
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 Pedialink 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

the implementation of effective interventions. The parents/caregivers should be reminded that the diagnosis is not meant to assign blame and that the diagnosis itself does not change who the child/adolescent is, but could provide an understanding of the reasons that he/she behaves in the way she/he does. Many families, instead of being angry appear to be relieved to know that the problems that they experience with their child have an explanation. In fact, an accurate diagnosis can be a relief for the child who can be helped to understand that many of his/her difficulties have a medical reason.¹⁷ Of course, the appropriate management of a child with an FASD requires an understanding of the nature of the brain injury and the need to provide supports in the child's/adolescent's environments.¹⁸ Considering the profile of the child with an FASD, a unique set of parenting skills is needed, and caregivers need to be educated about their child's neurobehavioral needs.¹ Families may need parenting classes and even family counseling.¹⁹

It is important to realize that with structural brain abnormality or CNS dysfunction, medications may not target primary symptoms but may help address coexisting conditions such as attention-deficit hyperactivity disorder (ADHD) or anxiety disorder. Children with an FASD may benefit from the use of stimulants for concomitant ADHD and selective serotonin reuptake inhibitors (SSRIs) for comorbid depression or anxiety, but medical providers should fully understand that medication would not alter all behaviors seen, as this does not address the structural brain differences. Furthermore, traditional behavioral interventions may not have the expected effect or may require modification of existing interventions to address the neurodevelopmental disorder.²⁰ Applying the traditional behavioral model, this child or adolescent would be punished for not cleaning his room or not finishing his homework or not doing well on a test, when this same child could have accommodations such as visual reminders and breaking down tasks into manageable parts and school accommodations/interventions. It is important for parents and caregivers to understand that their child cannot do something because the CNS abnormalities affect some of their child's abilities in educational, behavioral, and adaptive functioning.^{21,22} The diagnostic process opens up access to existing resources and evidence-based interventions specific to FASDs and to community-based services. If applicable, the clinician may need to refer the biological mother to counseling or addiction services within the

community to prevent future birth exposures. It is best to prepare for this potential situation by being aware of the resources available in the community.^{20,23}

The National Organization on Fetal Alcohol Syndrome (NOFAS) has a list of treatment centers for women along with other resources on FASDs. NOFAS also houses the Circle of Hope, which is the Birth Mothers' Network that can provide support services to the biological mother.²⁴ The newly developed AAP FASD toolkit also has scripts that clinicians may be able to use when discussing the initial diagnosis and management with the family.²⁵ Once a diagnosis is made, the family can be directed to resources including scientifically validated interventions.

Table I displays scientifically validated interventions for FASDs:

Good buddies: The University of California, Los Angeles, has evaluated a friendship training program that aims to alleviate some of the social skills problems in children with an FASD. This training teaches various social skills that help the children learn how to interact with friends, join into a group, and resolve conflict when it arises. This training is conducted for 90 min a week over the course of 12 weeks. The parents receive concurrent training on issues related to FASDs including understanding of the skills being taught to their children. The program increased the children's knowledge of acceptable social behaviors as confirmed by parental report, with positive changes found up to 3-months post-training.²⁶

MILE program: The Marcus Autism Center in Atlanta, Georgia, has evaluated a specialized math-tutoring program to increase math skills in children with an FASD. The program includes a psycho-educational program that provides learning strategies to the child and training for the child's teacher and guardian. Parents are required to attend workshops that teach parents about FAS, special education, and methods for being an advocate for their child and another one that trains them on building positive behavioral regulation skills. Once the parents complete the workshops, the children receive 6 weeks of tutoring and the educator meets with the child's teacher to discuss the effects of prenatal alcohol exposure. The MILE program was found to increase knowledge of FASDs, topics related to advocacy, and behavior regulation. After participation, caregivers reported fewer behavioral

TABLE 1. Evidence-based educational and behavioral interventions for fetal alcohol spectrum disorders

Intervention	Methodology	Outcomes
Good buddies: Friendship training, ²⁹ UCLA, Los Angeles, CA	Groups meet over 12-week period and child is taught how to interact with friends, how to enter a group of children already playing, and how to negotiate conflict	Improved the children's social skills and decreased problem behaviors
Mathematics Interactive Learning Experience (MILE) Emory University, GA ³⁰	Mathematics learning program featuring psychoeducational program providing learning strategies to the child and training for the child's teacher and guardian	Improved math knowledge and skills in children with an FASD
Families Moving Forward (FMF), University of Washington, Seattle, WA ³²	Provides 16 sessions of in-home training and support to families over a 9–11-month period, held every other week	Improved caregiver comfort and improves child behaviors
Parents and Children Together (PACT) Children's Research Triangle, Chicago, IL ³¹	This program builds executive function skills in 75-min sessions once a week over the course of 12 weeks with a concurrent parent education group	It improved executive functioning skills such as memory, cause and effect, and planning and problems solving
USFA Kids (US Fire Administration for Kids) ³⁸	This is a computer-based program that teaches and reinforces basic safety skills	This game allowed children to use virtually learned basic safety skills in a real-world simulation
Parent–Child Interaction Therapy, University of Oklahoma ³²	Parents learn new skills through a coach who help create a positive discipline program	Decreased parental stress and improved child behaviors

problems, and 58.6% of the children who participated in the MILE program showed a gain in math skills, compared to 23.1% of those in the control group.²⁷

Neurocognitive habilitation: The Children's Research Triangle in Chicago, Illinois, has developed a program to educate and support families caring for a child with a diagnosis of FAS or Alcohol-Related Neurodevelopmental Disorder (ARND) as well as improve executive functioning skills. The executive function training teaches self-control and behavioral awareness through the metaphor of a car engine. This program is held in 75-min sessions once a week over the course of 12 weeks with a concurrent parent education group. Children who participated in this program had significant improvement in their executive functioning.²⁸

Parent–child interaction therapy: The University of Oklahoma Health Services Center evaluated two group-based interventions aimed to reduce behavior problems and decrease parenting stress in a population of children with FASDs. This therapy was intended to enhance the relationship between parent and child and increase social skills, thus decreasing problem behaviors. This intervention lasted for 14 weeks, with weekly 90-min sessions. During the majority of the sessions, skills were practiced with coaching through a one-way mirror and a listening device placed in the parent's ear. Families received feedback after each session. Over time, parent

distress decreased as a result of this program, and child behavior problems were reduced. The study also reports evidence of a parent-only education intervention being effective.²⁹

Families moving forward program (FMF)—Behavioral consultation: Olson et al. developed this intervention by enrolling 5–11-year-old children and their caregivers in a study that was designed to improve parent's self-efficacy and decrease their child's problem behavior using a model of sustained, supportive behavioral consultation. FMF uses strategies that will help parents change the home environment in order to adjust to the child's specific needs. FMF provides direct support and coaching to families but also offers consultation to school personnel and refers to community services as needed. Recruited families received either FMF or standard of care. FMF was implemented over 16 in-home sessions every other week over the course for 9–11 months. Post-intervention, decreased parental stress and reduced child problem behaviors were noted in the FMF group when compared to controls.²⁹

Other promising educational and behavioral interventions include the use of a brief parent education program to help parents understand the neurobehavioral basis of FASDs. Burns, Davis, and Senturias studied 31 parents/caregivers of children 2–11 years of age who had an FASD diagnosis and were recruited from the Weisskopf Child Evaluation Center at the University of Louisville. The families were provided 2–3 h of

a parent education program that utilized the book All About Me to help parents/caregivers and other individuals in the child's life understand FASDs and their child's unique neurobehavioral profile. At one year post-intervention, there was a statistically significant decrease in both the child's problem behavior intensity scores ($p = 0.0188$) and child problem behavior scores ($p = 0.0076$) on the Eyberg Child Behavior Inventory (ECBI) when compared to baseline. One year later, 100% of parents who responded ($n = 13$) stated that they found the FASD Education Program to be useful; 100% of parents ($n = 13$) reported that the education program has had a positive impact on their relationship with their child. This pilot work shows that this program has the potential to be used in an experimental study of the impact of brief, targeted, FASD parent education on child behavior in this population.³⁰

Web-based resources can also be very helpful to families who need help navigating their child's developmental, educational, and behavioral challenges at home, in school, and in the community include. These resources are referenced within the AAP FASD toolkit³¹ including <http://www.do2learn.com>,³² www.nofas.org,³³ <http://www.kyfasd.org/free-downloads-and-important-links.html>,³⁴ and http://www.fasdcenter.samhsa.gov/documents/Reach_To_Teach_Final_011107.pdf.³⁵

Conclusion

In the past 10 years, great progress has been made in recognizing and diagnosing FAS and the FASDs. Fetal alcohol syndrome can be diagnosed in the primary care setting, and pediatric and adolescent care providers should be alert to the possibility of fetal alcohol spectrum disorders in the context of prenatal alcohol exposure. Knowledge of the differential diagnosis for FAS/FASD can help providers be more comfortable in making the diagnosis and may help decide about subsequent referrals. The AAP FASD Algorithm within the AAP FASD Toolkit for diagnosis of children with FAS/FASDs is available for use in the medical home, which can make the diagnostic and referral process more comprehensive and seamless.³⁶ Clinicians can now turn to the DSM-V for the ND-PAE (former Alcohol-Related Neurodevelopmental Disorder) criteria that can help guide the process of

identification and diagnosis of FASDs. There are now scientifically validated interventions that can help address the needs of children with FASDs and their families.²⁹ Moreover, the American Academy of Pediatrics FASD Expert Panel has created an FASD toolkit that can help pediatric clinicians manage and coordinate care for children and adolescents with fetal alcohol spectrum disorders.³⁷ It is hoped that in the next 10 years, clinicians will be able to utilize the available tools such as the AAP FASD Toolkit to help them manage FAS/FASDs within the medical home and that researchers will continue to find effective interventions that can impact children and families living with FASD. Programs need to be established, which will raise the visibility of cognitive, social, and emotional behaviors associated with an FASD for parents, teachers, and community service providers and provide a range of accessible techniques for parents and teachers to employ to support children diagnosed with an FASD. With a persistent and intentional focus on both prevention and management, a great deal of pain and distress can be ameliorated.

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