6. Access to Care and Support

Short description

People with FASD and their families need accessible, affordable, and coordinated support throughout life. FASD United advocates for stronger disability services, healthcare coverage, family navigation, employment and housing supports, and FASD-informed practices across the systems that serve children, adolescents, and adults.

Our Position

People with fetal alcohol spectrum disorders (FASD) and their families deserve access to services and supports that recognize their strengths, respond to individual needs, and promote quality of life. FASD is lifelong, but access to FASD-informed care is often fragmented and difficult to navigate. Individuals and families may encounter barriers to diagnosis, healthcare, disability services, behavioral health treatment, and other essential supports. These barriers can be especially significant during the transition from childhood to adulthood.

FASD United supports a coordinated, accessible continuum of care that extends throughout the lifespan. Support should be person-centered, culturally and linguistically responsive, and available in the communities where people live. Federal, state, Tribal, and local policies should strengthen recognition of FASD within existing systems while addressing gaps in eligibility, affordability, coverage, and service availability.

Our Policy Goals

1. Improve access to disability services and supports.

Strengthen recognition of FASD within disability service systems and reduce barriers that prevent eligible individuals from receiving appropriate assistance. Pursue policy changes that improve access for people whose needs are not adequately addressed by existing eligibility criteria.

2. Expand healthcare coverage and affordability.

Improve access to FASD-informed diagnostic, medical, behavioral health, and therapeutic services. Address gaps in insurance coverage, reimbursement, and provider availability.

3. Strengthen lifelong services, particularly for adults.

Expand access to supports for independent living, housing, employment, supported employment, workplace accommodations, mental health, and community participation. Ensure that individuals and families can navigate transitions between child and adult service systems.

4. Improve coordination and family navigation.

Strengthen connections among healthcare, education, disability, behavioral health, child welfare, justice, and community service systems. Support navigation services and peer connections that help people find and use appropriate resources.

5. Expand FASD-informed practices across service systems.

Promote training, accommodations, and individualized responses in the settings where people with FASD receive services. Include people with FASD and families in the design and evaluation of policies and programs intended to support them.

Alignment with Community-Driven Policy Recommendations

The following community-driven recommendations align with this position:

- **Continuum of Care:** Expand coordinated, evidence-based supports throughout the lifespan, including services related to education, employment, and daily living.
- **Agency Collaboration:** Improve coordination among agencies and service providers.
- **Grassroots Efforts:** Recognize and strengthen the role of community organizations and peer networks in helping individuals and families access support.
- **Diagnosis and Screening:** Reduce diagnostic and reimbursement barriers that can interfere with access to appropriate care.

FASD Respect Act Alignment

Section 104 of the SUPPORT for Patients and Communities Reauthorization Act of 2025 authorizes comprehensive FASD identification, intervention, and service delivery activities. It includes opportunities to strengthen state and Tribal capacity, adapt existing programs to better address FASD, and develop or disseminate FASD-informed interventions and resources.

The law provides a framework for improving services and coordination, but it does not automatically establish FASD eligibility for all disability programs, expand Medicaid benefits, require private insurance coverage, or create a nationwide entitlement to FASD-specific services. Achieving broader access will require additional funding, policy changes, and implementation across multiple systems.

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
- McLachlan, K., Flannigan, K., Temple, V., Unsworth, K., & Cook, J. L. (2020). Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with fetal alcohol spectrum disorder. Alcoholism: Clinical and Experimental Research, 44, 1609–1624. https://doi.org/10.1111/acer.14385
- Petrenko, C. L., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. European Journal of Medical Genetics, 60(1), 79–91. https://doi.org/10.1016/j.ejmg.2016.10.005