



FASD United

Policy & Training Center

April 2023 Policy Forum

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FASD United
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS
Formerly NOFAS



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Organization Update

Advocacy Week

SEPTEMBER 18-21, 2023
WASHINGTON, DC

Monday

Tuesday

Wednesday

Thursday

← Affiliate Summit →

National
Research
Briefing

National
Research
Briefing

Hill Day

The Red
Shoes
Gala

Hill Day



affiliate update



FASD United
Affiliate Network

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FASD Respect Act 2.0

Bill Contents

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



The FASD Respect Act

Building the Foundation for Change

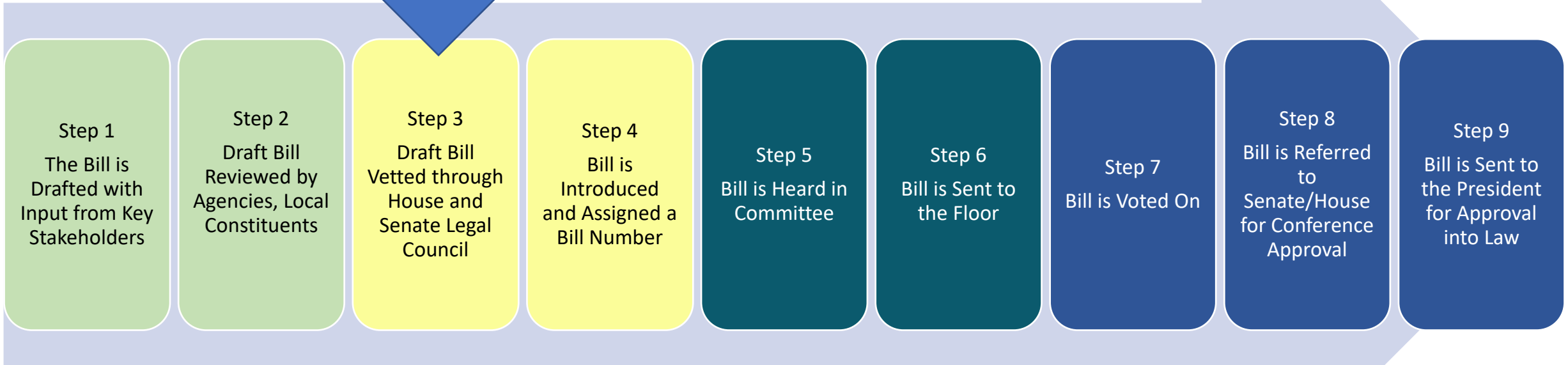
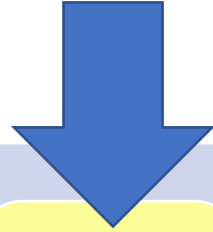
#FASDRESPECT

Bill Status

- Currently with Senate Legislative Council with revisions
 - View a copy of the draft text here: <https://bit.ly/RespectDraft>
 - Bring questions to the weekly policy drop-in. Wednesdays 12-12:30 Eastern.
- Lead Authors/Sponsors committed
 - Sen. Lisa Murkowski (Alaska)
 - Sen. Amy Klobuchar (Minnesota)
 - Rep. Betty McCollum (Minnesota)
 - Rep. Don Bacon (Nebraska)



Pathway to Law

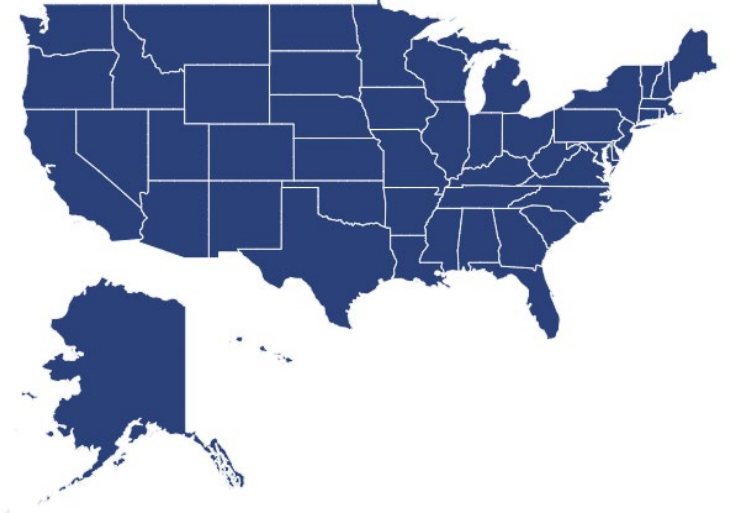


The 118th Congress Lasts for 2 years.



The FASD Respect Act
Building the Foundation for Change
#FASDRESPECT

What do we do now?



- DC
 - Jenn & Susan in DC May 8-12 for targeted Hill Meetings
- In your State
 - Targeted legislator meetings – FASD United will reach out to constituents in the targeted districts to set up virtual hill meetings.

A 3D-rendered graphic featuring a central blue arrow pointing upwards, which stands out from a grid of grey arrows pointing downwards. The text "State Updates" is overlaid on the blue arrow.

State Updates

Bills We Are Watching

- Florida - S0228
 - Revising the definition of the term "developmental disability" to include fetal alcohol spectrum disorders; defining the term "fetal alcohol spectrum disorders", etc.
- Hawaii – SB318
 - Requires the Department of Health to establish and administer a 5-year pilot program to implement a co-management system of care for the diagnosis and treatment of persons with fetal alcohol spectrum disorders
- Nevada – AB138
 - AN ACT relating to fetal alcohol spectrum disorders; making certain provisions applicable to fetal alcohol spectrum disorders; requiring the Medicaid program to provide coverage of certain services to persons with fetal alcohol spectrum disorders; providing that fetal alcohol spectrum disorder is a developmental disability; and providing other matters properly relating thereto.
- New York - S01866
 - Adds fetal alcohol spectrum disorders to the definition of developmental disability.

State Bills Passed This Month

- Hawaii HB899 - Designates the month of September as Fetal Alcohol Spectrum Disorder Awareness Month to promote public awareness of the risks of alcohol consumption during pregnancy.
- Washington HB1168 - Providing prevention services, diagnoses, treatment, and support for prenatal substance exposure. (Pending Gov. Signature, expected to pass)
- North Dakota – The C.A.R.L. Act - Introducing the introvert from North Dakota

State Report Cards

- Data Collection has Begun
- Measuring:
 - Education Access
 - Diagnostic Capacity
 - CAPTA Response
 - Eligibility for Disability Services
 - Support Availability
 - FASD “friendly/unfriendly” legislation



Why is FASD not recognized as a [federal] developmental disability?

- Developmental disabilities services may be very well-suited to address lifelong care needs of those with FASD. Individuals with an FASD do not automatically qualify for developmental disabilities services under federal and state law. Caregivers need to go through an application process with possible appeals to see if their child may be deemed eligible due to his or her specific difficulties.
- The eligibility for developmental disability services is a very complex system of federal and state laws and regulations which has evolved over the years to provide services for those with intellectual disabilities.

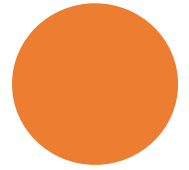
Developmental Disabilities and Waiver Services

TW: The word “retarded” or “retardation” is used in the historical context in this portion of the presentation. FASD United in no way condones or endorses the use this term.

Why is FASD not recognized as a [federal] developmental disability? Continued...

FASD is a spectrum – functioning varies wide. Some individuals can live independently, attain full-time employment, and raise a family. Many, though, require at least some supports through adulthood, and others require a very high level of supports, including residential placements and services

Only about 25 percent of individuals with FASD have an intellectual disability—an IQ less than 70. Many people with FASD have average or above intellectual abilities, but still struggle with executive skills, social communication, self-regulation, and adaptive skills.



History of “developmental disability programs”

1971 - The Intermediate Care Facility for People with Mental Retardation (ICF/MR) program was established in 1971 as an optional service under states' Medicaid programs.

Permitted states for the first time to receive federal matching funds for institutional programs serving only individuals with mental retardation.

1981 - The Medicaid waivers (Section 1915(c) of the Social Security Act - provided states with a mechanism for furnishing home and community-based alternatives to institutionalization in ICFs/MR, nursing facilities and hospitals for those with mental retardation and related conditions. Benefits vary by state, but often include financial aid, access to health care, transportation and in-home support.

1983- AAMR (American Association of Mentally Retarded) expanded definition from conception to age 18. 1984 DD act extended age of onset to 22 years.



CURRENT FEDERAL DEFINITION of DEVELOPMENTAL DISABILITY

To meet this eligibility, an individual must have:

1) a **diagnosis of intellectual disability or have a condition other than mental illness that results in a developmental disability** which results in impairment of general intellectual functioning or adaptive behavior similar to that of an individual with the condition of intellectual disability.

Participants linked to the ICF/IID level of care must meet the “**related condition**” definition when they are not diagnosed as having an intellectual disability.



CURRENT FEDERAL DEFINITION of DEVELOPMENTAL DISABILITY

Persons with related conditions (42 CFR 435.1009)

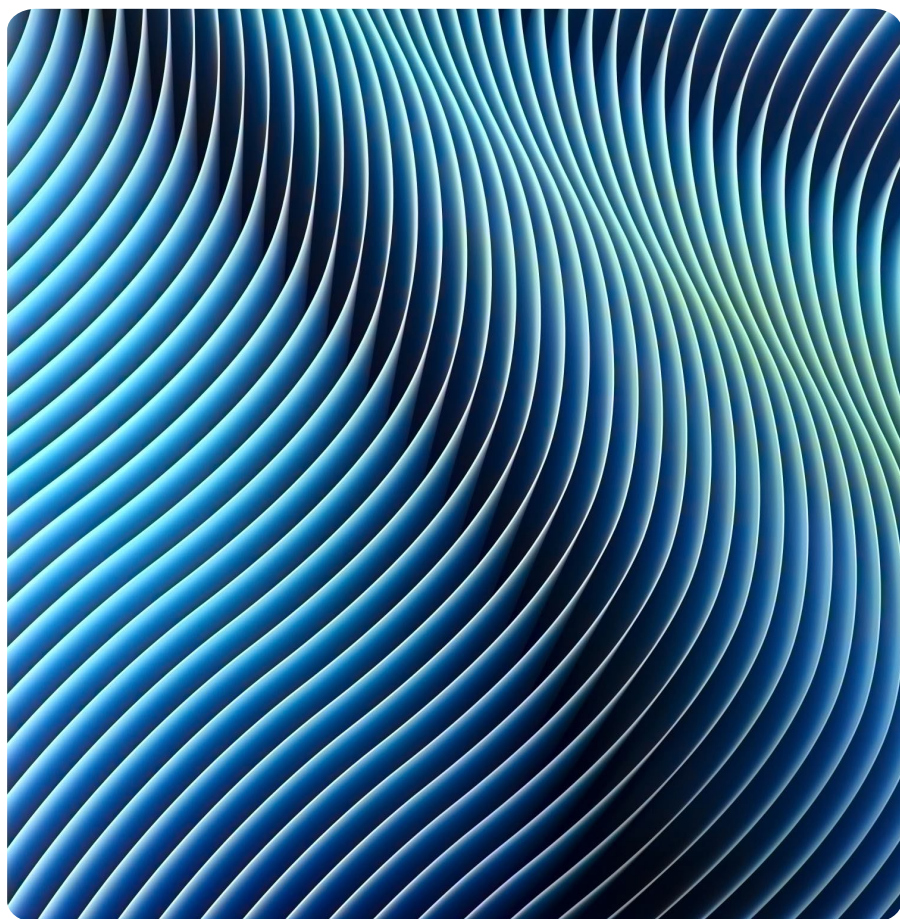
Persons with related conditions relates to individuals who have a severe, chronic disability that meets all of the following conditions:

- (a) it is attributable to, **(1) cerebral palsy or epilepsy or (2) any other condition, other than mental illness**, found to be closely related to intellectual disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of intellectually disabled and requires treatment or services similar to those required for these persons,
- (b) it is manifested before the person reaches the age of 22,
- (c) it is likely to continue indefinitely
- (d) results in substantial functional limitations in three or more of the following areas of major life activities: (1) self care; (2) understanding and use of language; (3) learning; (4) mobility; (5) self direction; (6) capacity for independent living.



ELIGIBILITY DEFINITIONS OF DEVELOPMENTAL DISABILITIES VARIES IN STATES

- Under the Medicaid waiver program states have considerable discretion in determining specific program or service eligibility criteria, the nature of the supports to be offered, the number of individuals to be served, the total dollar amount available to meet the needs of each recipient, and other key program parameter
- States are advised that this level of care is defined as serving persons with “Intellectual disability or persons with related conditions.” Participants linked to the ICF/IID level of care must meet the “related condition” definition when they are not diagnosed as having an intellectual disability.
- Identifying related conditions may involve some discretion on the part of a clinician or evaluator. Note the definition of related condition does not require that an individual have an intellectual disability so long as other related conditions criteria are met.



Why is it difficult for families to obtain services?

Eligibility for services is so complicated and varies from state to state.

State councils on developmental disability can provide more about available resources and eligibility requirements in each state.

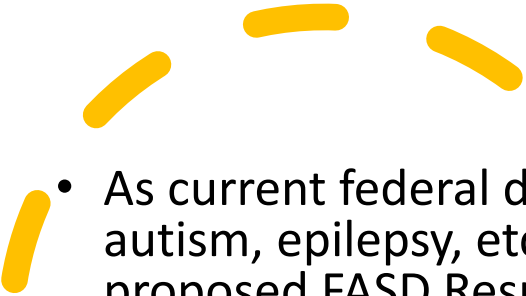
Lack of knowledge about the disability of FASD and resources for diagnosis hampers services.

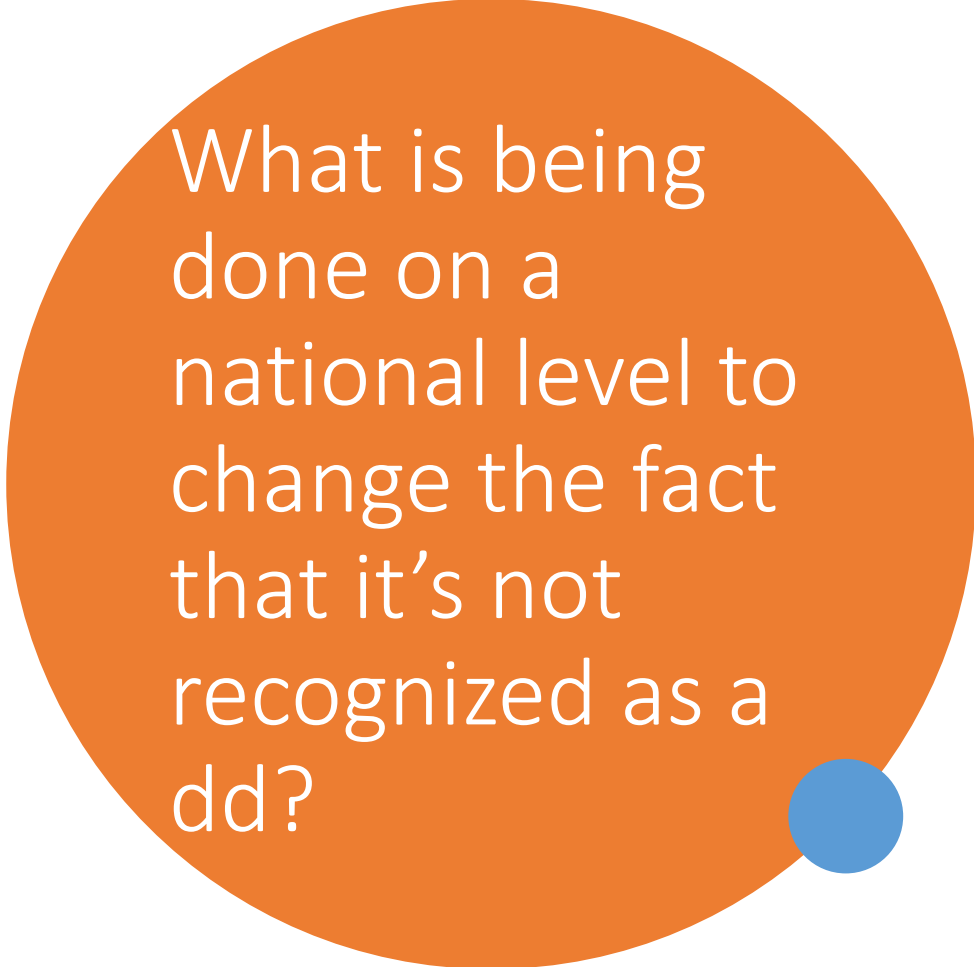
Is FASD recognized as a dd in any state? If so, which ones?

- Some states utilize “categorical” eligibility criteria referencing specific related conditions by medical diagnoses or type, such as mental retardation, spina bifida, autism, etc.
- Other states use “functional” criteria, such as that provided by the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15002 Sec 102)6 (DD Act) that are based on a person’s adaptive abilities or capacity to perform tasks at a specific level.
- The majority of states, however, utilize a combination of the two approaches referencing both categorical and functional criteria.

Examples:

- MN - FASD as a “related condition” within the definition of developmental disabilities in MN Statutes §252.27.
- WA – Persons with FASD have an IQ threshold of 78 instead of 70, however in 2025 IQ will no longer be used.

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- As current federal definition is NOT categorical (i.e. autism, epilepsy, etc.), advocacy through the proposed FASD Respect Act will provide funding to states for FASD education, services and program to apply for a Medicaid waiver for FASD.
 - Under the Medicaid home and community-based waiver program, states have discretion in determining specific program or service eligibility criteria, the nature of supports to be provided, and the number of individuals to be served.
 - Individuals with DD, their families, and advocates have pushed to expand eligibility and improve the quality of services and supports received (good example autism).



What is being done on a national level to change the fact that it's not recognized as a dd?

FASD and Education

Legislation on FASD and IDEA



**The FASD
Respect Act**

Building the
Foundation for
Change

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Together, we can do this.



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