The Surveillance and Epidemiology of Autism Spectrum Disorders (ASDs) at the Centers for Disease Control and Prevention (CDC)

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  - Epidemiology teams
    - The Centers for Autism and Developmental Disabilities Research and Epidemiology
    - The Study to Explore Early Development
- Prevention teams
  - Learn the Signs Act Early
The Prevalence of Autism Spectrum Disorders (ASDs)

- Behaviorally defined conditions
  - Affects social, communication, and behavioral development

- Previously considered low incidence disorders
  - 1990’s: 4-5 per 10,000 children with autism (1 in 2,000)
The Prevalence of ASDs

- Rise in number of persons with ASDs identified
- More children receiving special education services

Children with Autism Served

School Year (# states reporting) *includes DC & PR

Newschaffer, Falb, & Gurney, 2005
The Prevalence of ASDs

- Rise in number of persons with ASDs identified
  - More children diagnosed in medical or clinical settings

Associated milestones in the United States:
- 1991: Hib and hepatitis B virus vaccines recommended for infants and children
- †1993: Licensure of first formulation of Hib vaccine (PRP-T) that contained no thimerosal
- ‡1999: Joint AAP/USPDS recommendation that thimerosal be removed as soon as possible from childhood vaccines
- §2001: All new lots of routine childhood vaccines (other than influenza vaccine) contain no more than traces of thimerosal
- ¶2002: Expiration dates for residual lots of routine childhood vaccines (other than influenza vaccine) that contain more than traces of thimerosal

Schechter & Grether, 2008
The Prevalence of ASDs

- Little *population-based* data on ASD prevalence and features of persons with ASDs
  - Challenges:
    - Behaviorally-defined nature of ASDs
    - Burdens associated with direct screening and observation
  - ASD prevalence estimates vary widely
    - Differences:
      - Case finding
      - Case ascertainment
      - Catchment area
      - Definition of ASDs
The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- Ongoing, active surveillance of children with developmental disabilities since 1991
  - Intellectual disability
  - Cerebral palsy
  - Hearing loss
  - Vision impairment
- 5-county catchment area
- ASD surveillance added in 1996
MADDSP Records-Based ASD Surveillance

- Identify
- Screen
- Abstract
- Review
Identify

- Potential children with ASD from pool of 8-year old children at *multiple* sources
  - Educational Sources
    - Georgia Department of Education
      - All children receiving special education services at public schools
  - Health sources
    - Hospitals and clinics; private medical sources
      - Children screened or served for select diagnostic/billing/discharge codes
Source files for ASD “triggers”
- Limited to social triggers
  - Reduced eye contact
  - No interest in other children
Abstract

- Source files with any ASD “trigger”
  - Demographic information
  - Reason for referral
  - Special education eligibility
  - Delays prior to 3 years
  - Regression or plateau
  - Behavioral features
  - Previous diagnoses and associated conditions
  - Evaluation summary/impression
  - Test data
MADDSP ASD Records-Based Surveillance Review

- Abstracted data to determine if child meets ASD surveillance criteria
  - Clinician reviewer
    - Advanced degree with training and experience in ASD assessment and diagnosis
    - Research trained and reliable in coding surveillance records
  - Standardized coding scheme
    - Based on Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)
    - Code line-by-line according to written standards
- Secondary review; consensus review
MADDSP Surveillance Methods Extended

Autism and Developmental Disabilities Monitoring (ADDM) Network

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## Most Recent ASD Prevalence Report from the ADDM Network (12/18/09)

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of Sites</th>
<th>8-year-old Population</th>
<th>Number of Children with ASD</th>
<th>Average Prevalence per 1,000</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</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>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</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>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</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>4.6-9.8</td>
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<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>308,038</td>
<td>2,759</td>
<td>9.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4.2-12.1</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>11(14)</td>
<td>In process</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Why is the identified prevalence of ASDs rising?

- No single explanation; multiple factors at play
  - Changes in diagnostic criteria
  - Increased awareness in community
  - Changes in availability of services
  - Recognition that ASDs can co-occur with other conditions
  - True increase in symptoms in population
    - Increased risk due to environmental and/or genetic factors
ASD Prevalence from ADDM 2006 versus Previously Documented ASD

Prevalence of ASD (per 1,000)

- ADDM 2006 ASD Prevalence
- Previously Documented ASD Classification Prevalence

States: Florida, Alabama, Colorado, Wisconsin, Pennsylvania, South Carolina, Maryland, Georgia, North Carolina, Missouri, Arizona
ASD Prevalence Based on Sex and Race/Ethnicity

- **Sex differences in identified ASD prevalence**
  - Males = 14.5 per 1,000 (1 in 70 males)
  - Females = 3.2 per 1,000 (1 in 315 females)
    - Ratio = about 4.5 males to every females with ASD

- **Race/ethnicity differences in identified ASD prevalence**
  - White, non-Hispanic = 9.9 per 1,000 (1 in 100 children)
  - Black, non-Hispanic = 7.2 per 1,000 (1 in 140 children)
  - Hispanic = 5.9 per 1,000 (1 in 170 children)
Early Concerns and ASD Diagnoses Among Children who Meet ASD Surveillance Criteria

- 70-95% had a documented developmental concern before the age of 3 years
- 13-30% had a reported developmental regression by 24 months of age
- Yet the average age of earliest ASD diagnosis was 4 years, 6 months; ranging from 3 years, 6 months to 5 years
Special Education Participation and ASD Placement

<table>
<thead>
<tr>
<th>State</th>
<th>% in Special Education</th>
<th>% in Autism Eligibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td>96</td>
<td>48.6</td>
</tr>
<tr>
<td>Colorado</td>
<td>75.9</td>
<td>34.1</td>
</tr>
<tr>
<td>Georgia</td>
<td>89.7</td>
<td>60</td>
</tr>
<tr>
<td>Maryland</td>
<td>84.8</td>
<td>75.7</td>
</tr>
<tr>
<td>North Carolina</td>
<td>90</td>
<td>61.4</td>
</tr>
<tr>
<td>South Carolina</td>
<td>83.7</td>
<td>51.2</td>
</tr>
</tbody>
</table>

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ADDM Network Conclusions

- Average prevalence of ASDs approaching 1% of 8-year-old children
  - 1 in 100 children
- ASD prevalence increased 57% between 2000 and 2006
  - Multiple factors at play
- Differences in identified ASD prevalence based on sex and race/ethnicity
  - Higher prevalence in boys
  - Lower prevalence in Hispanic children
    - May be due to limited access to services
- Significant delays exist between note of first concern or delay and first ASD diagnosis
ADDM Network Strengths

- Collaborative, multi-site surveillance system
  - Same methods used by similar teams across multiple years
- Record-review methodology allows application to large populations
- Confirmation of ASD symptoms through standardized and reliable clinician review using DSM-IV-TR criteria
- Multi-source ascertainment, including school records at some sites
- Quality control of study implementation (from data abstraction to clinician review)
- Creation of multi-year population-based data for additional analyses (e.g., advanced parental age)
ADDM Network Challenges

- Maintenance of the network of sites over time
  - Resource restrictions
  - Competitive process

- Site-specific differences in methodology
  - Access to education records
  - Quality of information in records

- Timeliness
  - Labor intensive process
  - Retrospective review

- Validation of ASD in children determined to meet ASD surveillance criteria
ASDs are an urgent public health issue

A coordinated and collaborative response is needed to
  - Improve early identification and access to services
  - Better understand how to intervene and reduce debilitating symptoms
  - Address the many needs of affected persons and families to improve daily functioning and long-term outcomes
  - Intensify search for risk factors

Prevalence estimates can help plan policy, education, and intervention services to address the aforementioned needs
CDCs Role in the Prevention of Developmental Disabilities

Surveillance → Epidemiology → Prevention
Challenges in Unraveling the ASD Etiology

- Behaviorally defined disorders
  - No biological test to confirm presence/absence
  - Behavioral presentation changes with development
- Complex group of disorders
  - Many areas of development affected
  - Often associated with other conditions
- Wide range of impairment
- Complexity of possible causes
  - Likely to be multiple forms of autism
  - Likely to be multiple causes
What do we know about causes?

- Genetic factors undoubtedly play an important role
- Environmental factors also play an important role
  - Prenatal exposures
  - Pre- and peri-natal factors
- Complex genetic/environmental interaction important to consider
  - What predisposes a fetus/child?
  - What environmental exposures are risky?
Etiologic Domains to Consider

- Infection and immune function
- Hormonal function
- Pre- and peri-natal factors
- Maternal lifestyle factors
- Toxicological exposures
Study to Explore Early Development (SEED)

- Multi-year, multi-site collaborative study
- Designed to identify possible risk factors for ASDs
  - Aforementioned etiologic domains
  - Genes
  - Relationship between genetic and non-genetic factors
  - Physical and behavioral characteristics unique to children with ASDs
    - Subtypes?
- Designed to fund programs with an explicit epidemiologic focus
SEED Design and Data Collection

- Compare 3 groups of children (2700 children and families)
  - With ASD
  - With other developmental problems
  - From the general population
- On 23 components of data collection
  - Caregiver interviews
  - Self-administered questionnaires
  - Medical record abstraction
  - Developmental evaluation
  - Physical exam
  - Biological samples

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SEED Strengths

- Multi-site study focusing on etiology
  - Enhance generalization to US population
- Population-based identification of participants
  - Reduce bias in who is invited to participate
- Two comparison groups
  - Reduce inaccurate conclusions on who and who does not have a risk factor
- Uniform study protocol
  - Can pool data across sites
- Largest sample size planned to date
  - Enhance statistical power to detect meaningful differences
SEED Challenges

- **Burdensome data collection**
  - Not all invited agree to participate
  - Those who agree to participate may not complete entire data collection process

- **Cannot answer all ASD questions: no one study can!**
  - Can, however:
    - Help interpret previous findings
    - Better understand risk factors for ASDs
    - Generate new hypotheses for future research
    - Assist planning next generation of ASD studies
More children with ASDs are identified now than in the past
- 57% increase in ASDs from 2000-2006

CDC is responding to this urgent public health concern by:
- Continuing to monitor the number of children with ASDs to help plan policy, educational, and intervention strategies
- Conducting a population-based study to increase our understanding of ASD risk factors

Yet community-based developmental screening and evaluation of very young children is needed to identify and treat children as soon as possible to improve developmental outcomes
Community-Based Developmental Screening

- The American Academy of Pediatrics (AAP) recommends developmental screening at 9, 18, and 24 or 30 months, or whenever a parent or provider concern is expressed
  - Administration of a standardized tool is best practice
- The AAP also recommends ASD-specific screening at the 18 and 24 month well child visits
- Yet screening for ASDs in general pediatric practice remains low
  - 82% of pediatricians surveyed screened for general delays but only 8% screened for ASDs (Dosreis et al., 2006)
  - Highlights need for continued professional awareness, education, and development
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)
For more information visit:

- The Autism and Developmental Disabilities monitoring Network

- The Study to Explore Early Development
  - http://www.cdc.gov/ncbddd/autism/seed.html

- The “Learn the Signs, Act Early” Campaign
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