community report on autism 2021

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

CDC

community report on autism 2021

AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK

A Snapshot of Autism Spectrum Disorder among 8-year-old and 4-year-old Children in Multiple Communities across the United States in 2018

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

Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ 2021, 70 (No. SS-11): 1-16.

Shaw KA, Maenner MJ, Bakian AV, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ 2021, 70 (No. SS-10): 1-14.

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

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

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Executive Summary ● ● ● ● ● ●

Since 2000, CDC has been tracking the prevalence and characteristics of children with autism spectrum disorder (ASD) in diverse communities throughout the United States through the Autism and Developmental Disabilities Monitoring (ADDM) Network.

Key Findings At-A-Glance

These findings are based on analysis of data collected from health and special education records (if available) of 8-year-old and 4-year-old children who lived in one of 11 different areas throughout the United States in 2018.

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

- The ADDM Network found no overall difference in the percentage of White, Black, Hispanic, and Asian or Pacific Islander 8-year-old children identified with ASD. However, at several sites, the percentage of Hispanic children identified with ASD was lower compared to White or Black children.

- Children born in 2014 were 50% more likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010.

1 in 44

8-year-old children identified with ASD in 2018

*Based on tracking within 11 communities in the United States

The 2021 Community Report on Autism highlights the ADDM Network's most recent findings on ASD in 8-year-old and 4-year-old children. Data reported on 8-year-old children give us a comprehensive picture of the number and characteristics of children identified with ASD, while data reported on 4-year-old children tell us more about progress in the early identification of ASD.

The ADDM Network found that 1 in 44 (2.3%) 8-year-old children were identified with ASD in 2018, based on tracking within 11 communities in the United States. The estimated percentage of children identified with ASD is higher than in previous reports, though participating communities have changed over time. These findings indicate there are many children with ASD who need services and support now and as they grow into adolescence and adulthood.

Knowing how many children have ASD is just part of the picture. 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, and researching risk and protective factors for ASD. Through the _Learn the Signs. Act Early._ Program, CDC will continue to promote early identification—the most powerful tool we have now for making a difference in the lives of children with ASD.

The ADDM Network's goals are to

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

Provide information on the characteristics of children with ASD, including sex, race/ethnicity, presence of intellectual disability, age of evaluation and diagnosis;

Determine whether ASD identification 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 2018

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 in communities across the ADDM Network.

How many 8-year-old children were identified with ASD in 2018?

About **1 in 44** (2.3%) 8-year-old children were identified with ASD by the ADDM Network.

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

The percentage of children identified with ASD **varied widely** across geographic areas.
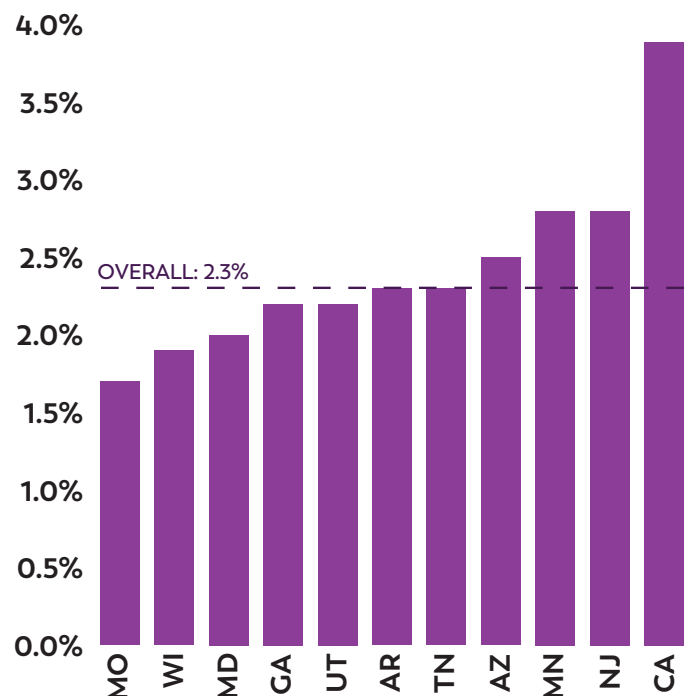
Across the ADDM Network, the percentage of 8-year-old children who were identified with ASD ranged from a low of **1.7% or 1 in 60 children in Missouri to a high of 3.9% or 1 in 26 children in California**. Sites with limited or no direct access to special education records had lower percentages of children identified with ASD.

1 in 44

8-year-old children were identified with ASD in 2018 by the ADDM Network

Percentage of 8-year-old children
identified with ASD by ADDM Network Site

OVERALL: 2.3%

Chart values (by site): MO, WI, MD, GA, UT, AR, TN, AZ, MN, NJ, CA

Y-axis: 0.0%, 0.5%, 1.0%, 1.5%, 2.0%, 2.5%, 3.0%, 3.5%, 4.0%

Which children were more likely to be identified with ASD?

Among 8-year-old children, boys were more than **4 times as likely** to be identified with ASD as girls.

The ADDM Network found no overall difference in the percent of Black, White, Hispanic, and Asian or Pacific Islander 8-year-old children identified with ASD. However, at several sites, the percent of Hispanic children identified with ASD was lower compared with Black or White children.

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

Among 8-year-old children identified with ASD who had intelligence quotient (IQ) scores available, approximately **one-third (35.2%) also had intellectual disability**.

When were children evaluated and diagnosed?

Findings from the ADDM Network show that **72% of 4-year-old children** with ASD in 2018 received a developmental evaluation by 36 months of age.

More children who were born in 2014 (1.36%) received an ASD diagnosis or ASD special education classification by 48 months of age **compared to children born in 2010** (0.89%).

8-year-old boys

were more than 4x as likely to be identified with ASD as girls.

Approximately 1/3

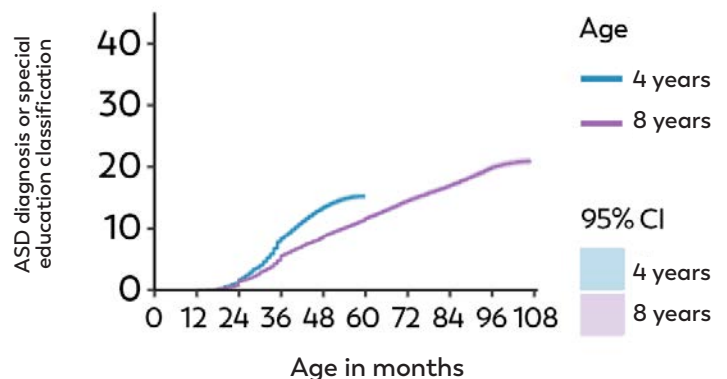of **8-year-old** children identified with ASD also had intellectual disability

72% of 4-year-old children with ASD

in 2018 received a developmental evaluation by 36 months of age

More children are being identified with ASD by 48 months

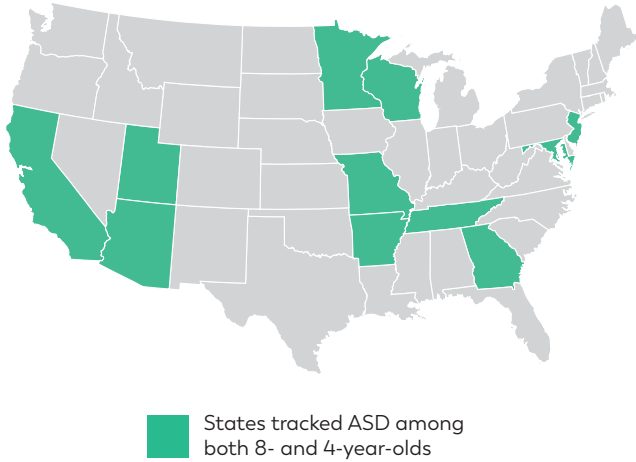
Cumulative incidence of ASD identified per 1000 children.

A Deeper Dive

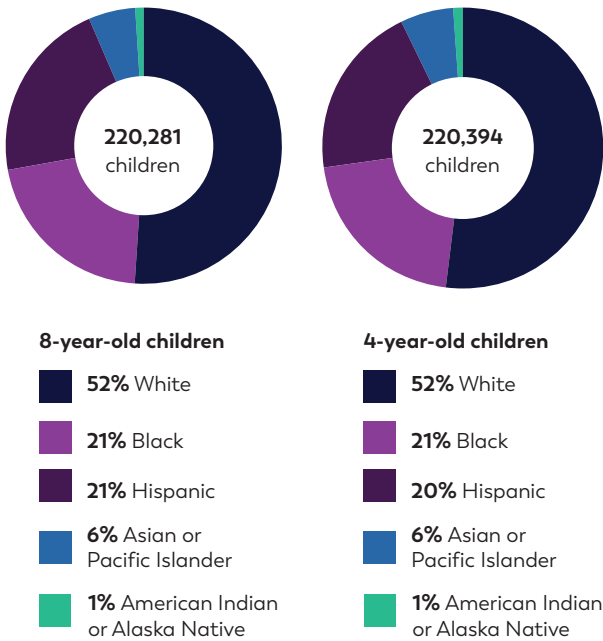Frequently Asked Questions
About ADDM Network Data

A Deeper Dive

Frequently Asked Questions About the ADDM Network Data

STATES WITH ADDM SITES
Surveillance Year 2018

■ States tracked ASD among both 8- and 4-year-olds

POPULATION BY RACE/ETHNICITY IN 2018

220,281 children

220,394 children

8-year-old children

- **52%** White
- **21%** Black
- **21%** Hispanic
- **6%** Asian or Pacific Islander
- **1%** American Indian or Alaska Native

4-year-old children

- **52%** White
- **21%** Black
- **20%** Hispanic
- **6%** Asian or Pacific Islander
- **1%** American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

How was this information collected?

The ADDM Network uses a systematic record-review method. Specifically, the information reported by the ADDM Network is based on the analysis of data collected from the health and special education records (if available) of 8-year-old and 4-year-old children who lived in one of 11 different areas throughout the United States in 2018.

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

The 2018 tracking area included specific areas of Arizona, Arkansas, California, Georgia, Maryland, Minnesota, Missouri, New Jersey, Tennessee, Utah, and Wisconsin (see site pages for more information).

What is the key take-away message?

There continue to be many children 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 compared to others?

Currently, research does not show that living in certain communities puts children at greater risk for developing ASD. These differences in the percentage of children identified with ASD across areas may be due to differences in availability of services for early detection and evaluation, diagnostic practices, and other differences in documentation of ASD symptoms. For example, there may be differences in whether children have insurance or meet the eligibility criteria for access to early intervention services (1). These differences can help us learn more about the policies and programs that have contributed to advancements in early identification and better support for children.

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 among 8-year-old Children

The Autism and Developmental Disabilities Monitoring (ADDM) Network data found no overall difference in the percent of Black, White, Hispanic, and Asian or Pacific Islander children identified with ASD by 8 years of age in 2018. However, disparities still exist in some communities.

This finding is consistent with data from the ADDM Network for the 2016 surveillance year, published in March 2020. While significant progress has been made in closing the gap in the identification of ASD among 8-year-old children in certain racial and ethnic populations, the percent of Hispanic children identified with ASD was still lower in several communities when compared to White or Black children.

These findings, among 8-year-olds, may indicate that efforts to promote ASD identification are working but suggest that more can be done to improve ASD identification particularly among Hispanic children. 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 (2). More work is needed to improve identification of ASD within Hispanic communities.

For the first time, the ADDM Network reported data on the percent of American Indian or Alaska Native (AI/AN) children identified with ASD. The percent of 8-year-old AI/AN children identified with ASD was slightly higher compared to White children; and similar to Black, Hispanic, and Asian or Pacific Islander children. Additional efforts are needed to collect more data on AI/AN children to provide a more detailed picture of ASD identification and access to services among this group.

Differences continue in ASD identification among Black children with co-occurring intellectual disability.

Although progress has been made in the equitable identification of ASD, concerns remain around the percentage (49.8%) of Black children identified with ASD and intellectual disability (ID), which is high compared to White or Hispanic children. ID is often seen in children with ASD and can indicate a type of substantial impairment. More work is needed to understand why this disparity continues to exist. A high percentage of children identified with ASD and ID might suggest a need for improvement in the evaluation and early identification of developmental concerns in children when a cognitive impairment is not present.

Future directions

The racial and ethnic gap in the identification of ASD are narrowing among 8-year-old children, 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 patterns continue to change over time. This information can help states and communities develop and evaluate strategies to increase awareness and improve identification of ASD and referral to services.
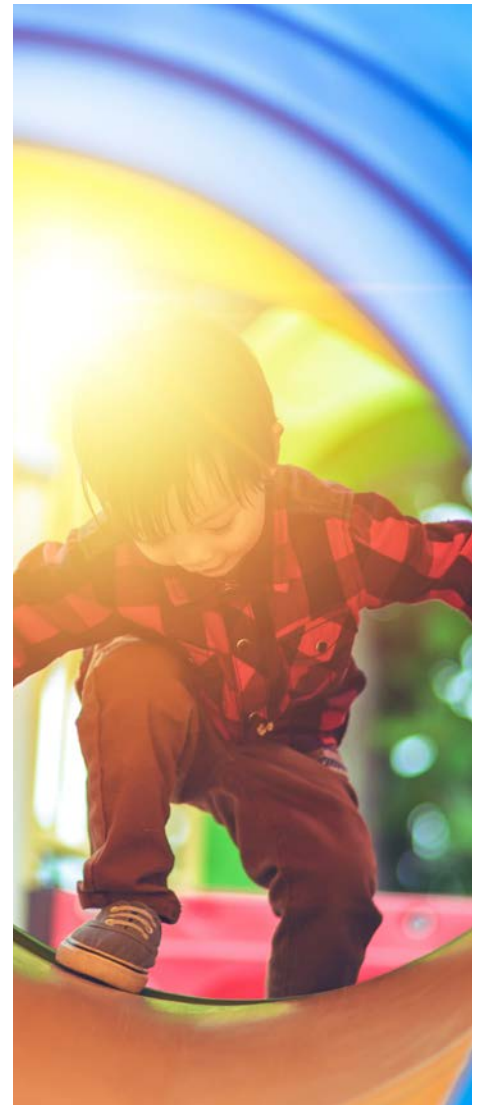
Spotlight On

Progress in Evaluation and Diagnosis of Autism Spectrum Disorder among 4-year-old children

Knowing how many children have ASD is just part of the picture. Understanding more about the characteristics of children with ASD, such as age of diagnosis, is also important.

Monitoring, screening, evaluating, and diagnosing children with ASD as early as possible are important steps to make sure that children receive the services and supports they need to reach their full potential.

The latest report from the 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.

Tracking ASD among 4-year-old children

Tracking ASD among 4-year-old children increases our understanding of the characteristics and progress in the early identification of younger children with ASD. Early identification can help families get early access to services in their communities.

In 2010, CDC began monitoring ASD among 4-year-old children living in a subset of communities participating in the broader ADDM Network. For the first time in 2018, surveillance among 4-year-old children expanded to all 11 sites participating in the ADDM Network.

### Key findings from the ADDM Network

More children are being identified with ASD at an earlier age

Children born in 2014 (4-year-olds) were 1.5 times as likely as children born in 2010 (8-year-olds) to be identified as having ASD by 48 months of age. This means more children are being identified as having ASD by 4 years of age now than before.

These findings are consistent with previous reports and may indicate greater awareness of ASD among families, healthcare providers, and educators to evaluate and identify children early.

More children are being identified with ASD by 48 months
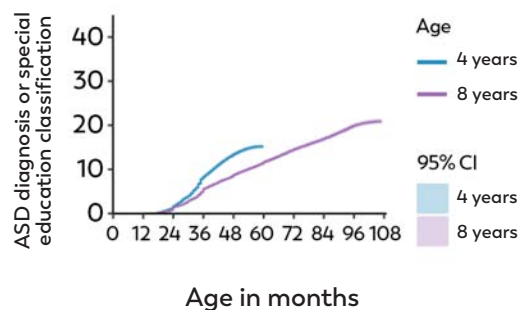

Cumulative incidence of ASD identified per 1000 children.

Racial and economic disparities are different from previous reports

Among 4-year-old children, new patterns were found in the identification of ASD by race and median household income compared to previous ADDM Network data:

- More Black, Hispanic, and Asian or Pacific Islander children were identified with ASD compared to White children; and

- Children living in lower income neighborhoods had a higher rate of ASD identification compared to children living in higher income neighborhoods.

These findings may suggest improvements in ASD awareness, identification, and access to services in communities serving Black, Hispanic, and Asian or Pacific Islander children, and children living in lower income neighborhoods. Continued efforts are needed to ensure that all children with ASD are identified early and connected to the services they need as soon as possible.
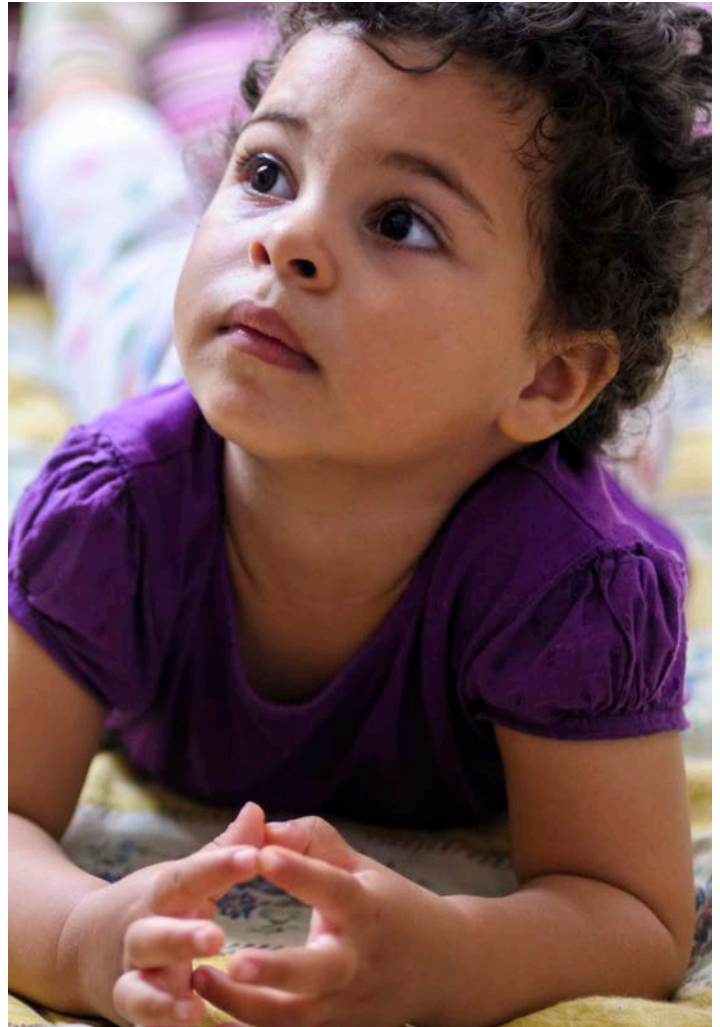
Steps in the process to diagnose ASD

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.

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 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

Data for Action

How Can You Use the ADDM Network Findings?

There are many children 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:

• Guide research on ASD.

ADDM Network findings have helped inform the Interagency Autism Coordinating Committee's Strategic Plan for ASD research (3).

• Inform and 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 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 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 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 research groups in local communities.

ADDM Network Site Snapshots

ADDM Network Site Snapshots

A Snapshot of Autism Spectrum Disorder in 2018

The Autism and Developmental Disabilities Monitoring (ADDM) Network tracked ASD at sites within these states in 2018.
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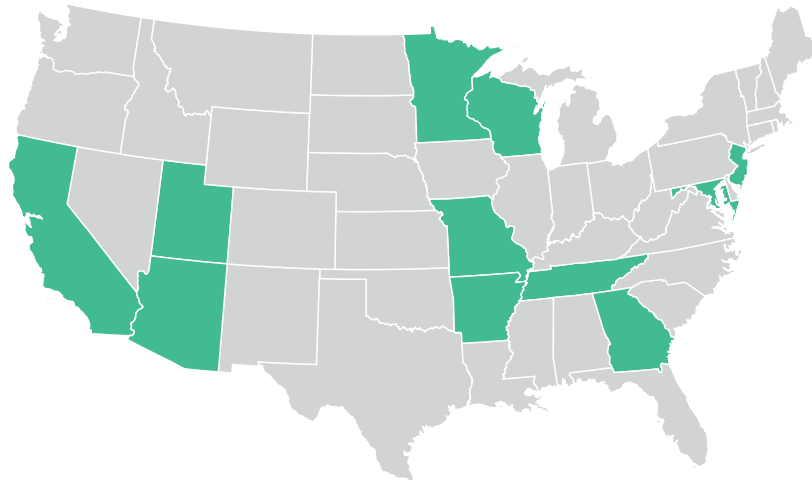
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> **NOTE:** Although these 11 states host the ADDM Network Sites, the entire state is not necessarily included in the tracked area. Please see individual ADDM Network site pages for a closer look at the specific sites.

A Snapshot of Autism Spectrum Disorder in

Arizona

Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
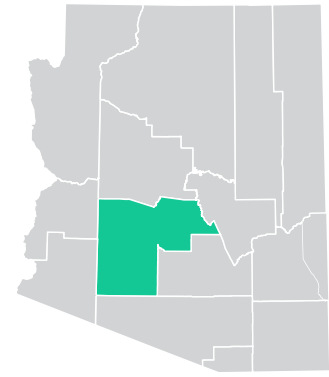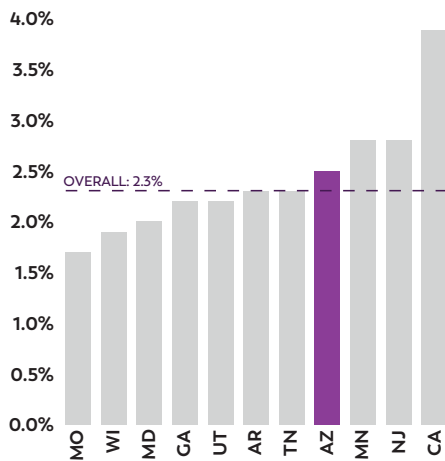
■ SITE TRACKING AREA
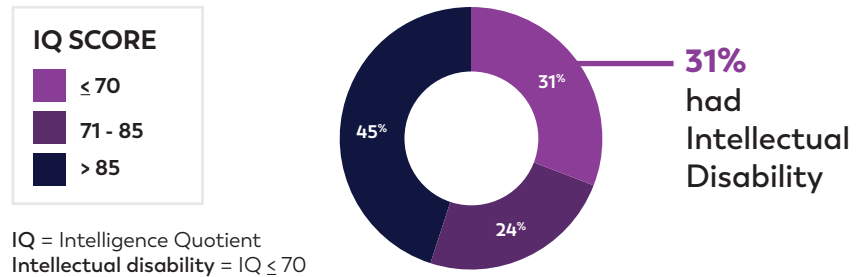
Among 8-year-olds | **Among 4-year-olds**

About 1 in 40

Or 2.5% of **8-year-old** children in an area of Arizona were identified with ASD by ADDSP in 2018

OVERALL: 2.3%

(bar chart, y-axis 0.0%–4.0%, states: MO WI MD GA UT AR TN AZ MN NJ CA)

This percentage is higher than the overall percentage identified with ASD (2.3%) in all communities where CDC tracked ASD among 8-year-olds in 2018.
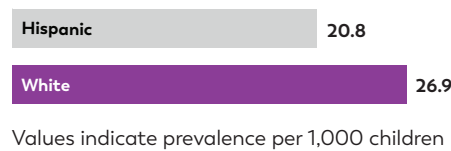
IQ data were available for 88%

Of **8-year-old** children identified with ASD by ADDSP

IQ SCORE
- ≤ 70
- 71 - 85
- > 85

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

(donut chart: 31%, 24%, 45%)

31% had Intellectual Disability

Among 8-year-olds

White children were 1.3x as likely to be identified with ASD as Hispanic children

Hispanic	20.8
White	26.9

Values indicate prevalence per 1,000 children

About 1 in 99

Or 1% of **4-year-old** children were identified with ASD by ADDSP in 2018
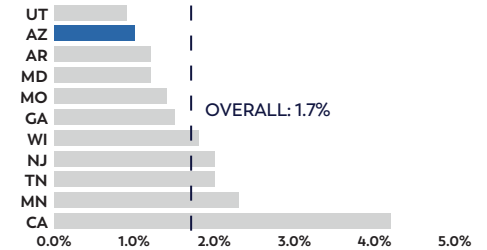
(bar chart, states: UT AZ AR MD MO GA WI NJ TN MN CA; x-axis 0.0%–5.0%)

OVERALL: 1.7%

This percentage is lower than the overall percentage identified with ASD (1.7%) in all communities where CDC tracked ASD among 4-year-olds in 2018.

8-year-old boys

Were 3.4x as likely to be identified with ASD as girls

● ● ● ◗ | ▲

Children who were born in 2014 (0.86%) were **1.5x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children who were born in 2010 (0.58%)

(line chart: ASD diagnosis or special education classification vs Age in months, Age: 4 years, 8 years, 95% CI: 4 years, 8 years)

Cumulative incidence of ASD identified per 1000 children.

4-year-old boys

● ● ● ● ◗ | ▲

Were 4.7x as likely to be identified with ASD as girls

What are the key take-away messages?

- More children with average or above average intelligence quotient scores are being identified with ASD since ADDSP started tracking ASD in 2000.
- White children were more likely to be identified with ASD than Black or Hispanic children. This may reflect cultural or socioeconomic differences 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, the difference has been decreasing over the years.
- As has been seen in previous years, the percentage of boys identified with ASD is higher than girls; a better understanding of sex differences may also lead to the development of more effective screening tools for ASD in boys and girls.
- More children are being diagnosed with ASD by age 4 years than in previous reports.

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 for and diagnosis of ASD.
- Improve screening tools to increase accuracy of screening for ASD.
- Improve collaborations in the ASD community among providers, researchers, and families.

How and where was this information collected?

ADDSP 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 4 years old and 8 years old and living in part of Maricopa county in metropolitan Phoenix in 2018.

8-year-old children in tracking area: 13,313
- 43% White
- 7% Black
- 43% Hispanic
- 4% Asian or Pacific Islander
- 3% American Indian or Alaska Native

4-year-old children in tracking area: 13,929
- 44% White
- 8% Black
- 41% Hispanic
- 3% Asian or Pacific Islander
- 4% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

What else does ADDSP do besides provide estimates of ASD?

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-old children with ASD. 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. ADDSP seeks to expand research on adults with ASD.

"The data collected by ADDM provides a critical look at the needs of the autism community. These data support the need for improving the accessibility of diagnostic evaluations. Early diagnosis is critical because it promotes positive life outcomes for all those affected by autism."

JOSHUA ANBAR, PhD
Southwest Autism Research and Resource Center (SARRC)

Resources

ARIZONA AUTISM COALITION
www.azautism.org

ARIZONA EARLY INTERVENTION PROGRAM
602-542-4446
www.des.az.gov/services/disabilities/developmental-infant

AZ FIND
928-637-1871
www.azed.gov/specialeducation/az-find

AZA UNITED
602-773-5773
www.azaunited.org

CDC'S LEARN THE SIGNS. ACT EARLY.
Megan Wills
Arizona's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

RAISING SPECIAL KIDS
602-242-4366
www.raisingspecialkids.org

SOUTHWEST AUTISM RESEARCH AND RESOURCE CENTER (SARRC)
602-340-8717
www.autismcenter.org

AUTISM SOCIETY OF SOUTHERN ARIZONA
520-770-1541
www.as-az.org

CONNECT WITH ADDSP
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A Snapshot of Autism Spectrum Disorder in

Arkansas

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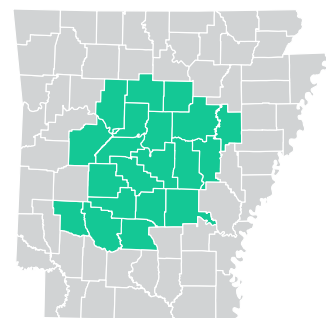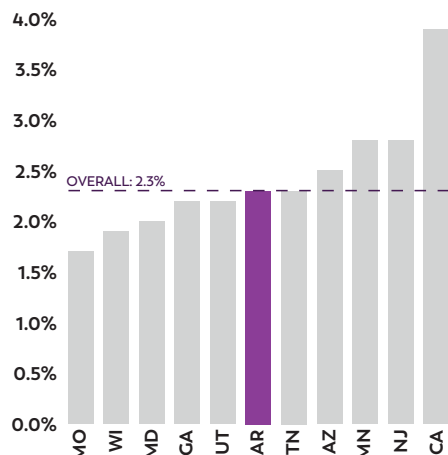
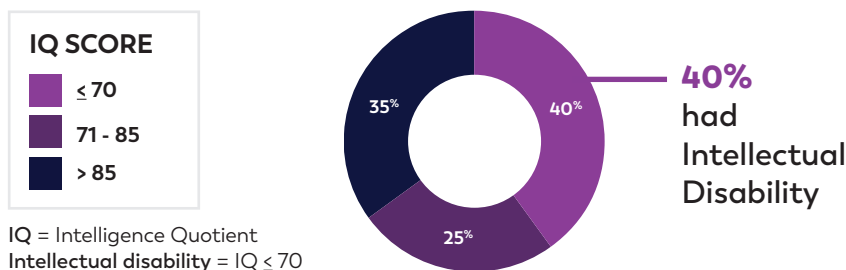**SITE TRACKING AREA**

Among 8-year-olds **Among 4-year-olds**

About 1 in 44

Or **2.3%** of **8-year-old** children in an area of Arkansas were identified with ASD by AR-ADDM in 2018

Bar chart with OVERALL: 2.3% reference line. States (left to right): MO, WI, MD, GA, UT, AR, TN, AZ, MN, NJ, CA

This percentage is the same as the overall percentage identified with ASD (2.3%) in all communities where CDC tracked ASD among 8-year-olds in 2018.

IQ data were available for 89%

Of **8-year-old** children identified with ASD by AR-ADDM

IQ SCORE
- ≤ 70
- 71 - 85
- > 85

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

Donut chart: 40%, 25%, 35%

40% had Intellectual Disability

Among 8-year-olds

White children were 1.6x as likely to be identified with ASD as Hispanic children

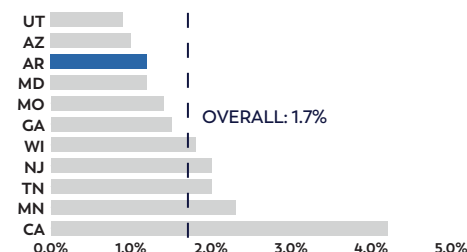|	
Hispanic	14.9
Black	19.2
White	23.8

Values indicate prevalence per 1,000 children. ASD prevalence was similar between White and Black children.

By 56 months of age

About half of **8-year-olds** were identified with ASD by health or educational sources

About 1 in 84

Or **1.2%** of **4-year-old** children were identified with ASD by AR-ADDM in 2018

Bar chart with OVERALL: 1.7% reference line. States (top to bottom): UT, AZ, AR, MD, MO, GA, WI, NJ, TN, MN, CA

This percentage is lower than the overall percentage identified with ASD (1.7%) in all communities where CDC tracked ASD among 4-year-olds in 2018. This is the first year AR-ADDM has tracked prevalence among 4-year-olds.

Overall, **4-year-olds** who met the ADDM case definition

92% had an ASD diagnosis by a health care provider
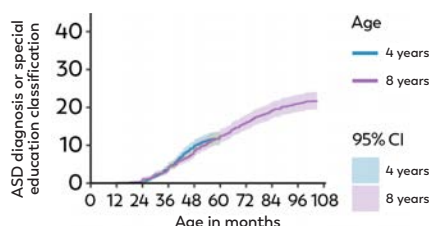
79% had an ASD ICD code

18% had autism special education eligibility

Children who were born in 2014 were **just as likely** to be identified with ASD by 48 months of age as children who were born in 2010

Cumulative incidence chart. Y-axis: ASD diagnosis or special education classification. X-axis: Age in months (0 12 24 36 48 60 72 84 96 108). Age: 4 years, 8 years. 95% CI: 4 years, 8 years.

Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- More children were identified with ASD in 2018 than in previous AR-ADDM and ADDM Network data.
- In Arkansas, Hispanic children were less likely to be identified with ASD than White children. Sustained efforts are needed to reduce disparities and identify individuals with ASD as early as possible in order to provide support.

How can this information be useful?

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

- Promote earlier identification of ASD.
- Plan for ASD services and training.
- Guide future ASD research.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Partners in Arkansas might consider different ways to continue to lower the age of first evaluation and diagnosis by community providers.

How and where was this information collected?

AR-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in one of 21 counties in central Arkansas in 2018.

8-year-old children in tracking area: 15,435
- 64% White
- 25% Black
- 10% Hispanic
- 1% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 15,387
- 63% White
- 26% Black
- 10% Hispanic
- 1% Asian or Pacific Islander
- <1% American Indian or Alaska Native

* Estimates may not sum to 100% due to rounding.

What else does AR-ADDM do besides provide estimates of ASD?

AR-ADDM collaborates with the Arkansas Department of Health and investigators from the University of Arkansas for Medical Services (UAMS) to track the number and characteristics of 8-year-olds and 4-year-olds with ASD, as well as follow up on 16-year-olds whose records were reviewed in previous tracking years.

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 collaborates with the Arkansas Department of Education to conduct analyses and present findings to Special Education staff across the state. AR-ADDM strives to work together with community partners to improve identification and reduce disparities among children with ASD and other developmental disabilities.

"The Arkansas Children's Hospital, Community-Based Autism Liaison and Treatment (CoBALT) project clinic keeps us very busy! As a primary care provider, I am very happy that Arkansas has a program such as CoBALT. Because of the autism surveillance work done through AR-ADDM, we are aware of our estimated prevalence rates and know that we have to work on providing early intervention for children. Our work in CoBALT can assist families to obtain quicker access to autism screening and diagnosis, and quicker referral for therapy services. It's wonderful to see such a partnership in Arkansas."

SHERYL DAVIDE-URETA, MD
Team Leader, Arkansas Children's Hospital CoBALT

Resources

FIRST CONNECTIONS
Services for children under 3 years with developmental delays or disabilities
1-800-643-8258 | dhs.arkansas.gov/dds/firstconnectionsweb/#fc-home

DEPT. OF EDUCATION'S SPECIAL EDUCATION UNIT
Special education services for school-aged children with disabilities
1-800-482-8437 | arksped.k12.ar.us

ARKANSAS AUTISM RESOURCE AND OUTREACH CENTER
Support, education, and advocacy for families of individuals with ASD
1-800-342-2923 | aaroc.org

UAMS DENNIS DEVELOPMENTAL CENTER
Diagnostic and other services for children with developmental delays and disabilities 501-364-1830 | pediatrics.uams.edu/clinical-programs-affiliates/dennis-developmental-center/

ARKANSAS AUTISM PARTNERSHIP MEDICAID WAIVER PROGRAM
Provides intensive, evidence-based intervention for 20-30 hours/week in the homes of young children with autism who meet eligibility criteria
www.uofapartners.uark.edu/projects/autism-partnership/

HEALTHY CHILD CARE ARKANSAS
Training for childcare providers
www.healthychildcarear.org/

COMMUNITY-BASED AUTISM LIAISON AND TREATMENT (CoBALT) PROJECT
Comprehensive diagnostic assessments, early intervention services, and family support
www.pediatrics.uams.edu/specialties/developmental-pediatrics/cobalt-program/

CDC'S LEARN THE SIGNS. ACT EARLY.
Angela Scott
Arkansas Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH AR-ADDM
Allison Hudson
Research Program Manager
University of Arkansas for Medical Sciences, Developmental Pediatrics – Little Rock, AR
aehudson@uams.edu | 501-364-3612

A Snapshot of Autism Spectrum Disorder in

California

Findings from the California Autism and Developmental Disabilities Monitoring (CA-ADDM) program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
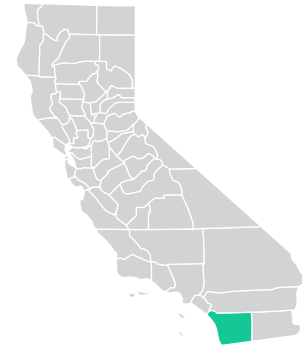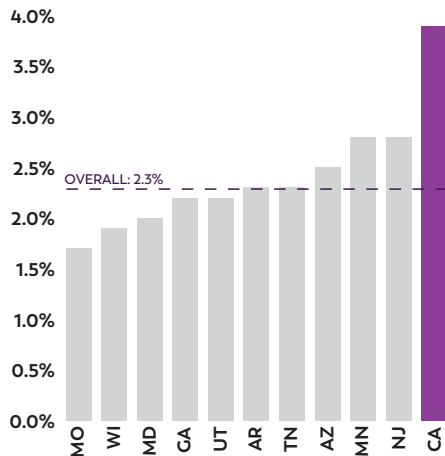
■ SITE TRACKING AREA

Among 8-year-olds   Among 4-year-olds

About 1 in 26

Or 3.9% of **8-year-old** children in an area of California were identified with ASD by CA-ADDM in 2018
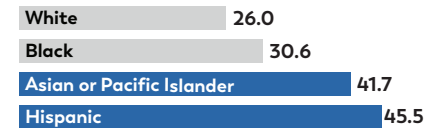

This percentage is higher than the average percentage identified with ASD (2.3%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2018.

Children who were born in 2014 (3.7%) were **1.6x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (2.3%).

Cumulative incidence of ASD identified per 1000 children.

By 36 months of age

Half of **8-year-old** children were diagnosed with ASD

About 1 in 24

Or 4.2% of **4-year-old** children were identified with ASD by CA-ADDM in 2018
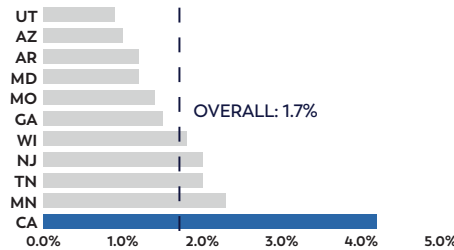
This percentage is higher than the average percentage identified with ASD (1.7%) in all communities in the United States where CDC tracked ASD among 4-year-olds in 2018.

Among 8-year-olds

There were no significant differences in ASD prevalence between White, Black, Asian or Pacific Islander, and Hispanic children
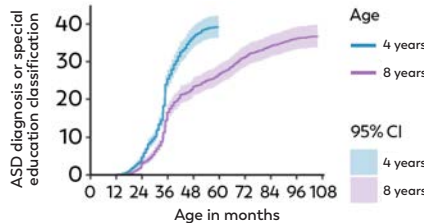
Among 4-year-olds

Hispanic 4-year-old children were 1.8x as likely and Asian or Pacific Islander children were 1.6x as likely to be identified with ASD as White children. They were also 1.5x as likely to be identified with ASD as Black children

White	26.0
Black	30.6
Asian or Pacific Islander	41.7
Hispanic	45.5

Values indicate prevalence per 1,000 children.

What are the key take-away messages?
- The percentage of children identified with ASD is higher in California compared to other sites where CDC tracks ASD for both 4-year-old and 8-year-old children.
- More children with ASD in California received their first diagnosis at a younger age compared to other sites. Additionally, the co-occurrence of intellectual disabilities is lower for both 4-year-old and 8-year-old children identified with ASD in California.
- Among 4-year-olds, Hispanic and Asian or Pacific Islander children were more likely to be identified with ASD than White children. Hispanic children were also more likely to be identified with ASD than Black children.
- There were no differences in the number of 8-year-old children identified with ASD across racial and ethnic groups.
- Differences exist in the percentages of boys and girls identified with ASD. However, this difference is smaller at younger ages, which may reflect differences in screening and diagnostic patterns.

How can this information be useful?
CA-ADDM's latest findings can be used to:
- Promote early identification of ASD.
- Plan for service needs of individuals with ASD and their families and provide trainings related to ASD to healthcare and education providers.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.
- Improve collaborations across the ASD community among providers, researchers, and families.

Partners in California might consider different ways to:
- Increase awareness of developmental monitoring among all racial and ethnic groups.
- Empower parents/caregivers to act early if there is concern about their child's development.
- Lower the age of first evaluation by community providers by identifying and addressing barriers to evaluation and diagnosis.

How and where was this information collected?
CA-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in parts of San Diego County in 2018.

8-year-old children in tracking area: 15,076
- 24% White
- 9% Black
- 52% Hispanic
- 14% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 16,796
- 30% White
- 9% Black
- 47% Hispanic
- 14% Asian or Pacific Islander
- 1% American Indian or Alaska Native

* Estimates may not sum to 100% due to rounding.

What else does CA-ADDM do besides provide estimates of ASD?
CA-ADDM collaborates with the California Department of Public Health, investigators from the University of California San Diego, and health, education, and early intervention systems that serve children with developmental disabilities and their families to understand the number and characteristics of 4-year-olds and 8-year-olds with ASD in select areas of California. Upon request, CA-ADDM offers workshops and trainings for local professionals and provides tailored data reports and presentations on the number and characteristics of children with ASD in California and across the ADDM Network. CA-ADDM works with interdisciplinary partners to identify ways the data can help improve our understanding of the needs of families in California. In addition, CA-ADDM works with clinical research groups to inform partners on scientific developments and promote innovative approaches to ASD identification in the community.

"CA-ADDM has given us a greater insight into the community we serve. As a school district, we can use this data to target the outreach and identification of students in order to more effectively provide early intervention services. It also provides a lens to help us find and partner with agencies in our community to ensure our students and families are accessing supports critical to their success at home and at school."

**DEANN RAGSDALE, Assistant Superintendent, Educational Services,
La Mesa-Spring Valley School District**

Resources

DEPARTMENT OF DEVELOPMENTAL SERVICES REGIONAL CENTERS
916-654-1690
www.dds.ca.gov/rc/

CALIFORNIA EARLY START
800-515-2229
www.dds.ca.gov/services/early-start/

FIRST FIVE CALIFORNIA
916-263-1050
www.ccfc.ca.gov/

DEPARTMENT OF EDUCATION SPECIALIZED PROGRAMS
916-445-4613
www.cde.ca.gov/sp

UC SAN DIEGO AUTISM CENTER OF EXCELLENCE
858-534-6912
www.medschool.ucsd.edu/som/neurosciences/centers/autism/pages/default.aspx

NATIONAL FOUNDATION FOR AUTISM RESEARCH
858-679-8800
www.nfar.org/what-we-do/parent-programs

CDC'S LEARN THE SIGNS. ACT EARLY.
Fran Goldfarb
Michele Rogers
CA Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH CA-ADDM
Karen Pierce, PhD
University of California San Diego
8110 La Jolla Shores Dr, Ste 202
La Jolla, CA 92037
858-534-6912
kpierce@health.ucsd.edu

A Snapshot of Autism Spectrum Disorder in

Georgia

Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
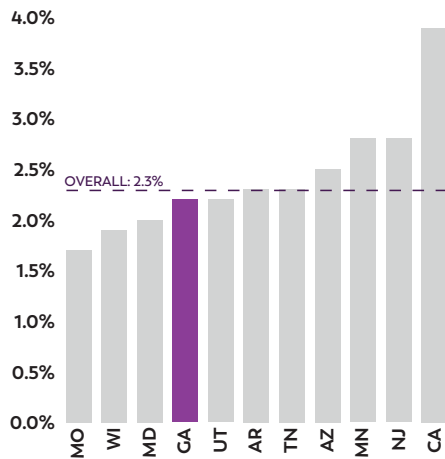
SITE TRACKING AREA

| Among 8-year-olds | Among 4-year-olds |

About 1 in 46

Or 2.2% of **8-year-old** children were identified with ASD by MADDSP in 2018

OVERALL: 2.3%

This percentage is about the same as the average percentage identified with ASD (2.3%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2018.

By 3 years of age

About 49% of children identified with ASD received a comprehensive developmental evaluation
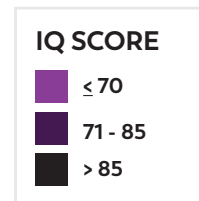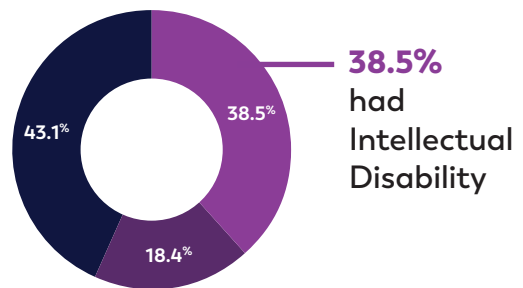
This is a 32% increase from 2016.

8-year-old children with both ASD and ID were identified earlier than children with ASD who did not have ID

IQ data were available for 69%
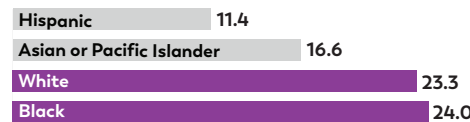
Of **8-year-old** children identified with ASD

IQ SCORE

■	≤ 70
■	71 - 85
■	> 85

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

43.1% 38.5% 18.4%

**38.5%** had Intellectual Disability

Among 8-year-olds

White and Black children were 2x as likely to be identified with ASD as Hispanic children. Black children were 1.4x as likely to be identified as Asian or Pacific Islander children

Hispanic	11.4
Asian or Pacific Islander	16.6
White	23.3
Black	24.0

Values indicate prevalence per 1,000 children. There were no significant differences in identification between other races or ethnicities.

Among 4-year-olds

Black children were 1.7x as likely to be identified with ASD as Hispanic children. White children were 0.7x as likely as Black children and Hispanic children were 0.6x as likely as Asian or Pacific Islander to be identified with ASD

Hispanic	10.0
White	12.0
Black	17.1
Asian or Pacific Islander	17.7
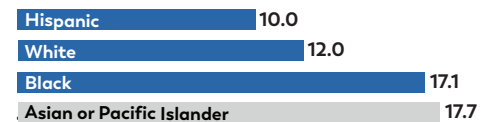
Values indicate prevalence per 1,000 children.

Children who were born in 2014 (1.0%) were **1.4x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (0.7%).
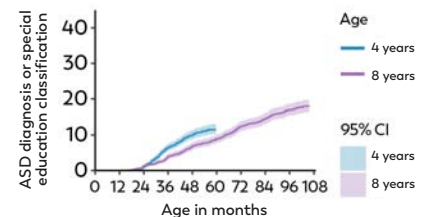
Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- More children are being diagnosed by age 4 years compared to age 8 years than in previous study years.
- While the proportion of Black and White children identified with ASD is about the same, Hispanic and Asian or Pacific Islander 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.

How can this information be useful?

MADDSP's latest findings can be used to:

- Promote early identification of ASD.
- Plan for ASD services and training.
- Guide future ASD research.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Partneres in Georgia might consider different ways to:

- Lower the age of first evaluation by community providers.
- Increase awareness of ASD among Hispanic and Asian or Pacific Islander families.
- Identify and address barriers 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 4 years old and 8 years old and living in either DeKalb or Gwinnett county in Georgia in 2018.

8-year-old children in tracking area: 23,580
- 26% non-Hispanic White
- 40% non-Hispanic Black
- 25% Hispanic
- 9% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 23,040
- 27% non-Hispanic White
- 40% non-Hispanic Black
- 23% Hispanic
- 9% Asian or Pacific Islander
- <1% American Indian or Alaska Native

* Estimates may not sum to 100% due to rounding.

What else does MADDSP do besides provide estimates of ASD?

MADDSP is an intramural program administered by the Centers for Disease Control and Prevention. MADDSP collaborates with health and education systems that serve children with developmental disabilities and their families to understand the number and characteristics of 4- and 8-year-olds with ASD and intellectual disability in select areas of Georgia. MADDSP provides tailored data reports and presentations to data providers and community organizations upon request.

"MADDSP and ADDM data have again demonstrated that an evidence-based surveillance system can provide meaningful data for monitoring the prevalence of ASD and has really shaped statewide priorities in Georgia to lower the age of diagnosis, increase the capacity to diagnose and serve these individuals, and to reduce the racial/ethnic disparities in diagnosis and services. These data were especially important to help pass legislation to mandate insurance coverage and are often used to increase national priorities for how to best support individuals with ASD at home, in schools, and in the community."

MICHAEL J. MORRIER PhD, BCBA-D
Associate Professor, Emory University School of Medicine

Resources

ATLANTA AUTISM CONSORTIUM
Support for collaboration among families, researchers, clinicians, educators, and advocates
https://atlautism.org

THE ARC AUTISM NOW
Resources and information on community-based programs
https://autismnow.org

AUTISM SPEAKS
Information and resources for families
www.autismspeaks.org

BABIES CAN'T WAIT
Services for children under the age of 3 years with developmental delays or disabilities
www.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

PARENT TO PARENT OF GEORGIA
Support for parents of children with special needs
1-800-229-2038
p2pga.org

CDC'S LEARN THE SIGNS. ACT EARLY.
Bridget Ratajczak
GA Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH MADDSP
addm@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) Program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
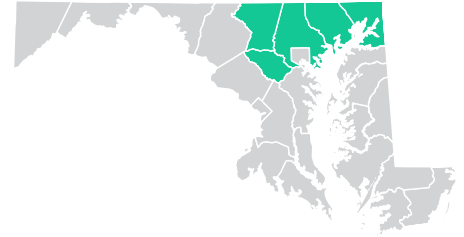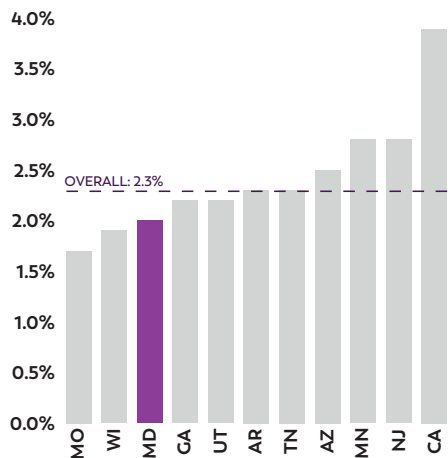
SITE TRACKING AREA

`Among 8-year-olds` `Among 4-year-olds`

About 1 in 49

Or 2.0% of **8-year-old** children were identified with ASD by MD-ADDM in 2018

This percentage is lower than the overall percentage identified with ASD (2.3%) in all communities where CDC tracked ASD among 8-year-olds in 2018.

8-year-old boys

Were 4.4x as likely to be identified with ASD as girls

Among 8-year-olds

Black children were 1.4x as likely to be identified with ASD as White children. No additional significant differences in ASD prevalence were found between Black, White, Hispanic, and Asian or Pacific Islander children

White	15.6
Hispanic	19.1
Asian or Pacific Islander	19.2
Black	24.8
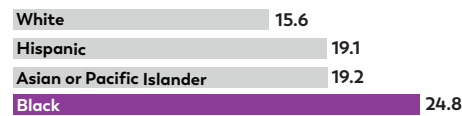
Values indicate prevalence per 1,000 children.

By 45 months of age

Half of **8-year-old** children identified with ASD were diagnosed

Children who were born in 2014 (0.97%) were **1.5x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (0.66%).
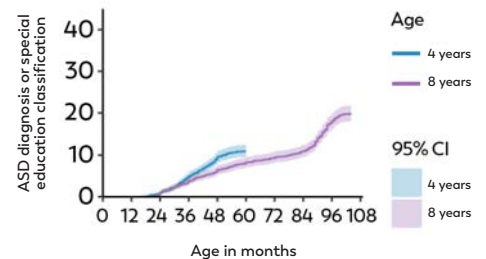

Cumulative incidence of ASD identified per 1000 children.

By 3 years of age

About 66% of **8-year-old** children identified with ASD received a comprehensive developmental evaluation

By 3 years of age

About 83% of **4-year-old** children identified with ASD received a comprehensive developmental evaluation

What are the key take-away messages?

- Autism Spectrum Disorder (ASD) can be diagnosed as young as 18 months of age.
- In MD-ADDM, most children identified with ASD by 8 years of age were evaluated by age 3.
- 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.
- Many children with ASD need services and support, now and as they grow into adolescence and adulthood.

How can this information be useful?

MD-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 research.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

How and where was this information collected?

MD-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in 5 counties in Maryland in 2018.

Tracking areas
Baltimore, Carroll, Cecil, Harford, and Howard counties

8-year-old children in tracking area: 20,666
- 55% White
- 26% Black
- 9% Hispanic
- 10% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 19,818
- 56% White
- 25% Black
- 10% Hispanic
- 9% Asian or Pacific Islander
- <1% American Indian or Alaska Native

* Estimates may not sum to 100% due to rounding.

What else does MD-ADDM do besides provide estimates of ASD?

MD-ADDM collaborates with the Maryland Department of Health, the Maryland State Department of Education, the Kennedy Krieger Institute, and local school districts, to track the number and characteristics of 4-year-old and 8-year-old children with ASD. MD-ADDM offers presentations on the number and characteristics of children with ASD in Maryland and across the ADDM Network for stakeholders, state and local agencies, partnering institutes, and parent groups. MD-ADDM also participates in and organizes annual autism awareness month events in the community.

"The MD-ADDM site provides critical data to Maryland agencies serving the autism population. The data assists these agencies to allocate local resources, direct policy initiatives and may lead to increased capacity of services to help more families. Pathfinders for Autism utilizes the MD-ADDM data in our outreach and awareness efforts to better educate the general population and allows us to better distribute information and resources to Maryland's autism families."

REBECCA RIENZI
Executive Director, Pathfinders for Autism

The Maryland ADDM site lost its longtime principal investigator, Dr. Li-Ching Lee, in May 2021, when she passed away from breast cancer at age 54. Her work included autism prevalence and related research in the United States, as well as Taiwan, Bangladesh, and China. The Maryland ADDM site dedicates this year's report to Dr. Lee, honoring her devotion to children around the world, her colleagues, and the many students she mentored in her too-brief lifetime.

Resources

PATHFINDERS FOR AUTISM
443-330-5341
www.pathfindersforautism.org

CENTER FOR AUTISM AND RELATED DISORDERS AT KENNEDY KRIEGER INSTITUTE
443-923-7630
www.card.kennedykrieger.org

THE PARENTS' PLACE OF MARYLAND
410-768-9100
https://www.ppmd.org/

DEPARTMENT OF EDUCATION'S DIVISION OF SPECIAL EDUCATION AND EARLY INTERVENTION SERVICES
410-767-0238
www.marylandpublicschools.org/programs/Pages/Special-Education/index.aspx

ITINERIS
443-275-1100
https://www.itinerisbaltimore.org/

AUTISM SOCIETY OF BALTIMORE-CHESAPEAKE
410-655-7933
www.baltimoreautismsociety.org

COMMUNITY SERVICES FOR AUTISTIC ADULTS AND CHILDREN (CSAAC)
240-912-2220
http://csaac.org/

CDC'S LEARN THE SIGNS. ACT EARLY.
Rachel Demma
Maryland's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH MD-ADDM
**Dani Fallin, PhD**
dfallin@jhu.edu
Elise Pas, PhD
epas@jhu.edu
Johns Hopkins University

A Snapshot of Autism Spectrum Disorder in

Minnesota

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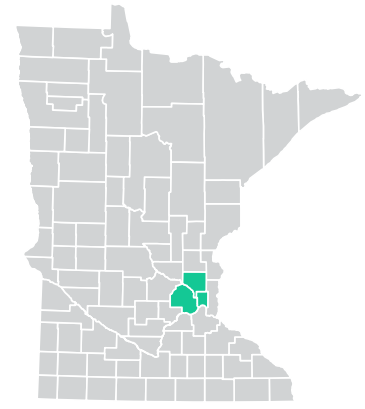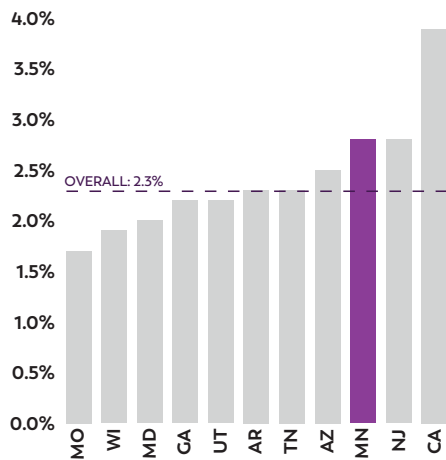
SITE TRACKING AREA

Among 8-year-olds | Among 4-year-olds

About 1 in 36

Or 2.8% of **8-year-old** children were identified with ASD by MN-ADDM in 2018

OVERALL: 2.3%

This percentage is higher than the average percentage identified with ASD in 2018, which was 2.3% of 8-year-olds across all ADDM sites
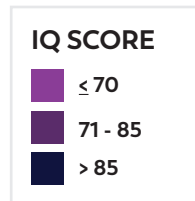
8-year-old boys

Were 4.2x as likely to be identified with ASD as girls

IQ data were available for 81%

Of **8-year-old** children identified with ASD

IQ SCORE

- ≤ 70
- 71 - 85
- > 85

29% had Intellectual Disability

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

By 3 years of age

45% of **8-year-old** children received a comprehensive developmental evaluation

By 63 months of age

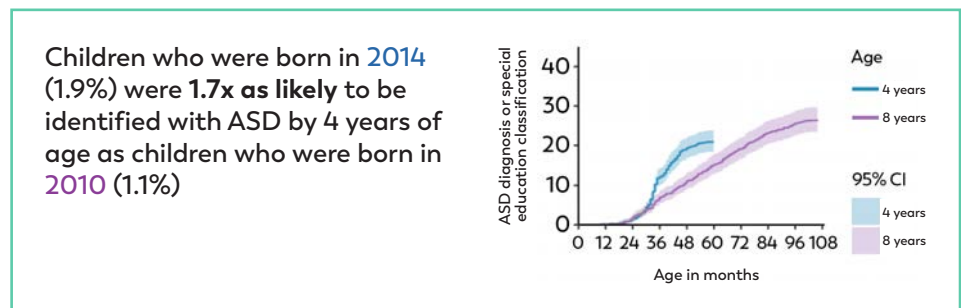Half of **8-year-old** children were diagnosed with ASD by a community provider

Among 8-year-old

Black children were 1.8x as likely to be identified with ASD as Hispanic children and 1.3x as likely to be identified with ASD as White children

Hispanic	18.1
White	25.0
Black	33.0

Values indicate prevalence per 1,000 children.

Children who were born in 2014 (1.9%) were **1.7x as likely** to be identified with ASD by 4 years of age as children who were born in 2010 (1.1%)

Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- MN-ADDM identified the third highest prevalence of ASD in the ADDM Network among 8-year-olds and the second highest prevalence of ASD in the ADDM Network among 4-year-olds. (refer to the Morbidity and Mortality Weekly Report (MMWR) for more details)
- In MN-ADDM there were differences between percentage of boys and girls identified, with more boys identified with ASD than girls. This is consistent with previous estimates and in the overall ADDM network.
- MN-ADDM findings also reveal some differences in prevalence across racial and ethnic groups. Black children in MN-ADDM were identified with ASD more frequently than White children in 2018 among both 4-year-old and 8-year-old children. Among 4-year-olds, Asian or Pacific Islander children were twice as likely to be identified with ASD than White children. (refer to the MMWR for more details)
- In the areas of Minnesota included in MN-ADDM, children with ASD are often being identified at much later ages than is recommended. MN-ADDM had the latest median age of diagnosis across all of the ADDM Network, and less than half of 8-year-old children with ASD had received a comprehensive evaluation by age 3 years. However, it is encouraging that a higher percentage of 4-year-old children were identified with ASD in early childhood compared to 8-year-old children; this means identification is happening earlier in the younger cohort. ASD can be reliably diagnosed by age 2 years or even younger.

How can this information be useful?

MN-ADDM's findings can be used to:

- Inform policies that promote early identification of ASD.
- Plan for the service needs of individuals with ASD and provide training to ASD service providers and families.
- Guide future ASD research.

Partners in Minnesota might consider different ways to:

- Increase access to early comprehensive evaluations by community providers
- Decrease age of ASD identification in educational and health care settings

How and where was this information collected?

MN-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old living in parts of three counties in 2018.

Tracking area
Parts of Anoka, Ramsey, and Hennepin counties

8-year-old children in tracking area: 10,081	**4-year-old children in tracking area: 10,529**
• 51% White	• 53% White
• 25% Black	• 25% Black
• 14% Hispanic	• 11% Hispanic
• 8% Asian or Pacific Islander	• 8% Asian or Pacific Islander
• 2% American Indian or Alaska Native	• 2% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

"I use information from the Minnesota ADDM program in my work as a parent advocate with Minnesota legislators. To be able to show that over 2% of children in Minnesota have autism, and that Minnesota has one of the higher autism rates compared to other states, helps to motivate people to action. It helps us understand the needs of children with autism in Minnesota today and what needs we should plan for as children become adults."

KELLY KAUSEL
mother of a child with autism and parent advocate

A Snapshot of Autism Spectrum Disorder in

Missouri

Findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
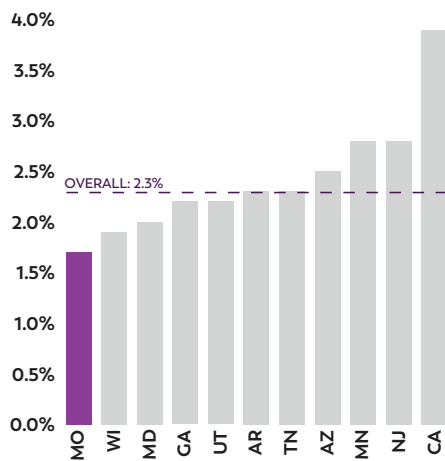
SITE TRACKING AREA

Among 8-year-olds **Among 4-year-olds**

About 1 in 60

Or 1.7% of **8-year-old** children were identified with ASD by MO-ADDM in 2018

OVERALL: 2.3%

This percentage is lower than the average percentage identified with ASD (2.3%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2018.

8-year-old boys

Were 3x as likely to be identified with ASD as girls

Among 8-year-olds

Black	14.3
Asian or Pacific Islander	17.0
White	17.8

Values indicate prevalence per 1,000 children.

By 3 years of age

41% of children with ASD had a comprehensive developmental evaluation

No significant differences in ASD prevalence were found between White, Black, and Asian or Pacific Islander children

Children who were born in 2014 (1.2%) were **1.6x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (0.7%)
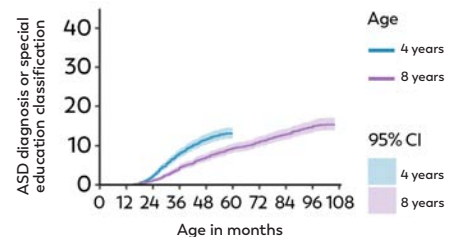
Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- ASD prevalence was similar for White and Black children, suggesting previously reported racial disparities in ASD identification continue to diminish.
- Despite diminishing disparities in identification across the ADDM Network, Black children were more likely to have ASD and ID compared to White children.
- Although there was no relationship between neighborhood-level socioeconomic status (SES) and ASD prevalence among 8-year-old children, higher SES was associated with higher ASD prevalence among 4-year-old children in MO-ADDM.

How can this information be useful?

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

- Plan for ASD services and training.
- Promote early identification and service initiation.
- Guide future ASD research.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

Partners in Missouri should continue to consider new ways to lower the age of first evaluation and diagnosis by community providers; this action will improve access to interventions and services to benefit children and their families.

How and where was this information collected?

MO-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in 1 of 5 counties in Missouri in 2018.

Tracking area
Franklin, Jefferson, St. Charles, St. Louis, St. Louis City counties

8-year-old children in tracking area: 24,481	4-year-old children in tracking area: 24,521
• 66% White	• 65% White
• 25% Black	• 26% Black
• 5% Hispanic	• 5% Hispanic
• 4% Asian or Pacific Islander	• 4% Asian or Pacific Islander
• <1% American Indian or Alaska Native	• <1% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

What else does MO-ADDM do besides provide estimates of ASD?

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

"The ADDM Network data is a vital tool that can be used by physicians and other providers to monitor our progress towards ensuring that we are identifying all children with ASD as early as possible and connecting families with appropriate services."

PAUL S. SIMONS, MD
Specialist in Developmental and Behavioral Pediatrics
Associate Professor of Pediatrics, Washington University School of Medicine

Resources

DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION'S OFFICE OF SPECIAL EDUCATION
573-751-5739
dese.mo.gov/special-education

DEPARTMENT OF MENTAL HEALTH'S DIVISION OF DEVELOPMENTAL DISABILITIES
dmh.mo.gov/dd/

FIRST STEPS
1-866-583-2392
www.mofirststeps.com/

MISSOURI FAMILIES FOR EFFECTIVE AUTISM TREATMENT
877-275-8988
www.mo-feat.org/

NAVIGATING AUTISM SERVICES
dmh.mo.gov/media/pdf/navigating-autism-services-community-guide-missouri

CDC'S LEARN THE SIGNS. ACT EARLY.
Alicia Curran
Missouri's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html
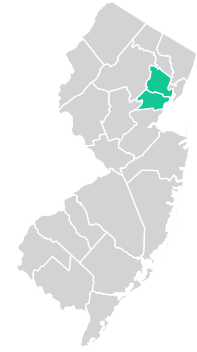
CONNECT WITH MO-ADDM
Robert Fitzgerald, PhD, MPH
Washington University in St. Louis
314-286-0151
fitzgeraldr@wustl.edu

A Snapshot of Autism Spectrum Disorder in
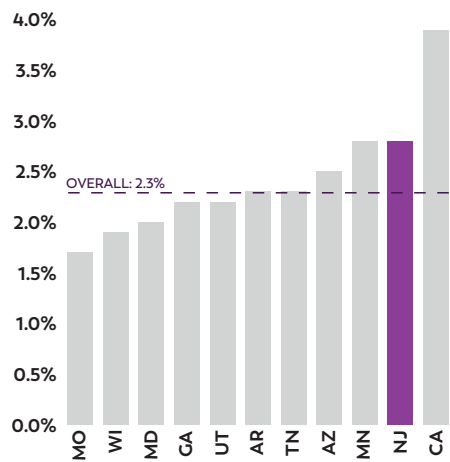
New Jersey

Findings from the New Jersey Autism Study (NJAS) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.

SITE TRACKING AREA

Among 8-year-olds | **Among 4-year-olds**

About 1 in 35

Or 2.8% of **8-year-old** children were identified with ASD by NJAS in 2018

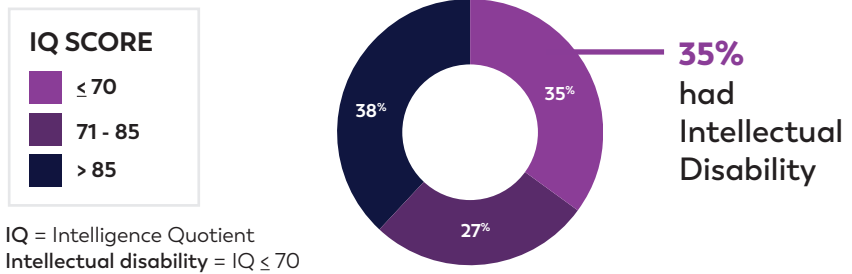OVERALL: 2.3%

MO WI MD GA UT AR TN AZ MN NJ CA

This percentage is higher than the average percentage identified with ASD (2.3%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2018.

Among 8-year-olds

No significant differences in the prevalence of ASD among White, Black, Hispanic, and Asian or Pacific Islander children were identified

White	24.0
Black	25.6
Asian or Pacific Islander	29.7
Hispanic	30.1

New Jersey had the highest proportion of **8-year-old children** with a documented ASD diagnostic statement (94%), compared to other ADDM Network sites

IQ data were available for 64%
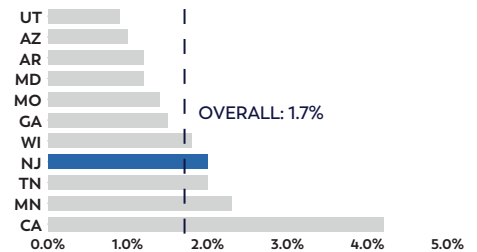
Of **8-year-old** children identified with ASD

IQ SCORE
- ≤ 70
- 71 - 85
- > 85

38% 35% 27%

35% had Intellectual Disability

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

About 1 in 51

Or 2.0% of **4-year-old** children were identified with ASD BY NJAS in 2018

This percentage is higher than the overall percentage identified with ASD (1.7%) in all communities where CDC tracked ASD among 4-year-olds in 2018.

UT AZ AR MD MO GA WI NJ TN MN CA

OVERALL: 1.7%

0.0% 1.0% 2.0% 3.0% 4.0% 5.0%

Among 4-year-olds

Hispanic children were 1.4x as likely to be identified with ASD compared to White children

White	15.2
Asian or Pacific Islander	16.4
Black	20.0
Hispanic	20.6
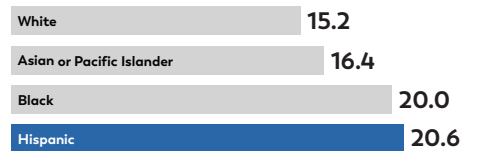
There were no significant differences in the prevalence of ASD among White, Black and Asian or Pacific Islander children. Values indicate prevalence per 1,000 children.

Children who were born in 2014 (1.8%) were **1.2x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (1.5%)
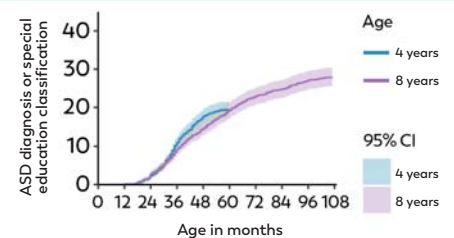
Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?
- The 2018 ADDM ASD prevalence estimates were higher than 2016 estimates among 8-year-old children.
- The ASD prevalence estimates among 8-year-old children ranged from 1.7% (Missouri) to 3.9% (California); New Jersey had the second highest prevalence estimate (2.8%) suggesting differences in ASD diagnosis across the ADDM Network sites.
- The ASD prevalence estimates among 4-year-old children ranged from 0.9% (Utah) to 4.2% (California), suggesting differences in ASD diagnosis across ADDM Network sites.
- Across ADDM sites, ASD rates were similar for Black, White, and Hispanic 8-year-old children; however, more Black children identified with ASD also had intellectual disability (refer to the MMWR for more details).

How can this information be useful?
The latest findings about ASD prevalence may be used to:
- Raise awareness in New Jersey of increasing ASD prevalence in the United States.
- Quantify the scope and magnitude of ASD prevalence in US metropolitan regions.
- Provide New Jersey specific information relevant for planning services to individuals with ASD.
- Guide future research in environmental (non-genetic) risk factors for ASD.

How and where was this information collected?
The New Jersey Autism Study 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 4 years old and 8 years old and living in two counties in New Jersey in 2018.

Tracking area
Essex and Union counties

8-year-old children in tracking area: 17,289
- 28% White
- 32% Black
- 34% Hispanic
- 6% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 17,286
- 26% White
- 31% Black
- 37% Hispanic
- 6% Asian or Pacific Islander
- <1% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

What else does NJAS do besides provide estimates of ASD?
NJAS promotes universal ASD screening of children at 18-, 24-, and 30-months using the Psychological Development Questionnaire (PDQ-1), a rapid and reliable parent report questionnaire. NJAS also advances the search for ASD risk factors.

"The CDC-ADDM Network and the New Jersey Autism Study data have been valuable resources, especially in our work in the early childhood space, toward understanding the scope and impact of ASD and related conditions on children, families and communities. These findings have been helpful to building and sustaining successful partnerships for ongoing promotion of parent-engaged developmental monitoring and early identification of ASD and other developmental disabilities in our state."

DEEPA SRINIVASAVARADAN
CDC Learn the Signs/Act Early Ambassador to New Jersey & State Parent Lead for Early Childhood Initiatives, SPAN Parent Advocacy Network

Resources

MOM2MOM
24/7 peer-support for parents of children with special needs
877-914-6662
www.mom2mom.us.com

NJ EARLY INTERVENTION SYSTEM
Services for children under the age of 3 years with developmental delays or disabilities
www.nj.gov/health/fhs/eis/

NJ DEPARTMENT OF EDUCATION OFFICE OF SPECIAL EDUCATION PROGRAM
Special education services for school-aged children with disabilities
www.nj.gov/education/specialed/

STATEWIDE PARENT ADVOCACY NETWORK
Support for parents, including parents of children with special needs
800-654-7726
www.spanadvocacy.org/

AUTISM NEW JERSEY
Information, education, and policy initiatives related to ASD
800-4-AUTISM
www.autismnj.org

AUTISM FAMILY SERVICES OF NEW JERSEY
Support services for families living with ASD
877-237-4477
www.autismfamilyservicesnj.org

ASPERGER SYNDROME EDUCATION NETWORK (ASPEN)
Education, support, and advocacy for individuals with ASD and their families
732-321-0880
www.aspennj.org

CDC'S LEARN THE SIGNS. ACT EARLY.
Deepa Srinivasavaradan
New Jersey's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH NJAS
Walter Zahorodny, PhD
Josephine Shenouda, MS
Rutgers-New Jersey Medical School
185 South Orange Avenue, F570
Newark, New Jersey 07101
973-972-9773
zahorodn@njms.rutgers.edu

A Snapshot of Autism Spectrum Disorder in

Tennessee

Findings from the Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDM) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.
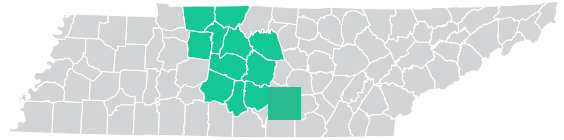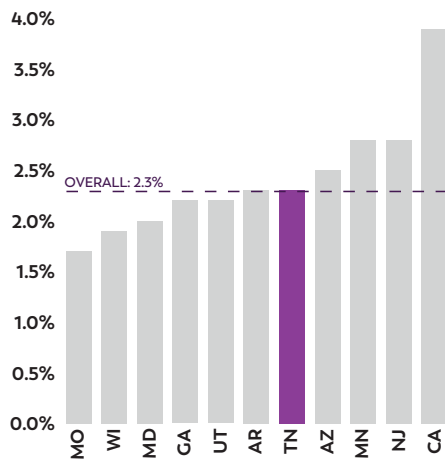
■ **SITE TRACKING AREA**

Among 8-year-olds   **Among 4-year-olds**

About 1 in 44

Or 2.3% % of children were identified with ASD by TN-ADDM in 2018

OVERALL: 2.3%

MO WI MD GA UT AR TN AZ MN NJ CA

This percentage is the same as the overall percentage identified with ASD (2.3%) in all communities where CDC tracked ASD among 8-year-olds in 2018.

By 3 years of age

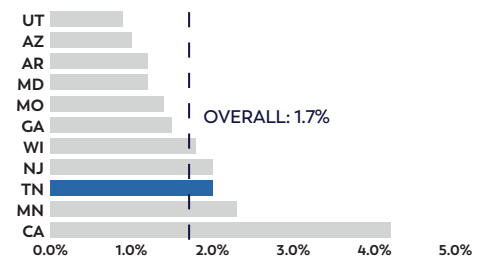41% of **8-year-old** children identified with ASD received a comprehensive developmental evaluation

By 4 years of age

Black children were 1.3x as likely and Hispanic children were 1.5x as likely to be identified with ASD as White children

White	16.8
Black	21.1
Hispanic	24.8

Values indicate prevalence per 1,000 children.

By 3 years of age

68% of **4-year-old** children identified with ASD received a comprehensive developmental evaluation

About 1 in 51

Or 2.0% of **4-year-old** children were identified with ASD by TN-ADDM in 2018

UT AZ AR MD MO GA WI NJ TN MN CA

OVERALL: 1.7%

This percentage is higher than the overall percentage identified with ASD (1.7%) in all communities where CDC tracked ASD among 4-year-olds in 2018.

Children who were born in 2014 (1.4%) were **1.7x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (0.8%)
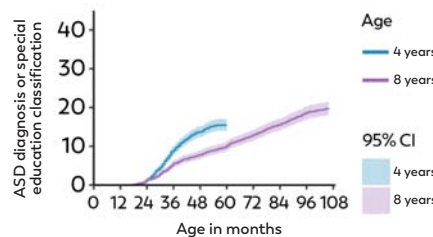
Cumulative incidence of ASD identified per 1000 children.

What are the key take-way messages?

- There are many children living with ASD who need services and support. The number of 8-year-old children identified with ASD in the area covered by TN-ADDM increased from 1 in 68 (1.5%) in 2014, to 1 in 64 (1.6%) in 2016, to 1 in 44 (2.3%) in 2018.
- Although an increasing number of children with ASD in Tennessee (41% of 8-year-olds; 68% of 4-year-olds) are initially evaluated prior to 3 years of age, a majority of children are still diagnosed at later ages (median age of diagnosis was 53 months of age among 8-year-old children with ASD).
- This is the first-time data has been available in Tennessee for 4-year-olds. About 1 in 51 (or 2%) of 4-year-old children were identified with ASD by TN-ADDM in 2018.
- In Tennessee, Black children and Hispanic children were more likely to be identified with ASD by 4-years-of-age than White children. This may reflect improved service and advocacy efforts targeting traditionally underserved communities, and the ADDM surveillance methods that better capture ASD.
- The increasing number of children identified with ASD in Tennessee may be tied to complex factors related to awareness and capacity for service.

How can this information be useful?

TN-ADDM's findings can be used to:
- Inform policies that promote earlier identification of ASD.
- Plan for ASD services and training across the lifespan.
- Increase awareness of ASD among traditionally underserved families.

Partners in Tennessee might consider different ways to:
- Continue to lower the age of first evaluation by community providers.
- Increase awareness of need for services and intervention opportunities for the growing number of Black and Hispanic children identified with ASD.
- Work to identify opportunities and address barriers to build capacity for systems of care to meet the needs of individuals with ASD and their families.

How and where was this information collected?

TN-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in one of 11 counties in Middle Tennessee in 2018.

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

8-year-old children in tracking area: 25,237
- 63% White
- 20% Black
- 14% Hispanic
- 3% Asian or Pacific Islander
- <1% American Indian or Alaska Native

4-year-old children in tracking area: 25,335
- 64% White
- 19% Black
- 14% Hispanic
- 3% Asian or Pacific Islander
- <1% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

Resources

VANDERBILT KENNEDY CENTER (VKC)
https://vkc.vumc.org/vkc/

TREATMENT AND RESEARCH INSTITUTE FOR AUTISM SPECTRUM DISORDERS (TRIAD)
https://vkc.vumc.org/vkc/triad/home

TENNESSEE DISABILITY PATHFINDER
1-800-640-4636
https://www.tnpathfinder.org/

TENNESSEE EARLY INTERVENTION SYSTEM
1-800-852-7157
www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html

AUTISM TENNESSEE
615-270-2077
https://autismtennessee.wildapricot.org/

CDC'S LEARN THE SIGNS. ACT EARLY.
Toni Whitaker
Tennessee's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

CONNECT WITH TN-ADDM
Zachary Warren, PhD
VKC/TRIAD
110 Magnolia Circle
Nashville, TN 37203
1-877-ASD-VUMC
autismresources@vanderbilt.edu

"Year after year, we are seeing more children diagnosed with autism. The encouraging news is that these children are getting diagnosed earlier, and that is thanks to partners like Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) and all early intervention professionals across the state. The earlier the diagnosis, the quicker our providers can start working with children and their families. Together, we will help them reach their goals and these children will have the childhood they deserve. A childhood that is defined by their own greatness."

BRAD TURNER
DIDD Commissioner

A Snapshot of Autism Spectrum Disorder in

Utah

Findings from the Utah Autism and Developmental Disabilities Monitoring (UT-ADDM) program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
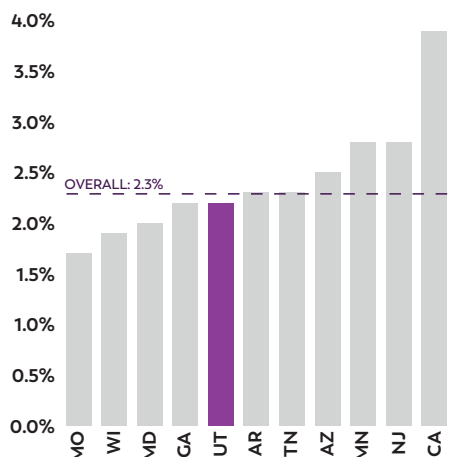
■ **SITE TRACKING AREA**

Among 8-year-olds | **Among 4-year-olds**

About 1 in 46

Or 2.2% of **8-year-old** children were identified with ASD in a three-county area in Utah by UT-ADDM in 2018

OVERALL: 2.3%

MO WI MD GA UT AR TN AZ MN NJ CA
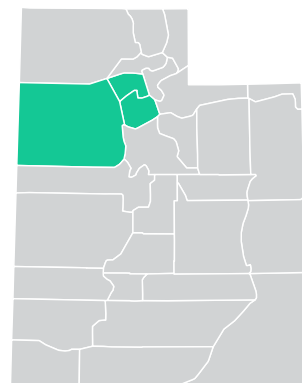
This percentage is similar to the average percentage identified with ASD (2.3%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2018.

By 54 months of age
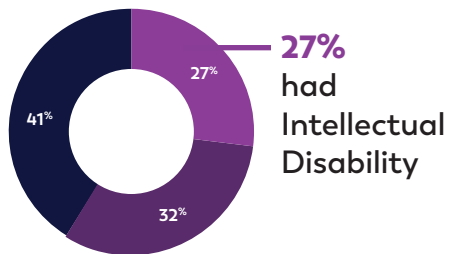
Half of **8-year-old** children identified with ASD were diagnosed

IQ data were available for 38% of 8-year-old children identified with ASD

27%

41%

32%

27% had Intellectual Disability

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

IQ SCORE ■ ≤ 70 ■ 71 - 85 ■ > 85

IQ data were available for 39% of 4-year-old children identified with ASD

41%

59%

59% had Intellectual Disability
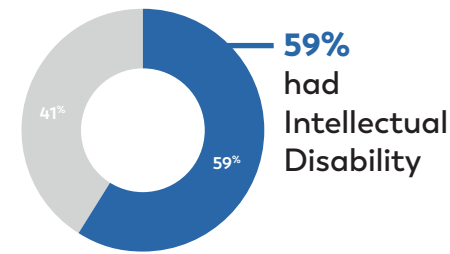
IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

IQ SCORE ■ ≤ 70

About 1 in 109

or 0.9% of **4-year-old** children were identified with ASD in a three-county area in Utah by UT-ADDM in 2018

This percentage is lower than the average percentage identified with ASD (1.7%) in all communities in the United States where CDC tracked ASD in 2018.

UT
AZ
AR
MD
MO
GA
WI
NJ
TN
MN
CA

OVERALL: 1.7%

0.0% 1.0% 2.0% 3.0% 4.0% 5.0%

8-year-old boys

Were 3.6x as likely to be identified with ASD as girls

Children who were born in 2014 were **just as likely** to be identified with ASD by 48 months of age as children born in 2010

Age
— 4 years
— 8 years

95% CI
■ 4 years
■ 8 years

ASD diagnosis or special education classification

0 12 24 36 48 60 72 84 96 108
Age in months
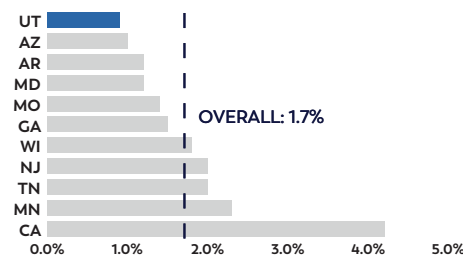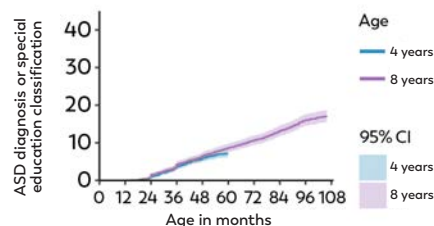
Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- UT-ADDM last participated in the ADDM Network in 2012. Utah's estimated prevalence of ASD identified among 8-year-old children increased from 1.7% in 2012 to 2.2% in 2018.
- As in 2012, ASD prevalence in 2018 was higher among non-Hispanic White than Hispanic children at age 8, but not at age 4. This difference could suggest difficulties for this population in accessing diagnostic or educational services for children who are identified after age 4, such as those less likely to have co-occurring intellectual disability.
- The percentage of children with ASD receiving an ASD diagnosis by 48 months did not differ between 4- and 8-year-olds. This provides evidence to support our pediatric community's efforts to re-evaluate ASD screening protocols and expand ASD diagnostic strategies in Utah to improve early identification of ASD.

What changes occurred between 2012 and 2018 that may have influenced changes in Utah's ASD prevalence rates?

In 2012, 2014, and 2017 the Utah legislature passed legislation that significantly reduced financial barriers to receiving autism treatment. Improving the affordability of ASD treatment may have increased access to autism services for more children to receive an ASD diagnosis.

How can this information be useful?

UT-ADDM's latest findings can be used to:
- Promote new initiatives aimed at fostering earlier identification of ASD.
- Plan for ASD services and training.
- Guide future ASD research.
- Inform policies promoting improved outcomes in health care and education for individuals with ASD.

How and where was this information collected?

UT-ADDM uses a record review method. Specifically, this information is based on the analysis of data collected from the health and special education records of children who were 4 years old and 8 years old and living in 1 of 3 counties in Utah in 2018.

Tracking area
Salt Lake, Davis, and Tooele counties

8-year-old children in tracking area: 25,459
- 71% White
- 3% Black
- 21% Hispanic
- 4% Asian or Pacific Islander
- 1% American Indian or Alaska Native

4-year-old children in tracking area: 25,064
- 71% White
- 3% Black
- 21% Hispanic
- 5% Asian or Pacific Islander
- 1% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

What else does UT-ADDM do besides provide estimates of ASD?

UT-ADDM's prevalence data are provided to our valued partners and used by them to support legislative initiatives that improve services for persons with ASD, such as the autism services legislation and the adult autism treatment program. UT-ADDM is leading projects to improve our knowledge of disparities in ASD recognition by race/ethnicity across the ADDM Network.

"We rely on Utah Registry of Autism and Developmental Disabilities (URADD) data when we advocate on behalf of families of children with autism. Our policymakers trust URADD's accuracy and reliability as they plan autism services across our state."

CHERYL SMITH
Founder and Past President, Autism Council of Utah

Resources

UTAH REGISTRY OF AUTISM AND DEVELOPMENTAL DISABILITIES (URADD)
Utah ADDM site and research center
www.medicine.utah.edu/psychiatry/research/labs/uradd/

UTAH PARENT CENTER
Support for parents of children with special needs
1-800-468-1160
www.utahparentcenter.org

AUTISM COUNCIL OF UTAH
Information and advocacy for families
autismcouncilofutah@gmail.com
www.autismcouncilofutah.org

UTAH DEPARTMENT OF HEALTH'S BUREAU OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS
Provides information about a range of services and resources
(801) 273-2800
www.health.utah.gov/cshcn/

HELP ME GROW UTAH
Information referral helpline and free screening services
(801) 691-5322
www.helpmegrowutah.org

BABY WATCH EARLY INTERVENTION
Services for children under the age of 3 years with developmental delays or disabilities
(801) 273-2800
www.utahbabywatch.org

CDC'S LEARN THE SIGNS. ACT EARLY.
Janel Preston
Utah Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

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A Snapshot of Autism Spectrum Disorder in

Wisconsin

Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help us to understand how many children have autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.
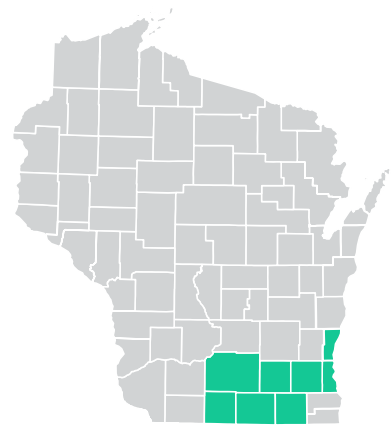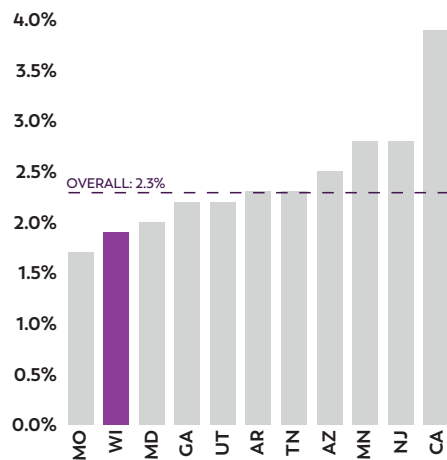
■ **SITE TRACKING AREA**

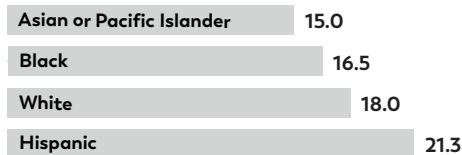**Among 8-year-olds**   **Among 4-year-olds**

About 1 in 53

Or 1.9% of **8-year-old** children were identified with ASD in WISADDS in 2018

This percentage is higher than it was in 2016 (1.7%) but still lower than the overall percentage identified with ASD (2.3%) in all communities where CDC tracked ASD among 8-year-olds in 2018.

Among 8-year-olds

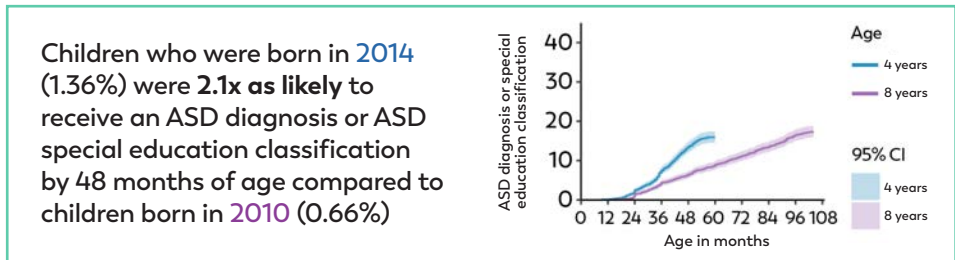ASD prevalence was similar among Black, White, Hispanic, and Asian or Pacific Islander children.

Asian or Pacific Islander	15.0
Black	16.5
White	18.0
Hispanic	21.3

Values indicate prevalence per 1,000 children.

Among 8-year-olds

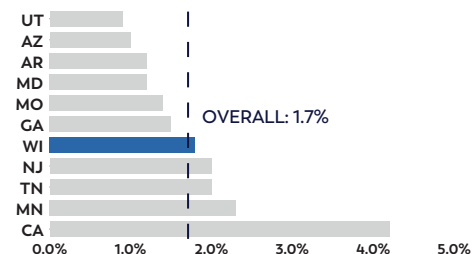**Fewer than half (48.1%)** with ASD received a comprehensive developmental evaluation by age 3 years

About 1 in 56

Or 1.8% of **4-year-old** children were identified with ASD in WISADDS in 2018

This percentage is higher than the overall percentage identified with ASD (1.7%) in all communities where CDC tracked ASD in 2018.

Among 4-year-olds

Black, Hispanic, and Asian or Pacific Islander children were respectively 1.4x, 2.4x, and 1.7x as likely to be identified with ASD as White children. Hispanic 4-year-old children were also 1.7x as likely to be identified with ASD as Black children
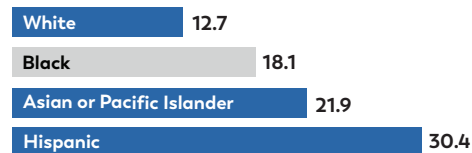
White	12.7
Black	18.1
Asian or Pacific Islander	21.9
Hispanic	30.4

Values indicate prevalence per 1,000 children.

Among both **4-year-old and 8-year-old** children, boys were **as likely as girls to be identified with ASD**

Children who were born in 2014 (1.36%) were **2.1x as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2010 (0.66%)

Cumulative incidence of ASD identified per 1000 children.

What are the key take-away messages?

- The percentage of 8-year-old children with ASD increased in southeastern Wisconsin, from 1.7% in 2016 to 1.9% in 2018.
- The prevalence of ASD has varied across racial and ethnic groups since 2002. For the first time, in 2018, the prevalence was higher for 4-year-old Hispanic children than any other group. The gap in prevalence between White and Black children narrowed.
- Regardless of age, boys are more likely to be identified with ASD than girls.
- Despite developmental concerns noted in many of the children's records by 3 years of age, only 48.1% of children identified with ASD received a comprehensive developmental evaluation by age 3 years.
- Information about cognitive functioning was available for 39.3% of children identified with ASD. Of those children, 44.7% are estimated to have intellectual disability.

How can this information be useful?

WISADDS' latest findings can be used to:

- Promote early identification of ASD.
- Plan for ASD services and training.
- Guide future ASD research.
- Inform policies promoting access to health care and education for individuals with ASD and improved outcomes over the life course.

Partners in Wisconsin might consider different ways to:

- Increase awareness of developmental monitoring and empower parents to act when there is a concern about their child's development.
- Lower the age of first evaluation by community providers.
- Increase awareness of ASD among Black and Asian communities and identify and address barriers to early evaluations and services.

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 special education records of children who were 4 years old and 8 years old and living in 1 of 8 counties in southeastern Wisconsin in 2018.

Tracking area

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

8-year-old children in tracking area: 29,664
- 57% White
- 19% Black
- 17% Hispanic
- 5% Asian or Pacific Islander
- 1% American Indian or Alaska Native

4-year-old children in tracking area: 28,689
- 59% White
- 20% Black
- 15% Hispanic
- 6% Asian or Pacific Islander
- 1% American Indian or Alaska Native

*Estimates may not sum to 100% due to rounding.

What else does WISADDS do besides provide estimates of ASD?

WISADDS collaborates with partners in Wisconsin to raise awareness about the number and characteristics of children with ASD. In addition to 8-year-olds and 4-year-olds, WISADDS conducts follow-up of outcomes at age 16. WISADDS is also engaged in training and dissemination of information related to developmental disabilities for professionals.

"The Latinx community is the largest minority and the fastest growing in the United States, yet many of their health care and social needs are not often taken into account when developing programs. Many times, programs are not developed with the collaboration of community experts and not considering the needs of this community, like language and culturally appropriate materials, particularly in the area of children with special needs. We are seeing a marked increase in the cases of autism in our community. Going forward we hope that more appropriate programs could be developed to address the needs of this vibrant community."

PATRICIA TELLEZ-GIRON, MD, Associate Professor, University of Wisconsin Department of Family Medicine and Community Health, Co-Chair of the Dane County Latino Health Council

Resources

AUTISM SOCIETY OF WISCONSIN
Information and support for families/providers
1-888-4-AUTISM
www.asw4autism.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

FINDING YOUR WAY
Guide for Wisconsin families who have children and youth with special needs and disabilities
www.ucedd.waisman.wisc.edu/fyw/

CDC'S LEARN THE SIGNS. ACT EARLY.
Kris Barnekow
Wisconsin's Act Early Ambassador
www.cdc.gov/ncbddd/actearly/ambassadors-list.html

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:
800-642-7837
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

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 (4).

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.

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.

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.

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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1. Twardzik, E., Cotto-Negrón, C., & MacDonald, M. Factors related to early intervention Part C enrollment: A systematic review. Disability and health journal. 2017; 10(4), 467–474.

2. Rosen-Reynoso M, Porche MV, Kwan N, Bethell C, Thomas V, Robertson J, Hawes E, Foley S, Palfrey J. Disparities in Access to Easy-to-Use Services for Children with Special Health Care Needs. Matern Child Health J. 2016; 20:1041-53.

3. Interagency Autism Coordinating Committee. IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2018-2019 Update. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2019/

4. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition.* Arlington, VA: American Psychiatric Association; 2013.

5. Council on Children with Disabilities; Section on Developmental Behavioral Pediatrics; Bright Futures Steering Committee; Medical Home Initiatives for Children with Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics.* 2006;118(1):405–420.

6. Hyman SL, Levy SE, Myers SM; Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics. Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics.* 2020;145(1): e20193447.