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Identification, Evaluation, and Management of Children with Autism Spectrum Disorder

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Learning Objectives

- Describe effective methods for screening and early identification of children with autism spectrum disorder (ASD) in primary care.
- Report the components of diagnostic and etiologic evaluation of children with ASD.
- Identify evidence-based interventions for the core deficits of ASD and associated co-occurring conditions.
- Report strategies to engage in shared decision-making and partnership with families/caregivers of children and youth with ASD.

Autism Spectrum Disorder (ASD): Introduction

- A neurodevelopmental disorder characterized by social and communication impairment and restricted and repetitive behaviors.
- ASD is common and reported prevalence is increasing.
  - 1 in 54 children 8 years of age meet criteria for ASD.
    - 1 in 64 children 4 years of age meet criteria for ASD.
  - More than 5 million Americans in the United States have ASD.
- All pediatric clinicians can expect to have children and youth with ASD in their practice.

Screening and Surveillance

- Developmental screening
  - Formal process that uses standardized tests at discrete ages
- Developmental surveillance
  - An ongoing, flexible, longitudinal, and cumulative process in which health care professionals identify children who may have developmental and behavioral problems

Screening and Surveillance

- General developmental screening should occur at the 9, 18, and 30 month well child visits.
- ASD specific screening should occur at the 18 and 24 month well child visits.
- Developmental surveillance should occur at every well child visit.

Note: More information on developmental surveillance and screening will be presented in a future PCO Webinar.

Screening and Surveillance

- The AAP does not support or endorse the use of any developmental screening tool over another.
  - Examples are provided in the ASD clinical report and AAP STAR Center website.
- Results of screening tests are not diagnostic.
  - Children identified at risk through screening and surveillance should have a diagnostic evaluation.
- Early identification and intervention can and does influence outcomes.
  - Children should be referred for developmental intervention as soon as the need becomes apparent and not wait for ASD diagnostic evaluation to take place.

Barriers to Early Identification of ASD

- Milder symptoms
- Average range intelligence
- Boys identified more frequently than girls (4:1)
- Co-existing conditions like attention-deficit/hyperactivity disorder (ADHD)
- Race, ethnicity, socioeconomic factors
- Culturally sensitive screening measures

Diagnostic Evaluation

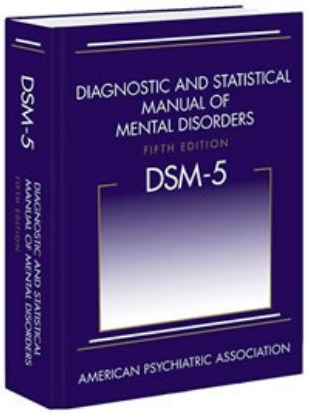
Diagnostic and Statistical Manual, Fifth Edition (DSM-5)

Deficits in social communication and interaction (all 3 required):

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behavior
3. Deficits in developing and maintaining relationships

Restricted, repetitive behavior/interests (2/4 required):

1. Repetitive speech, movements, or use of objects
2. Excessive adherence to routines
3. Highly restricted, fixated interests
4. Hyper/hypo-reactivity to sensory input



Diagnostic Evaluation

- Diagnosis depends on history and observation of specific behaviors and behavioral responses.
- Based on comprehensive history, direct observation, and clinical expertise
- No laboratory test or single biological marker is associated with ASD.
- General pediatricians, subspecialty pediatricians, and child psychologists comfortable with application of DSM-5 criteria can make an ASD diagnosis.

Diagnostic and Etiological Evaluation

- Medical, family, and social history
- Co-occurring conditions
  - Developmental
  - Behavioral
  - Medical
- Neurological examination
- Genetic evaluation
- Consider metabolic evaluation

Medical, Family, and Social History

- Reflects longitudinal experience with the patient.
- Reflects the impact of symptoms on function.
- History can be supported and informed by questionnaires.
  - No single questionnaire is appropriate for all settings or children.

Observation of behavior informs application of DSM-5 criteria.

Evaluation of Co-Occurring Developmental-Behavioral Conditions

- Cognition
- Language
- Adaptive function
- Motor
- Sensory processing
  - Hearing
  - Vision

Genetic Evaluation

- Should be recommended and offered to all families as part of the etiologic work up
  - Comprehensive history and physical examination
  - Consider referral to pediatric genetics
  - Laboratory studies
    - Fragile X
    - Chromosomal microarray
    - Workup may include whole exome sequencing

Neuroimaging, EEG, Metabolic Evaluation

- Neuroimaging is not recommended in routine diagnostic evaluation.
- EEG is not recommended as a routine baseline evaluation in the absence of clinical concern about seizures, atypical regression, or other neurological symptoms.
- Consider metabolic evaluation with consistent history.

Interventions

- Goals and Benefits of Intervention
  - Minimize core deficits
  - Maximize function
  - Eliminate problem behaviors
  - Increase school readiness
  - Improve academic performance
  - Support child and family

- Individualized based on child and family needs and goals

Intervention

- Most effective if early, intense, and involves the family.
- Helps families reinforce developmental skill building.
- Principles of behavioral intervention are associated with skill acquisition and improved outcome.

Interventions

- Early Intense Behavioral Intervention (EIBI) uses principles of applied behavior analysis (ABA) to teach communication and developmental skills.
  - Parent mediated approach can be used.
- Naturalistic Developmental Behavioral Interventions (NDBI) combine behavioral approaches with targeted interventions to enhance communication and development in natural settings.

Speech and Language Therapy/Communication

- Communication should be reinforced across the day.
- Practice language skills in integrated settings.
- Include intervention for pragmatics (social aspects) of language.
- About 30% of children with ASD do not speak.
  - Childhood apraxia of speech
  - Intellectual disability
- Supports for communication may include
  - Sign
  - Picture Exchange Communication System (PECS)
  - Voice output devices

Free and Appropriate Public Education (FAPE)

- Individuals with Disabilities Education Act (IDEA, 1974) & Rehabilitation Act (1973)
  - Entitled to early intervention (EI) and special education
- Least restrictive environment
- Integrated and co-taught classrooms
- Hierarchy of services
  - Response to intervention
  - Section 504 plan
  - Individualized Educational Program (IEP)

Social Skills Training/Social Communication

- Important to address in school and community settings
- Adult guided approaches
  - Social stories
- Peer mediated strategies
  - Reinforce peers to include children with ASD in play during recess
  - Group based approaches to learning social language
    - Social Thinking©
    - PEER Group©

Co-Occurring Conditions and Symptoms

- Medical conditions
  - Overweight/obesity
  - Sleep disorders
  - Gastrointestinal conditions
  - Seizures
- Behavioral/psychiatric conditions
  - ADHD
  - Anxiety
  - Irritability and aggression
  - Mood disorders

Psychopharmacology

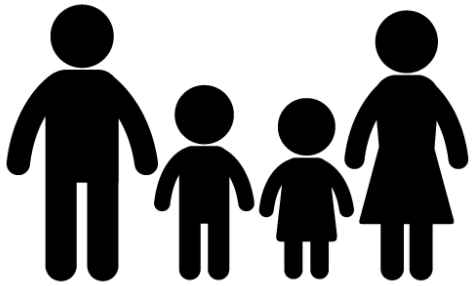
- May be helpful in addressing co-occurring symptoms or disorders, AFTER BEHAVIORAL INTERVENTIONS considered
- Clinicians should understand
  - Indications
  - Contraindications
  - Dosing
  - Potentially adverse effects
  - Drug-to-drug interactions
  - Monitoring requirements
  - Additive effects of behavioral and medication interventions

Complementary and Integrative Medicine (CIM)

- Families of children with ASD frequently (≥50%) use CIM treatments despite lack of evidence for their use.
- Characteristics associated with use are increased educational achievement of parents, younger age of children with ASD, and use of prescribed medication.
- Many treatments are benign, but some are associated with potential for significant harm.
- Use resources to learn more about CIM treatments.

Partnering with Families

- Provision of patient- and family-centered care is central to the medical home model for all children, including those with ASD.
- ASD has a significant impact on families.
  - Increased stress
  - Increased health care cost
  - Missed work/employment



Partnering with Families

- Connect family and peer support organizations, e.g.
  - Family to Family Health Information Centers
  - Parent 2 Parent USA
  - Autism Speaks
- Engage in shared decision-making
  - A process where clinicians and patients/families work together to select tests, treatments, management, and support packages – based on clinical evidence and patient/family preferences
  - Provides information on options, outcomes, supports, and uncertainties

Transition to Adulthood

- Planning for children and teens with ASD to understand and participate in their own health care should begin early in adolescence.
  - Planning to transition to adult health care systems should begin around age 12.
- Guardianship or alternatives to guardianship may need to be considered and discussed.
- Partner with families and youth to plan for health, academic, job, leisure/social, and residential needs.

Summary/Take Home Points

- ASD is a common neurodevelopmental disability that significantly impacts the lives of youth and families.
- Early identification and intervention improves outcomes.
- Collaboration across systems of care is needed to facilitate evidence-based interventions for core deficits of ASD and associated co-occurring conditions.
- Family-centered care and shared decision-making are critical components of the medical home model for youth with ASD and their families.

Resources: AAP Policy

- Identification, Evaluation, and Management of Children With Autism Spectrum Disorder https://pediatrics.aappublications.org/content/145/1/e20193447
- Executive Summary: Identification, Evaluation, and Management of Children With Autism Spectrum Disorder https://pediatrics.aappublications.org/content/145/1/e20193448
- Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening https://pediatrics.aappublications.org/content/145/1/e20193449
- Shared Decision-Making and Children with Disabilities: Pathways to Consensus https://pediatrics.aappublications.org/content/139/6/e20170956
- Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home https://pediatrics.aappublications.org/content/142/5/e20182587

Resources: AAP Tools

- www.aap.org/autism
  - *Caring for Children with Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians*, 3rd Edition https://toolkits.solutions.aap.org/autism/home
  - *Autism Spectrum Disorder: What Every Parent Needs to Know*, 2nd Edition https://shop.aap.org/autism-spectrum-disorder-paperback
  - HealthyChildren.org ASD articles for families/caregivers www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx
- Bright Futures National Center https://brightfutures.aap.org/Pages/default.aspx
- National Resource Center for Patient/Family-Centered Medical Home https://medicalhomeinfo.aap.org/Pages/default.aspx
- Screening in Practices Initiative www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/default.aspx

Resources: Other Organizations

- Family-to-Family Health Information Centers
  https://familyvoices.org/lfpp/f2fs
- Centers for Disease Control and Prevention
  - Autism and Developmental Disabilities Monitoring Network
    www.cdc.gov/ncbddd/autism/addm.html
  - Learn the Signs. Act Early. www.cdc.gov/ncbddd/actearly/index.html
- Autism Treatment Network Toolkits
  https://airpnetwork.org/what-we-do/toolkits
- Title V Children and Youth with Special Health Care Needs Programs
  www.amchp.org/Policy-Advocacy/MCHAdvocacy/Pages/StateProfiles.aspx
- Association of University Centers on Disabilities
  www.aucd.org/template/index.cfm

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