



community
report

autism

2023

AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK



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

community report on autism

2023

AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK

A Snapshot of Autism Spectrum Disorder among
4-year-old and 8-year-old Children in Multiple
Communities across the United States in 2023

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

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

Maenner MJ, Warren Z, Williams AR, et al. [Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020](#). MMWR Surveill Summ 2023, 72 (No. SS-2): 1-14.

Shaw KA, Bilder DA, McArthur D, et al. [Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020](#). MMWR Surveill Summ 2023, 72 (No. SS-1): 1-15.

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

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



Table of Contents

Executive Summary	6
Key Findings from the ADDM Network	10
A SNAPSHOT OF AUTISM SPECTRUM DISORDER IN 2020	
A Deeper Dive	13
FREQUENTLY ASKED QUESTIONS ABOUT ADDM NETWORK DATA	
Data Spotlights	16
Spotlight on “Progress in Early Identification Disrupted during the COVID-19 Pandemic among 4-year-old Children”.....	17
Spotlight on “A New Pattern in Racial and Ethnic Differences Emerges in Autism Spectrum Disorder (ASD) Identification among 8-year-old Children”.....	19
Data for Action: How Can You Use the ADDM Network Findings?	22
ADDM Network Site Snapshots	25
Overview	27
Arizona	28
Arkansas	30
California	32
Georgia	34
Maryland	36
Minnesota	38
Missouri	40
New Jersey	42
Tennessee	44
Utah	46
Wisconsin	48
Glossary	50
Community Report References	52
MMWR Reference	52

Executive Summary ● ● ● ● ● ●

The Children's Health Act of 2000 authorized the Centers for Disease Control and Prevention (CDC) to create the Autism and Developmental Disabilities Monitoring (ADDM) Network to track the number and characteristics of children with autism spectrum disorder (ASD)* and other developmental disabilities in diverse communities throughout the United States. The ADDM Network has been collecting and reporting ASD data from across the United States for more than twenty years.

Key Findings At-A-Glance

These findings are based on analysis of data collected from health and special education records of 8-year-old and 4-year-old children who lived in one of 11 different areas throughout the United States in 2020.

- ADDM Network communities reported increases in early ASD identification over time. Overall, children born in 2016 were 1.6 times as likely to receive an ASD diagnosis or ASD special education classification by 4 years of age compared to children born in 2012.
- Early ASD identification was disrupted following the start of the COVID-19 pandemic. Beginning around March 2020, children born in 2016 began to receive fewer ASD evaluations and identifications within ADDM Network communities than children born in 2012 during the same age window. **Communities can use these data to better understand how the pandemic could have affected early ASD identification among young children and anticipate future needs as these children get older.**
- The estimated percentage of 8-year-old children identified with ASD (1 in 36) continued to increase over previous years' ADDM Network estimates.
- For the first time, the percentage of 8-year-old Black, Hispanic, and Asian or Pacific Islander (A/PI) children identified with ASD was higher than among 8-year-old White children, which was the opposite of previously observed racial and ethnic differences across the ADDM Network. While this new pattern could indicate overall improvements in equitable identification of ASD, **it is important to consider other factors that may be leading to higher rates of ASD in historically under served populations.**

1 in 36

8-year-old children
identified with ASD in 2020

*Based on tracking within 11
communities in the United States



The 2023 *Community Report on Autism* highlights the ADDM Network's most recent findings on ASD in 8-year-old and 4-year-old children, based on data collected in 2020. The data analyzed in this report was collected in 11 communities across the United States. These communities also tracked and reported ASD data from 2018 which was included in the previous 2021 *Community Report on Autism*.

Early identification remains a major focus of CDC's ADDM Network, as it is one of the most important tools communities have in helping to make a difference in the lives of children with ASD. The earlier that children are identified with ASD, the earlier they can access services and supports. Prior to the COVID-19 pandemic, progress had been made in the early identification of ASD. In ADDM Network communities, children born in 2016 were 1.6 times as likely as children born in 2012 to be identified as having ASD by age 4 (48 months).

However, progress in early ASD identification declined dramatically with the start of the COVID-19 pandemic. In 2020, children with ASD born in 2016 received fewer ASD evaluations compared to children born in 2012 when they were 4 years old. Disruptions in timely evaluation of children during the pandemic could have long-lasting effects as a result of delays in the identification and initiation of services during this unprecedented time.

CDC's [Learn the Signs. Act Early.](#) Program took quick action and assessed the impact of the COVID-19 pandemic on early identification of ASD and other developmental disabilities. Act Early COVID-19 Response Teams helped to identify some promising practices to reduce the impact of the pandemic on early identification and service delivery. This included adding [Deputy Ambassadors](#) to expand access to early identification materials as well [as customized work plans](#) for individual communities.



EXECUTIVE SUMMARY

The ADDM Network continues to report overall increases in ASD prevalence estimates since monitoring began in 2000. In 2020, the ADDM Network found that 1 in 36 (2.8%) 8-year-old children were identified with ASD based on tracking within 11 communities in the United States. A higher percentage of ASD was observed for Black, Hispanic, and A/PI children than for White children, which could reflect improvements in identification among these groups, but highlights a need to understand racial and ethnic differences in ASD prevalence.

Knowing how many children have ASD is only part of the picture. ADDM data show that ASD is common across all groups of children. These findings highlight the need for timely and equitable access to [early identification and support services](#). 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 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 interventions that can help children with ASD succeed.

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—one of the most powerful tools communities have for making a difference in the lives of children with ASD.

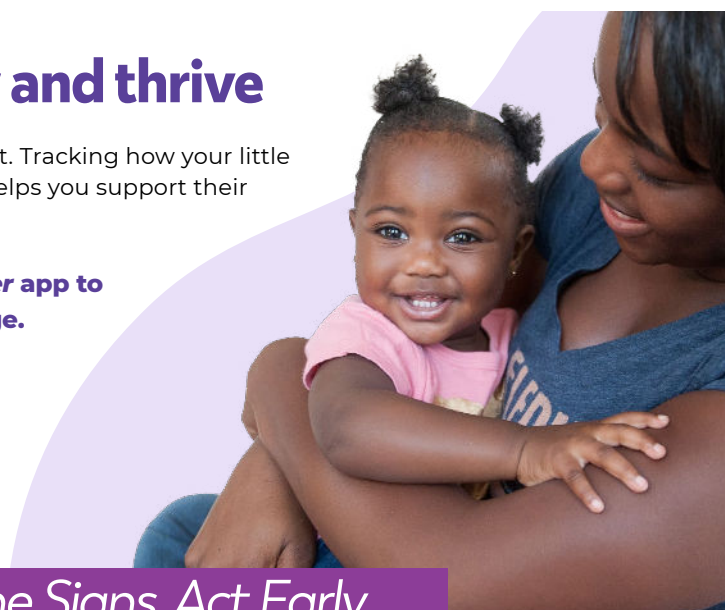
Help your child grow and thrive

Your child's early years are so very important. Tracking how your little one plays, learns, speaks, acts, and moves helps you support their development.

Download CDC's free *Milestone Tracker* app to find fun and easy activities for each age.



Learn the Signs. Act Early.



The ADDM Network's goals are to



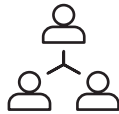
Obtain as complete a count as possible (also known as prevalence) of the number of children identified with ASD in each ADDM Network area and track changes in prevalence over time;



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 on children, families, and communities in the United States.

* CDC is aware that some members of the autism community prefer to use terms such as "person with autism," "person with ASD," "autistic person," and/or "person on the autism spectrum," while others prefer the use of other terms. CDC promotes person-first language but also promotes an awareness that language changes with time and individuals within groups sometimes have different opinions about the preferred language used to describe themselves. For the purposes of this report, the terms "autism spectrum disorder (ASD)" and "ASD" are used when referring to the DSM defined diagnosis. The terms "children with ASD" or "children identified with ASD" is also often used throughout this report in accordance with CDC guidance on person-first language.

A young child with curly hair and glasses is lying down, reading a book. The child is wearing a white t-shirt and a plaid shirt. The book has a green cover. A dark blue circular overlay is positioned in the lower-left corner, containing the title text.

Key Findings from the ADDM Network

Key Findings from the ADDM Network

A Snapshot of Autism Spectrum Disorder in 2020

Data from the Autism and Developmental Disabilities Monitoring (ADDM) Network helps 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.

There have been improvements in early ASD identification over time

More children who were born in 2016 (1.8%) received an ASD diagnosis or special education classification by 4 years of age compared with children born in 2012 (1.1%), suggesting progress in early ASD identification over time.

In 2020, children born in 2016 (4-year-olds) were **1.6 times as likely** as children born in 2012 (8-year-olds) to be identified as having ASD by 48 months of age.

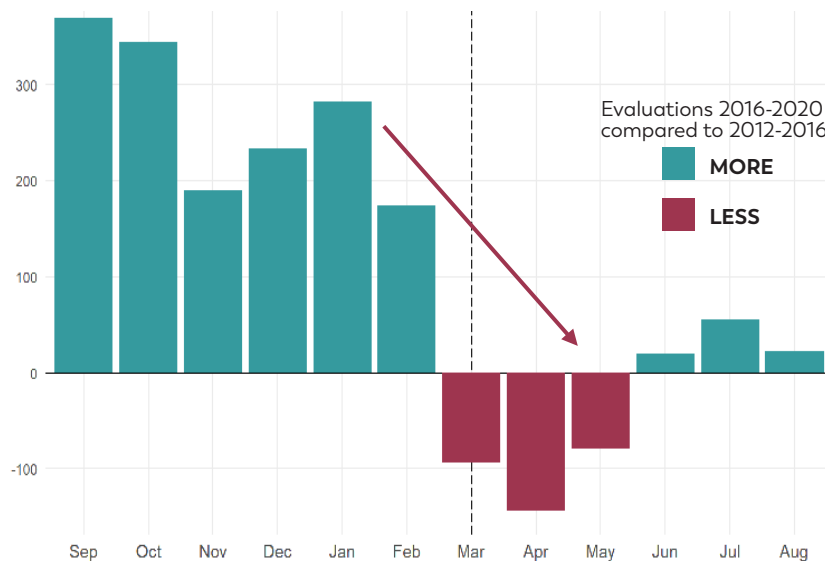
The COVID-19 pandemic impacted early ASD identification

Prior to the start of the COVID-19 pandemic, 4-year-old children were receiving more evaluations and identifications than 8-year-old children did when they were 4 years of age. However, around the start of the COVID-19 pandemic in March 2020, the rate of evaluation and ASD identification **decreased dramatically** among 4-year-old children compared with 8-year-old children when they were 4 years of age. Evaluations and ASD identification did not return to pre-pandemic levels through the end of 2020. Moving forward, it will be important to identify ways to support children who have experienced delays in early ASD identification and to improve equitable and timely access to early identification.

Children **age 4** were **1.6 times** as likely as children **age 8** to be identified as having ASD by 48 months.



From 2016 to the beginning of 2020, **4-year-old children** had more evaluations and identifications than children aged **8-years** (when they were 4) had from 2012 through 2016.



Displayed as 6 months prior and 6 months post-pandemic

How many 8-year-old children were identified with ASD in 2020?

About 1 in 36 (2.8%) 8-year-old children were identified with ASD by the ADDM Network.

The percentage of children identified with ASD varied across geographic areas in 2020

Across the ADDM Network, the percentage of 8-year-old children who were identified with ASD ranged from **2.3% or 1 in 43 children in Maryland to 4.5% or 1 in 22 children in California.** The ADDM Network monitored ASD at the same sites in 2018 and 2020, but some sites improved data access with education records available for the first times.

Certain children were more likely to be identified with ASD.

Among 8-year-old children, boys were **nearly 4 times as likely** as girls to be identified with ASD. However, 2020 marked the first time the ADDM Network found the percentage of girls identified with ASD to be **over 1%.**

Also in 2020, Black, Hispanic, and Asian or Pacific Islander children had a **higher percentage of ASD** than White children for the **first time among 8-year-olds.**

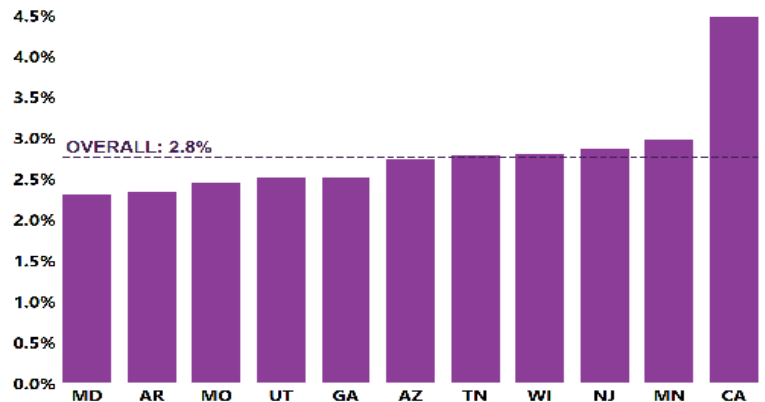
Among 8-year-old children identified with ASD who had intelligence quotient (IQ) scores available, more than one-third (37.9%) also had intellectual disability.

1 in 36

8-year-old children identified with ASD in 2020

*Based on tracking within 11 communities in the United States

Percent of 8-year-old children identified with ASD by ADDM Network Sites



For every girl identified with ASD,

Boys were nearly 4 times as likely to be identified



Black, Hispanic, and Asian or Pacific Islander children were more likely

to be identified with ASD than White children for the first time in ADDM.



Values indicate prevalence per 1,000 children

Approximately 1/3

Of 8-year-old children with ASD also had intellectual disability



A young boy with short dark hair is lying on a light-colored, textured carpet. He is wearing a striped shirt with red, blue, and green stripes. He is smiling and looking towards the camera. Several colorful paper airplanes are scattered around him on the carpet. One airplane is in the foreground, partially obscuring his face. Another is in the upper left, and others are in the upper right. The background is a plain, light-colored wall.

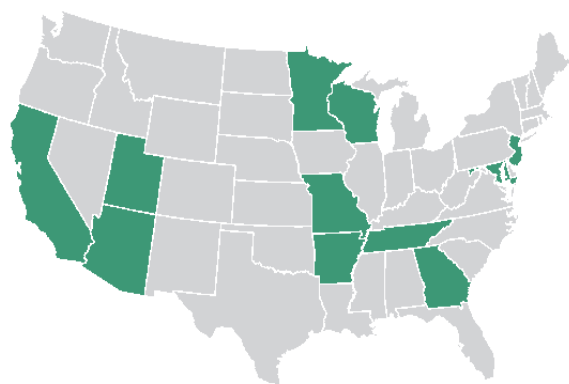
A Deeper Dive

Frequently Asked
Questions About
ADDM Network Data

A Deeper Dive

Frequently Asked Questions About the ADDM Network Data

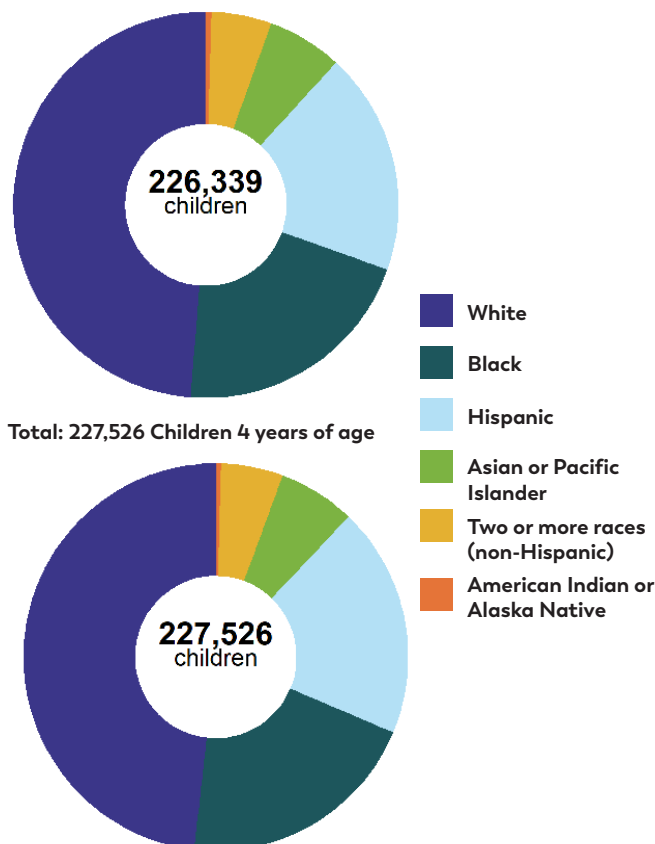
STATES WITH ADDM SITES
Surveillance Year 2020



SURVEILLANCE AMONG
4-year-olds & 8-year-olds

POPULATION BY RACE/ETHNICITY

Total: 226,339 Children 8 years of age



How was this information collected?

The ADDM Network uses a systematic record review method. Specifically, the information reported by the ADDM Network is based on the analysis of data collected from the health and special education records of 4-year-old and 8-year-old children who lived in one of 11 different areas throughout the United States in 2020. In 2018, CDC updated and simplified the way the ADDM Network collects and reviews data, resulting in faster publication of these data.

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

2020 Tracking area: specific sites in Arizona, Arkansas, California, Georgia, Maryland, Minnesota, Missouri, New Jersey, Tennessee, Utah, and Wisconsin (see "Site pages" for more information)

Population of 8-year-old children in tracking area: 226,339

- 49% White
- 21% Black
- 19% Hispanic
- 6% Asian or Pacific Islander
- 1% American Indian or Alaska Native
- 5% Two or more races (non-Hispanic)

Population of 4-year-old children in tracking area: 227,526

- 48% White
- 20% Black
- 19% Hispanic
- 6% Asian or Pacific Islander
- Less than 1% American Indian or Alaska Native
- 5% Two or more races (non-Hispanic)

What is the key message?

The COVID-19 pandemic brought disruptions to early ASD identification among young children. These disruptions may have long-lasting effects as a result of delays in identification and initiation of services. Communities could benefit from assessing local disruptions and continued monitoring of access to evaluation and support services for all children. ADDM data show that ASD is common across all groups of children. These findings highlight the need for timely and equitable access to [early identification and support services](#).

Why was the percentage of children identified with ASD higher in some areas than in 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 and diagnostic practices. 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 do the ADDM ASD percentage estimates differ from other ASD percentage 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

Progress in Early Identification Disrupted during the COVID-19 Pandemic among 4-year-old Children

The ADDM Network found evidence of progress in early identification among children born in 2016 compared with children born in 2012, but evaluations were disrupted after the onset of the COVID-19 pandemic.

Key Findings from the ADDM Network

More children are being identified with ASD at an earlier age

Overall, progress has been made in the early identification of ASD. In 2020, children born in 2016 (4-year-olds) were **1.6 times as likely** as children born in 2012 (8-year-olds) to be identified as having ASD by 48 months of age. This is important because the earlier a child is identified with ASD, the earlier they can access services and support.

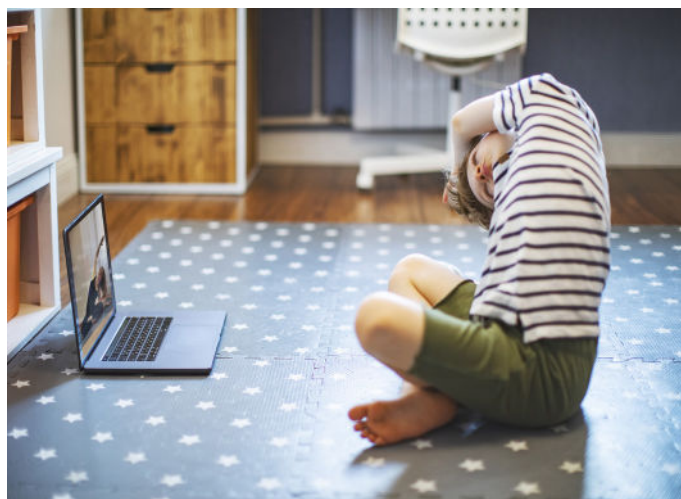
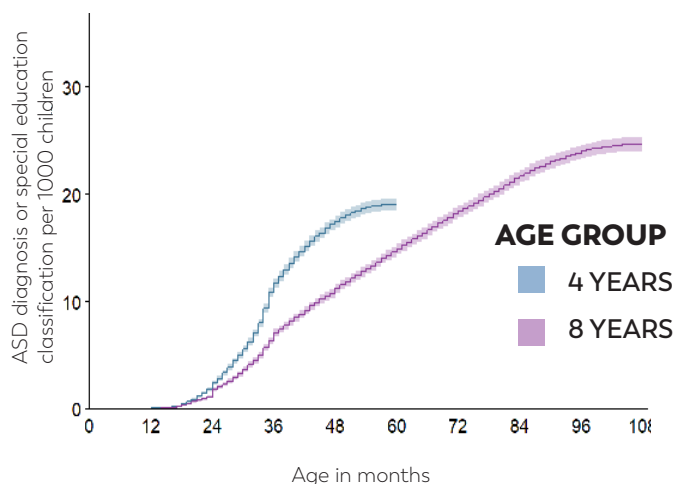
These patterns are consistent with previous reports and may indicate improvements in practices among families, healthcare providers, and educators to evaluate and identify children with ASD early.

COVID-19 disrupted progress in early ASD identification leading to a potential backlog of unidentified cases

Beginning around March 2020, children born in 2016 began to receive fewer evaluations and ASD identifications within ADDM Network communities compared to children born in 2012 during the same age window. Delays in evaluation could have long-lasting effects as a result of delays in identification and initiation of services during the COVID-19 pandemic.

Communities could benefit from evaluating the impact of these disruptions, children who may have experienced delays in evaluation and ASD identification, and considering strategies to lessen service disruptions and longer-term effects during public health emergencies in the future.

More children are being identified with ASD by 48 months



Tracking ASD among 4-year-old children

Understanding more about the characteristics of children with ASD, such as age of diagnosis and intellectual ability, helps us identify areas where progress has been made in early identification and areas where there are still opportunities for improvements.

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 that can help determine if there might be a delay. The [American Academy of Pediatrics](http://AmericanAcademyofPediatrics.org) recommends screening children for ASD at 18 and 24 months of age.
3. **A comprehensive developmental evaluation** is a thorough review of how a child plays, learns, communicates, acts, and moves, and whether those characteristics have changed over time. Various professionals can conduct developmental evaluations, including teachers, social workers, nurses, psychologists, doctors, physical therapists, 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 developmental evaluation to determine whether a child has ASD. Neurological and genetic testing can often rule out 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.

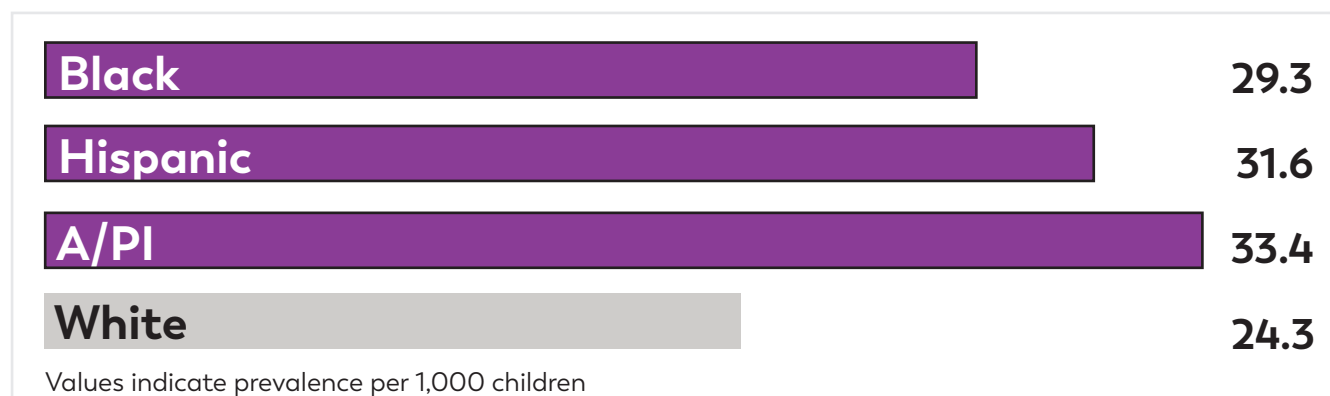


Spotlight On

A New Pattern in Racial and Ethnic Differences Emerges in Autism Spectrum Disorder (ASD)

Identification among 8-year-old Children

For the first time, the ADDM Network data found the percentage of 8-year-old children identified with ASD was higher among Black, Hispanic, and Asian or Pacific Islander (A/PI) children compared with White children.



Prior to 2016, the percentage of children identified with ASD by 8 years of age was higher among White children than among Black or Hispanic children. In recent years, differences in identification of ASD by race and ethnicity began to narrow. In fact, in 2018, there was no overall difference observed in the percentage of A/PI, Black, Hispanic, or White children identified with ASD by 8 years of age.

Also in 2018, a new pattern emerged in racial and ethnic differences among younger children, where the percentage of Black and Hispanic 4-year-old children identified with ASD was higher compared with White children aged 4 years. This pattern continued in 2020 among 4-year-old children and was seen for the first time among 8-year-old children.



These findings may indicate improvements in ASD awareness, identification, and access to services in communities serving Black, Hispanic, and A/PI children. If these findings do reflect improved identification among historically under served populations, it may be helpful to examine factors, such as social determinants of health, that could lead to higher rates of disability.

Reported differences in intellectual ability continue across ADDM sites

Intellectual disability (ID*) is often seen in children with ASD and can affect a person's ability to learn at an expected level and function in daily life. **Among 8-year-old children with ASD, more than one third (37.9%) also had ID**

On average, 8 year-old children with ID were diagnosed with ASD earlier than those without ID [age by which half of ASD diagnoses occurred: 43 months (with ID) versus 53 months (without ID)].

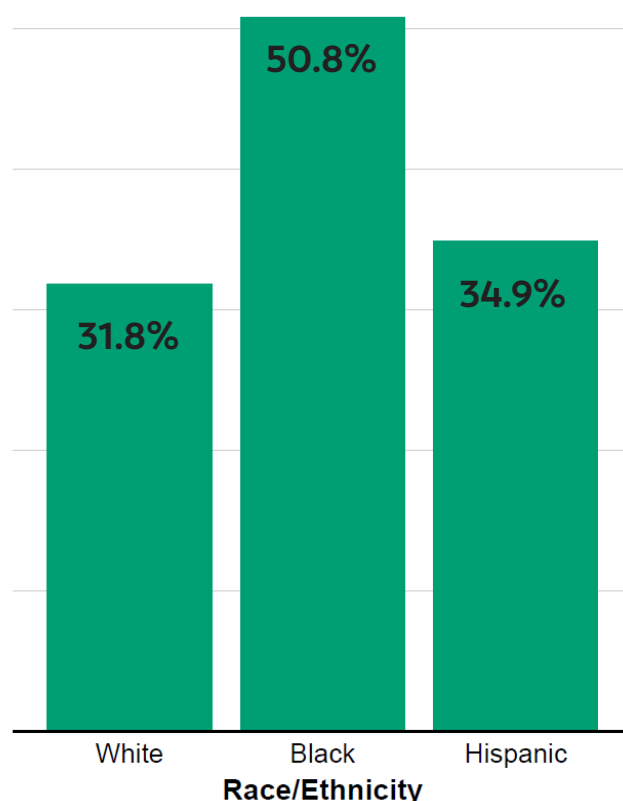
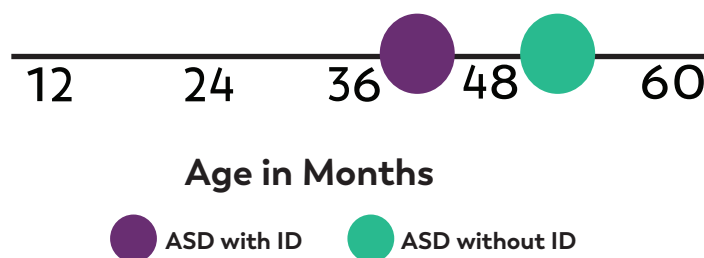
Although progress has been made in the identification of ASD among children of all races and ethnicities, concerns remain around the percentage of **Black children identified with ASD who also had ID (50.8% among 8-year-olds)**. This percentage is higher than for Hispanic (34.9%) or White (31.8%) children and remains consistent with previous reports from the ADDM Network.



Children with ASD and ID



*Intellectual disability (ID) = IQ \leq 70



Future Directions

The ADDM Network will continue to monitor the number and characteristics of children with ASD over time. States and communities have the potential to turn this ADDM Network data into action.

Data can provide early awareness of important public health trends, such as the new pattern in racial and ethnic differences which was first observed in 2018 among 4-year-old children identified with ASD and has since emerged in older children (8-year-olds). With this information, states and communities can plan and develop strategies to promote awareness and improve identification of ASD and referral to services.

More work is also needed to understand why the ADDM Network continues to find a higher percentage of Black children identified with ASD and ID when compared to other racial and ethnic groups. The continued increase in children identified with ASD—particularly among Black, Hispanic, and A/PI children and among girls—highlights the importance of equitable diagnostic, treatment, and support services for all children with ASD. Like previous reporting periods, there were considerable differences in findings across network sites, suggesting the need for more research to understand the reason for such differences and to develop successful identification strategies that can be applied across states.



ADDM Network Data for Action

Data for Action

How can the ADDM Network Findings Be Used?

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 (2).
- Inform and promote early identification efforts.
- ADDM Network findings on age of diagnosis of ASD support CDC's [Learn the Signs. Act Early.](#) Program, which aims to improve early identification by promoting early childhood developmental monitoring by parents, childcare providers, and healthcare providers.
- Improve developmental monitoring, a critical step in the early identification of developmental delays.
- Plan for resource and service needs.
- Target outreach to communities with higher rates of ASD and those living in low-income neighborhoods.

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 that 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.
- Assess current service needs following disruptions in evaluations and services during the COVID-19 pandemic.

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

- Promote early identification efforts for developmental concerns in children and help get those children diagnosed with ASD enroll in community-based support systems as soon as possible.
- 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



- Study the long-term impact of COVID-19 on ASD evaluation and early identification and consider strategies to lessen service disruptions during future public health.
- Strengthen community infrastructure to provide equitable diagnostic, treatment, and support services for all children with ASD.
- Develop standard tools for measuring and documenting abilities and challenges among children with ASD.
- Identify risk or protective factors leading to differences in intellectual ability among children with ASD.

Researchers can use this information to

- 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.

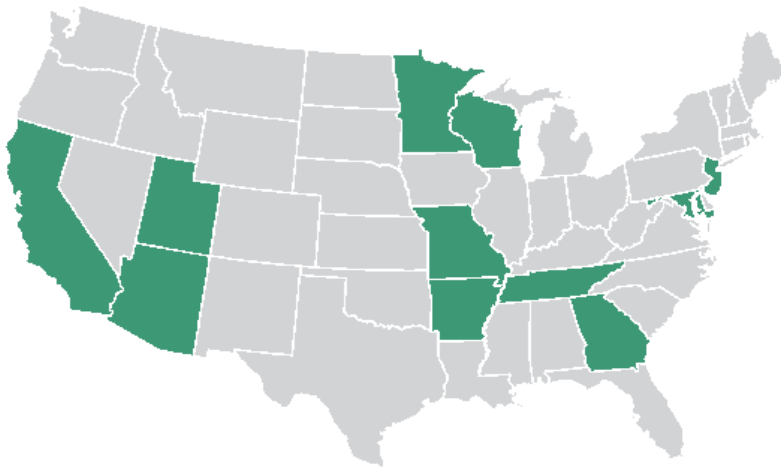
A young child with dark, curly hair is looking upwards and to the right. The child is wearing a grey long-sleeved shirt. A large green circle is overlaid on the bottom half of the image, containing white text. The background is blurred, showing what appears to be a living room with a couch and a plant.

ADDM Network Site Snapshots

ADDM Network Site Snapshots

A Snapshot of Autism Spectrum Disorder in 2020

The Autism and Developmental Disabilities Monitoring (ADDM) Network tracked ASD at sites within these states in 2020.



SURVEILLANCE AMONG

4-year-olds & 8-year-olds

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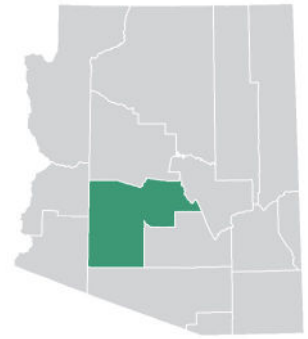
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NOTE: Although these 11 states host the ADDM Network Sites, the entire state is not necessarily included in the tracked area. Please see individual ADDM Network site pages for a closer look at the specific sites.

A Snapshot of Autism Spectrum Disorder in Arizona

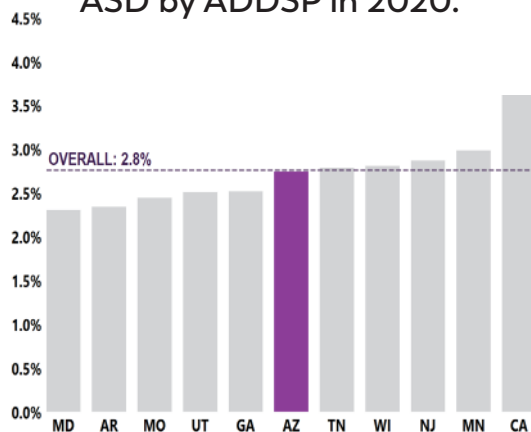
Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

1 in 36

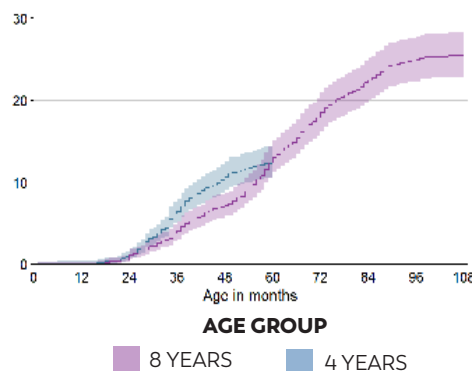
Or 2.7% of 8-year-old children were identified with ASD by ADDSP in 2020.



This percentage is similar to the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

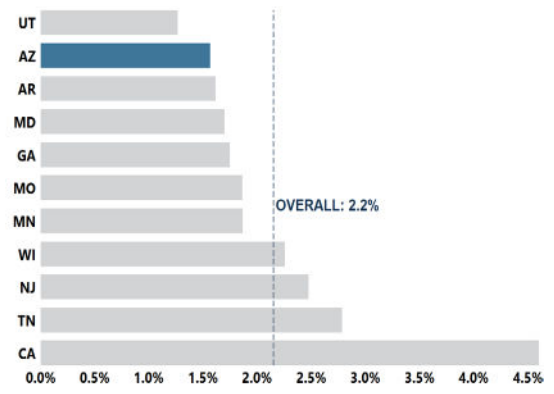
By 48 months

Children who were age 4 years (1.1%) were 1.5 times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children who were age 8 years (0.72%).



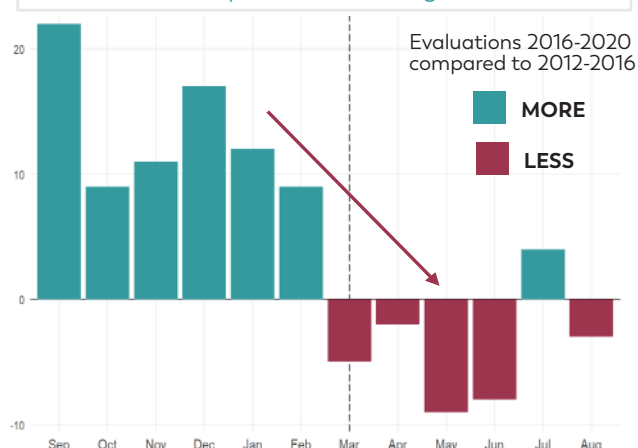
1 in 64

Or 1.6% of 4-year-old children were identified with ASD by ADDSP in 2020.



This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities where CDC tracked ASD among 4-year-olds in 2020

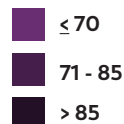
The COVID-19 pandemic disrupted many aspects of life, including the ability to evaluate children for ASD. In the early months of the pandemic, 4-year-old children were less likely to have an evaluation than 8-year-old children when they were the same age.



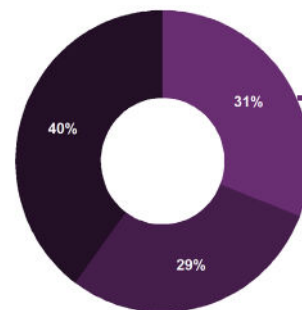
IQ data available for 81%

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

IQ SCORE



IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70



31% had Intellectual Disability

8 year-old boys were 4.3x and 4 year-old boys were 3.5x as likely as girls to be identified with ASD



What are the key take-away messages from Arizona's data?

- More children with average intelligence are being identified with ASD since ADDSP began tracking in 2000.
- As has been seen in previous years, the percentage of boys identified with ASD is higher than the percentage of 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.
- Inform efforts to improve screening tools for ASD.
- Improve screening tools to increase accuracy of screening for ASD.
- Improve collaborations in the ASD community among providers, researchers, and families.

Where was this information collected?

8-year-old children in tracking area: 13,118 **4-year-old children in tracking area: 13,349**

- | | |
|---------------------------------------|---------------------------------------|
| • 40% White | • 38% White |
| • 7% Black | • 7% Black |
| • 42% Hispanic | • 44% Hispanic |
| • 3% Asian or Pacific Islander | • 3% Asian or Pacific Islander |
| • 3% American Indian or Alaska Native | • 3% American Indian or Alaska Native |

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 2020.

What else does ADDSP do besides provide estimates of ASD?

ADDSP collaborates with the Arizona Department of Health Services and scholars from the University of Arizona to track the percentage and characteristics of 4-year-old and 8-year-old children with ASD. ADDSP also provides extensive ASD and developmental disabilities-related outreach to 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.

"Before this surveillance initiative focused our collective attention on autism, prevalence was extremely underestimated. Since its inception, though, it has most certainly encouraged healthcare professionals and community members alike to better monitor autism in the U.S. The trends we see through data collected, continue to create awareness and urgency, as well as, add a watchful lens on the significant changes in our healthcare systems — like revisions in diagnostic criteria, or efforts to improve early detection and screening. But perhaps most important, surveillance has shown us there is an substantial need within our community for added support, resources and awareness."

CHRISTOPHER SMITH, PhD

Southwest Autism Research and Resource Center (SARRC).

Resources

GET RESOURCES AND CONNECT FAMILIES TO SERVICES AND SUPPORT IN ARIZONA

ARIZONA AUTISM COALITION

www.azautism.org

ARIZONA EARLY INTERVENTION PROGRAM

602-542-4446

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

AZ FIND

978-637-1871

www.azed.gov/special-education/az-find/

AZA UNITED

602-773-5773

www.azaunited.org/

CDC'S LEARN THE SIGNS. ACT EARLY.

Megan Wills

Arizona's Act Early Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

RAISING SPECIAL KIDS

602-242-4366

www.raisingpecialkids.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

Sydney Pettygrove, PhD

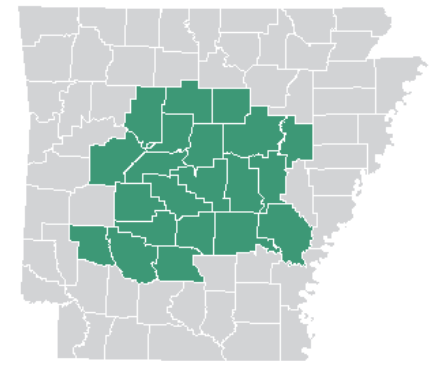
University of Arizona Health

Sciences Center

sydneyp@arizona.edu

A Snapshot of Autism Spectrum Disorder in Arkansas

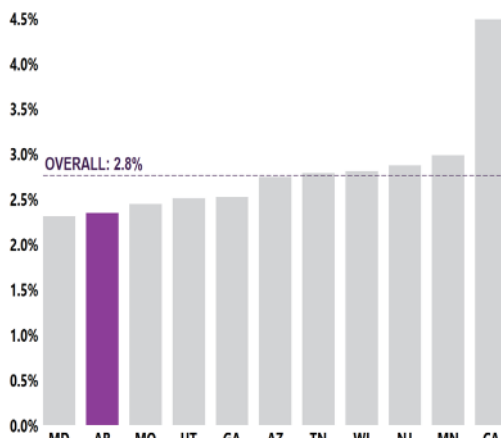
Findings from the Arkansas Autism and Developmental Disabilities Monitoring (AR-ADDN) Program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



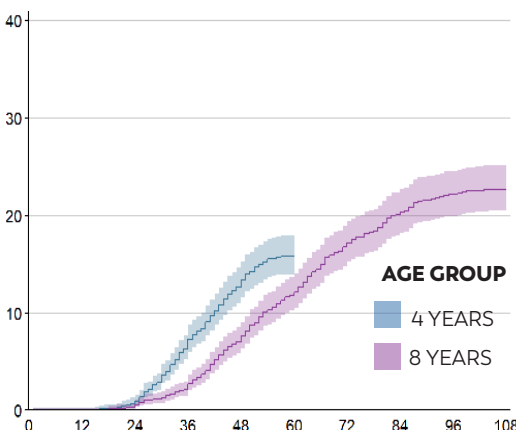
SITE TRACKING AREA

1 in 43

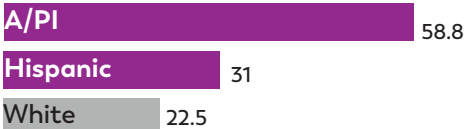
Or **2.4%** of 8-year-old children identified with ASD by AR-ADDN in 2020.



This percentage is slightly lower than the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.



Among **8-year-olds**, Asian/Pacific Islander (A/PI) and Hispanic children were 2.6 times as likely and children were 1.4 times as likely to be identified with ASD as White children.

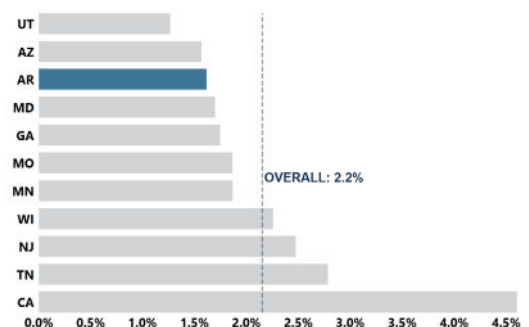


Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between White and Black 8-year-olds.

Among **4-year-olds**, Black children were 1.6 times as likely to be identified with ASD as White children.



About **1 in 62** or 1.6% of 4-year-old children were identified with ASD by AR-ADDN in 2020.



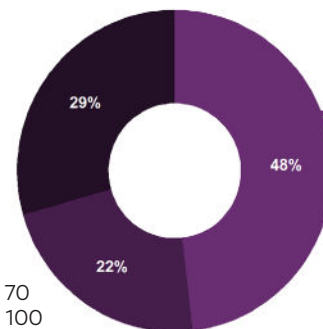
This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities where CDC tracked ASD among 4-year-olds in 2020.

IQ data available for 91% of 8-year-old children identified with ASD by AR-ADDN

IQ SCORE*

- ≤ 70
- 71 - 85
- > 85

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



48% had Intellectual Disability

By 48 months

Children who were **age 4** years were 1.8 times as likely to be identified with ASD by 48 months of age as **children who were age 8 years**.

About 88% of 4-year-old children

identified with ASD received a comprehensive developmental evaluation by 3 years of age.



What are the key take-away messages from Arkansas data?

- More children were identified with ASD in 2020 than in previous AR-ADDM and ADDM Network data.
- Children who were age 4 years in 2020 were more likely to be identified with ASD by 48 months of age than children who were age 8 years, indicating improvements in early identification of ASD.

How can this information be useful?

AR-ADDM's latest findings can be used to

- Promote early identification of ASD.
- Plan for ASD services and training.
- Guide future ASD research
- 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 2020.

8-year-old children in tracking area: 15,432 4-year-old children in tracking area: 15,387

- | | |
|--------------------------------|--------------------------------|
| • 61% White | • 60% White |
| • 24% Black | • 24% Black |
| • 9% Hispanic | • 10% Hispanic |
| • 1% Asian or Pacific Islander | • 1% Asian or Pacific Islander |
| • 4% Multiracial | • 5% Multiracial |

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 continue tracking the number and characteristics of 8-year-olds and 4-year-olds with ASD, as well as identifying characteristics of 16-year-olds with ASD.

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 early identification and reduce disparities among children with ASD and other developmental disabilities.

"I've taught language difficulties and disorders to undergraduate and graduate students who are interested in speech language pathology. Autism Spectrum Disorder is one of the major areas I cover in class. I start my class with the ADDM report that provides reliable and valuable information on ASD and other developmental disabilities. As a clinician, professor, and researcher, I appreciate what ADDM has been doing for our community."

SUNJUNG KIM THAO, Ph.D., CCC-SLP,
University of Central Arkansas Department of Communication Sciences and Disorders

Resources

GET RESOURCES AND CONNECT FAMILIES TO SERVICES AND SUPPORT IN ARKANSAS

FIRST CONNECTIONS

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

1-800-643-8258

<https://dhs.arkansas.gov/dds/firstconnectionsweb/#fc-home>

DEPARTMENT OF EDUCATION'S SPECIAL EDUCATION UNIT

Special education services for school-aged children with disabilities

1-800-482-8437

<https://dese.ade.arkansas.gov/Offices/special-education>

ARKANSAS AUTISM RESOURCE AND OUTREACH CENTER

Support, education, and advocacy for families of individuals with ASD

1-800-342-2923 | aarc.org

UAMS DENNIS DEVELOPMENTAL CENTER

Diagnostic and other services for children with developmental delays and other disabilities

501-364-1830

<https://medicine.uams.edu/pediatrics/specialties/programs/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

<https://uofapartners.uark.edu/projects/autism-partnership/>

HEALTHY CHILD CARE ARKANSAS

Training for child care providers in topics related to the overall well-being of children

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

COMMUNITY-BASED AUTISM LIAISON AND TREATMENT (COBALT) PROJECT

Comprehensive diagnostic assessments, early intervention services, and family support

<https://cobaltar.org/>

CDC'S LEARN THE SIGNS. ACT EARLY.

Alan Mease, Arkansas' Act Early Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

CONNECT WITH AR-ADDM

Allison Edwards Hudson

Research Program Manager

University of Arkansas for Medical Sciences,
Developmental Pediatrics- Little Rock, AR

aehudson@uams.edu

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

A Snapshot of Autism Spectrum Disorder in California

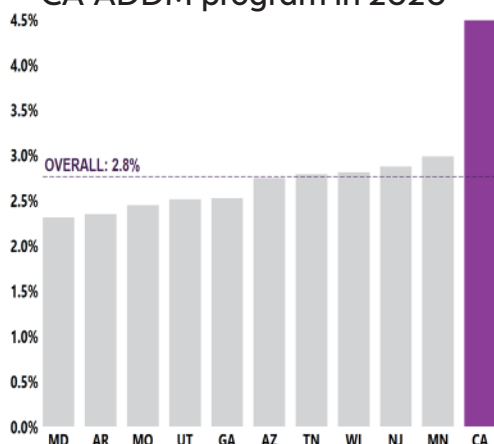
Findings from the California Autism and Developmental Disabilities Monitoring (CA-ADDMM) program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

1 in 22

Or 4.5% of 8-year-old children were identified with ASD by the CA-ADDMM program in 2020

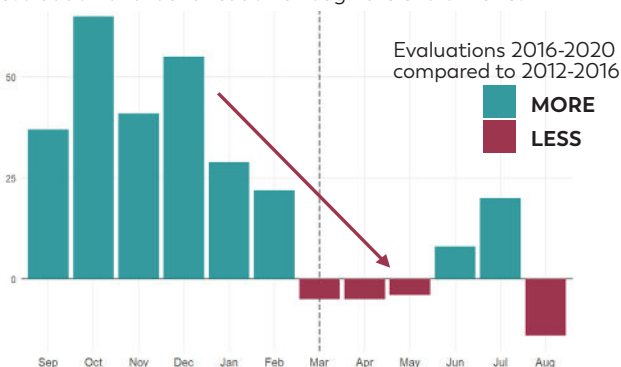


This percentage is higher than the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

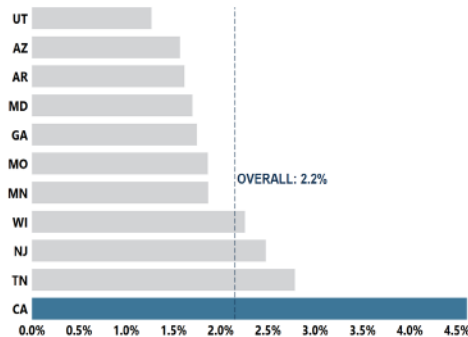
From 2016 through the beginning of 2020, 4-year-old children had more evaluations and identifications than the cohort aged 8 years had from 2012 through 2016.

The pandemic onset in March 2020 coincided with a stark drop-off in evaluations and identifications.

California experienced sustained drops in both evaluation and identification through the end of 2020.



About 1 in 22 or 4.6% of 4-year-old children were identified with ASD by the CA-ADDMM program in 2020.



This percentage is higher than the average percentage identified with ASD (2.2%) in all communities where CDC tracked ASD among 4-year-olds in 2020.

The median age of diagnosis for 8-year-old children in California was 36 months.

The median age of diagnosis was younger in CA-ADDMM than the average median age of diagnosis in all communities in the US where CDC tracked ASD in 2020 (49 months).

Asian/Pacific Islander 8-year-old children were 1.5 times as likely to be identified with ASD as White children.

A/PI 56.5

White 38.3

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

White 4-year-old children were less likely to be identified with ASD than other races and/or ethnicities.

White 31

Black 54.3

Hispanic 52.8

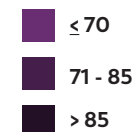
A/PI 45.5

Values indicate prevalence per 1000.

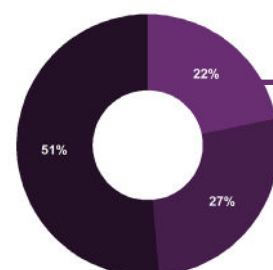
IQ data available for 87%

Of children identified with ASD by the CA-ADDMM Project

IQ SCORE



IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70



22% had Intellectual Disability

What are the key take-away messages from California data?

- 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 than in 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 than in other sites.
- Among 4-year-olds, White children were less likely to be identified with ASD than children of other races and/or ethnicities.
- Among 8-year-olds, Asian/Pacific Islander children were more likely to be identified with ASD than White, Hispanic, and multiracial children. There were no other differences in the number of 8-year-old children identified with ASD across racial and ethnic groups.
- Differences continue to persist in the proportion of boys and girls identified with ASD. However, these differences have decreased compared with previous years and may reflect differences in screening and diagnostic patterns.

How can this information be useful?

CA-ADDM latest findings can be used to

- Promote and track patterns in 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
- 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.
- Develop supports and services across the lifespan of individuals to better support the increasing number of children with ASD as they transition into adulthood and beyond.

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, early intervention, and special education records of children who were 4 years old and 8 years old and living in parts of San Diego County in 2020.

8-year-old children in tracking area: 15,828 4-year-old children in tracking area: 16,719*

- | | |
|--|--|
| • 23% White | • 26% White |
| • 7% Black | • 7% Black |
| • 49% Hispanic | • 47% Hispanic |
| • 12% Asian or Pacific Islander | • 12% Asian or Pacific Islander |
| • <1% American Indian or Alaska Native | • <1% American Indian or Alaska Native |
| • 8% Multiracial | • 8% Multiracial |

*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 helps us understand the impact we make on our community in many ways, such as by revealing the total percentage of children and families that are accessing supports. We are also able to examine possible disparities in service uptake between children from different demographic groups and use this knowledge to continue to refine and improve what we do. We are able to share the full extent of the impact of SDRC programs and services with our staff as well as local and state level policy makers to grow as an agency and provide the best possible care for children with autism and their families."

Kathy Karins, RN
Director of Clinical Services, San Diego Regional Center

Resources

GET RESOURCES AND CONNECT FAMILIES TO SERVICES AND SUPPORT IN CALIFORNIA

DEPARTMENT OF DEVELOPMENTAL SERVICES REGIONAL CENTERS

916-654-1690

<https://www.dds.ca.gov/rc/>

CALIFORNIA EARLY START

800-515-2229

<https://www.dds.ca.gov/services/early-start/>

FIRST FIVE CALIFORNIA

916-263-1050

<https://www.cffc.ca.gov/>

DEPARTMENT OF EDUCATION SPECIALIZED PROGRAMS

916-445-4613

<https://www.cde.ca.gov/sp/>

UC SAN DIEGO AUTISM CENTER OF EXCELLENCE

858-534-6912

<https://neurosciences.ucsd.edu/centers-programs/autism/index.html>

NATIONAL FOUNDATION FOR AUTISM RESEARCH

858-679-8800

<https://www.nfar.org/what-we-do/parent-programs>

CDC'S LEARN THE SIGNS. ACT EARLY.

Patricia Moore

Michele Rogers

CA Act Early Ambassadors

<https://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

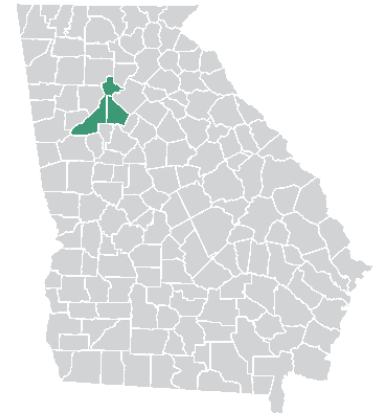
La Jolla, CA 92037

858-534-6912

kpierce@health.ucsd.edu

A Snapshot of Autism Spectrum Disorder in Georgia

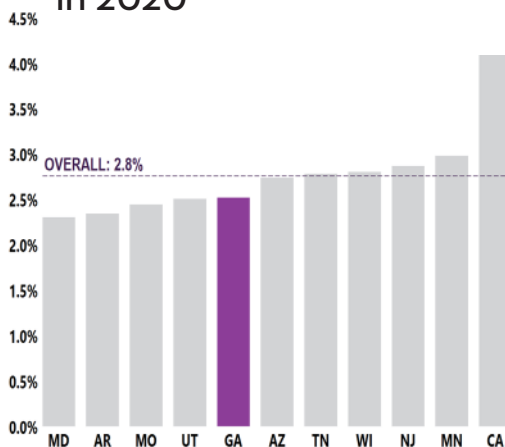
Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

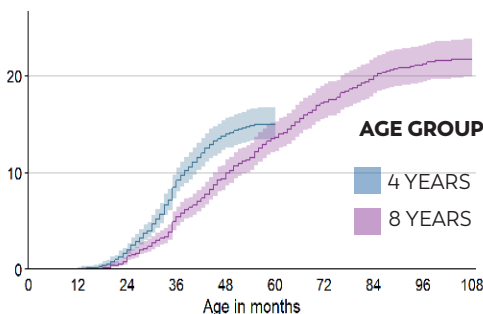
1 in 40

Or **2.5%** of 8-year-old children were identified with ASD by MADDSP in 2020



This percentage is similar to the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

Children who were age **4 years** were **1.4** times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared with children age **8 years**.

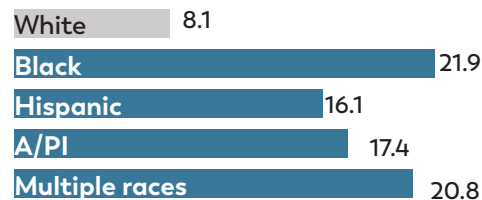


Among **8-year-olds**, Black children were 1.5 times more likely to be identified with ASD as White children.



Values indicate prevalence per 1000. There were no significant differences in identification between other races or ethnicities.

Children in other racial/ethnic groups were 2 or more times as likely to be identified with ASD compared to White children at age 4 years.



Values indicate prevalence per 1000

47% of 8-year-old children identified with ASD received a comprehensive developmental evaluation by 3 years of age.



Children who were age **8 years** with both **ASD** and **ID** were identified earlier

36 months

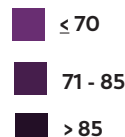
than children with ASD who didn't have ID.

40 months

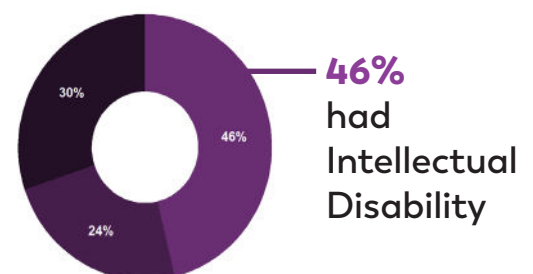
IQ data available for 72%

Of children identified with ASD by MADDSP

IQ SCORE



IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70



46% had Intellectual Disability

What are the key take-away messages from MADDSP?

- Children who were age 4 years in 2020 were 1.4 times as likely to receive an ASD diagnosis or ASD special education classification by age 48 months than children age 8 in 2020. This suggests progress in early identification of ASD.
- White children are less likely to be identified with ASD than Black children at age 8 years, but rates were similar by all other racial/ethnic groups. This is a change from surveillance year 2018 findings, which showed lower prevalence of ASD among Hispanic and Asian/Pacific Islander children

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

Partners in Georgia might consider different ways to

- 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 or 8 years old and living in either DeKalb or Fulton county in Georgia in 2020.

8-year-old children in tracking area: 21,921

- 26% non-Hispanic White
- 51% non-Hispanic Black
- 12% Hispanic
- 7% Asian or Pacific Islander
- 4% Multiracial

4-year-old children in tracking area: 21,985

- 26% non-Hispanic White
- 49% non-Hispanic Black
- 12% Hispanic
- 9% Asian or Pacific Islander
- 4% Multiracial

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

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

"As an occupational therapist in Atlanta, the research conducted by CDC's ADDM Network is crucial in our field. We rely on current information for therapy and program development for individuals with autism. The data provided by ADDM provides valuable information about autism that can help clinicians better understand and address the needs of individuals with autism and their families." -

AMITY STEVENS, MS, OTR/L, CAS

Owner/Occupational Therapist OT on the Go, LLC
(Certified Autism Specialist)

Resources

GET RESOURCES AND CONNECT FAMILIES TO SERVICES AND SUPPORT IN GEORGIA

ATLANTA AUTISM CONSORTIUM

Support for collaboration among families, researchers, clinicians, educators, and advocates

www.atlantaautismconsortium.org/

AUTISM SOCIETY OF GEORGIA

Information and support for families/providers

1-844-404-ASGa

www.autismsocietyga.org

AUTISM SPEAKS

Information and resources for families
770-451-0570

www.autismspeaks.org/georgia-0

BABIES CAN'T WAIT

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

1-888-777-4041

dph.georgia.gov/Babies-Cant-Wait

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.

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

Bridget Ratajczak

GA Act EarLY Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

CONNECT WITH MADDSP

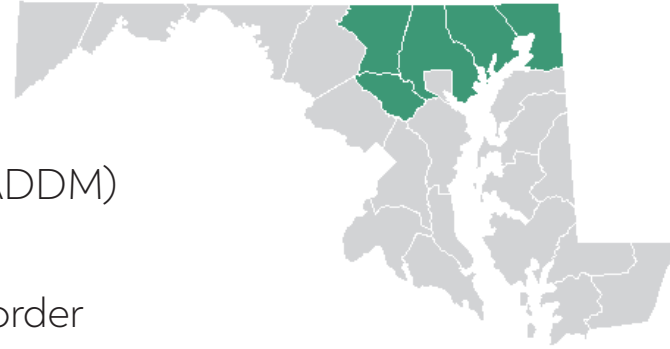
ADDM@cdc.gov

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

A Snapshot of Autism Spectrum Disorder in Maryland

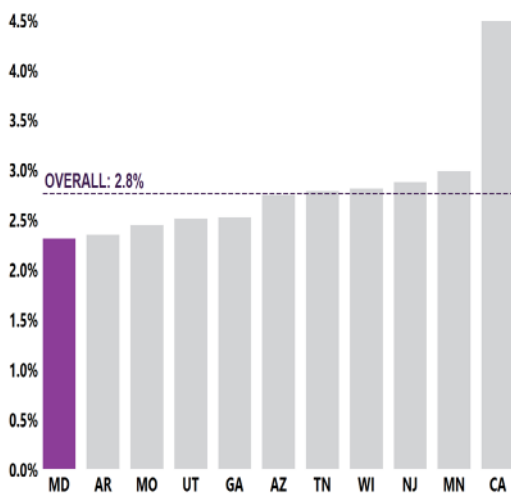
Findings from the Maryland Autism and Developmental Disabilities Monitoring (MD-ADDMM) program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

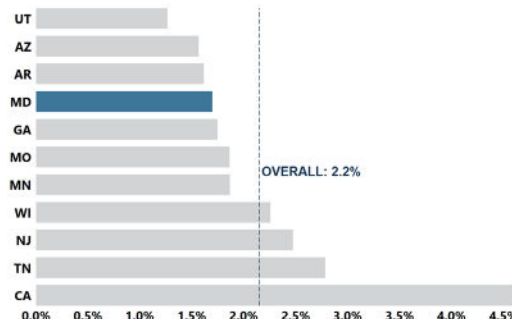
1 in 43

Or **2.3%** of 8-year-old children were identified with ASD in 2020



This percentage is lower than the overall percentage identified with ASD (2.8%) in all communities tracked by the CDC.

About 1 in 59 or 1.7% of 4-year-old children were identified with ASD in 2020.

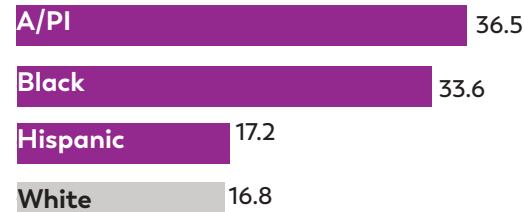


This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities tracked by the CDC.

About 83% of 4-year-old children identified with ASD received a comprehensive developmental evaluation by 3 years of age.

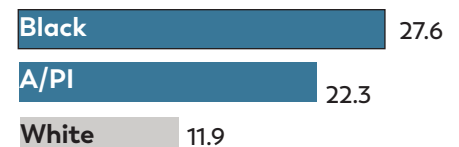


Among 8 year-olds, Asian/Pacific Islander (A/PI) and Black children were twice as likely to be identified with ASD as Hispanic and White children.



Values indicate prevalence per 1000.

Among 4-year-olds, Black children were 2.3 times as likely and Asian/Pacific Islander (A/PI) children were 1.9 times as likely to be identified with ASD as White children.



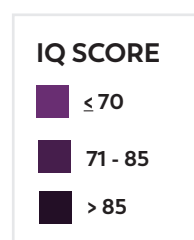
Values indicate prevalence per 1000. There were no significant differences in identification between Hispanic children and White children.

About 60% of 8-year-old children identified with ASD received a Comprehensive Developmental Evaluation by age 3 years. This is a 11% decrease from 2018.

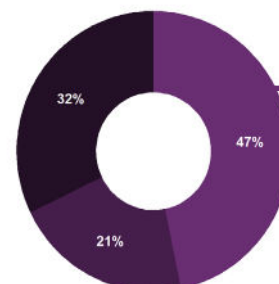


IQ data available for 60%

Of children identified with ASD by the MD-ADDMM Project



IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70



46.6% had Intellectual Disability

What are the key take-away messages Maryland data?

- The prevalence of ASD in MD-ADDM continues to increase.
- Following the onset of COVID-19 in March 2020, there was a reduction in the number of evaluations in all ADDM communities, including MD-ADDM.
- Black and Asian/Pacific Islander children are more likely to be identified with ASD than White children in MD-ADDM.
- Most 4-year-old and 8-year-old children identified with ASD in MD-ADDM had a comprehensive evaluation by age 3 years, but more 4-year-old children had one compared with 8-year-olds.

How can this information be useful?

MD-ADDM's latest findings can be used to

- Promote early identification of ASD.
- Identify and plan for the service needs of individuals with ASD.
- Improve collaborations between health providers, educators, researchers, and the children with ASD and their families.
- Inform policies promoting improved health and education outcomes.
- Guide future ASD research.

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 and 8 years-old and living in five counties in Maryland in 2020.

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

8-year-old children in tracking area: 21,278 4-year-old children in tracking area: 20,745

- | | |
|--|--|
| • 51% White | • 51% White |
| • 24% Black | • 23% Black |
| • 9% Hispanic | • 10% Hispanic |
| • 10% Asian or Pacific Islander | • 9% Asian or Pacific Islander |
| • <1% American Indian or Alaska Native | • <1% American Indian or Alaska Native |
| • 6% Multiracial | • 6% Multiracial |

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 for partners, state and local agencies, partnering institutes, parent groups, and the ADDM Network. MD-ADDM also participates in and organizes annual autism awareness month events in the community.

"There was a major impact of COVID-19 school closures on timely evaluations and early intervention and special education services. Our regular resources were not enough to address that increase in needs. The ADDM prevalence data are timely for planning and making budgetary requests for staffing to inclusively meet these needs." -

DR. TERRI SAVAGE

Executive Director, Department Of Special Education, Howard County Public School System

Resources

GET RESOURCES AND CONNECT FAMILIES TO SERVICES AND SUPPORT IN MARYLAND

PATHFINDERS FOR AUTISM

www.pathfindersforautism.org
443-330-5341

CENTER FOR AUTISM AND RELATED DISORDERS AT KENNEDY KRIEGER INSTITUTE

<https://www.kennedykrieger.org/patient-care/centers-and-programs/center-for-autism-and-related-disorders>
1-800-229-2038

THE PARENT'S PLACE OF MARYLAND

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

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

<http://marylandpublicschools.org/programs/Pages/Special-Education/index.aspx>
410-767-0238

ITINERIS

<https://www.itinerisbaltimore.org/>
443-275-1100

AUTISM SOCIETY OF BALTIMORE-CHESAPEAKE

www.baltimoreautismsociety.org
410-655-7933

COMMUNITY SERVICES FOR AUTISTIC ADULTS AND CHILDREN (CSAAC)

<http://csaac.org/>
240-912-2220

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

Kristen Paul
Maryland's Act Early Ambassador
<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

CONNECT WITH MD-ADDM

Christine Ladd-Acosta, PhD

claddac1@jhu.edu

Elise Pas, PhD

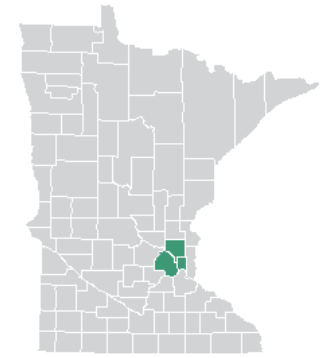
epas1@jhu.edu

Johns Hopkins University

Bloomberg School of Public Health

A Snapshot of Autism Spectrum Disorder in Minnesota

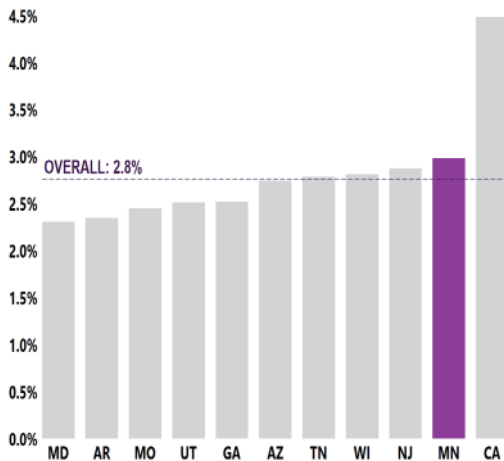
Findings from the Minnesota Autism and Developmental Disabilities Monitoring Network (MN-ADDN) help us understand more about autism in Minnesota, including number of children with autism spectrum disorder (ASD), their characteristics, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

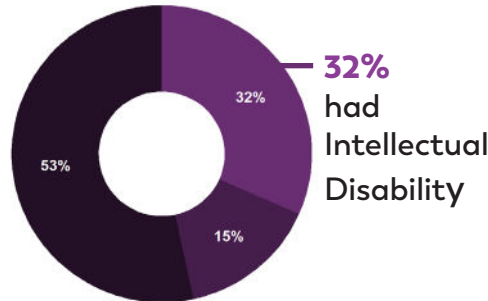
1 in 34

Or 3.0% of 8-year-old children were identified with ASD by MN-ADDN in 2020.



This rate is similar to the average percentage identified with ASD in 2020, which was 2.8% of 8-year-olds across all ADDN sites.

IQ data available for 86% of children identified with ASD by MN-ADDN.



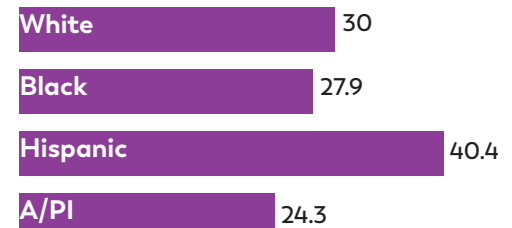
32% had Intellectual Disability

IQ SCORE*

- ≤ 70
- 71 - 85
- > 85

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

Among 8-year-olds, Black children were about equally likely to be identified with ASD as White children; Hispanic children were 1.3 times more likely to be identified with ASD than White, 1.4 times more likely than Black children, and 1.7 times as likely compared to Asian/Pacific Islander (A/PI) of the same age.



Values indicate prevalence per 1000.

Half of 8 year-old children

were diagnosed by a community provider by 59 months of age.

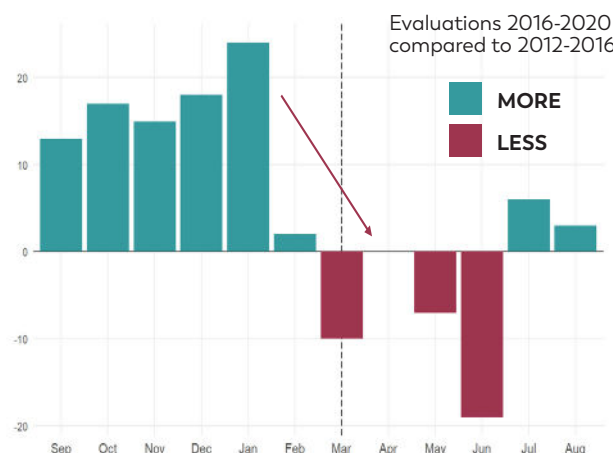
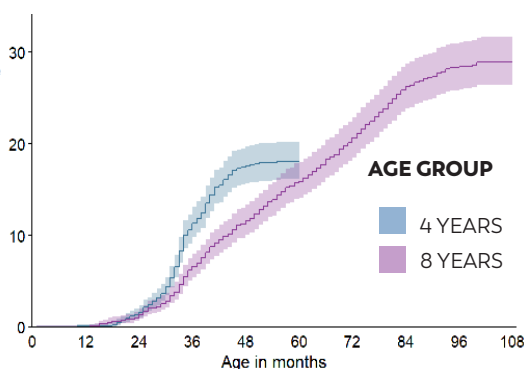


8-year-old Boys were 4.3 times as likely to be identified with ASD as girls.



More children in Minnesota are being identified with ASD at an early age.

Children who were age 4 years were 1.5 times as likely to be identified with ASD by 48 months of age as children who were age 8 years.



The COVID-19 pandemic disrupted many aspects of life, including the ability to evaluate children for autism. Before the pandemic, 4-year-old children had higher ASD identification than 8-year-old children had when they were aged 4 years. In the first few months of the pandemic, 4-year-old children were less likely to have an evaluation than 8-year-old children had when they were the same age.

What are the key take-away messages from Minnesota data?

- MN-ADDM identified a similar prevalence of ASD as other sites in the ADDM Network among both 8-year-olds and 4-year-olds.
- In MN-ADDM, there were differences between the percentage of boys and girls identified, with more boys identified with ASD than girls. This is consistent with previous estimates in MN-ADDM and in the overall ADDM network.
- MN-ADDM findings also reveal some differences in prevalence across racial and ethnic groups. Hispanic children in MN-ADDM were identified with ASD more frequently than White, Black, and Asian/Pacific Islander (A/PI) children at age 8. Among 4-year-olds, Black, Hispanic, and A/PI, children were more likely to be identified with ASD than White children.
- MN-ADDM had the latest median age of diagnosis in 8-year-old children across all of the ADDM Network, with fewer than half receiving 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 with 8-year-old children in MN-ADDM and all other ADDM sites; this means identification is happening earlier in the younger cohort. A diagnosis by an experienced professional can be considered reliable by age 2 years.

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 2020.

Tracking area: Parts of Anoka, Ramsey, and Hennepin counties, including Minneapolis-St. Paul

8-year-old children in tracking area: 16,150 4-year-old children in tracking area: 16,326

- | | |
|---------------------------------------|---------------------------------------|
| • 42% White | • 43% White |
| • 23% Black | • 23% Black |
| • 11% Hispanic | • 11% Hispanic |
| • 16% Asian or Pacific Islander | • 16% Asian or Pacific Islander |
| • 1% American Indian or Alaska Native | • 1% American Indian or Alaska Native |
| • 7% Multiracial | • 7% Multiracial |

*Estimates may not sum to 100% due to rounding

"I use information from the Minnesota ADDM program in so many areas of my life. As a parent of a child with autism, a policy maker with the Department of Human services and MN Legislator the data is INVALUABLE to ensure we are creating and funding programs and services to support children and families with autism in MN. The significance of Minnesota's prevalence and diagnosis age are important data points we need to make informed decisions and allocate funds for services now and in the future. It helps us understand the current needs and how to plan for the future."

KIM HICKS

MN House Representative and Parent of a child with Autism

Resources

RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN MINNESOTA

HELP ME GROW

1-866-693-GROW (4769)

www.helpmegrowmn.org

MDE.ECSE@state.mn.us

MINNESOTA AUTISM PORTAL

www.mn.gov/autism/

MINNESOTA DEPARTMENT OF EDUCATION

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

AUTISM SOCIETY OF MINNESOTA

www.ausm.org/

CDC'S LEARN THE SIGNS. ACT EARLY.

Jennifer Hall-Lande

Minnesota's Act Early Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

UNIVERSITY OF MN AUTISM AND NEURODEVELOPMENT CLINIC, MASONIC INSTITUTE FOR THE DEVELOPING BRAIN

612-365-0115

<https://midb.umn.edu/patient-care>

CONNECT WITH MN-ADDM PROJECT

Institute on Community Integration (ICI) University of Minnesota

150 Pillsbury Dr SE

Minneapolis, MN 55455

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

A Snapshot of Autism Spectrum Disorder in Missouri

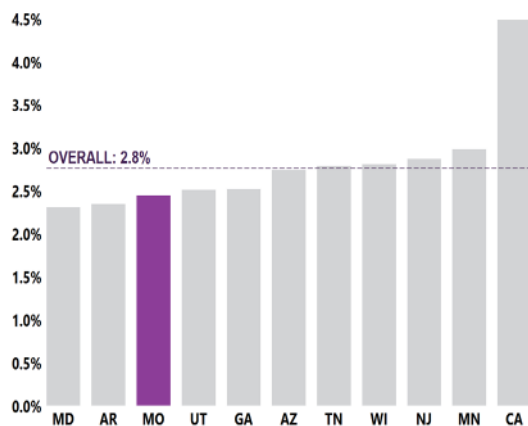
Findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDN) Project help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

1 in 41

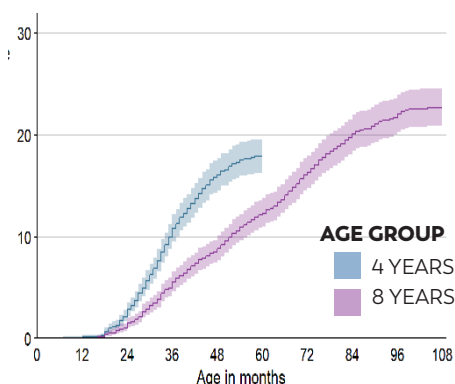
Or **2.5%** of 8-year-old children were identified with ASD by the MO-ADDN Project in 2020.



This percentage is lower than the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

Children who were born in 2016 (16%)

were almost 1.8 times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to **children born in 2012**.



Among 8-year-olds, Black children were 1.2 times as likely and Asian/Pacific Islander (A/PI) children were 1.5 times as likely to be identified with ASD as White children. Children with two or more races were less likely to be identified with ASD compared with all other races except Hispanic children.



Values indicate prevalence per 1000.

40% of 8-year-old children & 75% of 4-year-old children

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

4-year-old boys were 2.6x as likely to be identified with ASD than girls



IQ data available for 61%

of children identified with ASD by MO-ADDN



32% had Intellectual Disability

IQ SCORE*

- ≤ 70
- 71 - 85
- > 85

IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

*Percentages may not total 100 due to rounding

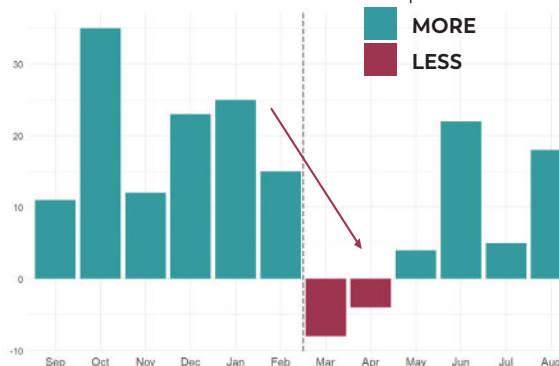
Overall, 81% of 8-year-olds who met the ADDN case definition had an ASD diagnosis by a health care provider; 54% had autism special education eligibility; and 72% had an ASD International Classification of Disease (ICD) code.

ASD diagnosis 81%

Education Eligibility 54%

ASD ICD code 72%

Evaluations 2016-2020 compared to 2012-2016



The COVID-19 pandemic disrupted many aspects of life, including the ability to evaluate children for autism. Before the pandemic, 4-year-old children had higher ASD identification than 8-year-old children had when they were aged 4 years. In the first few months of the pandemic, **4-year-old children were less likely to have an evaluation than 8-year-old children had when they were the same age.**

What are the key take-away messages from Missouri ADDM?

- For the first time, ASD prevalence was higher for Black and A/PI children than White children in MO-ADDM.
- Black children continue to be more likely to have ASD and ID compared with children of other races/ethnicities in communities included in the MO-ADDM network.
- A higher percentage of children born in 2016 had evaluations by 36 months of age and a diagnosis or special education eligibility by 48 months of age compared with children born in 2012.

How can this information be useful?

MO-ADDM'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 health and education outcomes for individuals with ASD.

Partners in Missouri might consider ways to promote early identification by community providers in order to facilitate access to interventions and services that will 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 one of five counties in Missouri in 2018.

Tracking area: Franklin, Jefferson, St. Charles, St. Louis counties and the City of St. Louis

8-year-old children in tracking area: 24,561

- 63% White
- 24% Black
- 5% Hispanic
- 3% Asian or Pacific Islander
- <1% American Indian or Alaska Native
- 5% Multiracial

4-year-old children in tracking area: 24,476

- 63% White
- 24% Black
- 5% Hispanic
- 4% Asian or Pacific Islander
- <1% American Indian or Alaska Native
- 5% Multiracial

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

MO-ADDM investigators at Washington University in St. Louis collaborate 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 several types of 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 Missouri ADDM ASD surveillance data, with its combination of health and educational data sources, provides a more comprehensive picture of where and when children with ASD are being identified in our region than we would otherwise have. As a diagnostic center, these data can help us to advocate for targeted community resources for our patients to better serve them in a more timely and economical way."

MICHAEL S. BUNIS, Psy.D.

Clinical Director of Washington University MO State Autism Center

Assistant Professor, Department of Psychiatry, Washington University School of Medicine

Resources

RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN MISSOURI

DEPARTMENT OF ELEMENTARY AND SECONDARY EDUCATION'S OFFICE OF SPECIAL EDUCATION

573-751-5739

dese.mo.gov/special-education

DEPARTMENT OF MENTAL HEALTH'S DIVISION OF DEVELOPMENTAL DISABILITIES

dmh.mo.gov/dd/

FIRST STEPS

1-866-583-2392

www.mofirststeps.com/

NAVIGATING AUTISM SERVICES

<https://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

<https://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

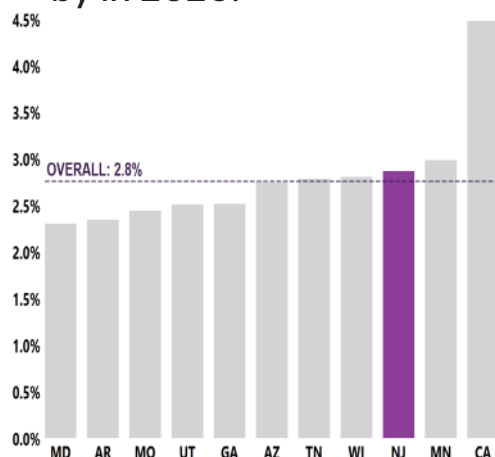
Findings from the New Jersey Autism Study (NJAS) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

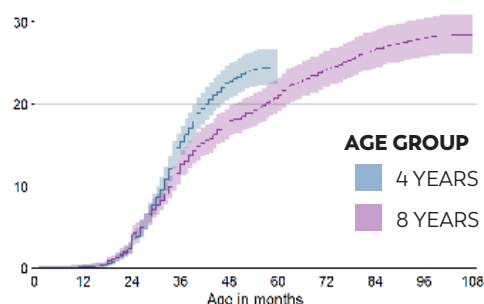
1 in 35

Or **2.9%** of 8-year-old children in New Jersey were identified with ASD by in 2020.



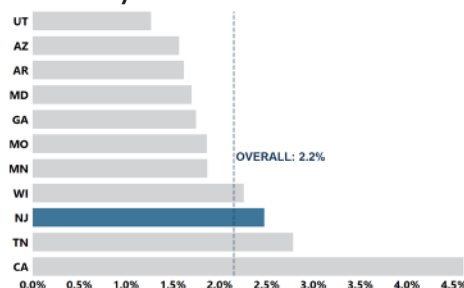
This is higher than the average identified with ASD (2.8%) across US communities where the ADDN Network tracked ASD among school-age children.

Children aged 4 years were 1.3 times as likely to receive an ASD diagnosis by 48 months of age compared to **children aged 8 years** in NJAS.



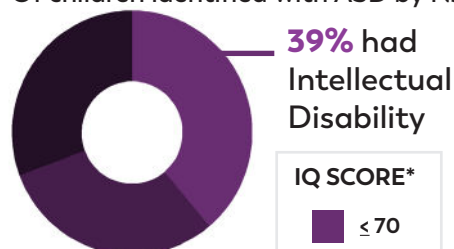
1 in 40

Or **2.5%** of 4-year-old children were identified with ASD by NJAS.



IQ data available for 63%

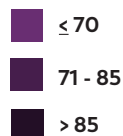
Of children identified with ASD by NJAS



IQ = Intelligence Quotient
Intellectual disability = IQ ≤ 70

39% had Intellectual Disability

IQ SCORE*

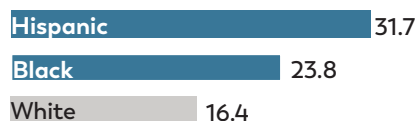


58% of 8-year-old children

were identified with ASD received a Comprehensive Developmental Evaluation by age 3 years



Among NJAS 4-year-olds, Hispanic children were 1.9 times as likely to be identified with ASD and Black children were 1.4 times as likely to be identified with ASD compared to White children.

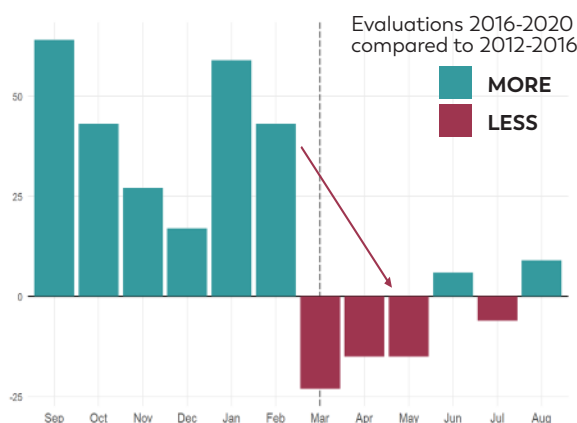


Values indicate prevalence per 1000.

Among 8 year olds, Hispanic, and Black children were 1.7 times as likely to be identified with ASD as White children.



Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between white and A/PI children in NJAS.



The COVID-19 pandemic disrupted many aspects of life, including the ability to evaluate children for autism. Before the pandemic, 4-year-old children had higher ASD identification than 8-year-old children had when they were aged 4 years. In the first few months of the pandemic, **4-year-old children were less likely to have an evaluation than 8-year-old children had when they were the same age.**

What are the key take-away messages from NJAS data?

- The ADDM Network ASD prevalence estimate was higher than the 2018 estimate.
- 2020 ASD prevalence estimates for 8-year-olds ranged from 2.3% (Maryland) to 4.5% (California). New Jersey had the third highest estimate (2.9%). These differences underscore the differences in ASD diagnoses across the ADDM Network.
- ASD estimates for 4-year-olds ranged from 1.3% (Utah) to 4.6% (California), in 2020, indicating differences in ASD diagnosis across the ADDM Network.
- Among 8-year-olds, the combined ADDM estimates showed ASD prevalence was higher for Black and Hispanic children compared with White children. More Black children with ASD also had intellectual disability compared with children from other racial ethnicity groups.

How can this information be useful?

The latest findings about ASD prevalence may be used to

- Raise awareness of increasing ASD in the United States.
- Quantify the scope of ASD across US regions.
- Provide New Jersey-specific information for service planning.
- Guide future research of ASD risk factors.

How and where was this information collected?

NJAS used a comprehensive record review method. Information is from 4- and 8-year-old children who were diagnosed with ASD, as indicated in health and education records in two New Jersey counties, in 2020.

Tracking area

Essex, and Union counties

8-year-old children in tracking area: 18,940 4-year-old children in tracking area: 19,120

- | | |
|--|--|
| • 27% White | • 26% White |
| • 31% Black | • 29% Black |
| • 34% Hispanic | • 35% Hispanic |
| • 6% Asian or Pacific Islander | • 6% Asian or Pacific Islander |
| • <1% American Indian or Alaska Native | • <1% American Indian or Alaska Native |

What else does the New Jersey Autism Study do besides provide ASD estimates?

NJAS used a comprehensive record review method. Information is from 4- and 8-year-old children who were diagnosed with ASD, as indicated in health and education records in two New Jersey counties, in 2020.

“Rigorous surveillance research by the New Jersey Autism Study has provided a compelling foundation for statewide policy changes that have improved access to healthcare, education, treatment, and lifelong services. These supporting data and systemic changes are life-changing for children and adults with autism.” –

SUZANNE BUCHANAN, PsyD, BCBA-D
Executive Director, Autism New Jersey

Resources

RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN NEW JERSEY

AUTISM NEW JERSEY

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

NJ EARLY INTERVENTION SYSTEM

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

AUTISM FAMILY SERVICES OF NEW JERSEY

Support services for families living with ASD
877-237-4477
www.autismfamilyservicesnj.org

NJ DEPARTMENT OF EDUCATION'S OFFICE OF SPECIAL EDUCATION PROGRAMS

Special education services for school-aged children with disabilities
www.nj.gov/education/special/

MOM2MOM

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

STATEWIDE PARENT ADVOCACY NETWORK

Support for parents, including parents of children with special needs
800-654-7726
www.spannj.org

NJ PARENT LINK

Early childhood, parenting, and professional resource center
<https://nj.gov/njparentlink/>

LEARN THE SIGNS. ACT EARLY.

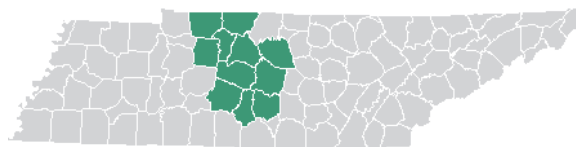
Deepa Srinivasavaradan
New Jersey Act Early Ambassador
<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

CONNECT WITH NJAS

Walter Zahorodny, PhD
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A Snapshot of Autism Spectrum Disorder in Tennessee

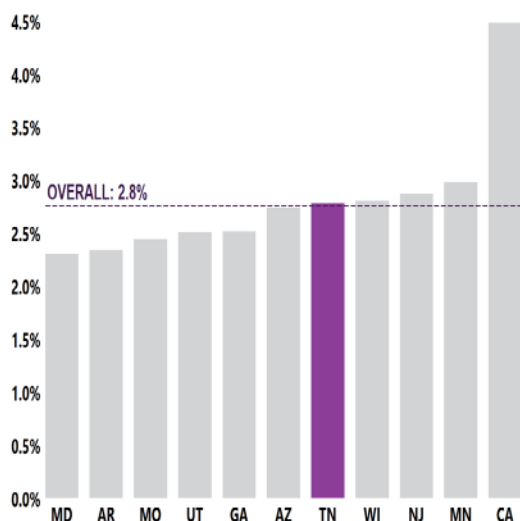
Findings from the Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDN) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

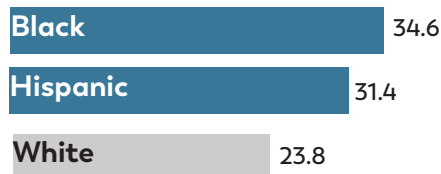
1 in 36

Or **2.8%** were identified with ASD by TN-ADDN in 2020



This percentage is the same as the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

Black children were 1.5 times as likely and Hispanic children were 1.3 times as likely to be identified with ASD by age **4-years** as White children.



Values indicate prevalence per 1,000 children.

In TN ADDN, **4-year-olds** who met the ADDN case definition:

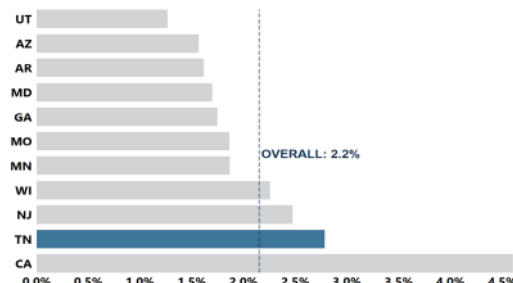
71% diagnosed by a healthcare provider

33% had Autism special education eligibility

93% had an ASD ICD* code

*International classification of disease code

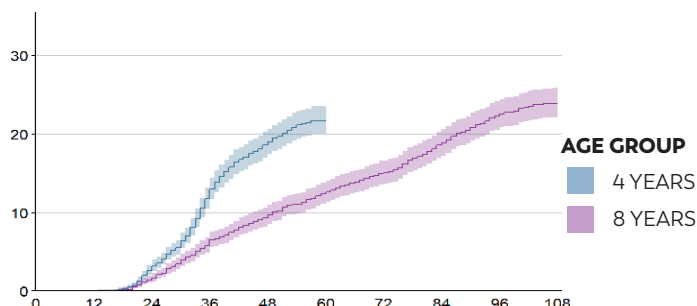
Among **4-year-old children**, **1 in 36** or **2.8%** were identified with ASD by TN-ADDN in 2020.



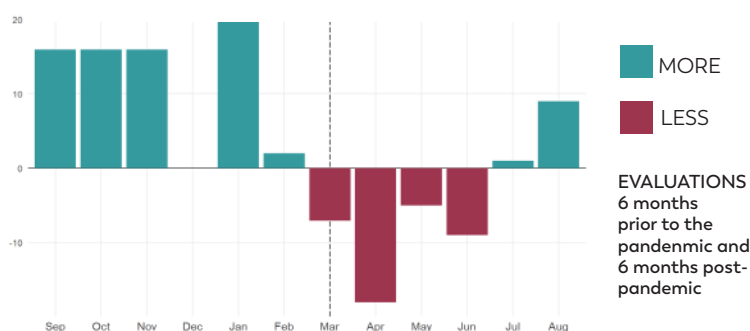
44% of **8-year-old children** and **67%** of **4-year-old children**

identified with ASD received a comprehensive developmental evaluation by age 3 years.

Children who were **age 4** were twice as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared with **children age 8 years**.



While **COVID-19 shut-downs** initially impacted the number of evaluations completed, TN saw some **recovery by the end of 2020**. It is possible that telemedicine-based assessment protocols helped.



EVALUATIONS 6 months prior to the pandemic and 6 months post-pandemic

What are the key take-away messages from TN-ADDM?

- 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 2.3% (1 in 44) in 2018 to 2.8% (1 in 36) in 2020.
- Although an increasing number of children with ASD in Tennessee (44% of 8-year-olds; 67% of 4-year-olds) are initially evaluated prior to 3 years of age, many children are still diagnosed at later ages (median age of diagnosis was 48 months of age among 8-year-old children with ASD).
- About 1 in 36 (or 2.8%) of 4-year-old children were identified with ASD by TN-ADDM in 2020.
- In Tennessee, Black children and Hispanic children were more likely to be identified with ASD by age 4 years than were White children. This may reflect improved service and advocacy efforts targeting traditionally underserved communities.
- 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 under served 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 that promote equitable and accessible screening, services, and supports for all children.

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 2020.

Tracking area

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

8-year-old children in tracking area: 25,588 4-year-old children in tracking area: 26,474

- | | |
|--|--|
| • 60% White | • 60% White |
| • 17% Black | • 17% Black |
| • 13% Hispanic | • 14% Hispanic |
| • 5% Multiracial | • 6% Multiracial |
| • 3% Asian or Pacific Islander | • 3% Asian or Pacific Islander |
| • <1% American Indian or Alaska Native | • <1% American Indian or Alaska Native |

"The data provided by TN-ADDM directly aligns with our goals of enhancing care and support of children with autism across all 95 Tennessee counties. Specifically, TN-ADDM data allows us to translate important community data regarding autism prevalence into meaningful action that better serves the under served of our state."

TOBI AMOSUN, MD, FAAP

Assistant Commissioner of the Division of Family Health and Wellness, Tennessee Department of Health

Resources

RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN TENNESSEE

VANDERBILT KENNEDY CENTER (VKC)

<https://vkc.mc.vanderbilt.edu/vkc/>

TREATMENT AND RESEARCH INSTITUTE FOR AUTISM SPECTRUM DISORDER (TRIAD)

<https://vkc.mc.vanderbilt.edu/vkc/triad/home/>

TENNESSEE DISABILITY PATHFINDER

1-800-640-4636

<https://vkc.mc.vanderbilt.edu/vkc/pathfinder/>

TENNESSEE EARLY INTERVENTION SYSTEM

1-800-852-7157

www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html

AUTISM TENNESSEE

615-385-2077

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

CDC'S LEARN THE SIGNS. ACT EARLY.

Toni Whitaker, MD

Tennessee's Act Early Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

CONNECT WITH TN-ADDM

Zachary Warren, PhD

VKC/TRIAD

110 Magnolia Circle

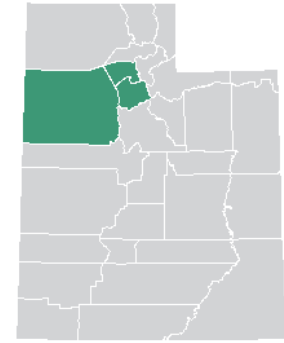
Nashville, TN 37203

1-877-ASD-VUMC

autismresources@vanderbilt.edu

A Snapshot of Autism Spectrum Disorder in Utah

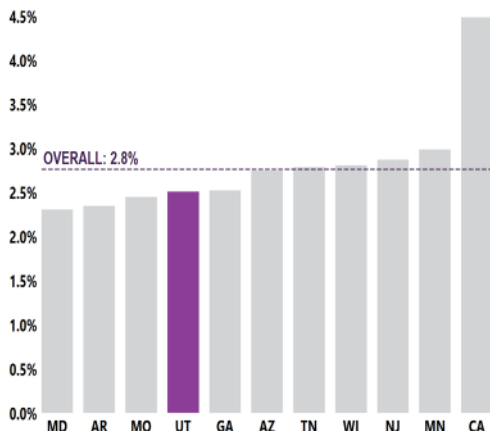
Findings from the Utah Autism and Developmental Disabilities Monitoring (UT-ADDM) Program help understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

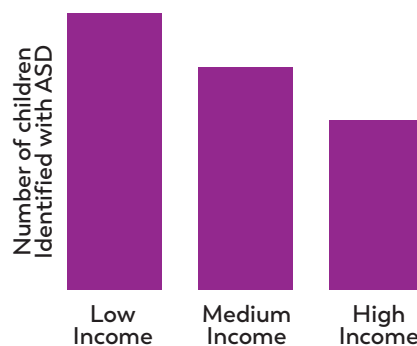
1 in 40

Or 2.5% of 8-year-old children were identified with ASD in a three-county area in Utah by UT-ADDM in 2020.



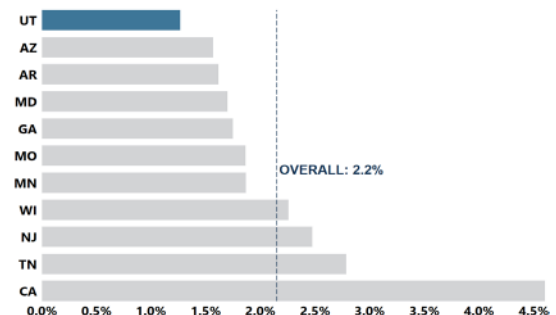
This percentage is similar to the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

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



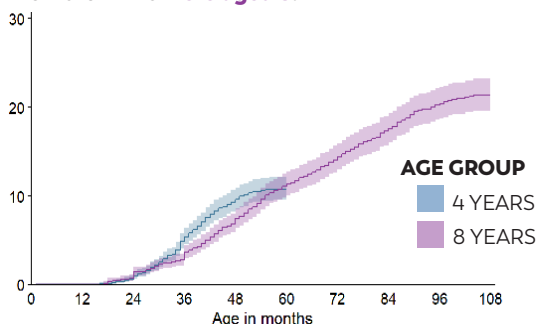
For every 2 children identified with ASD who were age 4 there was 1 child who was suspected but not confirmed to have ASD.

About 1 in 79 or 1.3% of 4-year-old children were identified with ASD in a three-county area in Utah by UT-ADDM in 2020.



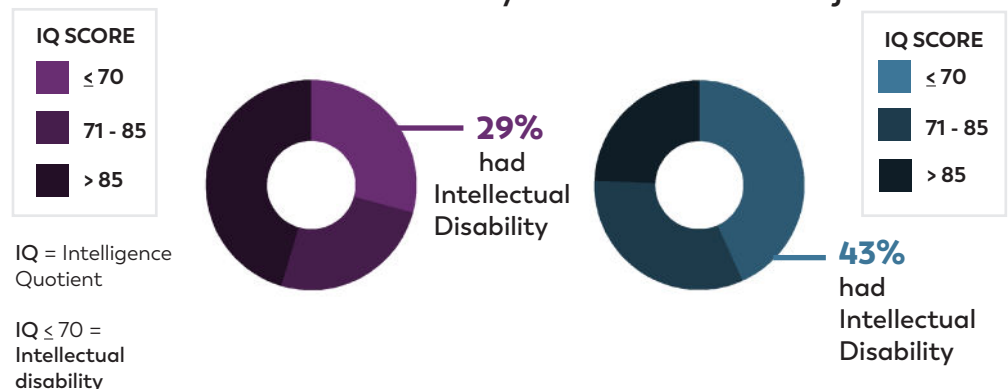
This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities tracked by the CDC.

Children who were age 4 were 1.3 times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children who were aged 8.



IQ data available for

51% Of 8-year-old and 48% 4-year-old children identified with ASD by the UT-ADDM Project



What are the key take-away messages in UT-ADDM?

- Utah's estimated prevalence of ASD among 8-year-old children increased slightly since our last study from 2.2% in 2018 to 2.5% in 2020.
- Compared with 2018 when there was no difference, 4-year-old children in 2020 were more likely than 8-year-old children in 2020 to be identified with ASD by 48 months. This suggests that there have been improvements in Utah in identifying ASD at earlier ages.
- The prevalence of suspected ASD suggests that many 4-year-old children in Utah may have experienced challenges accessing assessments for ASD in 2020. This finding supports continued efforts in Utah to expand ASD diagnostic strategies to improve identification at earlier ages.
- ASD prevalence was higher among children from lower socioeconomic backgrounds. This shows improved access to diagnostic and treatment services across the socioeconomic spectrum.

How can this information be useful?

Utah-ADDM's latest findings can be used to

- Promote new initiatives aimed at fostering earlier identification of ASD.
- Plan for ASD services and trainings.
- 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 health, early intervention, and special education records of 4-year-old and 8-year-old children living within a three-county area in Utah in 2020.

Tracking area

Salt Lake, Davis, and Tooele counties

8-year-old children in tracking area: 24,734 4-year-old children in tracking area: 24,330

- | | |
|---------------------------------------|---------------------------------------|
| • 68% White | • 67% White |
| • 2% Black | • 2% Black |
| • 21% Hispanic | • 22% Hispanic |
| • 4% Asian or Pacific Islander | • 5% Asian or Pacific Islander |
| • 1% American Indian or Alaska Native | • 1% American Indian or Alaska Native |
| • 4% Multiracial | • 4% Multiracial |

What else does UT-ADDM do besides tracking ASD among 4-8-year-olds?

UT-ADDM's prevalence data are provided to our valued partners and used to support legislative initiatives aimed at increasing the services available to persons with ASD and their families. Data from UT-ADDM are also used to help understand community needs related to ASD to inform resource and service development. UT-ADDM is leading projects to improve our knowledge of early life risk factors for ASD, differences in characteristics among children with ASD, and disparities in ASD recognition across the ADDM Network. Finally, UT-ADDM is active in conducting education and outreach activities in the community to provide the latest information on the epidemiology of ASD.

"This year's study shows how a wider range of families are accessing autism services, but more needs to be done so that children with autism receive a timely diagnosis to make the most of the treatment available."

CALLEEN KENNEY

Autism Council of Utah, Parent Consultant, Utah Family Voices, Family To Family Health Information Center at the Utah Parent Center

Resources

RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN UTAH

UTAH DEPARTMENT OF HEALTH AND HUMAN SERVICE'S BUREAU OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Provides information about a range of services and resources

(801) 273-2800

<https://health.utah.gov/cshcn/>

BABY WATCH EARLY INTERVENTION

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

(800) 961-4226

<https://health.utah.gov/cshcn/programs/babywatch.html>

HELP ME GROW UTAH

Information referral helpline and free screening services

(801) 691-5322

www.helpmegrowutah.org

CDC'S LEARN THE SIGNS. ACT EARLY. Janel Preston

Utah's Act Early Ambassador

<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

AUTISM COUNCIL OF UTAH

Information and advocacy for families

autismcouncilofutah@gmail.com

www.autismcouncilofutah.org

UTAH REGISTRY OF AUTISM AND DEVELOPMENTAL DISABILITIES (URADD)

Utah ADDM site and research center

(801) 587-8971

<https://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

CONNECT WITH UT-ADDM

Amanda V. Bakian, PhD

Deborah Bilder, MD

UT-ADDM Principal Investigators

University of Utah

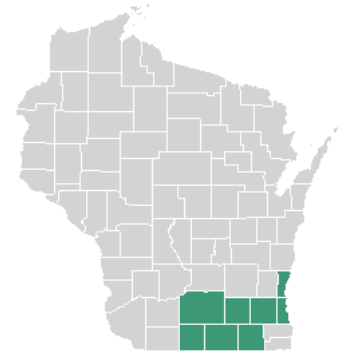
(801) 213-2881

amanda.bakian@hsc.utah.edu

deborah.bilder@hsc.utah.edu

A Snapshot of Autism Spectrum Disorder in Wisconsin

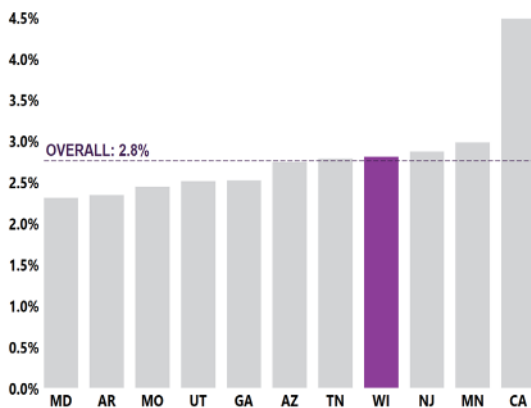
Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are evaluated and diagnosed.



SITE TRACKING AREA

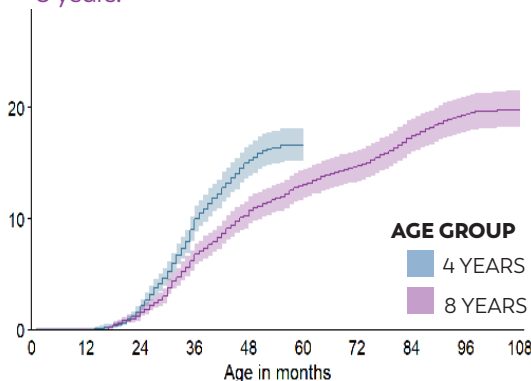
1 in 36

Or **2.8%** of 8-year-old children were identified with ASD in WISADDS in 2020.

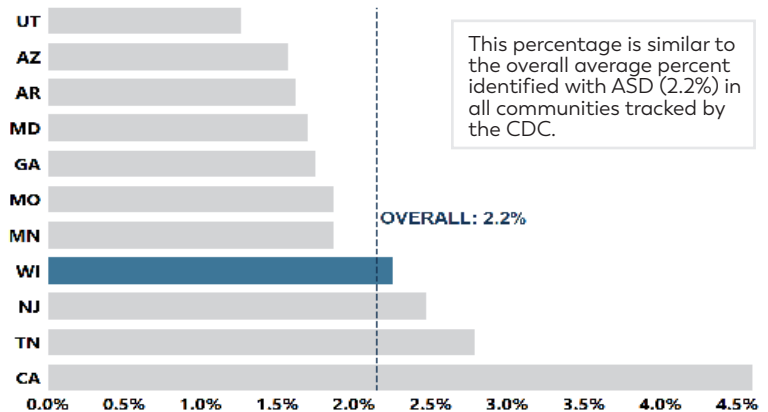


This percentage is higher than it was in 2018 (1.9%) and similar to the overall average percent identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

Children who were age 4 were 1.4 times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to **children aged 8 years**.



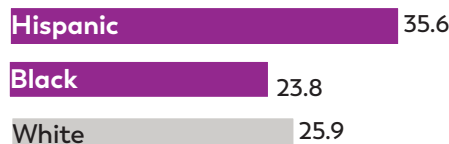
About 1 in 44 or 2.3% of 4-year-old children were identified with ASD in WISADDS in 2020.



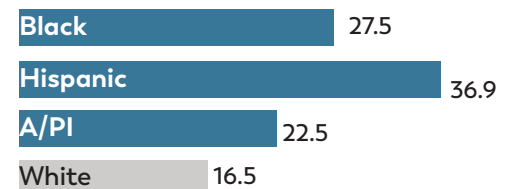
This percentage is similar to the overall average percent identified with ASD (2.2%) in all communities tracked by the CDC.

OVERALL: 2.2%

Among 8-year-old children, Hispanic Children were 1.4 times as likely to be identified with ASD as White children. Hispanic 8-year-old children were also 1.4 times as likely to be identified with ASD as Black children.



Among 4-year-olds, Black, Hispanic, and Asian Pacific Islander (A/PI) children were respectively 1.7 times, 2.2 times, and 1.4 times as likely to be identified with ASD as White children.



Boys were 3 times

More likely to be identified with ASD than girls among both **4-year-old** and **8-year-old children**.



Among 8-year-old children with ASD, more than half (58%) received a comprehensive developmental evaluation by age 3 years.



What are the key take-away messages in WISADDS data?

- The percentage of 8-year-old children identified with ASD increased in southeastern Wisconsin, from 1.9% in 2018 to 2.8% in 2020.
- Among both 4-year-old and 8-year-old children, boys were more likely to be identified with ASD than girls.
- 57.5% of 8-year-old children identified with ASD received a comprehensive developmental evaluation by age 36 months, an increase from 2018.
- The prevalence of ASD has varied across racial and ethnic groups since 2002 in WISADDS. In 2020, the prevalence among 4-year-old Hispanic children was higher than any other group. The overall prevalence has increased more for Black, Hispanic, and Asian/Pacific Islanders than for White children.

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, such as research to better understand prevalence differences across all racial and ethnic groups.
- 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 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 4-year-old and 8-year-old children living in one of eight counties in southeastern Wisconsin in 2020.

Tracking area: Dane, Green, Jefferson, Milwaukee, Ozaukee, Rock, Walworth, and Waukesha counties

8-year-old children in tracking area: 28,789 **4-year-old children in tracking area: 28,852**

- | | |
|--|---------------------------------------|
| • 55% White | • 54% White |
| • 17% Black | • 18% Black |
| • 17% Hispanic | • 17% Hispanic |
| • 6% Asian or Pacific Islander | • 6% Asian or Pacific Islander |
| • .3% American Indian or Alaska Native | • 0% American Indian or Alaska Native |
| • 5% Multiracial | • 5% Multiracial |

What else does WISADDS do besides tracking ASD among 4- and 8-year-olds?

WISADDS collaborates with partners in Wisconsin to raise awareness about the number and characteristics of children with ASD. This information is useful for planning to meet the growing demand for autism services in our community. 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.

"This report underscores the importance of autism in our community. For the past 50 years, Waisman Center researchers, clinicians, educators and community partners have worked to advance our understanding of autism and other developmental disabilities and to improve outcomes over the life course for individuals and families in Wisconsin. During this time, we have seen steady increases in the number of children on the autism spectrum and the need for services. We are grateful to be a part of the ADDM Network and to have this information on the prevalence of autism in our population and across the nation."

QIANG CHANG, PhD

Professor of Medical Genetics and Neurology, Director, Waisman Center, University Of Wisconsin-Madison

Resources

GET RESOURCES TO CONNECT FAMILIES TO SERVICES AND SUPPORT IN WISCONSIN

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.waisman.wisc.edu/cedd/pdfs/products/community/FYW_e.pdf

CDC'S LEARN THE SIGNS. ACT EARLY.

Resources for families and professionals on child development and what to do if there is a concern
Kris Barnekow
Wisconsin's Act Early Ambassador
<https://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
at 800-642-7837
<https://www.dhs.wisconsin.gov/mch/well-badger.htm>

CONNECT WITH WISADDS

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

Glossary

A

Autism spectrum disorder

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges. People with ASD may communicate, interact, behave, and learn in different ways. Signs of ASD begin during early childhood and usually last throughout a person's life (3).

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, physical therapists, and speech-language pathologists. Specialists, such as developmental pediatricians, often use the results of a developmental evaluation to determine if a child has ASD.

Community provider

A community provider is a medical or educational professional within the ADDM Network communities 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).

COVID-19

COVID-19 (coronavirus disease 2019) is a disease caused by a virus named SARS-CoV-2 that was first detected in 2019. It is very contagious and has spread around the world. COVID-19 most often causes respiratory symptoms that can feel much like a cold, the flu, or pneumonia.

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 (ID) means that a person has difficulties 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

Pandemic

An illness that spreads around the world.

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. The ADDM network provides prevalence estimates every other year.

S

Social determinants of health

Social determinants of health (SDOH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies, racism, climate change, and political systems. The CDC has adopted this SDOH definition from the World Health Organization.

Special education eligibility or classification

The specific 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 or monitoring)

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

V

Validated screening tool

A tool that has been tested to determine how good it is in screening for a particular situation. These screening tools are tested by comparing them to an already approved test (also known as a 'gold standard' test).

Community Report References

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

MMWR Report References

Maenner MJ, Warren Z, Williams AR, et al. [Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020](#). *MMWR Surveill Summ* 2023, 72 (No.SS-2): 1-14.

Shaw KA, Bilder DA, McArthur D, et al. [Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020](#). *MMWR Surveill Summ* 2023, 72 (No.SS-1): 1-15.



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