



# Community Report on Autism 2018



# 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 2014

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:

Baio J, Wiggins L, Christensen DL, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018, 67 (No. SS-6): 1-23.

To read the full scientific report, please go to [www.cdc.gov/mmwr](http://www.cdc.gov/mmwr)

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

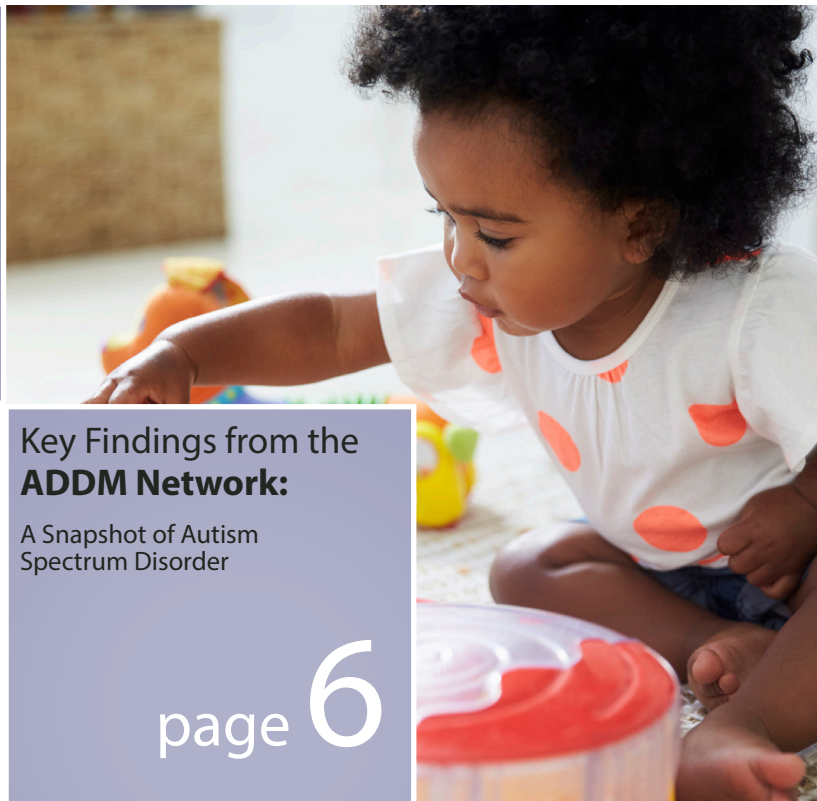
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# Executive Summary

## 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) is higher than in previous reports. About 1.7%, or 1 in 59, of 8-year-old children were identified with ASD, based on tracking within 11 communities in 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, while we have made progress in reducing racial and ethnic disparities in the identification of ASD in children, 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?

For more than two decades, CDC's ADDM Network has been tracking 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 in 8-year-old children and empower those working 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?

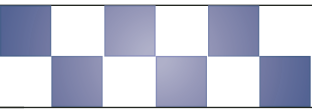
These findings are based on the analysis of information collected from the health and special education (if available) records of 8-year-old children who lived in areas of Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin in 2014.

- The estimated percentage of 8-year-old children identified with ASD is higher than previous estimates from the ADDM Network.



- While a higher percentage of white children were identified with autism compared to black children, and even more so compared to Hispanic children, these differences were smaller when compared with estimates from previous years.
- Children identified with ASD are still not receiving comprehensive developmental evaluations as early as they could be.
- Recent changes in the clinical definition of autism did not have much impact on the percentage of school-aged children identified as having ASD by the ADDM Network. Prevalence estimates based on the old and new ASD surveillance case definition were similar, due in part to the inclusion of children with a previous ASD diagnosis in the new surveillance definition. It may be too soon to determine the long-term impact of the recent changes in the clinical definition of autism and we will continue to monitor the impact on identification of children with ASD by the new surveillance case definition in our next surveillance report.

*For a more in-depth look at the Key Findings, please go to page 6.*



**1 in 59**  
children living in  
ADDM sites are  
identified with ASD



**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 the interventions that can help children with ASD, 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 ensure that all children with ASD are evaluated, diagnosed, and connected to services.

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.



**1.7%**  
children living in  
ADDM sites  
were identified  
with ASD

# 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 16 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. CDC also operates an additional ADDM site in Georgia. The ADDM Network tracks more than 300,000 8-year-old children.

## 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 of children with ASD, including sex, race/ethnicity, co-occurring intellectual ability, and age of evaluation and diagnosis;
- 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; and
- Understand the impact of ASD and related conditions upon children, families, and communities in the United States.

## How does ADDM develop estimates?

The ADDM Network estimates the number of children with ASD using a record review method. This review includes both children who have an ASD diagnosis and children who haven't received a diagnosis but do have documented behaviors that are consistent with ASD.







## 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
<b>Population-based screening and evaluation</b>	Screening and evaluating a sample of all children in a population, within a defined age group.	Can provide high accuracy, but can be costly and time-consuming, and might produce skewed results based on who agrees to participate.
<b>National surveys</b>	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.
<b>Registries</b>	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.
<b>Administrative data</b>	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.
<b>Systematic record review (ADDMM Network's Method)</b>	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 are the advantages of the ADDMM Network method?

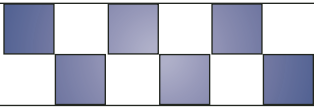
There are several major advantages to using the ADDMM Network method for tracking the number and characteristics of children with ASD. For example, the ADDMM Network

- 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; and
- 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.

## What else is the ADDMM Network doing?

In 2010 and 2012, the Early ADDMM Network, a subset of the ADDMM 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 ADDMM Network tracked ASD among 4-year-olds in areas of Arizona, Colorado, Missouri, New Jersey, North Carolina, and Wisconsin. Tracking among 4-year-old children increases our understanding of the characteristics and early identification of younger children with ASD.

Some ADDMM Network sites also track the number and characteristics of children with other developmental disabilities including cerebral palsy and intellectual disability.



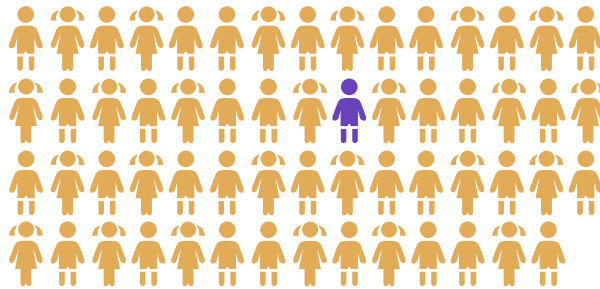
# Key Findings from the ADDM Network:

## A Snapshot of Autism Spectrum Disorder in 2014

Data from the Centers for Disease Control and Prevention's 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?

**1.7%**  
is the average percentage identified with ASD

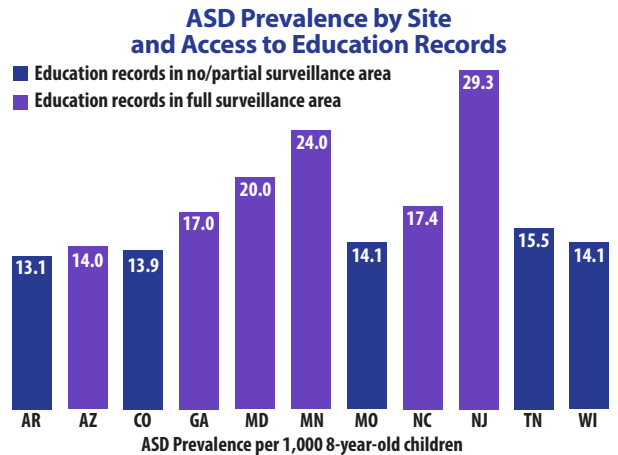


**1 in 59**  
8-year-old children were identified with ASD by ADDM in 2014

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

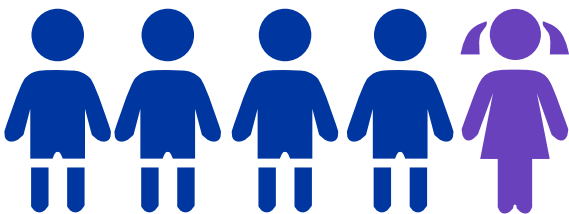
The percentage of children identified with ASD ranged widely across geographic areas.

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 77 or 1.3% in areas of Arkansas to a high of 1 in 34 or 3% in areas of New Jersey.



### Which children were more likely to be identified with ASD?

**Boys were 4 times more likely** to be identified with ASD than girls.



**1.1x**  
MORE LIKELY  
among white vs black children

**1.2x**  
MORE LIKELY  
among white vs Hispanic children

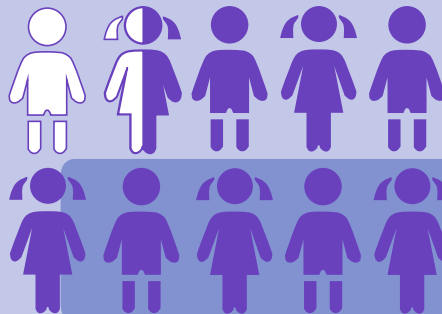
**1.1x**  
MORE LIKELY  
among black vs Hispanic children

White children were still 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. However, these differences were smaller when compared with estimates from previous years.

## When were children evaluated and diagnosed?

### Of children identified with ASD...

...about 85% had developmental concerns by 3 years of age.



...but only about 42% received a comprehensive developmental evaluation by 3 years of age.



- About 42% of children identified with ASD were evaluated for developmental concerns by 3 years of age. This percentage is lower than the goal set by Healthy People 2020 that 47% of children with ASD have a first evaluation by 3 years of age.



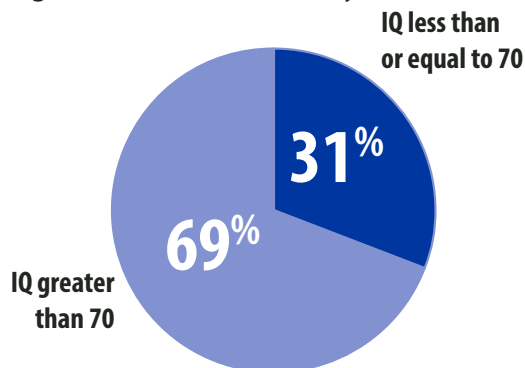
- Even though ASD can be diagnosed as early as 2 years of age, most children were not diagnosed with ASD by a community provider until after 4 years of age.



- About 80% 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 20% 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.

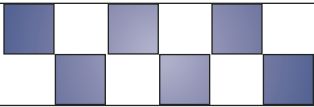
## What was the intellectual ability of the children identified with ASD?

Among children identified with ASD who had intelligence quotient (IQ) scores available, **nearly a third also had intellectual disability (IQ score ≤70)**. A quarter were in the borderline range for intellectual disability.



## What effect did the recent change in diagnostic criteria have on prevalence estimates?

- In 2014, ASD prevalence was estimated using a surveillance case definition based on the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV-TR); **ASD prevalence was also independently estimated using a new surveillance case definition based on the DSM-5 criteria.**
- The new surveillance case definition included children who had documented symptoms consistent with the DSM-5 diagnostic criteria as well as children who had a previous ASD diagnosis, even if they didn't have documentation of all the behavioral criteria.
- ASD prevalence was about **4% higher among children who met the DSM-IV-TR** surveillance case definition compared to ASD prevalence among children who met the new DSM-5 case definition.



# A Deeper Dive:

## Frequently Asked Questions About the ADDM Network Data

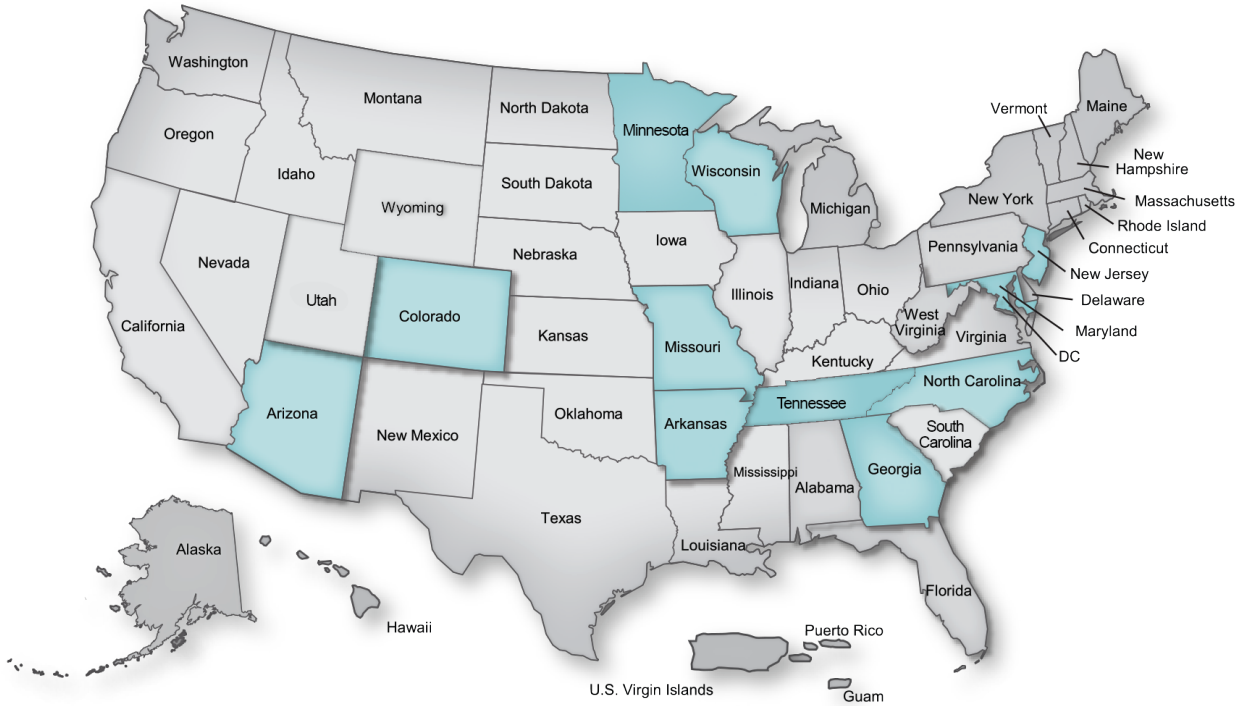
### How was this information collected?

As discussed in detail on page 4, the ADDM Network uses a systematic record review method. Specifically, this information reported by the Network 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 2014.

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

- Tracking area: Specific areas of Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin (see state pages for more information)
- Children in tracking area: 325,483 8-year-olds
  - 51 percent white
  - 22 percent black
  - 21 percent Hispanic
  - 5 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native

## Autism and Developmental Disabilities Monitoring (ADDM) Network Sites



■ Tracking Year 2014 Sites



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## What is the key take-away message?

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 was the percentage of children identified with ASD higher in some areas but not in others?

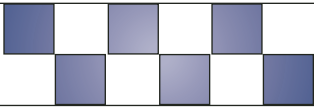
The percentage of children identified with ASD was significantly higher in areas of New Jersey and Wisconsin in 2014 compared with 2012, while the percentage stayed the same in other areas. Currently, research does not show that living in certain communities puts children at greater risk for developing 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.

## 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, some researchers outside the ADDM Network estimate 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 report as many as 1 in 50 or 1 in 36 children have ASD?

Estimates from the ADDM Network, the National Survey of 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.



# 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 public health goals.
  - 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 (1).
- Guide our research and the research of other scientists across the country.
  - ADDM Network findings have helped inform the Interagency Autism Coordinating Committee’s Strategic Plan for ASD research (2).
- Promote early identification efforts.
  - 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 early childhood developmental monitoring by parents, childcare providers, and healthcare providers.

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

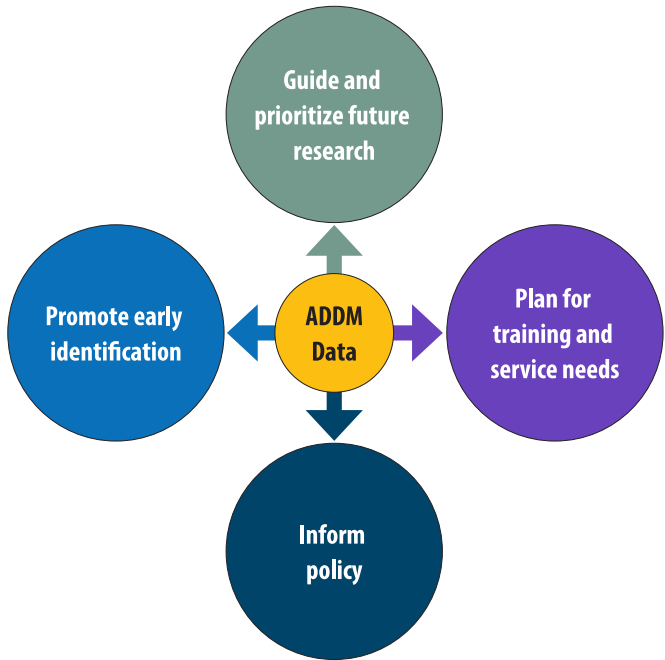
- Promote early identification efforts in order to lower the age when children are first evaluated for developmental concerns, diagnosed with ASD, and enrolled in community-based support systems.
- Plan for resource and service needs.
- Target outreach to under-identified groups of children, such as 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 abilities and challenges among children with ASD.



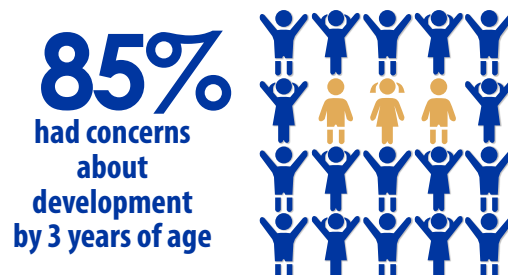
# Spotlight On:

## Delay Between First Concern to Accessing Services

Monitoring, screening, evaluating, and diagnosing children with autism spectrum disorder (ASD) as early as possible is important to make sure children receive the services and support they need to reach their full potential. There are several steps in this process.

### Concerns about Development

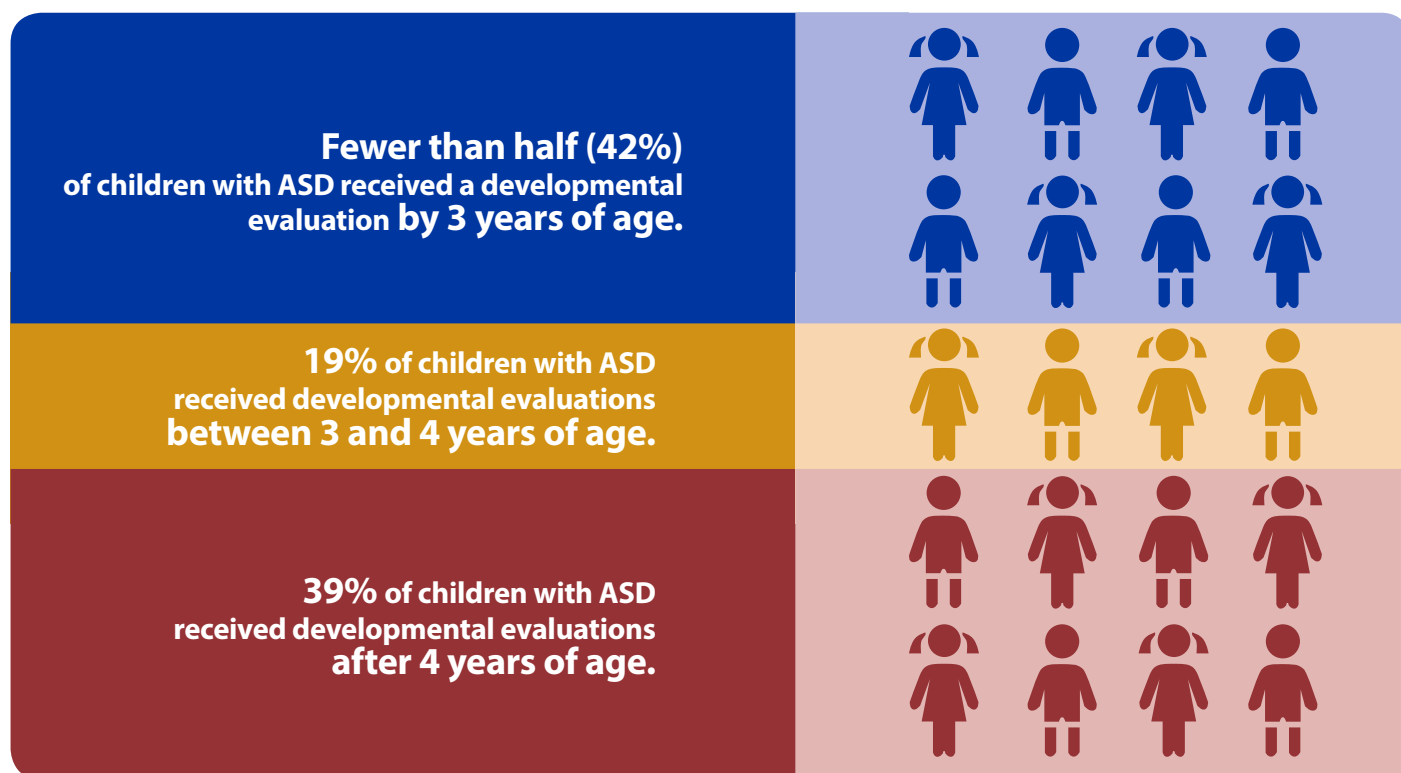
Most children (85%) identified with ASD had concerns about their development noted in their records by 3 years of age. Parents or caregivers may notice a concern through ongoing tracking of a child's development (developmental monitoring) and/or developmental screening. A concern about development is a reason to have a comprehensive developmental evaluation.

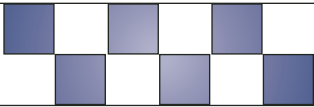


### Receiving a Comprehensive Developmental Evaluation

A comprehensive developmental evaluation is often a key step in getting access to services, including through the school system.

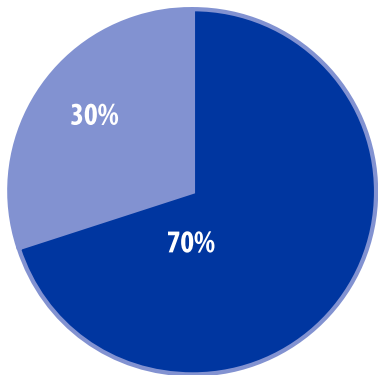
The majority of children with ASD had concerns about their development documented in their records before 3 years of age. However, there was frequently a lag between first concern and first developmental evaluation. This lag may affect when children with ASD can begin to get the services they need. Getting services as early as possible can make a difference in the development of a child with ASD.





## Diagnosis

A **medical diagnosis** can be a key step in getting medical services provided through health insurance.



Of the children who received an ASD diagnosis, the average age of diagnosis was a little under 4 and a half years (4 years and 4 months).

**30% of children** who met the ADDM Network surveillance case criteria for ASD **had not received a formal ASD diagnosis by 8 years of age**, potentially limiting the services they receive.

## Steps in the Process



- **Developmental monitoring** is important for all children. Caregivers, such as parents, healthcare providers, and early educators, should know developmental milestones—how children grow, move, communicate, interact, learn, and play. This information helps caregivers know what to expect at different ages, get ideas on how to promote positive development, and recognize 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](http://www.cdc.gov/ActEarly).



- **A developmental screen** is a short test using a validated screening tool to tell if a child is learning basic skills, and it can help determine if there might be a delay. The American Academy of Pediatrics recommends screening children for ASD at 18 and 24 months of age.



- **A comprehensive developmental evaluation** is a thorough review of the child's behavior and development. This evaluation can include clinical observation, parental reports of developmental and health histories, psychological testing, and speech and language assessments. A comprehensive developmental evaluation is often a key step in getting services, including through the school system.



- **Diagnosis** occurs when a developmental pediatrician, a child neurologist, a child psychiatrist, or a child psychologist uses the results of the comprehensive evaluation to determine if a child has ASD. Neurological and genetic testing can rule out other disorders and can check for genetic or neurological problems that sometimes occur along with ASD. A medical diagnosis can be a key step in getting medical services provided through health insurance.



## Spotlight On:

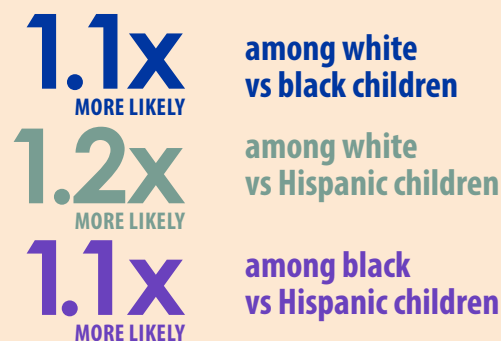
### Racial and Ethnic Differences in Children Identified with Autism Spectrum Disorder (ASD)

ADDM reports have consistently noted that more white children are identified with ASD than black or Hispanic children. Previous studies have shown that stigma, lack of access to healthcare services due to non-citizenship or low-income, and non-English primary language are potential barriers to identification of children with ASD especially among Hispanic children. A difference in identifying black and Hispanic children with ASD relative to white children means these children may not be getting the services they need to reach their full potential.

This ADDM report found that the racial and ethnic differences in identifying 8-year-old children with ASD persist, but also some indications that the differences may be narrowing.

#### Throughout the ADDM Network

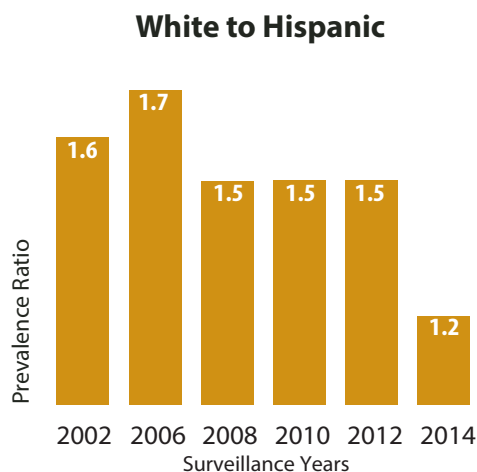
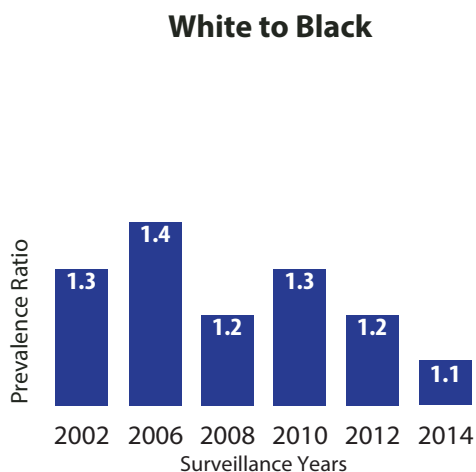
Black and Hispanic children continued to be less likely to be identified with ASD than white children. These differences suggest that black and Hispanic children may face socioeconomic or other barriers that lead to a lack of or delayed access to evaluation, diagnosis, and services.

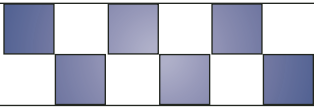


#### Prevalence Ratio

The prevalence ratio measures the difference in the likelihood of a condition between two groups. A prevalence ratio of 1.0 means there is no difference between the two groups. A prevalence ratio over 1.0 shows a difference between the two groups. Larger prevalence ratios show greater differences

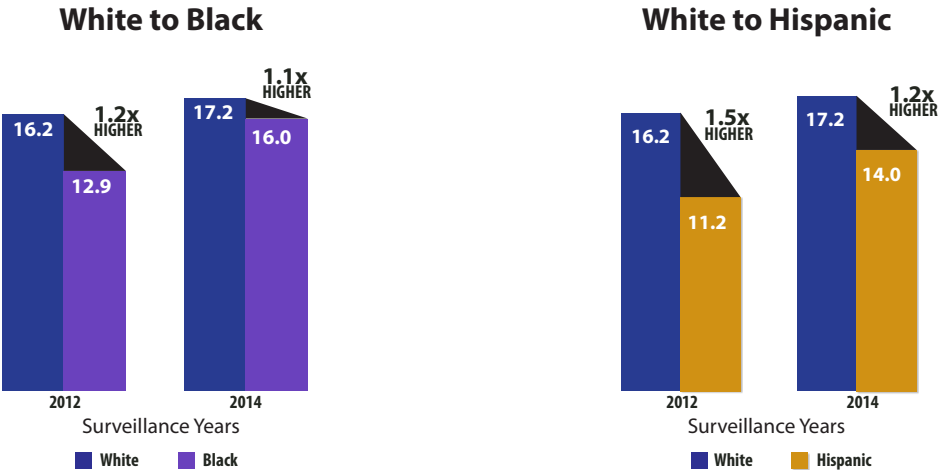
between groups. Prevalence ratios were lower in the most recent ADDM report than in previous reports, which shows reduced racial and ethnic differences in identifying children with ASD.





## Changing Differences in Identification

While a higher percentage of white children were identified with ASD compared to black children and even more so compared to Hispanic children, *these differences were smaller when compared with estimates from previous years.* These reduced differences may be due to more effective outreach directed toward minority communities and *efforts to have all children screened for ASD.*



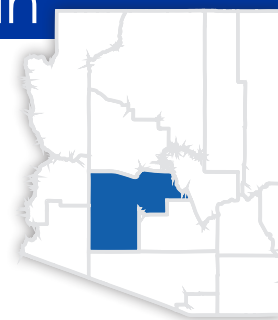
## Looking Ahead

The reduced differences in ASD prevalence for black and Hispanic children relative to white children may be due to more effective outreach directed toward minority communities and efforts to have all children screened for ASD. The ADDM Network will continue to monitor ASD prevalence to find out if the narrowing of racial and ethnic differences in children identified with ASD continues. This helps both states and communities develop and evaluate targeted strategies to increase awareness and improve identification of ASD in black and Hispanic communities.

# A Snapshot of Autism Spectrum Disorder in

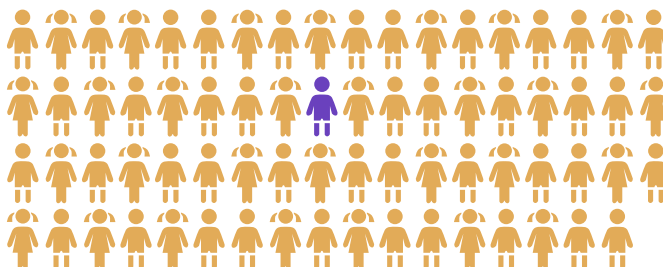
## Arizona

Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help us to 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.



**1.4%**

is slightly lower than the average percentage identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 71**

8-year-old children were identified with ASD by ADDSP in 2014

### Disparities in Identification

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

**3.2x**  
MORE LIKELY

among boys vs girls

**1.6x**  
MORE LIKELY

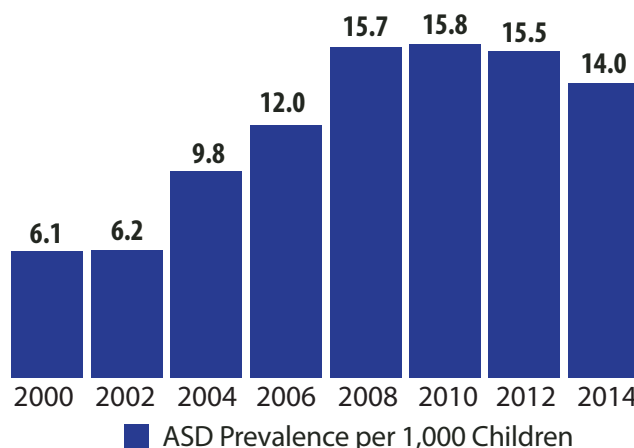
among white vs Hispanic children

**1.9x**  
MORE LIKELY

among black vs Hispanic children

### Prevalence in Arizona

In **2000**, an estimated **1 in 154 children (0.6%)** were identified with ASD. By **2008**, this number increased to **1 in 64 children (1.6%)**. Since 2008, the prevalence in Arizona has remained fairly steady.



### Of children identified with ASD...

**...over 90%** had developmental concerns by 3 years of age.



**...but only 34%** received a comprehensive developmental evaluation by 3 years of age.

# Arizona

## Frequently Asked Questions

### What are the key take-away messages?

- Fewer than half of the children identified with ASD received a comprehensive developmental evaluation by 3 years of age despite concerns about developmental delays. This lag between first concern and first developmental evaluation leads to delays in diagnosis and connection to the services and support the children need.
- Although ASD can be diagnosed as early as 2 years of age, in Arizona, the median age of diagnosis by a community provider is 4 years and 8 months of age.
- 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.
- Hispanic children are less likely to be identified with ASD compared to non-Hispanic children in Arizona. This may reflect cultural differences, socioeconomic differences, and/or differences in access to diagnostic and therapeutic services.
- More children with average intelligence levels are being identified with ASD. This may reflect increased awareness of the signs of autism, differentiated from other developmental disabilities.

### 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

- Lower the age of diagnosis by community providers.
- Increase awareness of ASD among Hispanic and minority families.
- Identify cultural, educational, and economic barriers to decreasing the age of evaluation and diagnosis in Hispanic, rural, and other underserved children.

### 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 2014.

- Children in tracking area: 24,952 8-year-olds
  - 49.3 percent white
  - 5.4 percent black
  - 39.2 percent Hispanic
  - 3.9 percent Asian or Pacific Islander
  - 2.2 percent American Indian or Alaska Native

### What has been the effect of the change in the diagnostic criteria used to identify children with ASD?

Surveillance year 2014 was the first year we were able to compare prevalence estimates based on the change in the American Psychiatric Association Diagnostic and Statistical Manual (DSM) criteria for ASD. In Arizona, 80 percent of children identified with ASD met both DSM-IV-TR and DSM-5 surveillance criteria. Among all ADDM sites, 86 percent of children identified with ASD met both sets of criteria.

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

ADDSP collaborates with the Arizona Department of Health Services 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 through the Arizona Leadership Education in Neurodevelopmental Disabilities. Training and outreach also extends to minority communities and rural service providers throughout Arizona.

## Get Resources and Connect Families to Services and Support in Arizona

### Arizona Autism Coalition

[www.azautism.org](http://www.azautism.org)

### Arizona Early Intervention Program

602-542-4446

<https://des.az.gov/services/disabilities/developmental-infant>

### AZ Find

800-352-4558

[www.azed.gov/special-education/az-find/](http://www.azed.gov/special-education/az-find/)

### AZA United

602-773-5773

[www.azaunited.org/](http://www.azaunited.org/)

### CDC's Learn the Signs. Act Early.

Kyle Lininger, Arizona's Act Early

Ambassador

[Kyle@AS-AZ.org](mailto:Kyle@AS-AZ.org)

### Raising Special Kids

602-242-4366

[www.raisingpecialkids.org/](http://www.raisingpecialkids.org/)

### Southwest Autism Research and Resource Center (SARRC)

602-340-8717

[www.autismcenter.org/](http://www.autismcenter.org/)

### Connect with ADDSP

Sydney Pettygrove, PhD

Margaret Kurzius-Spencer, PhD

Univ. of Arizona Health Sciences Center

[sydneyp@u.arizona.edu](mailto:sydneyp@u.arizona.edu)

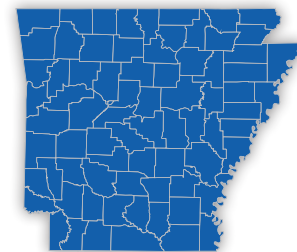
[mkurzius@email.arizona.edu](mailto:mkurzius@email.arizona.edu)

***“These statistics can create change. Our community can understand that there is a need to serve those affected when you put a number on it. Thank you, ADDSP, for making the world aware that we all are affected by autism in some capacity. And, we all need to make the world a better place for those who are affected.”***

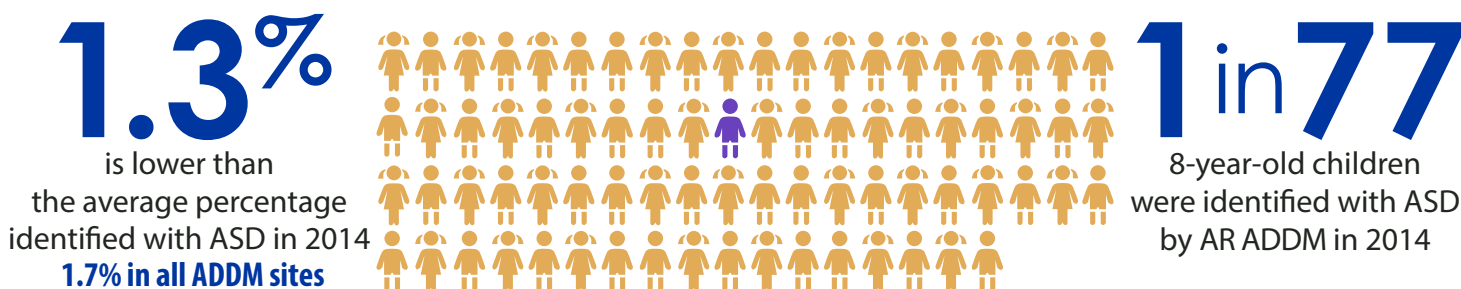
- Brie Seward, Associate Director,  
The Autism Society of Southern Arizona

# A Snapshot of Autism Spectrum Disorder in

## Arkansas

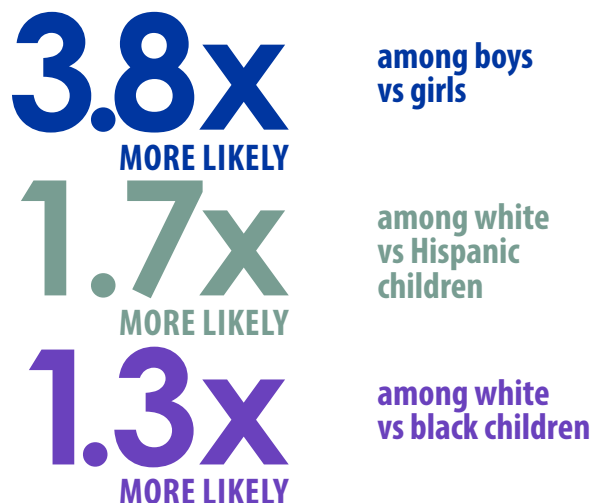


Findings from the Arkansas Autism and Developmental Disabilities Monitoring (AR ADDM) Program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



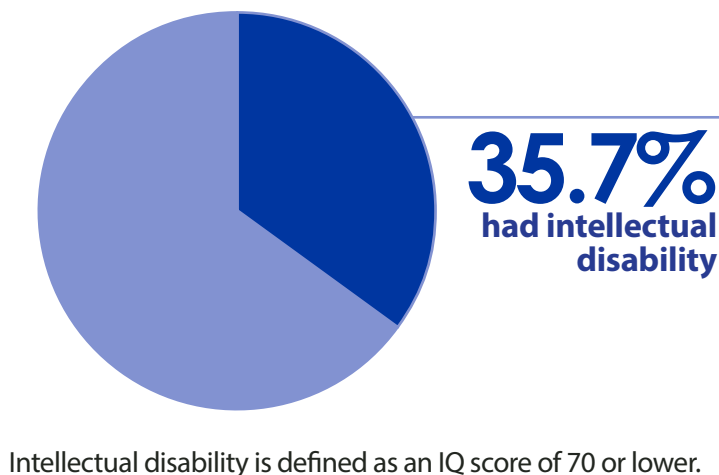
### Disparities in Identification

Boys were more likely to be identified with ASD than girls. Black children were more likely than Hispanic children to be identified with ASD, but white children were still most likely to be identified with ASD.



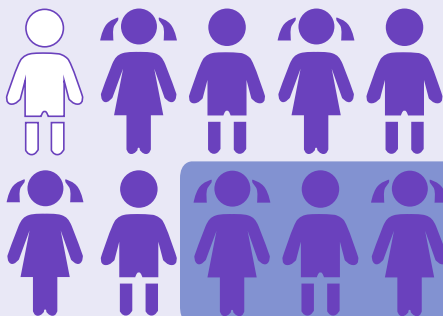
### Intellectual Disability in Arkansas

Arkansas had **intelligence quotient (IQ) data available for 88.3% of children identified with ASD**. Of those children, 35.7% had intellectual disability.



### Of children identified with ASD...

**...about 92%** had developmental concerns by 3 years of age.



**...but only about 31%** received a comprehensive developmental evaluation by 3 years of age.

# Arkansas

## 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 others factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were diagnosed with ASD by a community provider by 4 years, 11 months of age.
- Efforts may be directed toward evaluating and diagnosing all children with ASD as early as possible so that they can be connected to the services they need.

### 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 and diagnosis by community providers.

### How and where was this information collected?

AR ADDM uses a record review method. Specifically, 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 the 75 counties in Arkansas in 2014.

- Children in tracking area: 39,992 8-year-olds
  - 65 percent white
  - 19 percent black
  - 13 percent Hispanic
  - 2 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native

### What else does AR ADDM do besides track 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.

*"The work of AR ADDM has been very valuable to me in my role as a local special education director for three rural school districts in Van Buren County. Prevalence of autism in schools has skyrocketed, growing so quickly that it makes it difficult to keep adequate resources and supports in place for students, staff members, and families. When I examine our data I find that autism is no longer a low incidence disability in my three districts and it requires that I be diligent in supporting staff with resources and supports. The work of AR ADDM has allowed us to look at real data that has meaning around the prevalence of autism in our state. I have used the data over the years when I do presentations locally and at the state level. I hope that work continues- it is so very important!"*

- Deb Swink, Special Education Director  
Clinton, Shirley, and South Side School Districts

## Get Resources and Connect Families to Services and Support in Arkansas

### First Connections

Services for children under the age of 3 years with developmental delays or disabilities  
1-800-643-8258  
[www.arkansas.gov/dhs/ddds/FirstConn](http://www.arkansas.gov/dhs/ddds/FirstConn)

### Department of Education's Special Education Unit

Special education services for school-aged children with disabilities  
1-800-482-8437  
[arksped.k12.ar.us](http://arksped.k12.ar.us)

### Arkansas Autism Resource and Outreach Center

Support, education, and advocacy for families of individuals with ASD  
1-800-342-2923  
[aaroc.org](http://aaroc.org)

### Dennis Development Center (DDC) and Schmieding Development Center (SDC)

Diagnostic multidisciplinary team evaluations for children presenting with developmental and behavioral concerns. Provides comprehensive developmental assessments of children from birth to 21 years of age  
DDC 501-364-1830  
SDC 479-750-0125  
<https://pediatrics.uams.edu/clinical-programs-affiliates/>

### CDC's Learn the Signs. Act Early.

Alan Mease, Arkansas' Act Early Ambassador  
[Alan.Mease@arkansas.gov](mailto:Alan.Mease@arkansas.gov)

### Project Connect Resource Guide

Arkansas resources for families and professionals on child development and what to do if there is a concern  
[www.adcpi.org/Assets/projectconnect\\_resourceguide\\_smallsize.pdf](http://www.adcpi.org/Assets/projectconnect_resourceguide_smallsize.pdf)

### Spotting Autism in Early Child Care Settings

Training for child care providers on identifying children at risk for being diagnosed with autism. Available through Healthy Child Care Arkansas  
[www.healthychildcareAR.org](http://www.healthychildcareAR.org)

### Community-Based Autism Liaison and Treatment (CoBALT) Project

Comprehensive diagnostic assessments, early intervention services, and family support  
[www.pediatrics.uams.edu/specialties/developmental-pediatrics/cobalt-program/](http://www.pediatrics.uams.edu/specialties/developmental-pediatrics/cobalt-program/)

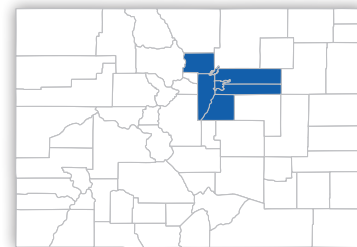
### Connect with AR ADDM

Allison Hudson  
University of Arkansas for Medical Sciences  
1 Children's Way, Slot 512-4  
Little Rock, AR 72202  
501-364-3612  
[aehudson@uams.edu](mailto:aehudson@uams.edu)

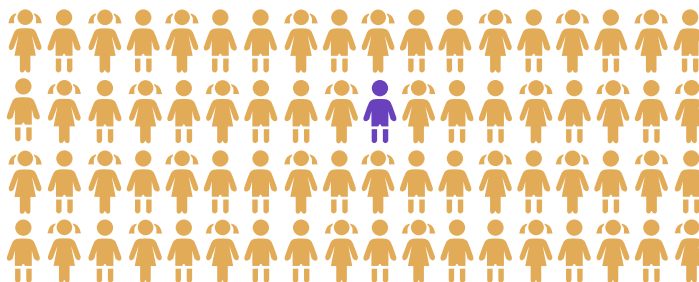
# A Snapshot of Autism Spectrum Disorder in

## Colorado

Findings from the Colorado Autism and Developmental Disabilities Monitoring (CO-ADDM) Project help us to 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.



**1.4%**  
is lower than  
the average percentage  
identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 72**  
8-year-old children  
were identified with ASD  
by CO-ADDM in 2014

### Disparities in Identification

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

**3.9x**  
MORE LIKELY

among boys  
vs girls

**1.4x**  
MORE LIKELY

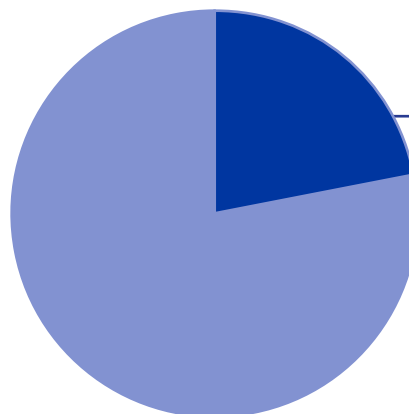
among white  
vs Hispanic  
children

NO SIGNIFICANT  
DIFFERENCE

among black vs  
Hispanic children or  
white vs black children

### Intellectual Disability in Colorado

Colorado had **intelligence quotient (IQ) data available for 76% of children identified with ASD**. Of those children, 21.4% had intellectual disability.



**21.4%**  
had intellectual  
disability

Intellectual disability is defined as an IQ score of 70 or lower.

### Of children identified with ASD...

**...about 89%**  
had developmental concerns  
by 3 years of age.



**...but only about 46%**  
received a comprehensive developmental  
evaluation by 3 years of age.

# Colorado

## 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 were 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 in Colorado.
- Despite the developmental concerns noted in many of the children's records by 3 years of age, 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.
- Although ASD can be diagnosed as early as 2 years of age, about half of children were not diagnosed with ASD by a community provider until after age 4 years and 3 months. Of the children identified with ASD in Colorado through the CO-ADDM Project, only 58 percent had either eligibility for autism special education services or a clinical autism diagnosis documented in their records.

### 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

- 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 all children are evaluated and diagnosed.

### How and where was this information collected?

The CO-ADDM Project uses a record review method. Specifically, 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 in Colorado in 2014.

- Tracking area: Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, and Jefferson counties
- Children in tracking area: 41,128 8-year-olds
  - 55 percent white
  - 7 percent black
  - 33 percent Hispanic
  - 5 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native

### What else does CO-ADDM do besides track 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 in Colorado, and links families and community partners with resources to improve collaboration across the ASD community in Colorado.

***"In Colorado, we are especially concerned about disparities that may occur in clinical diagnoses as well as educational identification of ASD. To address this concern, researchers at the University of Colorado Denver have increased our collaborative efforts with the Colorado Department of Education to understand the data and contexts that may influence disproportionality pertaining to ASD educational identification, particularly among African American and Latino populations. We are hopeful that our findings will influence the promotion of more culturally and linguistically responsive ASD identification practices in the schools"***

- Bryn Harris, PhD, NCSP, LP; Associate Professor, School of Education and Human Development & Department of Pediatrics, University of Colorado Denver  
- Brook Carson, PhD; State Autism Specialist, Colorado Department of Education

## Get Resources and Connect Families to Services and Support in Colorado

### Autism Society of Colorado

720-214-0794  
[www.autismcolorado.org](http://www.autismcolorado.org)

### Colorado sites of Autism Treatment Network

[www.jfkpartners.org](http://www.jfkpartners.org)  
[www.childrencolorado.org](http://www.childrencolorado.org)

### Department of Education's Office of Special Education

[www.cde.state.co.us/cdesped](http://www.cde.state.co.us/cdesped)  
Brooke Carson, Autism Specialist  
303-866-6691  
[carson\\_b@cde.state.co.us](mailto:carson_b@cde.state.co.us)

### Early Intervention Colorado

1-888-777-4041  
[www.eicolorado.org/](http://www.eicolorado.org/)

### Family Voices Colorado

800-881-8272  
[www.familyvoicesco.org](http://www.familyvoicesco.org)

### CDC's Learn the Signs. Act Early.

Eileen Auer Bennet, Colorado's Act Early Ambassador  
[eileen@coloradoabcd.org](mailto:eileen@coloradoabcd.org)

### The Arc of Colorado

303-864-9334  
[www.thearcofco.org](http://www.thearcofco.org)

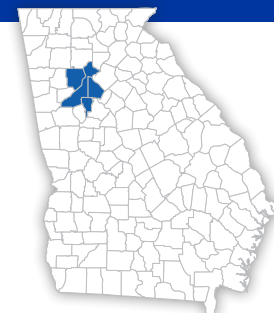
### Connect with CO-ADDM

Tiffany C. White, PhD, MSPH  
Colorado Department of Public Health and Environment  
4300 Cherry Creek South Drive  
Denver, CO 80228  
303-692-2680  
[tiffany.white@state.co.us](mailto:tiffany.white@state.co.us)



# A Snapshot of Autism Spectrum Disorder in

## Georgia



Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help us to 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.

**1.7%**

is the same as the average percentage identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 59**

8-year-old children were identified with ASD by MADDSP in 2014

### Disparities in Identification

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. There were no significant differences between white and black children.

**4.9x**  
MORE LIKELY

among boys vs girls

**1.4x**  
MORE LIKELY

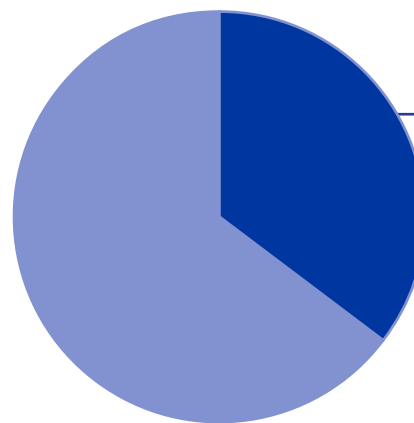
among white vs Hispanic children

**1.4x**  
MORE LIKELY

among black vs Hispanic children

### Intellectual Disability in Georgia

Georgia had **intelligence quotient (IQ) data available for 85.7% of children identified with ASD**. Of those children, 35.3% had intellectual disability.

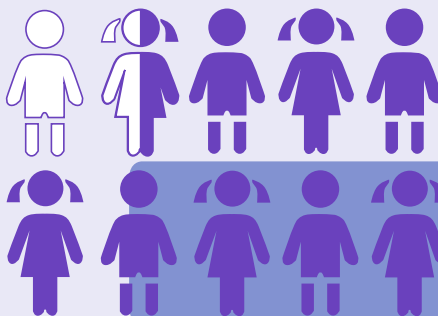


**35.3%**  
had intellectual disability

Intellectual disability is defined as an IQ score of 70 or lower.

### Of children identified with ASD...

**...about 86%**  
had developmental concerns by 3 years of age.



**...but only about 38%**  
received a comprehensive developmental evaluation by 3 years of age.

# Georgia

## 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 proportion of black and white children identified with ASD was about the same. However, Hispanic children were less likely to be identified with ASD than black or white children. This may reflect cultural and/or socioeconomic differences, such as language barriers and delayed or lack of access to services, as compared to white and black children in Georgia.
- Though developmental concerns were noted in many children's records by 3 years of age, 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 diagnosed and connected to the services they need.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were not diagnosed with ASD by a community provider until after 4 years, 5 months of age.
- Efforts may be directed toward evaluating and diagnosing all children with ASD as early as possible so that they can be 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

- 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 all children are evaluated and diagnosed.

### How and where was this information collected?

MADDSP uses a record review method. Specifically, 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 in Georgia in 2014.

- Tracking area: Clayton, Cobb, DeKalb, Fulton, and Gwinnett counties
- Children in tracking area: 51,161 8-year-olds
  - 30 percent white
  - 43 percent black
  - 19 percent Hispanic
  - 7 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native

### What else does MADDSP do besides track 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. In addition, MADDSP partners with community organizations to host annual ASD awareness month events. Upon request, MADDSP offers workshops and 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 key information on the number of children identified with ASD in multiple areas of the United States. The information obtained not only gives us a valuable estimate of the number of children in the population, but provides a way to evaluate important changes, such as the use of different diagnostic criteria.”***

- Catherine Rice, PhD; Director, Emory Autism Center

## Get Resources and Connect Families to Services and Support in Georgia

### Atlanta Autism Consortium

Support for collaboration among families, researchers, clinicians, educators, and advocates  
[www.atlantaautismconsortium.org](http://www.atlantaautismconsortium.org)

### Autism Society of Georgia

Information and support for families/providers  
1-844-404-ASGa  
[www.autismsocietyga.org](http://www.autismsocietyga.org)

### Autism Speaks

Information and resources for families  
770-451-0570  
[www.autismspeaks.org/georgia](http://www.autismspeaks.org/georgia)

### Babies Can't Wait

Services for children under the age of 3 years with developmental delays or disabilities  
1-888-777-4041  
[dph.georgia.gov/Babies-Cant-Wait](http://dph.georgia.gov/Babies-Cant-Wait)

### Department of Education

#### Special Education Services and Supports

Special education services for school-aged children with disabilities  
404-656-3963  
[www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/default.aspx](http://www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/default.aspx)

### Parent to Parent of Georgia

Support for parents of children with special needs  
800-229-2038  
[p2pga.org](http://p2pga.org)

### CDC's Learn the Signs. Act Early.

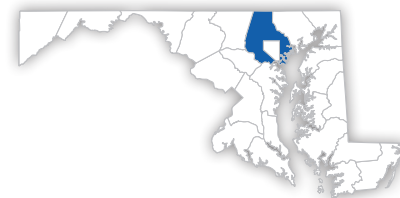
Jennie Couture, Georgia's Act Early Ambassador  
[Jennie.Couture@decal.ga.gov](mailto:Jennie.Couture@decal.ga.gov)

### Connect with MADDSP

Deborah Christensen, PhD  
Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities  
404-498-3836  
[DChristensen@cdc.gov](mailto:DChristensen@cdc.gov)

# A Snapshot of Autism Spectrum Disorder in

## Maryland



Findings from the Maryland Autism and Developmental Disabilities Monitoring (MD-ADDMM) Program help us to 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.

**2.0%**

is higher than the average percentage identified with ASD in 2014  
**1.7% in all ADDMM sites**



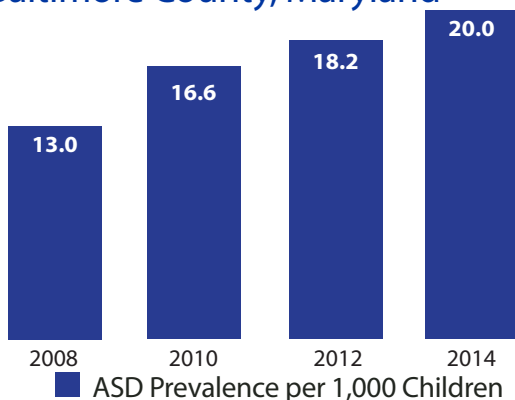
**1 in 50**

8-year-old children were identified with ASD by MD-ADDMM in 2014

### Disparities in Identification

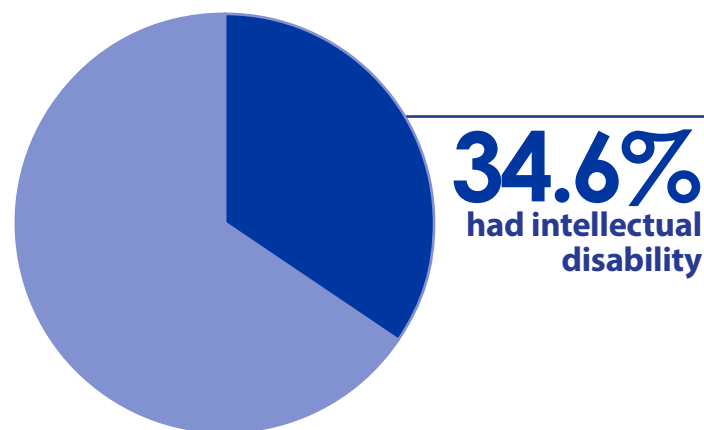
Boys were **4.5 times** more likely to be identified with ASD than girls. No significant differences were found in the percentage of white, black, and Hispanic children identified with ASD.

### Autism Over Time in Baltimore County, Maryland



### Intellectual Disability in Maryland

Maryland had **intelligence quotient (IQ) data available for 78.4% of children identified with ASD**. Of those children, 34.6% had intellectual disability.



Intellectual disability is defined as an IQ score of 70 or lower.

### Of children identified with ASD...

**...about 92%** had developmental concerns by 3 years of age.



**...but only about 56%** received a comprehensive developmental evaluation by 3 years of age.

# Maryland

## 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 others factors, such as how providers diagnose and document ASD symptoms among boys versus girls.
- Despite the developmental concerns noted in many (92 percent) of the children's records by 3 years of age, only slightly more than half (56 percent) 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.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were diagnosed with ASD by a community provider by 4 years, 4 months of age.
- Efforts may be directed toward evaluating and diagnosing all children with ASD as early as possible so that they can be 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?

MD-ADDM uses a record review method. Specifically, 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 2014.

- Children in tracking area: 9,955 8-year-olds
  - 50 percent white
  - 34 percent black
  - 8 percent Hispanic
  - 7 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native

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

MD-ADDM collaborates with the Maryland Department of Health and Mental Hygiene and investigators from Johns Hopkins University and partners with the Maryland State Department of Education and the Kennedy Krieger Institute to track the number and characteristics of 8-year-olds with ASD and/or intellectual disability in Baltimore County, 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.

Get Resources and Connect Families to Services and Support in **Maryland**

**Autism Society of Baltimore-Chesapeake**  
[www.baltimoreautismsociety.org](http://www.baltimoreautismsociety.org)

**Center for Autism and Related Disorders at Kennedy Krieger Institute**  
[www.card.kennedykrieger.org](http://www.card.kennedykrieger.org)

**Department of Education's Division of Special Education and Early Intervention Services**  
<http://www.marylandpublicschools.org/programs/Pages/Special-Education/index.aspx>

**Pathfinders for Autism**  
[www.pathfindersforautism.org](http://www.pathfindersforautism.org)

**The League for People with Disabilities, Inc.**  
[www.leagueforpeople.org](http://www.leagueforpeople.org)

**CDC's Learn the Signs. Act Early.**  
Sunyoung Ahn, Maryland's Act Early Ambassador  
[sa1442@georgetown.edu](mailto:sa1442@georgetown.edu)

**Connect with MD-ADDM**  
Li-Ching Lee, PhD, ScM  
Johns Hopkins Bloomberg School of Public Health  
615 N. Wolfe St., Suite E6032  
Baltimore, MD 21205  
410-502-0605  
[llee38@jhu.edu](mailto:llee38@jhu.edu)

*"The work that Maryland-ADDM does informs and supports policies that improve access to diagnosis and early intervention, which is so important to the autism community in Maryland. We are fortunate that Maryland was chosen as an ADDM Network site because it allows us to see our state's trends. This knowledge is a valuable tool in helping us guide our local resources. Our hope is that this data is used to help further research to find a cause as well as help families gain access to more meaningful services."*

- Rebecca Rienzi  
Executive Director, Pathfinders for Autism

# A Snapshot of Autism Spectrum Disorder in

## Minnesota

Findings from the Minnesota-Autism and Developmental Disabilities Monitoring Network (MN-ADDM) help us to 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.



**2.4%**

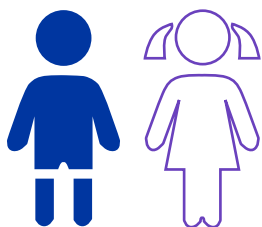
is higher than the average percentage identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 42**

8-year-old children were identified with ASD by MN-ADDM in 2014

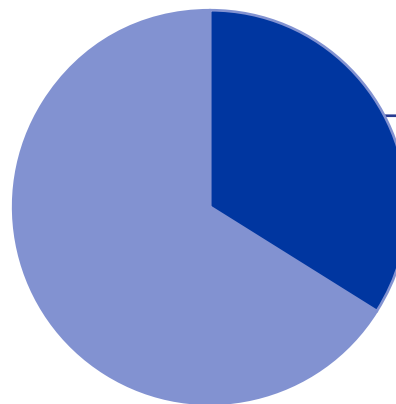
### Disparities in Identification



**Boys were 4.6 times 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.

### Intellectual Disability in Minnesota

Minnesota had **intelligence quotient (IQ) data available for 79.9% of children identified with ASD.** Of those children, 28.1% had intellectual disability.



**28.1%** had intellectual disability

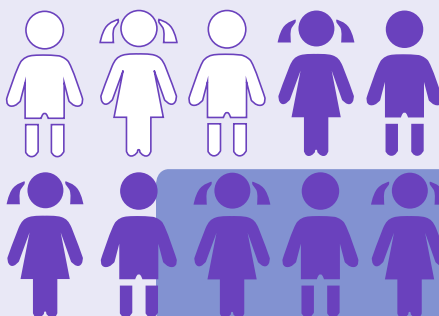
Intellectual disability is defined as an IQ score of 70 or lower.



**ASD can be diagnosed as early as 2 years of age;** however, about half of children were not diagnosed with ASD by a community provider until after 4 years, 8 months of age.

### Of children identified with ASD...

**...about 73%** had developmental concerns by 3 years of age.



**...but only about 34%** received a comprehensive developmental evaluation by 3 years of age.

# Minnesota

## Frequently Asked Questions

### What are the key take-away messages?

- This is the first time MN has been a part of the ADDM network, and we are building our geographic area. The findings in this report reflect a small number of children concentrated in a large metropolitan area. The higher prevalence estimate is not unanticipated for a large metropolitan area.
- In MN there were differences between percentage of boys and girls identified, with more boys than girls. This is consistent with previous estimates.
- We found varying prevalence rates across racial and ethnic groups in Minnesota. The small number of children in some of these groups makes it difficult to determine whether the rates of children with autism truly are different across groups. As the geographic area for MN-ADDM grows, we will be better able to judge whether there are true differences in prevalence estimates. If differences are found, it will be important to focus on general health disparities that may influence these differences.
- In Minnesota, we identify autism much later than when first concerns are reported. The lag between first concern and diagnosis is concerning due to what we know about the importance of early intervention.

### How can this information be useful?

MN-ADDM's 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 Minnesota might consider finding 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 in 2014. In addition to the race/ethnicity categories routinely studied by CDC, in MN we are interested in understanding prevalence for Hmong and Somali immigrant populations.

- Tracking area: Parts of two counties (Hennepin and Ramsey) including the large metropolitan cities of Minneapolis and St. Paul
- Children in tracking area: 9,767 8-year-olds
  - 39 percent white non-Hispanic
  - 28 percent black/non-Somali
  - 15 percent Hispanic
  - 8 percent Hmong
  - 8 percent Asian or Pacific Islander/non-Hmong
  - 6 percent Somali
  - 2 percent American Indian or Alaska Native

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

MN-ADDM collaborates with a wide variety of community ASD organizations and several Minnesota state agencies including the Minnesota Departments of Education (MDE), Human Services (DHS), and Health (MDH). MN-ADDM uses an active community advisory board consisting of parents/family members, advocates, researchers, service providers, administrators, faith leaders, educators, clinicians, and community organizers to inform, guide and support the work of MN-ADDM. In Minnesota, we also partner with the CDC funded "Learn the Signs. Act Early" (L TSAE) project and Help Me Grow MN to conduct outreach and educational activities on early developmental screening and early identification in under-identified communities such as Latino, Hmong, and Somali communities. MN-ADDM together with MN Act Early has translated and customized ASD and L TSAE outreach materials and resources for our local diverse communities. A short film series was developed in partnership with MN DHS to raise awareness of ASD for local diverse communities (e.g., Somali, Hispanic, Hmong, African American, and American Indian). They are designed to help families access evaluation resources, early intervention services, and ASD support resources.

Get Resources and Connect Families to Services and Support in **Minnesota**

#### Help Me Grow

1-866-693-GROW (4769)  
helpmegrowmn.org  
MDE.ECSE@state.mn.us

#### Minnesota Autism Portal

[www.mn.gov/autism/](http://www.mn.gov/autism/)

#### Autism Society of Minnesota

[www.ausm.org](http://www.ausm.org)

#### CDC's Learn the Signs. Act Early. MN

[www.ltsae.umn.edu](http://www.ltsae.umn.edu)  
Jennifer Hall-Lande,  
Minnesota's Act Early Ambassador  
[hall0440@umn.edu](mailto:hall0440@umn.edu)

#### University of Minnesota Autism and Neurodevelopmental Disorders Clinic

612-625-3617  
[www.pediatrics.umn.edu/divisions/clinical-behavioral-neuroscience/division-sections/autism-clinic](http://www.pediatrics.umn.edu/divisions/clinical-behavioral-neuroscience/division-sections/autism-clinic)

#### Connect with MN-ADDM

Institute on Community Integration  
University of Minnesota  
150 Pillsbury Dr. SE  
Minneapolis, MN 55455  
[addm.umn.edu](http://addm.umn.edu)  
[autism@umn.edu](mailto:autism@umn.edu)

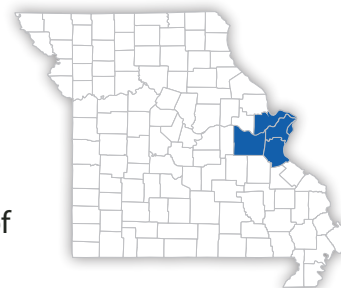
***"MN-ADDM data are important to find out if autism is specific to us or is something that we share with other communities. How do the characteristics of autism affect us compared to other communities?"***

- Yusuf Samatar, Somali Parent and Community Advisory Board Member

# A Snapshot of Autism Spectrum Disorder in

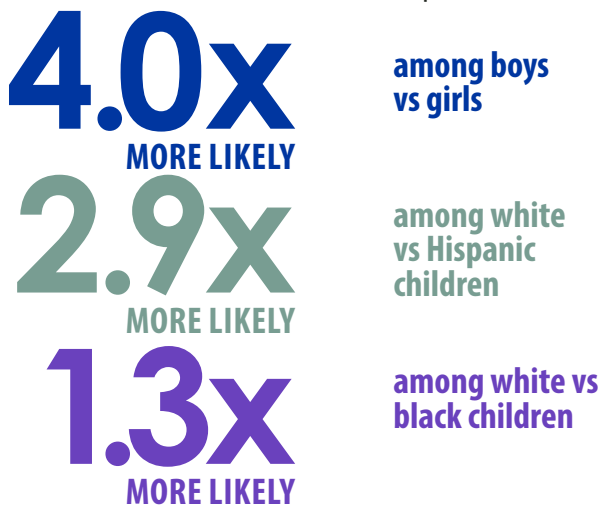
## Missouri

The latest findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) Project provide the 7th “snapshot” of ASD in our community in the past 14 years. The ongoing monitoring of autism spectrum disorder (ASD) adds to our understanding of how the number and characteristics of children with ASD are changing over time in our state.



### Disparities in Identification

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. No significant differences were found between black and Hispanic children.



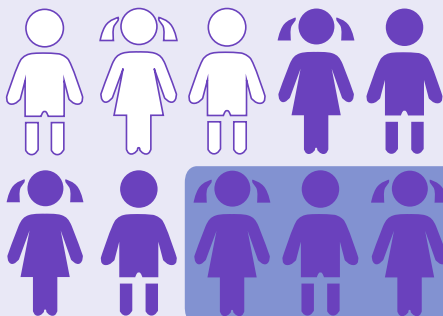
**ASD can be diagnosed as early as 2 years of age;** however, about half of children were not diagnosed with ASD by a community provider until after 4 years, 8 months of age. When looking at age of first diagnosis by ASD subtype, children were diagnosed at a range of ages.

ASD Subtype	Median* Age of Diagnosis
Autistic disorder	4 years, 6 months
Pervasive developmental disorder-not otherwise specified (PDD-NOS)	4 years, 7 months
Asperger disorder	5 years, 5 months

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

### Of children identified with ASD...

**...about 72%** had developmental concerns by 3 years of age.



**...but only about 32%** received a comprehensive developmental evaluation by 3 years of age.

# Missouri

## 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 others 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 3 years of age, 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.
- Efforts may be directed toward evaluating and diagnosing all children with ASD as early as possible so that they can be 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?

MO-ADDM uses a record review method. Specifically, 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 in Missouri in 2014.

- Tracking area: Franklin, Jefferson, St. Charles, St. Louis, and St. Louis City counties
- Children in tracking area: 25,333 8-year-olds
  - 65 percent white
  - 26 percent black
  - 5 percent Hispanic
  - 4 percent Asian or Pacific Islander
  - Less than 1 percent 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 monitors 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.

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](http://dese.mo.gov/special-education)

#### Department of Mental Health's Division of Developmental Disabilities

[dmh.mo.gov/dd/](http://dmh.mo.gov/dd/)

#### First Steps

1-866-583-2392  
[www.mofirststeps.com/](http://www.mofirststeps.com/)

#### CDC's Learn the Signs. Act Early.

Alicia Curran, Missouri's Act Early Ambassador  
[CurranA@health.missouri.edu](mailto:CurranA@health.missouri.edu)

#### Missouri Families for Effective Autism Treatment

877-275-8988  
[www.mo-feat.org/](http://www.mo-feat.org/)

#### Navigating Autism Services

[dmh.mo.gov/dd/autism/docs/navigationguide.pdf](http://dmh.mo.gov/dd/autism/docs/navigationguide.pdf)

#### Connect with MO-ADDM

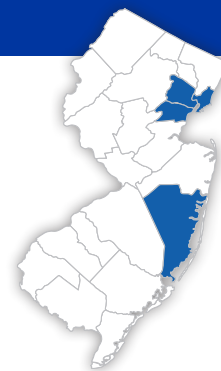
Robert Fitzgerald, PhD, MPH  
Washington University in St. Louis  
314-286-0151  
[fitzgeraldr@wustl.edu](mailto:fitzgeraldr@wustl.edu)

***"I think we definitely see this ADDM data as important as it speaks to the importance of early intervention for children and families here in Missouri. We continue to see an increase in our First Steps referral numbers and this data helps to capture the importance of ASD awareness and the continuing need for early intervention and early childhood supports. The data helps with current and future planning for our program."***

- Howard Smith  
Director,  
Region 1 (Greater St. Louis Region-  
St. Louis City/St. Charles County)  
St. Louis Area First Steps-Benchmark  
Human Services

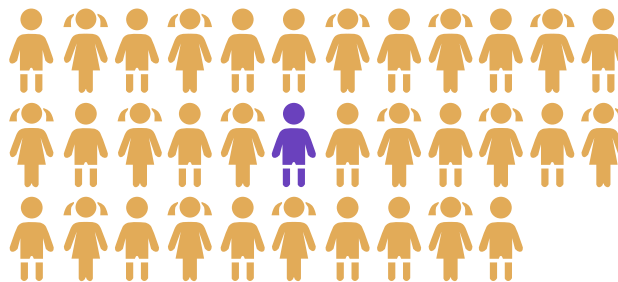


# A Snapshot of Autism Spectrum Disorder in New Jersey



Findings from the New Jersey Autism Study (NJAS) help us to understand more about the scope of autism spectrum disorder (ASD) in children, describe the expression of ASD in those children, and identify disparities in the prevalence or detection of ASD.

**3.0%**  
is higher than  
the average percentage  
identified with ASD in 2014  
**1.7% in all ADDM sites**

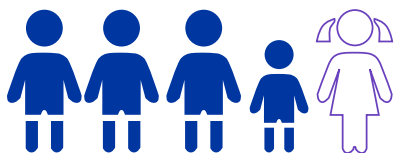


**1 in 34**  
8-year-old children  
were identified with ASD  
by NJAS in 2014

## Disparities in Identification

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

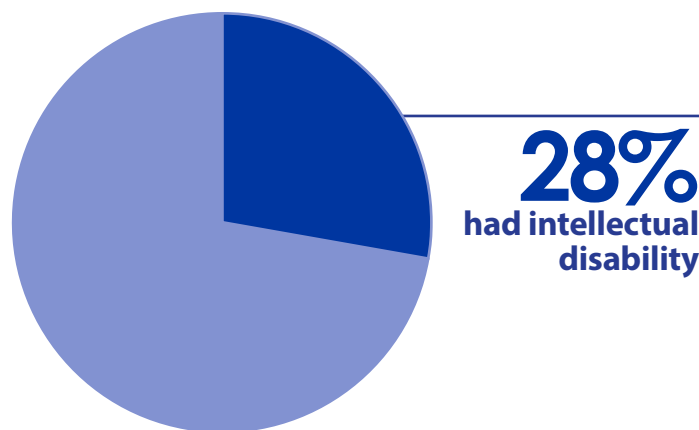
**3.7x** among boys  
vs girls  
**MORE LIKELY**



No significant difference was found in the percentage of white, black, and Hispanic children with ASD.

## Intellectual Disability in New Jersey

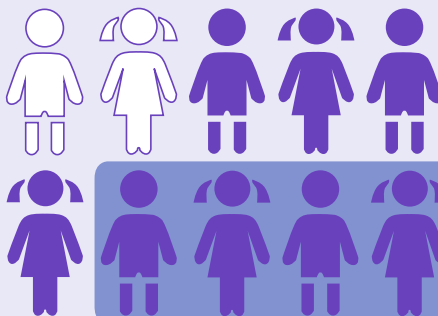
New Jersey had **intelligence quotient (IQ) data available for 72.1% of children identified with ASD**. Of those children, 28% had intellectual disability.



Intellectual disability is defined as an IQ score of 70 or lower.

## Of children identified with ASD...

**...about 80%**  
had developmental concerns  
by 3 years of age.



**...but only 40%**  
received a comprehensive developmental  
evaluation by 3 years of age.

# New Jersey

## Frequently Asked Questions

### What are the key take-away messages?

- The percentage of children with ASD increased in New Jersey, from about 2.5 percent in 2012 to about 3 percent, in 2014. Rising numbers of children with ASD need services and support, now, and will require significant resources as they grow into adolescence and adulthood.
- Boys continue to have a higher ASD prevalence than girls. In 2014, almost 4 percent of boys in the area were identified with ASD, compared to about 1 percent of girls.
- ASD prevalence in New Jersey did not vary by race or ethnicity in 2014, unlike in 2012, suggesting that progress has been made in identifying all children with ASD.
- In spite of the fact that developmental concerns are noted in many of children's records by 3 years of age, fewer than half of children with ASD received a comprehensive developmental evaluation by this same age. This lag between first concern and first developmental evaluation may affect when children are being diagnosed and connected to the services they need.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were not diagnosed with ASD by a community provider until after 4 years of age.
- Future efforts may emphasize the importance of screening young children with standard tools and connecting families to needed services before 3 years of age.
- The percentage of children with ASD continues to be higher in New Jersey compared to other areas in the United States where CDC tracks ASD. It is not known exactly why this is so, but geographic differences in evaluation and diagnostic practices for children with developmental concerns may play a role.

### How can this information be useful?

The latest findings may be used to

- Promote early identification of ASD,
- Plan for enhanced services and training,
- Guide future research, and
- Inform policies promoting improved health and quality of life outcomes for individuals with ASD.

### How and where was this information collected?

NJAS uses a comprehensive, active case-finding method based on the analysis of information from the health and special education records of children who were 8 years old and living in one of 4 counties in New Jersey in 2014.

- Tracking area: Essex, Hudson, Union, and Ocean counties
- Children in tracking area: 32,935 8-year-olds
  - 41 percent white
  - 22 percent black
  - 31 percent Hispanic
  - 6 percent Asian or Pacific Islander
  - Less than 1 percent 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.

***"The CDC ADDM and NJAS have been driving forces in advancing awareness and urgency for funding and policy changes to help more children and adults access the medical and behavioral treatment they need."***

- Suzanne Buchanan, PsyD, BCBA-D  
Executive Director, Autism New Jersey

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

### **Autism New Jersey**

Information, education, and policy initiatives related to ASD  
800-4-AUTISM  
[www.autismnj.org](http://www.autismnj.org)

### **Early Intervention System**

Services for children under the age of 3 years with developmental delays or disabilities  
[www.nj.gov/health/fhs/eis/](http://www.nj.gov/health/fhs/eis/)

### **Autism Family Services of New Jersey**

Support services for families living with ASD  
877-237-4477  
[www.autismfamilyservicesnj.org](http://www.autismfamilyservicesnj.org)

### **Asperger Syndrome Education Network**

Education, support, and advocacy for individuals with ASD and their families  
732-321-0880  
[www.aspennj.org](http://www.aspennj.org)

### **Department of Education's Office of Special Education Program**

Special education services for school-aged children with disabilities  
[www.nj.gov/education/specialed/](http://www.nj.gov/education/specialed/)

### **CDC's Learn the Signs. Act Early.**

Deepa Srinivasavaradan,  
New Jersey's Act Early Ambassador  
[deepas@spannj.org](mailto:deepas@spannj.org)

### **Mom2Mom**

24/7 peer-support for parents of children with special needs  
877-914-6662  
[www.mom2mom.us.com](http://www.mom2mom.us.com)

### **Statewide Parent Advocacy Network**

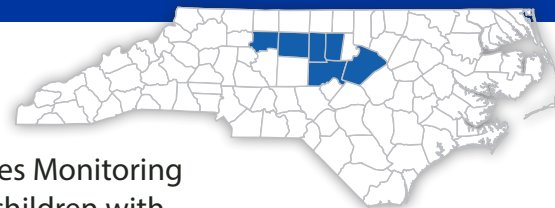
Support for parents, including parents of children with special needs  
800-654-7726  
[www.spannj.org](http://www.spannj.org)

### **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](mailto: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 us to 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.

**1.8%**  
is similar to  
the average percentage  
identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 57**  
8-year-old children  
were identified with ASD  
by NC-ADDM in 2014

### Disparities in Identification

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.

**4.3x**  
MORE LIKELY

among boys  
vs girls

**1.6x**  
MORE LIKELY

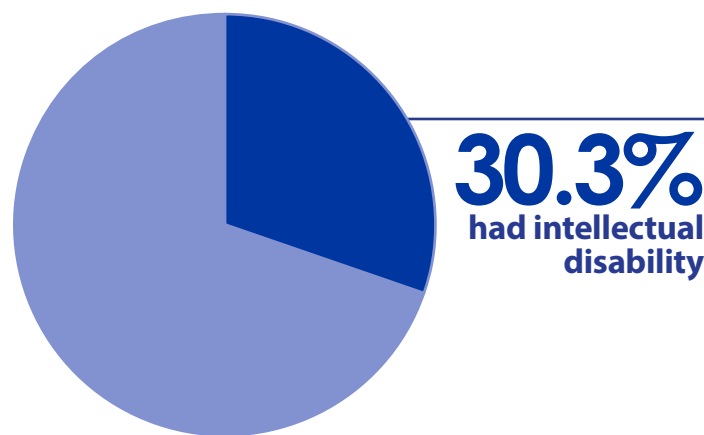
among white  
vs Hispanic  
children

**1.4x**  
MORE LIKELY

among black  
vs Hispanic  
children

### Intellectual Disability in North Carolina

North Carolina had **intelligence quotient (IQ) data available for 89.2% of children identified with ASD**. Of those children, 30.3% had intellectual disability.



Intellectual disability is defined as an IQ score of 70 or lower.

### Of children identified with ASD...

**...about 93%**  
had developmental concerns  
by 3 years of age.



**...but about 66%**  
received a comprehensive developmental  
evaluation by 3 years of age.

# North Carolina

## 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 were 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 3 years of age. 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.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were not diagnosed with ASD by a community provider until after 3 years, 4 months of age.
- Efforts may be directed toward evaluating and diagnosing all children with ASD as early as possible so that they can be connected to the services they need.

### 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 all 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 6 counties (Alamance, Chatham, Forsyth, Guilford, Orange, and Wake) in central North Carolina in 2014.

- Children in tracking area: 30,283 8-year-olds
  - 50 percent white
  - 25 percent black
  - 18 percent Hispanic
  - 6 percent Asian or Pacific Islander
  - Less than 1 percent 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 Society of North Carolina

800-442-2762

[www.autismsociety-nc.org/](http://www.autismsociety-nc.org/)

#### The Carolina Institute for Developmental Disabilities

919-966-5171

[www.cidd.unc.edu/](http://www.cidd.unc.edu/)

#### CDC's Learn the Signs. Act Early.

Rebecca Edmonson Pretzel, North Carolina's Act Early Ambassador

Becky.Edmondson@cidd.unc.edu

[www.ncactearly.com](http://www.ncactearly.com)

#### North Carolina Infant-Toddler Program

919-707-5520

[www.beeearly.nc.gov/](http://www.beeearly.nc.gov/)

#### TEACCH Autism Program

[www.teacch.com/](http://www.teacch.com/)

#### Connect with NC-ADDM

Julie Daniels, PhD

University of North Carolina at Chapel Hill

919-966-7096

[Julie\\_Daniels@unc.edu](mailto:Julie_Daniels@unc.edu)

***“Given the importance of early identification and intervention, as well as supports and services for children with autism spectrum disorders and their families, these data enable us to assess how we are doing as a state in identifying children.”***

- Jill Singer

Early Intervention Branch Head

Division of Public Health

Early Intervention Branch

North Carolina Department of Health and Human Services

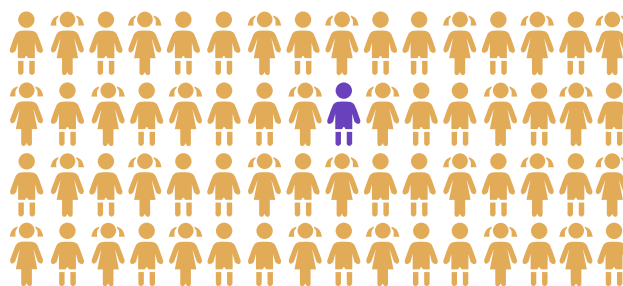
# A Snapshot of Autism Spectrum Disorder in

## Tennessee



Findings from the Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDM) help us to 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.

**1.6%**  
is slightly lower than the average percentage identified with ASD in 2014  
**1.7% in all ADDM sites**



**1 in 64**  
8-year-old children were identified with ASD by TN-ADDM in 2014

### Disparities in Identification

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

**4.7x**  
MORE LIKELY

among boys vs girls

**1.5x**  
MORE LIKELY

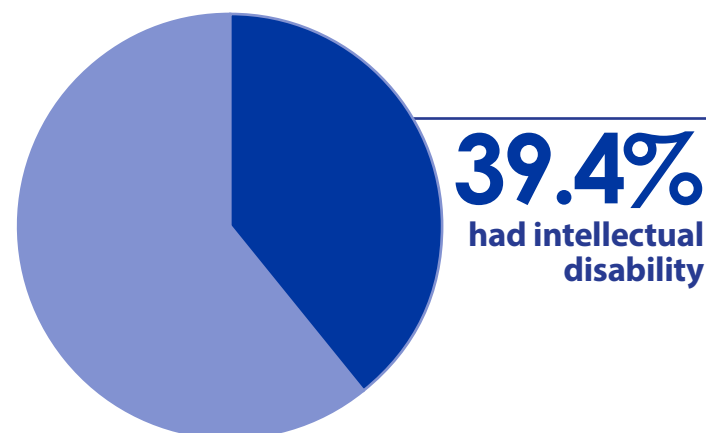
among white vs Hispanic children

NO SIGNIFICANT DIFFERENCE

among white vs black or black vs Hispanic children

### Intellectual Disability in Tennessee

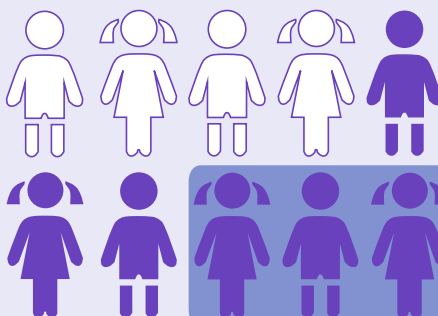
Tennessee had **intelligence quotient (IQ) data available for 70.8% of children identified with ASD**. Of those children, 39.4% had intellectual disability.



Intellectual disability is defined as an IQ score of 70 or lower.

### Of children identified with ASD...

**...about 61%**  
had developmental concerns by 3 years of age.



**...but only about 34%**  
received a comprehensive developmental evaluation by 3 years of age.

# Tennessee

## Frequently Asked Questions

### What are the key take-away messages?

- There are many children living with ASD who need services and support, now and as they grow into adolescence and adulthood.
- This is the first time data from ADDM are available for TN. The percentage of children with ASD in TN (1.6 percent) was very similar to current estimates across the United States (1.7 percent).
- Despite the developmental concerns noted in many of the children's records by 3 years of age, only about one-third (34 percent) of children with ASD received a comprehensive evaluation by this same age. This gap between early concerns and first developmental evaluation may affect when children are diagnosed and the intervention services they need.
- ASD can be diagnosed as early as 2 years of age; however, about half of children were not diagnosed with ASD by a community provider until after 4 years, 8 months of age.

### How can this information be useful?

TN-ADDM's 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 Tennessee 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 all 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 in Middle Tennessee in 2014.

- Tracking area: Bedford, Cheatham, Davidson, Dickson, Marshall, Maury, Montgomery, Rutherford, Robertson, Williamson, and Wilson
- Children in tracking area: 24,940 8-year-olds
  - 64 percent white
  - 20 percent black
  - 13 percent Hispanic
  - 3 percent Asian or Pacific Islander
  - Less than 1 percent American Indian or Alaska Native.

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

TN-ADDM is a collaboration between the Tennessee Department of Health, the Tennessee Department of Education, and investigators from Vanderbilt University Medical Center to track the percentage and characteristics of 8-year-olds with ASD and/or intellectual disability. In addition, TN-ADDM has been collaborating with the Tennessee Department of Children's Services in order to better understand the percentage and characteristics of children with ASD who experience allegations of child abuse and neglect. Training and outreach activities associated with TN-ADDM have been designed to build clinical and educational partnerships across our region and to extend knowledge and family support to rural and traditionally underserved communities in Tennessee.

Get Resources and Connect Families to Services and Support in **Tennessee**

#### Vanderbilt Kennedy Center (VKC)

[vkc.mc.vanderbilt.edu/vkc/](http://vkc.mc.vanderbilt.edu/vkc/)

#### Treatment and Research Institute for Autism Spectrum Disorder (TRIAD)

[vkc.mc.vanderbilt.edu/vkc/triad](http://vkc.mc.vanderbilt.edu/vkc/triad)

#### Tennessee Disability Pathfinder

1-800-640-4636

[vkc.mc.vanderbilt.edu/vkc/pathfinder/](http://vkc.mc.vanderbilt.edu/vkc/pathfinder/)

#### Tennessee Early Intervention System

1-800-852-7157

[www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html](http://www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html)

#### Autism Tennessee

615-385-2077

[autismtn.org](http://autismtn.org)

#### CDC's Learn the Signs. Act Early.

Toni Whitaker,  
Tennessee's Act Early Ambassador  
[twhitaker@uthsc.edu](mailto:twhitaker@uthsc.edu)

#### Connect with TN-ADDM

Alison Vehorn, MS  
Pablo Juárez, MEd, BCBA  
Zachary Warren, PhD  
Vanderbilt Kennedy Center  
110 Magnolia Circle  
Nashville, TN 37203  
1-877-ASD-VUMC  
[autismresources@vanderbilt.edu](mailto:autismresources@vanderbilt.edu)

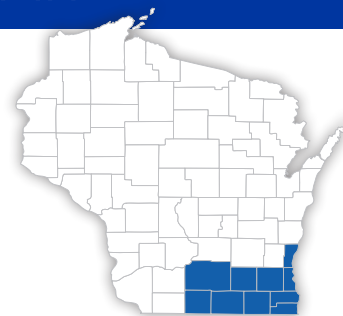
*"I use the information from ADDM every time I talk to families and professionals about what we are seeing in our community and across the state of Tennessee. The new TN-ADDM data will allow us to contribute not just to a larger national scientific understanding of the prevalence of ASD, but also to understand the impact of autism in our own backyard, to better equip those working to understand and serve individuals with ASD."*

- Quentin Humberd, MD  
Developmental Behavioral Pediatrician  
Chair of the Tennessee Governor's Council  
on Autism Spectrum Disorder

# A Snapshot of Autism Spectrum Disorder in

## Wisconsin

Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help us to 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.



**1.4%**

is lower than the average percentage identified with ASD in 2014  
**1.7% in all ADDM sites**

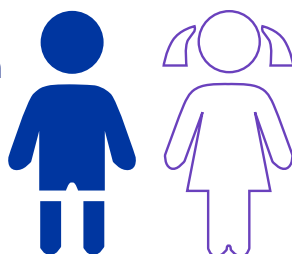


**1 in 71**

8-year-old children were identified with ASD by WISADDS in 2014

### Disparities in Identification

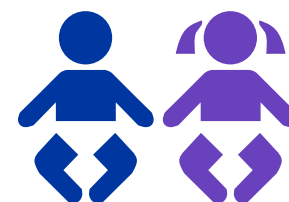
**Boys were 3.4 times more likely to be identified with ASD than girls.**



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

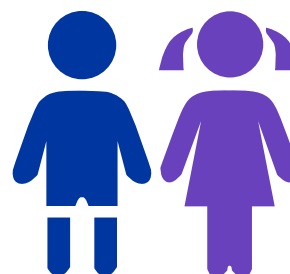
### Age of Diagnosis

**ASD can be diagnosed as early as 2 years of age.**



**For the first time in 2014**, WISADDS, along with all ADDM sites, was able to determine ASD case status under both pre-2013 diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) and the newer DSM-5 diagnostic criteria for ASD.

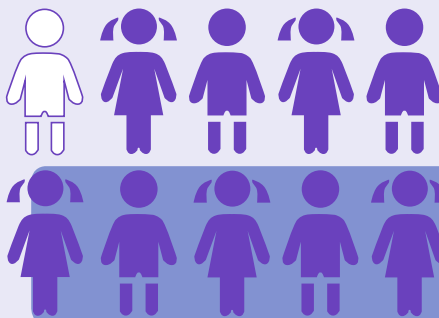
Among children meeting criteria for ASD under DSM-IV, more than **90% also met criteria for ASD under DSM-5.**



**However, about half of children were not diagnosed** with ASD by a community provider until after 4 years, 3 months of age. About 28% of children with ASD had not received a formal diagnosis of ASD by 8 years of age.

### Of children identified with ASD...

**...about 90%** had developmental concerns by 3 years of age.



**...but only about 47%** received a comprehensive developmental evaluation by 3 years of age.

# Wisconsin

## Frequently Asked Questions

### What are the key take-away messages?

- The percentage of children with ASD increased in southeastern Wisconsin from about 1.1 percent in 2012 to about 1.4 percent in 2014.
- Hispanic and black children were 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 3 years of age, 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.
- Efforts may be directed toward early developmental screening of all children so those who have ASD can be identified early 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

- Increase awareness of developmental monitoring and empower parents to act if there is a concern about their child's development.
- Lower the age of first evaluation by community providers.
- Increase awareness of ASD among Hispanic and black families, identify and address barriers in order to decrease the age at which all children are evaluated and diagnosed.

### How and where was this information collected?

WISADDS uses a record review method. This information is based on the analysis of data collected from the health and education records of children who were 8 years old and living in one of 10 counties in southeastern Wisconsin in 2014.

- Tracking area: Dane, Green, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Rock, Walworth, and Waukesha counties
- Children in tracking area: 35,037 8-year-olds
  - 59 percent white
  - 19 percent black
  - 18 percent Hispanic
  - 4 percent Asian or Pacific Islander
  - Less than 1 percent 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.

Get Resources and Connect Families to Services and Support in **Wisconsin**

#### Autism Society of Wisconsin

1-888-4-AUTISM  
[www.asw4autism.org](http://www.asw4autism.org)

#### Birth to Three Program, Wisconsin Department of Health Services

[www.dhs.wisconsin.gov/birthto3/index.htm](http://www.dhs.wisconsin.gov/birthto3/index.htm)

#### Finding Your Way

[www.waisman.wisc.edu/cedd/pdfs/products/community/FYW\\_e.pdf](http://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.pdf)

#### CDC's Learn the Signs. Act Early.

[www.ActEarly.wisc.edu](http://www.ActEarly.wisc.edu)  
Gail Chodron, Wisconsin's Act Early Ambassador  
608-890-0145  
[chodron@wisc.edu](mailto:chodron@wisc.edu)

#### Wisconsin First Step

1-800-642-7837  
[www.mch-hotlines.org/wisconsin-first-step](http://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  
[maureen.durkin@wisc.edu](mailto:maureen.durkin@wisc.edu)

***"It has been incredibly helpful to have WISADDS data as we work with partners in state government and the Wisconsin legislature to develop, implement and advocate for policies to support families, children, and adults with disabilities. These data have informed our work to improve access to evaluation and treatment services and ensure comprehensive medical and long-term supports for children with autism and other developmental disabilities."***

- Elizabeth Hecht  
Co-Director, Family Voices of Wisconsin





# 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 (3).

- *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 is 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. Specialists, such as developmental pediatricians, often use the results of a developmental evaluation 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 intelligence 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 defined as 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 defined as 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. 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.



# References

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4. Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee and Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1):405-420.
5. Johnson CP, Myers SM, American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorder. *Pediatrics*. 2007;120(5):1183-1215.



# ADDM Network

[www.cdc.gov/Autism](http://www.cdc.gov/Autism)