Autism: AAP guidance includes updates, searchable topics, executive summary
by Susan L. Hyman M.D., FAAP; Susan E. Levy M.D., FAAP

Representing the first update in 12 years, an AAP clinical report on autism spectrum disorder (ASD) is a comprehensive document that is searchable by topic for easy information access.


Following are significant changes in the report.

Prevalence increases

Since 2007, efforts have been made to increase awareness of ASD symptoms, promote universal screening in primary care and advocate for community services. The reported prevalence of ASD has increased from one in 155 (2007) to one in 59 (2018). While most individuals with ASD are male, there may be different phenotype(s) in females accounting for this difference.

Children with average cognition, attention-deficit/hyperactivity disorder (ADHD) and underserved groups may be diagnosed later. About 40% of individuals with ASD also have intellectual disability.

Single diagnosis

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) published in 2013 consolidated the category of pervasive developmental disorders (PDD) (autistic disorder, Asperger disorder, PDD-NOS [not otherwise specified] and disintegrative disorder) into a single diagnosis of ASD with modifiers (with intellectual disability). It also allowed diagnoses of co-occurring conditions like ADHD and anxiety.

DSM-5 describes levels of symptoms and support needs within two categories: impairment in social communication and restricted and repetitive behaviors.

Early diagnosis, early intervention impact outcomes

The AAP continues to recommend routine developmental and ASD screening in toddlers. While ASD can be diagnosed when a child is younger than 2 years of age, the average age of diagnosis in the U.S. remains over 3 years of age.

Although screening tools are being developed and studied, the AAP does not endorse a specific tool (see resources).

Most respondents to a 2017 pediatric practice survey reported routine ASD screening. Improving methods to identify toddlers at risk for ASD is a research imperative.

Practices should track children at risk to ensure they have diagnostic evaluation(s) and indicated services throughout childhood, as some children may not be identified until school age.

Waits for diagnostic evaluations at specialty clinics often are long. When developmental concerns are identified, pediatricians should refer children to early intervention (0-3 years of age) or school services to initiate services.
Early identification, diagnosis and referral to evidence-based interventions are associated with improved outcomes.

**Interventions**

Evidence supports the use of behavioral interventions (e.g., applied behavior analysis) for skill building. All states require insurance coverage of autism services. Combinations of developmental and behavioral approaches and inclusion of parent-mediated therapies have moved from research to community settings.

At school age, social skills should be addressed through pragmatic language therapy, teaching play and interaction with peers. Many students with ASD have challenges with executive functioning, ADHD or anxiety, impacting academic performance and requiring treatment. Behavioral approaches should be implemented prior to consideration of medication. Interventions targeting sensory symptoms of ASD are popular despite limited evidence.

**Genetics and neurobiology**

Research examining the genetics and neurobiology of ASD has progressed rapidly.

Many genes associated with brain development have been identified, and 30%-40% of individuals have findings on chromosomal microarray testing. Families should be counseled about the genetics of ASD and offered testing. Understanding of gene-environment interaction and research into potential immunologic factors that affect brain development are increasing.

**Co-occurring medical conditions**

Pediatricians often see young children with severe food selectivity and sleep problems who are later diagnosed with ASD.

Food refusal on the basis of texture, color, presentation or taste may be associated with sensory differences, anxiety or perseverative rigidity. Most children with ASD do not have nutritional deficiencies, but a dietary history should be included during health supervision. Obesity is more common. Constipation is common and may be associated with behavioral symptoms.

Problems with sleep onset and maintenance are frequent in children with ASD and should be addressed with behavioral management strategies. Melatonin may be helpful with sleep onset.

Wandering is a major cause of morbidity and mortality and should be addressed through anticipatory guidance throughout the lifespan.

While a routine electroencephalogram is not necessary, individuals with ASD are at increased risk for seizures.

Medical aspects of ASD should be identified and managed in the medical home with referral to specialty care as needed.

**Lifespan issues**

Families should be supported to work on transitions to post-secondary education, work and adult health providers. Pediatricians should begin discussing transition needs in middle adolescence and have a process in their practices.
Collaboration with families and patients

While choices of intervention extend beyond the medical arena, the pediatric health care provider is a resource for information, referral and interpreting often-conflicting claims. Involving patients in shared decision-making allows the goals and values of the patient and family to help guide therapeutic choices. This leads to enhanced satisfaction with the care experience.

Need for research and program development

Progress has been made in understanding the evaluation, neurobiology and treatment of ASD. However, much work remains related to accurate and early diagnosis; understanding the underlying brain functions so targeted treatment can be tested; and developing equitable, affordable interventions for affected individuals and families from diagnosis through employment and adult life.

Drs. Hyman and Levy are lead authors of the clinical report and executive summary. Dr. Hyman is a member of the AAP Council on Children with Disabilities (COCWD) Executive Committee and former chair of its Autism Subcommittee. Dr. Levy is immediate past chair of the Autism Subcommittee and former member of the COCWD executive committee.

Resources

- The clinical report includes 11 tables of resources, including autism screening tests.
- AAP Autism Initiatives
- AAP autism toolkit
- Healthychildren.org article, “What are the Early Signs of Autism?”
- National Autism Association Big Red Safety Box on wandering
- Improving transitions