ISSUE BRIEF

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How can child protection agencies better address fetal alcohol spectrum disorders?

This brief was developed by Children and Family Futures, in partnership with Casey Family Programs. For a self-assessment tool and resource list, see the companion brief: *Which resources can help strengthen agency responses to fetal alcohol spectrum disorders?*

Fetal alcohol spectrum disorders (FASD) are the largest known causes of intellectual disability, with their harmful lifelong effects spreading across various stages of development, from infancy through adolescence to adulthood.[1]

Children and adults who receive diagnoses at an early age and grow up in stable environments, however, are two to four times more likely to avoid adverse life outcomes due to FASD.[2] In addition to early identification and a nurturing home environment, two other factors that can help mitigate future disabilities include involvement in special education and social services, and an absence of violence in their lives.[3]

Child welfare and health care systems report difficulty in screening, diagnosing, and responding to FASD with appropriate interventions. This brief is intended to provide child protection agencies the awareness and strategies they need to respond more effectively to the needs of children and families affected by FASD.

Definitions: Cause and effects

Prenatal alcohol exposure (PAE) occurs when a developing fetus is exposed to alcohol.

Fetal alcohol spectrum disorders (FASD) is the umbrella term used to describe the range of preventable intellectual (neurodevelopmental) disabilities and birth defects that result from PAE.

Source: American Academy of Pediatrics

Prevalence

Recent diagnostic studies estimate that as many as 1 in 20 children in the U.S. suffer effects related to prenatal alcohol exposure (PAE).[4] The presence of FASD — the range of harmful conditions caused by PAE — has been documented in as many as 17% of all substantiated cases of child maltreatment.[5] PAE can create lifelong cognitive and behavioral disabilities. Alcohol is a teratogen, meaning it can directly interfere with fetal development and cause permanent damage to the brain and other organs.[6]

Data compiled in the 2023 Pregnancy Risk Assessment Monitoring System (PRAMS) indicated that about 1 in 9 pregnant women (11.3%) reported drinking alcohol in the past 30 days.[7] While all instances of PAE carry a potential risk of FASD, not every instance of PAE leads to FASD. Still, the FASD conditions resulting from PAE are typically misdiagnosed or not diagnosed at all. The American Academy of Pediatrics sums up FASD screening directly: "Most children with an FASD are never diagnosed or are misdiagnosed, despite frequent occurrence of severe disabilities in neurocognitive, adaptive, and behavioral function."[8]

Four types of FASD

Clinical practice and research have classified FASD conditions into four categories:

1. **Fetal alcohol syndrome**. The most severe form of FASD, includes specific facial features (small eye openings, thin upper lip, smooth ridge between nose and upper lip); small stature; and challenges with learning, memory, attention, executive functioning, self-regulation, and communication.
2. **Alcohol-related neurodevelopmental disorder.** Individuals with this condition may have the same combination of impairments from fetal alcohol syndrome, but none of the physical markers.
3. **Alcohol-related birth defects.** Problems include those with the heart, kidneys, bones, or hearing.
4. **Neurobehavioral disorder associated with prenatal alcohol exposure.** This emerging term encompasses all fetal alcohol-related conditions except alcohol-related neurodevelopmental disorder.

Source: U.S. Centers for Disease Control and Prevention

One study found that over 86% of children in foster care and adopted children with FASD[9] had never been previously diagnosed or had been misdiagnosed.[10] Research also indicates that alcohol use during pregnancy co-occurs frequently with use of illicit drugs, as nearly 40% of pregnant respondents who reported current drinking also reported current use of one of more other substances.[11]In the context of prenatal exposure, alcohol use is inextricably linked with other forms of substance use. While alcohol use must be recognized as a distinct and often invisible driver of prenatal exposure-related conditions, it remains inseparable from other substance use in practice. This fact requires a response that both differentiates alcohol's unique impact and acknowledges its frequent co-occurrence with illicit drug use. Additional data about alcohol use and pregnancy is available online through the online archive of the U.S. Centers for Disease Control and Prevention.

The prevalence of FASD has led to the American College of Obstetricians and Gynecologists and American Society of Addiction Medicine recommending that prenatal health care providers use universal prenatal screening with validated screening tools for prevention and early treatment. Under-diagnosis and under-reporting continue, however, resulting from a combination of a lack of training among health care providers, stigma about alcohol use during pregnancy among providers, widely varying child welfare policies regarding substance exposure, and fear among pregnant and parenting women that self-reports of alcohol use may usher in a child protective services investigation and/or removal of their infants.

The role of child protection agencies

Child protection agencies are critical players in preventing, identifying, and intervening in response to FASD. Their role is not solitary, but rather one of shared responsibility that forges and sustains partnerships with other agencies and community organizations. A unified approach can improve the lives of

children and adults who are potentially and currently affected by FASD. The goals of preventing and responding to the effects of PAE require wider public health and community support, and child protection agencies can play a crucial convening role for efforts to keep these children with their families and prevent child placement.

Child protection agencies should seek to partner with other agencies and service providers that specialize in the diagnosis and treatment of FASD. Such partnerships ensure that young children receive screening, assessments, and early intervention services, and that their parents and caretakers receive family-centered substance use disorder treatment.

A companion to this brief provides child protection agencies and their partners a self-assessment tool and a list of resources with detailed practice tips for strengthening their response to children and families affected by FASD.

Responding to state policy variations

The Child Abuse Prevention and Treatment Act (CAPTA) is a federal law that provides funding to states to prevent child abuse and neglect.[12] States that receive CAPTA funding are required to adopt policies and procedures so that newborns identified as affected by prenatal substance abuse, including those impacted by FASD, receive a Plan of Safe Care (POSC) before discharge from the hospital. CAPTA requires states to use funding to expand the development of POSC to respond to the needs of both infants who are identified as affected by substance use and their family or caregivers.

At least 25 states require that a report of prenatal substance use or detected substance exposure at birth is legally deemed child maltreatment.[13,14] CAPTA specifically uses the word “notification” when talking about infants born affected by substance use, withdrawal, or FASD and states that a notification is not an indication of child abuse or neglect. Notification processes are shaped by state legislation, specifically whether or not a state codifies prenatal exposure as abuse or neglect. Child protection agencies also vary in their responses to prenatal alcohol or other substance use, with some states’ policies not accepting a case until the child is born, while others have interagency policies, often with maternal and child health, which respond with referrals to treatment or short-term interventions during pregnancy.

Child protection agency staff need to understand how their state laws and regulations treat these matters as a guide to their responses to the POSC requirements. The federal POSC requirements clearly adopt a family-centered perspective that gives equal importance to both children and parents, recognizing that early bonding and attachment are critical to family functioning and child well-being.

Prenatal alcohol and other substance exposure raises issues that can create tension between child risk and safety, and a concern that reporting substance exposure can divert parents from treatment needed for themselves and their children. Early identification of substance use during pregnancy can lead to timely referrals to treatment, which improves outcomes for families, but punitive reporting policies can discourage pregnant individuals from seeking treatment. A further challenge is the reality of stigma associated with prenatal alcohol use and fear that child welfare agencies may remove a child if parental substance use is detected or admitted.

Research indicates racial and socioeconomic disparities exist in screening for substances in newborns and reporting following diagnosed substance exposure.[15,16] Infants born to Black mothers were more likely than those born to white mothers to be screened, regardless of whether or not they met the standard criteria for screening.[17] Disparities in screening and reporting often stem from provider discretion and screening policies that increase the risk of bias and disproportionate involvement with child welfare.[18] In contrast to punitive policies, some states and localities have developed more supportive measures that reassure pregnant and parenting women that seeking family-centered treatment will provide them and their infants with the care that both need. While not required under CAPTA, some jurisdictions implement prenatal POSC to respond to the care and treatment needs of infants with prenatal exposure and their families. Engagement by peer staff with lived experience is also a strategy used by both health care providers and child welfare protection agencies to engage and retain parents — including mothers and fathers — who need help responding to the needs of children affected by FASD. Additional information on other

supportive measures, including care coordination, access to MAT, and availability of community-based wraparound services, is highlighted in the companion assessment tool and resource list.

Identifying FASD

Despite the well-documented risks and effects of PAE, it remains significantly under-identified in clinical and community settings. One major challenge is the lack of routine and standardized screening for alcohol use during pregnancy, often due to constraints related to available time by child protection agency workers and stigma. Many pregnant individuals experience stigma related to their substance use and therefore may underreport alcohol use out of fear of judgment or legal or child welfare consequences, further complicating identification. Symptoms of FASD can overlap with other developmental conditions, making identification and diagnosis difficult without a confirmed history of exposure.

> "Raising our niece who has FASD has been a journey filled with love, learning, and a lot of advocacy, but to fully understand the experience it's important to say that every day can be extremely challenging. Navigating our relationship with her parents hasn't always been easy, but with compassion and patience on everyone's part we have all been able to move beyond blame and guilt. Our niece, who has become our daughter, is almost 36 now, and the level of structure she needs is much greater than other 36-year-olds. We've come to understand that she has a 'gap in her executive functioning' that is part of the experience of those with FASD and it contributes to her inability to follow through. As she's reached chronological milestones — turning 18, having children of her own — it has become clear that the level of structure and support she needs from us will not really lessen."
>
> –Former Kinship Caregiver for a Child with FASD

The challenge of identifying PAE is best resolved by training child welfare professionals in close cooperation with health care providers who have the diagnostic tools to recognize its symptoms. Detecting PAE at birth is difficult because alcohol metabolizes quickly compared to other substances.

The goal of the child welfare system is to promote the well-being of children by ensuring safety, achieving permanency, and strengthening families. Child protection agency staff respond to reports of child maltreatment to determine if the allegations are true and if intervention is necessary to protect the child. The steps in this process include the identification of risk factors and protective factors. As child protection agency workers conduct their assessment, parental alcohol and other substance use may emerge as a factor, prompting further evaluation of the child's safety and the family's support needs.

Importantly, parental alcohol or other substance use in and of itself does not necessarily mean that a child is unsafe, although it can increase their risk of harm. For instance, it can result in a decrease in parents' cognitive functioning that affects their ability to properly care for and attend to their child's needs. As staff complete their investigation, they determine: 1) the strengths and needs of the family, 2) if the allegations are true, 3) if the child is currently safe and next steps if they are not, and 4) if further child welfare intervention or community resources are needed, which may include placing the child in protective custody.

Screening for the effects of FASD requires training in recognizing its effects, which may include:

- **Neurocognitive impairment** including developmental delays, poor abstract reasoning and executive functioning to associate acts with their consequences, difficulty retaining new information, and remembering verbal instructions.
- **Self-regulation** indicated by mood or behavioral dysregulation, being irritable, frequently upset, easily frustrated, having poor impulse control, difficulty following rules, frequently interrupting others, and engaging in risky behavior.

- **Adaptive functioning** including difficulties using language to express oneself, linking words with feelings, reading social cues and following social norms, making and keeping friends, understanding time, and managing daily routines.[19]

Specifically in children up to age 3, FASD may manifest as mild or severe developmental delays, challenges with self-regulation (manifesting as trouble with sleep, fussiness, difficulty being soothed, and sensitivity to being overstimulated), and disorganized or unfocused play.[20]

"One of the hardest parts from the very beginning was helping my child manage big emotions. A small change in routine or a loud noise could trigger a meltdown that might last for hours. We tried many strategies — visual schedules, sensory tools, calming corners — but it was a constant process of trial and error. What worked one day might not work the next. I also had to learn to stay calm myself because my reactions set the tone. It wasn't just about teaching my child to regulate, it was about co-regulating with them every single day."

–Adoptive Parent of a Child with FASD

Child protection agencies can be instrumental in identifying FASD symptoms that prompt referrals for further evaluation, which could lead to an FASD diagnosis and intervention. Health clinics, university-based diagnostic clinics, early care and education providers, and schools' special education professionals also can assess children and students for these conditions with adequate training. Child protection agency staff will benefit from familiarity with these other entities that can provide more intensive assessments and diagnoses. Some child protection agencies have participated in joint training efforts with health care providers and hospitals, reviewing strategies for cooperation as they learn more about FASD.

Collaborative support for interventions in response to FASD

A challenge for parents and resource parents is achieving openness when indications of PAE are present in a child. This openness is essential to prepare parents and caretakers to meet the needs of the child. A lesson for parents and caretakers is that often these children *cannot* observe norms without help, not that they *will not*. Understanding this distinction helps to build realistic expectations of the child and understand developmental and behavioral challenges.

Multiple interventions have been tested and proven effective with children who have FASD, including behavior and education therapies that teach appropriate social skills[21] and improve self-regulation and executive function.[22,23] Parents and caretakers also may benefit from specialized training that can help them support their child and cope with FASD-related symptoms. The further task for child welfare is to connect these children to these interventions to ensure the best outcomes, and to help stabilize their families and support their parents and caretakers.

"We learned that getting services for our child wasn't as simple as just asking. We had to advocate, educate, and sometimes even fight for what we knew our child needed. FASD isn't always recognized the way other diagnoses are, so we had to explain over and over again what it means and why our child needed support. It was exhausting at times and became clear that the service systems didn't talk to each other. We had to be case managers in ways we didn't expect."

–Adoptive Parent of a Child with FASD

In planning and implementing these interventions with children and families affected by FASD, child protection agencies should become familiar with funding streams under the control of their partners, rather

than relying solely on the child welfare system itself or one-time project grants. Larger funding streams, especially Medicaid and Individuals with Disabilities Education Act for specialized early care and education, can be much more helpful in sustaining effective interventions than time-limited grants.

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