

CDC Informational Briefing on Autism: Findings from the Latest Prevalence Report

Autism and Developmental Disabilities Monitoring (ADDM) Network

11 Sites, United States, 2010

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Centers for Disease Control and Prevention

**Meeting of the Interagency Autism Coordinating Committee
National Institutes of Health
Bethesda, Maryland
April 8, 2014**



How common is Autism Spectrum Disorder?

Estimates of population prevalence vary widely across time and space

- **Different case ascertainment methods**
 - National or community surveys
 - Clinical samples or registries
 - Record-review methodology


- **Different case definitions**
 - Parent report of historical diagnosis
 - Diagnostic criteria (DSM-III, III-R, IV, IV-TR, 5)
 - Diagnostic instruments (screening checklists, observational tools)

- **Challenges in tracking autism prevalence**
 - Complex nature of the disorders
 - Lack of biologic markers for diagnosis

Expansion of CDC's Developmental Disabilities Surveillance Programs

[Congress](#) > [Legislation](#)

H.R. 4365: Children's Health Act of 2000

106th Congress 
1999-2000

To amend the Public Health Service Act with respect to children's health.

SEC. 102. Developmental disabilities surveillance and research programs.

(a) National Autism and Pervasive Developmental Disabilities Surveillance Program.

(1) In general. The Secretary of Health and Human Services... acting through the Director of the Centers for Disease Control and Prevention, may make awards of grants and cooperative agreements for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities...

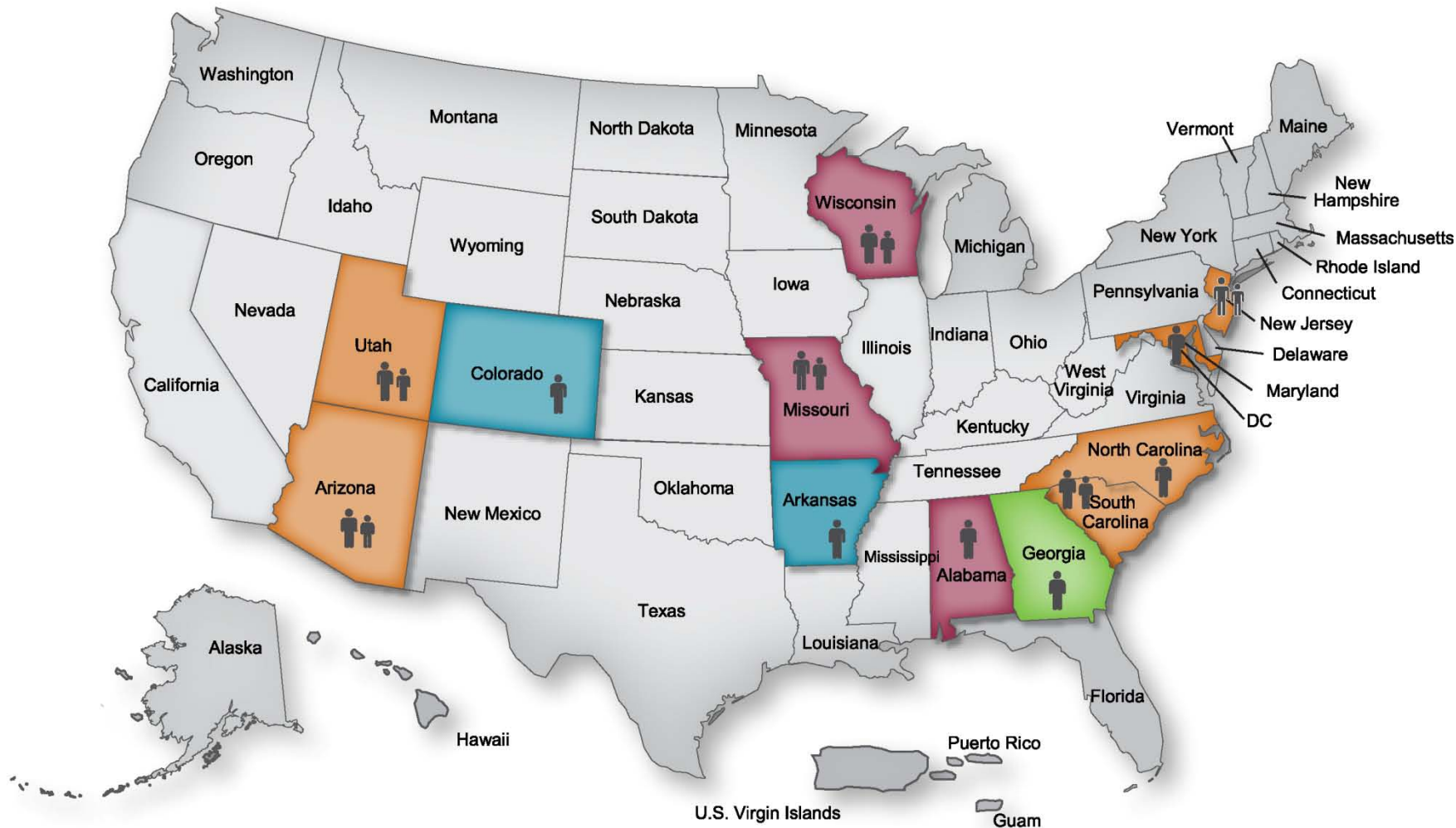
(2) Eligibility. To be eligible to receive an award under paragraph (1) an entity shall be a public or nonprofit private entity (including health departments of States and political subdivisions of States, and including universities and other educational entities).








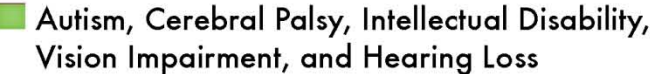
Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy

- **Currently there are 11 funded ADDMM sites, plus CDC/MADDSP**
- **Autism prevalence among 8 year olds is monitored in all sites**
- **Piloting autism surveillance among 4 year olds in six sites**
- **Some sites also track Cerebral Palsy (4) and/or Intellectual Disability (7)**

Current ADDM Network Sites, Surveillance Years 2010 and 2012



 Monitoring 8 year olds
 Monitoring 4 and 8 year olds

 Autism
 Autism, Cerebral Palsy
 Autism, Intellectual Disability
 Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss

ADDM Network Methods

- Multisite, multisource (educational and healthcare settings), records-based surveillance methodology

Screening and abstraction
of records at multiple data
sources in community

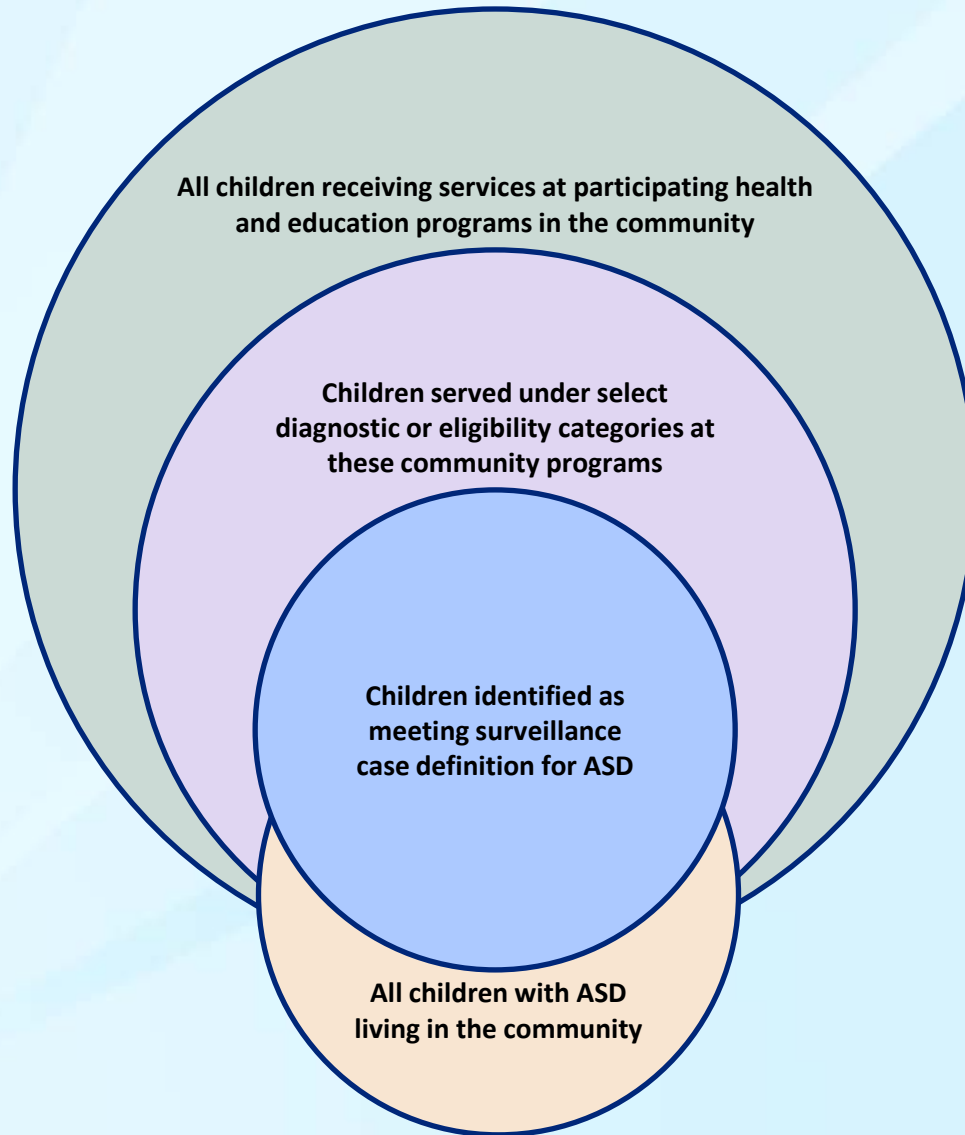


All abstracted evaluations
reviewed by trained
clinicians to determine
ASD case status

Evaluating Data Quality and Completeness

- Abstraction Quality Control
 - 10% sample of all “abstracted” records checked for accuracy of content
 - 10% sample of all “reviewed not abstracted” records checked for triggers
- Clinician Review Interrater Agreement
 - 10% sample of all records double-blind reviewed by 2 clinicians to check IRR
 - Target interrater agreement: 90% for final case status, 85% for eval diagnosis, 80% for all other coded items
 - All “low certainty” cases reviewed by 2 clinicians to reach consensus on final case status based on clinical judgment
- Validation study completed in Fulton County, Georgia
 - High positive predictive value (79%); higher when factoring in clinical judgment
 - Low sensitivity (60%); offset somewhat by “file not found” sensitivity analysis

ADDM Casefinding Net



MADDSP/ADDM Methodology

- Strengths

- Large, population-based study of autism (vs. studies done on small samples)
- Record review methodology maximizes population coverage (vs. direct screening, which is more costly, time-consuming, voluntary, restricted)
- Multiple-source case ascertainment, including both health and special education records in most sites
- Coding scheme and systematic review of behavioral descriptions to determine case status (based on DSM-IV-TR diagnostic criteria)
- Information on presence of other developmental disabilities

- Limitations

- Underascertainment of children with undocumented symptoms, children not being served in abstraction facilities / public special education programs
- Imprecision of population counts, especially in latter part of each decade when postcensal projections may become less accurate

ADDM Network Autism Prevalence Reports



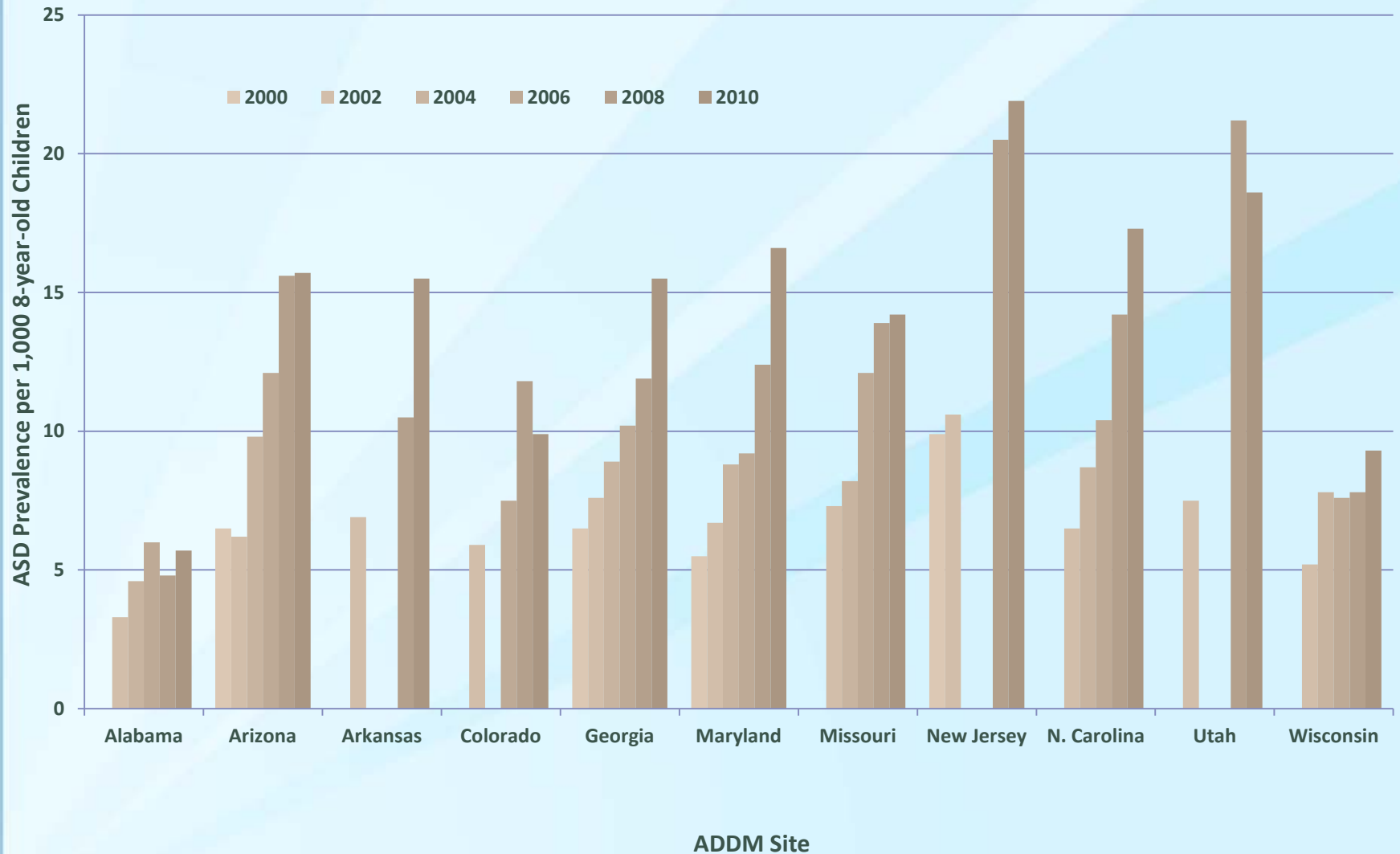
- **2007:** First report in MMWR SS - 2000 & 2002 surveillance years
 - **1 in 150** 8-year-old children in these communities were identified with ASD
- **2009:** Second report in MMWR SS - 2004 & 2006 surveillance years
 - **1 in 110** 8-year-old children in these communities were identified with ASD
 - Autism prevalence **increased 57%** between 2002 and 2006
- **2012:** Third report in MMWR SS - 2008 surveillance year
 - **1 in 88** 8-year-old children in these communities were identified with ASD
 - Detailed comparisons to earlier ADDM surveillance years (2002 & 2006)
 - Autism prevalence increased 78% between 2002 and 2008
 - Autism prevalence increased 23% between 2006 and 2008

ADDM Network ASD Prevalence Results

Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	8-year-old Population	Number of children with ASD	Prevalence per 1,000 Children (Range among Sites)
2000	1992	6	187,761	1,252	6.7 (4.5-9.9)
2002	1994	14	407,578	2,685	6.6 (3.3-10.6)
2004	1996	8	172,335	1,376	8.0 (4.6-9.8)
2006	1998	11	308,038	2,757	9.0 (4.2-12.1)
2008	2000	14	337,093	3,820	11.3 (4.8-21.2)
2010	2002	11	363,749	5,338	14.7 (5.7-21.9)

Change in ASD Prevalence Among ADDM Sites



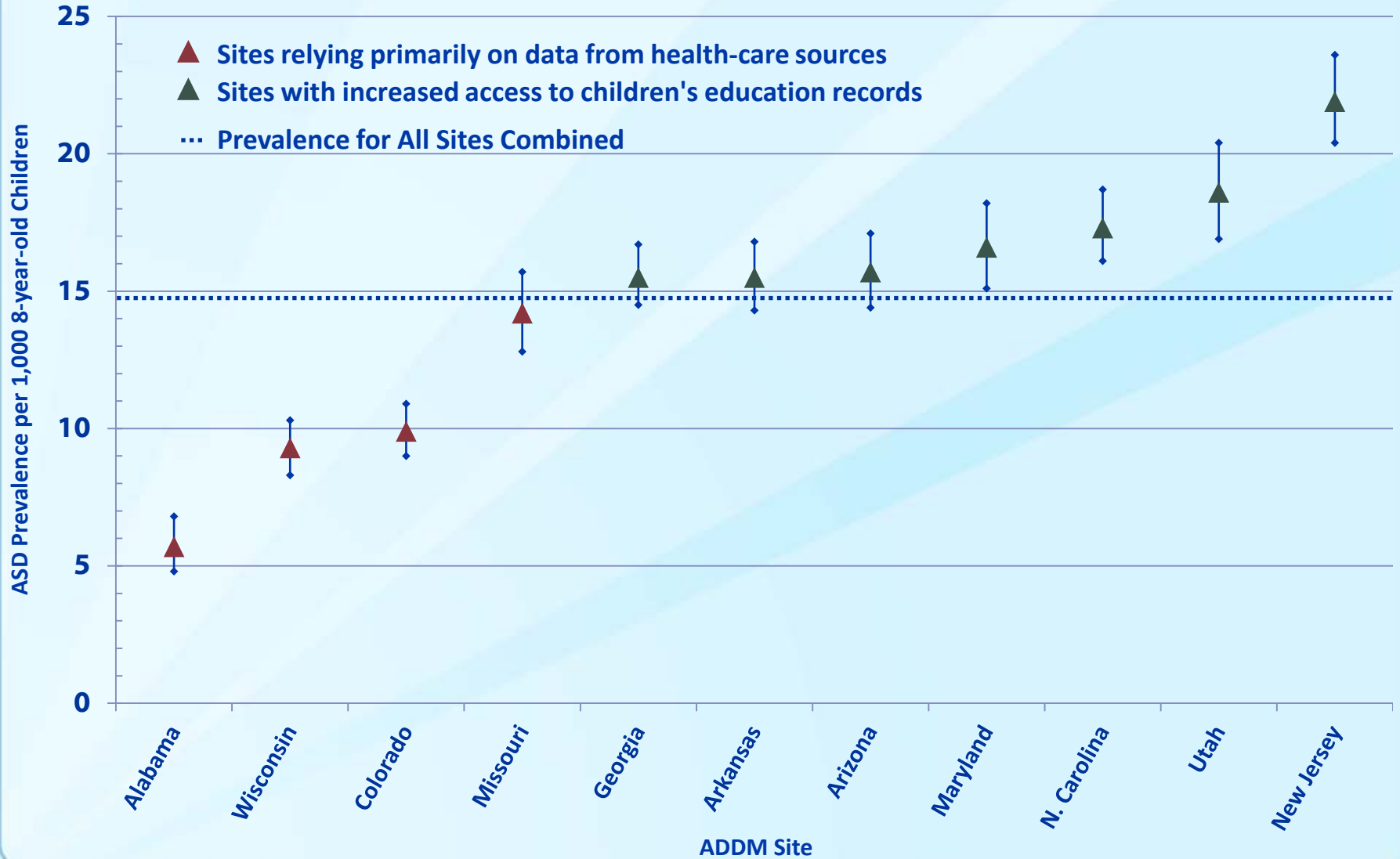
ADDM 2010 ASD Prevalence among Children aged 8 Years

- Overall ASD prevalence for ADDM 2010 was **14.7** per 1,000 (one in 68) children aged 8 years, based on combined data from 11 sites
- ASD prevalence was **23.7** per 1,000 boys and **5.3** per 1,000 girls (4.5:1 ratio)
- ASD prevalence among white children (**15.8** per 1,000) was significantly greater than that among black (**12.3** per 1,000) and Hispanic children (**10.8** per 1,000)
 - White children were approximately 30% more likely to be identified with ASD than black children and were almost 50% more likely to be identified with ASD than Hispanic children.

ADDM 2010 ASD Prevalence among Children aged 8 Years

- ASD prevalence estimates varied among sites
(from 5.7 to 21.9 per 1,000)
 - Highest prevalence estimates were for New Jersey (21.9), Utah (18.6), North Carolina (17.3), and Maryland (16.6)
 - Three sites between 15–16 per 1,000 (Arizona, Arkansas, Georgia)
 - Four sites with limited or no access to education records (Alabama, Colorado, Missouri, Wisconsin) reported lowest prevalence estimates among all ADDM sites

Variation in estimated prevalence (per 1,000 population) of autism spectrum disorder (ASD) among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010

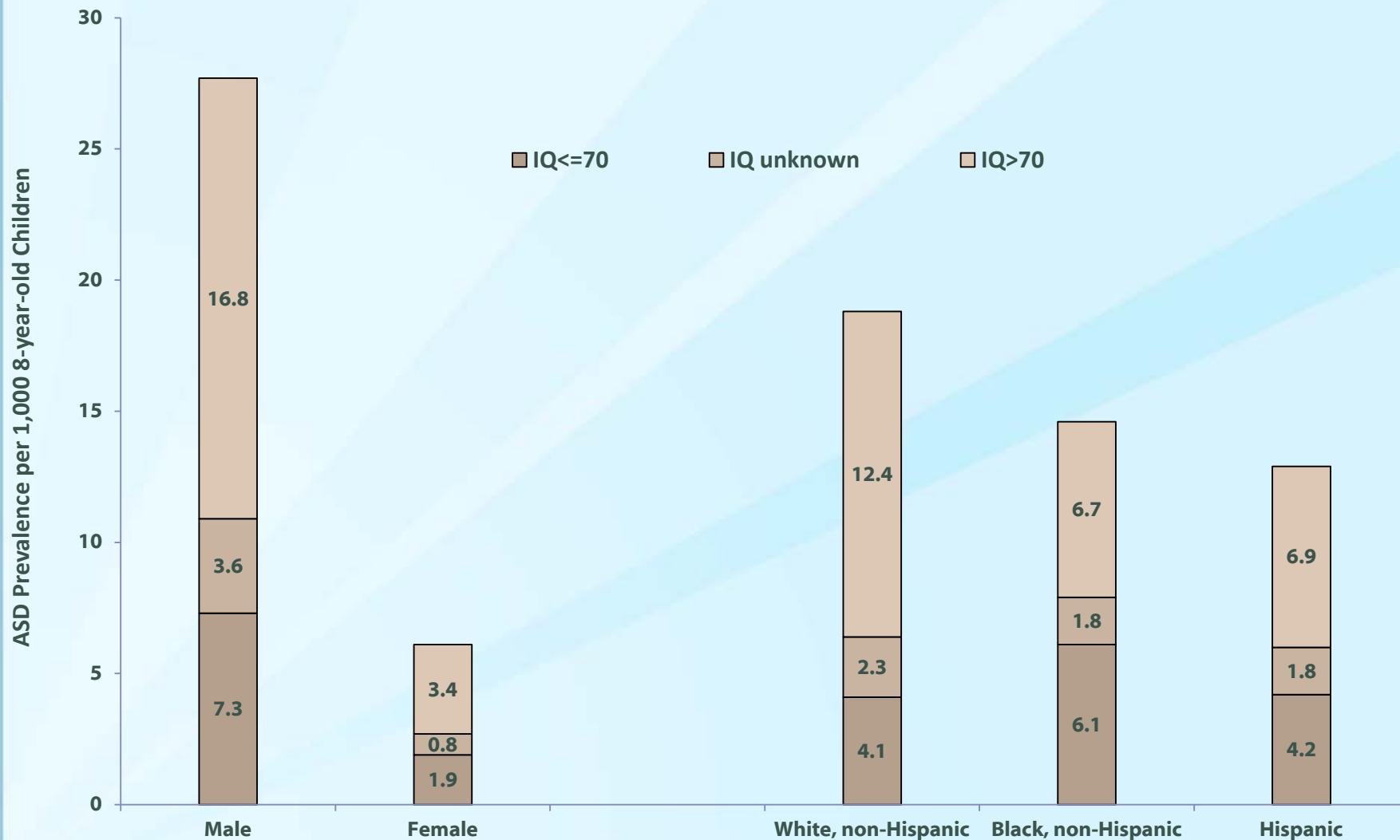


ADDM 2010 ASD Prevalence among Children aged 8 Years

- Among the seven sites with sufficient data on intellectual ability:
 - 31% of children with ASD had IQ scores in the range of intellectual disability (IQ \leq 70)
 - 23% in the borderline range (IQ = 71–85)
 - 46% in the average or above average range of intellectual ability (IQ >85)

Prevalence of ASD by most recent IQ score and by sex and race/ethnicity — ADDM Network, seven sites*, 2010

* Includes sites that had intellectual ability data available for $\geq 70\%$ of children who met the ASD case definition.



Earliest Known ASD Diagnosis

Median Age and Proportion by Diagnostic Subtype

ADDM Network, 2010

(Combining data from 11 sites reporting for 2010 surveillance year)

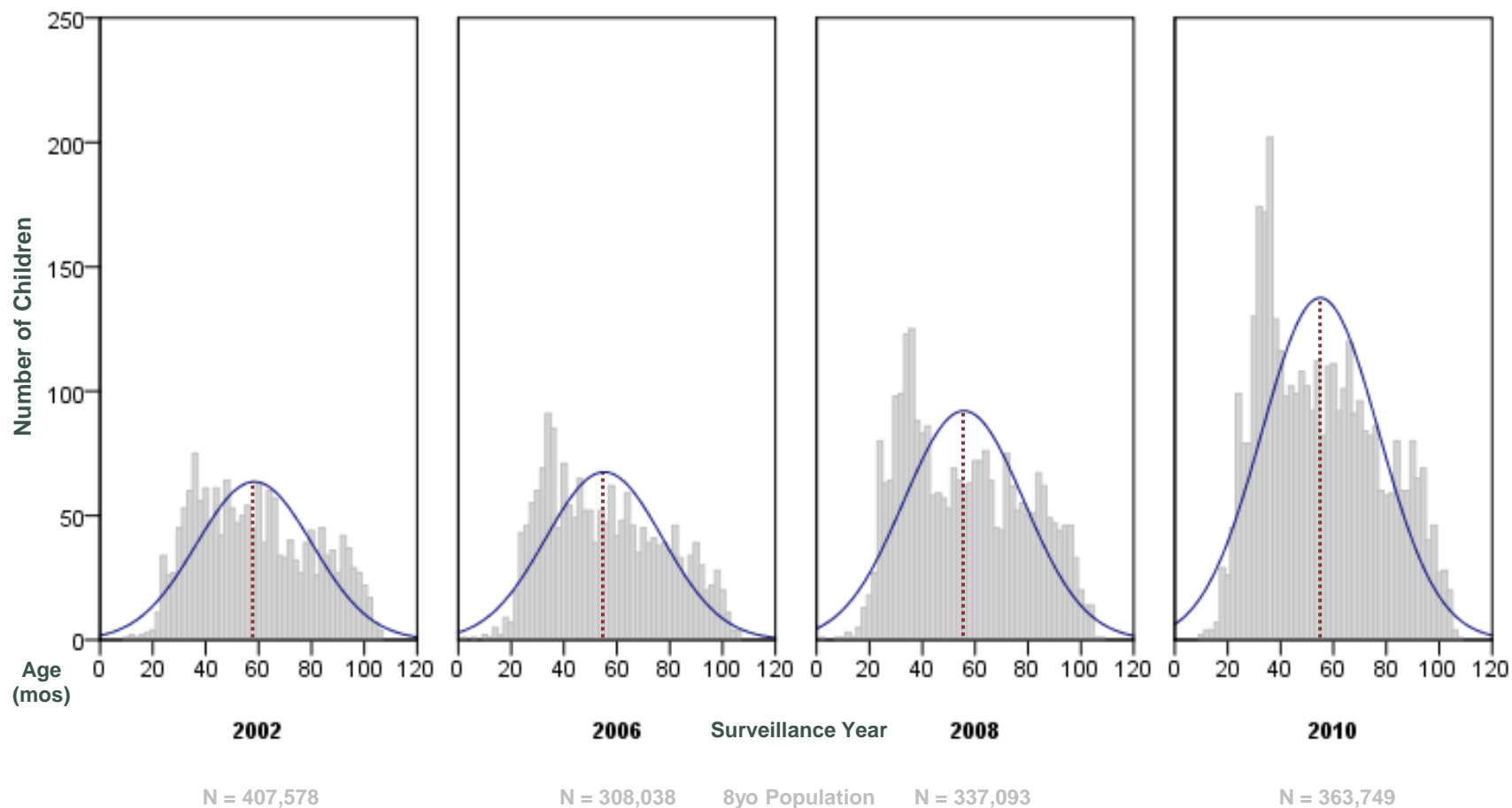
Subtype of Earliest Diagnosis:	Autistic Disorder	ASD/PDD	Asperger Disorder
Distribution of Subtypes:	43%	46%	11%
Median Age of Earliest Diagnosis:	48 Months	50 Months	74 Months

Limitations:

- 1) Diagnostic information obtained from evaluation records may not capture the exact age of each child's earliest diagnosis
- 2) Instability of diagnostic subtypes over time

Age of Earliest Known ASD Diagnosis

Children Aged 8 Years, ADDM Network, 2002-2010



Implications of ADDM Network Findings

- ASD continues to be seen as an urgent public health concern
 - Prevalence estimates continue to increase in most ADDM Network communities as well as in other large-scale studies
- Better identification among certain subgroups
 - Still concerned about disparities in prevalence across sites and among children of minority race/ethnicity, low socioeconomic status
- More children than ever are being recognized as having ASD
 - Still concerned that 20% of surveillance-identified children with ASD are not classified with autism by community providers, while for other children ASD is not recognized as early as it can be

Challenges: Understanding Autism Prevalence

- Wide variation in prevalence estimates across time and space
 - Increased awareness in communities
 - Increased symptoms in population vs. documentation of symptoms
 - Geographic differences in diagnostic practices, program eligibility
 - Changes in policy affecting availability of services
 - No single explanation - multiple factors at play
 - Questions about prevalence among older children and adults
- Changing criteria used to diagnose autism (DSM-IV, DSM-5)
- Limited data on severity of autism symptoms

ADDM Network Publications (Autism)

1. Retention of autism spectrum diagnoses by community professionals: Findings from the ADDM Network, 2000 and 2006. *Journal of Developmental and Behavioral Pediatrics*. June 2012. Wiggins LD, Baio J, Schieve L, Lee LC, Nicholas J, Rice CE.
2. Prevalence of autism spectrum disorders, ADDM Network, 14 Sites, United States, 2008. *MMWR Surveillance Summaries*. March 2012. CDC.
3. Have secular changes in perinatal risk factors contributed to the recent autism prevalence increase? Development and application of a mathematical assessment model. *Annals of Epidemiology*. October 2011. Schieve LA, Rice C, Devine O, Maenner MJ, Lee LC, Fitzgerald R, Wingate MS, Schendel D, Pettygrove S, Van Naarden Braun K, Durkin M.
4. Racial disparities in community identification of autism spectrum disorders over time; metropolitan Atlanta, Georgia, 2000-2006. *Journal of Developmental and Behavioral Pediatrics*. April 2011. Jarquin VG, Wiggins LD, Schieve LA, Van Naarden-Braun K.
5. Socioeconomic Inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS ONE*. July 2010. Durkin MS, Maenner MJ, Meaney FJ, Levy SE, DiGuseppi C, Nicholas JS, Kirby RS, Pinto-Martin JA, Schieve LA.
6. Changes in autism spectrum disorder prevalence in 4 areas of the United States. *Disability and Health Journal*, July 2010. Rice CE, Nicholas J, Baio J, Pettygrove S, Lee L, Van Naarden Braun K, Doernberg N, Cunniff C, Newschaffer C, Meaney FJ, Charles J, Washington A, King L, Kolotos M, Mancilla K, Mervis CA, Carpenter L, Yeargin-Allsopp M.
7. Risk for cognitive deficit in a population-based sample of U.S. children with autism spectrum disorders: Variation by perinatal health factors. *Disability and Health Journal*. July 2010. Schieve LA, Baio J, Rice CE, Durkin M, Kirby RS, Drews-Botsch C, Miller LA, Nicholas JS, Cunniff C.
8. Evaluation of a records-review surveillance system used to determine the prevalence of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. June 2010. Avchen R, Wiggins LD, Devine O, Van Naarden-Braun K, Rice C, Hobson N, Schendel D, Yeargin-Allsopp M.
9. Autism spectrum disorders and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*. May 2010. Levy S, Giarelli E, Lee L, Schieve L, Kirby R, Cunniff C, Nicholas J, & Rice C.
10. Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. *Disability and Health Journal*. April 2010. Giarelli E, Wiggins LD, Rice CE, Levy SE, Kirby, RS, Pinto-Martin J, Mandell D.
11. Prevalence of Autism Spectrum Disorders, ADDM Network, United States, 2006. *MMWR Surveillance Summaries*. December 2009. CDC.
12. Brief report: Prevalence of autism spectrum disorders, ADDM Network, United States, 2004. *MMWR Surveillance Summaries*. December 2009. CDC.
13. Developmental regression in children with an autism spectrum disorder identified by a population-based surveillance system. *Autism*. July 2009. Wiggins LD, Rice CE, Baio J.
14. Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of the American Academy of Child and Adolescent Psychiatry*. May 2009. Shattuck PT, et al.
15. Racial and ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*. March 2009. Mandell D, Wiggins L, Carpenter L, Daniels J, DiGuseppi C, Durkin M, Giarelli E, Morrier M, Nichols J, Pinto-Martin J, Shattuck P, Thomas K, Yeargin-Allsopp M, Kirby R.
16. Advanced Parental Age and the Risk of Autism Spectrum Disorder. *American Journal of Epidemiology*. December 2008. Durkin MS, Maenner MJ, Newschaffer CJ, Lee LC, Cunniff CM, Daniels JL, Kirby RS, Leavitt L, Miller L, Zahorodny W, Schieve LA.
17. Relationships between multiple births and autism spectrum disorders, cerebral palsy, and intellectual disabilities: ADDM Network - 2002 Surveillance Year. *Autism Research*. October 2008. Van Naarden Braun K, Schieve L, Daniels J, Durkin M, Giarelli E, Kirby RS, Lee LC, Newschaffer C, Nicholas J, Pinto-Martin J.
18. A Public Health Collaboration for the Surveillance of Autism Spectrum Disorders. *Paediatric and Perinatal Epidemiology*. March 2007. Rice C, Baio J, Van Naarden Braun K, Doernberg N, Meaney FJ, Kirby R, for the ADDM Network.
19. Prevalence of autism spectrum disorders, ADDM Network, six sites, United States, 2000. *MMWR Surveillance Summaries*. February 2007. CDC.
20. Prevalence of autism spectrum disorders, ADDM Network, 14 Sites, United States, 2002. *MMWR Surveillance Summaries*. February 2007. CDC.
21. Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders, ADDM Network, 14 sites, United States, 2002. *MMWR Surveillance Summaries*. February 2007. Van Naarden Braun K, et al.
22. Examination of the Time Between First Evaluation and First Autism Spectrum Diagnosis in a Population-Based Sample. *Journal of Developmental and Behavioral Pediatrics*. April 2006. Wiggins LD, Baio J, Rice C.

Moving Forward

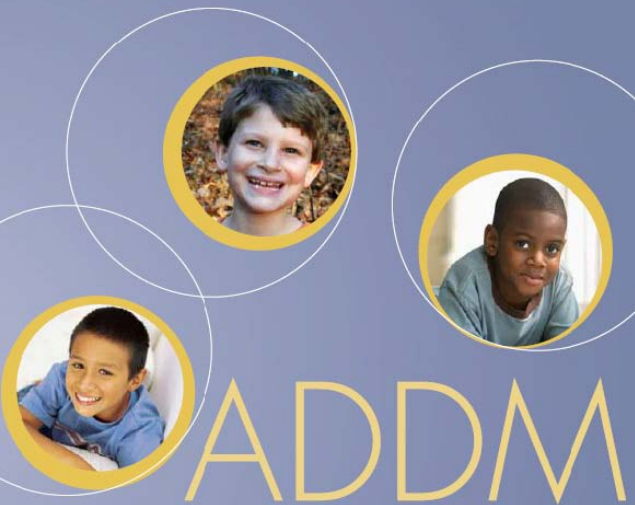
- Continue ongoing surveillance to evaluate temporal trends
- Investigator-initiated analyses
 - Timing and stability of diagnosis
 - Incorporating DSM-5 criteria
 - Socioeconomic disparities
 - Intellectual functioning
 - Geospatial analyses
 - Birth characteristics
 - Parental age
 - Multiple births
 - Gestational age and birthweight

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Community Report on Autism



ADDMM
Autism and Developmental Disabilities Monitoring Network -2012

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

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)

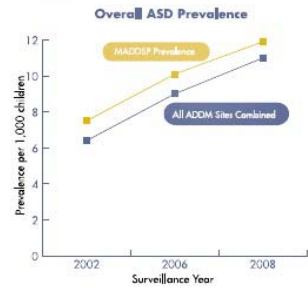
Race/ Ethnicity

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

Overall ASD Prevalence




Surveillance Year	MADDSP Prevalence (per 1,000)	All ADDM Sites Combined (per 1,000)
2002	~7.5	~6.5
2006	~10.0	~8.5
2008	~12.0	~11.0

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

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%

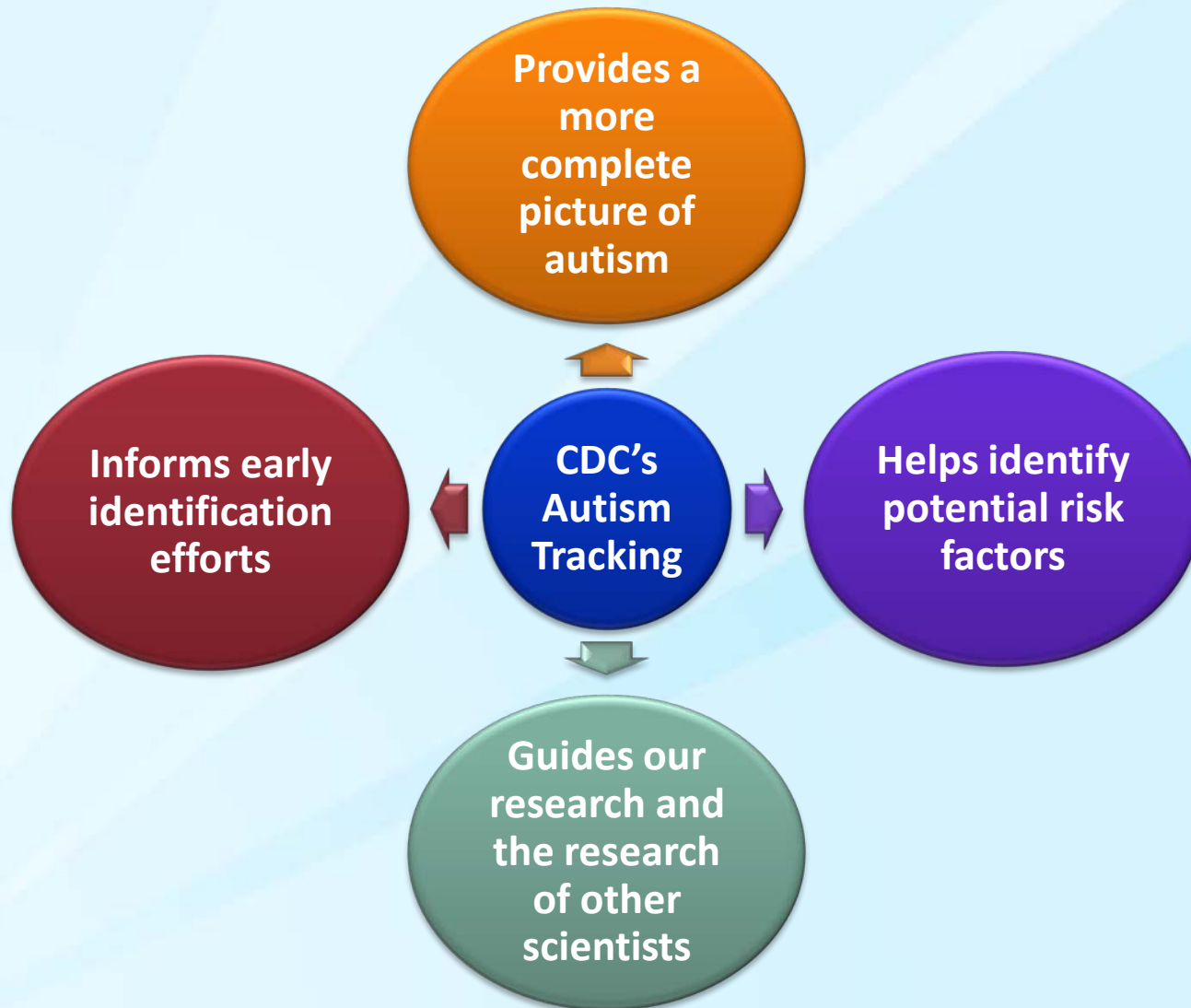


Yellow - Counties in the ADDM Network in 2008

ADDMM Network

To download a copy of the Community Report, please visit www.cdc.gov/autism

More Than Just A Number...



CDC's Autism Public Health Actions

- Surveillance:
 - Autism and Developmental Disabilities Monitoring (ADDM) Network
 - Document and understand changes in ASD prevalence over time
 - Expand monitoring to include younger populations
- Research:
 - Study to Explore Early Development (SEED)
 - Identify factors that may put children at risk for ASD
- Awareness:
 - *Learn the Signs. Act Early.*
 - Improve early identification of developmental delays and ASD
- Collaboration:
 - Interagency Autism Coordinating Committee (IACC)
 - Public/Private coordination of research efforts to address ASD