7. Research and Data

Short description

Better research and data are essential to understanding FASD and improving support across the lifespan. FASD United advocates for greater investment in research on diagnosis, effective interventions, and living experiences, alongside responsible data collection that informs policy, identifies service gaps, and respects the privacy and dignity of individuals and families.

Our Position

Research and data are essential to improving the identification, understanding, and support of people with fetal alcohol spectrum disorders (FASD). Despite advances in knowledge about prenatal alcohol exposure and its effects, important gaps remain in understanding diagnostic needs, effective interventions, long-term outcomes, and the experiences of people with FASD throughout their lives. Better evidence is needed to guide healthcare, education, disability services, public policy, and resource allocation.

FASD United supports sustained investment in research that addresses the priorities of people with FASD and their families. Research should extend beyond prevalence and prevention to include quality of life, effective supports, service access, and outcomes across the lifespan. Data collection must be responsible, transparent, and attentive to privacy, stigma, and the potential consequences of disclosing sensitive information.

Our Policy Goals

1. Increase investment in FASD research.

Support sustained federal and other public investment in research addressing FASD diagnosis, interventions, services, and outcomes. Encourage coordination among research institutions, federal agencies, and community partners.

2. Expand research on effective interventions and lifelong support.

Prioritize research on approaches that improve quality of life, health, education, employment, independent living, and community participation. Address gaps in evidence concerning adolescents, adults, and aging individuals with FASD.

3. Improve prevalence and service-needs data.

Strengthen appropriate methods for understanding the prevalence of FASD and identifying unmet service needs. Support data that can inform planning, program development, and equitable allocation of resources.

4. Center people with FASD and families in research.

Promote meaningful participation by people with living and lived experience in setting research priorities, developing studies, interpreting findings, and communicating results. Research should reflect the diversity of the FASD community and avoid framing people primarily through deficits or costs.

5. Promote ethical, transparent, and useful data practices.

Protect privacy and confidentiality, respect applicable consent requirements, and address concerns about stigma and punitive uses of information. Encourage responsible sharing of research findings in accessible formats that can inform policy and practice.

Alignment with Community-Driven Policy Recommendations

The following community-driven recommendations align with this position:

- **Research:** Increase research on diagnosis, living experience, and effective interventions.
- **FASD Data:** Improve the collection and use of information about prevalence and support needs, with attention to transparency, privacy, and stigma.
- **Diagnosis and Screening:** Strengthen the evidence base for diagnostic approaches and identification practices.
- **Continuum of Care:** Develop evidence that improves interventions and services throughout the lifespan.
- **Agency Collaboration:** Encourage coordinated research and data efforts across relevant 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, including culturally and linguistically appropriate interventions. It also authorizes activities to strengthen state and Tribal capacity and disseminate information about evidence-based or evidence-informed approaches.

These provisions provide opportunities to improve the evidence available to agencies, professionals, and communities. They do not establish a comprehensive national FASD surveillance system, guarantee funding for every research priority, or require uniform data collection across all states. Additional investment and coordination will be needed to address those broader 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
- May, P. A., Chambers, C. D., Kalberg, W. O., et al. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. JAMA, 319(5), 474–482.
- FASD United, Language and Stigma Guide.