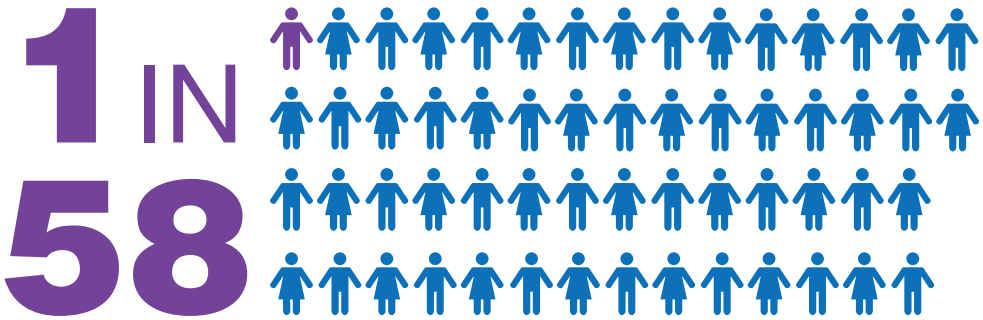
Connect with SC-ADDM
Walter Jenner, MS, CAS
Charleston, SC 29425
843-532-4992
jennerw@musc.edu

A Snapshot of Autism Spectrum Disorder in Utah



Findings from the Utah Autism and Developmental Disabilities Monitoring (UT-ADDM) Project help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Utah and how this important information can be useful to you.

About 1 in 58 or 1.7% of 8-year-old children were identified with ASD by UT-ADDM in 2012. This percentage is higher than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.



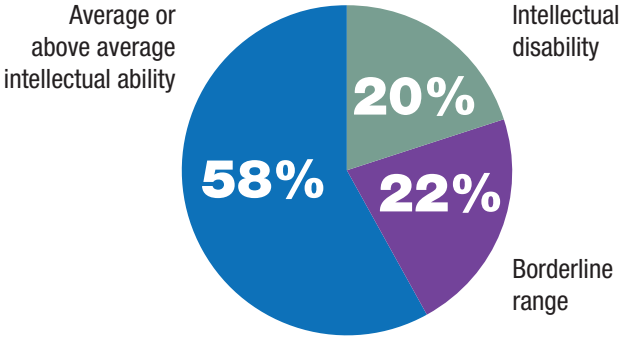
Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than Hispanic children.

4.3x MORE LIKELY among boys vs girls

1.3x MORE LIKELY among white vs Hispanic children

* No significant differences between white and black children or black and Hispanic children

Among children identified with ASD who had IQ scores available, less than a quarter also had intellectual disability.



* Intelligence quotient (IQ) scores available for at least 70% of children identified with ASD by UT-ADDM. Intellectual disability defined as IQ score ≤ 70.

About 81% of children identified with ASD had concerns about their development noted in their health and/or education records by age 3 years.

About 38% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

Even though ASD can be diagnosed as early as age 2 years, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 2 months.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who 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 children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in Utah.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

UT-ADDM's latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Utah might consider different ways to

1. Lower the age of first evaluation by community providers.
2. Increase awareness of ASD among Hispanic families, and identify and address barriers 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 three counties (Salt Lake, Davis, Tooele) in Utah in 2012. Overall, the tracking area included 24,945 eight-year-olds (73% white, 2% black, 19% Hispanic, 5% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else did UT-ADDM do besides tracking ASD among 8-year-olds?

UT-ADDM collaborated with the Utah Department of Health and investigators from the University of Utah to track the number and characteristics of 8-year-olds and 4-year-olds children with ASD and/or intellectual disability. UT-ADDM, as an extension of the Utah Registry of Autism and Developmental Disorders (URADD), provided community outreach through participation in community events, awareness activities, and professional education meetings.

"At the Utah Autism Coalition, we are very grateful for the work of UT-ADDM. Very little practical work can be done before someone measures the size of a problem. The efforts of the UT-ADDM were crucial in helping us convince our state legislature to take reasoned action."

-Jon Owen
President of the Utah Autism Coalition

Get Resources and Connect Families to Services and Support in Utah

Autism Council of Utah
www.autismcouncilofutah.org

Baby Watch Early Intervention Services
801-273-2998
www.utahbabywatch.org

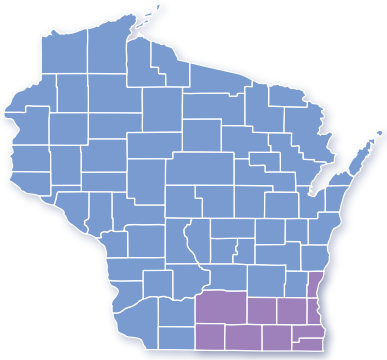
Learn the Signs. Act Early
health.utah.gov/utahactearly/

Utah Parent Center
801-272-1051
www.utahparentcenter.org

Utah State Office of Education
801-538-7587
www.schools.utah.gov/sars

Connect with UT-ADDM
Deborah Bilder, MD
University of Utah
801-585-9107
Deborah.Bilder@hsc.utah.edu

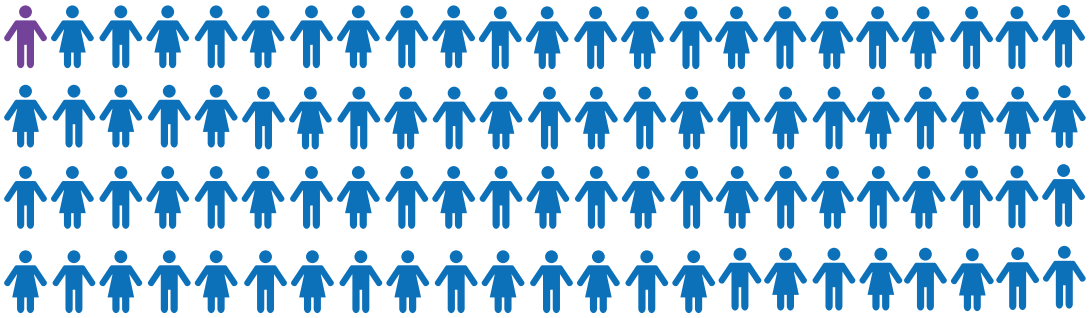
A Snapshot of Autism Spectrum Disorder in Wisconsin



Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed. Read on to learn more about ASD in Wisconsin and how this important information can be useful to you.

About 1 in 92 or 1.1% of 8-year-old children was identified with ASD by WISADDS in 2012. This percentage is lower than the average percentage identified with ASD (1.5%) in all communities in the United States where CDC tracked ASD in 2012.

1 IN 92



Boys were more likely to be identified with ASD than girls. White children were more likely to be identified with ASD than black or Hispanic children.

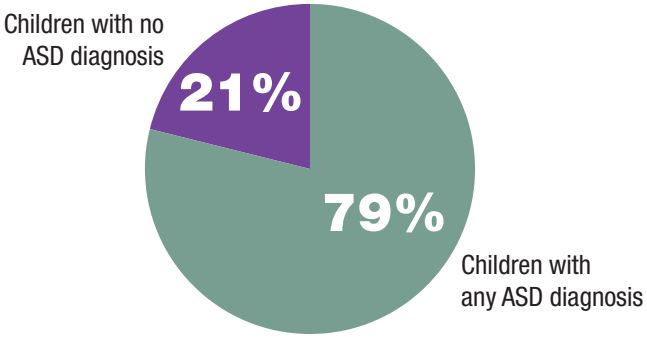
4.2x MORE LIKELY among boys vs girls

2.1x MORE LIKELY among white vs black children

1.6x MORE LIKELY among white vs Hispanic children

* No significant differences between black and Hispanic children

Most of the children identified by WISADDS as having ASD had a diagnosis of ASD documented in their health records. The remaining children had documented symptoms of ASD, but had not yet been diagnosed with ASD by a community provider.



About 90% of children identified with ASD had concerns about their development noted in their health records by age 3 years.

About 42% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.

About half of children were diagnosed with ASD by a community provider by age 4 years and 2 months, even though ASD can be diagnosed as early as age 2 years.

Frequently Asked Questions

What are the key take-away messages?

- Many children are living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- The percentage of children with ASD increased in southeastern Wisconsin, from about about 0.9% in 2010 to about 1.1% in 2012.
- Hispanic and black children are less likely to be identified with ASD than white children. This may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to white children in Wisconsin.
- Despite the developmental concerns noted in many of the children's records by age 3 years, less than half of children identified with ASD received a comprehensive developmental evaluation by this same age. The lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.

How can this information be useful?

WISADDS' latest findings can be used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform policies promoting improved outcomes in health care and education for individuals with ASD. Stakeholders in Wisconsin might consider different ways to

1. Lower the age of first evaluation by community providers.
2. Increase awareness of ASD among Hispanic and black families, and identify and address barriers in order to decrease the age at which Hispanic and black 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 records of children who were 8 years old and living in one of 10 counties (Dane, Green, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Rock, Walworth, Waukesha) in southeastern Wisconsin in 2012. Overall, the tracking area included 35,556 8-year-olds (61% white, 18% black, 16% Hispanic, 4% Asian or Pacific Islander, less than 1% American Indian or Alaska Native).

What else does WISADDS do besides tracking ASD among 8-year-olds?

WISADDS collaborates with the Wisconsin Department of Health Services and investigators from the University of Wisconsin-Madison to track the number and characteristics of 8-year-olds with ASD, cerebral palsy, and/or intellectual disability. WISADDS also tracks the number and characteristics of 4-year-olds with ASD. WISADDS facilitates training and provides access to materials related to developmental disabilities for professionals.

"The WISADDS data are important to me as a parent because they convey what families across the state are experiencing. These data have been invaluable as we respond to the need for early identification, access to diagnostic services, and professional training. For example, seeing the data on disparities in identification has given us valuable insight into which children we may be missing."

-Gail Chodron, PhD
Wisconsin's Act Early Ambassador

Get Resources and Connect Families to Services and Support in Wisconsin

Autism Society of Wisconsin
1-888-4-AUTISM
www.asw4autism.org

Birth to Three Program, Wisconsin Department of Health Services
www.dhs.wisconsin.gov/birthto3/index.htm

Finding Your Way
www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.pdf

Learn the Signs. Act Early.
www.ActEarly.wisc.edu

Wisconsin First Step
1-800-642-7837
www.mch-hotlines.org/wisconsin-first-step

Connect with WISADDS
Maureen Durkin, PhD, DrPH
University of Wisconsin-Madison
Waisman Center
1500 Highland Ave, Room s101E
608-263-7507
mdurkin@wisc.edu

What Else Do I Need to Know?

How can I tell if a child's development is on track?

You can follow a child's development by looking for developmental milestones—that is, how he or she plays, learns, speaks, moves, and acts. Developmental milestones are things most children can do by a certain age. The American Academy of Pediatrics recommends that children be screened for general development using standardized, validated tools at 9, 18, and 24 or 30 months, and for ASD at 18 and 24 months or whenever a parent or provider has a concern. Parents should talk with their child's doctor at every visit about the milestones their child has reached and what to expect next. Learn more about developmental milestones and get free milestone checklists at CDC's "Learn the Signs. Act Early." website, www.cdc.gov/Milestones.

As a professional who works with children, what should I do if I think a child might have ASD?

You are a valuable resource to parents! They look to you for information on their child, and they trust you. Visit CDC's "Learn the Signs. Act Early." website, www.cdc.gov/ActEarly for tools and resources to help you educate parents on the full range of child development. For tips on sharing concerns about a child's development, visit http://www.firstsigns.org/concerns/parent_parent.htm.

Can schools help and what is IDEA?

This ADDM Network report highlights the important role public school systems play in providing evaluating and serving children with ASD. The Individuals with Disabilities Education Act (IDEA) is a law that ensures that all children with disabilities, from birth through 21 years of age, can get free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. IDEA also provides for evaluation of children who might have or be at risk for developmental disabilities. For more information about IDEA, please visit http://idea.ed.gov/. To find the contact information for a free evaluation in your state, please visit www.cdc.gov/ncbddd/actearly/parents/states.html

What kinds of treatments or educational interventions can help people with ASD?

There are many different types of treatments available for people with ASD, and there is no single best treatment. Each person with ASD has unique strengths. Promoting these strengths while supporting new skills is critical. Early intervention is important, but intervention at any age can be life-changing.

For guidance on choosing a treatment program, visit the Treatment Options section of the National Institute of Mental Health's autism website at www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/index.shtml. You can also access a report on evidenced-based practices for children, youth, and young adults with ASD at http://autismpdc.fpg.unc.edu/content/ebp-update.

Can medication help children with ASD?

There are no medications that can cure ASD or treat the core symptoms; however, there are medications that can help some people with ASD function better. To learn more about medications and ASD, visit the Food and Drug Administration's website at www.fda.gov.

What do we know about adolescents and adults living with ASD?

The number, characteristics, and needs of adolescents and adults living with ASD in the United States have not been well studied. By parent report, almost 2% of adolescents have ASD (38). They may face unique challenges during adolescence and as they transition to adulthood. Adolescents with ASD seem to be at increased risk for certain health conditions. For example, adolescents with ASD are more likely to be obese than adolescents without developmental disabilities (39). Adolescents also encounter significant issues with accessing appropriate services and gaining employment (40-41). Over time, the number of young adults with ASD seeking vocational rehabilitation services has increased, but the percent of adults with ASD who are employed, the number of hours they work, and the wages they earn have not improved.

For information on interventions for adolescents and young adults with ASD, read the Agency for Healthcare Quality Research's review: http://effectivehealthcare.ahrq.gov/ehc/products/271/1197/CER65_Autism-Adolescents_executivesummary_20120724.pdf.

For resources related to the transition from adolescence to adulthood, you can download the Autism Speaks' Transition Tool-Kit: www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

Where Can I Get More Information?

The resources that follow will help you learn more about ASD and find services for children and adults with ASD and their families.

Developmental Milestones and Early Identification

"Learn the Signs. Act Early."
www.cdc.gov/ActEarly or 1-800-CDC INFO
Access tools and resources for healthcare providers and early childhood educators, including information on screening tools and free educational materials to give to parents.

Birth to Five: Watch Me Thrive
www.hhs.gov/WatchMeThrive
Find resources related to developmental and behavioral screening and support.

General Information about ASD

CDC Autism Information Center
www.cdc.gov/autism or 1-800-CDC INFO
Check out a full range of resources for parents, educators, researchers, and healthcare providers at this site. Also, learn what CDC is doing to better understand ASD and the causes and risk factors.

Training and Technical Assistance for Professionals

Association of Maternal and Child Health Programs
www.amchp.org/programsandtopics/CYSHCN/projects/spharc
Access the State Public Health Autism Resource Center, a comprehensive resource center for Title V programs and others interested in improving systems for children and youth with ASD and their families.

CDC's Autism Case Training
www.cdc.gov/ncbddd/actearly/act.html
Access an online training or class-room based curriculum designed to educate healthcare providers on fundamental components of identifying, diagnosing, and managing autism spectrum disorder through real life scenarios.

CDC's Watch Me! Celebrating Milestones and Sharing Concerns Training
www.cdc.gov/ncbddd/watchmetraining/
Access an online training for early care and education providers that provides tools and best practices for monitoring the development of children and talking about it with their parents.

The Early Childhood Technical Assistance Center (ECTA)
Use ECTA to find state contacts for early intervention programs for infants and toddlers from birth to 3 years (http://ectacenter.org/contact/ptccoord.asp) and preschool special education for children from 3 to 5 years old (http://ectacenter.org/contact/619coord.asp).

Educating Children with Autism
www.nap.edu/books/0309072697/html/
Read a review of early intervention, preschool, and school programs designed for young children with ASD by the National Academy of Sciences.

The National Professional Development Center on Autism Spectrum Disorders
http://autismpdc.fpg.unc.edu/
Access resources from this project to promote the use of evidence-based practice for children and adolescents with ASD.

The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children
http://pediatrics.aappublications.org/cgi/content/full/107/5/e85
Learn about treatments and interventions physicians use to treat ASD in this report from the American Academy of Pediatrics.

Technical Assistance and Dissemination Network
www.tadnet.org
Access links to a variety of websites and online resources that focus on special education issues, such as policy, technology, curriculum, and parent trainings.

Other Resources

The Arc's Autism NOW
http://autismnow.org/
Learn about additional resources for individuals with ASD, their families and other stakeholders.

Autism Society
www.autism-society.org or 1-800-3AUTISM (328-8476)
Find local resources and an Autism Society chapter in your state by clicking on the "Chapters" link.

Autism Speaks
www.autismspeaks.org or 1-888-AUTISM2 (288-4762)
Read about what ASD is and how to cope with it. Learn about research and efforts to raise awareness about the disorder.

Autistic Self-Advocacy Network
http://autisticadvocacy.org/
Learn about the self-advocate community and access resources on public policy advocacy, community engagement, and quality of life oriented research.

Easter Seals
www.easterseals.com or 1-800-221-6827
Find an Easter Seals program near you and learn about services for people with ASD.

Family Voices
www.familyvoices.org/ or 1-888-835-5669
Learn more about this national network that provides information and support for parents raising children with special healthcare needs or disabilities, or both. For contacts in your state, go to: www.familyvoices.org/states.

Operation Autism. A Resource Guide for Military Families
www.operationautismonline.org/
Operation Autism directly supports U.S. military families touched by ASD. It is sponsored and maintained by the Organization for Autism Research.

The Autism Science Foundation (ASF)
www.autismsciencefoundation.org
Learn more about the ASF, which provides funding to scientists and organizations conducting, facilitating, and promoting autism research.

National Institute of Neurological Disorders and Stroke
www.ninds.nih.gov/disorders/autism/autism.htm
Read about research being done on ASD (available in English and Spanish).

CDC's Study to Explore Early Development (SEED)
www.cdc.gov/seed
Learn more about the largest study in the United States to help identify factors that might put children at risk for ASD and other developmental disabilities.

Clinical Trials
www.clinicaltrials.gov or 301-496-4000
Access a searchable database of the National Institutes of Health that provides patients, family members, and the public with information about current, ongoing clinical research studies.

Interagency Autism Coordinating Committee (IACC)
www.iacc.hhs.gov
Learn about the IACC and access the IACC's Strategic Plan for Autism Research.

Organization for Autism Research (OAR)
www.ResearchAutism.org or 703-243-9710
Learn more about OAR's mission to apply research to the challenges of ASD, and access their resources for families and providers.

Other Federal Agencies or Websites

Department of Education
www.ed.gov
Find resources to assist with the educational needs of children with ASD and other developmental disabilities.

Disability.gov
www.disability.gov
Access comprehensive information on disability programs and services in communities nationwide.

Food and Drug Administration (FDA)
www.fda.gov
Learn about drugs that the FDA has approved to treat children with ASD.

Health Resources and Services Administration (HRSA)
www.mchb.hrsa.gov/programs/autism/
Learn more about HRSA's implementation of the Autism CARES Act.

National Council on Disability
www.ncd.gov
Find out more about disability-related issues on civil rights, cultural diversity, education, emergency management, employment, financial assistance & incentives, health care, housing, long term services and supports, technology, transportation, and youth perspectives.

National Institute of Mental Health
www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders
Find out about the process of diagnosing ASD and about treatment options, including medications used to help people with ASD.

Office of Special Education and Rehabilitative Services
http://www2.ed.gov/about/offices/list/osers/index.html
Learn more about the Department of Education's support to parents and individuals, school districts, and states in three main areas: special education, vocational rehabilitation, and research.

U.S. Department of Health and Human Services (HHS)
www.hhs.gov/autism/
Learn more about ASD and access links to government agencies working to address ASD.

* We provide links to web pages if you would like to learn more about a topic or organization. Some of these pages are on the CDC website and others are on outside websites. Links to organizations outside of CDC are included for information only and do not indicate any form of endorsement or approval from CDC or the Department of Health and Human Services (HHS). CDC has no control over the information at these sites. The views and opinions of these organizations are not necessarily those of CDC or HHS.

Glossary

Autism spectrum disorder
Autism spectrum disorder (ASD) is a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. Signs of ASD begin during early childhood and usually last throughout a person's life (1).

- *Autistic disorder* is often associated with more severe symptoms of ASD, such as difficulties with communication. Autistic disorder is no longer diagnosed separately but rather included as part of ASD.
- *Pervasive developmental disorder-not otherwise specified* (PDD-NOS) often has some but not all symptoms of 'autistic disorder'. Pervasive developmental disorder-not otherwise specified is no longer diagnosed separately but rather included as part of ASD.
- *Asperger disorder* is often associated with milder or fewer symptoms of ASD. Although symptoms are present early in life, Asperger disorder is usually diagnosed when a child was school-aged or later. Asperger disorder is no longer diagnosed separately but rather included as part of ASD.

Comprehensive developmental evaluation
A comprehensive, developmental evaluation is a thorough review of how a child plays, learns, communicates, acts, and moves, and whether those characteristics have changed over time. A range of professionals can conduct developmental evaluations, including teachers, social workers, nurses, psychologists, doctors, and speech-language pathologists. The results of a developmental evaluation are often used by specialists, such as developmental pediatricians, to determine if a child has ASD.

Community provider
A community provider is a medical or educational professional who works with children with developmental disabilities (including, psychologist, physician, teacher, learning specialist, speech/language pathologist, occupational therapist, physical therapist, nurse, social worker, etc.) within the ADDM Network communities. In this report, the term 'community provider' is used, for example, to help distinguish between whether children have been identified as having ASD in their specific communities by a community provider or whether they have been identified as having ASD by the ADDM Network based on symptoms documented in their records.

Developmental delay
A developmental delay is a persistent delay experienced by a child in reaching one or more developmental milestones—how children grow, move, communicate, interact, learn, and play.

Healthy People 2020
Healthy People 2020 provides science-based, 10-year national objectives across a variety of health topics with the aim of improving the health of all Americans.

Prevalence
Prevalence is a scientific term that describes the number of people with a disease or condition among a defined group at a specific period in time. Prevalence is usually expressed as a percentage or proportion of the defined group.

Intellectual disability
Intellectual disability means that a person has difficulty learning at an expected level and functioning in daily life. In this report, intellectual disability is measured by intellectual quotient (IQ) test scores of less than or equal to 70.

- *Borderline range* intellectual functioning means that a person has lower than average intelligence but does not have intellectual disability. In this report, borderline range is measured by IQ test scores of 71 to 85.
- *Average or above average intellectual ability* means that a person can learn at an expected level and function in daily life. In this report, average or above average intellectual ability is measured by IQ test scores of greater than 85.

Special education eligibility
Special education eligibility is the specific category in which a child is included as part of their eligibility for special education and related services at school under the Individuals with Disabilities Education Act (IDEA). Those categories include autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

Surveillance (also known as 'tracking')
In public health, surveillance is defined as the continuous, systematic collection, analysis, and interpretation of health-related data.

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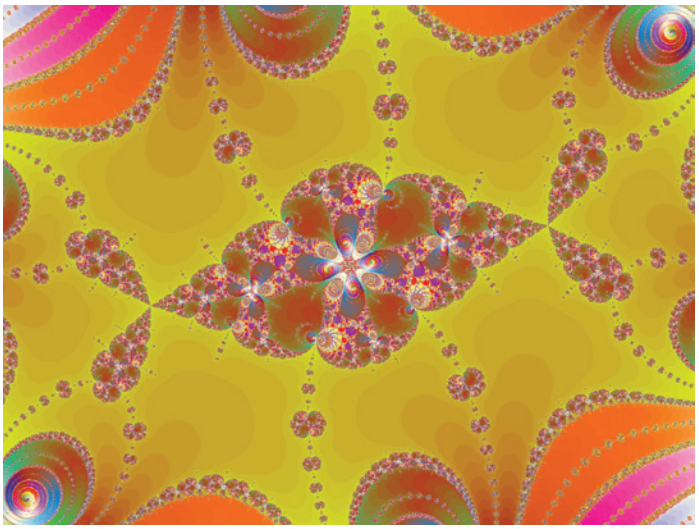

Bonbon, fractal art image by Matt Ward, a young man with ASD from Wisconsin

www.cdc.gov/Autism

National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

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