Fetal Alcohol Spectrum Disorders: What Pediatric Providers Need to Know

Angela Nash, PhD, APRN, CPNP-PC, PMHS, & Leah Davies, LMSW

ABSTRACT
Prenatal alcohol exposure is the cause of fetal alcohol spectrum disorders (FASDs), the prevalence of which is similar to that of other developmental disabilities like Down syndrome and autism. Children, adolescents, and adults who live with the disabilities associated with prenatal alcohol exposure face extraordinary challenges throughout their lives. Pediatric providers need to be able to identify patients with FASD because early recognition and intervention is known to improve life outcomes for affected individuals. The purposes of this continuing education activity are to report what is known about the prevalence of FASDs; to detail the spectrum of problems experienced by affected individuals; and to suggest specific strategies for preventing, identifying, and managing FASDs in clinical practice. J Pediatr Health Care. (2017) 31, 594-606.

KEY WORDS
Developmental disability, FASDs, fetal alcohol spectrum disorders, neurobehavioral disorder, prenatal alcohol exposure

OBJECTIVES
1. Discuss why the prevalence of drinking by pregnant women suggests the need for universal screening for prenatal alcohol exposure.
2. Describe the spectrum of physical and neurobehavioral problems experienced by individuals with FASD.
3. List factors identified from a history and physical that should alert Pediatric PCPs to the need for referral for an FASD evaluation.
4. Discuss Pediatric primary care management of patients with FASD.
5. List factors that promote optimal development for Pediatric patients with FASD.

Prenatal alcohol exposure (PAE) is the leading known cause of preventable birth defects and developmental disabilities (Burd, 2016; McClellan & Expert Panel on FASD, 2009). Many factors influence the severity of fetal alcohol spectrum disorders (FASDs); however, PAE is the necessary component, making FASDs completely preventable (May & Gossage, 2011; Williams, Smith, & AAP Committee on Substance Abuse, 2015). FASD is an umbrella term describing the range of negative effects that can occur including physical and central nervous system (CNS) malformations, deficits in growth, and neurocognitive impairments (e.g., in behavior, self-regulation, and adaptive skills). Specific disorders include fetal alcohol syndrome (FAS), partial FAS, alcohol-related birth defects, and neurobehavioral disorder associated with PAE (ND-PAE; Hagan et al., 2016; Hoyme et al., 2016; Williams et al., 2015). Although FASDs are permanent conditions, with early recognition and intervention specific symptoms are manageable, and affected individuals’ life outcomes can be improved (Bertrand & Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium, 2009).

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Pediatric providers need to be able to identify patients with FASD and manage their care. The purposes of this article are to report what is known about FASDs; to detail the spectrum of problems experienced by affected individuals; and to suggest specific strategies for preventing, identifying, and managing FASDs.

TERATOGENIC EFFECTS OF ALCOHOL

The fetus is sensitive to alcohol’s teratogenic effects throughout gestation. At 1 to 2 hours after maternal alcohol ingestion, the fetal blood alcohol concentration reaches a level equivalent to that of the mother, and the process of amniotic reuptake prolongs the time of PAE. Elimination of alcohol from the fetus is dependent on the mother’s metabolic capacity, which varies considerably among pregnant women (Burd, Blair, & Dropp, 2012; May & Gossage, 2011). A number of mechanisms contribute to the physical and neurologic effects of PAE on the developing fetus (Gray, Mukherjee, & Rutter, 2009; Kane, Phelan, & Drew, 2012). Toxic byproducts of alcohol metabolism accumulate, disrupting the growth, division, and survival of cells throughout the body. Depending on the timing and severity of PAE, associated malformations can occur in the cardiac, skeletal, renal, ophthalmic, auditory, and neurologic systems (Hoyme et al., 2016). The sensitivity of the fetus to alcohol varies depending on the dose, pattern, and timing of PAE, as well as on general fetal health and wellness (May et al., 2013; O’Leary & Bower, 2012).

Animal studies have consistently shown that moderate to heavy PAE induces negative effects on neurodevelopment, and several studies have suggested that low to moderate PAE can produce functional damage on the developing fetal brain without obvious effects on other systems (Gray et al., 2009). Experimental human studies to determine the impact of the dose, timing, and pattern of PAE on outcomes are not ethically feasible; however, case-control and cohort studies with humans have shown consistent associations between moderate to heavy PAE and poor neurodevelopmental outcomes (Gray et al., 2009; O’Leary & Bower, 2012). The evidence for adverse effects from low to moderate PAE from observational studies is less robust because of challenges in accurately measuring the dose, pattern, and timing of alcohol consumption from self-reports, controlling for the presence of confounding factors, and a lack of consensus on diagnostic criteria in the scientific literature (Gray et al., 2009; O’Leary & Bower, 2012). Despite these methodologic challenges, evidence on the magnitude of the problem and the spectrum of disabilities associated with PAE support advising all women of childbearing age that there is no known “safe” level of alcohol consumption during pregnancy and that abstinence is the healthiest choice (Hoyme et al., 2016; Williams et al., 2015).

Several maternal factors affect the severity of effects from PAE. These include the pattern of maternal drinking (timing, quantity, and...
frequency), genetics, and maternal health history (Liyanage, Curtis, Zachariah, Chudley, & Rastegar, 2016; May & Gossage, 2011). The pattern of drinking found to be most harmful to the fetus is binge drinking, defined as drinking enough to raise the blood alcohol content level to 0.08 g/dl (Williams et al., 2015). Although metabolism and other genetic factors cause variability, for most women this means drinking approximately four standard drinks and for adolescents, drinking approximately three standard drinks in about 2 hours (Figure 1; National Institute on Alcohol Abuse and Alcoholism, 2016).

One study examined epidemiologic data to determine which maternal variables were most influential on affected children's intelligence and behavior at age 7 years (May et al., 2013). Frequent drinking (more than seven drinks per week) was associated with lower IQ scores (May et al., 2013; National Institute on Alcohol Abuse and Alcoholism, 2016). Maternal physical characteristics associated with higher severity of FASD in the child included low body mass index, small head circumference, and maternal weathering (e.g., advanced age, poor nutrition, and smoking). Maternal environmental factors associated with higher severity included low

FIGURE 2. Fetal alcohol syndrome facial phenotype. Examples of the full FAS facial phenotype (small eyes, smooth philtrum, and thin upper lip) across race and age. (a) White. (b) White infant. (c) African American. (d) Asian American. (e) Hispanic. (f) Native American.

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socioeconomic status, low education level, rural residence, social isolation, and belonging to social groups that promote heavy drinking (May & Gossage, 2011; May et al., 2013).

The absence of the protective liver enzyme alcohol dehydrogenase, which promotes rapid alcohol metabolism, is a genetic risk factor (May & Gossage, 2011). Paternal and maternal genetic factors may contribute to the sensitivity or resistance of the fetus to alcohol (Liyanage et al., 2016). A growing body of research has shown how alcohol leads to alterations in gene expression in key brain regions (e.g., vascular endothelial growth factor A, an important regulator of blood vessel formation and the corpus callosum; Caputo, Wood, & Jabbour, 2016). Advances in epigenetic research may enhance our ability to determine specific risk factors that predict FASD severity, demystifying the wide spectrum of deficits associated with PAE (Liyanage et al., 2016).

**FASDs DESCRIBED**

A wide range of problems can result from PAE (Williams et al., 2015). The most easily identifiable manifestation on the spectrum is FAS, which includes physical (e.g., fetal alcohol facial phenotype) and CNS malformations, growth deficits, cognitive disabilities, and neurobehavioral impairment (behavior, self-regulation, and adaptive skills; Olson et al., 2009; Warren, Hewitt, & Thomas, 2011; Williams et al., 2015; Figure 2, Figure 3). Individuals with partial FAS have CNS abnormalities and functional deficits at the same level as FAS but may not meet all the specific criteria for FAS. Alcohol-related birth defects are diagnosed in individuals with a history of PAE and physical malformations in the absence of neurobehavioral problems (May et al., 2009). Alcohol-related neurodevelopmental disorder or the newly proposed mental health disorder ND-PAE are diagnosed in individuals with PAE who experience many of the cognitive, neurobehavioral, and adaptive functioning deficits associated with FAS but may or may not exhibit the typical dysmorphic characteristics (Hagan et al., 2016; Williams et al., 2015; Table 1).

FASDs affect people from all socioeconomic strata and are highly heterogeneous disorders that manifest uniquely in each individual. Children, adolescents, and adults who live with the disabilities associated with PAE face extraordinary challenges throughout their lives, and most require some level of external support (Burd, 2016). Affected children without the specific FAS physical criteria often remain undiagnosed or encounter challenges qualifying for the appropriate interventions and support (Hagan et al., 2016). FASDs represent a

**FIGURE 3. Lip–philtrum guide.** University of Washington Lip–Philtrum Guides 1(A) and 2(B) are used to rank upper lip thinness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guides reflect the full range of lip thickness and philtrum depth, with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. This guide is used for White patients and those of all other races with lips like Whites. A second Guide is available for African American patients and all other races with lips as full as African Americans.
tremendous public health burden, with estimated annual costs up to $4 billion (medical and psychiatric care, foster care, special education, supportive employment, social security benefits, juvenile and adult corrections, long-term care, lost productivity, prevention and research; Centers for Disease Control and Prevention [CDC], 2016a; Lupton, Burd & Harwood, 2004; Popova, Lange, Probst, Gmel, & Rehm, 2016).

**FASDs affect people from all socioeconomic strata and are highly heterogeneous disorders that manifest uniquely in each individual.**

### EPIDEMIOLOGY

#### Prevalence of Alcohol Use by Women

Drinking is very common in adolescents and women of childbearing age. A recent systematic review and meta-analysis estimated the global prevalence of alcohol use during pregnancy to be 9.8% (Popova, Lange, Probst, Gmel, & Rehm, 2017). Almost 50% of all U.S. pregnancies are unintended, and 80% of teen pregnancies are unintended, so PAE may occur before a woman is aware of the pregnancy (CDC, 2014; Salas-Wright, Vaughn, Ugalde, & Todic, 2015). Most women decrease or abstain from drinking when they discover they are pregnant, but 9.3% of adults and 13.4% of adolescents report continued drinking throughout pregnancy (Center for Behavioral Health Statistics and Quality, 2016; Johnston et al., 2017; Salas-Wright et al., 2015). This may be due to a lack of knowledge of the potential adverse effects of PAE or may indicate the need for professional intervention for substance use disorder. Approximately 20% of women report binge drinking, which is the pattern of drinking associated with the highest risk for FASDs (Substance Abuse and Mental Health Services Administration, 2014b; Table 2).

### Prevalence of FASDs

Estimating the exact prevalence of FASDs in the general population is challenging, and a range of estimates exist based on the method used. Passive surveillance systems involve reviewing existing records (birth certificates, clinical records, registries of children with developmental disabilities) in a particular geographic area for probable or documented cases (May & Gossage, 2001). The disadvantage of this method is that FASDs are often underidentified (May et al., 2009). The CDC (2016a) reports

### TABLE 1. Brief diagnostic criteria for FASDs

<table>
<thead>
<tr>
<th>Type of disorder</th>
<th>Diagnostic criteria</th>
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| FAS              | With or without documentation of PAE, requires all of the following:  
|                  | - All 3 characteristic facial anomalies  
|                  |  o Short palpebral fissures  
|                  |  o Thin upper lip<sup>a</sup>  
|                  |  o Smooth philtrum<sup>b</sup>  
|                  | - Height and/or weight <10th percentile (prenatal and/or postnatal)  
|                  | - Structural CNS abnormalities  
|                  | - Neurobehavioral and cognitive impairment |
| pFAS             | With documentation of PAE, requires the following:  
|                  | - ≥2 characteristic facial anomalies  
|                  | - Neurobehavioral impairment |
|                  | Without documentation of PAE, requires all of the following:  
|                  | - ≥2 characteristic facial anomalies  
|                  | - Growth deficiency or structural CNS abnormalities  
|                  | - Neurobehavioral and cognitive impairment |
| ARBD             | Documentation of PAE  
|                  | >1 specific malformation in the following systems:  
|                  |  o Cardiac  
|                  |  o Skeletal  
|                  |  o Renal  
|                  |  o Ophthalmic  
|                  |  o Auditory |
| ND-PAE           | Requires documentation of PAE  
|                  | - Neurobehavioral impairment  
|                  | - Cognitive deficits  
|                  | - With or without physical anomalies |

Note. ARBD, Alcohol-related birth defect; CNS, central nervous system; FAS, fetal alcohol syndrome; FASDs, fetal alcohol syndrome disorders; ND-PAE, neurodevelopmental disorder associated with prenatal alcohol exposure; PAE, prenatal alcohol exposure; pFAS, partial FAS.  
<sup>a</sup>Ranks 4 and 5 on University of Washington Lip–Philtrum Guides 1(A) and 2(B). See Figure 3.

### TABLE 2. Alcohol use by U.S. women of childbearing age: Percentage of women surveyed who reported drinking at least once in the past 30 days

<table>
<thead>
<tr>
<th>Age group</th>
<th>Not pregnant</th>
<th>Pregnant</th>
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</table>
| Adults    | 50% drank    | 9.4% drank  
|           | 19% 1st trimester  
|           | 5% 2nd trimester  
|           | 4.4% 3rd trimester |
|           | 20% binge drank  
|           | Average of 3.1 binge episodes  
|           | 2.3% binge drank  
|           | Average of 4.6 binge episodes |
| Adolescents | 22% drank    | 13.4% drank  
|            | 27.6% 1st trimester  
|            | 21.6% 2nd trimester  
|            | 5.4% 3rd trimester |
|            | 12.4% binge drank  
|            | Data unavailable |

Sources: Salas-Wright et al., 2015; Substance Abuse and Mental Health Services Administration, 2014.
prevalence estimates for FAS at 0.3 infants of every 1,000 live births. This is considered to be a low estimate, because it is based on passive surveillance methods (CDC, 2016a).

The active case-ascertainment surveillance method involves in-person physical examinations, cognitive behavioral testing, and interviewing the mothers of all children in a large population or geographic area to identify cases (May & Gossage, 2001). Estimates from active surveillance with certain high-risk populations around the world have resulted in very high rates, which can bias estimates for the general population (Roozen et al., 2016). A recent study that used active case-ascertainment methods with a middle class community selected to represent the general U.S. demographic resulted in much higher rates than previously accepted estimates (May et al., 2014). A consented sample of 70.5% of all first graders in public and private schools received examinations (physical, dysmorphology, development, and neurocognitive), and their mothers were interviewed (May et al., 2014). In this sample the prevalence of FAS was 6 to 9 cases per 1,000 births, and the prevalence of FASDs was estimated at 24 to 48 cases per 1,000 births (May et al., 2014). Although not generalizable, this study suggests that FASDs are more common than older estimates predicted.

A systematic review and meta-analysis of prevalence studies that used rigorous methods to reduce bias estimated the global prevalence of FAS in the general population to be about 1.5 cases per 1,000 births (Popova et al., 2017). No global estimates exist for the prevalence of FASDs, but the prevalence ratio of FASDs to FAS is considered to be around 10 to 1, or about 15 cases of FASDs per 1,000 births worldwide (Chudley, 2008; Popova et al., 2017). In comparison, Down syndrome occurs in 1.4 of every 1,000 births, and autism occurs in 14 of every 1,000 births (CDC, 2016b, 2016d).

FASD IDENTIFICATION, REFERRAL, AND MANAGEMENT

Making the diagnosis of FASDs is difficult and requires a specialty team (Hoyme et al., 2016). Because of their role in developmental surveillance, primary care physicians (PCPs) are the most appropriate team members to identify and refer patients with signs and symptoms of FASDs for diagnostic evaluation (American Academy of Pediatrics [AAP], 2016; Hagan et al., 2016). The continuum of conditions under the umbrella of FASDs can be recognized and the interventions benefit individuals of any age, but early (<age 6 years) identification, diagnosis, and therapy result in the best outcomes for affected patients (AAP, 2016; Williams et al., 2015).

Identification and Referral

In a pediatric medical home, complete histories should routinely include history of known or suspected PAE and/or other risk factors (e.g., siblings with FASDs, patient in foster care or adopted; AAP, 2016). Parental concerns or FASD signs and symptoms (e.g., growth deficits, CNS abnormalities, behavioral/developmental issues, or the cardinal FAS facial characteristics) identified during a routine health maintenance visit should trigger the gathering of data on FASD-specific characteristics, including (a) height and/or weight ≤ 10th percentile, (b) smooth philtrum, (c) thin upper lip, (d) short palpebral fissures, (e) CNS abnormalities (e.g., microcephaly or focal neurologic deficits) and/or impaired neurobehavioral functioning (cognition, self-regulation, and adaptive functioning), and (f) PAE. If one or more of these characteristics are present, a referral to FASD diagnostic and developmental services, as well as to a genetics specialist (to rule out potential differential diagnoses), should be considered. If FASD-specific services are unavailable, referral to a developmental pediatrician is recommended. Referral for early childhood or school-based developmental services can be done as soon as FASD is suspected (AAP, 2016; Hagan et al., 2016).

If all characteristics (a through f) are present, FAS should be suspected and the appropriate referrals for developmental services made (AAP, 2016). If one or more (a through f) are present, referral to an FASD clinic or the best available professionals should be considered for help with diagnosis and referral for early childhood or school-based services (AAP, 2016; Bertrand et al., 2004; Hoyme et al., 2016). If impaired neurobehavioral functioning is the presenting issue and the patient has a history of more than minimal PAE, ND-PAE should be considered and the appropriate referrals made (AAP, 2016). This diagnosis is the most frequently missed because of the absence of the specific physical characteristics. The diagnostic process for ND-PAE is complex because of the many potential interacting factors (e.g., genetic, environmental, or other toxic exposures), variability of PAE (dose, duration, and timing), and potential interactions among other factors (prenatal and postnatal environments, genetics, and exposure to other toxic substances). Therefore, it is important to refer these patients to diagnostic professionals with FASD experience (Hagan et al., 2016; Hoyme et al., 2016). Other documents that contribute to the diagnostic process include a review of school records (if the child is school aged), birth information, and any psychological or developmental examinations. The AAP recommends considering referral to an FASD clinic and genetics specialist if PAE is suspected but not confirmed,
even if none of the data points are identified (AAP, 2016).

Missed Diagnoses and Misdiagnoses
FASDs are undiagnosed in many children, and, consequently, their neurobehavioral disabilities are untreated (Burd, 2016; Hoyme et al., 2016). Factors that contribute to missed diagnoses or misdiagnosis include (a) a lack of awareness of FASDs, (b) a lack of physical stigmata, (c) an unknown history of PAE, and (d) high rates of co-occurring mental health disorders associated with FASDs (Chasnoff, Wells, & King, 2015). One study examined a random sample of 547 foster or adopted children ages 4 through 18 years who had been referred to a children’s mental health center for behavioral problems (Chasnoff et al., 2015). Few (6.0%) of the children came to the clinic with a prior FASD diagnosis. A team of FASD experts conducted a comprehensive diagnostic assessment. Of the 547 children, about 30% met the diagnostic criteria for an FASD, and 86.5% of those had been misdiagnosed or had never received an FASD diagnosis. Almost all (94%) of the children had one or more co-occurring mental health diagnoses. After the comprehensive assessment, the mental health diagnoses changed significantly. In particular, previously undiagnosed or unaddressed learning and/or communication disorders were identified. This resulted in significant alterations in treatment (psychotropic medicine and therapies; Chasnoff et al., 2015). The study shows how underrecognized FASDs are in certain high-risk populations and implies that the therapeutic plan and potential outcomes for many children would significantly change with broader identification and referral of FASDs.

Medical Home Management
The PCP has an essential role in identifying and managing FASDs (Hoyme et al., 2016). A PCP who suspects an FASD should assess the child for comorbid conditions and secondary disabilities, understanding that many variables can compound an individual’s presentation. These variables include (a) PAE severity and timing; (b) maternal health; (c) birth complications; (d) exposure to poor parenting or role models; and (e) the child’s experience(s) of abuse, neglect, trauma, toxic stress, or other adverse experiences (AAP, 2016). As soon as the diagnosis is made, the next health maintenance visit should be scheduled, and the child should be identified as having special health care needs. The medical home should coordinate comprehensive continuing care and facilitate referrals to diagnostic, mental health, early childhood developmental services and educational services (AAP, 2016; Hoyme et al., 2016).

PROBLEMS OF CHILDREN WITH FASD
The manifestation of problems commonly associated with FASDs are age and development dependent (Burd, 2016; Hagan et al., 2016). Awareness of the problems experienced by affected individuals should inform pediatric PCPs’ care planning and management.

Physical Problems
The physical problems associated with FASDs manifest early and are the most readily identifiable. These can include miscarriage or fetal demise; prematurity, low birth weight, and sudden infant death syndrome; CNS abnormalities (e.g., microcephaly, reduced brain volume, and malformations of the corpus callosum); congenital heart defects (e.g., malformations in the outflow tract such as transposition of the great arteries); abnormalities of the kidney (e.g., renal hypoplasia or hydronephrosis) and/or optic system (e.g., small palpebral fissures, hypertelorism, strabismus, optic nerve hypoplasia, or tortuosity of retinal vessels); and/or auditory processing delays. Besides the cardinal facial features (small palpebral fissures, smooth philtrum, and thin upper lip), other possible facial abnormalities include micrognathia, cleft palate, and maxillary hypoplasia (Abdelrahman & Conn, 2009; Bertrand et al., 2004; Caputo et al., 2016; Stephen et al., 2012; Williams et al., 2015).

Neurobehavioral Problems
Neurobehavioral problems associated with FASDs can range from subtle to severe and typically vary in presentation as a child grows. Affected children’s IQ scores can range from very low to normal, but adolescents and adults tend to have lower academic achievement scores than their IQ scores would suggest (Streissguth & O’Malley, 2000). Table 3 details typical neurocognitive, behavioral, and adaptive functioning problems that FASD-affected children experience by developmental phase.

Other Comorbid Conditions
Individuals with FASDs experience comorbid conditions at much higher rates than the general population. A systematic review and meta-analysis of studies reporting cause of death and comorbidity of FASDs identified 428 comorbid conditions, including congenital malformations, genetic abnormalities, and mental and behavioral disorders (Popova, 2016). The most prevalent conditions (pooled prevalence > 67%) included disorders of special senses and the peripheral nervous system, conduct disorders, expressive and receptive language disorders, developmental deficiencies, and chronic serous otitis media. Other conditions (affecting > 50%) included hearing loss, retinal
malformations, substance abuse and/or dependence, and attention deficit hyperactivity disorder (Popova, 2016). Little evidence supports the use of specific medications for this population, yet these children often present to PCPs after being prescribed multiple psychotropic medicines (AAP, 2016). The PCP should evaluate children taking these medications for effect, appropriateness, and potential interactions and refer for psychological intervention, because most patients receive more benefit from intense forms of mental health and family therapy than from medication.

Secondary Disabilities

Although a person with FAS may have severe CNS malformations and neurobehavioral and cognitive impairments, these same challenges often make them more easily identifiable by PCPs. FASDs have been called the “invisible disability” because affected individuals (especially those with ND-PAE) may seem typical in appearance, so their deficits and behaviors are frequently misunderstood or misinterpreted as willful or defiant (Blaschke, Maltaverne, & Struck, 2009). The cognitive, adaptive, and social deficits associated with FASDs (Table 3) may prompt them to develop maladaptive behaviors, leading to a pattern of life-long physical, mental, social, and behavioral challenges. Adverse environmental conditions (e.g., frequent changes in caretaker placement, victimization, etc.) exacerbate the problems. These factors can lead to the development of secondary disabilities in adolescence and adulthood, including educational disruption, legal trouble, difficulty securing or keeping a job, confinement in psychiatric institutions or jail, inappropriate sexual behavior, and substance use disorders (Blaschke et al., 2009). Another troubling finding is that affected females have a higher risk of having an alcohol- or substance-exposed pregnancy themselves (Grant et al., 2013). Most individuals with FASDs need ongoing social support and mental health services.

Individuals with signs of FASDs must be identified early so they can receive a diagnosis and interventions to prevent secondary disabilities. Secondary disabilities and negative life outcomes have been shown to be mitigated by a loving and stable family; positive role models; predictable, structured routines; and clear, reasonable expectations (Streissguth & O’Malley, 2000). Additional factors that can reduce the odds of negative life outcomes in affected individuals include early diagnosis (before age 6 years), a high percentage of life in a nurturing stable home environment, having basic needs met, few changes in caretakers, a lack of victimization, and eligibility for social and educational services (Blaschke et al., 2009; Streissguth et al., 2004).

See the BOX for resources on primary care management.

Interventions

Although there is no cure for FASDs, it is widely accepted that early identification and referral to appropriate interventions mitigate the chances of secondary disabilities (Chasnoff et al., 2015; Streissguth et al., 2004). Although no medications have been specifically approved to treat FASDs, medications targeting an individual’s specific symptoms can be helpful and are often prescribed; however, these children often respond differently than children without PAE (CDC, 2016c; Hagan et al., 2016). Other interventions involve educating and equipping parents and children with strategies for coping with FASD deficits (CDC, 2016c; National Organization on Fetal Alcohol Syndrome, 2015). Evidence-based interventions for people with an FASD involve providing parent education, support, and skills; addressing social skills; addressing specific learning challenges around mathematics, executive functioning skills, and self-regulation; and developing strategies to address challenging behaviors (Bertrand & Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium, 2009). Most research around interventions for those with an FASD focuses on young children. Unfortunately, research targeting adolescents or adults with FASDs is lacking (Substance Abuse and Mental Health Services Administration, 2014; see the BOX for resources on interventions).

Educational Strategies

Education of children and adolescents requires a team approach (teachers; parents; administrators; health care and community providers; medical, developmental, and mental health services; Blaschke et al., 2009). Parents and teachers should recognize that students with FASDs are capable of learning, but they tend to function at lower levels than their similarly aged peers. Structure, consistency, brevity, variety, and repetition are keys to working with affected students (Blaschke et al., 2009). Parents and educators need to be concrete, simple, specific, and consistent with their instructions. These students have difficulty generalizing learning from one situation to another and do best with predictable routines. Memory problems may necessitate frequent repetition and re-teaching. Supervision is important for teaching appropriate behavior because they tend to be naive and easily victimized (Blaschke et al., 2009; Evensen & Lutke, 1997). See the BOX for Web links to educational resources.

Parental Support

PCPs should play an active role in educating and supporting parents to become experts about and
<table>
<thead>
<tr>
<th>Deficit</th>
<th>Infant and toddler</th>
<th>Preschool</th>
<th>School age</th>
<th>Adolescent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurocognitive</td>
<td>- Cognitive or global delays</td>
<td>- Cognitive or global delays</td>
<td>- Lower IQ</td>
<td>Same as school age, plus</td>
</tr>
<tr>
<td></td>
<td>- Increased or decreased muscle tone</td>
<td>- Problems learning sequential information</td>
<td>- Expressive/receptive language discrepancy</td>
<td>- Poor cognitive flexibility</td>
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<td></td>
<td>- Balance/coordination deficits</td>
<td>- Inability to follow multistep instructions</td>
<td>- Learning disabilities (math)</td>
<td>- Problems applying new knowledge or new strategies</td>
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<td>- Poor retention and recall</td>
<td>- Poor working memory</td>
<td>- Poor problem solving</td>
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<td></td>
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<td></td>
<td>- Sequencing</td>
<td>- Increasing reading and math difficulties</td>
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<td>- Recall</td>
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<tr>
<td>Self-regulation</td>
<td>- Jitteriness</td>
<td>- Active, impulsive</td>
<td>- Poor abstract reasoning</td>
<td>Same as school age, plus</td>
</tr>
<tr>
<td></td>
<td>- Poor habituation and self-soothing</td>
<td>- Inattentive</td>
<td>- Hyperactive/impulsive</td>
<td>- Risky behaviors increase</td>
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<td></td>
<td>- Problems with stress reactivity</td>
<td>- Emotion dysregulation</td>
<td>- Problems shifting/sustaining attention</td>
<td></td>
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<td></td>
<td>- Sleep problems</td>
<td>- Easily frustrated</td>
<td>- Mood lability</td>
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<td></td>
<td>- Sensory processing issues</td>
<td>- Easily overwhelmed and frustrated</td>
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<td>- Problems transitioning</td>
<td>- Problems with organization and planning</td>
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<td>- Poor self-soothing</td>
<td>- Problems complying with rules</td>
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<td></td>
<td>- Problems waiting</td>
<td>- Test limits</td>
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<td></td>
<td></td>
<td>- Demanding of attention</td>
<td>- Unaware of consequences of behavior</td>
<td></td>
</tr>
<tr>
<td>Adaptive</td>
<td>- Fine and/or gross motor delays</td>
<td>- Fine and/or gross motor delays</td>
<td>- Risky behavior</td>
<td>Same as school age plus</td>
</tr>
<tr>
<td></td>
<td>- Feeding difficulties</td>
<td>- Balance/coordination problems</td>
<td></td>
<td>- Problems managing time and money</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Poor social boundaries, overly friendly</td>
<td></td>
<td>- Employment problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Delays in dressing, bathing, etc.</td>
<td></td>
<td>- Problems learning coordinated motor skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Accident prone</td>
<td></td>
<td>- Frequently exploited</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Problems with independent living</td>
</tr>
</tbody>
</table>

Note. Although considerable variation exists among affected children from all categories of severity, when compared with control subjects, those with FASDs perform poorly on all cognitive and behavioral tests. The poorest performers have more dysmorphology (May et al., 2014). Executive functions are mental processes (working memory, flexibility, and self-control) that help individuals plan, focus attention, filter distractions, prioritize, remember instructions, and regulate behavior. FASDs, fetal alcohol spectrum disorders.

Sources: Blaschke, Maltaverne, & Struck, 2009; Burd, 2016; Hagan et al., 2016; Hoyme et al., 2016; May et al., 2014; SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence, 2007.
advocates for their FASD-affected child. Parents have four basic needs: receiving a diagnosis, accepting the child's deficits and processing emotions, developing a new understanding of their child's behavior, and receiving support from a knowledgeable community (Baskin, Delja, Mogil, Gorospe, & Paley, 2016). PCPs can serve as strong advocates for appropriate educational intervention and community services for affected children (Bernstein-Clarren, 2004; Bertrand et al., 2004). Care coordination should include referrals for mental health services and parent coaching and support (AAP, 2016). See the BOX for parent resources.

PCPs should be aware that an FASD is a diagnosis of both the mother and child. Alcohol use during pregnancy is a complex issue, and birth mothers often endure tremendous guilt when they learn that their child's problems are related to their drinking (National Organization on Fetal Alcohol Syndrome, 2017). Mothers report that they drank before they were aware of the pregnancy, they were not aware that PAE is harmful, or they were addicted to alcohol and unable to stop independently (National Organization on Fetal Alcohol Syndrome, 2017). Pregnancy is a time when mothers are highly motivated to seek treatment (Center for Substance Abuse Treatment, 2015). PCPs have a powerful role in supporting the recovery and parental role of biological mothers of children with FASDs. See the BOX for birth mother resources.

PCPs have a powerful role in supporting the recovery and parental role of biological mothers of children with FASDs.

PREVENTION

Alcohol Screening and Brief Intervention

Over 30 years of evidence shows that universal screening using validated tools is an effective method for identifying individuals at risk for having an alcohol-exposed pregnancy and provides the opportunity for clear and consistent messaging about the risks associated with alcohol use (Gifford & Bearer, 2015). For this reason, the U.S. Preventive Services Task Force and many other organizations recommend alcohol screening and brief interventions as part of routine clinical practice (AAP Committee on Substance Use & Prevention, 2016; CDC, 2014). Universal screening of women and adolescents of childbearing age allows PCPs to identify risk and to address PAE before a pregnancy occurs (AAP Committee on Substance Use & Prevention, 2016; CDC, 2014; Gifford & Bearer, 2015). Validated tools can be administered verbally or integrated into previsit questionnaires (AAP Committee on Substance Use & Prevention, 2016; CDC, 2014). PCPs who identify risky alcohol use have the privilege of influencing behavior change through brief interventions (short conversations designed to stimulate a patient’s own motivation for changing). Screening forms the basis for informed medical decision making and care planning. The whole process of screening and advice typically takes just a few minutes, is inexpensive, and is reimbursable in many cases (CDC, 2014). When repeated routinely over time, screening reinforces knowledge around preventing FASDs. Waiting until a woman or adolescent is aware that she is pregnant (which may be well into her first trimester) to advise her to discontinue drinking alcohol can preclude an opportunity for prevention (Barry et al., 2009). See the BOX for resources on the use of validated screening tools with women and adolescents.

PAE Biomarkers

Although widely used, self-report measures tend to underestimate alcohol consumption (McQuire et al., 2016). To provide a safety net for newborns and identify women in need of intervention, some researchers have advocated for universal screening of mothers and newborns for PAE via biomarkers. Biomarkers currently under study include fatty acid ethyl esters (products of ethanol metabolism) and micro-RNAs (tiny RNAs that repress protein translation; Balaraman et al., 2016; Coriale et al., 2014). High levels of these biomarkers correlate with moderate to heavy drinking. Although promising, biomarkers are not supported for use in clinical practice at this time. A systematic review of studies that used biomarkers found that the methodologic quality of studies was generally poor, the diagnostic accuracy of PAE biomarkers varied widely across studies, and participant recruitment from high-risk populations limited the generalizability of the findings (McQuire et al., 2016).

SUMMARY

Evidence is mounting that the prevalence of FASD is at least as common as developmental disorders such as Down syndrome and autism (CDC, 2016b; CDC, 2016d; Popova et al., 2017). Individuals with FASDs have a wide variety of comorbid conditions and secondary disabilities for which health care providers can provide intervention. Well-informed PCPs can reduce this burden significantly through early identification, referral to services, and advocating for families.
BOX. Fetal alcohol spectrum disorders provider resources

<table>
<thead>
<tr>
<th>Source</th>
<th>Topics</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance Use Screening, Brief Intervention, and Referral to Treatment (SBIRT)</td>
<td>AAP SBIRT youth article and policy statement, AAP SBIRT youth Web site</td>
<td><a href="https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Pages/Substance-Use-Screening.aspx">https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Pages/Substance-Use-Screening.aspx</a></td>
</tr>
</tbody>
</table>

Note. AAP, American Academy of Pediatrics; NIAAA, National Institute on Alcohol Abuse and Alcoholism; NOFAS, National Organization on Fetal Alcohol Syndrome; SBIRT, Screening, Brief Intervention and Referral to Treatment.

REFERENCES


Center for Behavioral Health Statistics and Quality. (2016). Key substance use and mental health indicators in the United States: Results from the 2015 national survey on drug use and health.
Rockville, MD: Substance Abuse and Mental Health Services Administration.
disorders: A systematic literature review including meta-analysis. Alcoholism, Clinical and Experimental Research, 40(1), 18-32.


