



community  
report on  
**autism**  
2020

**AUTISM AND DEVELOPMENTAL DISABILITIES  
MONITORING (ADDM) NETWORK**



National Center on Birth Defects  
and Developmental Disabilities  
Centers for Disease Control and Prevention



HELPING CHILDREN  
LIVE TO THE FULLEST  
BY UNDERSTANDING  
DEVELOPMENTAL DISABILITIES





# community report on autism

2020

## AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK

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A Snapshot of Autism Spectrum Disorder among  
8-year-old Children in Multiple Communities across  
the United States in 2016

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 reports:

Maenner MJ, Shaw KA, Baio J, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ* 2020, 69 (No. SS-4): 1-12.

Shaw KA, Maenner MJ, Baio J, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016. *MMWR Surveill Summ* 2020, 69 (No. SS-3): 1-11.

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

For more than two decades, CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network has been tracking the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities in diverse communities throughout the United States.

## Key Findings At-A-Glance

These findings are 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 2016.

- The estimated percentage of 8-year-old children identified with ASD is higher than previous estimates from the ADDM Network.
- For the first time, ADDM Network data found no overall difference in the number of black children identified with autism compared to white children. However, the number of Hispanic children identified with autism is still lower compared to white or black children.
- Overall, progress has been made toward the [Healthy People 2020](#) goal of increasing the percentage of children with ASD who receive their first developmental evaluation by 36 months.
- More children who were born in 2012 received an ASD diagnosis by 4 years of age compared to children born in 2008.

## 1 in 54

### 8-year-old children identified with ASD in 2016

\*Based on tracking within 11 communities in the United States

The 2020 Community Report on Autism highlights the ADDM Network's most recent findings on ASD in 8-year-old children, showing that the estimated percentage of children identified with ASD is higher than in previous reports. In 8-year-old children, about 1.85%, or 1 in 54, were identified with ASD in 2016, based on tracking within 11 communities

in the United States. While 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, they also offer good news that screening and awareness continue to identify children who will benefit from services.

- Knowing how many children have ASD is just part of the picture. While findings also show that significant progress has been made in reducing racial and ethnic disparities in the identification of ASD in children, CDC and its partners continue efforts to:
- Ensure that children are evaluated and diagnosed as soon as possible after developmental concerns are identified; and
- Promote efforts for early and equitable identification of ASD and timely enrollment in services.

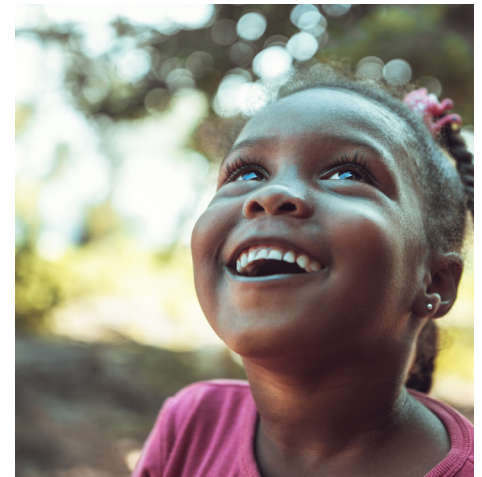
Service providers (such as healthcare organizations and

school systems), researchers, and policymakers can use ADDM Network findings to:

- Support service planning;
- Inform policies that promote improved outcomes in health care and education; and
- Guide research on risk and protective factors for ASD and the interventions that can help children with ASD succeed.

Together, those who work with or on behalf of children—from healthcare providers to educators to community advocates—can ensure that all children with ASD are identified and connected to the services they need as early as possible.

CDC will continue tracking the number and characteristics of children with ASD, researching risk and protective factors for ASD, and promoting early identification—the most powerful tool we have now for making a difference in the lives of children with ASD—through CDC’s [Learn the Signs. Act Early.](#) program.



## The ADDM Network’s goals are to



Obtain as complete a count as possible (also known as prevalence) of the number of children with ASD in each ADDM Network area and identify changes in prevalence over time;



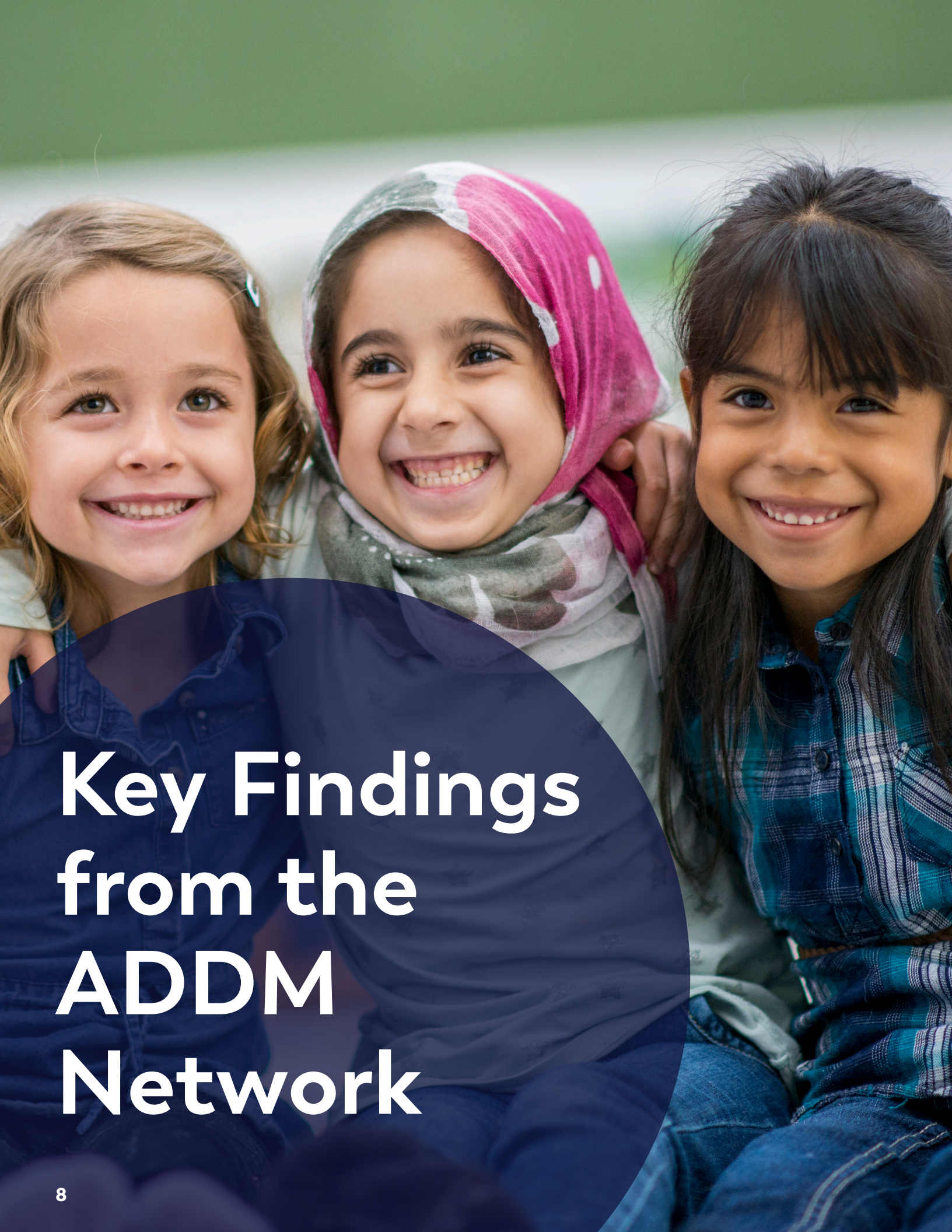
Provide information on the characteristics of children with ASD, including sex, race/ethnicity, whether or not intellectual disability is present, and age of evaluation and diagnosis;



Determine whether ASD is more common in some groups of children than among others (for example, among boys versus girls), 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.



# Key Findings from the ADDM Network



# Key Findings from the ADDM Network

## A Snapshot of Autism Spectrum Disorder in 2016

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

### How many children were identified with ASD?

About **1 in 54** or 1.85% of 8-year-olds were identified with ASD by the ADDM Network.

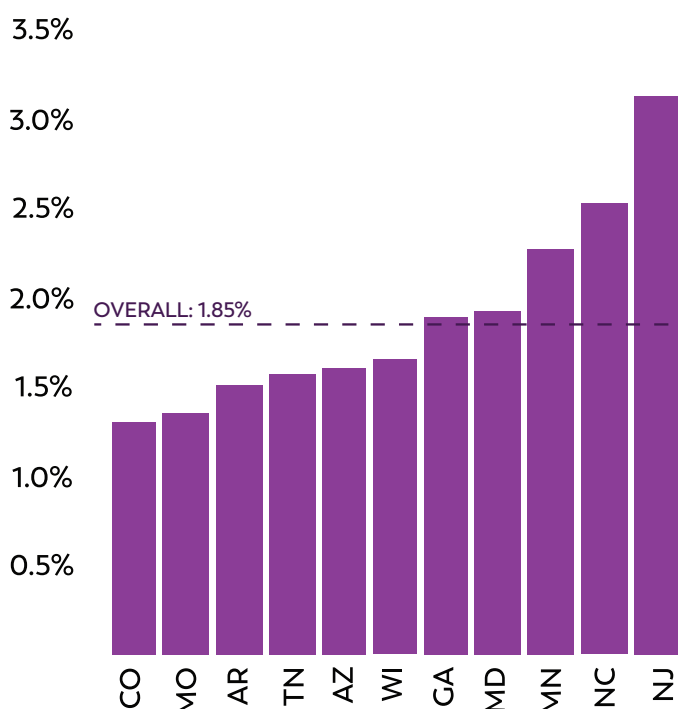
### How did the percentage of children identified with ASD range across geographic areas?

The percentage of children identified with ASD **ranged widely** across geographic areas from a low of **1 in 76 or 1.3% in Colorado** to a high of **1 in 32 or 3.1% in areas of New Jersey**.

## 1 in 54

8-year-old children were identified with ASD in 2016

### Percentage of children identified with ASD by ADDM Network Site



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

For every **one girl identified** with ASD, **4 boys** were identified.

For the first time, ADDM Network data found **no overall difference in the number of black children identified with autism compared to white children.** However, the number of Hispanic children identified with autism is still **lower** compared to white or black children.

## When were children evaluated and diagnosed?

Findings from the Early ADDM Network\* show that **74% of 4-year-old children** with ASD in 2014 received a developmental evaluation by 36 months of age. This increased to **84% of 4-year-old children** with ASD in the 2016 group.

**More children** who were born in 2012 (1.02%) received an ASD diagnosis by **4 years of age** compared to children born in 2008 (0.83%).

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

Among children identified with ASD who had intelligence quotient (IQ) scores available, **approximately one-third** also had intellectual disability.

\*The Early ADDM Network is a subset of sites participating in the broader ADDM Network that monitors ASD among 4-year-old children.

## For every girl identified with ASD,

4 boys were identified



## White & black children were 1.2x more likely

To be identified with ASD than Hispanic children



Values indicate prevalence per 1,000 children

## More evaluated by 36 months

4-year-old children with ASD who received evaluation 2016 vs. 2014



## Approximately 1/3

Of children with ASD also had intellectual disability



A young boy with dark hair, wearing a bright blue hooded jacket, is smiling and looking to his left. He is riding a bicycle, with the handlebars visible at the bottom of the frame. The background is a blurred green field. A semi-transparent blue circle is overlaid on the right side of the image, containing the title and subtitle text.

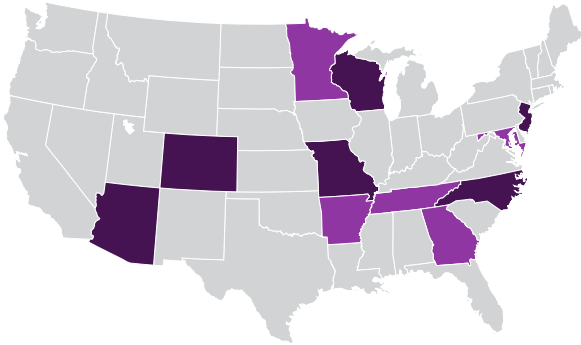
# A Deeper Dive

Frequently Asked  
Questions About  
ADDM Network Data

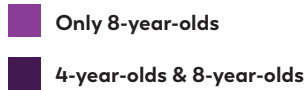
# A Deeper Dive

## Frequently Asked Questions About the ADDM Network Data

STATES WITH ADDM SITES  
Surveillance Year 2016

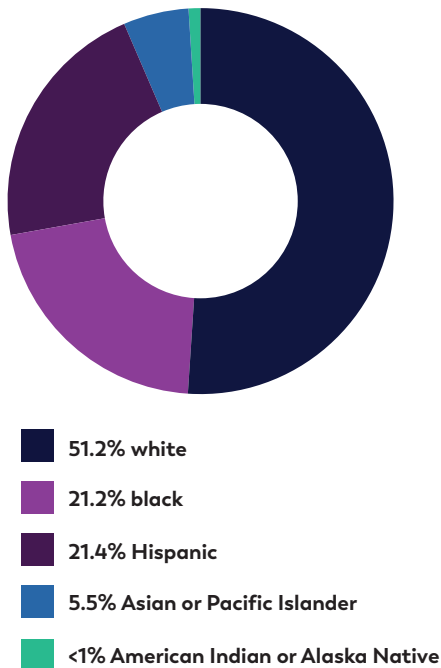


SURVEILLANCE AMONG



POPULATION BY RACE/ETHNICITY

Total: 275,419 Children 8 years of age



### How was this information collected?

The ADDM Network uses a systematic record review method. Specifically, the 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 2016.

### 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 ADDM Network site pages for more information).

### 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. Efforts to ensure that all children with ASD are evaluated and diagnosed as early as possible can help them be connected to the services they need.

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

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 records alone 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 the ADDM Network monitor future changes.

## Why does the ADDM ASD prevalence estimate differ from other ASD prevalence estimates?

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 parental experiences, can provide insight into how many children have been diagnosed with ASD and other developmental disabilities. The ADDM Network further enriches our understanding of ASD by working with communities across the United States to collect information on specific characteristics of children with ASD and track changes over time in those communities and within groups with similar characteristics.





# Data Spotlights

# Spotlight On

## Closing the Racial and Ethnic Gap in the Identification of Autism Spectrum Disorder

For the first time, the Autism and Developmental Disabilities Monitoring (ADDM) Network data found no overall difference in the number of black children identified with ASD by 8 years of age compared to white children, but ethnic disparities remain.

In past reports, the ADDM Network has consistently found that more white children are identified with autism spectrum disorder (ASD) than black or Hispanic children. While significant progress has been made in closing the gap in the identification of ASD between populations of white and black children, the number of Hispanic children identified with ASD is still lower compared to white or black children. Previous studies have shown that stigma, lack of access to healthcare services, and non-English primary language are potential barriers to identification of children with ASD, especially among Hispanic children. These barriers mean that certain groups of children may not be getting the services they need to reach their full potential. More work is needed to improve identification of ASD within Hispanic communities.

### **Differences continue in the age at identification of ASD among black and Hispanic children compared to white children.**

Racial and ethnic differences still exist in how early ASD is identified through evaluation and diagnosis, especially when the child with ASD also has intellectual disability. Overall, black and Hispanic children with ASD received evaluations later than white children with ASD.

In addition, black and Hispanic children with ASD and intellectual disability were diagnosed at a later age than white children with ASD and intellectual disability. This delay in diagnosis may limit opportunities to receive services that could improve outcomes and quality of life.



### **Future directions**

Racial and ethnic gaps in the identification of ASD are closing, and targeted community outreach and efforts to have all children screened for ASD are ongoing. The ADDM Network will continue to monitor the number and characteristics of children with ASD to find out if these gaps continue to narrow. This information can help states and communities develop and evaluate strategies to increase awareness and improve identification of ASD and referral to services in black and Hispanic communities.

# Spotlight On

## Progress in Evaluation and Diagnosis of Autism Spectrum Disorder

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

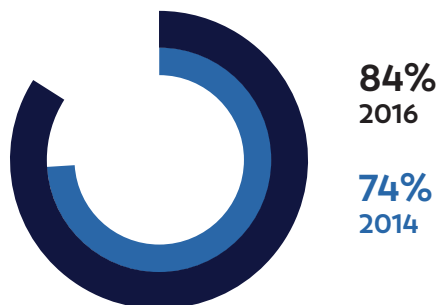


### Tracking ASD among preschool-aged children

Tracking ASD among preschool-aged children increases our understanding of the characteristics and early identification of younger children with ASD. Early identification helps families get earlier access to services in their communities. The Early Autism and Developmental Disabilities Monitoring (Early ADDM) Network collects information about ASD prevalence and early identification among 4-year-old children in a subset of six communities from the broader ADDM Network of 11 communities. The latest report from the Early ADDM Network provides critical information on progress made toward early identification of children with ASD and informs providers—particularly public schools—of future service needs.

### More evaluated by 36 months

4-year-old children with ASD who received evaluation 2016 vs. 2014



### Key findings from the Early ADDM Network

#### More children are being evaluated for ASD at an earlier age than previously reported

In 2016, a higher percentage (84% compared to 74%) of children identified with ASD by 4 years of age received their first developmental evaluation by 36 months compared to those in 2014. In addition, it indicates progress has been made toward the Healthy People 2020 goal of increasing the percentage of children with ASD who receive their first developmental evaluation by 36 months.



## More children are being diagnosed with ASD at an earlier age

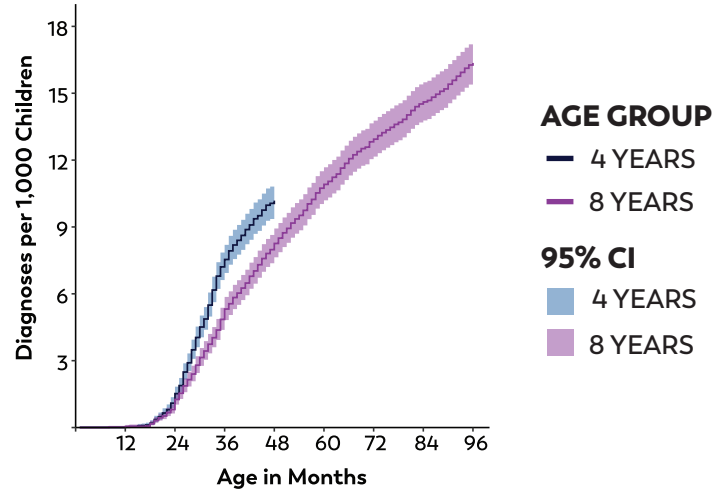
More children who were born in 2012 (1.02%) received an ASD diagnosis by 4 years of age compared to children born in 2008 (0.83%). This means more children are being diagnosed with ASD by age 4 now than previously.

### Implications

These are positive findings because **the younger a child is** when he or she receives a developmental evaluation or ASD diagnosis, **the sooner the child can begin to receive needed services.**

## Comparing children aged 4 and 8 years

In 2016 shown by age at ASD diagnosis



## Steps in the process to diagnose ASD

1. **Developmental monitoring** (also known as tracking or surveillance) is important for all children. Caregivers, such as parents, healthcare providers, and early educators, can learn how to look for 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).
2. **A developmental screen** is a short test using a validated screening tool to identify whether a child is learning basic skills, and it can help determine if there might be a delay. The [American Academy of Pediatrics](http://www.aap.org) recommends screening children for ASD at 18 and 24 months of age.
3. **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. Various professionals can conduct developmental evaluations, including teachers, social workers, nurses, psychologists, doctors, and speech-language pathologists. 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 those through the school system.
4. **Diagnosis** occurs when a developmental pediatrician, child neurologist, child psychiatrist, or child psychologist uses the results of the comprehensive evaluation to determine whether a child has ASD. Neurological and genetic testing can often exclude other disorders and can check for genetic and neurological problems that sometimes occur along with ASD. A medical diagnosis can be a key step in getting medical services provided through health insurance.



# ADDM Network Data for Action

# ADDM Network 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 advance 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](#) to increase 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 research on ASD.**

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 of ASD 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.**

CDC's Learn the Signs. Act Early. program offers free tools, including the [Milestone Tracker app](#), that service providers can promote among parents to help improve developmental monitoring, a critical step in the early identification of developmental delays.

- **Plan for resource and service needs.**
- **Target their outreach to under-identified groups of children, such as 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 equal 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 groups in local communities.
- Develop standard tools for measuring and documenting abilities and challenges among children with ASD.

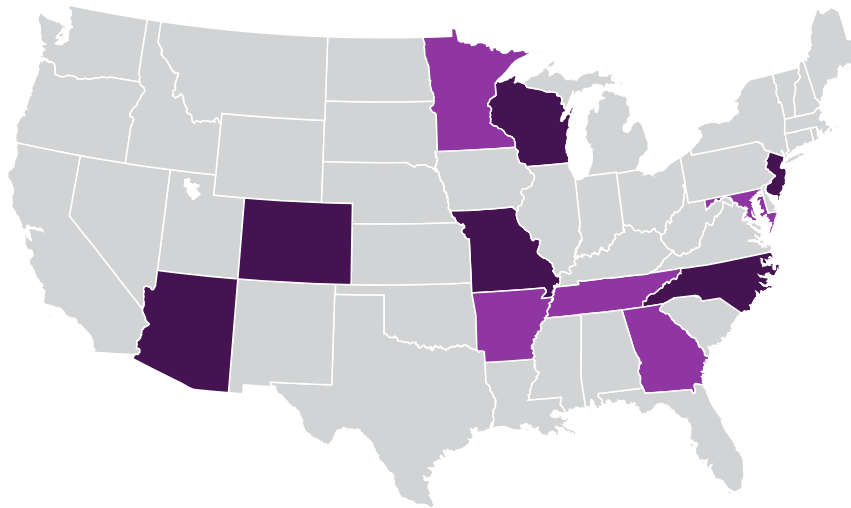
A young child with curly hair is smiling and playing with colorful blocks. The child is wearing a blue and white checkered shirt. The background is blurred, showing other children and a red and blue plaid shirt. A large teal circle is overlaid on the bottom right of the image, containing the text.

# ADDM Network Site Snapshots

# ADDM Network Site Snapshots

## A Snapshot of Autism Spectrum Disorder in 2016

The Autism and Developmental Disabilities Monitoring (ADDM) Network tracked ASD at sites within these states in 2016.



### SURVEILLANCE AMONG

- Only 8-year-olds
- 4-year-olds & 8-year-olds

### Arizona

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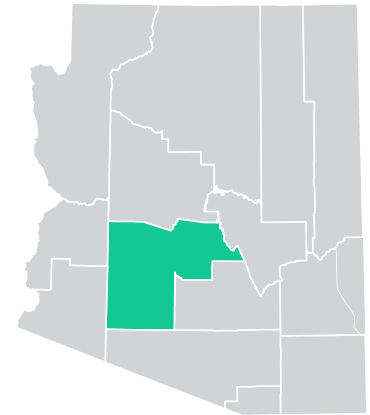
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**NOTE:** Although these 11 states host the ADDM Network Sites, the entire state is not necessarily included in the tracked area. Please see individual ADDM Network site pages for a closer look at the specific sites.

# A Snapshot of Autism Spectrum Disorder in Arizona

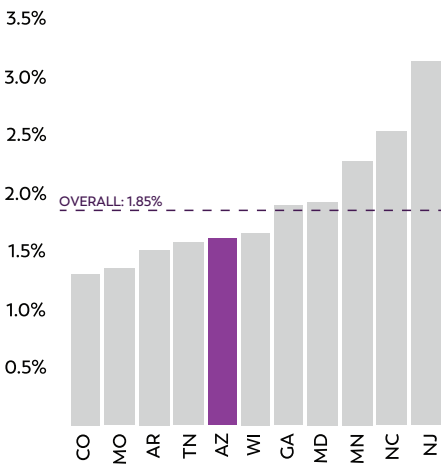
Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 63

Or 1.6% of 8-year-old children in an area of Arizona were identified with ASD by ADDSP in 2016



This percentage is lower than the average percentage identified with ASD (1.85%) in 2016 in all communities in the United States where CDC tracked ASD in 2016.

## By 57 months

Half of children identified with ASD were diagnosed

## White children were 1.5x more likely

To be identified with ASD than Hispanic or black children



Values indicate prevalence per 1,000 children

## Boys were 4.2x

More likely to be identified with ASD than girls



## 38% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



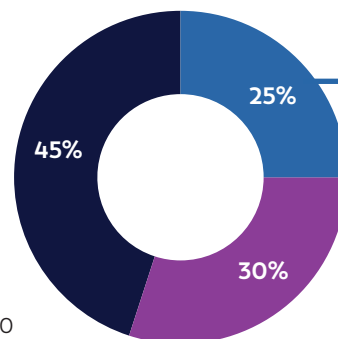
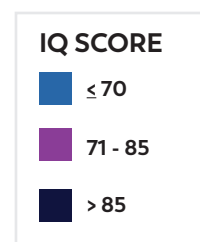
## 68% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 91%

Of children identified with ASD by ADDSP



**25%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

## What are the key take-away messages?

- More children with average or above-average intelligence are being identified with ASD since ADDSP began tracking in 2000.
- White children were more likely to be identified with ASD than black or Hispanic children. This may reflect cultural or socioeconomic and/or differences in access to diagnostic and therapeutic services.
- Although Hispanic children are less likely to be identified with ASD compared to non-Hispanic children in Arizona, this difference has been decreasing over the years.
- Differences between the percentage of boys and girls identified with ASD continue; a better understanding of sex differences may also lead to the development of more effective screening tools for ASD in boys and girls.

## How can this information be useful?

ADDSP's latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide ASD research;
- Inform policies that promote improved outcomes in health care and education for individuals with ASD;
- Identify cultural, educational, and economic barriers to decreasing the age of evaluation and diagnosis;
- Improve screening tools to increase accuracy of the screening test result for ASD;
- Improve collaborations across the ASD community among providers, researchers, and families; and
- Increase awareness of associated behavioral, cognitive, and/or physical features in children with autism.

## Where was this information collected?

Information was collected from health and education records of children who were 8 years old and living in part of Maricopa County in metropolitan Phoenix in 2016.

### 8-year-old children in tracking area: 17,656

- 45% white
- 7% black
- 41% Hispanic
- 4% Asian or Pacific Islander
- 3% other

## What else does ADDSP do?

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. ADDSP also provides extensive ASD- and developmental disabilities-related outreach and training of students, parents, educators, and clinicians. Further, ADDSP data help guide ASD research in the public health community.

“CDC’s ADDM Network provides a crucial understanding of the characteristics about the growing number of individuals identified with ASD in multiple areas of the United States. The information obtained by the Network has provided the data necessary to create collaborations with different providers who address the needs of the autism community across their lifespan.”

**JENNIFER ANDREWS, PhD, University of Arizona**

## Resources

### 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.

**Megan Wills**

Arizona’s Act Early Ambassador

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### 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)

### AUTISM SOCIETY OF SOUTHERN ARIZONA

520-770-1541

[info@as-az.org](mailto:info@as-az.org)

### CONNECT WITH ADDSP

**Sydney Pettygrove, PhD**

**Argelia Benavides, MPH**

University of Arizona Health Sciences Center

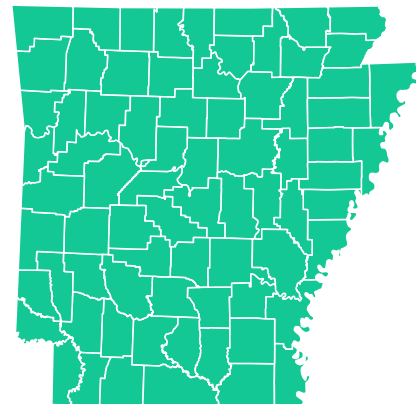
[sydneyp@arizona.edu](mailto:sydneyp@arizona.edu)

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



# A Snapshot of Autism Spectrum Disorder in Arkansas

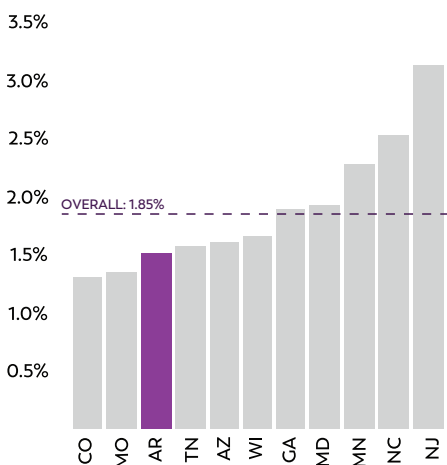
Findings from the Arkansas Autism and Developmental Disabilities Monitoring (AR-ADDM) Program help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 66

Or 1.5% of 8-year-old children in Arkansas were identified with ASD by AR-ADDM in 2016



This percentage is lower than the average percentage identified with ASD (1.85%) in 2016 in all communities in the United States where CDC tracked ASD in 2016.

## By 56 months

Half of children identified with ASD were diagnosed

## White children were 1.4x more likely

To be identified with ASD than black children



## White children were 1.7x more likely

To be identified with ASD than Hispanic children



Arkansas is 1 of 2 sites Where white children were still more likely to be identified with ASD than black children.

Values indicate prevalence per 1,000 children

## 33% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



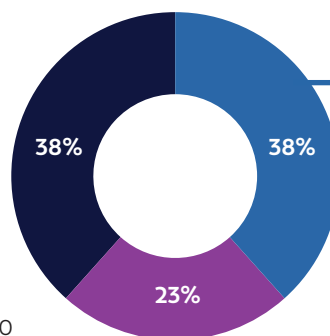
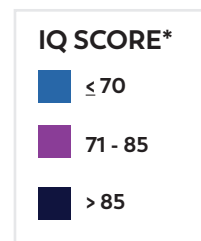
## 81% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 96%

Of children identified with ASD by AR-ADDM



38% had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70  
\*Percentages may not total 100 due to rounding

## What are the key take-away messages?

- Many children and families are living with ASD and need services and support, now and as they grow into adolescence and adulthood.
- In Arkansas, white children remain more likely to be identified with ASD than black or Hispanic children.
- Enhanced efforts are needed for early and equitable identification of ASD and timely enrollment in services.

## How can this information be useful?

AR-ADDM's latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

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

## How and where was this information collected?

AR-ADDM uses a record review method. Data were collected and analyzed from the health and special education records of children who were 8 years old and living in any of the 75 counties in Arkansas in 2016.

### 8-year-old children in tracking area: 40,225

- 64% white
- 20% black
- 13% Hispanic
- 2% Asian or Pacific Islander
- 1% other

## What is AR-ADDM doing currently?

AR-ADDM collaborates with the Arkansas Department of Education, Arkansas Department of Health, and investigators from the University of Arkansas for Medical Services (UAMS) to continue tracking the percentage and characteristics of children with ASD. AR-ADDM recently added 4-year-olds and 16-year-olds to the tracking of 8-year-olds. In addition, AR-ADDM partners with UAMS' Department of Pediatrics and Arkansas Children's Hospital to provide training to physicians and staff using AR-ADDM's individualized presentations on the number and characteristics of children with ASD. AR-ADDM also cosponsors educational events for families and educators and collaborates on developmental disabilities awareness events. Visit <https://pediatrics.uams.edu/ar-addm> for more information.

"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 have 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**

## Resources

### FIRST CONNECTIONS

Services for children under the age of 3 years with developmental delays or disabilities  
1-800-643-8258

<https://dhs.arkansas.gov/dds/>

[firstconnectionsweb/#fc-home](https://firstconnectionsweb/#fc-home)

<https://humanservices.arkansas.gov/about-dhs/ddds/autism>

### DEPARTMENT OF EDUCATION'S SPECIAL EDUCATION UNIT

Special education services for school-aged children with disabilities (ages 3 to 21 years)  
1-800-482-8437

[www.arkansased.gov/divisions/learning-services/special-education](http://www.arkansased.gov/divisions/learning-services/special-education)

### 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 DEVELOPMENTAL CENTER (DDC) AND SCHMIEDING DEVELOPMENT CENTER (SDC)

Diagnostic multidisciplinary team evaluations for children presenting with developmental and behavioral concerns (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  
[amease@eqhs.org](mailto:amease@eqhs.org) | [www.cdc.gov/actearly](http://www.cdc.gov/actearly)

### PROJECT CONNECT RESOURCE GUIDE

Arkansas resources for families and professionals on child development and what to do if there is a concern

[http://www.adcpti.org/Assets/projectconnect\\_resourceguide\\_smallsize.pdf](http://www.adcpti.org/Assets/projectconnect_resourceguide_smallsize.pdf)

### SPOTTING AUTISM IN EARLY CHILD CARE SETTINGS

Training for childcare providers on identifying children at risk for being diagnosed with autism

<http://www.healthychildcarear.org/>

### COMMUNITY-BASED AUTISM LIAISON AND TREATMENT (COBALT) PROJECT

Comprehensive diagnostic assessments, early intervention services, and family support

<https://cobaltar.org/>

### CONNECT WITH AR-ADDM

**Allison Hudson**

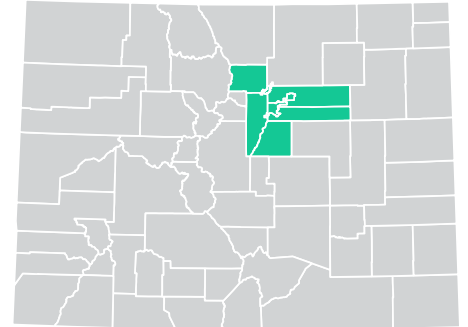
University of Arkansas for Medical Sciences  
1 Children's Way, Slot 512-4, Little Rock, AR 72202

[ahudson@uams.edu](mailto:ahudson@uams.edu)

<https://pediatrics.uams.edu/ar-addm>

# A Snapshot of Autism Spectrum Disorder in Colorado

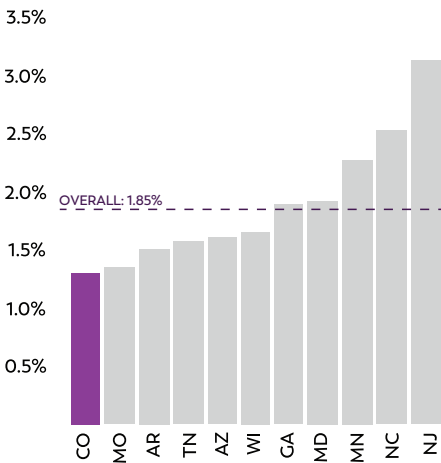
Findings from the Colorado Autism and Developmental Disabilities Monitoring (CO-ADDM) Project help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 76

Or **1.3%** of 8-year-old children in an area of Colorado were identified with ASD by the CO-ADDM Project in 2016



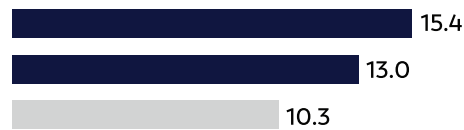
This percentage is lower than the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## Boys were 4.5x

More likely to be identified with ASD than girls



**White children and black children were 1.3 times and 1.5 times more likely, respectively, to be identified with ASD than Hispanic children**



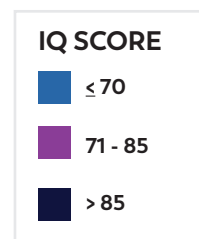
Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and black children.

## By 48.5 months

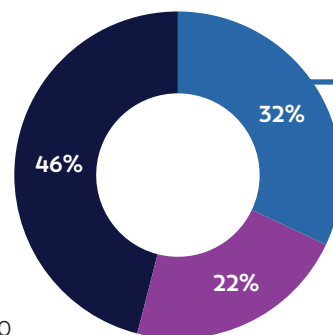
Half of children identified with ASD were diagnosed

## IQ data available for 76%

Of children identified with ASD by the CO-ADDM Project



IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70



**32%** had Intellectual Disability

## 48% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



## 67% of children

Identified with ASD had a documented ASD diagnosis



## What are the key take-away messages?

- Many children are living with ASD, and they need services and support, now and as they grow into adolescence and adulthood.
- Hispanic children are less likely to be identified with ASD than white or black children. Research does not show that being Hispanic makes a child less likely to develop ASD. This difference in identification may reflect cultural and/or socioeconomic differences, such as delayed or lack of access to services, as compared to other groups in Colorado.
- Evaluating and diagnosing all children with ASD as early as possible can help them be connected to the services they need.

## How can this information be useful?

The CO-ADDM Project's latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Stakeholders in Colorado might consider different ways to:

- Lower the age of first evaluation by community providers; and
- Increase awareness of ASD among Hispanic families and identify and address barriers to evaluation and diagnosis in order to decrease the age at which Hispanic children are evaluated and diagnosed.

## How and where was this information collected?

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 seven counties in Colorado in 2016.

### Tracking area

Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, and Jefferson counties

### 8-year-old children in tracking area: 40,874

- 54% white
- 7% black
- 34% Hispanic
- 5% Asian or Pacific Islander

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

The CO-ADDM Project collaborates with 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 with ASD.

## Resources

### **AUTISM SOCIETY OF COLORADO**

*Information and support for families/providers*

720-214-0794

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

### **COLORADO SITES OF AUTISM TREATMENT NETWORK**

*Services for children with ASD*

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

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

### **DEPARTMENT OF EDUCATION'S OFFICE OF SPECIAL EDUCATION**

*Special education services for school-aged children with disabilities*

[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**

*Services for children under the age of 3 years with developmental delays or disabilities*

1-888-777-4041

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

### **FAMILY VOICES COLORADO**

*Support for parents of children with special needs*

800-881-8272

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

### **LEARN THE SIGNS. ACT EARLY.**

*Resources for families and professionals on child development and what to do if there is a concern*

**Eileen Auer Bennet**

Colorado's Act Early Ambassador

[eileen@coloradoabcd.org](mailto:eileen@coloradoabcd.org)

### **THE ARC OF COLORADO**

*Support and advocacy for individuals with disabilities and their families*

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

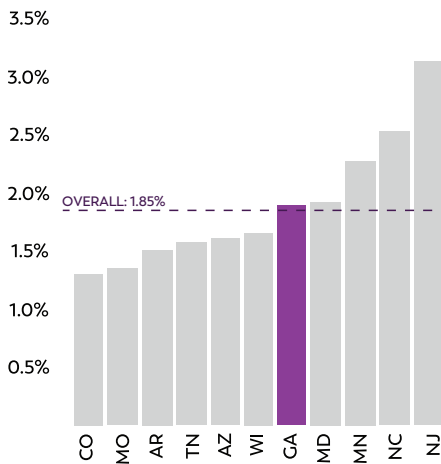
Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 53

Or **1.9%** of 8-year-old children in metropolitan Atlanta were identified with ASD by MADDSP in 2016



This percentage is about the same as the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## Boys were 4x

More likely to be identified with ASD than girls



## White and black children were nearly 2x as likely

To be identified with ASD than Hispanic children



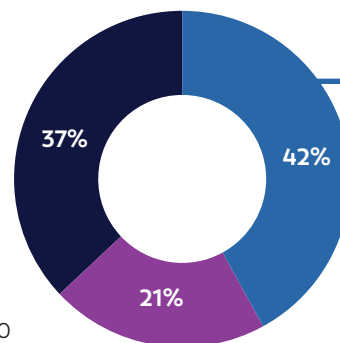
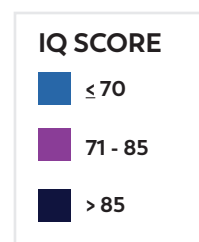
Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and black children.

## By 55 months

Half of children identified with ASD were diagnosed

## IQ data available for 84%

Of children identified with ASD by MADDSP



**42%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

## 37% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



## 67% of children

Identified with ASD had a documented ASD diagnosis



## What are the key take-away messages?

- Many children are living with ASD, and they need services and support, now and as they grow into adolescence and adulthood.
- While the proportion of black and white children identified with ASD is about the same, Hispanic children are less likely to be identified with ASD. This may reflect cultural and/or socioeconomic differences, such as language barriers, and delayed or lack of access to services.
- 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 the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Stakeholders in Georgia might consider different ways to:

- Lower the age of first evaluation by community providers; and
- Increase awareness of ASD among Hispanic families and identify and address barriers to evaluation and diagnosis 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 two counties in Georgia in 2016.

### Tracking area

DeKalb and Gwinnett counties

### 8-year-old children in tracking area: 24,113

- 27% white
- 41% black
- 24% Hispanic
- 8% Asian or Pacific Islander

## What else does MADDSP do besides provide estimates of ASD among 8-year-old children?

MADDSP is a program administered by the Centers for Disease Control and Prevention (CDC). MADDSP collaborates with health and education systems that serve children with developmental disabilities and their families to understand the number and characteristics of 8-year-olds with ASD, intellectual disability, and cerebral palsy in select areas of Georgia. Upon request, MADDSP offers workshops and trainings for local professionals and provides tailored data reports and presentations.

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“CDC’s ADDM Network has consistently generated critically important information not only on how common ASD is but also on a range of prevailing challenges affecting the population at large, in Georgia and in the country. Thanks to this information, national priorities were established to reduce the age of diagnosis, to address unacceptable healthcare disparities across sectors of our community, and to build a concerted effort to afford all children with ASD, irrespective of the race, ethnicity or level of income of their families, with what they need in order to fulfill their promise.”

**AMI KLIN, PhD, Director, Marcus Autism Center, Emory University School of Medicine, and Children’s Healthcare of Atlanta**

## Resources

### 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-0](http://www.autismspeaks.org/georgia-0)

### 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’S 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

1-800-229-2038

[p2pga.org](http://p2pga.org)

### CDC’S LEARN THE SIGNS. ACT EARLY.

Resources for families and professionals on child development and what to do if there is a concern

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

### CONNECT WITH MADDSP

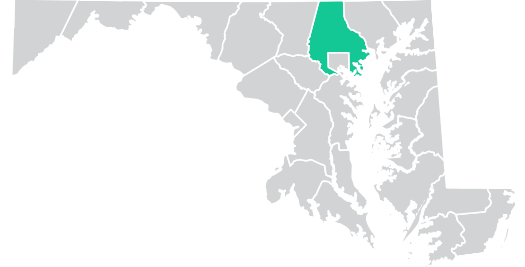
[maddsp@cdc.gov](mailto:maddsp@cdc.gov)

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

# A Snapshot of Autism Spectrum Disorder in Maryland

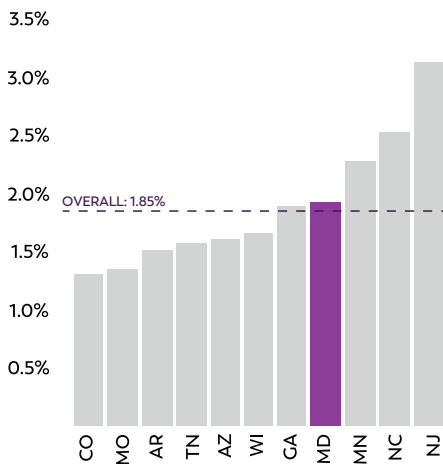
Findings from the Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) Project help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 52

Or 1.9% of 8-year-old children in an area of Maryland were identified with ASD by the MD-ADDM Project in 2016



This percentage is about the same as the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## By 47.5 months

Half of children identified with ASD were diagnosed

## No significant differences in ASD prevalence

Were found among white, black, and Hispanic children

## Boys were 3.9x

More likely to be identified with ASD than girls



## 48% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



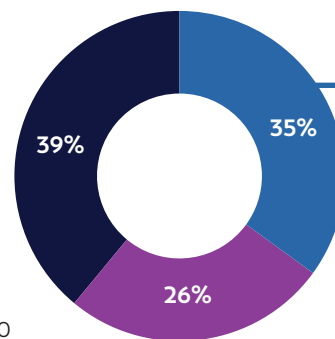
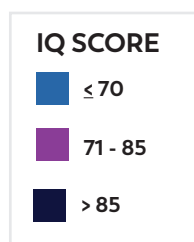
## 78% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 65%

Of children identified with ASD by the MD-ADDM Project



**35%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

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

- Many children with ASD need services and support, now and as they grow into adolescence and adulthood.
- ASD can be diagnosed as young as 18 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?

Stakeholders in Maryland might consider different ways to lower the age of first evaluation by community providers.

### Where was this information collected?

The MD-ADDM Project 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 2016.

#### 8-year-old children in tracking area: 9,993

- 48% white
- 35% black
- 9% Hispanic
- 7% Asian or Pacific Islander
- 1% other

### What is MD-ADDM doing currently?

The MD-ADDM Project collaborates with the Maryland Department of Health and investigators from Johns Hopkins University, as well as 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. The MD-ADDM Project 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. The MD-ADDM Project also participates in and organizes annual autism awareness month events in the community.

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“MD-ADDM Project data help us plan person-centered services for individuals with autism so they can achieve their fullest potential. We appreciate having an ADDM site in Maryland to inform us of the number and characteristics of individuals with autism in the community that we serve.”

**ERIC SALZANO, Executive Director, Community Services for Autistic Adults and Children Inc. (CSAAC)**

## Resources

### **PATHFINDERS FOR AUTISM**

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

### **CENTER FOR AUTISM AND RELATED DISORDERS AT KENNEDY KRIEGER INSTITUTE**

[www.card.kennedykrieger.org](http://www.card.kennedykrieger.org)

### **THE PARENT'S PLACE OF MARYLAND**

<https://www.ppmmd.org/>

### **DEPARTMENT OF EDUCATION'S DIVISION OF SPECIAL EDUCATION AND EARLY INTERVENTION SERVICES**

<http://marylandpublicschools.org/programs/Pages/Special-Education/index.aspx>

### **ITINERIS**

<https://www.itinerisbaltimore.org/>

### **AUTISM SOCIETY OF BALTIMORE-CHESAPEAKE**

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

### **COMMUNITY SERVICES FOR AUTISTIC ADULTS AND CHILDREN (CSAAC)**

<http://csaac.org/>

### **CDC'S LEARN THE SIGNS. ACT EARLY.**

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

### **CONNECT WITH MD-ADDM Li-Ching Lee, PhD, ScM**

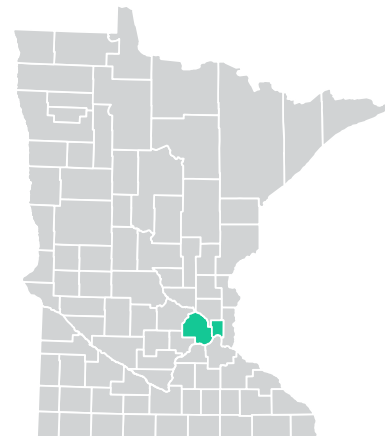
Johns Hopkins University  
615 N. Wolfe St., Suite E6032  
Baltimore, MD 21205  
410-502-0605

[llee38@jhu.edu](mailto:llee38@jhu.edu)



# A Snapshot of Autism Spectrum Disorder in Minnesota

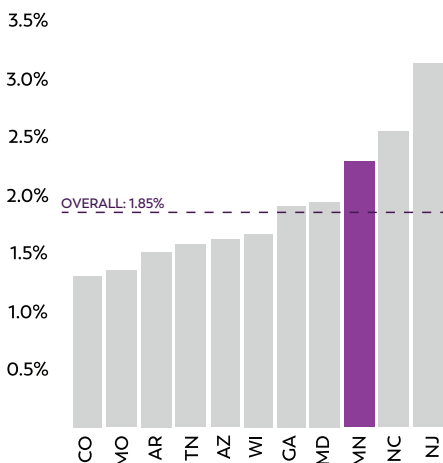
Findings from the Minnesota Autism and Developmental Disabilities Monitoring Network (MN-ADDM) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 44

Or **2.3%** of 8-year-old children in an area of Minnesota were identified with ASD by MN-ADDM in 2016



This is higher than the average percentage identified with ASD in 2016 (1.85%) in all communities in the United States where CDC tracked ASD data in 2016.

## By 56 months

Half of children identified with ASD were diagnosed

## No significant differences in ASD prevalence

Were found among white, black, and Hispanic children

## Boys were 3.9x More likely to be identified with ASD than girls



## 39% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



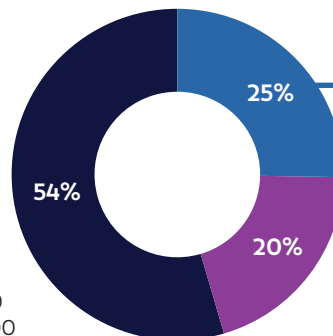
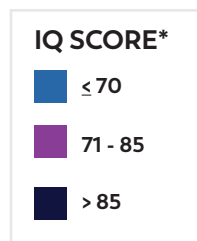
## 54% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 90%

Of children identified with ASD by MN-ADDM



**25%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70  
\*Percentages may not total 100 due to rounding

## What are the key take-away messages?

- Minnesota identified the third highest prevalence of ASD in the ADDM Network.
- In Minnesota, there were differences between percentage of boys and girls identified, with more boys being identified than girls. This is consistent with previous estimates and other states in the ADDM Network.
- MN-ADDM findings also reveal no differences in ASD prevalence across racial and ethnic groups in Minnesota. The small number of children in some of these groups makes it difficult to determine whether ASD prevalence is truly different across groups. MN-ADDM will continue to track ASD prevalence and use this information to address health difference between groups in Minnesota.
- Although ASD can be diagnosed as young as 18 months of age, MN-ADDM is identifying children with ASD at much later ages. MN-ADDM will continue to work with the community to promote regular developmental screening and early identification.

## How can this information be useful?

MN-ADDM's findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes for people with ASD.

## How and where was this information collected?

MN-ADDM 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 parts of two counties in 2016.

### Tracking area

Parts of Ramsey and Hennepin counties, including Minneapolis-St. Paul

### 8-year-old children in tracking area: 13,728

- 42 % white
- 27% black
- 15% Hispanic
- 15% Asian or Pacific Islander
- 1% other

## Resources

### HELP ME GROW

1-866-693-GROW (4769)

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

[MDE.ECSE@state.mn.us](mailto:MDE.ECSE@state.mn.us)

### MINNESOTA AUTISM PORTAL

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

### MINNESOTA DEPARTMENT OF EDUCATION

<https://education.mn.gov/MDE/dse/sped/cat/aut/>

### AUTISM SOCIETY OF MINNESOTA

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

### CDC'S LEARN THE SIGNS. ACT EARLY. PROJECT-MN

<https://addm.umn.edu/ltsae>

### UNIVERSITY OF MN AUTISM AND NEURODEVELOPMENT (VOYAGER) CLINIC

612-365-8400

<https://www.mhealth.org/childrens/locations/buildings/2512-building/>

[pediatric-specialty-care-voyager-clinic](https://www.mhealth.org/childrens/locations/buildings/2512-building/pediatric-specialty-care-voyager-clinic)

### CONNECT WITH MN-ADDM PROJECT

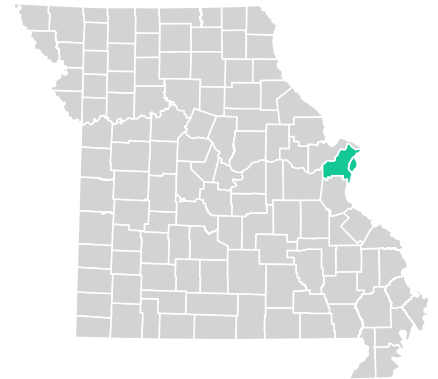
**Institute on Community Integration (ICI) University of Minnesota**

150 Pillsbury Drive SE  
Minneapolis, MN 55455

<https://addm.umn.edu/autism@umn.edu>

# A Snapshot of Autism Spectrum Disorder in Missouri

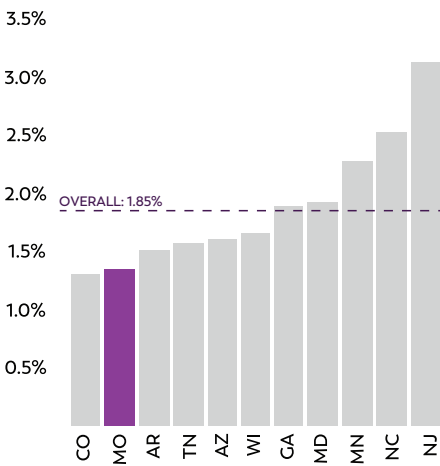
Findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) Project help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 74

Or 1.4% of 8-year-old children in St. Louis and St. Louis City counties were identified with ASD by the MO-ADDM Project in 2016



This percentage is lower than the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## White children were more likely

To be identified with ASD than Hispanic children

## No significant differences

In ASD prevalence were found between white and black children

## By 56 months

Half of children identified with ASD were diagnosed

## Boys were 3x

More likely to be identified with ASD than girls



## 40% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



## 91% of children

Identified with ASD had a documented ASD diagnosis



## What are the key take-away messages?

- ASD prevalence was similar for white and black children, suggesting that previously reported differences between groups may be diminishing.
- Despite the national health priority that children with ASD have their first developmental evaluations by age 36 months, the age at which half of children were diagnosed remains largely unchanged.
- Continued efforts should be directed toward evaluating and diagnosing all children with ASD as early as possible so they can be connected to the services they need.
- ASD prevalence continues to be higher in boys than girls. The reasons for this observed difference warrant further investigation.

## How can this information be useful?

The MO-ADDM Project's latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Stakeholders in Missouri might consider different ways to lower the age of first evaluation and diagnosis by community providers.

## How and where was this information collected?

The MO-ADDM Project 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 two counties in Missouri in 2016.

### Tracking area

St. Louis, St. Louis City counties

### 8-year-old children in tracking area: 15,635

- 50% white
- 40% black
- 5% Hispanic
- 5% Asian or Pacific Islander

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

The MO-ADDM Project investigators at Washington University in St. Louis, in collaboration with the Missouri Department of Health and Senior Services and community partners, track the number and characteristics of 8-year-olds and 4-year-olds with ASD and 8-year-olds with cerebral palsy. In addition, the MO-ADDM Project conducts various ASD-related public health, research, and clinical activities to inform various stakeholders (such as clinicians, educators, and families) on the latest scientific developments, best practices for early intervention, and clinical care for children with ASD.

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“Early childhood is the most critical window for intervention success – especially for those with autism. ADDM data provides a “snapshot” of how many children have been identified in Missouri and what gaps in care need to be addressed. This information is critical to ensure that all Missouri children reach their greatest potential!”

**ALICIA BREWER CURRAN, Missouri's Act Early Ambassador, Mother of a child with autism**

## Resources

### 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/)

### MISSOURI FAMILIES FOR EFFECTIVE AUTISM TREATMENT

877-275-8988

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

### NAVIGATING AUTISM SERVICES

[https://dmh.mo.gov/media/pdf/navigating-autism-services-](https://dmh.mo.gov/media/pdf/navigating-autism-services-community-guide-missouri)

[community-guide-missouri](https://dmh.mo.gov/media/pdf/navigating-autism-services-community-guide-missouri)

### CONNECT WITH MO-ADDM

**Robert Fitzgerald, PhD, MPH**

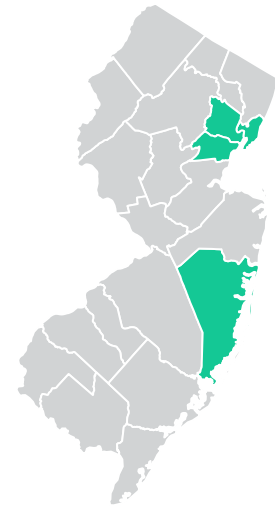
Washington University in St. Louis

314-286-0151

[fitzgeraldr@wustl.edu](mailto:fitzgeraldr@wustl.edu)

# A Snapshot of Autism Spectrum Disorder in New Jersey

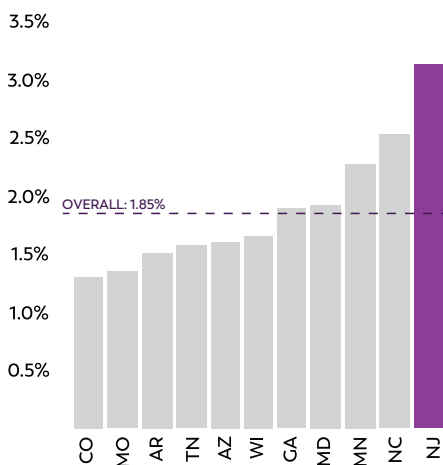
Findings from the New Jersey Autism Study (NJAS) help increase understanding about the scope of autism spectrum disorder (ASD) in children, describe the characteristics of ASD in those children, and identify differences between groups in the prevalence or detection of ASD.



**SITE TRACKING AREA**

## 1 in 32

Or **3.1%** of 8-year-old children in an area of New Jersey were identified with ASD by NJAS in 2016



This percentage is higher than the average identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## By 51 months

Half of children identified with ASD were diagnosed

**White children were 1.3x** More likely to be identified with ASD than black children



Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and Hispanic children or between black and Hispanic children.

**Boys were 4x** More likely to be identified with ASD than girls



**44% of children**

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



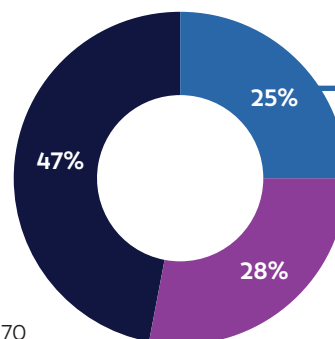
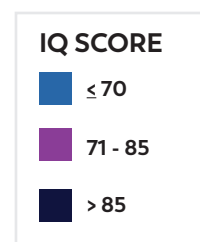
**81% of children**

Identified with ASD had a documented ASD diagnosis



**IQ data available for 71%**

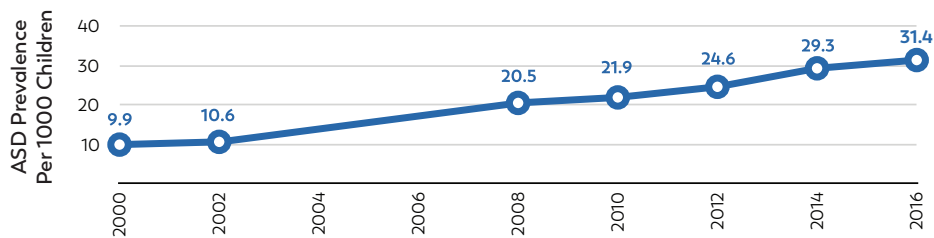
Of children identified with ASD by NJAS



**25%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

### AUTISM OVER TIME IN NEW JERSEY



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

- The percentage of children with ASD increased in an area of New Jersey from about 2.9% in 2014 to about 3.1% in 2016.
- Rising numbers of children with ASD need services and support, now and as they grow into adolescence and adulthood.
- Boys continue to have a higher ASD prevalence than girls. In 2016, 5% of boys in an area of New Jersey were identified with ASD, compared to about 1.2% of girls.
- Future efforts may emphasize the importance of screening young children with standardized tools and connecting families to needed services before age 3 years.
- 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 the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- 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 four counties in New Jersey in 2016.

##### Tracking area

Essex, Hudson, Union, Ocean counties

##### 8-year-old children in tracking area: 33,031

- 40% white
- 22% black
- 32% Hispanic
- 6% Asian or Pacific Islander

#### What else does NJAS do besides track 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 Psy.D, BCBA-D; Executive Director, Autism New Jersey**

## Resources

### 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/)

### 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

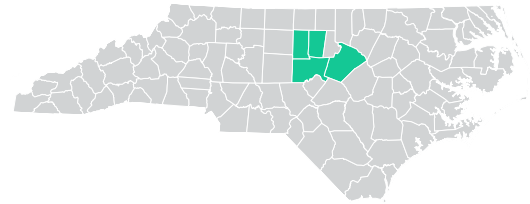
Support for parents, including parents of children with special needs  
800-654-7726  
<https://spanadvocacy.org/>

### 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

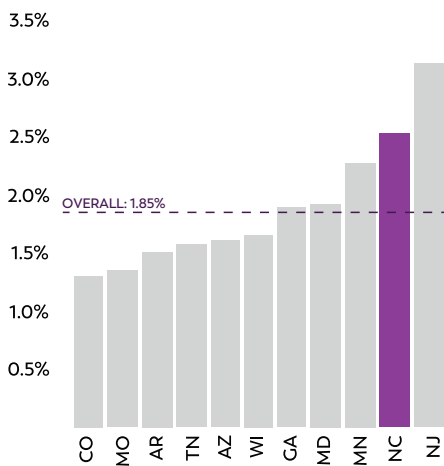
The North Carolina Autism and Developmental Disabilities Monitoring (NC-ADDM) Project helps determine the number of children with autism spectrum disorder (ASD) in the central part of North Carolina, the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 39

Or **2.5%** of 8-year-old children in central North Carolina were identified with ASD by the NC-ADDM Project in 2016



This percentage is higher than the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## By 38 months

Half of children identified with ASD were diagnosed

## Black children were 1.4x

More likely to be identified with ASD than Hispanic children



Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between Hispanic and white children or white and black children.

## Boys were 4.7x

More likely to be identified with ASD than girls



## 62% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



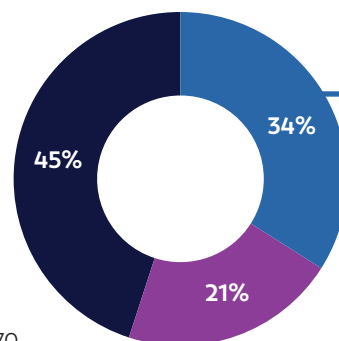
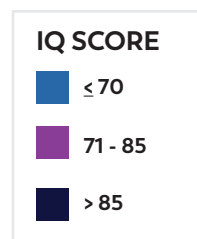
## 57% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 91%

Of children identified with ASD by the NC-ADDM Project



**34%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

## What are the key take-away messages?

- Many children with ASD need services and support, now and as they grow into adolescence and adulthood.
- Hispanic children are less likely to be identified with ASD than white or black children in North Carolina. This may reflect cultural or socioeconomic factors that impact access to services compared to other groups in North Carolina.
- Among the areas where CDC tracks ASD across the United States, central North Carolina had the highest percentage of children identified with ASD who had received a comprehensive developmental evaluation by age 3 years. This is good news, but there is still more to be done to ensure that all children are evaluated as soon as concerns about their development are identified.
- Evaluating and diagnosing all children with ASD as early as possible can help them get connected to the services they need.

## How can this information be useful?

The NC-ADDM Project's latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

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

## How and where was this information collected?

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

### Tracking area

Alamance, Chatham, Orange, and Wake counties

### 8-year-old children in tracking area: 19,291

- 55% white
- 21% black
- 17% Hispanic
- 7% Asian or Pacific Islander

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

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

## Resources

### 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.cidid.unc.edu/](http://www.cidid.unc.edu/)

### LEARN THE SIGNS. ACT EARLY.

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

### NORTH CAROLINA INFANT-TODDLER PROGRAM

919-707-5520

[www.beearly.nc.gov/](http://www.beearly.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

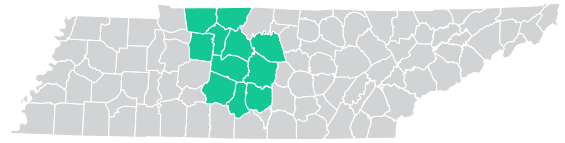
919-966-7096

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



# A Snapshot of Autism Spectrum Disorder in Tennessee

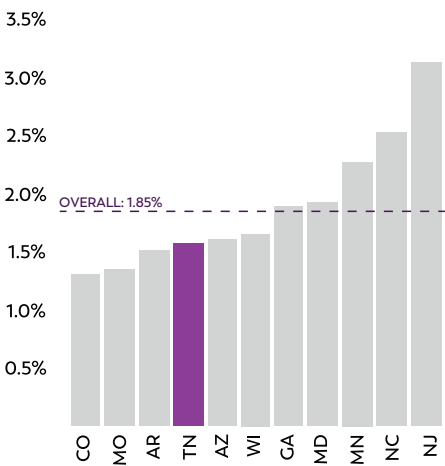
Findings from the Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDM) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



■ SITE TRACKING AREA

## 1 in 64

Or 1.6% of 8-year-old children in an area of Tennessee were identified with ASD by TN-ADDM in 2016



This is slightly lower than the overall average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

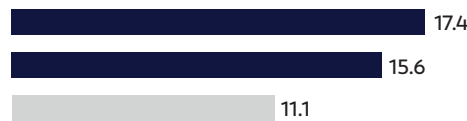
## Boys were 4.6x

More likely to be identified with ASD than girls



## White children were 1.4x more likely and black children were 1.6 times more likely

To be identified with ASD than Hispanic children



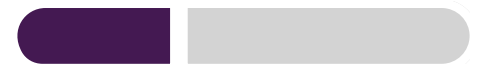
Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and black children.

## By 51 months

Half of children identified with ASD were diagnosed

## 36% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



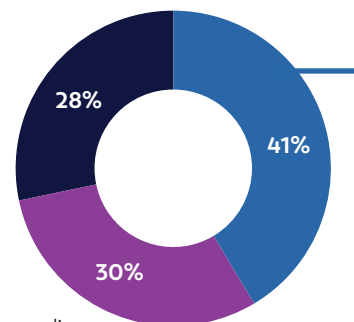
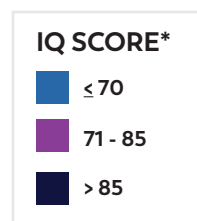
## 76% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 77%

Of children identified with ASD by TN-ADDM



**41%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70  
\*Percentages may not total 100 due to rounding

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

- There are many children with ASD who need services and support. The number of children identified with ASD in Tennessee increased from 1 in 68 (1.5%) in 2014 to 1 in 64 (1.6%) in 2016.
- Children with ASD in Tennessee have a wide range of abilities and challenges (such as 41% with IQ 70 or below).
- Most children with ASD in Tennessee (64%) are not evaluated prior to 3 years of age.
- The median age of diagnosis for children in Tennessee was 51 months of age.
- Hispanic children were less likely to be identified with ASD than black or white children. This may reflect differences related to lack of access to services, socioeconomic status, and cultural factors.

## How can this information be useful?

TN-ADDM's findings can be used to:

- Inform policies that promote earlier identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families; and
- Increase awareness of ASD among traditionally underserved families.

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 2016.

### Tracking area

Bedford, Cheatham, Davidson, Dickson, Marshall, Maury, Montgomery, Rutherford, Robertson, Williamson, and Wilson counties

### 8-year-old children in tracking area: 25,839

- 63% white
- 20% black
- 14% Hispanic
- 3% Asian or Pacific Islander

## Resources

### VANDERBILT KENNEDY CENTER (VKC)

[vkc.vumc.org](http://vkc.vumc.org)

### TREATMENT AND RESEARCH INSTITUTE FOR AUTISM SPECTRUM DISORDER (TRIAD)

[triad.vumc.org](http://triad.vumc.org)

### TENNESSEE DISABILITY PATHFINDER

1-800-640-4636

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

### 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

<https://autismtennessee.wildapricot.org/>

### CDC'S LEARN THE SIGNS. ACT EARLY.

<https://www.cdc.gov/ncbddd/actearly/index.html>

### CONNECT WITH TN-ADDM

Zachary Warren, PhD  
VKC/TRIAD

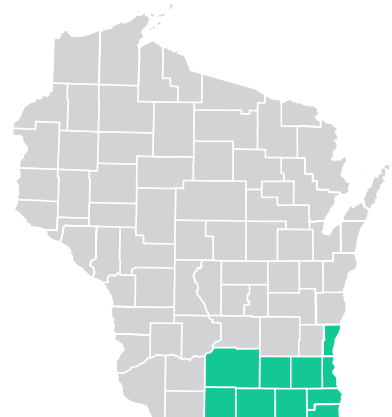
110 Magnolia Circle  
Nashville, TN 37203

1-877-ASD-VUMC

[autismresources@vumc.org](mailto:autismresources@vumc.org)

# A Snapshot of Autism Spectrum Disorder in Wisconsin

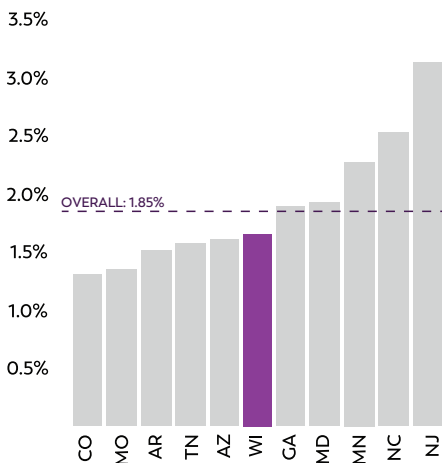
Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 60

Or 1.7% of 8-year-old children in an area of Wisconsin were identified with ASD by WISADDS in 2016



This percentage is lower than the average percentage identified with ASD (1.85%) in all communities in the United States where CDC tracked ASD in 2016.

## Boys were 4.2x

More likely to be identified with ASD than girls.



## White children were 1.2x more likely

To be identified with ASD than black children



## And 1.1x more likely Than Hispanic children



Values indicate prevalence per 1,000 children

## By 49 months

Half of children identified with ASD were diagnosed

## 50% of children

Identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



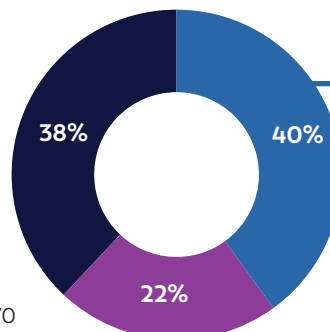
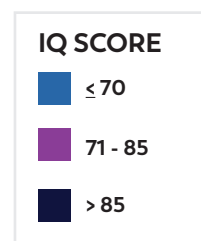
## 81% of children

Identified with ASD had a documented ASD diagnosis



## IQ data available for 65%

Of children identified with ASD by WISADDS



**40%** had Intellectual Disability

IQ = Intelligence Quotient  
Intellectual disability = IQ ≤ 70

## What are the key take-away messages?

- The percentage of children with ASD in southeastern Wisconsin increased from about 1.4% in 2014 to about 1.7% in 2016.
- Outreach to Hispanic and black communities is needed to ensure timely access to autism-related services.
- Half of children identified with ASD received a comprehensive developmental evaluation by age 3 years, suggesting that many children aren't receiving services as early as possible.

## How can this information be useful?

WISADDS' latest findings can be used to:

- Promote early identification of ASD;
- Plan for the service needs of individuals with ASD and provide trainings related to ASD for healthcare providers and families;
- Guide future ASD research; and
- Inform policies promoting access to health care and education for individuals with ASD and improved outcomes across the lifespan.

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; and
- Increase awareness of ASD among Hispanic and black families and identify and address barriers to evaluation and diagnosis in order to decrease the age at which Hispanic children are evaluated and diagnosed.

## How and where was this information collected?

WISADDS uses a record review method. Specifically, 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 2016.

### Tracking area

Dane, Green, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Rock, Walworth, and Waukesha counties

### 8-year-old children in tracking area: 35,034

- 58% white
- 19% black
- 18% Hispanic
- 5% Asian or Pacific Islander

## What else does WISADDS do besides tracking the frequency of ASD among 8-year-olds?

WISADDS collaborates with the Wisconsin Department of Health Services and investigators from the University of Wisconsin-Madison to describe 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.

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"We have the opportunity to work with a lot of different people in the communities we serve. Being able to use WISADDS data to inform parents, educators, medical personnel, social workers, and more helps us deliver trusted, accurate information that everyone can understand. Recently we have been meeting with teams around early identification and screening. The information about when something was noticed and when something was diagnosed helps our teams figure out where the gaps are in the system of care."

**TIM MARKLE, Director of the Southern Regional Center for Children and Youth with Special Health Care Needs, Wisconsin**

## Resources

### AUTISM SOCIETY OF GREATER WISCONSIN

Information and support for families/providers  
1-888-4-AUTISM  
[www.autismgreaterwi.org/](http://www.autismgreaterwi.org/)

### BIRTH TO THREE PROGRAM, WISCONSIN DEPARTMENT OF HEALTH SERVICES

Services for children under the age of 3 years with developmental delays or disabilities  
[www.dhs.wisconsin.gov/birthto3/index.htm](http://www.dhs.wisconsin.gov/birthto3/index.htm)

### FINDING YOUR WAY

Guide for Wisconsin families who have children and youth with special needs and disabilities  
[www.waisman.wisc.edu/cedd/pdfs/products/community/FYW\\_e.pdf](http://www.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.pdf)

### LEARN THE SIGNS.

#### ACT EARLY.

Resources for families and professionals on child development and what to do if there is a concern  
**Kris Barnekow**  
Wisconsin's Act Early Ambassador  
414-229-7151  
[krisb@uwm.edu/](mailto:krisb@uwm.edu/)

### WELL BADGER RESOURCE CENTER

Information and referral hotline for families/providers working with children and youth with special needs: Maternal and Child Health and First Step Resource line at 800-642-7837  
<https://www.dhs.wisconsin.gov/mch/well-badger.htm>

### CONNECT WITH WISADDS

**Maureen Durkin, PhD, DrPH**  
University of Wisconsin-Madison  
Waisman Center  
1500 Highland Ave, Room s101E  
608-263-7507  
[mdurkin@wisc.edu](mailto:mdurkin@wisc.edu)

# Glossary

## A

### **Autism spectrum disorder**

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges. 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).

Individuals with *autistic disorder* often have more severe symptoms of ASD, such as difficulties with communication. Autistic disorder is no longer diagnosed separately but rather included as part of ASD.

Individuals with *pervasive developmental disorder-not otherwise specified* (PDD-NOS) often have some but not all symptoms of 'autistic disorder.' PDD-NOS is no longer diagnosed separately but rather included as part of ASD.

Individuals with *Asperger syndrome* often have milder or fewer symptoms of ASD. Although symptoms are present early in life, Asperger syndrome is usually diagnosed when a child is school-aged or later. Asperger syndrome is no longer diagnosed separately but rather included as part of ASD.

## C

### **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 providers**

A community provider is a medical or educational professional who works with children with developmental disabilities (including psychologists, physicians, teachers, learning specialists, speech/language pathologists, occupational therapists, physical therapists, nurses, social workers, and others) 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 health and/or education records.

## D

### **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

## H

### **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.

## I

### **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. (*cont.*)

*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..

## P

### **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.

## S

### **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. These categories include autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment.

### **Surveillance**

(also known as ‘tracking’)

In public health, surveillance is defined as the continuous, systematic collection, analysis, and interpretation of health-related data.

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**National Center on Birth Defects  
and Developmental Disabilities**  
Centers for Disease Control and Prevention



**HELPING CHILDREN**  
LIVE TO THE FULLEST  
BY UNDERSTANDING  
DEVELOPMENTAL DISABILITIES

[cdc.gov/autism](https://cdc.gov/autism)

