

Give **FASD** a Seat at the Table

Affiliate Monthly Meeting
July 17, 2025



FASD United
Affiliate Network



FASD United Initiatives:
How Can Affiliates Get Involved &
Leverage Resources?



Welcome

Happy Disability Pride Month!



Affiliate Network

For attendance, please put your full name and Affiliate name in the chat.

**Ice Breaker Question:
What is something you do *every* summer?**



FASD United
Affiliate Network

Updates from FASD United

Move FASD

Event Packages

Event Needs	FASD United Affiliate Package
Move FASD logo & sponsor logo	✓
Kick-Off Meeting	✓
Marketing flyer for your event	✓
Registration software & event registration support	✓
Event marketing social media (8 media tiles with suggested captions)	✓
Sponsor outreach flyer with your organizations information	✓
Branded sign-in sheet	✓
Template press release	✓
Day-of Event Support/Staff	X
Primary contact for event questions	X
Venue search and permit applications (if applicable)	X



Scan QR code or [CLICK HERE](#) to fill the Move FASD interest form. You can email Emma Baldwin at FASD United with any questions: baldwin@fasdunited.org



ANEC Self-Nominations Open Today





Programs Offered



Justice Center



Affiliate Network



Policy & Training Center



Family Navigator



Recovering Mothers Anonymous



Media and Communications Hub



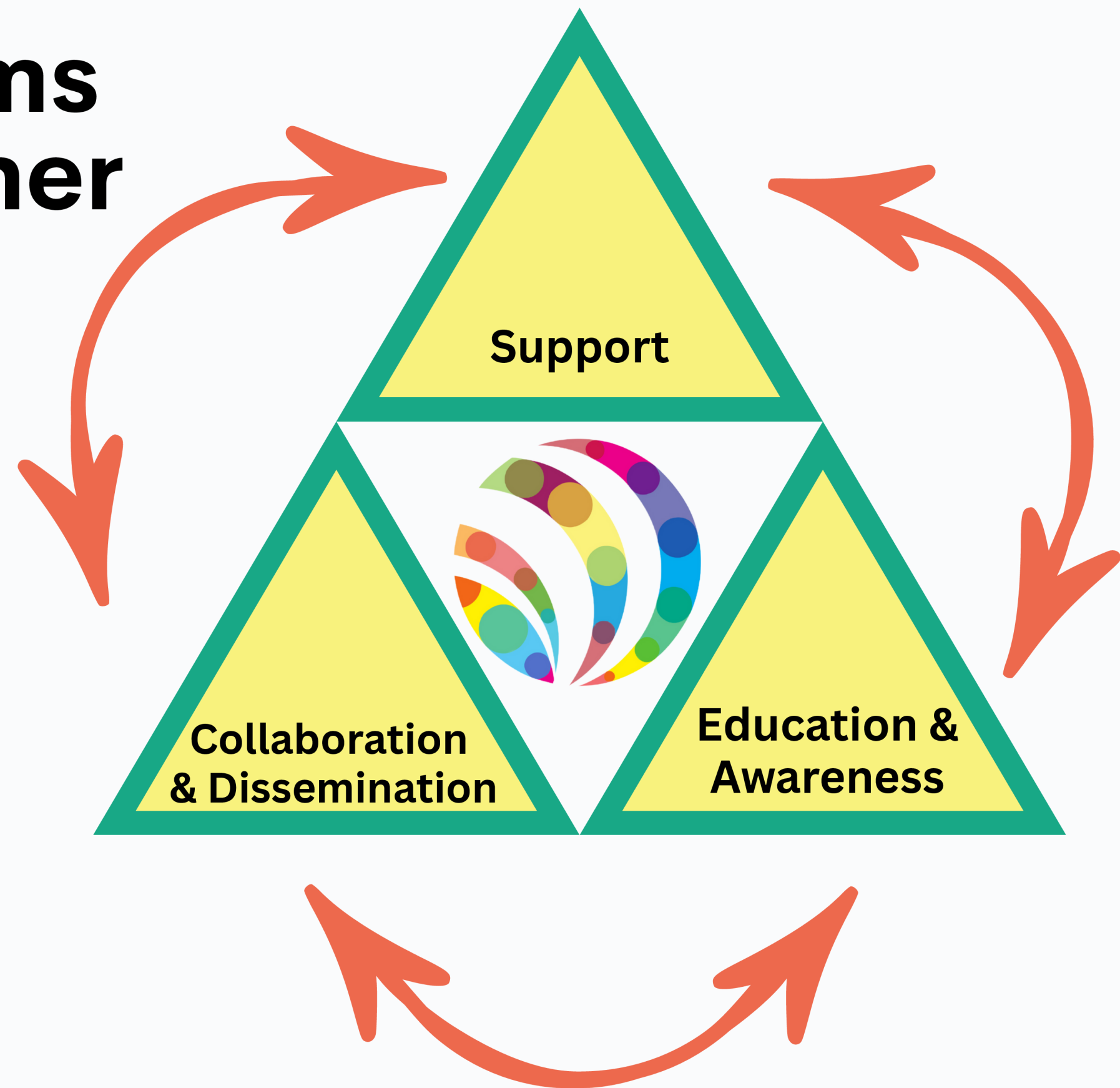
Resource Directory





How our programs support each other

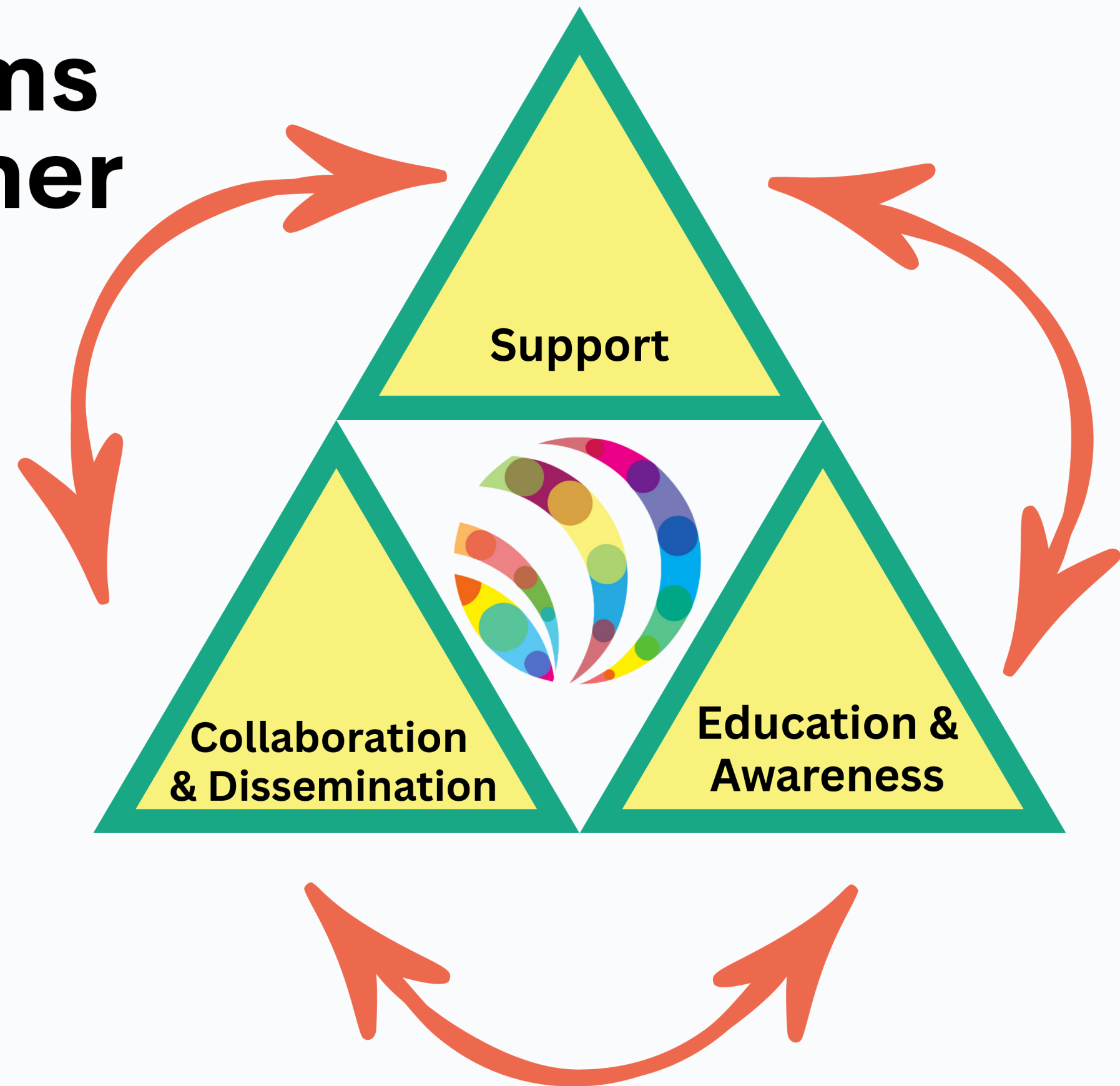
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How our programs support each other

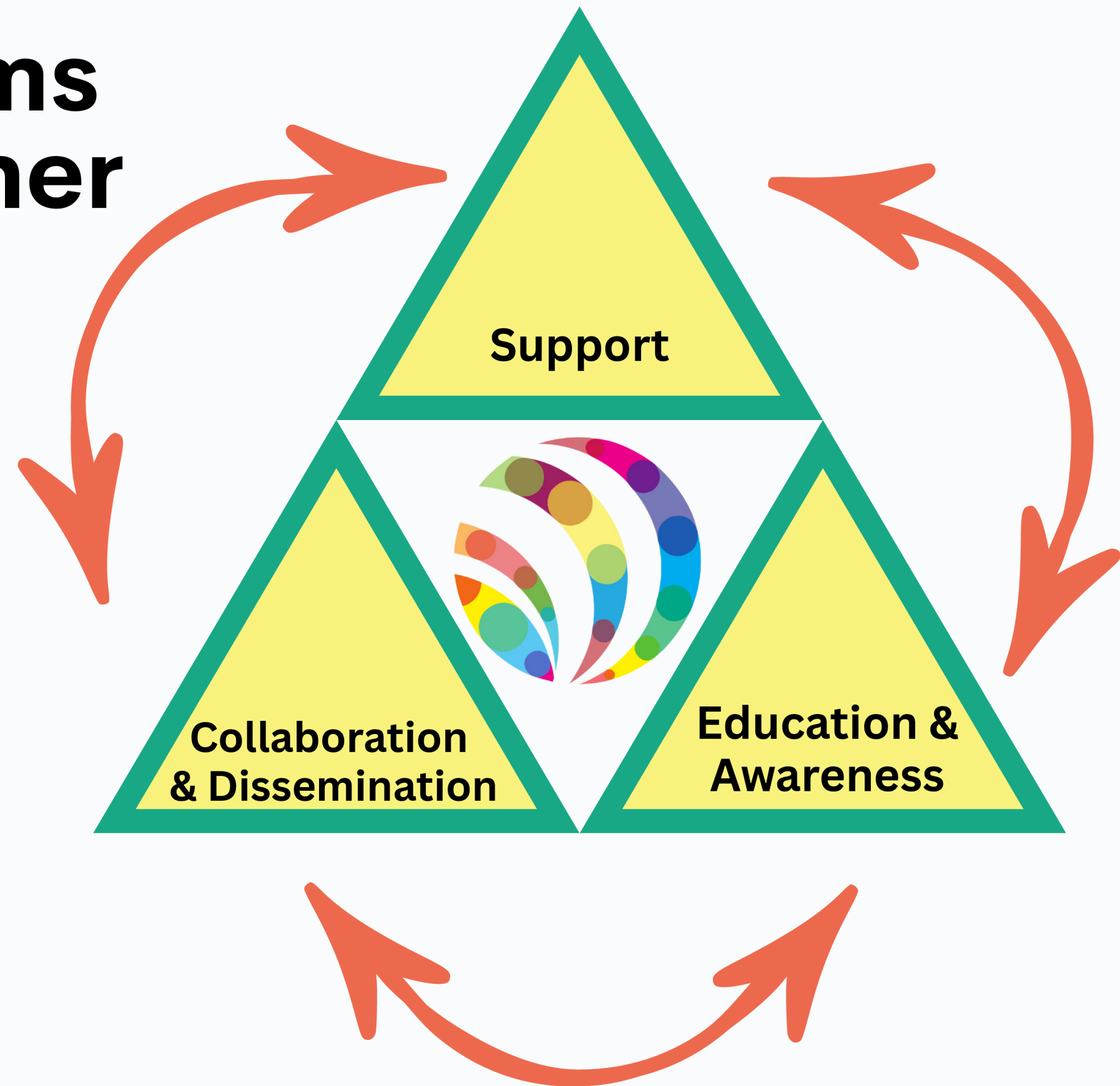
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2. We record data from and assess the needs of individuals & families.





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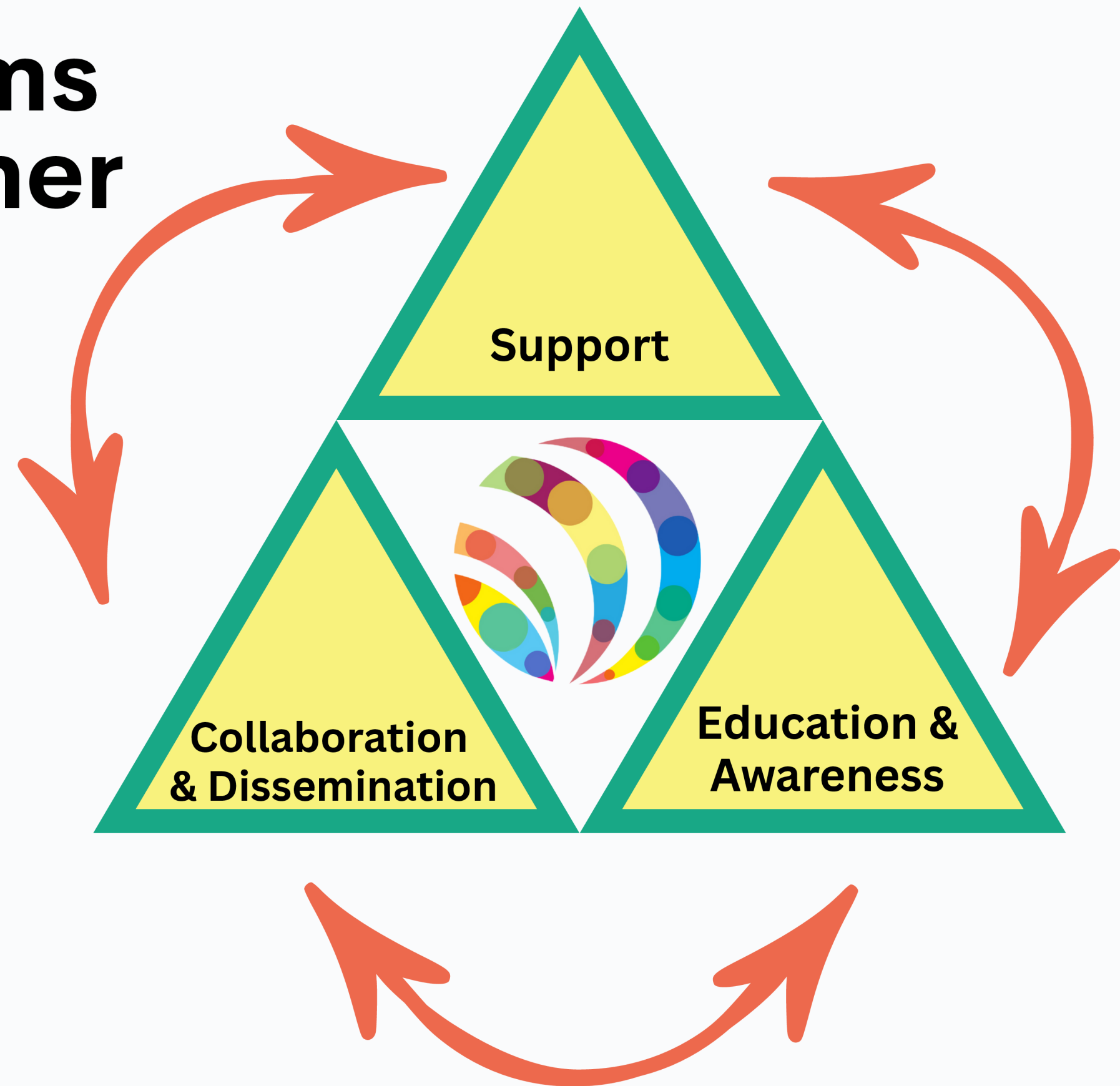
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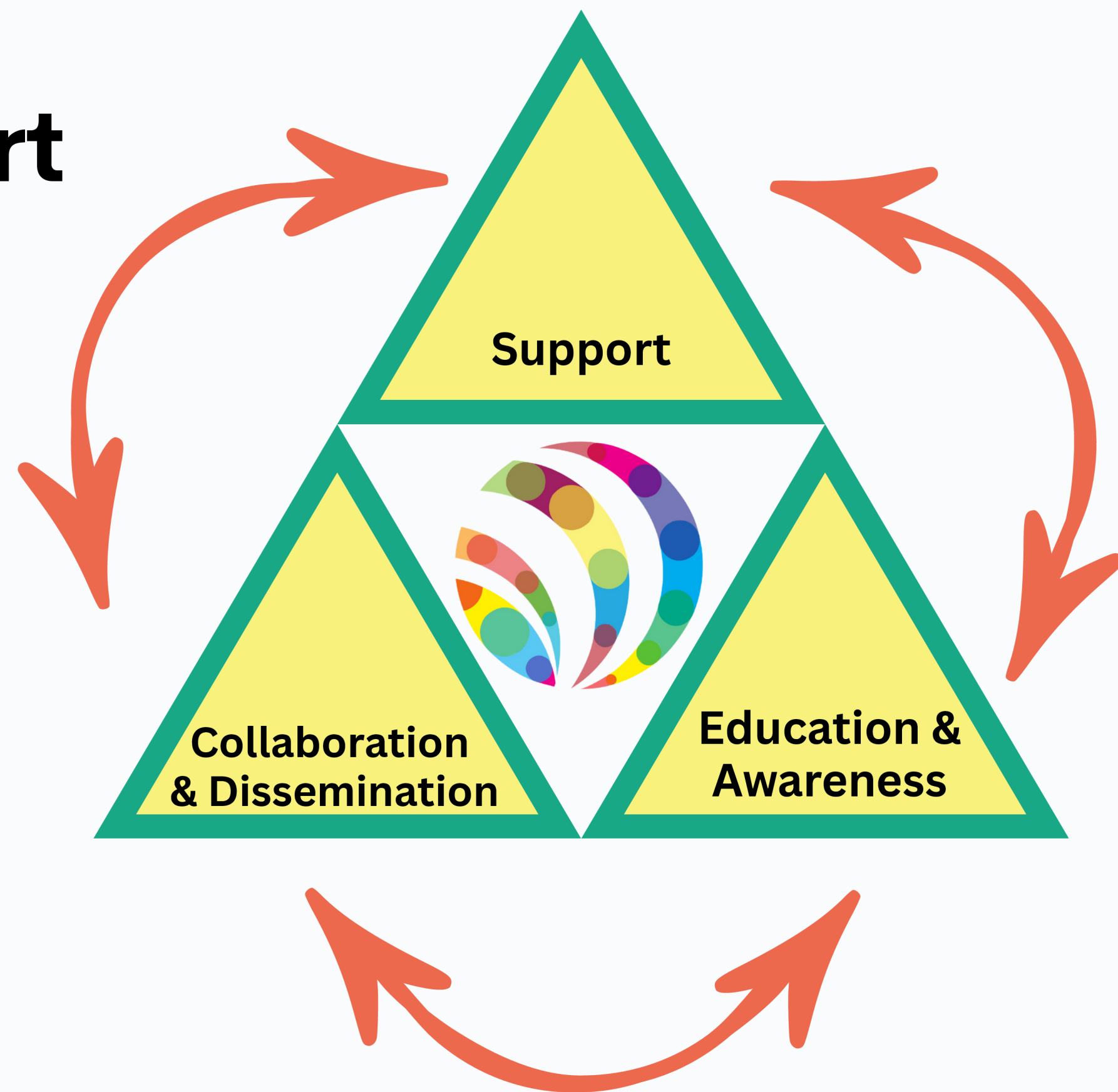
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4. We work with Affiliates/partners to create and disseminate materials.





How our programs support each other

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2. We record data from and assess the needs of individuals & families.
3. We create materials & programming in response to assessed needs.
4. We work with Affiliates/partners to create and disseminate materials.
5. Affiliates/partners refer individuals/families to the Family Navigator.





Family Navigator

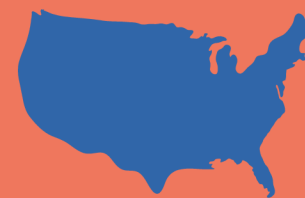


Family Navigator

The Family Navigator program is a zero-barrier national resource where individuals, families, and professionals can call to find local resources. Navigators provide personalized one-on-one peer support, referrals to vetted resources and services, and assistance with medical, educational, and disability benefits.



We answered over **1000 inquiries in 2024**, offering support to more than **800 individuals**.



Over 1200 professionally vetted resources for all 50 states. Customized referrals for each individual and family request.



Heather French
Director of
Navigation &
Resources



Laura Bousquet
Family Navigator



Kristen Eriksen
Family Navigator



Support Resources & Navigation

Current State Departments Project



Kathy White
Resource
Associate



Krystal Starwich
Program Support
Contract



Resource Directory

The Resource Directory staff collected state health department contacts to start advocating for them to house FASD information & resources on their websites.

- Outreach has been completed to 31 states without FASD information on their health websites
- 10% of states responded
- We will turn contacts over to Affiliates.
 - Can you outreach your state and ask them to add information about FASD to their websites? We can share a script.



States to Outreach

Current State Departments Project

Alabama

Arkansas

Colorado

Connecticut

Georgia

Hawaii

Idaho

Illinois

Iowa

Kansas

Louisiana

Maine

Montana

Nebraska

New Hampshire

New Mexico

New York

North Carolina

North Dakota

Oklahoma

South Dakota

Tennessee

Texas

Utah

Vermont

Virginia

West Virginia

Wyoming

If you have capacity to do outreach to your state and would like a script or support, please contact Sarah Brown at Brown@FASDunited.org



Sarah Brown
Director of Program
Services



Policy & Advocacy



Chris Melfi
Policy Coordinator



The **Policy and Training Center** works to achieve public policy outcomes on behalf of individuals living with FASD and to train stakeholders to participate effectively in the pursuit of policy objectives.



Over **130 advocates** trained and supported in reaching their legislators through our Policy Center



Over **120 legislators** or their staff were educated on FASD in the 118th Congress.



Policy & Advocacy



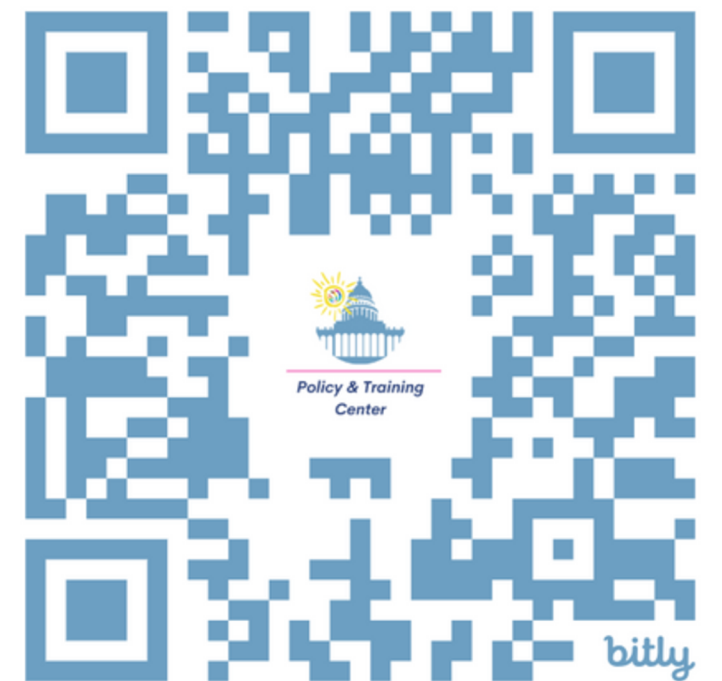
Chris Melfi
Policy Coordinator

[BIT.LY/DROPINADVOCATE25](https://bit.ly/DROPINADVOCATE25)



**DROP IN
& ADVOCATE**
weekly

[BIT.LY/POLICYFORUM25](https://bit.ly/POLICYFORUM25)



**FASD UNITED'S
MONTHLY
POLICY FORUM**



Media & Comms Hub



Andy Kachor
Communications
Director



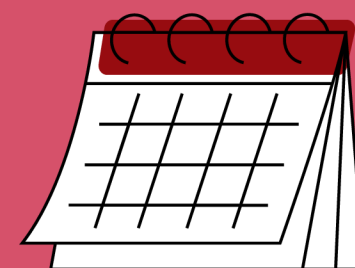
Sophie Sissi
Media Director



Liv Gargiulo
Media Associate



*Media and
Communications Hub*



14 years of continuous content provided weekly through our media center's Weekly Roundup

A hub for resources and information on FASD and the effects of prenatal alcohol exposure, including the Weekly Roundup email newsletter, print and digital educational materials, social media channels, and videos featuring people living with FASD.



Media & Communications Hub

Major Projects and Engagement Opportunities



LANGUAGE AND STIGMA GUIDE



TOOLS FOR EFFECTIVE AND RESPECTFUL COMMUNICATION ABOUT FETAL ALCOHOL SPECTRUM DISORDERS AND PRENATAL ALCOHOL EXPOSURE



[Click here to view.](#)

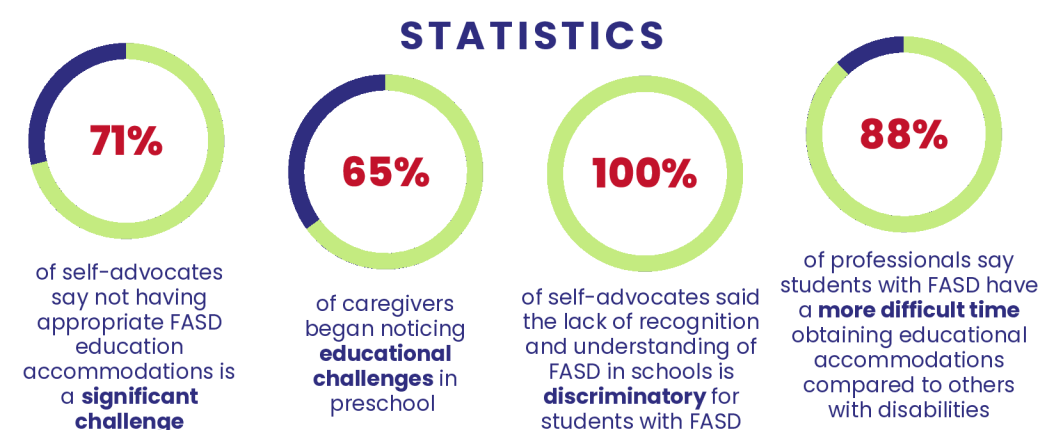
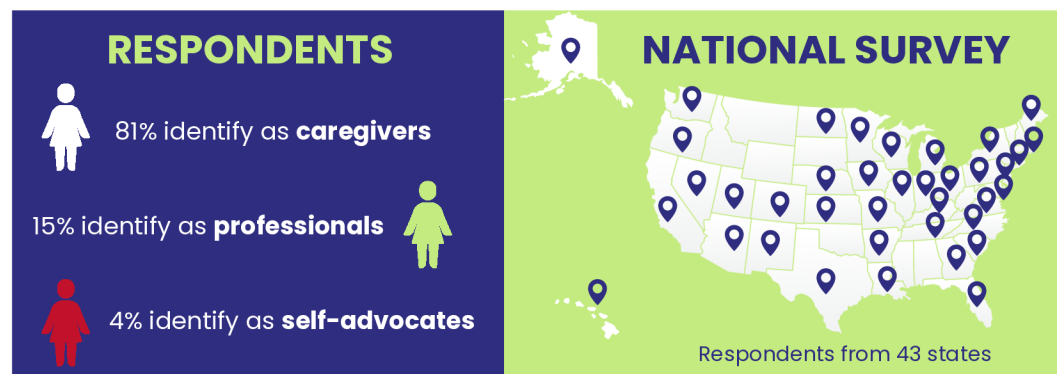
FASD AND SPECIAL EDUCATION SURVEY RESULTS



Fetal alcohol spectrum disorders occur in school aged children at a rate of **1 in 20** That's a child in every classroom.

<https://www.cdc.gov/fasd/data/index.html>

Students with fetal alcohol spectrum disorders (FASDs) often face unique challenges, barriers, and stigma in school and rarely have access to proper accommodations. In order to quantify these challenges, the **FASD and Special Education** Survey focused on educational experiences for students with FASDs. The survey, which was based off a similar survey completed in 2017-18, was active from March 2023 to February 2024. A total of **684** caregivers, professionals, and self-advocates from 43 states responded, sharing strengths, barriers and recommendations.



May PA, Chambers CD, Kalberg WO, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA. 2018;319(5):474-482. doi:10.1001/jama.2017.21896

[Click here to view.](#)

Tracking & Sharing Research

Research Bank: Open to the public and updated weekly.

- [Explore Research](#)
- [Submit Research](#) to be featured in Round-Up and in Research Bank.

Research Opportunities: We post opportunities for individuals and professionals to get involved in FASD/PAE research.

- [Submit research opportunity here.](#)

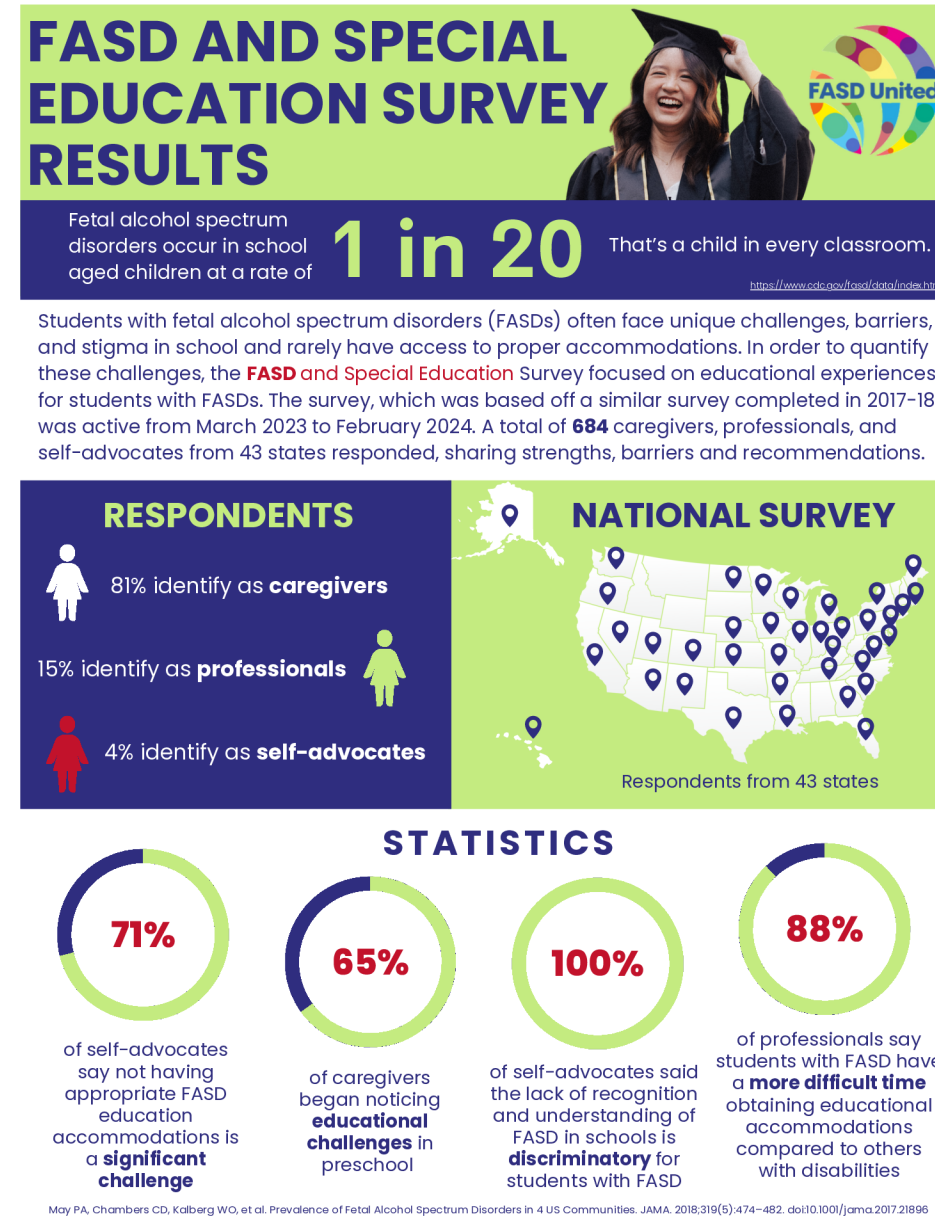


Media & Communications Hub

Major Projects and Engagement Opportunities



- Currently being translated into Spanish.
- Option to join the review committee.
- We may request support from WtC Work Group.



- Currently working with an advisory committee made up primarily of education professionals with a connection to/knowledge of FASD.
- Survey results will be published in 2026.
- *Affiliates needed to support dissemination to agencies, policymakers, etc.*

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Media & Comms Hub

Materials Requests

We can send postcards to you for use at conferences and events.

[Order them here!](#)



Terri Cullen
Admin Assistant



FASD NATIONAL PARTNER NETWORK



Media & Comms Hub

*CDC National Partner
Network FASD Toolkit*

The CDC NPN brings together a variety of professional organizations to

1. reduce prenatal alcohol and other substance use,
2. improve support services and access to care, and
3. improve identification and health of children and families with FASDs.
4. produce media (print & digital) to bring awareness and education about FASD.

[Access Here!](#)



Sarah Brown
Director of Program
Services



FASD Awareness Month



Sarah Brown
Director of Program
Services

Impact Week



Emma Baldwin
Director of
Partnerships

Move FASD
event support



Sophie Sissi
Media Director



Andy Kachor
Communications
Director

Awareness Month Media
media support

Awareness Month Toolkit
*collection of awareness
resources*

Run
Walk
Dance
Relay
Move
FASD
2025 *Join the movement.*





Self-Advocates and Living Experience



Casidee Gonzales
Director of Special
Projects

Glimpses of FASD:

- Short form videos – [Visit the webpage here](#)
- Feature diverse perspectives and people
- Show perspectives of people diagnosed with FASD, specifically to inform research, policy, and professional education.

Living Experience Collaborators: Speaker's Bureau

- Tracked in database, similar to affiliates.
- Communication about PLE opportunities, receive Family Nav information, and event information.
- Easy way to get new people/others involved with FASD United and our collaborators!

Stars for Starla

Celebrating the Strengths & Talents of People with FASD



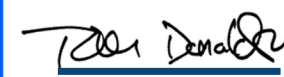
Terri Cullen
Admin Assistant

**WHEN YOU COUNT THE STARS
BEGIN WITH YOURSELF**

THIS IS PRESENTED TO

Brenna

You are a Star: For advocating for the FASD Respect act by meeting with Indiana Senator Braun and reading the speech you prepared about living with FASD.


TOM DONALDSON
President FASD United

 **Stars for Starla**
Celebrating the Strengths & Talents of Youth with FASD

 **FASD United**
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NIFAS

Stars for Starla started as a national awareness campaign, focusing on the strengths and talents of youth with FASD.

Issue an Award [HERE](#).



Starla was a child with FASD (Fetal Alcohol Spectrum Disorder), who during her life, felt that the stigma associated with FASD needed to stop.

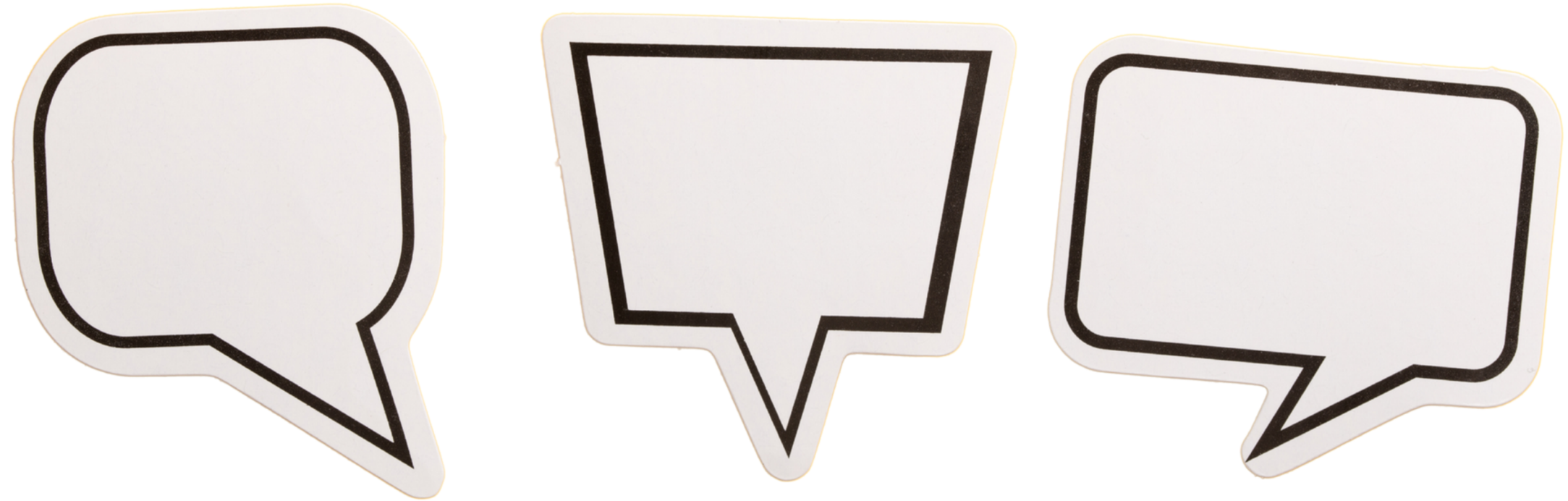
A powerful self advocate, Starla wanted everyone in her community educated about FASD and how best to support people living with it.

Breakout Discussion

Questions:

Are there any FASD United programs/initiatives that you want to lean on for support for your Affiliate?

What kind of programming/support does not currently exist, but would benefit your Affiliate if it existed?





FASD United
Affiliate Network

Q&A

***Please write your question(s) in the chat.**

FASD UNITED STAFF



Kathy Mitchell
Sr. VP of Prevention
& Recovery Services



Sarah Brown
Director of Program
Services



Casidee Gonzales
Director of Special
Projects



Liv Gargiulo
Media Associate



Chris Melfi
Policy Coordinator



Tom Donaldson
President/CEO



Emma Baldwin
Director of
Partnerships



Sophie Sissi
Media Director



Cecelia Cooper
Accountant



Kim Catino
Accounting Assistant



Terri Cullen
Admin Assistant



Jenn Wisdahl
COO



Jo Votolato
Conference
Director



Kathy White
Resource
Associate



Andy Kachor
Communications
Director



**Rouxian (Susan)
Huang**
Research Review Intern



Krystal Starwich
Program Support
Contract



Heather French
Director of
Navigation &
Resources



Laura Bousquet
Family Navigator



Kristen Eriksen
Family Navigator



FASD United
Affiliate Network

CloseOut

More Questions?