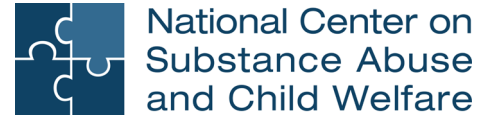


UNDERSTANDING FETAL ALCOHOL SPECTRUM DISORDERS: CHILD WELFARE PRACTICE TIPS



The National Center on Substance Abuse and Child Welfare (NCSACW) developed this technical assistance tool for child welfare professionals who serve children and families affected by prenatal exposure to alcohol and parental substance use disorders. It provides a broad overview of fetal alcohol spectrum disorders (FASD), their effect on child development, and treatment for FASD.

Child welfare professionals play a key role supporting children and families affected by FASD through effectively partnering with other agencies and service providers who specialize in the diagnosis and treatment of FASD, ensuring young children receive assessments and early intervention services, and providing family-centered substance use disorder (SUD) treatment. The final section of this document provides detailed practice tips to help child welfare professionals partner with these other agencies and, in doing so, best support infants, children, and families affected by FASD using a collaborative, family-centered approach.

WHAT IS FASD?

FASD is an umbrella term describing the range of effects and group of disorders that occur when an individual has been affected by prenatal exposure to alcohol. The symptoms range from mild to severe and affect each person differently. The diagnoses are based on particular symptoms and include:

Fetal Alcohol Syndrome (FAS)

FAS represents the part of the FASD spectrum that includes specific facial features (small eye openings, thin upper lip, smooth ridge between nose and upper lip); small stature; and a variable range of issues with learning, memory, attention, executive functioning, self-regulation, and communication.

Alcohol-Related Neurodevelopmental Disorder (ARND)

Individuals with ARND may have the same combination of impairments listed under FAS but none of the physical markers.

Alcohol-Related Birth Defects (ARBD)

People with ARBD have problems with the heart, kidneys, bones, or hearing.

Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

This is the emerging term encompassing all fetal alcohol-related conditions except ARBD. Although the range and types of impairments are the same as mentioned above, ND-PAE encompasses individuals with and without the facial features and small stature of FAS.¹

PREVALENCE OF ALCOHOL USE DURING PREGNANCY AND FASD

Alcohol remains the most frequently used substance during pregnancy second only to tobacco.² A 2020 study found that current use of alcohol during pregnancy among women aged 18-44 increased from 9.2% in 2011 to 11.3% in 2018, while binge drinking (four or more drinks on one occasion) rates increased from 2.5 to 4%.³ In 2020, the Centers for Disease Control and Prevention (CDC) found reports of alcohol use among pregnant women are higher in the first trimester of pregnancy—19.6% of pregnant women reported current alcohol use in the first trimester vs. 4.7% in the second or third trimesters. They also found that over 40% of pregnant women who reported current alcohol use also reported current use of at least one other substance, most commonly tobacco, marijuana, and opioids.⁴

The CDC states that there is **no safe time** to drink alcohol during pregnancy and **no known safe amount of alcohol** to consume during pregnancy or when trying to get pregnant.



FASD prevalence is estimated to range between **1-5% of children** in the United States.^{5,6}

The rate is estimated to be higher—6% for FAS and nearly 17% for FASD—among children and youth involved with child welfare services.⁷

Many believe FASD prevalence rates are underestimated since professionals often overlook or misdiagnose the disorder in children and youth. One study found that over 86% of foster and adopted youth with FASD had never been previously diagnosed or had been misdiagnosed.⁸ Missed diagnoses and misdiagnoses can result from a number of reasons, including:



Lack of Screening and Testing – Alcohol is not typically detected by routine toxicology panels on newborns in the hospital since it metabolizes very quickly.⁹ There are also inconsistencies in screening for prenatal alcohol and other substance use among healthcare providers and child welfare professionals. There are currently no lab tests (e.g., blood, imaging, biopsy) available specifically for FASD. Diagnosis will be much more accessible under the new ND-PAE diagnostic schema since mental health clinicians can make the behavioral diagnosis without a physician.



Complexity of Symptoms – Children under 3 can be difficult to diagnose because the deficits in higher-level cognitive functioning often do not show until school age.¹⁰ FASD can also masquerade as other mental health disorders or behavioral challenges, such as attention deficit hyperactivity disorder, bipolar disorder, oppositional defiant disorder, autism spectrum disorder, and learning disabilities. **The abnormal facial features are present in fewer than 20% of individuals with FASD;¹¹ thus, many cases can be missed if providers are only looking for the presence of these features.**



Stigma and Fear – Shame and guilt may prevent women from admitting alcohol use during pregnancy, which can render diagnosis more difficult. Women may fear child welfare involvement and child removal if they disclose prenatal alcohol use.



Lack of Education and Training – Child welfare professionals don't often receive the education and training necessary to identify FASD signs and symptoms. Current trainings on prenatal substance exposure for child welfare professionals are typically focused more heavily on exposures to substances *other* than alcohol, such as opioids.¹² Medical school programs typically do not include any specialized content on FASD, thus leaving healthcare providers also ill equipped to adequately identify, diagnose, and treat these issues.

SYMPTOMS AND EFFECTS OF FASD

While there is a wide range of severity and effect on development, prenatal exposure to alcohol is the single largest known preventable cause of intellectual disability.¹³ Prenatal alcohol exposure can cause difficulties with self-regulation, memory and reasoning—which often leads to the perception of “disobedience” in children and “irresponsibility” in adults.

Impairment associated with FASD generally falls into one or more of the following domains.¹⁴

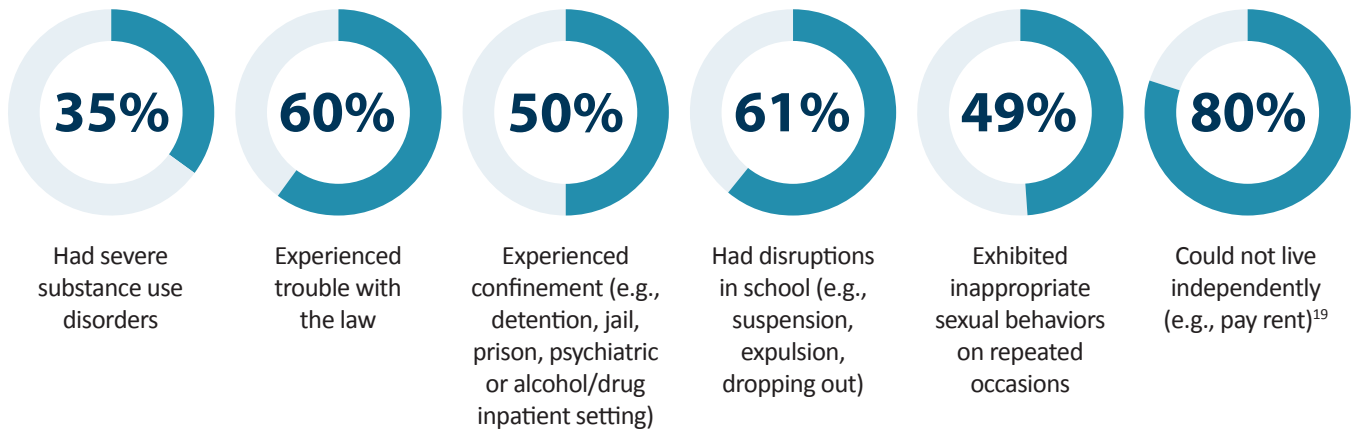
Domain	Impairment	Examples of Associated Difficulties
Neurocognitive Impairment	Global impairment	Developmental delays, applying new knowledge, abstract reasoning
	Poor executive functioning	Difficulty with judgment, impulse control, organization, planning, flexibility, associating acts with their consequences, and estimating time, distance, weight, and volume
	Learning deficits	Difficulty retaining new information and learning math
	Memory problems	Difficulty remembering verbal instructions, retaining learned information, and making the same mistake many times
	Visual–spatial reasoning	Difficulty with alignment, solving puzzles, understanding directionality, reading maps, and poor proprioception
Self-Regulation	Mood or behavioral regulation	Irritable, frequently upset, hyperresponsive, easily frustrated, difficulty with being overstimulated and calming down
	Attention	Trouble shifting attention and staying focused on tasks or new information
	Impulse control	Difficulty waiting, following rules, frequently interrupting others, and engaging in risky behavior
Adaptive Functioning	Communication	Difficulty understanding figurative language (e.g., jokes, sarcasm), using language to express oneself, linking words with feelings, and social communication conventions
	Social	Trouble reading social cues and following social norms, making and keeping friends, understanding social consequences, and issues with gullibility
	Daily living	Problems with understanding time, managing daily routines, understanding money, maintaining finances and employment
	Motor	Problems with coordination, balance, and fine motor skills (e.g., drawing, writing, using utensils)

Specifically in infants, FASD may manifest as mild or severe developmental delays, challenges with self-regulation (e.g., trouble with sleep, fussiness, difficulty being soothed, and sensitivity to being overstimulated), and disorganized or unfocused play.

Increased Risk of Child Welfare Services Involvement – The brain-based impairments associated with FASD can make these children hard to parent—putting them at a higher risk for abuse and neglect. Caregivers may be unequipped to handle the neurobehavioral effects and unable meet the complex needs of these children, which can also increase the likelihood of placement disruption.¹⁵

Lack of knowledge about FASD and its associated brain-based impairments often cause parents, caregivers, and service providers to misinterpret the primary disabilities of children with FASD as “willful disobedience.”¹⁶ This misinterpretation leads to inappropriate interventions or harsher, more punitive approaches, which can cause feelings of shame, blame, or frustration in the child or adolescent. Alternatively, caregivers who have a greater knowledge of FASD are more likely to identify their child’s misbehaviors in relation to their neurodevelopmental disabilities and feel more confident in managing the behaviors.¹⁷

Secondary Disabilities – If not properly identified and treated, FASD can result in other diagnoses and lifelong complications known as secondary disabilities.¹⁸ In a study of children, youth, and adults with FASD:



However, children and adults who received a diagnosis at an earlier age and grew up in a stable environment were two to four times more likely to escape these adverse life outcomes.²⁰ Protective factors that can help mitigate secondary disabilities include: 1) early identification and, if possible, diagnosis; 2) stable and nurturing home environments; 3) involvement in special education and social services; and, 4) absence of violence.^{21,22}

TREATMENT AND SERVICES FOR FASD

FASD is a lifelong, chronic disorder with no known cure, but available treatment models have been shown to improve the adjustment of the child and family to the effects. Treatment aims to improve the symptoms of FASD through a range of supports, such as early intervention services, mental health therapy, medication, environmental modifications, and parenting education and training.²³

Treatment and services should be implemented through an *FASD-informed approach* that acknowledges the specific, brain-based impairments and challenges associated with the condition and provides tailored modifications to services.²⁴ Everyone involved with a child with FASD must adapt their communication, environment, and expectations to help manage associated dysregulation and provide support for executive functioning impairments.

This section highlights treatment strategies that can improve outcomes for children and youth with FASD.

- Early identification and diagnosis of FASD before age 6** has been identified as one of the most important protective factors to promote positive long-term outcomes for individuals with FASD.²⁵ Universal screening for alcohol and other SUDs among all pregnant women—as well as universal screening for developmental delays among infants and children—can promote early identification. Screening for developmental delays and referral to agencies who provide early intervention services under Part C of *Individuals with Disabilities Education Act (IDEA)* are required by law for all infants and children aged 0-3 involved in substantiated child abuse and neglect cases.²⁶ In the absence of formal diagnosis (as when the child is under 3 and too young for traditional FASD diagnostic evaluation), the designation “likely FASD” is beginning to be used as it points to helpful anticipatory guidance and resources for parents and caregivers.

- **Engagement in early intervention and therapeutic services** for children has been shown to improve child and family outcomes.²⁷ IDEA Part C provides early intervention services to infants and toddlers with disabilities (aged 0-2) and their families to address developmental concerns. Early intervention programs that begin sooner in the child’s development—and are more intensive—produce larger positive effects. Some early intervention methods aim to improve children’s later outcomes by improving their self-regulation, cognitive, and executive functioning skills. One example is the [***Incredible Years Child Training Program***](#), an evidence-based curricula that promotes social competency and reduces conduct problems, and includes specific programs for babies (0-1 year), toddlers (1-3 years), preschoolers (3-6 years), and school age children (6-12 years). The book [***Guided Growth: Educational and Behavioral Interventions for Children and Teens with FASD and Early Trauma***](#) offers strategies for addressing both FASD and early trauma.
- **Special education services resulting from an Individualized Education Plan (IEP)** guide supports and accommodations that help with dysregulation and cognitive impairments for school-age children with FASD. IDEA Part B funds special education and related services for children and youth aged 3-21. Currently, there is not a specific eligibility category for FASD under IDEA, but diagnosis of FASD can sometimes qualify for special education and related services under the category of “other health impairment.” Children who do not qualify for special education under IDEA may qualify for special help in a regular classroom setting under section 504 of the Rehabilitation Act of 1973. Whether through an IEP or 504 plan, it is essential to thoroughly lay out supports known to be helpful in keeping children with FASD calm and accommodating for slow processing, poor auditory processing, impaired memory and abstract reasoning, and much younger functioning overall.
- **Special training, services, and support can help caregivers understand challenging behaviors through the lens of brain damage rather than disobedience**, as well as implement parenting strategies tailored for FASD.²⁸ Importantly, some birth parents may have undiagnosed FASD themselves; thus, parenting education should be individualized based on the parents’ level of intellectual functioning and learning preference. The [***Families Moving Forward Program***](#) is a promising practice for children aged 3-12 with FASD and their caregivers. It is an individualized program that uses cognitive behavioral therapy, motivational interviewing, and positive behavior support to provide psychoeducation, behavior planning, and proactive parenting strategies. The National Organization on Fetal Alcohol Syndrome (NOFAS) offers a [***brochure highlighting four promising programs***](#) designed for children with FASD and their families.
- Children with FASD do better when **caregivers and service providers implement positive behavior support approaches that include behavior plans and adaptations to the environment** based on their unique neurodevelopmental and sensory needs.²⁹ These accommodations, sometimes called “antecedent strategies,” are proactive techniques to modify the child’s environment, parenting behaviors, or daily schedules to anticipate and prevent misbehavior.³⁰ Parents who use antecedent strategies are less likely to use punishment for misbehavior and remain more focused on redirecting and calming their children when they are dysregulated.
- **A pediatric medical home plays a critical role in facilitating diagnosis, treatment, planning, and ongoing care coordination** for children and families receiving services from multiple systems and providers, such as specialists, mental health professionals, occupational therapists, early intervention and special education, and other community partners.^{31,32} See the American Academy of Pediatrics’ [***description of potential interprofessional team members***](#) for a summary of team-based care for an individual with an FASD.



PRACTICE TIPS FOR CHILD WELFARE PROFESSIONALS

Child welfare professionals play a vital role in partnering with other service providers who offer comprehensive, family-centered services to support children with FASD along with their parents, caregivers, and families. They can also help identify signs and symptoms of parental alcohol use and dysregulation in infants, children, and youth that could indicate FASD. This section provides practical tips child welfare professionals can use to meet the needs of families affected by alcohol use disorder and FASD.



CONDUCT UNIVERSAL SCREENING TO PROMOTE EARLY IDENTIFICATION

- Speak with all pregnant individuals about their alcohol and other drug use while linking families with maternal and child health providers. Use a validated screening tool, such as the [*4Ps Plus*](#), which consists of five questions to identify pregnant women at risk of alcohol, tobacco, marijuana, and illicit drug use.³³ Identification of use during pregnancy can also come from medical records, collateral reports, and court reports. For older foster and adoptive children, birth mothers can provide vital information on prenatal alcohol use to encourage a proper diagnosis.
- Screen every parent for current alcohol and other SUDs using a validated screening tool. Upon a positive screen, discuss results with the parent and jointly identify resources and schedule an appointment for a clinical SUD assessment. With informed consent, communicate screening results and child welfare case details with the SUD provider and prenatal care provider, if applicable. For more information on screening for SUDs in child welfare, see the NCSACW resource [*Understanding Screening and Assessment of Substance Use Disorders – Child Welfare Practice Tips*](#).
- Screen all children, youth, and adolescents for neuro-behavioral, social-emotional, and developmental issues that could be related to FASD. For example, the [*Ages and Stages Questionnaire, Third Edition \(ASQ-3\)*](#) assesses the development of children aged 1 month to 5 ½ years in the areas of communication, gross-motor skills, fine motor skills, problem solving, and personal-social skills. This tool allows professionals to identify children that might need an in-depth evaluation for developmental delays. Developed specifically for children with FASD, the *Prenatal and Neurodevelopmental Assessment* is a screening tool to identify child developmental, learning, or behavioral challenges.³⁴



ENGAGE CHILDREN AND FAMILIES IN SPECIALIZED SERVICES AND SUPPORTS

- Refer families with suspected FASD to appropriate service providers, early intervention programs, a pediatrician who specializes in FASD (if available), and substance use and mental health disorder treatment providers.
- When speaking with families who have a child with FASD, use warm, non-judgmental, and non-stigmatizing language to minimize shame associated with alcohol use during pregnancy. Show empathy and support related to parenting challenges and difficult behaviors associated with FASD. Help them to grasp the difference between child behaviors that can be shaped and those that result from brain damage, and help them understand the ways to support their child given that damage.
- Link parents and caregivers with supportive parenting programs specifically for children with FASD. NOFAS offers a [*resource directory for FASD services*](#) by state.
- Offer practical tips and strategies to help parents, educators, and service providers effectively work with children with FASD. The [*Eight Magic Keys*](#) are a set of practical guidelines to assist with support.

- In some cases, kin families and grandparents raising a child or adult affected by FASD will need support from child welfare agencies to prepare for transitions to other caretakers when grandparents are gone or no longer able to provide care. The [Grandfamilies and Kinship Support Network](#) is a useful resource in this area.



COLLABORATE WITH CROSS-SYSTEMS PARTNERS

- Develop partnerships with healthcare providers and community-based agencies that have expertise in serving children and adolescents with FASD. While the number of providers with this particular specialty is limited, they do exist and can be found through an online search or the [NOFAS resource directory](#). Become familiar with the services they provide and develop communication pathways to share information (with appropriate signed consent) regarding children and families jointly served.
- Invite all cross-systems partners serving the child and family to the family team meeting to discuss needs, monitor progress in treatment and services, and jointly monitor family outcomes. Examples of these partners may include pediatricians specializing in FASD, occupational therapists, substance use and mental health services providers, obstetricians, and early childhood education providers.
- Work closely with the local regional center for early intervention services for children under 3. Develop partnerships with the local public school system for children over 3 to ensure receipt of special education services and an IEP for children with FASD.
- Seek further training on FASD and alcohol use during pregnancy to increase knowledge of identification, symptoms, and treatment strategies. Apply the principles gained in training on FASD and provide supports to caregivers based on a neurodevelopmental approach. This means recognizing and responding to the biologically based dysregulation, executive functioning problems, and poor thinking experienced by children with FASD, rather than recommending traditional parenting techniques.
- Develop partnerships with healthcare providers, such as obstetricians, hospital social workers, and pediatricians, to develop and implement notification procedures when an infant is identified as affected by prenatal substance exposure, withdrawal symptoms, or FASD. Develop and implement a Plan of Safe Care (POSC) to address the health and SUD treatment needs of the infant with FASD and their affected family or caregiver (per the 2016 Comprehensive Addiction and Recovery Act amendments to the Child Abuse Prevention and Treatment Act³⁵). For more information on developing POSCs, see the NCSACW resource [Plan of Safe Care Learning Modules](#), and series of briefs called [How States Serve Infants and Their Families Affected by Prenatal Substance Exposure](#).

LEARN MORE

[Prenatal Alcohol and Other Drug Exposures in Child Welfare Study: Final Report](#), Children’s Bureau, 2021

[Tribal Child Welfare Systems’ Experiences With Prenatal Exposure to Alcohol and Other Drugs: A Case Study](#), Children’s Bureau, 2021

[Treatment Improvement Protocol 58: Addressing Fetal Alcohol Spectrum Disorders, Substance Abuse and Mental Health Services Administration, 2010](#)

[A Collaborative Approach to the Treatment of Pregnant Women with Opioid Use Disorders: Practice and Policy Considerations for Child Welfare, Collaborating Medical and Services Providers](#), Substance Abuse and Mental Health Services Administration, 2016

[Video: Fetal Alcohol Spectrum Disorders \(FASDs\)](#), First 5 Santa Clara County, 2021

[FASD United: The National Voice on Fetal Alcohol Spectrum Disorders \(website\)](#)

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