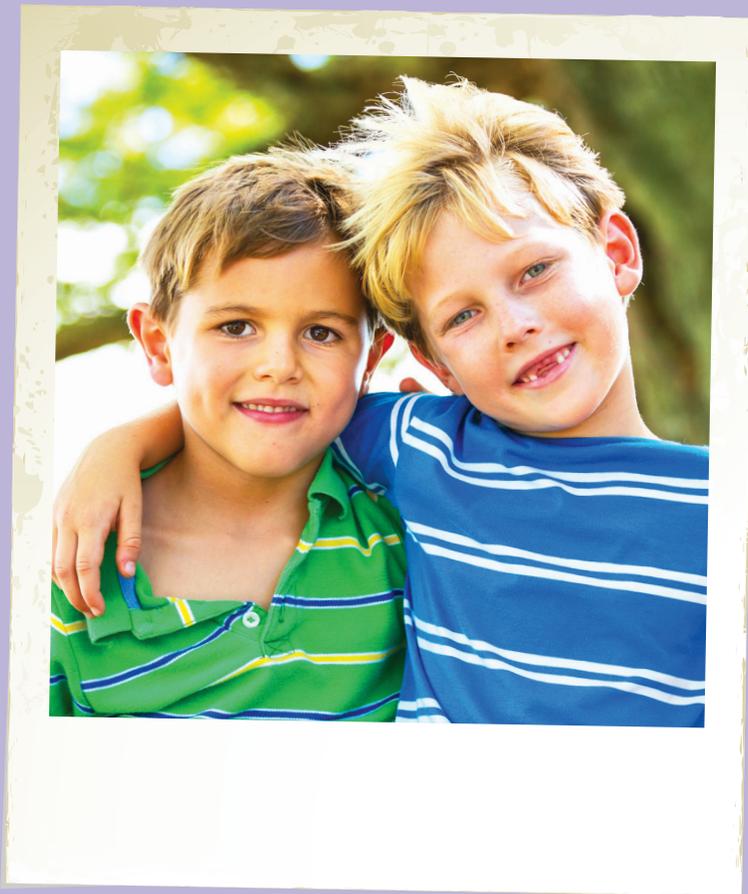


# Community Report on **Autism**

2014



From the Autism and  
Developmental Disabilities  
Monitoring Network

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





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

A Snapshot of Autism Spectrum Disorder among 8-year-old Children  
in Multiple Communities across the United States in 2010

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

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

CDC. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and  
Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. MMWR 2014; 63  
(No. SS 2):1-21.

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

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

The findings and conclusions in this report are those of the authors and do not necessarily  
represent the official position of the CDC.



# Table of Contents

Executive Summary . . . . .	4
What Is Autism Spectrum Disorder? . . . . .	5
What Is the The ADDM Network? . . . . .	8
Key Findings . . . . .	14
Data for Action: How Can You Use The ADDM Network Data? . . . . .	15
State by State: Key Findings and Resources . . . . .	17
Alabama . . . . .	18
Arizona . . . . .	20
Arkansas . . . . .	22
Colorado . . . . .	24
Georgia . . . . .	26
Maryland . . . . .	28
Missouri . . . . .	30
New Jersey . . . . .	32
North Carolina . . . . .	34
Utah . . . . .	36
Wisconsin . . . . .	38
A Community Perspective: Success Stories from the ADDM Network . . . . .	40
What Else Do I Need to Know? . . . . .	43
Where Can I Get More Information? . . . . .	45
References . . . . .	48

## Executive Summary

### Introduction

CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network data show that the estimated number of children identified with autism spectrum disorder (ASD) continues to rise. The ADDM Network found that about 1 in 68 children were identified with ASD based on tracking across multiple areas of the United States. Some characteristics of children with ASD have remained the same—boys were almost 5 times more likely to be identified with ASD than girls; white children were still more likely to be identified with ASD than black or Hispanic children; and most children with ASD were diagnosed after age 4, even though ASD can be diagnosed as early as age 2. However, the picture of ASD in communities is also changing—almost half of children identified with ASD had average or above average intellectual ability. More is understood about ASD than ever before, but many important questions remain unanswered. We encourage stakeholders in communities across the country to use these data to raise awareness and take action to help children.

### What is the purpose of this report?

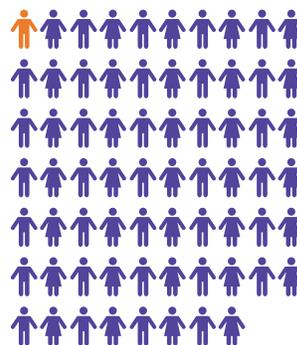
This is the fifth Community Report from the ADDM Network, which tracks the number and characteristics of children with ASD and other developmental disabilities in diverse communities throughout the United States. The purpose of this Community Report is to highlight the ADDM Network's most recent scientific findings in a way that is useful for stakeholders living in the ADDM Network communities and to provide information for awareness and action.

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

CDC's ADDM Network has been at the forefront of documenting changes in the number of children identified with ASD over the past decade. CDC data have laid the foundation for research into who is likely to develop ASD, why ASD develops, and how to best support individuals, families, and communities affected by ASD. There remains an urgent and immediate need to continue the search for answers and provide help to people living with ASD.

The ADDM Network's latest snapshot directs the focus on what we know now and what else we need to know to further characterize and address the needs of children with ASD and their families. Service providers (such as healthcare organizations and school systems), researchers, and policymakers can use ADDM Network data to support service planning, guide research into what factors put a child at risk for ASD and what interventions can help, and inform policies that promote improved outcomes in health care and education. CDC will continue tracking the changing number and characteristics of children with ASD, researching what puts children at risk for ASD, and promoting early identification, the most powerful tool we have now for making a difference in the lives of children.

#### NUMBER OF CHILDREN IDENTIFIED WITH ASD



**1 in 68**

## What Is Autism Spectrum Disorder?

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

Previously, the term "ASD" collectively referred to the following three conditions that were diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger disorder (2). ASD now encompasses a single diagnosis of "autism spectrum disorder" (see pg. 14 for more information on this change). The term "spectrum" in ASD means that each person can be affected in different ways, and symptoms can range from mild to severe. People with ASD share some similar symptoms, such as difficulties with social interaction, difficulties with communication, and highly focused interests and/or repetitive activities. How the symptoms affect a person's functioning depends on the severity and combination of those symptoms.

### Developmental Monitoring

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

### Screening, Evaluation, and Diagnosis

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

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

**A Comprehensive Evaluation** is a thorough review of the child's behavior and development. These evaluations can include clinical observation, parental reports of developmental and health histories, psychological testing, and speech and language assessments. A range of professionals can conduct comprehensive evaluations, including but not limited to teachers, social workers, nurses, psychologists, doctors, and speech-language pathologists.

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

*"The Autism Science Foundation relies on CDC prevalence data to guide our research on the underlying causes of autism and the treatment needs of individuals with autism. The data provide critical insight into how we can best meet the real needs of real people."*

- Alison Singer

Co-Founder and President, Autism Science Foundation

## Signs and Symptoms

A child with ASD might:

- ✓ Not respond to his or her name by 12 months of age (for example, appear not to hear).
- ✓ Not point at objects to show interest by 14 months of age (for example, point at an airplane flying over).
- ✓ Not play “pretend” games by 18 months of age (for example, pretend to “feed” a doll).
- ✓ Avoid eye contact and want to be alone.
- ✓ Have trouble understanding other people’s feelings or talking about his or her own feelings.
- ✓ Have delayed speech and language skills (for example, use words much later than siblings or peers or not use words to communicate).
- ✓ Repeat words or phrases over and over.
- ✓ Give unrelated answers to questions.
- ✓ Get upset by minor changes in routine (for example, getting a new toothbrush).
- ✓ Have obsessive interests (for example, having a very strong interest in trains that is difficult to interrupt).
- ✓ Flap his or her hands, rock his or her body, or spin in circles.
- ✓ Have unusual ways of playing with or using objects, such as spinning or lining them up repeatedly.
- ✓ Have unusual reactions to the way things sound, smell, taste, look, or feel.

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



## Risk Factors and Causes

ASD is a complex disorder, and most scientists who study ASD believe that there is no single cause. We have learned that there are likely many causes for multiple types of ASD. There may also be many different factors that make a child more likely to have ASD, including environmental and genetic factors. Understanding more about these factors will help us learn about the causes.

- ❑ Most scientists agree that differences in certain genes are one of the factors that can make it more likely for a person to develop ASD (5).
- ❑ Children who have a sibling with ASD are at a higher risk of also having ASD (6-11).
- ❑ ASD tends to occur more often in people who have certain genetic or chromosomal conditions, such as fragile X syndrome or tuberous sclerosis (12-15).
- ❑ When taken during pregnancy, the prescription drugs valproic acid and thalidomide have been linked with a higher risk of ASD (16-17).
- ❑ There is some evidence that the period for developing ASD occurs before, during, and immediately after birth (18).
- ❑ Children born to older parents are at greater risk for having ASD (19).

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

### **Economic Costs**

Caring for a child with ASD can place a heavy economic burden on families and communities. It is estimated to cost at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. Taken together, it is estimated that total societal costs of caring for children with ASD were over \$11.5 billion in 2011 (20).

The costs of ASD extend beyond paying for a child’s services and supports—parents of children with ASD have reported high levels of stress related to a unique set of issues (21). These include issues with access to needed services and quality of care compared to parents of children with other developmental disabilities or mental health conditions. Some parents also report having to stop work to care for their child with ASD (22-23). Mothers who maintain employment end up working about 7 hours less per week and earn 56% less than mothers of children with no major health issues (24). The costs of ASD take both a financial and emotional toll on families.



### **Staying Healthy with ASD**

Children with ASD need healthcare and health programs for the same reasons anyone else does—to stay well, active, and participate in their community. Some conditions have been found to be more common among children with ASD such as anxiety, attention deficits, Down syndrome, depression, epilepsy, fragile X syndrome, gastrointestinal problems, hearing loss, intellectual disability, obesity, sensory-processing difficulties, sleep problems, tuberous sclerosis, and vision impairment (25-28). It is important to recognize these conditions and treat them accordingly. Regular medical and dental examinations are essential components of a child’s care plan, as are preventive measures such as routine childhood immunizations and flu shots.

*“The numbers in CDC’s reports represent real children in every neighborhood across the country. They need access to proven behavioral therapies. They need educational support. Many need better medicines to manage their most disabling symptoms. And we need far more research to improve our understanding and treatment of autism and its complexity of related medical conditions.*”

*We know that the earlier we diagnose autism and intervene with effective therapies, the better the outcomes. But while autism can be reliably identified by age 2, the average age of diagnosis in our country lags behind. For minority populations, the delay is even greater. Even after a parent, teacher, or physician raises concerns about autism, many of our children must wait months for a full evaluation and diagnosis. And even then, high-quality services remain out of reach for far too many families.”*

*- Liz Feld  
President, Autism Speaks*

## What is the ADDM Network?

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

The information presented in this Community Report is from the 2010 tracking year, when the ADDM Network tracked ASD among 8-year-old children in areas of Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin.

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



### The ADDM Network's goals are to:

- ❑ Obtain as complete a count as possible of the number of children with ASD in each ADDM Network area and identify changes over time.
- ❑ Provide information on the characteristics of children with ASD.
- ❑ Determine whether ASD is more common in some groups of children than among others and if those differences are changing over time.
- ❑ Understand the impact of ASD and related conditions upon children, families, and communities in the United States.

## What is prevalence?

The ADDM Network tracks the prevalence of ASD among children. Prevalence is a scientific term that describes the number of people with a disease or condition among a defined group at a specific period in time. For example, CDC estimated the prevalence of ASD among 8-year-olds in 2010 in metropolitan Atlanta, Georgia, by counting all of the 8-year-olds in metropolitan Atlanta who were identified with ASD, and then dividing that number by the total number of 8-year-olds living in metropolitan Atlanta during 2010. The resulting number is usually expressed as a percentage or proportion of the defined group.



Number of 8-year-olds with ASD



**= PREVALENCE**



Total number of 8-year-olds

*“The CDC continues to do important work in this area, shining a bright light on what families associated with The Arc and our chapters experience everyday – autism spectrum disorder touches so many people, of all cultures and backgrounds, and we must do more to support people with autism spectrum disorder to achieve their goals and to foster an inclusive society.”*

*- Peter V. Berns*

*Chief Executive Officer, The Arc*

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

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

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

*“Autism Society Affiliates nationwide use CDC data to: track changes in overall prevalence, understand diagnostic differences and service needs based on gender and ethnicity and effectively advocate and educate in their communities.”*

*- Jim Ball*

*Executive Chairman, Autism Society of America Board*

## What Is the ADDM Network's Method?

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

# Community partnerships are the key.



## What Are the Advantages of This Method?

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

- ❑ Is the largest, ongoing ASD tracking system in the United States.
- ❑ Uses a method that is population-based, which means that we study these conditions among thousands of children from diverse communities across the country.
- ❑ Is able to look at not only how many children have ASD in multiple communities across the United States, but also which groups of children are more likely to be identified with ASD and at what age they are likely to be diagnosed.
- ❑ Collects information from multiple sources in the community where children are served, including schools and local clinics.
- ❑ Uses expert clinician reviewers and standard criteria to make a decision, based on review of behaviors documented in multiple records, about whether a child has ASD, which means that children with ASD are included in the total count even if they did not have an ASD diagnosis in their records.
- ❑ Requires many steps to maintain quality and precision, including collecting and reviewing information on all children the same way using the same criteria.

## *DSM-5 and the ADDM Network*

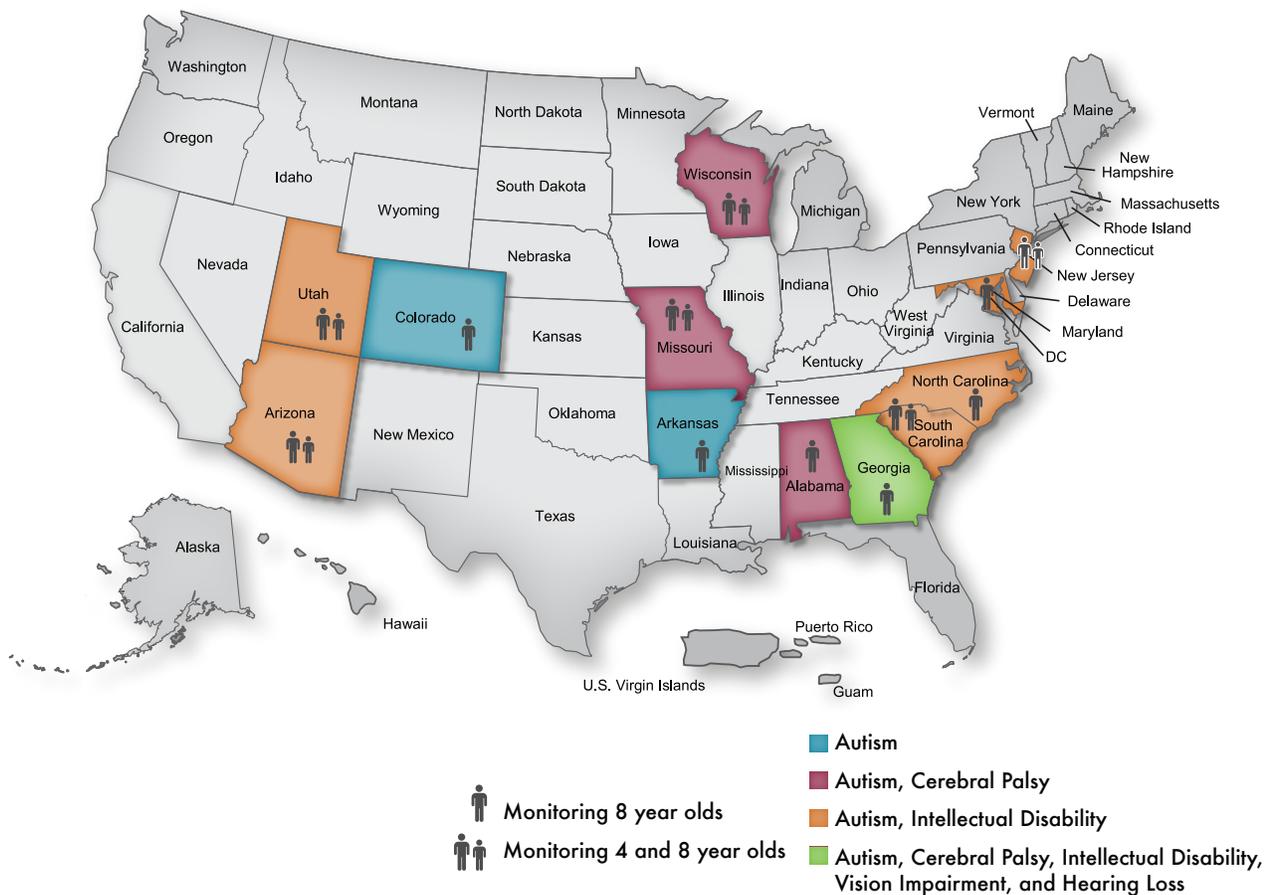
In May 2013, the American Psychiatric Association released a new edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, which is what doctors and other service providers use to diagnose mental disorders and conditions among children and adults. This new edition, also known as *DSM-5*, includes new criteria for diagnosing children and adults with ASD. **It important to note that the information in this Community Report is based on data collected in 2010 before the *DSM-5* was being used by doctors and other service providers to diagnose ASD. That means that the information in this report reflects the ASD criteria in the previous edition, *DSM-IV-TR*.**

We do not know exactly what impact *DSM-5* will have on estimates of the number of identified children with ASD in the community. An initial analysis using data from the ADDM Network found that estimates of the number of children identified with ASD might be lower using the current *DSM-5* criteria than using the previous *DSM-IV-TR* criteria (29). As doctors and other service providers start using the *DSM-5* criteria, they might diagnose ASD using new or revised tools or they might document symptoms differently. These changes in everyday community practice could offset the *DSM-5*'s effect on estimates of the number of children with ASD. Because of the way that it collects data, the ADDM Network is uniquely positioned to track these changes. The ADDM Network will be able to use both the previous *DSM-IV-TR* and the current *DSM-5* criteria to estimate the number of children with identified ASD from tracking year 2014 and onward. CDC will continue to evaluate the effect of using the *DSM-5* on trends in how doctors diagnose ASD. CDC will also continue to examine how other service providers, such as educators, evaluate and document symptoms as they transition to using the *DSM-5* criteria.

## What else is the ADDM Network doing?

Ongoing tracking is essential to our understanding of ASD. Since 2000, the ADDM Network has continued to collect data to produce estimates of the number and characteristics of children with ASD every 2 years among 8-year-old children. Starting in 2010, the Early ADDM Network, a subset of the ADDM Network, tracked ASD among 4-year-olds in areas of Arizona, Missouri, New Jersey, Utah, and Wisconsin. Some ADDM Network sites also track the number and characteristics of children with other developmental disabilities including cerebral palsy, intellectual disability, hearing loss, and vision impairment. The ADDM Network continues to analyze ADDM Network data to answer questions about potential risk factors for ASD and characteristics of children with ASD, and to understand more about the increase in ASD over time. In 2011, CDC brought together a diverse group of professionals and community stakeholders to develop a plan to better understand changes in ASD prevalence over time. The [summary](#) of the “Workshop on U.S. Data to Evaluate Changes in the Prevalence of Autism Spectrum Disorders” is a valuable resource that can help researchers and others make sense of data on the changing group of children with ASD. A full list of publications and reports based on CDC’s work in ASD can be found on our website at [www.cdc.gov/autism](http://www.cdc.gov/autism).

## Current ADDM Network Sites, Tracking Year 2012



# Key Findings

## A Snapshot of Autism Spectrum Disorder Among 8-Year-Old Children

The following estimates are based on information collected from the health and special education (if available) records of children who were 8 years old and lived in areas of Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin in 2010. These areas included a total population of 363,749 8-year-old children (representing 9% of 8-year-olds that lived in the United States in 2010). Overall, the ADDM Network identified 5,338 children with ASD, including children with and without a diagnosis documented in their records.

### How many children were identified with ASD?

**1 in 68** children (or 14.7 per 1,000 8-year-olds) was identified with ASD.

- ❑ This new estimate is roughly 30% higher than the estimate for 2008 (1 in 88), 60% higher than the estimate for 2006 (1 in 110), and 120% higher than the estimates for 2000 and 2002 (1 in 150).
- ❑ The number of children with ASD varied widely by community, from 1 in 175 children in areas of Alabama to 1 in 45 children in areas of New Jersey.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 42 boys were identified with ASD.
- ❑ 1 in 189 girls were identified with ASD.

White children were more likely to be identified with ASD than black or Hispanic children. Black children were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 63 white children were identified with ASD.
- ❑ 1 in 81 black children were identified with ASD.
- ❑ 1 in 93 Hispanic children were identified with ASD.
- ❑ 1 in 81 Asian or Pacific Islander children were identified with ASD.

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

Among children identified with ASD in the 7 sites with sufficient data on intellectual ability:

- ❑ 31% had intellectual disability (IQ ≤ 70).
- ❑ 23% were in the borderline range (IQ = 71-85).
- ❑ 46% had average or above average intellectual ability (IQ > 85).

### When were children first evaluated for developmental concerns?

Less than half (44%) of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

### How many children were diagnosed with ASD and when were they first diagnosed?

72% of children identified with ASD had a diagnosis documented in their records.

- ❑ On average, those children were not diagnosed with ASD until age 4 years and 5 months, even though children can be diagnosed as early as age 2 years.
- ❑ When looking at age of first diagnosis by subtype, on average, those children were diagnosed with:
  - Autistic Disorder at age 4 years
  - Pervasive Developmental Disorder-Not Otherwise Specified at age 4 years and 2 months
  - Asperger Disorder at age 6 years and 2 months

### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

About 80% of children identified with ASD either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 20% of children identified with ASD had documented symptoms of ASD in their records, but had not yet been classified as having ASD by a community provider.

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

1. Due to the small number of children in the Asian or Pacific Islander group, we were unable to make comparisons to other racial and ethnic groups.  
2. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

*“ CDC data are a wonderful asset to professionals, advocates, and families – from understanding how a condition affects your community to building the case on how to address it.”*

*- Adriane Griffen*

*Chairperson, Friends of the National Center on Birth Defects and Developmental Disabilities*

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

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

The federal government uses this information to –

- ❑ Measure progress toward goals.
  - For example, ADDM Network data are used to measure progress toward the **Healthy People 2020** goals of increasing the proportion of children with ASD with a first evaluation by 36 months of age and enrolled in special services by 48 months of age (30).

Guide our research and the research of other scientists across the country.

- For example, ADDM Network data have helped inform the Interagency Autism Coordinating Committee’s **Strategic Plan** for ASD research (31).
- ❑ Promote early identification efforts.
  - For example, ADDM Network data on average age of diagnosis support CDC’s “**Learn the Signs. Act Early.**” program, which aims to lower the average age of diagnosis by promoting developmental monitoring among parents, childcare providers, and healthcare providers.

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

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

Policymakers and community leaders can use this information to –

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

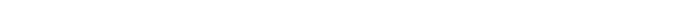
Researchers can use this information to –

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

*“ CDC’s data give Easter Seals and the individuals and families that we serve the information that is essential to our efforts to close service gaps so that children and adults with autism spectrum disorder can live, learn, work and play in their communities.”*

*- Mary Andrus*

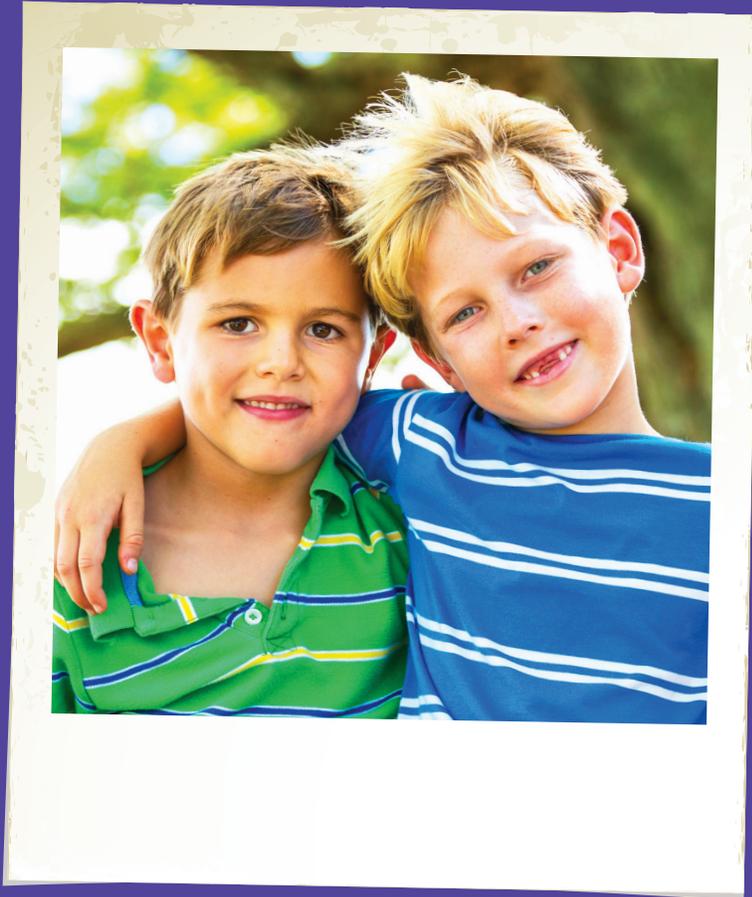
*Assistant Vice President, Government Relations  
Easter Seals*



# State by State:

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## Key Findings and Resources



# Alabama

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Alabama:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Alabama

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in one of nine counties in 2010 (see sidebar). Overall, the Alabama Autism Surveillance Program (AASP) identified 125 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 175** children (or 5.7 per 1,000 8-year-olds) was identified with ASD. This estimate is lower than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

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

- ❑ 1 in 114 boys was identified with ASD.
- ❑ 1 in 417 girls was identified with ASD.

White and black children were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 161 white children was identified with ASD.
- ❑ 1 in 189 black children was identified with ASD.

#### When were children first evaluated for developmental concerns?

53% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

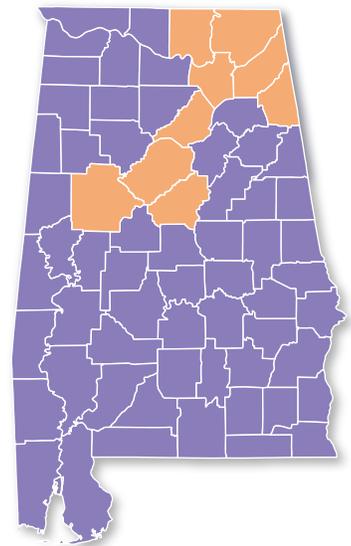
#### When were children first diagnosed with ASD by a community provider??

On average, children were diagnosed at age 4 years and 7 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 3 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 5 months.
- ❑ Asperger disorder at age 6 years and 1 month.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

76% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 24% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: Blount, Cherokee, DeKalb, Jackson, Jefferson, Madison, Marshall, Shelby, and Tuscaloosa counties (area covered by education sources was smaller than area covered by health sources)

Children in tracking area: 21,833 8-year-old children, of whom about 59% were white, 31% were black, 8% were Hispanic, and 2% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Alabama Autism Surveillance Program (AASP) was established in 2002 as an ADDM Network site in collaboration with the Alabama Department of Public Health and investigators from Department of Health Care Organization and Policy in the School of Public Health at the University of Alabama at Birmingham. AASP partners with the Autism Society of Alabama, the Alabama State Department of Education, and many other state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 8-year-old children with ASD or cerebral palsy, or both, living in select areas of Alabama. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. AASP data are important to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education**

AASP's education and outreach efforts focus on awareness events for ASD and cerebral palsy, training sessions for professionals and families regarding access to ASD resources, and detailed presentations on data from AASP and the ADDM Network. This outreach is designed to inform state and local partners about ASD in a manner that supports ASD service and systems building in our state. Education and outreach are conducted in partnership with the Alabama Interagency Autism Coordinating Council (AIACC), the Autism Society of Alabama (ASA) and other partners. Through our partnership with ASA, AASP staff members provide workshops and trainings for parents, teachers, and primary care providers to promote early recognition of ASD signs, to enhance our providers' capacity to identify and diagnose ASD, and to improve our system of care for children with ASD and their families.

#### **For more information about AASP, please contact:**

Martha Wingate, DrPH  
University of Alabama at Birmingham  
School of Public Health,  
1665 University Boulevard,  
RPHB 320  
Birmingham, AL 35294  
Phone: 205-934-6783  
E-mail: mslay@uab.edu

#### **Access Resources and Help Connect Families to Services and Supports in Alabama**

##### **Alabama's Early Intervention System**

Phone: 1-800-543-3098

Web: [www.rehab.alabama.gov/ei](http://www.rehab.alabama.gov/ei)

##### **Alabama State Department of Education**

Phone: 334-242-8114

Web: [www.alsde.edu](http://www.alsde.edu)

##### **Autism Society of Alabama**

Web: [www.autism-alabama.org](http://www.autism-alabama.org)

##### **Alabama Interagency Autism Coordinating Council**

Phone: 205-478-3402

E-mail: [anna.mcconnell@mh.alabama.gov](mailto:anna.mcconnell@mh.alabama.gov)

Web: [www.autism.alabama.gov](http://www.autism.alabama.gov)

##### **Glenwood Autism and Behavioral Health Center**

Web: <http://glenwood.org/>

##### **Learn the Signs. Act Early.**

Anna McConnell, Alabama's Act  
Early Ambassador

Phone: 205-478-3402

E-mail: [anna.mcconnell@mh.alabama.gov](mailto:anna.mcconnell@mh.alabama.gov)

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

Web: [www.uab.edu/civitansparksparks/act-early-alabama](http://www.uab.edu/civitansparksparks/act-early-alabama)

<sup>1</sup> Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup> This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Arizona

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Arizona: *What You Need To Know*

### *A Snapshot of Autism Spectrum Disorder in Arizona*

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in metropolitan Phoenix in 2010 (see sidebar). Overall, the Arizona Developmental Disabilities Surveillance Program (ADDSP) identified 530 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

### *How many children were identified with ASD?*

**1 in 64** children (or 15.7 per 1,000 8-year-olds) was identified with ASD.

This estimate is slightly higher than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

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

- ❑ 1 in 40 boys was identified with ASD.
- ❑ 1 in 167 girls was identified with ASD.

White and black children were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 53 white children was identified with ASD.
- ❑ 1 in 61 black children was identified with ASD.
- ❑ 1 in 94 Hispanic children was identified with ASD.
- ❑ 1 in 52 Asian or Pacific Islander children was identified with ASD.

### *When were children first evaluated for developmental concerns?*

36% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

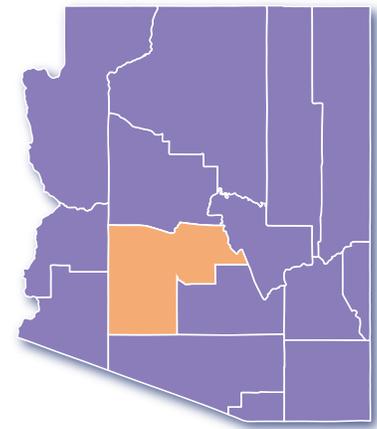
### *When were children first diagnosed with ASD by a community provider<sup>2</sup>?*

On average, children were diagnosed at age 4 years and 11 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 10 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 7 months.
- ❑ Asperger disorder at age 6 years and 7 months.

### *How many children had an eligibility for autism special education services at school or had an ASD diagnosis?*

74% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 26% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



### Site Information

Tracking area: Part of Maricopa County that included metropolitan Phoenix (including 15 school districts).

Children in tracking area: 33,768 8-year-old children, of whom about 48% were white, 6% were black, 41% were Hispanic, 3% were Asian or Pacific Islander, and 2% were American Indian/Alaska Native



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Arizona Developmental Disabilities Surveillance Program (ADDSP) was established in 2000 as an ADDM Network site in collaboration with the Arizona Department of Health Services and investigators from University of Arizona (Department of Pediatrics and Mel and Enid Zuckerman College of Public Health). ADDSP partners with the Arizona Department of Education and numerous local agencies that serve children with developmental disabilities to track the number of 4-year-old and 8-year-old children with ASD, intellectual disability, or both living in select areas of Arizona. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. ADDSP data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

ADDSP staff offer workshops to healthcare and other service providers to increase recognition of the early signs of ASD and to enhance their capacity to diagnose and report ASD.

#### **For more information about ADDSP, please contact:**

Sydney Pettygrove, PhD  
University of Arizona  
Arizona Health Sciences Center  
1501 N. Campbell Ave  
Tucson, AZ 85724  
Phone: 520-626-3704

Margaret Kurzius-Spencer, PhD  
See address above  
Phone: 520-626-5174

#### **Access Resources and Help Connect Families to Services and Supports in Arizona**

##### **Arizona Early Intervention Program**

Phone: 602-532-9960  
OR 888-439-5609.  
Web: <http://azdes.gov/AzEIP/>

##### **Arizona Department of Education, Exceptional Student Services.**

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

##### **Arizona Autism Coalition**

Phone: 480-268-1453  
Web: <http://azautism.org>

##### **Autism Society of Greater Tucson**

Phone: 520-770-1541.  
Web: [www.autismsociety  
greatertucson.org](http://www.autismsocietygreatertucson.org)

##### **Autism Society of Greater Phoenix**

Phone: 480-940-1093  
Web: [www.phxautism.org](http://www.phxautism.org)

##### **Learn the Signs. Act Early.**

Ann Mastergeorge, Arizona's  
Act Early Ambassador  
Phone: 520-621-6933  
E-mail: [amastergeorge@  
email.arizona.edu](mailto:amastergeorge@email.arizona.edu)  
Web: [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Arkansas

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Arkansas:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Arkansas

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in Arkansas in 2010 (see sidebar). Overall, the Arkansas Autism and Developmental Disabilities Monitoring Program (AR-ADDMM) identified 605 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 65** children (or 15.5 per 1,000 8-year-olds) was identified with ASD.

This estimate is about the same as the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

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

- 1 in 40 boys was identified with ASD.
- 1 in 172 girls was identified with ASD.

White children were more likely to be identified with ASD than black and Hispanic children<sup>1</sup>.

- 1 in 57 white children was identified with ASD.
- 1 in 91 black children was identified with ASD.
- 1 in 110 Hispanic children was identified with ASD.
- 1 in 87 Asian or Pacific Islander children was identified with ASD.

#### When were children first evaluated for developmental concerns?

35% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

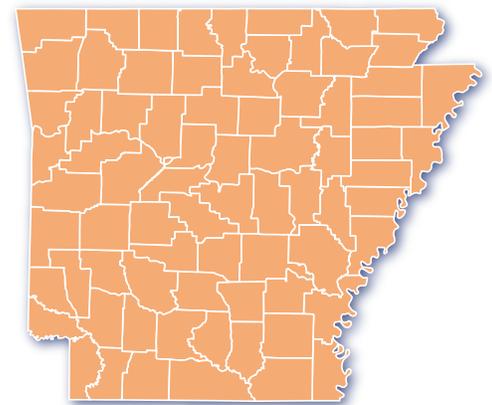
#### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 5 years and 1 month, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- Autistic disorder at age 4 years and 7 months.
- Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 5 years and 3 months.
- Asperger disorder at age 6 years and 3 months.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

77% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 23% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: All 75 counties in Arkansas

Children in tracking area: 38,956 8-year-old children, of whom about 68% were white, 19% were black, 11% were Hispanic, and 2% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Arkansas Autism and Developmental Disabilities Monitoring (AR-ADDM) Program was established in 2002 as an ADDM Network site in collaboration with the Arkansas Department of Health and investigators from the University of Arkansas for Medical Services (UAMS). AR-ADDM partners with state programs, agencies, and organizations that serve children with developmental disabilities and their families to track the number of 8-year-old children with ASD, intellectual disability, or both living in Arkansas. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. AR-ADDM data be can used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

AR-ADDM offers individualized presentations on the number and characteristics of children with ASD. In partnership with UAMS Department of Pediatrics and Arkansas Children's Hospital, AR-ADDM staff provide training to physicians and staff in medical grand rounds, co-sponsor educational events for families and educators (such as, TeamUP), and collaborate on developmental disabilities awareness events (such as Walk Now for Autism Speaks). AR-ADDM's investigators provide leadership in federal, state, and local programs offering training on diagnosis and management of ASD, including Autism Treatment Network, Community-Based Autism Liaison and Treatment (CoBALT), and Leadership Education in Neurodevelopmental Disabilities.

#### **For more information about AR-ADDM, please contact:**

Allison Hudson  
University of Arkansas for Medical Sciences  
Department of Pediatrics,  
Developmental Pediatrics  
1 Children's Way, Slot 512-41  
Little Rock, AR 72202  
Phone: 501-364-3612  
E-mail: aehudson@uams.edu

#### **Access Resources and Help Connect Families to Services and Supports in Arkansas**

##### **First Connections (Part C Early Intervention)-AR Infant and Toddler Program**

Phone: 1-800-643-8258

Web: [www.arkansas.gov/dhs/ddds/FirstConn](http://www.arkansas.gov/dhs/ddds/FirstConn)

##### **Arkansas Department of Education, Special Education Unit**

Phone: 501-682-4221

Web: <https://arksped.k12.ar.us>

Request services through:

Phone: 1-800-482-8437

Web: <https://arksped.k12.ar.us/sections/circuit.html>

##### **Autism Speaks/Autism Treatment Network Site Hannah Field**

Phone: 501-364-4665

Web: [HCFeild@uams.edu](mailto:HCFeild@uams.edu)

##### **Arkansas Autism Resource and Outreach Center**

Phone: 1-800-342-2923

Web: <http://aaroc.org/>

##### **The Dennis Developmental Center**

Phone: 501-364-1830

Web: [www.uams.edu/ddc](http://www.uams.edu/ddc)

##### **Learn the Signs. Act Early.**

Peggy Schaefer Whitby, Arkansas'  
Act Early Ambassador

University of Arkansas

Phone: 479-575-3302

E-mail: [pschaeffe@uark.edu](mailto:pschaeffe@uark.edu)

<sup>1</sup> Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup> This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Colorado

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Colorado:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Colorado

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in one of seven counties in 2010 (see sidebar). Overall, the Colorado Autism and Developmental Disabilities Monitoring Project (CO-ADDMM) identified 384 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 101** children (or 9.9 per 1,000 8-year-olds) was identified with ASD.

This estimate is lower than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

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

- ❑ 1 in 65 boys was identified with ASD.
- ❑ 1 in 238 girls was identified with ASD.

White were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 88 white children was identified with ASD.
- ❑ 1 in 109 black children was identified with ASD.
- ❑ 1 in 164 Hispanic children was identified with ASD.
- ❑ 1 in 135 Asian or Pacific Islander children was identified with ASD.

#### When were children first evaluated for developmental concerns?

41% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

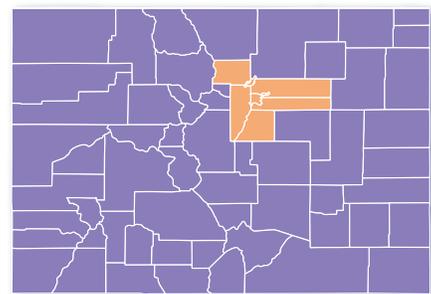
#### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 5 years, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 3 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 5 years.
- ❑ Asperger disorder at age 7 years.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

65% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 35% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, and Jefferson counties

Children in tracking area: 38,806 8-year-old children, of whom about 56% were white, 6% were black, 33% were Hispanic, and 5% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network site. The Colorado Autism and Developmental Disabilities Monitoring Project (CO-ADDM) was established in 2002 as an ADDM Network site and is a joint undertaking with Colorado Department of Public Health and Environment and JFK Partners at the University of Colorado Denver School of Medicine. CO-ADDM partners with other state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 8-year-old children with ASD living in select areas of Colorado. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. CO-ADDM data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

CO-ADDM offers tailored presentations on the number and characteristics of children with ASD in Colorado and across the ADDM Network. It also serves to link families and community partners with resources to improve collaboration across programs in Colorado.

#### **For more information about CO-ADDM, please contact:**

Kelly R. Kast, MSPH  
Colorado Department of Public Health and Environment  
4300 Cherry Creek South Drive  
Denver, CO 80228  
Phone: 303-692-2680  
E-mail: [kelly.kast@state.co.us](mailto:kelly.kast@state.co.us)

#### **Access Resources and Help Connect Families to Services and Supports in Colorado**

##### **Early Intervention Colorado**

Phone: 888-777-4041

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

##### **Colorado Department of Education**

Melinda Graham

Phone: 303-866-6707

E-mail: [graham\\_m@cde.state.co.us](mailto:graham_m@cde.state.co.us)

Web: [www.cde.state.co.us/cdesped/sd-autism](http://www.cde.state.co.us/cdesped/sd-autism)

##### **Autism Society of Colorado**

Phone: 720-214-0794

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

##### **Family Voices Colorado**

Phone: 800-881-8272

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

##### **The Arc of Colorado**

Phone: 303-864-9334

Web: [www.thearcofco.org](http://www.thearcofco.org)

##### **Autism Treatment Network**

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

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

##### **Learn the Signs. Act Early.**

Debra Efird, Colorado's

Act Early Ambassador

E-mail: [debbie.efird@ucdenver.edu](mailto:debbie.efird@ucdenver.edu)

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

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Georgia

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Georgia:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Georgia

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in one of five counties in 2010 (see sidebar). Overall, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) identified 754 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 64** children (or 15.5 per 1,000 8-year-olds) was identified with ASD. This estimate is about the same as the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 39 boys was identified with ASD.
- ❑ 1 in 181 girls was identified with ASD.

White children were more likely to be identified with ASD than black children<sup>1</sup>. White and black children were more likely to be identified with ASD than Hispanic children.

- ❑ 1 in 55 white children was identified with ASD.
- ❑ 1 in 71 black children was identified with ASD.
- ❑ 1 in 93 Hispanic children was identified with ASD.
- ❑ 1 in 81 Asian or Pacific Islander children was identified with ASD.

#### When were children first evaluated for developmental concerns?

45% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

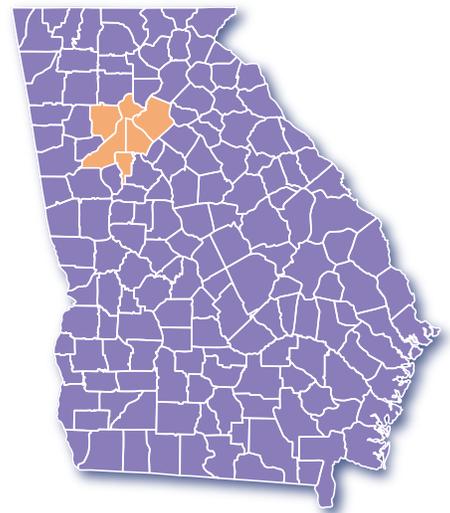
#### When were children first diagnosed with ASD by a community provider??

On average, children were diagnosed at age 4 years and 1 month, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 3 years and 9 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 1 month.
- ❑ Asperger disorder at age 6 years.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

87% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 13% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: Clayton, Cobb, DeKalb, Fulton, and Gwinnett counties

Children in tracking area: 48,529 8-year-old children, of whom about 33% were white, 43% were black, 18% were Hispanic, and 6% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) was established in 1991 by the Centers for Disease Control and Prevention (CDC), and, since 2000, MADDSP has served as the model site in CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. MADDSP partners with the Georgia Department of Public Health, the Georgia Department of Education, and other state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 8-year-old children with ASD, cerebral palsy, hearing loss, intellectual disability, and/or vision impairment in metro Atlanta. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. MADDSP data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

MADDSP collaborates with community organizations to host annual autism awareness month events in Georgia in order to engage with community partners that make MADDSP possible, and to raise awareness of ASD by portraying the lives of individuals with the condition. MADDSP staff offer workshops and trainings for parents, teachers, and healthcare providers to increase knowledge of ASD and build capacity among community members. MADDSP staff also offer tailored data reports and presentations on the number and characteristics of children with ASD and other developmental disabilities in metro Atlanta and across the ADDM Network.

#### **For more information about MADDSP, please contact:**

Kim Van Naarden Braun, PhD  
Centers for Disease Control and Prevention  
National Center on Birth Defects and Developmental Disabilities  
1600 Clifton Road, Mail Stop-E86  
Atlanta, GA 30333  
Phone: 404-498-3860  
E-mail: [KVanNaarden@cdc.gov](mailto:KVanNaarden@cdc.gov)  
Web: [www.cdc.gov/MADDSP](http://www.cdc.gov/MADDSP)

#### **Access Resources and Help Connect Families to Services and Supports in Georgia**

##### **Georgia's Babies Can't Wait early intervention system**

Phone: 404-657-2762

Web: <http://dph.georgia.gov/Babies-Cant-Wait>

##### **Georgia Department of Education's Special Education Services and Supports**

Phone: 404-656-3963

Web: [www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/default.aspx](http://www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Pages/default.aspx)

##### **Autism Society Georgia**

Web: [www.asaga.com](http://www.asaga.com)

##### **Autism Speaks**

Phone: 770-451-0570

E-mail: [georgia@autismspeaks.org](mailto:georgia@autismspeaks.org)

##### **Parent 2 Parent of Georgia**

Phone: 1-800-229-2038

Web: <http://p2pga.org/>

##### **Atlanta Autism Consortium**

E-mail: [executive-director@atlantaautismconsortium.org](mailto:executive-director@atlantaautismconsortium.org)

Web: [www.hsi.gatech.edu/atl-autism/about](http://www.hsi.gatech.edu/atl-autism/about)

##### **Autism Plan for Georgia**

Donna Johnson

E-mail: [DJohnson@Ga-AutismPlan.com](mailto:DJohnson@Ga-AutismPlan.com)

Web: <http://ga-autismplan.com/>

##### **Learn the Signs. Act Early.**

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

<sup>1</sup> Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup> This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Maryland

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Maryland:

### What You Need To Know



### A Snapshot of Autism Spectrum Disorder in Maryland

The following estimates are based on information collected from the health and special education records of children who were 8 years old in 2010 and living in one of six counties in 2010 (see sidebar). Overall, Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) identified 458 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

### How many children were identified with ASD?

**1 in 60** children (or 16.6 per 1,000 8-year-olds) was identified with ASD. This estimate is higher than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 37 boys was identified with ASD.
- ❑ 1 in 179 girls was identified with ASD.

White children were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 60 white children was identified with ASD.
- ❑ 1 in 65 black children was identified with ASD.
- ❑ 1 in 102 Hispanic children was identified with ASD.
- ❑ 1 in 84 Asian or Pacific Islander children was identified with ASD.

### When were children first evaluated for developmental concerns?

45% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 4 years and 8 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 2 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 7 months.
- ❑ Asperger disorder at age 6 years and 2 months.

### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

88% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 12% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.

### Site Information

Tracking area: Anne Arundel, Baltimore, Carroll, Cecil, Harford, and Howard counties

Children in tracking area: 27,605 8-year-old children, of whom about 64% were white, 23% were black, 7% were Hispanic, and 6% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) Project was established in 2001 as an ADDM Network site in collaboration with the Maryland Department of Health and Mental Hygiene and investigators from the Johns Hopkins Bloomberg School of Public Health. MD-ADDM partners with the Maryland State Department of Education, the Kennedy Krieger Institute, Mt. Washington Pediatric Hospital, and other organizations that serve children with developmental disabilities and their families to track the number of 8-year-old children with ASD, intellectual disability, or both in select areas of Maryland. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. MD-ADDM data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

MD-ADDM offers presentations on the number and characteristics of children with ASD in Maryland and across the ADDM Network for our data sources, stakeholders, state and local agencies, and parent groups. Also, MD-ADDM participates in and organizes annual autism awareness month events in our community.

#### **For more information about MD-ADDM, please contact:**

Li-Ching Lee, PhD ScM  
Johns Hopkins University  
Bloomberg School of Public Health,  
Department of Epidemiology  
615 N. Wolfe Street, Suite E6032  
Baltimore, MD 21205  
Phone: 410-502-0605  
E-mail: llee2@jhsph.edu

#### **Access Resources and Help Connect Families to Services and Supports in Maryland**

##### **Maryland State Department of Education's Division of Special Education and Early Intervention Services**

Web: [www.marylandpublicschools.org/MSDE/divisions/earlyinterv/index.html](http://www.marylandpublicschools.org/MSDE/divisions/earlyinterv/index.html)

##### **The Center for Autism and Related Disorders (CARD) at the Kennedy Krieger Institute**

Web: [www.kennedykrieger.org/patient-care/patient-care-centers/center-autism-and-related-disorders](http://www.kennedykrieger.org/patient-care/patient-care-centers/center-autism-and-related-disorders)

##### **Learn the Signs. Act Early.**

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

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Missouri

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Missouri:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Missouri

The following estimates are based on information collected from the health records of children who were 8 years old and living in one of five counties in 2010 (see sidebar). Overall, the Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM) identified 359 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 70** children (or 14.2 per 1,000 8-year-olds) was identified with ASD. This estimate is very similar to the average estimate of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 43 boys was identified with ASD.
- ❑ 1 in 200 girls was identified with ASD.

White children were more likely to be identified with ASD than black children<sup>1</sup>.

- ❑ 1 in 73 white children was identified with ASD.
- ❑ 1 in 119 black children was identified with ASD.
- ❑ 1 in 81 Hispanic children was identified with ASD.
- ❑ 1 in 118 Asian or Pacific Islander children was identified with ASD.

#### When were children first evaluated for developmental concerns?

54% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

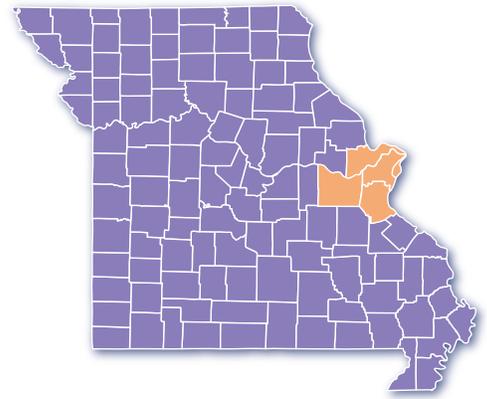
#### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 3 years and 10 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 11 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 3 years and 3 months.
- ❑ Asperger disorder at age 6 years and 3 months.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

88% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 12% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

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

Children in tracking area: 25,367 8-year-old children, of whom about 67% were white, 25% were black, 4% were Hispanic, and 3% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM) was established in 2003 as an ADDM Network site in collaboration with the Missouri Department of Health and Senior Services and investigators from the School of Medicine at Washington University in St. Louis. MO-ADDM partners with state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 4-year-old and 8-year old children with ASD, cerebral palsy, or both in select areas of Missouri. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. MO-ADDM data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

The leadership of MO-ADDM is engaged in a broad range of autism-related public health, research, and clinical activities that encompass regular efforts to appraise clinicians, educators, families, and other stakeholders, as well as the general public, on new scientific developments including epidemiology, best practices for early intervention, clinical care, and education of children affected by ASD. MO-ADDM investigators are also involved in the training of physicians in the fields of pediatrics, child neurology, and child psychiatry.

#### **For more information about MO-ADDM, please contact:**

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

#### **Access Resources and Help Connect Families to Services and Supports in Missouri**

##### **Department of Elementary and Secondary Education**

Web: <http://dese.mo.gov/>

##### **First Steps**

Phone: 1-866-583-2392

##### **Missouri Families for Effective Autism Treatment**

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

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

Web: <http://dmh.mo.gov/dd/>

##### **Learn the Signs. Act Early.**

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

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# New Jersey

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in New Jersey:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in New Jersey

The following estimates are based on information collected from the health and special education records of children who were 8-year-olds and living in one of four counties in 2010 (see sidebar). Overall, the New Jersey Autism Study (NJAS) identified 696 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 45** children (or 21.9 per 1,000 8-year-olds) was identified with ASD. This estimate is higher than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 28 boys was identified with ASD.
- ❑ 1 in 133 girls was identified with ASD.

White children were more likely to be identified with ASD than black children<sup>1</sup>.

- ❑ 1 in 44 white children was identified with ASD.
- ❑ 1 in 56 black children was identified with ASD.
- ❑ 1 in 47 Hispanic children was identified with ASD.
- ❑ 1 in 48 Asian or Pacific Islander children was identified with ASD.

#### When were children first evaluated for developmental concerns?

41% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

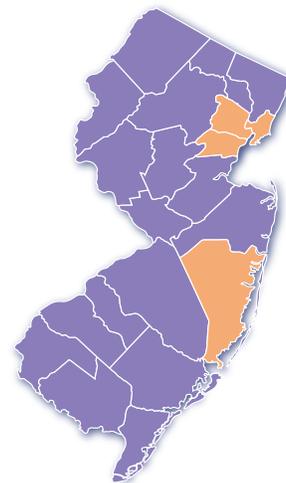
#### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 4 years, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 3 years and 4 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 3 years and 9 months.
- ❑ Asperger disorder at age 6 years and 7 months.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

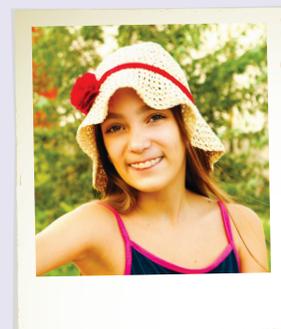
76% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 24% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: Essex, Hudson, Union, and Ocean counties

Children in tracking area: 31,723 8-year-old children, of whom about 43% were white, 23% were black, 28% were Hispanic, and 5% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### Public Health Action

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The New Jersey Autism Study (NJAS) was established in 2000 as an ADDM Network site in collaboration with the New Jersey Department of Health and Senior Services and investigators from Rutgers-New Jersey Medical School. NJAS partners with the New Jersey Department of Education and other state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 4-year-old and 8-year-old children with ASD, intellectual disability, or both in select areas of New Jersey. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. NJAS data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### Training and Education on Autism Spectrum Disorder

NJAS offers training on the identification and diagnosis of ASD, makes presentations on ASD tracking and our scientific findings, sponsors workshops on ASD topics, and assists families and policy makers in understanding the scope and consequences of ASD.

#### For more information about NJAS, please contact:

Walter Zahorodny, PhD  
Rutgers-New Jersey Medical School  
185 South Orange Avenue, F570  
Newark, New Jersey 07101  
Phone: 973-972-9773  
E-mail: zahorodn@njms.rutgers.edu  
Web: [www.njms.rutgers.edu/departments/pediatrics/njas/](http://www.njms.rutgers.edu/departments/pediatrics/njas/)

#### Access Resources and Help Connect Families to Services and Supports in New Jersey

##### New Jersey Early Intervention System

Web: [www.nj.gov/health/fhs/eis/](http://www.nj.gov/health/fhs/eis/)

##### New Jersey Department of Education's Office of Special Education Program

Mary B. Haspel, Autism  
and Multiple Disabilities Specialist  
E-mail: [mary.haspel@doe.state.nj.us](mailto:mary.haspel@doe.state.nj.us)

Web: [www.nj.gov/education/specialed/](http://www.nj.gov/education/specialed/)

##### Autism New Jersey

Phone: 800-4-AUTISM

Web: [www.autismnj.org](http://www.autismnj.org)

##### Autism Family Services of New Jersey

Phone: 877-237-4477

Web: [www.autismfamily-servicesnj.org](http://www.autismfamily-servicesnj.org)

##### Statewide Parent Advocacy Network

Phone: 800-654-7726

Web: [www.spannj.org](http://www.spannj.org)

##### Asperger Syndrome Education Network

Phone: 732-321-0880

Web: [www.aspennj.org](http://www.aspennj.org)

##### Governor's Council for Medical Research and Treatment of Autism

Web: [www.state.nj.us/health/autism/](http://www.state.nj.us/health/autism/)

##### Learn the Signs. Act Early.

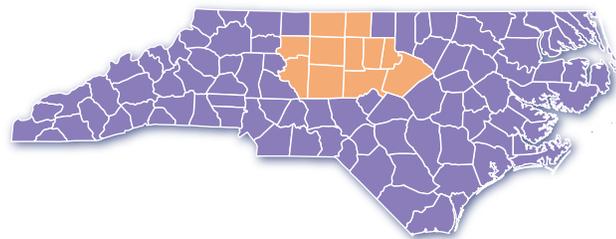
Web: [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# North Carolina

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in North Carolina: What You Need To Know



### A Snapshot of Autism Spectrum Disorder in North Carolina

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in one of eleven counties in 2010 (see sidebar). Overall, North Carolina Autism and Developmental Disabilities Monitoring Project (NC-ADDMM) identified 655 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

### How many children were identified with ASD?

**1 in 58** children (or 17.3 per 1,000 8-year-olds) was identified with ASD. This estimate is higher than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 35 boys was identified with ASD.
- ❑ 1 in 179 girls was identified with ASD.

White and black children were more likely to be identified with ASD than Hispanic children<sup>1</sup>.

- ❑ 1 in 53 white children was identified with ASD.
- ❑ 1 in 64 black children was identified with ASD.
- ❑ 1 in 103 Hispanic children was identified with ASD.
- ❑ 1 in 53 Asian or Pacific Islander children was identified with ASD.

### When were children first evaluated for developmental concerns?

59% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 3 years and 8 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 3 years and 1 month.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 3 months.
- ❑ Asperger disorder at age 6 years and 4 months.

### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

75% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 25% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.

### Site Information

Tracking area: Alamance, Caswell, Chatham, Davidson, Durham, Forsyth, Guilford, Orange, Randolph, Rockingham, and Wake counties

Children in tracking area: 37,783 8-year old children, of whom about 54% were white, 25% were black, 16% were Hispanic, and 5% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The North Carolina Center for Autism and Developmental Disabilities Monitoring Project (NC-ADDM) was established in 2002 as an ADDM Network site in collaboration with the North Carolina Department of Health and Human Services and investigators from the University of North Carolina—Chapel Hill. NC-ADDM partners with state and local agencies and organizations to track the number of 8-year-old children with ASD, intellectual disability, or both living in central North Carolina. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. NC-ADDM data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

NC-ADDM provides data on the number and characteristics of 8-year-old children with ASD and intellectual disability to the health and educational agencies in the state that diagnose and serve children with these disabilities. We work with the North Carolina Autism Alliance and other interdisciplinary partners to use our data to continually identify ways our data can help improve our understanding of the needs and opportunities of families in North Carolina.

#### **For more information about NC-ADDM, please contact:**

Julie Daniels, PhD  
University of North Carolina at Chapel Hill  
Gillings School of Global Public Health  
Chapel Hill, NC 27599  
Phone: 919-966-7096  
E-mail: Julie\_Daniels@unc.edu

#### **Access Resources and Help Connect Families to Services and Supports in North Carolina**

##### **North Carolina Infant-Toddler Program.**

Web: [www.ncei.org](http://www.ncei.org)

##### **TEACCH Autism Program.**

Web: <http://teacch.com/>

##### **Autism Society of North Carolina**

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

##### **Autism Speaks**

Web: [www.autismspeaks.org](http://www.autismspeaks.org)

##### **Study to Explore Early Development (SEED)**

Web: [www.ncseed.org](http://www.ncseed.org)

##### **Learn the Signs. Act Early.**

Rebecca Edmondson Pretzel,  
North Carolina's

Act Early Ambassador

Phone: 919-949-6148

E-mail: [becky.edmondson@cidd.unc.edu](mailto:becky.edmondson@cidd.unc.edu)

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

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Utah

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Utah:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Utah

The following estimates are based on information collected from the health and special education records of children who were 8 years old and living in one of three counties in 2010 (see sidebar). Overall, the Utah Autism and Developmental Disabilities Monitoring Project (UT-ADDM) identified 442 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 54** children (or 18.6 per 1,000 8-year-olds) was identified with ASD.

This estimate is higher than the average number of children identified with ASD (1 in 68) in all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 34 boys was identified with ASD.
- ❑ 1 in 135 girls was identified with ASD.

White and Hispanic children were about equally likely to be identified with ASD<sup>1</sup>.

- ❑ 1 in 52 white children was identified with ASD.
- ❑ 1 in 60 Hispanic children was identified with ASD.

#### When were children first evaluated for developmental concerns?

33% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

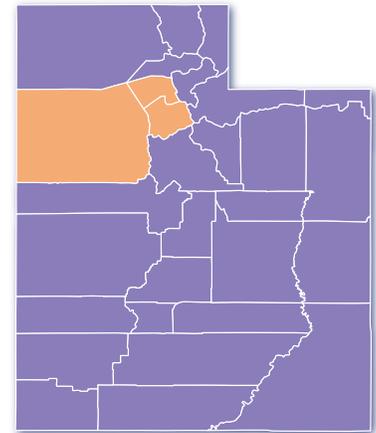
#### When were children first diagnosed with ASD by a community provider<sup>2</sup>?

On average, children were diagnosed at age 4 years and 5 months, even though children can be diagnosed as early as age 2 years. When looking at age of first diagnosis by subtype, on average, children were diagnosed with:

- ❑ Autistic disorder at age 4 years and 2 months.
- ❑ Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 4 months.
- ❑ Asperger disorder at age 5 years and 8 months.

#### How many children had an eligibility for autism special education services at school or had an ASD diagnosis?

90% of children either had an eligibility for autism special education services at school or had an ASD diagnosis. The remaining 10% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



#### Site Information

Tracking area: Salt Lake, Davis, and Tooele counties

Children in tracking area: 23,756 8-year-old children, of whom about 73% were white, 2% were black, 20% were Hispanic, and 4% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities, as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Utah Autism and Developmental Disabilities Monitoring Project (UT-ADDM) was established in 2002 as an ADDM Network site in collaboration with the Utah Department of Health and investigators from the University of Utah. UT-ADDM partners with state and local agencies and organizations that serve children with developmental disabilities and their families to track the number of 4-year-old children and 8-year-old children with ASD, intellectual disability, or both. This program also contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. UT-ADDM data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

UT-ADDM and the Utah Registry of Autism and Developmental Disorders (URADD) provide community outreach through their participation in community events, awareness activities, and professional education meetings. Our ASD estimates are used by the Utah Department of Health, Utah State Office of Education, the Utah Legislature, and by community leaders to inform decision and policymaking and to increase community awareness of ASD.

#### **For more information about UT-ADDM, please contact:**

Deborah Bilder MD  
University of Utah  
Department of Psychiatry, Division of Child and Adolescent Psychiatry  
650 Komas Drive, Suite 206  
Salt Lake City, UT 84108  
Phone: 801-585-9107  
E-mail: Deborah.Bilder@hsc.utah.edu

#### **Access Resources and Help Connect Families to Services and Supports in Utah**

##### **Baby Watch Early Intervention**

Web: [www.utahbabywatch.org/  
contactus.htm](http://www.utahbabywatch.org/contactus.htm)

##### **The Utah State Office of Education**

Web: [www.schools.utah.gov/sars](http://www.schools.utah.gov/sars)

##### **The Autism Council of Utah**

Web: [http://autismcouncil  
ofutah.org](http://autismcouncilofutah.org)

##### **Autism Speaks**

Web: [www.autismspeaks.org](http://www.autismspeaks.org)

##### **The Utah Parent Center**

Web: [http://www.utahparent  
center.org](http://www.utahparentcenter.org)

##### **The Child Development Clinic**

Web: [http://health.utah.gov/  
cshcn/CDC/](http://health.utah.gov/cshcn/CDC/)

##### **Utah Registry of Autism and Developmental Disorders**

Web: [http://utahautism  
registry.org/](http://utahautismregistry.org/)

##### **Learn the Signs. Act Early.**

Tracy Golden, Utah's  
Act Early Ambassador  
Phone: 801-597-5386  
E-mail: [tracy.golden@uvu.edu](mailto:tracy.golden@uvu.edu)  
Web: [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)

<sup>1</sup> Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup> This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

# Wisconsin

## Tracking Autism Spectrum Disorder and Other Developmental Disabilities in Wisconsin:

### What You Need To Know

#### A Snapshot of Autism Spectrum Disorder in Wisconsin

The following estimates are based on information collected from health records of children who were 8 years old and living in one of ten counties in 2010 (see sidebar). Overall, the Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS) identified 330 children with autism spectrum disorder (ASD), including children with and without a diagnosis documented in their records.

#### How many children were identified with ASD?

**1 in 108** children (or 9.3 per 1,000 8-year-olds) was identified with ASD. This estimate is lower than the average estimate of children identified with ASD (1 in 68) in the all areas of the United States where CDC tracks ASD.

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

Boys were almost 5 times more likely to be identified with ASD than girls.

- ❑ 1 in 65 boys was identified with ASD.
- ❑ 1 in 323 girls was identified with ASD.

White children were more likely to be identified with ASD than black and Hispanic children<sup>1</sup>.

- ❑ 1 in 95 white children was identified with ASD.
- ❑ 1 in 217 black children was identified with ASD.
- ❑ 1 in 179 Hispanic children was identified with ASD.

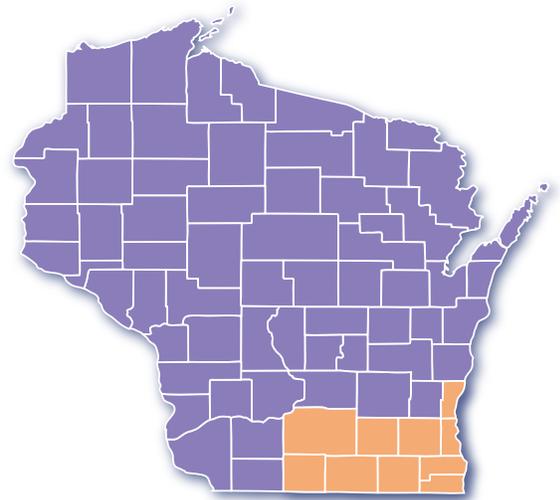
#### When were children first evaluated for developmental concerns?

51% of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.

#### How many children were diagnosed with ASD and when were they first diagnosed by a community provider<sup>2</sup>?

88% of children identified with ASD had a diagnosis documented in their records.

- ❑ On average, those children were diagnosed at age 4 years and 2 months, even though children can be diagnosed as early as age 2 years.
- ❑ When looking at age of first diagnosis by subtype, on average, those children were diagnosed with:
  - Autistic disorder at age 3 years and 5 months.
  - Pervasive developmental disorder not otherwise specified at age 4 years and 3 months.
  - Asperger disorder at age 6 years and 1 month.



#### Site Information

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

Children in tracking area: 35,623 8-year-old children, of whom about 62% were white, 18% were black, 16% were Hispanic, and 4% were Asian or Pacific Islander



More is understood about ASD than ever before, but there is an urgent need to continue the search for answers and provide help for people living with ASD.

### **Public Health Action**

The Centers for Disease Control and Prevention (CDC) funds programs to track the number and characteristics of children with ASD and other developmental disabilities as part of the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. The Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS) was established in 2003 as an ADDM Network site in collaboration with the Wisconsin Department of Health Services and investigators from the Waisman Center and Department of Population Health Sciences at the University of Wisconsin-Madison. WISADDS tracks the number of 8-year-old with ASD and cerebral palsy in southeastern Wisconsin. This program contributes information on the characteristics of children with ASD and on factors that put children at risk for this condition. WISADDS data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children and families in our community get the help they need.

### **Training and Education on Autism Spectrum Disorder**

WISADDS sponsors workshops and training in early identification of developmental disabilities for pediatric healthcare providers serving Wisconsin. The goals are to improve the ability of providers to recognize early signs of ASD, refer families to get the help they need, and to standardize diagnostic practices related to ASD. More information can be found at <http://wismhi.org>.

#### **For more information about WISADDS, please contact:**

Maureen Durkin, PhD, DrPH  
University of Wisconsin-Madison  
Waisman Center  
1500 Highland Ave, Room S101E  
Madison, Wisconsin 53705  
Phone: 608-263-2128  
E-mail: [mdurkin@wisc.edu](mailto:mdurkin@wisc.edu)  
[www.waisman.wisc.edu/wisadds](http://www.waisman.wisc.edu/wisadds)

#### **Access Resources and Help Connect Families to Services and Supports in Wisconsin**

##### **Wisconsin First Step**

Phone: 1-800-642-7837

Web: [www.mch-hotlines.org](http://www.mch-hotlines.org)

##### **Autism Society of Wisconsin**

Phone: 1-888-4-AUTISM

Web: [www.asw4autism.org](http://www.asw4autism.org)

##### **Wisconsin Regional Centers for Children and Youth with Special Health Care Needs**

Web: <http://www.dhs.wisconsin.gov/health/children/RegionalCenters/index.htm>

##### **Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities**

Web: [www.waisman.wisc.edu/cedd/pdfs/findingyourway.pdf](http://www.waisman.wisc.edu/cedd/pdfs/findingyourway.pdf)

##### **Learn the Signs. Act Early.**

Gail Chodron, Wisconsin's Act Early Ambassador

Phone: 608-890-0145

E-mail: [Chodron@wisc.edu](mailto:Chodron@wisc.edu)

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

Web: [www.ActEarly.wisc.edu](http://www.ActEarly.wisc.edu)

<sup>1</sup>. Due to small numbers of children, we are unable to detect statistical differences between certain racial and ethnic groups.

<sup>2</sup>. This information is based on children who had a diagnosis from a community provider documented in their records. Because the diagnoses were made in 2010 or earlier, they reflect DSM-IV-TR subtypes. This excludes children whose only ASD classification was an ICD-9 billing code or an eligibility for autism special education services.

## A Community Perspective: Success Stories from the ADDM Network

ADDM Network sites partner with stakeholders in the ADDM Network communities to put the data to work for children with ASD and their families. Read the stories below to learn more about how ADDM Network sites have used data or leveraged the tracking site infrastructure and expertise to make a positive impact on their local communities.

### Addressing disparities in the identification of children with ASD in Missouri

The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM) has consistently reported higher estimates of the number of children identified with ASD and an earlier average age of identification for white children compared to children of other racial and ethnic groups. As a result, MO-ADDM has been proactive in sharing these data with stakeholders and developing partnerships to begin to better understand and address these potential disparities. MO-ADDM has collaborated with local and national partners on several recent initiatives to raise awareness of potential disparities in ASD identification in the region. In February 2013, Easter Seals Midwest's Autism Services division hosted a community event in St. Louis entitled "Autism Awareness and Understanding in the African American Community". The event consisted of a moderated panel discussion of local experts as well as a question and answer session with the public. MO-ADDM staff participated in the event and shared MO-ADDM data highlighting differences in identification and age of diagnosis by race and ethnicity. In August 2013, MO-ADDM partnered with the Autism Society of America and St. Louis ARC to host a half-day meeting of ASD stakeholders, including representatives from the medical, education, mental health, state government, and advocacy and other support communities statewide. The meeting, entitled "Disparities in Autism Identification: A Community Conversation,"

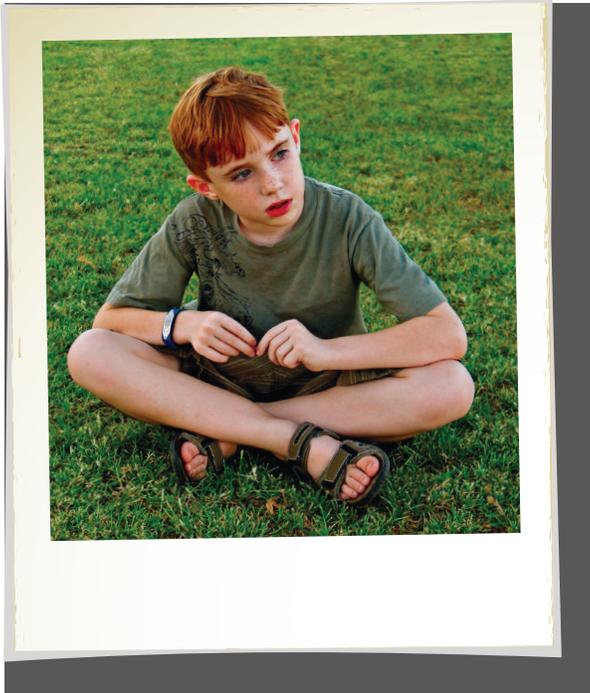
began with a presentation of ASD tracking data from the overall ADDM Network as well as specifically from MO-ADDM. MO-ADDM will continue to provide data that can be used by local stakeholders to move forward local initiatives that help children and families with ASD.

*"Through partnering with colleagues from MO-ADDM and the resulting data, we at Easter Seals Midwest have become increasingly more aware of the disparities in age of diagnosis among different populations. We are committed to making real progress toward Child Find initiatives and facilitating earlier access to diagnosis and treatment for all children."*

*- Jeanne Marshall, MEd, MA, BCBA, LBA  
Vice President, Autism Services,  
Easter Seals Midwest*

### Building a comprehensive resource network for ASD in Colorado

People with ASD often deal with a complex system of care. This complexity can influence families' ability to navigate the system, clinicians' ability to refer families for specialized evaluation, diagnosis, and services, and, for public health agencies, the ability to accurately identify the number of children with ASD. Families, clinicians, and public health officials are continually seeking a better understanding of ASD resources. In 2013, the Colorado Autism and Developmental Disabilities Monitoring Project (CO-ADDM) site began addressing this issue by collaborating with Colorado Autism and Neurodevelopmental Disabilities Options (CANDO) to conduct a statewide survey of licensed psychologists and psychiatrists. Results from the survey highlight (a) the limited resources for underserved families particularly those in rural areas and for non-English speaking families,



(c) an interest in clinician training on ASD evaluations and interventions, and (c) a strong interest among clinicians to coordinate ASD resources. Based on this information, CANDO and CO-ADDM are taking action. They are working with newly identified providers to get them into Colorado's ASD tracking system, so we have a more complete picture of ASD in Colorado; developing webinar trainings for ASD evaluation and treatment to help expand services for underserved families statewide; and, developing a comprehensive resource guide for families and service providers.

### Promoting early identification for children with ASD in Wisconsin

The Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) site has tracked the number and characteristics of children with ASD in southeastern Wisconsin since 2002. Over that time, WISADDS has identified a several year gap between the age when developmental concerns are first noted and when a child receives an ASD diagnosis. In partnership with the Wisconsin Statewide Medical Home Initiative (WiSMHI) and Project LAUNCH (Linking Actions for Unmet Needs in Children's Health),

WISADDS provides training and technical assistance to pediatric primary care teams to support implementation of developmental and ASD screening into their well-child visits. Since January 2012, this partnership has provided onsite trainings for 129 pediatric and family medicine doctors and residents and 155 care team members across 20 practices and residency programs in Wisconsin. Follow-up surveys conducted six to nine months after training indicate that 83% have successfully implemented use of a validated screening tool within their practice. Although significant progress has been made in this area, further support is needed to ensure that all children in Wisconsin receive early screening for developmental delays and are referred, as appropriate, for intervention and supports. WISADDS will continue to monitor the progress toward earlier identification of children with ASD in Wisconsin.

### Improving access to services for children with ASD in Utah

Early intervention can have a significant impact on a child's ability to learn new skills. Barriers to early intervention include too many costs and not enough trained providers. In 2012, new legislation was signed into law in Utah that created three ASD treatment pilot programs that have improved access to ASD services and generated data needed to inform Utah's next steps toward improving the lives of children with ASD. Data from the Utah Autism and Developmental Disabilities Monitoring site (UT-ADDM) helped raise awareness of the burden of ASD upon children in Utah and supported these efforts to improve access to ASD services. In 2007, CDC released data from the UT-ADDM site estimating that about 1 in 133 8-year-old children had been identified as having ASD, one of the highest estimates among the communities included in the ADDM Network. In 2012, CDC released updated estimates from the UT-ADDM site indicating that 1 in 47 8-year-old children had been identified as having ASD, which was the highest estimate among ADDM Network communities. In anticipation of these results, supporters met with members of the Utah State Legislature about affordable and accessible ASD intervention services in Utah. Utah's high estimates of ASD among children

were cited as a call to action by this group. By tracking ASD estimates, ASD-related service access, and age at earliest ASD diagnosis, UT-ADDM will continue to provide important information with which to evaluate Utah's progress towards early identification and treatment of ASD.

*"I am grateful to have actual data from a reputable source to educate and bring about change for good. Being able to show that Utah has such a high rate of ASD brings home the reality that services and programs have to be implemented now. I use the data from the CDC to influence positive solutions for this group of kids for early intervention, and also to identify solutions for the gaps coming as they age and transition."*

- Cheryl Smith

Parent of a young man with ASD,

Founding Member of the Autism Council of Utah

## Strengthening partnerships in the ASD community in Georgia

ASD stakeholders in the community, such as clinicians, educators, and families, need to have the most up-to-date information on the number and characteristics of children with ASD to promote early identification, plan for training and service needs, and inform policy. The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) has tracked developmental disabilities in metro Atlanta since 1991, and this tracking depends upon ongoing collaboration with state health and education agencies, community providers, and other local organizations. However, it can be difficult to bring all those collaborators together on a regular basis. For over six years, MADDSP and its partners have hosted annual awareness events to both disseminate data and engage tracking

collaborators in a unique and compelling way. MADDSP has found that the most powerful tool for achieving this dual purpose is to provide a forum that gives voice to individuals and families living with ASD. As such, these events feature nationally renowned keynote speakers that either have ASD themselves or have another personal connection to ASD. Past speakers include Dr. Temple Grandin, Eustacia Cutler, John Elder Robison, Dr. Richard Grinker and Dr. Stephen Shore. Events have drawn as many as 500 community stakeholders, from researchers to parents to teachers. These inspiring and informative events continue to be an opportunity to engage local stakeholders and put essential data on ASD in the hands of people who need it most.



## What Else Do I Need To Know?

### *Does this mean that the prevalence of ASD is 1 in 68 children in all U.S. communities?*

It is important to remember that this estimate is based on children living in 11 communities across the United States. The number of children with ASD varied widely by community, from 1 in 175 in part of Alabama to 1 in 45 in part of New Jersey.

### *What do you think is causing the variation by geographic area, sex, race/ethnicity, and level of intellectual ability?*

Currently, research does not show that living in certain communities, being a boy, being of white race or having a certain intellectual ability puts children at greater risk for developing ASD. Although true differences in risk have not been ruled out, the variation in the estimated number of children identified with ASD by geographic area, by sex, by race and ethnicity, and level of intellectual may be due to other factors. For example, it may be that providers diagnose ASD and document ASD symptoms in different ways. Or, it may be that families have unequal access to services based on where they live, how much money they make, how educated they are, or what language they speak. More work is needed to understand if and how variation in the number of children identified with ASD is due to these and other factors. There are many opportunities for public health professionals to collaborate with parents, providers, and educators to reduce potential disparities in the identification of children with ASD.

### *How many children in the United States have ASD?*

There is not a full count of all individuals with ASD living in the United States. However, based on the ADDM Network reports to date, we can estimate that over 1% of children from birth to 21 years of age have ASD.

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

You can follow a child's development by looking for developmental milestones—that is, how he or she plays, learns, speaks, moves, and acts. Developmental

milestones are things most children can do by a certain age. The American Academy of Pediatrics recommends that children be screened for general development using standardized, validated tools at 9, 18, and 24 or 30 months and for ASD at 18 and 24 months or whenever a parent or provider has a concern. Parents should talk with their child's doctor at every visit about the milestones the child has reached and what to expect next. Learn more about developmental milestones and get free milestone checklists at CDC's "Learn the Signs. Act Early." [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly).

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

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

### *Do schools help and what is IDEA?*

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

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

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

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

### **Can medication help children with ASD?**

There are no medications that can cure ASD or treat the core symptoms; however, there are medications that can help some people with ASD function better. To learn more about medications and ASD, go to the Food and Drug Administration's website at [www.fda.gov/](http://www.fda.gov/).

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

The number, characteristics, and needs of adolescents and adults living with ASD in the United States are understudied (31). By parent report, almost 2% of adolescents have ASD (32). They may face unique challenges during adolescence and as they transition to adulthood. Adolescents with ASD seem to be at greater risk for certain health conditions. For example, adolescents with ASD are more likely to be obese than adolescents without developmental disabilities (33). Adolescents also encounter significant issues with accessing appropriate services and gaining employment (34-35). Over time, the number of young adults with ASD seeking vocational rehabilitation services has increased, but the percent of adults with ASD who are employed, the number of hours they work, and the wages they earn have not improved. For information on interventions for adolescents and young adults with ASD, read the Agency for Healthcare Quality

Research's review: [http://effectivehealthcare.ahrq.gov/ehc/products/271/1197/CER65\\_Autism-Adolescents\\_executivesummary\\_20120724.pdf](http://effectivehealthcare.ahrq.gov/ehc/products/271/1197/CER65_Autism-Adolescents_executivesummary_20120724.pdf). For resources related to the transition from adolescence to adulthood, you can download the Autism Speaks' Transition Tool-Kit: <http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit>

*“The Autistic Self Advocacy Network values the availability of high quality data about autism. CDC data highlight the need for similar data on autistic adults to understand more about autism across the lifespan.”*

*- Ari Ne'eman*

*President, Autistic Self Advocacy Network*



## Where Can I Get More Information?\*

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

### *Developmental Milestones and Early Identification*

#### **“Learn the Signs. Act Early.”**

[www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly) or 1-800-CDC INFO

Access tools and resources for health care providers and early childhood educators, including information on screening tools and free educational materials to give to parents.

#### **Birth to Five: Watch Me Thrive**

[www.hhs.gov/WatchMeThrive](http://www.hhs.gov/WatchMeThrive)

Find resources related to developmental and behavioral screening and support.

### *General Information About ASD*

#### **CDC Autism Information Center**

[www.cdc.gov/autism](http://www.cdc.gov/autism) or 1-800-CDC INFO

Check out a full range of resources for parents, educators, researchers, and practitioners at this site. Also, learn what CDC is doing to better understand ASD and the causes and risk factors.

### *Training and Technical Assistance for Professionals*

#### **Association of Maternal and Child Health Programs**

[www.amchp.org/programsandtopics/CYSHCN/projects/spharc](http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc)

Access the State Public Health Autism Resource Center, a comprehensive resource center for Title V programs and others interested in improving systems for children and youth with ASD and their families.

#### **CDC’s Autism Case Training**

[www.cdc.gov/ncbddd/actearly/ACT/class.html](http://www.cdc.gov/ncbddd/actearly/ACT/class.html)

Find healthcare provider resources for identifying, diagnosing, and managing ASD with real life scenarios

#### **The Early Childhood Technical Assistance Center (ECTA)**

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

#### **Educating Children with Autism**

[www.nap.edu/books/0309072697/html/](http://www.nap.edu/books/0309072697/html/)

Read a review of early intervention, preschool, and school programs designed for young children with ASD by the National Academy of Sciences.

#### **The National Professional Development Center on Autism Spectrum Disorders**

<http://autismpdc.fpg.unc.edu/>

Access resources from this project that promotes the use of evidence-based practice for children and adolescents with ASD.

#### **The Pediatrician’s Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children**

<http://pediatrics.aappublications.org/cgi/content/full/107/5/e85>

Learn about treatments and interventions physicians use to treat ASD in this report from the American Academy of Pediatrics.

#### **Technical Assistance and Dissemination Network**

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

Access links to a variety of websites and online resources that focus on special education issues, such as policy, technology, curriculum, and parent trainings.

### *Other Resources*

#### **The Arc’s Autism NOW**

<http://autismnow.org/>

Learn about additional resources for individuals with ASD, their families and other stakeholders.

### **Autism Society**

[www.autism-society.org](http://www.autism-society.org) or 1-800-3AUTISM (328-8476)

Find local resources and an Autism Society chapter in your state by clicking on the “Chapters” link.

### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org) or 1-888-AUTISM2 (288-4762)

Read about what ASD is and how to cope with it. Learn about research and efforts to raise awareness about the disorder.

### **Autistic Self-Advocacy Network**

<http://autisticadvocacy.org/>

Learn about the self-advocate community and access resources on public policy advocacy, community engagement, and quality of life oriented research.

### **Easter Seals**

[www.easterseals.com](http://www.easterseals.com) or 1-800-221-6827

Find an Easter Seals program near you and learn about services for people with ASD.

### **Family Voices**

[www.familyvoices.org/](http://www.familyvoices.org/) or 1-888-835-5669

Learn more about this national network that provides information and support for parents raising children with special health care needs or disabilities, or both.

For contacts in your state, go to:

[www.familyvoices.org/states](http://www.familyvoices.org/states).

### **Operation Autism. A Resource Guide for Military Families**

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

Learn about supports for U.S. military families touched by ASD.

### **Research**

#### **The Autism Science Foundation (ASF)**

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

Learn more about the ASF, which provides funding to scientists and organizations conducting, facilitating, and promoting autism research.

#### **National Institute of Neurological Disorders and Stroke**

[www.ninds.nih.gov/disorders/autism/autism.htm](http://www.ninds.nih.gov/disorders/autism/autism.htm)

Read about research being done on ASD.

### **CDC’s Study to Explore Early Development (SEED)**

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

Learn more about the largest study in the United States to help identify factors that might put children at risk for ASD and other developmental disabilities.

### **Clinical Trials**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov) or 301-496-4000

Access a searchable database of the National Institutes of Health that provide patients, family members, and the public with information about current, ongoing clinical research studies.

### **Interagency Autism Coordinating Committee (IACC)**

[www.iacc.hhs.gov](http://www.iacc.hhs.gov)

Visit this site to learn about the IACC and to access the IACC approved Strategic Plan for Autism Research.

### **Organization for Autism Research (OAR)**

[www.ResearchAutism.org](http://www.ResearchAutism.org) or 703-243-9710

Learn more about OAR’s mission to apply research to the challenges of ASD and access their resources for families and providers.

### **Other Federal Agencies or Websites**

#### **Department of Education**

[www.ed.gov](http://www.ed.gov)

Find resources to assist with the educational needs of children with ASD and other developmental disabilities.

#### **Disability.gov**

[www.disability.gov](http://www.disability.gov)

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

#### **Food and Drug Administration**

[www.fda.gov](http://www.fda.gov)

Learn about drugs that the FDA has approved to treat children with ASD.

#### **Human Resources and Services Administration (HRSA)**

<http://mchb.hrsa.gov/programs/autism/>

Learn more about HRSA’s implementation of the Combating Autism Act of 2006.

## National Council on Disability

[www.ncd.gov](http://www.ncd.gov)

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

## National Institute of Mental Health

[www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders](http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders)

Find out about the process of diagnosing ASD and about treatment options, including medications used to help people with ASD.

## Office of Special Education and Rehabilitative Services

<http://www2.ed.gov/about/offices/list/osers/index.html>

Learn more about the Department of Education's support to parents and individuals, school districts, and states in three main areas: special education, vocational rehabilitation, and research.

## U.S. Department of Health and Human Services (HHS)

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

Learn more about ASD and access links to government agencies working to address ASD

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

*“ In Arkansas, we use the ADDM data to guide our outreach. For example, the 2010 statewide surveillance report indicated a decrease in the number of children from minority communities diagnosed with an autism spectrum disorder, specifically black/African-American children. This prompted systematic outreach to these communities, the development of a research team to determine the variables affecting access to services for these children, and monitoring of the ADDM data to determine if we are reaching families from minority, rural, and low socioeconomic communities.”*

*- Peggy J. Schaefer Whitby PhD  
Arkansas Act Early Ambassador*



## References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, fifth edition. Arlington, VA: American Psychiatric Association; 2013.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. Washington, DC: American Psychiatric Association; 2000.
3. Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee and Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1):405-420.
4. Johnson CP, Myers SM, American Academy of Pediatrics Council on Children with Disabilities. Identification and evaluation of children with autism spectrum disorder. *Pediatrics*. 2007;120(5):1183-1215.
5. Huquet G, Ey E, Bourgeron T. The genetic landscapes of autism spectrum disorders. *Annu Rev Genomics Hum Genet*. 2013; 14: 191-213.
6. Rosenberg RE, Law JK, Yenokyan G, McGready J, Kaufmann WE, Law PA. Characteristics and concordance of autism spectrum disorders among 277 twin pairs. *Arch Pediatr Adolesc Med*. 2009; 163(10): 907-914.
7. Hallmayer J, Cleveland S, Torres A, Phillips J, Cohen B, Torigoe T, Miller J, Fedele A, Collins J, Smith K, Lotspeich L, Croen LA, Ozonoff S, Lajonchere C, Grether JK, Risch N. Genetic heritability and shared environmental factors among twin pairs with autism. *Arch Gen Psychiatry*. 2011; 68(11): 1095-1102.
8. Ronald A, Happe F, Bolton P, Butcher LM, Price TS, Wheelwright S, Baron-Cohen S, Plomin R. Genetic heterogeneity between the three components of the autism spectrum: A twin study. *J. Am. Acad. Child Adolesc. Psychiatry*. 2006; 45(6): 691-699.
9. Tani ai H, Nishiyama T, Miyahci T, Imaeda M, Sumi S. Genetic influences on the board spectrum of autism: Study of proband-ascertained twins. *Am J Med Genet B Neuropsychiatr Genet*. 2008; 147B(6): 844-849.
10. Ozonoff S, Young GS, Carter A, Messinger D, Yirmiya N, Zwaigenbaum L, Bryson S, Carver LJ, Constantino JN, Dobkins K, Hutman T, Iverson JM, Landa R, Rogers SJ, Sigman M, Stone WL. Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study. *Pediatrics*. 2011; 128: e488-e495.
11. Sumi S, Tani ai H, Miyachi T, Tanemura M. Sibling risk of pervasive developmental disorder estimated by means of an epidemiologic survey in Nagoya, Japan. *J Hum Genet*. 2006; 51: 518-522.
12. DiGuseppi C, Hepburn S, Davis JM, Fidler DJ, Hartway S, Lee NR, Miller L, Rutenber M, Robinson C. Screening for autism spectrum disorders in children with Down syndrome. *J Dev Behav Pediatr*. 2010; 31:181-191.
13. Cohen D, Pichard N, Tordjman S, Baumann C, Burglen L, Excoffier E, Lazar G, Mazet P, Pinquier C, Verloes A, Heron D. Specific genetic disorders and autism: Clinical contribution towards their identification. *J Autism Dev Disord*. 2005; 35(1): 103-116.
14. Hall SS, Lightbody AA, Reiss AL. Compulsive, self-injurious, and autistic behavior in children and adolescents with fragile X syndrome. *Am J Ment Retard*. 2008; 113(1): 44-53.
15. Zecavati N, Spence SJ. Neurometabolic disorders and dysfunction in autism spectrum disorders. *Curr Neurol Neurosci Rep*. 2009; 9(2): 129-136.
16. Christensen J, Grønberg TK, Sørensen MJ, Schendel D, Parner ET, Pedersen LH, Vestergaard M. Prenatal valproate exposure and risk of autism spectrum disorders and childhood autism. *JAMA*. 2013;309(16): 1696-1703.
17. Strömland K, Nordin V, Miller M, Akerström B, Gillberg C. Autism in thalidomide embryopathy: a population study. *Dev Med Child Neurol*. 1994;36(4): 351-356.
18. Gardener H, Spiegelman D, Buka SL. Perinatal and neonatal risk factors for autism: a comprehensive meta-analysis. *Pediatrics*. 2011;128(2):344-355.
19. Durkin MS, Maenner MJ, Newschaffer CJ, Lee LC, Cunniff CM, Daniels JL, Kirby RS, Leavitt L, Miller L, Zahorodny W, Schieve LA. Advanced parental age and the risk of autism spectrum disorder. *Am J Epidemiol*. 2008;168(11):1268-1276.
20. Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA. Economic burden of childhood autism spectrum disorders. *Pediatrics*. 2014 [Epub ahead of print]
21. Schieve LA, Boulet SL, Kogan MD, Yeargin-Allsopp M, Boyle CA, Visser SN, Blumberg SJ, Rice C. Parenting aggravation and autism spectrum disorders: 2007 National Survey of Children's Health. *Disabil Health J*. 2011;4(3):143-152.
22. Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*. 2013 [Epub ahead of print]
23. Kogan MD, Strickland BB, Blumberg SJ, Singh GK, Perrin JM, van Dyck PC. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics*. 2008;122(6):e1149-e1158.
24. Cidav Z, Marcus SC, Mandell DS. Implications of childhood autism for parental employment and earnings. *Pediatrics*. 2012;129(4):617-623.
25. Schieve LA, Gonzalez V, Boulet SL, Visser SN, Rice CE, Van Naarden Braun K, Boyle CA. Concurrent medical conditions and health care use and needs among children with learning and behavioral developmental disabilities, National Health Interview Survey, 2006-2010. *Res Dev Disabil*. 2012;33(2): 467-476.

26. Tuchman R, Cuccaro M, Alessandri M. Autism and epilepsy: Historical perspective. *Brain Dev.* 2010;32(9):709-718.
27. Kancherla V, Van Naarden Braun K, Yeargin-Allsopp M. Childhood vision impairment, hearing loss and co-occurring autism spectrum disorder. *Disabil Health J.* 2013;6(4):333-342.
28. Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cunniff C, Nicholas J, Reaven J, Rice CE. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *J Dev Behav Pediatr.* 2010;31(4): 267-275.
29. Maenner MJ, Rice CE, Arneson CL, Cunniff C, Schieve LA, Carpenter LA, Van Naarden Braun K, Kirby RS, Bakian RS, Durkin MS. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry.* 2014;71(3): 292-300.
30. U. S. Department of Health and Human Services. Healthy People 2020. Retrieved from <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=26>
31. Interagency Autism Coordinating Committee. IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2012 Update. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/strategic-plan/2012/index.shtml>.
32. Blumberg SJ, Bramlett MD, Kogan MD, Schieve LA, Jones JR, Lu MC. Changes in the prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011-2012. *Natl Health Stat Rep* 2013;65:1-11.
33. Phillips KL, Schieve LA, Visser S, Boulet S, Sharma AJ, Kogan MD, Boyle CA, Yeargin-Allsopp M. Prevalence and impact of unhealthy weight in a national sample of US adolescents with autism and other learning and behavioral disabilities. *Matern Child Health J.* 2014; [Epub ahead of print].
34. Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. *Arch Pediatr Adolesc Med.* 2011;165(2):141-146.
35. Burgess S, Cimera RE. Employment outcomes of transition-aged adults with autism spectrum disorders: a state of the States report. *Am J Intellect Dev Disabil.* 2014;119(1): 64-83.



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