



PRoF Alliance

A Practical Guide for Designing and
Implementing FASD Diagnostic and
Clinical Care Practices

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Building FASD Diagnostic Care Practices

Frequent questions from FASD-informed health care providers:

- How do we start a clinic?
- How do we do FASD diagnosis?

**After 14 years of running a clinic,
we have learned a lot.**

Until now, much of this knowledge had not been formally documented or shared in a meaningful way.

Who could benefit from this information?
How do we share this information?



Sharing What We Learned

Objective: Develop a practical guide for clinics and providers who are interested in implementing FASD diagnostic and clinical care practices.

Proof Alliance and Wilder Research conducted semi-structured interviews with FASD diagnosticians and medical experts across the United States.

Clinicians interested in integrating FASD diagnostic services into their practices also participated in semi-structured interviews.

Proof Alliance provided written information on clinic processes.

Clinicians provided feedback and edits. Additional Proof Alliance provided written information on clinic processes.

An FASD clinical best practice guide was developed.

Sharing What We Learned

A Practical Guide for Designing and Implementing Fetal Alcohol Spectrum Disorder (FASD) Diagnostic and Clinical Care Practices *Tips and lessons learned from clinicians*



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

Tips and lessons learned from clinicians

i 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.

Designing the business model	2
Hiring and training providers and staff	3
Conducting intakes and determining alcohol exposure	4
Services, community-based supports and referrals	6
Resources	11
Sources	13

? 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}

Sharing What We Learned

1

Designing the Business Model

2

Hiring and Training Providers and Staff

3

Conducting Intakes and Determining Prenatal Alcohol Exposure (PAE)

4

Services, Community Based Supports and Referrals

Designing the Business Model

Key Components:

- **Select and align an FASD diagnostic model with your resources**
 - Engage staff in defining mission and values
 - Leverage existing partnerships and build new outside partnerships for diagnostic collaboration
 - Enhance awareness, early identification and care coordination
- **Optimize funding and reimbursement strategies**
 - Explore billing options (e.g., using complex case billing)
 - Identify partnerships that can open additional funding opportunities

Hiring and Training Providers and Staff

Key Components:

- **Prioritize hiring and training FASD-informed staff**
 - Training in understanding of neurodiversity and invisible disabilities
 - Value living experience and adaptability in recruitment
- **Enlist diagnostic partners** from outside agencies or clinics.
- *If possible:* **establish care coordinator roles, provide ongoing education on FASD diagnosis** and indicators and **create teaching opportunities** for medical and behavioral health trainees.

Conducting Intakes

Key Components:

- **Streamline intake processes** by providing tailored, pre-filled packets, secure electronic forms and support for caregivers; minimize paperwork burden and ensure clarity in documentation.
- *If possible:* **obtain records and information on prenatal alcohol exposure from multiple sources** (medical, social, legal, caregiver accounts); ensure legal permissions and consider potential biases in records.

Determining PAE and Diagnosing FASD

Key Components:

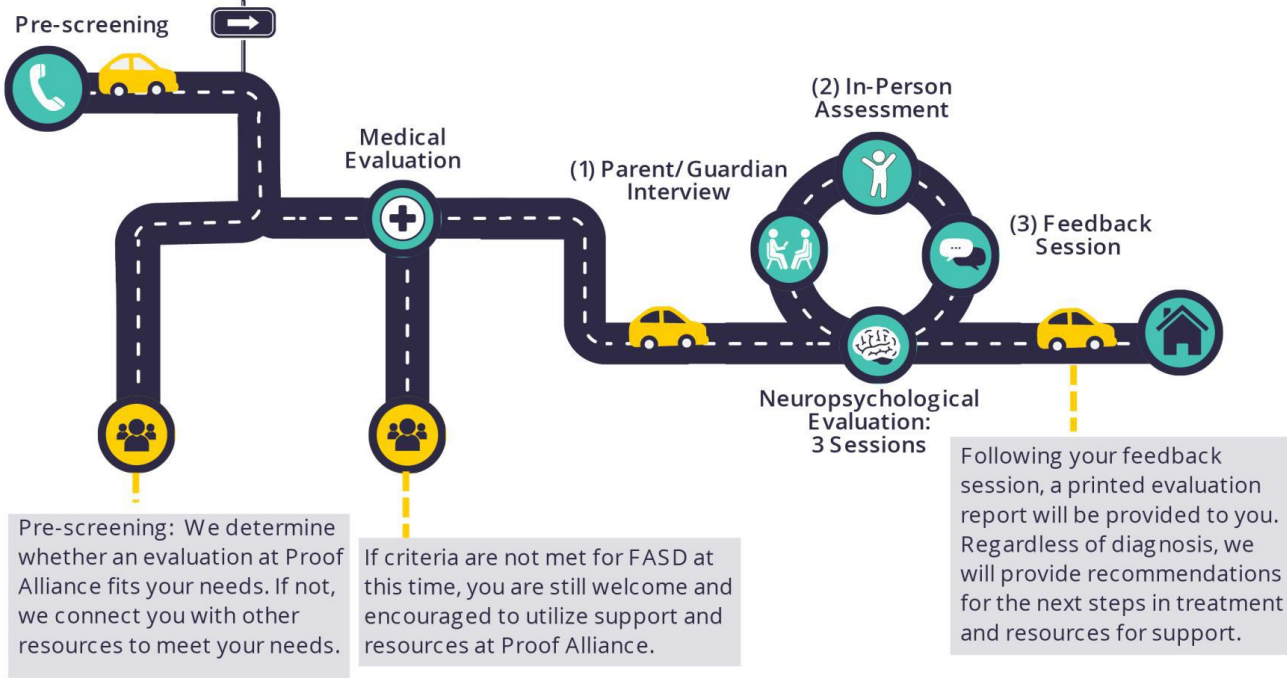
- **Approach discussions about alcohol use with sensitivity, avoid blame and educate families** about evolving guidelines and the commonality of unintentional prenatal exposure.
- **FASD diagnosis is a process of both inclusion and exclusion:** consider genetic, environmental and trauma history.
- **Communicate the importance of early connection** to services and re-evaluation.

3

Determining PAE and Diagnosing FASD

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.



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

Services, Community Based Supports and Referrals

Key Components:

- **Rapidly connect families to appropriate diagnostic, intervention and community-based supports, regardless of official FASD diagnosis or confirmed prenatal alcohol exposure.**
- **Refer for comprehensive assessments** (neuropsychological, hearing/vision, genetic, sleep, etc.) and ensure mental health, occupational, speech and physical therapies are FASD-informed.
- **Facilitate access** to school accommodations organized activities, case management, family support services and peer networks; provide written materials and guidance for external resources.

Services, Community Based Supports and Referrals

Key Components:

- **Conduct trauma-informed and culturally-sensitive meetings with families** to review results, build rapport, normalize self-care and tailor education; establish care coordinator roles for ongoing support.
- **Maintain high-quality ongoing care** through multidisciplinary collaboration, regular follow-ups, shared documentation and support for transitions to adulthood.
- **Encourage provider education on FASD** and identify regional resources to enhance clinical practices.



Resources

- American Academy of Pediatrics' FASD Toolkit
- American College of Obstetricians & Gynecologists' FASD Prevention Program
- Centers for Disease Control and Prevention's FASD resources
- FASD United
- Proof Alliance
- The SAFEST Choice Learning Collaborative
- FASD Collaborative Project
- University of Washington's diagnostic tools (e.g., lip-philtrum guides)



Summary

A Practical Guide for Designing and Implementing Fetal Alcohol Spectrum Disorder
(FASD) Diagnostic and Clinical Care Practices
Tips and lessons learned from clinicians



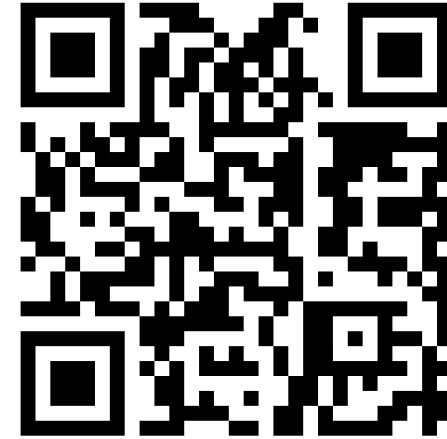
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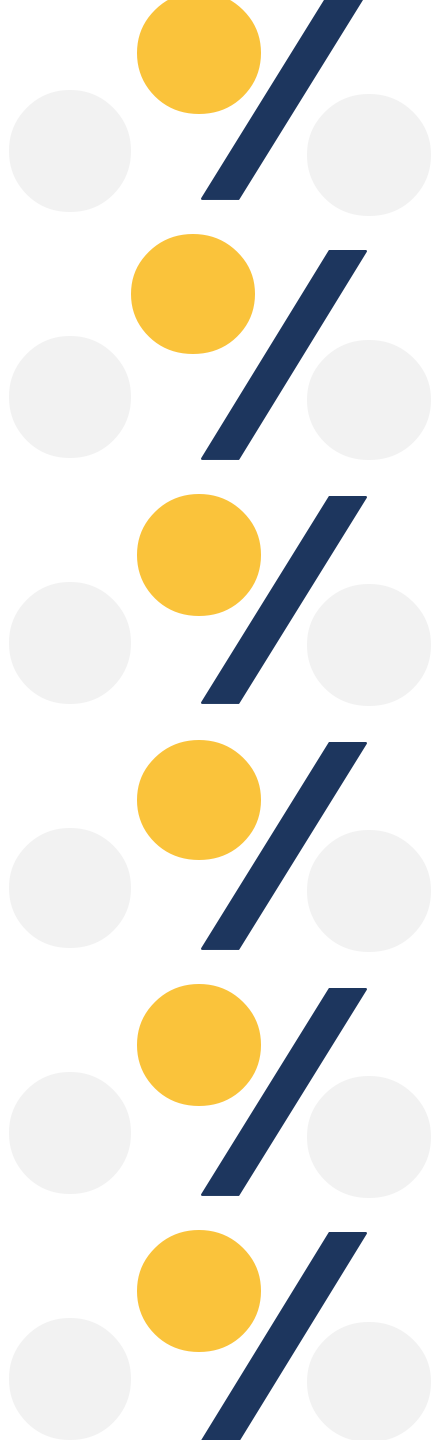
- Empower clinicians and organizations to start diagnosing FASD
- Provide relevant, actionable steps for implementing FASD diagnostic and care practices
- Promote strengths-based, respectful, and timely diagnosis
- Improve access to services.

Proof Alliance Website

- Screening resources
- Diagnostic guidelines
- Training and skill building opportunities

www.proofalliance.org





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