

# Using Data to Identify Disparities in Autism Prevalence and Access to Services

Maureen Durkin, PhD, DrPH

SPHARC Peer-to-Peer Exchange

April 16, 2019



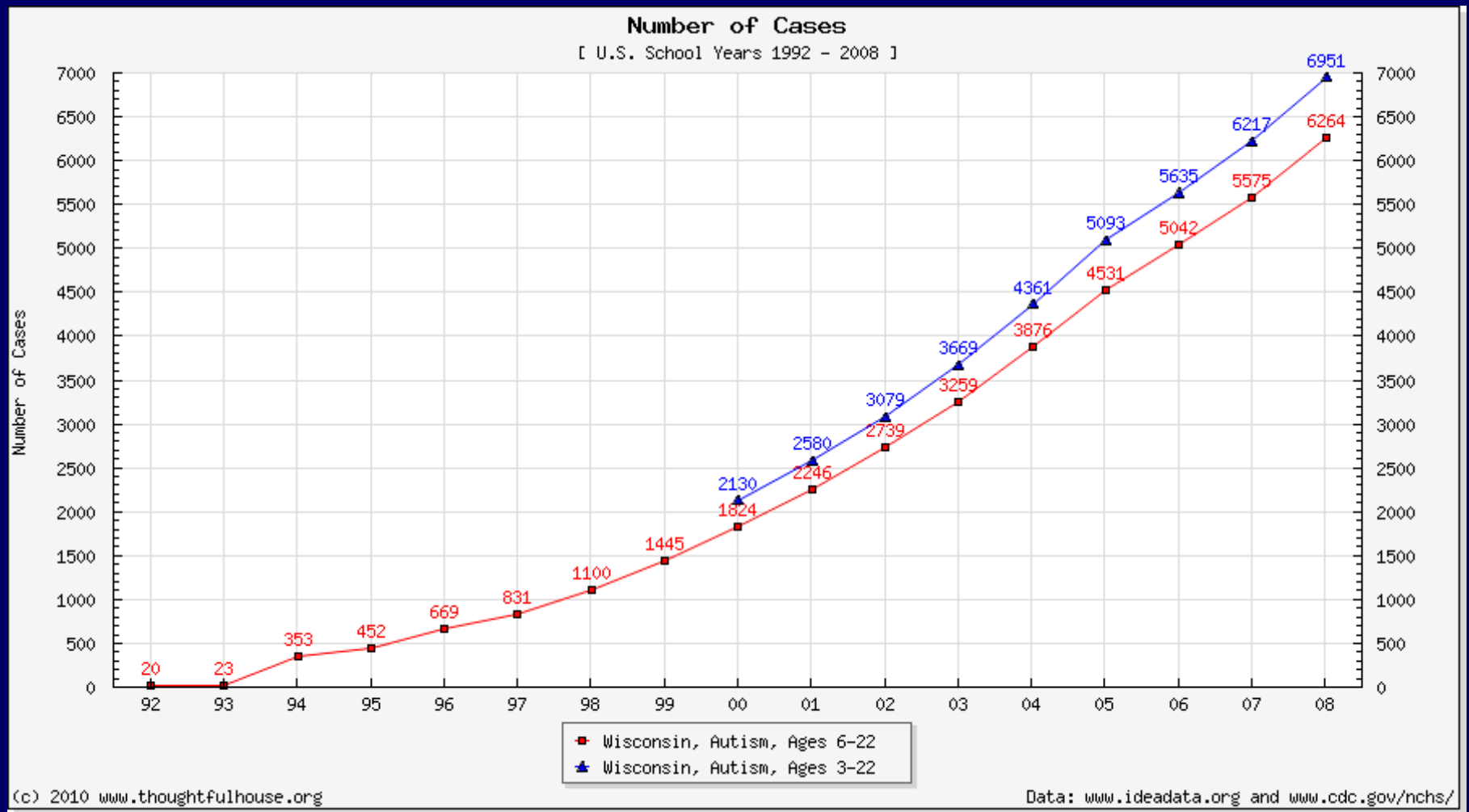
# Epidemiology: The Basic Science of Public Health

- The study of the frequency & distribution of diseases, disability or other health outcomes in *populations*
- A basis for determining
  - Prevalence, incidence and impacts
  - Health disparities
  - Service needs
  - Causes and risk factors
  - Natural history
  - Effectiveness & cost-effectiveness of treatments
  - Public health policy

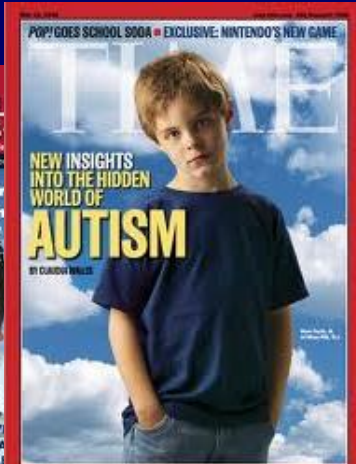
### Autism and Developmental Disabilities Monitoring (ADDMM) Network Sites, Tracking Years 2014 and 2016



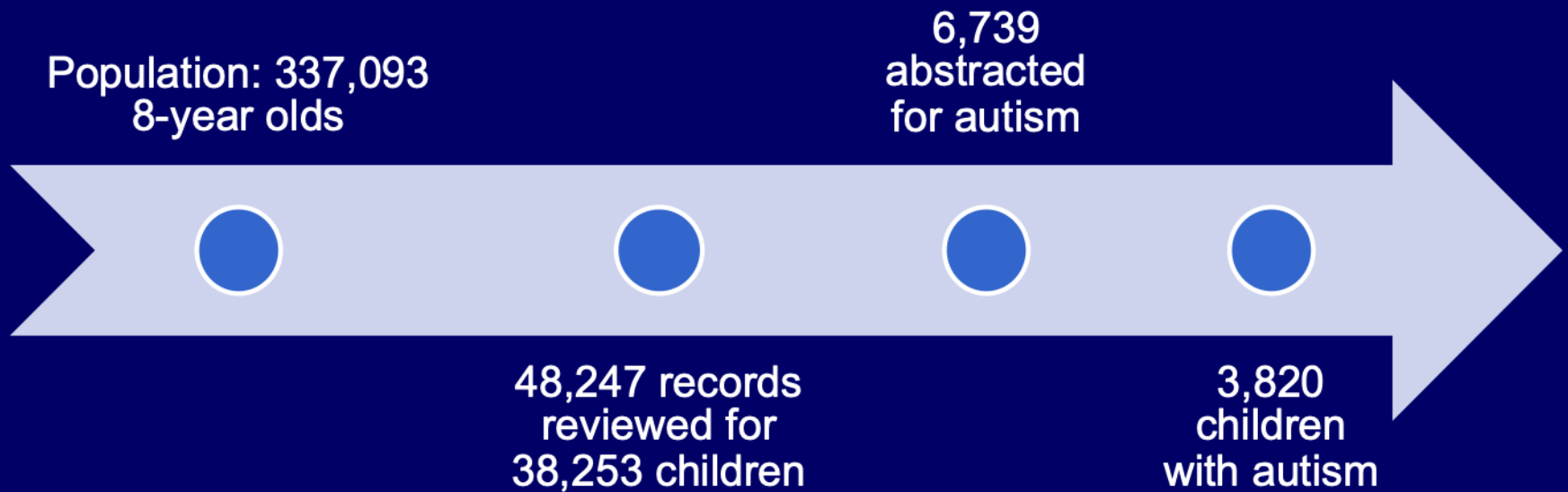
# Number of children with autism in Wisconsin: special education enrollment, 1992-2008



# Concerns Over Increases in Autism...



# Population and Sample, 2008



# Autism Prevalence in the U.S.

Centers for Disease Control and Prevention  
**MMWR**

Morbidity and Mortality Weekly Report

Surveillance Summaries / Vol. 63 / No. 2

March 28, 2014

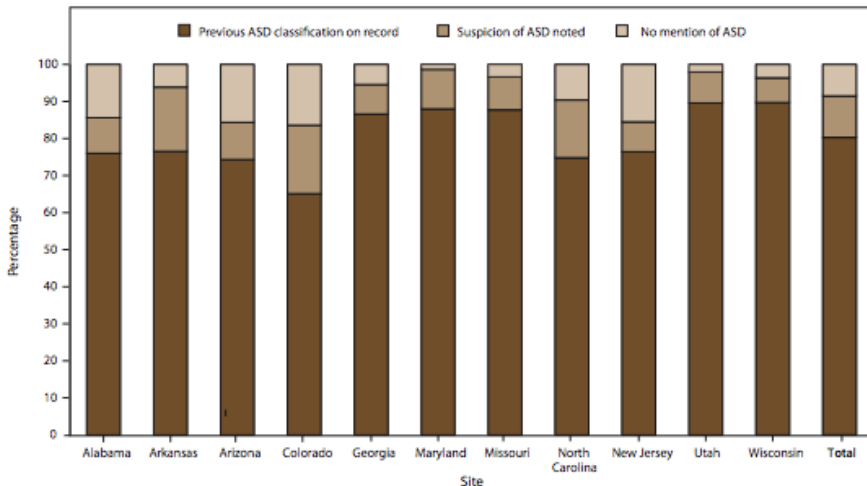
Centers for Disease Control and Prevention  
**MMWR**  
 Morbidity and Mortality Weekly Report  
 Surveillance Summaries / Vol. 61 / No. 3  
 March 30, 2012

Prevalence of Autism Spectrum Disorders —  
 Autism and Developmental Disabilities Monitoring  
 Network, 14 Sites, United States, 2008



## Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010

FIGURE 5. Percentage of children with autism spectrum disorder at age 8 years who had previous autism spectrum disorder classification on record, suspicion of the disorder noted, or no mention of the disorder, by site — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010



**MMWR**

Morbidity and Mortality Weekly Report

[www.cdc.gov/mmwr](http://www.cdc.gov/mmwr)

Surveillance Summaries

December 18, 2009 / Vol. 58 / No. SS-10

Prevalence of Autism Spectrum  
 Disorders — Autism and  
 Developmental Disabilities  
 Monitoring Network,

# Prevalence of Autism Spectrum Disorder (ASD) Among 8 Year-Old Children, U.S.

CDC's ADDM Network, 2000 – 2014

Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites	Prevalence per 1,000 (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 (8.7-21.9)	1 in 68
2012	2004	12	14.6 (8.2-24.6)	1 in 68
2014	2006	11	16.8 (13.1-29.3)	<b>1 in 59</b>

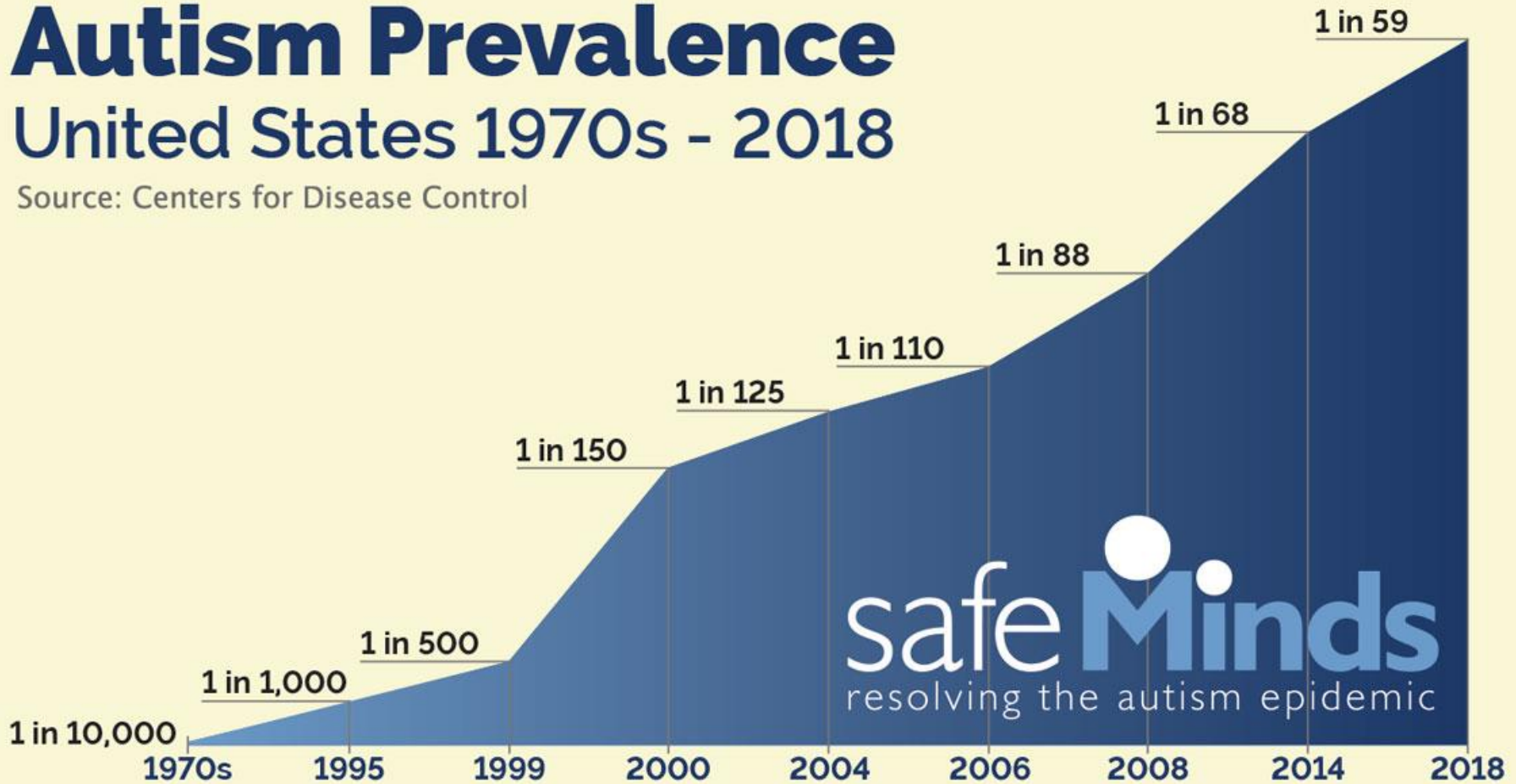
<http://www.cdc.gov/ncbddd/autism/data.html>



# Autism Prevalence

## United States 1970s - 2018

Source: Centers for Disease Control



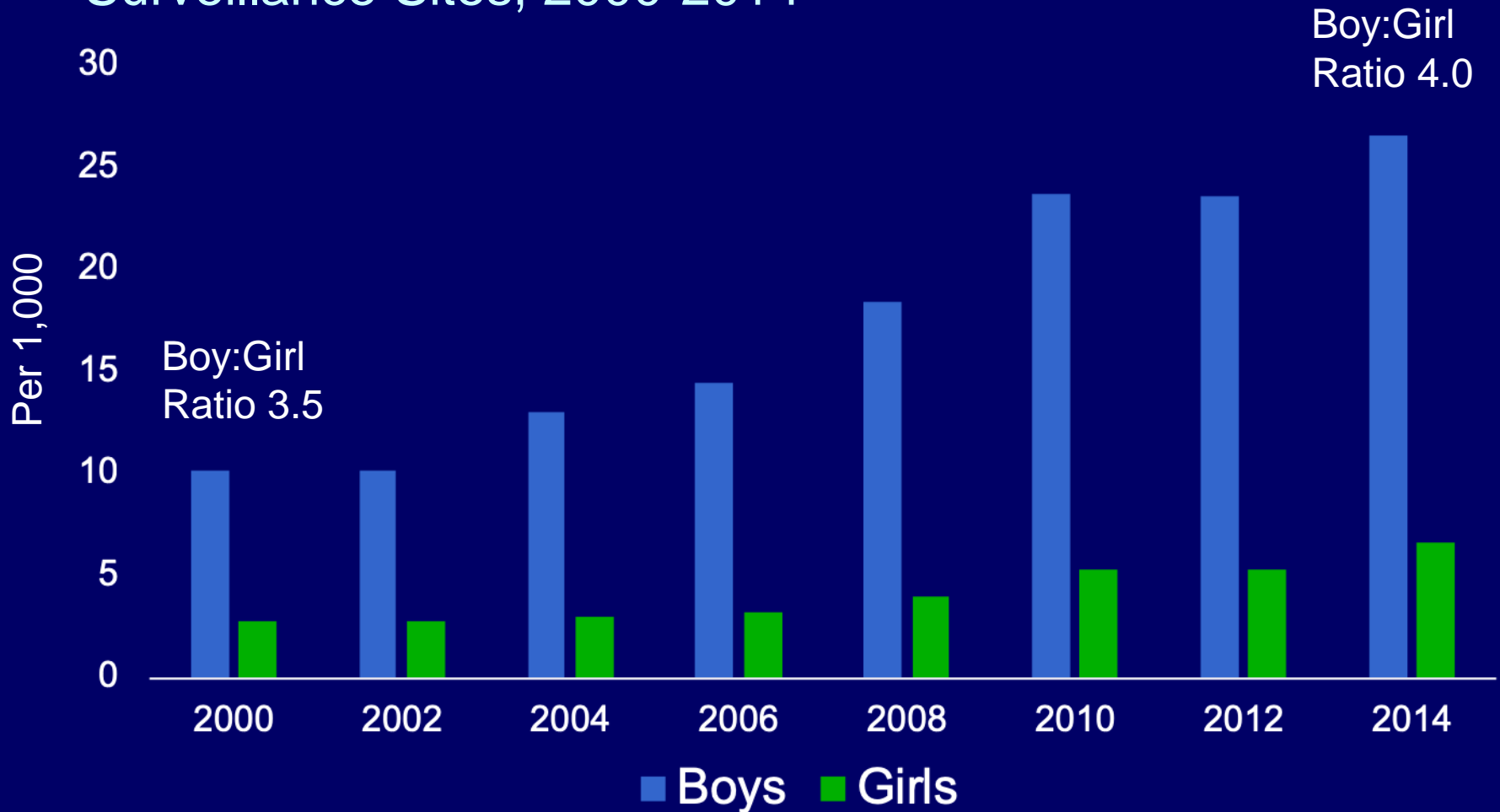
SafeMinds advocacy priorities are based on the following guiding principles:

- *Autism is a national emergency*
- *Autism is a treatable, dynamic multi-organ disease process*
- *Federal research focus on causation must shift from genetics to environment, while accounting for the interplay of genes and the environment, and its effect over time*
- *Research agenda must be driven by leveraged public-private partnerships*

**Autism: a novel form of mercury poisoning**

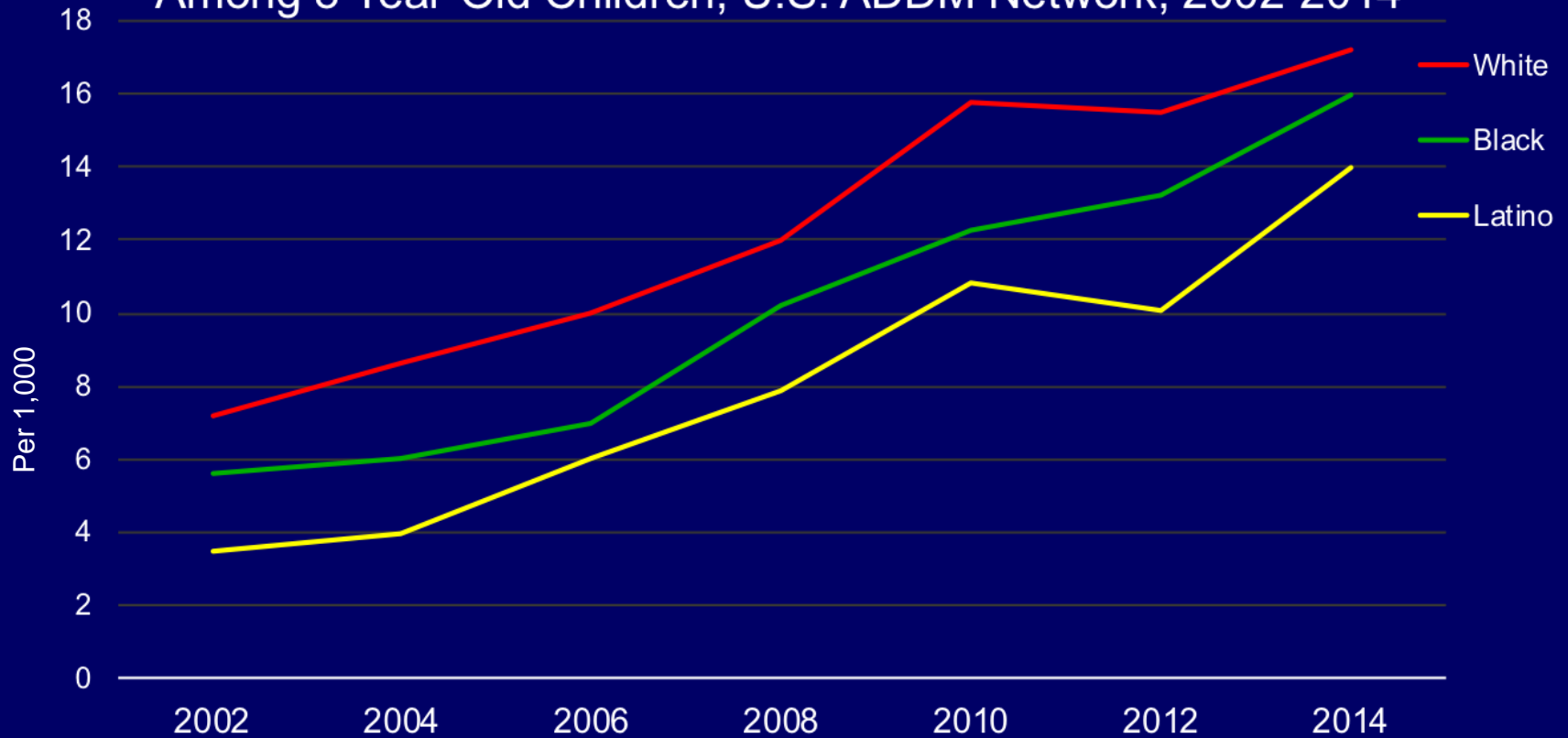
<https://safeminds.org/news/u-s-autism-prevalence-rate-soars-to-1-in-59-children/>

# Trends in the Prevalence (per 1,000) of ASD Among 8 Year-Old Children by Sex, U.S. ADDM Network Surveillance Sites, 2000-2014



Sources: CDC's ADDM Network ASD prevalence reports, MMWR, published 2007-2018.

# Racial/Ethnic Disparity in Prevalence (per 1,000) of ASD Among 8 Year-Old Children, U.S. ADDM Network, 2002-2014



Sources: CDC's ADDM Network ASD prevalence reports, MMWR, published 2007-2018.

# Possible explanations of the increase in autism prevalence

- Expansion of diagnostic criteria
- Gradual adoption of autism as a special education reporting category since 1992
- Increased awareness, training, services
- Improved screening & diagnostic tools
- Changes in diagnostic practices:
  - Diagnostic substitution
  - Diagnostic accretion
  - Expansion of developmental screening (AAP 2006)
- Change in risk factors

# A Snapshot of Autism Spectrum Disorder in Wisconsin



Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.

**1.4%**  
is lower than  
the average percentage  
identified with ASD in 2014  
**1.7% in all ADDM sites**



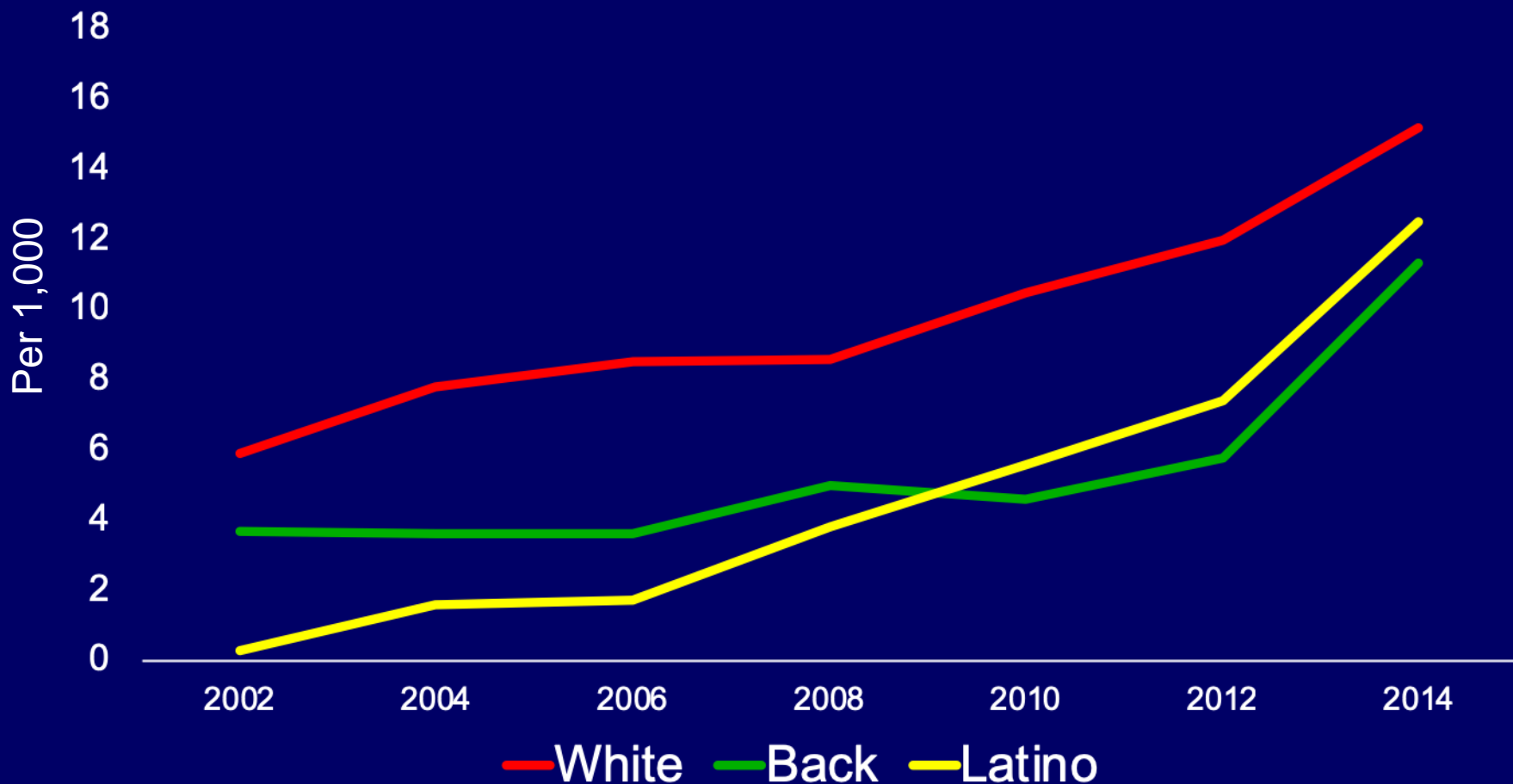
**1 in 71**  
8-year-old children  
were identified with ASD  
by WISADDS in 2014

## Community Report on Autism 2018

~14,000 school age children

<https://www.cdc.gov/ncbddd/autism/addm.html>

# Trends in the Prevalence (per 1,000) of ASD Among 8 Year-Old Children by Race and Ethnicity, **Wisconsin** ADDM Network Surveillance Site, 2002-2014



Sources: CDC's ADDM Network ASD prevalence reports, MMWR, published 2007-2018.

# Autism and Socioeconomic Status (SES)

Leo Kanner

## *Autistic Disturbances of Affective Contact, 1943*

**S**INCE 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits—and, I hope, will eventually receive—a detailed consideration of its fascinating peculiarities. In this place, the limitations neces-

arrangements.

There is one other very interesting common denominator in the backgrounds of these children. *They all come of highly intelligent families.* Four fathers are psychiatrists, one is a brilliant lawyer, one a chemist and law school graduate employed in the government Patent Office, one a plant pathologist and a professor of forestry, one an advertising copy writer who has a graduate degree and has studied in three universities, one is a mining engineer and a business man. Nine of the eleven mothers are college graduates, two have only high-school education, one was secretary in a large office and the other ran a theatrical booking office in New York. Among the others, there was a free-lance writer, a physician, a graduate nurse, and Frederick's mother was successively a secretary, the director of secretarial studies in a girls' school, and a teacher. Among the grandparents and collaterals there are many physicians, writers, journalists, and students of art. All but three of the children represented either in *Who's Who in America* or in *American Men of Science*, or in both.



*Brit. J. Psychiat.* (1980), 137, 410–417

## Childhood Autism and Social Class: A Question of Selection?

By LORNA WING

ВАН ГОРНА ВИНГ

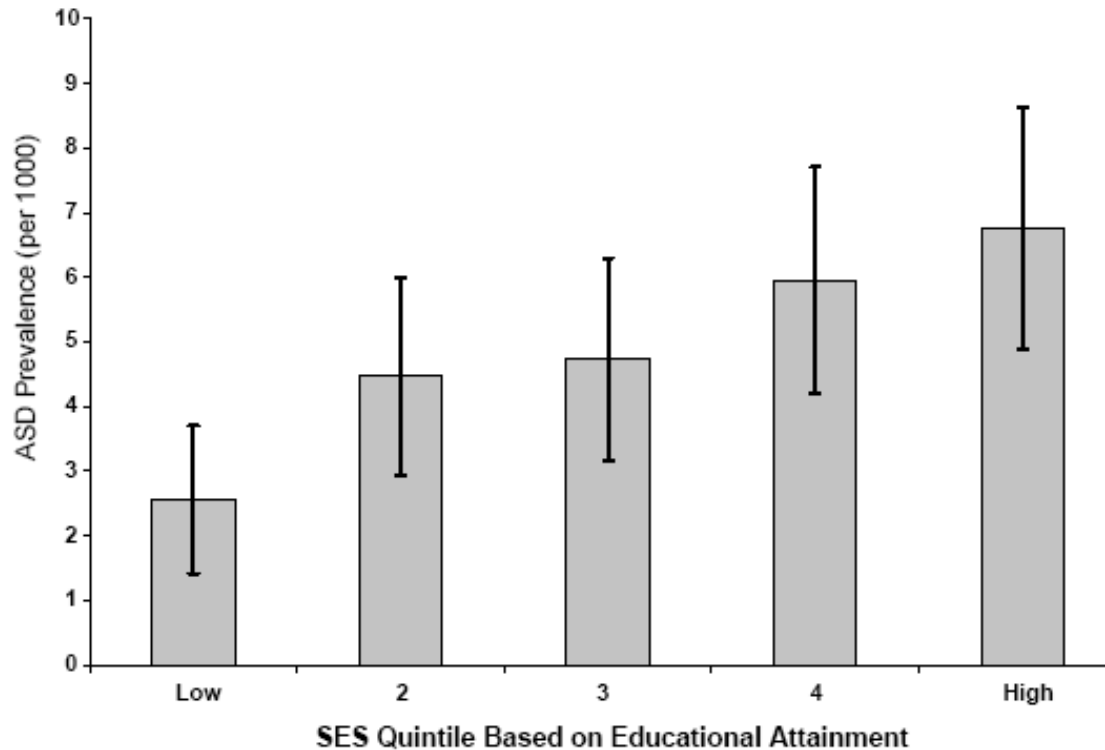


. But it remains true that a knowledgeable and determined parent of an autistic child is more likely to obtain an informed diagnosis.



## Socioeconomic Disparity in the Prevalence of Autism Spectrum Disorder in Wisconsin

*Matthew J. Maenner, BS; Carrie L. Arneson, MS; Maureen S. Durkin, PhD, DrPH*

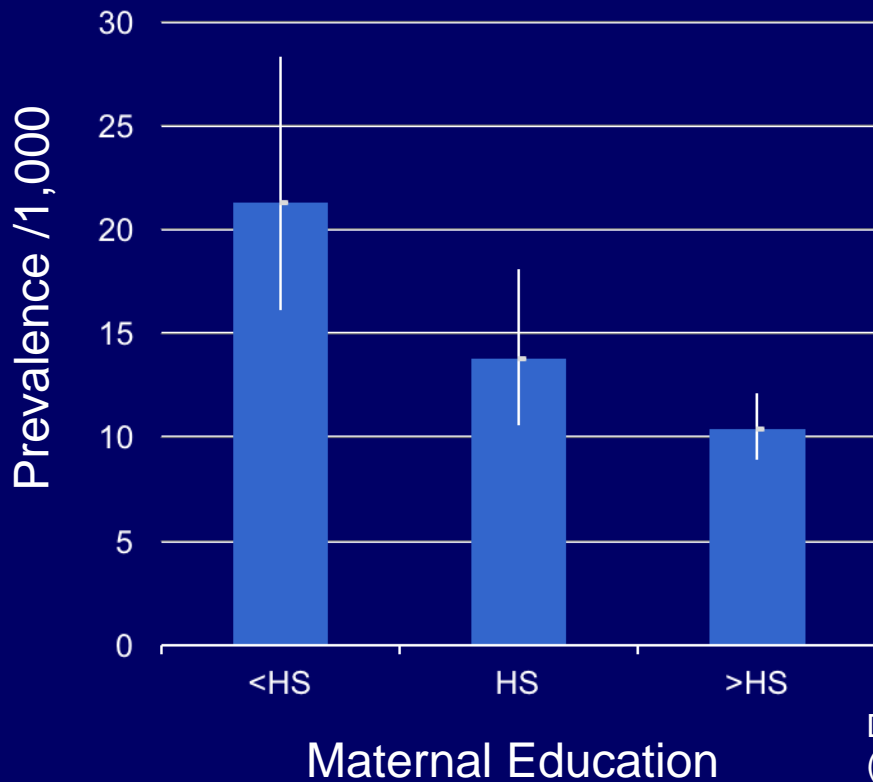


**Figure 1.** Prevalence of Autism Spectrum Disorder (ASD) by Socioeconomic Status (SES). Note: black bars indicate 95% confidence intervals.

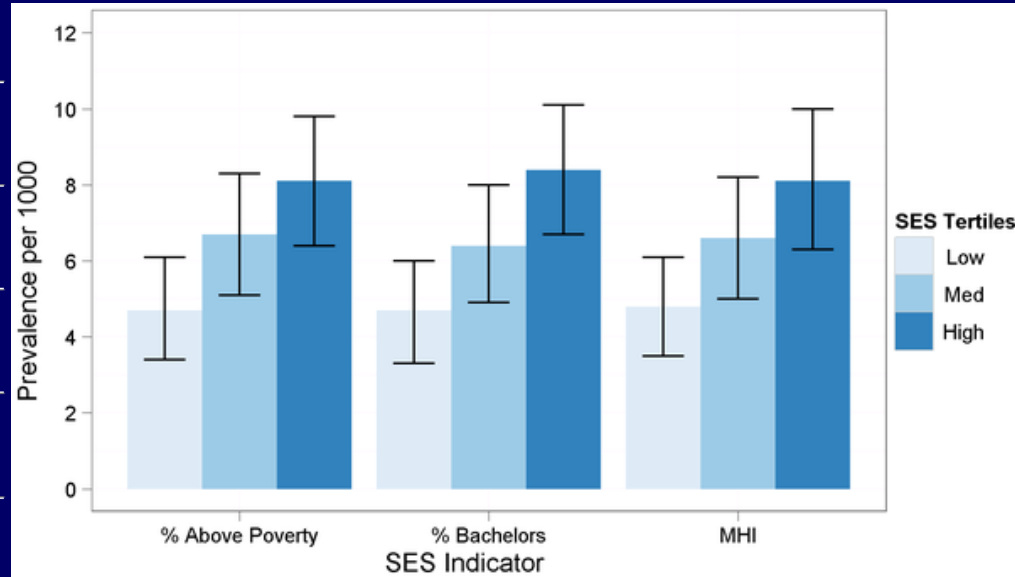
• N = 181 cases, 36,989 children (age 8 years) under surveillance in 2002

Contrast between ASD and other developmental disabilities in the U.S: Low socioeconomic status (SES) is the predominant risk factor for child disabilities generally, but in the US its association with ASD is in the opposite direction.

## ID



## ASD



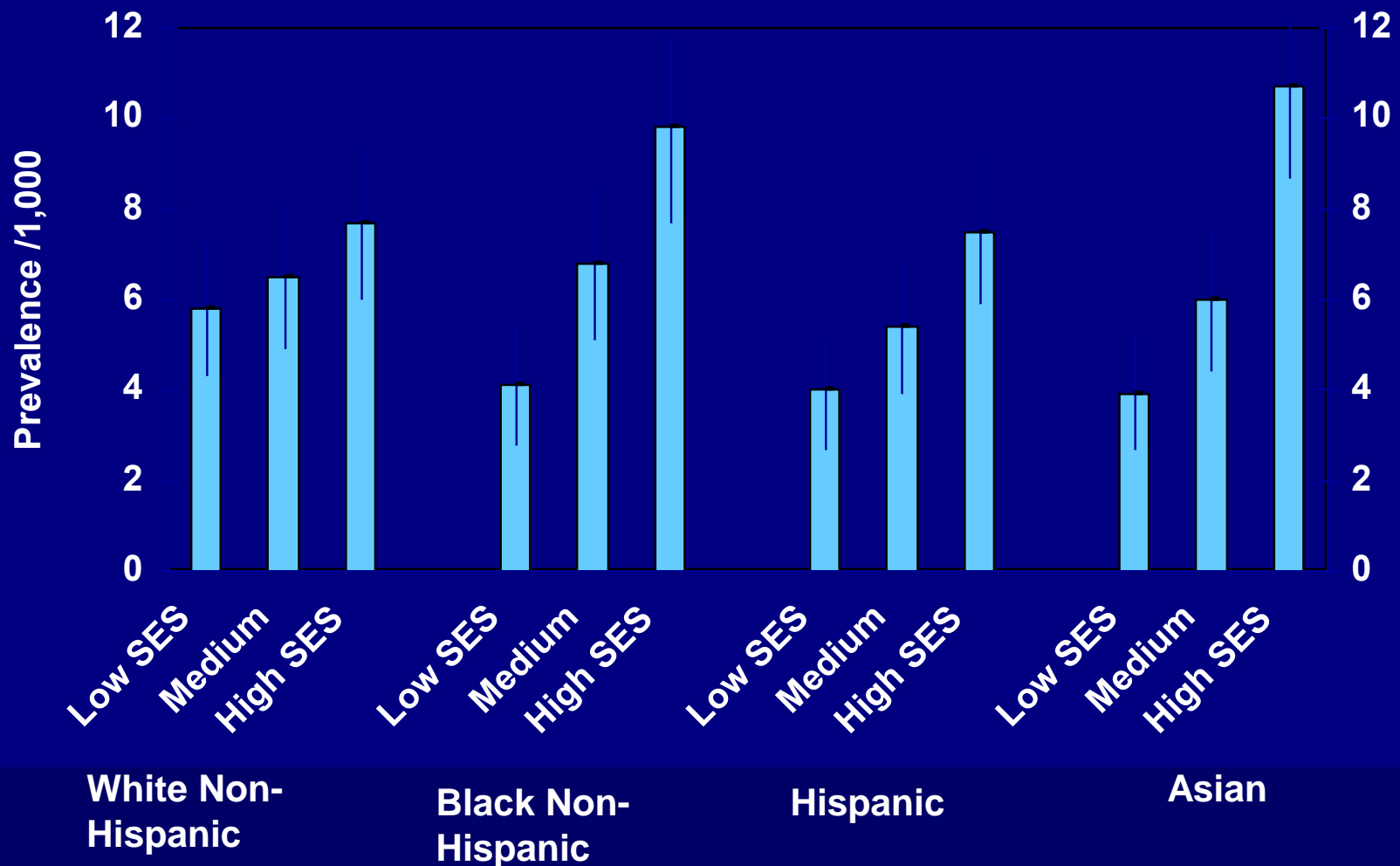
Maenner MJ, et al, *Annals of Epidemiology*, 2016; 26:222-26.  
ID=intellectual disability

Durkin MS, Maenner MJ, Meaney FJ, Levy SE, DiGuseppi C, et al. (2010) Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study. PLoS ONE 5(7): e11551. doi:10.1371/journal.pone.0011551 <http://journals.plos.org/plosone/article?id=info:doi/10.1371/journal.pone.0011551>

# Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study

*PLoS One* 2010

Maureen S. Durkin<sup>1,2,3\*</sup>, Matthew J. Maenner<sup>1,3</sup>, F. John Meaney<sup>4</sup>, Susan E. Levy<sup>5</sup>, Carolyn DiGiuseppi<sup>6</sup>, Joyce S. Nicholas<sup>7</sup>, Russell S. Kirby<sup>8</sup>, Jennifer A. Pinto-Martin<sup>9</sup>, Laura A. Schieve<sup>10</sup>



Based on ADDM data from 12 U.S. states, population of 557,689 8-year-old children in 2002, including 3,680 with ASD.  
SES = Socioeconomic Status

# Implications of SES Gradient

- If the SES gradient is due only to ascertainment bias, this would imply that
  - there are significant SES disparities in access to diagnostic and other services for children with autism in communities across the United States; and
  - current estimates of autism prevalence are inaccurate, with children of low and medium SES being under-identified and underserved relative to those with high SES.

# SES and Clinician Bias:

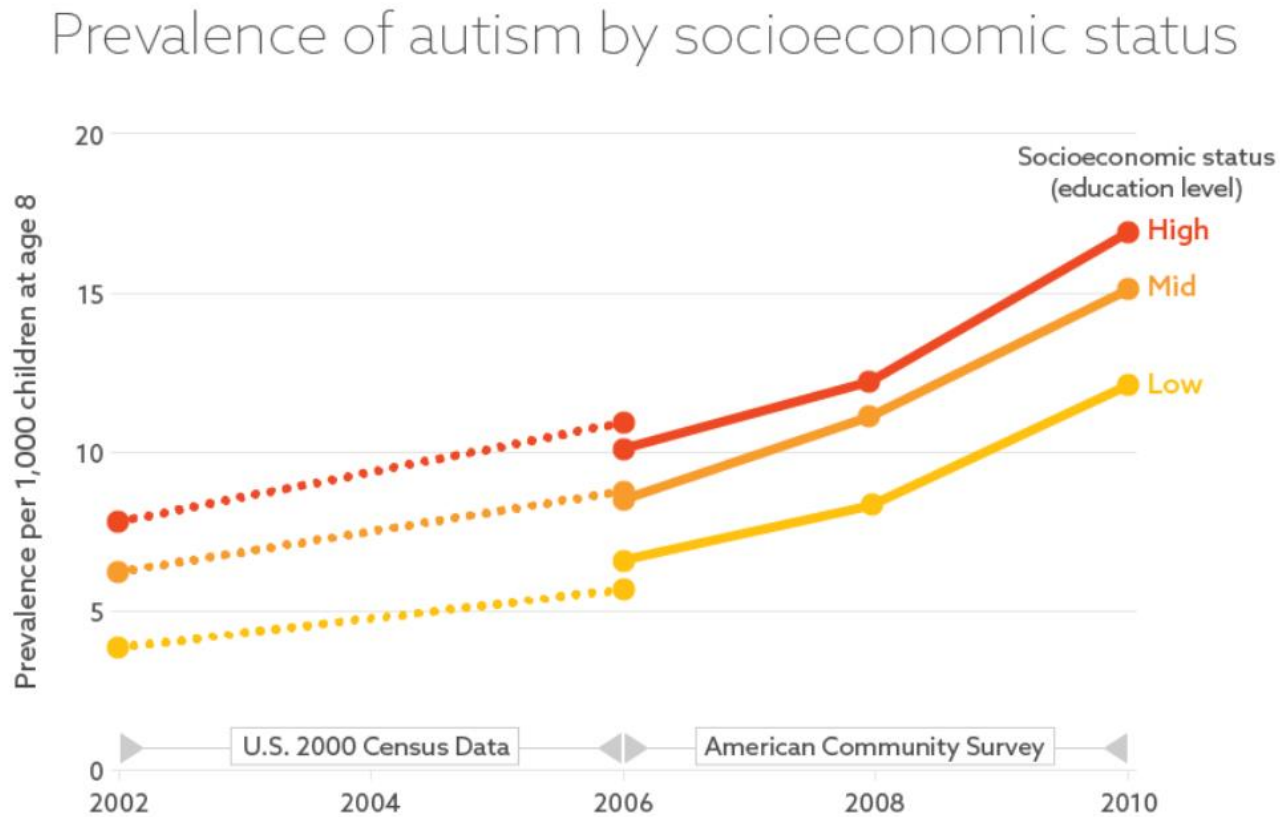
In addition to biased ascertainment resulting from those with higher SES having greater access to diagnostic services, as suggested by Wing, it is possible that bias on the part of clinicians might contribute to ascertainment bias. Cuccuro et al. found that clinicians were more likely to assign autism diagnoses to vignettes of high SES vs. low SES children, all else equal.

Cuccuro ML, et al Professional perceptions of children with developmental difficulties: the influence of race and socioeconomic status. *J Autism Devel Disorders*, 1996; 26(4):461-9.

# Additional Potential Implications of an SES Gradient in ASD Prevalence

- Physical or social environmental exposures for which children living in more advantaged environments might have heightened risks
- Immunological factors (such as those suggested by the “hygiene hypothesis”)
- Other biological factors (for example, those associated with parental age)
- Also possible that the SES association is a result of confounding by unknown factors associated with both high SES and susceptibility to autism

# Persistence of the SES disparity in autism prevalence, 2000-2010, despite more screening and awareness



Spectrum | Autism Research News

<https://spectrumnews.org>

NEWS

Race, class contribute to disparities in autism diagnoses

BY HANNAH FURFARO

20 NOVEMBER 2017

AJPH RESEARCH

## Autism Spectrum Disorder Among US Children (2002–2010): Socioeconomic, Racial, and Ethnic Disparities

Maureen S. Durkin, PhD, DrPH, MPH, Matthew J. Maenner, PhD, Jon Baio, EdS, Deborah Christensen, PhD, Julie Daniels, PhD, Robert Fitzgerald, PhD, Pamela Imm, MS, Li-Ching Lee, PhD, Laura A. Schieve, PhD, Kim Van Naarden Braun, PhD, Martha S. Wingate, DrPH, and Marshalyn Yeargin-Allsopp, MD

# Evidence from Sweden that the ASD-SES association in the US might be due to disparities in access to services

## Parental Socioeconomic Status and Risk of Offspring Autism Spectrum Disorders in a Swedish Population-Based Study

Dheeraj Rai, M.B.B.S., MRCPsych, Glyn Lewis, FRCPsych, Ph.D., Michael Lundberg, M.P.H.,  
 Ricardo Araya, MRCPsych, Ph.D., Anna Svensson, M.Sc., Ph.D.,  
 Christina Dalman, M.D., Ph.D., Peter Carpenter, M.B.Ch.B., FRCPsych,  
 Cecilia Magnusson, M.D., Ph.D.

Parental Socioeconomic Status at Time of Child's Birth	All Autism Spectrum Disorders		
	Cases/Controls 4,709/46,489	Crude OR (95% CI)	Adjusted OR <sup>a</sup> (95% CI)
<b>Household disposable income (individualized)</b>			
Quintile 1 (Lowest)	847/8,151	1.2 (1.1–1.4)	1.3 (1.2–1.5)
Quintile 2	1,121/9,447	1.4 (1.3–1.6)	1.4 (1.3–1.6)
Quintile 3	1,051/9,710	1.3 (1.2–1.4)	1.3 (1.2–1.5)
Quintile 4	878/9,574	1.1 (1.0–1.2)	1.1 (1.0–1.2)
Quintile 5 (highest)	812/9,607	1.0 (Ref)	1.0 (Ref)



# Assessment of racial and ethnic bias in autism spectrum disorder prevalence estimates from a US surveillance system

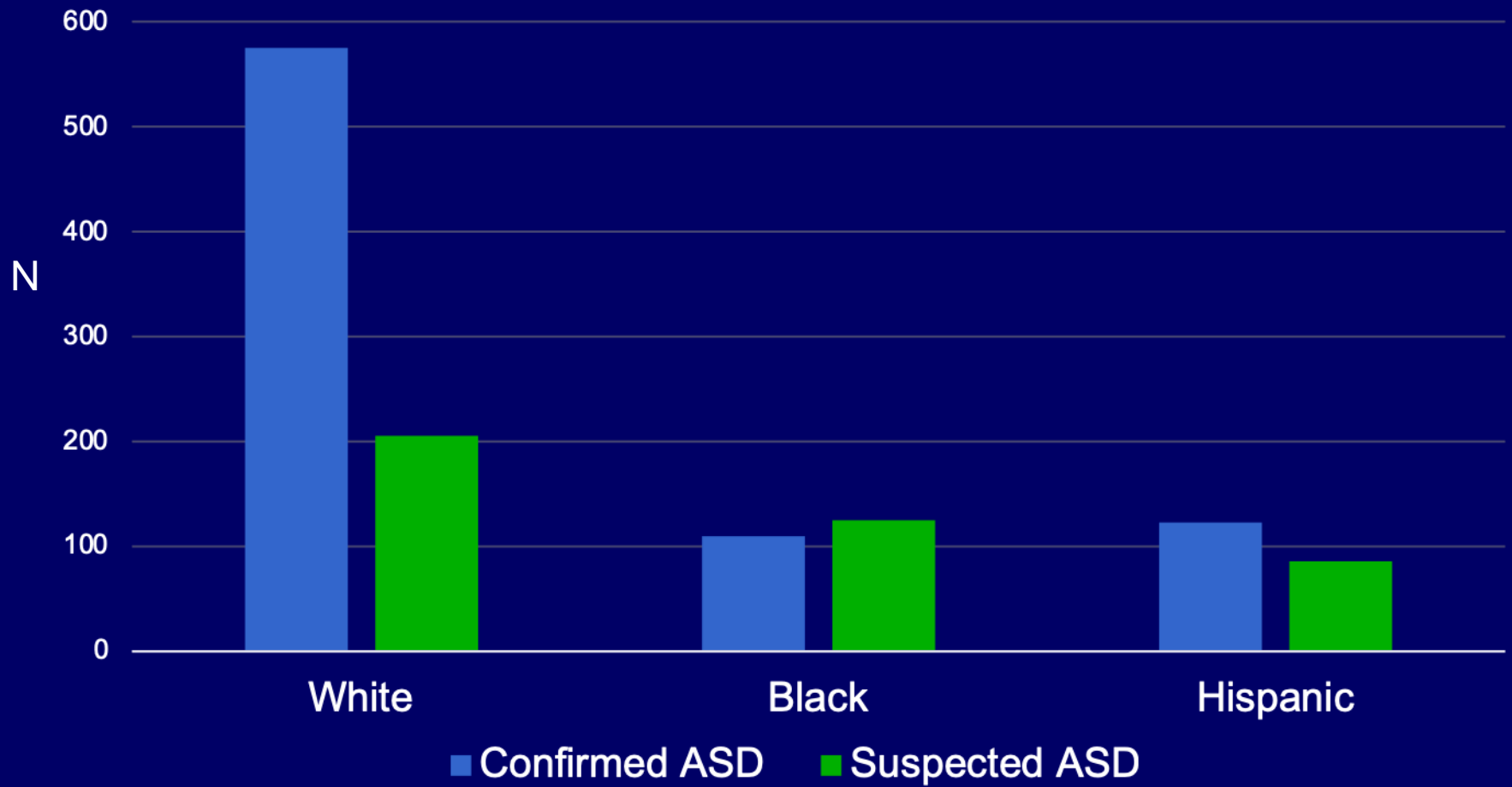
Pamela Imm<sup>1</sup>, Tiffany White<sup>2</sup>  
and Maureen S Durkin<sup>1</sup> 



Autism  
1-9  
© The Author(s) 2019

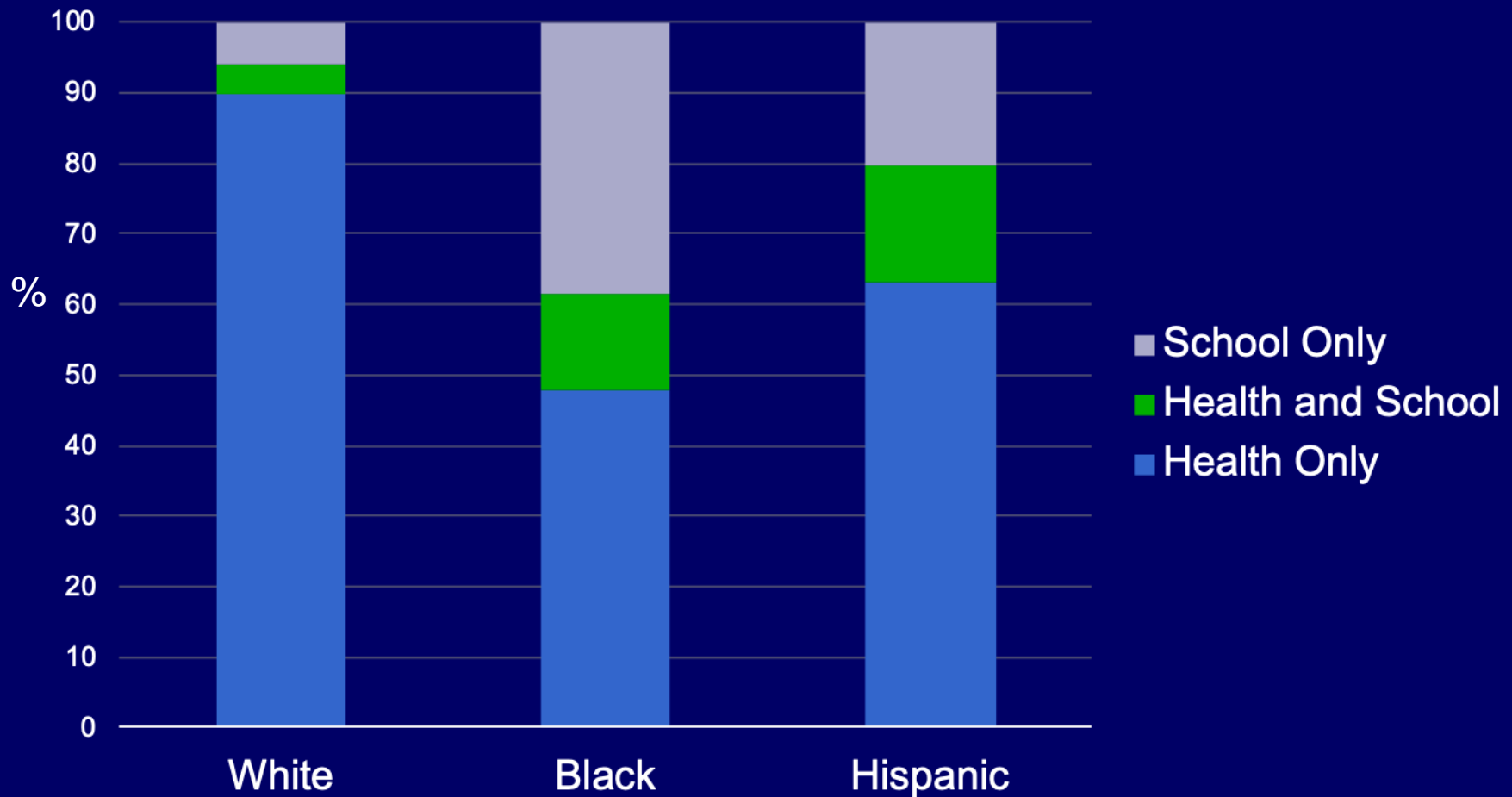
In conclusion, our findings suggest there is under-ascertainment of ASD among Black and Hispanic children in the United States due to disparities in the documentation of developmental concerns and assessments in administrative records. These disparities may contribute to findings of lower ASD prevalence in Black and Hispanic children and may point to the need for strategies to improve health equity and access to developmental assessments, diagnosis and treatment of ASD.

# Wisconsin ADDM: Confirmation of ASD More Likely for White Children than for Black and Hispanic Children



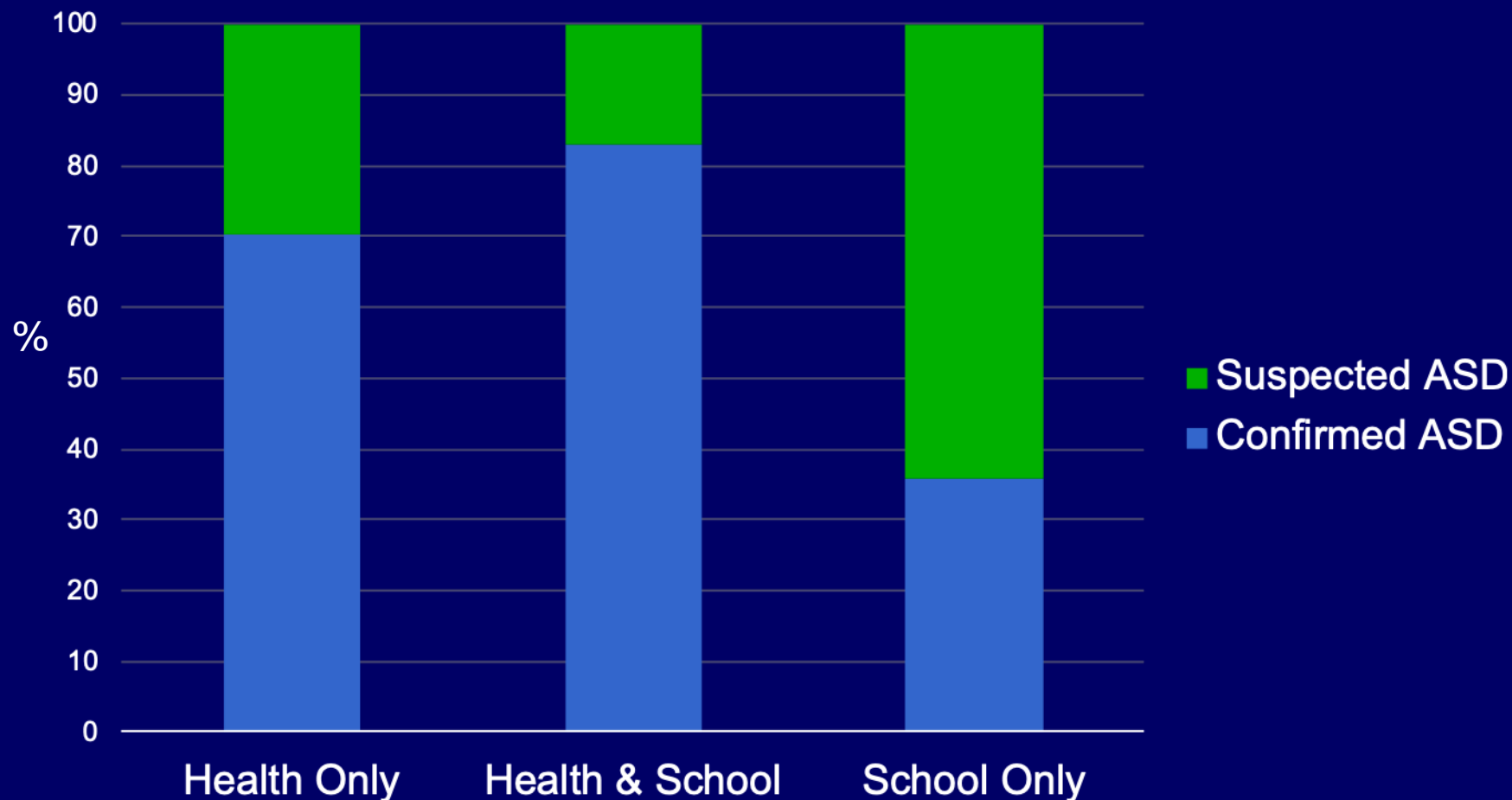
Preliminary data, surveillance years 2012 and 2014

# Wisconsin ADDM: Health Records Documenting ASD More Likely for White Children than for Black and Hispanic Children



Preliminary data, surveillance years 2012 and 2014

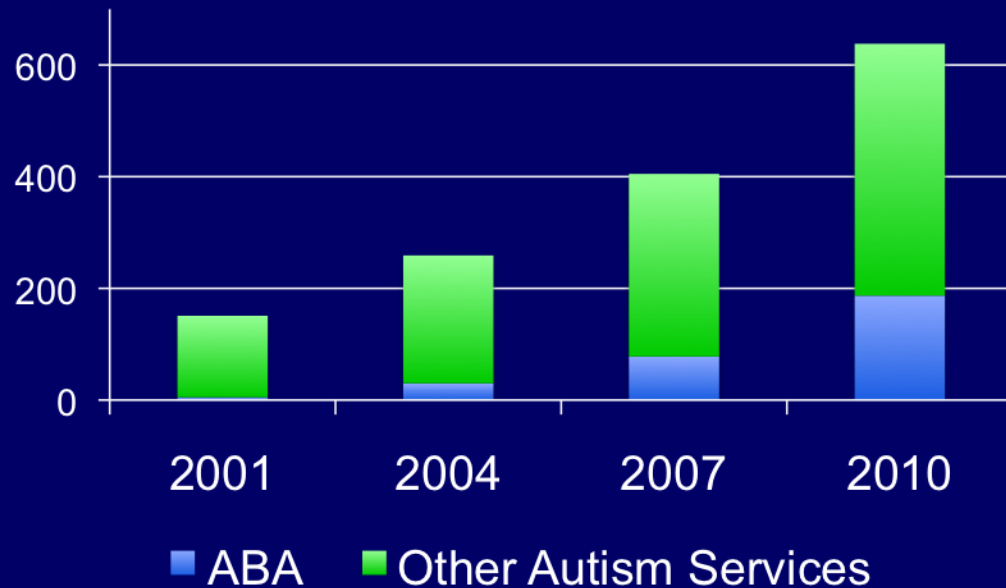
# Wisconsin ADDM: Health Records Documenting ASD More Likely for Confirmed than Suspected ASD Cases



Preliminary data, surveillance years 2012 and 2014

# Costs of Autism

- >\$2,000 for a diagnosis
- >\$50,000/yr for therapeutic services
- Most expensive category of special education
- Lifetime cost of ASD in US: \$3.2 million



(In millions US\$, Source: California Dept of Developmental Services)

# Act Early Wisconsin

## Learn the Signs. Act Early.



## Milestone and Disability Specific

## Fact Sheets

<http://www.actearly.wisc.edu/>

## Milestone Tracker App



**Some signs of development are obvious. Algunas muestras del desarrollo son obvias.**

**Some are not so obvious. Algunas no son tan obvias.**

**It's time to change how we view a child's growth.**

As they grow, children are always learning new things. There are four areas of the brain you should be watching to see what's going on. Because every child develops at his or her own pace, you can't tell how much their skills are growing until you see other children the same age. This is so in public, and if you have any concerns, talk with your child's doctor or nurse.

By the end of 12 months, most children can do this:

- take their shoes or a sock
- walk back or transfer papers
- respond to sound with speech
- make simple words (mama, dada)

By the end of 18 months, most children can do this:

- use simple phrases (bye-bye)
- walk or crawl on uneven ground
- respond to sound with speech
- make simple words (mama, dada)

By the end of 24 months, most children can do this:

- point to interesting objects
- walk or crawl on uneven ground
- use simple phrases (bye-bye)
- make simple words (mama, dada)

By the end of 30 months, most children can do this:

- use simple phrases (bye-bye)
- walk or crawl on uneven ground
- use simple phrases (bye-bye)
- make simple words (mama, dada)

**Why is development important?**

- when children are children
- when children are children
- when children are children
- when children are children

**Why is development important?**

- when children are children
- when children are children
- when children are children
- when children are children

**Learn the Signs. Act Early.**

**It's time to change how we view a child's growth.**

**Learn the Signs. Act Early.**

### Developmental Screening FACT SHEET

**What is child development?** In language or other areas, but less than half of children

**What will my child do that is not done by other children the same age?** Children reach milestones of language and motor skills at different rates. Some children reach milestones of language and motor skills at different rates. Some children reach milestones of language and motor skills at different rates.

**What are Autism Spectrum Disorders (ASD)?** Autism spectrum disorders (ASD) are a group of developmental disabilities caused by problems with the brain. Scientists do not know yet exactly what causes the problem. ASDs are caused by a person's brain not working in different ways. They are very different from each other. They are not caused by anything a parent did or did not do. They are not caused by anything a parent did or did not do. They are not caused by anything a parent did or did not do.

**What are the signs of ASD?** People with ASD may have problems with social interaction and communication skills. They might repeat words or phrases, and might not react to things in their daily activities. Many people with ASD also have other conditions, such as anxiety, depression, or learning difficulties. ASDs are not caused by anything a parent did or did not do.

**Why is development important?** When a child's development is delayed, it can affect their ability to learn and interact with others. Early identification and intervention can help children reach their full potential.

**Learn the Signs. Act Early.**

**It's time to change how we view a child's growth.**

Shows affection for playmates

uses four- to five-word sentences

initiates adults (claps after adult claps)

points to interesting objects

plays pretend (talks on toy phone)

uses simple gestures (waves "bye-bye")

makes sounds (such as "ma" and "ba")

**It's natural to measure your child's height and weight. But you should measure other ways your child is growing, too.**

From birth to 5 years, there are milestones your child should reach in terms of how they play, learn, speak, and act. A delay in any of these areas could be a sign of a developmental problem, even autism. The good news is, the earlier it's recognized the more you can do to help your child reach her full potential. Talk with a doctor or nurse about your child's total development.

**Learn the Signs. Act Early.**

## Autism Spectrum Disorder (ASD)

ASD Homepage > Data & Statistics

# Autism Data Visualization Tool

## ABOUT 1 IN 59 CHILDREN

WERE IDENTIFIED WITH AUTISM SPECTRUM DISORDER  
AMONG A 2014 SAMPLE OF 8 YEAR OLDS FROM 11 US COMMUNITIES  
IN CDC'S ADDM NETWORK

### ASD Data Visualization

Explore the information below to see autism spectrum disorder (ASD) prevalence estimates and demographic characteristics at the national, state, and community levels. Click on methodology to learn more about the data sources.

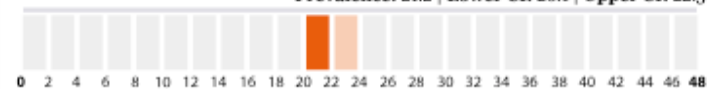
Select state:

**Special Education Child Count**      Prevalence: 9.1 | Lower CI: 9.1 | Upper CI: 9.2



**National Survey of Children's Health**

Prevalence: 21.2 | Lower CI: 20.1 | Upper CI: 22.3



**Medicaid**

Prevalence: 8.2 | Lower CI: 8.2 | Upper CI: 8.3



**ADDM Network**

Prevalence: 14.8 | Lower CI: 14.4 | Upper CI: 15.2



### WHY THIS MATTERS

By comparing different data sets, we see that some confidence intervals are wide, while others are narrow. When a confidence interval is wide, the true prevalence may be anywhere within that range, making it less certain. A narrow confidence interval means we can be more certain about the reported prevalence.

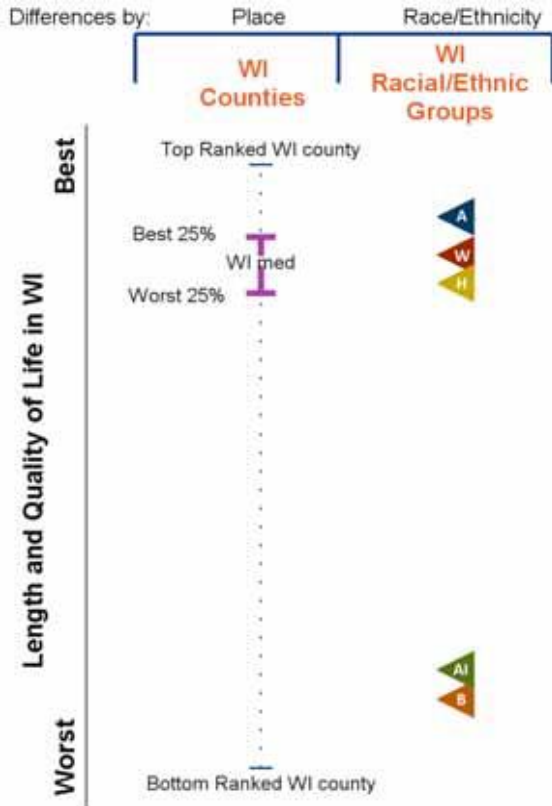
**Note:** The graph above shows data from 2012, the most recent year for which all data sets had data.

<sup>1</sup>ADDM estimate = the total for all sites combined.

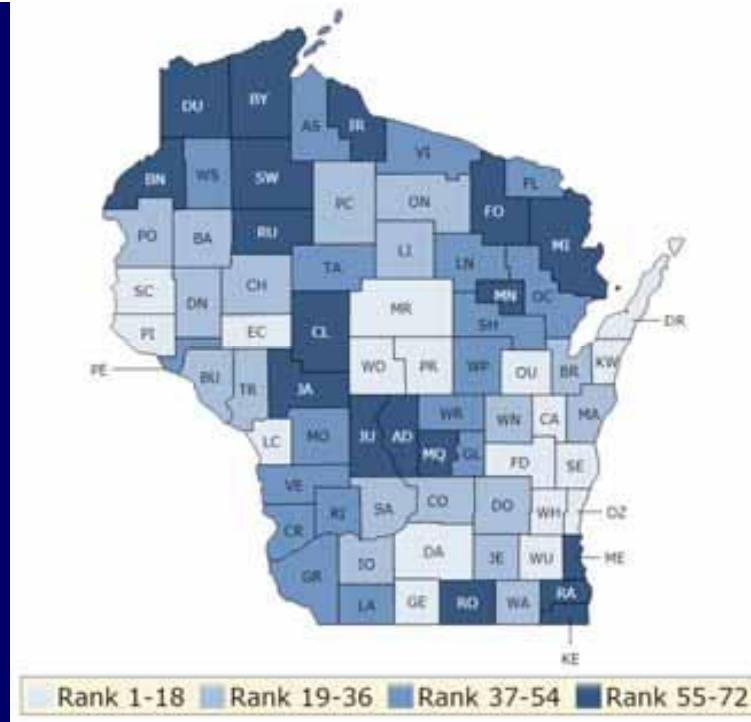
# County Health Rankings & Roadmaps

Building a Culture of Health, County by County

## Health Outcomes in Wisconsin



▲ AI/AN ▲ Asian/PI ▲ Black ▲ Hispanic ▲ White  
 Data for every racial/ethnic group may not be available due to small numbers



In 2017, in Wisconsin, more than 180,000 children lived in poverty

49% of Wisconsin's children in poverty were living in a household that spends more than 1/2 of its income on housing costs

Leaving little left over for other essentials like...



Healthy Food



Transportation



Medical Care





# Acknowledgments

## Wisconsin Surveillance of Autism and Developmental Disabilities System team:

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Data collection was coordinated at each site by ADDM Network project coordinators: Anita Washington, MPH, Yasmee Williams, MPH, Kwin Jolly, MS, Research Triangle Institute, Atlanta, Georgia; Neva Garner, University of Alabama at Birmingham; Kristen Clancy Mancilla, University of Arizona, Tucson; Allison Hudson, University of Arkansas for Medical Sciences, Little Rock; Andria Ratchford, MSPH, Colorado Department of Public Health and Environment, Denver; Yolanda Castillo, MBA, Colorado Department of Education, Denver; Claudia Rojas, Yanin Hernandez, University of Miami, Coral Gables, Florida; Kara Humes, Rebecca Harrington, MPH, Johns Hopkins University, Baltimore, Maryland; Rob Fitzgerald, MPH, Washington University in St. Louis, Missouri; Josephine Shenouda, MS, University of Medicine and Dentistry of New Jersey, Newark; Paula Bell, University of North Carolina, Chapel Hill; Rachel Reis, University of Pennsylvania, Philadelphia; Lydia King, PhD, Medical University of South Carolina, Charleston; Amanda Bakian, PhD, Amy Henderson, University of Utah, Salt Lake City; Carrie Arneson, MS, University of Wisconsin, Madison; Susan Graham Schwartz, MSPH, CDC. Additional assistance was provided by project staff including data abstractors, clinician reviewers, epidemiologists, and data management/programming support. Ongoing ADDM Network support was provided by Joanne Wojcik, Victoria Wright, National Center on Birth Defects and Developmental Disabilities, CDC, Rita Lance, Northrop Grumman, contractor to CDC.



# Conclusions

- >1% of U.S. children have an autism spectrum disorder
- Service delivery system not prepared to meet the needs
- Disparities in access to diagnoses and services persist
- Need for ongoing monitoring and understanding of:
  - Epidemiology of autism spectrum disorder
  - Uses and limitations of screening, early detection
  - Strategies for enhancing access to care, health equity
  - Disability across the life-course, transition to adulthood