

## CARING FOR PATIENTS WITH PRENATAL ALCOHOL EXPOSURE: A NEEDS ASSESSMENT

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### ABSTRACT

#### Background

Prenatal alcohol exposure (PAE) is the United States' most common preventable cause of birth defects and intellectual and developmental disabilities collectively referred to as Fetal Alcohol Spectrum Disorders (FASD).

#### Objective

This study was designed to identify gaps in pediatric providers' knowledge and practices regarding FASD patient identification, diagnosis, management and referral, and to inform needs-based FASD resource development.

#### Methods

Pediatric providers (pediatricians, trainees, nurse practitioners) were exposed to survey links embedded in newsletters electronically distributed to the membership of two national professional societies. Survey responses were compiled and analyzed using descriptive statistics.

#### Results

Of the 436 respondents, 71% were pediatricians and 88.2% suspected that a child in their practice could have an FASD. Only 29.2% of respondents felt "very comfortable" diagnosing or referring an individual with suspected FASD. Merely 11.5% were satisfied with their current FASD knowledge base and practice behaviour. Most respondents (89.6%) indicated online continuing education courses as preferred learning method and suggested their knowledge and practices would be best enhanced through FASD-specific diagnostic and referral checklists or algorithms, and patient education brochures and fact sheets.

#### Conclusions

This study showed that few respondents were satisfied with their current FASD knowledge or practice behaviours. Continuing FASD education, particularly through online courses, was strongly desired. To maximize FASD recognition and optimize care for patients with FASDs, pediatric care providers must ensure that their FASD knowledge base, practice skills and provision of medical home care remain current.

**Key Words:** *fetal alcohol syndrome, fetal alcohol spectrum disorder, needs assessment*

**Abbreviations:** *AAP – American Academy of Pediatrics; ARBD – alcohol-related birth defects; ARND – alcohol-related neurodevelopmental disorder; CDC – Centers for Disease Control and Prevention; FAS – fetal alcohol syndrome; FASD(s) – fetal alcohol spectrum disorder(s); NCBDDD – National Center on Birth Defects and Developmental Disabilities; ND-PAE – Neurobehavioral Disorders – Prenatal Alcohol Exposure; NAPNAP – National Association for Pediatric Nurse Practitioners; PAE – Prenatal Alcohol Exposure*

## INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is an umbrella term describing a broad range of prenatal alcohol exposure (PAE) associated adverse physical, mental, behavioral, and/or developmental<sup>1</sup> effects last a lifetime. PAE is the most common preventable cause of intellectual and developmental delay and disabilities. Despite alcohol use warnings and increasing public awareness about the dangers of alcohol use during pregnancy, some women continue to drink (including binge drinking) alcohol during pregnancy.<sup>2-4</sup> Some women report decreasing or eliminating alcohol use during pregnancy, but 7.6% of pregnant women report continued alcohol use with 1.4% binge drinking.<sup>2</sup>

The FASD continuum includes fetal alcohol syndrome (FAS), Partial FAS, Alcohol-Related Birth Defects (ARBD), Alcohol-Related Neurodevelopmental Disorder (ARND), and Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE). FAS (a severe manifestation of PAE) has stringent facial, growth and central nervous system diagnostic criteria.<sup>1</sup>

Approximately 40,000 American infants are born with a FASD annually.<sup>5</sup> Because different diagnostic criteria are used for ascertainment, reported FASD prevalence rates fluctuate,<sup>6</sup> and the true prevalence and overall impact are likely under-recognized.<sup>7</sup> Recently, the Centers for Disease Control and Prevention (CDC) found FAS in 3 of 10,000 American children 7 to 9 years of age.<sup>8</sup> Other recent studies have reported rates of FASD (24 to 48 cases) and FAS (6 to 9 cases) per 1000 children.<sup>9</sup> Given this FASD prevalence, it is essential that pediatric providers are or become fully prepared to provide optimal care for individuals with a FASD<sup>10</sup>

including being knowledgeable, competent, and comfortable with FASD screening, suspicion, and either diagnosis and/or referral for a comprehensive FASD diagnostic assessment, especially because FASDs frequently go undiagnosed even when PAE is known. Chasnoff et al, reviewed cases of foster and adopted children and found that in 86% of those who met criteria were not recognized as having a FASD.<sup>11</sup>

A 2003 collaborative AAP-CDC survey of pediatricians' knowledge, training and experience in the care of children with FAS reported that respondents were generally aware of FAS clinical signs, symptoms and epidemiology, but had infrequent clinical experience with patients with FAS.<sup>12</sup> Most (62%) felt prepared to identify possible FAS, but only 13% reported using standardized FAS diagnostic criteria. Few (34%) felt prepared to manage or coordinate FAS treatment. PAE was inconsistently sought and 65% of respondents were concerned the FAS diagnosis might stigmatize the child and family. Most respondents did not routinely address alcohol use during pregnancy as part of adolescent female patient care and 45% never addressed the topic. Most providers (77%) cited lack of training as a diagnostic barrier. Only 28% reported being trained to use FAS screening or diagnosis tools. Only 3% reported excellent training in FAS diagnosis and treatment. Half reported being trained to screen patients for risky drinking, and 69% reported training to deliver patient education about the adverse effects of PAE. Only 29% cited time constraints as a barrier. Furthermore, many pediatricians were uncomfortable with FAS diagnosis and management needs and were unfamiliar with specialty and community resources.<sup>12</sup>

Recognizing the need for more training about FASDs, the CDC established national Regional Training

Centers in 2003. These centers worked to expand FASD educational outreach to thousands of providers nationally. In 2010, the AAP and CDC engaged in an interagency cooperative agreement to optimize care of patients with a FASD by enhancing provider education and access to diagnostic and management tools. A new needs assessment survey, *Optimizing FAS/FASD Care: Provider Needs Assessment*, was developed to gather information from pediatric providers, identify gaps in FASD knowledge, training and practice, and inform needs-based resource development that would improve effective patient- and family-centred FASD prevention, screening, early identification, intervention, management and referral.

### METHODS

A joint AAP-CDC FASD Expert Panel used existing FASD surveys as the foundation for the current needs assessment survey whose objectives were to understand the FASD-related clinical practices of providers and to determine provider's preferred methods of education and resource attainment. The survey (Appendix A) queried providers about triggers to suspect a FASD, options to assess and manage a FASD, and methods used to screen for PAE and to provide alcohol-related counselling. General provider information was collected, including their continuing education preferences, practice type (e.g., private practice, hospital-based, academic, etc.), and geographic practice location. The University of Texas Institutional Review Board granted exempt research approval, since the collected information was not linked in an identifiable manner to individual respondents and survey results would only be reported in aggregate.

In late 2010, the AAP electronically distributed the survey link by including it in the *AAP OnCall* e-newsletter and posting it on the daily AAP email list, *SmartBrief*. Approximately 80% of US board-certified pediatricians comprise the AAP membership of general pediatricians, pediatric subspecialists, and pediatric residents. Using the online Survey Monkey® tool, the AAP targeted survey distribution to the AAP Council on Community Pediatrics, and certain AAP Sections: Young Physicians, Ambulatory and Practice Medicine, and Adoption and Foster Care. The survey was also

circulated by e-news flash to the National Association for Pediatric Nurse Practitioners (NAPNAP). Survey participation was voluntary and respondents remained anonymous. No incentives to participate were offered. No specific media prompts or additional mailings were employed to increase the electronic survey response rate. Data from the survey were downloaded using the survey tool administrative functions and saved as Excel files. Responses to each survey item were analyzed using descriptive statistics.

### RESULTS

#### Demographics

The survey was completed by 436 providers. Most respondents self-identified as pediatricians (71%), nurse practitioners (21%), and other. Respondents practiced in a community clinic or hospital-base (~30%), private practice (37%), academic centre (~22%), or other (Table 1). Practice locations represented 47 of the 50 states and the District of Columbia. Respondents were relatively even distributed across US census regions with Region 3(the South) having the highest representation (34.5%) (Table 2).

**TABLE 1** Profession and Practice Type Descriptive Characteristics of Respondents

<b>Profession: Respondents - 415</b>	<b>No.</b>	<b>%</b>
Pediatrician	296	71.3
Nurse Practitioner	85	20.5
Other	34	8.2

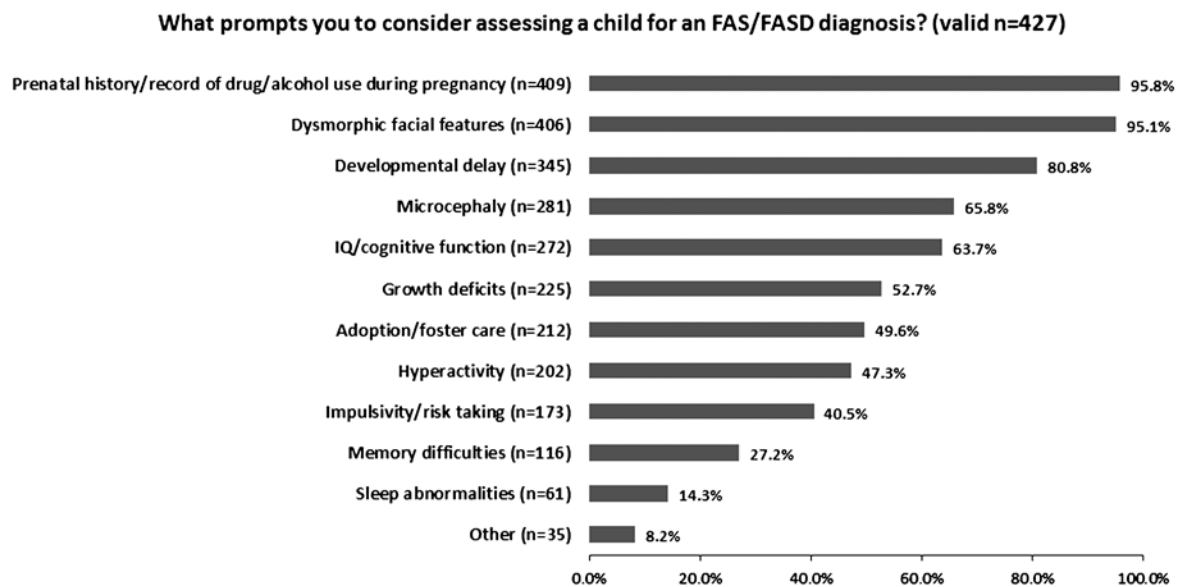
  

<b>Practice Type: Respondents - 414</b>	<b>No.</b>	<b>%</b>
Private Practice	154	37.2
Federally Qualified Health Center	39	9.4
Metropolitan Health District	1	0.2
Community Hospital	34	8.2
Children's Hospital	50	12.1
Academic Medicine w/ Trainees	73	17.6
Academic Faculty Practice	16	3.9
Other	47	11.4

**TABLE 2** Location of Respondents by Census Region

	<i>n</i>	%
<i>Region 1: Northeast</i>		
Division 1: New England (CT, ME, MA, NH, RI, VT)	27	6.7
Division 2: Middle Atlantic (NJ, NY, PA)	53	13.2
<b>Region 1 Subtotal</b>	<b>80</b>	<b>19.9</b>
<i>Region 2: Midwest</i>		
Division 3: East North Central (IN, IL, MI, OH, WI)	61	15.1
Division 4: West North Central (IA, KS, MN, MO, SD)	30	7.4
<b>Region 2 Subtotal</b>	<b>91</b>	<b>22.6</b>
<i>Region 3: South</i>		
Division 5: South Atlantic (DE, DC, FL, GA, MD, NC) SC, VA, WV)	82	20.3
Division 6: East South Central (AL, KY, MS, TN)	14	3.5
Division 7: West South Central (AR, LA, LA, OK, TC)	43	10.7
<b>Region 3 Subtotal</b>	<b>139</b>	<b>34.5</b>
<i>Region 4: West</i>		
Division 8: Mountain (AZ, CO, ID, NM, MT, UT, WY)	27	6.7
Division 9: Pacific (AK, CA, HI, OR, WA)	66	16.4
<b>Region 4 Subtotal</b>	<b>93</b>	<b>23.1</b>
Total Respondents - None from NE, ND, NV	403	

**FIG. 1** Respondents describe what prompts them to consider assessing a child for an FAS/FASD diagnosis.



**Recognition of Risk**

Most respondents (88.2%) indicated they suspected a child in their practice might have a FASD. The most important items identified as prompting

consideration for a diagnostic assessment for a FASD were a history of PAE, characteristic facial features, and/or developmental delay. Practitioners also cited microcephaly, IQ/cognitive function, growth deficits,

**TABLE 3** Diagnosis and Referral for suspected FAS/FASD

<b>Comfort making diagnosis or referring for suspected FAS/FASD Respondents - 415</b>	<b>No.</b>	<b>%</b>
Very comfortable	121	29.2
Somewhat comfortable	195	47.0
Not comfortable	99	23.9

<b>Referral resources used for suspected FAS/FASD* Respondents - 426</b>	<b>No.</b>	<b>%</b>
Early Intervention (0-3 program)	269	63.1
Developmental Pediatrics	252	59.2
Dysmorphology/Genetics	244	57.3
School System	75	17.6
FAS/FASD Clinic	65	15.2
Psychology (Child)	64	15.0
Social Work	41	9.6
Psychiatrist (Child)	34	8.0
Rarely Referred	19	4.5
Other	46	10.7

<b>Preferred referral resources for FAS/FASD diagnosis/evaluation, if available* Respondents - 423</b>	<b>No.</b>	<b>%</b>
Developmental Pediatrics	296	70.0
FAS/FASD Clinic	288	68.1
Dysmorphology/Genetics	231	54.6
Early Intervention (0-3 program)	216	51.1
Psychology (Child)	85	20.0
School System	78	18.4
Social Work	76	18.0
Psychiatry (Child)	58	13.7
Other	15	3.5

\*Multiple responses allowed.

adoption/foster care, hyperactivity, and/or impulsivity as triggers for an assessment for a FASD (Figure 1). Three-quarters of respondents reported some comfort making a diagnosis/referral for a suspected FASD

with 29% responding they were “very comfortable” (Table 3).

The majority (57.7%) of respondents reported in their practice they routinely suspect, assess and/or refer patients for a FASD diagnosis. Practitioner perceptions and beliefs were strong practice behaviour determinants. The following were factors most influential on FASD-related practice behaviour:

- limited provider knowledge, skills and time
- provider’s personal beliefs about the developmental potential and service needs for individuals with FASDs
- limited access to FASD-related diagnostic and management resources

Providers did not know specific PAE thresholds for fetal risk; were unfamiliar with screening tools (46%); and lacked training to screen for PAE (40.6%), diagnose a specific FASD (31.9%), and/or manage on an ongoing basis an individual with a FASD (26.2%). Having limited time was a barrier to 46.3% of respondents. When a FASD was suspected, providers referred patients to infant learning programs (63%), developmental pediatrics (59%), and/or genetics/dysmorphology services (57%) with the referral preferences being based on locally available services.

### **Preventive Screening**

Nearly 60% of respondents indicated ‘always or almost always’ screening for alcohol use in all patients 10–21 years of age while other providers “sometimes” (30.8%) or “rarely or never” (9.4%) screened. Practitioner counselling of adolescent patients about the harms of alcohol was similar. Most respondents (87%) indicated that they do not use specific tools to provide anticipatory guidance about alcohol use. Regarding counselling adolescent patients about the harms of drinking alcohol during pregnancy, respondents “always or almost always” (22.3%) and “sometimes” (55.7%) offered counselling. In comparison, respondents indicated that they “always or almost always” (70.4%) and “sometimes” (24%) counsel all patients ages 10–21 about sexual behaviour and risk-taking, including the prevention of sexually transmitted infections and pregnancy.



**TABLE 4** Practice Variation in Screening for Parental Alcohol Use

<b>Screen Parents: Respondents – 422</b>		
	<b>No.</b>	<b>%</b>
Yes	245	58.0
No	177	42.0

<b>Frequency of Screening for Alcohol Respondents – 309</b>		
	<b>No.</b>	<b>%</b>
Every visit	39	12.6
First visit	72	23.3
New patient visit only	54	17.5
When mother is pregnant	18	5.8
Prenatal visit	15	4.9
Patient w/symptoms FAS/FASD	47	15.2
Rarely/never	64	20.7

<b>Screening Method Employed* Respondents – 277</b>		
	<b>No.</b>	<b>%</b>
Informal questions during visit	178	64.3
Questions on quantity/frequency	131	47.3
Standardized tool	27	9.7
Other	33	11.9

\*Multiple responses were allowed

The majority (58%) of respondents have a practice standard to screen parents for alcohol use using parameters ranging from a prenatal visit to every patient visit. However, less than 10% of practitioners employed a standardized alcohol use screening tool. Most parental screening involved either informal questioning during the visit (64%) or specific quantity and frequency questions (47%) (Table 4).

Only 11.5% of respondents indicated satisfaction with their current FASD knowledge and practice behaviour. The vast majority of respondents (89.6%) expressed interest in taking an online FASD educational course for credit. The majority of those seeking to enhance their own FASD-related

knowledge and practice behaviour were interested in diagnostic criteria checklists, a reference guide for health professionals, an algorithm to guide diagnosis/ referral, a list of regional FASD diagnostic centers/clinics, and fact sheets and patient education materials. Fewer practitioners felt their practice behaviour would be enhanced through experience with specific alcohol consumption and risk thresholds, mentored practice with FASD diagnostic and management tools, or a FASD-specific website. Respondents selected their top three preferred learning methods. An online educational course was preferred by 75.1% over the 28.8% who wanted a live in-person course. More respondents (53.4%) preferred a web-based reference guide compared those who wanted a traditional print format (29.5%). Professional medical conferences sponsored by national professional societies appealed to 41% of survey participants and had greater appeal than a grand rounds presentation or a visiting professor expert (23.2%).

## DISCUSSION

This study demonstrates a gap between perceived and desired skill and knowledge for identification, treatment, and management of a FASD by pediatric providers. Gahagan previously explored a similar gap focusing solely on FAS.<sup>12</sup> The current study explored the clinical beliefs and practices of primary care providers regarding FASDs and determined preferred educational methods and resources to meet the identified practitioner's needs to optimize patient care.

Very few survey respondents were satisfied with their current FASD-related knowledge or practice behaviours, and most expressed interest in continuing education. Practitioners were aware of indications to consider a diagnostic FASD assessment. The beliefs and behaviours expressed suggest that practitioner awareness and practices have improved over time but still warrant attention. The recent survey showed an increase in overall practitioner comfort with diagnosing or referring a patient for a suspected FASD, but concern continued about making a FASD diagnosis in the medical home, and supporting patient referrals and case management.

Compared with the 2003 survey results,<sup>12</sup> considerably fewer respondents cited lack of training as a barrier, but an additional 37% cited lack of time to screen patients and make a specific FASD diagnoses. Perceived time constraints could reflect growing practice management pressures to increase efficiency, productivity and payment for care. Both surveys showed a similarly low percentage of practitioners believing the diagnosis would not change patient management or prognosis (14% and 11%). The various patient referral patterns identified may reflect differential service availability. Consultation with developmental pediatrics was highly desired, and the correspondingly high referral rate reflects broad national availability of this resource. In contrast, patient access to a FASD specialty program/clinic was preferred, but the very low referral rate suggests limited availability.

At minimum, most adolescents received screening and counselling in the primary care setting about alcohol use and its associated harms, but specific anticipatory guidance tools were not routinely used. Although alcohol use is one of the most high-risk behaviours and a top contributor to adolescent morbidity and mortality, including sexual risk, unplanned pregnancy and unintended PAE, pediatric providers less often discussed alcohol risks during pregnancy. Counselling adolescents about alcohol use and pregnancy improved considerably from previously when 45% never discussed the topic with female adolescent patients. These findings indicate an opportunity for FASD prevention in the primary care medical home regarding screening and counselling adolescent patients. The screening and anticipatory guidance practices of this sample of American pediatrics providers demonstrate there is ample opportunity for education and training to align trainee and practitioner practice behaviours with current standards of care, such as the AAP Bright Futures' recommendations.<sup>13</sup>

Respondents expressed strong interest in gaining knowledge and training about FASDs, and strong preferences in learning methods. Practitioners' perceived knowledge and practice gaps informed the priorities and development of AAP/CDC FASD Expert Panel activities, education and training product

development, and audience access and engagement. FASD-specific resource development included a reference guide for health professionals, algorithm to guide diagnosis/referral, list of regional FASD diagnostic centers/clinics, fact sheets and other patient education materials, AAP PediaLink online review course for CME credit, AAP Toolkit with free web site access [www.aap.org/fasd](http://www.aap.org/fasd), and a national visiting professorship program. Regional FASD Centers for Research and Training continue to provide conferences, training opportunities and locally focused print and mixed media educational resources for providers and families. These resources are readily available for community and health care providers' use and incorporation into electronic health records and patient portals.

Alcohol and other substance use screening, brief intervention and referral to treatment (SBIRT)<sup>14</sup> education has become increasingly routine in medical residency training over recent years, so graduates recently entering practice may have more skills and less concerns in these areas. Established medical providers are likely to be less knowledgeable and skilled in SBIRT practices, thus forming a population ripe to benefit from SBIRT training and continued education. AAP policy statements and clinical reports regarding the medical home and foster care remain additional resources for knowledge and skills development to optimize FASD prevention and care integration across medical, behavioral, educational and community settings. A recent AAP policy statement on patient and family-centred care coordination contains resources for providers engaged in care-planning and care coordination across systems.<sup>15</sup> Since coordinating multiple providers, systems and services is needed to achieve the full potential of an individual with a FASD and support patient/family goals, these care integration standards help define optimal medical home care for the person with a FASD.

The needs assessment study design had inherent sampling limitations because it relied on the email distribution of national association newsletters and a random portion of the readership opening an electronic link to complete the survey with no follow up or incentives for participation. The estimated audience for AAP

News OnCall and AAP Smart Brief is approximately 55,000, so all of these individuals could have been potentially exposed to the survey link. Because there were no prompts, tracking, or follow up, it is not possible to discern how many individuals were actually exposed to the survey link. Therefore, the authors are not able to provide an accurate denominator. Still, respondents were broadly representative of pediatric care providers from the AAP and NAPNAP memberships and widely distributed across the country, but the findings may not be representative of all pediatric care providers or medical home practices. Those most interested in FAS or another FASD were more likely to complete the survey. The respondents are likely to be biased toward those interested in the topic or who view its relevance to their clinical practice more highly. The very low response rate may also reflect a lack of understanding of the prevalence of the FASDs and the relevance of the diagnosis on their patient population. Even more worrisome is that it is likely that the responders despite their self-assessment of needing more knowledge about FASDs were more well-informed about FASD than the non-responders. Self-reported perceptions of practice behaviours and patient populations may be confounded by such as social desirability bias, and thus skew the reported estimates of abilities, practices, services, resource availability and numbers of patients with PAE-related conditions. Medical home screening of adolescents' alcohol use and PAE prevention although infrequent may be overestimates based on this survey population valuing FASDs as part of their patient care role. A comparison between the FAS and FASD survey results were limited by differences in the component questions.

### CONCLUSIONS

Given the prevalence of alcohol use by women who are sexually active or pregnant in the United States, pediatricians are likely to encounter individuals with FASDs in their practices. That is why it is important for pediatricians to be familiar with the feature of FASDs over the course of a lifetime. Although FASDs last a lifetime with no "cure," there are evidence-based management options that can improve outcomes for affected individuals. Pediatricians should be familiar with these

resources. Individuals with FASDs can experience more positive social, psychological, medical, and academic outcomes with longitudinal intervention and treatments that maximize potential. Protective factors like early age of diagnosis with a FASD; early interventions support services; various school-based educational accommodations; parental and teacher education about the condition; and being in a stable nurturing home environment have been effective in helping children with FASDs reach their developmental and educational potential. Without these protective factors, children with a FASD are at risk for adverse outcomes such as school dropout, substance use disorder, and involvement with the criminal justice system.

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## APPENDIX A

### OPTIMIZING FAS/FASD CARE: PROVIDER NEEDS ASSESSMENT

The purpose of this needs assessment is to gather information from the pediatric healthcare provider's perspective and identify gaps in addressing Fetal Alcohol Syndrome (FAS)/Fetal Alcohol Spectrum Disorders (FASD) optimally. Many children with FAS/FASD remain undetected because there is a lack of accurate, routine screening and referral in prenatal clinics and pediatric health care settings. By identifying potential information and resource gaps such as this, the AAP will be better able to determine what tools might help providers with FAS/FASD prevention, screening and early identification, intervention and management as well as referral.

The term FASD describes the range of outcomes that can occur in an individual whose birth mother drank alcohol anytime during pregnancy. FASD is not intended as a clinical diagnosis, but refers to a continuum of conditions or 'disorders' that may include physical, mental, behavior, and/or learning disabilities with possible lifelong implications. FAS represents the tip of the FASD iceberg and those individuals most severely affected by alcohol exposure *in utero*. Other disorders in the spectrum are Alcohol-Related Neurodevelopmental Disorder and Alcohol-Related Birth Defects.

**Thank you** for taking the time to complete this survey and improve the care of pediatric patients.

<b>QUESTIONS</b>
<b>Have you ever suspected that a child in your practice may have fetal alcohol syndrome (FAS) or another fetal alcohol spectrum disorder (FASD)?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No
<b>What prompts you to consider assessing a child for an FAS/FASD diagnosis? (Please select all that apply.)</b> <input type="checkbox"/> Prenatal history/record of drug/alcohol use during pregnancy <input type="checkbox"/> Adoption/foster care <input type="checkbox"/> Dysmorphic facial features <input type="checkbox"/> Microcephaly <input type="checkbox"/> Growth deficits <input type="checkbox"/> Developmental delay <input type="checkbox"/> Memory difficulties <input type="checkbox"/> IQ/cognitive function <input type="checkbox"/> Hyperactivity <input type="checkbox"/> Impulsivity/risk taking <input type="checkbox"/> Sleep abnormalities <input type="checkbox"/> Other (Please Specify)_____
<b>If you have a patient with a suspected FASD, where do you refer him/her for diagnosis or evaluation based on resources available in your community/referral system? (Please select all that apply.)</b> <input type="checkbox"/> Developmental pediatrician <input type="checkbox"/> Dysmorphologist / Clinical geneticist <input type="checkbox"/> Early Childhood Intervention Program (ECI or 0-3 Program) <input type="checkbox"/> FAS/FASD Clinic <input type="checkbox"/> Psychiatrist (child) <input type="checkbox"/> Psychologist (child) <input type="checkbox"/> School system <input type="checkbox"/> Social worker <input type="checkbox"/> These patients are rarely, if ever, referred to other resources. <input type="checkbox"/> Other (Please Specify)_____
<b>If the following resources were all available in your community or referral system, which of them would be your most preferable referral resources for diagnosis or evaluation of a patient with a suspected FASD? (Please select all that apply.)</b> <input type="checkbox"/> Developmental pediatrician <input type="checkbox"/> Dysmorphologist / Clinical geneticist <input type="checkbox"/> Early Childhood Intervention Program (ECI or 0-3 Program) <input type="checkbox"/> FAS/FASD Clinic <input type="checkbox"/> Psychiatrist (child) <input type="checkbox"/> Psychologist (child) <input type="checkbox"/> School system <input type="checkbox"/> Social worker <input type="checkbox"/> Other (Please Specify)_____
<b>In your practice, do you screen parents for alcohol use?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No

<p><b>If yes, how often?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Every visit</li><li><input type="checkbox"/> First visit</li><li><input type="checkbox"/> New patient visits only</li><li><input type="checkbox"/> When a patient's mother is pregnant</li><li><input type="checkbox"/> When conducting a prenatal visit with prospective parent(s)</li><li><input type="checkbox"/> Whenever a patient shows signs or symptoms of possible FAS/FASD</li><li><input type="checkbox"/> Rarely/never</li></ul>
<p><b>If you do screen parents for alcohol use, what screening method do you use? (Please check all that apply.)</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Questions to define quantity and frequency of use</li><li><input type="checkbox"/> Standardized screening tool (i.e. CAGE, AUDIT, TACE, or TWEAK, etc.)</li><li><input type="checkbox"/> Informal questions during visit</li><li><input type="checkbox"/> Other (Please Specify) _____</li></ul>
<p><b>How often do you counsel any adolescent patient (age 10–21) about the harms of alcohol?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Always or almost always</li><li><input type="checkbox"/> Sometimes</li><li><input type="checkbox"/> Rarely/Never</li><li><input type="checkbox"/> Comments: _____</li></ul>
<p><b>Do you use specific tools to provide anticipatory guidance regarding alcohol use to any adolescent patient (age 10–21)?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes</li><li><input type="checkbox"/> No\</li></ul> <p>If yes, please specify:</p>
<p><b>How often do you screen any adolescent patient (both male and/or female between the ages 10–21) regarding their alcohol consumption?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Always or almost always</li><li><input type="checkbox"/> Sometimes</li><li><input type="checkbox"/> Rarely/Never</li><li><input type="checkbox"/> Comments: _____</li></ul>
<p><b>How often do you counsel any adolescent patient (both male and/or female between the ages 10–21) about the harms of drinking alcohol during pregnancy?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Always or almost always</li><li><input type="checkbox"/> Sometimes</li><li><input type="checkbox"/> Rarely/Never</li><li><input type="checkbox"/> Comments: _____</li></ul>
<p><b>How often do you counsel any adolescent patient (both male and/or female between the ages 10–21) about sexual behavior and risk-taking, including the prevention of sexually transmitted infections and pregnancy?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Always or almost always</li><li><input type="checkbox"/> Sometimes</li><li><input type="checkbox"/> Rarely/Never</li><li><input type="checkbox"/> Comments: _____</li></ul>
<p><b>How comfortable are you making the diagnosis of or referring a patient for suspected FAS/FASD?</b></p> <ul style="list-style-type: none"><li><input type="checkbox"/> Very comfortable</li><li><input type="checkbox"/> Somewhat comfortable</li><li><input type="checkbox"/> Not comfortable</li></ul>

**Many providers in their daily practice do not suspect or consider FAS/FASD, and do not refer patients for FAS/FASD diagnostic evaluation and/or management resources. Please indicate which of the following factors may contribute to your practice. (Please select all that apply)**

- I do consider potential FASD and/or refer patients for FAS/FASD diagnosis in my practice
- Belief that it does not apply to my patient population
- Belief that only a specialist should make this diagnosis
- Belief that making the diagnosis will not change management or prognosis
- Concern about stigma attached to FAS/FASD; sensitive nature of topic
- Unfamiliar with screening tools
- Lack of training in how to screen
- Lack of time to screen as a routine during office visits
- Lack of specific personal training to make diagnosis
- Lack of time needed to make the diagnosis
- Lack of specialists to assist in diagnostic evaluation
- Lack of diagnostic referral resources
- Not familiar with management strategies once a diagnosis is made
- Lack comfort/confidence with managing the diagnosis
- Lack of training in patient management of treatment options
- Lack of treatment referral resources
- Need to triage this with competing medical problems
- Unaware of the threshold at which alcohol consumption is risky for FAS/FASD
- Other (please specify) \_\_\_\_\_

**Would you be interested in taking an online CME course addressing FAS or FASD?**

- Yes
- No

**Which other resources would help you enhance your knowledge and practice behavior about FAS or FASD? (Please select all that apply.)**

- I am satisfied with my current FAS/FASD knowledge base and practice behavior
- A FAS/FASD fact sheet
- A list or checklist of the FAS/FASD diagnostic criteria
- A list of the regional FAS/FASD diagnostic centers/clinics
- Patient educational materials (brochures/handouts)
- A reference guide/manual for healthcare professionals
- Mentored practice with FAS/FASD diagnosis and management tools
- Algorithm to guide diagnosis or referral
- FAS/FASD specific Website
- Thresholds for alcohol consumption and risk
- Other (please specify) \_\_\_\_\_

**How would you prefer to learn more about FAS or FASD? (Please select your top three methods.)**

- CME live course
- CME online course
- Medical conference (i.e., AAP NCE, PAS, SPR)
- Reference guide available in book format
- Online reference guide
- Visiting professorship/grand rounds
- Other (please specify) \_\_\_\_\_



**What best describes your practice?**

- Private practice
- Federally qualified health center/rural health center
- Metropolitan health district affiliated practice
- Community-hospital affiliated practice
- Children's hospital-based practice
- Academic medicine training program clinics with trainees
- Academic medicine faculty practice
- Other please specify \_\_\_\_\_

**Please indicate in which U.S. state your practice is located. (Select from the drop-down list.)**

**Please indicate which credentials describe you - M.D., D.O., PNP, pediatrician, family practitioner, etc. From the drop-down list, please select all that apply.**

**We welcome any COMMENTS and SUGGESTIONS you might wish to share:**

