Give FASD a seat at the table.

March 2024
Policy Forum

Wednesday
March 27th, 2024

Program Contact: Jenn Wisdahl
wisdahl@FASDUnited.org
202-601-2530
Chris Melfi
Melfi@fasdunited.org
Organization Update
9th International Research Conference on Adolescents and Adults with Fetal Alcohol Spectrum Disorders

Review, Respond and Relate
Integrating Research, Policy and Practice Around the World

Registration is NOW OPEN!
April 11-14, 2024
FASD Respect Act 2.0

Bill Contents
- Education, Awareness and Services across community agencies
- Building State and Tribal Systems
- Centers for Excellence
Pathway to Law

Step 1
The Bill is Drafted with Input from Key Stakeholders

Step 2
Draft Bill Reviewed by Agencies, Local Constituents

Step 3
Draft Bill Vetted through House and Senate Legal Council

Step 4
Bill is Introduced and Assigned a Bill Number

Step 5
Bill is Heard in Committee

Step 6
Bill is Sent to the Floor

Step 7
Bill is Voted On

Step 8
Bill is Referred to Senate/House for Conference Approval

Step 9
Bill is Sent to the President for Approval into Law

The 118th Congress Lasts for 2 years.
The 118th ends in December 2024.
Updates

• Appropriations
  • FY2024
  • FY2025
  • HHS
  • DOD
  • Agriculture???
What Happened in March

Meetings

- Rep. Don Beyer (D-VA-8)
- Rep. Marc Molinaro (R-NY-19)
- Rep. Debbie Dingell (D-MI-6)
- Rep. Beth Van Duyn (R-TX-24)
- Rep. Betty McCollum (D-MN-4)
- Rep. Don Bacon (R-NE-2)
- Rep. Henry Cuellar (D-TX-28)
- Rep. Jake Auchincloss (D-MA-4)
- Rep. Katherine Clark (D-MA-5)
- Sen. Joe Manchin (D-WV)
- Sen. Shelley Moore Capito (R-WV)
- Sen. Lisa Murkowski (R-AK)
- Sen. Amy Klobuchar (D-MN)
- Sen. Jerry Moran (R-KS)

New Co-Sponsors


49 in the House

11 in the Senate
What do we do now?

- **Continue.** Keep asking for Co-Sponsors for The FASD Respect Act
- Get Endorsements – Thanks AUCD!!
- Be active in your state.
Capitol Hill Developmental Disabilities Resource Fair


Research Presentations on:
• Environmental Approaches to Prevent Alcohol Problems
• Prevention of Alcohol Misuse Among Cherokee Nation Youths
• Motivations for Alcohol Protective Behavioral Strategies Use
Resources

• Sample legislation for a State FASD Advisory Committee

• Template for a Governor’s Executive Order creating a State FASD Advisory Committee
Guidance

• This is not a solo opportunity – check in and involve others in your state.

• Templates need to be customized to your state with data specific to your state.

• Let FASD United know you are working on this so we can connect other interested parties to help.

• Start now. Do not wait for the FASD Respect Act to pass to start the work.
Email us if you want:

- Contact info for people working on state-level policy
- To be listed as a contact within your state

Program Contact: Melfi@fasdunited.org
www.nofaspolicycenter.org/state-policy-templates
State Information Sheets

**How is FASD Recognized in the State of Alaska?**

- **FASD is recognized by the State Department of Health**
  Information is available on the state department of health website and the state has an FASD specific program.

- **The state includes FASD in its definition of Developmental Disability**
  Alaska Stat. § 47.80.000

- **People with FASD can qualify for waiver services without additional diagnosis.**
  Although FASD is not a named condition, a person with FASD could still qualify. There is no IQ cut off for waiver services and they would have to be diagnosed prior to age 22.

- **FASD is recognized by the state under IDEA for Special Education**
  FASD is listed as a named condition under OHI and the state has an online training program.

- **The state requires a warning sign for alcohol sales**
  Warning signs are required for both onsite and offsite alcohol sales.

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**This information has not been verified through the State of Alaska**
FETAL ALCOHOL SPECTRUM DISORDERS

IN WASHINGTON

Why The FASD Respect Act Needs Your Support

Fetal Alcohol Spectrum Disorders (FASD) are lifelong physical, developmental, behavioral, and intellectual disabilities caused by prenatal alcohol exposure.

According to the CDC, FASD impacts as many as 1 in 20 in the US — 2.5x more than autism.

Of the over 84,890 babies born annually in Washington, almost 4240 are estimated to have a FASD, far in excess of current diagnostic capacity.

Roughly 85% of children seen in diagnostic clinics are either adoptees or are in foster care, children living with their biological parents lack access to diagnosis due to stigma and untrained medical staff.

Most people with FASD won’t qualify for disability services, even with a diagnosis.

Over 90% of individuals with FASD will develop co-morbid mental health conditions.

High rates of older youth and adults with FASD struggle with independent living and employment.

Individuals with FASD, with or without a diagnosis, face high rates of incarceration and recidivism.

Even at lower prevalence rates, the estimated average annual cost to Washington for FASD is over $4,711 billion in health care, special education, residential care, productivity losses and corrections costs.

Raising a child with FASD costs 30X more than the cost of successful prevention efforts.

Of the 1.09 Million students in Washington schools, as many as 54,700 may have FASD, yet far fewer are diagnosed.

FASD is not tracked in special education under IDEA, and most schools lack training and supports for students with FASD.

Without appropriate diagnosis and support, students with FASD face higher than average school exclusion rates.

An estimated 380,700 of the 7.6 Million people living in Washington could be impacted by FASD.

For more information go to www.nofaspolicycenter.org
Making sense of the numbers on the economic cost of FASD

- Data on the economic burden of FASD are scarce

- Existing estimates likely underestimate the full economic impact of this disorder on the affected individuals, their caregivers, and society.

- Many costs are not easily identified because (1) the Federal programs that support FAS research and services are administered under the auspices of several departments of the Federal Government and (2) children with FAS often are not distinguished from other program recipients.

- However, the current research is sufficient to demonstrate that FASD is a serious public health problem associated with tremendous economic burden.
Economic costs of FASD- Center for Disease Control*

Cost of FASDs*
*The lifetime cost of care for one individual with FAS in 2002 was estimated to be $2 million. This is an average for people with FAS and does not include data on people with other FASDs. People with certain disabilities, such as profound intellectual disability, have much higher costs. It is estimated that the cost to the United States for FAS alone is over $4 billion annually.*

✓ **Does not include** the cost for loss of productivity, the cost of special education or expected additional costs for juvenile or criminal justice, substance abuse treatment, mental health care, or vocational services.

✓ Dollar costs reported are expected to be underestimates of the true costs.

✓ All of the estimated dollars are based on FAS alone

✓ "Old data" – from the late Dr. Sally Anderson

Results: Thirty-two studies from 4 countries met the inclusion criteria (United States [n = 20], Canada [n = 9], Sweden [n = 2], and New Zealand [n = 1]).

Studies were NOT included if they did not include costs for FASD

Included health care, special education, residential care, criminal justice system, productivity losses due to morbidity and premature mortality, productivity losses of caregivers of children with FASD, and intangible costs.

Not included: corrections and intangible (due to unavailability)

US cost studies (4) – $68,151

Estimates vary considerably due to the different methodologies used by different studies

The mean annual cost for children with FASD was estimated to be $22,810 and for adults $24,308.

Date of published review: November/December 2018
Date range of studies: 1980 – 2013
Based on 20 studies
CALCULATING THE TOTAL ECONOMIC FASD COST

1) U.S. population* 335,893,238
2) Prevalence** 6,717,865
   (2% - average from May, et. al prevalence study)
3) Times per person costs*** 23,804
   with corrections **** 31,000

TOTAL (with corrections) $160B $208B

*US Census, January 2024
**2% - average from May, et. al. prevalence study from JAMA 2018
***Multi-country Updated Assessment of the Economic Impact of Fetal Alcohol Spectrum Disorder: Costs for Children and Adults – Greenmyer, Klug, Kambeltz, Popova, and Burd, November-December 2018 - converted to May 2017 currency values using online inflation calculators.
State Proclamation Project

Give FASD a seat at the table by submitting Proclamation requests in all 50 states.

• What’s the purpose of Ceremonial Proclamations?

• What can state advocates do?

• How can FASD United help?

www.nofaspolicycenter.org/how-to-issue-an-fasd-awareness-month-proclamation/
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