
Managing Children and Adolescents With Fetal Alcohol Spectrum Disorders in the Medical Home

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Children and adolescents living with a fetal alcohol spectrum disorder (FASD) have health and medical needs that are similar to the general population, but they also have unique needs specific to their diagnosis. Assisting families in the many facets of the disorder is an important task for the pediatric and adolescent care clinician. The ability of clinicians to either recognize features of an FASD or make the diagnosis of fetal alcohol syndrome (FAS) within the office setting increases the likelihood of making more appropriate management decisions.

Pediatricians can diagnose FAS based on the Centers for Disease Control (CDC) FAS Guidelines for Referral and Diagnosis (cdc.gov/fasd).¹ The new algorithm for diagnosis and evaluation of FASDs created by the American Academy of Pediatrics (AAP) FASD Expert Panel further illustrates that this can be streamlined into a seamless process within the medical home. This algorithm, which is found within the newly launched AAP FASD Toolkit (aap.org/fasd),² describes a step-wise approach for a clinician who is faced with a child or adolescent with features of or who is at high risk for an FASD. Within this algorithm, the pediatric clinician is guided to make the diagnosis of FAS based on facial, growth, and CNS criteria and the history of alcohol use during pregnancy. Signs or symptoms of an FASD include growth deficits of height and/or weight at or below the 10th percentile at any age, head circumference at or below 10th percentile, developmental or

behavioral concerns, and characteristic facial features that include short palpebral fissures, smooth philtrum, and thin upper lip. Risk factors for FAS or an FASD include known/suspected maternal alcohol or other substance use, having a sibling with FAS/FASD, and having been or being in foster/adoptive care. In addition, if a parent or caregiver is concerned about an FASD, further evaluation is recommended.

For those who do have signs or symptoms but do not meet full criteria for FAS, referrals to an FASD diagnostic clinic, developmental-behavioral pediatrician, geneticist, and/or neurologist can be made to assist in the diagnostic and evaluation process. Typically, FASD clinics have a combination of the following: developmental-behavioral pediatrician, psychologist or neuropsychologist, speech-language pathologist, occupational therapist, and/or social worker. Evaluations in an FASD clinic help elucidate the child's or adolescent's particular strengths and challenges and generally include a combination of the following: IQ testing (e.g., Wechsler Intelligence Scale for Children-IV), developmental testing (e.g., Bayley Scales of Infant Development-III), executive function testing (Behavior Rating Inventory of Executive Function), adaptive skills assessment (Vineland II), behavioral/emotional assessment (e.g., Child Behavior Checklist and Children's Depression Inventory), speech-language assessment (e.g., Clinical Evaluation of Language Fundamentals-IV), tests of visual-motor abilities (Visual Motor Index-V), and tests of academic achievement (Wechsler Individual Achievement Test-II). Some FASD clinics already have a geneticist or a referral may be made to a geneticist. Referral to Neurology may be needed for children who have CNS abnormalities but do not have facial/growth abnormalities, as they may be able to pinpoint other neurological abnormalities or comorbid neurological findings that need to be addressed. A more

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comprehensive list of resources for diagnosis and management of the FASDs is listed by state and can be found at the National Organization for Fetal Alcohol Syndrome (NOFAS) website www.nofas.org.³

⁴The AAP FASD toolkit (aap.org/fasd) is a newly launched online tool to help navigate diagnostic and management strategies for FASD, including providing resources to parents and referrals to outside agencies. It contains the algorithm for diagnosis of FAS/FASD and the first Pediatric online CME course on FASDs.⁵ This should provide the clinical and practice management tools such as sample care plans for patients; references for billing and coding; and printable handouts for families, schools, and other individuals participating in the child's/adolescent's care.

It may be helpful for clinicians to know that Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure (ND-PAE) (previously referred to as Alcohol-Related Neurodevelopmental Disorder) is now in the Appendix of Diagnostic Statistical Manual of Mental Disorders-5 (DSM-5), and this is referenced in the diagnosis/differential diagnosis publication included in this article.⁶ The AAP Alcohol-Related Neurodevelopmental Disorders (ARND) workgroup and the AAP FASD Expert Panel are discussing how this may be included in a future version of the AAP FASD algorithm.^{7,8}

Children with an FASD can be challenging to manage, and therefore it is important to provide early medical, developmental, and behavioral supports as well as anticipatory guidance to benefit the child and the family.⁹ The diagnosis of FAS results in automatic qualification for services under Individuals with Disability Education Act (IDEA) Part C. In addition, consideration for FAS should also prompt referral for evaluation through the state's early intervention organization.¹ The school system becomes critical after 3 years of age. School evaluation should be requested for the child with prenatal alcohol exposure and any developmental, behavioral, or learning difficulties. This will help school staff create appropriate educational services that address the child's developmental disability. One of the factors that has previously been identified by Streissguth et al. to reduce the rates of secondary disabilities (e.g., mental health problems and problems with the law) is receiving services for the child's developmental disabilities.¹⁰ Despite having IQs within the normal range, children with FASDs can struggle academically, and this translates to a

higher risk of disrupted school experiences especially if they do not receive the appropriate educational interventions.¹¹ Many children with an FASD appear to need significant supports similar to children with learning disabilities and no alcohol exposure. Examples of effective strategies to teach children with an FASD include using "hands-on" activities and concrete examples, breaking down tasks and reducing lesson size, individualizing instruction to address ability and not grade level, giving instructions at the student's pace, and helping students recognize their unique strengths and challenges.¹²

Following diagnosis and evaluation of the child's medical and neurobehavioral profile, the next step in the management process is referral for medical, psychological, developmental, and educational interventions. If the child or adolescent exhibits poor growth (prenatal, postnatal, or both), referral to a nutritionist may be helpful. Some children with FAS/FASD have repeated bouts of otitis media,¹³ and referral to ear, nose, and throat specialists may need to be considered. There is also evidence of immune system abnormalities in children exposed to alcohol in utero. This may explain frequent infections in some young children with an FASD.¹⁴ Sleep problems can be a challenge¹⁵ and need to be addressed in a comprehensive fashion.¹⁶ Children should be evaluated for potential spinal anomalies, and persistent urinary and bowel incontinence should prompt evaluation for a tethered cord. Some children with an FASD may have cardiac or renal abnormalities that should prompt further investigation. Refer to a geneticist if there is a question about comorbid genetic conditions.

Part of the diagnostic, evaluation, and management process includes counseling about the diagnosis. Counseling may provoke a variety of responses from either biological or adoptive parents. The AAP FASD Toolkit suggests strategies for working with families of children with an FASD within the medical home. It is important to provide the diagnosis with the goal of providing assistance to the child and family without blaming the mother who used alcohol during pregnancy. Usually mothers do not use alcohol to harm their unborn infants. Counseling should include affirmation of positive attributes in the child and in the family, explanation of findings that support the diagnosis, and discussion regarding the importance of an accurate diagnosis. The diagnosis can help provide the appropriate framework for understanding a child's developmental and behavioral challenges and inform

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