Autism Developmental Disabilities Monitoring Network

Prevalence of the Autism Spectrum Disorders (ASDs) in Multiple Areas of the United States, 2000 and 2002

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

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

information: www.cdc.gov/mmwr/mmwr_ss or www.cdc.gov/autism

* This report summarizes the main findings reported in the following published reports: Centers for Disease Control and Prevention (CDC). Prevalence of —Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. MMWR SS 2007;56(SS-1)(1)

Centers for Disease Control and Prevention (CDC). Prevalence of —Autism Spectrum Disorders --- Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. MMWR SS 2007;56(SS-1)(2)

To read the MMWR reports in their entirety, go to www.cdc.gov/mmwr.

To read more about autism, go to CDC's autism site at www.cdc.gov/autism.

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The findings and conclusions in this report are those of the author(s) and do not necessarily represent the views of the funding agency.

Introduction

The number of children with Autism Spectrum Disorders (ASDs) has risen over the past decade, but it is unclear whether the increase is due to changes in diagnosis or to a true increase in cases. The causes and risk factors for ASDs are also unclear. To get a better picture of the scope of ASDs in this country, the Centers for Disease Control and Prevention (CDC) has established the Autism and Developmental Disabilities Monitoring (ADDM) Network. The network is working to gain accurate counts of children with ASDs, to identify differences in how ASDs affect various subgroups, and to characterize the ASD population. This report summarizes the findings from the first years of the ADDM Network's program.

In the report you will find:

- An overview of ASDs
- A discussion about the prevalence of ASDs
- An overview of the ADDM Network
- ADDM Network results to date
- Resources for learning more about ASDs and support for families

What Are Autism Spectrum Disorders?

Autism spectrum disorders (ASDs) are lifelong developmental disabilities. People with ASDs have impairments in social skills and verbal and nonverbal communication. They often have repetitive behaviors or unusual interests. ASDs are part of the broader category of Pervasive Developmental Disorders (PDD) and include Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Each of the behaviors associated with ASDs may range from mild to severe. Some individuals may have relatively good verbal skills and only a minimal language delay but have significantly impaired social skills. Others may be nonverbal or have very little ability or interest in communicating or interacting with others. People with ASDs often do not take part in pretend play, have a hard time initiating social interactions, and engage in self-stimulatory behaviors (e.g., flapping hands, making unusual noises, rocking from side to side, or toe-walking).

There is no medical test for ASDs. Typically, a diagnosis is made after a thorough evaluation. Such an evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and possibly the use of one or more autism diagnostic tests.

Children with an ASD may have other developmental disabilities, such as mental retardation, seizure disorder, fragile X syndrome, or tuberous sclerosis. Also, some children may have mental health problems such as depression or anxiety. Some children with ASDs may also have attention deficits, sleeping disorders, sensory issues, sleep problems, and gastrointestinal disorders.

To learn more about these and other conditions, visit the National Institutes of Health website:
www.nimh.nih.gov/publicat/autism.cfm#intro

A child or adult with an ASD might:

- not play "pretend" games (pretend to "feed" a doll)
- not point at objects to show interest (point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- be very interested in people, but not know how to talk to, play with, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for instance, stop saying words they were once using)

How Many People Have An Autism Spectrum Disorder?

What is prevalence?

Each year since the early 1990s, special education programs in the United States have been required to report how many children receive services for an Autism Spectrum Disorder (ASD). From 1994 to 2005, the number of children ages 6–21 years receiving services for autism increased from 22,664 to 193,637.(3,4) And those numbers likely do not include all children with ASDs, because some children receive special education for a particular need, like speech therapy, and not for a classification of autism.

It is clear that more children than ever before are being diagnosed with an ASD. But, it is unclear how much of this increase is due to changes in how we identify and classify ASDs in people, and how much is due to a true increase in the number of people who have autism and related disorders.

Why has it been hard to get accurate reports of prevalence for ASDs?

Prevalence is a measure of the number of cases of a disease or condition in a defined group of people over a defined period of time. For example, how many 8-year-olds were identified with autism in 2000 in Atlanta, Georgia? By monitoring ASDs, we can find out whether the prevalence of autism is increasing, decreasing, or staying the same over time.

Autism was first described by Dr. Leo Kanner in 1943.(5) Surveys to find the prevalence of autism started in the mid-1960s in England.(6) Diagnostic criteria for autism and related developmental disabilities came out in 1980, (7,8) and they have been revised several times. Thus, one challenge in getting an accurate count of people with autism has been a changing, more inclusive definition, to consider autism as a spectrum of disorders.(9,10) Another challenge is that the United States has not had a population-based system to track the full range of ASDs over time. And the fact that autism and related disorders are diagnosed by behavioral observation of development makes describing the population of people with ASDs challenging, especially when the criteria for defining ASDs have changed over time.

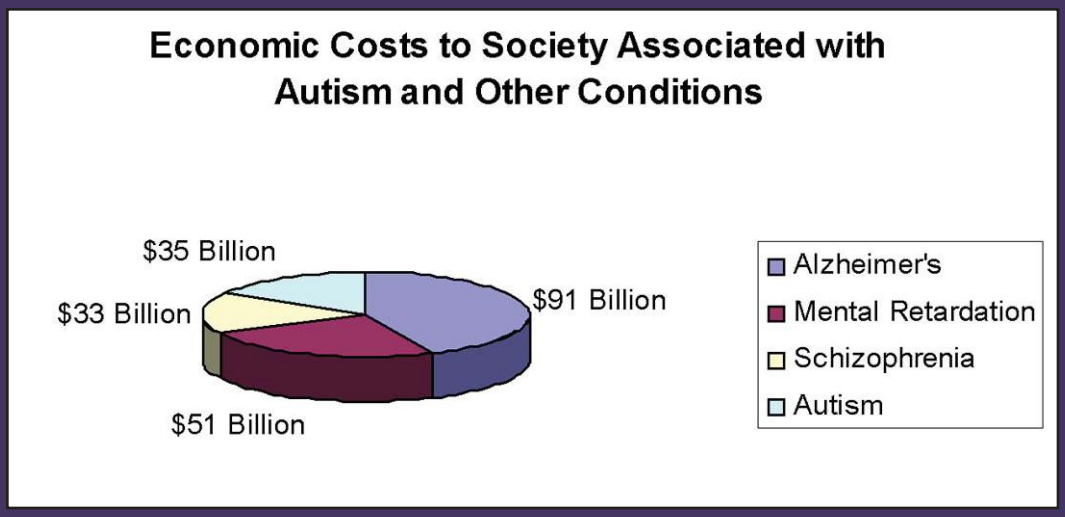
What do we already know about the prevalence of ASDs?

For decades, the best estimate for the prevalence of autism was 4 to 5 per 10,000 children. In 2004, CDC partnered with the American Academy of Pediatrics to issue an Autism A.L.A.R.M. (11) to educate physicians about ASDs. At that time, data from several studies that used the current criteria for diagnosing autism and ASDs such as Asperger's disorder and Pervasive Developmental Disabilities found prevalence rates between 2 and 6 per 1,000 individuals. (9,10). Put another way—data showed that as many as 1 in 166 children have an ASD. Studies in Europe and Scandinavia have found as many as 12 in 1,000 children with an ASD.(12,13) Studies done in the United States over the past decade have found rates between 2 to 7 per 1,000 children.(14-17)

Why is the accurate reporting of autism prevalence important?

Accurate reporting of prevalence allows us to compare ASDs among populations and to compare the number of people with ASDs at different points in time. It shows the magnitude of the problem and describes the characteristics, such as race, ethnicity, and gender, of people with ASDs. This information can help direct research. It allows researchers to ask more informed questions to better understand risk factors for and possible causes of ASDs.

A recent study (18) (see box on page 7) found that the economic costs associated with autism are approximately $35 billion dollars per year. These costs include education for children with ASDs and treatments to help reduce the symptoms of the disorders. Families, public agencies, and some private agencies bear the responsibility of paying for these services. Accurate reporting of the prevalence of ASDs can help providers plan for the funding and resources—such as therapies, trained teachers, diagnosticians, health care providers, and related service professionals—needed to support children with ASDs and their families. Precise reporting of ASDs can also raise awareness, encourage commitment by service providers and researchers, and help lead the way to more effective intervention and prevention.

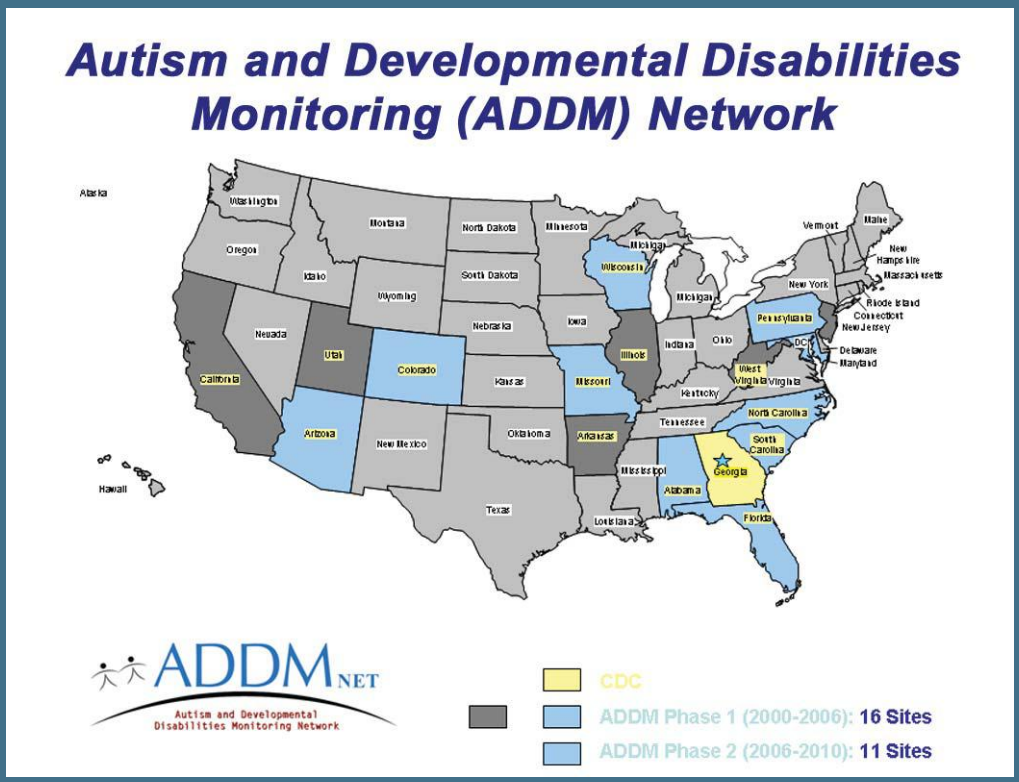


How can we get the most accurate information about the prevalence of autism?

The Centers for Disease Control and Prevention (CDC) has established the only collaborative network to determine the prevalence of ASDs in the United States—the Autism and Developmental Disabilities Monitoring (ADDM) Network. To get the most accurate data possible, the ADDM Network is guided by the following principles, outlined by Rutter (10):

- Use a large enough population that a substantial number of individuals with autism will be included.
- Use a defined population that would contain all people likely to have autism.
- Have a systematic, standardized screening of the total population.
- Include a focus on an age group for which diagnostic assessments are known to be reliable and valid.
- Include diagnosis by trained professionals using high-quality, standardized research assessments.

This report summarizes the results of the first years of the ADDM Network's efforts. Additional reports will update prevalence information over time. As this is the first multisite report from the ADDM Network, these data provide an important standard (or baseline) with which to compare future prevalence data.



** California and Florida statistics are not individually addressed in this Report, but will be forthcoming. Their methodology varies from the states represented here.*

What is the ADDM Network?

The Autism and Developmental Disabilities Monitoring (ADDM) Network is the largest multi-site collaboration to monitor ASDs in the United States. Its mission is aimed at achieving multiple goals:

- To obtain as complete a count as possible of the number of children with an ASD in each project area
- To report comparable, population-based ASD prevalence estimates from different sites and to determine if these rates are changing over time
- To study whether autism is more common in some groups of children than in others
- To provide data to characterize the ASD population

The Children's Health Act of 2000 authorized CDC to create the ADDM Network. Since the network's inception, CDC has funded programs in 16 sites covering 17 states—Alabama, Arizona, Arkansas, California, Colorado, Delaware, Florida, Georgia, Illinois, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, and Wisconsin.

The ADDM sites work together to maintain consistent study methods, based on CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), which monitors the occurrence of developmental disabilities among 8-year-old children in metropolitan Atlanta. CDC has been working on the methodology for developmental disability surveillance for more than 20 years, and its application to ASDs was undertaken following concerns about increases in autism during the mid-'90s. The ADDM Network does not rely solely on a child's previous ASD diagnosis or special education eligibility category to classify a child as a case or suspected case of ASD.

ADDM Network Mission

Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy

To find out more about CDC's prevalence and monitoring programs for developmental disabilities, please visit:

www.cdc.gov/ncbddd/dd/ddsurv.htm

What methods did the ADDM sites use for their study?

Each ADDM site identified for its study area a geographic region with a large enough population and identified children who were 8 years old in the targeted study year. The methodology includes screening records at multiple sources that educate, diagnose, treat, and provide services for children with developmental disabilities, and abstracting detailed behavioral data on potential case children. A panel of clinicians with expertise in identifying and assessing ASDs systematically reviewed the abstracted information based on DSM-IV-TR autism, (8) and determined whether the identified children met the requirements of the monitoring program to be considered ASD cases. All program staff received extensive training and met ongoing quality assurance standards.

What does the ADDM Network Tell Us About Autism Spectrum Disorders?

States Participating in the ADDM Network

2000 Arizona, Georgia, Maryland, New Jersey, South Carolina, and West Virginia

2002 Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, West Virginia, and Wisconsin

Population of 8-Year Olds in the Study Area

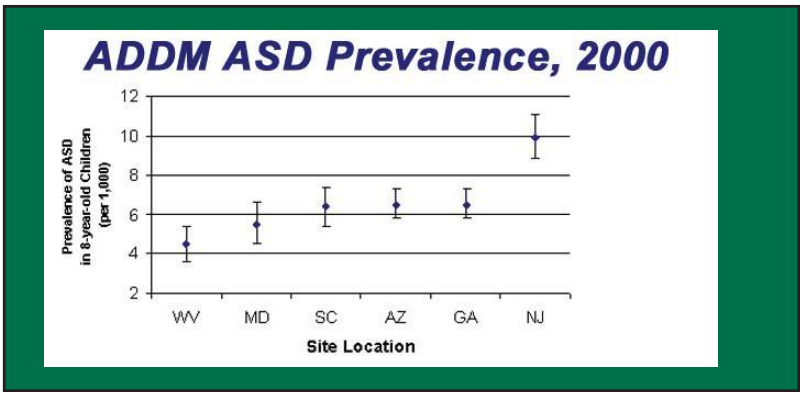
2000 187,761 8-year-olds across 6 study areas
(approximately 4.5% of all 8-year-olds in the United States)

2002 407,578 8-year-olds across 14 study areas
(approximately 10% of all 8-year-olds in the United States)

Results

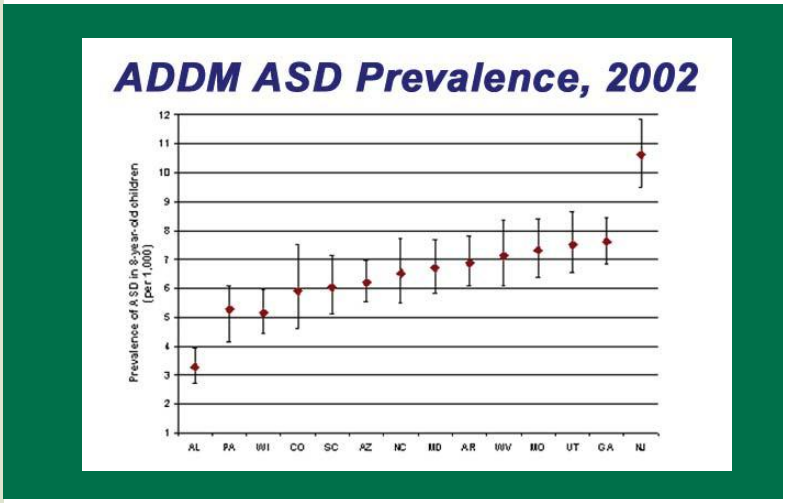
2000 ASD Prevalence

Number of 8-year-old children identified with an ASD: 1,252
Total prevalence of ASDs: 4.5 (1 in 222) to 9.9 (1 in 101) per 1,000 8-year-old children.
Overall average prevalence of ASDs across all sites: 6.7 per 1,000 8-year-old children, or approximately 1 in 150 children.
Boys: 6.6 to 14.8 per 1,000 8-year-old children
Girls: 2.0 to 4.3 per 1,000 8-year-old children
White, non-Hispanic: 4.5 to 11.3 per 1,000 8-year-old children
Black, non-Hispanic: 5.3 to 10.6 per 1,000 8-year-old children



2002 ASD Prevalence

Number of 8-year-old children identified with an ASD: 2,685
Total prevalence of ASDs: 3.3 (1 in 303) to 10.6 (1 in 94) per 1,000 8-year-old children.
Overall average ASD prevalence: 6.6 per 1,000 children, or approximately 1 in 150 children.
Boys: 5.0 to 16.8 per 1,000 8-year-old children
Girls: 1.4 to 3.1 per 1,000 8-year-old children
White, non-Hispanic: 3.3 to 12.5 per 1,000 8-year-old children
Black, non-Hispanic: 3.4 to 7.7 per 1,000 8-year-old children
Hispanic: 0.3 to 9.7 per 1,000 8-year-old children



[1] For 2000, prevalence was reported for White and Black, non-Hispanic children only because of small numbers in the population for other racial and ethnic groups. Future reports from individual sites will report on additional subgroups when enough information is available.

Note on prevalence graphs: Because the ADDM sites do not make up a nationally representative sample, the rates should not be generalized to every community in the United States. Rates may be higher or lower in some places. However, the average estimated prevalence across all sites was 6.7 per 1,000 8-year-old children (or approximately 1 in 150) can help communities estimate for planning and identification purposes how many children may have an ASD in their community.

Results From Sites With 2 Years of ASD Prevalence Data

Prevalence was stable from 2000 to 2002 in Arizona, Maryland New Jersey, and South Carolina, but it increased slightly in Georgia and significantly [2] in West Virginia, indicating the need for ongoing monitoring over time.

Special Education Classifications

2000 Between 70% (Maryland) and 97% (Arizona) of the 8-year-old children with ASDs were receiving special education services.

2002 Between 61% (Maryland) and 97% (New Jersey) of the 8-year-old children with ASDs were receiving special education services.

If children with ASDs were identified only on the basis of receiving special education services or having a documented diagnosis for an ASD, with the prevalence of ASD would have been underestimated by as much as 30%.

[2] In this report we use the term significant to mean that the rates have increased more over time than is likely just to chance alone. As a result, we use significant to imply that the true rates likely increase over the time period.

Cognitive Functioning

2000 Three sites (AZ, GA, and SC) had test results on intellectual ability for more than 80% of the children identified. In these sites, between 40% (AZ) and 62% (GA) of the children identified with ASDs also had cognitive impairment (IQ≤70, also referred to as an Intellectual Disability or Mental Retardation).

2002 Seven sites (AR, AZ, CO, GA, NC, SC, and UT) had test results on intellectual ability for more than 80% of the children identified. In these sites between 33% (UT) and 59% (SC) of the children identified with ASD also had cognitive impairment (IQ≤70, also referred to as an Intellectual Disability or Mental Retardation).

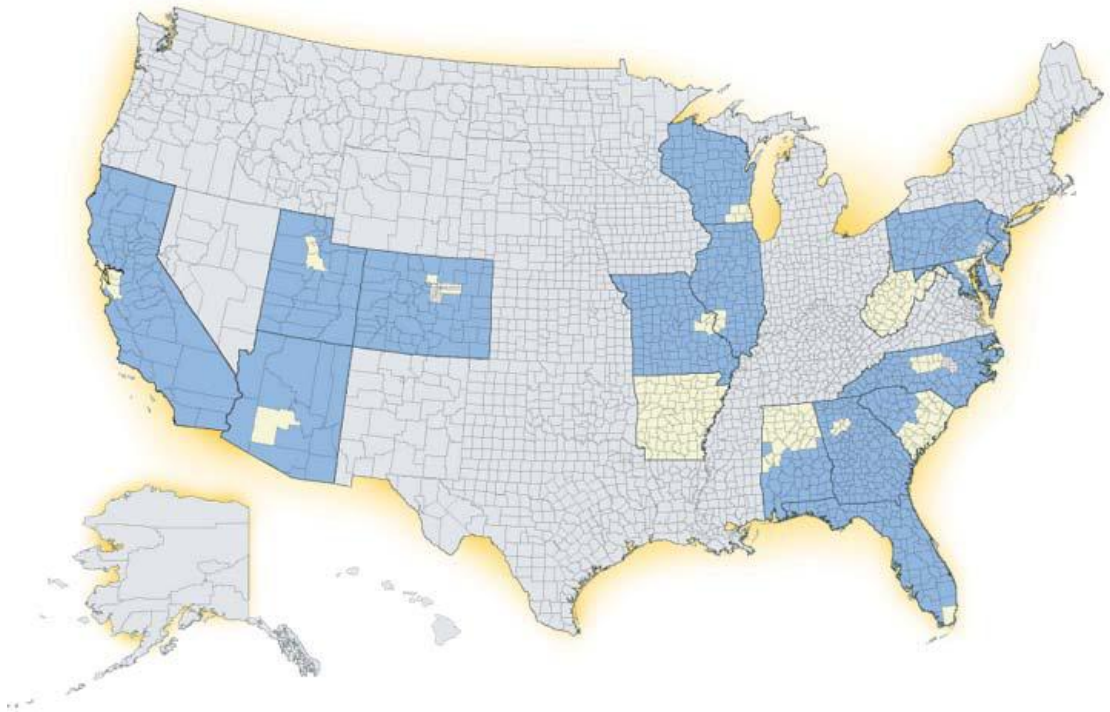
Early Developmental Concerns and Age of ASD Diagnosis

2002 Between 69% and 88% of children with an ASD had documented developmental concerns before the age of 3 years. Median age range of earliest reported ASD diagnosis was 4years,4 months (NJ, WV) to 4 years, 8 months (GA).

2002 Between 51% and 91% of children with an ASD had documented developmental concerns before the age of 3 years. Median age range of earliest reported ASD diagnosis was 4 years, 1 month (UT) to 5 years, 6 months (AL).

ADDM State by State

ADDM NET
Autism and Developmental Disabilities Monitoring Network



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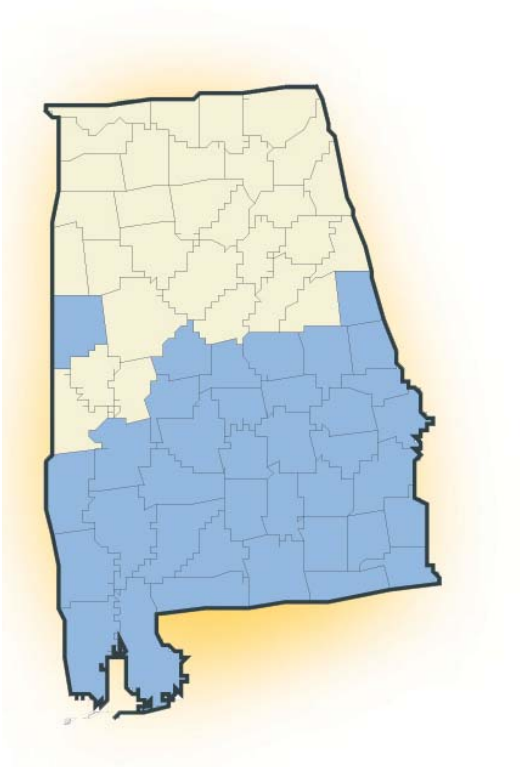
Alabama Autism and Developmental Disabilities Monitoring (ADDM) Network Project



Yellow- Counties in the ADDM Network

What part of Alabama is included in the AL ADDM ASD Study?

32 counties: Bibb, Blount, Calhoun, Cherokee, Clay, Cleburne, Colbert, Cullman, Dekalb, Etowah, Fayette, Franklin, Greene, Hale, Jackson, Jefferson, Lamar, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, Pickens, Shelby, St. Clair, Sumter, Talladega, Tuscaloosa, Walker, and Winston Counties

Population of 8-Year-Old Children in Study Area, 2002

35,472 (58% of all 8-year-olds in AL)*
69.2% White, non-Hispanic
26.6% Black, non-Hispanic
2.9% Hispanic
15.2% of children in special education

Results

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 116
Total prevalence of ASDs: 3.3 per 1,000
Boys: 5.0 per 1,000
Girls: 1.4 per 1,000
White, non-Hispanic: 3.3 per 1,000
Black non-Hispanic: 3.4 per 1,000
Hispanic: 1.9 per 1,000
Median age of ASD diagnosis 5 years, 6 months

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Arizona ADDM

Arizona Autism Spectrum Surveillance Program

What part of Arizona is included in the ADDM ASD Study?

Maricopa County (metropolitan Phoenix, Arizona)

Population of 8-Year-Old Children in Study Area, 2000

45,322 8-year-old children born in 1992 (57.7% of all 8-year-olds in AZ)
54.2% White, non-Hispanic
4.5% Black, non-Hispanic
10.7% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

45,113 8-year-old children born in 1994 (55.2% of all 8-year-olds in AZ)*
56.0% White, non-Hispanic
5.30% Black, non-Hispanic
34.0% Hispanic
13.9% of children in special education

Results

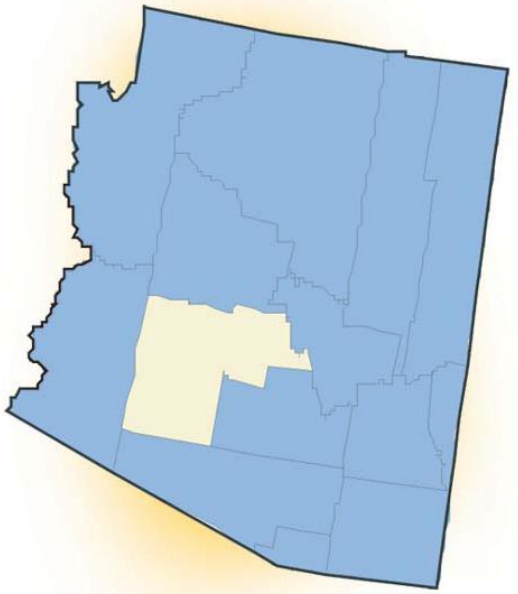
Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 295
Total prevalence of ASDs: 6.5 per 1,000
Boys: 9.7 per 1,000
Girls: 3.2 per 1,000
White, non-Hispanic: 8.6 per 1,000
Black, non-Hispanic: 7.3 per 1,000
Median age of ASD diagnosis 4 years, 5 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 280
Total prevalence of ASDs: 6.2 per 1,000
Boys: 10.1 per 1,000
Girls: 2.2 per 1,000
White, non-Hispanic: 7.7 per 1,000
Black, non-Hispanic: 6.3 per 1,000
Hispanic: 3.4 per 1,000
Median age of ASD diagnosis 5 years, 3 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)



Yellow- County in the ADDM Network

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Arkansas Autism and Developmental Disabilities Monitoring (ADDM) Network Project

What part of Arkansas is included in the ADDM ASD Study?

Entire State

Population of 8-Year-Old Children in Study Area, 2002

36,472 (99.4% of all 8-year-olds in AR)*
71.2% White-Non-Hispanic
21.3% Black-Non-Hispanic
5.7% Hispanic
10.8% of children in special education

Yellow- County in the ADDM Network

Results

Number of 8-year-old children identified with an ASD: 251
Total prevalence of ASDs: 6.9 per 1,000
Boys: 10.7 per 1,000
Girls: 2.9 per 1,000
White, non-Hispanic: 7.4 per 1,000
Black, non-Hispanic: 5.8 per 1,000
Hispanic: 2.9 per 1,000
Median age of ASD diagnosis 4 years, 11 months

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* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

Colorado ADDM

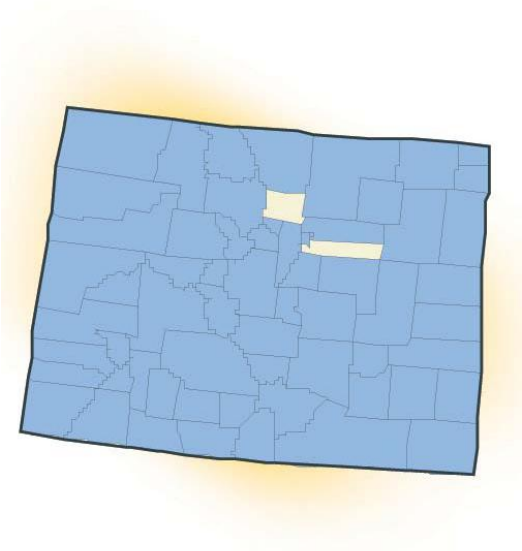
Colorado Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Colorado is included in the ADDM ASD Study?

2 counties in metropolitan Denver: Arapahoe and Boulder

Population of 8-Year-Old Children in Study Area, 2002

11,020 (17.7% of all 8-year-olds in CO)
68.2% White-Non-Hispanic
8.5% Black-Non-Hispanic
18.4% Hispanic
11.4% of children in special education



Yellow- County in the ADDM Network

Results

Number of 8-year-old children identified with an ASD: 65
Total prevalence of ASDs: 5.9 per 1,000
Boys: 9.9 per 1,000
Girls: 1.7 per 1,000
White, non-Hispanic: 6.4 per 1,000
Black, non-Hispanic: 6.4 per 1,000
Hispanic: 2.0 per 1,000
Median age of ASD diagnosis 5 years, 4 months

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* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

Georgia Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Georgia is included in the ADDM ASD Study?

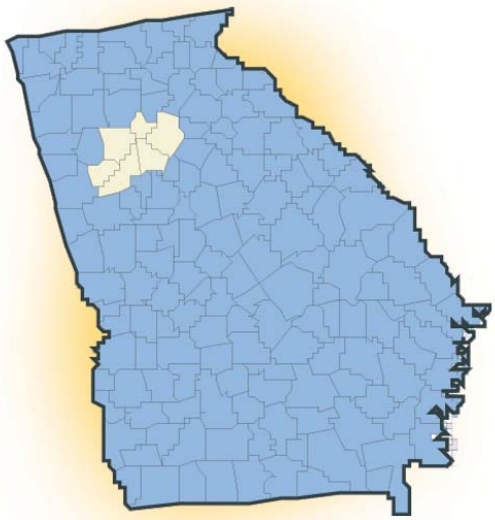
5 counties of metropolitan Atlanta: Clayton, Cobb, DeKalb, Fulton, and Gwinnett

Population of 8-Year-Old Children in Study Area, 2000

43,593 (35.1% of all 8-year-olds in GA)
40.7% White-Non-Hispanic
44.8% Black-Non-Hispanic
9.8% Hispanic
9.9% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

44,299 (35.7% of all 8-year-olds in GA)*
41.5% White-Non-Hispanic
44.1% Black-Non-Hispanic
14.4% Hispanic
10.1% of children in special education



Yellow- Counties in the ADDM Network

Results

Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 285
Total prevalence of ASDs: 6.5 per 1,000
Boys: 11.0 per 1,000
Girls: 2.0 per 1,000
White, non-Hispanic: 7.9 per 1,000
Black, non-Hispanic: 5.3 per 1,000
Median age of ASD diagnosis 4 years, 8 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 337
Total prevalence of ASDs: 7.6 per 1,000
Boys: 12.4 per 1,000
Girls: 2.6 per 1,000
White, non-Hispanic: 8.9 per 1,000
Black, non-Hispanic: 6.8 per 1,000
Hispanic: 4.6 per 1,000
Median Age of ASD diagnosis 4 years, 10 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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Maryland ADDM

Maryland Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Maryland is included in the ADDM ASD Study?

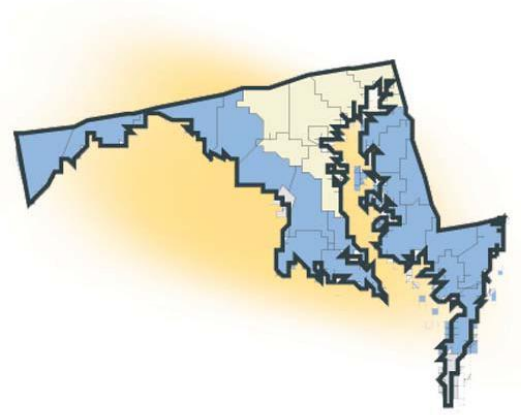
2000-4 counties (Carroll, Cecil, Harford, Howard) plus Baltimore City
2002-5 counties (Baltimore, Carroll, Cecil, Harford, Howard) plus Baltimore City

Population of 8-Year-Old Children in Study Area, 2000

21,532 (26.8% of all 8-year-olds in MD)
53.6% White-Non-Hispanic
39.5% Black-Non-Hispanic
10.6% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

21,532 (26.8% of all 8-year-olds in MD)*
53.6% White-Non-Hispanic
39.5% Black-Non-Hispanic
10.6% of children in special education



Yellow- Counties in the ADDM Network

Results

Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 118
Total prevalence of ASDs: 5.5 per 1,000
Boys: 8.6 per 1,000
Girls: 2.2 per 1,000
White, non-Hispanic: 4.9 per 1,000
Black, non-Hispanic: 6.1 per 1,000
Median age of ASD diagnosis 4 years, 6 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 199
Total prevalence of ASDs: 6.7 per 1,000
Boys: 10.2 per 1,000
Girls: 3.0 per 1,000
White, non-Hispanic: 7.0 per 1,000
Black, non-Hispanic: 6.2 per 1,000
Hispanic: 1.4 per 1,000
Median age of ASD diagnosis 5 years

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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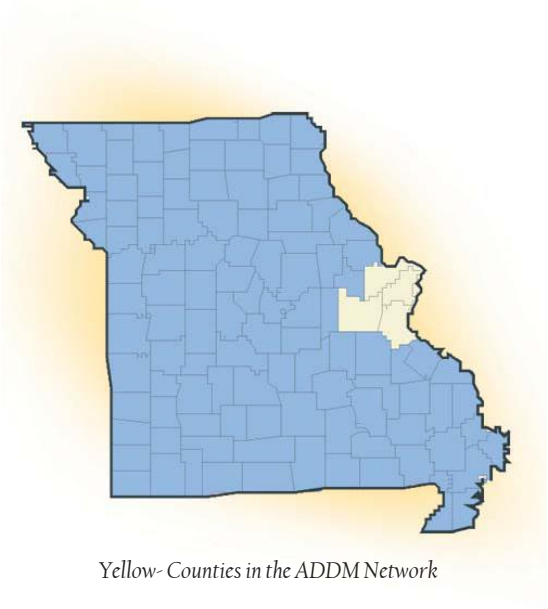
Missouri Autism Developmental Disabilities Monitoring (ADDM) Network Project



Yellow- Counties in the ADDM Network

What part of Missouri is included in the ADDM ASD Study?

5 counties in metropolitan St. Louis (St. Louis, St. Louis City, Franklin, Jefferson, St. Charles)

Population of 8-Year-Old Children in Study Area, 2002

28,049 (36.4% of all 8-year-olds in MO)*
67.9% White-Non-Hispanic
27.9% Black-Non-Hispanic
2.0% Hispanic
12.7% of children in special education

Results

Number of 8-year-old children identified with an ASD: 205
Total prevalence of ASDs: 7.3 per 1,000
Boys: 11.3 per 1,000
Girls: 3.1 per 1,000
White, non-Hispanic: 7.7 per 1,000
Black, non-Hispanic: 4.7 per 1,000
Hispanic: 1.8 per 1,000
Median age of ASD diagnosis 4 years, 8 months

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* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

New Jersey ADDM

New Jersey Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of New Jersey is included in the ADDM ASD Study?

4 counties (Essex, Union, Hudson, and Ocean) including metropolitan Newark

Population of 8-Year-Old Children in Study Area, 2000

29,714 (25% of all 8-year-olds in NJ)
40.0% White-Non-Hispanic
26.0% Black-Non-Hispanic
12.1% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

29,748 (25% of all 8-year-olds in NJ)*
42.6% White-Non-Hispanic
27.0% Black-Non-Hispanic
24.9% Hispanic
13.0% of children in special education

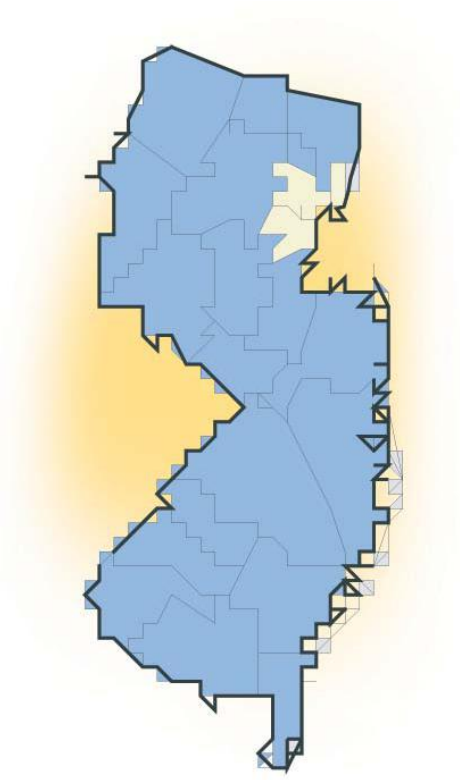
Results

Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 295
Total prevalence of ASDs: 9.9 per 1,000
Boys: 14.8 per 1,000
Girls: 4.3 per 1,000
White, non-Hispanic: 11.3 per 1,000
Black, non-Hispanic: 10.6 per 1,000
Median age of ASD diagnosis 4 years, 4 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 316
Total prevalence of ASDs: 10.6 per 1,000
Boys: 16.8 per 1,000
Girls: 4.0 per 1,000
White, non-Hispanic: 12.5 per 1,000
Black, non-Hispanic: 7.7 per 1,000
Hispanic: 9.7 per 1,000
Median age of ASD diagnosis 4 years, 7 months



Yellow- Counties in the ADDM Network

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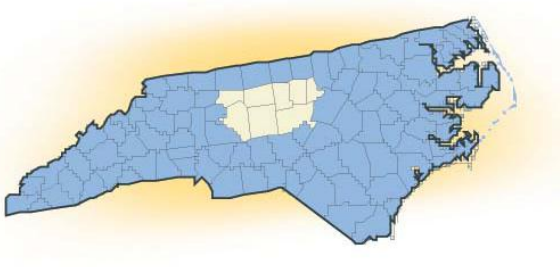
* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

North Carolina Autism Developmental Disabilities Monitoring (ADDM) Network Project



Yellow- Counties in the ADDM Network

What part of North Carolina is included in the ADDM ASD Study?

8 central counties of North Carolina (Alamance, Chatham, Davidson, Durham, Forsyth, Guilford, Orange, and Randolph Counties)

Population of 8-Year-Old Children in Study Area, 2002

20,725 (18.3% of all 8-year-olds in NC)*
58.5% White-Non-Hispanic
30.3% Black-Non-Hispanic
8.2% Hispanic
14.5% of children in special education

Results

Number of 8-year-old children identified with an ASD: 135
Total prevalence of ASDs: 6.5 per 1,000
Boys: 10.6 per 1,000
Girls: 2.1 per 1,000
White, non-Hispanic: 6.4 per 1,000
Black, non-Hispanic: 7.2 per 1,000
Hispanic: 4.1 per 1,000
Median age of ASD diagnosis 4 years, 5 months

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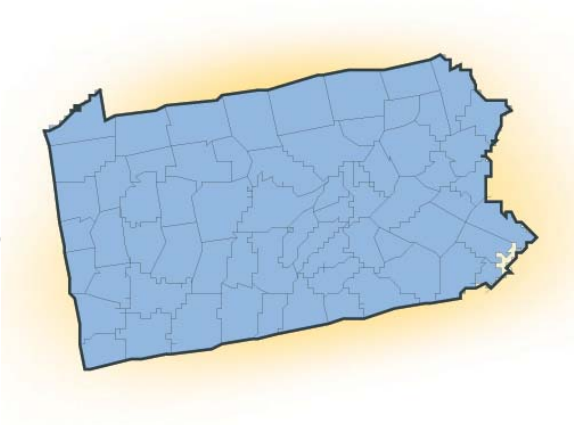
* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

Pennsylvania ADDM

Pennsylvania Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Pennsylvania is included in the ADDM ASD Study?

Philadelphia County



Yellow- County in the ADDM Network

Population of 8-Year-Old Children in Study Area, 2002

21,061 (13.23% of all 8-year-olds in PA)*
27.5% White-Non-Hispanic
54.1% Black-Non-Hispanic
14.0% Hispanic
7.5% of children in special education

Results

Number of 8-year-old children identified with an ASD: 111
Total prevalence of ASDs: 5.3 per 1,000
Boys: 8.7 per 1,000
Girls: 1.8 per 1,000
White, non-Hispanic: 7.6 per 1,000
Black, non-Hispanic: 4.2 per 1,000
Hispanic: 4.7 per 1,000
Median age of ASD diagnosis 4 years, 10 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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South Carolina Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of South Carolina is included in the ADDM ASD Study?

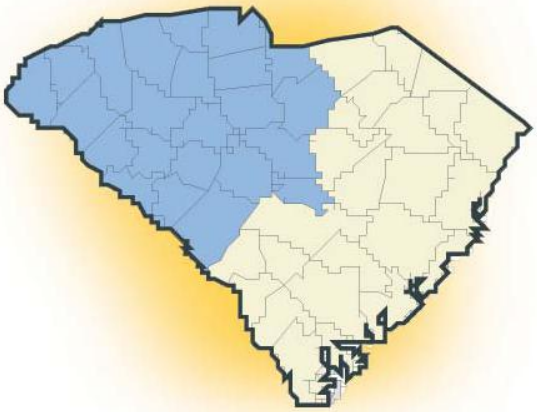
Coastal and PeeDee Region: 23 Counties

Population of 8-Year-Old Children in Study Area, 2000

24,535 (42% of all 8-year-olds in SC)
47.9% White, Non-Hispanic
47.3% Black, Non-Hispanic
16.9% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

23,191 (42% of all 8-year-olds in SC)*
50.1% White, Non-Hispanic
45.5% Black, Non-Hispanic
2.95% Hispanic
18.5% of children in special education



Yellow- Counties in the ADDM Network

Results

Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 155
Total prevalence of ASDs: 6.3 per 1,000
Boys: 7.9 per 1,000
Girls: 3.1 per 1,000
White, non-Hispanic: 6.5 per 1,000
Black, non-Hispanic: 5.8 per 1,000
Median age of ASD diagnosis 4 years, 6 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 140
Total prevalence of ASDs: 6.0 per 1,000
Boys: 9.2 per 1,000
Girls: 2.7 per 1,000
White, non-Hispanic: 6.0 per 1,000
Black, non-Hispanic: 5.5 per 1,000
Hispanic: 4.4 per 1,000
Median age of ASD diagnosis 5 year, 4 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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Utah ADDM

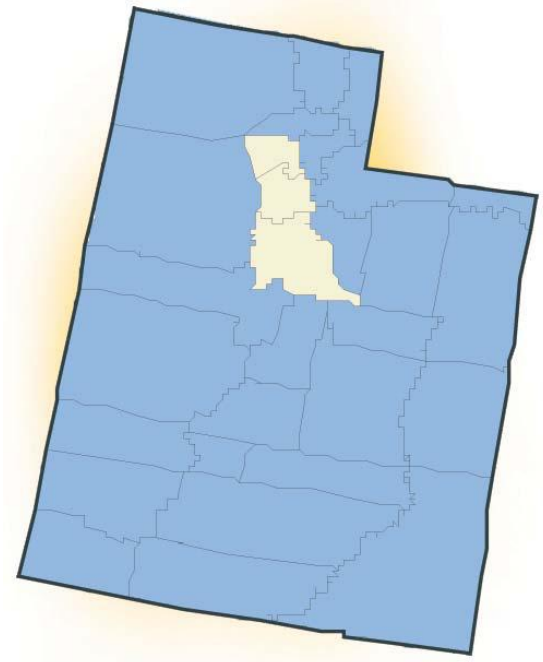
Utah Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Utah is included in the ADDM ASD Study?

3 counties in metropolitan Salt Lake City (Salt Lake, Davis, and Utah Counties)

Population of 8-Year-Old Children in Study Area, 2002

2002: 26,108 (67.6% of all 8-year-olds in UT)*
81.2% White-Non-Hispanic
1.4% Black-Non-Hispanic
13.2% Hispanic
13.0% of children in special education



Yellow- Counties in the ADDM Network

Results

Number of 8-year-old children identified with an ASD: 196
Total prevalence of ASDs: 7.5 per 1,000
Boys: 12.7 per 1,000
Girls: 2.0 per 1,000
White, non-Hispanic: 8.0 per 1,000
Black, non-Hispanic: 5.5 per 1,000
Hispanic: 4.4 per 1,000
Median age of ASD diagnosis 4 years, 1 month

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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West Virginia Autism Developmental Disabilities Monitoring (ADDM) Network Project

Yellow- Counties in the ADDM Network

What part of West Virginia is included in the ADDM ASD Study?

Entire state

Population of 8-Year-Old Children in Study Area, 2000

23,065 (100% of all 8-year-olds in WV)
93.1% White-Non-Hispanic
3.5% Black-Non-Hispanic
16.0% of children in special education

Population of 8-Year-Old Children in Study Area, 2002

21,472 (100% of all 8-year-olds in WV)*
93.7% White-Non-Hispanic
4.4% Black-Non-Hispanic
1.1% Hispanic
7.7% of children in special education

Results

Autism Spectrum Disorder (ASD) Prevalence, 2000

Number of 8-year-old children identified with an ASD: 104
Total prevalence of ASDs: 4.5 per 1,000
Boys: 6.6 per 1,000
Girls: 2.4 per 1,000
White, non-Hispanic: 4.5 per 1,000
Black, non-Hispanic: Not Reported
Median Age of ASD diagnosis 4 years, 4 months

Autism Spectrum Disorder (ASD) Prevalence, 2002

Number of 8-year-old children identified with an ASD: 153
Total prevalence of ASDs: 7.1 per 1,000
Boys: 11.0 per 1,000
Girls: 3.0 per 1,000
White, non-Hispanic: 6.8 per 1,000
Black, non-Hispanic: 6.4 per 1,000
Hispanic: Not Reported
Median age of ASD diagnosis: 4 years, 6 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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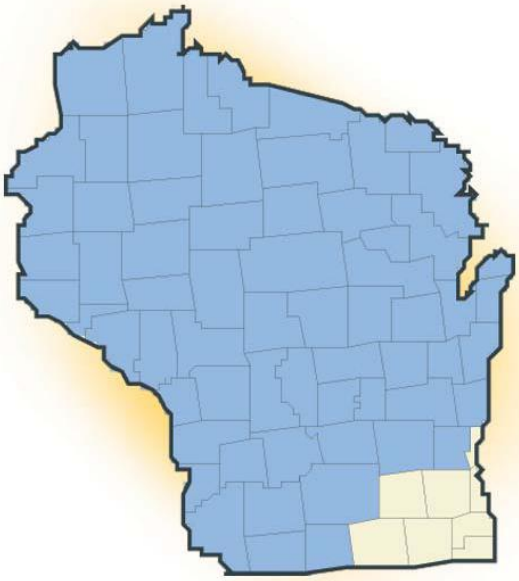
Wisconsin ADDM

Wisconsin Autism Developmental Disabilities Monitoring (ADDM) Network Project

What part of Wisconsin is included in the ADDM ASD Study?

10 counties of southeastern Wisconsin: Kenosha, Racine, Milwaukee, Ozaukee, Waukesha, Jefferson, Rock, Dane, Green and Walworth



Yellow- Counties in the ADDM Network

Population of 8-Year-Old Children in Study Area, 2002

35,126 (48% of all 8-year-olds in WI)*
68.0% White, Non-Hispanic
18.7% Black, Non-Hispanic
9.7% Hispanic
10.7% of children in special education

Results

Number of 8-year-old children identified with an ASD: 181
Total prevalence of ASDs: 5.2 per 1,000
Boys: 7.9 per 1,000
Girls: 2.3 per 1,000
White, non-Hispanic: 5.9 per 1,000
Black, non-Hispanic: 3.7 per 1,000
Hispanic: 0.3 per 1,000
Median Age of ASD diagnosis 4 years, 6 months

* Please see MMWR SS report for additional information by race/ethnicity (American Indian/Alaska Native, and Asian/Pacific Islander)

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What do the ADDM Network results tell us about the prevalence of ASD in the United States?

Most ADDM Network sites identified between 5.2 and 7.6 per 1,000 8-year-old children with ASDs in 2002. The prevalence was significantly lower (3.3 per 1,000) in Alabama and higher (10.6 per 1,000) in New Jersey). The average ASD prevalence was 6.7 per 1,000 in 2000 and 6.6 per 1,000 in 2002, or approximately 1 in 150 children. Prevalence was stable from 2000 to 2002 in 4 of the 6 sites with data for both years, but it increased slightly in Georgia and significantly in West Virginia, indicating the need for ongoing monitoring of prevalence over time. These data provide important information about the prevalence of ASDs in multiple areas of the United States and will be used to study trends in the occurrence of these disabilities over time.

How many children in the United States have an ASD?

There is not a full population count of all individuals with an ASD in the United States. However, using the prevalence data stated above (approximately 1 in 150 children with an ASD), we can estimate that if 4 million children are born in the United States every year, approximately 26,670 children will eventually be diagnosed with an ASD. Assuming the prevalence rate has been constant over the past two decades, we can estimate that about 560,000 individuals between the ages of 0 and 21 have an ASD. However, many of these individuals may not be classified as having an ASD until school-age or later. Since behaviors related to the ASDs are usually present before the age of 3 years, it is important to make sure the individuals are being classified and are receiving appropriate intervention services as early as possible.

How do the rates of ASDs compare with those of other childhood disabilities?

About 2% of children under the age of 18 have a serious developmental disability, such as mental retardation, cerebral

palsy, hearing loss, and vision impairment. (19) Mental retardation (or intellectual disability) is the most common. Down syndrome is a genetic disorder often associated with mental retardation/intellectual disability. Down syndrome occurs in 1 out of 800 births, which makes the disorder less common than ASDs. (20) About 17% of children have some type of developmental disability, including more mild conditions such as speech and language disorders, learning disabilities, and ADHD. These conditions appear to be more common than ASDs. (19)

Children's health and development may also be affected by diseases, such as juvenile diabetes and cancer. Juvenile diabetes is prevalent in about 1 in every 400 to 500 children and adolescents. Childhood cancer has a prevalence rate of 1.5 per 10,000 children, far less than that for ASDs. (22)

How many children with ASDs are being served through public special education programs?

In 2005, about 223,942 children ages 3–21 were served under the "Autism" classification for special education services. (5) Not all children with an ASD receive special education services under the classification of "autism," so the education data underestimate the actual prevalence of the ASDs. While it is clear that more children are getting special education services for autism than ever before, it is important to remember that this classification was only added in the early 1990s and the growth in the number of children classified may be due in part to the addition of this as a special education category.

How does the number of children with ASDs in special education compare with that of other disabilities?

In 2005, according to administrative counts from the Individuals with Disabilities Education Improvement Act (IDEA), 6,109,569 children ages 6–21 received services through 13 special education categories in public special education programs. Specific learning disability was the most frequent education category identified, and speech and language impairment was second. Together, these two categories made up 64.5% of all special education placements. The mental retardation classification made up about 9% (545,492). Autism made up about 3% (193,637) of children in special education. (5)

How can I tell if my child's development is on track?

Children develop at their own pace, so it can be hard to tell exactly when a child will learn a particular skill. But, there are age-specific milestones designed to measure a child's development in the first few years of life. To learn more about developmental milestones, visit "Learn the Signs. Act Early." (www.cdc.gov/actearly), a campaign by CDC and national partners to educate parents, health care professionals, and child care providers about early childhood development, including potential early warning signs of autism and other developmental disabilities.

What should I do if I think my child might have an ASD?

If you are concerned about your child's development, or think that your child might have an ASD, talk to your child's health care professional and/or teacher. Your child's health care professional may refer your child to a developmental pediatrician or psychologist for a full developmental evaluation. (For tips on how to share your concerns with your health care professional, visit the First Signs website at www.firstsigns.org.) Your child's teacher may ask the special education department of your local school district to do a psycho-educational evaluation to be completed of your child.

What services are available for children with ASDs?

The Individuals with Disabilities Education Improvement Act (IDEA) (23) is a law that ensures that all children with disabilities, from birth through 21 years of age, can get a 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 www.ed.gov/policy/speced/guid/idea/idea2004.html.)

Children ages 3–21 can receive educational assessments and programs from public schools. Programs can include direct teaching or consultation by a special education teacher and/or related services such as speech/language therapy, occupational/physical therapy, and supportive counseling. Infants and toddlers can receive assessments and programs through public health departments or other state agencies. All children receiving services under IDEA should have an Individualized Family Service Plan (IFSP), for children under 3, or an Individualized Education Program (IEP), for children 3 and older. The IEP and IFSP provide a detailed plan to meet the unique and specific educational needs of each child.

What kinds of treatments or therapies can help children with ASDs?

According to reports by the American Academy of Pediatrics (24) and the National Research Council, (25) educational interventions thought to help children with ASDs are those that provide structure, direction, and organization for the child. Educational interventions must be tailored to the child and take into account his or her overall developmental status and specific strengths and needs.

Can medication help children with ASDs?

No medication can cure ASDs or treat the core symptoms of ASD—that is, the communication and social impairments and the repetitive or unusual behaviors that make up the disorder. But, medications have helped with some of the symptoms of autism in some people. For instance, medication might be used to help with a person's high energy levels, inability to focus, depression, or seizures. Also, the U.S. Food and Drug Administration has approved the use of risperidone (an antipsychotic drug) to treat 5- to 16-year-old children with ASDs who have severe tantrums, aggression, and self-injurious behavior.

Medications may not affect a person with an ASD in the same way they would affect another person. So, it is important to work with a health care professional who has experience treating people with ASDs. Also, parents must watch their child's progress and reactions while he or she is taking a particular medication to be sure that the side effects of the treatment do not outweigh the benefits.

What can I do to keep my child with an ASD healthy?

It is important to remember that children with ASDs can get sick or injured just like all children. Regular medical and dental exams should be part of your child's intervention plan. Often, it is difficult to determine if a child's behavior is related to his or her ASD or is caused by a separate health condition. For instance, head banging could be a symptom of an ASD, or it could be a sign that the child is having headaches. In those instances, a thorough physical exam is needed.

If You Are Concerned, Act Quickly

The sooner you get a diagnosis, the sooner you can start appropriate treatment and the better the progress your child can make. Although there is currently no cure for ASDs, most people believe that recognizing the signs of developmental delay as early as possible and immediately seeking early intervention services right away may have the greatest impact on overall improvement.

Summary

While, it is clear that more children than ever before are being classified as having an Autism Spectrum Disorder, it is unclear how much of this increase is due to changes in how we identify and classify ASDs in people, or whether this is due to a true increase in prevalence. However, using our current standards, the ASDs are the second most common serious developmental disability after mental retardation/intellectual impairment, but are still less common than other conditions that affect children's development, such as speech and language impairments, learning disabilities, and ADHD. The impact of having a developmental disability is immense for the families affected and for the community services that provide intervention and support for these families. It is important that we treat common developmental disabilities (DDs), and especially the ASDs, as conditions of urgent public health concern, do all we can to identify children's learning needs, and begin intervention as early as possible to enable all children to reach their full potential.

Where Can I Get More Information?

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

Developmental Milestones and Warning Signs for Developmental Disabilities

Learn the Signs. Act Early. Campaign
www.cdc.gov/actearly
Find out if your child's development is on track and learn the signs of developmental delays.

General Information About Autism

CDC Autism Information Center
http://www.cdc.gov/autism
Check out a full range of resources for parents, educators, researchers, and practitioners. Also learn what CDC is doing to better understand ASDs and their causes and risk factors.

Autism Speaks
www.autismspeaks.org
Read about what autism is and how to cope with it. Also learn about efforts to raise awareness about the disorder.

Services and Support for Children with ASDs

Autism Society of America
www.autism-society.org or 1-800-3-AUTISM
This national organization can link you to local resources. Click on the "Chapters" link to find an ASA chapter in your state.

National Early Childhood Technical Assistance Center
www.nectac.org
Find early intervention programs in your state.

Questions Often Asked by Parents About Special Education Services
http://www.nichcy.org/pubs/ideapubs/lg1txt.htm or 1-800-695-0285
Get answers to your questions about services provided under the Individuals with Disabilities Education Improvement Act. Also available en Español.

Note: Your public school special education director can also help guide you with a referral to the local infant, toddler, or preschool assessment and intervention programs in your area.

Diagnosis and Treatment of ASDs

Educating Children with Autism
http://www.nap.edu/books/0309072697/html/
Read a review of interventions for autism, by the National Academy of Sciences.

National Institute of Mental Health
http://www.nimh.nih.gov/publicat/autism.cfm
Find out about the process of diagnosing ASDs and about treatment options, including medications used to help people with ASDs.

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 ASDs in this report from the American Academy of Pediatrics.

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