

Affiliate Network Guidelines



FASD United
Affiliate Network

This document provides guidance on becoming a member of the FASD United Affiliate Network and how to maintain membership. This diverse and active network unites organizations, associations, tribes, and other entities that address FASD into a national and international network. Functioning as a coalition, each affiliate organization maintains its independence and identity while contributing to a collective voice.

FASD United Affiliate Network Guidelines (10/1/2025)



About FASD United

At FASD United, we believe the world is ready for change. Our work creates a movement that leverages the truth and power of the lived experience of FASD.

Vision

An FASD-informed world where people living with FASD and prenatal alcohol exposure are recognized and supported.

Mission

FASD United empowers people living with FASD and prenatal alcohol exposure to educate systems of care and the public, enact policies, and unite communities everywhere.

History

In 1990, FASD United was first incorporated in South Dakota as The National Organization on Fetal Alcohol Syndrome (NOFAS). In 1991, the organization moved its headquarters to Washington, D.C.

During the 1990s, FASD United played a pivotal role in the establishment of the National Task Force on FAS/FAE, contributing to the groundbreaking 1996 Institute of Medicine Report and the launch of the Interagency Coordinating Committee on FAS at the National Institute on Alcohol Abuse and Alcoholism (NIAAA). In 2002, FASD United expanded its reach by establishing its Affiliate Network. The Circle of Hope birth mothers' network was a significant milestone in 2004. The organization's successful advocacy led to the 2005 advisory on alcohol and pregnancy issued by the U.S. Surgeon General. FASD United initiated the observance of September as FASD Awareness Month, a testament to our commitment to raising awareness and fostering understanding.

In September 2021, we marked a new chapter in our journey, officially renaming from NOFAS to FASD United. This change reflects our unwavering commitment to serve the entire FASD spectrum and solidifies our position as the national expert, unifying all parties across the FASD field. In 2022, we continued to make strides with the launch of the Family Navigator program, a crucial resource for families navigating the complexities of FASD. Our Policy & Training Center also made a significant impact by introducing the FASD Respect Act in the U.S. Congress, a testament to our ongoing commitment to advocate for the rights and needs of individuals with FASD.





Purpose

The primary goal of the FASD United Affiliate Network is to unite organizations, associations, tribes, and other entities that address FASD into a national and international network. The network functions as a coalition, and each affiliate organization maintains its independence and identity.

The objectives of the network are to:

- share information and resources
- build the capacity of the FASD constituency
- set common goals and messages
- seek consensus on the multi-faceted issues in the FASD arena
- collaborate on a range of public health and advocacy programs and services to increase advocacy activity
- leverage resources
- strive to overcome the stigma and boundaries associated with the disorders



FASD United and each affiliate organization respects:

- the identity, culture, policies, and traditions of each member organization
- the image, reputation, and public standing of each member organization
- individuals with FASD and their biological mothers and all family members, and caregivers



Benefits to Affiliates



- Free and discounted materials and resources
- Participation in affiliate activities, committees, and workgroups.
- Monthly affiliate conference call.
- Free or discounted attendance at FASD United events and activities, including conferences, benefits, and briefings.
- Opportunity to apply for mini-grants.
- Members-only Facebook page (FASD United Affiliate Network FB page)
- Opportunity to serve in leadership roles with the affiliate network.
- Technical Assistance (TA) can be provided by peers within the affiliate network and/or from FASD United and may consist of both strategic guidance and direct assistance with tasks such as
 - developing a logic model (goal, objectives, outcomes)
 - securing and maintaining non-profit status
 - grassroots advocacy
 - fundraising and proposal development
 - public awareness strategies, materials and website development, and
 - nonprofit governance and administration including incorporation and IRS filings. Those wishing to receive TA may contact the Chair of the Affiliate Executive Council or FASD United office directly.
- Promote your organization and programs through the FASD United website, FASD United Weekly Roundup e-newsletter, and social media sites.

Eligibility

Any organized entity worldwide with either a sole or significant focus or specific program on FASD may be eligible to join the affiliate network.

Business Structure

In the United States, any incorporated non-profit organization, American Indian/Alaska Native Tribe, County/City/ State Agency, or University program is eligible. Organizations must be incorporated and in good standing in their state. Non-profit organizations must either have 501(c)3 status or have an application seeking charitable status pending with the Internal Revenue Service. Non-U.S. entities organized as charitable or public service organizations under the guidelines of their country may also join. Don't hesitate to contact FASD United with any questions about eligible business structures.

Minimum Standards

As of January 1, 2020, an organization must maintain the following minimum standards to become and remain a member of the affiliate network.

1. Non-Profit Status – Organizations must 1) have tax-exempt status, 2) have applied for their status through your Secretary of State office, or 3) be working on the application seeking tax-exempt status. This requirement will not apply to universities, state or local agencies, or tribal-based entities.
2. Primary Contact – Each organization must name an individual as its authorized agent. This person will represent the organization in the affiliate network.
3. Telephone Number and/or Email Address—Affiliate organizations must have a publicly accessible telephone number and/or email address (preferably on the organization's website domain). Calls may be answered by voice mail, and emails may be answered with an auto-reply message.
4. Bank Account—Organizations must have a corporate bank account. This requirement does not apply to universities, state or local agencies, or tribal-based entities.
5. Website and Domain – Organizations must maintain a website consisting of at least a description of the mission, objectives, programs/activities, 2) internal or external link(s) to information and resources, 3) contact information, and 4) a merchant account. The FASD United Affiliate Network logo should be included on a landing page, and a statement recognizing them as a member of the affiliate network should be displayed on the affiliate agency website.
6. Inquiries/Materials Fulfillment—Organizations should be able to respond to telephone, email, and/or website requests for information or materials or refer requests to FASD United.
7. Contact List – It is recommended that each organization maintain a list of contacts, members, supporters, etc. This list (or database) can be as basic as an Excel file or other electronic format that stores information. This information is for the sole use of the organization only. FASD United or the Affiliate Network will have no access to this information.
8. FASD-Specific Activity -- Each year, members must conduct at least one FASD-specific activity, such as a support group meeting, public awareness event, briefing, training, fundraising event, etc.
9. Affiliate Network Participation. Each year, members must participate in at least one affiliate activity, such as attending Impact Week, or by participating in a minimum of 80% (minimum of 8 calls per year) of the monthly conference calls or meaningful participation in one of the affiliate workgroup committees.
10. Affiliate Materials -- Affiliate organizations should be able to upload materials created by the Affiliate Network to their website with a link to the Affiliate Network Website to promote the Affiliate Network's work.

As the network is intended to be an inclusive space to grow community, organizations not meeting the minimum requirements may be allowed to join the Affiliate Network based on other merits and/or a desire to work towards the goal of meeting all requirements. Those exceptions will be reviewed on a case-by-case basis in consultation between the organization, and Affiliate and FASD United leadership.

Existing Affiliate Organizations

Before applying to the FASD United Affiliate Network, the applicant should contact FASD United to determine the status of any existing affiliate organization(s) in their state. If there is an existing affiliate organization in the state, applicants are encouraged to contact the existing affiliate to identify opportunities for collaboration to meet their state's needs best. The applicant should include key points from this discussion in their application. The FASD United Executive Council will make the final decision on membership applications.

Given our shared mission and in the spirit of collaboration, member organizations are encouraged to use evidence-based training, infographics, and materials to further their organization's mission. When materials or information created by other organizations or researchers are utilized by a member organization, appropriate attribution should be clearly made in all promotional and disseminated materials (e.g., citation). It is also agreed that affiliate member organizations will work in good faith to have clear prior communication, understanding, and agreement with their fellow affiliates if their activities could or do encroach on or involve an area, service, or location served by another affiliate organization.

These criteria shall also apply to governed entities and sub-entities outside the United States.

Ending Affiliation

The relationship between FASD United and each affiliate organization is considered to be permanent until terminated by one or both parties or superseded by a subsequent agreement. Either FASD United or the affiliate organization may terminate the affiliate agreement at any time by submitting a written notice to the subject organization's authorized agent.

Criteria for Maintaining Affiliate Status

As of January 1, 2021, all Affiliate members will complete an annual Commitment Form that will be submitted at the same time as the annual dues (by March 31). This form will ask the affiliate member to examine their level of participation in the preceding year and to declare their organizations' ability to meet the minimum standards as outlined above.

The FASD United Partnerships Director, in collaboration with the Affiliate Network Executive Council (ANEC), will review the annual Commitment Form and confirm the status of each affiliate organization. If an affiliate organization's status has changed, the FASD United Partnerships Director and the named affiliate organization will discuss a process for addressing concerns if the affiliate organization wishes to remain an active Affiliate member.

The review criteria that the FASD United Partnerships Director will follow are included as an Appendix to this document.

Mission Compatibility



Although FASD United Affiliates are self-governing and autonomous, it is important that organizations joining the affiliate network have a mission that is compatible with FASD United. The FASD United mission includes the following key objectives:

1. Raise awareness about the risk of alcohol use during pregnancy Support anyone directly or indirectly affected by FASD
2. Build and activate a constituency within the FASD community
3. Eliminate stigma and shame around FASD

Any organization motivated by one or more of these principles and who does not support goals or objectives contrary to these values is an ideal candidate for affiliation with FASD United. Affiliates do not need to adopt the FASD United mission and are not limited to the goals stated by FASD United.

Organizations that meet the eligibility criteria are encouraged to apply to the network.

Autonomy

Affiliate member organizations are autonomous and maintain their own names and branding mechanisms, including logos and messaging. FASD United requests that the name "FASD United" not be incorporated into the Affiliate organization name.

Application Process

The FASD United Affiliate application may be submitted to FASD United anytime. Prospective affiliates are encouraged to schedule a conversation with the Affiliate/Partnerships Director to begin the application process.

Dues

The annual dues structure is based on the member organization's FASD-related revenue and is payable by March 31 each year.

Revenue	Dues
\$0 – \$50,000	\$50
\$50,001 – \$100,000	\$100
\$100,001 – \$250,000	\$200
\$205,001 and above	\$325

Leadership

The affiliate network is governed by the FASD United Affiliate Network Executive Council (ANEC). Council members serve two-year terms. Members may serve as many as three consecutive terms. FASD United maintains a permanent seat on the Council. Each member serves as a representative of a region of the Affiliate Network.

The Executive Council election and term years begin January 1. Nominations to be included on the slate of candidates for the January election should be submitted to FASD United from July – August of the previous year. Nominees must be either staff or board members of an affiliate organization. Self-nominations are allowed. Members are elected by a vote of the full affiliate network membership, with each organization in good standing having one vote.

The powers vested in the Executive Council include:

1. Determining the eligibility of applicants
2. Voting on applications to join the network
3. Revising the affiliate network guidelines
4. Planning the affiliate activities
5. Determining the use of funds from dues or other sources
6. Establishing and prioritizing programmatic and legislative/policy initiatives



Authorized Agent and Address

Each affiliate will name a board or executive staff member to serve as their authorized agent. This person will conduct all official correspondence with FASD United. The Partnerships Director is the authorized agent for FASD United. The authorized affiliate address should be the official address of the organization. Each affiliate organization is expected to have its own authorized agent and address.



Policies and Position Statements

FASD United realizes that although affiliate organizations have compatible missions and programs, our policies may not always agree. FASD United periodically releases organizational policy statements on issues such as the acceptance of funds, the composition of the board of directors, and the FASD United position on various federal, state, and other legislation and policies. As the legal authority of FASD United, the Executive Committee of the Board of Directors is responsible for governing the organization and ratifying all policies.

FASD United will share all organizational statements with affiliates. Affiliates are not obligated to adopt, sponsor, or consider any FASD United statement. However, affiliates are welcome to adopt any or all FASD United policies, position statements, and guidelines.

FASD United encourages affiliate organizations to share their position statements and policies with members of the network, as well as to thoughtfully and appropriately share their thoughts or questions with FASD United about any of its policies.



Donors

Donors give funds for various reasons, most often because of a personal relationship. Some donors give to FASD United or an affiliate organization, but they would not consider giving to another member of the affiliate network. Other donors may specifically focus on FASD or, for other reasons, contribute to multiple network members. It is imperative that organizations communicate before approaching other organizations' donors so as not to interfere with existing relationships and to determine if it is appropriate for multiple organizations to approach a common donor. Generally, if an entity has previously cultivated a specific funding source, it should be reserved for that entity until such time as the relationship is no longer valid.

Organizations should respect other organization's wishes regarding donors.

Often, there are many funding sources within a single corporation or other entity. By communicating, organizations can help each other identify a donor in their geographic region or who may be interested in their specific program.

Give **FASD** a
Seat at the Table



FASD United
Affiliate Network



**Affiliate Monthly
Meetings**

Monthly Meetings

The purpose of the Affiliate Monthly Meeting is to give updates on the general FASD community and FASD United, and share resources with Affiliates. There are often break-out sessions to encourage connectivity and resource/knowledge-sharing among Affiliate organizations.

Time: Third Thursday of the month from 3:00 – 4:00 pm EST

Zoom Link: <https://us06web.zoom.us/j/86865019922?tk=12wk6aKAXKzPMbON2V3kX3g-v8KWqZQxYw99E06xF1Y.DQcAAAAUOY8EEhZJNUFJN0hJX1FENmY3RXd2LU11WF9BAAAAA>
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MEETING YOU
***Where
You're At***

"Where You're At" Sessions

Where You're At (WYA) Sessions are as-needed, workshop-style meetings that are usually 30-45 minutes and focus on a topic relevant to only a subset of Affiliate members.

Time: As-needed

Zoom Link: Sent with announcement and registration emails.

	Eligibility to become FASD United Affiliate	Active Partner Status Maintenance Requirements	At-Risk Status*
Non-profit status	Provide evidence of tax-exempt status, such as 501(c)3 or is affiliated with a university, state agency, or tribal-based entity	Continually maintains tax-exempt status	Loss of tax-exempt status
Primary contact information	Establish primary contact for affiliate as the authorizing agent	Maintains primary contact for the organization	Loss of primary contact for the organization
Telephone number and email address	Provides active telephone number and email address for the affiliate	Maintains active telephone number and email address	Lack of maintenance of telephone or email for the affiliate
Bank Account	Provide evidence of corporate bank account	Maintain corporate bank account	No corporate bank account
Website and domain	Has new/existing website for the organization, showing direct connection to FASD, including a description of the mission, objectives, programs/ activities, and resources, contact information, and a merchant account, FASD United logo included on landing page of affiliate agency website	Actively maintains website, including the information required for eligibility	No website or active maintenance of website; website does not maintain focus on FASD or is missing required information
Inquiries/Materials Fulfillment	Has process established to respond to telephone, email and website requests for information or materials	Actively maintains process for responding to inquiries and material requests	Lack of effective maintenance of processes for responding to inquiries and materials
Contact List Method	Has created a mechanism for contacts, members, supporters, i.e. lists	Actively maintains contact/member/supporter listing	Lack of maintenance of contact/member/supporter listing
Annual FASD specific activity	Plans to conduct annual FASD specific activity	Conducts annual FASD specific activity	Does not conduct annual FASD specific activity
Participation in affiliate network activities	Designate one or more individuals who assigned to attend FASD United Affiliate Network activities	Actively participates in 75% of monthly calls, attends partnerships and participates in affiliate workgroups	Does not participate in required affiliate network activities

Work Group Guidelines

This section provides all information regarding the creation and maintenance of the FASD Affiliate Network Work Groups.



FASD United
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FASD United Affiliate Network Work Group Policies



- Each work group will have a clearly defined purpose.
- The Affiliate Network Work Groups are Affiliate-driven.
- Each work group will meet regularly, at least quarterly.
- Each work group will identify deliverables for the year when it forms, and renew or redefine those deliverables at the end of the calendar year for the coming calendar year.
- Each work group will have *at most* two Co-Chairs who share responsibilities for leading the work group. ONE chair must be identified as the liaison between the FASD United and the Work Group.

Chair Responsibilities

Each work group will have a **single** Work Group Chair. The chair will act as the liaison between the Work Group, ANEC, and the Partnerships Director. Their responsibilities include:

- Refine the Work Group parameters for their particular work group.
- Create a roster with work group members' names, Affiliate, and contact information (email & optionally, phone number).
- Identify a recurring meeting day & time, and share that with the Partnerships Director.
- Create the written agenda for each meeting and send out the agenda at least 3 days in advance and even further in advance if possible (barring an emergency).
- Be listed as the host on recurring Zoom meetings, and be responsible for sending out to members & new members.
- Facilitate work group meetings.
- Document key agreements, action items, and task assignments from each meeting and provide electronically to all work group members promptly. All notes must be reviewed and edited for accuracy and action items.
- Communicate with ANEC Chair and the Partnerships Director, as needed.
- Quarterly and end-of-year updates to Partnerships Director and ANEC on deliverable progress and support needs from ANEC or the larger Affiliate Network.



Current Work Groups - 2025

Affiliate work groups (AWG) meet on their own regular schedule to collaborate on a focused goal or product related to topics relevant to the FASD community and/or to support the facilitation of the Affiliate Network. There are currently 3 active AWGs: the Connectivity Work Group, Widening the Circle, and Mental Health.

Connectivity

Purpose: The mission of the Connectivity Work Group is to cultivate a sense of connection, build community, and promote collaboration within the FASD United Affiliate Network.

Chairs	Meeting time	Deliverables
<u>Kristen Eriksen</u> , MassFASD	Second Thursday. 2:00 pm EST	Onboarding sessions for new Affiliates. Methods & platforms for Affiliate-Affiliate communication. Connection of Affiliates with shared interests.

Widening the Circle

Purpose: To build on knowledge, understandings, and tools that FASD advocates, providers, and researchers have developed over decades, the work group provides resources, opportunities for learning and meaningful conversations, and capacity building related to diversity, equity, inclusion, and belonging (DEIB) in our Network, focused, in particular, on the intersectional nature of FASD.

Chairs	Meeting time	Deliverables
Kallio Hunnicutt-Ferguson	Quarterly; Contact chair for more info	Presentation: Addressing FASD: Working With and Learning From Indigenous Communities Mini-Modules for Affiliates

Mental Health

Purpose: To provide clinicians with a deep understanding of brain-based differences (BBDs) to enhance mental health support. The focus is on developing a comprehensive understanding of BBDs to improve assessment, treatment planning, and service delivery. By bringing together the community of providers through education, awareness, and collaboration, we aim to foster more compassionate, tailored, and effective mental health services across the lifespan.

Chairs	Meeting time	Deliverables
Tamra Cajo	3rd Monday. 2:00 pm EST	Mental Health Website

