

ADDMM

Autism and Developmental
Disabilities Monitoring
Network -2012



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

Prevalence of Autism Spectrum Disorders (ASDs)
Among Multiple Areas of the United States in 2008

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

This community report summarizes the main findings from the following published report: Centers for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2008. *Morbidity and Mortal Weekly Report* (MMWR) 2012; Vol. 61(3).

To read the MMWR report in its entirety, go to www.cdc.gov/mmwr.

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

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

TABLE OF CONTENTS

Executive summary	1
What are autism spectrum disorders?	2
Why do we need to know how many people have ASDs ?	3
What is the ADDM network?	4
Results.....	6
State by state	8
How can the data be used?	37
Questions and answers	38
What else do I need to know?.....	39
Where can I get more information?.....	40



EXECUTIVE SUMMARY

The Centers for Disease Control and Prevention (CDC) estimates that about 1 in 88 children has been identified with an autism spectrum disorder (ASD). CDC's estimate comes from the Autism and Developmental Disabilities Monitoring (ADDM) Network, which monitors the number of 8-year-old children with ASDs living in diverse communities throughout the United States. In 2007, CDC's ADDM Network first reported that about 1 in 150 children had an ASD (based on children who were 8 years old in 2002). Then, in 2009, the ADDM Network reported that 1 in 110 children had an ASD (based on children who were 8 years old in 2006). Most recently, the ADDM Network reported that 1 in 88 children had an ASD (based on children who were 8 years old in 2008). This means that the estimated prevalence of ASDs increased 23% during 2006 to 2008 and 78% during 2002 to 2008 (1–4).

At CDC, we understand that people may be concerned when they hear these study results and we have been working to understand what's causing the increase. We know that some of the increase is probably due to the way children are identified and served in local communities, although exactly how much is due to these factors is unknown. To understand more, we need to keep accelerating our research. We recognize that people need answers now, and we hope these updated prevalence estimates will help communities to plan better for the supports and services that families need. We are working, together with our partners, on the search for risk factors and causes and to address the growing needs of individuals, families, and communities affected by ASDs.

Here are the key findings from this report:

- More children were diagnosed at earlier ages—a growing number of them by 3 years of age. Still, most children were not diagnosed until after they were 4 years of age. On average, diagnosis was a bit earlier for children with autistic disorder (4 years) than for children with the more broadly defined autism spectrum diagnoses or pervasive developmental disorder—not otherwise specified (4 years, 5 months), and diagnosis was much later for children with Asperger disorder (6 years, 3 months).
- As has been detailed in previous reports, we also found that almost five times as many boys were being identified with ASDs as girls (1 in 54 compared to 1 in 252). Research exploring why there are differences in the identified prevalence among males and females is ongoing and knowing that the conditions are more common among boys can help direct our search for causes.
- The largest increases over time were among Hispanic and Black children. We suspect that some of this was due to better screening and diagnosis. However, this finding explains only part of the increase over time, as more children were identified in all racial and ethnic groups.
- The majority (62%) of children the ADDM Network identified as having ASDs did not have intellectual disability. The largest increases during 2002 to 2008 were among children without intellectual disability (those having IQ scores higher than 70), although there were increases in the identified prevalence of ASDs at all levels of intellectual ability.

The ADDM Network prevalence reports help us understand the characteristics of children with ASDs and shed light on the very real impact of the conditions on families and communities living in several communities in the United States. While many studies of ASDs have focused on small groups of individuals, the ADDM Network monitors these conditions among thousands of children from diverse communities across the country. This ongoing, population-based approach allows the ADDM Network to monitor changes in the identification of ASDs and better describe the characteristics of children with these conditions, such as the average age of diagnosis and disparities in identification. These data help direct our research into potential risk factors and can help communities direct their outreach efforts to those who need it most.

In summary:

We are finding that more children than ever before are being diagnosed with ASDs and they are not being diagnosed as early as they could be. The emotional and financial tolls on families and communities are staggering and therapies can cost thousands of dollars. We recognize that families are frustrated and want answers now. We will continue working to provide essential data on ASDs, to understand the recent increase and why some children are more likely to be identified than others, and to improve early identification in hopes that all children have the opportunity to thrive

WHAT ARE AUTISM SPECTRUM DISORDERS?

Autism spectrum disorders (ASDs) are a group of developmental disabilities that often are diagnosed during early childhood and can cause significant social, communication, and behavioral challenges over a lifetime. People with ASDs have a different way of understanding and reacting to people and events in their world. These differences are caused by the way their brain processes information.

This group of developmental disabilities is considered a “spectrum” of disorders. This means ASDs affect each person in different ways, and symptoms can range from mild to severe. People with ASDs share some similar symptoms, such as problems with social interaction, problems with communication, and highly focused interests or repetitive activities. But, there are differences in when the symptoms begin or are first noticed and in how the symptoms affect a person’s functioning.

There are three main subtypes of autism spectrum disorders

- Autistic disorder
- Asperger disorder
- Pervasive developmental disorder-not otherwise specified (PDD-NOS)

Diagnosis

At this time, there is no medical test, such as a blood test or brain scan, to diagnose ASDs. Instead, they are diagnosed by qualified professionals who conduct comprehensive psychological and behavioral evaluations. These evaluations can include clinical observation, parental reports of developmental and health histories, psychological testing, speech and language assessments, and possibly the use of one or more questionnaires developed specifically for people with ASDs. Also, neurologic and genetic testing can be used to rule out other disorders.

A person with an ASD might:

- Not respond to his or her name by 12 months of age (e.g., appear to not hear).
- Not point at objects to show interest by 14 months of age (e.g., not point at an airplane flying over).
- Not play “pretend” games by 18 months of age (e.g., 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 (e.g., use words much later than siblings or peers).
- Repeat words or phrases over and over.
- Give unrelated answers to questions.
- Get upset by minor changes in routine (e.g., getting a new toothbrush).
- Have obsessive interests (e.g., get “stuck” on ideas).
- Flap his or her hands, rock his or her body, or spin in circles.
- Have unusual reactions to the way things sound, smell, taste, look, or feel.

“The Autism Society relies on CDC data to determine how to direct its efforts to serve all individuals affected by autism.”

– Jim Ball, Autism Society Board Chairman

WHY DO WE NEED TO KNOW HOW MANY CHILDREN HAVE ASDS?

We need to know how many children have ASDs, so that realistic plans can be made to support these children and their families. Some of the resources that are needed include therapies, trained teachers, diagnosticians, health care providers, and related service professionals. Understanding the characteristics and number of children who have ASDs is key to promoting awareness of the condition, helping educators and providers to plan and coordinate service delivery, and identifying important clues for further research.

Preparing Communities

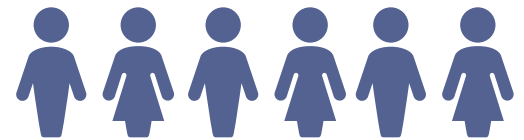
If communities and service systems are not prepared to meet the needs of people with ASDs, it takes a toll on families. Families living with ASDs have unique stresses(5). Therapies are expensive and families spend time on long waiting lists. Many parents even report having to stop work to care for their child with an ASD(6). Annual medical expenditures per child with an ASD range from \$2,100 to \$11,200. Additionally, we know that intensive behavioral interventions for a child with an ASD can cost from \$40,000 to \$60,000 per year and that the nonmedical costs of special education for a child with an ASD are about \$13,000 per year(7). Eventually the cost to individual families extends into lost productivity and other financial problems for communities.

What Is Prevalence?

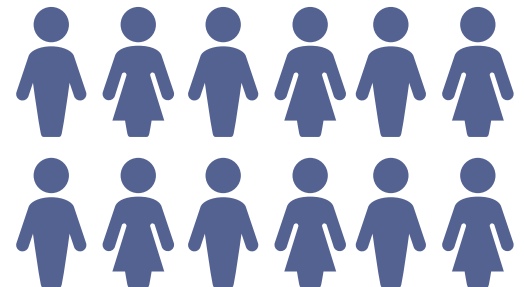
Prevalence is a scientific term describing the number of individuals with a disease or condition among a defined group of people at a specific period in time. For example, we estimated the prevalence of ASDs among 8-year-olds in 2008 in Atlanta, Georgia, by counting all of the 8-year-olds in Atlanta who were identified with ASDs, and then dividing that number by the total number of 8-year-olds living in Atlanta during 2008. By monitoring ASDs in the same way over time, we can find out whether more, fewer, or the same number of children are being identified with ASDs.

Estimating the prevalence of ASDs at any given time is not simple. Prior to the ADDM Network, the United States did not have a system to track ASDs in multiple communities. Some challenges we still face are:

1. The change to a broader, more inclusive, definition of ASDs(8, 9). This means more people could be classified as having ASDs over time.
2. There is no medical test for ASDs. Diagnosis of ASDs depends on observations of behavior and development.



Number of 8-year-olds with ASDs



Total number of 8-year-olds

= PREVALENCE

"We have used the ADDM data to raise public awareness of autism by 43 percent through our Ad Council campaign and other efforts. And, these data are also very useful in guiding some of our research funding decisions."

– Mark Roithmayr, President, Autism Speaks

Researchers have used different ways to estimate the prevalence of ASDs and each method has advantages and disadvantages.

Method	What Is It?	Advantages and Disadvantages
Population Screening and Evaluation	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 a bias based on who participates.
Registries	Voluntarily including oneself (or one's child) on a list of people with ASDs	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.
Administrative Data	Looking at service records from Medicare and agencies like the U.S. Department of Education	Relatively low cost, BUT underestimates prevalence because not all children with ASDs are receiving services for their conditions.
Systematic Record Review (ADDM Network Method)	Reviewing health and educational records to identify children with autism behaviors	Cost-effectively provides estimate of the prevalence of ASDs from large communities and identifies children who might not have a clear ASD diagnosis already; BUT, it relies on the quality and quantity of information in records.

WHAT IS THE ADDM NETWORK?

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to determine the number of people with ASDs in multiple communities in the United States. The ADDM Network sites all collect data using the same methods, which are modeled after CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

- Authorized by the Children's Health Act of 2000, the ADDM Network has been funded by CDC at 14 sites since 2000. Sites are selected through a competitive award process and are not intended to form a nationally representative sample.
- The sites represented in this report include areas of Alabama, Arizona, Arkansas, Colorado, Florida, Georgia, Maryland, Missouri, New Jersey, North Carolina, Pennsylvania, South Carolina, Utah, and Wisconsin.

The ADDM Network's goals are to:

- Provide data about prevalence (how common ASDs are in a specific place and time period).
- Describe the population of children with ASDs.
- Compare the identified prevalence of ASDs among different groups of children in different areas of the country.
- Identify changes in the identified prevalence of ASDs over time.
- Understand the impact of ASDs and related conditions in U.S. communities

What Is the ADDM Network's Method?

The ADDM Network's method is population-based, which means that researchers study these conditions among thousands of children from diverse communities across the country.

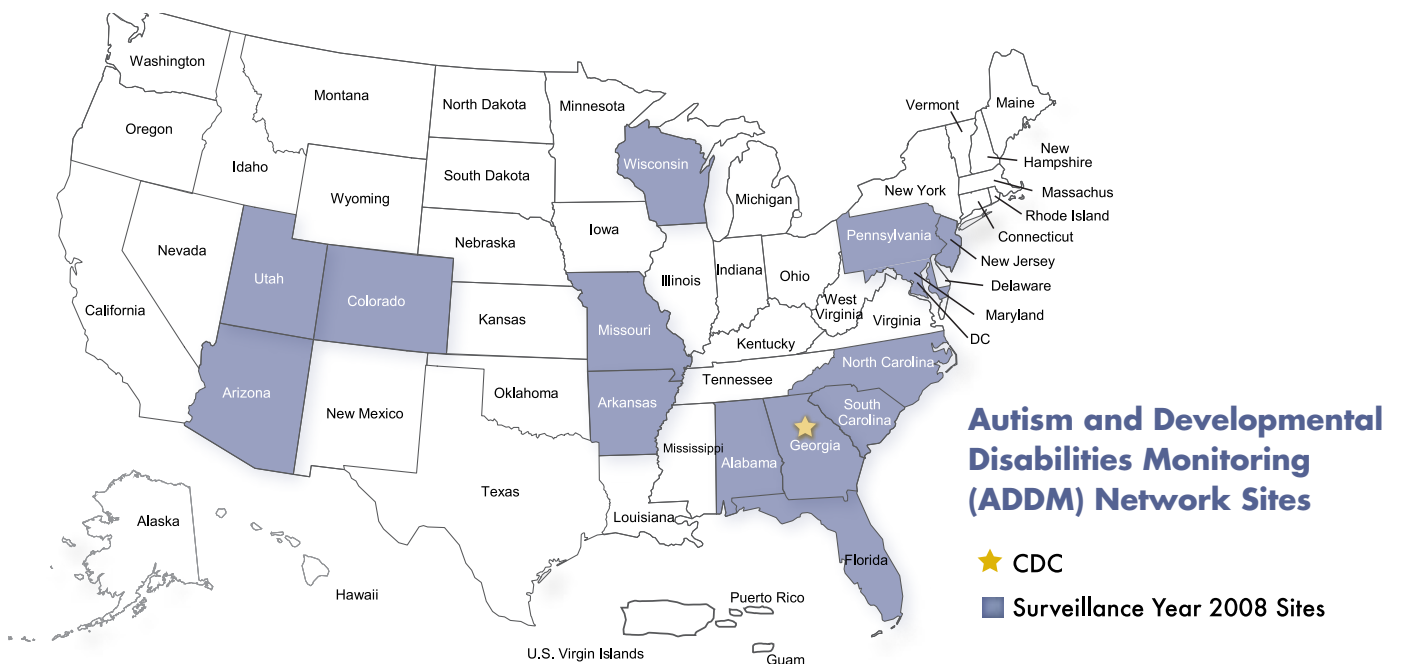
- The ADDM Network estimates the number of people with ASDs by reviewing records at multiple sources that educate, diagnose, treat, and provide services to children with developmental disabilities to ensure as complete a count as possible of children with ASDs.
- A panel of clinicians with expertise in identifying and assessing ASDs systematically reviews developmental assessment information from the records using the Diagnostic and Statistical Manual of Mental Disorders, Fourth Revision, Text Revision (10) definition of ASDs and determines whether the identified children meet the requirements of the monitoring program and could be considered as having ASDs.
- Record review does not rely solely on the presence of an ASD diagnosis, but also includes review of records for children who have behaviors consistent with ASDs, even if they do not have a diagnosis.

What Are the Advantages of This Method?

Although the ADDM Network sites do not make up a nationally representative sample, their combined surveillance areas represent approximately 8% of the 8-year-old population residing in the United States and provide the most complete estimate of the prevalence of ASDs in the United States. While the prevalence of ASDs might be higher or lower in different places, combined results from the ADDM Network are similar to those of other U.S. studies (11). This ongoing, population-based approach allows the ADDM Network to monitor changes in the identified prevalence of ASDs and better describe the characteristics of children with these conditions.

What Else Is the ADDM Network Doing?

The ADDM Network continues to collect data to produce ASD prevalence estimates every 2 years. Ongoing monitoring of the identified prevalence of ASDs is essential to our understanding of the conditions. Currently, the ADDM Network is collecting information on children who were 8 years old in 2010, and for the first time also is monitoring ASDs among 4-year-olds. In addition to prevalence reports, the ADDM Network has published many findings on potential risk factors for ASDs and characteristics of individuals identified with ASDs. Some ADDM Network sites also study the prevalence of other developmental disabilities, including cerebral palsy, intellectual disability, hearing loss, and vision impairment. A list of publications can be found on our website at: <http://www.cdc.gov/ncbddd/autism/addm-articles.html>.



RESULTS

Part of US Population included in the ADDM Network

8-Year-Old Children: 337,093 (8.4% of the all the 8-year-old children in the US in 2008)

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of 8-year-old children identified with ASDs: **3,820**

Overall prevalence of ASDs: **11.3 per 1,000 (or 1 in 88)**

Range of prevalence estimates across sites: **4.8 per 1,000 to 21.2 per 1,000**

Boys: **18.4 per 1,000 (or 1 in 54)**

Girls: **4.0 per 1,000 (or 1 in 252)**

Race/ Ethnicity

White, non-Hispanic: **12 per 1,000**

Black, non-Hispanic: **10.2 per 1,000**

Hispanic: **7.9 per 1,000**

Asian or Pacific Islander: **9.7 per 1,000**

Documented ASD Diagnosis

Not all children that the ADDM Network identified as having ASDs actually had an ASD diagnosis in their records.

Children with ASDs who had a diagnosis documented in their records: **79%**

Median earliest age ASDs were documented in their records: **4 years, 6 months**

Age varied by subtype of Autism Spectrum Disorder

Autistic Disorder: **4 years, 0 months**

ASD/PDD: **4 years, 5 months**

Asperger Disorder: **6 years, 3 months**

Intellectual Ability

There were seven ADDM Network sites that had intellectual ability information for a majority (80% or more) of the children they identified. The ADDM

Network defined intellectual disability as having an IQ test score of less than or equal to 70 or having a qualified professional document intellectual disability in the record. Although we know an IQ score does not fully characterize the abilities of people with ASDs, tracking IQ level helps us describe the population on a common measure of functioning.

Children with ASDs who did not have intellectual disability: **62%**

Children with ASDs who had intellectual disability: **38%**

Changes in Prevalence of ASDs

Difference between last ADDM Network report (2006) and current ADDM Network report (2008): **23% increase**

Difference between first ADDM Network report (2002) and current ADDM Network report (2008): **78% increase**

ASDs Prevalence changes by Race/ Ethnicity, 2002-2008

The largest increases in prevalence over time were among Hispanic and black children

White, non-Hispanic children: **70% increase**

Black, non-Hispanic children: **91% increase**

Hispanic children: **110% increase**

Network Information

States Participating in ADDM NETWORK, 2008

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

Number of education and health records reviewed across all ADDM Network sites for the 2008 surveillance year: 48, 247

Median number of evaluations reviewed for each child identified with an ASD: 5

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Alabama

The Alabama Autism Surveillance Program (AASP)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 174

Total prevalence of ASDs: 4.8 per 1,000 (or 1 in 210)

Boys: 8.1 per 1,000 (or 1 in 123)

Girls: 1.1 per 1,000 (or 1 in 909)

Race/ Ethnicity

White: 5.0 per 1,000

Black: 4.0 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 66%

Median earliest age ASD was documented in their records: 5 years, 1 month

Autistic Disorder: 4 years

ASD/PDD: 5 years, 2 months

Asperger Disorder: 6 years, 10 months

SITE INFORMATION

Part of Alabama Included in ADDM, 2008

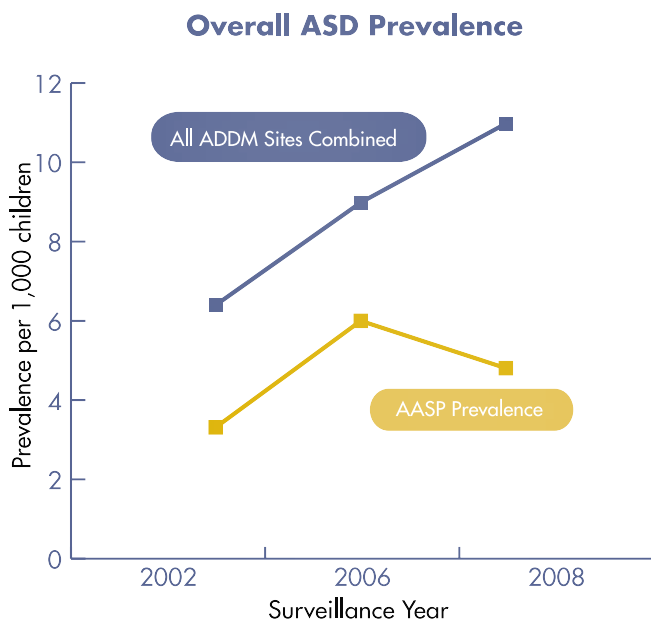
32 counties: Bibb, Blount, Calhoun, Cherokee, Clay, Cleburne, Colbert, Cullman, Dekalb, Etowah, Fayette, Franklin, Greene, Hale, Jackson, Jefferson, Lamar, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, Pickens, Shelby, St. Clair, Sumter, Talladega, Tuscaloosa, Walker, and Winston

Population of 8-Year-Old Children in Study Area, 2008

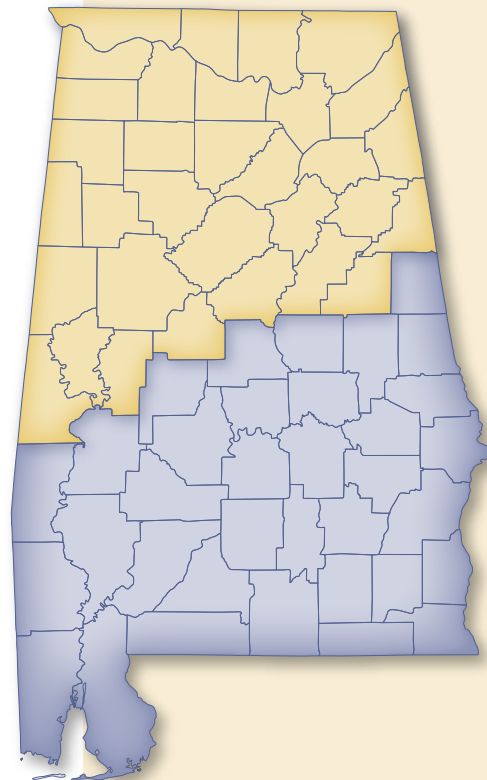
8-Year-Old Children: 36,566

White: 67%

Black: 25.4%



AASP also reported data for the 2004 surveillance year. See the earlier ADDM Network report for this information.



Yellow - Counties in the ADDM Network in 2008

Alabama

The Alabama Autism Surveillance Program (AASP)

The Alabama Autism Surveillance Program (AASP) is a multisource investigation to monitor the number of 8-year-old children in the population with ASDs or cerebral palsy, or both. This surveillance system provides an accurate count of the number of children and families residing in Alabama living with these disorders. The investigators are members of the Department of Health Care Organization and Policy in the School of Public Health at the University of Alabama at Birmingham (UAB), working as agents of the Alabama Department of Public Health. The AASP is a joint undertaking with CDC, the Autism Society of Alabama, other Alabama state partners, the Alabama State Department of Education, and many other agencies and organizations that serve children with developmental disabilities and their families. The AASP has completed the 2002, 2004, 2006, and 2008 surveillance years, and will continue to collect data for the 2010 and 2012 surveillance years.

What kinds of education and training programs does AASP offer to people who work with children who have ASDs or other developmental disabilities?

Through their partnership with the Autism Society of Alabama (ASA), study staff provides workshops and trainings for parents, teachers and primary health care providers to increase recognition of the early signs of ASDs and to enhance their ability to identify and diagnose ASDs, including childhood autism, Asperger syndrome, atypical autism, and pervasive developmental disorder not otherwise specified.

What are some of the resources available in Alabama for children with developmental disabilities, their families, and the professionals who serve them?

- The Autism Society of Alabama (www.autism-alabama.org) is a nonprofit, community-based organization dedicated to advocacy, community education, and support for families. The ASA promotes autism awareness and education throughout various communities and educational and medical organizations. The ASA has helped to establish parent support groups throughout the state, supports local walks and events for children with autism and their families, and publishes a quarterly newsletter.
- The Alabama Department of Education, along with Special Education Services, has established Autism Alabama, a website where parents and educators can find on-line training resources and materials on ASDs. Visit <http://alex.state.al.us/autismAL/> for more information.
- Glenwood Autism and Behavioral Health Center offers treatment and educational services to children, adolescents and adults with ASDs and other mental health disorders. You can visit <http://glenwood.org/> for more information on the programs Glenwood provides.
- The UAB Autism Spectrum Disorders Clinic provides diagnostic evaluations, outpatient therapy, social skills groups, school-based consultations, and in-service trainings/presentations to individuals with ASDs, their families, educators and communities. For more information, please visit <http://circ-uab.infomedia.com/content2.asp?id=104879>.
- United Cerebral Palsy (UCP) of Greater Birmingham and UCP of Huntsville and Tennessee Valley provide programs and services to children and adults with cerebral palsy, autism and other developmental disabilities. Please visit <http://www.ucpbham.com/home.html> or <http://www.ucphuntsville.org/> for more information.

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Arizona

The Arizona Developmental Disabilities Surveillance Program (ADDSP)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 507

Total prevalence of ASDs: 15.6 per 1,000 (or 1 in 64)

Boys: 25.1 per 1,000 (or 1 in 40)

Girls: 5.4 per 1,000 (or 1 in 185)

Race/ Ethnicity

White: 20.7 per 1,000

Black: 16.1 per 1,000

Hispanic: 8.9 per 1,000

Asian or Pacific Islander: 19.0 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 57%

Median earliest age ASD was documented in their records:
4 years, 9 months

Autistic Disorder: 4 years, 8 months

ASD/PDD: 4 years, 6 months

Asperger Disorder: 6 years, 4 months

SITE INFORMATION

Part of Arizona Included in ADDM, 2008

A subset of Maricopa County including metropolitan Phoenix, Arizona

Population of 8-Year-Old Children in Study Area, 2008

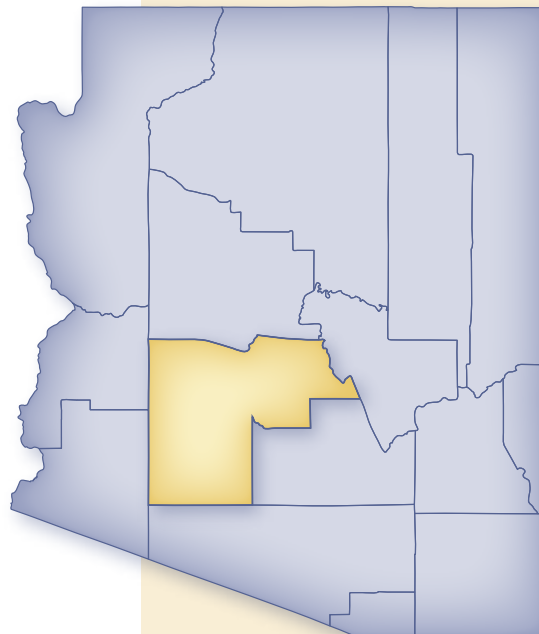
8-Year-Old Children: 32,601

White: 46.1%

Black: 5.5%

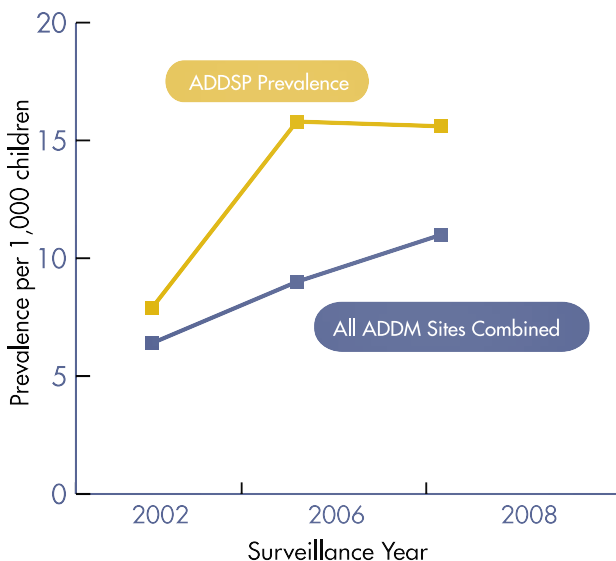
Hispanic: 43.6%

Asian or Pacific Islander: 2.7%



Yellow - County in the ADDM Network in 2008

Overall ASD Prevalence



ADDSP also reported data for the 2000 and 2004 surveillance years. See the earlier ADDM Network reports for this information.

Arizona

The Arizona Developmental Disabilities Surveillance Program (ADDSP)

The Arizona Developmental Disabilities Surveillance Program (ADDSP) is a multisource investigation to monitor the number of 8-year-old children in the population with ASDs or intellectual disability, or both. This surveillance system provides an accurate count of the number of children and families in Arizona living with these disorders. The investigators are members of the Department of Pediatrics and the Mel and Enid Zuckerman College of Public Health at the University of Arizona. The ADDSP is a joint undertaking with CDC, the Arizona Department of Education, and many other agencies and organizations that serve children with developmental disabilities and their families. The ADDSP has completed the 2000, 2002, 2004, 2006, and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

What kinds of education and training programs does the program offer to people who work with children who have ASDs or other developmental disabilities?

The project staff will provide workshops to medical and nonmedical personnel to increase recognition of the early signs of ASDs and to enhance their capacity to diagnose and report autism, including childhood autism, Asperger syndrome, atypical autism, and pervasive developmental disorder not otherwise specified. Staff also will give talks about autism to pediatric faculty and staff at major hospitals in the Phoenix community.

What are some of the resources available in Arizona for children with developmental disabilities, their families, and the professionals who serve them?

- Arizona Department of Education, Exceptional Student Services is accountable for ensuring that all special education programs, regulations, and procedures are in compliance with the Individuals with Disabilities Education Act (IDEA) and eligible children and youth with disabilities are receiving a free appropriate public education (<http://www.azed.gov/special-education>).
- Arizona Division of Developmental Disabilities provides services and supports to help eligible individuals with developmental disabilities achieve self-sufficiency and independence and offers supports for family members and other caregivers (<https://www.azdes.gov/ddd/>).
- Autism Society is dedicated to improving the lives of all affected by autism, and local chapters reach out to individuals and their families with information, support, and encouragement. Arizona chapters include: Autism Society of Northern Arizona (<http://www.nazasa.org/>), Autism Society of Greater Tucson (<http://www.autismsocietygreatertucson.org/>), and Autism Society of Greater Phoenix (<http://www.phxautism.org>).
- Raising Special Kids is a non-profit organization of families helping families of children with disabilities and special health needs (<http://www.raisingpecialkids.org>).
- The Southwest Autism Research and Resource Center (SARRC) is a nonprofit, community-based organization dedicated to autism research, education, and community outreach. The center also provides information to families and professionals on current research about autism and related disorders (www.autismcenter.org).

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Arkansas

Arkansas Autism and Developmental Disabilities Monitoring Program (AR-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 52

Total prevalence of ASDs: 10.5 per 1,000 (or 1 in 95)

Boys: 17.5 per 1,000 (or 1 in 57)

Girls: 3.6 per 1,000 (or 1 in 278)

Race/ Ethnicity

White: 13.5 per 1,000

Black: 7.1 per 1,000

Hispanic: 10.1 per 1,000

Asian or Pacific Islander: No children identified in this group.

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 69%

Median earliest age ASD was documented in their records:

4 years, 4 months

Autistic Disorder: 4 years, 7 months

ASD/PDD: 3 years, 10 months

Asperger Disorder: 7 years, 4 months

SITE INFORMATION

Part of Arkansas Included in ADDM, 2008

Pulaski County (metropolitan Little Rock, Arkansas)

Population of 8-Year-Old Children in Study Area, 2008

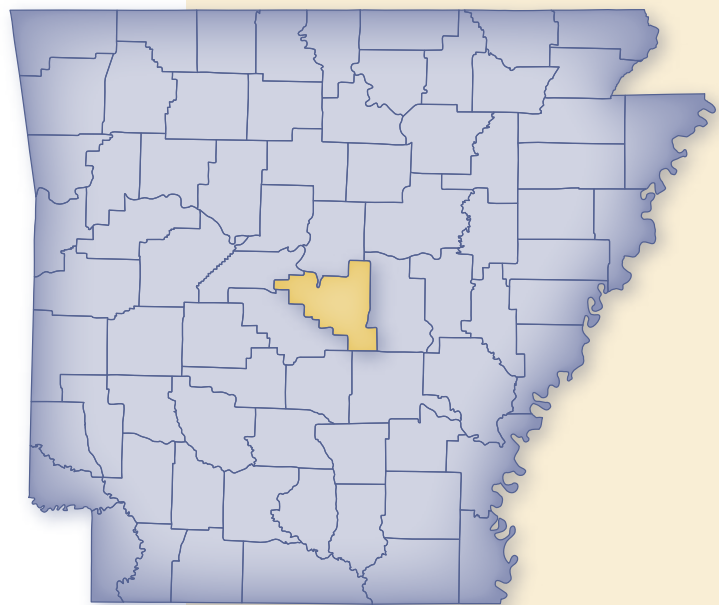
8-Year-Old Children: 4,940

White: 48%

Black: 42.8%

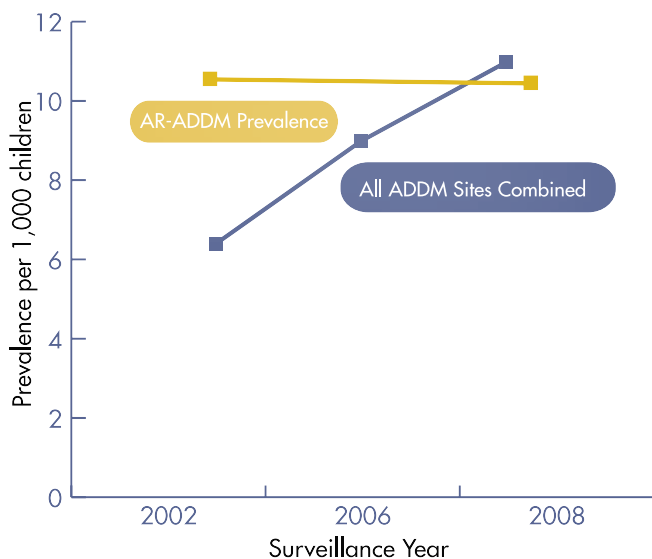
Hispanic: 6%

Asian or Pacific Islander: 2.5%



Yellow - County in the ADDM Network in 2008

Overall ASD Prevalence



AR-ADDM collected data for the 2002 and 2008 surveillance years only. The data shown are based on the surveillance area covered in both time points.

Arkansas

Arkansas Autism and Developmental Disabilities Monitoring Program (AR-ADDM)

The Arkansas Autism and Developmental Disability Monitoring (AR ADDM) Project is a multisource investigation to monitor the number of 8-year-old children in the population with ASDs or other developmental disabilities. This surveillance system provides an accurate count of the number of children and families in Arkansas living with these disorders. The investigators are members of the University of Arkansas for Medical Sciences (UAMS). AR ADDM is a joint undertaking with CDC and other state programs, agencies and organizations that serve children with developmental disabilities and their families. The AR ADDM Project has completed the 2002 (entire state) and 2008 (Pulaski County only) surveillance years and will continue to collect data for the 2010 and 2012 surveillance years (entire state).

What part of Arkansas is included in the ADDM Network for 2008?

AR ADDM covered Pulaski County only for the 2008 surveillance year. This was a smaller study area compared to most ADDM sites and the AR ADDM results might be affected by looking at this smaller population of 8-year-old children.

What kinds of education and training programs does AR ADDM offer to people who work with children who have ASDs or other developmental disabilities?

The project provides continuing education courses to professionals from the following disciplines: physical therapy, occupational therapy, speech pathology, education, and pediatrics.

What are some of the resources available in Arkansas for children with ASDs, their families, and the professionals who serve them?

- The Arkansas Autism Alliance (AAA) is a collaborative effort among research scientists and physicians of Arkansas Children's Hospital and Research Institute and The University of Arkansas for Medical Sciences (<http://arkansasautismalliance.org/>).
- Arkansas Autism Resource and Outreach Center is a non-profit organization that provides comprehensive services for the Arkansas autism community (<http://aaroc.org/>).
- The Arkansas Disability Coalition is a statewide organization that assists families and individuals with all types of disabilities by providing information, support, resources, and training (<http://www.adcpti.org/>).
- Arkansas Department of Education, Special Education ensures that all eligible children and youth with disabilities are receiving a free appropriate public education (<http://arksped.k12.ar.us/default.html>).
- The Arkansas Department of Human Services' Division of Developmental Disabilities offers a variety of services to people with developmental disabilities who are eligible for services (<http://humanservices.arkansas.gov/ddds/Pages/default.aspx> or call 501-683-0870).
- The Arkansas Autism Society provides information about autism and forms the basis for support groups for the families of children with ASDs (www.arkansasautism.org).
- The Dennis Development Center's autism clinic at UAMS provides diagnostic evaluations for children (www.uamshealth.com/medical-services/pediatrics/dennis-center).

For further information, please contact:

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Colorado

Colorado Autism and Developmental Disabilities Monitoring Program (CO-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 91

Total prevalence of ASDs: 11.8 per 1,000 (or 1 in 85)

Boys: 20.1 per 1,000 (or 1 in 50)

Girls: 2.9 per 1,000 (or 1 in 345)

Race/ Ethnicity

White: 14.8 per 1,000

Black: 10.5 per 1,000

Hispanic: 6.7 per 1,000

Asian or Pacific Islander: Fewer than 5 children identified

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 63%

Median earliest age ASD was documented in their records:
4 years, 6 months

Autistic disorder: 4 years, 4 months

ASD/PDD: 4 years, 6 months

Asperger Disorder: 6 years, 7 months

SITE INFORMATION

Part of Colorado Included in ADDM, 2008

Arapahoe County (metropolitan Denver, Colorado)

Population of 8-Year-Old Children in Study Area, 2008

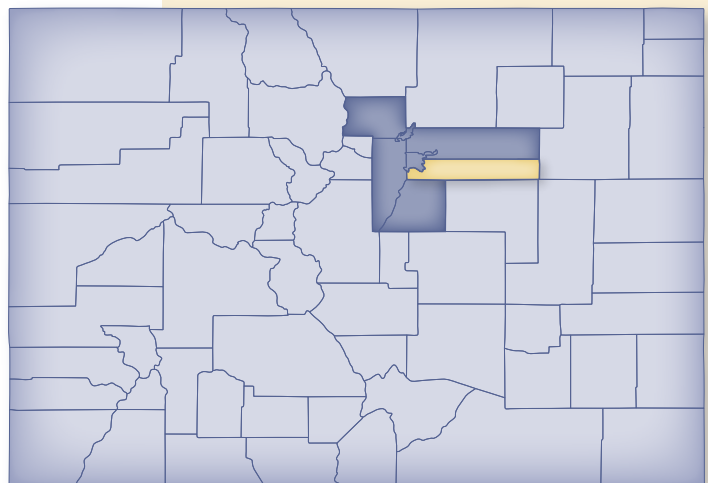
8-Year-Old Children: 7,725

White: 51.7%

Black: 13.6%

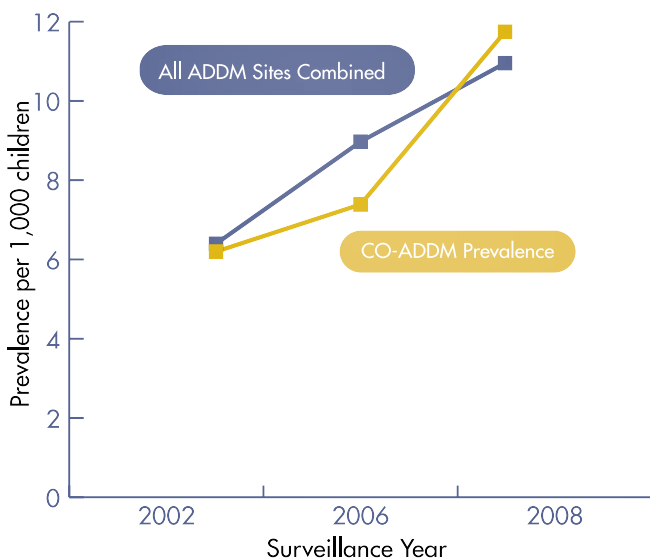
Hispanic: 28.9%

Asian or Pacific Islander: 5.0%



Yellow - County in the ADDM Network in 2008
Dark purple - Adams, Broomfield, Boulder, Dever, Douglas, and Jefferson counties were also a part of the ADDM Network for 2008. See full ADDM Network MMWR report for information from these counties.

Overall ASD Prevalence



Colorado

Colorado Autism and Developmental Disabilities Monitoring Program (CO-ADDM)

The Colorado Autism and Developmental Disabilities Monitoring (CO-ADDM) Program is a multisource public health project to monitor the number of 8-year-old children in the population with ASDs. This monitoring system provides an accurate count of the number of children with ASDs residing in Colorado starting with the year 2002. CO-ADDM is a joint undertaking with CDC, the Colorado Department of Public Health and Environment, JFK Partners at the University of Colorado at Denver, and the Colorado Department of Education. CO-ADDM has completed the 2002, 2006, and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

What part of Colorado is in CO-ADDM?

In 2002, two counties in the Denver Metropolitan area took part in the program: Arapahoe and Boulder. In 2006, only Arapahoe County participated. In 2008, Arapahoe County, which had access to both health and education sources, participated. Adams, Broomfield, Boulder, Denver, Douglas, and Jefferson counties also participated though CO-ADDM had access to health sources only; results from these counties can be found in the published report at: www.cdc.gov/mmwr.

What kinds of education and training programs does CO-ADDM offer to people who work with children who have ASDs or other developmental disabilities?

CO-ADDM clinicians created autism awareness seminars that were presented to interested providers to improve their capacity for recognizing the early signs of ASDs and for establishing standard referral practices.

What are some of the resources available in Colorado for children with developmental disabilities, their families, and the professionals who serve them? In Colorado, such resources include

- The Colorado Department of Education Exceptional Student Services Unit (www.cde.state.co.us/cdesped/index.asp)
- The Autism Society of Colorado (www.autismcolorado.org)
- The Autism Society of Boulder County (www.autismboulder.org)
- The Autism Society of Larimer County (www.autismlarimer.org)
- The Autism Society of America, Pike's Peak Chapter (www.asappr.org)
- Family Voices (www.familyvoicesco.org)
- The ARC of Colorado (www.thearcofco.org)
- Early Childhood Connections (www.earlychildhoodconnections.org)
- Colorado Cross-Disability Coalition (303-839-1775; ccdconline.org)
- Community Centered Boards (303-866-7450; cdhs.state.co.us/ddd)
- El Grupo VIDA (Information, referrals and support groups for Spanish-speaking parents. 303-904-6073; elgrupovida.org)
- EMPOWER Colorado (1-866-213-4631; empowercolorado.com)
- Health Care Program for Children with Special Needs (303-692-2370; hccolorado.org)
- Parent to Parent of Colorado (P2P) (1-877-472-7201; p2p-co.org)
- PEAK: Colorado's Parent Training & Information Center (1-800-284-0251; peakparent.org)
- Parents Encouraging Parents (303-866-6846; cde.state.co.us/cdesped/PEP.asp).

For more information, please contact:

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Florida

Florida Autism and Developmental Disabilities Monitoring Project (FL – ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 211

Total prevalence of ASDs: 7.2 per 1,000 (or 1 in 139)

Boys: 11.3 per 1,000 (or 1 in 88)

Girls: 2.9 per 1,000 (or 1 in 345)

Race/ Ethnicity

White: 4.6 per 1,000

Black: 3.0 per 1,000

Hispanic: 8.2 per 1,000

Asian or Pacific Islander: Fewer than 5 children identified

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 70%

Median earliest age ASD was documented in their records:
3 years, 6 months

Autistic disorder: 3 years

ASD/ PDD: 3 years, 7 months

Asperger Disorder: 4 years, 11 months

SITE INFORMATION

Part of Florida Included in ADDM, 2008

1 county (Miami-Dade) in south Florida

Population of 8-Year-Old Children in Study Area, 2008

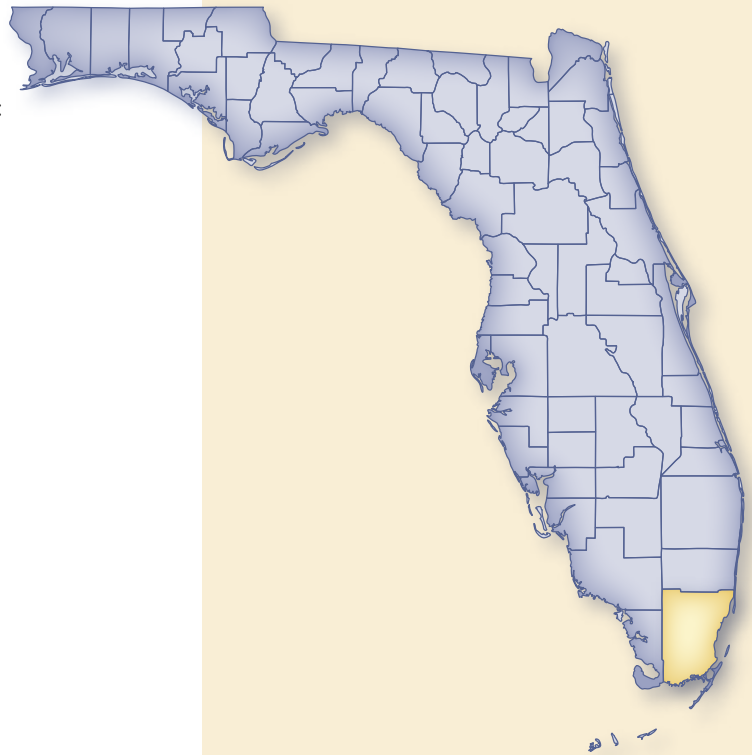
8-Year-Old Children: 29,366

White: 23.9%

Black: 21.5%

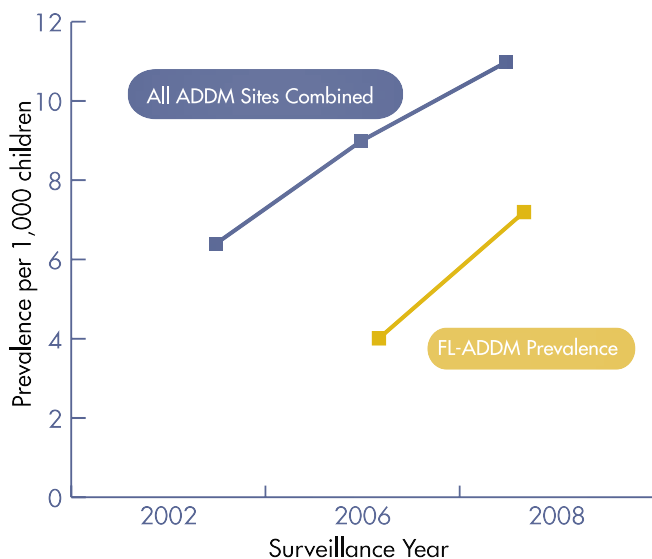
Hispanic: 52.9%

Asian or Pacific Islander: 1.5%



Yellow - County in the ADDM Network in 2008

Overall ASD Prevalence



FL-ADDM collected data for the 2006 and 2008 surveillance years only. The data shown are based on the surveillance area covered in both time points.

Florida

Florida Autism and Developmental Disabilities Monitoring Project (FL – ADDM)

The Florida Autism and Developmental Disabilities Monitoring (FL-ADDM) Project is a multisource investigation to monitor the number of 8-year-old children in the population with ASDs. This surveillance system helped establish an accurate count of the number of children and families living with ASDs residing in Florida. The investigators are members of the University Of Miami Department Of Psychology, in association with the University of Miami Center for Autism and Related Disabilities (UM-CARD). The FL-ADDM is a joint undertaking with CDC and other Florida state partners, agencies, and organizations that serve children with developmental disabilities and their families. FL-ADDM has completed the 2006 and 2008 surveillance years.

What kinds of education and training programs does FL-ADDM offer to people who work with children who have ASDs or other developmental disabilities?

UM-CARD provides parent training to improve family members' understanding of the nature of ASDs. Community awareness is enhanced through an on-going system of professional training on the nature of identification of and intervention with children with ASDs.

What are some of the resources available in Florida for children with developmental disabilities, their families, and the professionals who serve them?

- Autism Society of Florida is a statewide organization that supports individuals with autism, their families, and caregivers (<http://www.autismfl.com/>). In addition to the state chapter, there are several local chapters: Autism Society of Treasure Coast, Autism Society of Emerald Coast (<http://www.ecautismsociety.com/>), Autism Society of Miami-Dade (<http://www.autismsocietymiami.org/>), and Autism Society of Broward County (<http://asabroward.org/>).
- Florida Department of Education's Exception Education and Student Services administers programs for students with disabilities (<http://www.fldoe.org/ese/>).
- University of Miami Center for Autism and Related Disabilities (UM-CARD) was developed specifically to facilitate improved service delivery for children with autism (www.umcard.org). Currently, five other Florida state CARDS are located at universities in Jacksonville, Orlando, Gainesville, Tampa, and Tallahassee. Its excellence in clinical service provision has allowed UM-CARD to forge close working relations with the community involved in all aspects of care and services for children with autism, including the Miami-Dade public schools. Related programs include the Miami Children's Hospital Dan Marino Center in Broward County (www.mch.com).

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Georgia

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 601

Total prevalence of ASDs: 11.9 per 1,000 (or 1 in 84)

Boys: 19.6 per 1,000 (or 1 in 51)

Girls: 3.8 per 1,000 (or 1 in 263)

Race/ Ethnicity

White: 11.8 per 1,000

Black: 11.9 per 1,000

Hispanic: 7.1 per 1,000

Asian or Pacific Islander: 15.9 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 62%

Median earliest age ASD was documented in their records: 4 years, 8 months

Autistic Disorder: 4 years, 5 months

ASD/PDD: 4 years, 6 months

Asperger Disorder: 6 years

SITE INFORMATION

Part of Georgia Included in ADDM, 2008

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

Population of 8-Year-Old Children in Study Area, 2008

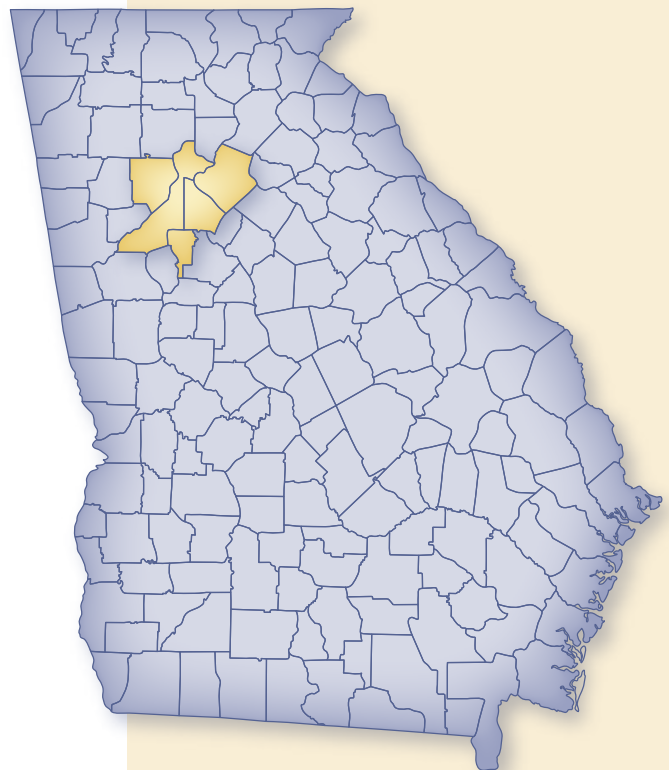
8-Year-Old Children: 50,427

White: 37.1%

Black: 41%

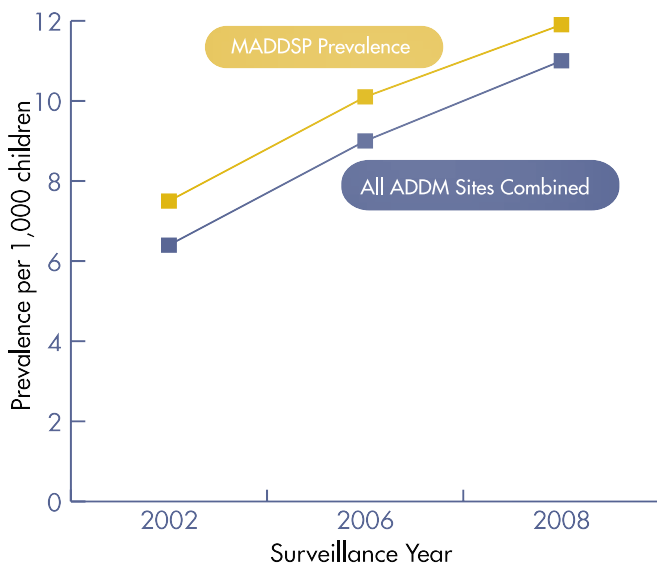
Hispanic: 15.6%

Asian or Pacific Islander: 5.9%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



MADDSP also reported data for the 2000 and 2004 surveillance years. See the earlier ADDM Network reports for this information.

Georgia

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) is a multisource investigation to monitor the number of 8-year-old children in the population with selected developmental disabilities, including ASDs. The Centers for Disease Control and Prevention established MADDSP in 1991 as the first system of its kind for monitoring the numbers of children with developmental disabilities. Since then, MADDSP has been tracking the numbers of 8-year-old children with intellectual disability, cerebral palsy, hearing loss, and vision impairment in the five counties of metropolitan Atlanta. Autism was added as a fifth disability in 1996. MADDSP provides opportunities for special studies through which CDC staff members can identify risk factors for these disabilities and determine whether programs to prevent disabilities have been effective.

MADDSP is the model for all of the other ADDM Network sites and has contributed a wealth of information on the characteristics, risk factors, costs, and implications of developmental disabilities.

Does MADDSP conduct community outreach?

MADDSP partners with community organizations such as the Autism Society, Autism Speaks, and CADEF: the Childhood Autism Foundation to host autism awareness events in Georgia. MADDSP staff also provide workshops and trainings for parents, teachers and primary health care providers to increase awareness and recognition of the early signs of developmental disabilities.

What are some of the resources available in Georgia for children with developmental disabilities, their families, and the professionals who serve them?

- CDC's Learn the Signs. Act Early. campaign is an effort to raise awareness about developmental milestones and the importance of screening and early intervention. Visit www.cdc.gov/actearly for more information.
- Autism Speaks goal is to change the future for all who struggle with autism spectrum disorders. Contact the GA Chapter of Autism Speaks at www.walknowforautismspeaks.org/georgia
- The Georgia Department of Behavioral Health and Developmental Disabilities offers a variety of services to people with developmental disabilities who are eligible for services. Contact your Regional Office for more information. <http://dbhdd.georgia.gov/portal/site/DBHDD/> or call the Georgia Crisis and Access Line: 1-800-715-4225
- The Autism Society of Greater Georgia is a great resource for all affected by autism. To find out more, visit <http://www.asaga.com> or call (770) 904-4474.
- Parent 2 Parent of Georgia is another great resource for families affected by disabilities. Visit their roadmap to services at <http://p2pga.org/roadmap/> or call 1-800-229-2038.

For more information, please contact:

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E-mail: kbn5@cdc.gov

Website: www.cdc.gov/MADDSP



Maryland

The Maryland Autism and Developmental Disabilities Monitoring Project (MD-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 336

Total prevalence of ASDs: 12.4 per 1,000 (or 1 in 80)

Boys: 20.5 per 1,000 (or 1 in 49)

Girls: 3.9 per 1,000 (or 1 in 256)

Race/ Ethnicity

White: 12.9 per 1,000

Black: 11.7 per 1,000

Hispanic: 5.9 per 1,000

Asian or Pacific Islander: 8.2 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 73%

Median earliest age ASD was documented in their records:
5 years, 6 months

Autistic Disorder: 4 years, 11 months

ASD/PDD: 5 years, 7 months

Asperger Disorder: 6 years, 7 months

SITE INFORMATION

Part of Maryland Included in ADDM, 2008

6 counties: Anne Arundel, Baltimore, Carroll, Cecil, Harford, and Howard

Population of 8-Year-Old Children in Study Area, 2008

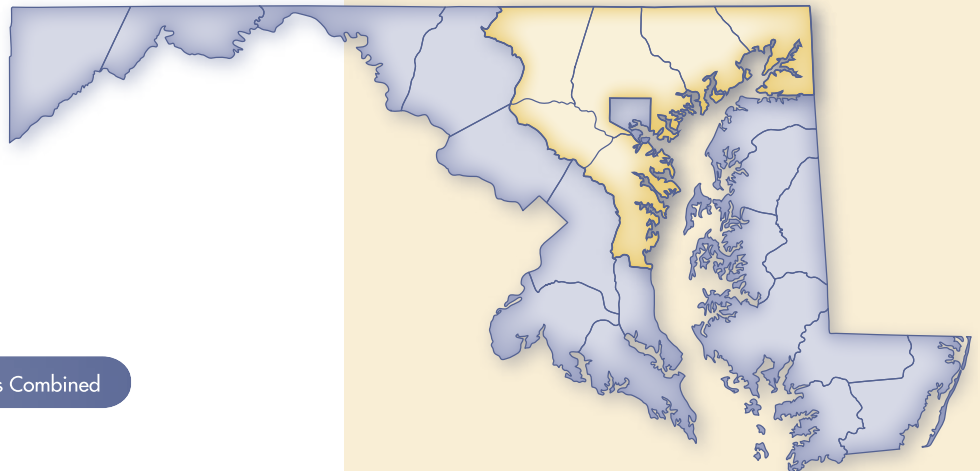
8-Year-Old Children: 27,022

White: 67.9%

Black: 21.4%

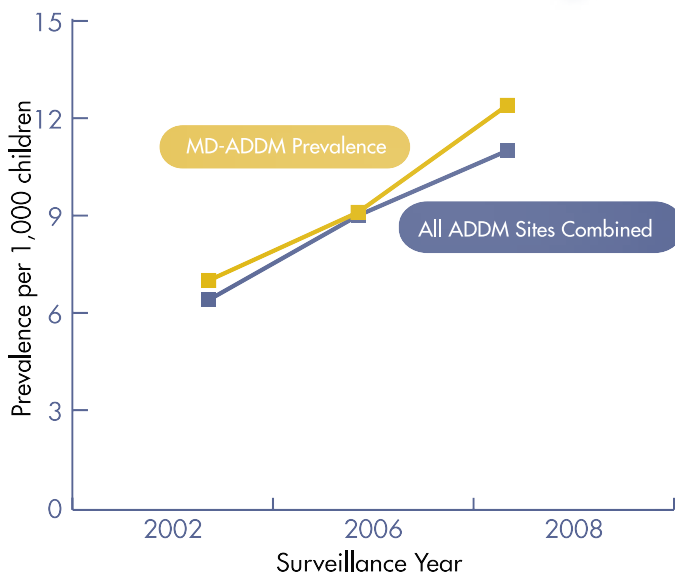
Hispanic: 5.0%

Asian or Pacific Islander: 5.4%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



MD-ADDM also collected data for the 2000 and 2004 surveillance years. See the earlier ADDM Network reports for this information. The data shown are based on the surveillance area covered at all three time points.

Maryland

The Maryland Autism and Developmental Disabilities Monitoring Project (MD-ADDM)

The Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) Project is a multisource investigation to determine and monitor the number of 8-year-old children in the population with ASDs. This surveillance system provides an accurate count of the number of children and families residing in Maryland living with these disorders. The investigators are members of the Johns Hopkins Bloomberg School of Public Health. MD-ADDM is a joint undertaking with CDC and the Maryland State Department of Education, schools in participating counties, the Kennedy Krieger Institute, Mt. Washington Pediatric Hospital, and the University of Maryland Medical System. MD-ADDM has completed the 2000, 2002, 2004, 2006, and 2008 surveillance years, and will continue to collect data for the 2010 and 2012 surveillance years.

What are some of the resources available in Maryland for children with developmental disabilities, their families, and the professionals who serve them?

- The Center for Autism and Related Disorders (CARD) at the Kennedy Krieger Institute (www.card.kennedykrieger.org) is a multifaceted, multidisciplinary program for children with autism and their family members. CARD combines research and clinical (assessment and intervention) services, as well as community outreach and training, to help improve the lives of individuals with autism, their families, and the community that cares for them.
- The League for People with Disabilities, Inc. (www.leagueforpeople.org) offers camping and therapeutic recreation services for participants who have an autism waiver. The program focuses on each person's abilities and works with trained professionals so that participants reach their goal.
- Maryland State Department of Education's Division of Special Education and Early Intervention Services collaborates with families, local early intervention systems, and local school systems to ensure that all children and youth with disabilities have access to appropriate services and educational opportunities (www.marylandpublicschools.org/MSDE/divisions/earlyinterv).
- Autism Society of America (ASA): Dedicated to increasing public awareness about autism by providing information and education, and supporting research and advocating for programs and services for the autism community (<http://www.autism-society.org>). To find out more about ASA local chapters in Maryland, please visit <http://www.autism-society.org/get-involved/state-resources/maryland.html>.
- AutismConnect: An organization that provides stakeholders in Maryland with an online resource to assist them in locating and securing resources for individuals with autism (www.autismconnectmd.org).
- Pathfinders for Autism: A parent sponsored, non-profit organization dedicated to improving the lives of individuals with autism and their families (www.pathfindersforautism.org).

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Missouri

The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 357

Total prevalence of ASDs: 13.9 per 1,000 (or 1 in 72)

Boys: 21.6 per 1,000 (or 1 in 46)

Girls: 5.9 per 1,000 (or 1 in 169)

Race/ Ethnicity

White: 14.6 per 1,000

Black: 9.3 per 1,000

Hispanic: 9.0 per 1,000

Asian or Pacific Islander: 9.8 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 78%

Median earliest age ASD was documented in their records:

3 years, 9 months

Autistic Disorder: 4 years, 10 months

ASD/PDD: 3 years, 3 months

Asperger Disorder: 6 years, 3 months

SITE INFORMATION

Part of Missouri Included in ADDM, 2008

5 counties: St. Louis, St. Louis City, Franklin, Jefferson, and St. Charles

Population of 8-Year-Old Children in Study Area, 2008

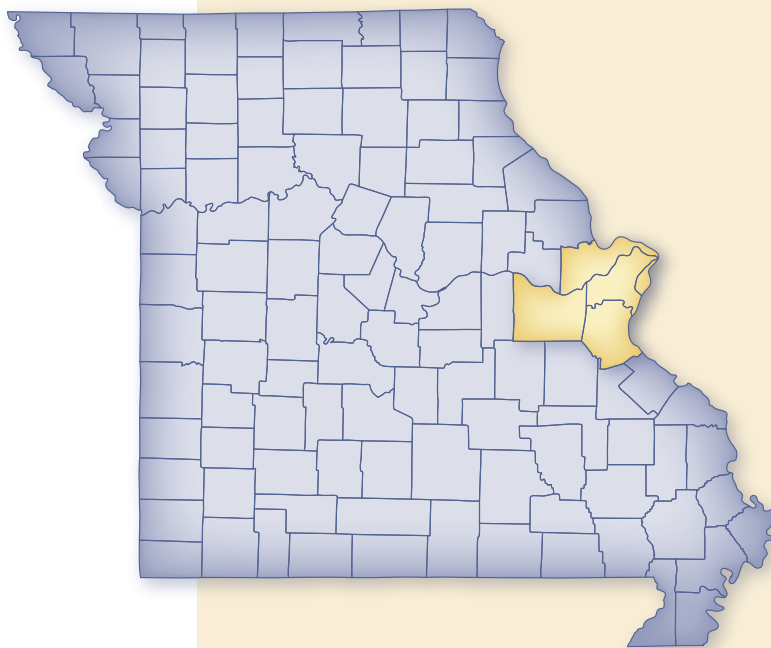
8-Year-Old Children: 25,668

White: 69.0%

Black: 24.0%

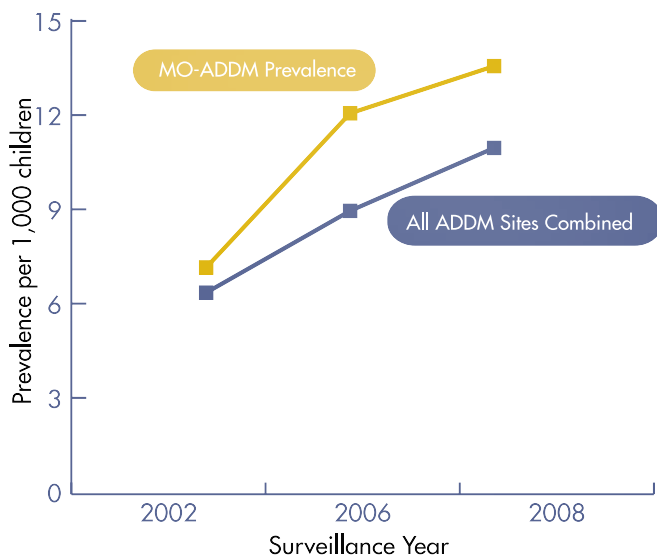
Hispanic: 3.5%

Asian or Pacific Islander: 3.2%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



MO-ADDM also reported data for the 2004 surveillance year. See the earlier ADDM Network report for this information.

Missouri

The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM)

The Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) Project is a multisource surveillance project designed to monitor the number of 8-year-old children with ASDs, or cerebral palsy (CP), and co-occurring epilepsy (2002-2006 surveillance years) among children with ASDs or CP, or both. The goal of this project is to generate accurate, population-based prevalence estimates of ASDs and CP (the latter added for the 2006 surveillance year) among 8-year-old children living in the metropolitan St. Louis area. The investigators are members of the School of Medicine at Washington University. MO-ADDM is a joint undertaking comprised of investigators at the School of Medicine at Washington University, the Missouri Department of Health and Senior Services, the CDC and other Missouri state and local partners. Since 2003, MO-ADDM has completed the 2002, 2004, 2006, and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

What kinds of education and training programs does MO-ADDM offer to people who work with children who have ASDs or other developmental disabilities?

MO-ADDM investigators offer lectures at the two main children's hospitals in the area on diagnostic criteria for autism, as well as their early signs and symptoms. Investigators also work with other stakeholders in Missouri to develop educational programs for therapists and special education teachers.

What are some of the resources available in Missouri for children with developmental disabilities, their families, and the professionals who serve them?

- The Missouri Department of Mental Health's Division of Developmental Disabilities (<http://dmh.mo.gov/dd/>) coordinates developmental disability services in Missouri.
- Missouri Families for Effective Autism Treatment (MO-FEAT) provide advocacy, education, and support services for families and the autism community and support early diagnosis and effective autism treatment. For more information, including the MO-FEAT Resource Directory, visit <http://www.mo-feat.org/index.htm>.
- Washington University's Intellectual and Developmental Disabilities Research Center (WUIDDRC) is focused on improving care for children with developmental disabilities through research, advocacy, and clinical services. Find out more at <http://iddrc.wustl.edu/>
- Washington University's Division of Child and Adolescent Psychiatry (<http://wuchild.wustl.edu>) provides leading edge psychiatric care and research opportunities.

For more information, please contact:

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New Jersey

The New Jersey Autism Study (NJAS)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 145

Total prevalence of ASDs: 20.5 per 1,000 (or 1 in 49)

Boys: 34.2 per 1,000 (or 1 in 29)

Girls: 5.8 per 1,000 (or 1 in 172)

Race/ Ethnicity

White: 21.0 per 1,000

Black: 20.6 per 1,000

Hispanic: 20.0 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 68%

Median earliest age ASD was documented in their records:
4 years, 10 months

Autistic Disorder: 3 years, 2 months

ASD/PDD: 4 years, 3 month

Asperger Disorder: 5 years, 6 months

SITE INFORMATION

Part of New Jersey included in ADDM, 2008

Union County (metropolitan Newark, New Jersey)

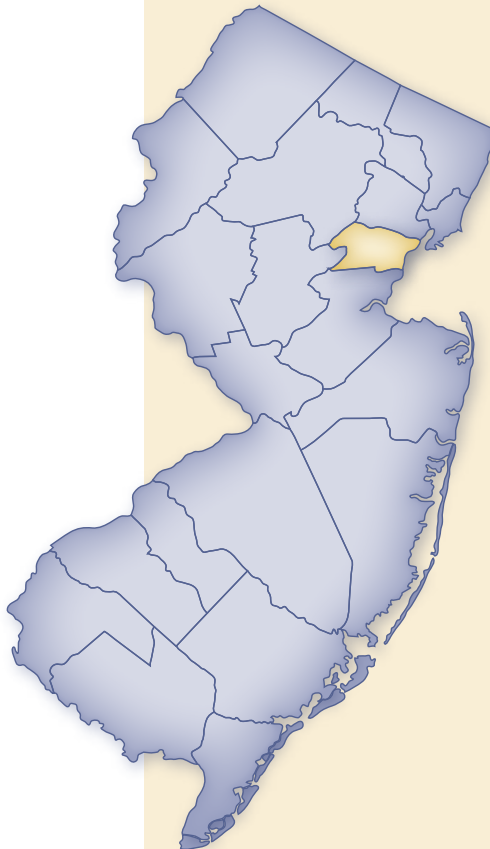
Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 7,082

White: 43.7%

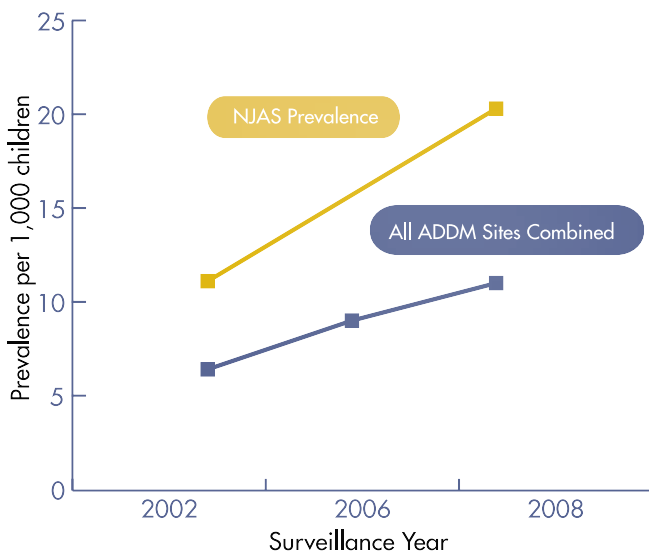
Black: 22.6%

Hispanic: 28.9%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



NJAS also collected data for the 2000 surveillance year. See the earlier ADDM Network report for this information. The data shown are based on the surveillance area covered in both time points.

New Jersey

The New Jersey Autism Study (NJAS)

The New Jersey Autism Study (NJAS) is a multisource public health surveillance system established to monitor the number of 8-year-old children in the population with ASDs or other developmental disabilities. This surveillance system has established an accurate baseline count of the number of New Jersey children living with ASDs and tracks changes in the expression of this disorder, over time. NJAS is a joint undertaking of researchers at the New Jersey Medical School, working in cooperation with the New Jersey Departments of Education and Health, the CDC and numerous New Jersey developmental health centers and school districts. NJAS has completed ASD surveillance activities for 2000, 2002, and 2008 surveillance years and will monitor ASDs for 2010 and 2012. NJAS covered a smaller area for the 2008 surveillance year (population of less than 10,000) which may affect the prevalence estimate.

The findings of the New Jersey Autism Study have been instrumental to the development and implementation of several initiatives to improve the quality of services provided to children and adults with ASDs. These include:

- New Jersey Governor's Council for Biomedical Research and Treatment of Autism <http://www.nj.gov/health/autism/>
- The New Jersey Registry for Autism <http://www.state.nj.us/health/fhs/sch/index.shtml>

What part of New Jersey is included in the ADDM Network for 2008?

NJAS covered Union County only for the 2008 surveillance year. This was a smaller study area compared to most ADDM sites and the NJAS results might be affected by looking at this smaller population of 8- year-old children.

What kinds of education and training programs does the program offer to people who work with children who have ASDs or other developmental disabilities?

NJAS sponsors training of professionals in the use of the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview for Research (ADI-R) — autism diagnostic instruments, and supports the early identification of autism through use of autism screeners.

What are some of the resources available in New Jersey for children with developmental disabilities, their families, and the professionals who serve them?

- New Jersey Department of Education, Special Education Program (<http://www.nj.gov/education/specialed/>)

New Jersey is served by excellent parent information and resource programs, including:

- Autism New Jersey (www.autismnj.org)
- Autism Family Services of NJ (www.autismfamilyservicesnj.org)
- Asperger Syndrome Education Network (www.aspennj.org)
- Statewide Parent Advocacy Network (www.spannj.org)

For more information, please contact:

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North Carolina

The North Carolina Center for Autism and Developmental Disabilities Monitoring Project (NC – ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 525

Total prevalence of ASDs: 14.2 per 1,000 (or 1 in 70)

Boys: 23.1 per 1,000 (or 1 in 43)

Girls: 5.1 per 1,000 (or 1 in 196)

Race/ Ethnicity

White: 14.6 per 1,000

Black: 15.4 per 1,000

Hispanic: 7.6 per 1,000

Asian or Pacific Islander: 11.8 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 66%

Median earliest age ASD was documented in their records:
3 years, 10 months

Autistic Disorder: 3 years, 3 months

ASD/PDD: 4 years, 7 months

Asperger Disorder: 6 years, 7 months

SITE INFORMATION

Part of North Carolina Included in ADDM, 2008

11 counties: Alamance, Caswell, Chatham, Davidson, Durham, Forsyth, Guilford, Orange, Randolph, Rockingham, and Wake.

Population of 8-Year-Old Children in Study Area, 2008

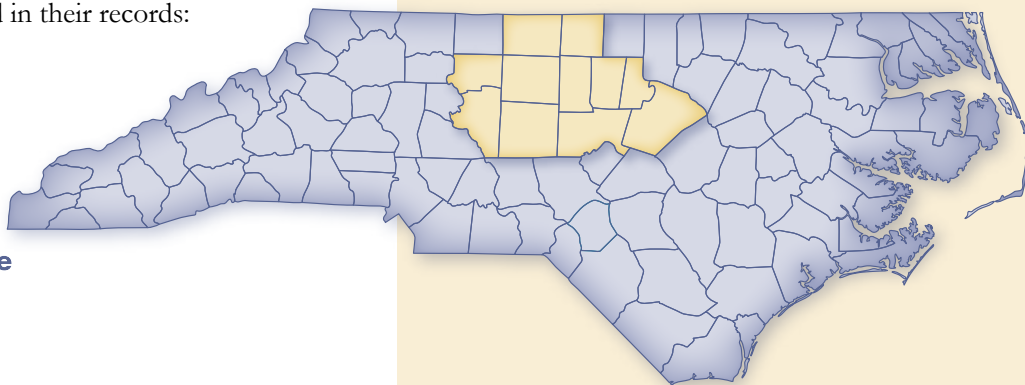
8-Year-Old Children: 36,913

White: 57%

Black: 25.5%

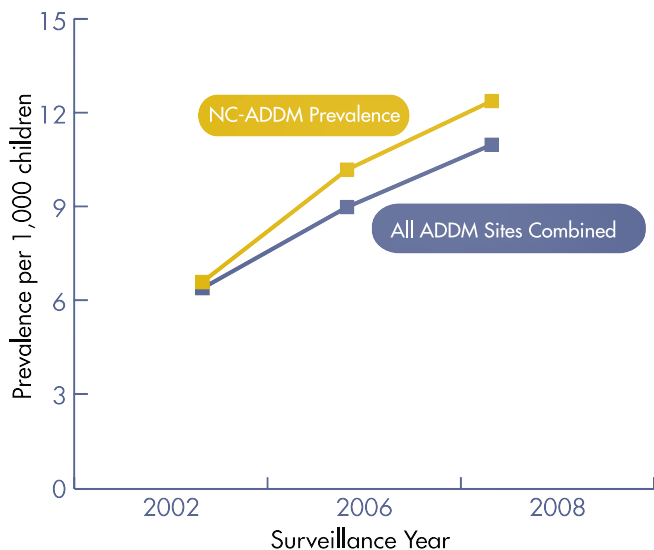
Hispanic: 13.5%

Asian or Pacific Islander: 3.7%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



NC-ADDM also reported data for the 2004 surveillance year. See the earlier ADDM Network report for this information. The data shown are based on the surveillance area covered at all three time points.

North Carolina

The North Carolina Center for Autism and Developmental Disabilities Monitoring Project (NC – ADDM)

The North Carolina Center for Autism and Developmental Disabilities Monitoring (NC-ADDM) Project is a multisource investigation to determine and monitor the number of 8-year-old children in the population with ASDs or intellectual disability. This project provides an accurate count of the number of North Carolina children with ASDs and intellectual disability. NC-ADDM has completed the 2002, 2004, 2006, and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

What kinds of education and training programs does NC-ADDM offer to people who work with children who have ASDs or other developmental disabilities?

NC ADDM shares information through newsletter, presentations, and scientific publications with physicians, educators, and others who serve children with developmental disabilities and ASDs.

What are some of the resources available in North Carolina for children with developmental disabilities, their families, and the professionals who serve them? A few resources include:

- The Children's Developmental Service Agency (www.ncei.org)
- Division of Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) (www.teacch.com)
- Autism Society of North Carolina (www.autismsociety-nc.org), Autism Society of NC Summer Camp Program (www.veryspecialcamps.com),
- Families for Early Autism Treatment (FEAT) of North Carolina (<http://featofnc.moonfruit.com>)

For more information, please contact:

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Pennsylvania

The Pennsylvania Autism and Developmental Disabilities Surveillance Program (PADDSP)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 245

Total prevalence of ASDs: 13.3 per 1,000 (1 in 75)

Boys: 22.2 per 1,000 (1 in 45)

Girls: 4.3 per 1,000 (1 in 233)

Race/ Ethnicity

White: 14.3 per 1,000

Black: 12.7 per 1,000

Hispanic: 9.1 per 1,000

Asian or Pacific Islander: 8.4 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 85%

Median earliest age ASD was documented in their records: 4 years, 11 months

Autistic Disorder: 3 years, 7 months

ASD/PDD: 4 years, 11 months

Asperger Disorder: 5 years, 10 months

SITE INFORMATION

Part of Pennsylvania Included in ADDM, 2008

Philadelphia County

Population of 8-Year-Old Children in Study Area, 2008

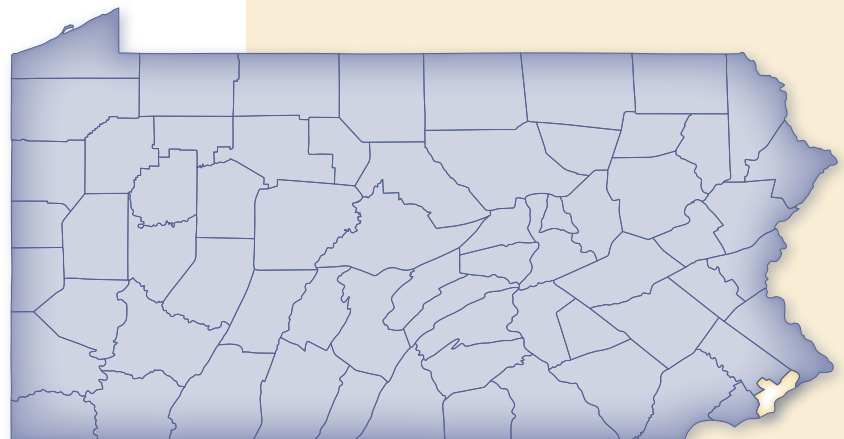
8-Year-Old Children: 18,440

White: 28.1%

Black: 49.1%

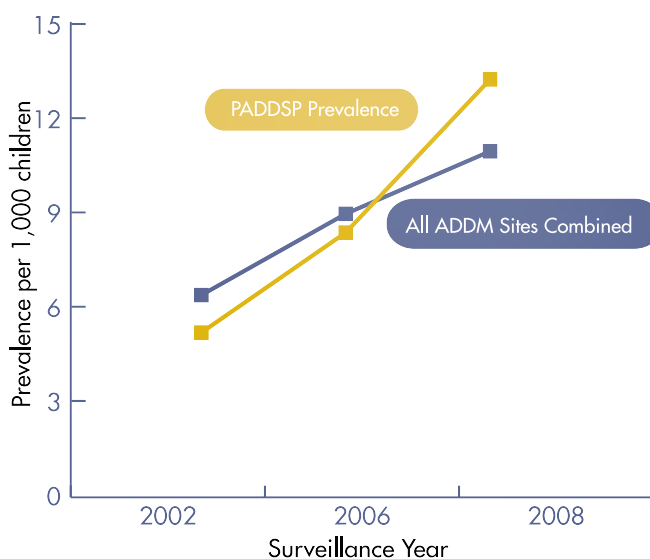
Hispanic: 16.6%

Asian or Pacific Islander: 5.8%



Yellow - County in the ADDM Network in 2008

Overall ASD Prevalence



Pennsylvania

The Pennsylvania Autism and Developmental Disabilities Surveillance Program (PADDSP)

The Pennsylvania Autism and Developmental Disabilities Surveillance Program (PADDSP) is a multisource public health program established to monitor the number of 8-year-old children in the population with ASDs. This surveillance system provided an accurate count of the number of 8-year-old children in Philadelphia County with ASDs. The investigators were members of the University of Pennsylvania School of Nursing and The Children's Hospital of Philadelphia. PADDSP studied biennial sequential years to identify if there were trends in the diagnosis and treatment of ASDs. PADDSP completed data collection for the 2002, 2006, and 2008 surveillance years.

What kinds of education and training programs did the program offer to people who work with children who have ASDs or other developmental disabilities?

PADDSP Director provides education and outreach programs to inform health care providers, educators, and the community about the need to monitor the prevalence of autism and the educational and health care needs of children with autism and their families.

What are some of the resources available in Pennsylvania for children with developmental disabilities, their families and the professionals who serve them? Other autism programs include the

- ASCEND. The Asperger and Autism Alliance for Greater Philadelphia. <http://www.ascendgroup.org/>
- Autism Institute at Gwynedd Mercy College.
<http://www.gmc.edu/academics/education/AbouttheAutismInstitute.php>
- Autism Society of America chapters: Autism Society of Pittsburgh (<http://www.autismsocietypggh.org/>), Autism Society of Greater Philadelphia (<http://www.asaphilly.org/>), Autism Society of Greater Harrisburg (<http://www.autismharrisburg.com>), Autism Society of Butler County (<http://autismsocietyofbutlercounty.tripod.com/>), Autism Society of Berks County (<http://www.autismsocietyofberks.org>), Autism Society of Northwestern Pennsylvania (<http://www.nwpa-asa.org>), and Autism Society of Lehigh Valley (<http://www.asalehighvalley.org/>).
- Autism Centers of Excellence (ACE) at Drexel University School of Public Health
- The Center for Autism (www.thecenterforautism.org),
- The Center for Autism Research (www.research.chop.edu/programs/car),
- The Regional Autism Center (www.chop.edu/service/autism-center/home.html).

For more information, please contact:

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South Carolina

The South Carolina Autism and Developmental Disabilities Monitoring Program (SC-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 264

Total prevalence of ASDs: 11.1 per 1,000 (1 in 90)

Boys: 18.3 per 1,000 (1 in 55)

Girls: 3.5 per 1,000 (1 in 286)

Race/ Ethnicity

White: 10.2 per 1,000

Black: 9.9 per 1,000

Hispanic: 7.0 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 69%

Median earliest age ASD was documented in their records:
4 years, 6 months

Autistic Disorder: 3 years, 10 months

ASD/PDD: 4 years, 10 months

Asperger Disorder: 6 years, 9 months

SITE INFORMATION

Part of South Carolina Included in ADDM, 2008

23 counties: Allendale, Bamberg, Barnwell, Beaufort, Berkeley, Charleston, Chesterfield Clarendon, Colleton, Darlington, Dillon, Dorchester, Florence, Georgetown, Hampton, Horry, Jasper, Lee, Marion, Marlboro, Orangeburg, Sumter, and Williamsburg

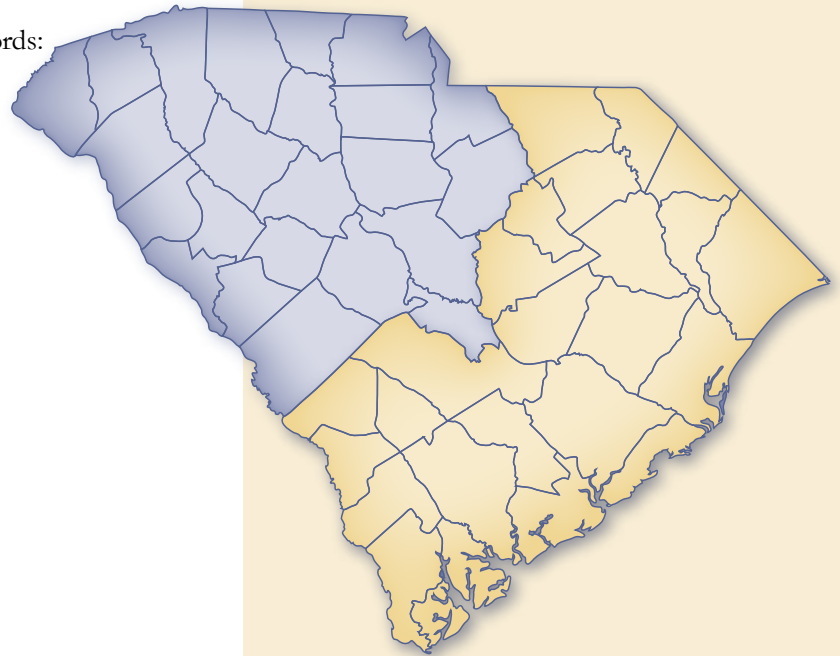
Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 23,769

White: 52.6%

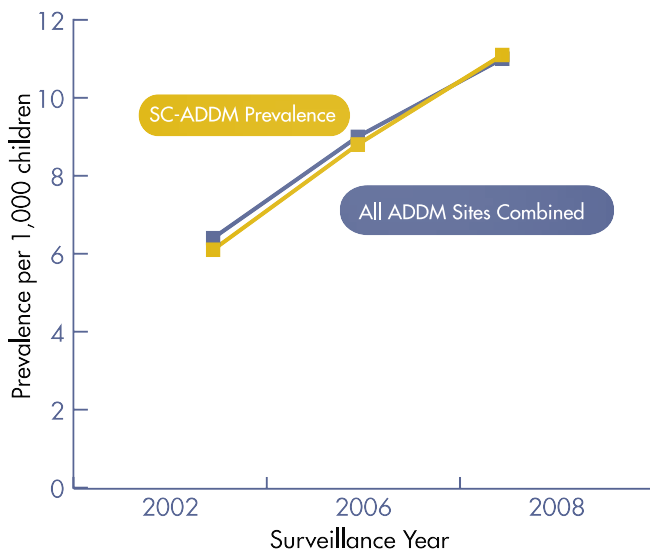
Black: 40.2%

Hispanic: 5.4%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



SC-ADDM also reported data for the 2000 and 2004 surveillance years. See the earlier ADDM Network reports for this information.

South Carolina

The South Carolina Autism and Developmental Disabilities Monitoring Program (SC-ADDM)

The South Carolina Autism and Developmental Disabilities Monitoring Program (SC-ADDM) is a multisource public health surveillance system established to monitor the number of children in the population with ASDs or other developmental disabilities. In 2000, SC ADDM was established as an ADDM Network site. SC ADDM is currently conducting surveillance of ASDs in 4 year olds as well as 8 year olds, ASDs and intellectually disabilities, and ASDs and Fragile X. This surveillance system provides an accurate count of the number of children and families residing in South Carolina living with these disabilities. The investigators are members of the Department of Pediatrics; Division of Developmental Pediatrics; and Department of Medicine, Division of Biostatistics and Epidemiology at the Medical University of South Carolina (MUSC). SC-ADDM has completed the 2000, 2002, 2004, 2006 and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

What kinds of education and training programs does the program offer to people who work with children who have ASDs or other developmental disabilities?

The SC ADDM team has contributed information on the characteristics and risk factors of ASDs, including;

- Over 140 presentations to professional groups at a local, state and national level
- Over 35 publications on autism in peer reviewed journals

The SC-ADDM team continues to present programs to health care providers, educators, service providers, and the community to increase awareness, screening, diagnosis, and early intervention efforts.

SC-ADDM team members continue to be active participants of the National CDC campaign Learn the Signs/Act Early including helping to develop and implement the SC Act Early Strategic Plan. <http://www.cdc.gov/ncehd/actearly/index.html>. This included a training program to assist pediatricians to identify signs and to make earlier ASD diagnosis

SC ADDM has hosted four conferences on ASD for professionals and the public. A recent initiative is to host the first scientific meeting for all South Carolina autism researchers.

What are some of the resources available in South Carolina for children with developmental disabilities, their families, and the professionals who serve them? Other autism resources in South Carolina include:

- The South Carolina Department of Disabilities and Special Needs (<http://ddsn.sc.gov>)
- South Carolina Autism Society (www.scautism.org)
- Greenwood Genetic Clinic (www.ggc.org)
- Family Connection (www.familyconnections.org)
- Family Resource Center (www.frdsn.org)
- Developmental Evaluation Centers at the Medical University of South Carolina (www.musckids.com/vincemoseley)
- University of South Carolina (<http://scatn.med.sc.edu/>)
- Greenville Hospital System (<http://www.ghschildrens.org/autism-wonders-home.php>)
- SC Early Intervention Programs (<http://www.scfirststeps.org/>),
- South Carolina Public Schools Special Education Directors http://ed.sc.gov/agency/programs-services/173/documents/Coordinator_list.pdf

For more information, please contact:

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Utah

Utah Autism and Developmental Disabilities Monitoring Project (UT-ADDM)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 45

Total prevalence of ASDs: 21.2 per 1,000 (1 in 47)

Boys: 31.7 per 1,000 (1 in 32)

Girls: 11.7 per 1,000 (1 in 85)

Race/ Ethnicity

White: 40.0 per 1,000

Other race/ethnicity: 6.5 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 69%

Median earliest age ASD was documented in their records:
4 years, 5 months

Autistic Disorder: 4 years, 4 months

ASD/PDD: 4 years, 4 months

Asperger Disorder: 5 years, 8 months

SITE INFORMATION

Part of Utah Included in ADDM, 2008

Part of 1 county in northern Utah

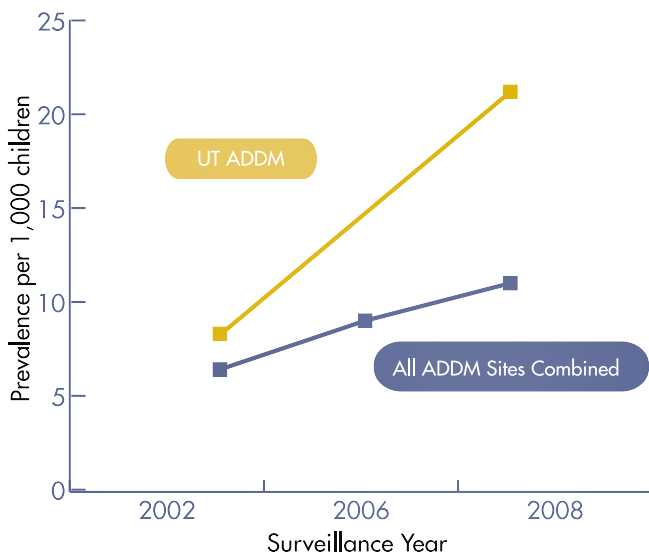
Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 2,123

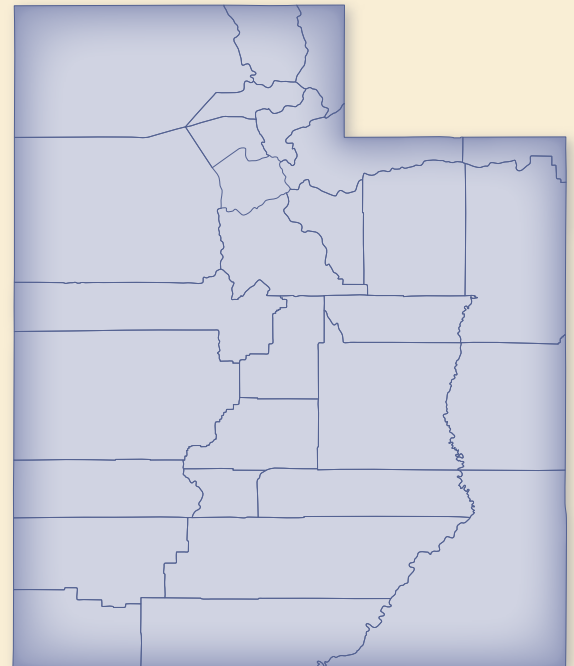
White: 42.3%

Other race/ethnicity: 56.1%

Overall ASD Prevalence



UT ADDM collected data for the 2002 and 2008 surveillance years only. The data shown are based on the surveillance area covered in both time points.



Utah Autism and Developmental Disabilities Monitoring Project (UT-ADDM)

Utah Autism and Developmental Disabilities Monitoring Project (UT-ADDM) is a multisource investigation to monitor the number of 8 and 4-year-old children in the population with ASDs or other developmental disabilities. In 2002, UT ADDM was established as an ADDM Network site in collaboration between the Utah Department of Health and investigators from the University Of Utah School Of Medicine. This surveillance project provides an accurate count of the number of children and families residing in Utah living with these disorders. Investigators are members of the University of Utah, School of Medicine's Department of Psychiatry. UT-ADDM is a joint undertaking with CDC and other state programs, agencies, and organizations that serve children with developmental disabilities and their families. The UT-ADDM Project has completed the 2002 and 2008 surveillance years, and will continue to collect data for the 2010 and 2012 surveillance years.

This program has also contributed information on the characteristics and risk factors of ASDs and intellectual disability, including:

- Establishing that maternal age and breech presentation were potential risk factors for ASD (<http://www.ncbi.nlm.nih.gov/pubmed/19403494>)
- Identifying the prevalence of communication disorders and co-occurring autism, intellectual disability and emotional/behavioral disorders (<http://www.ncbi.nlm.nih.gov/pubmed/17971495>)
- Providing insight into autism rate changes in school and health sources (<http://www.ncbi.nlm.nih.gov/pubmed/21538173>)

What part of Utah is included in the ADDM Network for 2008?

UT ADDM covered part of one county in northern Utah for the 2008 surveillance year. This was a smaller study area compared to most ADDM sites and the UT ADDM results might be affected by looking at this smaller population of 8- year-old children.

What kinds of education and training programs does the project offer to people who work with individuals who have ASDs?

UT-ADDM staff will support training on autism for Utah educators, community health providers, and families. Training for community health providers will be coordinated through state collaborative continuing education programs.

What are some of the resources available in Utah for children with developmental disabilities, their families, and the professionals who serve them?

- Baby Watch is Utah's network of services for children ages birth to three with developmental delays or disabilities. Visit <http://www.utahbabywatch.org/> for more information.
- The Utah Parent Center and Autism Council of Utah are rich resources for all affected by autism. To find out more, visit <http://www.utahparentcenter.org/> or <http://autismcouncilofutah.org/>
- Utah's Children with Special Health Care Needs provides clinical diagnostic services for children with developmental delays, complicated medical issues and associated behavior problems. To find out what is available in your area visit <http://health.utah.gov/cshcn/>.
- The Neurobehavior H.O.M.E. Program is a center of excellence for meeting the medical and mental health needs of people with developmental disabilities. For more information call (801) 581-5515 or visit <http://healthcare.utah.edu/home/>.

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E-mail: judith.zimmerman@hsc.utah.edu

Website: www.Utahautismregistry.com



Wisconsin

Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS)

RESULTS

Autism Spectrum Disorder (ASD) Prevalence, 2008

Number of children identified with ASDs: 267

Total prevalence of ASDs: 7.8 per 1,000 (1 in 129)

Boys: 11.7 per 1,000 (1 in 85)

Girls: 3.7 per 1,000 (1 in 270)

Race/ Ethnicity

White: 8.6 per 1,000

Black : 5.0 per 1,000

Hispanic: 3.8 per 1,000

Documented ASD Diagnosis

Children with ASD diagnosis in their records: 83%

Median earliest age ASD was documented in their records:
4 years, 5 months

Autistic Disorder: 3 years, 10 months

ASD/PDD: 4 years, 4 months

Asperger Disorder: 6 years, 2 months

SITE INFORMATION

Part of Wisconsin Included in ADDM, 2008

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

Population of 8-Year-Old Children in Study Area, 2008

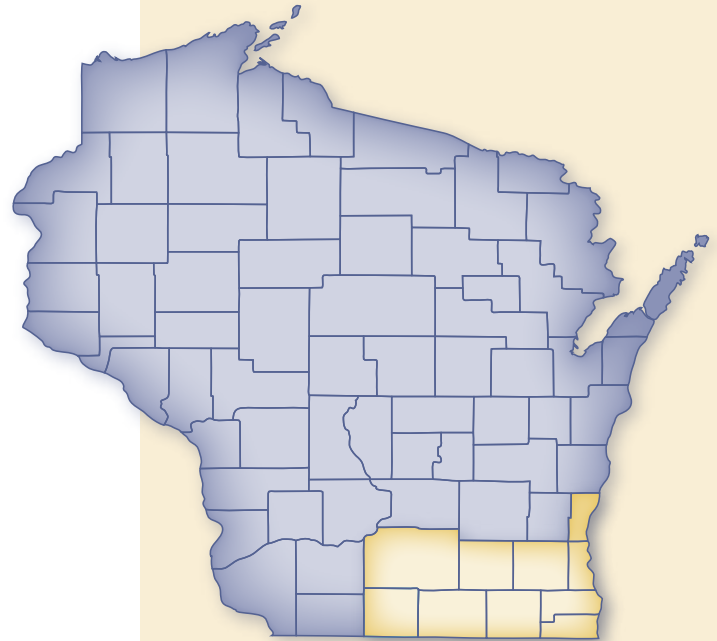
8-Year-Old Children: 34,451

White: 65.2%

Black: 16.9%

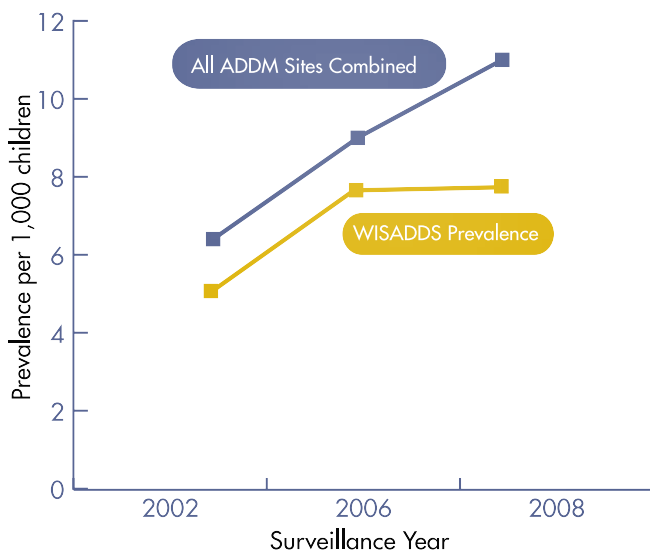
Hispanic: 13.7%

Asian or Pacific Islander: 3.7%



Yellow - Counties in the ADDM Network in 2008

Overall ASD Prevalence



WISADDS also reported data for the 2004 surveillance year. See the earlier ADDM Network report for this information.

Wisconsin

Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS)

Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS) is a multisource public health surveillance system established to monitor the number of children in the population with ASDs or other developmental disabilities. WISADDS was established in 2003 as an ADDM Network site in collaboration between the Wisconsin Department of Health Services and investigators from the Waisman Center and Department of Population Health Sciences at University of Wisconsin-Madison. WISADDS is currently conducting surveillance of ASDs and cerebral palsy. In addition to prevalence counts, this program contributes information on the characteristics and risk factors for ASDs, including:

- Age of identification of ASDs, (www.ncbi.nlm.nih.gov/pubmed/19318992)
- The relationship between both maternal and paternal age and ASD risk, (www.ncbi.nlm.nih.gov/pubmed/17404129)
- Socioeconomic disparities in the prevalence of ASDs. (www.ncbi.nlm.nih.gov/pubmed/20634960, www.ncbi.nlm.nih.gov/pubmed/19743757)

What kinds of education and training programs does WISADDS offer to people who work with children who have ASDs or other developmental disability?

The project sponsors workshops and training in early identification of developmental disabilities for pediatricians and other pediatric health care providers serving southeastern Wisconsin. The goal is to improve the ability of providers to recognize early signs of ASDs and cerebral palsy and for standardized diagnostic practices related to ASDs, including childhood autism, Asperger syndrome, atypical autism, and pervasive developmental disorder not otherwise specified.

What are some of the resources available in Wisconsin for children with developmental disabilities, their families, and the professionals who serve them?

- Wisconsin promotes CDC's Learn the Signs. Act Early. campaign in an effort to raise awareness about developmental milestones and the importance of screening and early intervention. Visit www.ActEarly.wisc.edu for more information.
- Wisconsin Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) provide confidential information, referral and follow-up so all families of children and youth with special health care needs and providers have access to complete and accurate information. The Regional Center staff regularly provides training related to early identification, autism, developmental screening, and community-based resources. To find out what is available in your area, visit www.dhs.wisconsin.gov/health/children/overview/index.htm.
- Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities is another valuable resource that provides brief descriptions of programs, services and systems of support available in Wisconsin. You can download the booklet at www.waisman.wisc.edu/cedd/pdfs/findingyourway.pdf.
- Wisconsin First Step is a 24-hour hotline and searchable online database for families and providers who support the needs of children and youth with special needs: call 1-800-642-7837 or visit www.mch-hotlines.org.
- The Autism Society of Wisconsin is a rich resource for all affected by autism. To find out more or to locate your local chapter, visit www.asw4autism.org or call 1-888-4-AUTISM.

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HOW CAN THE DATA BE USED?

The ADDM Network reports help us understand the characteristics of children with ASDs living in several U.S. communities. While many studies of ASDs have focused on small groups of individuals, the ADDM Network monitors the conditions among thousands of children from diverse communities across the country. This ongoing, population-based approach allows the ADDM Network to monitor changes in the identified prevalence of ASDs. Understanding the characteristics of children with these conditions, such as the average age of diagnosis and disparities in identification, can help communities to direct their outreach efforts to those who need it most.

Service Provision and Planning

More children than ever before are receiving services for ASDs. Knowing how many children have ASDs can help educators and providers to plan and coordinate service delivery. Communities also have used ADDM Network data on the average age of diagnosis to bolster their efforts to promote and increase early identification of ASDs. In this report, we have included data on the average ages of diagnosis by subtype: autistic disorder (4 years), autism spectrum diagnoses or pervasive developmental disorder-not otherwise specified (4 years, 5 months), and Asperger disorder (6 years, 3 months). These data tell us that many times there is a significant gap between when someone (for example, a parent or provider) first is concerned about a child's development and when the child actually is diagnosed as having an ASD. Information like this can help communities develop service and support plans to address factors that might be contributing to this delay.

Awareness and Policy

Understanding how many children have ASDs is key to promoting awareness of these conditions. These data provide a reliable estimate of the prevalence and describe how this estimate is changing over time. This information can be helpful when advocates are working to bring a community together to address the growing needs of families living with ASDs. Right now, whether a child is able to see a provider for an evaluation right away and whether a family can afford treatment depends on where he or she lives. Many communities have long waiting lists to see providers and, while some states mandate coverage of treatment for ASDs, others do not. These data might help communities to promote equity in access to care so that all children have access to evaluations and treatment when they need them.

Research and Coordination

Understanding the characteristics of children with ASDs can provide important clues for further research. For example, according to the most recent data, ASD prevalence is almost five times higher among boys than among girls, with about 1 in 54 boys and 1 in 252 girls having an ASD. Research exploring why there are differences in the identified prevalence among males and females is ongoing and knowing that the conditions are more common among boys can help to direct our search for causes. At a community level, ADDM Network data can be useful for promoting and informing research. For many communities, ADDM Network data have served as an impetus for the creation of research consortia, task forces, or commissions focused on coordination of ASD activities.

"Easter Seals uses these data to advocate for increasing the availability of essential services so that individuals with autism and their families can live, learn, work and play in their communities."

– Mary Andrus, Easter Seals

QUESTIONS AND ANSWERS

Does this mean that the prevalence of ASDs is 1 in 88 children in all U.S. communities?

It is important to remember that the estimate of 1 in 88 is an average based on data collected from 14 sites in the ADDM Network. ASD prevalence estimates from the 14 sites range from 4.8 per 1,000 (Alabama) to 21.2 per 1,000 (Utah).

Why is there such a wide range in identified prevalence from site to site?

Within the ADDM Network sites, most estimates were near the average of 11.3 per 1,000. On average, estimated ASD prevalence was significantly higher at the ADDM Network sites that had access to education records and health records than those that had access to health records only. The number of records available, better documentation in records, and increased awareness in communities also can affect prevalence estimates.

What is causing the increase in children identified with ASDs?

For such complex conditions like ASDs, no single factor can explain why more children are being identified with ASDs. Some of the increase likely has been due to changes in the diagnosis and treatment of ASDs, some to greater awareness, and some to better record keeping, although exactly how much is due to these factors is unknown. To fully understand what's causing the rest of this increase, we need to better understand the risk factors for ASDs. We understand that the emotional and financial tolls on families and communities are staggering. We will continue monitoring prevalence so we can better understand who is being identified, and why. And, we will work to improve early identification in the hope that all children have the opportunity to thrive.

What do we know about the causes and risk factors for ASDs?

Most scientists who study ASDs believe that there is no single cause. Research has shown that:

- Both genetic and non-genetic factors play a role in whether or not a person will have an ASD.
- Children who have a sibling or parent with an ASD are at a higher risk of having an ASD.
- Children born to older parents also are at a higher risk of having an ASD.
- ASDs tend to occur more often among people who have certain genetic or chromosomal conditions. About 10% of children with ASDs also have been identified as having Down syndrome, fragile X syndrome, tuberous sclerosis, or other genetic and chromosomal disorders.
- When taken during pregnancy, the prescription drugs valproic acid and thalidomide have been linked with a higher risk of ASDs.
- A small percentage of children who are born prematurely or with low birthweight are at a greater risk for having ASDs.

CDC actively is searching for the possible reasons some people develop ASDs through our Study to Explore Early Development (SEED). SEED currently is the largest study in the United States to help identify factors that might put children at risk for ASDs and other developmental disabilities. While we know that no one study will have all the answers, SEED will contribute to our understanding of complex risk factors for ASDs.

How many children in the United States have ASDs?

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

“The CDC prevalence data offer important clues that will guide autism research, informing our search for the underlying causes of autism and our efforts to develop better treatments.

– Alison Singer, President, Autism Science Foundation

How does the prevalence of ASDs compare with other childhood disabilities?

About 15% of children in the United States have a developmental disability (12). Conditions such as attention-deficit/hyperactivity disorder (8%), learning disabilities (7%), and communication disorders (6%) are more common than ASDs. Although developmental disabilities have increased overall during the past 10 years, ASDs have had the most rapid increase when compared with the other conditions.

What is the government doing about autism?

CDC plays a vital role in the federal response to ASDs, providing essential data on the burden of the conditions. At CDC, we know that the only way we're going to make progress is to work together. The federal response to ASDs is coordinated by the Interagency Autism Coordinating Committee (IACC), which has both federal and public members with a range of perspectives; these members include advocacy groups, researchers, and individuals with ASDs. The IACC was established to coordinate ASD-related activities across the federal government; facilitate the exchange of information on ASD activities among member agencies; and increase public understanding of the member agencies' activities, programs, and policies. The committee also provides a public forum for discussions related to ASD research, screening, education, and interventions, and is charged with developing, implementing and tracking progress towards a National Strategic Plan for Autism Research.

Learn more about IACC on their website, www.iacc.hhs.gov.

WHAT ELSE DO I NEED TO KNOW?

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

You can follow your child's development by looking for developmental milestones—that is, how he or she plays, learns, speaks, and acts. Developmental milestones are things most children can do by a certain age. Talk with your child's doctor at every visit about the milestones your 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." website, www.cdc.gov/ActEarly.

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

As a parent, you know your child best. If your child is not meeting the milestones for his or her age, or if you think there could be a problem with the way your child plays, learns, speaks, or acts, talk with your child's doctor and share your concerns. Don't wait.

For tips on how to share your concerns with your health care professional, visit www.cdc.gov/concerned and the First Signs website at www.firstsigns.org.

What is IDEA?

The Individuals with Disabilities Education Act (IDEA) (13) 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 children with ASDs?

There is no single best treatment for children with ASDs. Each person with an ASD has unique strengths. Promoting these strengths while supporting new skills is important. It is important to talk with your child's health care provider as soon as possible if you think your child has an ASD or other developmental delay. According to reports by the American Academy of Pediatrics (14) and the National Research Council (15), educational interventions that provide structure, direction, and

organization for children are thought to help those with ASDs. Educational interventions must be tailored to each child and take into account his or her overall developmental status and specific strengths and needs. It is important to remember that early intervention is 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/publications/autism/complete-index.shtml.

Can medication help children with ASDs?

There are no medications that can cure ASDs or treat the core symptoms; however, there are medications that can help some people with ASDs function better. For example, medication might help manage high energy levels, inability to focus, depression, or seizures. Also, the U.S. Food and Drug Administration has approved the use of risperidone and aripiprazole (antipsychotic drugs) to treat at certain ages children with ASDs who experience severe tantrums, aggression, and self-injurious behaviors. For more information, visit the Food and Drug Administration's website at www.fda.gov/.

Medications might not affect all children in the same way. It is important to work with a health care professional who has experience in treating children with ASDs. Parents and health care professionals must closely monitor a child's progress and reactions while he or she is taking a medication to be sure that any negative side effects of the treatment do not outweigh the benefits.

To learn more about medications and ASDs, go to the National Institute of Mental Health's autism website at www.nimh.nih.gov/health/publications/autism/complete-index.shtml#pub4.

Are there health conditions associated with having ASDs?

It is important to remember that children with ASDs can get sick or injured just like children without ASDs. There are, however, some conditions that have been found to co-occur with ASDs such as: intellectual disability, epilepsy, tuberous sclerosis, Down syndrome, fragile X syndrome, depression, anxiety, attention deficits, sensory-processing difficulties, gastrointestinal issues, and sleep problems (16). It is important to recognize these conditions and treat them accordingly. Regular medical and dental examinations should be part of your child's intervention plan, as should preventive measures such as routine childhood immunizations.

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 of Developmental Disabilities

“Learn the Signs. Act Early.”

www.cdc.gov/ActEarly or 1-800-CDC INFO

Find out if your child's development is on track and learn the signs of developmental delays, get examples of what to say to health care professionals, and get tips about what to do if you have to wait for an appointment.

General Information About ASDs

CDC Autism Information Center

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 ASDs and the causes and risk factors.

Autism Speaks

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.

American Academy of Pediatrics

www.aap.org/healthtopics/autism.cfm

Download resources for parents and providers and listen to interviews with pediatricians, researchers, and parents.

Services and Support for Children with ASDs

Autism Society

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.

National Early Childhood Technical Assistance Center (NECTAC)

www.nectac.org or 919-962-2001

Use NECTAC to find state contacts for early intervention programs for infants and toddlers from birth to 3 years old (Part C Programs www.nectac.org/contact/ptccoord.asp) and preschool special education for children from 3 to 5 years old (state Section 619 www.nectac.org/contact/619coord.asp)

Easter Seals

www.easterseals.com or 1-800-221-6827

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

Questions Often Asked by Parents About Special Education Services

<http://nichcy.org/publications/lg1> or 1-800-695-0285

Get answers to your questions about services provided under the Individuals with Disabilities Education Act (available in English and Spanish).

Note: Your public school special education director also can 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

Association of Maternal and Child Health Programs

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 ASDs and their families.

Educating Children with Autism

www.nap.edu/books/0309072697/html/

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

National Institute of Mental Health

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 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 ASD in this report from the American Academy of Pediatrics.

Family Voices

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.

Operation Autism. A Resource Guide for Military Families

www.operationautismonline.org/

Operation Autism directly supports U.S. military families touched by ASDs. It is sponsored and maintained by the Organization for Autism Research.

Research

CDC's Study to Explore Early Development (SEED)

www.cdc.gov/ncbddd/autism/seed.html

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

Interagency Autism Coordinating Committee (IACC)

www.iacc.hhs.gov

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

Clinical Trials

www.clinicaltrials.gov or 301-496-4000

Access a searchable database that provides patients, family members, and the public with information about current, ongoing clinical research studies.

The Autism Science Foundation (ASF)

www.autismsciencefoundation.org or 646-723-3978

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

Read about research being done on ASDs (available in English and Spanish).

Organization for Autism Research (OAR)

www.ResearchAutism.org or 703-243-9710

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

Other Federal Agencies

Department of Education (ED)

www.ed.gov/

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

Technical Assistance and Dissemination Network (TA&D Network)

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.

Office of Special Education and Rehabilitative Services

www2.ed.gov/about/offices/list/osers

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

Food and Drug Administration (FDA)

www.fda.gov

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

Human Resources and Services Administration (HRSA)

mchb.hrsa.gov/programs/autism/

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

National Dissemination Center for Children with Disabilities

<http://nichcy.org>

Find information on programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; and research-based information on effective practices for children with disabilities.

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

www.hhs.gov/autism/

Learn more about ASDs and access links to government agencies working to address ASDs.

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www.cdc.gov/autism

National Center on Birth Defects and
Developmental Disabilities

Centers for Disease Control and Prevention
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Atlanta, GA