



The Role of Integrated Care in a Medical Home for Patients With a Fetal Alcohol Spectrum Disorder

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Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe preventable birth defects and intellectual and/or developmental disabilities resulting from prenatal alcohol exposure. The American Academy of Pediatrics has a previous clinical report in which diagnostic criteria for a child with an FASD are discussed and tools to assist pediatricians with its management can be found. This clinical report is intended to foster pediatrician awareness of approaches for screening for prenatal alcohol exposure in clinical practice, to guide management of a child with an FASD after the diagnosis is made, and to summarize available resources for FASD management.

abstract

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INTRODUCTION

Prenatal alcohol exposure (PAE) is the most common preventable cause of intellectual and developmental delay and disabilities in the United States.¹ Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe preventable birth defects and intellectual and/or developmental disabilities that result from PAE. In 2010, the American Academy of Pediatrics (AAP) conducted a needs assessment of pediatricians and found that during training, many pediatric clinicians did not receive sufficient education about the hazards of PAE and the options for universal screening for prenatal alcohol use.² Addressing this knowledge gap in 2015, the AAP released a clinical report with the goals of aiding pediatricians with the diagnosis of a child with an FASD, stressing the importance of universal screening for PAE (www.aap.org/FASD).³

After the release of the AAP clinical report, pediatricians expressed a need for further clinical guidance regarding managing an individual with an FASD within the medical home beyond diagnosis. Many medical home providers are reluctant to screen for PAE when unsure of how to

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manage patients after a diagnosis of an FASD. For some pediatricians, it can seem like a daunting task to care for an individual with an FASD, but there are aspects of integrated care and providing a medical home that can be instituted as with all children with complex medical diagnoses.⁴ In addition, not recognizing an FASD can lead to inadequate treatment and less-than-optimal outcomes for the patient and family. This clinical report provides an approach to caring for children with an FASD and their families.

The goal and scope of this clinical report is to support pediatric providers in managing patients after a diagnosis of an FASD. It emphasizes the lifelong effects of having an FASD and suggests strategies to support families who are interacting with early intervention services, the educational system, the behavioral and/or mental health system, other community resources, and the transition to adult-oriented health care systems when appropriate.

EPIDEMIOLOGY

In a survey conducted between 2011 and 2013, approximately 1 in 10 pregnant women in the United States reported drinking alcohol in the past 30 days, and about 1 in 33 pregnant women report binge drinking (having 4 or more drinks at one time) in the past 30 days.^{5,6} Studies of grade school children suggest that the rate of an FASD is estimated at 24 to 48 per 1000 children,⁷ thus approaching the prevalence of other disorders, such as autism spectrum disorder (<https://www.cdc.gov/ncbddd/autism/data.html>). In addition, studies suggest the rates of FASDs are even higher in certain regions of the United States and among vulnerable populations, such as children in foster care, internationally adopted children, and/or some children of American Indian or Alaska Native descent.^{8–10}

Alcohol is a known teratogen.¹¹ All drinks containing alcohol have the potential to harm a developing fetus, but not every developing fetus exposed to alcohol will develop an FASD. Harm may occur even before a woman recognizes she is pregnant, which is especially significant, because nearly half of all pregnancies in the United States are unplanned.¹² Currently, it is not possible to predict which fetuses will be affected. The safest choice is for women to completely refrain from alcohol consumption while pregnant or trying to get pregnant. The AAP endorsed the following message via the 2015 clinical report³ (www.cdc.gov/ncbddd/fasd/facts.html):

- There is no amount of alcohol during pregnancy that is risk free.
- There is no kind of alcohol during pregnancy that is risk free.
- There is no time during pregnancy when alcohol consumption is risk free.

FASD TERMINOLOGY AND LIFE SPAN

FASD is not a specific diagnostic term; rather, it is an overarching expression covering a range of possible conditions resulting from PAE.^{3,13–17} The signs and symptoms of an FASD vary by individual and can include physical stigmata as well as mental, behavioral, and learning problems. The term FASD includes all of the following conditions: fetal alcohol syndrome (FAS), partial FAS, alcohol-related birth defects, alcohol-related neurodevelopmental disorder, and neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE; Table 1).^{3,16,17} FAS is often the condition associated with PAE under the FASD umbrella that individuals are familiar with.

Several FASD diagnostic frameworks are available. The AAP devised the “Flow Diagram for Medical Home Evaluation of Fetal Alcohol

Spectrum Disorders”¹⁸ (see Fig 1) to facilitate greater clinical recognition of children with an FASD, acknowledging that FASD could and would be beneficial to recognize in individuals of any age (www.aap.org/FASD). For further detail about specific FASD diagnostic schema, please see other sources.^{13–15,17}

ROLE OF THE MEDICAL HOME AND CARE INTEGRATION

For nearly 5 decades, the medical home concept has evolved from a place to store medical records for children with special care needs¹⁹ to a setting in which high-quality care is delivered for all children, including those with an FASD.²⁰ Provision of a medical home includes continuity, care coordination, cultural competence, patient and family centeredness, compassion, and care consistency across the lifespan of children and their families.^{20,21} The care provided in the medical home may facilitate the patient- and family-centered care necessary for children with special health care needs, and especially those children with an FASD, to optimize their potential and support their families and caregivers.²² Providing a medical home for children and youth with an FASD optimizes their potential and supports their families and caregivers. This clinical report seeks to highlight the role of a medical home for children and youth with an FASD and describe key constructs and management of this important population of children.

Approach to Universal Screening and Documentation of PAE in the Pediatric Encounter

Early identification of developmental disorders, including FASDs, is critical to the well-being of children and their families. Screening for PAE is an important function of the medical home. Although potentially challenging, it is an appropriate and necessary responsibility

TABLE 1 Criteria for Diagnosis of FASD and Related Disorders

Terminology	Diagnostic Features
FAS	Explicit diagnostic criteria that include all of the following: Three facial abnormalities (ie, smooth philtrum, thin vermilion border, and small palpebral fissures). Also may see midface hypoplasia, micrognathia, microcephaly, epicanthal folds Growth deficiency (height and/or wt \leq 10th percentile at any age) Structural, neurologic, or functional CNS abnormalities Prenatal exposure to alcohol ^a
Partial FAS	Some but not all of the physical features of full FAS (above) CNS damage (structural, neurologic, and/or functional impairment) Confirmed prenatal exposure to alcohol
Alcohol-related birth defects	Classification for individuals who do not have the facial characteristics of full FAS Significant birth defects affecting the heart, eyes, kidneys, and/or bones resulting from PAE Hearing may also be affected Usually do not meet criteria for CNS structural or functional abnormalities Confirmed prenatal exposure to alcohol
Alcohol-related neurodevelopmental disorder	Cluster of symptoms that may include intellectual disabilities as well as challenges with behavior and learning resulting from PAE May also have a CNS anomaly Often perform poorly in school and have difficulties with math, memory, attention, judgment, and impulse control Confirmed prenatal exposure to alcohol
ND-PAE	Have impairment of neurocognition, self-regulation, and adaptive functioning Combines deficits in these 3 areas in conjunction with evidence of PAE, childhood onset of symptoms, and significant distress or impairment in social, academic, occupational, or other important area of function Confirmed prenatal exposure to alcohol

CNS, central nervous system. Adapted from Hoyme HE, Kalberg WO, Elliott AJ, et al. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*. 2016;138(2):e20154256 and Fetal Alcohol Spectrum Disorders Expert Panel. Flow Diagram for Medical Home Evaluation of Fetal Alcohol Spectrum Disorders. Elk Grove Village, IL: American Academy of Pediatrics; 2013. Available at: www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/Algorithm-for-Evaluation.aspx. Accessed December 18, 2017.

^a Confirming PAE is not necessary if the first 3 features are present.¹⁷

of all pediatric providers. Early identification of a child at risk for an FASD because of a positive screen result for PAE prompts careful monitoring followed by further evaluation, developmental or behavioral monitoring, and diagnosis and treatment, if warranted. Ideally, screening for PAE would be a component of a pediatrician's routine family assessment during a clinical encounter.

Pediatric providers, as well as obstetricians and gynecologists, have a unique opportunity to identify and engage families regarding alcohol consumption during pregnancy. Pediatric providers, collaborating with other interested partners, such as the American College of Obstetrics and Gynecology, can enhance practice and policy changes for women and children before and during pregnancy. Communication of PAE from the obstetric provider to the pediatrician would facilitate

screening and monitoring of (high-risk) infants and children. Ideally, pediatric primary care providers would adopt a "universal screening" approach of alcohol exposure in their patients. In practice, multiple opportunities already exist to incorporate this screening into office workflows. In fact, screening for PAE can be completed during any family interactions, especially the following times: in prenatal visits, in newborn or infant visits, at the time of adoption, and as new patients and families join the practice. For PAE screening resources, visit www.aap.org/pae.

- A prenatal encounter is an ideal time for a pediatric provider to engage with a family about prenatal substance exposure, including alcohol.
- In the newborn nursery setting, when a new mother typically has been interested in discussing

health issues possibly affecting her infant, a provider can use this time to screen for PAE as part of the discussion about the newborn infant's health.

- In the office setting, this discussion could be part of the pregnancy history. It could be included in the discussion of maternal medical issues, medications, tobacco, and substance use during pregnancy.
- During the newborn period and first few months of infancy, pediatric providers generally inquire about any number of prenatal or pregnancy risk factors possibly affecting the infant's health history. This inquiry could include screening for PAE if screening has not already been performed. Some practices could also include this in their routine postpartum depression screening at 1, 2, and 4 months,²³ screening for maternal health, or while

Flow Diagram* for Medical Home Evaluation of FASDs

Universal Flow Diagram Symbols

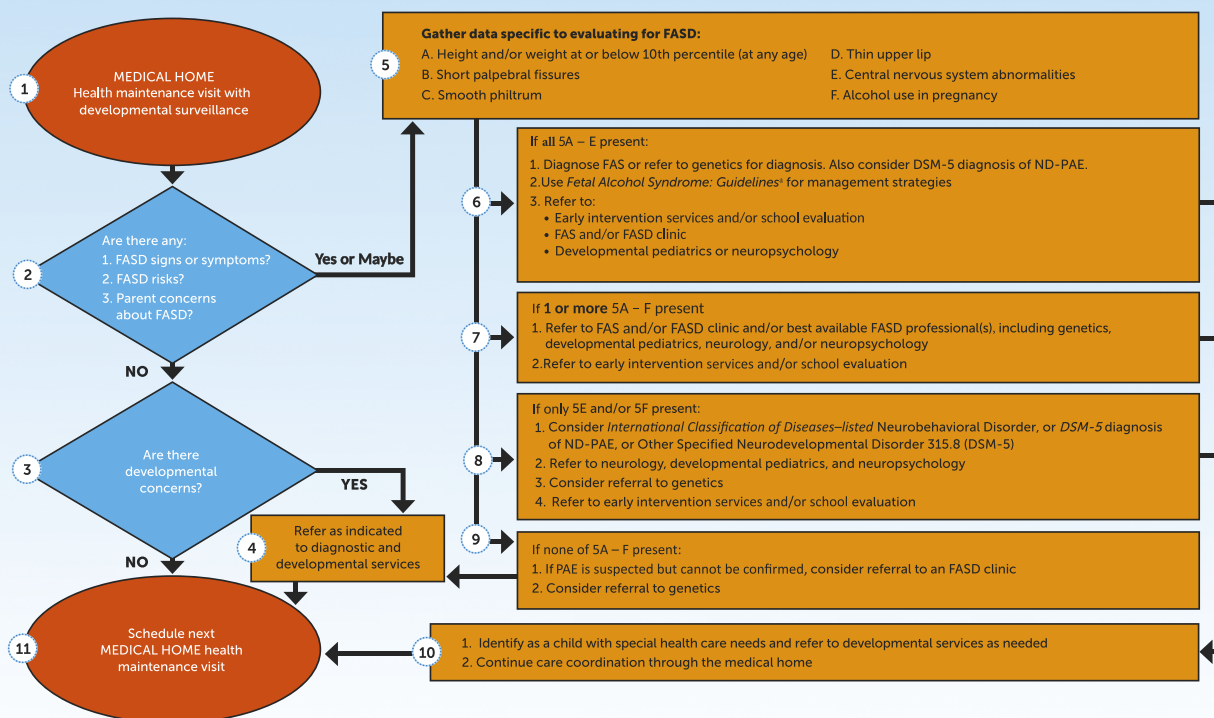


FIGURE 1

Flow diagram for medical home evaluation of FASDs. ^aPage 2: Flow diagram pathway details; FAS criteria; selected resources. The flow diagram was developed by the FASD Expert Panel of the AAP via cooperative agreement #5U380T000167 with the Centers for Disease Control and Prevention; does not necessarily represent the views of the Centers for Disease Control and Prevention.

screening for history of trauma using an Adverse Child Event Screener in practice.²⁴

- All patients who are new to a practice benefit from screening for exposure to prenatal alcohol, regardless of the age of the child. In addition, patients who present with emerging behavioral issues at any age warrant rescreening for PAE, regardless of previous positive or negative screening results.

Once screening for PAE is completed and documented as positive, there is little need for repeated screening unless there is potential for a

change in answers. Using a standard script may ease potential physician discomfort and provide reassurance to the caregiver when discussing topics that may be sensitive. Incorporating the “universal screening” for PAE in either decision support prompts or electronic health record questions are key.

There is no uniformly accepted practice regarding documenting PAE. The tools available through the *Bright Futures Tool and Resource Kit* are compatible with, but do not require, an electronic health record. The main components of the *Bright Futures Tool and Resource Kit* are available

for review and reference at <https://brightfutures.aap.org/materials-and-tools/tool-and-resource-kit>. Pediatricians are encouraged to work with other members of their practice to develop a standard process for screening, documentation, and follow-up within their office and/or clinical setting and team.

As mandated reporters of child abuse and neglect, health care providers should be cognizant of their state’s laws regarding prenatal and/or postnatal maternal substance use and understand obligatory child abuse reporting laws in their states and should know how to

make a report to the responsible agency that investigates cases of alleged child abuse or neglect in their jurisdiction.^{25,26} Under the federal Child Abuse Prevention and Treatment Act (CAPTA), health care providers are mandated reporters. CAPTA does not require clinicians to report to child protective services if a child has been exposed prenatally to alcohol (ie, for a positive PAE screening result). Referral to child protective services is required if the child has been diagnosed with an FASD in the period between birth and 3 years. The intent of this referral is to develop safe care and possible treatment plans for the infant and caregiver if needed, not to initiate punitive actions.

CAPTA mandates referral, not reporting, so states are able to establish their own definitions and practices related to reporting child abuse and neglect. A small number of states have included the presence of an FASD in their abuse and neglect codes. Physicians are encouraged to be aware of their respective state laws on this matter.

If a child is diagnosed with an FASD in a state where a mandatory referral or report to child protective services is necessary, health care providers can engage families in this process with a transparent and caring direct approach. To set the stage for a transparent interaction up front, a health care provider can discuss all of the following: (1) the risks of parental substance abuse and its effects on children; (2) the requirements for mandated reporting to child protective services; (3) the resources and services available to the family; and (4) how child welfare can be a support to the family.

States vary widely with respect to the reporting guidelines and requirements; as such, a discussion of these is beyond the scope of this clinical report. The practicing provider's specific state guidelines and knowledge will inform their

counseling. Additional information about the CAPTA Reauthorization Act of 2010 is available from the American Bar Association.²⁷ Additional information about referral requirements under CAPTA and Individuals with Disabilities Education Act are available from the Early Childhood Technical Assistance Center.²⁸

Medical Home Management and Treatment Strategies

The primary care medical home plays a pivotal role in the continuity and integration of care for children with an FASD. Although there is no cure for FASDs, there are evidence-based treatment options that can improve outcomes for affected individuals. Treatment options are aimed at improving the symptoms and/or providing environmental modifications, as well as parenting strategies and educational interventions to optimally address the brain-based problems experienced by children with FASDs.³ Studies suggest an increased odds of mitigating adverse life outcomes for individuals with an FASD when the diagnosis was made before 6 years of age and also being reared in a stable home environment with appropriate, integrated support services.^{29,30} As such, screening and diagnosis of an FASD in childhood may benefit both patients and their families and allow pediatricians to link patients with an FASD to necessary resources.

Each person with an FASD is unique, so management needs to be tailored to the requirements of the individual. Some children with an FASD may experience growth issues and failure to thrive requiring follow-up and management that uses evidence-based practice guidelines. In addition, any significant congenital defects resulting from PAE affecting the heart, eyes, kidneys, and/or bones warrant evaluation, referral, and appropriate follow-up in the medical home. Fewer than 20% of

children with adverse effects from PAE will present with dysmorphic facial features, and the majority of pediatricians will encounter and need to manage behavioral issues related to PAE.^{14,31}

Some children with an FASD may have typical intelligence and fail to qualify for services in the public school system, yet still have specific functional issues. Often when children with an FASD are further assessed by a developmental pediatrician or psychologist, they may receive another concomitant diagnosis, such as a specific learning disability or attention-deficit/hyperactivity disorder (ADHD), for which they could receive either accommodation or an individualized education program (IEP) from the school system.

Children with an FASD may exhibit signs and symptoms also observed in mood, anxiety, autism spectrum, and disruptive behavior disorders (eg, ADHD). These children are also at risk for a receptive or expressive language disorder.³² Some of the parent-identified behavior challenges for children with an FASD include but are not limited to externalizing behaviors, cognitive difficulties, and social difficulties and/or maladjustment.³³ Some children with an FASD have behavioral issues, such as impulsivity, aggressiveness, and/or hyperactivity.³² The effects of PAE can include impaired executive function, leading to poor judgment and organic brain dysfunction that can manifest as an inability to comprehend social rules and expectations, learning disabilities, academic and employment difficulties, and challenges navigating activities of daily living.³² Often, a potential lack of stranger anxiety can put individuals with an FASD at risk for abuse and trauma.³³

Pediatricians can use typical evidence-based diagnostic and standard screening approaches to diagnose comorbid conditions

(eg, flow diagrams, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM-5]*, referral to specialists).³⁴ If comorbid or co-occurring diagnoses are confirmed, pharmacologic treatment may begin as indicated. If the comorbid condition is ADHD, the 2011 clinical practice guidelines from the AAP recommend that doctors prescribe behavior therapy as the first line of treatment of preschool-aged children (4–5 years of age) with ADHD.³⁵ Parent training in behavior therapy has the most evidence of being effective, and teachers and early childhood caregivers can use behavior therapy in the classroom as well. However, traditional behavioral therapy that does not consider the child's neurobehavioral challenges does not work well for children with an FASD because they often do not respond to typical reward and consequence approaches. Efforts can be made to find behavioral therapists who have been trained in treating children with an FASD. Stimulants and/or atypical antipsychotic agents may be useful in treating the impulsivity, aggressiveness, and/or hyperactivity and oppositional defiant and conduct disorders that may co-occur in individuals with an FASD, especially if those are accurate co-occurring diagnoses and not merely symptoms of the brain damage attributable to PAE. Some pediatricians may be comfortable prescribing stimulants and/or atypical antipsychotic agents, but others may seek referrals to developmental and behavioral specialists, child and adolescent psychiatrists, and/or pediatric neurologists. Treatment approaches could include feedback and assessment from teachers, therapists, and families as well as administration of validated scales, including but not limited to such scales as the Vanderbilt (<https://shop.aap.org/adhd-vanderbilt-assessment-forms-package/>) and the Screen for Child Anxiety Related

Emotional Disorders for anxiety-related disorders.³⁶ A resource on pediatric psychopharmacology for the treatment of childhood ADHD, depression, and anxiety may be useful to medical practitioners when they treat these comorbid symptoms in children with FASDs.^{37,38}

The heterogeneity of FASD manifestations calls for tailoring treatments to meet individual needs. Inattention, hyperactivity, and impulsivity afflict 50% to 90% of children with FASD and are 3 to 9 times more common than in the general population.^{39,40} A large proportion of children with an FASD are affected by oppositional defiant disorder or conduct disorder, including lack of social judgment and failure to learn from experience. Moreover, it can be difficult to tease out the individual effects of ADHD and coexisting cognitive defects on learning in patients with an FASD.⁴¹

Research on the pharmacologic treatment of FASDs is lacking. Stimulants appear to be effective in managing hyperactivity and impulsivity but are less effective in managing inattention. Risperidone is widely used for aggression, but no controlled studies of risperidone in children with an FASD have been published.⁴¹

There is some evidence to suggest that virtual reality training, cognitive control therapy, language and literacy therapy, mathematics intervention, and rehearsal training for memory may be beneficial strategies. Three studies evaluating social communication and behavioral strategies (2 randomized controlled trials) suggest that social skills training may improve social skills and behavior at home and attention process training may improve attention.⁴²

The nuances and overlap of symptoms of FASDs with other diagnoses make them challenging to distinguish. Children with an

FASD may also have been exposed to other drugs and toxins in utero, and the diagnostician may not always be able to determine what etiology is accounting for which deficit or challenge.^{15,33} Not all children will fit neatly into *DSM-5* criteria for specific diagnoses,³⁴ including an FASD, but their clinical picture and symptomatology may still warrant treatment and support services. Although the response to medication management can be variable and unpredictable in this population of children with an FASD, approaches with typical stimulant, mood dysregulation prescribing practices can be used with the appropriate medications (eg, methylphenidate or amphetamine derivatives, guanfacine, risperidone, aripiprazole, selective serotonin reuptake inhibitors, etc). Variability in clinical profile and response to treatment can pose challenges for the primary care pediatrician caring for children with an FASD and supports the need for collaboration with mental health specialists such as neuropsychologists, clinical psychologists, developmental and/or behavioral pediatricians, child and adolescent psychiatrists, pediatric behavioral mental health clinicians, and developmental therapists (eg, speech, physical, and occupational therapists).⁴³

Many children with an FASD are born to a parent(s) who has a substance use disorder including but not always limited to just alcohol. Children of parents with substance use disorders are also at greater risk of later mental health and behavioral problems, including developing a substance use disorder themselves. Exposure to a parent using substances is considered an adverse childhood experience.⁴⁴ Youth with an FASD should be screened for substance use, as should all youth in routine pediatric practice. Resources for substance use screening, brief interventions, and

referrals to treatment are available for pediatricians.⁴⁵ Nearly 60% of individuals with an FASD in the criminal justice system have a history of substance use issues.²⁹

At times, children with an FASD may be placed with a foster or adoptive family. A 2013 meta-analysis suggests the prevalence of FAS is 6% and the prevalence of an FASD is 16.9% in child welfare settings.¹⁰ As a particularly vulnerable population, children in foster care and adoptive settings warrant special consideration. Pediatricians caring for youth in foster care may not have access to the biological mother or the pregnancy history, and prenatal substance exposure information is often missing, not available, or inaccurate. Still, this population is at increased risk of having PAE-related health and behavioral issues that are best addressed in a timely manner. Pediatricians partnering with foster and adoptive parents as well as child welfare agencies to proactively address issues have the potential to favorably impact outcomes in this population. Thus, pediatricians may have an opportunity to help disrupt multigenerational cycles of substance use by being informed about the effects of parental substance use on children, intervening when necessary, and collaborating with the family, other health care providers, and appropriate government agencies to address the issues involved.

Given the complex array of systems and services requiring navigation and coordination for children with an FASD and their families, a high-quality primary care medical home with partnerships with families, specialists, therapists, mental and/or behavioral health professionals, and community partners is critical, as it is for all children with special health care needs.

Supporting Families After the Diagnosis Is Made and Providing Patient- and/or Family-Centered Care

Supporting a patient and family after a diagnosis of an FASD is integral to a high-quality medical home. Often, families are distressed and need support and linkages to resources in the days after a diagnosis as they begin to process and begin their journey to support their child. Because the provision of patient- and family-centered care is ideal in practice,⁴⁶ actively involving patients and families in decision-making is also important. Patients and families should be part of goal setting and creating, implementing, and updating a formal, written plan of care with family and/or patient input that is sensitive to their language, values, and culture.^{47,48} Linking families with other families or caregivers with shared experiences can be helpful in diagnosis and long-term support for families.^{46,49} After the diagnosis of an FASD, patients may need referrals to neuropsychologists, clinical psychologists, developmental and/or behavioral pediatricians, child and adolescent psychiatrists, pediatric developmental therapists (speech, physical, and occupational therapy), and behavioral mental health clinicians and partners. Patients will also often need help with education, coordination, integration, and navigation of the needed services and supports to maximize the potential of their child with an FASD.

Parenting a child with an FASD can prove challenging because a child with an FASD may not respond to typical parenting practices. This often creates stress and frustration for parents and caregivers. A child with an FASD is a child with special health care needs, and children with special health care needs are 4 times more likely to be victims of abuse than their typically developing peers.^{50,51} To productively parent a child with an FASD, caregivers may benefit

from special training and education about the child's condition and parenting strategies and approaches that are more likely to be successful. Often, trying different approaches to parenting that exemplify understanding of the child's unique strengths and weaknesses can make a tremendous improvement in the child and his or her family's functioning. Traditional behavioral approaches may not work for children with an FASD because they may have impaired cause-and-effect reasoning as well as an inability to apply learning from one situation to another despite having a normal or low-average IQ.⁷ It can be helpful for pediatricians to reframe difficult or challenging behaviors for parents or caregivers of children with an FASD. Reframing helps parents understand that behaviors or difficulties of a child with an FASD may result from prenatal brain damage rather than willful disobedience, thus avoiding the "can't versus won't" misinterpretation. A child with an FASD may have difficulty learning from his or her own experiences. For example, many things that other children pick up naturally (eg, playground rules) may need to be presented explicitly to a child with an FASD. Furthermore, a child with an FASD may benefit from having communication and consensus among caregivers about reasonable and consistent adjustments to expectations, rules, and models of discipline. Children with an FASD often thrive better in a structured environment where there are reasonable rules, routines, and supervision.³³ Structured environments help to provide calming techniques before learning activities or other stressful situations.⁵² Picture schedules, visual cues, and repetitions all provide support for the mastery of concepts for a child with an FASD.

Some tools and evidence-based interventions have been shown to

help families in which a child has an FASD. The cultural values, belief systems, and context of patients and families are relevant when recommending interventions. Resources, supports, and suggestions are available in the areas of parenting and education, attention and self-regulation, adaptive functioning, and nutrition and medication that also address potential cultural barriers and strategies for clinicians when making recommendations.⁵³

All About Me is a downloadable manual for parenting strategies in the light of differences in brain function commonly observed in children with an FASD. It was developed by Kentucky's Prevention Enhancement Site for Fetal Alcohol Spectrum Disorders and is a helpful free resource available at http://www.fasdnetwork.org/uploads/9/5/1/1/9511748/all_about_me..pdf. Also, the following 8 Magic Keys are a set of strategies parents, teachers, and others can use when they care for and interact with children who have an FASD⁵⁴:

- Concrete: Speak in concrete terms; do not use idioms, abstract language, or words with double meanings.
- Consistency: Use the same key words all the time.
- Repetition: Children with an FASD have chronic memory problems, so teach and reteach; repeat instructions multiple times.
- Routine: Keep the child's routine and environment calm, stable, and predictable, with few changes.
- Simplicity: Children with an FASD are literal thinkers, so euphemisms or abstractions can be confusing; give only 1 or 2 instructions at a time.
- Specific: Be explicit and say exactly what you mean.
- Structure: Provide an environment with clear structure and boundaries.

- Supervision: Provide constant supervision to keep the child safe and to help him or her develop appropriate behaviors.

Although these tools are clinically informed and anecdotally useful, they are not evidence based or specific for an FASD.

Role of Care Integration and Care Planning for Individuals With an FASD Over Time

Although the medical home is poised to provide care for children with medical and behavioral complexity such as those with an FASD, care coordination and integration is necessary to support families requiring multiple systems and services.²² Care coordination is a "cross-cutting system intervention,"⁵⁵ which is "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services."⁵⁶ "Organizing care for children with an FASD involves the marshalling of personnel and other resources needed to carry out all necessary patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care."²² A framework for care coordination is provided (Fig 2) to foster high-quality care for children with an FASD.⁵⁷

The myriad of lifelong problems resulting from PAE is extensive. Significant cognitive and behavioral issues ensue from the effects of alcohol on the brain, as well as physical abnormalities, including heart, lung, and kidney defects.⁷ The neurobehavioral aspects of an FASD include hyperactivity and behavior problems, difficulty with judgment and social skills, attention and learning difficulties, and drug and alcohol issues.⁷ This paradigm supports the need for a collaborating and integrated medical home for

children with an FASD consisting of neuropsychologists, developmental and/or behavioral pediatricians, child and adolescent psychiatrists, pediatric therapists (speech, physical, and occupational therapy), behavioral and mental health clinicians, and community partners all working together, effectively communicating, and coordinating care across systems.

Community Partnerships in Education, Mental, and Behavioral Health

People with an FASD are at increased risk for learning disabilities, mental illness, addiction, school failure, dropping out of school, and interactions with the criminal justice system. Over their lifetimes, people with an FASD may need a plethora of services to maintain and improve their functioning, including support in the medical, education, specialty care, vocational services, and behavioral health systems (Table 2).

Early intervention has been shown to be beneficial for children 0 to 3 years old with developmental delays, including children with an FASD.⁵⁸ Children with an FASD without significant delay (>25%) may still benefit from early intervention services and/or surveillance, given their risk for developmental delay and behavioral challenges. Appropriate early intervention services can favorably impact some common challenges experienced by children with an FASD, including word comprehension, learning, naming, academic skills, visual motor integration, and fine motor speed and/or coordination.^{59,60}

Children with an FASD who are also 3 years old or older can receive services through the school system, local mental health agencies, or in private therapy under educational, physical, and/or mental health diagnoses. Care coordination across systems is a key construct that can help patients and families with an

PEDIATRIC CARE COORDINATION FRAMEWORK

Care Coordination Definition:

Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

Defining Characteristics of Care Coordination

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Patient- and family-centered 2. Proactive, planned, and comprehensive | <ol style="list-style-type: none"> 3. Promotes self-care skills and independence 4. Emphasizes cross-organizational relationships |
|---|---|

Care Coordination Competencies:

- 1) Develop partnerships
- 2) Communicate proficiently
- 3) Use assessments for intervention
- 4) Facile in care-planning skills (patient- and family-centered)
- 5) Integrate all resource knowledge
- 6) Possess goal and/or outcome orientation
- 7) Approach is adaptable and flexible
- 8) Desire continuous learning
- 9) Apply solid team-building skills
- 10) Adept with information technology

Care Coordination Functions:

- 1) Provide separate visits and care coordination interactions
- 2) Manage continuous communications
- 3) Complete and analyze assessments
- 4) Develop care plans (with family)
- 5) Manage and track tests, referrals, and outcomes
- 6) Coach patient and/or family skills learning
- 7) Integrate critical care information
- 8) Support and/or facilitate all care transitions
- 9) Facilitate patient- and family-centered team meetings
- 10) Use health information technology for care coordination

FIGURE 2

Pediatric care coordination framework. Adapted with permission from the Commonwealth Fund; Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: Commonwealth Fund; 2009.

FASD navigate the complex array of services needed to support a child or youth with an FASD. A child with an FASD may receive early intervention until 3 years of age and, when appropriate, receive special education in local public schools until age 22. In addition, children with an FASD can receive services through local mental health agencies or in private therapy under educational, physical, and/or

mental health diagnoses.⁶⁰ Some individuals with an FASD can receive adult services from various state agencies for life. Proper services often help individuals with an FASD maximize their long-term potential. Without proper services, treatment or supports, individuals with an FASD may be at higher risk for referrals to child welfare, juvenile justice facilities, adult prisons or jails, and homeless shelters.^{29,44} Care

coordination across systems is a key construct that can help to navigate the complex array of services needed to support a child or youth with an FASD.²²

Partnering with families in addressing the developmental, behavioral, and educational concerns of children with an FASD is valuable in practice. Garnering appropriate educational supports

TABLE 2 Resources for Practitioners Caring for Children and Youth With FASDs in a Medical Home

	Resource
FASD general resources	<p>AAP FASD toolkit: www.aap.org/fasd</p> <p>PAE screening resources: www.aap.org/pae</p> <p>Centers for Disease Control and Prevention: www.cdc.gov/fasd</p> <p>FAS Diagnostic and Prevention Network. FAS facial photography and measurement instruction using images and animations to teach accurate measurement of FAS facial features: http://depts.washington.edu/fasdpn/htmls/photo-face.htm</p> <p>National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov</p> <p>NIAAA Collaborative Initiative on Fetal Alcohol Spectrum Disorders: www.cifasd.org</p> <p>Handouts easily downloaded for education: https://pubs.niaaa.nih.gov/publications/FASDFactsheet/FASD.pdf</p> <p>National Institute on Child Health and Human Development: www.nichd.nih.gov</p> <p>National Organization for Fetal Alcohol Syndrome: www.nofas.org; national and state resource directory: www.nofas.org/resource-directory</p>
Mental health resources	<p>National Association on Mental Illness: a grassroots organization with advocacy and educational resources with local and state chapters to support clinicians and families: http://www.nami.org/</p> <p>American Academy of Child and Adolescent Psychiatry: resources and support for primary care providers, families, and youth: https://www.aacap.org/</p>
SAMHSA	<p>Fetal Alcohol Spectrum Disorders Center for Excellence: https://www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center</p> <p>Substance Abuse and Mental Health Services Administration. Addressing Fetal Alcohol Spectrum Disorders. Treatment Improvement Protocol Series 58. HHS Publication No. (SMA) 13-4803. Rockville, MD: Substance Abuse and Mental Health Services Administration; 2014: https://store.samhsa.gov/shin/content//SMA13-4803/SMA13-4803.pdf</p> <p>SAMHSA treatment locator: www.samhsa.gov/treatment/index.aspx</p>
Education and disability services	<p>National Dissemination Center for Children with Disabilities http://www.parentcenterhub.org/disability-landing/</p> <p>All about the IEP: http://www.parentcenterhub.org/iep/</p> <p>Assistive Technology State Programs: connects users to programs that can help them find funding for assistive technology, which is any sort of device or service that allows a person with a disability to perform more difficult or unmanageable tasks: http://www.resnaprojects.org/allcontacts/statewidecontacts.html</p> <p>Learning Disabilities Association of America: provides parental support services, educates policy makers on legislation regarding learning disabilities, works with school programs that address learning disabilities, and publishes materials for adults with learning disabilities about workplace issues, adult literacy, parenting, and assistive technology: http://ldaamerica.org/</p> <p>National Center on Accessible Instructional Materials: serves as a resource to educate parents and teachers on accessible educational materials for children who are unable to use regular printed text: http://aem.cast.org/</p> <p>National Disability Navigator Resource Collaborative: informs people with disabilities about their health insurance options through the Affordable Care Act, helping them enroll in the best possible insurance available to them through the Marketplace: http://www.nationaldisabilitynavigator.org</p>
Employment disability services	<p>Job Accommodation Network: works with both potential job seekers and employers and helps people with disabilities market their skills and assists employers in understanding the requirements of the Americans with Disabilities Act: https://askjan.org/</p> <p>SourceAmerica: helps people with significant disabilities find jobs by networking with community nonprofit agencies to fulfill contracting needs for the federal government, offers training to people with disabilities who are trying to find employment, and helps them find the best work environment for their needs: http://www.sourceamerica.org/</p> <p>Think Beyond the Label: connects qualified candidates with disabilities to businesses looking to hire said candidates through a network of online tools, information, and training to help job seekers find suitable positions and works with businesses to ensure that 7% of their workforce consists of people with disabilities, as mandated by law. http://www.thinkbeyondthelabel.com/</p>

TABLE 2 Continued

	Resource
Medical home and care coordination resources	<p>AAP National Center for Medical Home Implementation: provides tools and resources for care coordination with specific supports, templates, and guides for pediatricians: http://www.medicalhomeinfo.org/</p> <p>Agency for Healthcare Research and Quality Care Coordination Accountability Measures for Primary Care Practice: a report that presents selected measures from the Care Coordination Measures Atlas that are well suited for primary care practice. The selected measures are divided into 2 sets: Care Coordination Accountability Measures (from the patient and/or family perspective) and Companion Measures (from the health care professional and system perspectives; ie, self-assessment): http://www.ahrq.gov/qual/pcpaccountability/pcpaccountability.pdf</p> <p>The Pediatric Care Coordination Curriculum: a 4-module core curriculum developed by physicians, nurses, social workers, family partner organizations, and family members demonstrating the principles, key concepts, and activities that are necessary to successfully provide care coordination and multidisciplinary, team-based care: http://www.childrenshospital.org/care-coordination-curriculum</p> <p>Care Mapping Tool User Guides: family driven tool to support family and/or professional partnerships in working on care mapping. http://www.childrenshospital.org/care-coordination-curriculum/care-mapping</p> <p>Jeanne W. McAllister and Lucile Packard Foundation for Children’s Health. <i>Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs</i>, a tool that provides a set of recommendations and templates for shared care planning: https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs</p> <p>ADHD: Clinical Practice Guideline for the Diagnosis, Evaluation, and Treatment of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. <i>Pediatrics</i>. 2011; http://pediatrics.aappublications.org/content/early/2011/10/14/peds.2011-2654. This updates the AAP recommendations for day-to-day care of patients with ADHD. It is complemented by an interactive overview of the ADHD Care Process algorithm that provides step-by-step guidance for implementing the guideline recommendations. A toolkit is available at: http://shop.aap.org/Caring-for-Children-with-ADHD-A-Resource-Toolkit-for-Clinicians/</p>
Transition to adult-oriented systems	<p>The National Health Care Transition Center, Got Transition, also developed and published the Six Core Elements of Health Care Transition and created Web-based tools and resources to aid pediatric and adult providers in transition processes: www.GotTransition.org</p>
Patient- and family-centered care	<p>Family Voices: a national, nonprofit, family-led organization promoting quality health care for all children and youth, particularly those with special health care needs: www.familyvoices.org</p> <p>Institute for Patient- and Family-Centered Care: fosters the understanding of patient- and family-centered care for professionals, patients, and families seeking to integrate these concepts into all aspects of health care: http://www.ipfcc.org/</p> <p><i>Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnership in the Medical Home</i>. A comprehensive monograph with strategies for partnering with families as reported by practices, including offering peer and family support and providing information and education through written materials, programs, and events: https://medicalhomeinfo.aap.org/tools-resources/Documents/Positioning_FINAL_May24.pdf</p>

HHS, Health and Human Services; NIAAA, National Institute on Alcohol Abuse and Alcoholism; SAMHSA, Substance Abuse and Mental Health Services Administration.

tailored to the child’s needs as part of an Individual Family Service Plan (IFSP) or an IEP is paramount for all children with special health care needs experiencing developmental, behavioral, and educational challenges.⁶¹ An IFSP is a plan for special services for young children with developmental delays and only applies to children from birth to 3 years of age. The IFSP focuses on the family because most young children spend most of their time with their family.

Once a child turns 3 years old, an IEP is put into place. An IEP is a plan for special services for children with developmental delays provided by the school system. The IEP is

focused on the child more than the family. In addition, section 504 of the Rehabilitation Act requires that schools make “reasonable accommodations” to ensure that children are not denied a “free and appropriate public education because of a disability.”⁶² When supporting children with an FASD in their medical home, collaborating with early intervention services and educational systems maximizes their potential. As such, working collaboratively with educational partners, in the context of an IEP when relevant, encompassing the necessary emotional, cognitive, and behavioral supports for children with an FASD is important, as it is with

all children with special health care needs experiencing developmental, behavioral, and educational challenges.⁶³

To better educate a child with an FASD, teachers and educators may benefit from special training and education about the child’s condition. Teaching caregivers about learning challenges, including the need for repetition, one-step commands, innovative training, and educational strategies for patients and families is imperative and an area that continues to evolve.⁶⁴ Challenges associated with disabilities that are not addressed early not only persist but also may become more severe and result in additional disabilities

or problems as an individual ages. Training and understanding the specific needs of a child with an FASD in both home and school settings cannot be overemphasized. Resources, books, and support groups specific to FASDs are available for clinicians and families.^{65,66}

Pediatricians may also need to support families in accessing mental health services for patients and families, including individual and/or family therapeutic services and possibly trauma-informed counseling services, depending on the circumstances. Mothers and families with substance use issues may also be in need of treatment resources for addiction or preventive services.⁴⁴ Partnerships with communities foster an understanding of available services and care integration for patients and families in the medical home.²²

Legal Issues and the Criminal Justice System

Because individuals with an FASD often have additional concerns such as mental health problems, substance use disorders, an inability to comprehend social rules and expectations, learning disabilities, school and employment difficulties, behavioral issues (eg, impulsivity, aggressiveness, hyperactivity, and poor judgement), housing insecurity, and challenges navigating activities of daily living, they may be more vulnerable to having interactions with the criminal justice system, either as a victim or an offender.^{16,67} Individuals with an FASD have been shown to have a higher rate of incarceration and arrest, with a significant portion of people with an FASD facing legal trouble at some point.^{16,67,68} One study found that approximately 60% of the 415 adolescents and adults with FASDs who lived in the Pacific Northwest and were enrolled in the Fetal Alcohol Follow-up Study of the University of Washington's Fetal

Alcohol and Drug Unit had legal issues defined as being charged, arrested, convicted, or otherwise in trouble with the authorities.³⁰ The most common criminal complaint (45%) in these cases was crimes against persons.³⁰ Individuals in prison have much higher rates of FASDs than the general population, but it is not currently possible to estimate the exact number of individuals with an FASD that are in the American criminal justice system because of unavailability and/or limitations in available data.^{16,29} In 2015, the total cost of FASDs in Canada was estimated to be a staggering \$9.7 billion Canadian dollars, of which criminal justice systems accounted for 40%, health care 21%, education 17%, social services 13%, and others 9%.⁶⁹ Specifically, the total cost per person with an FASD per year was estimated at \$27 000 Canadian dollars in 2015.⁶⁹

Fast and Conry⁶⁷ found that individuals with an FASD have neurologic impairments including learning disabilities, impulsivity, weak executive function, poor judgment, and limited social skills, increasing their susceptibility to criminal behavior and victimization. Individuals with an FASD may not be able to advocate in their own defense because the court systems and law enforcement officials (eg, police, officers of the court) usually use advanced language and/or give directions possibly perceived as confusing and/or conflicting to a person with an FASD. Also, individuals with an FASD can have memory and learning deficits that prevent them from learning from their past experiences and applying those experiences to new situations.⁶⁷ Many crimes committed by people with an FASD may be related to their environmental and psychosocial issues, including permanent effects PAE had on their brain. For example, a person with an

FASD may steal because he or she has trouble understanding the abstract concept of ownership. Specifically, from the perspective of a person with an FASD, if the real owner is not there, then the object has no owner and is therefore available to be acquired.⁷⁰

Law enforcement and other individuals in the criminal justice system are not always familiar with FASDs and their lifelong effects. This lack of experience can lead to misunderstanding and inappropriate treatment of the individual with an FASD during a law enforcement or legal encounter. In many cases, education targeting the law enforcement and legal system is needed for people with FASDs to have fair treatment and appropriate support. A medical information card explaining what an FASD represents can help affected individuals interact with law enforcement. When law enforcement officers understand that the individual they are dealing with has an FASD, they can call a designated support person as soon as possible. Sample content of the medical information card could include the following language:

"I have a medical diagnosis of Fetal Alcohol Spectrum Disorder (FASD). Because of this, I may not understand abstract concepts (such as legal rights). If you need my cooperation or I need help, please call the person listed on the back of this card."

Transitioning the Individual to Adult-Oriented Systems When Appropriate

Family-centered care in a patient-centered medical home model may greatly improve transition experiences for a youth with an FASD. Youth with special health care needs obtaining care within a medical home are more likely to receive transition services than those who do not receive care through a medical home.⁷¹ Health care transition preparation is transdisciplinary and holistic, including resources for all aspects of

life for youth with an FASD (health care, educational, social, vocational, and recreational). Providers, care coordinators, and system navigators promote participation and inclusion in the adult environment to the fullest extent possible for each patient with an FASD. Individualized case management, care coordination, guidance in navigating available resources and the complex social services system, and broad communication with patients and families extending beyond health care are valuable to help youth reach their full potential.²² Most importantly, patients and families need to be included in transition planning to optimize success. There are several guidelines and resources available for those involved in transition planning.^{71,72}

CONCLUSIONS

PAE can alter normal fetal brain development, leading to permanent structural and/or functional changes that may manifest as a host of significantly impairing emotional, neurologic, cognitive, learning, and behavioral problems. PAE remains one of the leading preventable causes of birth defects, intellectual disability, and neurodevelopmental disorders. The effects of having an FASD last a lifetime. Given the high prevalence, FASDs are as common as other well-known conditions, such as autism spectrum disorder and trisomy 21 (Down syndrome). As such, general and subspecialist pediatricians will care for patients with an FASD who need access to integrated care in a medical home. A health care provider can support the individual and family, integrate care and/or services, facilitate access to community resources, and assist with the transition to adult-oriented systems when appropriate. Proper services often help individuals with an FASD maximize their long-term potential. Without proper services,

treatment, or supports, individuals with an FASD may be at higher risk for referrals to child welfare, juvenile justice facilities, adult prisons or jails, and homeless shelters.

RECOMMENDATIONS FOR PEDIATRICIANS

1. Understand the epidemiology of FASDs and that its prevalence approaches, if not exceeds, that of more commonly known conditions.
2. Collaborate and communicate with obstetric providers regarding prenatal alcohol exposure and risk factors to optimize screening and monitoring of children.
3. Understand the various classifications and diagnostic criteria for FASDs and implications for screening, care, and management.
4. Universally screen all infants, children, and youth for PAE at the time of initial visits and when additional cognitive and behavioral concerns arise.
5. Become familiar with reporting laws and mandates in your practicing states and/or territories related to exposures and child outcomes.
6. Monitor children exposed to alcohol prenatally for physical, developmental, behavioral, and cognitive effects of such exposure.
7. Consider comorbid conditions in children with an FASD (ADHD, depression) and use evidence-based screening tools, medication management, and behavioral interventions, often in collaboration with neurobehavioral professionals.
8. Consider the need to reevaluate the diagnosis of ADHD, oppositional defiant disorder, or other diagnoses the child or

youth may have been given and refer when necessary.

9. Partner with the mental health community, therapists, educational professionals, and families to best meet the needs of children with an FASD and to foster understanding of the diagnosis, management, and interventions for an FASD.
10. Recognize that children with an FASD may have cognitive, behavioral, and physical manifestations of their condition warranting specific treatment strategies and interventions specific to the nuances of an FASD.
11. Proactively partner with foster parents, adoptive parents, and child welfare agencies to address issues such as obtaining accurate histories of prenatal alcohol or drug use.
12. Link patients and families with resources and supports for early intervention services, the educational system, the behavioral/mental health system, transition to adult-oriented health care systems, and other community resources when appropriate.
13. Embrace a preventive approach to FASDs, as there is no amount of alcohol during pregnancy that is risk free, no kind of alcohol during pregnancy that is risk free, and no time during pregnancy when alcohol consumption is risk free; share this information with all families.
14. Provide a high-quality medical home for all children and youth, including those with an FASD, consisting of care coordination, care integration, transition planning, and patient- and family-centered care.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
ADHD: attention-deficit/hyperactivity disorder
CAPTA: Child Abuse Prevention and Treatment Act
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
FAS: fetal alcohol syndrome
FASD: fetal alcohol spectrum disorder
IEP: individualized education program
IFSP: Individual Family Service Plan
ND-PAE: neurobehavioral disorder associated with prenatal alcohol exposure
PAE: prenatal alcohol exposure

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