



FASD United
Affiliate Network

LISTENING SESSION REPORT

Summer

2024

PURPOSE

The Connectivity Committee of the FASD United Affiliate Network was newly formed in 2024. In order to find the most important, potential points of connection for affiliates and to provide a foundation for the Network's Executive Council's work on a strategic plan, the Connectivity Committee conducted a series of listening sessions.

APPROACH

In the summer of 2024, the co-chairs of the Connectivity Committee, Kristen Eriksen and David Deere, conducted a series of 8 listening sessions. Each affiliate was encouraged to select one representative to participate in one of the sessions, with 24 affiliates participating. In order to find the needs of the affiliates and to find the assets existing within the Network, five questions were posed to the participants.

- What is your affiliate's area of greatest strength, and what is one way you benefited from being part of the Affiliate Network?
- How can the Affiliate Network assist you over the coming year?
- How can the Affiliate Network impact FASD in the next two years?
- What can your affiliate do for the Affiliate Network?
- Are you interested in being part of a regional group?

FINDINGS

The questions were designed to discover both the strengths and needs of the Network. The comments from the participants are gathered into broad categories for this report.

STRENGTHS AND EXPERTISE WITHIN THE NETWORK

The Network is quite **diverse** in terms of the size and structure of affiliates, as well as areas of expertise and resources. There is currently a huge gap between expressed needs and knowledge of where available resources exist. A potential role for the **Connectivity Committee** is to help affiliates know where assistance is available and facilitate communication regarding those needs and resources. Affiliates with expertise in an area or activity might mentor other affiliates regarding the steps toward success. All the activities and resources listed in this section were self-identified by affiliates as already existing in the Network.

FASD AWARENESS

- Increased support or collaboration on awareness activities- examples: obtaining FASD Day/Month proclamations, lighting bridges for awareness, holding events throughout the state and larger awareness campaigns.
- Need for intentional outreach to colleges/universities.

DEVELOPED EXPERTISE IN TRAINING/TECHNICAL ASSISTANCE

- Need to develop training for professionals, families, and general public – including but not limited to the following topics and/or specific audiences: IEPs and navigating special education, prenatal exposure, prevention, social workers, physicians/PAs/nurse practitioners.
- Various approaches were identified for providing training using/developing a speakers bureau and identifying provider champions who promote training for professionals and offering clinical services (Affiliates might consider partnering with pediatricians and OB/GYNs who are identified as champions with the CDC National Partners program.)
- Methods and infrastructure for platforming and sharing living experiences.

SUPPORTS & INTERVENTIONS

- Need for more support groups – including for caregivers of adults with FASD.

DIAGNOSTIC CLINICS

There are affiliates who:

- Operate satellite clinics
- Use an interdisciplinary approach
- Operate a clinic without a physician

PARTNERSHIPS

- Can provide technical assistance for developing relationships.
- Partner with organizations devoted to caregiving.
- Partner with healthcare providers.
- In states with multiple affiliates, the organizations have defined roles and make mutual referrals.
- Several affiliates sit at the intersection of child welfare, substance use disorders, and/or mental health.
- Affiliates focused on fostering, adoption, and kinship care.

OTHER RESOURCES/STRENGTHS OF AFFILIATES

- FASD Collaborative (www.fasdcollaborative.com/sig) – has established Special Interest Groups (SIG). The established groups include: the knowledge share collective, diagnostic, child welfare, schools, allied health, mental health, housing and supports for adults, and higher education.
- Experience working with other affiliates to hold a summit (also other affiliates have expertise in finding external organizations to help plan events)
- Affiliates with a national constituency
- DEIB – example: Our Children Are Sacred
- Tip sheets
- Social media, graphic design, developing signage
- Connections within the larger disability community
- Using text to screen for alcohol and other drugs
- Setting up webpages
- Helped other affiliates apply for funding
- State level advocacy

NEEDS AND WANTS OF AFFILIATES

The affiliates identified a range of issues they would like to see addressed. Some are very specific for their state or region, while others are more cross-cutting and would best be addressed by the entire Network. In some cases, the resource desired is already available but not known by the affiliate requesting the resource. This suggests a need for more effective communication with each other.

TRAINING/TECHNICAL ASSISTANCE

- Hold a regional conference
- Training for health professionals, particularly physicians
- Have canned presentations for training topics
- Create a database of available trainings.

FASD AWARENESS

- Identify and recruit a celebrity champion for FASD Awareness
- Need uniformity in messaging/training

SUPPORTS AND INTERVENTIONS

- Better, and more accessible, supports and interventions
- Services in rural areas
- Parent to parent & peer to peer supports
- More adult services
- Improved school experience for students with an FASD
- Support groups
- Housing

DIAGNOSTIC CLINICS

- Establish a diagnostic clinic – including one using telemedicine.
- Simplify and standardize the diagnostic process
- Need list of diagnostic codes
- Guidance on working with insurance companies
- Use the ECHO approach to develop expertise (a person or group with expertise who leads a community of practice, typically using a videoconference platform).

EXTERNAL PARTNERSHIPS

- FASD United assist with getting attention of provider community
- Establish Special Interest Groups (SIG) – groups around common interests
- More collaboration between non-profit and for-profit agencies
- Help finding state-level partners
- Community building
- Better connections with disability community

ADVOCACY

- FASD United to assist affiliates with local/state policy.
- Eligibility for disability services

CAPACITY-BUILDING

- Keeping up with research
- Shift from medical to social model
- Finding resources – including print and digital resources
- Resource repository
- Finding financial resources
- Forms/documents in plain language – especially legal forms
- More diversity, including outreach to tribal communities
- Focus on justice system – data collection, screening, mitigation
- Reduce stigma – using a national campaign
- Marketing – become vocal
- PSAs from FASD United for use by affiliates

OTHER NEEDS

- Regional working group of affiliates
- Better networking among affiliates
- Buddy system for affiliates
- Help finding board members
- Ethics training for board
- End duplication of efforts – more collaboration among affiliates
- Searchable database of affiliate activities, assets, and resources
- More funding
- Connect affiliates (listserv, communication tools)
- Spotlight on affiliate successes/best practices
- Mentoring
- More clarity of what FASD United has to offer affiliates
- Identify network expertise in prevention, school services, diagnosis, health care, mental health, transition to adulthood, disabilities
- Focus on affiliates in monthly calls – supporting one another
- Help with developing bylaws, applications, grant writing (Consider the FASD Collaborative Incubator Series)
- Map with icons showing focus of affiliates
- Use LinkedIn
- Sustainability
- Help building a database

RECOMMENDATIONS

The Affiliate Network Executive Council might consider prioritizing developing better options for communication between and among affiliates. This would allow affiliates to address their specific needs by reaching out to their Network peers for mentoring and technical assistance. The Network has a vast array of expertise and a willingness to share with one another. The Council can play a critical role in facilitating the connection and collaboration needed and wanted. Considering the items identified by the affiliates, the Council and the affiliates might also select an initiative, or limited number of initiatives, to address on a national level.

In addition to promoting communication among the affiliates, the Connectivity Work Group might also take steps to assist interested affiliates in establishing regional working groups or special interest groups (SIG).

