

Autism Spectrum Disorder: Findings from CDC's Autism and Developmental Disabilities Monitoring Network



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



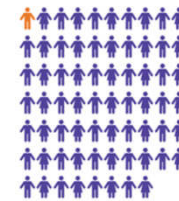
Disclosure

- I have nothing to disclose.

Outline

- Part 1: Recent Data on the Number and Characteristics of Children with Autism Spectrum Disorder
- Part 2: Understanding More About Increasing Prevalence Over Time and the Future Impact of DSM-5
- Part 3: Resources for Parents, Healthcare Providers, and Educators

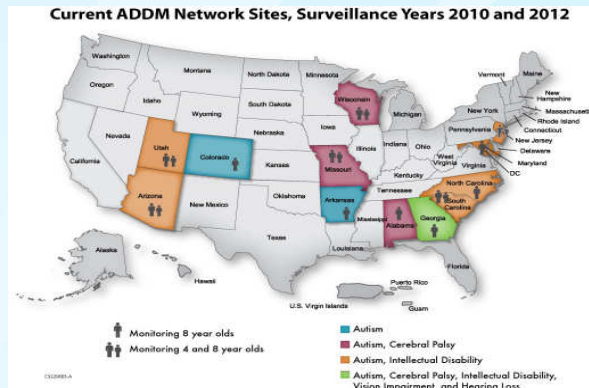
NUMBER OF CHILDREN
IDENTIFIED WITH ASD



1 in 68

**PART 1: NUMBER AND CHARACTERISTICS OF
CHILDREN WITH ASD**

Autism and Developmental Disabilities Monitoring (ADDM) Network



Only collaborative network to monitor ASD and other developmental disabilities in multiple communities across the United States

CDC's Method for Conducting ASD Surveillance



Multisite, multisource, records-based

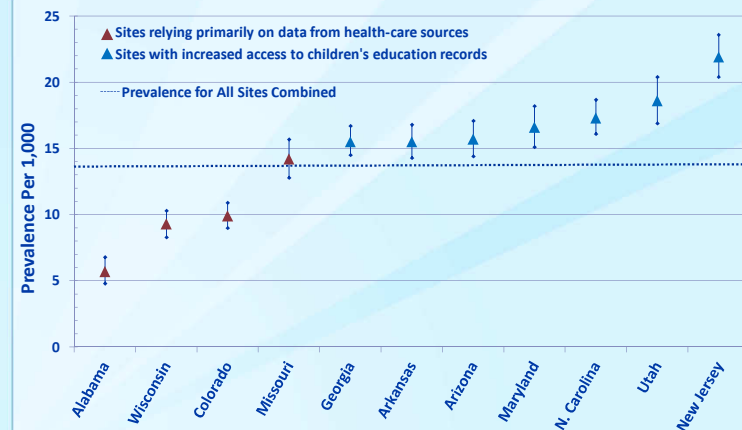
ADDM Network ASD Prevalence Results Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Estimated Prevalence (per 1,000 Children)
2000	1992	6	6.7
2002	1994	14	6.6
2004	1996	8	8.0
2006	1998	11	9.0
2008	2000	14	11.3
2010	2002	11	14.7

About 1 in 68 children (or 14.7 per 1,000 8 year olds) were identified with ASD in 2010

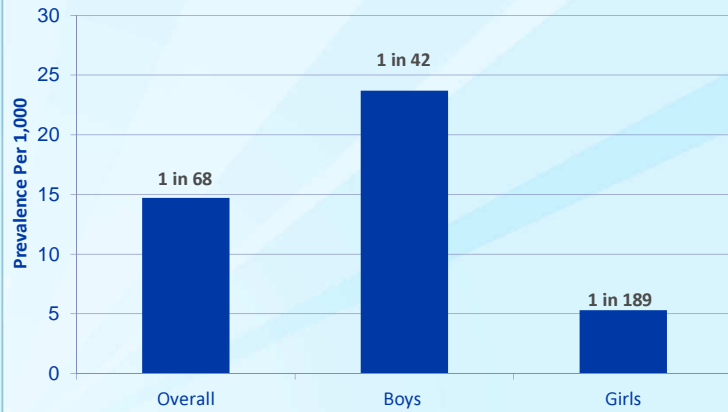
MMWR Surveillance Summaries: February 9, 2007 / 56(SS-1); December 18, 2009 / 58(SS-10); March 30, 2012 / 61(3); March 28, 2014 / 63(SS-02).

Variation in ASD Prevalence among 8 year olds ADDM Network, 2010

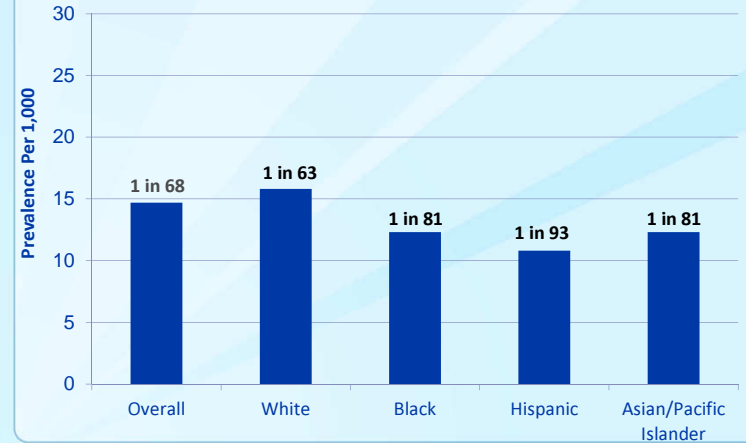


MMWR Surveillance Summaries March 28, 2014 / 63(SS02):1-21

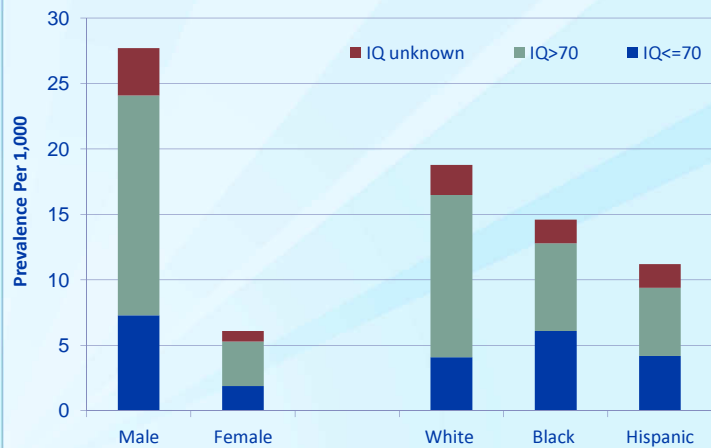
ASD Prevalence among 8 year olds by Sex
ADDM Network, 2010



ASD Prevalence among 8 year olds by Race/Ethnicity
ADDM Network, 2010



ASD Prevalence by most recent IQ score, Sex & Race/Ethnicity
ADDM Network, seven sites*, 2010



Age at Earliest Documented Diagnosis
ADDM Network, 2010

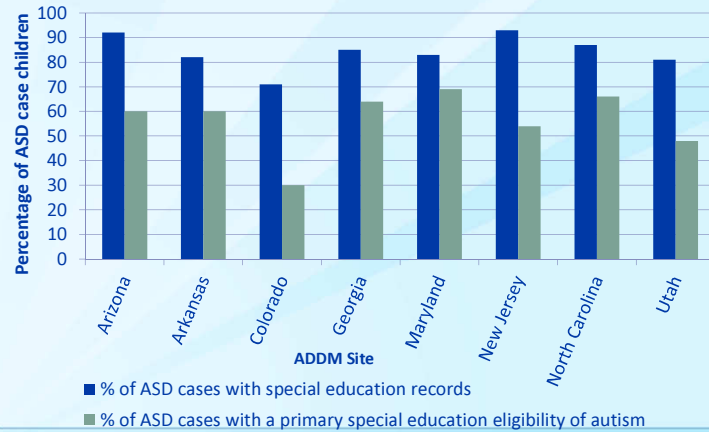
Diagnostic Subtype	Autistic Disorder	ASD/PDD	Asperger Disorder
Median Age	4 years	4 years, 2 months	6 years, 2 months

Most children identified with ASD were not diagnosed until after age 4, even though children can be diagnosed as early as age 2

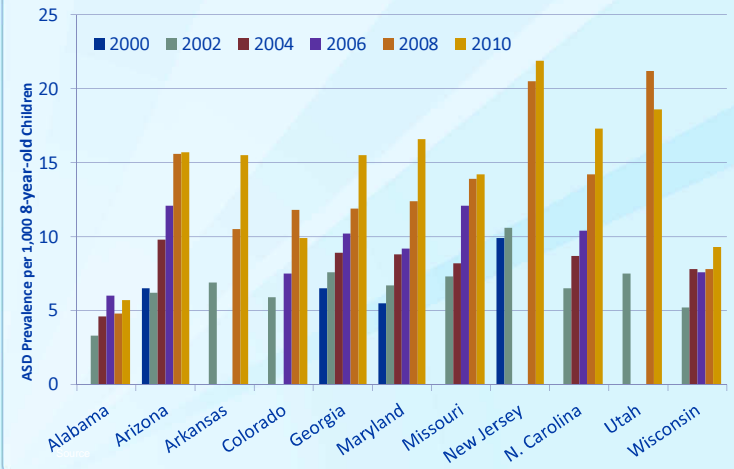
Limitations:

- 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

Receipt of Special Education Services for ASD ADDM Network, 2010



Change in ASD Prevalence Among ADDM Sites



Implications of CDC's ASD Data

- More children are being recognized with ASD, particularly those with average to above average intellectual ability
- Continued disparities in prevalence across sites and minority race/ethnicities
- Some children are still not recognized as early as they could be

How Can the Data Be Used?



How Can the Data Be Used?

"Autism Society affiliates nationwide use CDC data to track changes in overall prevalence, understand diagnostic differences based on gender and ethnicity, and effectively advocate and educate in their communities."

-Jim Ball,
Executive Chairman,
Autism Society of America
board

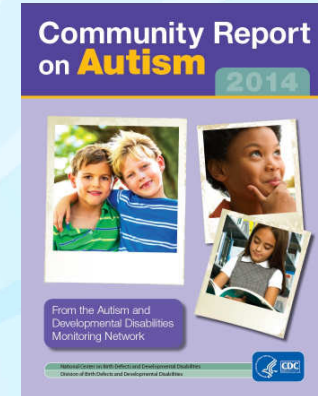
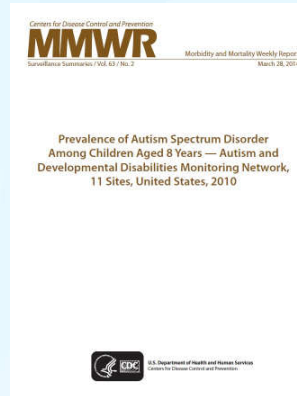
"The numbers in CDC's reports represent real children in every neighborhood across the country."

-Liz Feld
President,
Autism Speaks

"The Autism Science Foundation relies on CDC prevalence data to guide our research on the underlying causes of autism and the treatment needs of individuals with autism."

-Alison Singer,
Co-Founder and President,
Autism Science Foundation

Want to Learn More?



www.cdc.gov/Autism



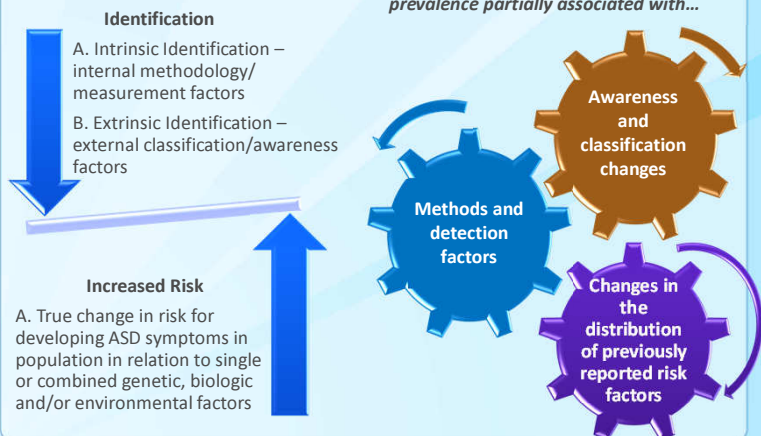
PART 2: INCREASE IN PREVALENCE OVER TIME AND FUTURE IMPACT OF DSM-5

Challenges: Understanding ASD 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
- **Changing criteria used to diagnose ASD (DSM-IV, DSM-5)**
- **Limited data on severity of ASD symptoms**
- **Questions about prevalence among older children and adults**

Evaluating Changes in ASD Prevalence Over Time

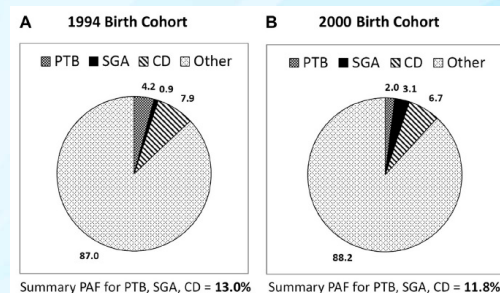
Hypothesis: Increases in observed ASD prevalence partially associated with...



Rice et al., 2013

Population Attributable Fractions for Three Perinatal Risk Factors for Autism, 2002 and 2008, ADDM Network

- About **12-13%** of ASD prevalence among children in multiple U.S. communities was related to being born preterm birth (PTB), small for gestational age (SGA), and/or by Cesarean delivery (CD).



Schieve et al., 2014

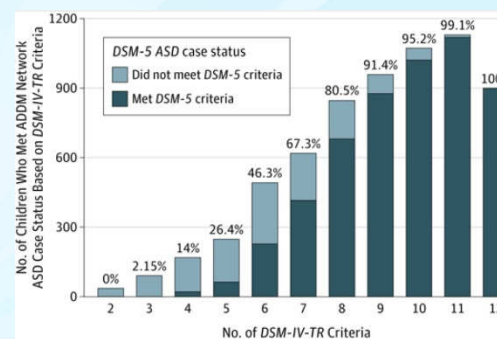
DSM-5: Updated Definition and Diagnostic Criteria for ASD

- Diagnosis based on behavioral symptoms—definition and diagnostic criteria set forth in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*
 - DSM-5 (2013): Autism Spectrum Disorder
- What's new about DSM-5...
 - No ASD "subtypes"
 - Must have 5 of 7 criteria across 2 domains
 - Social Communication domain (3 of 3 req'd sx)
 - Repetitive/Restricted domain (2 of 4 req'd sx)
 - Some of the DSM-5 criteria combine multiple DSM-IV-TR criteria
 - Historical symptoms count toward diagnosis
 - No more strict age requirements

APA, 2000.; APA, 2013

Potential Impact of DSM-5 on ASD Prevalence

- Initial analysis using data from communities across the U.S. found that autism prevalence estimates might be lower using the current DSM-5 criteria compared with using the previous DSM-IV-TR criteria.
 - Many of the children who met DSM-IV-TR criteria but did not meet DSM-5 criteria were missing only one of the necessary symptoms to meet DSM-5 criteria.



Maenner et al., 2014



PART 2: CDC RESOURCES

Importance of Early Identification

- ❑ ADDM Network data show that most children identified with ASD were diagnosed after age 4, even though ASD can be diagnosed as early as age 2
- ❑ Most powerful tool we have now to make a difference in the lives of children with ASD = *early identification and connection to appropriate services and supports*

Resources

- ❑ CDC's *Learn the Signs. Act Early.* program provides **free tools** to help every parent track their child's development and **free resources** for doctors and educators
- ❑ Visit www.cdc.gov/ActEarly



Conclusions

- ❑ **CDC data show that more children are being identified with ASD than ever before**
 - Updated estimates are important for raising awareness, planning for services, developing appropriate policies, and informing research
- ❑ **Understanding ASD prevalence change is complicated – no single explanation**
 - Identification factors are significant, but are they sufficient?
 - Much work needs to be done to obtain data and develop methods to evaluate the multiple, overlapping identification and risk factors contributing to the change in prevalence
- ❑ **CDC's ADDM Network will be able to track the impact of DSM-5 on prevalence over time**

Acknowledgements

- Thank you to the dedicated, creative, and hard-working staff at each ADDM Network site!
- Thank you to our community partners that support our activities—we could not do this without you!



Thank You!

For more information please contact Centers for Disease Control and Prevention

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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.

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