

AUTISM SCREENING



Overview

- What is autism
- What are the early signs of autism
- Why should we screen all children for developmental disorders, including autism
- When should we screen
- How do we screen
- What do we do with a positive screen
- Additional resources

What is Autism?

- Autism is a complex neurological disorder that negatively impacts the way in which a child interacts with his or her environment
- Typically occurs before 3 years of age
- Can be associated with language and social regression (20-40%)
- Three core features:
 - Impairment in social interactions
 - Impairment in communication
 - Repetitive and/or restricted interests and behaviors



Autism in the USA

- Occurs 1 in 150 births (all ASD's) *CDC 2007*
- M:F 3-5:1
- Over 1.5 million individuals have been identified as having autism
- Autism is the fastest growing developmental disorder in the country
- It will cost close to 1 million dollars per person to educate and care for an individual with autism over the course of his or her lifetime
- Most insurance companies do not cover the cost of treatment

What Causes Autism

- Heterogeneity across individuals with autism suggest multiple causes
- A small percentage of children have an identifiable disorder
 - ▣ Chromosomal (e.g., Down syndrome, 15q11 dupl.)
 - ▣ Genetic (Fragile X syndrome, Tuberous Sclerosis, William syndrome)
 - ▣ Metabolic (mitochondrial disorders)
 - ▣ Other (e.g., congenital CMV, IVH in premature infant)
- Most do not
 - ▣ About 30% show pattern of regression

What Causes Autism Family Studies

- Very high concordance for identical twins (4 twin studies to date)
 - ▣ Identical twins: 36-96% both affected
 - ▣ Non-identical same sex twins: 0-30% both affected
- Current ASD recurrence risk for siblings is about 5%
- Language disorders, social skill deficits, and anxiety are more common in family members of children with autism

Freitag, Molecular Psychiatry, 2007, 12, 2-22

Current ASDs or Pervasive Developmental Disorders (DSM-IV-TR; APA 2000)

- Autistic Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder – Not Otherwise Specified
- Childhood Disintegrative Disorder
- Rett's Disorder

Autistic Disorder

- Diagnostic Criteria:
 - Differences in development begin before the age of 3
 - Differences are not caused by some other known disorder or illness
 - The person meets at least 6 criteria in three areas:
 - Impairment in social interaction
 - Impairment in communication
 - Restricted, repetitive, stereotyped patterns of interests and activities

Autistic Disorder (cont.)

- Qualitative Social Impairment:
(a person must show at least 2 of these)

- ▣ Impaired nonverbal communication (eye contact, gestures, facial expressions)
- ▣ Failure to develop peer relationships
- ▣ Lack of spontaneous seeking to share enjoyment and interests with others
- ▣ Lack of social or emotional reciprocity (understanding of another)



Autistic Disorder (cont.)

- Qualitative Communication Impairment (a person must have at least 1 of these):
 - ▣ Impaired development of spoken language (without gestures)
 - ▣ Impairment in ability to have a conversation
 - ▣ Stereotyped, repetitive use of language
 - ▣ Lack of imaginative, social or imitative play

Autistic Disorder (cont.)

- Restricted, Repetitive Behaviors, Interests and Activities (a person must have at least 1 of these):
 - ▣ Abnormal preoccupations
 - ▣ Inflexible adherence to specific, nonfunctional routines or rituals
 - ▣ Stereotyped repetitive motor movements
 - ▣ Persistent preoccupation with parts of objects (rather than the whole object)



Pervasive Developmental Disorder, NOS

- ▣ Used to diagnose children who have many of the symptoms of Autistic Disorder, but who do not meet all the diagnostic criteria
- ▣ May be used to diagnose a child who is very young and meets some of the criteria for Autistic Disorder, but not all at this time
- ▣ Sometimes considered more “mild” but this is not always the case

Asperger's Disorder

- ▣ Diagnosed using the same criteria of social impairment and restricted patterns of behavior, interests, and activities as Autistic Disorder (minimum of 3)
- ▣ Applies ONLY when a child has had normal language development and has no cognitive or adaptive delay

1st Birthday Party Videotapes

(Osterling & Dawson, 1994)

- ▣ 4 behaviors identified children with Autism
 - ▣ Pointing
 - ▣ Showing objects
 - ▣ Looking at others
 - ▣ Orienting to name



Symptoms Present Before 24 Months

- Poor eye contact
- Lack of social smiling
- Lack of social orienting
 - ▣ orienting to name
 - ▣ orienting to human voice
- Delayed or absent pretend (symbolic) play
 - ▣ 16-18 mos: simple pretend play
 - ▣ 18-20 mos: complex pretend play
 - ▣ 24 mos: imaginative play



Symptoms Present Before 24 Months

- Poor joint attention: limited inclination to share enjoyment, interests, or achievements with other people
 - ▣ 8 mos: gaze monitoring (follows parents gaze)
 - ▣ 10-12 mos: follow a point
 - ▣ 12-14 mos: proto-imperative pointing (child begins to point to obtain an object)
 - ▣ 14-16 mos: proto-declarative pointing (child points or brings something to the parent with the goal of interacting with the parent)



Alternative Diagnoses

- Global developmental delay (mental retardation)
- Speech/language disorder
- Hearing impairment
- Vision impairment
- Mental health disorder (e.g. ADHD)
- Regulatory disorder
- Attachment disorder

Why Should We Screen

- Diagnosing developmental disorders is critical to children and their families
- Screening for and diagnosing developmental disorders is an integral function of the primary care medical home and an appropriate responsibility of all pediatric health care professionals
- Early identification should lead to further evaluation, diagnosis, and treatment
- Federal law (IDEA) mandates early identification of and intervention for developmental disabilities

AAP Policy Statement, Pediatrics, Vol 118, July 2006, 405-420

Why Screen Specifically for Autism

- Research tells us that early identification and treatment of autism brings dramatic improvement for most individuals
- Every dollar spent on a child before the age of five will save \$35-50 dollars over the course of that child's lifetime

Early Intervention Is Important for Children with Autism

- Early intervention provided to children with ASD/PDD before 3.5 years of age is more effective than after 5 years (Fensk, et al 1985 Harris and Handleman, 2000)
- Intervention provided before 3 years may be even more effective (McGee, 1999)
- Early Social Interaction Project (Woods & Wetherby, 2006)
 - 17 children who entered in 2nd year vs 18 who entered services in the 3rd year
 - 2rd year group had significantly better performance on verbal and nonverbal development but similar in play

When Should We Screen

- Developmental surveillance should be performed at every well-child visit
- Standardized developmental screening tests should be administered regularly at the 9, 18, and 30* month visits (*If there is not a 30 month visit, this should be done at the 24 month visit)
- At the 18-month visit, an autism specific tool should also be administered (earlier if there are risk factors present or whenever a concern about autism is raised)
- Repeat screening at the 24 or 30-month visit

AAP Policy Statement, Pediatrics, Vol 118, July 2006, 405-420 and Vol 120, Nov 2007, 1183-1215

How Should We Screen

- Suggested Assessment Tools
 - General Behavior and Development Surveillance
 - Watching children
 - Listening to parents concerns
 - Asking non-standardized questions
 - General Behavior and Development Screens
 - Ages and Stages Questionnaire (ASQ)
 - Parents Evaluation of Developmental Status (PEDS)

Ages & Stages Questionnaire

- Parent completed questionnaire
- Series of 19 age-specific questionnaires screening
 - ▣ Communication, gross motor, fine motor, problem-solving, and personal adaptive skills
- Results in pass/fail score for domains
- Ages 4 – 60 months
- Administration time: 10-15 minutes for parent, 2-5 minutes for provider
- Cost-\$4.60 for materials and administration time

Parents Evaluation of Developmental Status (PEDS)

- Parent completed questionnaire
- 10 questions about parent concerns about behavior, development, and academic progress
- Scores high, moderate, low risk for problems
- Ages birth-8 years
- Administration time 2 minutes if parents complete independently
- Cost-\$1.19 material and administration time

Autism Specific Screening Tools

- ❖ CHAT Baron–Cohen et al 1992
 - ❖ Parent completed questionnaire and provider administered items (5 minutes)
- ❖ Modified Check List for Autism in Toddlers(M-CHAT) Robins et al 2001
 - ❖ Parent completed questionnaire (5-10 minutes)
- ❖ PDD Screening test – Siegel 1996
 - ❖ Parent completed questionnaire (10-15 minutes to complete, 5 minutes to score)
- ❖ Screening Tool for Autism – Stone et al 2000
 - ❖ Directly administered tool (20 minutes)

Autism Specific Screening Tools (cont.)

- The Infant/Toddler Checklist from the Communication and Symbolic Behavior Scales Developmental Profile

Checklist for Autism in Toddlers (CHAT)

- Section A: To be completed by parent
 1. Does your child enjoy being swung, bounced on your knee, etc?
 2. Does your child take an interest in other children?
 3. Does your child like climbing on things, such as up stairs?
 4. Does your child enjoy playing peek-a-boo/hide-and-seek?
 - 5. Does your child ever pretend, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?**
 6. Does your child ever use his/her index finger to point, to ask for something?

CHAT (cont.)

- Section A (cont.)
 - 7. Does your child ever use his/her index finger to point, to indicate interest in something?**
 8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling or dropping them?
 9. Does your child ever bring objects over to you (parent) to show you something?



CHAT (cont.)

- Section B: Physician or healthcare provider
 1. During the appointment, has the child made eye contact with you?
 2. **Get the child's attention, then point across the room at an interesting object and say "Oh Look! There's a (name of toy)!" Watch child's face. Does the child look across to see what you are pointing at?**
 3. **Get the child's attention, then give child a miniature toy cup and teapot and say "Can you make me a cup of tea?" Does the child pretend to pour out tea, drink it, etc.?**

CHAT (cont.)

- Section B (cont.)
 4. **Say to the child "Where's the light?", or "Show me the light". Does the child point with his/her index finger at the light?**
 5. Can the child build a tower of bricks? (If so, how many____)

CHAT scoring

- Key items

 - Section A

 - A5: Pretend play

 - A7: Protodeclarative pointing

 - Section B

 - B2: Following a point

 - B3: Pretending

 - B4: Producing a point



CHAT scoring

- High risk for autism: fail (no answer) A5,A7, B2, B3, B4
- Medium risk for autism: fail A7, B4 (but not in high risk group)
- Low risk for autism: Not in other two risk groups

CHAT video

Modified Checklist for Autism in Toddlers (M-CHAT)

- 23 items (yes/no)
- parent report checklist
- children ages 16 months to 30 months old
- Six critical items were identified
- Positive screen: any 3 of the total items or any 2 of the 6 critical items failed

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.?
- 2.Does your child take an interest in other children?**
- 3.Does your child like climbing on things, such as up stairs?
- 4.Does your child enjoy playing peek-a-boo/hide-and-seek?
- 5.Does your child ever pretend, for example, to talk on the phone or take care of dolls, or pretend other things?

M-CHAT (cont.)

- 6.Does your child ever use his/her index finger to point, to ask for something?
- 7.Does your child ever use his/her index finger to point, to indicate interest in something?**
- 8.Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling, or dropping them?
- 9. Does your child ever bring objects over to you (parent) to show you something?**
- 10.Does your child look you in the eye for more than a second or two?
- 11.Does your child ever seem oversensitive to noise? (e.g., plugging ears)

M-CHAT (cont.)

- 12. Does your child smile in response to your face or your smile?
- 13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)**
- 14. Does your child respond to his/her name when you call?**
- 15. If you point at a toy across the room, does your child look at it?**
- 16. Does your child walk?
- 17. Does your child look at things you are looking at?

M-CHAT (cont.)

- 18. Does your child make unusual finger movements near his/her face?
- 19. Does your child try to attract your attention to his/her own activity?
- 20. Have you ever wondered if your child is deaf?
- 21. Does your child understand what people say?
- 21. Does your child sometimes stare at nothing or wander with no purpose?
- 23. Does your child look at your face to check your reaction when faced with something unfamiliar?



Red Flags

- RED FLAGS that should always prompt an evaluation regardless of screening tool
 - No babbling, pointing, or gestures by 12 months
 - No single words by 16 months
 - No 2 word phrases by 24 months
 - ANY loss of language or social skills

What To Do With a Positive Screen or When Multiple Risk Factors or Red Flags are Present

- **Refer for diagnostic evaluation and concurrently to Early Intervention/Early Childhood Education Services**
- Provide parental education
- Detailed history and physical
 - Are there clues to the diagnosis
 - Are there co-morbid medical problems, e.g. Seizures, Sleep disturbances, GI
- Hearing screen
- Consider lead screening (always get if PICA is present)
- Consider alternative diagnosis



What To Do With a Positive Screen (cont.)

- Medical Team Diagnostic Evaluation
 - ▣ Suggested for all children with possible ASD
- Major Centers in Oregon
 - ▣ CDRC-Portland, Eugene, Medford
 - ▣ Emanuel Children's Hospital
 - ▣ Portland Hearing and Speech Institute
 - ▣ Providence Neurodevelopmental Center for Children
 - ▣ Kaiser Permanente Developmental Pediatrics (KP patients only)

What To Do (cont.)

- **While waiting for a formal evaluation, give families local referrals and resources**
 - ▣ Consider local consultants (e.g. primary care providers who have an interest in child development)
 - ▣ Early intervention
 - ▣ Cacoon nurse
 - ▣ County Developmental Disability
 - ▣ Swindells Resource Center
(503-215-2429)



Additional Resources To Give To Families

- Autism society of Oregon
www.oregonautism.com
- Autism Society of America
www.autism-society.org
- Help Autism Now Society, HANS
www.helpautismnow.com
- First Signs
www.firstsigns.org
- Autism Speaks
www.autismspeaks.org
- Northwest Autism Foundation
www.autismnwaf.org

Summary

- Developmental surveillance and screening is important
- Autism specific screening should be done at all 18 month visits
- Screening should include a validated instrument
- **Anyone with a positive screen should be referred for a formal medical evaluation and diagnosis and EI evaluation**
- Anyone with a positive screen should be given information on local resources
- Early identification and treatment of autism brings dramatic improvement for most individuals

Additional Resources

- CHAT
 - www.autismresearchcentre.com/tests/chat_test.asp
- M-CHAT
 - www.dbpeds.org/media/mchat.pdf
 - www.firstsigns.org/downloads/m-chat.pdf
- The Infant/Toddler Checklist
 - www.brookespublishing.com/store/books/wetherby-csbsd/CSBSDP_Checklist.pdf

Additional Information on Treatment

- Early Intervention, ASAP
 - Intensive, 25 hours per week, 12 months per year
 - Target social attention, peer interaction, functional spontaneous language, appropriate toy play
- Applied Behavior Analysis
- Structured Teaching
- Developmental Models
- Speech and Language Therapy
- Social Skills Instruction
- Occupational Therapy and Sensory Integration
- Medical Management, e.g. Seizures, Sleep disturbances, GI, Psychopharmacology
- Complementary and Alternative Medicine

Additional Information on Implementing a Screening Program

- Establish who will take the leadership role
 - ▣ The leader needs to be committed to this problem and project
- Develop a shared agenda
 - ▣ Involve those most directly affected by the change
 - ▣ Explore general understanding of the problem
 - ▣ Provide information and answer questions
 - ▣ Discuss benefits and barriers to screening, practice resources, community resources

Implementing a Screening Program

- Planning for change
 - ▣ Establish a working group
 - ▣ Survey a few charts to assess your current screening levels
 - ▣ Develop a goal, (i.e. 90% screened at the 3 screening visits)

Implementing a Screening Program

- Establish protocols
 - Which screening tools will be used
 - How will eligible patients be identified
 - How will the screens move from storage to family to provider
 - Who will score the screening tools
 - How will abnormal screens be managed
 - How will community resources be updated

Implementing a Screening Program

- Establish a timeline and target date
- Establish a structured review and evaluation of protocol and mechanism for feedback
- All stakeholders should be surveyed:
 - Providers, Staff, and Families
 - Has screening improved care and satisfaction
 - Is the screening program efficient and a good use of time