The AAP Autism Screening Guidelines
Integrating Screening Guidelines In Primary Care Practice

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Autism Spectrum Disorder

- Includes Autistic Disorder, Asperger Syndrome, and PDD (Pervasive Developmental Disorder) nos
- Current prevalence: 6 per 1000 or 1 in 166
- Male : Female Ratio: 2:1 to 6.5:1, even higher in high-functioning ASD and Aspergers
- If an older sibling has ASD, the recurrence risk is 5-6%
ASD: Key Features

- Qualitative impairment in reciprocal social interaction
- Qualitative impairment in communication
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and other activities
Impairment in social relatedness

- Marked impairment of non-verbal behaviors (eye contact, gestures)
- Failure to develop age appropriate peer relationships
- Lack of social-emotional reciprocity (empathy)
- Lack of spontaneous seeking to share interests, achievement or enjoyment
Communication Impairment

- Absent/delayed language without attempts to compensate
- Marked impairment in ability to sustain conversation
- Stereotypic or repetitive use of language
- Lack of make-believe, social imitative play
Restricted/Repetitive Behaviors

- Restricted interests, abnormal in focus/intensity
- Inflexible, non-functional routines
- Pre-occupation with parts of objects
- Stereotypic motor mannerisms
- Insistence on sameness
ASD: Defining Characteristics

- Joint Attention
- Theory of Mind
- Symbolic Play
- Reciprocal Imitation
ASD: Etiology

- Mainly genetic in origin, and genetic mechanisms are complex

- Environmental factors may modulate phenotypic expression. Probably during fetal brain development.

- Implicated genetic sites on chromosomes 2, 3, 6, 7, 13, 15, 16, 17, 22
ASD subtypes

- **Idiopathic**: meet criteria for ASD with no comorbid medical condition known to cause autism. Most ASD. Less likely to have GDD/MR or dysmorphic features.

- **Secondary**: have an identifiable syndrome or medical disorder known to be associated with autism. Less than 10% of ASD.
Asperger’s Syndrome

- Separate from high-functioning autism
- Impaired social skills
- Restricted, repetitive patterns of behavior/interests

**BUT**

- Relatively normal language development
- No significant cognitive deficits
- V IQ > P IQ
- Older age at diagnosis
Secondary ASD

- Fragile X
- Tuberous Sclerosis
- Phenylketonuria
- Fetal Alcohol Syndrome
- Angelman Syndrome
- Rett Syndrome
- Smith-Lemli-Opitz Syndrome
The goal of General developmental screening & Autism screening is Early identification.
2001 statement:

Developmental surveillance is an important method of detecting delays. Moreover, the use of standardized developmental screening tools at periodic intervals will increase accuracy. Successful early identification of developmental disabilities requires the pediatrician to be skilled in the use of screening techniques, actively seek parental concerns about development, and create links with available resources in the community.
2006 statement

Developmental surveillance should be a component of every preventive care visit. **Standardized developmental screening tools should be used** when such surveillance identifies concerns about a child's development & for children who appear to be at low risk of a developmental disorder at the **9-, 18-, and 30-month* visits.**

Establish **working relationships** with state and local programs, services, and resources.

Use a **quality-improvement model** to **integrate surveillance and screening into office procedures** and to monitor their effectiveness and outcomes.

*Note: Because the 30-month visit is not yet a part of the preventive care system and is often not reimbursable by third-party payers at this time, developmental screening can be performed at 24 months of age. In addition, because the frequency of regular pediatric visits decreases after 24 months of age, a pediatrician who expects that his or her patients will have difficulty attending a 30-month visit should conduct screening during the 24-month visit.

Management of Children with Autism Spectrum Disorders, Scott M. Myers, Chris Plauche Johnson, and the Council on Children with Disabilities
Surveillance at every visit

Four risk factors for surveillance

Routine ASD screen at 18 months and 24 months
Surveillance factors

- Sibling with ASD
- Parent concern, inconsistent hearing, unusual responsiveness
- Other caregiver concern
- Pediatrician concern

If 2 or more, refer for EI, ASD Evaluation, and Audiology simultaneously.

If 1 and child at least 18 mos old, use screening tool. When screen is positive, refer for EI, ASD Evaluation, and Audiology.
The Role of Primary Care for Early Identification

- ASD is presumably present at birth, with onset of symptoms before 36 months.
- Accurate diagnosis possible at 18-24 months, maybe earlier (Early Sibs studies).
- Parents first voice concerns around 18 months, but diagnosis is typically not until 3 years or older.
Myths about Autism

☐ The child with autism...
  ■ Is not affectionate
  ■ Does not form attachments
  ■ Never makes eye contact
  ■ Does not communicate
  ■ Engages in self-stimulatory and repetitive behaviors all the time

☐ All children with repetitive behaviors have autism

☐ All children with poor social skills have Asperger syndrome
How early can ASD be identified?

- Home movies research 12-18 months *(Palomo et al, 2006)*
  - Less pointing to share an interest
  - Less eye contact as part of an integrated communicative act
  - Less communicative babbling, lack of response to name
  - Experts unable to detect autism in children <12 months
  - Confirms the reality of regression subset (33-39%)

- Research on baby siblings *(Mitchell et al, 2006)*
  - By 12 months, differences in gesture and receptive language
  - 15 of 97 siblings had ASD by age 2 years
Autism Screening Tool for Primary Care

The MCHAT
Modified Checklist for Autism in Toddlers: MCHAT

- For 16-48 months
- Sensitivity: 85% Specificity: 93%
- Questionnaire completed by parent
- 5-10 minutes to complete (parent)
- Simple Scoring
- Download form and scoring
  - www.firstsigns.org/downloads/mchat.PDF
  - www.firstsigns.org/downloads/mchat_scoring.PDF
M-CHAT: Sample Items

Parent report

- Does your child take an interest in other children?
- Does your child ever use his/her index finger to point, to indicate interest in something?
- Does your child ever seem oversensitive to noise?
- Does your child imitate you?
MCHAT Information

- MCHAT Follow-up Interview: clarifying questions that can be used to increase positive predictive value of a positive screen.

- Translations of MCHAT in 14 languages

http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html
Joint Attention is Key

- Protoimperative pointing: 12-14 months of age
- Protodeclarative pointing: 14–16 months of age
“Red Flags” for ASD in 2nd year

ASD red flags

- Regression
- “In his own world”
- Lack of showing, sharing interest or enjoyment
- Using the caregivers hands to obtain needs
- Repetitive movements with objects
- Lack of appropriate gaze
- Lack of response to name
- Unusual prosody/pitch of vocalizations
- Repetitive movements or posturing of body

Wetherby and Woods (2003) esi.fsu.edu
Does Screening Mean Becoming an Expert in Evaluating a Child’s Development? NO…

Screening is looking at the whole population to identify those at risk. Identified children are referred for assessment. Assessment determines the existence of delay or disability which generates a decision regarding intervention.

Screening is optimized by Surveillance… periodic screening gives a longitudinal perspective of a child’s developmental progress.
The Office Systems Approach

- Organizational tool: Getting Started Worksheet

- Multidisciplinary: involves practice staff at all levels

- Networking: guides practice in building relationships with community partners
Using a Preventive Services Prompting Sheet

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Coding & Billing

- Screening code: 96110
- 0.25 RVU's
- Reimbursement variable
Role of the Medical Home

- Screening & surveillance
- Partnering with parents as experts on their child
- Providing information and resources for parents
- Networking with community resources
- Facilitate linkages for families with Part C, preschools, and other diagnostic and treatment resources.
AAP Autism Toolkit

- CD ROM
- Identification, including descriptions of Level 1 (for primary care) and Level 2 screening tools
- Referrals
- Physician Fact Sheets
- Family Handouts
When the MCHAT or Surveillance is Positive

AAP Recommendation is for simultaneous referral for:

- Evaluation and diagnosis
- Early Intervention services
- Audiologic evaluation
Referrals for Positive MCHAT

- Evaluation and Diagnosis:
  Also, if concern re global delays, intellectual disability, or suspect Genetic or neurologic disorder:
  D&B Pediatrician/Geneticist/Neurologist
- Early Intervention Services (Part C)
- Audiologic Evaluation: Pediatric Audiologist
Autism Diagnosis Tools

- **CARS (Childhood Autism Rating Scale):** For > 2 yrs. old; 15-item, direct observation; 5-10 minutes.

- **ADOS (Autism Diagnostic Observation Schedule):** For toddlers to adults; direct observation, 30-45 minutes.

- **ADI-R (Autism Diagnostic Interview):** For mental age > 2 yrs.; structured interview; 1.5 – 2.5 hours.
Goals of Treatment

☐ Minimize core features

☐ Maximize functional independence

☐ Maximize quality of life

☐ Maximize family function
Treatment is Comprehensive

- Intervention as soon as diagnosis suspected; do not wait for definitive diagnosis
- 25 hours per week, 12 months per year in “systematically planned, developmentally appropriate educational activities.”
- Low student:teacher ratio.
- Inclusive experience with typically developing peers.
Educational Interventions are Foundation of Treatment

- Applied Behavioral Analysis
- Structured teaching – TEACCH
- Developmental
- Relationship focused
- Speech and Language Therapy, including use of augmentative and alternative communication
- Social Skills Instruction – joint attention
- OT (Sensory Integration) Therapy – evidence base not yet established
Common Behavioral Issues

- Disruption/aggression 15-64%
- Self-injurious 8-38%
- Eating 25-52%
- Sleeping 36%
- Toileting 40%

Problems correlate with rigidity/restricted interests/need for sameness
Behavioral Treatment

Positive Behavioral Support

- Proactive arrangement of the physical environment to prevent occurrence of problem behavior
- Routine curriculum incorporates social skill development
- Functional behavioral analysis used for individualized behavior management plans
Medical Management

- Challenges in routine health care due to difficulties with social interaction, communication, and negotiating a new and unfamiliar environment.
- Average visit requires twice as much time as for a child without an ASD.
- Strategies in the office to promote familiarity
Associated Medical Conditions

- Gastrointestinal: chronic constipation/diarrhea, recurrent abdominal pain. Studies inconsistent, with rates of 9% to 70%
- Seizures: 11 – 39%. More likely with co-morbid severe global delays and motor deficits.
- Sleep problems
Psychopharmacology

- Goal is to minimize core symptoms and associated behaviors, and facilitate interventions.
- Be sure environmental and behavioral strategies are in place.
- Pharmacotherapy is not the primary treatment.
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52 – 92% of parents of children with autism report using CAM for their children

NIH budget for CAM research - $120M

PCP needs to: be knowledgeable, provide balanced information, maintain communication, help families know how to evaluate information, evaluate CAM studies by clinical research standards.
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Resources for Clinicians and Families

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☐ TEACCH  www.teacch.com
☐ FSN (Family Support Network)  http://fsnnc.med.unc.edu

National
☐ www.firstsigns.org
☐ www.aap.org
☐ www.cdc.gov/ncbddd/autism/screening
☐ www.cdc.gov/ncbddd/autism/actearly
☐ www.nichd.nih.gov/autism
☐ www.ibis-network.org
☐ www.autismspeaks.org