Pediatrics TeleECHO

Setting the Stage: Overview of Autism in the US

Paul S. Carbone MD
Associate Professor of Pediatrics
University of Utah
Infantile autism

“...inability to relate themselves in the ordinary way to people and situations...”

“...anxiously obsessive desire for the maintenance of sameness.”
DSM-III: Diagnostic and Statistical Manual of Mental Disorders

DSM-III-R: Diagnostic and Statistical Manual of Mental Disorders, Revised

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders

DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Text Revision

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
<table>
<thead>
<tr>
<th>Infantile autism</th>
<th>Autism Spectrum Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...inability to relate themselves in the ordinary way to people and situations...”</td>
<td>Persistent deficits in social communication and social interaction across multiple contexts</td>
</tr>
<tr>
<td>“...anxiously obsessive desire for the maintenance of sameness.”</td>
<td>Restricted, repetitive patterns of behavior, interests, or activities</td>
</tr>
</tbody>
</table>
Autism Spectrum Disorder

Social communication and social interaction
- Deficits in social-emotional reciprocity
- Deficits in nonverbal communication
- Deficits in developing and maintaining relationships

Restricted, repetitive behaviors
- Stereotyped or repetitive behaviors
- Insistence on sameness; rituals
- Restricted interests
- Sensory aberrations

DSM-5
Co-occurring Conditions

ASD

Psychiatric Conditions
- ADHD
- Depression
- Anxiety
- Mood disorder

Medical Conditions
- Sleep Disorders
- Gastrointestinal Conditions/Feeding problems
- Overweight/Obesity
- Seizures

Intellectual Disability
Motor symptoms
1 in 59

Jacquelyn Bertrand, PhD*; Audrey Mars, MD†; Coleen Boyle, PhD*; Frank Bove, ScD§; Marshalyn Yeargin-Allsopp, MD*; and Pierre Decoufle, ScD*

## Identified Prevalence of Autism Spectrum Disorder

**ADDM Network** 2000 – 2012
Combing Data from All Sites

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites Reporting</th>
<th>Prevalence per 1,000 Children (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 (5.7 – 21.9)</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2012</td>
<td>2004</td>
<td>11</td>
<td>14.6 (8.2 – 24.6)</td>
<td>1 in 68</td>
</tr>
</tbody>
</table>
Most recent estimated ASD Prevalence

1 in 59 children living in ADDM sites are identified with ASD
Why the increase in prevalence?

Changes in diagnostic criteria
Diagnostic substitution
Greater case finding incentive due to treatment availability
Improved awareness of parents, health care providers and school evaluators
Increased recognition among high functioning individuals
?? Other factors
What is the average age of ASD diagnosis in the US?

4 ½ years old

At what age is therapy for ASD most effective?

Before 4 ½ years old

The benefits of early identification for young children with ASD

Early intensive developmental/behavioral interventions result in significant improvement in cognition, language, adaptive behavior in children as young as 18 months. (Lovaas, 1987; Dawson, 2010)

How early can autism be diagnosed?

- Signs of autism emerge over the first 18-24 months and are not present at birth

- Difficult because of different patterns of symptom emergence (heterogeneity!)

How do we recognize the earliest signs of autism?

- Family history
- Listen to parents
- Look for the early signs:
  - Early social skill deficits
  - Language delay or odd use of language
  - Restricted interests, repetitive behaviors or movements
Early Identification

- ASD Surveillance
- ASD Screening
- Comprehensive Diagnostic Evaluation
Ask about concerns regarding behavior and development and family history
Observe for early signs (all well visits)
Brief standardized tool that aids the identification of children at-risk (18, 24 month visits)
M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or animal, does your child look at the toy or animal?)
   Yes  No

2. Have you ever wondered if your child might be deaf?
   Yes  No

3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)
   Yes  No

4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)
   Yes  No

5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
   Yes  No

6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)
   Yes  No

7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)
   Yes  No

8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)
   Yes  No

9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)
   Yes  No

10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)
    Yes  No

11. When you smile at your child, does he or she smile back at you?
    Yes  No

12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)
    Yes  No

13. Does your child walk?
    Yes  No

14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?
    Yes  No

15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)
    Yes  No

16. If you turn your head to look at something, does your child look around to see what you are looking at?
    Yes  No

17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”?)
    Yes  No

18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)
    Yes  No

19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)
    Yes  No

20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)
    Yes  No

© 2009 Diana Robins, Deborah Fein, & Marianne Barton
Identify children at-risk for ASD, do not provide a diagnosis
The definitive diagnosis of ASD is made by a specialist or team of specialists with expertise in ASD.
Comprehensive Diagnostic Evaluation

- Developmental history
- Physical exam
- Observation
- Autism specific diagnostic tests
- Cognitive testing
- Ideally interdisciplinary
- Etiologic workup
Long-term management

- Goals: maximize functional potential, minimize maladaptive behaviors and support individuals and their families
  - Behavioral/developmental interventions
  - Educational interventions
  - Speech, occupational, physical therapy
  - Medical management
    - Treat co-occurring medical and psychiatric conditions
    - Address complementary and alternative therapy questions
    - Refer to community based services
Transition to adulthood

- Housing
- Employment
- Social participation
- Sexuality/gender issues
- Guardianship
- Medical issues
The health status of adults on the autism spectrum

Lisa A Croen¹, Ousseny Zerbo¹, Yinge Qian¹, Maria L Massolo¹, Steve Rich², Stephen Sidney¹ and Clarissa Kripke³

Medical conditions
Epilepsy
Constipation
Insomnia
Dyslipidemia
Diabetes
Hypertension
Obesity
Stroke

Psychiatric conditions
Anxiety
Depression
Bipolar Disorder
Dementia
Suicide attempts

Individuals in the control group died at a mean age of 70 compared with 54 in the ASD group (40 for the low-functioning ASD, 58 for high functioning ASD)
My favorite books with autism as a theme

Non-fiction
- Neurotribes: The Legacy of Autism and the Future of Neurodiversity
- Asperger’s Children: The Origin of Autism in Nazi Vienna
- The Reason I Jump

Fiction
- The Curious Incident of the Dog in the Night-time
- The Rosie Project
- Eleanor Oliphant is Completely Fine
- A Man Called Ove
What is Applied Behavioral Analysis (ABA)?

**Method**: build functionally useful behaviors and reduce problematic ones

**Focus**: small, measurable units of behavior are taught systematically

**Goal**: build on simple responses into complex and fluid combinations of age-appropriate responses
Co-occurring behavioral/psychiatric conditions

ADHD
Anxiety
Depression
Mood Disorder