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
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 ADDM 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)
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
All children receiving services at participating health and education programs in the community

Children served under select diagnostic or eligibility categories at these community programs

Children identified as meeting surveillance case definition for ASD

All children with ASD living in the community
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

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

ASD Prevalence per 1,000 8-year-old Children

ADD Herbert Site

- Alabama
- Arizona
- Arkansas
- Colorado
- Georgia
- Maryland
- Missouri
- New Jersey
- N. Carolina
- Utah
- Wisconsin

Year
- 2000
- 2002
- 2004
- 2006
- 2008
- 2010
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.
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

- Sites relying primarily on data from health-care sources
- Sites with increased access to children’s education records

ASD Prevalence per 1,000 8-year-old Children

AddM Site: Alabama, Wisconsin, Colorado, Missouri, Georgia, Arkansas, Arizona, Maryland, N. Carolina, Utah, New Jersey
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 ≤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 ≥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)

<table>
<thead>
<tr>
<th>Subtype of Earliest Diagnosis:</th>
<th>Autistic Disorder</th>
<th>ASD/PDD</th>
<th>Asperger Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution of Subtypes:</td>
<td>43%</td>
<td>46%</td>
<td>11%</td>
</tr>
<tr>
<td>Median Age of Earliest Diagnosis:</td>
<td>48 Months</td>
<td>50 Months</td>
<td>74 Months</td>
</tr>
</tbody>
</table>

**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

2002  N = 407,578
2006  N = 308,038
Surveillance Year
2008  N = 337,093
2010  N = 363,749

N = 337,093  N = 308,038
8yo Population  N = 337,093
N = 363,749
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


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
Acknowledgments

Martha Wingate, PhD, University of Alabama at Birmingham; Russell S. Kirby, PhD, University of South Florida, Tampa; Sydney Pettygrove, PhD, Chris Cunniff, MD, University of Arizona, Tucson; Eldon Schulz, MD, University of Arkansas for Medical Sciences, Little Rock; Tista Ghosh, MD, Colorado Department of Public Health and Environment, Denver; Cordelia Robinson, PhD, University of Colorado at Denver and Health Sciences Center; Li-Ching Lee, PhD, Johns Hopkins University, Rebecca Landa, PhD, Kennedy Krieger Institute, Baltimore, Maryland; John Constantino, MD, Robert Fitzgerald, PhD, Washington University in St. Louis, Missouri; Walter Zahorody, PhD, Rutgers University New Jersey Medical School, Newark; Julie Daniels, PhD, University of North Carolina, Chapel Hill; Joyce Nicholas, PhD, Jane Charles, MD, Medical University of South Carolina, Charleston; William McMahon, MD, Deborah Bilder, MD, University of Utah, Salt Lake City; Maureen Durkin, PhD, DrPH, University of Wisconsin, Madison; Jon Baio, EdS, Deborah Christensen, PhD, Kim Van Naarden Braun, PhD, Heather Clayton, PhD, Alyson Goodman, MD, Nancy Doernberg, Marshalyn Yeargin-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: Eric Lott, University of Alabama at Birmingham; Kristen Clancy Mancilla, University of Arizona, Tucson; Allison Hudson, University of Arkansas for Medical Sciences, Little Rock; Kelly Kast, MSPH, Colorado Department of Public Health and Environment, Denver; Kwinettaion Jolly, MS, Research Triangle Institute, Atlanta, Georgia; Ann Chang, Rebecca Harrington, PhD, Johns Hopkins University, Baltimore, Maryland; Rob Fitzgerald, MPH, Washington University, St. Louis, Missouri; Josephine Shenouda, MS, Rutgers New Jersey Medical School, Newark; Paula Bell, University of North Carolina, Chapel Hill; Colin Kingsbury, MS, Amanda Bakian, PhD, Amy Henderson, University of Utah, Salt Lake City; Carrie Arneson, MS, University of Wisconsin, Madison; Anita Washington, MPH, Gal Frenkel, MPH, Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, 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 Victoria Wright, National Center on Birth Defects and Developmental Disabilities, CDC.
Community Report on Autism

To download a copy of the Community Report, please visit [www.cdc.gov/autism](http://www.cdc.gov/autism)
More Than Just A Number…

CDC’s Autism Tracking

Provides a more complete picture of autism

Informs early identification efforts

Helps identify potential risk factors

Guides our research and the research of other scientists
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