

UNDERSTANDING FETAL ALCOHOL SPECTRUM DISORDERS FOR SUBSTANCE USE TREATMENT PROFESSIONALS



National Center on
Substance Abuse
and Child Welfare

The National Center on Substance Abuse and Child Welfare (NCSACW) developed this technical assistance tool for substance use treatment professionals who serve parents with alcohol and other substance use disorders (SUD) and their infants and children who may be affected by prenatal alcohol exposure. It provides a broad overview of Fetal Alcohol Spectrum Disorders (FASD), the symptoms and effects of FASD in infants and children, screening for FASD, and supports and interventions found to be helpful. It also highlights signs of FASD among adults in SUD treatment.

SUD treatment professionals play a key role in supporting children and families affected by FASD through ensuring young children receive assessments and early intervention services, providing family-centered SUD treatment, and effectively partnering with other agencies and service providers who specialize in FASD. This tip sheet offers practical tips for SUD treatment professionals to recognize the signs of FASD and offer tailored supports for the infants, children, and adults they serve.

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 have the same combination of impairments listed under FAS but none of the physical markers.

Alcohol-Related Birth Defects (ARBD)

People with ARBD may 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

Many infants and children of parents who are in SUD treatment may be affected by prenatal alcohol exposure. 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 – SUD and mental health treatment, child welfare, and healthcare professionals are often not provided the education and training necessary to identify FASD signs and symptoms. 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.

Due to the challenges in identifying and diagnosing FASD, many parents in SUD treatment programs may also have undiagnosed FASD themselves. Adults with FASD have an increased prevalence of SUDs and mental disorders.¹²

SYMPTOMS AND EFFECTS OF FASD IN INFANTS AND CHILDREN

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, waiting turn, 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 maintaining employment
	Motor	Problems with coordination, balance, and fine motor skills (e.g., drawing, writing, and using utensils)

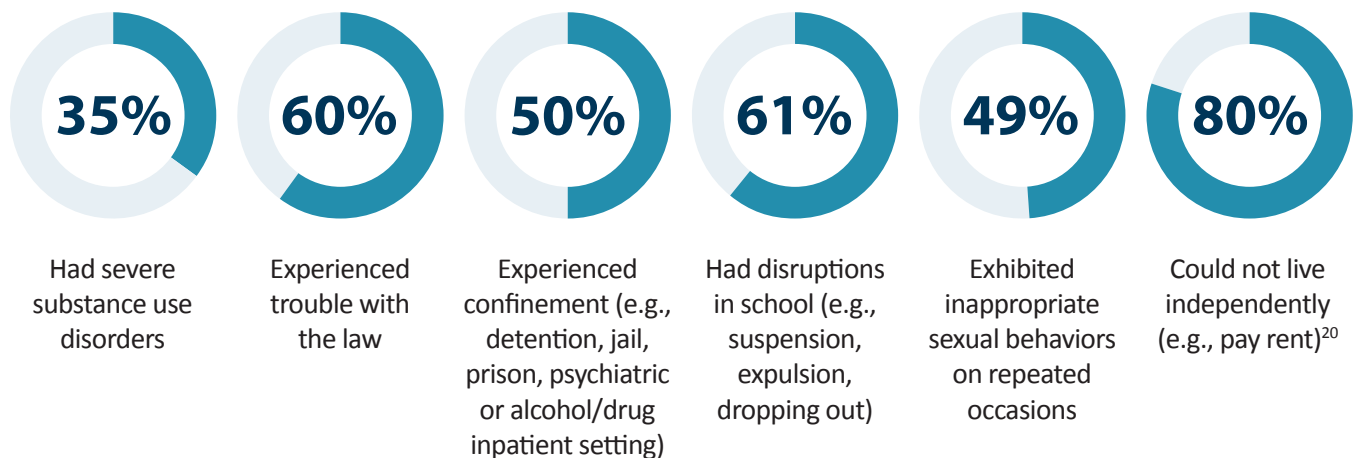
Specifically in infants, FASD may manifest as mild or severe developmental delays, challenges with self-regulation (e.g., trouble with sleep, fussiness, difficulty being soothed, and sensitivity to being overstimulated), and disorganized or unfocused play.

Parenting Challenges Related to FASD – The brain-based impairments associated with FASD can make children hard to parent and put 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 both 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

Further, parents and caregivers with FASD themselves may experience additional parenting challenges related to the neurobehavioral effects of their own FASD. These may include difficulty with: 1) organizing and planning; 2) generalizing from one situation to another; 3) consistently and effectively implementing consequences; 4) recognizing and acting on children's sensory cues such as hunger, temperature, and pain; and, 5) and issues with impatience, temper, and impulsivity.¹⁸ These added challenges require a system of supports and safeguards to promote child and family safety and well-being—and most importantly, understanding and patience on the part of program staff.

Secondary Disabilities – If not properly identified and treated, FASD can result in other diagnoses and lifelong complications known as secondary disabilities.¹⁹ 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.²¹ 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.^{22,23}

TREATMENT AND SERVICES FOR INFANTS AND CHILDREN WITH 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 for FASD in childhood aims to improve the symptoms through a range of supports, such as early intervention services, mental health therapy, medication, environmental modifications, and parenting education and training.²⁴

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.²⁵ Everyone involved with parents and children with FASD must adapt their communication, environment, and expectations to help manage associated dysregulation and provide support for executive functioning impairments. The following include treatment strategies that can improve outcomes for children and youth with FASD.

- **Early identification and diagnosis of FASD before the age of 6** has been identified as one of the most important protective factors to promote positive long-term outcomes for individuals with FASD.²⁶ 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.²⁷ 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.²⁸ 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.²⁹ 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.³⁰ 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.³¹ 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.^{32,33} 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: SUPPORTING INFANTS AND CHILDREN WITH FASD WHOSE PARENTS ARE IN TREATMENT

Substance use treatment professionals can use the following practice tips to identify FASD in infants and children whose parents are in treatment and provide family-centered, FASD-informed services.

- Speak with all parents in treatment about their alcohol and other drug use during pregnancy to determine any potential exposures. Asking a mom, “Before you found out you were pregnant, roughly how much were you drinking?” is a helpful way to reduce the shame and guilt around potentially harming their child. Screen all children, youth, and adolescents whose parents are in treatment 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
- Provide warm, nonjudgmental psycho-education and resources to parents and caregivers whose children may have FASD. Make sure they grasp the difference between 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.
- 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) on children and families jointly served.
- 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 to increase knowledge of identification, symptoms, and treatment strategies. Apply the principles gained 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 child welfare services to assist with the development and implementation of 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*](#).





SIGNS AND EFFECTS OF FASD AMONG ADULTS IN SUD TREATMENT

Treatment professionals serve a number of adults with SUDs who have undiagnosed FASD. The neurobehavioral effects of FASD significantly influence success in treatment. For example, a study of women who had diagnosed or suspected FASD were less likely to attend and complete SUD treatment than those without FASD.³⁶ It is crucial that treatment professionals recognize and tailor their services to meet the unique needs of parents with FASD and SUDs.

Treatment professionals can begin to recognize the pattern of FASD in adults they serve by looking for the following indicators. Notably, these indicators should be watched for following the completion of the acute phase of withdrawal to not confuse these behaviors with active substance use.

- Fidgetiness in meetings
- Lots of talk but poor listening skills
- Able to “say all the right things,” but unable to follow through
- Show insight but with little corresponding behavior change
- Initial likeability
- Persistent lying
- Always placing blame on others
- Frequent rule breaking, but acting surprised and angry at consequences
- Facial features of FAS (in a very few)

Although few will be accurately diagnosed, many adults in SUD treatment do have some combination of the neurological impairments of FASD, hampering their treatment and recovery process in the absence of specialized adaptations and services. Some examples of these neurological impairments include:

- Poor focus—may be easily distracted from program material, process, and priorities
- Bad memory—may forget the past negative effects from using drugs or alcohol
- Chronic hyperarousal—may experience crises, agitation, and disorganization over small things
- Difficulty connecting cause and effect—may have a hard time moving through the recovery process and 12-steps, as they require consciousness of consequences
- Poor impulse control—may have trouble resisting resuming substance use or may continue to place themselves in risky situations
- Higher verbal skills than thinking ability—can “talk the talk” without corresponding action in the treatment and recovery process



PRACTICE TIPS: SUPPORTING ADULTS WITH FASD IN SUD TREATMENT

Treatment professionals can use the following strategies and treatment modifications to mitigate the effects of FASD-related impairments on the treatment and recovery process.

- Screen all clients for FASD at the onset of treatment. While there is as yet no validated screening instrument for FASD, treatment professionals can infer a possible FASD by looking for signs and symptoms (as outlined above) and distinguishing them from current substance use. When speaking with the client, inquire whether the pattern of behavior existed before substance use began, which may be an indication of a neurodevelopmental challenge related to FASD. In addition, treatment professionals can inquire about past experiences that may point to effects of FASD, including history of:
 - Known or suspected maternal alcohol use
 - School difficulties
 - Trouble with the law
 - Child welfare services involvement
 - Diagnosis of ADHD, bipolar disorder, or borderline personality disorder
 - Problems managing money, relationships, time, and anger
 - Crisis-to-crisis living pattern
 - Sensitivity to environmental stimuli (lights, sounds, crowds)
 - Trouble completing tasks, projects, and jobs

- Even without a formal FASD diagnosis, treatment providers should move forward with making adaptations to the treatment approach for any clients with suspected effects of FASD.
- Be open with the client about suspected FASD and help them understand their challenging behavior within the context of brain damage rather than any “character defect.” Provide the individual with education and training on FASD to help them gain knowledge and acceptance of their neurological limitations.
- Reinterpret challenging behaviors through the lens of clients’ brain-based impairments and tailor expectations of treatment progress accordingly. For example, meltdowns, “laziness,” avoidance, untruth or other troublesome behaviors may derive from damage to the brain. Work with the individual to identify solutions and techniques to address these brain-based impairments.
- Recognize that it is highly likely that clients with FASD have experienced most or all of the secondary disabilities discussed previously, unless they were raised with many protective factors. While many clients in SUD treatment have experienced domestic violence, sexual abuse, mental illness, trauma, and academic and employment problems—clients with FASD in treatment have an even higher risk of these experiences. This calls for trauma-informed treatment services.
- Make adaptations to SUD treatment and services to respond to FASD-related impairments:
 - Use concrete language including short, simple sentences and be prepared to repeat information. Do not use sarcasm or humor, as it could be misunderstood. Use visual guides to support verbal communication.
 - Offer a structured environment and direct, practical support and resources to fill in the gaps in neurological functioning. Examples may include helping with transportation, offering reminder phone calls, allowing flexibility for late arrivals or missed appointments, reducing visual and auditory stimuli in the environment, and allowing for longer program duration.
 - Promote consistent and repetitive use of calming techniques and exercises to help with self-regulation.
 - Make consequences short, immediate, and meaningful. Since cause-and-effect thinking is often impaired along with memory, long-term rewards or punishments become meaningless. Short-term consequences need to be explicitly tied to the behavior and consistently used.
 - When a rule is consistently broken, follow these steps: 1) Stop what has not been working, such as verbal warnings, lecturing, isolating, and losing privileges; 2) Assess what might be going wrong, such as client issues with memory, sensory overload, cognitive difficulty, poor listening ability, or sequencing problems; or environmental challenges such as too much unstructured time, unclear communication, staff’s overheated reaction, or over stimulating environment; 3) Make changes to treatment environment or staff behavior to respond to the issue. For example, if it is an issue with memory, find a way to remind the client. If the problem is related to sensory overload, reduce input. If a concept is too complicated, even though the client says they understand, use simpler and more concrete language.
 - Provide parenting supports and services for parents in treatment who have FASD. Examples of strategies to improve organizational skills in parenting may include: creating a consistent schedule of activities for the day, using positive self-talk to transition between the day’s activities, and applying parenting techniques consistently. Much of this will be very challenging for someone with FASD to do independently, and thus close connection and support from a trusted provider will be very helpful.

LEARN MORE

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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