Fetal Alcohol Spectrum Disorders (FASDs)
Common, Complex and Unrecognized

AMERSA 47th Annual Conference
November 3, 2023
Washington DC
Agenda

- Overview .................................................................Daniel P. Alford, MD, MPH
- Personal Experience .......................................................Susan Terwey, MS
- The State of the Science ................................................Jeffrey Wozniak, PhD
- Clinical Presentation & Treatment .........................Vincent C. Smith, MD, MPH
- Prevention, Resources & Advocacy .....................Kendra Gludt, MPH
- Final Thoughts ...............................................................Susan Terwey, MS
Learning Objectives

- Describe the full spectrum and prevalence of FASDs
- Summarize the neuropathology of prenatal alcohol exposure (PAE)
- Discuss stigma and shame as it relates to PAE
- Describe clinical presentations and evidence informed care of individuals with an FASD
- Name prevention efforts and national resources that support individuals and families affected by FASDs
Fetal Alcohol Toxicity

- Experimental and clinical studies demonstrate alcohol is a teratogen
- Prenatal alcohol exposure can impair brain development throughout all stages of gestation
  - Alcohol quickly equilibrates between the maternal and fetal compartments and rapidly reaches the fetus
  - The amniotic sac serves as a reservoir for alcohol, prolonging fetal exposure
  - Approximately 1 in every 13 infants prenatally exposed to alcohol will develop FASD
- Variables leading to fetal damage are complex and interrelated
  - Maternal and fetal genetics, maternal health and nutrition
  - Alcohol dose, pattern and timing of exposure
  - Binge drinking (4+ drinks/occasion) is associated with more severe effects

Jones K et al. *Lancet* 1973
Abel EL et al. *J Pharm Exp Ther* 1978
Chernoff GF *Teratology*, 1977
Petrelli B, et al. *Biochem Cell Biol.* 2018
Popova S, et al. *Biochem Cell Biol* 2018
Fetal Alcohol Spectrum Disorders (FASDs)

- **FAS**: Fetal Alcohol Syndrome

- **pFAS**: Partial FAS

- **ARND**: Alcohol-Related Neurodevelopmental Disorder

- **ARBD**: Alcohol-Related Birth Defects

- **ND-PAE**: Neurobehavioral Disorder associated with Prenatal Alcohol Exposure
Fetal Alcohol Spectrum Disorders (FASDs)

- FASDs are a range of conditions attributable to prenatal alcohol exposure that include behavioral, learning, and physical problems.
- In the US, FASDs are the most common **preventable** developmental disabilities.
- FASDs are **permanent**.
- In the US, an estimated 1-5% of 1st grade children may have an FASD¹.
- FASDs occur in all socioeconomic and ethnic groups².

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1. May PA et al. *JAMA*. 2018
Comparison of FASDs and Other Conditions

- **FASDs**: Actual FASD numbers unknown, these are likely conservative estimates. Affects 1 in 20 school-aged children (5%).
- **Autism Spectrum Disorder**: Affects 1 in 44 children (2.3%).
- **Down Syndrome**: Affects 1 in 700 births (0.14%).
- **Spina Bifida**: Affects 1 in 2,758 births (0.004%).

References:
- May JA, et al. *JAMA*. 2018

Additional sources:
- [www.healthline.com/health/birth-defects](http://www.healthline.com/health/birth-defects)
- [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html)
- [www.cdc.gov/ncbddd/spinabifida/data.html](http://www.cdc.gov/ncbddd/spinabifida/data.html)
Prevention Challenge

Non-Pregnant Women of Reproductive Age

• 54% report alcohol use in previous 30 days\(^1\)
• 18% report binge drinking in previous 30 days\(^1\)

Unintended Pregnancies

• 49% of pregnancies are unplanned\(^1\)
• Pregnancy may not be known for up to 6 weeks or later into the pregnancy\(^2\)

Pregnant Women

• 13.5% report alcohol use in previous 30 days\(^3\)
• 5% reported binge drinking in previous 30 days\(^3\)

Reasons for Alcohol Use During Pregnancy

4 Themes

Theme 1: *Influence of individual beliefs*
- Belief alcohol has beneficial properties
- Belief alcohol is harmful only in specific types and quantities
- Belief alcohol is less harmful than other prenatal exposures (e.g., smoking)

Theme 2: *Influence of culture*
- Social acceptability and pressure for alcohol consumption
- Alcohol consumed as part of tradition and custom
- Alcohol consumed based on intuitive decision making influenced by personal/peer experiences in the community

Popova S et al. *Drug Alcohol Rev.* 2022
Reasons for Alcohol Use During Pregnancy

4 Themes

Theme 3: *Influence of knowledge and advice*
- Consumed alcohol for other health conditions (e.g., nausea)
- Lack of awareness/knowledge of the adverse impacts of alcohol on the fetus
- Insufficient or mixed advice from medical practitioners

Theme 4: *Influence of pregnancy circumstances*
- Consumed alcohol as a coping mechanism for adverse events during pregnancy
- Unplanned or unwanted pregnancy
- Alcohol use disorder

Education Gaps & Mixed Messaging

• Lack of education and awareness among health care providers
  • Only 16% of pregnant persons with known past 30-day alcohol consumption were advised by a health care provider to quit or reduce their alcohol use (Luong J, et al. MMWR 2023)

• Mixed messaging...

  “more than the occasional drink is likely perfectly fine,...Specifically, one to two drinks a week in the first trimester, and up to a drink a day in the second and third trimester, is likely safe”

Expecting Better by Emily Oster

• Campaigns that use blaming and shaming language, such as “FASD is 100% preventable”, can stigmatize and isolate pregnant individuals who use alcohol
Personal Experience

Susan Terwey, MS
Atypical?

- Caucasian
- Middle class
- Master Level education
- Professional in the FASD Field – 13 years
- Social Drinker
- Infertility issues - adoptions, unplanned pregnancy
Parenting History

- Foster mom to kids with FASD and prenatal alcohol exposure
- Infertility issues - adoptions, unplanned pregnancy
- Prenatal care
Realizing I was a “Birth Mom”

- Bio son was the most challenging of all: sensory, high risk, refusals/hiding, behavior room, learning gaps
- School Special Ed assessments (504), Psych eval - no questions about prenatal alcohol exposure
- Anger management, 2 school changes
- Neighborhood alcohol use
- FASD lightbulb flickers
- 1st detox at age 14 – intake interview
- Juvenile court charges – County social worker, FASD Assessment
- Adult detox interview
- Awareness of adults with SUD dealing with undiagnosed FASD issues
The state of the science of Fetal Alcohol Spectrum Disorders

Jeffrey R. Wozniak, Ph.D.
Professor
Department of Psychiatry & Behavioral Sciences
University of Minnesota
How and when does alcohol disrupt neurodevelopment?
1. First trimester (gastrulation):
   • Pregnancy loss
   • Impact on the neural tube
   • Small brain, eye defects, facial dysmorphology

2. Second trimester (neurogenesis):
   • Impact on cell multiplication
   • Abnormal migration of neurons

3. Third trimester (synaptogenesis):
   • Impact during the brain’s growth spurt
   • Effects on synaptogenesis / long lasting impacts on plasticity

Medina, A.E. The Neuroscientist, 17(3): 274-287
• **Day 7** (day 17 or 18 in human); 0.2 BAC (5-6 drink equiv. two doses)
• Craniofacial effects
• Forebrain, midline brain anomalies, callosum, hippocampus, basal ganglia
• **Day 8.5**: equivalent to week 4 (day 21-24) in humans -> different pattern of anomalies
Apoptosis from ethanol exposure (single “binge” model)

- Third-trimester model (brain growth spurt; 7-day-olds)
- Millions of neurons are signaled to self-destruct (apoptosis)
- Significant behavioral and learning deficits

Third-trimester model in rats: **Iron deficiency exacerbates damage from alcohol (myelination, in this case);** In humans, myelination occurs from week 14 into adolescence.

Prenatal alcohol exposure contributes to negative pregnancy outcomes by altering fetal vascular dynamics and the placental transcriptome

Marisa R. Pinson\(^1\) | Alexander M. Tseng\(^1\) | Amy Adams\(^1\) | Tenley E. Lehman\(^1\) | Karen Chung\(^1\) | Jessica Gutierrez\(^2\) | Kirill V. Larin\(^2\) | Christina Chambers\(^3,4\) | Rajesh C. Miranda\(^1,5,6\) | Collaborative Initiative on Fetal Alcohol Spectrum Disorders

- Mouse model - single exposure
- Disruption in fetal blood flow
- Altered gene expression in the placenta
- Intrauterine growth restriction
- Ethanol-exposed fetuses were shorter and weighed less
The influence of *paternal* alcohol consumption on offspring

- In large *human* cohort: association between father’s drinking and child behavior (anxiety & aggression)

- *Animal* studies have shown:
  - Paternal peri-conception alcohol consumption is associated with offspring hyperactivity (Abel et al. 1993)
  - Histone modifications (epigenetic effects) (Cambiasso et al. 2022)

What have we learned about neurodevelopmental impacts of alcohol from people with FASD?
Major structural anomalies sometimes occur in FASD

Typical Development

Fetal Alcohol Syndrome
Diffusion imaging reveals white matter anomalies in FASD

Inter-Hemispheric Functional Connectivity Disruption in Children With Prenatal Alcohol Exposure

Jeffrey R. Wozniak, Bryon A. Mueller, Ryan L. Muetzel, Christopher J. Bell, Heather L. Hoecker, Miranda L. Nelson, Pi-Nian Chang, and Kelvin O. Lim

Figure 1. fMRI time-series from one control subject illustrating high correlation between BOLD signal change in right and left medial orbital frontal cortex.

Figure 2. fMRI time-series from one FASD subject illustrating low correlation between BOLD signal change in right and left medial orbital frontal cortex.
Cortical complexity is altered in FASD

Hippocampal subfield abnormalities and memory functioning in children with fetal alcohol spectrum disorders

Donovan J. Roediger 1, Alyssa M. Krueger 2, Erik de Water 3, Bryon A. Mueller 1, Christopher A. Boys 1, Timothy J. Hendrickson 1, Marijah Schumacher 1, Sarah N. Mattson 1, Kenneth L. Jones 1, Kelvin D. Lim 1, CIFASD 1, Jeffrey R. Weinzimer 1, 2

https://doi.org/10.1016/j.ntt.2020.106944
An example from a non-clinical sample

Adolescent Brain Cognitive Brain Development (ABCD) Birth Cohort Study:

- 7201 unexposed
- 2518 exposed

Figure shows relative behavioral and cognitive deficits for exposed vs. unexposed children

Lees et al. 2021
Association of prenatal alcohol exposure with psychological, behavioral, and neurodevelopmental outcomes in children from the ABCD study;
American Journal of Psychiatry, 177:11
Example of the cycle of secondary disability

- Early developmental disruption
- Behavior regulation/learning probs.
- Drug/alcohol use
- Low self-esteem
- Peer rejection
FASD and predisposition for substance use?

Those with FASD are at high risk for substance use from:

1. Genetic / early life adversity
2. Physiological change (GABA receptor sensitivity; Dopamine)

Is medication effective for FASD?
Medications for FASD

• Animal studies – prenatal ethanol exposure leads to hyper-sensitivity to methylphenidate later in life
  • Means et al. (1984)
  • Ulug & Riley (1983)

• Human studies:
  • Oesterheld et al (1998): stimulants treated hyperactivity, but not attention deficits in those with FASD
  • Poor responsivity to stimulants:
    • O’Malley & Hagermann (1998)
    • O’Malley & Nanson (2002)
    • Snyder et al. (1997)
Psychotropic medication algorithm for FASD
(Mansfield Mela, MBBS; U. Saskatchewan: canfasd.ca/algorithm)

• Consensus-based comprehensive decision-tree addressing four common symptom clusters in FASD:
  • Hyperarousal
  • Emotion dysregulation
  • Hyperactivity / inattention
  • Cognitive inflexibility

• First and second line medications recommended


How do we target neurodevelopment in FASD?
Example: Choline is an essential nutrient for humans

- Classified as essential nutrient
- Cells die by apoptosis without it

- Multiple needs:
  1. Cell membrane
  2. Lipid metabolism
  3. Precursor to acetylcholine
  4. Gene expression (development)

- Deficiency -> neural tube disorders

(Albright et al., 1998; Eagle, 1955; Zeisel et al., 1997; Cho et al., 2006; Zeisel et al., 2003; Shaw et al., 2004; Smithells et al., 1976; Zeisel, 2009b; Albright et al., 1999a; Albright et al., 1999b)
2009 Phase 1 study: delivery system development

- Two arms: 500 mg. choline vs. placebo per day
- Based on adequate intake of 200-250 mg. per day
- Fruit-flavored drink mix
- 9 month duration
Elicited Imitation (memory) performance

Fig 1. EI items after short delay
- 21 point increase for young choline

γ = -16.05, 95% CI [-31.71, -0.40], t(84.7) = -2.09, p = 0.045.
Four-year follow-up of a randomized controlled trial of choline for neurodevelopment in fetal alcohol spectrum disorder

<table>
<thead>
<tr>
<th>Variables</th>
<th>Choline (n = 15)</th>
<th>Placebo (n = 16)</th>
<th>t or χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male %)</td>
<td>53.3</td>
<td>52.943.8</td>
<td>0.27</td>
<td>.60</td>
</tr>
<tr>
<td>Baseline</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, M (SD)</td>
<td>3.81 (0.823)</td>
<td>3.95 (0.75)</td>
<td>0.51</td>
<td>.62</td>
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<tr>
<td>IQ</td>
<td>84.53 (12.57)</td>
<td>78.59 (21.48)</td>
<td>0.98</td>
<td>.332</td>
</tr>
<tr>
<td>Follow Up</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, M (SD)</td>
<td>8.57 (1.01)</td>
<td>8.59 (0.99)</td>
<td>0.05</td>
<td>.97</td>
</tr>
<tr>
<td>Height, M (SD)</td>
<td>128.84 (7.95)</td>
<td>129.61 (8.05)</td>
<td>0.28</td>
<td>.78</td>
</tr>
<tr>
<td>Weight, M (SD)</td>
<td>28.73 (11.36)</td>
<td>29.23 (7.07)</td>
<td>0.15</td>
<td>.89</td>
</tr>
</tbody>
</table>

Table 3: Stanford-Binet Intelligence Scale—Fifth Edition group comparison results

<table>
<thead>
<tr>
<th>EMMean (SE)</th>
<th>Placebo (n = 16)</th>
<th>Choline (n = 15)</th>
<th>Statistic</th>
<th>Significance</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal IQ</td>
<td>88.3 (2.8)</td>
<td>90.6 (3.1)</td>
<td>F (1, 28) = 0.29</td>
<td>p = 0.60</td>
<td>PE² = 0.01</td>
</tr>
<tr>
<td>Non-Verbal IQ</td>
<td>85.6 (2.1)</td>
<td>92.9 (2.4)</td>
<td>F (1, 28) = 5.17</td>
<td>p = 0.03*</td>
<td>PE² = 0.17</td>
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<tr>
<td>Fluid Reasoning</td>
<td>88.1 (3.7)</td>
<td>90.3 (4.1)</td>
<td>F (1, 28) = 0.15</td>
<td>p = 0.70</td>
<td>PE² = 0.01</td>
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<tr>
<td>Knowledge</td>
<td>85.0 (2.3)</td>
<td>87.5 (2.6)</td>
<td>F (1, 28) = 0.50</td>
<td>p = 0.49</td>
<td>PE² = 0.02</td>
</tr>
<tr>
<td>Quantitative Reasoning</td>
<td>93.1 (2.1)</td>
<td>92.7 (2.3)</td>
<td>F (1, 28) = 0.02</td>
<td>p = 0.90</td>
<td>PE² = 0.00</td>
</tr>
<tr>
<td>Visual-Spatial Processing</td>
<td>91.3 (3.0)</td>
<td>98.3 (3.3)</td>
<td>F (1, 28) = 2.38</td>
<td>p = 0.14</td>
<td>PE² = 0.08</td>
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<tr>
<td>Working Memory</td>
<td>84.0 (2.5)</td>
<td>94.4 (2.8)</td>
<td>F (1, 28) = 7.74</td>
<td>p = 0.01*</td>
<td>PE² = 0.23</td>
</tr>
<tr>
<td>Full-Scale IQ</td>
<td>86.1 (2.4)</td>
<td>91.1 (2.7)</td>
<td>F (1, 28) = 1.86</td>
<td>p = 0.19</td>
<td></td>
</tr>
</tbody>
</table>
Summary

- Alcohol has numerous negative impacts on the developing brain
- Even single episodes can be harmful
- Cognitive & behavioral effects are often present, even when the craniofacial elements are not
- We’ve learned a great deal by collaborating with individuals with lived experience of FASD who contribute to research
- New interventions may take advantage of windows of neuroplasticity and opportunities to optimize remaining brain development
FASDs Clinical Presentation and Evidence-Informed Treatment

Vincent C. Smith, MD, MPH
Division Chief of Newborn Medicine
Boston Medical Center
Professor of Pediatrics
Boston University Chobanian & Avedisian School of Medicine
Clinical Presentation
Brain Areas Affected By Prenatal Alcohol Exposure

- **Hypothalamus**: appetite, emotions, temperature, and pain sensation
- **Cerebellum**: coordination and movement
- **Basal Ganglia**: spatial memory, switching gears, working toward goals, predicting behavioral outcomes, and the perception of time
- **Corpus Callosum**: passes information from the left brain (rules, logic) to the right brain (impulse, feelings) and vice versa
- **Hippocampus**: memory, learning, emotion
- **Amygdala**: emotions
- **Frontal Lobes**: impulses and judgment; controls executive function

Source: Dr. Sarah Mattson, University of San Diego
Neurobehavioral Disorder

Neurobehavioral Characteristics

• **Neurocognition**
  Learning, memory, math, executive functioning, visual-spatial, IQ/DD

• **Self-regulation**
  Attention, impulsivity, emotional lability, outbursts

• **Adaptive Functioning**
  Communication, social, daily living skills, motor

Physical Characteristics

~20% of children affected

• Growth restriction

• Facial features:
  - Smooth philtrum
  - Thin upper lip
  - Short palpebral fissures

Facial Features

It's a common myth that all people with an FASD have a specific set of facial features.

The fact is, only a small percent of people with FASD have these facial features; for the vast majority of individuals with an FASD, their disability is invisible.

Examples of facial phenotypes across race and age.
Diagnosis of FASD
FASD Diagnostic Schema Available

Currently available guidelines:

- Canadian guidelines for FASD diagnosis (Cook et al, *CMAJ*, 2015)
- National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (CDC 2004)
- FASD 4-digit diagnostic code (Astley and Clarren, *Alcohol*, 2000)

Historically available guidelines:

- FASD: Canadian guidelines for diagnosis (Chudley et al, *CMAJ*) 2005
- Fetal Alcohol Syndrome (The Lancet, 1973)

The Diagnostic and Statistical Manual version 5 published by the American Psychiatric Association also proposes criteria for neurobehavioral disorder associated with prenatal alcohol exposure.
Assessment Domains for Diagnosis

- History of Prenatal Alcohol Exposure
- CNS (structural, neurologic, functional)
- Growth
- Dysmorphic Facial Features
Screening Concepts or Information Needed to Understand Potential PAE

- General alcohol use in the home
- Amount and type(s) of alcohol consumed *before* finding out they were pregnant
- Amount and type(s) of alcohol consumed *after* finding they were pregnant
- Occurrence of binge drinking (4 or more drinks in one sitting)
  - Women more likely to disclose this behavior
  - Indicative of general drinking
  - Most harmful to the fetus
When to Consider a FASD Diagnosis?

- Developmental, cognitive, or behavioral concerns
- Complex medical concerns (e.g., cardiac)
- Growth deficits
- History of maternal alcohol or drug use
- History of adoption or child welfare involvement
- A sibling diagnosed with a FASD
- Dysmorphic facial characteristics associated with FAS are present
Diagnostic Dilemmas

ADHD

- Externalizing
- Hyperactivity
- Impulsivity

Inattentive

FASD

- Unpredictable inconsistent
- Social communication difficulty
- Restricted and repetitive behaviors
- Difficulty relating to others

ASD
FASDs Resources

- The AAP FASD Toolkit: [aap.org/fasd](http://aap.org/fasd)
- Comprehensive, one-stop resource
Flow Diagram for Medical Home Evaluation of FASDs

1. MEDICAL HOME HEALTH MAINTENANCE VISIT with developmental surveillance

2. Any FASD...
   - Signs or symptoms?
   - Risks?
   - Parent concerns?

3. Are there developmental concerns?

4. Refer as indicated to Diagnostic and developmental services

5. Gather data specific to evaluating for FASD:
   A. Height and/or weight at or below 10th percentile (at any age)
   B. Short palpebral fissures
   C. Smooth philtrum
   D. Thin upper lip
   E. CNS abnormalities
   F. Alcohol use in pregnancy

6. If ALL 5A-E present:
   1. Diagnose FAS or refer to genetics for diagnosis; consider DSM-5 diagnosis of ND-PAE
   2. Use FAS Guidelines for management strategies
   3. Refer to: early intervention services/school evaluation; FAS/FASD clinic; developmental pediatrics or neuropsychology

7. If one or more 5A-F present:
   1. Refer to FAS/FASD clinic and/or best available FASD professionals
   2. Refer to early intervention services/school evaluation

8. If only 5E and/or 5F present:
   1. Consider ICD-listed Neurobehavioral Disorder; DSM-5 diagnosis of ND-PAE; 315.8 (DSM-5)
   2. Refer to neurology, developmental pediatrics, and neuropsychology
   3. Consider referral to genetics
   4. Refer to early intervention services/school evaluation

9. If NONE of 5A - 5F present:
   1. If exposure suspected/not confirmed consider FASD clinic
   2. Consider referral to genetics

10. Developmental Services as needed
    Care coordination

11. Schedule next: MEDICAL HOME HEALTH MAINTENANCE VISIT

Potential Benefits of a Diagnosis

• Parental relief

• Access to evidence-based interventions

• Avoids unnecessary testing, referrals, and interventions

• Reduce recurrence
Non-Pharmacologic Treatments
Evidence Informed Programs for FASD

• Zones of Regulation (late preschool thru adulthood)
• Math Interactive Learning Experience (MILE)
• Go FAR
• Parents and Children Together (PACT)
• Families Moving Forward
• Good Buddies

Access to some of these programs remains limited in many communities

A fundamental element is teaching parents how to interact with their children at home
The Zones of Regulation

Zone of Regulation
(modified for children with FASDs)

- Zones of Internal states
  - Blue = low/under arousal
  - Green = optimal
  - Yellow = increased arousal
  - Red = high arousal, low emotional control

- Practical skills and strategies provided for each Zone

Teaches skills & strategies
Includes parent education and skill building
Teaches children in group settings
Can be modified for the pediatric setting

- Created by an occupational therapist, Leah Kuypers
- Zones of regulation: systematic, cognitive-behavioral approach to teach how to regulate feelings, energy & sensory needs

https://zonesofregulation.com/index.html
Math Interactive Learning Experience (MILE)

Ages: 3-9 years

- 6-week intervention
- Improves math skills and handwriting
- Improves behavior per parent report
- Educate parents and teachers about FASD
- 1:1 instruction for children

http://msacd.emory.edu/Research/MILE.html
GoFar
Ages 5-10 years

- FAR: “F” Focus/Plan, “A” Act, “R” Reflect
  - Improves behavioral and educational outcomes in FASD
- Parents/Caregivers learn parenting strategies
- Incorporates a computer game to teach children to control impulsive and problematic behavior
- 10 weekly sessions

http://msacd.emory.edu/Research/GOFAR.html
Parents and Children Together (PACT)

*Ages: 6-12 years*

- 12-week group therapy intervention
  - Equal time spent training parent & child separately, parent & child together
- Parent goals:
  - Understand brain changes due to PAE
  - Prevent/intervene in child’s behavioral difficulties
- Child goals:
  - Improve executive function
  - Improve emotional regulation

https://www.cebc4cw.org/program/parents-and-children-together-pact/
Families Moving Forward

Ages: 3-12 years

- Caregiver support and coaching
  - Education about PAE effects
  - Teaching proactive parenting strategies
- School/provider consultation
- Community resource linkage
- Training and support provided through Seattle office

https://familiesmovingforwardprogram.com/
Familiesmovingforward@seattlechildrens.org
Good Buddies

- Teaches social skills
- 12-week group sessions for child and parents
- Instruction + practice + homework
- Build a play date
- Explicit, “in-your-pocket”

Evidence Informed Programs for Child Behavior Problems \textit{(not specific for FASD)}

- Parent/Child Interaction Therapy (PCIT)
- Parenting through Change
- Incredible Years
- Attachment and Biobehavioral Catch-up (ABC)
- Guided Growth
Parent-Child Interaction Therapy (PCIT)

- For young children with emotional/behavioral disorders
- Improve quality of parent-child relationships and interaction patterns
- Live-coaching model (parents in room with child, therapist watching by one-way mirror or video, coaching through an earpiece)
Parenting Through Change

Target: parents of 2-18 yo

- Group parenting intervention
  - weekly lessons (10, 12, and 14 week formats)
- Oppositional/defiant, conduct problems
- ADHD symptoms
- Delinquency, deviant peer associations
- Substance use
- Depression
- Academic problems

https://www.cebc4cw.org/program/parenting-through-change/detailed
https://www.generationpmto.org/
The Incredible Years (Programs for 0-18 y)

Program Components:
- IY Child Program
  aka Dinosaur School
  (Classroom and Small Group Treatment)
- IY Parent Program
  (BASIC and ADVANCE)
- IY Teacher Program
  (Classroom Management)

Targets:
- Decrease Risk Factors
- Increase Protective Factors

Proximal (Short-term) Outcomes:
- Increased School Readiness
- Emotion Regulation, Social Competence
- Improved Parenting Interactions and Relationships
- Improved Teaching and Relationships with Students and Parents

Distal (Long-term) Outcomes:
- Reduced Youth School Drop Out
- Increased Academic Achievement
- Reduced Youth Conduct Disorders & Criminal Activity
- Reduced Youth Drug and Alcohol Problems

https://incredibleyears.com/programs/
Attachment and Biobehavioral Catch-up (ABC) 6-24 months

- Home visiting program
- Caregiver intervention to help caregivers nurture infants and toddlers, foster their development, and form strong and healthy relationships
- Adapted for telehealth
- ABC team provides training for parent coaches.

http://www.abcintervention.org/
Guided Growth: Educational and Behavioral Interventions for Children and Teens with FASDS and Early Trauma

- Interactive training and prerecorded webinars, videos, books
- Leadership Institute – technical assistance for creating system of care for families at risk for/affected by prenatal substance exposure
FASD Tools for Parents
Take Home Points

• Prenatal alcohol exposure is the most common *preventable* cause of intellectual disability and behavior disorder
• The effects of prenatal alcohol exposure are lifelong
• Documentation of prenatal alcohol exposure is often a limitation of in the diagnosis of FASD
• There are benefits to making a FASD diagnosis
• There are evidence-informed programs to support individuals, families, and providers affected by FASD
FASD Prevention, Resources, and Advocacy

Kendra Gludt, MPH
Director of National Programs
Our mission is to prevent fetal alcohol spectrum disorders (FASD) and to support all impacted.
FASD Resources

Identification of FASD:
- Screening
- Diagnosis

FASD Informed Professionals and Parents

Prevention of Prenatal Alcohol Exposure

Culturally Responsive Programs

Policy Change
Interagency Coordinating Committee on FASD

FASD-Related Work of the ICCFASD Agencies

ICCFASD

- CDC: Centers for Disease Control and Prevention
- IHS: Indian Health Service
- HRSA: Health Resources and Services Administration
- NIH: National Institutes of Health
- ACF: Administration for Children & Families
- CMS: Centers for Medicare & Medicaid Services
- DOJ: United States Department of Justice
- SAMHSA: Substance Abuse and Mental Health Services Administration

The purpose of this consortium is to inform and develop effective interventions and treatment approaches for Fetal Alcohol Spectrum Disorders (FASD), through multidisciplinary research involving basic, behavioral and clinical investigators and projects. We hope to develop an infrastructure to foster collaboration and coordinate basic, clinical and translational research on FASD.

cifasd.org
CDC FASD Communication Materials

LET'S TALK
ALCOHOL AND PREGNANCY

For more information, visit www.cdc.gov/fasd

LET'S TALK
ABOUT ALCOHOL USE DURING PREGNANCY.

ALCOHOL USE DURING PREGNANCY IS ASSOCIATED WITH AN INCREASED RISK OF:
MISCARRIAGE
STILLBIRTH
SIDS
PRETERM BIRTH

AS WELL AS A RANGE OF LIFELONG BEHAVIORAL, INTELLECTUAL, AND PHYSICAL DISABILITIES, KNOWN AS FETAL ALCOHOL SPECTRUM DISORDERS (FASDs).

DURING PREGNANCY, ALCOHOL CAN PASS FROM THE PREGNANT PERSON TO THE FETUS AND AFFECT ITS DEVELOPMENT.

https://www.cdc.gov/ncbddd/fasd/partners-tools.html
Understanding Clinical Data and Pathways to Inform Surveillance of Children with FASD

A feasibility project that will
• Characterize information accessible within health-related data systems for children suspected of or diagnosed with FASD.
• Describe the referral, evaluation, and diagnosis processes.

Findings will be used to inform the development of future public health surveillance activities.

Recipients:
Emory University
Minnesota Department of Health and Proof Alliance

Period of Performance: 9/1/2022 – 8/31/2025

https://www.cdc.gov/ncbddd/fasd/partnerships.html
Online Training and Resources for Medical Professionals

Collaborative for Alcohol-Free Pregnancy

www.cdc.gov/ncbdd/fasd/searchable-training/index.html

AAP FASD Toolkit and Resources


ACOG FASD Champions

www.acog.org/programs/fasd

B-SMART Podcast on FASD

www.bmc.org/addiction/training-education/b-smart
Prevent FASD and care for children affected by it

- HRSA funded virtual ECHO® sessions for pediatric and prenatal practices, 2020-2024.
- Collaboration between Proof Alliance and Boston Medical Center.
- Teaches healthcare teams how to screen for prenatal alcohol exposure, counsel on FASD, and care for patients impacted by FASD.
- Free Continuing Education Credits.
- Since it started three years ago, 57 clinic practices participated across 15 states.
- Currently recruiting for prenatal practices to enroll, starts in February 2024.
Proof Alliance Online Training

Trainings available for:

- Caregivers and foster caregivers
- Social service providers
- Medical professionals
- Substance use treatment providers
- People in treatment for substance use disorders
- Justice and corrections professionals
- Educators, paraprofessionals, after-school programs
- Middle/ high school students
- College students
- General Population

learn.proofalliance.org
Creative FASD Prevention: Being in Unexpected Places

Not just pregnancy related spaces, not just women.

- Liquor stores
- College campuses
- Beer tasting events
- Special Olympics
- Pride festival

Going where people are getting their information.

- Social media
- Influencers
Social Media Campaign:

How much alcohol is safe to drink during pregnancy?

Let's find out

Pregnancyalcoholcalculator.org
Drinkingwhilepregnant.org
Fasdproof.org
**Proof Alliance FASD Communication Materials**

### Busting the Myths about Drinking During Pregnancy

Drinking alcohol during pregnancy can cause birth defects, brain injury, and fetal alcohol spectrum disorders (FASD). There is no known amount of alcohol that can be considered safe during pregnancy. All major health groups advise that if a person is pregnant or may become pregnant, they should abstain from alcohol.

There are many myths surrounding alcohol use during pregnancy.

<table>
<thead>
<tr>
<th>MYTH</th>
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</thead>
<tbody>
<tr>
<td>Wine is safe to drink during pregnancy. Wine is safe to drink especially if it’s just one or two glasses here and there.</td>
<td>FASD is only common in certain communities.</td>
<td>It’s safe to drink alcohol at the end of the pregnancy.</td>
</tr>
<tr>
<td>FACT</td>
<td>FACT</td>
<td>FACT</td>
</tr>
<tr>
<td>All types of alcohol contain chemicals known as teratogens. These are harmful to a developing baby. Drinking any kind of alcohol can impact the baby’s development. The safest choice is to not drink any.</td>
<td>In the United States, 1 in 7 pregnancies are exposed to alcohol. As many as 1 in 20 children have an FASD. FASD affects people from all races, all ethnicities and all income levels.</td>
<td>The baby’s brain develops throughout the entire pregnancy. Drinking at any time during pregnancy can cause permanent brain injury. The safest choice is to not drink if you’re pregnant.</td>
</tr>
</tbody>
</table>

### Understanding Behaviors of FASD

Fetal alcohol spectrum disorders (FASD) include brain injury and disabilities caused by prenatal alcohol exposure.

Drinking alcohol during pregnancy can cause changes to brain size, structure and functioning. This type of brain injury can lead to issues with behavior.

Without an understanding of the challenges faced by people with FASD, typical behaviors may be seen as purposefully misbehaving or acting out; however, it is often just the opposite. When it seems like a child won’t do something, it might be that they can’t do it – at least not without support.

Remember that everyone with an FASD has the ability to succeed.

Strategies, support and interventions can help improve outcomes, behavior and overall well-being for people with FASD.

**Challenges and Strategies**

It is important to note that each person with FASD is unique and has different strengths and challenges. Not every person with FASD will demonstrate all of the effects below. More so, this is not a complete list of all the possible behavioral effects of FASD.

Due to brain injury, people with FASD may have difficulty with:

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https://www.proofalliance.org/article/fact-sheets-and-strategy-guides/
Support for Families, Youth, and Caregivers

- Support groups
- Retreats
- Social events
- Life skills
- Advocacy
- Caregiver conference
- Online support spaces
- Panel presentations
- Podcasts
- Resource navigation
Proof Alliance Family Support

Visit Events Calendar: proofalliance.org/events
FASD United Affiliate Network

Click to find out more about the FASD United Affiliate in your area.

fasdunited.org

recoveringmothers.org
The **Our Children Are Sacred** app is your resource for **FASD information** and **returning to culture**.

[QR Code for App Store]

[QR Code for Google Play]

[Logos of Our Children Are Sacred and PR%F Alliance]

[Logo of Native REACH]
Policy changes are happening all the time and vary from state to state.

Conclusions: "Most policies targeting alcohol use during pregnancy do not appear to be associated with less alcohol consumption during pregnancy."
National Policy Advocacy: FASD RESPECT ACT

The FASD Respect Act (H.R. 3946/S.1800) is legislation addressing FASD on a national level.

Bi-partisan legislation:

• Co-sponsored in the Senate by Senator Amy Klobuchar (D-Minnesota) and Senator Lisa Murkowski (R-Alaska)

• Co-sponsored in the House of Representatives by Representative Betty McCollum (D-Minnesota, 4th District) and Representative Don Bacon (R-Nebraska, 2nd)

https://nofaspolicycenter.org/the-fasd-respect-act/
National Policy Advocacy: FASD RESPECT ACT

The FASD Respect Act (H.R. 3946/S.1800) would allow the US Department of Health and Human Services to provide:

• Funding for education, awareness, and services across community agencies and systems of care for infants to adults

• Provide funding to state and tribal systems for FASD services throughout the lifespan

• Create Centers for Excellence to guide states and other systems of care in
  • Expanding diagnostic capacity
  • Public awareness and outreach about FASD
  • Training and technical assistance on prevention
  • Supports and interventions for people diagnosed with FASD

https://nofaspolicycenter.org/the-fasd-respect-act/
FASD Resources:

Identification of FASD:
- Screening
- Diagnosis

FASD Informed Professionals and Parents

Prevention of Prenatal Alcohol Exposure

Culturally Responsive Programs

Policy Change

All of these improve when we increase *awareness* and decrease *stigma*. 
Closing Comments

Susan Terwey, MS
Closing Comments

- Biggest regret of my life
- Typical? Yes – a lightbulb may be going off for some of you - Clear message, no message, inaccurate message
- Biases often based on class and culture
- Uncomfortable asking – “don’t want to damage the relationship”
- We don’t disclose unless asked – repeatedly
- “Make it okay” – your openness may open the door for disclosure
- Kids don’t blame their moms, we shouldn’t either.