Early Autism Detection Screening and Referral

www.theautismprogram.org
Early Autism Detection and Referral

Learning Objectives:

- Define autistic spectrum disorders, their epidemiology and etiology;
- Recognize the earliest signs of autism;
- Learn how to routinely assess young children for autism;
- Identify common misconceptions about the causes and stereotypes of autism;
- Learn how to refer to the Early Intervention system, Special Education system, and specialists for children who show signs of autism;
- Become familiar with the team approach to diagnosis and the importance of evidence-based treatment of autistic spectrum disorders
What is Autism?

- Neurodevelopmental disorder with a spectrum of clinical conditions
- 3 areas of dysfunction:
  - Social interaction/social relatedness difficulty
  - Communication impairment
  - Restrictive/repetitive behaviors and interests
DSM-IV Classification: Pervasive Developmental Disorders

Pervasive Developmental Disorder

- Autism
- Asperger’s Syndrome
- PDD – NOS (not otherwise Specified)
- Rett’s Syndrome
- Childhood Disintegrative Disorder
ASD Basic Facts

- Present at birth, with onset of symptoms before 36 months
- Accurate diagnosis possible at 18-24 months or earlier
- Parents first voice concerns around 18 months, but diagnosis is typically not until 3 years or older
- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention [1]
ASD Epidemiology

- Prevalence: 1 in 110
- ASD more prevalent in pediatric population than:
  - Cancer
  - Diabetes
  - Downs Syndrome
- Male to female ratio: 4 to 1
ASD Causes

- Strong genetic influence
- Evidence supports polygenic inheritance
- Recurrence risk is 2-7% in siblings

Autism does NOT result from:
- Poor parenting
- MMR vaccine
- Thimerosal preservative in vaccines
What Are the Earliest Signs of Autism?

Delays or abnormalities in:

- Joint Attention
- Social Interaction
- Play Behavior
## Typical Development: Joint Attention

<table>
<thead>
<tr>
<th>Interaction</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocal smiling</td>
<td>2 months</td>
</tr>
<tr>
<td>Gaze monitoring</td>
<td>8 months</td>
</tr>
<tr>
<td>Follows a point</td>
<td>9 months</td>
</tr>
<tr>
<td>Showing objects</td>
<td>10 months</td>
</tr>
<tr>
<td>Pointing to obtain an object</td>
<td>12 months</td>
</tr>
<tr>
<td>Pointing to indicate to another an object of interest</td>
<td>14 months</td>
</tr>
<tr>
<td>Social referencing</td>
<td>14 months</td>
</tr>
</tbody>
</table>
# Typical Development: Social Interaction

<table>
<thead>
<tr>
<th>Mth</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Interest in faces, smiles back, initiates smile</td>
</tr>
<tr>
<td>6</td>
<td>Relates to parents with joy, smiles often when playing</td>
</tr>
<tr>
<td>9</td>
<td>Orients to name, moves back &amp; forth, plays give &amp; take</td>
</tr>
<tr>
<td>12</td>
<td>Uses gestures to get needs met, repeats actions</td>
</tr>
<tr>
<td>15</td>
<td>Check parent's facial expression, draws attention to objects of interest, begins to show empathy</td>
</tr>
<tr>
<td>18</td>
<td>Plays pretend, attracts parental attention by looks or gestures</td>
</tr>
<tr>
<td>24</td>
<td>Enjoys playing next to other children, offers toys</td>
</tr>
<tr>
<td>36</td>
<td>Imagines self as a character, talks for objects, plays show and tell, talks about feelings</td>
</tr>
</tbody>
</table>
## Typical Development: Play Behavior

<table>
<thead>
<tr>
<th>Age</th>
<th>Type of Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-12 mths</td>
<td><strong>Sensorimotor</strong> – mouthing, fingering toy without regard to function</td>
</tr>
<tr>
<td>12+ mths</td>
<td><strong>Functional play</strong> – using toy as it was intended</td>
</tr>
<tr>
<td>16+ mths</td>
<td><strong>Symbolic play</strong> – giving objects identities other than intended</td>
</tr>
<tr>
<td>30+ mths</td>
<td><strong>Imaginative play</strong> – pretending without toys or props</td>
</tr>
</tbody>
</table>
Identification and Evaluation of Children With Autism Spectrum Disorder

October 29, 2007

PEDIATRICS Vol. 120 No. 5 November 2007, pp. 1162-1182
(doi:10.1542/peds.2007-2362)
AAP Screening Strategy

- Look for following risk factors at each visit. Give one point for each
  - Family history of ASD, esp. siblings
  - Elicit parental concerns
  - Other caregiver concerns
  - Pediatrician concern
- To elicit concerns, need to know the best questions to ask

Johnson CJ, Myers Setall Pediatrics, 120(5), November 2007, 1183-1215
Screening Algorithm-Simplified

One Risk Factor

If 18 or 24 month old visit- administer ASD screening tool

One Risk Factor

18 months or older- Administer ASD screening tool

Two Risk Factors

- Parental Education
- Refer for ASD eval
- Refer to EI/school
- Audiology
- Follow-up

If less than 18 months-evaluate Social and language skills

Johnson CJ, Myers S et al Pediatrics, 120(5), November 2007,1183-1215
Autism Screening Tools

- CHecklist for Autism in Toddlers (CHAT)
- Modified CHecklist for Autism in Toddlers (M-CHAT)
- Social Communication Questionnaire
What is the M-CHAT?

- Modified Checklist for Autism in Toddlers
- 23 item parent completed checklist
- Age range -
  - originally developed for 18-24 months of age, can use to 30 months
- Two step screening process
  - Questionnaire in the office
  - If fails, the need structured follow-up telephone or personal interview to review positive questions
- Without second step, over referral rate is 90%
- Download from http://www2.gsu.edu/~psydlr at no charge
- Medicaid reimbursed
M-CHAT Scoring

- Screen if “failed” if
  - Fail two critical times OR
  - Fail any three items

- Critical items include:
  - Interest in other children
  - Proto declarative pointing
  - Showing objects
  - Imitation
  - Response to name
  - Follow point
# M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?  
   - Yes  
   - No

2. Does your child take an interest in other children?  
   - Yes  
   - No

3. Does your child like climbing on things, such as up stairs?  
   - Yes  
   - No

4. Does your child enjoy playing peek-a-boo/hide-and-seek?  
   - Yes  
   - No

5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?  
   - Yes  
   - No

6. Does your child ever use his/her index finger to point, to ask for something?  
   - Yes  
   - No

7. Does your child ever use his/her index finger to point, to indicate interest in something?  
   - Yes  
   - No

8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them?  
   - Yes  
   - No

9. Does your child ever bring objects over to you (parent) to show you something?  
   - Yes  
   - No

10. Does your child look you in the eye for more than a second or two?  
    - Yes  
    - No

11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)  
    - Yes  
    - No
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Does your child smile in response to your face or your smile?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Does your child imitate you? (e.g., you make a face—will your child imitate it?)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>14. Does your child respond to his/her name when you call?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>15. If you point at a toy across the room, does your child look at it?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>16. Does your child walk?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>17. Does your child look at things you are looking at?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>18. Does your child make unusual finger movements near his/her face?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>19. Does your child try to attract your attention to his/her own activity?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>20. Have you ever wondered if your child is deaf?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>21. Does your child understand what people say?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>22. Does your child sometimes stare at nothing or wander with no purpose?</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>23. Does your child look at your face to check your reaction when faced with something unfamiliar?</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>
Listen to Parents

Parents:

- Are aware of the possibility of autism
- Do have concerns when something is wrong
- Do give accurate and reliable information about their children
- Need your questions to generate discussion about their child’s development

Child care providers are also a good resources when addressing developmental concerns of a child
Autism Identification: Behavioral Red Flags

Investigate further and consider autism if the child:

- Doesn’t know how to play with toys in a typical fashion
- Restricted patterns of interest
- “Toe walks”
- Has unusual attachments
- Lines things up
- Presents with sensory symptoms
- Has odd movement patterns and/or very repetitive behaviors
- Demonstrates echolalia
- Throws prolonged or frequent tantrums
- Is hyperactive
Diagnosis of Autism

- **Developmental Testing**
  - Developmental Profile
  - Speech evaluation – including pragmatics and interaction
  - Autism specific standardized tools

- **Medical Work Up**
  - Genetic Testing
  - Chromosomal testing
  - DNA testing
  - Fluorescence in situ
  - Hybridization (FISH)
  - Metabolic testing
  - Brain MRI
  - Lead Screening
  - EEG and imaging studies in some cases
Language Delay:
Absolute indications for immediate evaluation

12 months: No babbling and no pointing or other gestures

16 months: No single words

24 months: No functional 2-word phrases (not echolalic)

Any age: Any loss of language or social skills
Autism Assessment
18 – 36 months

- Deficits are more important than the presence of specific behaviors

Lack of:
- Use of eye contact to regulate social interaction
- Orienting to name
- Joint attention behaviors: pointing & showing
- Pretend play
- Imitation
- Nonverbal communication
- Language development
Autism Assessment
18 – 36 months

- Autism screening tools are recommended for primary care setting
- At 18 and 24 month visit use autism screening tool and direct observation to assess child for:

<table>
<thead>
<tr>
<th>Social</th>
<th>Language</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using gestures:</td>
<td>Using 7-10 words</td>
<td>Engaging in simple</td>
</tr>
<tr>
<td>- pointing</td>
<td>Understanding 1-step</td>
<td>pretend play</td>
</tr>
<tr>
<td>- waving</td>
<td>command</td>
<td></td>
</tr>
<tr>
<td>- shaking head</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Refer for further evaluation if concerned
<table>
<thead>
<tr>
<th>Myth</th>
<th>Truth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children with autism ...</td>
<td></td>
</tr>
<tr>
<td>Make no eye contact.</td>
<td>Eye contact is often demonstrated, but not always</td>
</tr>
<tr>
<td>Are not affectionate.</td>
<td>Are affectionate on their own terms.</td>
</tr>
<tr>
<td>Do not talk or have functional speech.</td>
<td>Many children with autism will develop functional speech, but not all.</td>
</tr>
<tr>
<td>Do not point.</td>
<td>May develop gestures later than usual</td>
</tr>
<tr>
<td>Are geniuses.</td>
<td>Can have intellectual functioning that ranges from significant intellectual disability to normal intelligence.</td>
</tr>
<tr>
<td>Have no hope for improvement.</td>
<td>A small number of children move off of the spectrum.</td>
</tr>
</tbody>
</table>
Case Study

- An 18 month old comes in for health supervision. His mother has concerns that he has frequent tantrums but otherwise notes that he is fine. He has 20 words.
- How would you proceed here according to AAP guidelines?
Autism Assessment: Staff Roles

- **Front office staff**
  - Maintain and update referral list
  - Provide information on logistics of referral

- **Allied health professionals**
  - Distribute patient education
  - Provide routine feedback

- **Clinical providers**
  - Observe child’s behavior
  - Listen to parent’s concerns
  - Advise parents on development and behavior
  - Make referrals
Autism Assessment: Reimbursement

- Autism assessment with observation and parental discussion falls under the general well child visit code
- Implement standardized developmental screening and autism specific screening to increase reimbursement using the 96110 code in Illinois for approved tools
Referrals for Children Who Show Signs of Autism

Research shows that early intervention can greatly improve a child’s development.[1],[2]

Under 3 years – refer to Early Intervention
3 years or above – refer to School District

For diagnostic confirmation consider:

- Medical Diagnostic through EI
- Developmental & behavioral pediatrician
- Child psychologist
- Pediatric neurologist
- Child psychiatrist
0 – 3: Early Intervention

- Child and Family Connections (CFC)
- 25 sites in Illinois
- Functions:
  - Assist in screening/evaluation
  - Determine eligibility
  - Assess needs
  - Plan for services
  - Identify providers
- Phone or fax referral to local CFC
- Initial evaluation is FREE!
- Family charged monthly fee on a sliding scale once services begin

Call 1-800-323-GROW for nearest CFC
Ages 3 – 21: Special Education

- Mandated by federal IDEA legislation
- Programs managed and vary by school district
- Make referrals in writing!
- Individualized Education Plan (IEP) for each child
- Services for children with autism may include:
  - Speech therapy
  - Occupational therapy
  - Communication assistance (PECS)
  - Teacher education on classroom management
  - Evidence-based treatments
Encouraging Next Steps

- Acknowledge parent’s fear and grief
- Provide information on how to tell others
- Provide parent with information on the referral sources
- Encourage communication
- Set a follow-up appointment
- Share evidence-based treatment options
Autism Intervention

Issues to consider when choosing a treatment plan:

- Evidence-based
- Cost
- Time
- Family involvement
- Available resources
Collaborative Partners

Initial Creation and Dissemination:
- The Autism Program of Illinois (TAP)
- Illinois Chapter of American Academy of Pediatrics (ICAAP)

Ongoing dissemination:
- TAP
- ICAAP
- EDOPC
- Maternal Child Health Bureau
- Advocate Health Care Healthy Steps Program