Screening for Prenatal Alcohol Exposure: An Implementation Guide for Pediatric Primary Care Providers

Research over the past 50 years has underscored the harmful effects of alcohol on the developing fetus and subsequent lifelong physical, behavioral, and learning disabilities. Screening for prenatal alcohol exposure (PAE) is a key component of heath supervision visits for newborns and new patients according to *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents (4th Edition)*.

Early identification of developmental disorders, including fetal alcohol spectrum disorders (FASDs), is critical to the well-being of children and their families. Screening for PAE is an essential function of the primary care medical home and the responsibility of pediatric clinicians. Early identification of a child at risk for developmental disability because of a positive screen for PAE should lead to further evaluation and, when warranted, diagnosis and treatment. Pediatricians are well positioned to screen children for PAE and FASDs, spearheading the process of accurate diagnosis, and coordination of care necessary to improve health and psychosocial outcomes for children with an FASDs and their families.

This implementation guide offers an evidence-informed method to determine a history of PAE and is intended to support pediatricians and other pediatric clinicians in facilitating early identification of children who are at risk for one of the FASDs.

ALCOHOL USE DURING PREGNANCY

About 1 in 10 pregnant women in the United States reports drinking alcohol in the past 30 days, and about 1 in 33 pregnant women reports binge drinking (having 4 or more drinks at one time) in the past 30 days. Studies suggest that fetal alcohol syndrome (FAS), the most involved of the FASDs, occurs in just under 1% of the population, while 1% to 5% of grade school children have neurodevelopmental disabilities secondary to PAE that meet criteria for an FASD diagnosis. Rates of children with FASDs are even higher among vulnerable populations, such as children in foster care, children adopted internationally, and children of American Indian descent. Yet, most children with an FASD are never diagnosed or are misdiagnosed, despite frequent occurrence of severe disabilities in neurocognitive, adaptive, and behavioral function.

There is no amount of alcohol known to be safe to drink during pregnancy. All drinks that contain alcohol have the potential to harm a developing fetus. Although not all children who are prenatally exposed to alcohol develop an FASD, many do. Currently, it is not possible to predict which fetuses will be affected. The safest choice is for women to refrain completely from alcohol use while pregnant or trying to get pregnant.

- 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.

Additional data about alcohol use and pregnancy is available online at www.cdc.gov/vitalsigns/fasd.

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FETAL ALCOHOL SPECTRUM DISORDERS (FASDS)

FASD is an overarching term that encompasses a range of possible conditions, including fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related birth defects (ARBDs), alcohol-related neurodevelopmental disorder (ARND), and neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE). The term "FASD" is not meant to be a specific diagnosis, but rather a range of clinical presentations. Although distinct facial features and growth deficiencies first led to recognition of alcohol's effects on the fetus, it is now known that characteristic facial features are present for less than 20% of children with an FASD. Children with FASDs have a constellation of physical, behavioral, and cognitive abnormalities resulting from PAE. Signs and symptoms of FASDs range from mild to severe, with each individual affected slightly differently. FASDs are the leading cause of preventable intellectual and developmental disabilities in the Western world. These disabilities may not be observed on physical examination, yet can be devastating to normal development, making PAE screening of all children all the more imperative.

Information about the individual FASD diagnoses can be found as a part of the AAP FASD Toolkit.

SCREENING FOR PRENATAL ALCOHOL EXPOSURE

Screening for PAE is an integral component of a pediatrician's routine family assessment. Screening for PAE can identify children at risk for developing one of the FASDs, **but a positive screen does not equate to an FASD diagnosis**. Developmental surveillance of at-risk children within the medical home can help health care providers recognize signs and symptoms of PAE if they emerge and can prompt early intervention to improve the child's outcome over a lifetime. When normalized to all patients, "universal screening" questions about drinking decrease stigmatization. Even more importantly, one of the greatest barriers to diagnosis of a child with an FASD remains the lack of documentation of PAE, making it more important that pediatricians document the results of their screening of all patients for future reference.

"A transparent, caring, and direct approach when engaging the parent will help maintain a positive relationship, which is in the child's best interest."

– Vincent C. Smith, MD, MPH, FAAP

Screening for PAE can be conducted at any family interaction time—prenatal visits, in the newborn period, at the time of adoption, and as new patients and families join a practice.

SAMPLE QUESTIONS

Screening for prenatal alcohol exposure can be incorporated into a standard script to help ease potential pediatrician discomfort and provide reassurance to the caregiver when discussing topics that may be sensitive. During birth history, anticipatory guidance, or any other appropriate portion of the parent interview, after asking standard guidance questions (eg, about medications, tobacco, home environment), one can ask about prenatal alcohol exposure.

The following are examples of questions to screen for prenatal alcohol exposure:

- How far along were you before you found out you were pregnant?
- Before you knew you were pregnant, how much alcohol (beer, wine, or liquor) did you drink?
- After you found out you were pregnant, how much alcohol did you drink?

SCREENING WHEN MEETING A FAMILY DURING A PRENATAL VISIT

When meeting a family for the first time prior to delivery, routine screening could include inquiry about the birth mother's alcohol consumption along with asking about other health risks. The results of a screen for PAE conducted during a prenatal visit need to be documented and retained to be added to the child's health record after birth.

Any acknowledgement of alcohol consumption during pregnancy counts as a positive screen. If a screen is positive, the pediatrician has the opportunity to educate the parents about the harmful effects alcohol can have on the developing fetus and encourage the mother to stop drinking. Providing information and education about the risks of alcohol use during pregnancy can result in a pregnant woman stopping drinking, thereby lowering the risk of her child developing an FASD. In addition, children of mothers who stop drinking during pregnancy tend to have better neurodevelopmental outcomes than children of mothers who continued to drink throughout pregnancy. Research has shown that parents who screened positive for substance use/alcohol use were open to the pediatrician discussing their alcohol use with them and presenting them with follow-up options. Pregnant women can be directed to their primary care physician or to community resources for further assessment, management, and services. Pediatricians, other pediatric clinicians, and other members of the practice team may find it efficient to have a prepared list of community, regional, state, and national resources to offer. Likewise, options for adult primary care providers can be helpful for pregnant women without an established medical home.

Components of alcohol screening and brief intervention in primary care can be found on the Centers for Disease Control and Prevention (CDC) Web site: http://www.cdc.gov/ncbddd/fasd/alcohol-screening.html

SCREENING WHEN MEETING A FAMILY FOR A HEALTH SUPERVISION VISIT OR NEW PATIENT VISIT

When meeting a family for a health supervision visit, screening for PAE can be incorporated into the pediatrician's routine health maintenance questions if screening has not been completed previously.

- In the office setting, during the newborn period and first months of life, as pediatricians are getting to know the child and family, they generally inquire about a range of prenatal and pregnancy factors that bear on the infant's health history. This is an ideal setting to include screening for PAE, if screening has not already been conducted.
- There are many reasons why families may change to a new pediatric practice. When a child comes under the care of a pediatrician for the first time **at any age**, screening for PAE can be conducted as part of a comprehensive family health history.

Asking about PAE may be incorporated into taking a birth history, providing anticipatory guidance, or conducting any other appropriate portions of the parent interview. For example, questions about PAE may be added after asking standard questions about the pregnancy, tobacco use in the home, nutrition, or other aspects of the home environment.

- Pediatricians may want to begin by inquiring about general topics related to the pregnancy and then move toward more specific questions about prenatal exposures.
- Questions about alcohol use during pregnancy can be explained as an important part of the earliest history of the child, similar to when asking about smoking, nutrition, and other aspects of pregnancy.
  - "It helps us to identify as early as possible anything that could affect your child."
- Ask open-ended questions (that cannot be answered yes or no).
  - "How much alcohol were you drinking before you knew you were pregnant? (NOT "Did you drink alcohol when you were pregnant?")
  - "After you found out you were pregnant, how much alcohol (beer, wine or liquor) did you drink?"
- Be attuned to body language or hesitation in the response.
  - "I heard a little pause – a lot of people do not realize right away when they are pregnant and sometimes that means they drank alcohol before even knowing about the pregnancy."
- Follow up on non-specific responses.
  - **Pediatrician: "**How much did you drink before you found out you were pregnant?"

    Mother: "I used to have some drinks when I was out with the girls on the weekend."

    Pediatrician: "Okay. About how much did you drink over the weekend?

    Mother: "Maybe 2 or 3 wine spritzers."

    Pediatrician: "And was that most weekends?"

    Mother: "About a couple times a month."

There is still value in knowing prenatal alcohol exposure, even if it is not possible to quantify the amount. A positive screen provides the opportunity for a "teachable moment" to engage the parent, empathetically explain the potential risk without judgment, and stress the importance of close supervision of the child for developmental or other problems associated with PAE.

- **Pediatrician:** "Not all children exposed to alcohol during pregnancy have problems, and we cannot predict who will and who will not, so we want to follow those children closely."

ADOPTION AND FOSTER CARE

Children who have been adopted and children in foster care are a population of children with a higher prevalence of prenatal exposure to alcohol or other drugs and of potentially having an undiagnosed FASD. When children are adopted or enter foster care, pediatricians gather information about the child's background, including biological family history, details about pregnancy and delivery, and the child's early history, if this information is available in adoptive/foster care records. This assessment could include inquiry regarding the potential for prenatal alcohol exposure. Foster or adoptive parents should be encouraged to ask their case worker for the information.

CULTURAL SENSITIVITY

PAE screening should be conducted in a manner that is culturally sensitive. Cultural sensitivity considers the beliefs, values, actions, customs, and unique health care needs of distinct population groups. Taboos and strong beliefs regarding alcohol use may be more pronounced in certain racial, ethnic, or cultural groups. Religious or social repercussions for drinking alcohol may influence how a mother will respond to screening. Information about providing culturally effective care is available from the American Academy of Pediatrics. Universal screening of all new families eliminates unconscious bias like singling out a family on the basis of physical or socioeconomic characteristics.

DOCUMENTATION AND NEXT STEPS

Pediatricians and other pediatric clinicians are encouraged to work with other members of their practice to develop a common process for PAE screening and documentation of the results. When screening is completed, document that PAE screening was conducted and the results of the screening in the patient's chart. There is no uniformly accepted practice regarding documenting PAE screening results. The tools available through the *Bright Futures Tool and Resource Kit* are compatible with, but do not require, an electronic health record (EHR). All components of the *Bright Futures Tool and Resource Kit* are available at https://brightfutures.aap.org.

Once a child screens positive for PAE, there is no need to continue to screen that individual. After documenting it in the medical record, the provider then monitors closely for developmental delays, behavior problems, social difficulties, and cognitive deficits and school challenges, among other potential problems. Attention problems or learning problems in math should receive particular consideration.

A child who initially screens negative for PAE but subsequently develops behavioral problems accompanied by deficits in neurocognitive, social and adaptive skills, and self-regulation may be reevaluated for possible PAE.

Diagnosis opens the door to therapeutic services and supports that can positively influence outcomes for the child and family. Building a solid collaboration among health care professionals and other service providers (eg, psychiatrists, psychologists, social workers, therapists) and agencies (eg, schools, mental health agencies, agencies serving children and youth with special health care needs, child protective services) improves the effectiveness of support for children and their families.

The Flow Diagram for Medical Home Evaluation of Fetal Alcohol Spectrum Disorders was designed to facilitate greater clinical recognition of children with FASDs. The flow diagram is available at www.aap.org/fasd as part of the AAP FASD toolkit.

REQUIRED REPORTING

Under the federal Child Abuse Prevention and Treatment Act (CAPTA), health care providers are mandated reporters. The CAPTA *does not require* clinicians to report to child protective services if a child has been prenatally exposed to alcohol (ie, for a positive PAE screening). Referral to child protective services *is required* if the child has been diagnosed with an FASD in the period between birth and 3 years of age. 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*.

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

If the child is ultimately diagnosed with an FASD in a state where a mandatory referral or report to child protective services is necessary, health care professionals should 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 professional can discuss all of the following: (1) the risks and effects to children around parental substance abuse; (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.

Additional information about the CAPTA Reauthorization Act of 2010 is available from the American Bar Association. Additional information about referral requirements under CAPTA and IDEA are available from the Early Childhood Technical Assistance Center.

CHALLENGES WITH SCREENING FOR PRENATAL ALCOHOL EXPOSURE

Challenges may arise when screening for PAE in some settings. The following address some specific challenges that can be associated with screening implementation or follow up to a positive screen.

DOCUMENTATION AND ELECTRONIC HEALTH RECORDS (EHRS)

CHALLENGE: There is no easy solution to documenting results of a screen for PAE in some EHRs. Existing systems may be hard to modify if there is no standard template.

SOLUTION: Each provider/group/clinic will need to identify a way to consistently document PAE screening results for their practice. In many cases, a new field can be added by working with the practice's EHR vendor representative. Additionally, many EHR vendors have established pediatric user groups, which may provide guidance on how to document PAE in the practice's EHR.

If adding a field specific to PAE is not feasible within the practice's EHR system, there are likely existing fields where this information could be documented. Many EHR systems have a "problem list" and/or a "health concerns" field as part of the Common Clinical Data Set required by all federally-certified EHR systems. Regardless of the method chosen, it is essential for providers within a practice to be consistent in how and where they document screening results. Some resources to address EHR challenges include the following:

- AAP Clinical Report: Health Information Technology and the Medical Home

- Special Requirements of EHR Systems in Pediatrics
- Pediatric Aspects of Inpatient Health Information Technology Systems
- AAP FASD Toolkit practice management resources: quick tips for documenting screening results

EDUCATION AND AWARENESS OF FETAL ALCOHOL SPECTRUM DISORDERS (FASDS)

CHALLENGE: A 2010 needs assessment of AAP members documented a gap between perceived and desired skills as well as knowledge for screening and identification, treatment, and management of children with FASDs. Pediatricians identified *education* as the most influencing practice behavior regarding early identification, evaluation, and referral of children at risk for one of the FASDs.

SOLUTION: Given growing recognition of the prevalence of FASDs, continuing medical education about this condition is imperative. Educational resources are available to pediatricians through the *PediaLink* online learning platform (www.pedialink.org), in the AAP FASD Toolkit (www.aap.org/FASD), and through the Centers for Disease Control and Prevention (www.cdc.gov/FASDtraining). These educational offerings address risk factors, screening and diagnostic tools, and therapeutic interventions once a diagnosis is made. In addition, each AAP district has a designated Regional Educational Awareness Liaison trained by the AAP and CDC to educate pediatricians and other pediatric clinicians on FASD screening, diagnosis, and treatment.

STIGMA

There can be significant stigma associated with consumption of alcohol while pregnant. It is helpful to understand the situation from the perspective of a biological mother in her own words.

"Think of me as an alcoholic who got pregnant and now needs your help to care for her child, not as a pregnant woman who drank."

– National Organization on Fetal Alcohol Syndrome

CHALLENGE: The pediatrician's comfort in identifying and addressing risk factors for FASDs with parents is essential for a high-quality, family-centered, and culturally competent medical home. There are multiple ways that a pediatrician's and other professionals' personal beliefs about prognosis and care of children at risk for one of the FASDs can influence outcomes for the child and family. A pediatrician's perceived or real judgment about a mother who is drinking or who drank alcohol during the pregnancy, as well as the perceived stigma of an FASD diagnosis for the child and his/her family, may influence the pediatrician's readiness to screen for PAE.

SOLUTION: Many pediatric clinicians do not believe that alcohol use during pregnancy is a problem in their patient population. However, it is estimated that 1 in 5 children grow up in a home in which someone uses drugs or misuses alcohol. More than 3 million women in the United States are at risk of exposing their developing babies to alcohol because they are drinking, having sex, and not using contraception (Green PP, McKnight-Eily LR, et al, 2016). About half of all pregnancies are unplanned and, even if planned, most women do not know they are pregnant until they are 4 to 6 weeks into the pregnancy. Furthermore, against common perception, the greatest number of women who drink during pregnancy are white and college-educated women. This makes universal PAE screening important.

Pediatricians can set an example and address stigma by following these simple strategies:

- Learn and share the facts about FASDs (www.cdc.gov/ncbddd/fasd)
- Get to know children and families living with an FASD (www.nofas.org/video)
- Speak up when friends, family, colleagues, or the media display false beliefs and negative stereotypes about alcohol use during pregnancy
- Treat patients with FASDs and their parents with the same respect and dignity as you would anyone else
- Talk openly of your own experience of caring for individuals with FASDs

"Think of screening for prenatal alcohol exposure like other difficult conversations such as depression and poverty. Mothers will be as comfortable answering questions about prenatal alcohol use as physicians feel asking them."

– Doug Waite, MD FAAP

MIXED MESSAGES RELATED TO ALCOHOL USE DURING PREGNANCY

Pediatricians and other pediatric clinicians have an important role in dispelling myths and media statements related to the effects of alcohol consumption during pregnancy.

Media headlines frequently are sensationalized to grab attention or reflect political agendas or marketing goals. Media 'frenzies' can create and spread misinformation. Pediatricians and other pediatric clinicians must provide families with accurate information and explanations in plain language regarding health and wellness, including the risk of prenatal exposure to alcohol. Pediatricians can speak to the large body of scientific research establishing that prenatal alcohol exposure can cause harm.

Pediatricians and other pediatric clinicians need to fully understand the spectrum of challenges related to PAE, which can range from mild to severe, and educate families about the impact of alcohol on an individual child and how to provide targeted interventions.

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