Practical Guide for Designing and Implementing Fetal Alcohol Spectrum Disorder (FASD) Diagnostic and Clinical Care Practices

Tips and lessons learned from clinicians

About this guide

This guide provides practical guidance for clinics and providers who are interested in designing and implementing FASD diagnostic and clinical care practices. It was developed by Proof Alliance in partnership with Wilder Research, with input from experienced FASD providers as well as providers interested in implementing FASD clinical practices. This guide contains lessons learned from Proof Alliance's 14-year journey designing and implementing our FASD diagnostic clinic. It is our hope that you and your organization can design and implement FASD diagnostic services and care quickly and more effectively based on what we have learned from our work with organizations, providers, and families. Throughout all FASD care practices, providers emphasize the importance of ensuring services and systems are collaborative, responsive and proactive, person-centered, strengths-based, trauma-informed and culturally responsive.

Why implement FASD diagnostic and clinical care practices?

- Early diagnosis and intervention are critical to helping people with an FASD achieve the best outcomes possible and mitigate the harmful effects of prenatal alcohol exposure.[1, 2, 3, 4]
- Prenatal alcohol exposure is one of the most common preventable causes of birth defects in the U.S.[5] It is estimated that 20% of fetuses are exposed to alcohol during the first trimester.[6]
- Missing an FASD diagnosis and misdiagnosing FASD are common, with some research indicating that 87% of youth with an FASD have never been diagnosed or were misdiagnosed.[7] Delayed diagnosis can lead to a wide range of negative outcomes related to education, mental health, substance use and criminal legal system involvement.[8, 9, 10]
- FASD has significant economic burden. Individuals with an FASD have higher rates of service utilization and greater healthcare costs and early intervention minimizes costs.[11, 12, 13, 14]

Designing the business model

Consider taking the following steps to prepare for providing FASD diagnostic and clinical services.

- Research FASD diagnostic models to identify the one that fits best based on the clinic setting, services and resources. Consider consulting with other providers who are experienced in specific models.
    - Ensure diagnostic processes and methods are aligned with the selected diagnostic model and corresponding diagnostic criteria.
- Determine the purpose, mission and values of your clinic's FASD services and engage staff to ensure strong shared understanding and buy-in.
- Leverage existing and build new community partnerships. They can be critical to raising awareness of FASD, ensuring early identification and optimizing care for families (e.g., relationships with school districts, child protection and adoption and foster care agencies).
    - Partnerships can open additional funding opportunities (e.g., funding streams only available to nonprofits) and pathways for sharing information and resources (e.g., trainings).
    - Identify partner agencies and organizations that you may need to share personal health information with and ensure your clinic has the necessary communication pathways to maintain confidentiality and HIPAA compliance (e.g., shared electronic health records systems).
- Explore alternative funding streams (e.g., grants, philanthropy) and assess opportunities with current funding sources to support non-billable work associated with FASD clinical care practices.
    - Explore billing options to maximize reimbursement (e.g., using "complex case" billing code when possible, billing for time spent reviewing records as part of the evaluation or sharing information between providers).
- Use an appointment reminder system to minimize burden for families.
    - Staff may benefit from creating a reminder schedule template aligned with the timing of key appointments or milestones that can be used across clients.
- Ensure all providers can access relevant electronic medical records pertaining to FASD for their clients. This may involve sharing information across different record systems and obtaining releases of information from families.
- Offer volunteer opportunities, such as caregivers with extensive FASD experience providing support to families of recently diagnosed individuals.
- Provide a visual organizer or guide on the diagnostic process your clinic follows to help families understand the steps involved. Proof Alliance's Diagnostic Roadmap is included in the Appendix at the end of this document as an example.

Hiring and training providers and staff

- Ensure providers and staff who are leading the implementation of FASD clinical care practices are FASD-informed and have a strong understanding of neurodiversity and invisible disabilities.
- Develop interview questions and hiring processes that will best identify providers and staff that are adaptable and collaborative.
- Remember the power of lived/living experience (i.e., knowledge that comes from direct or firsthand experience of having an FASD and/or caring for someone with an FASD). While finding qualified staff is a common challenge, this experience may be beneficial to prioritize.
- Leverage existing or create new family and/or care coordinator roles that can help families keep track of services and appointments.
- Consider building teaching and training opportunities for medical and behavioral health trainees, such as medical residents, postdoctoral fellows, or interns.
- Ensure providers are comfortable and well-trained with asking about alcohol use and exposure.
- Ensure providers have a strong understanding of the FASD diagnosis spectrum. See the Resources section for potential educational sources.
- Ensure providers are trained on possible indicators of FASD.

Possible FASD indicators

Small head circumference at any point in development

History of growth or developmental concerns at any age not due to another known cause, even if concerns have been resolved at the time of the appointment

Specific facial features (e.g., short palpebral fissure lengths, smooth philtrum, thin upper lip)

Emotional or behavioral concerns, including difficulties managing emotions

History of adoption or foster care experience, but remember that not all individuals with these experiences were exposed to alcohol during fetal development

Learning and academic challenges

Social or communication challenges (e.g., poor understanding of personal boundaries, easily manipulated or led by others, lack of fear of strangers)

Impulsivity and/or hyperactivity, especially if broader than typical ADHD presentation

Motor functioning delays

Difficulties concentrating or paying attention

Difficulties following directions and/or remembering essential information

Difficulties learning from consequences and/or making similar mistakes over and over

Information processing difficulties

Difficulties solving problems, reasoning or using judgment

Concrete, inflexible and/or literal thinking

Lack of success with previous treatments (e.g., ADHD interventions)

Conducting intakes and determining alcohol exposure

Consider taking the following steps to streamline the intake process:

- Create a tailored intake packet with all forms and documents needed during the intake process (e.g., releases of information, consent forms, state-specific Bill of Rights and Privacy Practices, parent or teacher rating scales). Excessive paperwork can be daunting and may prevent some families from following through.
    - Fill in as much information as possible for the family to reduce burden and prevent errors.
    - Use DocuSign and encrypted email to send paperwork to families. Indicate clearly where the family needs to sign and date each form.
    - Offer phone or video support to help caregivers complete the intake packet.
- Because there is no specific test that can confirm or rule out FASD, FASD should be considered a diagnosis of exclusion. Genetic, hormonal and environmental factors should be considered during diagnosis. Genetic testing is often needed before diagnosis (as indicated), especially if there is no reported history of prenatal alcohol exposure.
    - Remember that many individuals with FASD also have a history of trauma.
- Remember that diagnoses and services provided may change and research and guidelines evolve over time. Providers can convey to the family that it’s better to connect the individual earlier with services, even if they no longer meet the criteria later on.
    - Humility can also be an effective communication tool with families.
    - Consider sharing that reassessment is an important aspect of FASD care, as diagnoses can change if new information is available.

Determining prenatal alcohol exposure

Determining prenatal alcohol exposure can be time-consuming, resource-intensive, and difficult. Additionally, it is often a requirement to officially diagnose someone with a FASD. Considerations regarding determining prenatal alcohol exposure include the following:

- Some clinics opt to only serve individuals who have confirmed exposure, limiting the pool of potential clients that can be served by the clinic. Additionally, clinics are likely already working with individuals with FASD that haven’t been diagnosed or have been misdiagnosed. FASD is underdiagnosed and individuals with suspected prenatal alcohol exposure may benefit from services provided by the clinic or referrals to other supports.
- Identify a specific staff member at your clinic that will be responsible for contacting potential sources and obtaining records.
- Caregivers may be able to provide information regarding:
    - Health facilities and clinics that may have records pertaining to prenatal alcohol exposure

    - People, such as friends or family members of the birthing parent, who may be able to speak to potential prenatal alcohol exposure
    - Early childhood or family service providers the family received services from that may have conducted evaluations or coordinator care
- Legal parent/guardian permission may be required to access records.
- For youth in foster care, records may be obtainable through their social worker or state human or social services agencies.
    - Research has shown that bias against biological parents within the child welfare system can impact treatment and decision-making. Therefore, clinicians should consider these factors when gathering information from records.[15]

Potential methods or sources for determining prenatal alcohol exposure

There are several potential ways and sources to obtain information about prenatal alcohol exposure. While medical records, social service records and legal records are generally considered highly credible, they may not include all relevant information and may even include erroneous information. Potential methods or information sources include:

- Disclosure by birthing parent.
    - If appropriate, the client themselves may also provide information about their caregiver's alcohol use when they were growing up.
- First-hand eyewitness accounts of prenatal alcohol consumption.
    - Second- and third-hand accounts are considered less reliable. In these situations, seek corroborating information.
- Records from social services agencies
- Legal or court records
- Birth records
- Adoption records
- School records and evaluations
- Medical records, including occupational therapy, speech language therapy and mental health services
- Some states allow schools or health providers to look up immunization records, which may provide information about the individual's birth hospital or other clinics they have received services from.

Asking birthing parents about alcohol use

- Remember that asking about alcohol use can be sensitive and some parents may respond defensively. You may lose the chance to help the family if the conversation is approached insensitively. Strive to create a sense of safety, avoid implying blame or shame and convey that it takes courage to discuss alcohol use during pregnancy.

- Ask whether there may have been alcohol use during the pregnancy or even before the pregnant person knew they were pregnant. If the person says they don't remember or don't know when they got pregnant, ask about typical alcohol use before knowing they were pregnant.
- Share that many pregnant people do not realize they are pregnant immediately and many drink before they realize they're pregnant.[16, 17, 18]
- Share that research and guidelines evolve, and that the information families receive from their providers may change over time.

Recommended screening questions

There are several basic questions that many providers use to screen for prenatal alcohol exposure. Questions for the birthing parent may include:

- 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 many times did you drink alcohol?
- During your pregnancy, how many times did you have 4 or more drinks in a day?

Questions for the adoptive parent may include:

- Did [child]'s birthing parent drink alcohol before they knew they were pregnant?
- Did [child]'s birthing parent drink alcohol after they knew they were pregnant?
- How do you know? For example, did you observe alcohol use directly?

Services, community-based supports and referrals

Families and individuals impacted by FASD often need additional services. It is critical to connect families with appropriate services quickly to maximize benefit and avoid delays due to waitlists as much as possible, even if there is not an official diagnosis or confirmation of prenatal alcohol exposure. Providers should engage caregivers to ensure they understand the concerns, treatment(s) and how they can support their youth at home.

Providers may need to provide referrals for services not offered at their clinic, including diagnostic services and interventions and community-based supports.

Diagnostic services

- Neuropsychological assessment, including an evaluation of language, motor, behavioral, emotional, developmental and cognitive (e.g., memory, attention, impulse control) functioning.
    - While results can inform behavioral health treatment, don't wait for results to address immediate concerns.
    - Results can identify the individual's strengths and help families better understand their youth and how to best support them.

- Craniofacial measurements (e.g., head circumference, inner and outer canthal measurements)
    - Consider taking pictures of clients' faces to include in clinical documentation.
- Hearing and vision assessments. Remember that behavior concerns may be due to hearing or vision impairments and these should be addressed before neuropsychology assessments.
- Neurology if the individual is experiencing seizures or has coordination or motor concerns.
- Genetic testing if the individual has atypical facial features, a small head circumference or some other characteristic that may indicate a genetic concern.
- Blood testing and/or endocrinology if the individual has growth or thyroid concerns.
- Blood testing for iron or vitamin D deficiencies.
- Sleep assessment and/or referral for behavioral sleep therapy if the individual has sleep concerns.

Interventions and community-based supports

- Mental health assessments and services. It is critical to ensure mental health providers are FASD-informed and understand how FASD affects brain development and functioning to identify effective treatments. Specific services may include:
    - Individual therapy
    - Trauma-informed services. These are particularly important to consider for youth with an FASD because they are more likely to have trauma histories and adverse childhood experiences than youth without an FASD.[19]
    - Attachment-focused services or other services aimed at improving family functioning and/or relationships between the youth and their caregiver(s)
- Occupational therapy, including sensory processing assessment. Occupational therapy may be provided through a health clinic and/or the youth's school district. Consider connecting the youth with school and clinical services to maximize benefit, especially as school-based occupational therapy often limits services to those specific to supporting the youth's education.
- Speech language therapy. These services may also be provided through a health clinic and/or the youth's school district and receiving services through both entities will optimize benefits.
- Physical therapy may be needed if there are coordination or motor concerns.
- Accommodations or support plans at school (e.g., IEPs, Section 504 plans).
- Physical activity, which can improve mood regulation and overall health.
    - Organized activities also provide structure and opportunities to build healthy relationships with adults and peers.
- Case management, which may include service coordination support.
- Family services, which may include support groups and peer support networks for caregivers, in-home family support services, respite care, parenting and behavior management skills, mental

health services for caregivers, and education about FASD and what to expect regarding development. Many states have FASD organizations and resources. A list of FASD affiliates by state can be found at FASD United's website (fasdunited.org).

- Opportunities to connect with others with an FASD.

Meetings with families

Once an FASD diagnosis is suspected or confirmed, a trauma-informed provider or staff person should meet with the family to review results and identify resources. Creating a family or care coordinator role can be particularly helpful, as the role can focus specifically on supporting and guiding families affected by an FASD. This meeting should also:

- Aim to build rapport and trust.
- Avoid implying blame or shame.
- Convey that seeking treatment for an FASD is a positive step that will help their child reach their potential and that the more the family can learn about FASD, the better they can support and advocate for their youth.
- Include tailored content depending on the caregivers' existing knowledge of FASD, trauma, mental health and other relevant topics.
- Confirm understanding of the diagnosis, its implications and treatment.
- Normalize and encourage self-care and supports available for caregivers (e.g., support groups, mental health services, parenting skills training, respite services if available).
- Help families identify strengths and assets they can rely on and successes they have had caring for their youth, including existing social support systems.
- Provide written materials and assistance to help families access external services and resources. This can include services specific to FASD as well as other supports, such as enrolling in Medical Assistance or public assistance programs.

Ongoing care

There are several ways providers and clinics can ensure they continue to provide high-quality care to families on an ongoing basis, including:

- Conduct multidisciplinary team meetings to discuss client needs from various perspectives, identify appropriate treatments and share information, if possible. Unfortunately, these meetings are often not a billable service for many providers. In these situations, clinics can offer opportunities to meet over breaks and streamline the process of sharing and accessing clinical documentation.
- Provide opportunities for providers to share case presentations, if possible.
- Seek consultation and collaborate with other specialists as appropriate.
- Conduct follow-up evaluations regularly. Determine frequency based on the individual's concerns and with input from the individual's providers.

- Ensure families are seen by the same provider when possible. This helps build rapport, allows the provider to become more familiar with the individual and their family, increases the likelihood of disclosure of prenatal alcohol use and improves the provider's ability to tailor treatment to best meet the family's needs.
- Communicate when families should return next and under what circumstances (e.g., if a certain intervention isn't working).
- Promote shared documentation (including diagnosis, treatment plans, and recommendations made to families) among all providers in electronic medical records.
- Remind families to share any additional information they receive about prenatal alcohol exposure.
- Provide services for transitioning to adulthood if possible.
- Encourage providers to continue learning about FASD, including trainings and seeking out the stories of families affected by an FASD (e.g., books, podcasts).
- Identify other existing resources in your region that may support FASD clinical practices, such as free psychiatric assistance lines.

Resources

- American Academy of Pediatrics' FASD Toolkit
- American College of Obstetricians and Gynecologists' FASD Prevention Program
- Centers for Disease Control and Prevention's FASD resources
- FASD United
- FASD-related resources and trainings by the University of Minnesota's Adoption Medicine Clinic
- FASD Success
- Proof Alliance's FASD quarterly meetings for clinics to connect with and learn from one another
- Proof Alliance trainings
- Recommendations for asking about prenatal alcohol exposure
- SAFEST Choice Learning Collaborative
- The FASD Collaborative Project
- University of Washington's diagnostic tools (e.g., lip philtrum guides)

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Appendix: Proof Alliance Diagnostic Roadmap

The FASD Diagnostic Roadmap

What to expect when evaluating a child or teen for fetal alcohol spectrum disorders (FASD) at the Proof Alliance FASD Diagnostic Clinic.

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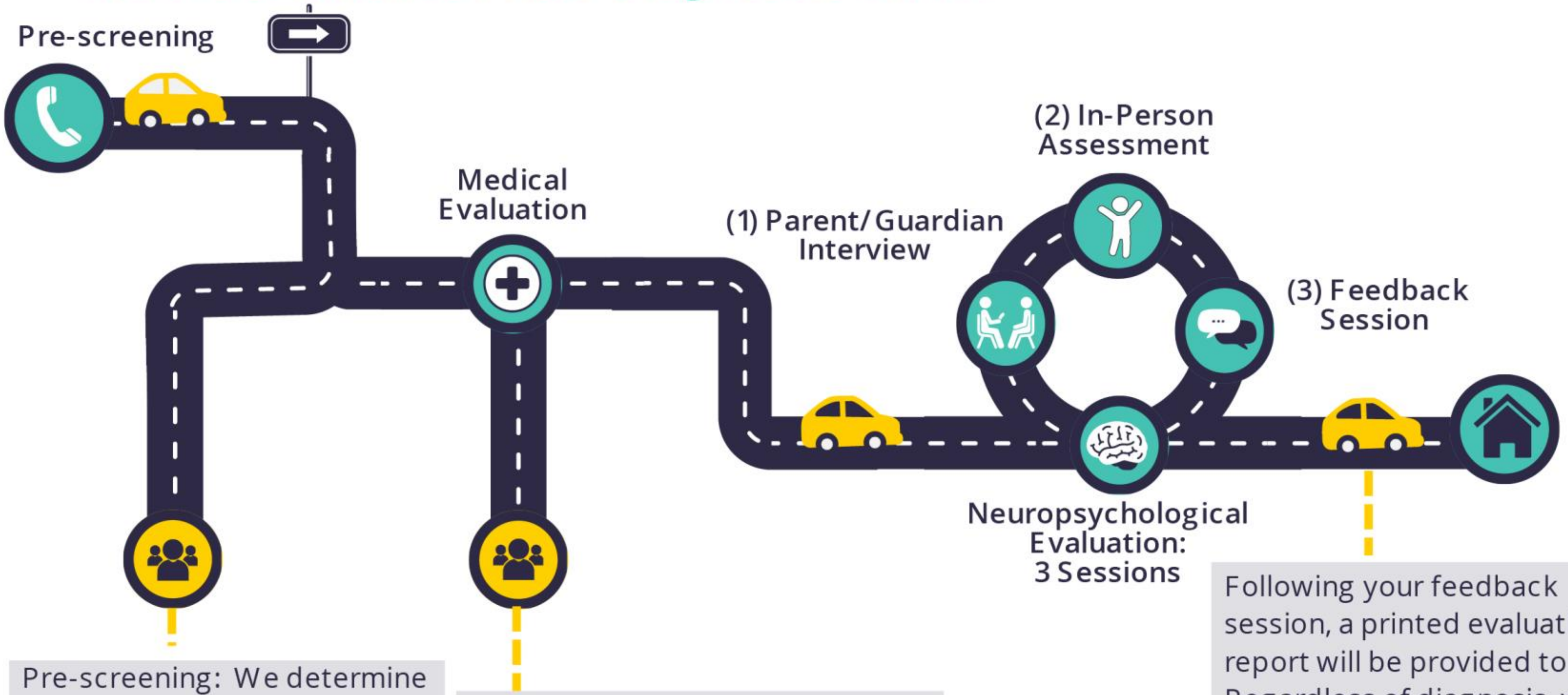

Pre-screening: We determine whether an evaluation at Proof Alliance fits your needs. If not, we connect you with other resources to meet your needs.

If criteria are not met for FASD at this time, you are still welcome and encouraged to utilize support and resources at Proof Alliance.

Following your feedback session, a printed evaluation report will be provided to you. Regardless of diagnosis, we will provide recommendations for the next steps in treatment and resources for support.

Questions? Contact Proof Alliance: (651) 917-2370

Pre-Screening

- Short phone call with parent/guardian
- Intake packet - Including releases and consent forms
- Once the intake packet is returned, you will be added to the waitlist and needed records will be requested

Medical Evaluation

- One session with a nurse practitioner (2.5 hours)
- The nurse practitioner will gather medical history including early health history and prenatal alcohol exposure history
- The nurse practitioner will assess the child's facial features and conduct a brief physical exam
- Discuss any evidence of prenatal alcohol exposure

For questions or support, contact the clinic or visit our website:

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Neuropsychological Evaluation

- Three sessions with a clinical psychologist
  - Parent/guardian interview (1 hour)
    - The psychologist will discuss the child’s areas of strength, their challenges, and needs with the caregiver
  - In-person assessment (3 hours)
    - The psychologist will assess the child’s learning, problem-solving, language, memory, and motor skills, as well as their emotions and behaviors, through a variety of activities.
  - Feedback session (45 minutes)
    - The psychologist will discuss the evaluation results, including treatment plans and recommendations for home, school, and community services, with caregivers.

Evaluation Report

A summary of the findings is prepared along with any specific recommendations for follow-up support, resources and treatment.

- Proof Alliance Resources for Caregiver and Youth Support:
  - 1-651-917-2370
    youthandfamily@proofalliance.org
  - On-demand webinars:
    learn.proofalliance.org

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