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

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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
Number of children with autism in Wisconsin: special education enrollment, 1992-2008
Concerns Over Increases in Autism...
Population and Sample, 2008

Population: 337,093 8-year olds

6,739 abstracted for autism

48,247 records reviewed for 38,253 children

3,820 children with autism

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
Prevalence of Autism Spectrum Disorder (ASD) Among 8 Year-Old Children, U.S. CDC’s ADDM Network, 2000 – 2014 Combining Data from All Sites

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites</th>
<th>Prevalence per 1,000 (range)</th>
<th>This is about 1 in x children</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7 (4.5-9.9)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6 (3.3-10.6)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0 (4.6-9.8)</td>
<td>1 in 125</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0 (4.2-12.1)</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3 (4.8-21.2)</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>2002</td>
<td>11</td>
<td>14.7 (8.7-21.9)</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2012</td>
<td>2004</td>
<td>12</td>
<td>14.6 (8.2-24.6)</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2014</td>
<td>2006</td>
<td>11</td>
<td>16.8 (13.1-29.3)</td>
<td>1 in 59</td>
</tr>
</tbody>
</table>

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

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.
SINCE 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-

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 professor of forestry, one an advertising copy writer who has a Ph.D., and has studied in three universities, one is a mining engineer-business man. Nine of the eleven mothers are college graduates. One has only high-school education, one was secretary in a firm, 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 the director of secretarial studies in a girls’ school, and the director of secretarial studies in a boys’ school. Among the grandparents and collaterals there are many physicians, lawyers, writers, journalists, and students of art. All but three of the fathers are represented either in Who’s Who in America or in American Men of Science, or in both.
Childhood Autism and Social Class: A Question of Selection?

By LORNA WING

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

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

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


http://journals.plos.org/plosone/article?id=info:doi/10.1371/journal.pone.0011551
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

Prevalence /1,000

White Non-Hispanic

Black Non-Hispanic

Hispanic

Asian

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

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

Prevalence of autism by socioeconomic status

Race, class contribute to disparities in autism diagnoses

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.

<table>
<thead>
<tr>
<th>Parental Socioeconomic Status at Time of Child’s Birth</th>
<th>Cases/Controls</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household disposable income (individualized)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quintile 1 (Lowest)</td>
<td>847/8,151</td>
<td>1.2 (1.1–1.4)</td>
<td>1.3 (1.2–1.5)</td>
</tr>
<tr>
<td>Quintile 2</td>
<td>1,121/9,447</td>
<td>1.4 (1.3–1.6)</td>
<td>1.4 (1.3–1.6)</td>
</tr>
<tr>
<td>Quintile 3</td>
<td>1,051/9,710</td>
<td>1.3 (1.2–1.4)</td>
<td>1.3 (1.2–1.5)</td>
</tr>
<tr>
<td>Quintile 4</td>
<td>878/9,574</td>
<td>1.1 (1.0–1.2)</td>
<td>1.1 (1.0–1.2)</td>
</tr>
<tr>
<td>Quintile 5 (highest)</td>
<td>812/9,607</td>
<td>1.0 (Ref)</td>
<td>1.0 (Ref)</td>
</tr>
</tbody>
</table>

*Adjusted OR*
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

Learn the Signs. Act Early.

Milestone and Disability Specific Fact Sheets

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

Milestone Tracker App
Autism Spectrum Disorder (ASD)

ASD 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.

https://www.cdc.gov/ncbddd/autism/data/index.html
Count the differences in Wisconsin.

Health Outcomes in Wisconsin

- Differences by: Place, Race/Ethnicity
- Top Ranked WI county
- Best 25%
- WI med
- Worst 25%
- Bottom Ranked WI county
- WI Counties
- Racial/Ethnic Groups

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 25% of its income on housing costs.

Leaving little left over for other essentials like...

- Healthy Food
- Transportation
- Medical Care

http://www.countyhealthrankings.org/explore-health-rankings
Acknowledgments

Wisconsin Surveillance of Autism and Developmental Disabilities System team:
Angelica Salinas, Ruth Benedict, Mary Schlaak, Jean Patz, Lynn Peterson, Lynn Boelter, Bob, Madison Carey, Maia Piccagli, Carrie Arneson

Martha Wingate, DrPH, Beverly Mulvihill, PhD, University of Alabama at Birmingham; Russell S. Kirby, PhD, University of South Florida, Tampa; Sydney Pettygrove, PhD, Chris Cunniff, MD, F. John Meaney, PhD, University of Arizona, Tucson; Eldon Schulz, MD, University of Arkansas for Medical Sciences, Little Rock; Lisa Miller, MD, Colorado Department of Public Health and Environment, Denver; Cordelia Robinson, PhD, University of Colorado at Denver and Health Sciences Center; Gina Quintana, Colorado Department of Education, Denver; Marygrace Yale Kaiser, PhD, University of Miami, Coral Gables, Florida; Li-Ching Lee, PhD, Johns Hopkins University, Rebecca Landa, PhD, Kennedy Krieger Institute, Baltimore, Maryland; Craig Newschaffer, PhD, Drexel University, Philadelphia, Pennsylvania; John Constantino, MD, Robert Fitzgerald, MPH, Washington University in St. Louis, Missouri; Walter Zahorodny, PhD, University of Medicine and Dentistry of New Jersey, Newark; Julie Daniels, PhD, University of North Carolina, Chapel Hill; Ellen Giarelli, EdD, Drexel University, Philadelphia, Pennsylvania; Jennifer Pinto-Martin, PhD, University of Pennsylvania; Susan E. Levy, MD, The Children’s Hospital of Philadelphia, Pennsylvania; Joyce Nicholas, PhD, Jane Charles, MD, Medical University of South Carolina, Charleston; Judith Zimmerman, PhD, University of Utah, Salt Lake City; Matthew J. Maenner, PhD, Maureen Durkin, PhD, DrPH, University of Wisconsin, Madison; Catherine Rice, PhD, Jon Baio, EdS, Kim Van Naarden Braun, PhD, Keydra Phillips, MPH, Nancy Doernberg, Marshall Yergin-Allsopp, MD, Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, CDC.

Data collection was coordinated at each site by ADDM Network project coordinators: Anita Washington, MPH, Yasmeen 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; Robert 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