FASD Diagnostic Capacity in the United States

Executive Summary

What is FASD?

Fetal alcohol spectrum disorders (FASD) are a group of diagnosable medical conditions that can occur in a person who was exposed to alcohol before birth.[1] Effects are lifelong and can include mental health conditions, learning disabilities, sensory issues, and physical manifestations.[2]

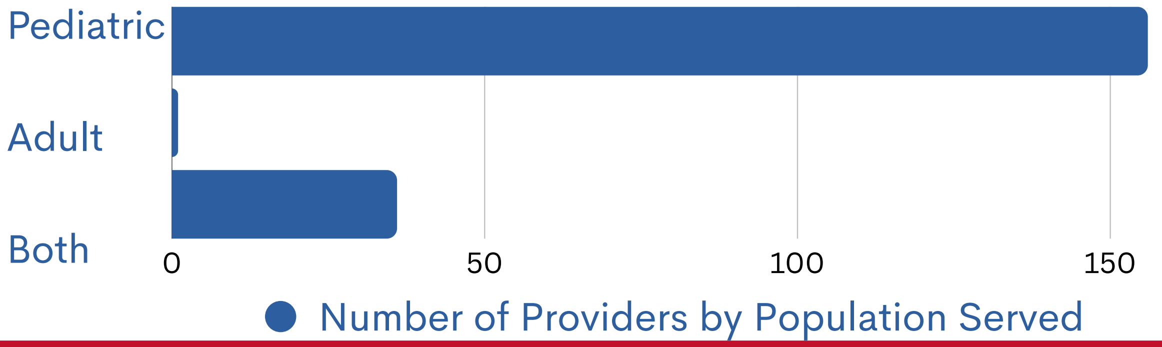
An estimated 1 in 20 Americans has an FASD.[3]

The Importance of Diagnosis

Diagnosis of FASD allows for an understanding of an individual's strengths and challenges, facilitating connection with appropriate intervention and support services. This can help reduce challenges and support healthier outcomes. Even if individuals do not meet the criteria for a diagnosis of FASD, a comprehensive multidisciplinary assessment process for those with prenatal alcohol exposure can provide important information about learning, behavior, and physical and mental health that will guide care and appropriate supports.[4]

Diagnostic Options in the United States

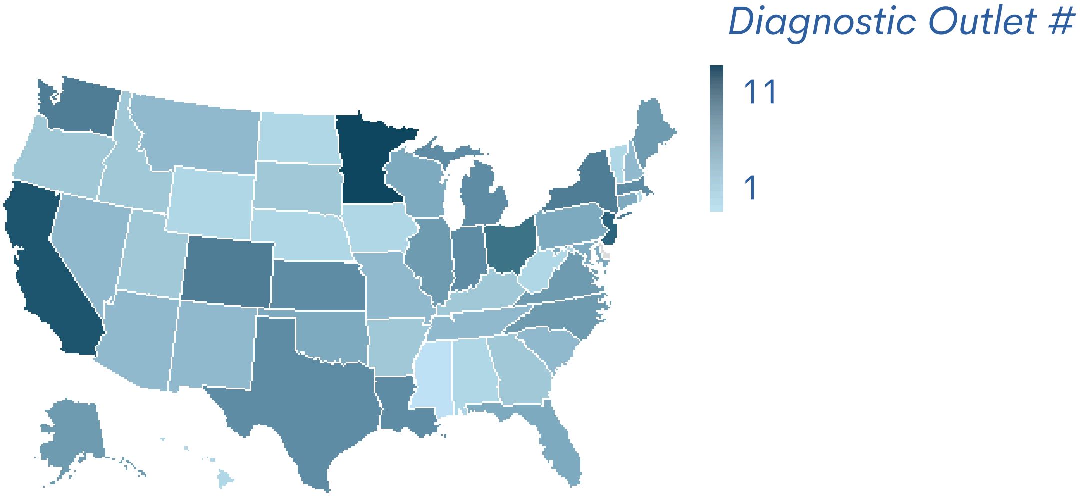
FASD United performed a 50-state review to identify clinics, clinicians, and hospital systems that are currently equipped to provide a diagnosis under the FASD umbrella. The review identified 193 providers currently offering FASD diagnostic services. Of these, 156 provide pediatric diagnostic services, one provides adult-only diagnostic services, and 36 provide both.



Capacity & Community Needs

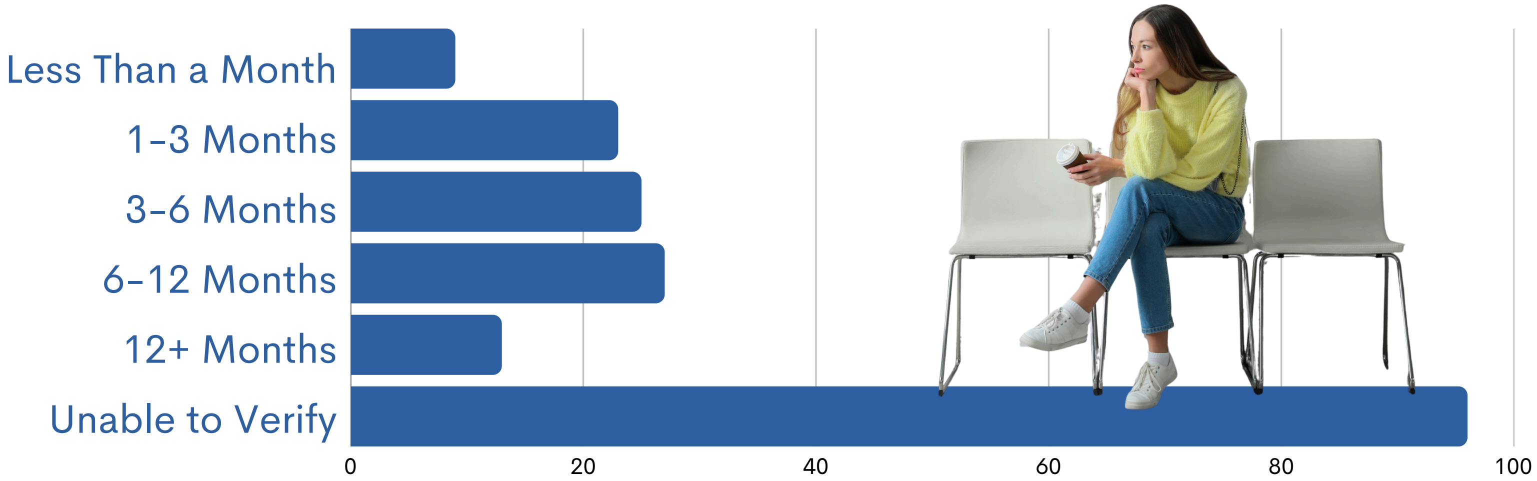
The prevalence of diagnostic outlets, even at presumed high diagnostic capacity rates, is insufficient to diagnose current prevalence rates of FASD. There are an estimated 16,572,464 people in the United States who may have an FASD[5], and less than 200 providers have stated availability to provide diagnostic assessments. While each state has at least one diagnostic site, Minnesota has the highest number with 11.

Diagnostic Outlets in the US



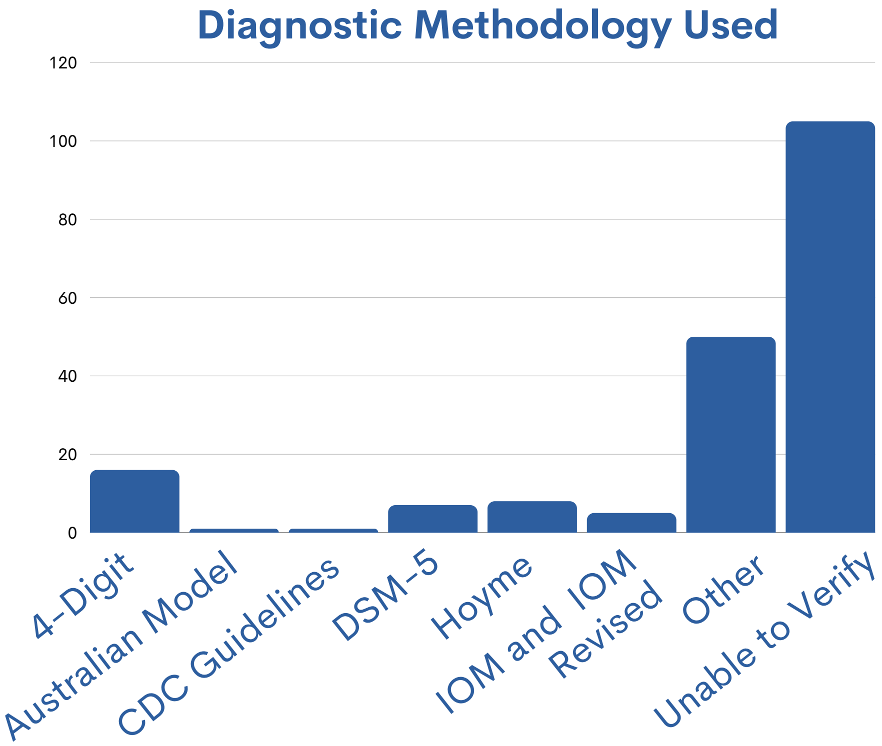
Wait Times

Of the diagnostic sites identified, 9 reported a wait time of less than a month, 23 sites reported a 1-3 month wait time, 25 sites reported a 3-6 month wait time, 27 reported a 6-12 month wait time, and 13 reported a 12+ month wait time. Some sites reported having up to a two-year waiting list, and some had closed their waitlists altogether due to high demand. Not all outlets were able to provide wait-time information.



Diagnostic Methodology Used

Diagnostic methodology is not standardized across the country and is largely unverifiable. Only 38 of the outlets surveyed were able to confirm which FASD diagnostic methodology was used, and of those, there were seven different methodologies in use. Approximately two-thirds of the diagnostic outlets indicated that more than one provider was involved in the process, with 13% overall specifically indicating the use of some kind of multidisciplinary team.



Use of an FASD-Informed Approach

Diagnostic sites were quantified by level of FASD-specific programs and awareness. Of the 193 providers, 113 were identified as Level 3 outlets with FASD-specific programs or services. 76 outlets were classified as Level 2, providing general disability programs with FASD knowledge. 4 sites were listed as Level 1, meaning that they provide general disability services with no FASD knowledge or lens. Only 34 states have Level 3 outlets that are specific to FASD or are considered to be FASD-trained.

Recommendations to Expand Diagnostic Capacity for FASD

Expanding diagnostic capacity is critical to improving outcomes for people with FASD.

Expand the age of eligibility for diagnostic assessments.
The vast majority of identified clinics only diagnose up to age 18, or in some cases, age 21. This highlights a significant challenge for adults to find a provider that can offer an age-appropriate assessment. This capacity issue may further perpetuate the falsehood that FASD is a childhood condition instead of one that affects a person across their lifespan.

Extend diagnostic capacity to rural areas.
While a team approach to diagnosis can provide meaningful value, it may be unrealistic to expect the model to scale to every community. In addition to investing in the expansion of multidisciplinary teams, expanding access to a single, well-trained medical provider in rural areas could significantly increase diagnostic capacity nationwide, rather than concentrating it in large metro areas or in places with FASD-specific research initiatives.

Expand autism diagnostic sites to include FASD.
There is already a large-scale diagnostic system built to evaluate autism spectrum disorder (ASD) across the country. While the diagnostic criteria differ, the process for assessing people for ASD and FASD is similar. Given this, it could be feasible that if these clinics and professionals were trained in one of the diagnostic methodologies for FASD, this could substantially expand capacity across the country. Additionally, training providers about the critical differences between the two disorders could lead to better diagnostic outcomes and appropriate interventions.

Build mentorship and training pipelines.
Our nationwide assessment identified that many FASD-informed professionals are retiring, and their roles are not being replaced. In addition, there is a nationwide shortage of behavioral health providers, especially in smaller or less densely populated regions. Creating opportunities for mentorship and training could help to maintain diagnostic capacity and critical institutional knowledge.

Connecting with Diagnostic Providers

If you are seeking an FASD assessment:

Although FASD is a common developmental disability, diagnostic, intervention, and other clinical services can be difficult to locate. If you want help identifying the diagnostic options in your region, FASD United can help.

Resource Directory

A comprehensive and vetted list of resources for individuals and families affected by prenatal alcohol exposure and FASD. At the bottom of the web page, there is a map. Click on your state to find the diagnostic providers we have identified.

Family Navigator Program

If you want help identifying and connecting with diagnostic sites, please contact the FASD United Family Navigators. The Navigators can also provide one-on-one peer support, referrals to resources and services, and information about FASD. This service is free and does not require a referral.

If you provide FASD assessments:

FASD United continues to update and share our list of diagnostic providers on an ongoing basis. If you provide FASD assessments and diagnostic services, please let us know via e-mail at information@fasdunited.org.

Sources

1. Centers for Disease Control. (2025). About fetal alcohol spectrum disorders (FASDs). https://www.cdc.gov/fasd/about/index.html
2. Waite, D., & Burd, L. (2023). Common developmental trajectories and clinical identification of children with fetal alcohol spectrum disorders: A synthesis of the literature. Advances in drug and alcohol research, 3, 10877. https://doi.org/10.3389/adar.2023.10877
3. May, PA, Chambers, CD, Kalberg, WO, Zellner, J, Feldman, H, Buckley, D, et al. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. JAMA. 319(5):474–82.
4. Cook, J., McFarlane, A., Flannigan, K., Hanlon-Dearman, A., & Unsworth, K. (2023). Why FASD diagnostic assessment is important. Canada FASD Research Network.
5. Population of United States (331,449,281) x estimated FASD prevalence in the United States (0.05).

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