3. Diagnosis and Early Identification

Short description

Timely and accurate FASD identification can help people understand their strengths and needs and connect with appropriate support. FASD United advocates for greater diagnostic capacity, consistent screening and referral practices, affordable evaluation, and access to interventions and services from early childhood through adulthood.

Our Position

People with fetal alcohol spectrum disorders (FASD) deserve access to timely, accurate, and respectful identification and diagnosis throughout their lives. An FASD diagnosis can help individuals and families better understand their strengths, needs, and experiences and can inform appropriate interventions and supports. Yet many people encounter barriers to diagnosis, including limited provider training, inadequate diagnostic capacity, costs, geographic disparities, and stigma.

Early identification can create opportunities for support during important developmental periods, but diagnosis remains valuable in adolescence and adulthood. FASD United supports expanding diagnostic capacity while ensuring that access to services is not unnecessarily delayed or denied when a formal diagnosis is unavailable. Identification should lead to meaningful support, not become an additional barrier to care.

Our Policy Goals

1. Expand access to FASD diagnostic services across the lifespan.

Increase the availability of qualified professionals and multidisciplinary diagnostic services, including in communities with limited access to specialized care. Address geographic, financial, and other barriers to evaluation.

2. Improve screening, identification, and referral practices.

Promote appropriate, evidence-informed screening and referral procedures in healthcare and other relevant service systems. Screening should be conducted respectfully, with attention to privacy, informed consent requirements, and the risk of stigma.

3. Strengthen diagnostic consistency and professional capacity.

Support appropriate clinical guidance, professional training, and coordination among providers to improve recognition of FASD and reduce missed or incorrect diagnoses.

4. Improve affordability and coverage.

Address barriers related to insurance coverage, reimbursement, and the cost of diagnostic evaluation and related services. Strengthen access for individuals who rely on public programs or who are uninsured.

5. Connect identification to appropriate intervention and support.

Improve referral pathways to developmental services, healthcare, education, disability supports, family navigation, and other resources. Ensure that people with possible FASD can receive appropriate needs-based services while evaluation is pending.

Alignment with Community-Driven Policy Recommendations

The following community-driven recommendations align with this position:

- **Diagnosis and Screening:** Improve access to diagnosis, strengthen screening practices, reduce barriers, and promote consistent procedures.
- **Continuum of Care:** Connect identification to coordinated, evidence-based services throughout life.
- **Professional Education:** Improve the ability of professionals across systems to recognize FASD and make appropriate referrals.
- **Agency Collaboration:** Strengthen coordination among healthcare, education, disability, and other service systems.

FASD Respect Act Alignment

Section 104 of the SUPPORT for Patients and Communities Reauthorization Act of 2025 authorizes research related to FASD diagnosis and prevention and activities to strengthen state and Tribal capacity for screening, diagnosis, targeted interventions, and professional training. These provisions provide a federal framework for expanding identification and diagnostic capacity.

The law does not establish universal diagnostic coverage, require all providers to screen for FASD, or guarantee access to a diagnostic evaluation. Additional implementation, funding, coverage, and policy efforts are necessary to achieve these goals.

Further Reading and References

- FASD United, FASD Symposium White Paper 1.1 and White Paper 1.2.
- SUPPORT for Patients and Communities Reauthorization Act of 2025, Public Law 119-44, Section 104: https://www.congress.gov/119/plaws/publ44/PLAW-119publ44.pdf
- Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. Pediatrics, 135(2), 264–270. https://doi.org/10.1542/peds.2014-2171
- FASD United, Language and Stigma Guide.