First Concerns

What if I (or the parents) have concerns about a patient?

- Remember that the AAP guidelines now indicate that all children should be screened for an ASD at their 18 and 24 month well-baby checks (Johnson, Myers, 2007).
- If you think you may have a patient with an ASD, begin with a Phase 1 screening.
  - Ask about caregiver concerns (see page 12)
  - Probe for age-appropriate skills in each developmental domain
  - Use direct observation
- Remember absolute indicators for immediate evaluation include:
  - No babbling by 12 months
  - No gesturing (e.g., pointing, waving ‘bye-bye’) by 12 months
  - No single words by 16 months
  - No spontaneous 2-word (non-echolalic) phrases by 24 months
  - Loss of any language or social skills at any age.
- If there are concerns from the check or the child demonstrates the absolute indicators, you may want to administer an autism screen:
  - The Checklist for Autism in Toddlers (Baron-Cohen et al., 1996)
  - The Modified Checklist for Autism in Toddlers (Robbins, Fein & Barton, 1999; see page 16)
- Social Communication Questionnaire (formerly the Autism Screening Questionnaire; Berument, Rutter, Lord, Pickles, & Bailey, 1999).
- Refer those at risk for an evaluation with ASD experts, otherwise referred to as a Phase 2 screening (Filipek et al., 1999). Some referral sources are listed within this toolkit (see page 22)
- The most conservative method would be to refer at any sign (i.e., see Autism Screening Poster, page 18) for further evaluation.
**WHAT IS AN AUTISM SPECTRUM DISORDER?**

Autism Spectrum Disorders is the popularized and lay-term for referring to the disorders referred to in the medical/clinical literature as Pervasive Developmental Disorders (PDDs), with impairments in:
- Functional communication
- Reciprocal socialization skills
- Repetitive behaviors, interests, and activities

<table>
<thead>
<tr>
<th>AUTISTIC DISORDER</th>
<th>ASPERGER’S DISORDER</th>
<th>PDD-NOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Impaired social skills</td>
<td>□ Impaired social skills</td>
<td>□ Impaired social skills</td>
</tr>
<tr>
<td>□ Impaired communication skills</td>
<td>□ Repetitive behaviors</td>
<td>□ Repeative behaviors AND Either</td>
</tr>
<tr>
<td>□ Presence of stereotyped or repetitive behavior</td>
<td>□ No significant language or cognitive delays</td>
<td>□ Impaired communication skills</td>
</tr>
<tr>
<td>□ Symptoms presents by age 3, diagnosed as young as 2 years</td>
<td></td>
<td>□ OR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Repetitive behaviors AND</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Not enough symptoms to diagnose another ASD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>PDD-NOS is NOT the same as PDD, which is the umbrella term for the spectrum of 5 disorders</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RETT’S DISORDER</th>
<th>CHILDHOOD DISINTEGRATIVE DISORDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Apparently normal development until 5 months with loss of skills after 5 months</td>
<td>□ Apparently normal development until 2 years</td>
</tr>
<tr>
<td>□ Social disengagement</td>
<td>□ Loss of skills (e.g., language, adaptive behavior)</td>
</tr>
<tr>
<td>□ Poor coordination</td>
<td>□ Impaired social skills</td>
</tr>
<tr>
<td>□ Severe language impairments</td>
<td>□ Impaired communication skills</td>
</tr>
<tr>
<td>□ Presence of repetitive behavior (especially hand-wringing)</td>
<td>□ Presence of repetitive behavior</td>
</tr>
</tbody>
</table>

- The social impairments in autism are significant and pervasive, interfering with functioning appropriate to the individual’s developmental age (Posey & McDougle, 2002).
- Several disorders can be mistaken for ASDs.
- ASDs must be distinguished from social awkwardness (Posey & McDougle, 2002).
- ASDs are more common in males, at a 4:1 ratio.
Questions to Ask Families Concerned about ASD Children under 2:

1. Does s/he smile in response/clearly notice the presence of other people?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

2. Can you soothe your child when s/he is upset?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

3. Does s/he show increased/ reduced sensory issues?  
YES/NO; If yes, briefly describe/give examples: ____________________________________________
__________________________________________________________________________________

4. Does s/he point, wave, or use other gestures?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

5. Does s/he understand your gestures?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

6. Is s/he babbling?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

7. Does s/he have any single words yet?  
YES/NO; If no, briefly describe/give examples: _____________________________________________
________________________________________________________________________________

8. Has s/he ever lost social skills?  
YES/NO; If yes, briefly describe/give examples: _____________________________________________
________________________________________________________________________________
Questions to Ask Families Concerned about ASD
Children 2 and over:

1. Is s/he using two word phrases?
   YES/NO; If no, briefly describe/give examples: ________________________________
   ________________________________________________________________________

2. Has s/he ever lost language (i.e., stopped talking)?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

3. Has s/he ever lost social skills?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

4. Is s/he bothered by small changes in his/her environment?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

5. Does s/he engage in repetitive motor movements?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

6. Does s/he ever intentionally injure him/herself?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

7. Has s/he ever lost language (i.e., stopped talking)?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

8. Does s/he have a high pain threshold?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

9. Does s/he have difficulty understanding social cues and social rules?
   YES/NO; If yes, briefly describe/give examples: ________________________________
   ________________________________________________________________________

10. Does s/he play with toys creatively or as they are meant to be used?
    YES/NO; If no, briefly describe/give examples: ________________________________
    ________________________________________________________________________

11. Does s/he have a consistent and functional way to express needs and desires?
    YES/NO; If no, briefly describe/give examples: ________________________________
    ________________________________________________________________________
PLACES TO GO FOR MORE INFORMATION

Basic overview of ASDs
http://www.handsinautism.org/autism101.html

Information on screening and early indicators
http://www.cdc.gov/ncbddd/autism/screening.htm
http://www.cdc.gov/ncbddd/autism/ActEarly/default.htm

Links to screeners to help identify ASDs (including the M-CHAT and SCQ)
http://www.firstsigns.org/screening/tools/rec.htm
http://depts.washington.edu/dataproj/chat.html

Information on developmental milestones
http://www.nichcy.org/Disabilities/Milestones/Pages/Default.aspx

Information on local options for diagnosis/assessment:
http://www.iidc.indiana.edu/irca/DiagAssess.html-diagnosis

Information on early intervention
http://www.nichcy.org/babies/overview/Pages/default.aspx - treatment

Information on local treatment providers

Information on the medical home
http://aappolicy.aappublications.org/cgi/content/abstract/pediatrics;118/1/405

REFERENCES


**Online Resources for Diagnosis & Screening**


Center for Disease Control and Prevention: [http://www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/)

Indiana Medical/Autism Waiver: [http://www.in.gov/fssa/ompp/2632.htm](http://www.in.gov/fssa/ompp/2632.htm)


**Screening Tools**


Modified Checklist of Autism in Toddlers (M-CHAT): [http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html](http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html)

Instructions and Permissions for Use of the M-CHAT

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999) is available for free download for clinical, research, and educational purposes. There are two authorized websites: the M-CHAT and supplemental materials can be downloaded from www.firstsigns.org or from Dr. Robins’ website, at http://www2.gsu.edu/~wwpsy/faculty/robins.htm

Users should be aware that the M-CHAT continues to be studied, and may be revised in the future. Any revisions will be posted to the two websites noted above.

Furthermore, the M-CHAT is a copyrighted instrument, and use of the M-CHAT must follow these guidelines:

1. Reprints/reproductions of the M-CHAT must include the copyright at the bottom (© 1999 Robins, Fein, & Barton). No modifications can be made to items or instructions without permission from the authors.

2. The M-CHAT must be used in its entirety. There is no evidence that using a subset of items will be valid.

3. Parties interested in reproducing the M-CHAT in print (e.g., a book or journal article) or electronically (e.g., as part of digital medical records or software packages) must contact Diana Robins to request permission (drobins@gsu.edu).

Instructions for Use

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The M-CHAT can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, we have developed a structured follow-up interview for use in conjunction with the M-CHAT; it is available at the two websites listed above. Users should be aware that even with the follow-up questions, a significant number of the children who fail the M-CHAT will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from http://www2.gsu.edu/~wwpsy/faculty/robins.htm or www.firstsigns.org. We also have developed a scoring template, which is available on these websites; when printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed M-CHAT.

Children who fail more than 3 items total or 2 critical items (particularly if these scores remain elevated after the follow-up interview) should be referred for diagnostic evaluation by a specialist trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional’s concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.
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.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does your child enjoy being swung, bounced on your knee, etc.?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>2. Does your child take an interest in other children?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>3. Does your child like climbing on things, such as up stairs?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>4. Does your child enjoy playing peek-a-boo/hide-and-seek?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>6. Does your child ever use his/her index finger to point, to ask for something?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>7. Does your child ever use his/her index finger to point, to indicate interest in something?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>9. Does your child ever bring objects over to you (parent) to show you something?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>10. Does your child look you in the eye for more than a second or two?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>12. Does your child smile in response to your face or your smile?</td>
<td>Yes</td>
<td>No</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>No</td>
</tr>
<tr>
<td>14. Does your child respond to his/her name when you call?</td>
<td>Yes</td>
<td>No</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>No</td>
</tr>
<tr>
<td>16. Does your child walk?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>17. Does your child look at things you are looking at?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>18. Does your child make unusual finger movements near his/her face?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>19. Does your child try to attract your attention to his/her own activity?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>20. Have you ever wondered if your child is deaf?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>21. Does your child understand what people say?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>22. Does your child sometimes stare at nothing or wander with no purpose?</td>
<td>Yes</td>
<td>No</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>No</td>
</tr>
</tbody>
</table>

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Autism Screening
Endorsement of any of these areas should warrant referral for evaluation

Children less than two years old:

- Inactive
  - limp/floppy
  - infrequent crying

- Irritable
  - inconsolable
  - soothed only by motion

- Limited Social Response
  - no social smile/gaze
  - limp/rigid when held

- Limited Functional Communication
  - limited understanding and/or use of specific gestures

Children two years and older:

- Little consistency in utilization of functional communication
  - cannot consistently express needs/desires
  - limited conversation skills

- Significant distress over even minor changes

- Any regression or loss of language skills
  - self-injurious behavior
  - repetition of motor activity

- Intense difficulty in understanding:
  - social interaction
  - environmental safety rules

- High pain tolerance
  - engaged others only to meet a particular need

- Focused and repetitive interests limit creative play

- Visual processing of information is most developed:
  - Stop!
Resources

“Learn the Signs. Act Early.”
Web: www.cdc.gov/actearly
Phone: 1-800-CDC-INFO

GOVERNMENT RESOURCES
- Centers for Disease Control and Prevention (CDC)
  National Center on Birth Defects and Developmental Disabilities
  Web: www.cdc.gov/ncbddd
- National Dissemination Center for Children with Disabilities
  Web: www.nichcy.org/states.htm
- Department of Education
  Web: www.ed.gov/index.html
- National Institute of Mental Health
  Phone: 1-866-615-6464
  Web: www.nimh.nih.gov
- State Health Insurance Program (SCHIP)
  Phone: 1-877-KIDS-NOW Web: www.insurekidsnow.gov

SPECIAL RESOURCES
- American Academy of Pediatrics
  Phone: 1-847-443-4000 Web: www.aap.org
- Parent to Parent-USA
  Web: www.p2pusa.org

AUTISM SPECTRUM DISORDERS (ASD)
- Autism Society of America (ASA)
  Phone: 1-800-3-AUTISM Web: www.autism-society.org
- Cure Autism Now
  Phone: 1-888-8-AUTISM Web: www.cureautismnow.org
- National Alliance for Autism Research
  Phone: 1-888-777-NAAR Web: www.naar.org
- Organization for Autism Research
  Phone: 1-703-351-5031 Web: www.researchautism.org
- Autism Coalition
  Phone: 1-914-935-1462 Web: www.autismcoalition.org
- First Signs
  Phone: 1-978-346-4380 Web: www.firstsigns.org
- National Institute of Child Health & Human Development
  Web: www.nichd.nih.gov/autism
- CDC’s National Immunization Program: “Vaccines and Autism” Internet Site
  Web: www.cdc.gov/nip/vacsafe/concerns/autism/default.htm

CEREBRAL PALSY
- United Cerebral Palsy
  Phone: 1-800-872-5827 Web: www.ucpa.org
- National Institute of Neurological Disorders and Stroke (NINDS)
  Web: www.ninds.nih.gov

MENTAL RETARDATION
- The Arc of the United States
  Phone: 1-301-565-3842 Web: www.thearc.org
- National Down Syndrome Society
  Phone: 1-212-460-9330 Web: www.ndss.org

HEARING LOSS
- Centers for Disease Control and Prevention, Early Hearing Detection and Intervention Program
  Web: www.cdc.gov/ncbddd/ehdi
- American Academy of Audiology
  Phone: 1-800-AAA-2336 Web: www.audiology.org
- American Academy of Pediatrics Bright Futures
  Phone: 1-847-434-4223 Web: brightfutures.aap.org/web/
- American Speech-Language-Hearing Association
  Phone: 1-800-638-8255 Web: www.asha.org

VISION LOSS
- National Federation of the Blind
  Phone: 1-410-659-9314 Web: www.nfb.org
- American Council of the Blind
  Phone: 1-800-424-8666 Web: www.acb.org
- American Foundation for the Blind
  Phone: 1-800-232-5463 Web: www.afb.org

ATTENTION-DEFICIT/HYPERACTIVITY DISORDER (ADHD)
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
  Phone: 1-800-233-4050 Web: www.chadd.org
- CHADD National Resource Center
  Phone: 1-800-233-4050 Web: www.help4adhd.org
- Attention Deficit Disorder Association (ADDA)
  Phone: 1-484-945-2110 Web: www.add.org