

The following is a draft report and has not yet be ratified by the FASD United Board of Directors. Some data is still being updated.



GIVING **FASD** A SEAT AT THE TABLE

2024





Table of Contents

Who is FASD United?	3
What is FASD?	4
What is FASD United's Impact?	5
Get to Know Our Programs and Projects	6
Get to Know Our Team!	7
Look Into Our Strategic Priorities	8
Get to Know Our Network of Supporters	9
Financials	10

About

Vision

Mission

Strategic Priorities

Values

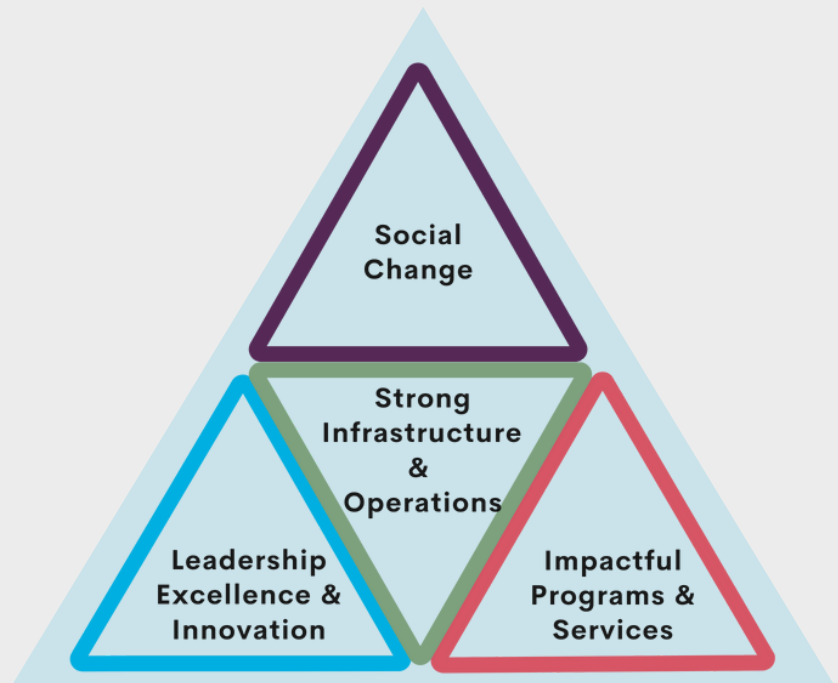
- ✓ Equity
- ✓ Respect
- ✓ Progress
- ✓ Integrity
- ✓ Unity



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

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

All of our work — every program and every project — is intentionally designed to fit this structure and align with these priorities. This is also *how we measure and understand our needs as an organization*.



A Message from FASD United President/CEO, Tom Donaldson



FASD United is grateful for our community and partners and proud of our shared accomplishments in 2024. We look back on a prosperous year of support to families and making progress in the FASD community and field.

Among our top achievements, we backed and organized the emotional return of the International FASD conference. We led advocates in the fight for the Respect Act, steered an Affiliate Network of 50 community-based organizations, and hosted the must-attend FASD Impact Week of leadership, advocacy, science, and fellowship. We published the essential Weekly Roundup and a ground-breaking Stigma & Language Guide to promote a culture that is inclusive of people with FASD. Each day chronicled our cause on social media, including when we set records supporting our community through the Family Navigator program.

What a year!

As for 2025, FASD United celebrates 35 years of meaningful and permanent change to improve outcomes for families and enshrine the voice of FASD at every table. We will continue to reduce prenatal alcohol use and improve support services and access to care as a member of the **Centers for Disease Control and Prevention's National Partner Network**, collaborate with the **Uniformed Services University Center for Health Services Research** in the development of an FASD clinical model—a model that will serve military families and be modified for civilian systems of care—and partner with the **Collaborative Initiative on FASD** to disseminate published research and bring science to practice. Of course, the Navigator, Affiliate Network, and the programs and team you rely on will continue to innovate and be there for you. Make plans to be there with us at the international conference in Seattle, Washington, March 20-23, and September 15-17, in Washington, D.C. for the biggest-ever Impact Week and FASD United's 35th Anniversary Gala.

Thank you for your inspiration and for all you do—see you on the front lines in 2025!

A handwritten signature in black ink that reads "Tom Donaldson". The signature is fluid and cursive, with the first name "Tom" being more prominent.

Tom Donaldson,
FASD United President/CEO

2024 IMPACT



FASD United brought back the international [FASD Research Conference](#) in Seattle, Washington, attracting nearly **600 attendees** from **28 different countries**.



Our [Family Navigators](#) hit a record of supporting over 1,000 calls for resources from individuals and families looking for support.

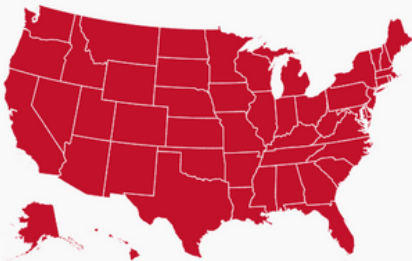


During the 118th Congress, language from the FASD Respect Act was approved by both the Senate HELP Committee and the House Appropriations Committee; this historic progress has paved the way for enactment during the 119th Congress.



Our [Affiliate Network](#) has gained 7 new member organizations, for a total of **48 total** affiliates!

Click on Your State to See More:



The FASD United team collected the data and published [50 State Data](#) sheets on policies statistics in each US state.

We maintained our [Platinum Seal of Transparency](#) through GuideStar by Candid, showcasing our credibility as a national organization.

Platinum
Transparency
2024

Candid.

"Thank you so much!! I feel a little more hopeful even just talking with you and having a some new direction and 'lifelines.'"
-Caregiver who used Family Navigator Services

Give **FASD** a seat at the table.



Fetal Alcohol Spectrum Disorders (FASDs) are a group of diagnosable medical conditions that can occur in a person who was exposed to alcohol before birth. Effects are lifelong and can include mental health conditions, learning disabilities, sensory issues, and physical manifestations such as heart defects, hearing and visual impairments, and more.

FASD affects an estimated 1 in 20 school-aged children. According to the National Institutes of Health (NIH), prenatal alcohol exposure is a leading cause of birth defects in the United States.

(Greenmayer, 2024)

Although prevalent, FASD remains under diagnosed due to:

- social stigma
- complexity of diagnosis
- reliance on facial features
- overlap with many diagnoses, such as ADHD, NAS, Nows and Autism
- generalized lack of diagnostic capacity

FASD belongs in conversations about:



Education



Mental Health



Policy



Child Welfare



Public Health



Justice



Healthcare



Substance Use



Neurodiversity



Pregnancy



Disabilities

Common experiences throughout the lifespan can include:

- Infancy: Birth defects (structural changes present at birth that can affect almost any part or parts of the body), feeding issues, and may be diagnosed as "failure to thrive."
- Childhood: School challenges, developmental delays, behavior issues
- Adolescence: Behavior issues, mental health struggles
- Adulthood: Employment, housing, legal issues

(Centers for Disease Control and Prevention. n.d)

Diagnoses under the FASD umbrella include:

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (pFAS)
- Neurobehavioral disorders associated with prenatal alcohol exposure (ND-PAE)
- Alcohol-related neurodevelopmental disorders (ARND)
- Alcohol-related birth defects (ARBD)
- Static Encephalopathy/Alcohol Exposed (SE/AE)



Who Does FASD affect?

Any individual may face the possibility of their child developing FASD if they consume alcohol during pregnancy. This includes people with substance use disorders (SUDs) and those who drank prior to recognition of pregnancy. Yet, FASD affects us all. Systems, providers, families, and individuals can benefit from access to accurate, FASD-informed information to promote healthy pre- and post-natal outcomes for everyone.

FASDs are lifelong and affect people uniquely throughout their lifespan.

Social Determinants of Health Related to FASD:

- Access to/quality of healthcare & education
- Access to nutritious foods
- Social and community context
- Economic stability
- Neighborhood & built environment

FASD-Informed Systems

People with FASD can thrive and succeed when systems are FASD-informed and FASD is given their seat at the table.

Recognition and accommodation of people with FASD and PAE is crucial. Modifications and shifts in practices and policies will support the complex needs of people with FASD. Key systems include:

- Neurodiversity
- Child Welfare
- Education
- Justice
- Public Health

Gosdin, L. K., Deputy, N. P., Kim, S. Y., Dang, E. P., & Denny, C. H. (2022). Alcohol Consumption and Binge Drinking During Pregnancy Among Adults Aged 18–49 Years — United States, 2018–2020. *MMWR Morb Mortal Wkly Rep*, 71(1), 10–13. DOI: <http://dx.doi.org/10.15585/mmwr.mm7101a2>

Greenmyer JR;Klug MG;Kambeitz C;Popova S;Burd L; "A Multicountry Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults." *Journal of Addiction Medicine*, U.S. National Library of Medicine, pubmed.ncbi.nlm.nih.gov/30383615/. Accessed 1 Mar. 2024.

Tabek Bakir, M. (2023, February 22). The prevalence of fetal alcohol spectrum disorders (fasds). Lompoc Valley Medical Center. Retrieved from <https://www.lompocvmc.com/blogs/2023/february/the-prevalence-of-fetal-alcohol-spectrum-disorder/#:~:text=How%20Common%20Are%20FASDs%3F,babies%20are%20born%20with%20FAS.>

Wozniak, J. R., Riley, E. P., & Charness, M. E. (2019). Clinical presentation, diagnosis, and management of fetal alcohol spectrum disorder. *The Lancet. Neurology*, 18(8), 760–770. [https://doi.org/10.1016/S1474-4422\(19\)30150-4](https://doi.org/10.1016/S1474-4422(19)30150-4)

Centers for Disease Control and Prevention. (2023, October 10). Data & statistics on fasds. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/ncbddd/fasd/data.html#Prevalence-of-FASDs>

Rutman, D. (2016). *Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD*. *Substance Abuse: Research and Treatment*, 10(Suppl 1), 13–20. <https://doi.org/10.4137/SART.S34543>

Centers for Disease Control and Prevention. (n.d.). Birth defects: Facts about birth defects. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/ncbddd/birthdefects/facts.html#:~:text=Birth%20defects%20are%20structural%20changes,vary%20from%20mild%20to%20severe>

FASD UNITED PROGRAMS



Family Navigator

[CLICK HERE](#)

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.



Resource Directory

[CLICK HERE](#)

The Resource Directory offers over 1,200 professionally vetted FASD resources for all 50 states. An interactive map can be found on our website that links to informative pdf documents with state-specific information.



Affiliate Network

[CLICK HERE](#)

The FASD Affiliate Network is a group of 48 autonomous organizations united to further FASD awareness, provide support and improve the quality of life for those affected by prenatal alcohol exposure.



Media and Communications Hub

[CLICK HERE](#)

Our Media and Communications Hub distributes information on FASD and PAE nationally through our websites, Weekly Round-up newsletter, and social media platforms.

FASD UNITED PROGRAMS



*Recovering Mothers
Anonymous*

[CLICK HERE](#)

A 2-step virtual support group offering a peer-mentorship network for people who consumed substances during pregnancy and may have a child with FASD. This group also completes grand rounds presentations in partnership with the American College of Obstetricians.



*Policy & Training
Center*

[CLICK HERE](#)

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. Legislative meetings take place throughout the year.



Justice Center

[CLICK HERE](#)

Our Justice Center addresses issues surrounding FASD and the justice system, including meetings of the FASD Justice Task Force.

FASD UNITED PROGRAMS

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.



Policy WITH PURPOSE **S.1800 & H.R. 3946**

This bi-partisan legislation was authored by Senators Lisa Murkowski (R-Alaska) and Amy Klobuchar (D-Minnesota) and Representatives Don Bacon (R-Nebraska, 2nd) Betty McCollum (D-Minnesota, 4th District). Provisions within the FASD Respect Act focus on educating systems of care, providing funding to state and tribal systems, and improving diagnostic capacity.

During the 118th Congress, language from the FASD Respect Act was approved by both the Senate HELP Committee and the House Appropriations Committee; this historic progress has paved the way for enactment during the 119th Congress. Thanks to advocates from across the country and the stewardship of FASD United, FASD is part of more conversations than ever before.

**Senate
Co-Sponsors**

13

**House
Co-Sponsors**

59

A PASSIONATE TEAM



Tom Donaldson
President / CEO



Kathy Mitchell
Sr. VP of Prevention
& Recovery Services



Jenn Wisdahl
Chief Operating
Officer



**Susan Shepard
Carlson**
Chair



Kathryn Shea,
LCSW
Vice Chair



Andy Kachor
Communications
Director



Musa Kamara
Affiliate Director



**Dr. Elizabeth
Barlet, MD**
Secretary



Michael Hogan,
CPA, CGMA
Treasurer



Heather French
Family Navigator



Sarah Brown
Director of Program
Services



Casidee Gonzales
Director of Special
Projects



**Michael "Keawe"
Anderson**



**Lucas Daniel
Boyce**



Chris Melfi
Policy Coordinator



Sophie Sissi
Media Director



Kristen Eriksen
Family Navigator



**Dr. Christie
Petrenko, PhD**



Christina Rich



Jo Votolato
Conference
Coordinator



Emma Baldwin
Development
Associate



Kathy White
Resource
Associate



**Dr. Omar Abdul-
Rahman**



**Constance
Mazelsky**



Cecelia Cooper
Part-time
Accountant



Laura Bousquet
Family Navigator



Liv Gargulio
Social Media
Associate

AND ENGAGED BOARD

RETURNING TO CONNECTION

203 Participants



CDC Meeting in Atlanta



A virtual 5k event that can happen at your own pace wherever you are.

Conferences!



American University Centers on Disability

Conferences!



American Public Health Association

Conferences!



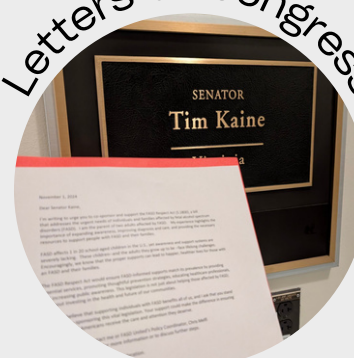
American Public Health Association

We took a seat at the table, educating systems.

Disability Day at the Capitol!



Letters to Congress



Disability Day at the Capitol!



Policy Coordinator, Chris Melfi, hand-delivered letters from advocates across the US to the front door of their representatives' offices!

FASD **IMPACT WEEK**

xx Participants



Participants are experts



FASD SYMPOSIUM

The first **FASD Symposium discussion** among people with living experience, professionals, families, agencies - and *more* - gathered to co-create updated recommendations for progress in the FASD field and community. *White Paper to be published in early 2025.*



162 Guests

Give FASD a seat at the Table



\$2xx,xxx Raised



One memorable night!



At **The Red Shoes Gala**, we honored Dr. Heather Carmichael Olsen with the 2024 Excellence Award, as well as the Honorable Senator Angus King for championing the FASD Respect Act in Maine. Producer & director, Dan Habib, spoke to the value of FASD having a seat at the table in the broader disability community.

109 Participants



90 Legislative Meetings



Inspired by activities from earlier in the week, advocates from across the country visited *all six* Congressional office buildings to urge their legislators to pass the **FASD Respect Act**.

In **partnership with the Uniformed Services University of Health Sciences (USUHS) Center for Health Services Research (CHSR)**, workshops were hosted that focused on FASD in the US military health system.

95 Participants



Interactive Sessions

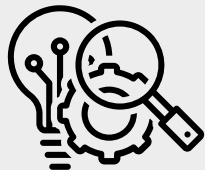


CONTENT You Don't Want to Miss



LANGUAGE AND STIGMA GUIDE

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



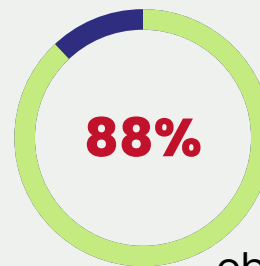
RESEARCH CITATION BANK

FASD UNITED TEAM DOCUMENTED AND CATALOGUED 236 PUBLISHED STUDIES ON FASD IN 137 SEPARATE JOURNALS.



FASD AND SPECIAL EDUCATION SURVEY RESULTS

Students with FASDs 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.



of professionals say students with FASD have a **more difficult time** obtaining educational accommodations compared to other disabilities.

of surveyed self-advocates said the lack of recognition and understanding of FASD in schools is **discriminatory** for students with FASD.





OUR STRATEGIC PLAN

Made collaboratively

Board Members and Staff met to finalize a strategic plan for FASD United. Over the 6 months prior, numerous stakeholders were surveyed and task force meetings were held to discuss the path forward and more importantly, the tangible actions needed to get there. From this work, our new mission, vision and values were developed along with four strategic priorities.

PRIORITIES, GOALS, AND ACTION



We review the plan annually as our organization learns the priorities and trends of the FASD community. This document is the guide stone to mark our path as we navigate a future where we empower people living with FASD and prenatal substance exposure to educate systems of care and the public, enact policies, and unite communities everywhere.

Thank you to everyone who participated, and to Mission Matters Consulting and Coaching Group for leading the conversation.

As we move into 2024 and beyond, we move forward, **United.**

STRATEGIC GOALS



Deliver innovative, robust programs and services based on scientific evidence and the lived experience of people with FASD

In support of this goal we will:

- Disseminate research, evidence-based and culturally appropriate knowledge about public health, clinical management, and all the facts of FASD to drive action.
- Strategically grow support programs, training, and services to respond to the needs of the FASD community, and amplify and accelerate impact.
- Reduce stigma and promote accessibility of services and resources in underserved communities.

Lead, advocate, and promote social change for an FASD-informed world.

In support of this goal we will:

- Be a leader in advocating for and changing legislative governmental, and nongovernmental policies supporting individuals diagnosed with FASD or PAE.
- Build on the strengths of our members, partners, and volunteers to extend the reach of FASD-informed programs, policies, and communications.
- Develop an ongoing, strategic approach to expand engagement and mobilization in seeking, recruiting, engaging, and energizing a supporter base.
- Promote diversity and inclusion and commit to centering the lived experiences and voices of influential people throughout our work.
- Develop public and private partnerships to leverage greater impact.



AND ACTIVITIES

Promote excellence and innovation as a mission-centered organization

Leadership
in Excellence
& Innovation

#3

In support of this goal we will:

- Maintain a culture that represents the organization's core values and promoting shared leadership.
- Continually develop and enhance the organization's practices to attract, support, and retain a diverse, engaged, and talented team.
- Increase diversity and engagement through governance best practices to maximize the board's leadership capacity.

Strong
Infrastructure
& Operations

#4

Strengthen internal capacity to expand mission impact and promote strategic growth.

In support of this goal we will:

- Prioritize revenue generation through strategic fundraising and earned income.
- Invest in robust, coordinated marketing and communications to enhance a recognizable, respected brand image.
- Optimize systems, planning, and internal procedures to improve operations and manage resources.
- Measure and prioritize strategic objectives and programs to maximize our effectiveness and efficiency, increase recognition of FASD, and improve outcomes for the FASD community.

FASD UNITED AFFILIATE NETWORK

FASD United Affiliate Network membership provides members access to:

- FASD United's unique expertise and resources as the national voice on FASD
- State of the field FASD-focused events and activities.
- Cutting edge training and support
- Meaningful networking and community building with professionals and peers in the FASD space.

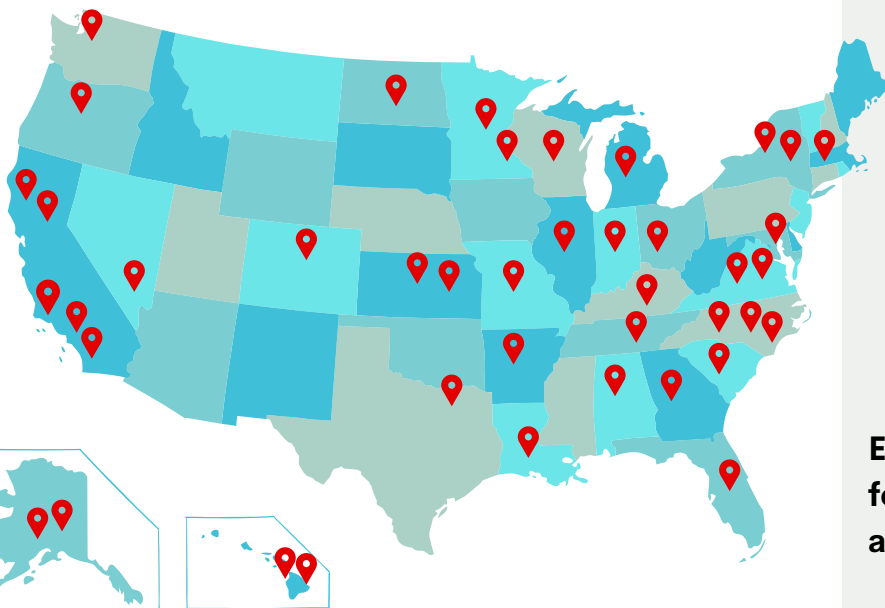


Affiliate status entitles a nonprofit, state agency, tribal organization or university to:

- Affiliate-centered technical and capacity building support tailored to organizations that do work in the FASD space
- Access to Affiliate-only meetings, events, and activities
- Certain kinds of FASD United branding or cobranding opportunities

Engage in discipline and sector-focused as well as local, regional, and national activities to:

- Elevate FASD as a public health and social concern
- Advocate for FASD-informed services and supports for people with FASD and their families
- Educate the public, legislators, and policy makers about FASD and the imperative for systems reform, including professional training about FASD (from the medical and legal fields to social work and education).



FASD United Affiliates are an autonomous group of organizations encompassing a wide array of disciplines, focuses and goals. They connect on the need for FASD supports, services, and prevention.



FIND AN AFFILIATE NEAR YOU



Alabama

FASD Alabama

Alaska

Alaska Center for FASD

Arkansas

Arkansas None for Nine

California

Center for Better Beginnings
FASD Network of Southern California
FASD Nor Cal
FASD Network of Northern California
Healthy Native Nation

Colorado

Illuminate Colorado

Delaware

Delaware FASD Alliance

Florida

The Florida Center for Early Childhood

Georgia

Emory MSACD

Hawaii

FASD Communities
Hawaii Fetal Alcohol Spectrum Disorders FASD Action Group

Illinois

The Center for Neurobehavioral Guidance

Indiana

Indiana Alliance on Prenatal Substance Exposure

Kansas

Dream Acres, Inc
Kansas FASD Support Network, Inc

Kentucky

The Papillion Center

Louisiana

LSUHSC Human Development Center

Massachusetts

Institute for Health and Recovery, Inc.

Scotland

Oshay's Brain Domain

Michigan

FASD Collaborative Project
MCFARES

Minnesota

Families Rising
Proof Alliance
Southwestern Mental Health Center

Missouri

St. Louis Arc

Nevada

Nevada Families for FASD Awareness

New York

DePaul's NCADD-RA
Justice For Orphans

North Carolina

Creating a Family
Proof Alliance NC
NCFASD Informed, Inc.

North Dakota

FASD - North Dakota

Ohio

Ohio Guidestone Center for FASD

Oregon

FASCETS Inc.

South Carolina

SC Department of Alcohol and Other Drug Abuse Services

South Dakota

University of South Dakota Center for Disabilities

Tennessee

Papillion Center for FASD-TN

Texas

Texas FASD Network

Virginia

Formed Families Forward
University of Virginia Children's Hospital

Washington

FASD Focus NW

Wisconsin

Orchids FASD Services of Wisconsin

Purposeful Fiscal Governance

Statement of functional Expenses YE 12.31.24 UNAUDITED

Expenses	Program Services	Fundraising & Deveopment	Management & General	Total
Salaries & Benefits	935,574.00	89,394.00	83,730.00	1,108,698.00
Subcontractors, consultants & honoraria	129,918.00	6,000.00	12,583.00	148,501.00
Travel	37,953.00	2,643.00	987.00	41,583.00
Materials	46,421.00	9,078.00	6,314.00	61,813.00
Other program related costs	365,404.00	37,682.00	11,310.00	414,396.00
Office Overhead(Rent, phone, supplies)	79,536.00	10,250.00	6,937.00	96,723.00
Total Expense	1,594,806.00	155,047.00	121,861.00	1,871,714.00

Statement of Financial Position as of 12.31.24 UNAUDITED

Current Assets

Cash & Equivalents	85,227.00
Accounts Receivable	269,410.00
Undeposited funds	5,021.00
Prepaid Expense	43,320.00
Total Current Assets	402,978.00

Lease & Improvements net of Amortization	112,952.00
Security Deposit	4,176.00

Total Assets	520,106.00
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Current Liabilities

Accounts Payable	83,060.00
Accrued Expenses	76,584.00
Deferred Revenue	8,550.00
Total Current Liabilities	168,194.00

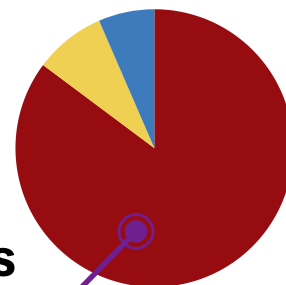
Long Term Liabilities

Long Term Lease	111,891.00
Deferred Rent	11,044.00

Net Assets-unrestricted	446,089.00
Net Income	(217,112.00)
Total Net Assets	228,977.00

Total Liabilities & Net Assets	520,106.00
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- Program Expenses
- Fundraising & Developme...
- General



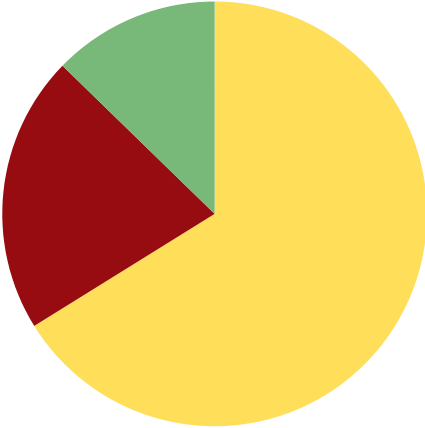
Expenses

85¢ per \$1

used for FASD United Program Expenses

Revenue

- Grant Revenue
- Events Revenue
- Donations



Statement of Activities YE 12.31.24 UNAUDITED

<u>Revenue</u>	
Grants	1,084,070.00
Donations	208,351.00
Events	346,278.00
Other	15,903.00
TOTAL REVENUE	1,654,602.00
<u>Expense</u>	
Salaries & Benefits	1,108,698.00
Subcontractors, consultants & honoraria	148,501.00
Travel	41,583.00
Materials	61,813.00
Other program related costs	414,396.00
Office Overhead(Rent, phone, supplies)	96,723.00
TOTAL EXPENSE	1,871,714.00
NET INCOME (LOSS)	(217,112.00)



**1054 31st Street NW, #204,
Washington, DC 20007**

Office Hours:

9am-5pm Eastern Weekdays

202-785-4585

Information@FASDUnited.org

Family Navigator Hours:

9am-10pm Eastern Weekdays

800-666-6327



**SCAN FOR MORE
INFORMATION**

FASD United is a 501(c)3 non-profit organization, and can accept tax-deductible contributions from your personal, corporate, or foundation accounts (Federal Tax Identification Number: 46-0412365).