



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

**August 2024
Policy Forum**

Wednesday
August 28th 2024

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FASD United

THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS

Organization Update

affiliate update



FASD United
Affiliate Network



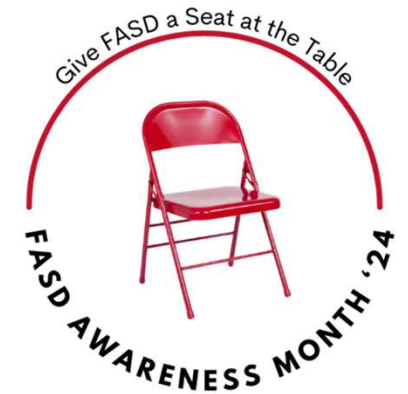
9TH INTERNATIONAL RESEARCH CONFERENCE ON

FETAL ALCOHOL SPECTRUM DISORDERS

MARCH 20 - 23, 2025
HYATT REGENCY, SEATTLE, WA

Call for Abstracts:
Now Open!

FASD
AWARENESS
Month
RESOURCES



Website Available

<https://fasdunited.org/fasd-awareness-month-2024/>

September is FASD Awareness Month

Create a Press Release

Customize/Copy this Press Release template and submit it to your local paper.

Our hope is that letters like this encourage members of your community to raise awareness about FASD in September.

You can even add specific events taking place around the community to the letter.



FOR IMMEDIATE RELEASE
September 9, 2024 \

Contact: (name of person submitting)
(phone) – or – (email)

(your city, your state) – (your organization) is joining the cause to celebrate September as FASD Awareness month and to increase awareness and support for people with Fetal Alcohol Spectrum Disorders (FASDs). FASD is a spectrum disorder describing the range of effects that can occur in an individual who was exposed to alcohol before birth.

Prenatal alcohol exposure is associated with an increased risk of miscarriage, stillbirth, prematurity, sudden infant death syndrome (SIDS), and a range of lifelong physical, behavioral, and intellectual disabilities. FASDs can impact physical, mental, behavioral, or cognitive development as well as cause growth deficiencies, central nervous system disabilities, and, in only about 10% of people diagnosed, specific facial characteristics. Studies show that up to 1 in 20 U.S. school children may be on the FASD spectrum, a rate more than double that of autism.

Unfortunately, FASD is under-recognized, with supports and services not widely available and far too few diagnostic and treatment services currently available. In addition to public health messaging on the importance of avoiding alcohol while pregnant, it is crucial to bring recognition and awareness of children and adults with FASDs and their need for services and support.

Individuals with FASDs benefit from structure, support, understanding, and most importantly, early diagnosis, early intervention, and FASD-informed medical and mental health care. Recognizing the strengths, talents, and gifts that individuals diagnosed with FASD bring to our communities is a great way to celebrate FASD Awareness Month.

Human service organizations, health care professionals, educators, and the public are called to action to work together to support the FASD community by increasing awareness, becoming educated, and supporting broader efforts to bring FASD-informed services, interventions, and supports to those with this disability. For more information on FASD or alcohol use during pregnancy, visit www.fasdundited.org or www.cdc.gov/fasd.

Sample Social Media Posts

For an Individual



- September marks the 51st FASD Awareness Month in the #US, join me in giving FASD a seat at the table and advocating for increased education and supports for those living with this common disability. #1in20

For an Organization

- The FASD community is stronger together, which is why (organization name) is shining a light onto those living with this prevalent disability during FASD Awareness Month 2024.



09.16-18.2024

FASD IMPACT WEEK

You're Invited
to the Table!

**Registration
Open Now!**

**9.16: FASD
Symposium**

**9.16 Eve: Red
Shoes Gala**

9.17: Hill Day

9.18: Partners Day

FASDUnited.org/fasd-impact-week-2024



Join us
September 17th
at 7 pm EST
for a virtual pre-
release showing
of *The Ride
Ahead!*

Open
Captioning and
Audio-Visual
Description will
be provided.



IN PERSON
IMPACT WEEK

VIRTUAL
OVER ZOOM





Running from September 6th to 16th



<https://runfasd.org/>

Join an **in-person event** or get moving on your own!

- 9/2: Norfolk, VA
- 9/7: Voorheesville, NY (Run with Coach Rebecca!)
- 9/8: Minneapolis, MN
- 9/8: Rochester, NY

FASD Respect Act 2.0

Bill Contents

- Education, Awareness and Services across community agencies
- Building State and Tribal Systems
- Centers for Excellence

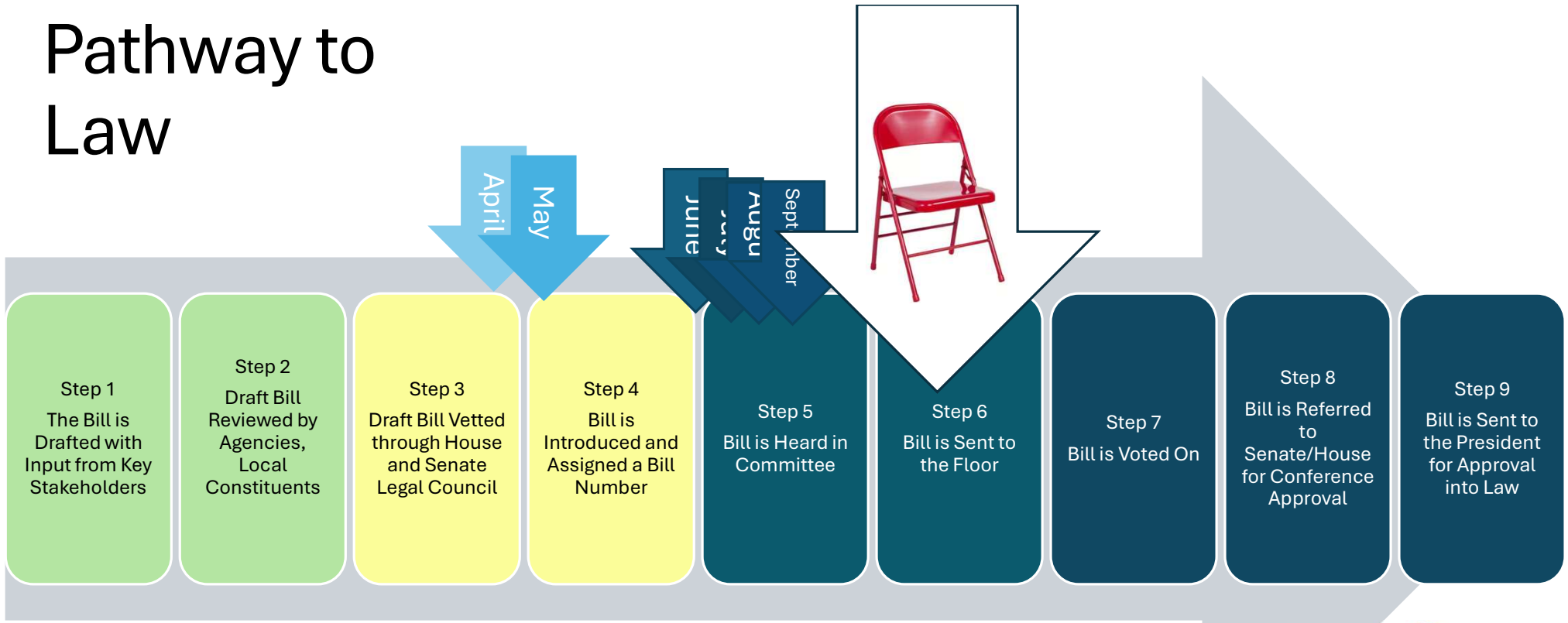


The FASD Respect Act

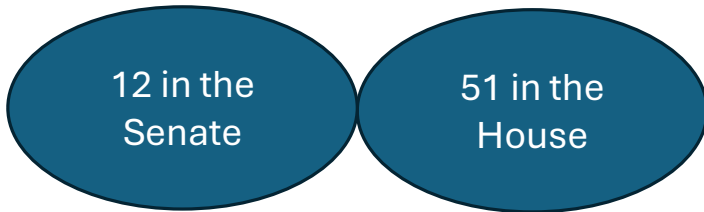
Building the Foundation for Change

#FASDRESPECT

Pathway to Law



Cosponsors



What Happened in August



Meetings

- Rep. Anna Eshoo (D-CA)
- Rep. Vicente Gonzalez (D-TX)
- National Conference of State Legislatures

Endorsements

- American Psychiatric Association
- FASCETS Center for Neurodiversity
- SCFASD Collaborative
- Numerous medical professionals from Texas

Disability News

- NCD Report on exclusionary practices preventing people with disabilities from participating in clinical trials
- Spotlight on developmental disability



National Conference of State Legislatures

- Over **5000 lawmakers and staff** in attendance
- **Most requested handouts:** Affiliate Network and Fact Sheet for Educators
- **Most asked question:** “How are you addressing FASD in your state?”
- **States and Countries with most in-depth interactions:** Arkansas, Alabama, Maryland, New York, Pennsylvania, South Carolina, Alaska, Georgia, Texas, Ohio, Wisconsin, Florida, Kentucky, Virginia, New Jersey, Washington, Arizona, Tennessee, Utah, North Carolina, Massachusetts, New Hampshire, Canada, Germany, India, Australia, Nigeria



Virtual Hill Day- October 2024

- A chance for the entire community to connect with their lawmakers
- Can serve as follow-up for those who attended Hill Day
- Final announcement at September Policy Forum





Hill Day
Preview





Policy & Training Center

FASD Respect Act Agenda

9 AM: Hill Day Kickoff

- Meet in the Hotel Conference Room to pick up leave-behind materials, receive any last-minute schedule updates, and to be inspired by our amazing advocates!

10 AM- 5:00 PM: Individual Meetings

- Head to the Hill for your scheduled meetings (see master schedule and your individual schedule for details)

What to Wear

Business casual, Hill Day shirts (black), and comfortable shoes!

Getting Around

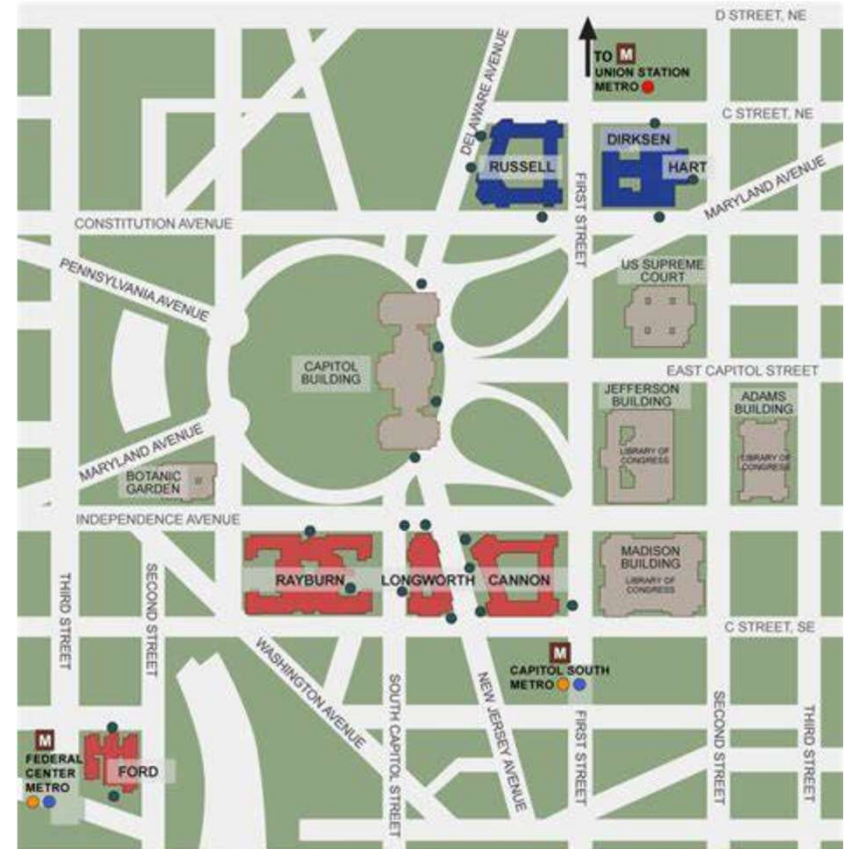
Uber/Lyft: Use the name of the Office Building as drop off address (~20 minutes)

Metro: Silver, Orange, or Blue line from Foggy Bottom to Capitol South (~40 minutes)

Need Help?

Call Chris Melfi at (202) 785-4585 or text him at (315) 450-6525

Capitol Hill Map



- House office building (Rayburn, Longworth, Cannon, Ford)
- Senate office building (Russell, Dirksen, Hart)
- Building entrances
- M Metro station
- Red line ● Blue line ● Orange line

FASD Respect Act

Talking Points



Policy & Training
Center

FASD

- Fetal alcohol spectrum disorders (FASD) are a group of conditions that can occur in a person who was exposed to alcohol before birth. The effects can include mental health and learning disabilities, heart defects, hearing impairments, and more.

Prevalence

- FASD is very common: **1 in 20 Americans has an FASD.**
- Fetal alcohol syndrome (FAS) is just one diagnosis within the FASD spectrum and accounts for only 10% of those with an FASD. Those without distinctive facial features are equally impacted, but less recognized and less likely to receive appropriate supports.
- FASD is both underdiagnosed and misdiagnosed.

Pregnancy and Alcohol

- CDC data shows that **1 in 7 pregnant people report drinking**, while 1 in 20 report binge drinking. There is no known safe amount of alcohol during pregnancy.

Costs Associated with FASD

- On average, FASD costs \$30,000 per year per person.
- **Investing in FASD-informed services and supports** can lead to positive, healthy outcomes while limiting the financial impact of FASD.



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FASD Respect Act

Talking Points

FASD Respect Act (S.1800/HR.3946)

- Reauthorizes FASD programs for education, public awareness, research, and building state and tribal capacity for identification, treatment, and support
- Establishes FASD Centers for Excellence to **build capacity to prevent prenatal alcohol exposure and to respond to the needs of individuals with FASD and their families.**
 - Assists states in addressing FASD inequities within their silos of care. Provides assistance to states with evidence-based programs so they can be duplicated.
- Federal funding for FASD has declined significantly since its original authorization in 1998 (see FASD Program Authorization and Funding for more)
- Broad, bipartisan support
 - 12 cosponsors in Senate, 51 cosponsors in House
 - Included in the Senate's Support Act by HELP Committee Ranking Member Cassidy (R-La), which made it through HELP Committee.

The Ask for Legislators

**Cosponsor S.1800/HR.3946,
the FASD Respect Act**

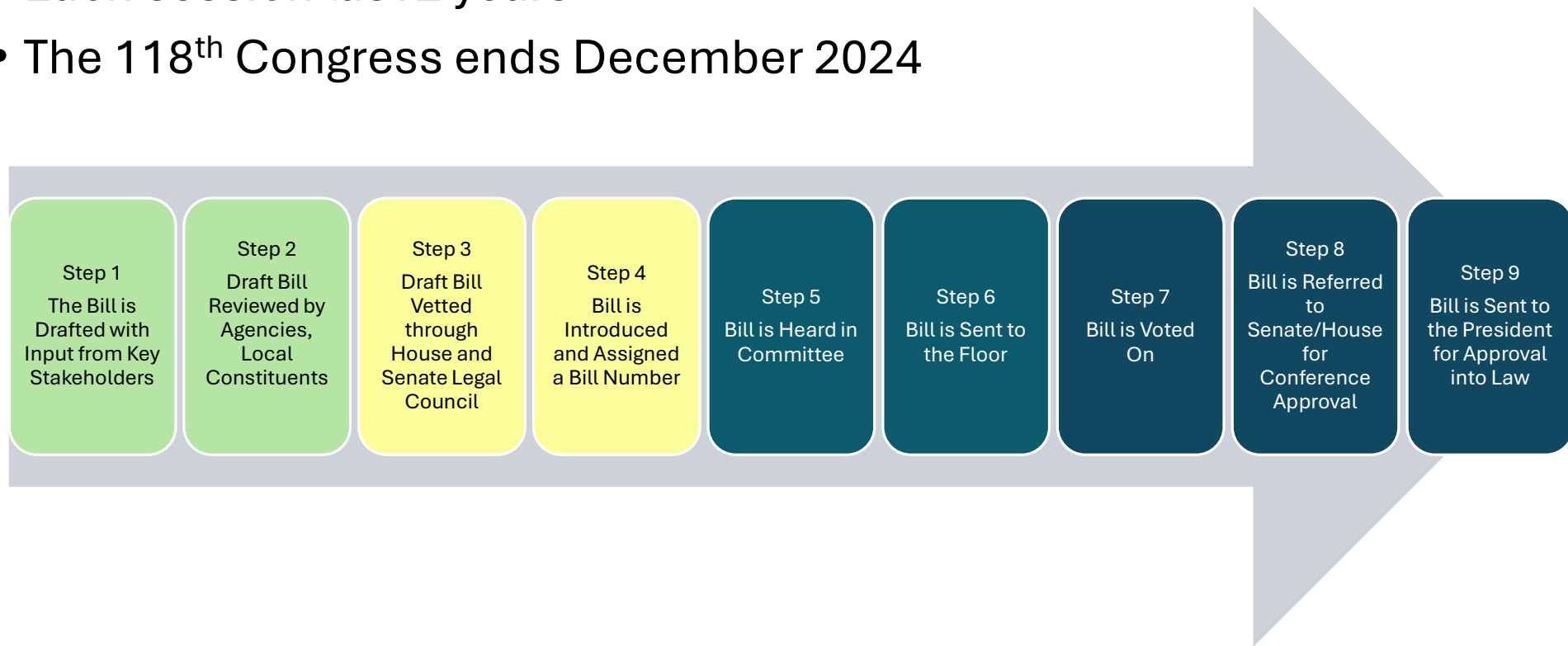
Leave Behind Materials



- FASD Respect Act State Sheets
- FASD Respect Act 1 pager
- Brief Background and Rationale
- Comparison of 117th Bill and 118th Bill
- History of Program Authorizations and Funding
- FASD Prevention and Clinical Guidelines Research Workshop Reports (upon request)

118th Congress

- Each session last 2 years
- The 118th Congress ends December 2024



State Data Sheets

How is FASD Recognized in Washington?

FASD stands for fetal alcohol spectrum disorders, a range of disabilities caused by prenatal alcohol exposure (PAE). As many as 1 in 20 children in the United States have an FASD. To learn more, visit FASDUnited.org



FASD is not recognized by the State Department of Health.

Information about FASD is not available on the Washington State Department of Health website.



The state does not include FASD in its definition of Developmental Disability.



People with FASD may qualify for waiver services through the State.

Although FASD is not a named condition, a person with FASD may still qualify. There is an IQ cutoff for waiver services, and individuals have to be diagnosed prior to age 18.



FASD is not recognized by the state for Special Education services.

FASD is not listed as a condition to qualify for Special Education.



The state tracks rates of alcohol-exposed pregnancies.

Questions about prenatal alcohol use are asked in the state's PRAMS survey.

- How can we use this information?
- Who should we share this with?
- How will this information evolve?

How Are Alcohol-Free Pregnancies Supported in the State of Washington?



The state requires a warning sign for alcohol sales.

Warning signs about the risks associated with prenatal alcohol exposure are required for alcohol sales.

CR: Wash. Admin. Code § 314-11-060



16% of people binge drink.

Binge drinking is especially risky, whether or not someone is pregnant. Reducing alcohol use can improve health outcomes.



48% of pregnancies are unintended.

Prenatal alcohol exposure can happen before pregnancy is confirmed. When pregnancy is unintended, this may take at least 4-6 weeks, and many people continue drinking during this time.



13.5% of pregnancies are exposed to alcohol.

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.

Sources:

- May, PA, Chambers, CD, Kalberg, WO, Zeltner, J, Feldman, H, Buckley, D, et al. (2018) Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA*. 319(5):424-432
- Goodlin JK, Deputy NP, Kim SY, Dang EP, Denny CH. Alcohol Consumption and Binge Drinking During Pregnancy Among Adults Aged 18-49 Years — United States, 2018-2020. *MMWR Morbidity and Mortality Weekly Report*. 2022;71(10):13.
- Alcohol Policy Information System. (2023) Warning Signs: Drinking During Pregnancy. <https://alcoholpolicy.nmasa.nh.gov/apis-policy-topics/warning-signs-drinking-during-pregnancy/24>
- Centers for Disease Control. (2024). BRFSS Prevalence & Trends Data. <https://www.cdc.gov/brfss/data-reports/>
- Guttmacher Institute. (2016). State Facts About Unintended Pregnancy: Washington. https://www.guttmacher.org/sites/default/files/factsheet/wa_17.pdf

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Local Resource on FASD:

