



Executive Summary: Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

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INTRODUCTION

Autism spectrum disorder (ASD) is a common neurodevelopmental disorder with reported prevalence in the United States of 1 in 59 children (approximately 1.7%). ASD significantly influences the lives of affected children and families because they may need extensive behavioral, educational, health, and other services. Primary care providers play a critical role in identifying, diagnosing, and managing ASD in children and providing support for their families. This document provides a summary of the clinical report "Identification, Evaluation, and Management of Children with Autism Spectrum Disorder," published concurrently in the online version of *Pediatrics*. In the years since 2007, when the American Academy of Pediatrics published the clinical reports "Identification and Diagnosis of Children with Autism Spectrum Disorders" and "Management of Children with Autism Spectrum Disorders," reported prevalence rates of children with ASD have increased, understanding of potential risk factors has expanded, awareness of co-occurring medical and behavioral conditions and genetic contribution to etiology has improved, and the body of research supporting evidence-based interventions has grown substantially. The updated document discusses evaluation and treatment as a continuum in 1 publication with a table of contents to help the reader identify topic areas within the report. ASD is more commonly diagnosed than in the past, and the significant health, educational, and social needs of individuals with ASD and their families constitute an area of critical need for resources, research, and professional education.

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1. TIMELY DIAGNOSIS, EARLY IDENTIFICATION, AND EVIDENCE-BASED INTERVENTION

- o *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) diagnosis: With the publication of the DSM-5 in 2013, there is a single category of ASD, replacing the subtypes of autistic disorder, Asperger syndrome, and pervasive developmental disorder not otherwise specified in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*. Core deficits are identified in 2 domains: social communication and interaction and restrictive, repetitive patterns of behavior. The DSM-5 recognizes that other co-occurring conditions like intellectual disability, language disorders, and behavioral health conditions such as attention-deficit/hyperactivity disorder and anxiety disorders may also be diagnosed in individuals with ASD. A diagnosis of ASD is made by a clinical evaluation that supports the DSM-5 criteria, including history and observation of characteristic behaviors, preferably using standardized approaches. Independent of age, a child who is evaluated for ASD should have standardized assessment of psychoeducational, adaptive, and language abilities, including pragmatic or social language.
- o Early identification: General developmental screening using a validated tool continues to be recommended at 9, 18, and 30 months of age. ASD is common, can be diagnosed as young as 18 months of age, and has evidence-based interventions. Research into newer tools has promise to extend the age of diagnosis lower. Therefore, ongoing developmental and behavioral surveillance in addition to screening for ASD at 18 and 24 months of age continues to be recommended in primary care.
- Screening or surveillance may take place in other settings, with communication of findings to the primary care provider. More accurate and culturally sensitive screening approaches are needed. Ongoing developmental surveillance through school age is important. Children with typical intellectual abilities may not be diagnosed until their social differences become evident with the increased demands of the school environment. Clinicians need to recognize that some children will be at increased risk for ASD because they have a sibling with ASD, were born preterm, were exposed to teratogens (eg, valproic acid), or have other risk factors.
- o Timely diagnosis: Toddlers and children should be referred for diagnostic evaluation when increased risk for developmental disorders (including ASD) is identified through screening and/or surveillance. Most children with ASD will have other developmental issues. Standard of care requires evaluation of multiple streams of development, including cognitive, communication, motor, and adaptive skills. In many settings, this evaluation may be best accomplished by team evaluations, including, for example, psychology, speech and language, occupational therapy, physical therapy, and special education. This type of evaluation may occur through an early intervention program, school system, or appropriate insurance-funded evaluator(s) whenever ASD, with or without other delays, is suspected. Children should be referred for intervention for all identified developmental delays at the time of identification and not wait for an ASD diagnostic evaluation to take place. The referral should be to a clinician experienced in diagnosis, which might be a developmental-behavioral or neurodevelopmental pediatrician, neurologist, psychiatrist, psychologist, or primary care provider with requisite training. Clinicians should be particularly aware of the potential for delayed diagnosis in children from underserved groups and whose families speak languages other than English.
- o Early and effective intervention: Clinicians should respond appropriately to family or clinical concerns and results of screening to avoid delays in diagnosis and treatment. Intervention for the communicative, adaptive, and behavioral deficits associated with ASD should take place as soon as the need becomes evident. Intervention is most effective if it is early, intense, and involves the family. Research has demonstrated that interventions using principles of behavioral intervention are associated with skill acquisition and improved outcome. There is evidence that training parents to support developmental skill building is helpful. Primary care providers should help families learn to interpret evidence about interventions so they can make informed decisions about their child's care. Many interventions, including many nutritional interventions, do not have evidence to support their use at this time. Families should be referred to community support resources and be included in the shared decision-making process.
- o Etiologic evaluation: The pediatric provider needs to consider genetic and neurologic disorders that are associated with ASD. Knowledge of the etiology of the child's condition can help guide monitoring for co-occurring conditions, potentially influence therapy choices, help families understand recurrence risk estimates, and help therapists provide individualized behavioral, educational, motor, and communication intervention plans.

Families should be offered genetic evaluation, including chromosomal microarray and fragile X testing, with consideration of other cytogenetic and molecular testing, as indicated. Consultation with a pediatric geneticist may be warranted. Metabolic testing, EEG, neuroimaging, and additional workup of medical symptoms are guided by history and physical examination.

- o Medical management of co-occurring conditions: The value of routine primary care visits and anticipatory guidance for children with chronic conditions is stressed. The primary care provider should be aware of common co-occurring conditions and include surveillance for and management of these conditions in the context of routine care with subspecialty referral, as appropriate. Examples of common co-occurring conditions are disorders of sleep, feeding problems, gastrointestinal symptoms, obesity, seizures, attention-deficit/hyperactivity disorder, anxiety, wandering or elopement, and others.

High-quality pediatric care calls for the development of systems to promote accurate and early identification, cost-effective and timely diagnosis, prompt implementation of evidence-based interventions, involvement of the patient and family in shared decision-making, and steps toward elimination of disparities in access to care for all children and youth with ASD. Care within a medical home, using a chronic care model in which health and community systems interact with informed patients and families to ensure more-satisfactory outcomes, is recommended for children with ASD.

2. COLLABORATION OF SYSTEMS OF CARE

- o Evidence-based interventions: Children and youth with ASD

should be provided evidence-based interventions to address the core social communication and interaction and restricted and repetitive behavior symptoms as well as associated impairments. Attention to social skills development should be addressed in school, community, behavioral health, and family settings. The primary care provider should be aware of the recommendation for educational services in the least-restrictive environment and the hierarchy of educational interventions based on a student's needs in school rather than a medical diagnosis of ASD.

- o Common co-occurring conditions: Although ASD is a neurodevelopmental disorder characterized by symptoms related to social interaction and repetitive behaviors, there is increasing awareness that physical, behavioral, and mental symptoms affect the care of children and youth with ASD. Children and youth with ASD should have anticipatory guidance for common co-occurring conditions in the context of well-child care, referral as necessary for specialty care, and ongoing management as possible in the medical home.
- o Behavioral health interventions: Providers should be aware of the common behavioral challenges faced by children and youth with ASD and be prepared to provide parent counseling and initial management of sleep problems, food refusal, and disruptive behaviors, with referral to appropriate specialty and mental health care if needed. It is important to evaluate the medical and behavioral causes for behavior change. Pain and discomfort from medical conditions and behavioral modifications should be addressed. Medication may be a useful addition for management of attention, hyperactivity, anxiety,

and disruptive behaviors as part of an overall treatment strategy.

- o Community services: The primary care provider needs to know where to refer families for information about community services, such as respite and leisure activities for individuals with ASD and other developmental disabilities. To promote wellness, communities should provide opportunities for individuals with ASD to participate in inclusive and appropriate active leisure activities. Clinicians should educate families about managing ASD as a chronic condition.

3. PLANNING FOR ADOLESCENCE AND TRANSITION TO ADULT SYSTEMS OF CARE

- o Communities should build services to promote social skills appropriate for work and postsecondary education, access to appropriate medical and behavioral health services, job skills development, and community leisure opportunities. The medical home provider should support the family and youth to advocate for appropriate postsecondary work or schooling, residential supports, and activities to maintain a healthy lifestyle. The family needs to plan for the needs of the child in adulthood by making the necessary preparations for public programs (such as Supplemental Security Income) and personal financial planning.
- o Pediatricians need to engage with families and youth to plan a transition to adult medical and behavioral health care.

4. PROMOTING SHARED DECISION-MAKING WITH INDIVIDUALS WITH ASD AND THEIR FAMILIES

Shared decision-making calls for the health care provider to engage in respectful, reciprocal dialogue to plan and monitor choices in care. The pediatrician can help educate youth

with ASD and their families about how to evaluate the evidence for interventions, advocate for participation in clinical research when appropriate, refer families to support organizations, include the patient in decision-making, and prepare families to navigate transitions.

5. ONGOING EDUCATION OF PEDIATRIC PROVIDERS TO SUPPORT AN INFORMED MEDICAL HOME FOR CHILDREN AND YOUTH WITH ASD

All children and youth with ASD should have a medical home, a source of care that is accessible, collaborative, culturally sensitive, knowledgeable, and cost-effective. To best serve patients and families affected by ASD, the clinician caring for children and youth with ASD should be familiar with issues related to diagnosis, co-occurring medical and behavioral conditions, and the impact of ASD on the family to provide a medical home for these patients. Actively addressing capacity building to care for children and youth with ASD requires initiatives directed at provider education and practice quality improvement and public health, educational, and social programs to support families in their journey from diagnosis to service provision to the transition to adult care.

6. SUPPORT FOR A NATIONAL AGENDA FOR BASIC, CLINICAL, AND HEALTH SERVICES RESEARCH ABOUT ASD

The American Academy of Pediatrics supports the current approach taken by the Interagency Autism Coordinating Committee of the National Institutes of Health of including representative stakeholders in planning a meaningful research agenda. Stakeholders include families and affected individuals, scientists, clinicians, and public health agencies. This committee's 2009 strategic plan, updated in 2017, identified 7 areas for research funding: (1) early

detection, (2) underlying biology, (3) genetic and environmental risk factors, (4) treatments and interventions, (5) services and implementation science, (6) life span services and supports, and (7) epidemiological surveillance and infrastructure. It is important that multiple levels of inquiry be pursued simultaneously to inform evidence-based clinical care. These include the following:

- o basic and translational science in the areas of genetics and epigenetics, neurobiology, environmental risk factors, and psychopharmacology to understand the typical and atypical brain development and function to develop ASD-specific behavioral and pharmacologic therapies;
- o clinical trials to test focused interventions informed by translational studies to provide the evidence necessary for community implementation;
- o epidemiological surveillance to gather data important for planning for current and future needs, including screening, diagnosis, and life span health and mental health services, with special attention to underserved populations; and
- o health services research to provide guidance for comprehensive, accessible, and culturally appropriate medical, educational, and behavioral care for children, youth, adults, and families affected by ASD.

Research in all of these areas is critical to move forward with early diagnosis, effective treatment, and evidence-based interventions at each age. To provide appropriate care to all children and families affected by ASD, organizations responsible for health, education, social services, and public health need to collaborate and build integrated and adequately funded and staffed systems. The pediatric health care provider plays a critical role in identifying young children at risk for

ASD; shepherding these children through diagnosis and into effective interventions; supporting the families, including siblings; anticipating and managing co-occurring health and behavioral disorders; and preparing the youth and family for transition to adult services. The updated clinical report provides the health care provider with information and resources to support the care of the child and family affected by ASD.

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ABBREVIATIONS

ASD: autism spectrum disorder
DSM-5: *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*

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POTENTIAL CONFLICT OF INTEREST: MeMix LLC is a company that makes an app (for phones). Dr Levy is on the advisory board for the app's development. This app is being developed to assist in nutritional and dietary management of children with autism. Dr Levy has not received any money yet from this company. This app is the focus of a National Institutes of Health R21 grant, for which Dr Levy is funded for ~2% of her salary. Once it is studied and marketed (if appropriate), Dr Levy will (possibly in the future) earn some money. Dr Levy has worked with MeMix LLC from 2015 to the present. Dr Hyman is the site principal investigator of a clinical trial of a novel agent being tested to promote social function in patients with autism. The University of Rochester (Dr Hyman's institution) was 1 of >40 sites and had 2 study participants in 2018. University of Rochester will be leaving the trial in 2019 (withdrawal submitted) because of staffing, and that reimbursement for staff time does not cover the cost of participation. Funding was for the staff to complete the assessments required for the clinical trial. Dr Hyman got no personal reimbursement from the company; the funding was for staff time for recruitment and assessment and clinical research center support for the trial. Dr Myers has indicated he has no potential conflicts of interest to disclose.

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