Advocating for patients who are neurodivergent

Working with individuals and families as they transition in care across the lifespan

FASD NATIONAL PARTNER NETWORK

Collaborative for Alcohol-Free Pregnancy

Partnering for Practice Change

Speakers

- Lily Bastian CNM, Expert Consultant, University of Alaska Anchorage
- Gina Schumaker, Center for Human Development, University of Alaska Anchorage
- Jenn Wisdahl, FASD United
- Jeffrey Quinlan MD FAAFP, Carver College of Medicine, University of Iowa
- Samuel Bauer MD FACOG, Obstetrics & Gynecology, Maternal Fetal Medicine, Duke University
- Yasmin Senturias MD, Developmental-Behavioral Pediatrics of the Carolinas Charlotte, Atrium Health

Acknowledgements

This workshop is a joint effort by members the FASD National Partner Network, part of the Collaborative for Alcohol-Free Pregnancy. We would like to thank the following organizations and people for their support in the development of this workshop, without whom this would not have been possible:

- Karen Crowley, Vice President, Nursing, Education, Research & Practice; Kassandra Greci, Sr. Manager, Women's Health Programs, AWHONN
- FASD United
- Rosa Arvizu, American Academy of Pediatrics (AAP)
- Absara Haile, American College of Obstetrician-Gynecologists (ACOG)
- Rajani Bharati, American Academy of Family Physicians (AAFP)
- Alexandra Edwards; Faith Ozer Green, University of Alaska Anchorage

Disclaimers

UAA: This presentation is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $605,000 with 100 percent funded by CDC/HHS. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government or of the University of Alaska Anchorage Institute of Social and Economic Research.

AAP: This program is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $425,000 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Disclaimers

AAFP: This presentation is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $603,907 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Workshop Learning Objectives

1. Define fetal alcohol spectrum disorders.
2. Discuss effective strategies for preventing alcohol-exposed pregnancies and fetal alcohol spectrum disorders.
3. Describe how FASDs can manifest in individuals in childhood, adolescence, or adulthood.
4. Discuss effect strategies for supporting people with an FASD as they transition in care across the lifespan.

Workshop Outline

1. Fetal alcohol spectrum disorders: An introduction, facilitated by Gina Schumaker and Jenn Wisdahl; Lecture by Dr. Quinlan
2. Manifestations of FASDs in late adolescence/adulthood: Lecture by Dr. Quinlan; Q&A facilitated by Gina Schumaker and Jenn Wisdahl

Break

3. Universal screening and brief intervention (ASBI/SBIRT) with case studies & practice: Lecture by Dr. Bauer, case studies facilitated by Lily Bastian

Break

4. Manifestations of FASDs in children 0-17: Lecture by Dr. Senturias
5. Transitioning to adulthood and continuing support/care: Moderated Q&A with Dr. Senturias, Gina Schmaker, and Jenn Wisdahl

Break

6. What healthcare providers can do to support transition in care: Case studies, discussion, and Q&A facilitated by Lily Bastian
7. Supporting people with an FASD or other types of neurodiversity through reproductive healthcare and/or pregnancy discussion: Q&A facilitated by Lily Bastian

Wrap up/Evaluation

Neurodiversity – What is it? Why does it matter?

- Neurodiversity is the idea that people experience and engage with people and the world around them in many different ways
- You can be working with someone who identifies as neurodiverse and not know it
- From a neurodiversity-positive perspective, there are no deficits, only differences in the way people interact with their environment
- When we identify, support, and embrace these differences, we can increase acceptance and inclusion of all people, improving health and well-being

Nicole Baumer & Julia Frueh (2021) *What is neurodiversity?*
www.health.harvard.edu/blog/what-is-neurodiversity-202111232645

Neurodiverse Conditions Can Have Overlapping Symptoms

There may be differences in similar parts of the brain, affecting how that person functions and interacts with their environment.

Neurodiverse conditions can include:

- Attention deficit/hyperactivity disorder (ADHD)
- Autism spectrum disorder (ASD)
- Traumatic brain injury (TBI – due to accidents, stroke, etc.)
- Learning disabilities, e.g., dyscalculia, dyslexia
- **Fetal alcohol spectrum disorders (FASDs)**

FASDs: A Lens for Discussing Neurodiversity

- People with an FASD have unique neurodevelopmental profiles that may impact their cognitive, behavioral, and social functions
- Highlights the importance of understanding and supporting people with diverse neurological differences
- A neurodiversity-informed approach promotes acceptance, inclusion, and empowerment
- Tools and discussion provided in this workshop may open doors to further conversation about how healthcare providers can best support neurodiverse individuals in their practice

FASD United (2023) *Learn more about different tables & saving seats: Neurodiversity.* fasdunited.org/give-fasd-a-seat-at-the-table/

Words Matter

A Tale of Two Women – Who has an FASD?

A Tale of Two Women – Who drank during pregnancy?

A Tale of Two Women

A Tale of Two Women

Fetal Alcohol Spectrum Disorders

Jeffrey Quinlan, MD FAAFP
Donald J. and Anna M. Ottilie Chair in the Department of Family Medicine
Roy J. and Lucille A. Carver College of Medicine | The University of Iowa

FASD
NATIONAL
PARTNER
NETWORK

Fetal Alcohol Spectrum Disorders (FASD)

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (PFAS)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)

Hoyme, Pediatrics 2016

Prenatal Alcohol Exposure

Prenatal alcohol exposure includes at least one of the following:

- 6 or more drinks/week for >= 2 weeks during pregnancy
- 3 or more drinks/occasion on >= 2 occasions during pregnancy
- Alcohol related social or legal problems around the time of pregnancy
- Lab documented intoxication during pregnancy
- Positive test for alcohol exposure biomarkers during pregnancy
- Positive validated screening tool for increased prenatal risk associated with alcohol use during pregnancy

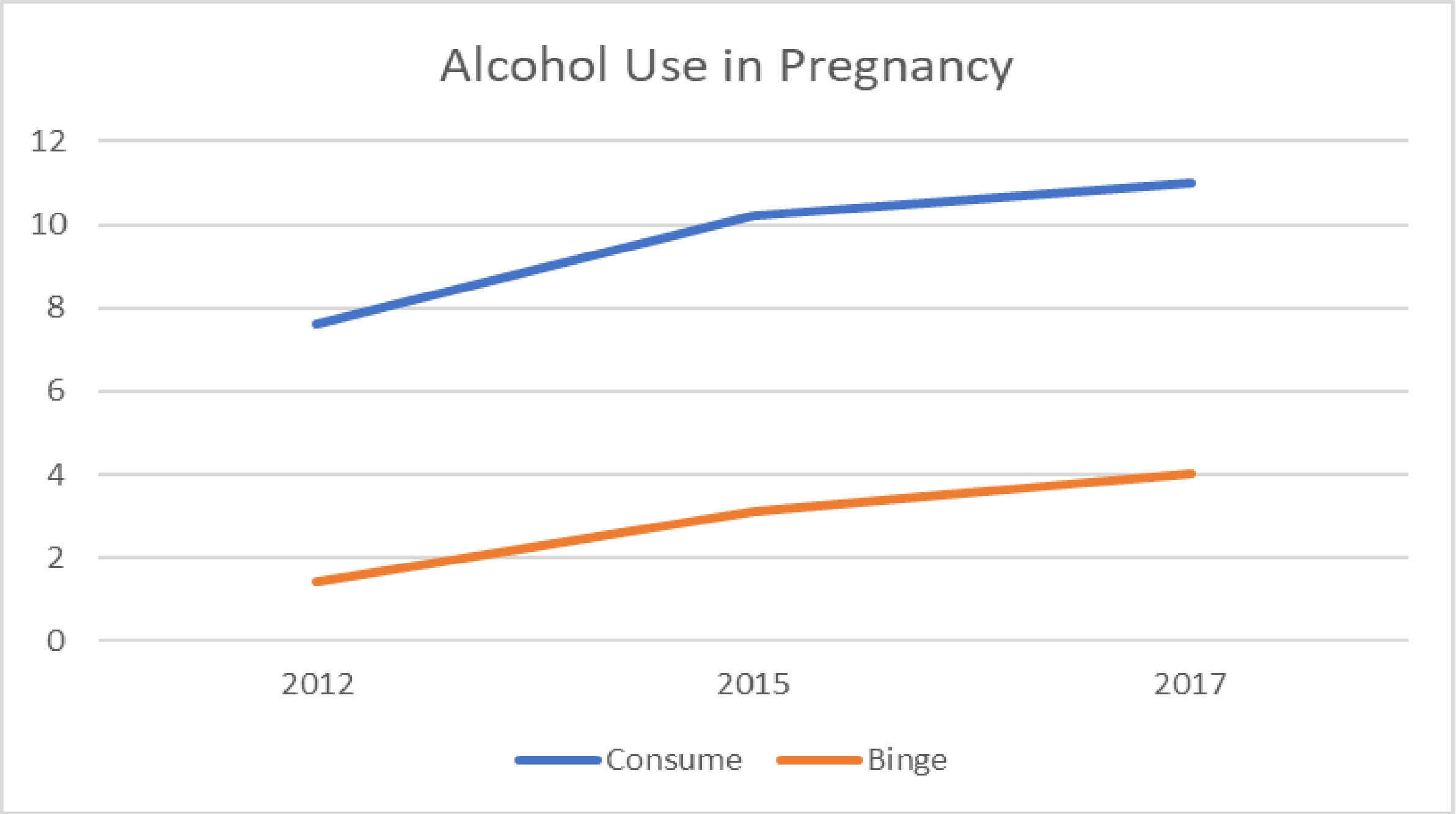
Hoyme, Pediatrics, 2016

Prenatal Alcohol Exposure

Documentation includes drinking levels reported by the mother three months before pregnancy recognition or at the time of a positive pregnancy test.

Information must be obtained by the mother or a reliable source, such as family member, social service agency, or medical record

Hoyme, Pediatrics, 2016


Alcohol Use in Pregnancy
12
10
8
6
4
2
0
2012
2015
2017
Consume
Binge

Impact of Alcohol Use

Alcohol Consumption

- Most common teratogen
- Most common cause of intellectual disability (non inherited)

Binge Drinking

- Behavioral problems
- Physical deformities

Joya, *Birth Defects Res A Clin Mol Teratol*, 2015
Alvik, *Alcohol Clin Exp Res*, 2013

Prevalence

FASD

- US – 33.5 in 1,000 children
- Worldwide – 22.8 in 1,000 children

FAS

- US – 0.3-0.8 in 1,000 children
- Worldwide – 2.9 in 1,000 children

Average age at diagnosis = 48.3 months

Fox, *MMWR Morb Mortal Wkly Rep*, 2015
Roozen, *Alcohol Clin Exp Res*, 2016
Moberg, *Birth Defects Res,* 2014

Findings Associated with Alcohol Use

Facial dysmorphology

- Short palpebral fissure
- Thin vermillion border of the upper lip
- Smooth philtrum

Growth deficiency

- Prenatal or postnatal
- Height and/or weight < 10th %tile for age

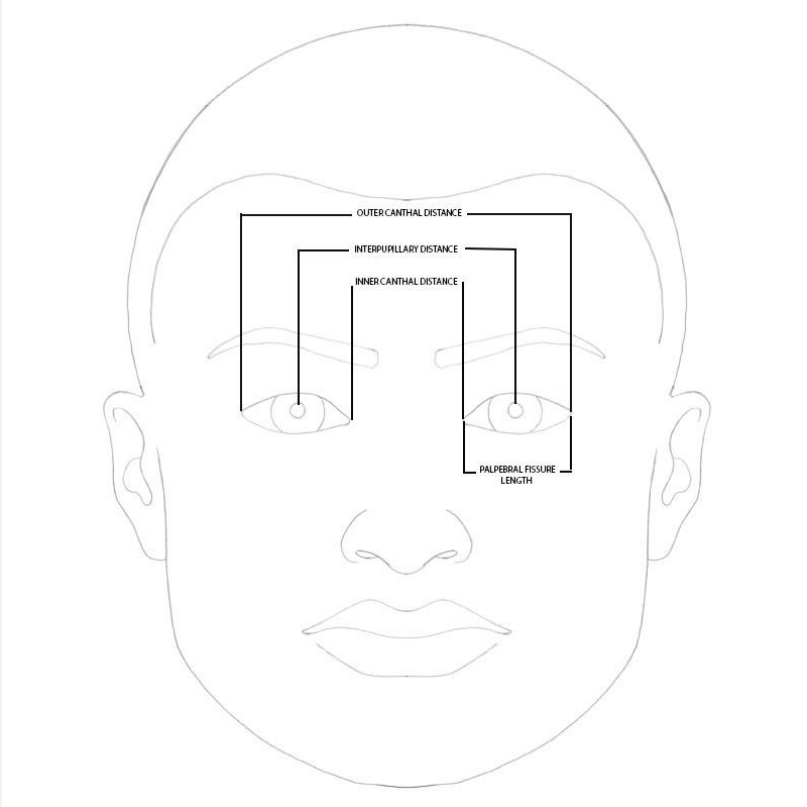
- Central nervous system dysfunction
  - Head circumference < 10th %tile for age
  - Structural brain abnormalities
  - Recurrent seizures (nonfebrile)
- Neurobehavioral impairments
  - Global impairment OR
  - Deficit in >= 1 domain
  - >= 1.5 SD below the mean

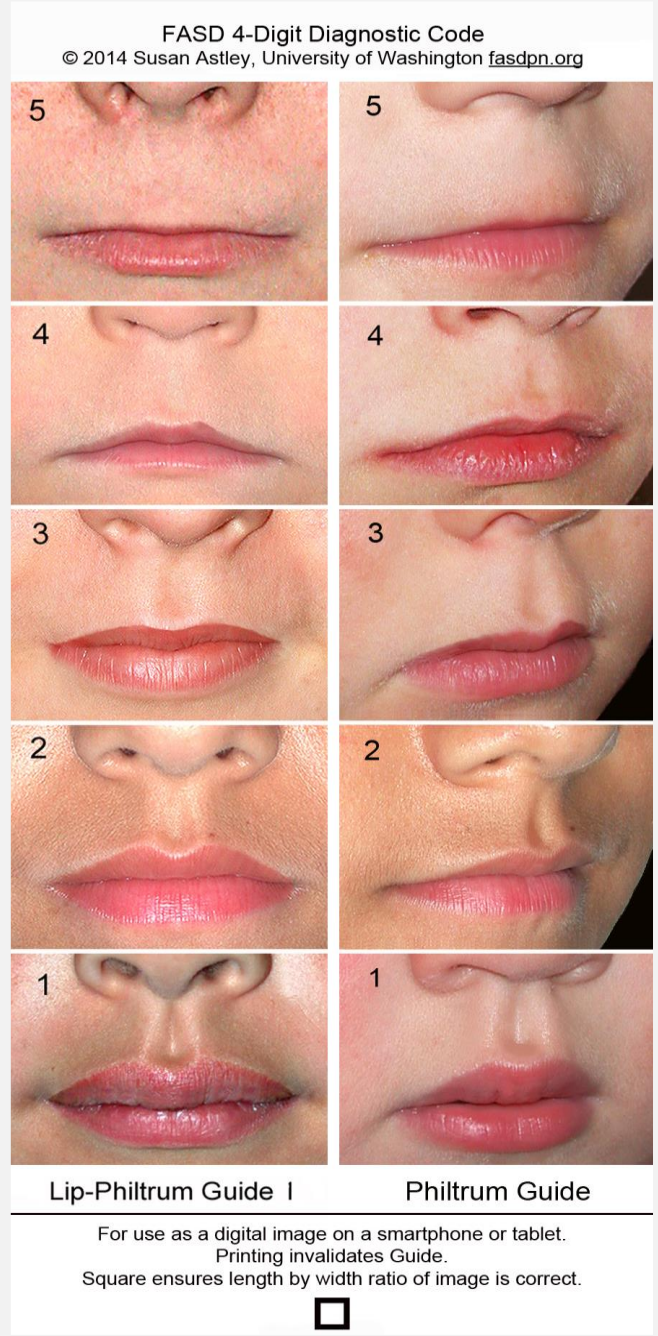
Facial Dysmorphology

Short Palpebral Fissures

- <= 10th %tile for age and race

Lip and Philtrum scores of 4 or 5 using University of Washington scoring guide





Palpebral Fissure Length (PFL) Z-score Calculator

Instructions: Enter data in yellow cells. All remaining cells will automatically compute.

Patient birth date (mm/dd/yyyy)	Date PFL Measured (mm/dd/yyyy)	Patient's age (years)	Patient's PFL (mm)
January 1, 1990	January 1, 2000	10.00	28.00

PFL Normal Growth Chart	Applicable Age Range	Mean PFL for Normal Population (mm)	Patient's PFL Z-score*
Caucasian Male or Female (Hall, 1989)	0-16 yrs	**28.69**	**-0.51**
Canadian Female (Clarren et al., 2010)	6-16 yrs	**26.03**	**1.55**
Canadian Male (Clarren et al., 2010)	6-16 yrs	**26.49**	**1.07**
Scandinavian Female (Stromland et al., 1999)	0-18 yrs	**26.84**	**0.88**
Scandinavian Male (Stromland et al., 1999)	0-18 yrs	**27.43**	**0.42**

* The PFL z-score reflects how many standard deviations (SDs) the patient's PFL is above or below the normal population mean. For example, if 1 year-old child had a PFL = 20 mm, that child's PFL would be 1.27 SDs below the population mean on the Stromland male PFL charts.

The University of Washington uses the Stromland PFL charts for Caucasians (click here to learn why)

References:

Astley SJ. Canadian palpebral fissure length growth charts reflect a good fit for two school and FASD clinic-based U.S. populations. J Popul Ther Clinc Pharmacol 2011:18(2):e231 -e241;April 8, 2011

Clarren SK, Chudley AE, Wong L, Friesen J, Brant R. Normal distribution of palpebral fissure lengths in Canadian school age children. Can J Clin Pharmacoogy 2010;17(1):e67-e78.

Hall JG, Froster-Iskenius UG, Allanson JE. Handbook of Normal Physical Measurements. Oxford University Press, 1989

depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm

Structural Brain Abnormalities

Includes:

- Temporal lobe asymmetry
- Change in size or shape of:
  - Corpus callosum
  - Cerebellum
  - Basal ganglia

MRI is the test of choice to identify structural abnormalities

Neurobehavioral Disabilities

Domains include:

- Deficient global intellectual ability
- Deficient cognition
- Poor behavior
- Poor self-regulation
- Poor adaptive skills

Disability in at least 2 domains

>= 1.5 SD from the mean for age

Fetal Alcohol Syndrome

- +/- documented exposure
- Facial dysmorphology (2 or more)
- Growth deficiency
- Central nervous system dysfunction
- Neurobehavioral impairments

Partial Fetal Alcohol Syndrome

- Documented prenatal exposure to alcohol
- Facial dysmorphology
- Neurobehavioral impairments
- +/- Growth deficiency
- +/- Central nervous system dysfunction

OR

- No documented prenatal exposure to alcohol
- Facial dysmorphology
- Neurobehavioral impairments
- Growth deficiency

  OR

- Central nervous system dysfunction

Alcohol-Related Neurodevelopmental Disorder

- Documented prenatal exposure to alcohol
- Neurobehavioral impairments
  - Global impairment

    OR
  - Deficits in >=2 domains
- Definitive diagnosis after age 3

Alcohol-Related Birth Defects

- Documented exposure to alcohol during pregnancy
- Malformations and dysplasias of:
  - Heart
  - Bone
  - Kidney
  - Vision
  - Hearing systems

pubs.niaaa.nih.gov/publications/arh25-3/153-158.htm

Differential Diagnosis

Condition	Cause
Aarskog Syndrome	X-linked recessive FGD1 mutation
Bloom Syndrome	Autosomal recessive BLM mutation
Cornelia de Lange Syndrome	Autosomal dominant or X-linked dominant mutations
Dubowitz Syndrome	Unknown
Fetal Hydantoin Syndrome	Phenytoin exposure prenatally
Fetal Valproate Syndrome	Valproate exposure prenatally
Noonan Syndrome	Autosomal dominant PTPN11 mutation
Phenylalanine Embryopathy	Maternal phenylketonuria
Toluene Embryopathy	Toluene exposure prenatally
Velocardiofacial Syndrome	Autosomal dominant 22q11 microdeletion
Williams Syndrome	Heterozygous 7q11, 23 deletion

Multidisciplinary Evaluation and Treatment Team

- Audiologist
- Cardiologist
- Developmental pediatrician
- Developmental therapist
- Family therapist
- Nephrologist
- Neurologist
- Occupational therapist
- Ophthalmologist Physical therapist
- Play therapist
- Primary care physician
- Psychiatrist
- Psychotherapist
- Sensory integration therapist
- Social worker
- Special education teachers
- Speech-language pathologist

Hoyme, Pediatrics, 2016
Chasnoff,Pediatrics, 2015

Treatment

- There is no cure for FASD
- Most recommendations for treatment are based on expert opinion
- Multidisciplinary teams are important in optimizing care
- Commonly occurring conditions need to be addressed

Commonly Occurring Conditions

System	Condition
Auditory	Chronic Serous Otitis Hearing loss – conductive, neurosensory
Cardiac	Aberrant great vessels ASD VSD
GI	Enteric neuropathy
Musculoskeletal	Camptodactyly and clinodactyly Flexion contractures Hypoplastic nails Radioulnar synostosis Scoliosis Spinal malformations

Norman, *Dev Disabil Res Rev*, 2009; Popova, *Lancet*, 2016; *Pediatrics*, 2000; Caputo, *Birth Defects Res C Embryo Today*, 2016; Gummel, *Eur J Ophthalmol*, 2013

Commonly Occurring Conditions

System	Condition	
Neurologic	Microcephaly Seizure disorders Spinal cord and structural brain abnormalities	
Vision	Ptosis Retinal malformation Strabismus Visual impairment	
Orofacial	Cleft lip and palate	
Psychiatric	ADD/ADHD Conduct disorder Intellectual disability	Language disorder Oppositional defiant disorder Substance use disorder
Kidney	Kidney abnormality (a-, dys-, hypoplastic Horseshoe kidney Hydronephrosis Ureteral duplications	

Nutritional Support

- ¼ of childhood with unmet basic needs
- 1/3 of childhood with someone who abuses alcohol or drugs
- > 50% do not consume the recommended dietary allowance of:
  - Fiber
  - Calcium
  - Vitamins D, E, and K
- Nutritionist and Social Worker referrals are necessary when problems are identified
- High calorie foods and supplements may be required

Streissguth. J Dev Behav Pediatr, 2004
Fuglestad Neurotoxicol Teratol, 2013
Young., Adv Nutr, 2014

Behavioral Health Support

Increased risk of:

- ADD/ADHD – 40-90%
- Mood Disorders – 50%
- Oppositional Defiant Disorder – 38%

Medications may be beneficial

Behavioral Therapy has shown some effectiveness

- Play Therapy
- Children's Friendship Training
- Case Managers

Burd, Neurotoxicol Teratol, 2003
Fryer, Pediatrics, 2007
O'Connor, Am J Drug Alcohol Abus,. 2002
Davis, J Dev Phys Disabil, 2011

Family Support

- By age 12, 61% experience physical or sexual abuse or witnessing domestic violence
- Those who remain in the care of their biologic mother are more likely to experience family dysfunction and instability
- Those who are raised in stable homes have improved outcomes
- Interventions should be aimed at stabilizing the home environment and improving parent-child interactions
  - Parental substance abuse referrals
  - Child discipline courses
  - Parent support groups
  - Child protective services

Bertrand, MMWR Recomm Rep, 2005
Streissguth AP, Bookstein FL, Barr HM, Sampson, J Dev Behav Pediatr, 2004

Q & A

UNIVERSAL ALCOHOL SCREENING AND BRIEF INTERVENTION (SBIRT): PREVENTION OF ALCOHOL-EXPOSED PREGNANCY – FETAL ALCOHOL SPECTRUM DISORDERS

Samuel T. Bauer, MD, MBA, FACHE, CPE, FACOG

Associate Professor, Obstetrics and Gynecology – Maternal-Fetal Medicine

Medical Director, Duke Perinatal, Quality and Digital Health

Duke Health

06.07.2024

DISCLOSURE

I have no financial relationship with a commercial entity producing health-care related products and/or services.

DISCLAIMER

We recognize that the ob-gyn field and parts of this presentation default to gendered and patient-provider language, but we do want to acknowledge that the term “woman” does not include all people who can get pregnant and not all people are patients.

OBJECTIVES

Learn about:

Overview of fetal alcohol spectrum disorders (FASDs) in pregnancy

Preventing alcohol-exposed pregnancy

Facts about alcohol use among pregnant women

Recommended screening and brief intervention techniques

Strategies to improve outcomes

HISTORY OF ALCOHOL USE IN PREGNANCY

The term FAS (Fetal Alcohol Syndrome) was first used in 1973 by Dr. David Smith and Dr. Ken Lyons Jones at the University of Washington.

In 1981 the Surgeon General issued an advisory against drinking[2] during pregnancy, which was updated in 2005.

In the 1970s and 1980s, ethanol was used as a tocolytic to delay preterm labor, until studies found that it is harmful to the fetus and does not perform better than a placebo.[1]

FETAL ALCOHOL SPECTRUM DISORDERS (FASDs)[3]

Describes the range of effects that can occur in an individual who is exposed to alcohol during the 9-month prenatal period before birth.

Effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

The term FASD is not intended for use as a clinical diagnosis.

DIAGNOSTIC TERMS UNDER THE UMBRELLA OF FASDs

- Fetal alcohol syndrome (FAS)
  - FAS is the medical diagnosis Q86.0 in the International Classification of Diseases (ICD-10)
- Partial fetal alcohol syndrome (pFAS)
- Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE)
- Alcohol-related neurodevelopmental disorder (ARND)
- Alcohol-related birth defects (ARBD)

WHAT CAUSES FASDs?

The cause of FASDs is fetal exposure to alcohol during the pregnancy.

Alcohol is a *teratogen*; thus capable of interfering with the development of a fetus, causing birth defects.

FACTS ABOUT FASDs

Prenatal alcohol use is the leading preventable cause of birth defects, developmental disabilities, and learning disabilities.

Most FASDs are not visible and cannot be diagnosed at birth.

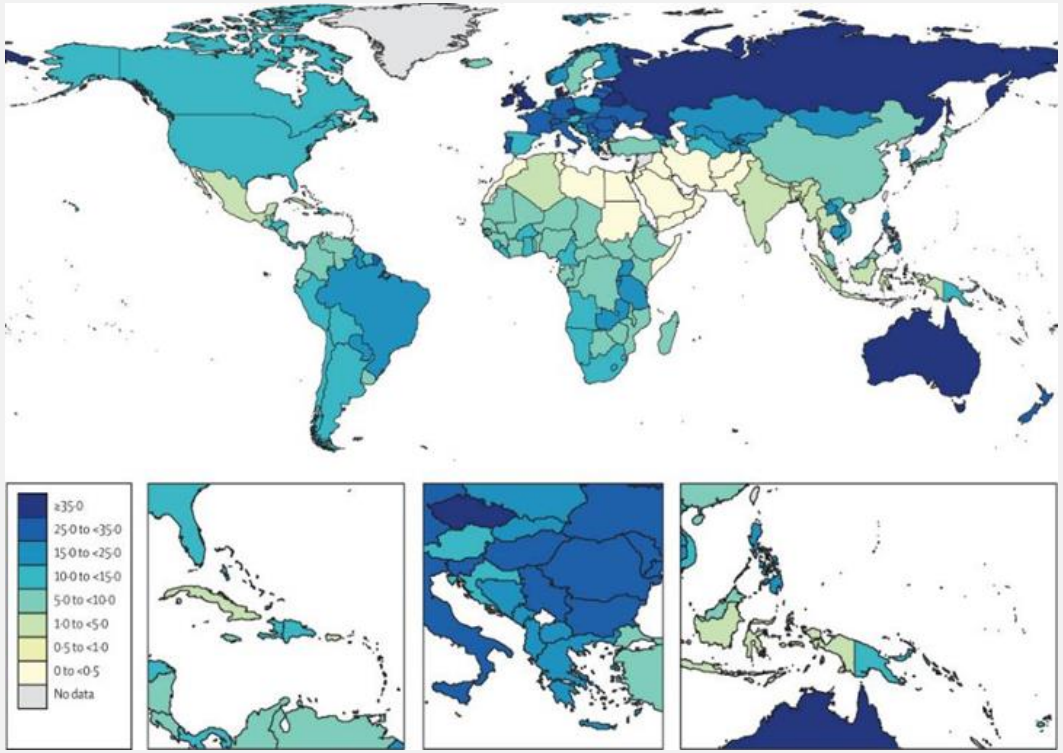
1 IN 20

Up to 1 in 20 U.S. school children may have FASDs.

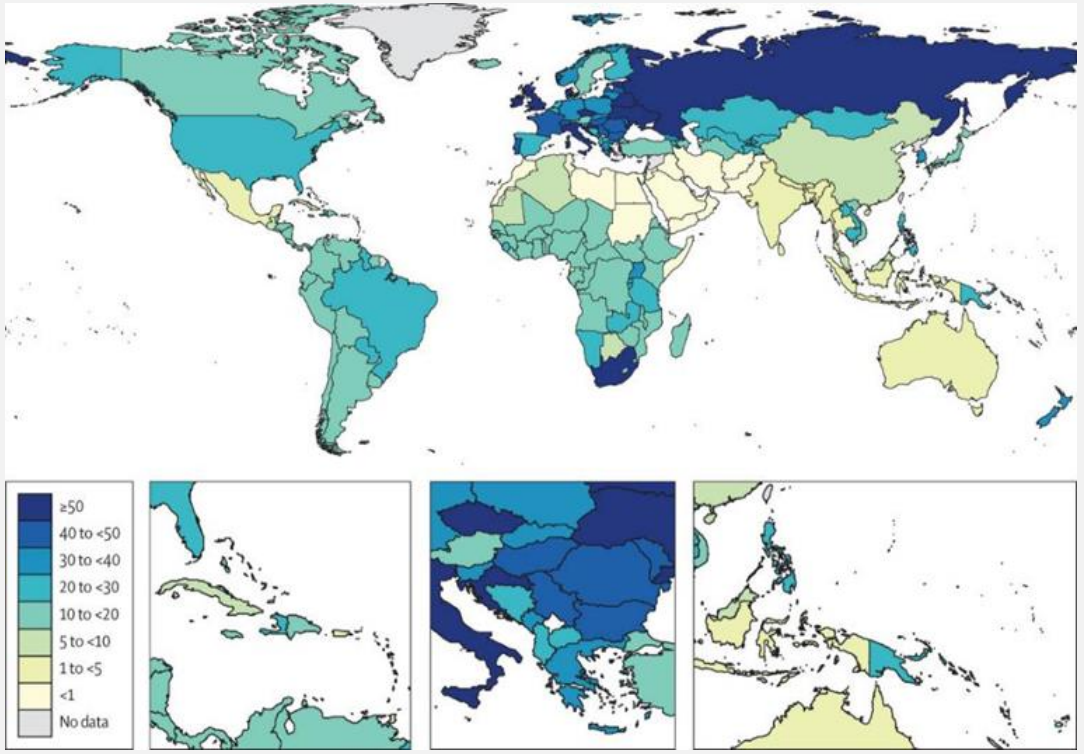
Source: www.cdc.gov/vitalsigns/fasd/index.html

POPULATION LEVEL RELATIONSHIP BETWEEN PREVALENCE OF ALCOHOL USE DURING PREGNANCY AND FAS[4]

Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012.



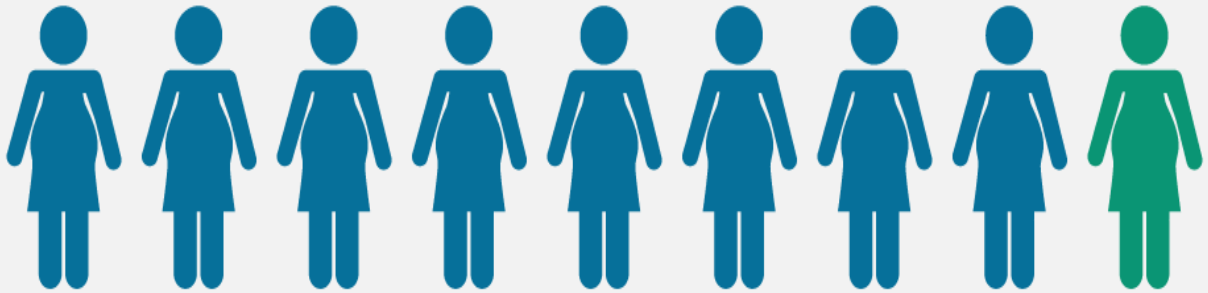
Global prevalence (per 10,000 people) of FAS among the general population in 2012.



RISKY ALCOHOL USE IS COMMON

- More than 3 million U.S. individuals are at risk of an alcohol-exposed pregnancy.[5]
- Although it is not recommended to drink alcohol, 3 in 4 who want to get pregnant as soon as possible report drinking alcohol.[5]
- Fetal alcohol spectrum disorders are preventable.

PREVALENCE OF ALCOHOL USE AMONG PREGNANT WOMEN IN THE U.S. AGED 18 – 44 YEARS[5]



1 in 9 pregnant women report alcohol use.*

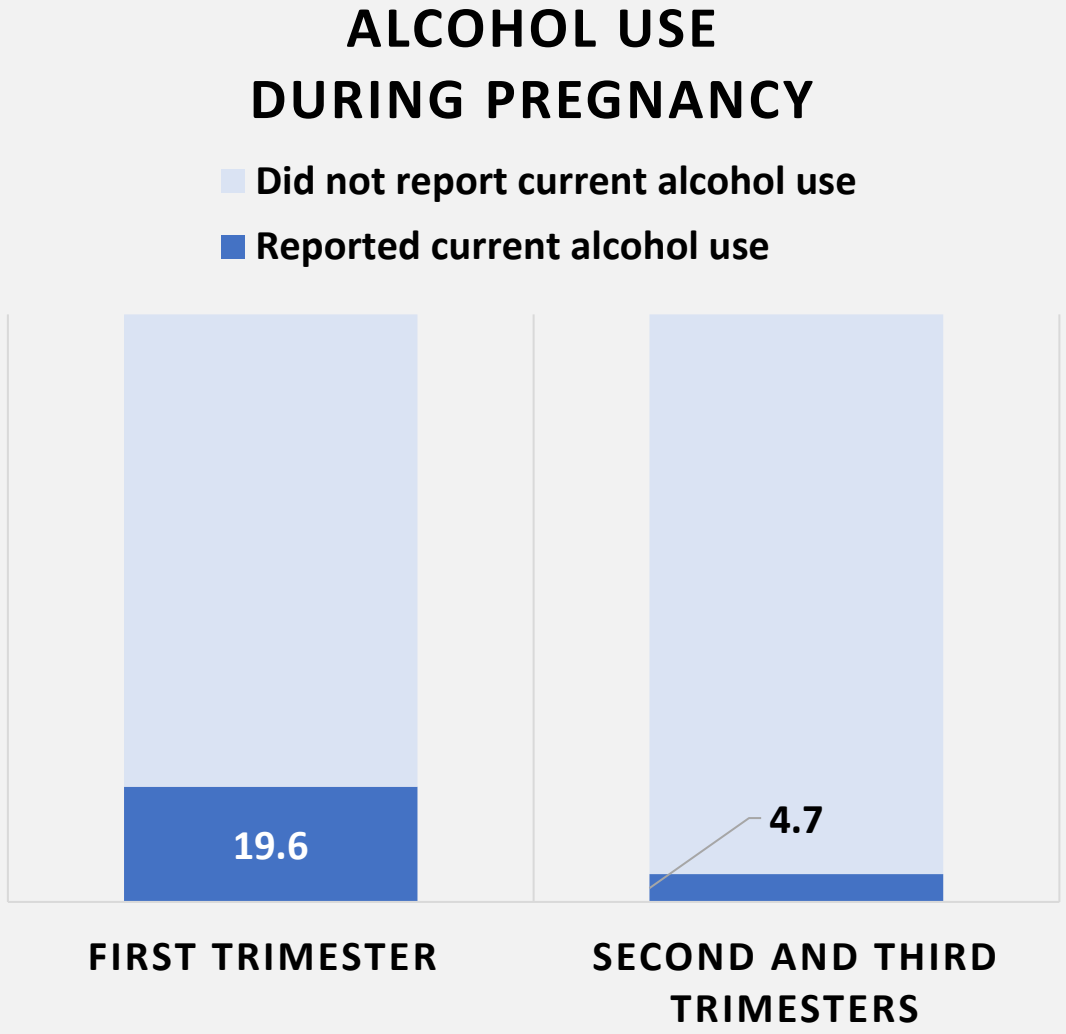
Of the pregnant women who use alcohol, 1 in 3 report binge drinking.**

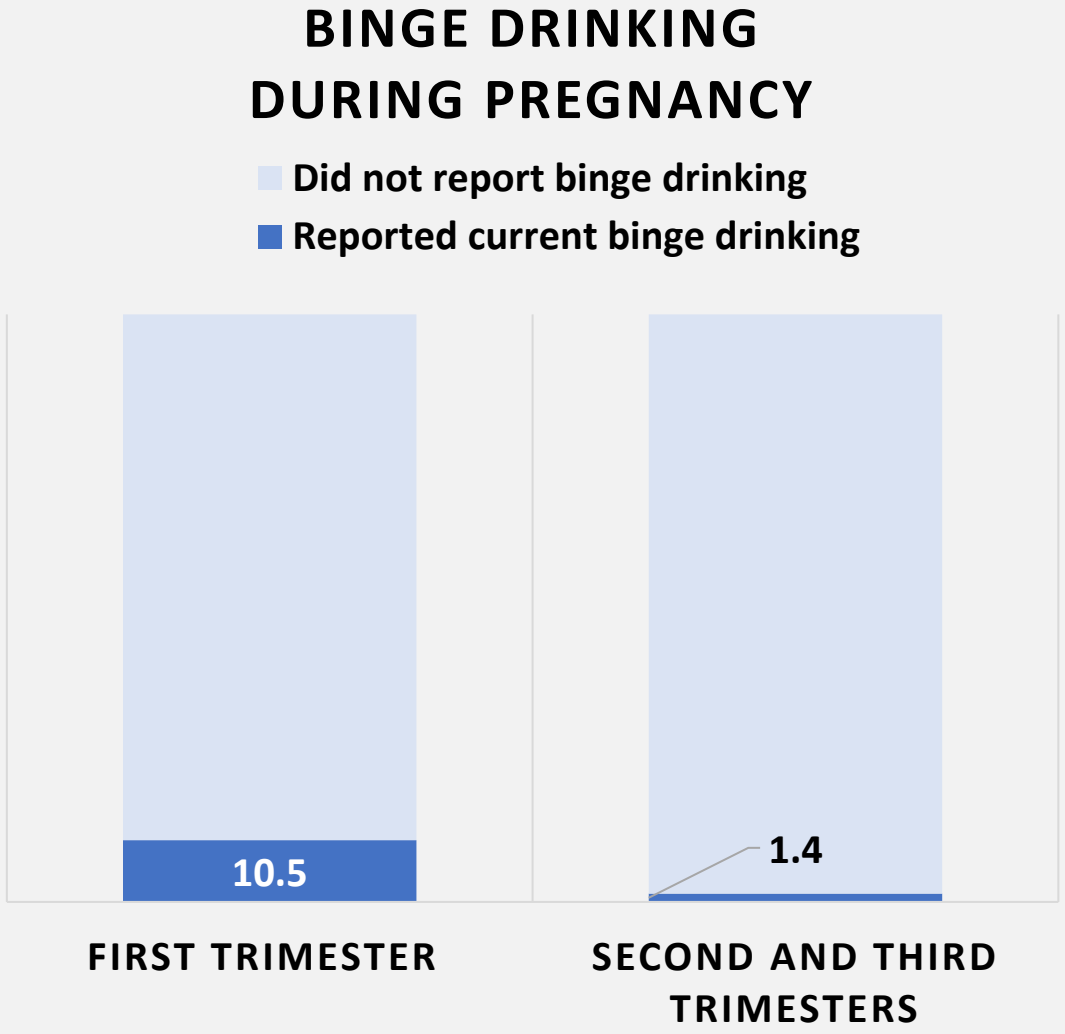
Source: CDC Behavioral Risk Factor Surveillance System (BRFSS), United States, 2015–2017

**Drinking alcohol was defined as having at least one drink of any alcoholic beverage in the past 30 days.*

***Binge drinking was defined as having consumed four or more drinks on at least one occasion in the past 30 days.*

ALCOHOL USE THAN WOMEN IN THEIR SECOND AND THIRD TRIMESTERS

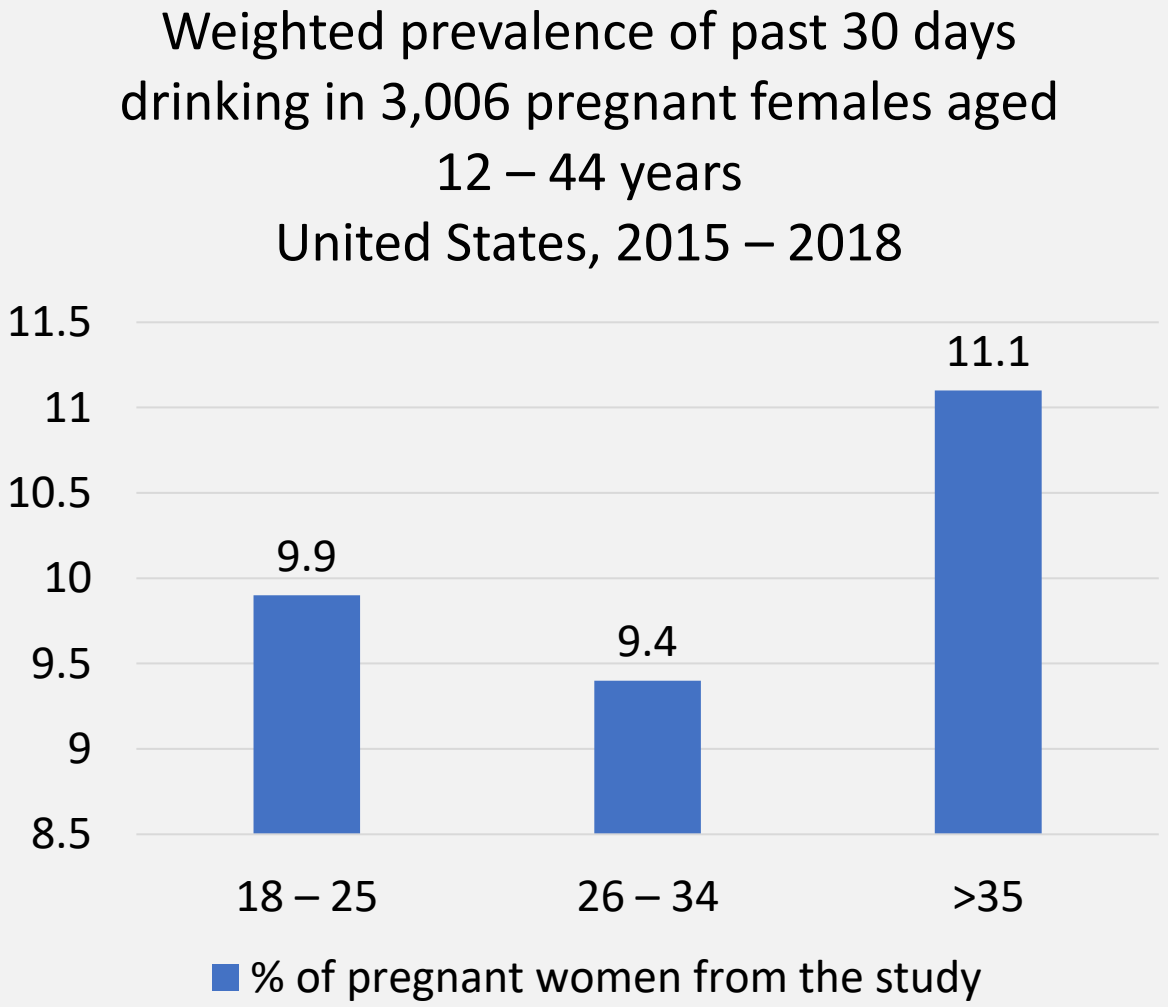




Source: www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

DEMOGRAPHIC BREAKDOWN: AGE

About 11% of pregnant women currently drinking are older than 35 years old

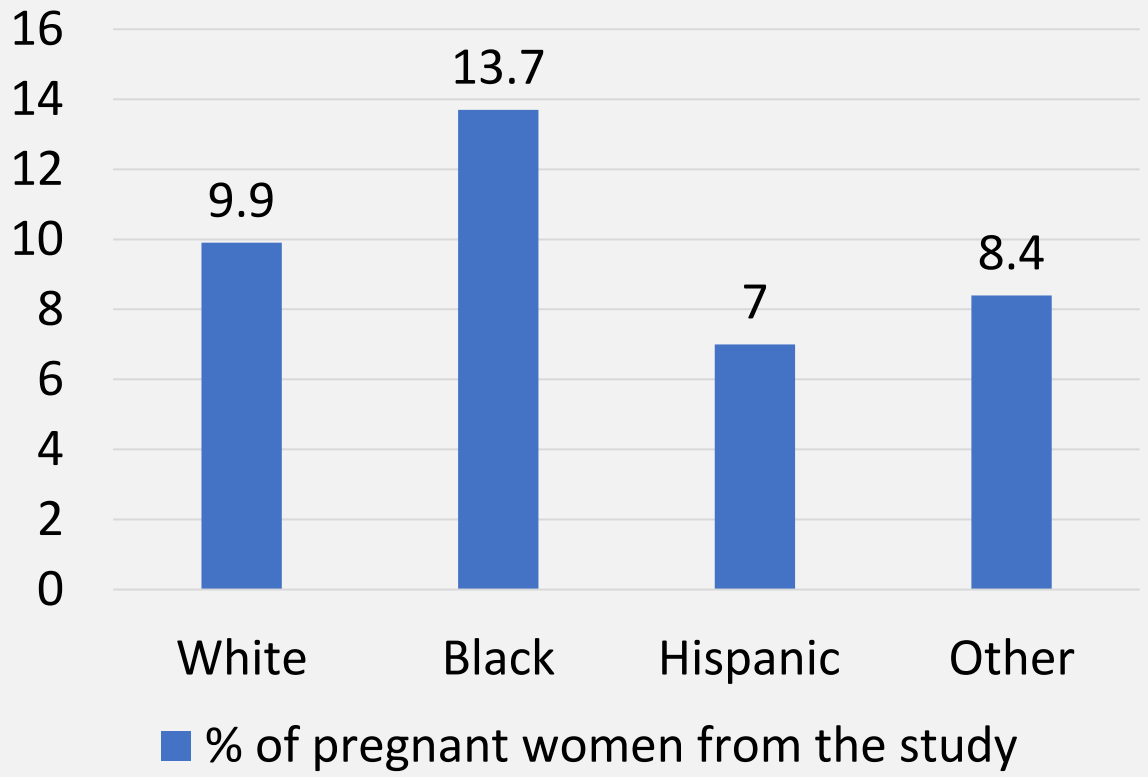


Source: www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

DEMOGRAPHIC BREAKDOWN: RACE/ETHNICITY

Almost 14% of pregnant women who reported currently drinking identified as Black

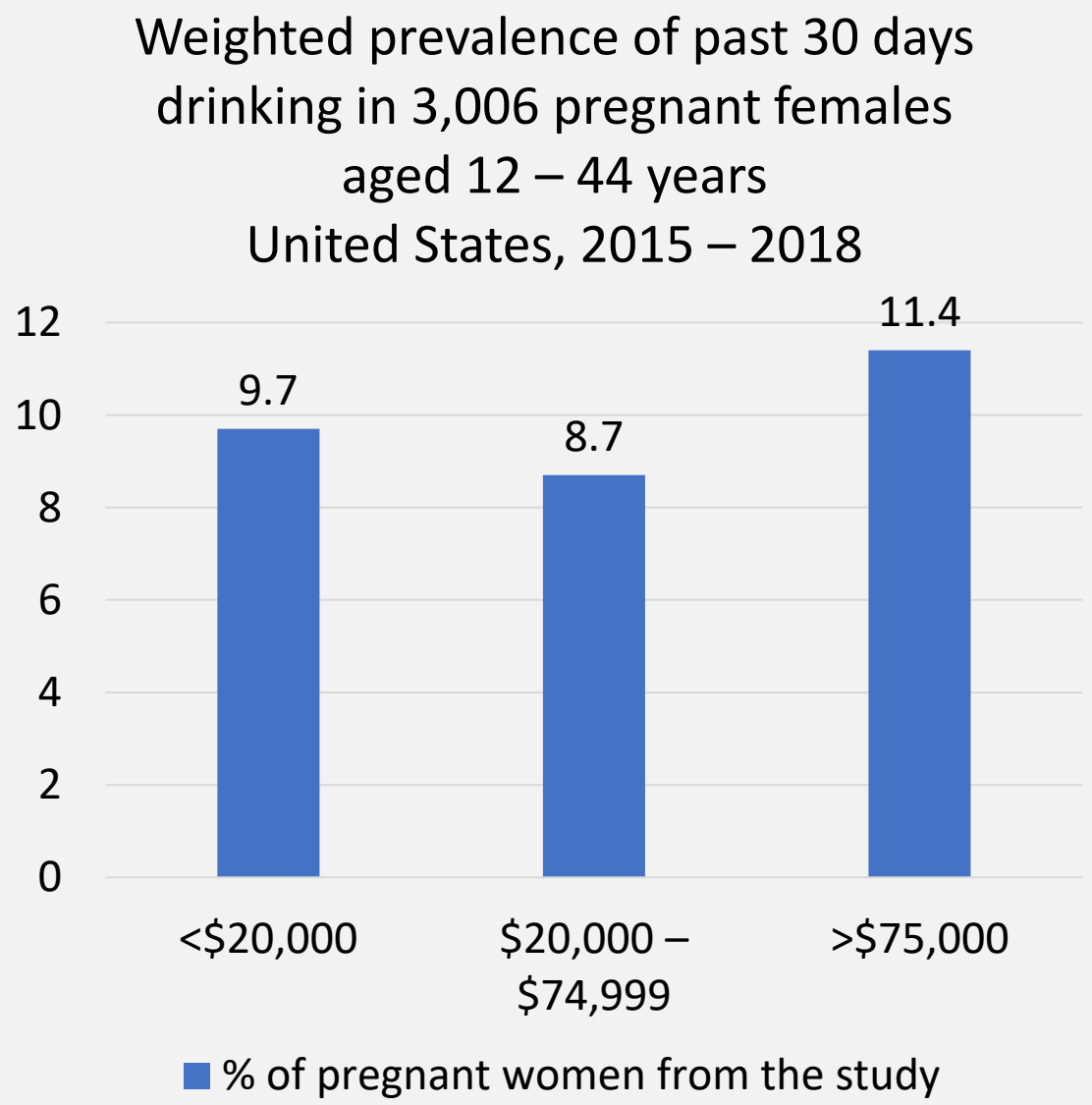
Weighted prevalence of past 30 days drinking in 3,006 pregnant females aged 12 – 44 years, United States, 2015 – 2018



Source: www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

DEMOGRAPHIC BREAKDOWN: INCOME

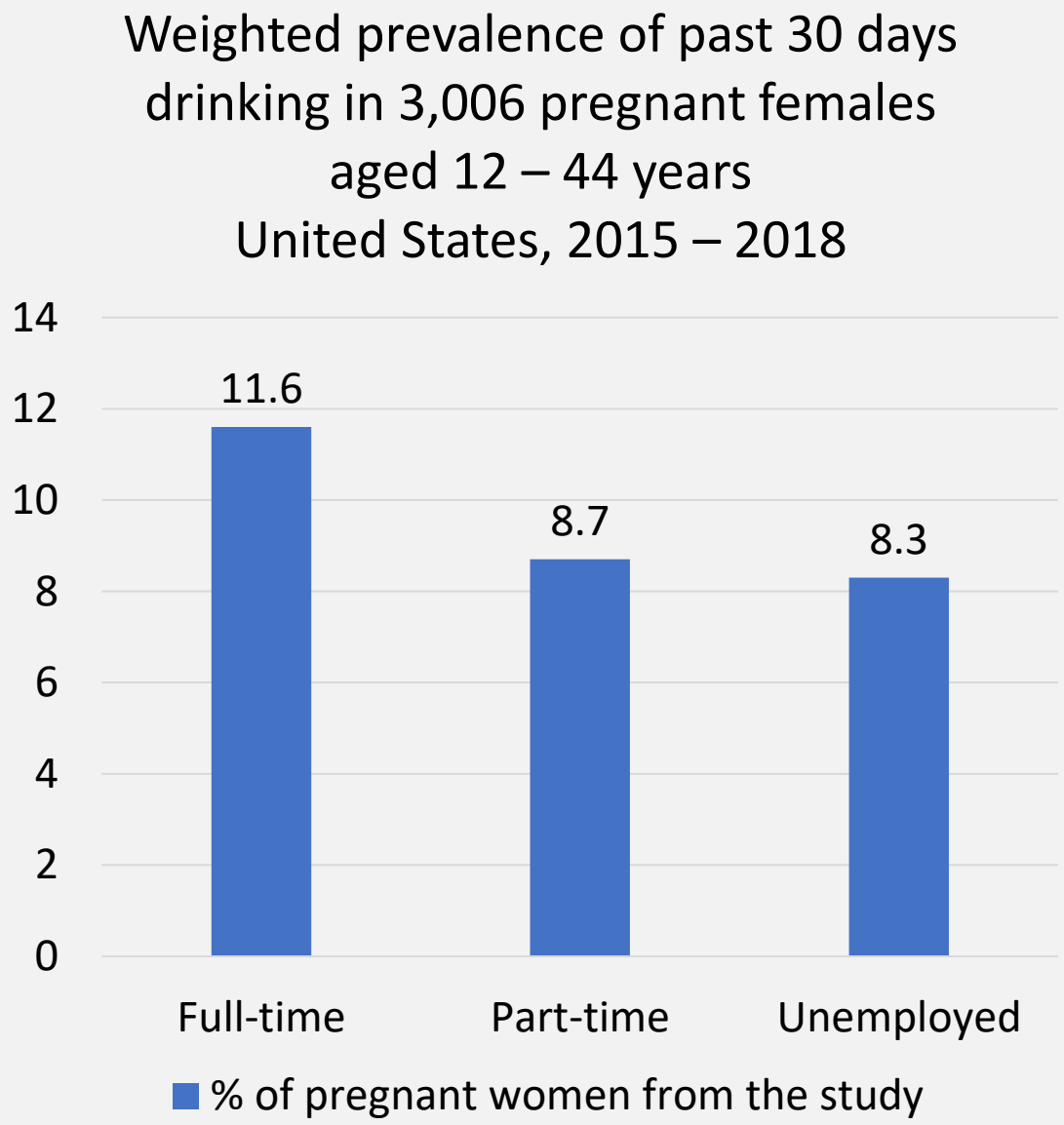
- **11.4% of pregnant women who reported currently drinking made more than $75,000 as income**
- **Only 9% of pregnant women who reported currently drinking made between $20,000 and $74,999 as income**



Source: www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

DEMOGRAPHIC BREAKDOWN: EMPLOYMENT

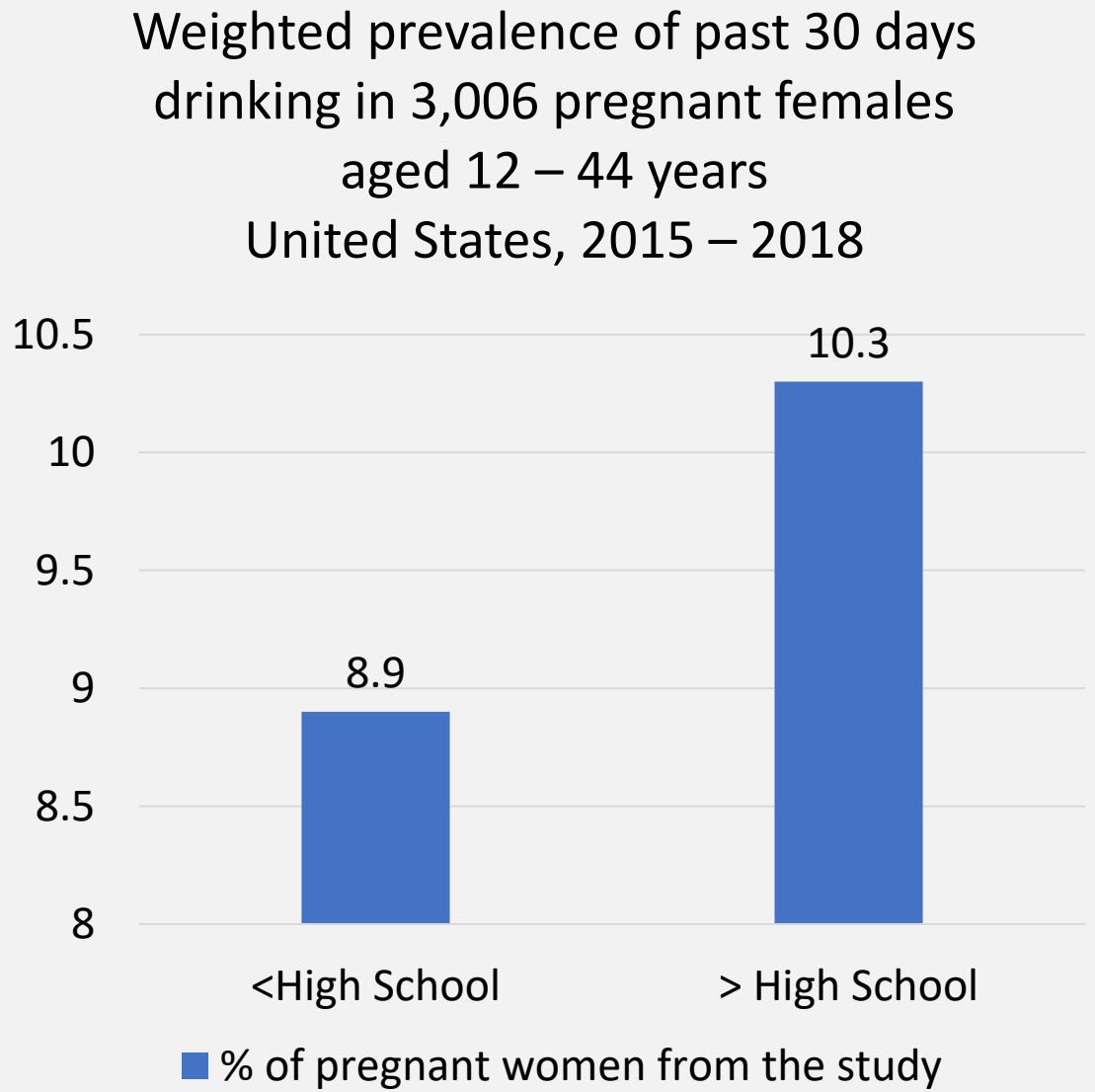
- **11.6% of pregnant women currently drinking reported working full-time**
- **About 8% reported to be unemployed**



Source: https://www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

DEMOGRAPHIC BREAKDOWN: EDUCATION

- **More than 10% of pregnancy women currently drinking completed more than a high school degree**
- **Less than 9% of pregnant women currently drinking completed less than a high school degree**

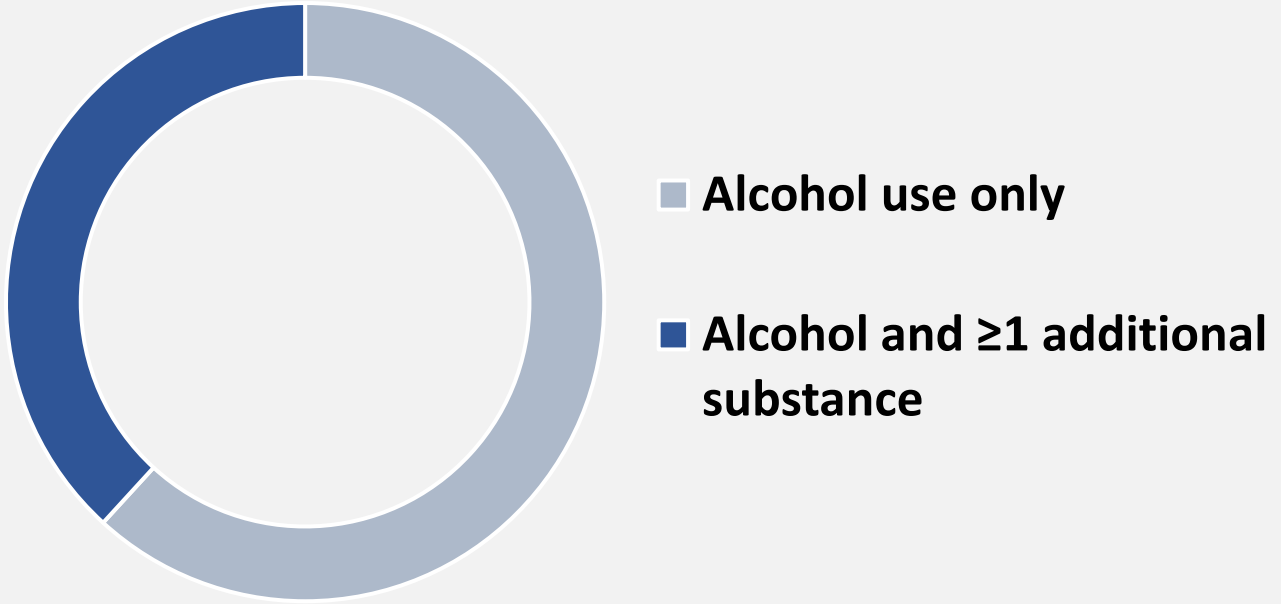


Source: www.cdc.gov/mmwr/volumes/69/wr/pdfs/mm6931a1-H.pdf

ALCOHOL AND OTHER SUBSTANCE USE

Approximately **40%** of pregnant individuals reporting current drinking also **reported current use of other substances**

Pregnant females who drank in the past 30 days (n = 282*)

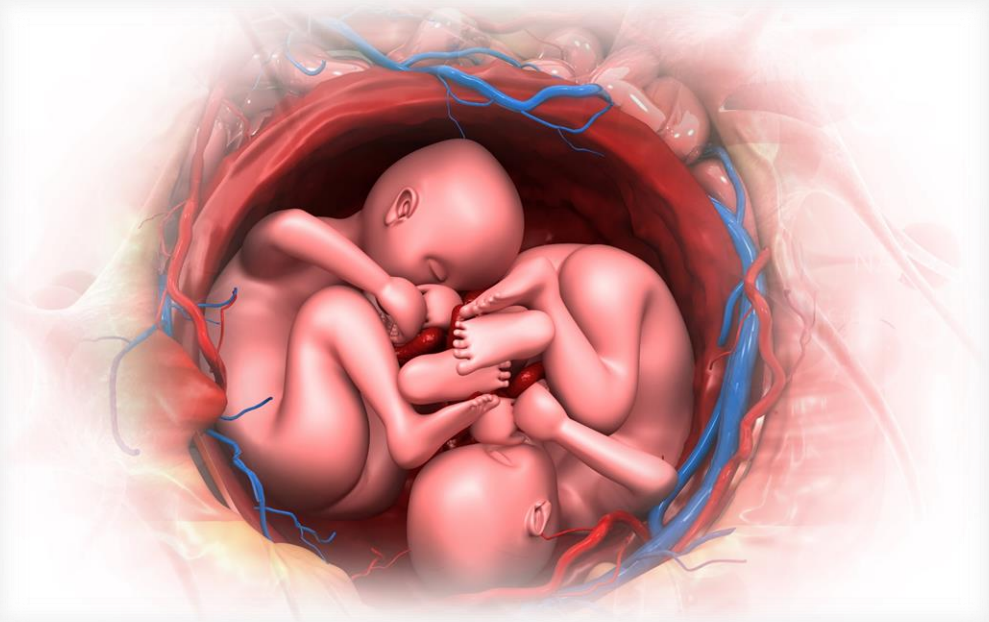


Source: www.cdc.gov/mmwr/volumes/69/wr/mm6931a1.htm?s_cid=mm6931a1_w#T1_down

OUTCOMES OF ALCOHOL-EXPOSED PREGNANCIES ARE DEPENDENT ON FETAL GENETICS[6]

A twin study found that nearly identical alcohol exposure in utero, such as between dizygotic twins, can result in immensely different child outcomes.

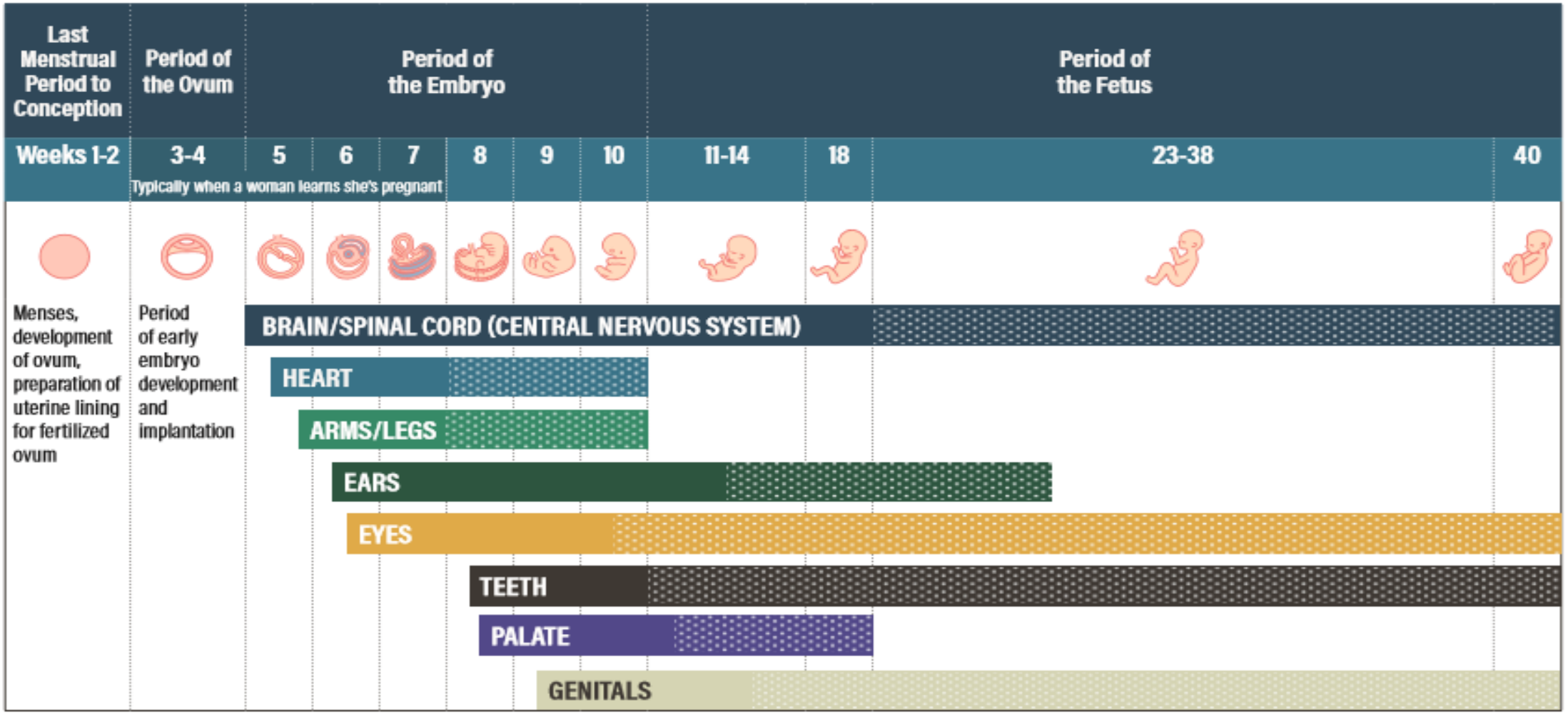
There is currently no way to predict which fetuses are more or less vulnerable.



CDC says…
NO known safe amount,
NO safe time, and
NO safe type of alcohol during pregnancy.

Alcohol and Brain Development

Brain development can be affected by alcohol at any time during pregnancy



MAJOR STRUCTURAL defects can occur

MAJOR FUNCTIONAL and MINOR STRUCTURAL defects can occur

*Adapted from Moore, 1993 and the National Organization on Fetal Alcohol Syndrome (NOFAS), 2009.

LONG-TERM EFFECTS

FASDs last a lifetime. There is no cure for FASDs, but research shows that early intervention treatment services can improve a child's development.

CS323487-A

Source: http://www.cdc.gov/vitalsigns/fasd/index.html

HERE'S WHAT WE KNOW: ZERO EXPOSURE = ZERO RISK

- Any alcohol exposure during pregnancy increases the chances of a baby developing an FASD.
- FASDs are permanent conditions and cannot be cured.
- Beer and wine are just as harmful as hard liquor.
- Binge drinking is especially harmful.*

**Binge = 4 or more standard drinks on one occasion for women*

WOMEN AND RISKY ALCOHOL USE[22]

Women are at higher risk than men from the same amount of alcohol use. Women's blood alcohol content (BAC) raises more quickly on average due to:

- Lower average body weight
- Lower concentration of water in women's bodies

WHAT COUNTS AS A STANDARD DRINK?[23]

12 oz Beer	8 – 9 oz Hard Seltzer	5 oz Wine	1.5 oz Spirit
			
~5% alcohol	~5 – 7% alcohol	~12% alcohol	~40% alcohol

WHAT IS LOW-RISK DRINKING?[24]

- Low-risk is not no risk.
- Women and people over 65 are generally advised to have no more than 3 drinks on any day and 7 drinks per week.
- Based on individual health and alcohol's effects, it may be advisable to drink less or not at all.

WHAT IS HEAVY OR AT-RISK DRINKING?[24]

- A "heavy-drinking day" is considered more than 4 drinks in a day for men and 3 drinks in a day for women and people over 65 years of age.
- About 1 in 4 people who drinks this much already has a substance use disorder and the rest are at a greater risk for developing these and other problems.

SHORT TERM RISKS[25]

- Injuries
- Violence
- Alcohol poisoning
- Risky sexual behavior
- For pregnant women: miscarriage, stillbirth, FASDs

LONG TERM RISKS[25]

- High blood pressure, heart disease, stroke, liver disease, and digestive problems
- Cancers
- Weakened immune system
- Learning and memory problems
- Mental health problems
- Social problems
- Alcohol use disorder

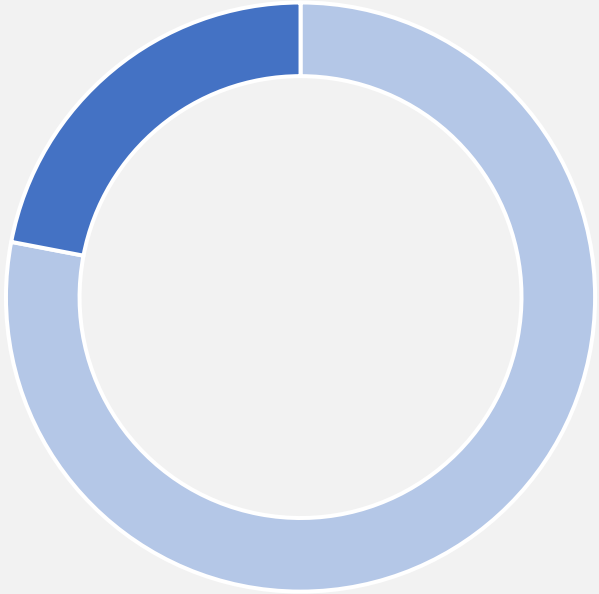
PREVENTION AND RISK REDUCTION

- Prevention starts with asking
- Use effective screening tools
- Ask routinely as part of your prenatal care
- Brief interventions can contribute to prevention

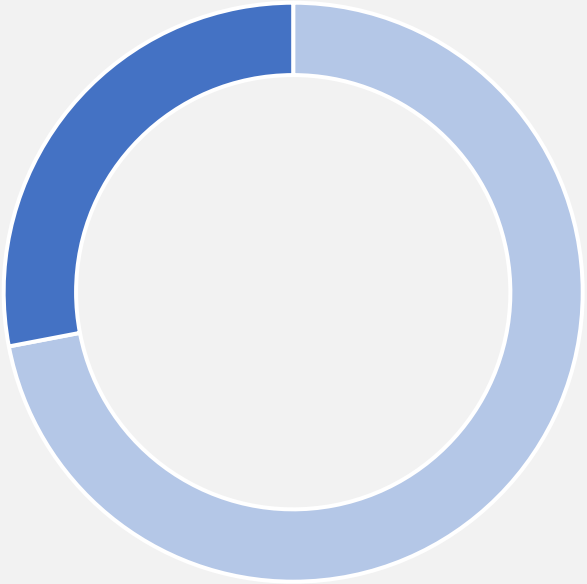
2010 SURVEY OF 800 ACOG FELLOWS[26]

58% did not use a validated screening tool

22% did not recommend abstinence



28% did not feel prepared to screen patients



97% of pregnant women surveyed

felt it was **appropriate** for their providers to **screen them** for alcohol use at **prenatal visits**

99% said they would disclose

their alcohol use if screened.[27]

SCREENING, BRIEF INTERVENTION AND REFERRAL TO TREATMENT (SBIRT)

Screening quickly
assesses the severity of substance use and identifies the appropriate level of intervention.

Brief intervention
focuses on increasing insight and awareness regarding substance use and motivation toward behavioral change.

Referral to treatment
provides those identified as needing more extensive treatment with access to specialty care.

Doctors, nurses, or other health professionals should screen every adult patient, including pregnant women, and counsel those who drink too much. Providers can help women avoid drinking too much, including avoiding alcohol during pregnancy, in 5 steps.

1 Assess a woman's drinking.

- Use a validated screener (e.g., AUDIT {US}*).
- Take 6-15 minutes to explain results and provide counseling to women who are drinking too much.
- Advise her not to drink at all if she is pregnant or might be pregnant.
- Come up with a plan together.

2 Recommend birth control if a woman is having sex (if appropriate), not planning to get pregnant, and is drinking alcohol.

- Review risk for pregnancy and importance of birth control use.
- Discuss full range of methods available.
- Encourage her to always use condoms to reduce risk of sexually transmitted diseases.

3 Advise a woman to stop drinking if she is trying to get pregnant or not using birth control with sex.

- Discuss the reasons to stop alcohol use before the woman realizes she is pregnant.

4 Refer for additional services if a woman cannot stop drinking on her own.

- Provide information on local programs or go to SAMHSA treatment locator. www.findtreatment.samhsa.gov
- Consider referral to treatment or recommend Alcoholics Anonymous. www.aa.org

5 Follow up yearly or more often, as needed.

- Set a time for return appointment.
- Continue support at follow-up.

 Source: www.cdc.gov/vitalsigns/fasd/index.html ACOG Resource Directories

EFFECTIVE INTERVENTION[28]

Brief interventions for at-risk alcohol and drug use are significantly more likely to occur if persons are screened with a standardized, validated instrument, such as the AUDIT (US) or CAGE-AID.

High rates of screening can be achieved if such screening is integrated into a clinical setting's existing care processes with well-planned information technology support.

Alcohol Screening and Brief Intervention (aSBI) Reference Guide

Utilize the USAUDIT[1] screening tool to assess a patient for risky alcohol use.

USAUDIT-C*	SCORING							SCORE
	0	1	2	3	4	5	6	
How often do you have a drink containing alcohol?	Never	Less than monthly	Monthly	Weekly	2–3 times a week	4–6 times a week	Daily	
How many drinks containing alcohol do you have on a typical day you are drinking?	1 drink	2 drinks	3 drinks	4 drinks	5–6 drinks	7–9 drinks	10 or more drinks	
How often do you have 4 or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	2–3 times a week	4–6 times a week	Daily	
							TOTAL:	

SCORING*: Pregnant: any use | **Non-pregnant:** ≥ 7 pts

Scores are considered positive for identifying risky drinking. Follow up with the full USAUDIT[1] to assess for alcohol use disorders that may require referral to treatment. **Adapted for the ob-gyn audience to only include information on screening women. See footnote[1] for original version.*

1. Babor TF, Higgins-Biddle JC, Robaina K. USAUDIT: the alcohol use disorder identification test, adapted for use in the United States: a guide for primary care practitioners. 2016. [accessed 2017 Dec 10]. https://www.ct.gov/dmhas/lib/dmhas/publications/USAUDIT-2017.pdf

---

When a patient screens positive for risky alcohol use, engage them in brief intervention using motivational interviewing such as the FRAMES[2] approach on the following page. If patient is pregnant, incorporate information about risks to her health and the developing baby.

1 Raise the subject / Build rapport	*"Do you mind if we talk about alcohol use?"*
2 Provide feedback	Explore using MI FRAMES (see next page)
3 Build readiness to change	Use Readiness Ruler (see next page)
4 Negotiate a plan	*"Can we follow-up at your next visit to check-in? Would you be willing to try cutting back by X drinks?"*

Core MI FRAMES Skills[2]

- **F** **Feedback**—Compare the patient's risk behavior with nonrisk behavior patterns. She may not be aware that what she considers normal is risky.
- **R** **Responsibility**—Stress that it is her responsibility to make the change.
- **A** **Advice**—Give direct advice (not insistence) to change the behavior.
- **M** **Menu**—Identify "risk situations" and offer options for coping.
- **E** **Empathy**—Use a style of interaction that is understanding and involved.
- **S** **Self-efficacy**—Elicit and reinforce self-motivating statements such as "I am confident that I can stop drinking." Help the patient to develop strategies, implement them, and commit to change.

2. Bien T, Miller W, Tonigan J. Brief interventions for alcohol problems: a review. Addiction 1993;88:315-336.

Key Techniques & Example Language

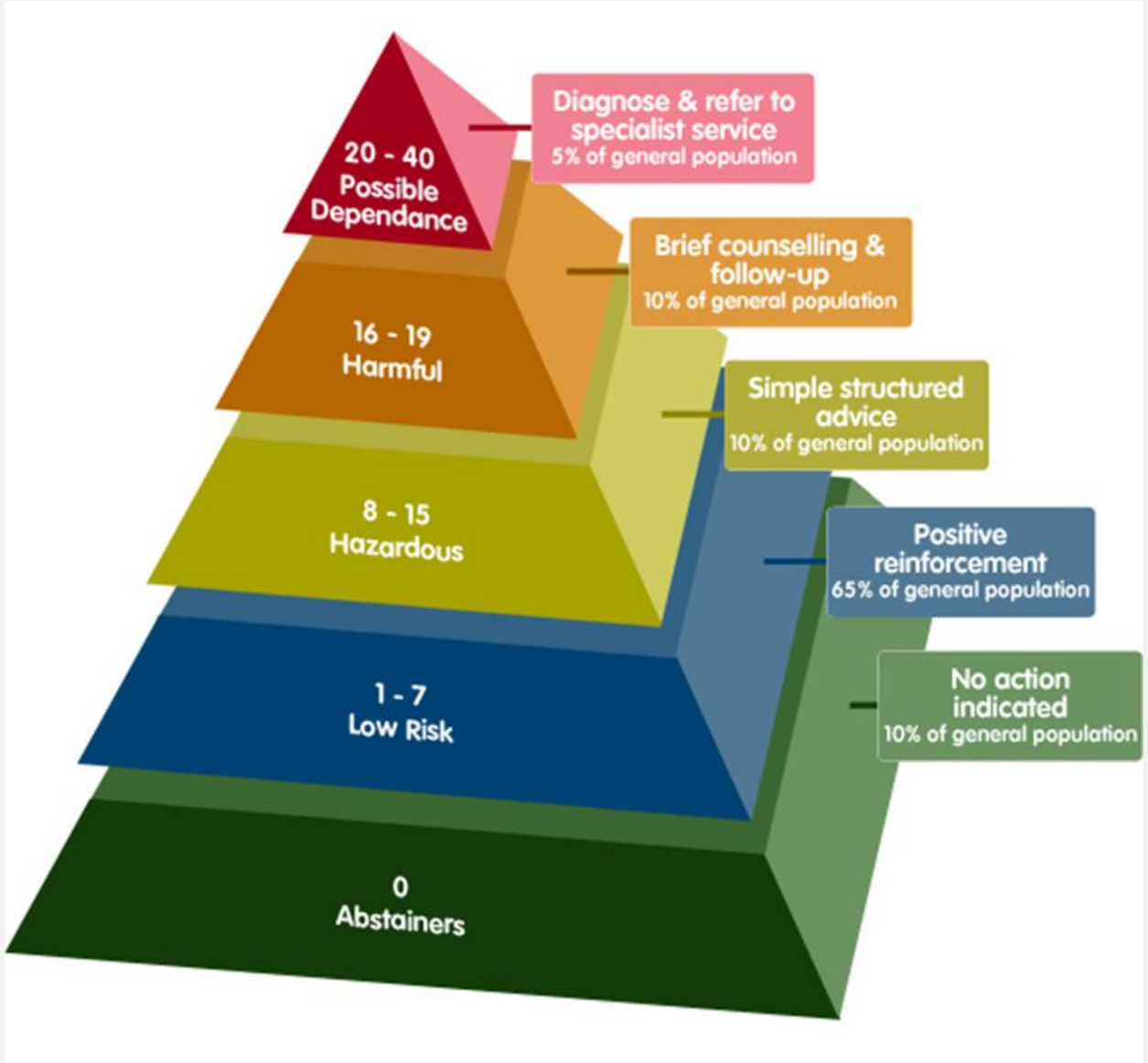
Express Empathy	• *I can imagine that you might feel...* • *I care about your health and want to understand your feelings about...*	
Develop Discrepancy	**Non-Pregnant Patients** • *I'm curious, what do you like about drinking...what don't you like about drinking...*	**Pregnant Patients** • *So, it sounds like drinking alcohol occasionally helps you to relax, but you're also concerned about your developing baby's health...*
Roll with Resistance	**Non-Pregnant Patients** • *So, you don't think abstinence would work for you right now...*	**Pregnant Patients** • *It sounds like you may have received conflicting advice and that is confusing to you...*
Support Self-Efficacy	• *What would a realistic change look like for you?* • *What changes have you tried that worked in the past?* • *What would help make reducing your alcohol use possible?*	

Readiness Ruler | **On a scale from 1 to 10:** How ready are you? How confident are you?

1	2	3	4	5	6	7	8	9	10
Not at all				Somewhat				Extremely	

INTERVENTION

- We are targeting the 20% of at-risk drinkers.
- Brief interventions are effective and can be performed in an office visit—for women who are drinking at risky levels but not dependent/addicted, raising the subject can be enough to get them to stop or cut back.
- Referrals to treatment should be based upon individual risk factors and patient motivation.



WHAT IS MOTIVATIONAL INTERVIEWING?[29]

Motivational Interviewing DOES:

- Elicit change from within the patient and not from outside influences.
- See readiness to change as a fluctuating product of interpersonal interaction.
- Believe that it is the patient's task to resolve ambivalence to change.
- See the therapeutic relationship as a partnership with the patient.

Motivational Interviewing DOES NOT:

- Argue that a patient has a problem and needs to change.
- Use an authoritative or expert stance, leaving the patient in a passive role.
- Impose a diagnostic label.
- Utilize a punitive or coercive manner.

ALCOHOL, PREGNANCY AND STIGMA

Women who drink or drank alcohol during pregnancy often experience:

- Judgmental attitudes from service providers
- Feeling of shame and/or guilt
- Depression
- Low self-esteem
- Fear of losing their children

REDUCE STIGMA[38]

- Move away from the behavior of the individual and onto the substance of alcohol
- Stigma prevents women from speaking openly with their health care providers or their child's pediatrician
- Change your language as you write and talk about FASDs. Use the term "prenatal alcohol exposure" rather than "maternal alcohol exposure"
- Support efforts that will increase access to substance use treatment for women and their children

REFERRAL TO TREATMENT

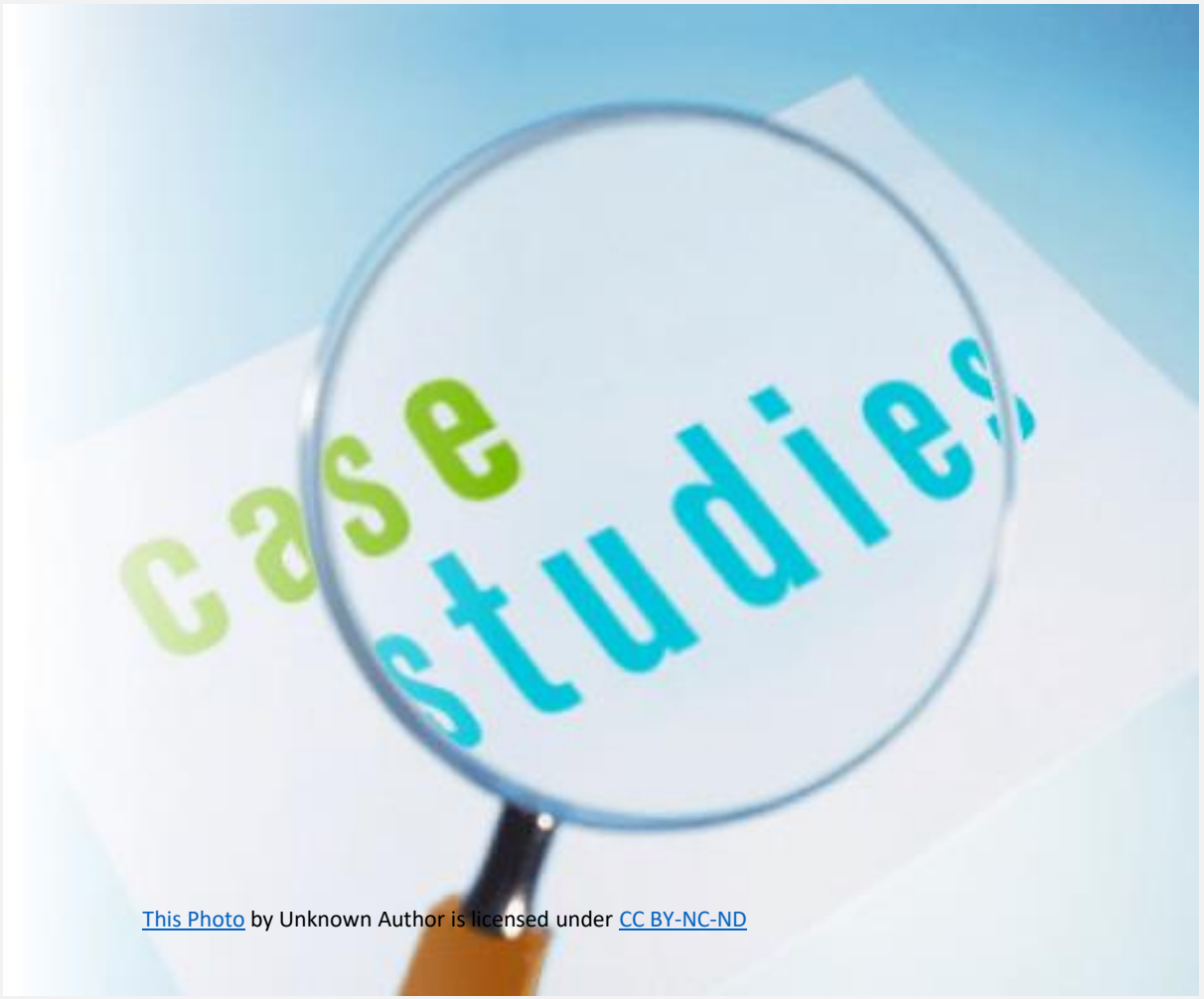
ACOG district directories: state specific resources for alcohol and drug treatment, FASD diagnosis, and other supportive services. Available at www.acog.org/alcohol

National Clinician Substance Use Consultation Center Warmline: Clinically supported advice on substance use management for healthcare providers https://nccc.ucsf.edu/clinician-consultation/substance-use-management/ or call (855) 300-3595 Monday – Friday, 9 a.m. – 8 p.m. ET

The Substance Abuse and Mental Health Services Administration (SAMHSA) treatment locator: https://www.findtreatment.gov/

The FASD United Circle of Hope: support group for women who use alcohol and other substances during pregnancy. Learn more at http://fasdunited.org/

Case Studies & Skills Practice



RESOURCES

Centers for Disease Control and Prevention (CDC)

Trainings, resources, brochures, posters, fact sheets

Collaborative for Alcohol-Free Pregnancy

Partnering for Practice Change

OV

American College of Obstetricians and Gynecologists

Provider and Patient Education Materials, Videos

www.acog.org/alcohol

FASD

Fetal Alcohol Spectrum Disorders Prevention

CDC TRAININGS

CDC Website

- Fetal Alcohol Spectrum Disorders (FASD) Training And Resources
  www.cdc.gov/FASDtraining

FASD Training Courses

- FASD Primer for Healthcare Professionals
- Preventing Alcohol-Exposed Pregnancies (AEPs)
- Diagnostic Overview of FASDs: Recognition and Referral
- Implementing Alcohol Screening and Brief Intervention in Clinical Practice
- Interprofessional Collaborative Practice as a Model for Prevention of AEPs

Mircrolearnings

- How to Begin a Conversation about Alcohol Use
- Making a Referral for an FASD Assessment: How to Talk with Families

FREE E-MODULE: ETHICS CME AND MOC

www.acog.org/education-and-events/emodules/emod019

WEBSITES AND SUPPORT

Federal Government Sites

Centers for Disease Control and Prevention (CDC): www.cdc.gov/fasd

National Institute on Alcohol Abuse and Alcoholism: www.niaaa.nih.gov/

National Institute on Drug Abuse: www.nida.nih.gov/

National Clearinghouse for Alcohol and Drug Information (NCADI): www.addiction.com/a-z/samhsas-national-clearinghouse-for-alcohol-and-drug-information/

Organizations

FASD United fasdunited.org/

- The Circle of Hope - Birth Mothers Network

The Arc of the United States www.thearc.org

NPs, Midwives, and Nurses: Partnering to Prevent FASDs: tinyurl.com/askaboutalcohol

REFERENCES

1. Hass et al. Cochrane Database of Systematic Reviews 2015; Issue 11. https://www.cochrane.org/CD011445/PREG_ethanol-alcohol-preventing-preterm-birth

2. Office of the Surgeon General. Press Release: "U.S. Surgeon General Releases Advisory on Alcohol Use in Pregnancy, February 21, 2005." Available at: www.hhs.gov/surgeongeneral/pressreleases/sg02222005.html

3. May PA, Chambers CD, Kalberg WO, Zellner J, Feldman H, Buckley D, et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA 2018;319(5):474-482.; https://www.cdc.gov/ncbddd/fasd/data.html

4. Popova S, Lange S, Probst C, Gmel G, Rehm J. Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. The Lancet Global Health 2017;5:e290-99.

5. Alcohol and Pregnancy. CDC Vital Signs. https://www.cdc.gov/vitalsigns/fasd/

6. Hemingway SJA, Bledsoe JM, Davies JK, Brooks A, Jirikowic T, Olson EM, et al. Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes fetal genetics influences fetal vulnerability. Advances in Pediatric Research 2019. https://www.longdom.org/articles/twin-study-confirms-virtually-identical-prenatal-alcohol-exposures-can-lead-to-markedly-different-fetal-alcohol-spectrum.pdf

7. Atypical fetal development: Fetal alcohol syndrome, nutritional deprivation, teratogens, and risk for neurodevelopmental disorders and psychopathology. Dev Psychopathol. 2018

8. Breastfeeding SO. Breastfeeding and the use of human milk. Pediatrics. 2012

9. Alcohol and breastfeeding. Basic Clin Pharmacol Toxicol. 2014

10. Drinking and smoking at 3 months postpartum by lactation history. Paediatr Perinat Epidemiol. 1990

11. Pediatrics August 2018; Breastfeeding and the use of human milk. Pediatrics. 2012

12. Cook JL, Green CR, de la Ronde S, Dell CA, Graves L, et al. Epidemiology and Effects of Substance Use in Pregnancy. Journal of Obstetrics and Gynaecology Canada 2017; 39(10):906–915. http://www.sciencedirect.com/science/article/pii/S170121631730508X?via%3Dihub

13. American College of Obstetricians and Gynecologists' Committee on Obstetric Practice, Mascola M, Borders AE, Terplan M. Committee Opinion 711: Opioid Use and Opioid Use Disorder in Pregnancy. ACOG Committee Opinion 2017. https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2017/08/opioid-use-and-opioid-use-disorder-in-pregnancy

14. Logan BA, Brown MS, Hayes MJ. Neonatal Abstinence Syndrome: Treatment and Pediatric Outcomes. Clinical Obstetrics and Gynecology 2013; 56(1):186–192. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3589586/

15. Benz J, Rasmussen C, Andrew G. Diagnosing fetal alcohol spectrum disorder: History, challenges and future directions. Pediatrics Child Health 2009;14(4): 231–237. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690536/

REFERENCES

16. Holmes AV, Atwood EC, Whalen B, Beliveau J, Jarvis JD, et al. Rooming-In to Treat Neonatal Abstinence Syndrome: Improved Family-Centered Care at Lower Cost. Pediatrics 2017;140(5). http://pediatrics.aappublications.org/content/early/2016/05/17/peds.2015-2929

17. Popova S et al. What Research Is Being Done on Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorders in the Russian Research Community? Alcohol and Alcoholism 2011;46:490-7. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3865815/

18. 5 P's Integrated Screening Tool. Institute for Health and Recovery 2005. http://www.mhqp.org/guidelines/perinatalpdf/ihrintegratedscreeningtool.pdf

19. Centers for Disease Control and Prevention. Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, 2014. https://www.cdc.gov/ncbddd/fasd/documents/alcoholsbiimplementationguide.pdf

20. American College of Obstetricians and Gynecologists' Committee on Health Care for Underserved Women. Committee Opinion 473: Substance Abuse Reporting and Pregnancy: The Role of the Obstetrician-Gynecologist. ACOG Committee Opinion 2014. https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2011/01/substance-abuse-reporting-and-pregnancy-the-role-of-the-obstetrician-gynecologist

21. Shea P. Distinguishing Fetal Alcohol Spectrum Disorders from Autism Spectrum Disorder. Medical Home Portal 2017. Retrieved from https://www.medicalhomeportal.org/issue/distinguishing-fetal-alcohol-spectrum-disorders-from-autism-spectrum-disorder

22. National Institute on Alcohol Abuse and Alcoholism. (2019). Women and Alcohol. Retrieved from https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/women-and-alcohol

23. National Institute on Alcohol Abuse and Alcoholism. (2008). Using the NIAAA clinician's guide. Retrieved from http://pubs.niaaa.nih.gov/publications/practitioner/CliniciansGuide2005/Guide_Slideshow.htm

24. National Institute on Alcohol Abuse and Alcoholism. (2010). Rethinking drinking: Alcohol and your health. (NIH publication no. 13-3770). Washington, DC: National Institutes of Health. p. 4.

25. Centers for Disease Control and Prevention. (2019). Alcohol Use and Your Health. Retrieved from https://www.cdc.gov/alcohol/fact-sheets/alcohol-use.htm#:~:text=Over%20time%2C%20excessive%20alcohol%20use,liver%20disease%2C%20and%20digestive%20problems.&text=Cancer%20of%20the%20breast%2C%20mouth,esophagus%2C%20liver%2C%20and%20colon

26. Anderson B et al. J Addiction Med 2010:3:114-21.

27. Marchetta et al. Alcohol Use and Binge Drinking Among Women of Childbearing Age – United States, 2006-2010. MMWR Morbidity and Mortality Weekly Report 2021. 61(28). https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6128a4.htm?s_cid=mm6128a4_w

28. Johnson, J. A., Woychek, A., Vaughan, D., & Seale, J. P. (2013). Screening for at-risk alcohol use and drug use in an emergency department: Integrating screening questions into electronic triage forms achieves high screening rates. Annals of Emergency Medicine, 62(3), 262-266.

29. Rollnick, S., & Miller, W. R. (n.d.). What is MI? Retrieved from http://www.motivationalinterview.net/clinical/whatismi.html

30. Can Benzodiazepines Be Used During Pregnancy? (2019). American Addiction Centers. Retrieved from https://americanaddictioncenters.org/benzodiazepine/can-benzodiazepines-be-used-during-pregnancy

REFERENCES

31. Phenobarbital Pregnancy and Breastfeeding Warnings. (2020) Drugs.com Retrieved from https://www.drugs.com/pregnancy/phenobarbital.html

32. Johnson BA. Naltrexone long-acting formulation in the treatment of alcohol dependence. Therapeutics and Clinical Risk Management, 2007.

29. Holmes AV, Atwood EC, Whalen B, Beliveau J, Jarvis JD, et al. Rooming-In to Treat Neonatal Abstinence Syndrome: Improved Family-Centered Care at Lower Cost. Pediatrics 2017;140(5). http://pediatrics.aappublications.org/content/early/2016/05/17/peds.2015-2929

30. Popova S et al. What Research Is Being Done on Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorders in the Russian Research Community? Alcohol and Alcoholism 2011;46:490-7. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3865815/

31. 5 P's Integrated Screening Tool. Institute for Health and Recovery 2005. http://www.mhqp.org/guidelines/perinatalpdf/ihrintegratedscreeningtool.pdf

32. Centers for Disease Control and Prevention. Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, 2014. https://www.cdc.gov/ncbddd/fasd/documents/alcoholsbiimplementationguide.pdf

33. Miller N and Gold M. Management of Withdrawal Syndromes and Relapse Prevention in Drug and Alcohol Dependence. American Family Physician, 1998. Retrieved from https://www.aafp.org/afp/1998/0701/p139.html

34. Naltrexone Pregnancy and Breastfeeding Warnings. (2019) Drugs.com Retrieved from https://www.drugs.com/pregnancy/naltrexone.html

35. Astley, S.J., Bailey, D., Talbot, T., Clarren, S.K. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS Diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. Alcohol & Alcoholism, (35) 5: 509-519.

36. American College of Obstetricians and Gynecologists. (2021). Caring for patients who have experienced trauma: ACOG committee opinion, number 825. Obstet Gynecol, 137(1), e94-e99.

37. Substance Abuse and Mental Health Services Administration . SAMHSA™s Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884 . Rockville : SAMHSA ; 2014 . Available at: https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4884.pdf . Retrieved November 24, 2020.

38. FASD United. FASD. http://fasdunited.org/

Treatment Across the Lifespan for Persons with Fetal Alcohol Spectrum Disorders

Presented by:

Yasmin Senturias, MD, FAAP

Collaborative for Alcohol-Free Pregnancy
Partnering for Practice Change

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

UC San Diego
SCHOOL OF MEDICINE

Rady Children's Hospital San Diego

School of Medicine and Public Health
UNIVERSITY OF WISCONSIN-MADISON

Acknowledgments

The AAP and the Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through National Partnerships collaborative thank the following experts for their help in developing this series of presentations:

- David Wargowski, MD, Kenneth L Jones, MD, Prachi Shah, MD, Yasmin Senturias, MD, Vincent C Smith, MD, MPH FAAP, H. Eugene Hoyme, MD, and Miguel Del Campo, MD (Screening, Assessment, and Diagnosis)
- Yasmin Senturias, MD, FAAP (ND-PAE)
- Yasmin Senturias, MD, FAAP, Vincent C. Smith, MD MPH FAAP, Prachi Shah, MD, and Joseph F. Hagan, MD FAAP (Treatment Across the Lifespan for Person with FASD)

Funded by the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention: U38OT0001, U84DD0011 & U84DD0010

Learning Objectives

1. Describe developmental and functional concerns for individuals with FASDs and their families across the lifespan.
2. Explain various treatment and support approaches for individuals with FASDs and their families.
3. Identify potential referrals, secondary conditions, risk factors, and care planning for individuals with FASDs.

Relevance to the Medical Home

- 1% to 5% of children affected; prenatal alcohol exposure (PAE) is the most prevalent cause of intellectual disability.
- PAE affects development and function; most pediatricians have patients with FASDs.
- Lifelong effects: cognitive & behavioral issues and perhaps growth or other physical issues.
- Serious consequences if not identified.

"Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus."

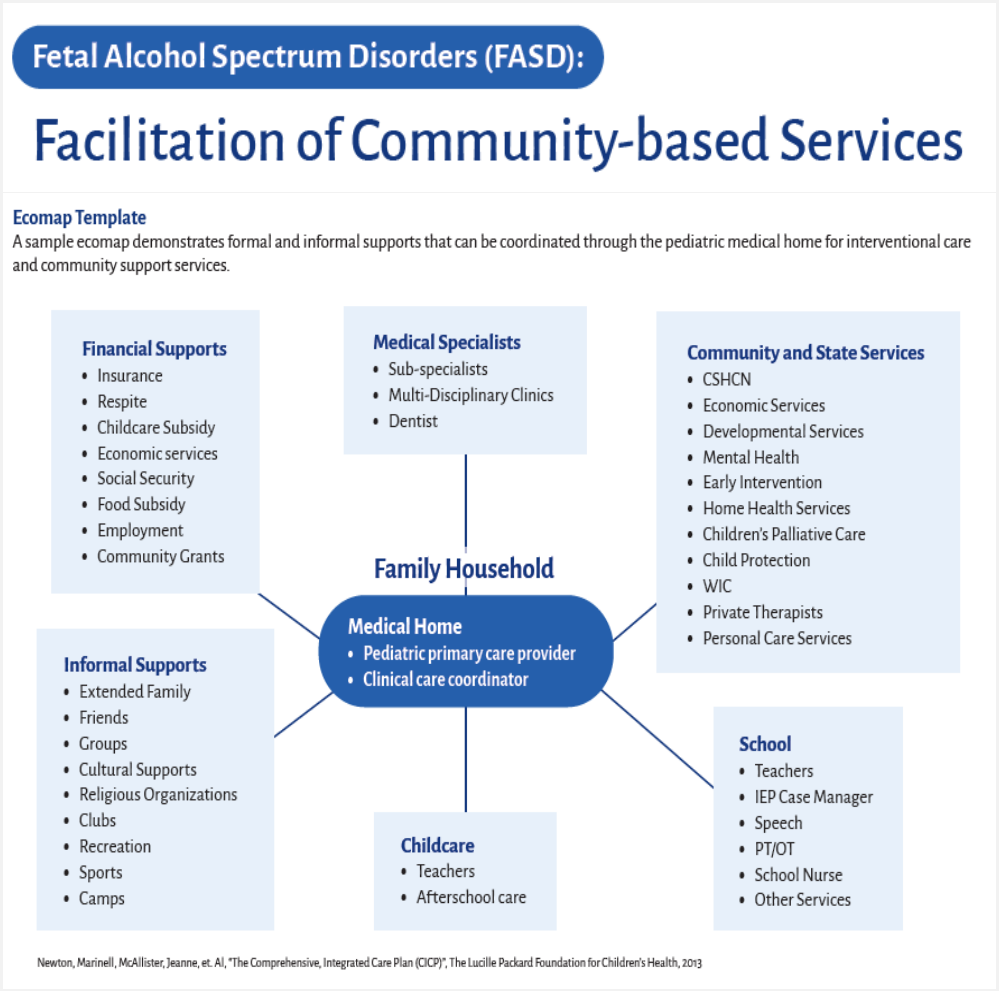
- Institute of Medicine, 1996

Beyond the Medical Home

- Problems related to prenatal alcohol exposure (PAE) may present to anyone who comes in contact with the child or family
  - Nurses and allied health professionals
  - Mental health (psychiatrists, psychologists, counselors)
  - Educators
  - Therapists (PT, OT ST, behavior)
  - Child welfare professionals & social workers
  - Addiction medicine

Beyond the Medical Home

- Anyone can make a referral or suggest a referral for diagnosis and management
- Support family through diagnostic process,
  answer questions
- Collaborate on treatment plan
- Participate in ongoing care
- **CONTINUED IDENTIFICATION OF EMERGING ISSUES**



Family-Centered Care

Recovery-friendly principles:

- Dyadic approach: parent's health and child's health and wellbeing.
- Recognize and build on strengths of parents and caregivers.
- Engage all members of the practice in using medically accurate and non-judgmental language.
- Collaborate with community-based providers (e.g., WIC, healthy start) 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.

Brain-Based Neurobehavioral disorder

Neurobehavioral Characteristics – functional impairments of:

- **Self-regulation –** attention, impulsivity, emotional lability, outbursts
- **Neurocognition –** learning, memory, math, executive functioning, visual-spatial, IQ/DD
- **Adaptive functioning –** communication, social, daily living skills, motor

Physical Characteristics (~20% of affected children)

- Growth restriction in height/weight/head circumference
- Facial features
  - Smooth philtrum
  - Thin upper lip
  - Short palpebral fissures

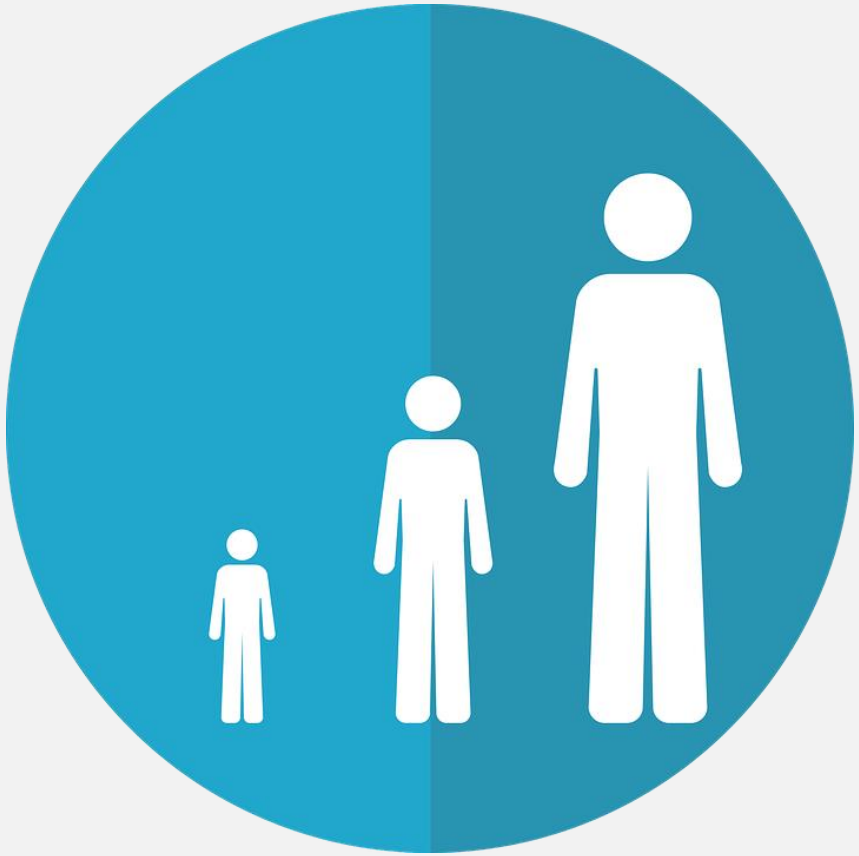
Source: Dr. Sarah Mattson, University of San Diego

Challenges to Identification and Management

- Insufficient training
- Discomfort with diagnosis
- Insufficient clinicians aware of, knowledgeable about, or accepting of diagnosis
- Bias
- Fear of stigmatizing the mother and child

Concerns Across the Life Span

- ✓ Birth to three years
- ✓ Preschool-School-age
- ✓ Adolescence



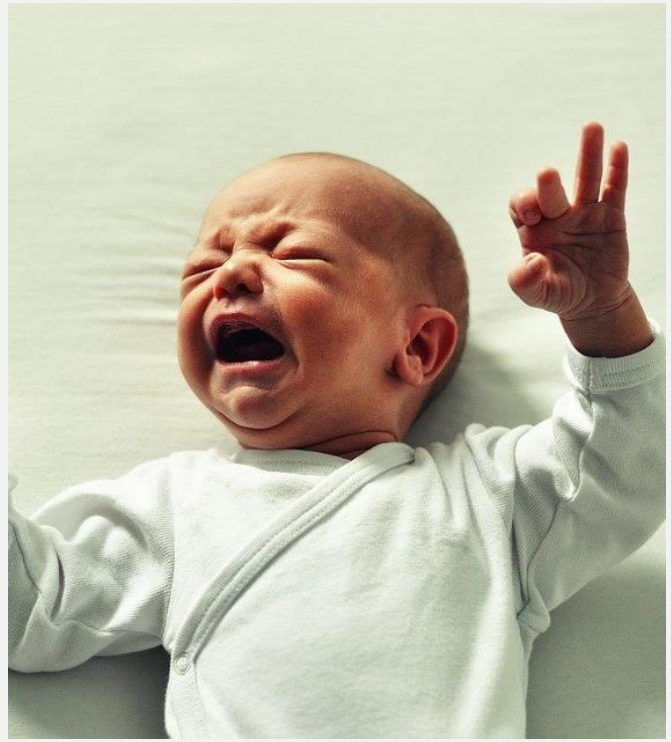
Common Presenting Concerns for 0-3 Years

Self-regulation – sleep, mood, and sensory deficits which may lead to feeding issues in infancy; later, impulsivity, distractibility

Neurocognition – may have normal milestones but have difficulty retaining skills, learning, or following instructions

Adaptive functioning – Social learning is particularly troublesome.

- Social and communication deficits
- Fine motor delays: drawing/ability, putting on clothes, ADLs



Common Presenting Concerns for 0-3 Years

Physical – Poor immune function, otitis media, upper respiratory infections.

- Feeding concerns – poor weight gain, failure to thrive
- Medical issues stemming from physical/congenital abnormalities (e.g. cardiac anomalies, seizures)

Management: 0-3 Years Old

Neurobehavioral Supports

- Early Intervention (EI) – adaptive skills and self-regulation
- Allied services: speech therapy, OT, PT
- Specialty care as indicated (e.g. sleep medicine, cardiology, behavior management)
- Calming strategies, treat ADHD – self regulation

Management: 0-3 Years Old

Medical Home

- Promote good sleep
- Promote exercise
- Promote healthy diet & good feeding habits
- Avoid overstimulation
- Address other medical concerns, as needed
- Be proactive even if infant is meeting milestones
- Practice Trauma Informed and Recovery Friendly care

Management: 0-3 Years Old

Specialty Referrals

- Early Intervention
- Speech, Occupational, Physical therapy
- Mental Health
- FASD-informed therapists
- Medical referrals as needed (Cardiology, Neurology, ENT, Sleep, etc.)

Management: 0-3 Years Old

Parental guidance

- Nurture the child's strengths
- Remind the child of his/her strength
- Explain brain basis for difficulties
- Explain "Can't vs Won't" interpretations of learning, memory or self regulation problems
- Stress importance of consistency and structure
- Parent support groups such as FASD United or Parent-to-Parent

Management: 0-3 Years Old

FASD specific, evidence-based/informed interventions

- 1:1 parent centered intervention to:
- Build advocacy skills
- Improve parenting skills
- Reduce parent stress
- Can be conducted remotely or APP
- Example: *Families Moving Forward* familiesmovingforward@seattlechildrens.org

Medications

- AAP & others recommend behavioral interventions first for attention/impulsivity, e.g. Parent Behavior Management Training
- Choline
- Melatonin for sleep

Common Presenting Concerns for Preschool to School-age: Neurocognition

- IQ
- Learning & memory: encoding, auditory memory, loss of mastered skills
- Executive functioning
- Math knowledge & skill
- Visual-spatial deficits/ grapho-motor
- Social skills, attention shifting

Common Presenting Concerns for Preschool to School-age: Self-Regulation

- Attention problems (shifting, sustaining & encoding)
- Impulsivity
- Difficulty with compliance
- Mood dysregulation (tantrums, outbursts, moodiness)
- Irritability
- Sleep/wake disturbances

Common Presenting Concerns for Preschool to School-age: Adaptive Functioning

Poor socialization

Difficulty learning social rules

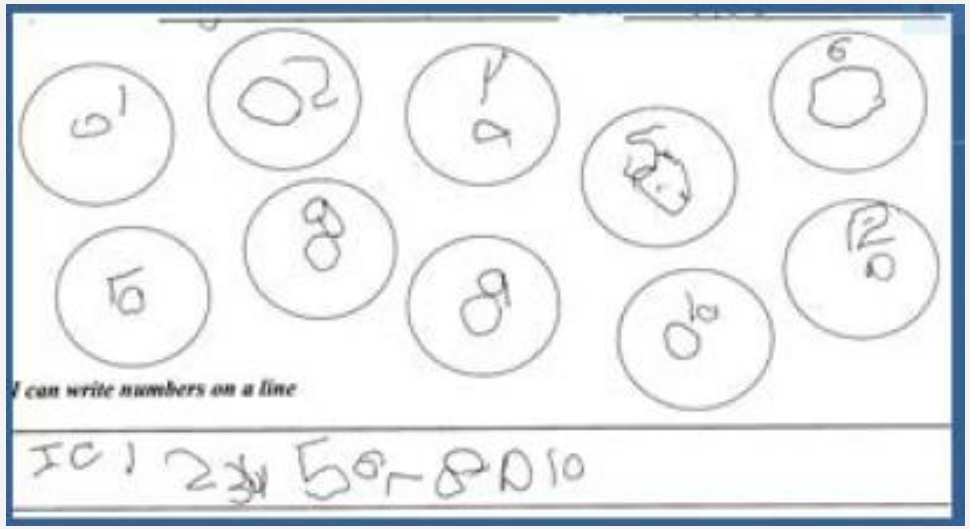
- slipping in, turn-taking, friendships

Poor social communication

- idioms, jokes, sarcasm
- acting younger

Common Presenting Concerns for Preschool to School-age: Adaptive Functioning cont.

- Poor boundaries (overly friendly)
- Poor writing skills (fine motor)
- Difficulty managing daily schedule



Numbers by 6-yr-old with an FASD

Source: Courtesy of J. Kable

Common Presenting Concerns for Preschool to School-age: Medical

- ADHD
- Anxiety
- Depression
- Sleep problems
- Impaired immune function (frequent otitis media & upper respiratory infections)

Management, Preschool to School-Age: Parental (and Teacher) Guidance

- Reiterate brain basis for difficulties
- Suggest picture schedules, visual cues and concrete instructions
- Incorporate explicit teaching strategies
- Teach calming strategies, teach in “calm alert states”

- Introduce concept of “zone of regulation”
- Because FASDs are often undiagnosed or under diagnosed, teacher and special educators feel they lack experience working with children with FASDs
- IEP or 504 plan under eligibility of “other health impaired” or intellectual disability if appropriate.

Management, Preschool to School-Age: Parental (and Teacher) Guidance

- Help reframe interpretation of behaviors from “Won’t” to “Can’t”
- Explain that transitions (e.g., new school year) may be difficult or result in regression of skills
- Encourage parent support groups such as FASD United or Parent-to-Parent
- Introduce a simplified learning environment, reduce distraction
- Reduce chances of failure or making wrong choices

Management, Preschool to School-Age: Medical Home

- Nurture the child's strengths
- Provide appropriate referrals for developmental , behavioral and other medical needs—FASD clinic, DBP, genetics, sleep medicine, endocrinology, cardiology, neurology
- Address sleep problems and difficulties with self-regulation (may require Melatonin)
- Treat comorbid conditions such as anxiety, ADHD by referring for therapy (prescribe medication as necessary)
- Anticipatory guidance: monitor friendships, bullying, peer pressure
- Promote good sleep, exercise, and healthy diet
- Practice trauma informed and recovery friendly care

Management: Preschool to School-Age

Referrals

- Special education (Part C/EI for preschoolers)
- Neuropsychological evaluation to determine strengths & weakness
- Allied services: speech therapy, OT, PT
- Specialty care as indicated, especially mental health/behavior management
- Refer to therapist who can deliver trauma-informed care.

Management: Preschool to School-Age

Medications

- AAP & others recommend parent behavioral therapy first for attention/impulsivity
- Choline/melatonin
- Be mindful of “prescription cocktails”

Management: Preschool to School-Age
FASD specific, evidence-based/informed interventions

- *MILE* – math knowledge and skills
- *Go Far* computer programs – executive functioning, fire safety, street safety
- *Good Buddies* – social skills and peer relationships
- *Parents and Children Together* and *Zones of Regulation* – internal awareness and executive functioning

Sample Evidence-Based Interventions for children with FASDs

MILE Program

- Tutoring, 1:1 or group
- FAR: Focus & Plan->Act->Reflect loop
- Behavioral component
- Adaptive materials
- Parent workshop

Courtesy of J. Kable

GoFAR

- Control impulsive and problem behaviors
- Five 1 hour sessions
- *FAR*: "F" Focus/Plan, "A" Act, "R" Reflect
- Caregivers are an important part of GoFAR.

Courtesy of J. Kable

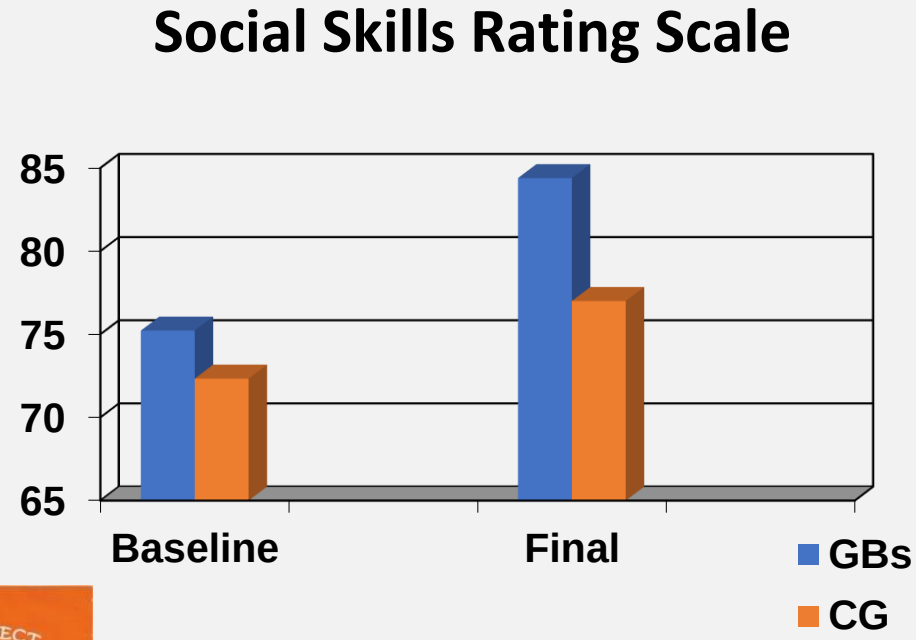
FIRE SAFETY

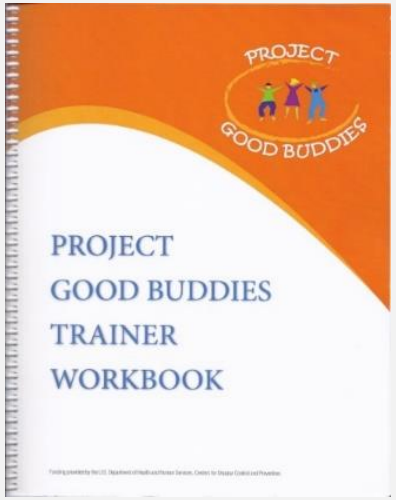
STREET SAFETY

Sample Evidence Based Interventions for children with FASDs

Good Buddies

- 12-week group sessions for child & parents
- Instruction + practice + homework.
- Build a play date
- Explicit, “in-your-pocket”





Sample Evidence Based Interventions for children with FASDs

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.

Parent And Children Together (PACT)

- Based on ALERT program developed for children with ADHD
- “How is your engine running?”
- Coordinated parent education component

Common Presenting Concerns for Adolescents

Age applicable problems in self-regulation, neurocognition & adaptive functioning

Secondary Issues, especially w/o intervention or supports:

- School drop out
- Homelessness
- Inappropriate sexual behavior
- Encounters with law enforcement (including confinement)

Medical:

- Higher risk of substance use
- Risky behaviors
- Unplanned pregnancy & STDs
- Worsening mental health issues
- Clearance for driving

Common Presenting Concerns for Adolescents

Self-Regulation

- ADHD
- Mood/anger
- Sleep issues
- Impulsivity

Common Presenting Concerns for Adolescents

Neurocognition

- Executive function
- IQ (Verbal and Nonverbal IQ)
- Learning (esp. math and writing)
- Memory
- Visual spatial skills
- Information processing
- Judgment and metacognition
- Risk of school dropout

Common Presenting Concerns for Adolescents

Adaptive Functioning

- Difficulties with peers and social relationships
- Dysmaturity (inappropriate expectations for maturity)
- Difficulty with complex language
- Poor activities of daily living

Management: Adolescents Educational Settings

- Monitor for learning, attention, and educational problems
- Neuropsychological testing to assess for higher order neurocognitive deficits
- Work on obtaining IEP, if not done yet
- Continue to nurture talents, skills, and strengths

Management: Adolescents Medical Home

- Neuropsychological re-testing to assess for higher order deficits and strengths
  - ADHD
  - Anxiety
  - Depression
  - DMDD
- Prevent and address substance use
- Counsel patient on risky sexual behavior (well before the teenage years and repeatedly after)
- Refer to therapist to deliver trauma-informed care, refer to OT/ST as needed
- Promote good sleep, healthy diet, and exercise
- Involve in the community (volunteer)
- Discuss transition planning with family

Management: Adolescents Transition Plan

- Create an environment that prepares the adolescent for the joys and challenges of adulthood
- May require application for supported living/housing/ and later for employment
- May require application for disability

Special Topic: Legal Issues

Types of Trouble with the Law

- Victim of a crime
- Manipulated to commit a crime
- Unwittingly commits a crime
- Wrong crowd

Reasons People With An FASD Get In Trouble With The Law

- Lack of impulse control and understanding consequences
- Vulnerability to peer pressure
- Poor planning
- Difficulty connecting cause and effect
- Poor delay of gratification
- Impaired social communication

THE AAP FASD TOOLKIT

The AAP FASD Toolkit (www.aap.org/fasd) is a free comprehensive resource for identification, diagnosis and medical home management on patients with a FASD.

Toolkit includes information on common diagnostic approaches and tools, a flow diagram for evaluation of FASDs, and guidelines for referral and diagnosis.

Transitioning to Adulthood

The FASD Transition Toolkit: Charting Success for Individuals with FASD

- *Society of Developmental and Behavioral Pediatrics Special Interest Group*

Take-Homes

Almost all clinicians will care for children with FASDs.

Children with FASDs may manifest with neurobehavioral and physical features that may vary across the lifespan

- **S**elf-regulation
- **N**eurocognition
- **A**daptive
- **P**renatal alcohol exposure

Children with FASDs may benefit from skill-building, developmental, medical, educational, and parenting interventions.

Q&A: Moderated by Jenn Wisdahl

References

American Psychiatric Association. *The Diagnostic and Statistical Manual of Mental Disorders: Fifthe edition. Arlington, VA, American Psychiatric Association,* 2013.

Anderson, S., Bartholow, B., Jirikowic, T., Nash, J., Snow, J., and Stratiner, M., (2017, November). Developing Self-Regulation in Children with FASD Using the Zones of Regulation. SIS Quarterly Practice Connections. 2(4)5-7.

Chasnoff, I.J., Schmidt, C., Telford, E., Bailey, L., & Groessle, A. (2011). Parents And Children Together: Improving regulation for children with fetal alcohol spectrum disorders. Children's Research Triangle: Chicago, IL.

Coles, CD**,** Kable, JA, & Taddeo, E (2009) Math performance and behavior problems in children affected by prenatal alcohol exposure: Intervention and follow-up. Journal of Developmental and Behavioral Pediatrics, 30 (1), 7-15, PMID 19194327

Coles, CD, Kable, JA, Taddeo, E., Strickland, DC (2015) A Metacognitive Strategy for Reducing Disruptive Behavior in Children with Fetal Alcohol Spectrum Disorders: GoFAR Pilot Alcoholism: Clinical and Experimental Research, 39 (11), 2224-2233.PMID: 265030669

Coles, CD, Kable, JA, Taddeo, E, & Strickland, DA (2018, in press) GoFAR: Improving attention, behavior, and adaptive functioning in children with fetal alcohol spectrum disorders (FASD): Brief Report. Developmental Neurorehabilitation

Hagan JF, Shaw JS, Duncan PM. (2017) *Bright futures: Guidelines for health supervision of infants, children, and adolescents, 4th edition*: American Academy of Pediatrics Elk Grove Village, IL.

Hagan JF (Chair), Balachova T, Bertrand J, Chasnoff I, Dang E, Fernandez-Baca D, Kable J, Kosofsky B, Senturias YN, Singh N, Sloane M, Weitzman C, Zubler J on behalf of Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure Workgroup. (2016). **Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure** Pediatrics, 138 (4), e20151553 **doi:** 10.1542/peds.2015-1553.

Kable, JA, Coles, CD, & Taddeo, E (2007) Socio-Cognitive Habilitation using the Math Interactive learning Experience (MILE) Program for Alcohol-Affected Children. Alcoholism: Clinical and Experimental Research, 31 (8), 1425-1434.

Millians, M**.** (2015). Educational needs and care of children with FASD. *Current Developmental Disorders Reports*.2, 210-218. doi:10.1007/s40474-015-0055-5

References, continued

O'Connor MJ, Frankel F, Paley B, et al. A controlled social skills training for children with fetal alcohol spectrum disorders. Alcohol Clin Exp Res 2006: 24(4): 639-48.

O'Connor MJ, Quattlebaum J, Castañeda M, Dipple KM (2016). Alcohol Intervention for Adolescents with Fetal Alcohol Spectrum Disorders: Project Step Up, a Treatment Development Study Alcoholism: Clinical and Experimental Research 2016; DOI: 10.1111/acer.13111. Epub 2016 May 24

Olson HC, Oti R, Gelo J, Beck S. "Family matters:" Fetal alcohol spectrum disorders and the family. Dev Disabil Res Rev 2009; 15: 235-49.

Padgett, L. S., Strickland, D., Coles, C. D. J Case Study: using a virtual reality computer game to teach fire safety skills to children diagnosed with fetal alcohol syndrome (2006). ournal of Pediatric Psychology, 31(1):65-70. doi: 10.1093/jpepsy/jsj030. [PMID: 15829610]

Senturias Y, Burns B. (2014) Managing children and adolescents with fetal alcohol spectrum disorders in the medical home. *Curr Probl Pediatr Adolesc Health Care*. 44(4); 96-101.May et al., *Pediatrics* 2014;134(5);855-66

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics*. 2004;25(4):228-238.

Turchi RM; Smith VC; COMMITTEE ON SUBSTANCE USE AND PREVENTION; COUNCIL ON CHILDREN WITH DISABILITIES. The Role of Integrated Care in a Medical Home for Patients With a Fetal Alcohol Spectrum Disorder. (2018). Pediatrics. 142(4). **doi:** 10.1542/peds.2018-2333

Turchi RM, Antonelli R. Council on Children with Disabilities. AAP Policy Statement-Patient and Family Centered Care Coordination: Integrating Care for Children and Youth Across Multiple Systems. *Pediatrics*. 133 (5) May 2014: 1451-1460.

Team Understood, & Lee, AM (nd). The Difference Between IEPs and 504 Plans. Retrieved December 29, 2016, from https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans

Williams, J; Smith V.C. et. al., (2015) Clinical Report - Fetal Alcohol Spectrum Disorders. *Pediatrics* 136; 2015-3113

Supporting Transition in Care and Reproductive Health Care for Neurodiverse Persons

Case studies, discussion, and Q & A

Moderated by Lily Bastian

FASD NATIONAL PARTNER NETWORK

Case Study: Karla

19 years old, cis female, she/her pronouns

Transitioning from pediatric care to adult primary care/family care

Health history: Diagnoses of ADHD, anxiety

Medications: Has been on medication for ADHD and anxiety in the past and they worked well for her, but has been unable to get those medications in recent months.

Other information: Feels she is struggling without her ADHD medication but has been told by family members that now she's an adult she shouldn't need it; is sexually active

Case study: Terry

28 years old, AFAB, they/them pronouns

Annual preventive care/reproductive health appointment

Has never been to a reproductive healthcare appointment, rarely been to a healthcare provider since leaving their family's family care clinic in their late teens

Health history: Diagnoses of FASD, ADHD, learning disabilities as a child. No current medications, says didn't always remember to take them.

Case study: Rebecca

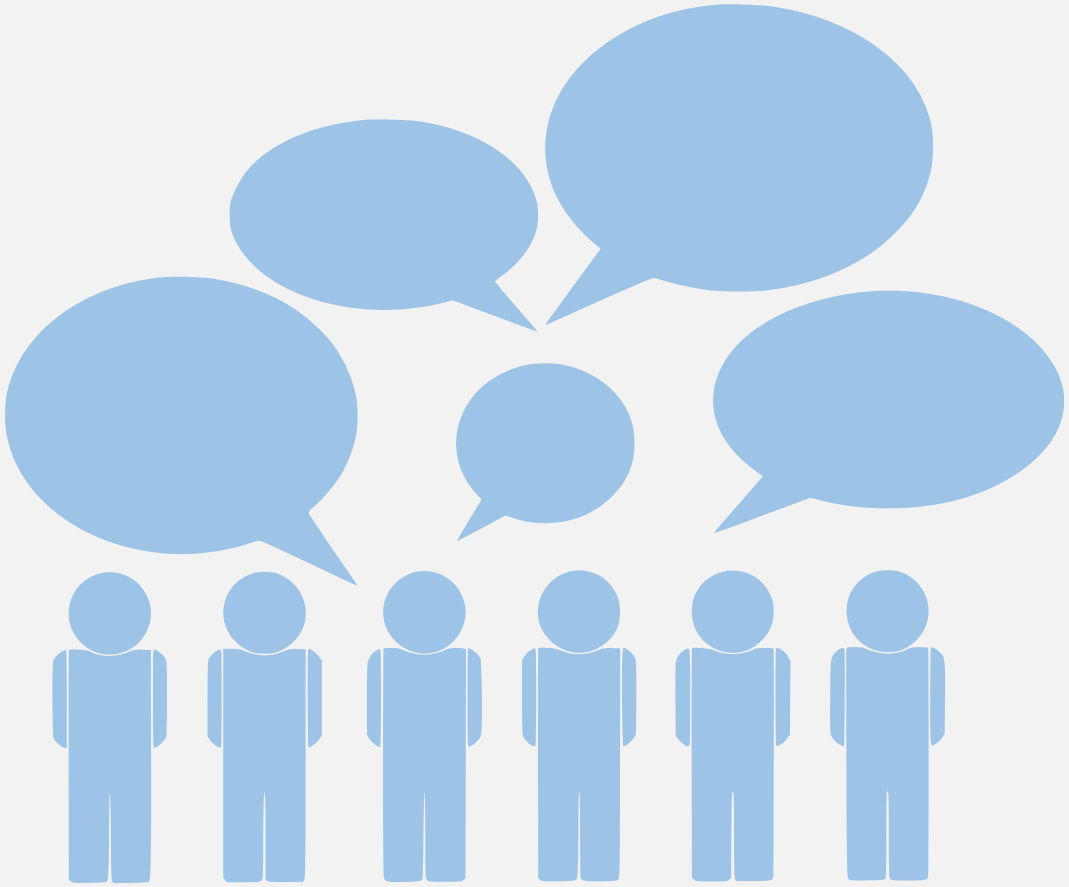
52 year old, cis female, she/her pronouns

Annual preventive care appointment

Attends these every 2-3 years, but not usually at the same clinic – this is the second time she's been to this one, but the last time was about 8 years ago

Health history: No official diagnoses, but knows that her mother drank at various points during her pregnancy, suspects that she may have an FASD after learning about it through a training at work.

Discussion



Resources

FASD United

NPs, Midwives, & Nurses: Partnering to Prevent FASDs

SCAN ME

CDC

Resources

AAP

AAFP

ACOG

Contact Information

AAP: Rosa Arvizu: rarvizu@aap.org

AAFP: Rajani Bharati: rbharati@aafp.org

ACOG: Absara Haile: ahaile@acog.org

FASD United: Jenn Wisdahl: wisdahl@fasdunited.org

University of Alaska Anchorage: Alexandra Edwards, aeedwards@alaska.edu

Thank you!

References

Anonymous. A personal experience of fetal alcohol spectrum disorder: finding a way to thrive. Developmental Medicine & Child Neurology. 2022;64(12):1442-1443. doi:10.1111/dmcn.15318

Carpita B, Migli L, Chiarantini I, et al. Autism spectrum disorder and fetal alcohol spectrum disorder: A literature review. Brain Sci. 2022;12(6) doi:10.3390/brainsci12060792

Coles CD, Grant TM, Kable JA, Stoner SA, Perez A, the Collaborative Initiative on Fetal Alcohol Spectrum Disorders. Prenatal alcohol exposure and mental health at midlife: A preliminary report on two longitudinal cohorts. Alcoholism: Clinical and Experimental Research. 2022;46(2):232-242. doi:10.1111/acer.14761

den Houting J. Neurodiversity: An insider's perspective. Autism. 2019;23(2):271-273. doi:10.1177/1362361318820762

Erng MN, Smirnov A, Reid N. Prevention of alcohol-exposed pregnancies and fetal alcohol spectrum disorder among pregnant and postpartum women: A systematic review. Alcoholism: Clinical and Experimental Research. 2020;44(12):2431-2448. doi:10.1111/acer.14489

Finnell DS, Nowzari S, Reimann B, Fischer L, Pace E, Goplerud E. Screening, Brief Intervention, and Referral to Treatment (SBIRT) as an integral part of nursing practice. Substance Abuse. 2014;35(2):114-118. doi:10.1080/08897077.2014.888384

Goodman DJ, Wolff KB. Screening for substance abuse in women's health: A public health imperative. Journal of Midwifery & Women's Health. 2013;58(3):278-287. doi:10.1111/jmwh.12035

References

Jacobson JL, Akkaya-Hocagil T, Ryan LM, et al. Effects of prenatal alcohol exposure on cognitive and behavioral development: Findings from a hierarchical meta-analysis of data from six prospective longitudinal U.S. cohorts. *Alcoholism: Clinical and Experimental Research*. 2021;45(10):2040-2058. doi:10.1111/acer.14686

Kautz-Turnbull C, Petrenko CLM. A meta-analytic review of adaptive functioning in fetal alcohol spectrum disorders, and the effect of IQ, executive functioning, and age. *Alcoholism: Clinical and Experimental Research*. 2021;45(12):2430-2447. doi:10.1111/acer.14728

Manriquez M, Starer J, Parisi V, Tracy E, McFadden T, Penney L. Fetal alcohol spectrum disorder prevention program: SBIRT's role in averting fetal alcohol spectrum disorders. *Birth Defects Research*. 2019;111(12):829-834. doi:10.1002/bdr2.1516

McLachlan K, Flannigan K, Temple V, Unsworth K, Cook JL. Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research*. 2020;44(8):1609-1624. doi:https://doi.org/10.1111/acer.14385

Ordenewitz LK, Weinmann T, Schlüter JA, et al. Evidence-based interventions for children and adolescents with fetal alcohol spectrum disorders – A systematic review. *European Journal of Paediatric Neurology*. 2021;33:50-60. doi:10.1016/j.ejpn.2021.02.001

Pagnin D, Zamboni Grecco ML, Furtado EF. Prenatal alcohol use as a risk for attention-deficit/hyperactivity disorder. *European Archives of Psychiatry and Clinical Neuroscience* 2019;269(6):681-687. doi:10.1007/s00406-018-0946-7

Rutman D. Becoming FASD informed: Strengthening practice and programs working with women with FASD. *Subst Abuse*. 2016;10(Suppl 1):13-20. doi:10.4137/sart.S34543

U.S. Preventive Services Task Force. Final recommendation statement: Unhealthy alcohol use in adolescents and adults: Screening and behavioral counseling interventions. U.S. Preventive Services Task Force. Accessed November 7, 2019. www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/unhealthy-alcohol-use-in-adolescents-and-adults-screening-and-behavioral-counseling-interventions