Surveillance of Autism Spectrum Disorders: Epidemiologic Studies and Prevention Strategies

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National Center on Birth Defects and Developmental Disabilities

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Autism Spectrum Disorders (ASDs) are defined by considerable impairments in social interaction and communication skills, and the presence of unusual behaviors and interests.

Our understanding of both the epidemiology and etiology of these serious developmental disorders is just recently emerging.
ASDs include autistic disorder, pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism), and Asperger Syndrome (a.k.a. Asperger’s Disorder).

ASDs can be identified as early as 14 months, and symptoms typically persist throughout a person’s life.

Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations.
ASDs are neurobiological disorders, meaning the behavioral symptoms are a result of differences in brain development.

For the majority of people with autism spectrum disorders, the cause is not known. There may be multiple causes that are a combination of genetic and environmental factors.

However, research has pointed to some possible risk factors:

- co-occurring with other conditions [Fragile X, PKU]
- sibling recurrence
- family history of psychiatric disorders
- adverse birth events
- advanced maternal and paternal age
- specific environmental exposures such as certain medications [valproic acid, thalidomide] or maternal/child illness [rubella]
Background

Estimates of population prevalence vary widely within the U.S. and abroad. Two primary factors contributing to this wide variation in prevalence estimates are:

- differences in case finding and ascertainment methods, and
- lack of standardization in evaluating diagnostic criteria for ASDs
Epidemiologic/Prevalence Studies

- Early epidemiologic studies in the 1970s (Denmark, UK, Japan) estimated the prevalence of autism at 4-5 per 10,000 (1 in 2500)

- Three US studies from 1980’s and early 1990’s estimated the prevalence of autistic disorder ranging from 3 to 4 per 10,000

- 1998 CDC study in Brick Township, NJ estimated the prevalence of Autistic disorder at 4 per 1,000 and the broader Autism Spectrum (ASD) at 6.7 per 1,000

- Other studies from outside the US in the 1990’s estimated the prevalence of Autism/ASD ranging from 1 to 6 per 1,000
Studies Based on ICD 10 or DSM-IV Criteria

Estimates from more recent population-based studies

- Kadesjo et al. (1999)
- Baird et al. (2000)
- Chakrabarti & Fombonne (2001)
- Bertrand et al. (2001)
- Yeargin-Allsopp et al. (2003)
- Tebruegge et al. (2004)
- Baird et al. (2006)

- Autistic disorder: range between 1.7 – 4.0 per 1,000
- Autism spectrum: 5.8 to 12.1 per 1,000
- Average range of recent estimates: 2-6 per 1,000 for all ASDs
- At 2-6 per 1,000 it was commonly estimated that ASD occurs in “as many as **1 in 166 children**”
Challenges Interpreting Autism Trends

- Studies conducted in diverse populations using different methods
- Changing diagnostic criteria (DSM-IIIR, DSM-IV, DSM-IV (TR), etc.)
- Expansion of autism to a “spectrum” of disorders
- Changes in level of awareness and use of diagnosis over time
- Changes in service eligibility
- Autism not a required category for U.S. DOE reporting until 1992
Statement of Need

- A more precise estimate of the public health impact of ASDs would serve to inform appropriate and well-coordinated responses by planners at the local and national level.
CDC/NCBDDD Role in Birth Defects and Developmental Disabilities Prevention

**Surveillance Systems**
- prevalence rates
- registry of cases
- monitor prevention

**Epidemiologic Studies**
- risk factors
- protective factors
- public concerns

**Prevention Programs**
- prevention strategies
- public policy
- education
CDC Autism Prevalence Study

- Incorporated into MADDSP in 1998 because of lack of US prevalence data and increasing public concern

- Challenges
  - Case definition based on description of behaviors
  - Continuum of behaviors – autism spectrum
  - No standard, readily available diagnostic test
Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- Ongoing, active surveillance program since 1991
- Records-based surveillance
- Multiple sources (education, healthcare, disability services)
- 5 counties of Metropolitan Atlanta
- ASD surveillance since 1998 (1996 surveillance year)
MADDSP Methods: Records-based Surveillance

**Identify** potential cases at multiple educational and health sources

- Educational: psycho-educational assessments, special education files; range of eligibility categories in special education from public schools
- Health: Discharge diagnoses, billing code, or referral reason at clinics, evaluation centers, etc.

**Screen** source files for DD indicators ("triggers")

- Behavioral/physical descriptions consistent with ASD or CP
- Standardized test scores for ID, HL and VI

**Abstract** source files with triggers
Abstraction of records is carried out in the field using a specially-designed MS Access database application.
Methods

- Case status is determined by clinicians who review the abstracted records using a systematic coding scheme based on DSM-IV diagnostic criteria.
A child is included as a confirmed autism case if he or she displays behaviors (as described in evaluation reports by a qualified professional) consistent with the DSM-IV-TR diagnostic criteria for Autistic Disorder, PDD-NOS, or Asperger’s Disorder, as scored by an ASD clinician reviewer.
Types of Data Collected

Demographic:
- Child and mother identifying information
- Date of birth, race, sex

Educational:
- Primary exceptionality,
- Cognitive, adaptive, and autism test scores

Medical/Clinical:
- Physical findings
- Associated medical conditions
- Other developmental disabilities
MADDSP ’96 Autism Pilot

prevalence rate per 1,000

White
Male
Female

Black
Male
Female

Racial/Ethnic Groups

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Expansion of Monitoring Activities

1998: ASD surveillance study in Brick Township, NJ
1999: WV funded to implement ASD surveillance program
2000: Four additional state health departments funded
2001: Three new state health departments funded
2002: Four new cooperative agreements were funded
2003: Three additional sites were funded
2006: Ten sites competitively funded for Phase 2
2009: Three Phase I sites reinstated
Autism and Developmental Disabilities Monitoring (ADDM) Network

- CDC
- 11 ADDM Sites 2006 - 2010 (10+CDC)
- 16 ADDM Sites 2001 - 2006 (15+CDC)
Mission of the ADDM Network

"Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy"
The objectives of the 14-state ADDM Network are:

- Determination of reliable ASD prevalence rates in the participating states
- Establishment of an ASD surveillance system to determine trends in ASD prevalence, and
- Development of population-based data for special studies

This is the first and only integrated multi-state ASD prevalence investigation in the United States.
Strengths

- Large, population-based study of autism
- Multiple-source case ascertainment, including school records
- Coding scheme and systematic review of abstracted information on behaviors to arrive at DSM-IV classification
- Information on presence of other developmental disabilities
- Record review methodology maximizes population coverage
- Monitor ASDs in children at age 8 because previous studies have shown that by this age most children with ASDs have been identified for population-based surveillance
Limitations

- No clinical validation of case status
- Difficult to get severity ratings and to subtype
- Underascertainment of children with milder phenotypes, e.g., PDD-NOS, Asperger’s Disorder
<table>
<thead>
<tr>
<th>Study Year</th>
<th>Birth Year</th>
<th># Sites</th>
<th>Status</th>
</tr>
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<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>Published</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>Published</td>
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<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>Published</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>Published</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>In process</td>
</tr>
</tbody>
</table>
## ADDM Network: Prevalence of ASDs

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th># sites</th>
<th>8-year-old Population (% of US)</th>
<th>8-year-old children with ASD</th>
<th>Average Prevalence per 1,000 children (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>187,761 (4.5%)</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 (10%)</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 (4.3%)</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 (7.9%)</td>
<td>2,759</td>
<td>9.0 4.2-12.1</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>11(14)</td>
<td>In process</td>
<td>In process</td>
<td></td>
</tr>
</tbody>
</table>
For every girl with ASD there are 3 to 7 boys identified (4.5:1).

Between 29% (CO) and 51% (SC) of children with an ASD also had cognitive impairment (average 41%). In most sites, girls were more likely to have cognitive impairment than boys.

Among all children meeting the ADDM surveillance case definition for ASD, approximately 77% had a documented ASD classification in their records, ranging from 65% (AZ) to 93% (MD).

Most children identified as ASD surveillance cases were receiving special education services at age 8. The proportion served under a primary exceptionality of autism ranged from 34% (CO) to 76% (MD).
ADDM 2006 Surveillance Year

% in SpEd
% Autism Elig

AZ  GA  MD  NC  SC  CO

CDC

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ADDM Network: Change in ASD Prevalence
2002 to 2006, 10 Sites
by Total, Sex, Race or Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Males</th>
<th>Females</th>
<th>NH White</th>
<th>NH Black</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avg % Change</td>
<td>57%</td>
<td>60%</td>
<td>48%</td>
<td>55%</td>
<td>41%</td>
<td>91%</td>
</tr>
</tbody>
</table>

The overall trend reflects increases in ASD prevalence - overall and among subgroups.

There was variation across sites.
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There was variation across sites.
Changing Prevalence of ASDs Over Time

- 1 in 2500 (early 1970s)
- 1 in 166 (late 1990s)
- 1 in 150 (early 2000s)
- 1 in 110 (mid 2000s)
In all reports, the majority of children identified with ASD had documented concerns by a parent or professional before 3 years of age, such as concerns about the child’s language, social, or play development, but the median age of earliest ASD diagnosis was approximately 4 ½ to 5 ½ years.

Over the 4 year period from 2002 to 2006, the age of earliest documented ASD diagnosis declined for all 10 sites included in both surveillance years, from 1 month (WI) to 15 months (AL), but the median age for most sites remains in the 50-60 month range.
Conclusions

- We do not know the prevalence of autism in most communities in the United States, but there are more children diagnosed with autism today than in the past.

- We do not know the etiology of most cases of autism.

- Recent attention to autism issues has the potential to lead to more answers through research.

- CDC is conducting research with many partners in an attempt to understand more about the prevalence, causes, and how to best support communities and families of children with autism and other developmental disabilities.
Other Epidemiologic Studies

Study to Explore Early Development (SEED)
- Funded by CDC; currently being implemented in 6 U.S. sites
- Enrolling children with ASD and 2 comparison groups
- Detailed family histories and biomarkers

Baby Sibling Studies
- High-risk group
- Prospective accounts of pregnancy and early development
- Early physical (head circumference) and developmental (language, eye gaze) characteristics
Prevention Strategies

- Purpose of etiologic studies is to identify risk factors that can help us identify children at risk and start intervening when treatments are most effective.

- Children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement.

- Brain is most responsive to retraining efforts during early childhood. Flip side is that the young child is also more susceptible to side effects from medications.
Prevention Strategies:
Developmental Screening

- In the United States, 17% of children have a developmental or behavioral disability, but less than 50% are identified before school, by which time significant delays may have already occurred and opportunities for treatment have been missed.

- Developmental screening is a procedure designed to identify children who should receive more intensive assessment, or diagnosis, for potential developmental delays. It can allow for earlier detection of delays and improve health and well-being for identified children.
Prevention Strategies: Developmental Screening

- The American Academy of Pediatrics recommends developmental screening at 9, 18, and 24 or 30 months, or whenever a parent or provider concern is expressed.

- Administration of a brief standardized tool is best practice.

- Studies sponsored by AAP show that only about 35% of pediatricians feel adequately trained in assessing children’s developmental status.
Prevention Strategies: Developmental Screening

The Centers for Disease Control and Prevention has established the following goals to help children reach their full potential:

1. Develop and test programs in primary care settings to screen children early on, identify those with autism and other delays, and ensure that these children receive appropriate care.

2. Increase health care providers’ knowledge and skill in developmental screening by incorporating training into professional health care education programs.

3. Raise awareness about the need for and benefits of developmental screening to identify and care for children with autism and other developmental disabilities or delays.
Partnerships to increase awareness

“Learn the Signs: Act Early” campaign

- American Academy of Pediatrics (AAP)
- Association of University Centers on Disabilities (AUCD)
- Autism Society of America (ASA)
- Autism Speaks
- First Signs
- Organization for Autism Research (OAR)
CDC's National Center on Birth Defects and Developmental Disabilities

Promoting the health of babies, children, and adults, and enhancing the potential for full, productive living