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



A Resource Toolkit for Clinicians

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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
|s
Early identification

AAP Policy Statements: Key Points

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.**



AAP Policy Statements: Key Points

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.*

- Identification and Evaluation of Children with Autism Spectrum Disorders, Chris Plauche Johnson, Scott M. Myers, and the Council on Children with Disabilities.
- Management of Children with Autism Spectrum Disorders, Scott M. Myers, Chris Plauche Johnson, and the Council on Children with Disabilities

AAP Policy Statements

Autism 2007

- Surveillance at every visit
- Four risk factors for surveillance
- Routine ASD screen at 18 months and 24 months

AAP Policy Statements

Autism 2007 (cont.)

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
- Huge potential benefits of early treatment

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

Name				DOB	Chart #					Place X in box when done. (or date in box if off schedule)				
	1 wk	1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	2 yr	30 mo	3 yr	4yr	5yr
Visit														
Date														
length/ht														
wt														
hc														
bmi														
bp														
hearing							or			or				
vision														
Edinburgh														
ASQ										or				
autism risk?														
MCHAT														
lead														
hgb														
dental var														
TB ?'s														
ROR book														

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

<input type="checkbox"/> Disruption/aggression	15-64%
<input type="checkbox"/> Self-injurious	8-38%
<input type="checkbox"/> Eating	25-52%
<input type="checkbox"/> Sleeping	36%
<input type="checkbox"/> 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

PHARMACOTHERAPY

Target Behavior	Medication	Studies to Support	Comments
ADHD behaviors	methylphenidate	Y, limited	
	atomoxetine	Y, limited	
	clonidine/guanfacine	very limited data	modest effect
	beta blockers	not supported	
	amantadine	Y, limited	
agitation/overarousal agression	risperidone	Y (FDA approved)	risks:obesity, hyper- lipidemia, metabolic syndrome
	other atypicals	N	
compulsions and anxiety	fluoxetine	Y	
	other SSRI's	limited	
	bupirone	no data	
sleep disruption	melatonin	Y	circadian rhythm dis
	hypnotics	not well studied	
severe mood disorder	risperidone	Y	risks:obesity, hyper- lipidemia, metabolic syndrome
	valproate	Y	
	lamotrigine	not supported	
	other AED's	no data	
	lithium	Y, limited	
self injury	risperidone	Y	
	naltrexone	Y	

Complementary & Alternative Medicine

- ❑ 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.

CAM

	Studies Support	Promising Studies	No Studies	Comment
BIOLOGIC				
Immunoglobulin	Y&N			pos & neg sm studies invasive & expensive
Antivirals			X	
Antifungals			X	endoscopic studies- no yeast overgrowth
Chelation			X	2 deaths
Secretin	N			>12 studies
Yeast-free diet			X	
Gluten-free diet		1 study		NIH studies in progress
Vit B6	N			
Vit C		1 study		improved sensorimotor
Magnesium	N			
Dimethylglycine	N			
Omega 3's		1 study		may help hyperactivity
NON-BIOLOGIC				
Auditory Integration	N			
Behavioral Optometry			X	
Craniosacral Manipulation			X	
Dolphin-assisted			X	
Music therapy		X		Improved communica- tion
Facilitated Communication	N			

Resources for Clinicians and Families

NC

- 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