

Autism and Developmental Disabilities Monitoring (ADDM) Network



The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with autism spectrum disorder (ASD) and other developmental disabilities living in different areas of the United States. The ADDM Network sites all collect data using the same methods, which are modeled after CDC's <u>Metropolitan Atlanta</u> <u>Developmental Disabilities Surveillance Program (MADDSP)</u>.

ADDM Network goals are to:

- Describe the population of children with ASD,
- Compare how common ASD is in different areas of the country,
- Identify changes in ASD occurrence over time, and
- Understand the impact of ASD and related conditions in US communities.

ADDM Network fact sheet

Nhat We've Learned

CDC estimates that about 1 in 68 children has been identified with ASD (or 14.6 per 1,000 8-year-olds). These estimates from the ADDM Network are based on data collected from health and special education records of children living in 11 communities across the United States during 2012. These 11 communities :hildren who were 8 years old because previous work has shown that, by this age, most children with \SD have been identified for services.

n 2007, CDC's ADDM Network first reported that about 1 in 150 children had ASD (based on 2002 data rom 14 communities). Then, in 2009, the ADDM Network reported that 1 in 110 children had ASD based on 2006 data from 11 communities). And, in 2012, the ADDM Network reported that 1 in 88 children had ASD (based on 2008 data from 14 communities). In 2014, the ADDM Network reported hat about 1 in 68 children had ASD (based on 2010 data from 11 communities). This means that the estimated prevalence of ASD increased roughly 123% during 2002 to 2010. However, the estimated prevalence of ASD stayed about the same between 2010 and 2012..

Here are some other key findings from our most recent report:

- The percentage of children identified with ASD ranged widely across geographic area. For example, in the areas where the ADDM Network reviewed both health and special education records, the percentage of children who were identified with ASD ranged from a low of 1 in 81 or 1.2% in areas of South Carolina to a high of 1 in 41 or 2.5% in areas of New Jersey.
- Boys were 4.5 times were more likely to be identified with ASD than girls.
- White children were more likely to be identified with ASD than black or Hispanic children. Black children were more likely to be identified with ASD than Hispanic children.
- Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.
- About 43% of children identified with ASD were evaluated for developmental concerns by age 3 years.
- Black and Hispanic children were less likely to be evaluated for developmental concerns by age 3 years than white children.
- Even though ASD can be diagnosed as early as age 2 years, most children were not diagnosed with ASD by a community provider until after age 4 years.

Article: <u>Prevalence and characteristics of autism spectrum disorder among children aged 8 years –</u> <u>Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012</u> <u>http://dx.doi.org/10.15585/mmwr.ss6503a1</u>)

Community Report: 2016 Community Report from the Autism and Developmental Disabilities <u>Monitoring Network</u>

Article: <u>Prevalence of Autism Spectrum Disorder, 2010</u> <u>http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w</u> Community Report: <u>Read the Community Report on the 2010 ADDM Network findings</u>

Current ADDM Network Activities

- In January 2015, CDC launched a 4th phase of funding for the ADDM Network. <u>Read the</u> <u>announcement</u> for more information.
- Currently, CDC funds 10 ADDM Network sites (plus <u>MADDSP</u>, which is the ADDM Network site administered by CDC)

- All 10 sites track ASD among 8-year-old children. Six sites also track ASD among 4-year-old children. Tracking among 4-year-old children increases our understanding of the characteristics and early identification of younger children with ASD.
- Some ADDM Network sites also track the prevalence of other developmental disabilities, including cerebral palsy, intellectual disability, hearing loss, and vision impairment.
- In addition to tracking, sites also conduct analyses of the data to better understand changes over time in the number of children identified with ASD, and carry out education and outreach activities in their local communities.

Read about the work taking place at each site by clicking one of the following links:

- Arizona Arkansas Colorado Georgia Maryland Missouri
- New Jersey
 North Carolina
 South Carolina
 Utah
 Wisconsin

ADDM Fact Sheet [PDF - 997 KB]

[>]revious ADDM Network Activities

The ADDM Network's first phase included funding for 14 sites. These sites include the current phase list above plus three additional sites. Read about the work at two of those former sites by clicking one of the following links:

- <u>Alabama</u>
- Florida
- Pennsylvania

ADDM Network Publications

To find ADDM publications related to ASD, visit our <u>Autism Articles page</u>. To find ADDM publications related to other developmental disabilities, including cerebral palsy, visit our <u>Developmental Disabilities</u> <u>Articles page</u>.

Related Pages

Developmental Disabilities

"Learn the Signs. Act Early." Campaign

CDC's National Center on Birth Defects and Developmental Disabilities

E-mail Your Friends

"Children with autism spectrum disorder are not being diagnosed as early as they could be. Learn the signs of autism and get help if you're concerned."

Send an E-mail (mailto:?subject=Facts%20about%20ASDs&body=Children with autism spectrum disorder are not being diagnosed as early as they could be. Learn the signs of autism and get help if you're concerned.http://www.cdc.gov/ncbddd/autism/facts.html)

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"Many children with autism spectrum disorder (ASD) are not being identified as early as they could be. Early identification is the most powerful tool we have right now to make a difference in the lives of children with ASD."

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"Too many children w/ autism are not being identified as early as they could be. Earlier is better. #ActEarly"

Share on Twitter (https://twitter.com/home?

status=Too%20many%20children%20w%2F%20autism%20are%20not%20being%20identified%2 0as%20early%20as%20they%20could%20be.%20Earlier%20is%20better.%20%23ActEarly%20htt p%3A%2F%2Fgoo.gl%2Fmu6s9o)

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Content source: Division of Birth Defects, National Center on Birth Defects and Developmental Disabilities, Centers

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Arizona Autism coalition Building an integrated community together

Blog

CDC Releases New Autism Data: 1 in 64 Arizonans Diagnosed With Autism

B Mar 27th ● Comments Off on CDC Releases New Autism Data: 1 in 64 Arizonans Diagnosed With Autism ▲ by arizonaautism

Today, the CDC (Centers for Disease Control and Prevention) released their new data on autism. The number of children diagnosed with autism in Arizona remains at 1 in 64 and nationwide has increased to 1 in 68, a 30% *increase from the previous national data released in 2012 of 1 in 88 diagnosed with autism.* The data is used to promote early identification, plan for training and service needs, guide research, and inform policy so that children with ASD and their families get the help they need.

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

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

White children were more likely to be identified with ASD than black and

Hispanic children

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

Here are 10 things you need to know about the CDC's latest report on autism as found on their site by clicking here.

10 Things You Need To Know About CDC's Latest Report from the Autism and Developmental Disabilities Monitoring Network

The following estimates are based on information collected from the health and special education (if available*) records of children who were 8 years old and lived in areas of Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin in 2010:

- About 1 in 68 children (or 14.7 per 1,000 8 year olds) were identified with ASD. It is important to remember that this
 estimate is based on 8-year-old children living in 11 communities. It does not represent the entire population of
 children in the United States.
- 2. This new estimate is roughly 30% higher than the estimate for 2008 (1 in 88), roughly 60% higher than the estimate for 2006 (1 in 110), and roughly 120% higher than the estimates for 2002 and 2000 (1 in 150). We don't know what is causing this increase. Some of it may be due to the way children are identified, diagnosed, and served in their local communities, but exactly how much is unknown.
- 3. The number of children identified with ASD varied widely by community, from 1 in 175 children in areas of Alabama to 1 in 45 children in areas of New Jersey.
- 4. Almost half (46%) of children identified with ASD had average or above average intellectual ability (IQ greater than 85).
- 5. Boys were almost 5 times more likely to be identified with ASD than girls. About 1 in 42 boys and 1 in 189 girls were identified with ASD.
- 6. White children were more likely to be identified with ASD than black or Hispanic children. About 1 in 63 white children, 1 in 81 black children, and 1 in 93 Hispanic children were identified with ASD.
- 7. Less than half (44%) of children identified with ASD were evaluated for developmental concerns by the time they were 3 years old.
- 8. Most children identified with ASD were not diagnosed until after age 4, even though children can be diagnosed as early as age 2.
- 9. Black and Hispanic children identified with ASD were more likely than white children to have intellectual disability. A

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tism

Arizona 1 in 64 Diagnosed with Autism (no change)

USA 1 in 68 Diagnosed with Autism (30% increase) 5/4/2016

previous study has shown that children identified with ASD and intellectual disability have a greater number of ASD symptoms and a younger age at first diagnosis. Despite the greater burden of co-occurring intellectual disability among black and Hispanic children with ASD, these new data show that there was no difference among racial and ethnic groups in the age at which children were first diagnosed.

0. About 80% of children identified with ASD either received special education services for autism at school or had an ASD diagnosis from a clinician. This means that the remaining 20% of children identified with ASD had symptoms of ASD documented in their records, but had not yet been classified as having ASD by a community professional in a school or clinic.

Dr. Sydney Pettygrove, Assistant Professor at the University of Arizona's College of Public Health and Specialty Adviser of the Tucson Council of the Arizona Autism Coalition recently presented her important work researching the prevalence of autism in the Arizona statewide population. Dr. Pettygrove also presented information on how prevalence numbers are determined and what that means for the community. You can view the presentation below:

Click here to view the Arizona Tracking ASD & Other Development Disabilities "What You Need To Know"

Click here to view the full report from the CDC

For media inquiries please contact info@azautism.org

The Arizona Autism Coalition improves the lives of individuals with Autism Spectrum Disorder and their families in Arizona by sharing resources and affecting autism systems reform through state-wide collaboration and advocacy. Your voice matters and the power of your vote can enhance the quality and quantity of services. Arizona legislators and other policymakers need to know when and how their decisions impact the lives of their constituents affected by autism. The Arizona Autism Coalition actively partners with other disability groups and advocates on behalf of the entire community. The Coalition is comprised of parents/family members affected by autism, representatives from provider agencies, medical professionals, local/state governmental agencies and other related special needs providers.

Location

4530 E. Muirwood Dr., Suite. 103 Phoenix, AZ 85048

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TODAY is <u>#AZGivesDay</u>! There's many amazing organizations in the <u>#Arizona #autism</u> community to support – please... https://t.co/SRJhSfRnrS about 4 hours ago from Facebook ReplyRetweetFavorite

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Data & Statistics



Prevalence

- About 1 in 68 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities
 Monitoring (ADDM) Network. [Read summary] [Read article]
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups. [Read summary] [Read article]
- ASD is about 4.5 times more common among boys (1 in 42) than among girls (1 in 189). [<u>Read article</u>]
- Studies in Asia, Europe, and North America have identified individuals with ASD with an average <u>prevalence</u> of between 1% and 2%. [<u>Data table</u>]
- About 1 in 6 children in the United States had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism. [Read summary]

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children
2000	1992	6	6.7 (4.5–9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7–21.9)	1 in 68
2012	2004	11	14.6 (8.2-24.6)	1 in 68

Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000 – 2012

Combing Data from All Sites

Learn more about prevalence of ASD »

Learn more about the ADDM Network »

Learn more about MADDSP »

Risk Factors and Characteristics

- Studies have shown that among identical twins, if one child has ASD, then the other will be affected about 36-95% of the time. In non-identical twins, if one
- child has ASD, then the other is affected about 0-31% of the time $\frac{141}{141}$

- Parents who have a child with ASD have a 2%–18% chance of having a second child who is also affected.^[5,6]
- ASD tends to occur more often in people who have certain genetic or chromosomal conditions. About 10% of children with autism are also identified as having <u>Down syndrome</u>, <u>fragile X syndrome</u>, <u>tuberous sclerosis</u>, or other genetic and chromosomal disorders.^[7-10]
- Almost half (about 44%) of children identified with ASD has average to above average intellectual ability. [<u>Read article</u>]
- Children born to older parents are at a higher risk for having ASD. [Read summary]
- A small percentage of children who are born prematurely or with low birth weight are at greater risk for having ASD. [Read summary]
- ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10%. [Read summary]

Diagnosis

- Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable. [Read summary] [Read summary]
- Even though ASD can be diagnosed as early as age 2 years, most children are not diagnosed with ASD until after age 4 years. The median age of first diagnosis by subtype is as follows.
 - Autistic disorder: 3 years, 10 months
 - Pervasive developmental disorder-not otherwise specified (PDD-NOS): 4 years, 1 month
 - Asperger disorder: 6 years, 2 months
- Studies have shown that parents of children with ASD notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age.[Read summary] [Read summary]

Economic Costs

- The total costs per year for children with ASD in the United States were estimated to be between \$11.5 billion - \$60.9 billion (2011 US dollars). This significant economic burden represents a variety of direct and in-direct costs,
- from medical care to energial education to lost narental productivity. [Read

article] [Read article]

Children and adolescents with ASD had average medical expenditures that exceeded those without ASD by \$4,110–\$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD. Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4–9.5 times greater. [Read article]

- In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were \$10,709 per child, which was about six times higher than costs for children without ASD (\$1,812). [Read summary]
- In addition to medical costs, intensive behavioral interventions for children with ASD cost \$40,000 to \$60,000 per child per year.^[11]

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