


FASD Awareness Month
September Grand Rounds Series


While you wait, take the AAP FASD Quiz!
(aap.org/fasd-quiz)

Welcome!



SCAN ME






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Housekeeping Items

- This session is being recorded and will be shared to registered participants.
- To protect patient privacy, please do not provide any protected health information during this session.
- Due to timing restrictions, individual consultation in this webinar will not be allowed.
- Questions may not necessarily be addressed in the sequence they were submitted.
- The FASD Champions Network can support pediatricians year-round
 - Contact us via email at rarvizu@aap.org or aap.org/FASD




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Acknowledgements

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 - Maribel Campos Rivera, MD, MSc MBA, FAAP (Neonatology / Family Perspective)
 - Julie Kable, PhD (Pediatric Psychology)
 - Marinell Newton, MSW, LICSW (Social Work)
 - Jill S. Rinehart, MD, FAAP (Primary Care / Rural Health)
 - Yasmin Senturias, MD, FAAP (Developmental and Behavioral Pediatrics)

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Today's Speaker



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MD, MPhil, FAAP

Assistant Professor of Pediatrics at Boston University Chobanian and Avedisian School of Medicine, Developmental behavioral pediatrician at Boston Medical Center



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Today's Speakers



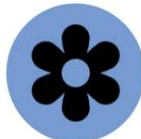
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State Innovation Specialist
Safe Babies, a program of ZERO TO THREE



Kristen Eriksen

Co-coordinator of massFAS, Family Navigator |
FASD United, Parent with Lived Experience



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Collaborative Conversations:
Supporting Families with Substance Use and FASDs
(In partnership with Zero to Three)

Mei Elansary, MD, MPhil, FAAP
FASD Champion, American Academy of Pediatrics

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AAP Grand Rounds
Webinar Series

- ✓ Foundations of FASD: Etiology and Evaluation
Friday, September 13 at 1 pm EST
Speaker: Roxanne Chang, MD, FAAP
- ✓ Collaborative Conversations: Supporting Families with Substance Use and FASDs
(AAP and Zero to Three Partnership) – September 20 at 2pm (Today)
- ☐ Managing ND Disorders in Primary Care –Monday, September 23 at 12pm EST
Speaker: Yasmin Senturias, MD, FAAP

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Disclosure

- In the past 24 months, I have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.
- I do not intend to discuss any unapproved/investigative use of a commercial product/device in my presentation.
- The views presented in this didactic do not necessarily represent the views and opinions of the AAP.

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Learning Objectives

1. **Recognize** the benefits of universal screening for alcohol and other substances in coordinating care for children and families.
2. **Appreciate** the role of an interdisciplinary approach in managing fetal alcohol spectrum disorders (FASDs) and addressing family needs.
3. **Apply** care coordination strategies to identify appropriate resources.

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Recap Session 1 Grand Rounds
Foundations of FASD: Etiology and Evaluation

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Cognitive / Behavioral Abnormalities
Areas of the Brain Affected By Prenatal Alcohol Exposure

Frontal Lobes
impulses and judgment; controls executive function

Hypothalamus
appetite, emotions, temperature, and pain sensation

Amygdala
emotions

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

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Common Manifestations of FASDs in Children 0-5 years of age

1. Self-regulation Challenges
2. Neurocognitive Challenges
3. Adaptive Skills Delays
4. Prenatal Alcohol Exposure

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Universal Screening

Understanding how universal screening for alcohol and other substances can be useful in coordinating care for children and their families

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Importance of Prevention: Alcohol Use and Pregnancy

ALCOHOL USE DURING PREGNANCY
From 2018-2020

1 IN 7 About 1 in 7 pregnant people in the United States reported drinking alcohol*
in the past 30 days


1 IN 20 About 1 in 20 pregnant people reported binge drinking**
in the past 30 days

*American College of Obstetricians and Gynecologists (ACOG) 2020
**ACOG 2020

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Prevention is Critical

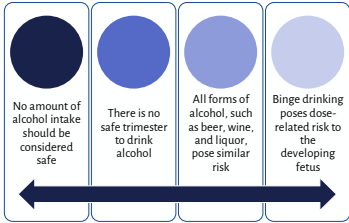


- Fetal alcohol spectrum disorders are the most common *preventable* cause of intellectual disability and behavior disorder
- Estimated as up to 5% of U.S. school-age children (more common than autism)
 - NOTE: Since the method for surveillance of FASDs differs from surveillance methods for these other conditions, these prevalence data should be interpreted with caution.
- Much higher prevalence among adopted children and children in foster care
- Neurodevelopmental challenges often become greater as age-related expectations increase
- Prenatal alcohol exposure has greater effects on brain development than most other drugs
- Alcohol is one of the most common substances used with other drugs among past 30-day polysubstance users

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Clinical Guidance on Alcohol Use during Pregnancy



No amount of alcohol intake should be considered safe	There is no safe trimester to drink alcohol	All forms of alcohol, such as beer, wine, and liquor, pose similar risk	Binge drinking poses dose-related risk to the developing fetus
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Substance Use Screening Tools

- AAP Implementation Guide
- AAP Bright Futures
- Substance Use Screening, Brief Intervention, and Referral to Treatment (SBIRT)

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Screening for Prenatal Alcohol Exposure

Screening for Prenatal Alcohol Exposure: An Implementation Guide and video available at www.aap.org/pae

- *"Think of screening for prenatal alcohol exposure like other difficult conversations such as depression and poverty. Mothers will be as comfortable answering questions about prenatal alcohol use as physicians feel asking them."*

-- Douglas Waite, MD, FAAP




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When to screen and how often?

AAP Bright Futures



Suggested contact points:

- ✓ All prenatal visits
- ✓ The earliest well child visits
- ✓ All new patient visits
- ✓ Whenever a related concern is observed or raised

Screening Process- 3 Screening Questions for Pediatricians


1. How often do you drink beer, wine or liquor in your household?
2. In the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?
3. During your pregnancy, how many times did you have 4 or more drinks in a day?

- If a positive response is obtained, additional questions about amount, frequency and timing may be appropriate for diagnostic purposes.

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AAP's Bright Futures

3 Screening Questions for Pediatrics



1. How often do you drink beer, wine or liquor in your household?

2. In the 3 months before you knew you were pregnant, how many times did you have 4 or more drinks in a day?

3. During your pregnancy, how many times did you have 4 or more drinks in a day?

- If a positive response is obtained, additional questions about amount, frequency and timing may be appropriate for diagnostic purposes.

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Supports to Screening
 Considerations for High-Risk Populations


- FASDs are underdiagnosed in children in the child welfare system
 - Prevalence of FASDs in foster care is as high as 16.9%
- Have a high index of suspicion for prenatal alcohol exposure in children
 - In the child welfare system
 - With a history of international adoption
 - With a history of parental substance abuse
 - A sibling diagnosed with an FASD

Source: Chouffet et al., 2013; Langer et al., 2018

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Supports to Screening
 FASDs and Trauma Often present similarly




- Cognitive/behavior problems are often the **point of entry** for referral
 - Because the neurodevelopmental profile of prenatal alcohol toxicity is broad and non-specific, **misdiagnosis or delays in an FASD diagnosis are common.**
 - Symptoms of prenatal alcohol exposure (PAE) often overlap with other conditions (e.g. behavioral sequelae of toxic stress, ADHD, ASD).
 - PAE is often not considered in the differential diagnosis of developmental and behavioral problems.


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Supports to Screening
 Trauma Informed Care Strategies



- Identify opportunities to mitigate toxic stress
- Enhance positive, supportive relationships
- Use tools
 - The Three R's (AAP Resource for Families): Calms stress response, help identify what they feel, and develop skills to manage emotions.
 - Reassurance
 - Returning to routine
 - Regulation



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Supports to Screening
Health Inequity, Racial Disparities, and FASDs

- Racial and ethnic disparities in FASD diagnosis and treatment persist
- Children who are minority / Black, indigenous, and people of color (BIPOC) are more likely to have a later / misdiagnosis:
 - Less access to mental health services, and are less often referred to neurodevelopmental clinics
 - African American males are often misdiagnosed with externalizing disorders, and neurodevelopmental diagnoses are often missed
 - FAS facial features are under-identified in children who are BIPOC
 - Misdiagnosis and missed diagnosis can contribute to higher secondary disabilities in children who are BIPOC
- **Universal screening is important for promoting health equity**


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Interdisciplinary Approaches
Understanding the role of an interprofessional care team to manage FASDs and other family needs

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Impact of Bias and Discrimination

- **Bias and discrimination** are well-established social determinants of health.
- Pediatricians uniquely understand that child development is shaped by the social ecology in which children are raised.
- **Understanding one's own biases** and gaining skills to engage in conversations about parental substance use is important for healthcare providers and multidisciplinary care teams

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What is Stigma?

- A socially created construct that discredits people identified by specific characteristics.
- **Public stigma:** the prejudice and discrimination that harms a labeled group when the general population endorses stigma about that group.
- **Self-stigma:** the harm to self-esteem and self-efficacy when stigmas are internalized.
- While characteristics like skin color lead to racism, marks for health conditions are typically diagnostic labels.

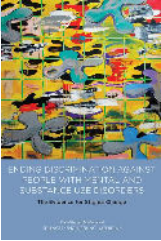
Source: Corrigan, Patrick W., et al. "Stakeholder perspectives on the stigma of fetal alcohol spectrum disorder." *Addiction Research & Theory*. 27:2 (2019): 170-177.

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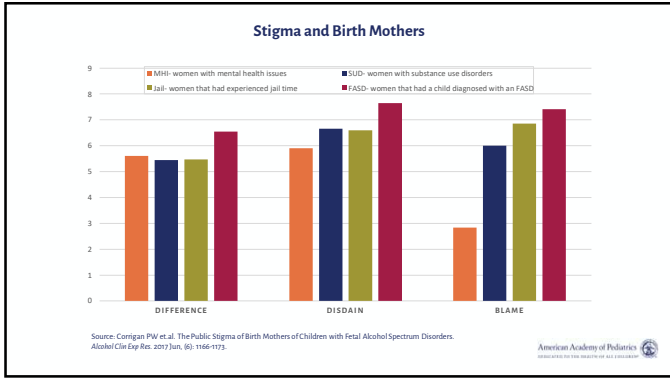
Social Psychological Constructs & Stigma

- **Stereotypes and prejudices** create a framework of social attitudes that enable discrimination.
- **Conscious or unconscious** outcomes can include indifference, disdain and blame.
- **The impact** can result in diminished care for both the mother and child.



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Family-Centered Care
Pediatric Medical Home Considerations

- Caring for children with FASDs in the pediatric medical home
 - Reducing stigma
 - Recovery-friendly medical home
 - Trauma-informed care
 - Families
 - Interdisciplinary colleagues
 - Educators
 - Care management and care conferences

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Family-Centered Care
Reducing Stigma

- Having empathetic conversations with children with FASDs and their families is important.
 - Mothers want their pediatrician to value and like them. Be gentle and non-judgmental, listen, and then provide information and education.
 - Fear of judgment for them or their child is one of the main concerns of families regarding an FASD diagnosis (including adoptive families).
 - Use non-stigmatizing language: "child with prenatal alcohol exposure" rather than "child whose mother drank during pregnancy".
 - Use person first language: "child with an FASD" or "child with prenatal exposure to alcohol" instead of "FASD kid"

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Family-Centered Care
Recovery-friendly and Trauma-informed

- **Recovery-friendly principles:**
 - Dyadic approach: health and well-being of parents and child
 - Recognize and build on the strengths of parents and caregivers
 - Engage all members of the practice in using medically accurate and non-judgmental language
 - Collaborate with community-based programs (e.g., WIC, Head Start, school) as well as adult and addiction medicine to support the family
- **Trauma-informed principles:**
 - Assess for trauma history and symptoms.
 - Build safe, stable, and nurturing relationships for children and adult caregivers
 - Support the caregiver-child relationship to build resilience and prevent traumatic stress reactions

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Interprofessional Care for Patients with FASDs

- Create and develop a team from different specialties to collaborate in planning & creating a "Medical Neighborhood"
- Establish a common goal
- Provide patient and family driven care
- Consider the patient and their family as core team members

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Care Coordination Strategies

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Interprofessional Care for Patients with FASDs

Coordinating care for children with FASDs and their families

- Problems related to prenatal alcohol exposure (PAE) may present to anyone who comes in contact with the child or family. Interdisciplinary providers include:
 - Nurses and allied health professionals
 - Mental health (psychiatrists, psychologists, counselors)
 - Educators
 - Therapists (physical therapy, occupational therapy, speech therapy, behavior)
 - Child welfare professionals & social workers
 - Addiction medicine

Fetal Alcohol Spectrum Disorders (FASD)

Facilitation of Community-based Services

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Interprofessional Care for Patients with FASDs
 Child welfare professionals & social workers

Child welfare professionals and social workers play a unique role as advocates and partners, ensuring that essential services are available from the outset for individuals with FASDs and their families.

- **Expert Navigation:** Expertise to navigate the complex array of services needed for families with FASD, ensuring that medical care, educational support, and therapeutic interventions are available from the outset.
- **Advocacy:** Secure resources that might otherwise be inaccessible, providing tailored support that can significantly improve outcomes for individuals with FASDs.
- **Early Involvement:** Ensure involvement from the start so that children diagnosed (or suspected) with FASDs receive ongoing guidance and support, which is crucial for their development and well-being.

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Interprofessional Care for Patients with FASDs
 Child welfare professionals & social workers

- **Holistic Support:** Individuals with FASDs and their families work across various disciplines, coordinating with home visitors, social workers, judicial leaders, attorneys, SUD providers, and mental health clinicians to provide comprehensive care.
- **Preventive Measures:** Help in implementing preventive measures and support systems to ensure the safety and well-being of both the child and the parent.

Child welfare professionals & social workers could play a unique role to ensure that individuals with FASDs and their families receive the necessary support and resources for alcohol and/or substance use recovery.

Often a trustworthy source of support!

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Interprofessional Care for Patients with FASDs
 Supporting educational and behavioral interventions

Working with the school systems- possible eligibility categories

- **Early intervention:**
 - 46 states (and DC) list FAS or PAE
 - Other states classify children 'at risk' due to conditions such as prenatal exposures and prematurity, making them eligible for immediate services
 - IDEA Part C, 0-36 months
- **Special education:**
 - Other Health Impairment (OHI)
 - Specific Learning Disability (SLD)
 - Specific Language Impairment (SLI)
 - Mild Mental Disability (MMD)/Functional Mental Disability (FMD)
 - IDEA Part B, 3 yrs and up


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Interprofessional Care for Patients with FASDs
Supporting educational and behavioral interventions

- **Individualized Family Support Plan (IFSP) (0-3 years)**
 - Continuum of care for early intervention and family support services
- **Individualized Education Program (IEP) (age 3-21 years)**
 - Documents parent and teacher concerns plus the child's current performance and strengths
 - Goals and benchmarks
 - Services, structure of day, transportation
- **504 plan (age 3-21 years)**
 - Section 504 of the Rehabilitation Act
 - A blueprint for how a child will have access to learning at school (accommodations)
 - Includes children under the FASD umbrella


Source: Team Understood. & Lee, AM (ed). The Difference Between IEPs and 504 Plans.



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Interprofessional Care for Patients with FASDs
Supporting educational and behavioral interventions

- **Obtaining appropriate services**
 - Prepare a pediatrician letter stating concern about the child's ability to learn in school and their strengths
 - AAP sample letter is available via: aap.org/fasd/educationalcare
 - Provide any additional requested information, including a referral letter
 - Educate school partners about brain-based learning differences
 - Promote FASD-informed approaches at school
 - Reassure parents of the benefits of special education resources
 - Work with the family and interprofessional care team to collaboratively address challenges, seek solutions, and look for ways to have the best outcome for the child as well as the family




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Take Homes
Supporting Families with Substance Use and FASDs



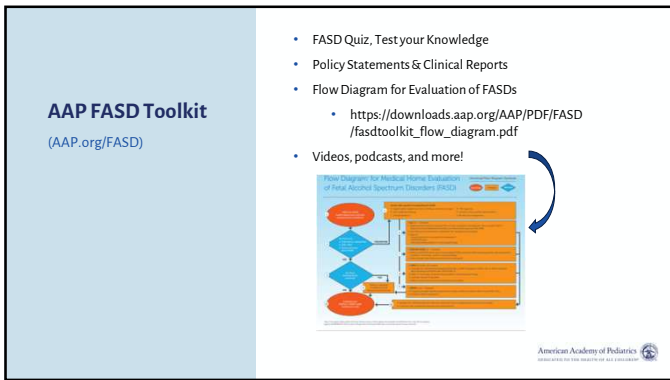
- Universal screening for alcohol and other substance exposures is the first step for coordinating care for children and their families.
- Interdisciplinary approaches in managing FASDs and addressing family needs are needed.
- Recovery-friendly and trauma-informed principles are central to family-centered care.



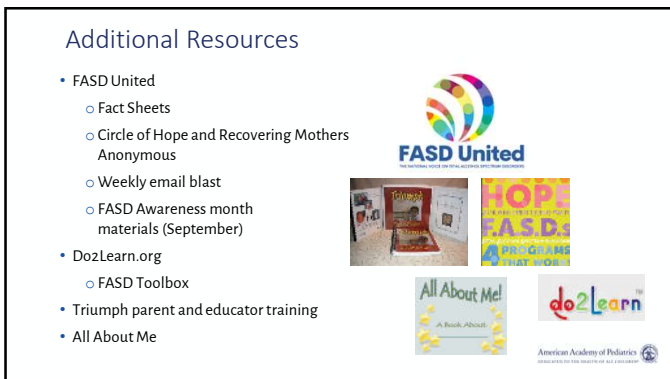
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Questions?

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