

Fetal Alcohol Spectrum Disorders (FASDs): Considerations in Provider Education and Health Systems, with Focus on Indigenous Populations

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No financial disclosures or conflicts of interest



Genetic Counseling

The process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.

- Abnormal fetal ultrasound
- Abnormal fetal genetic screening/testing results
- Teratogen exposure (*e.g.*, substance/**alcohol** use in pregnancy)
- Personal or family history of genetic disease (known or suspected), birth defects (*e.g.*, those associated with **FASD**), learning disability, fetal loss, recurrent miscarriage
- Work alongside MFM/MFM-geneticist (*e.g.*, **maternal FASD**)
- Evaluation and Assessment for children with birth defects, developmental delay, learning disabilities, etc., **diagnose FASD** and/or differentials



Objectives

How Health Providers/System can:

1. Improve their knowledge re: prenatal alcohol use and FASDs
2. Counsel, Diagnose, and Refer appropriately in the context of prenatal alcohol consumption, prevention, and intervention
3. Develop a healthcare program tailored for indigenous families with children who have FASD

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- What are FASDs?
- Inheritance of FASDs
- Diagnostic Criteria
- Why should we care?
- Who does FASD impact? ... with focus on Indigenous populations



Counsel, Diagnose, and Refer appropriately in the context of prenatal alcohol consumption, prevention, and intervention

- Personal Work
- Counseling & brief interventions in the prenatal period (PCP/OB)
- Appropriate diagnosis and referral in the postnatal period (pediatrician)
- Appropriate interventions and resources for the child and family (healthcare team)

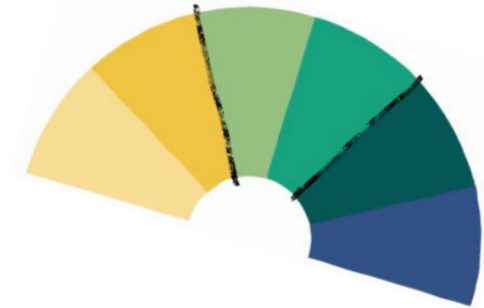
Develop a healthcare program tailored for indigenous families with children who have FASD

What are Fetal Alcohol Spectrum Disorders (FASDs)?

Group of conditions that occur in a person who was exposed to alcohol before birth. Effects range mild → severe and can include physical, mental, behavioral, and/or learning disabilities

- Fetal Alcohol Disorder (FAS) - ~20% of cases; most well-known, most severe and has **diagnostic criteria**.
- Alcohol-Related Birth defects (ARBD) - PAE and normal neurodevelopment with birth defects/dysplasias affecting organ systems and/or specific minor anomalies
- Alcohol-Related Neurodevelopmental Disorder (ARND) & Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)- PAE and CNS involvement: indicated by impairment in the following three areas: cognition, self-regulation, and adaptive functioning

The preceding do not meet the diagnostic criteria (typically, facial features) for FAS but have suggestive findings.



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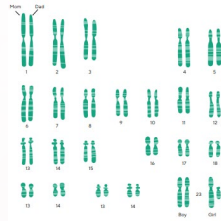
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Alcohol and Human Development

Genetics



Environment

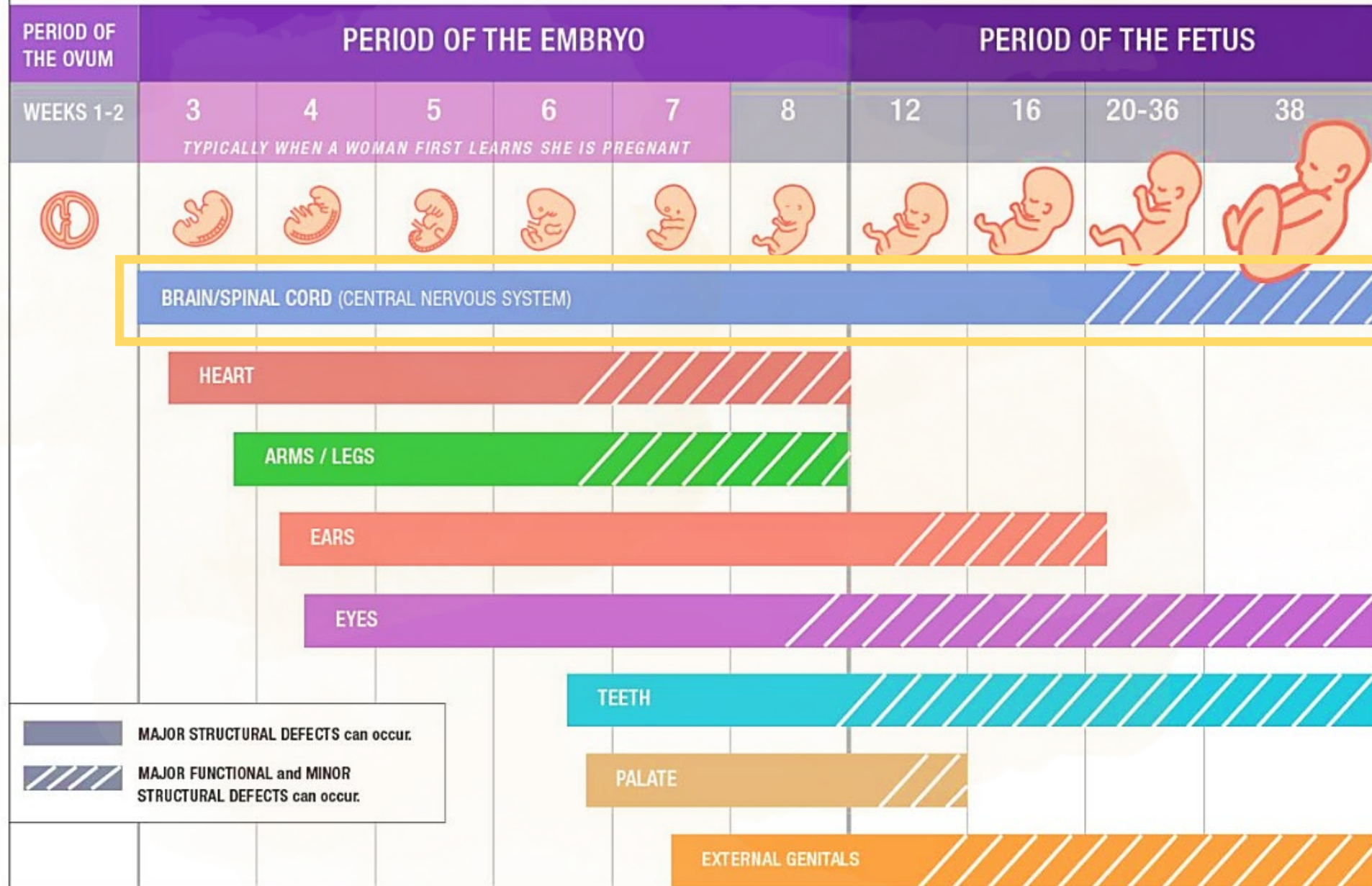
Alcohol

In utero alcohol exposure| teratogen that can cross the placenta and cause brain and other organ (e.g., heart, kidneys, eyes, skeletal system) damage + increase risk of stillbirth, spontaneous abortion, premature birth, IUGR, and low birth weight

Unknown Factors

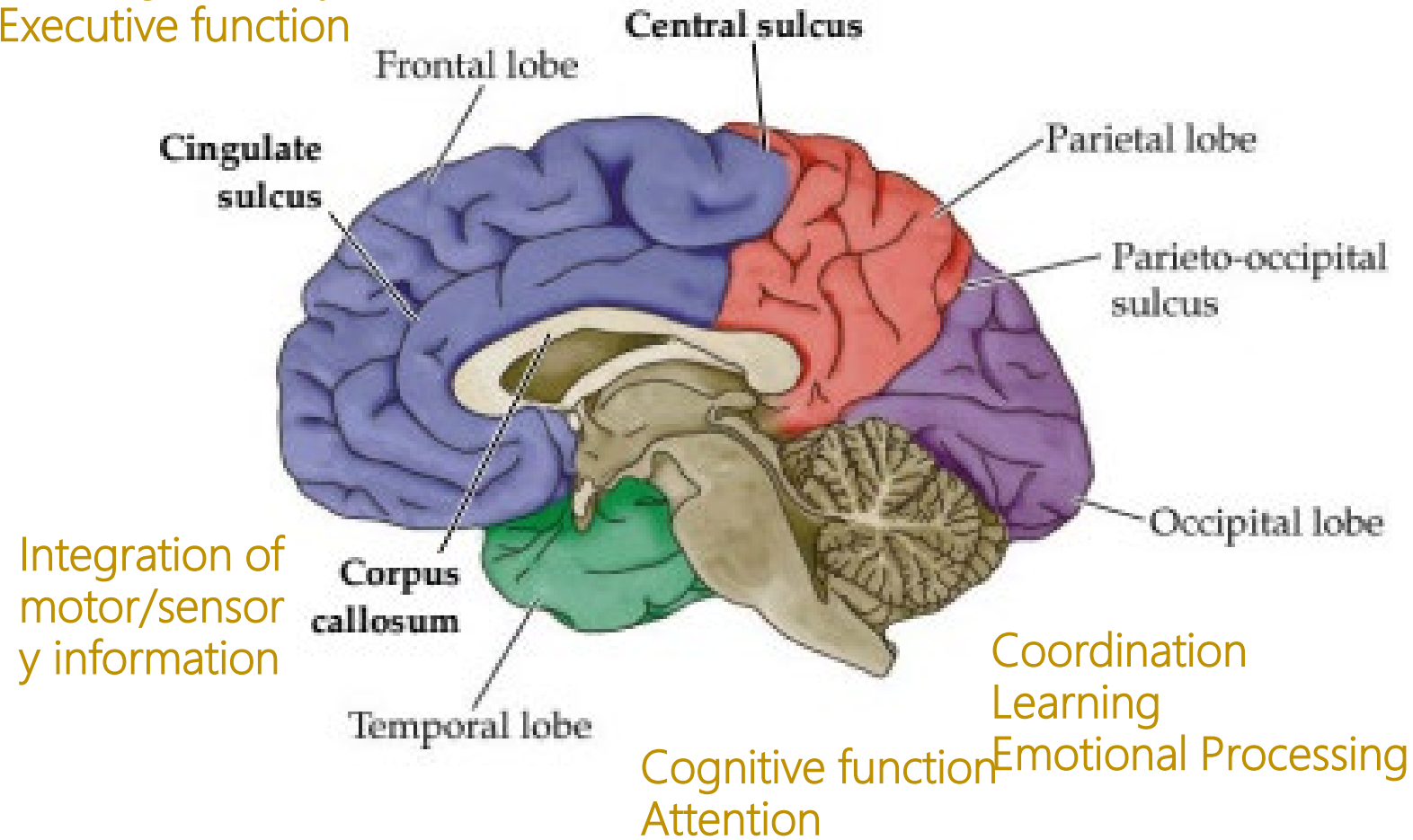


THIS CHART SHOWS THE MOST SENSITIVE TIMES OF A BABY'S DEVELOPMENT TO DEFECTS THROUGHOUT THE 38 WEEKS OF PREGNANCY.*

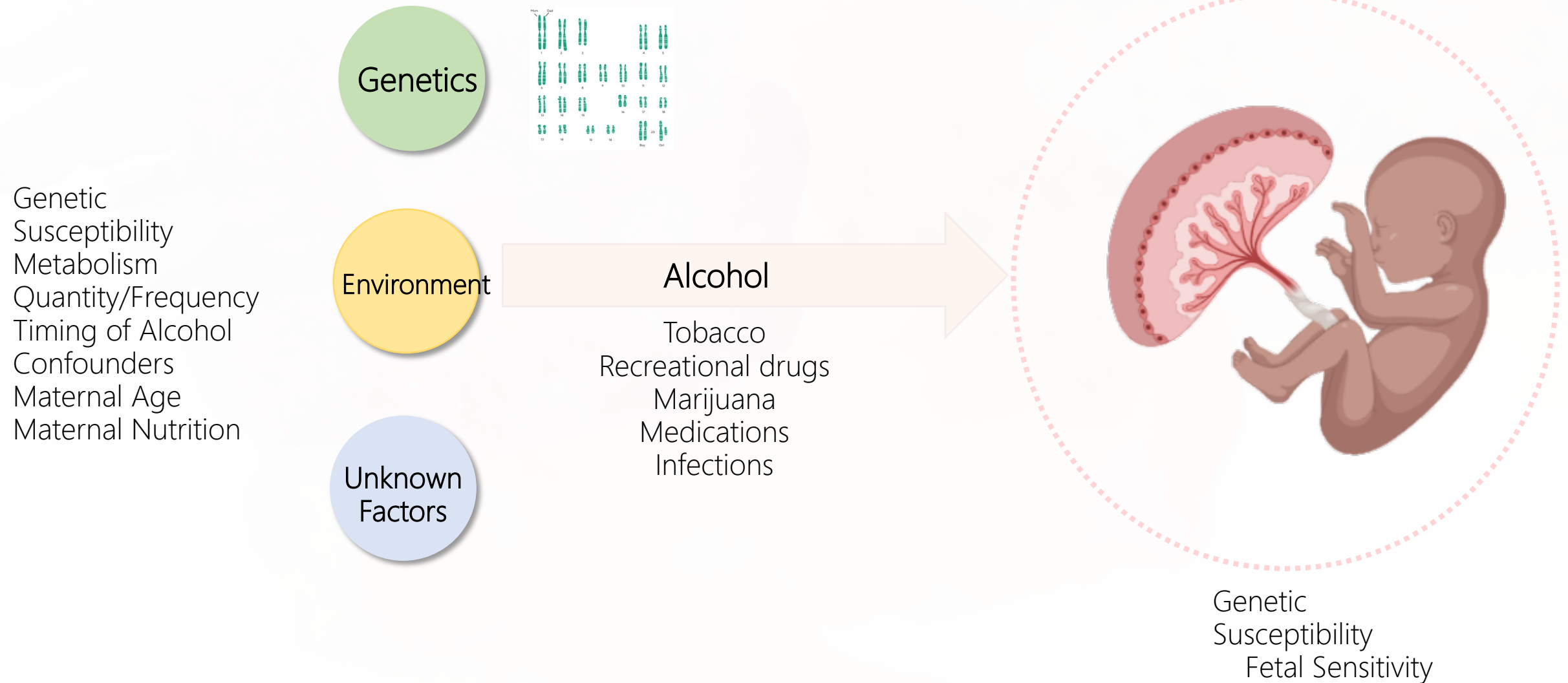


Alcohol and Human Development: Brain

Working memory
Executive function



Alcohol and Human Development



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FASDs: Diagnosis

No single Diagnostic criteria/guideline is used



FASDs: Diagnosis

Diagnosis of FAS occurs when a person meets all 3 criteria

1. Prenatal and/or postnatal growth deficiency
2. Three cardinal facial features (reduced palpebral fissure length, smooth philtrum, and thin upper vermilion lip border)
3. Any of a range of recognized structural, neurologic, and/or functional central nervous system deficits

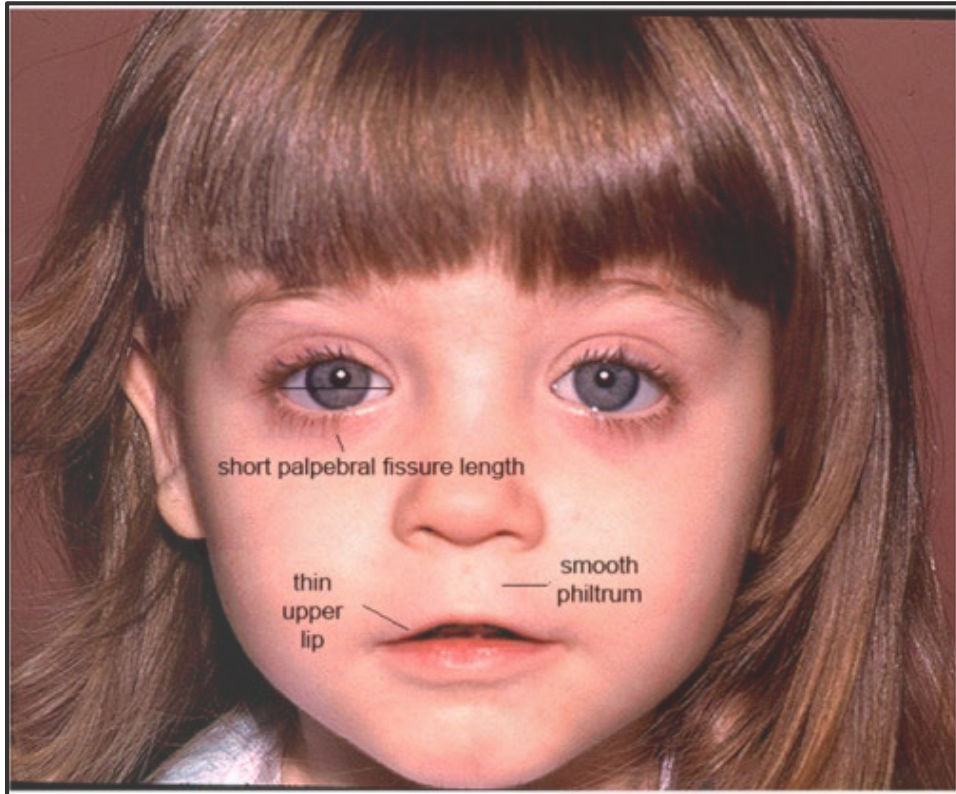


FIGURE 1
Child presenting with the 3 diagnostic facial features of FAS: (1) short palpebral fissure lengths, (2) smooth philtrum (Rank 4 or 5 on the Lip-Philtrum Guide), and (3) thin upper lip (Rank 4 or 5 on the Lip-Philtrum Guide). Legend written by Susan Astley, PhD. © 2015, Susan Astley PhD, University of Washington.



FIGURE 5
Young man presenting with the 3 facial features of FAS (small eyes, smooth philtrum, and thin upper lip) at 2 years of age and 20 years of age. Legend written by Susan Astley, PhD. © 2015, Susan Astley PhD, University of Washington.

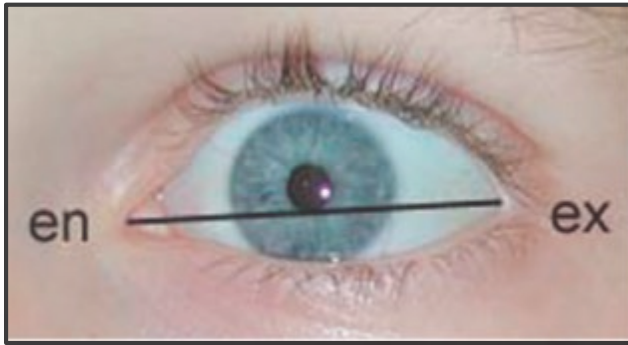


FIGURE 2
The palpebral fissure length is defined by the distance between the endocanthion (en) and exocanthion (ex) landmarks. Legend written by Susan Astley, PhD. © 2015, Susan Astley PhD, University of Washington.

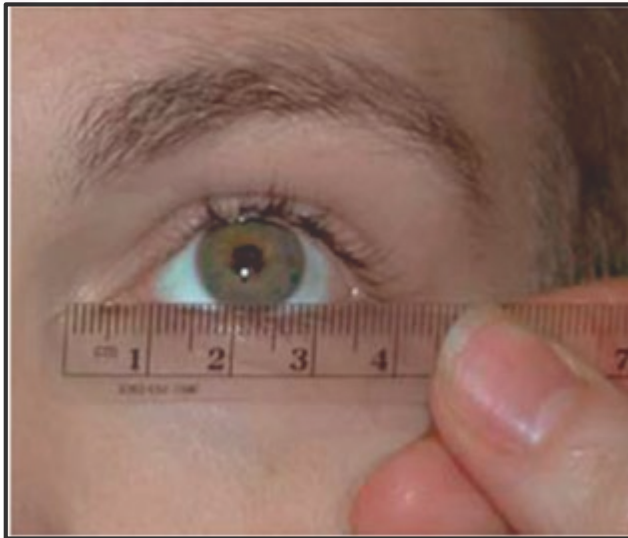


FIGURE 3
The palpebral fissure length (the distance from the inner corner to outer corner of the eye) being measured with a small plastic ruler. Legend written by Susan Astley, PhD. © 2015, Susan Astley PhD, University of Washington.

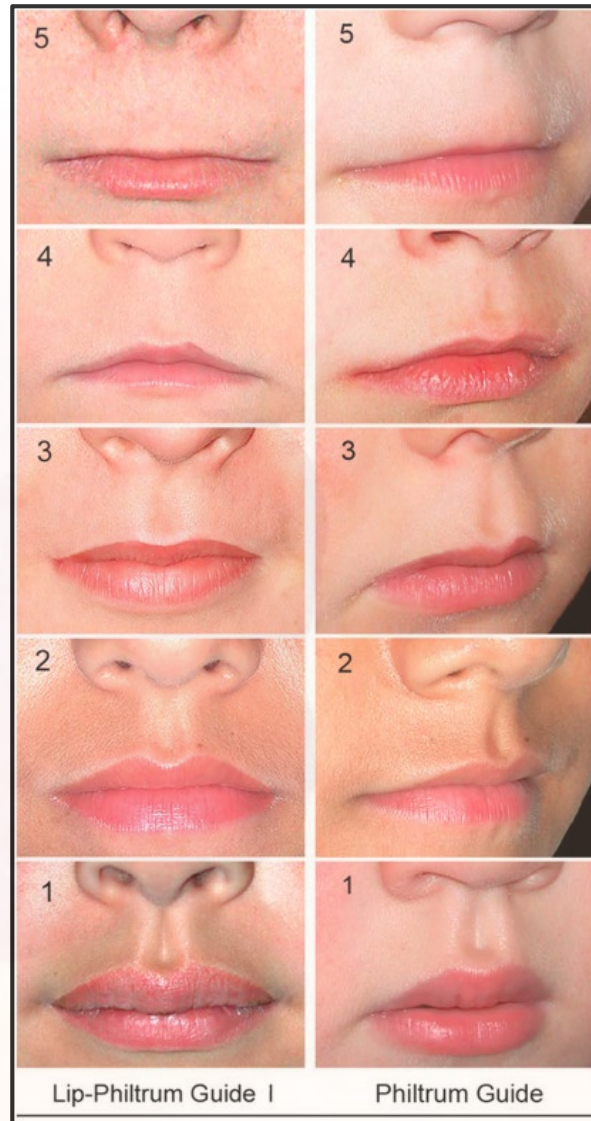


FIGURE 4A
Lip-Philtrum Guide 1 is one of two Guides (see Fig 4B) used to rank upper lip thickness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guide reflects the full range of lip thickness and philtrum depth observed among Caucasians with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 1 is used for Caucasians and all other races with lips like Caucasians. This guide is available from fasdgn.org as a free digital image for use on smartphones. © 2015 Susan Astley, PhD, University of Washington. Legend written by Susan Astley, PhD.

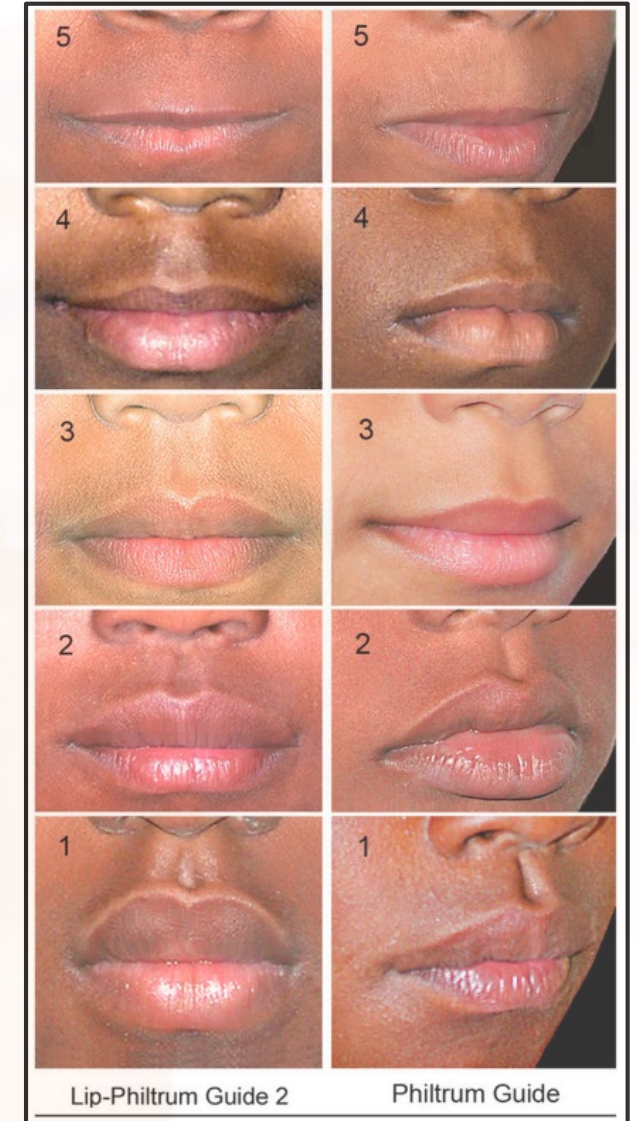


FIGURE 4B
Lip-Philtrum Guide 2 is one of two Guides (see Fig 4A) used to rank upper lip thickness and philtrum smoothness. The philtrum is the vertical groove between the nose and upper lip. The guide reflects the full range of lip thickness and philtrum depth observed among African Americans with Rank 3 representing the population mean. Ranks 4 and 5 reflect the thin lip and smooth philtrum that characterize the FAS facial phenotype. Guide 2 is used for African Americans and all other races with thicker lips like African Americans. This guide is available from fasdgn.org as a free digital image for use on smartphones. © 2015 Susan Astley, PhD, University of Washington. Legend written by Susan Astley, PhD.

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FASDs: Why Should We Care?

Preventable condition and prevalence indicates, to a certain degree, gaps in education, prenatal/mental services, & access to tailored cultural/religious/spiritual care

Individual Level

- 95% lifetime risk for mental illness, ADHD, substance use, addiction, suicide
- > rates of school disruptions, trouble with law, & under- or unemployment
- Failure to achieve age-appropriate socialization/communication skills → maladaptive and impaired social functioning

Economical Level

- 32-47 hours for one individual to be diagnosed with FASD = \$3110 to \$4570/ person excluding treatment costs, this equates to **\$3.6 to \$7.3 million/year**
- ~40,000 babies/Year are born with an FASD, costing nation ~\$6 billion (~1.8 billion in Canada)

Yet, most children with an FASD are never diagnosed or are misdiagnosed, despite frequent occurrence of severe disabilities in neurocognitive, adaptive, and behavioral function.



Alcohol Consumption in Pregnancy

Pooled Prevalence of FAS/FASD in the USA

- General Population:
 - FAS: 2 in 1000 (0.2%)
 - FASD: 15 in 1000 (1.5%)
- Indigenous Population:
 - FAS: 4 in 1000 (0.4%) [double rate- binge drinking]
 - FASD: 10 in 1000 (1%)

Among some tribes, the rates are 5.6 per 1000 livebirths (Alaska); but among some tribes they are comparable to that of the general population in the USA (range between 0.2 to 1.0).

Pooled Prevalence of FAS/FASD in Canada

- General Population:
 - FAS: 1 in 1000 (0.1%)
 - FASD: 5 in 1000 (0.5%)
- Indigenous Population:
 - FAS: 38 in 1000 (3.8%)
 - FASD: 80 in 1000 (8.0%)



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Alcohol Consumption in Indigenous Populations

The underlying cause of health disparities for any group are complex. For indigenous populations, trauma has led to the loss of the cultural, familial, religious, and spiritual components that can be utilized to develop adaptive coping strategies, as well as a sense of identity/community, and safety.

Alcohol Consumption in Indigenous Populations

Colonization

- Introduced large amounts of distilled spirits/wine to indigenous populations without tribes having time to develop guidelines to regulate alcohol use
- Early traders quickly established a demand for alcohol by introducing it as a medium of trade, often using it in exchange for highly sought-after animal skins and other resources



<https://crosscut.com/inside-crosscut/2020/11/why-learning-real-native-history-important-pnw-and-beyond>

Alcohol Consumption in Indigenous Populations

Residential Schools/American Indian Boarding schools

- “schools” led by the federal government/churches (60s to 90s) who assumed their own civilization was the pinnacle of human achievement
- Interpreted the socio-cultural differences between themselves and Indigenous Peoples as “proof” that (Canada’ s) first inhabitants were ignorant, savage, and—like children—in need of guidance. **They** felt the need to “civilize” Indigenous Peoples. Education—a federal responsibility—became the primary means to this end.



<https://www.catholicworldreport.com/2022/07/24/the-history-of-canadas-residential-schools/>

Alcohol Consumption in Indigenous Populations

System forcibly separated children from their families for extended periods of time and forbade acknowledging their heritage/culture/language



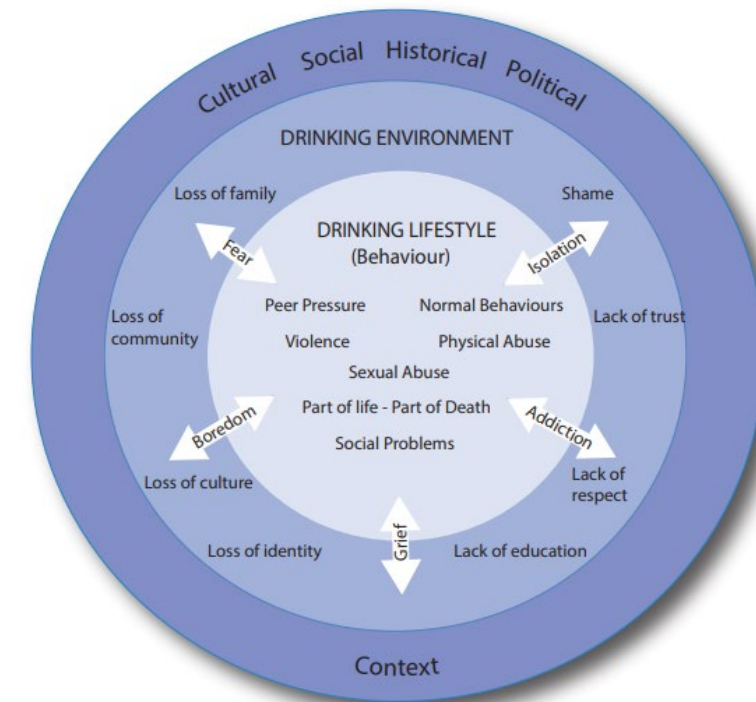
Indigenous artist RG Miller's haunting autobiographical painting recalls the horrific abuse he experienced at residential school. © RG Miller

- Emotional, psychological, physical, sexual abuse, common
- Students' hair cut, dressed in uniforms, given numbers, days strictly regimented
- Boys/girls separated + siblings rarely interacted, further weakening family ties
- Survivors recall being **beaten and strapped**; some **shackled to their beds**; **needles in tongues for speaking their native languages**
- Abuse, overcrowding, poor sanitation, and severely inadequate food & health care, resulted in a **shockingly high death toll**
- **Most students had only reached grade five by the time they were 18**, since students did not receive same education as general + school's were underfunded. Teachings focused on practical skills.

Alcohol Consumption in Indigenous Populations

- Residential schools systematically undermined Indigenous cultures across North America, disrupted families for generations, and contributed to a general loss of language, culture, community, & identity
- Many students grew up without experiencing a nurturing family life and without the knowledge and/or skills to raise their own families
- The history of Native Americans is filled with violence, oppression, displacement, and loss of self-determination
- This legacy of trauma is believed to be a factor in many problems, including alcohol abuse

Figure 20.1: Drinking Influences



© Roz Walker
Design: Chrissie Easton

So how can we use this information to help families at risk of having a child with FASD or who do have a child with FASD?

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Provider Education: Personal Work

- Lack of education, and a lot of stigma, generalizations, and lack of tolerance when it comes to indigenous populations
- Some indigenous populations are justifiably **distrusting of the healthcare system** (personal experiences, family' s experience, history of neglect and inadequate care), but also that a **conversation about alcohol and drug use in a pregnancy** could be grounds for taking action/ jeopardizing parental involvement



Compare states by

Substance abuse during pregnancy is a crime

Women have been prosecuted for drug use during pregnancy

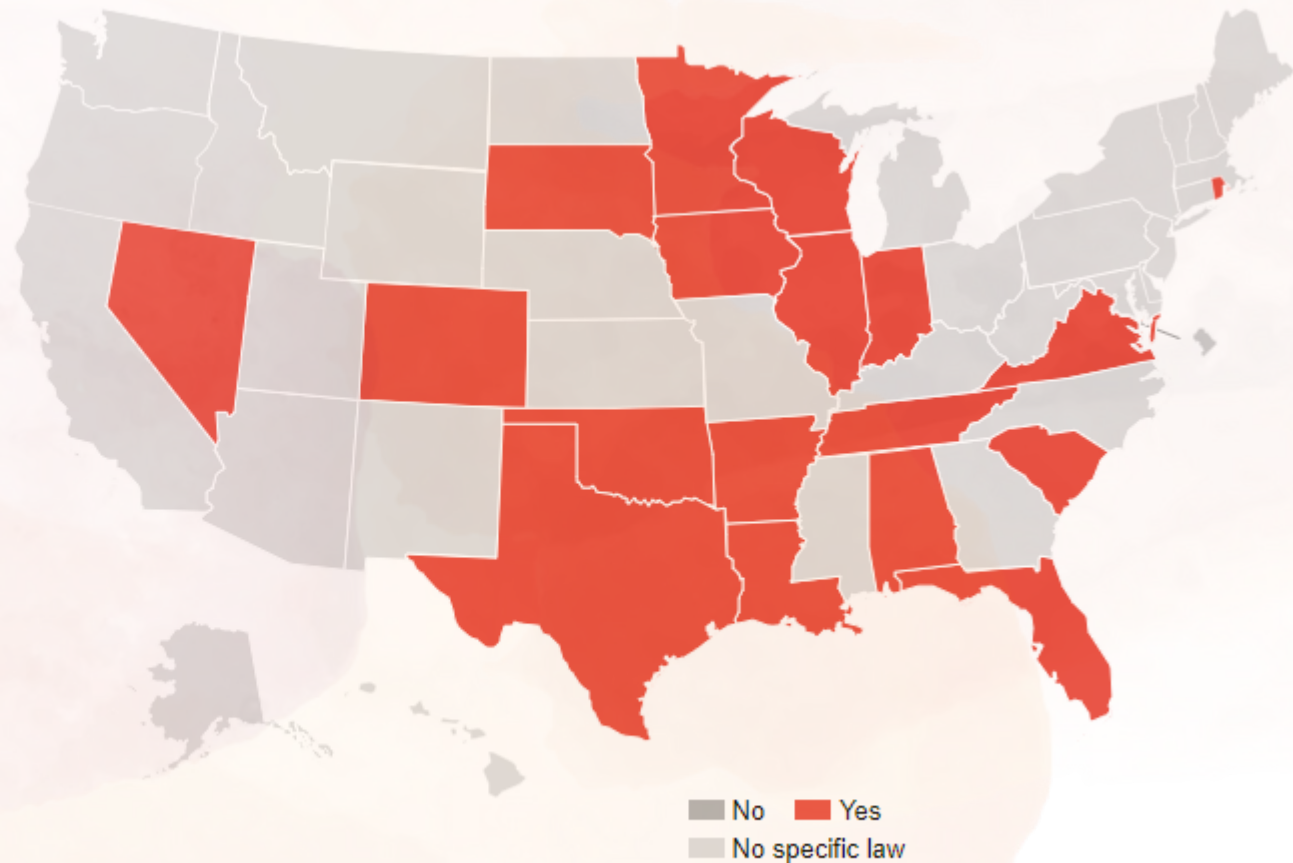
Substance abuse during pregnancy is child abuse

Eighteen states have laws that say drug use during pregnancy is child abuse.

Substance abuse during pregnancy is grounds for civil commitment

Health care workers must report drug abuse during pregnancy

Testing is required if drug use during pregnancy is suspected



■ No ■ Yes
■ No specific law

Compare states by

Substance abuse during pregnancy is a crime

Women have been prosecuted for drug use during pregnancy

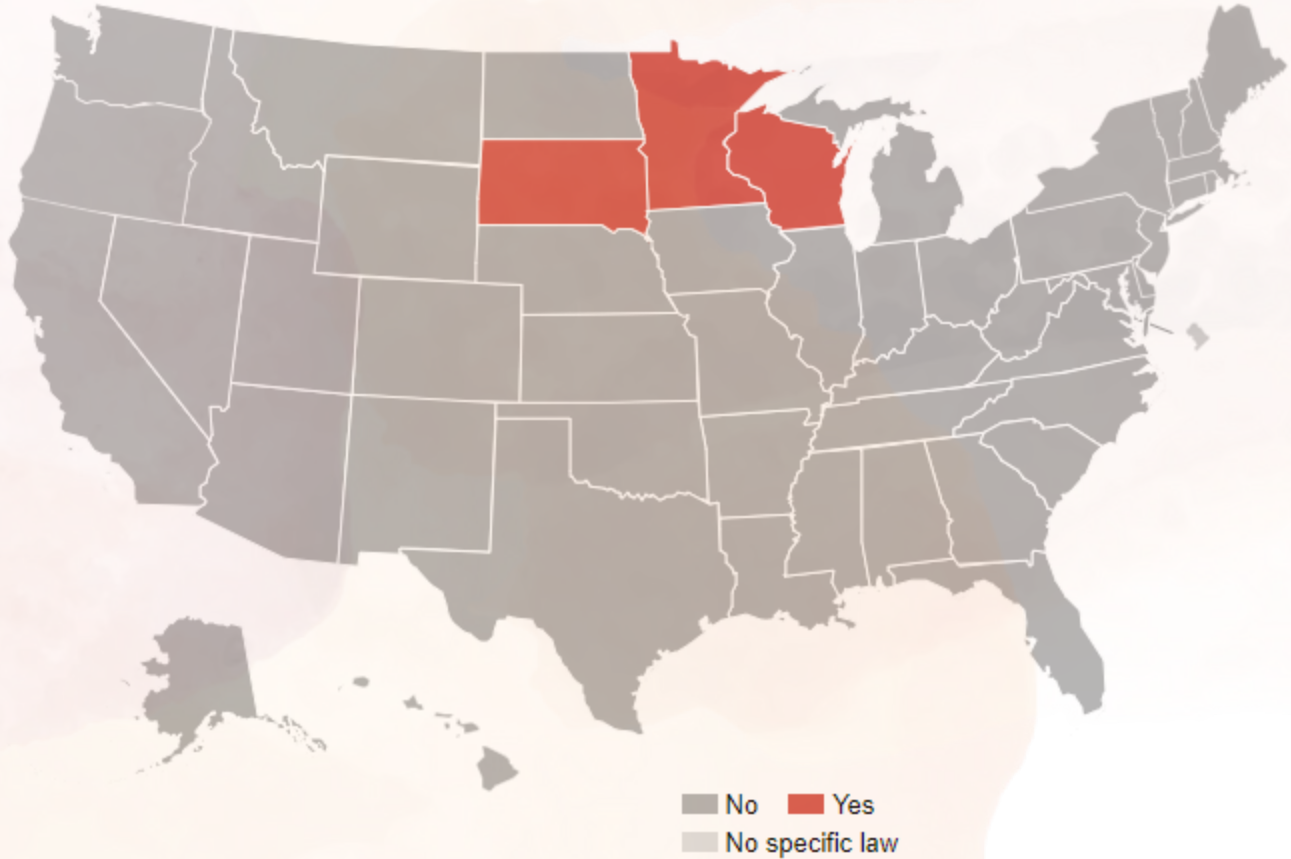
Substance abuse during pregnancy is child abuse

Substance abuse during pregnancy is grounds for civil commitment

In three states — Minnesota, South Dakota and Wisconsin — women who use drugs during pregnancy can be involuntarily committed to a treatment program. The Wisconsin law is especially draconian: A woman can be detained against her will for the duration of her pregnancy, her fetus has its own court-appointed lawyer, she can lose custody of her baby after birth — and the proceedings are mostly secret.

Health care workers must report drug abuse during pregnancy

Testing is required if drug use during pregnancy is suspected



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Provider Education: Screening for Prenatal Alcohol Use



Normalize information collection

- Incorporate screen into standard script/ “universal screening” →, ↓
stigma, general then specific
“... questions that I ask all women about their use of tobacco, alcohol, prescription and non-prescription drugs during pregnancy.”
“Before/after you knew you were pregnant, how much alcohol (beer, wine, liquor, etc.) did you drink?”

Remind the parents that the information will help to guide the child’ s care

Avoid reactions that indicate judgement if someone acknowledges alcohol use

- *E.g.*, if mom is concerned she drank before she knew she was pregnant, reassure she is not alone /awareness allows for improved outcomes
- Correct misconceptions (‘Once you’ ve drank then you’ re doomed’ ; ‘Marijuana is fine’)
- Care to use *“100% preventable”* and *“the mother’ s responsibility”* → perpetuate shame and guilt, fail to acknowledge complex picture associated with alcohol/substance use

Administer brief intervention and follow-up

- Know how to provide brief interventions and knowledge of **referral pathways** (GC, psychiatrist specializing in maternal health, etc.)

Provider Education: Screening for Prenatal Alcohol Use (OB)

The image shows two screenshots of the ACOG Clinical website. The top screenshot displays a Committee Opinion article titled "At-Risk Drinking and Alcohol Dependence: Obstetric and Gynecologic Implications" from August 2011. The bottom screenshot shows the "Fetal Alcohol Spectrum Disorders FAQs" page under the "Programs" section.

Top Screenshot: Committee Opinion Article

- Logo: ACOG | Clinical (The American College of Obstetricians and Gynecologists)
- Navigation: Clinical Guidance, Journals & Publications, Patient Education, Topics, Search
- Breadcrumbs: Home > Committee Opinion > At-Risk Drinking and Alcohol Dependence: Obstetric and Gynecologic Implications
- Title: At-Risk Drinking and Alcohol Dependence: Obstetric and Gynecologic Implications
- Metadata: Committee Opinion ⓘ | Number 496 | August 2011

Bottom Screenshot: Fetal Alcohol Spectrum Disorders FAQs

- Logo: ACOG (The American College of Obstetricians and Gynecologists)
- Navigation: About, Programs, Membership, Community, Donate, Search
- Menu: Clinical Information, Practice Management, Career Support, Education & Events, Advocacy, News, Topics (dropdown)
- Breadcrumbs: Home > Programs > Fetal Alcohol Spectrum Disorders Prevention > Fetal Alcohol Spectrum Disorders FAQs

Fetal Alcohol Spectrum Disorders FAQs

These FAQs can assist health care providers in conversations with patients about alcohol use.

Provider Education: Screening for Prenatal Alcohol Use (OB)



Journal of Obstetrics and Gynaecology Canada

Volume 42, Issue 9, September 2020, Pages 1158-1173.e1



SOGC Clinical Practice Guideline

Guideline No. 405: Screening and Counselling for Alcohol Consumption During Pregnancy

Lisa Graves MD [🔗](#) [✉](#), George Carson MD, Nancy Poole PhD, Tejal Patel MD,



SMFM Special Report

smfm.org

Substance use disorders in pregnancy: clinical, ethical, and research imperatives of the opioid epidemic: a report of a joint workshop of the Society for Maternal-Fetal Medicine, American College of Obstetricians and Gynecologists, and American Society of Addiction Medicine

Jeffrey Ecker, MD; Alfred Abuhamad, MD; Washington Hill, MD; Jennifer Bailit, MD; Brian T. Bateman, MD; Vincenzo Berghella, MD; Tiffany Blake-Lamb, MD; Constance Guille, MD; Ruth Landau, MD; Howard Minkoff, MD; Malavika Prabhu, MD; Emily Rosenthal, MD; Mishka Terplan, MD; Tricia E. Wright, MD; Kimberly A. Yonkers, MD

Provider Education: Screening for Prenatal Alcohol Use (OB)

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ACOG
The American College of
Obstetricians and Gynecologists

About | Programs | Membership | Community | Donate | Search

Clinical Information | Practice Management | Career Support | Education & Events | Advocacy | News | Topics

Home > Programs > Fetal Alcohol Spectrum Disorders Prevention > Tools and Videos for Providers

Tools and Videos for Providers

Videos

- Webinar
Prenatal Alcohol Exposure:
Prevention, Identification and
Support
- FASD Prevention Project: What
You Should Tell Her? [external link icon]
- Promoting Screening and Brief
Intervention, Dr. Karen Harris [external link icon]
- Promoting Screening and Brief
Intervention, Dr. Tricia Wright
[external link icon]
- Ob-Gyns and FASD, Jeanne
Mahoney [external link icon]

Provider Education: Screening for Prenatal Alcohol Use (Ped)

American Academy
of Pediatrics



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Patient Care

Early Childhood Gun Safety & Injury Prevention Mental Health Initiatives

Screening, Assessment, and Diagnosis

[Home](#) / [Patient Care](#) / [Fetal Alcohol Spectrum Disorders](#) / Screening, Assessment, and Diagnosis

This section guides pediatricians and nonphysician clinicians through the process of assessing and screening for a potential FASD.

ND-PAE Differential Diagnoses and Co-Occurring Diagnoses

View and download resources to guide pediatricians when making an FASD diagnosis.

Screening for Prenatal Alcohol Exposure

Information to help communicate with families about prenatal exposure to alcohol.

Interprofessional Team Approaches to Fetal Alcohol Spectrum Disorders

Referrals to specialists may be necessary if clear diagnostic criteria for an FASD are not met.

Assessment

Learn about the neurocognitive, behavioral, and physical features of children with an FASD.

Flow Diagram for Evaluation

Download the detailed AAP Flow Diagram for Medical Home Evaluation of Fetal Alcohol Spectrum Disorders (FASD) to guide pediatricians when diagnosing children with an FASD.

Common Diagnostic Approaches


Explore the four FASD diagnostic approaches.

Provider Education: Screening for Prenatal Alcohol Use (PCIP)



Fetal Alcohol Spectrum Disorders (FASDs)

FASD Homepage > Interventions

 FASD Homepage

Basics



Alcohol Use in Pregnancy



Interventions

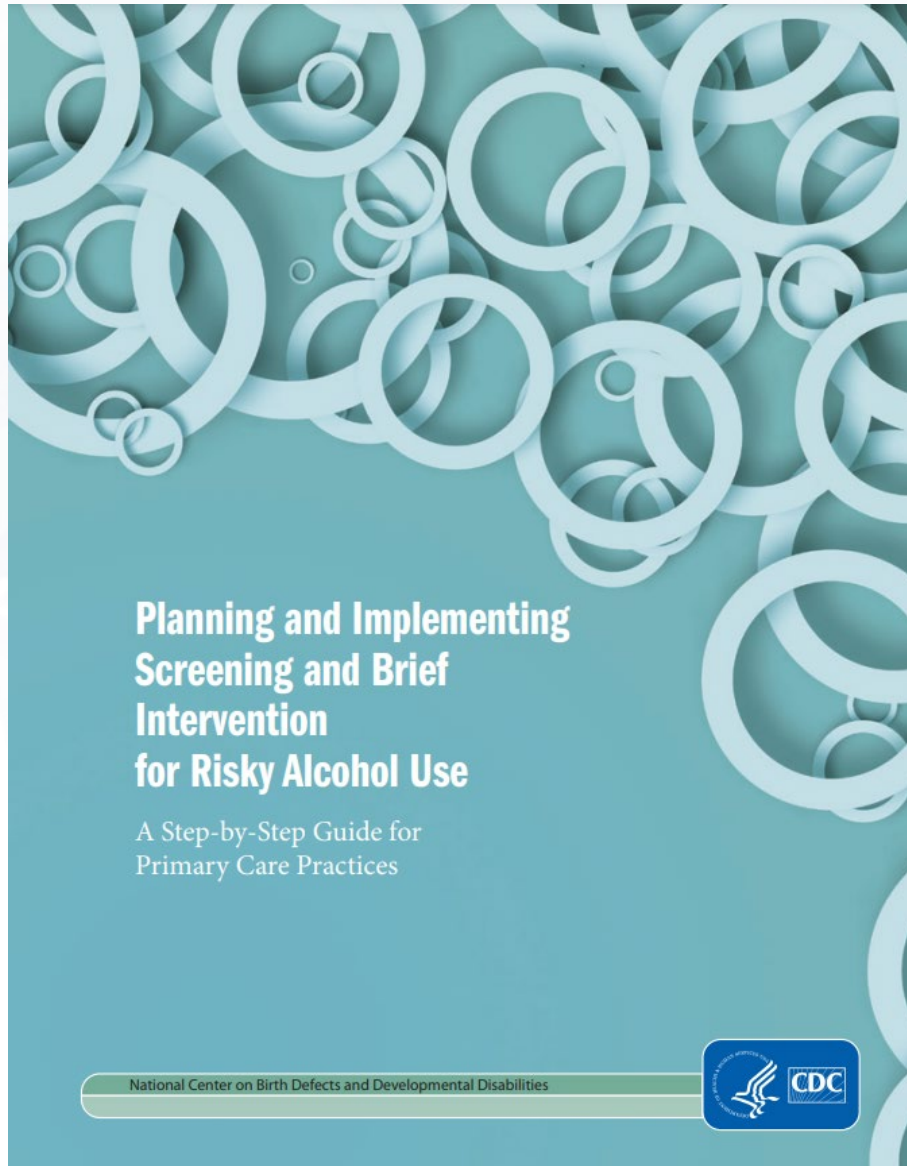


Alcohol Screening and Brief Intervention Efforts

[Print](#)

Alcohol Screening and Brief Intervention (SBI) is Effective at Reducing Excessive Drinking. CDC is working to make alcohol SBI a routine part of health care in primary care settings.

Provider Education: Screening for Prenatal Alcohol Use (PCP)

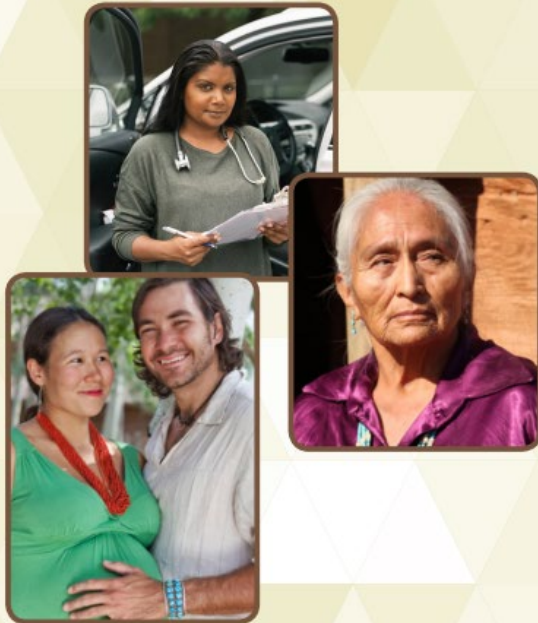


This Guide provides the process and resources necessary to help staff in any primary healthcare setting plan and implement alcohol Screening and Brief Intervention (SBI), an evidence-based approach recommended for all adults, including pregnant women. The Guide also provides information on excessive use and how it can be addressed through alcohol SBI.

Provider Education: Screening for Prenatal Alcohol Use (PCP)

Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use:

A Step-by-Step Guide for Tribal Communities



This Guide was adapted from Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices to improve cultural relevance for American-Indian/Alaska-Native communities.

Coding for FASD



Prevention of FASD
Coding Basics

Alcohol Abuse Counseling

- Code: Z71.41
- Description: Alcohol abuse counseling and surveillance of alcoholic (use additional code for alcohol abuse or dependence) For Z36.-, Encounter for antenatal screening of mother:
- Code: Z36.0
- Description: Encounter for antenatal screening for chromosomal anomalies
- Code: Z36.3
- Description: Encounter for antenatal screening for malformations
- Code: Z36.4
- Description: Encounter for antenatal screening for fetal growth retardation
- Code: Z36.83
- Description: Encounter for antenatal screening for congenital cardiac abnormalities
- Code: Z36.89
- Description: Encounter for antenatal screening for other specified antenatal screening

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FASDs: Diagnostic Challenges

- National surveys: Peds in USA/Canada not adequately trained for actual clinical diagnosis (esp strict guidelines for dysmorphology), referral, and management
- Access to a provider like developmental pediatrician or psychologist is limited + many peds rely on the school system when assessing for IEP
- AAP states that $\frac{3}{4}$ of children with one of the FASDs **have an attention problem** and may be diagnosed as having ADHD without considering other diagnoses (*e.g.*, Williams, Noonan, 22q deletion syndromes, trisomy 21, and fetal toluene embryopathy)
- Shame/guilt and stigma with diagnosis especially for birthing person

If this is so challenging, then why continue education about this condition?
Why not just treat the symptoms?



Provider Education: Appropriate Diagnosis

- Better understanding of self/child
- While behaviors may be the same, the underlying cause of behavior is different (selection of supports, treatment, and expected response to treatment, is different)
- Diagnosis **opens the door to therapeutic services and supports** that can positively influence outcomes for the child and family. **Collaborations between providers**(e.g., psychiatrists, psychologists, social workers, therapists); **agencies** (e.g., schools, mental health agencies, agencies serving children and youth with special needs, child protective services); **overall improving effectiveness of support for children and their families**
- Better documentation of prevalence and impact with hopes to increase funding and resources/implementation of intervention
 - Senate Bill 1016 - January 2023: *“the state board of education shall include FASD in the definition of other health impairment” in IEPs*
 - Senate Bill 188 - June 2022, amended- to include accessibility for early intervention services for *“FASD is highlighted as a condition in which an infant or toddler may require early intervention services”*

Provider Education: Appropriate Referral for Diagnosis

- Service that is lacking in northern California; UC Davis
- Cedars Sinai Medical Center- Pediatric Medical Genetics (Los Angeles)
- UCLA Fetal Alcohol Syndrome and Related Disorders Clinic (Los Angeles)
- San Diego State University- Center for Behavioral Teratology (San Diego)
- Santa Teresa Medical Center (San Jose)

Provider Education: Appropriate Diagnosis

AAP FASD Toolkit (www.aap.org/FASD); provides an evidence-based approach and resources to help identify children who may have one of the FASDs and facilitates management and care to improve lifelong health outcomes.



Screening, Assessment, and Diagnosis

This section guides pediatricians and nonphysician clinicians through the process of assessing and screening for a potential FASD.



Health Supervision

This section provides information on evidence-based interventions, resources for clinicians, and helping families of children with an FASD access services and community supports.



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Screening, Assessment, and Diagnosis

[Home](#) / [Patient Care](#) / [Fetal Alcohol Spectrum Disorders](#) / Screening, Assessment, and Diagnosis

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ND-PAE Differential Diagnoses and Co-Occurring Diagnoses

View and download resources to guide pediatricians when making an FASD diagnosis.

Screening for Prenatal Alcohol Exposure

Information to help communicate with families about prenatal exposure to alcohol.

Interprofessional Team Approaches to Fetal Alcohol Spectrum Disorders

Referrals to specialists may be necessary if clear diagnostic criteria for an FASD are not met.

Assessment

Learn about the neurocognitive, behavioral, and physical features of children with an FASD.

Flow Diagram for Evaluation

Download the detailed AAP Flow Diagram for Medical Home Evaluation of Fetal Alcohol Spectrum Disorders (FASD) to guide pediatricians when diagnosing children with an FASD.

Common Diagnostic Approaches

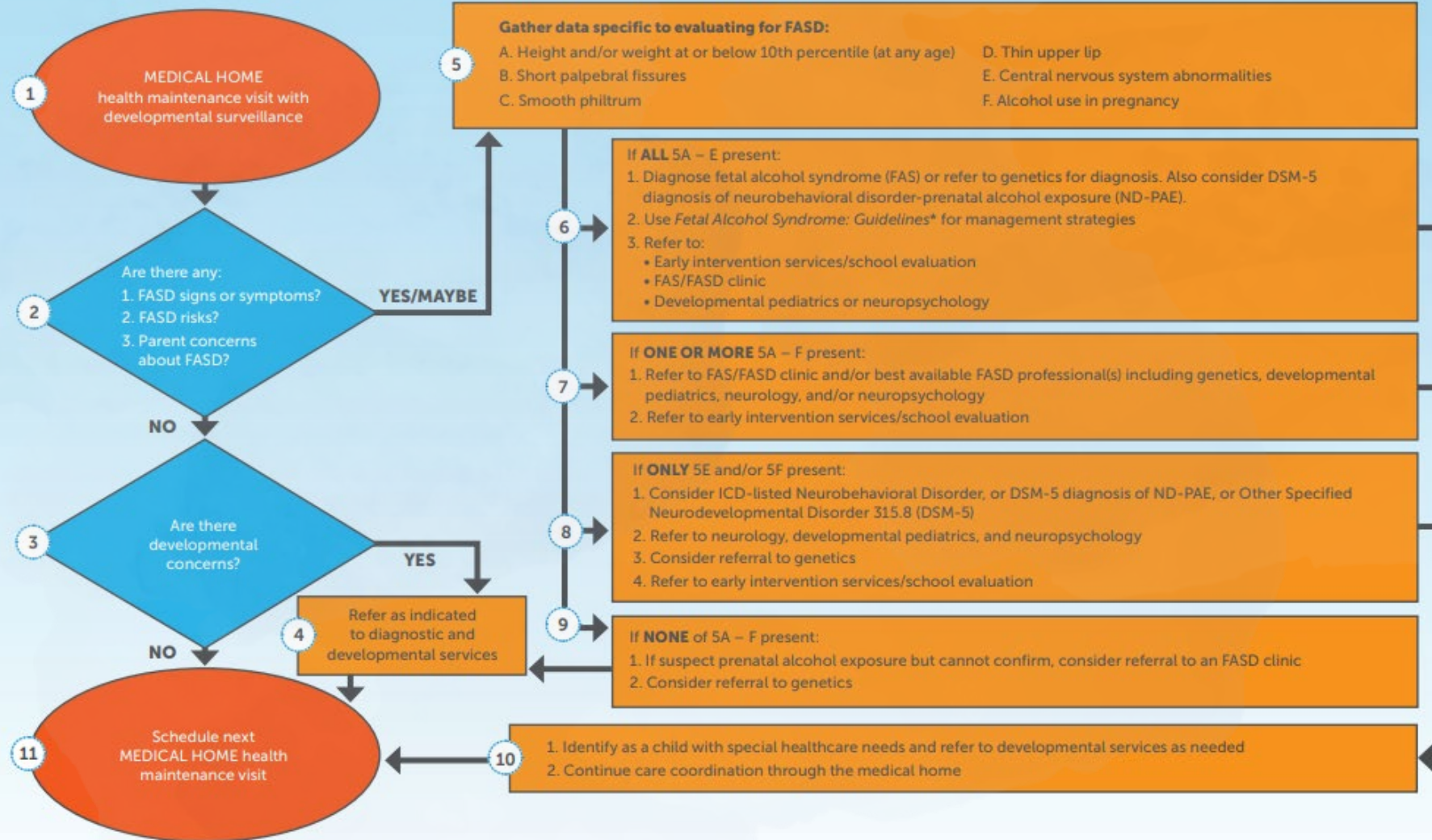
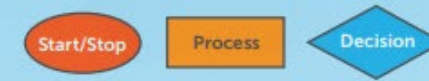
Explore the four FASD diagnostic approaches.

Last Updated 08/29/2022

Source American Academy of Pediatrics

Flow Diagram* for Medical Home Evaluation of Fetal Alcohol Spectrum Disorders (FASD)

Universal Flow Diagram Symbols



*Page 2: Flow Diagram pathway details; FAS criteria; Selected resources. The flow diagram was developed by the FASD Expert Panel of the AAP via cooperative agreement #5U38OT000167 with the Centers for Disease Control and Prevention (CDC); does not necessarily represent the views of the CDC.

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FAS DPN

FAS Diagnostic & Prevention Network



Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™



CanFASD

CANADA FASD RESEARCH NETWORK



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TABLE 3 Developmental Emergence of Neurocognitive and Behavioral Deficits Associated With FASD

Areas of Brain Vulnerability in FASD		Infancy: 0–2 y	Neurocognitive/Behavioral Deficits Associated With Developmental Stage	
<ul style="list-style-type: none"> • Cortical synaptogenesis • Development of cortical gray matter • Myelination of sensory pathways • Maturation of the limbic system 	Neurocognitive	<ul style="list-style-type: none"> • Delayed cognitive development or global developmental delay 	<ul style="list-style-type: none"> • Tremulousness, increased jitteriness • Difficulty with self-soothing, and being soothed • Emotional withdrawal, decreased infant affective functioning • Impaired stress reactivity; deficits in pain regulation • Less complex play • Delayed gross and fine motor milestones • Poor feeding: poor sucking. Easily fatigued 	
	Self-Regulation			<ul style="list-style-type: none"> • Myelination of motor pathways
	Adaptive			
Areas of Brain Vulnerability in FASD		Toddler/Preschool: 3–5	Neurocognitive/Behavioral Deficits Associated With Developmental Stage	
<ul style="list-style-type: none"> • Synaptogenesis • Development of cortical gray matter • Development of prefrontal cortex 	Neurocognitive	<ul style="list-style-type: none"> • Delayed cognitive development or global developmental delay 	<ul style="list-style-type: none"> • Attention: difficulties with attention regulation; hyperactivity and impulsivity; difficulty shifting attention; impaired visual and auditory attention; difficulty with sustained attention • Executive function: difficulty encoding information; difficulty with multistep directions; difficulty with planning and organization; poor understanding of consequences • Sleep deficits: shortened sleep duration; increased sleep anxiety; parasomnias • Sensory processing: difficulty modulating sensory input; sensory seeking • Delayed gross motor function: balance, coordination problems; “clumsiness” • Poor fine motor skills: difficulty with writing/drawing; poor dexterity; visual-spatial deficits; impaired visual-motor coordination • Delayed auditory processing: central auditory delay • Speech and language deficits: difficulties with language acquisition; receptive, expressive language delays; deficits in word processing/word recognition; articulation errors; deficits in social pragmatics • Memory deficits: difficulty remembering things previously learned 	
	Self-Regulation			
	Adaptive			
<ul style="list-style-type: none"> • Development of temporal lobes • Development of dorsal motor cortex • Development of temporal lobes 	Neurocognitive	<ul style="list-style-type: none"> • Lower intellectual quotient • Learning disabilities • Deficits in mathematics (numerical operations/global mathematics skills) 	<ul style="list-style-type: none"> • Executive function deficits: decreased working memory, decreased verbal fluency, poorer planning, sequencing, organization • Attention deficits: hyperactivity; impulsivity • Language: deficits in higher order language processing • Social pragmatics: deficits in social cognition: inappropriate social initiation/social interaction; inappropriate sexual behaviors • Memory: difficulty encoding/consolidating new memory • Language processing: impaired gestural communication; deficits in social perception • Visual-spatial: deficits in spatial processing; poor handwriting; impaired visual-motor integration 	
	Self-Regulation			
	Adaptive			
Areas of Brain Vulnerability in FASD		School-age: 6–12 y	Neurocognitive/Behavioral Deficits Associated With Developmental Stage	
<ul style="list-style-type: none"> • Decreased intracranial volume: <ul style="list-style-type: none"> • Decreased volume of parietal and temporal lobes • White matter abnormalities • Prefrontal cortex 	Neurocognitive	<ul style="list-style-type: none"> • Lower intellectual quotient • Learning disabilities • Deficits in mathematics (numerical operations/global mathematics skills) 	<ul style="list-style-type: none"> • Executive function deficits: decreased working memory, decreased verbal fluency, poorer planning, sequencing, organization • Attention deficits: hyperactivity; impulsivity • Language: deficits in higher order language processing • Social pragmatics: deficits in social cognition: inappropriate social initiation/social interaction; inappropriate sexual behaviors • Memory: difficulty encoding/consolidating new memory • Language processing: impaired gestural communication; deficits in social perception • Visual-spatial: deficits in spatial processing; poor handwriting; impaired visual-motor integration 	
	Self-Regulation			
	Adaptive			
<ul style="list-style-type: none"> • Temporal lobe • Parietal lobe 	Neurocognitive	<ul style="list-style-type: none"> • Lower intellectual quotient • Learning disabilities • Deficits in mathematics skills (numerical operations/global mathematics skills) 	<ul style="list-style-type: none"> • Executive function deficits: decreased working memory, decreased verbal fluency, poorer planning, sequencing, organization • Attention deficits: hyperactivity; impulsivity • Language: deficits in higher order language processing • Social pragmatics: deficits in social cognition: inappropriate social initiation/social interaction; inappropriate sexual behaviors • Memory: difficulty encoding/consolidating new memory • Language processing: impaired gestural communication; deficits in social perception • Visual-spatial: deficits in spatial processing; poor handwriting; impaired visual-motor integration 	
	Self-Regulation			
	Adaptive			
Areas of Brain Vulnerability in FASD		Adolescence: 13–21 y	Neurocognitive/Behavioral Deficits Associated With Developmental Stage	
<ul style="list-style-type: none"> • Decreased intracranial volume: <ul style="list-style-type: none"> • Decreased volume of parietal and temporal lobes • White matter abnormalities 	Neurocognitive	<ul style="list-style-type: none"> • Lower intellectual quotient • Learning disabilities • Deficits in mathematics skills (numerical operations/global mathematics skills) 	<ul style="list-style-type: none"> • Executive function deficits: decreased working memory, decreased verbal fluency, poorer planning, sequencing, organization • Attention deficits: hyperactivity; impulsivity • Language: deficits in higher order language processing • Social pragmatics: deficits in social cognition: inappropriate social initiation/social interaction; inappropriate sexual behaviors • Memory: difficulty encoding/consolidating new memory • Language processing: impaired gestural communication; deficits in social perception • Visual-spatial: deficits in spatial processing; poor handwriting; impaired visual-motor integration 	
	Self-Regulation			
	Adaptive			

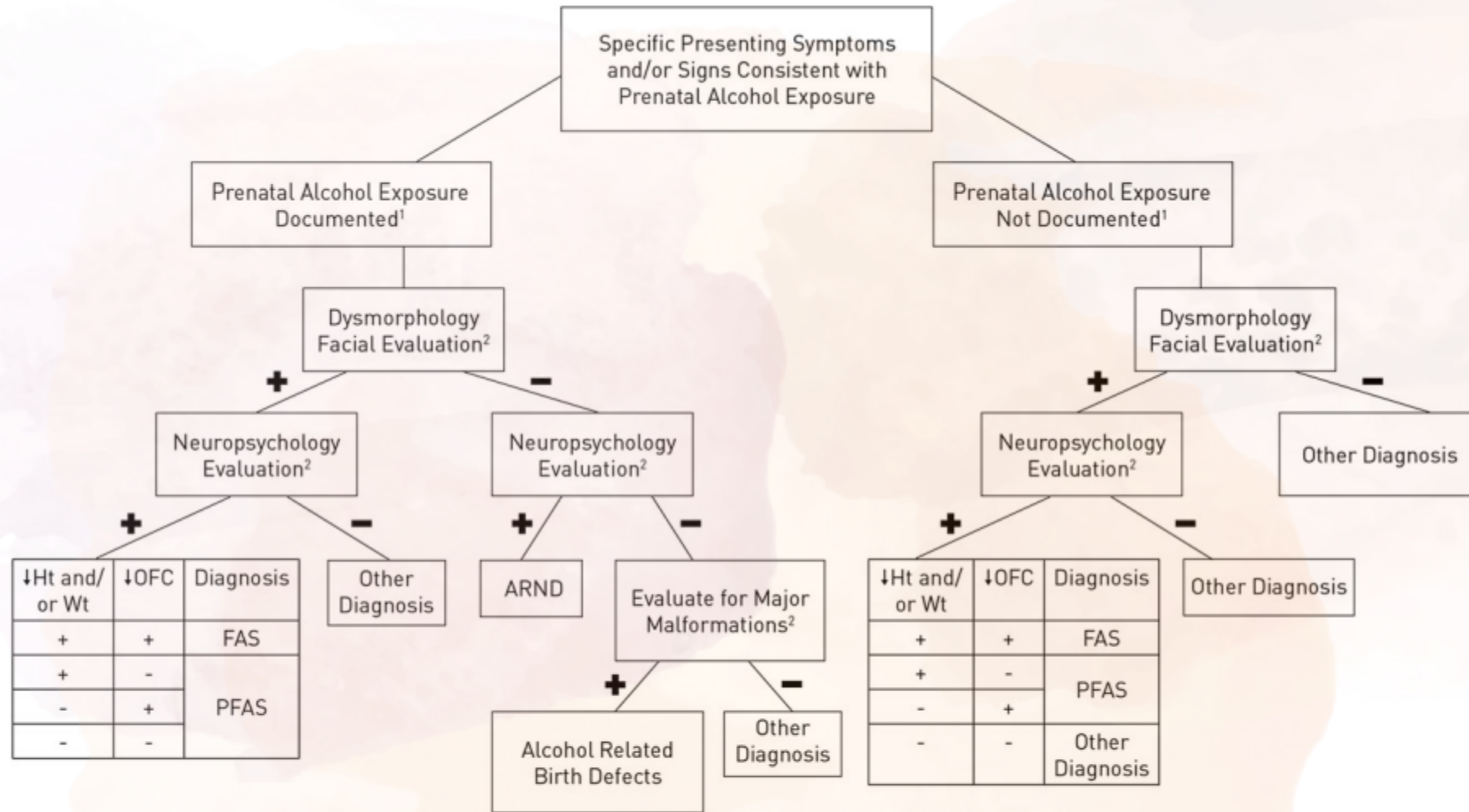


FIGURE 1

FASD diagnostic algorithm. See text for complete discussion. A positive dysmorphology facial evaluation requires 2 of the 3 cardinal facial features of FASD (short palpebral fissures, smooth philtrum, and thin vermilion border of the upper lip). Cutoffs for neuropsychological testing are -1.5 SD. Cutoffs for stature, weight, and head circumference are at the 10th percentile.

Provider Education: Appropriate Diagnosis

FASD Regional Champions

[Home](#) / [Patient Care](#) / [Fetal Alcohol Spectrum Disorders](#) / FASD Regional Champions

AAP established the Fetal Alcohol Spectrum Disorders (FASD) Regional Education and Awareness Liaisons (REAL) Champions Network in 2016.

The goals of the FASD champions network are to meet the identified needs to improve pediatricians' capacity for early identification of at-risk individuals and to address the role of stigma and bias in addressing prenatal alcohol exposure with families and caregivers. The Champions promote the AAP goal of obtaining a history of prenatal alcohol exposure to ALL pediatric patients. The FASD champions are available to work with pediatricians to facilitate educational, outreach, and practice change activities within their AAP region.

The FASD REAL Champions Network leads training sessions and facilitate webinars, present at conferences, and are available to respond to questions from chapter and district membership. Pediatricians can work within the FASD peer coaching program to improve skills and gain confidence with recognizing clinical and behavioral indicators of FASDs and increase their capacity to care for children and families affected by prenatal alcohol exposure.

For more information on the FASD champions network or to submit an inquiry about grand-rounds presentations, [contact us](#).



CODING FOR FETAL ALCOHOL SPECTRUM DISORDERS

Listed below are the most commonly used codes applicable to FASD patient care.

Code	Description
ICD-10-CM	
Primary Diagnosis	
P04.3	Newborn affected by maternal use of alcohol (Excludes Fetal Alcohol Syndrome)
Q86.0	Fetal alcohol syndrome (dysmorphic)
F06.30	Mood disorder due to known physiological condition, unspecified
P00.4	Newborn affected by maternal nutritional disorders
P01.9	Newborn affected by maternal complication of pregnancy, unspecified
G93.49	Encephalopathy, other (static)
G96.8	Other specified disorders of central nervous system
G96.9	Disorder of central nervous system, unspecified
Facial Features	
Q11.2	Microphthalmos
R68.89	Other general symptoms and signs (eg, dysmorphic features)
Growth	
R63.6	Underweight (Add additional code for BMI if known)
R63.3	Feeding difficulties
R62.51	Failure to thrive (child)
R62.52	Short stature (child)
Development	
R62.50	Lack of expected normal physiological development in childhood, unspecified
R62.0	Delayed milestone in childhood

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Develop a healthcare program tailored for indigenous families with children who have FASD



Non-pharmacologic psychosocial interventions are the first line treatment for children with FASD



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Provider Education: Appropriate Referral for Diagnosis

- PEDIATRICIAN
- DEVELOPMENTAL-BEHAVIORAL PEDIATRICIAN

These subspecialist pediatricians often have training in recognizing genetic syndromes which enables them to evaluate facial dysmorphology if a clinical geneticist is not available.
- GENETICIST/GENETIC COUNSELOR

Referral to a geneticist may be necessary when there is a need to screen for potential genetic conditions that may present with symptoms similar to those of an FASD.
- PSYCHOLOGIST/NEUROPSYCHOLOGIST/PSYCHIATRIST

Neurocognitive/psychological evaluation considering cognition, executive function, socio-emotional function, adaptive skills, academic achievement, and self-regulation within the context of the individual's family/community.
- NEUROLOGIST

Assess for central nervous system abnormalities, such as a seizure disorder, sleep issues or focal neurologic deficits.
- SOCIAL WORKER/FAMILY THERAPIST

Assessment of the individual's and family's strengths and challenges, serve as a family advocate for services and resources, and facilitate counseling services and connection to community resources.
- EARLY INTERVENTION SERVICES

Appropriate developmental assessment, monitoring, services, and support to assist in maximizing the potential of a child with developmental delays. Currently 46 states (and Washington, D.C.) recognize the diagnosis of FAS as a diagnosed condition which provides immediate eligibility for services.
- EDUCATIONAL SPECIALIST AND/OR SCHOOL FUNCTION EVALUATOR

Senate Bill 1016 (Gavin Newsom)- effective January 1, 2023: *"the state board of education shall include FASD in the definition of other health impairment" in section 3030 of ..."*
- OCCUPATIONAL/PHYSICAL THERAPIST
- SPEECH/LANGUAGE PATHOLOGIST

Provider Education: Appropriate Referral for Families

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Health Supervision

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This section provides information on evidence-based interventions, resources for clinicians, and helping families of children with an FASD access services and community supports.

Building Effective Partnerships with Families of Children with an FASD

Language and strategies to support families with a child with an FASD.

Behavioral Interventions

Evidence-based and informed behavioral interventions that are adaptable for children with an FASD and their families.

Case Studies

Review case studies for guidance on patient care and procedural steps that may be implemented in the pediatric medical home.

Pharmacologic Interventions

Overview of medications for the treatment of FASDs.



Behavioral Interventions in Fetal Alcohol Spectrum Disorders

[Home](#) / [Patient Care](#) / [Fetal Alcohol Spectrum Disorders](#) / Behavioral Interventions in Fetal Alcohol Spectrum Disorders

Suspecting and diagnosing an FASD is only the first step on the therapeutic journey for a child and caregiver. Fortunately, validated interventions for children with an FASD are available with additional interventions adaptable to the needs of these children and their families. The following section describes evidence-based and informed behavioral interventions that are adaptable for children with an FASD and their families.

Behavioral interventions improve facets of self-regulation, neurocognition, and adaptive functioning. Most were adapted specifically for the strengths and weaknesses of children with an FASD. They support positive behavioral techniques and provide specific instruction to children for skill building while helping parents reframe interpretations of behavior and develop specific parenting skills. Caregiver education and reframing of behaviors are key components of their effectiveness. Recognizing the neurodevelopmental challenges presented by an FASD may help guide therapy decisions and set expectations for parents and caregivers.

Pediatricians can direct parents and caregivers to these interventions to help them understand that children can benefit from structured environments with reasonable rules, routines, and supervision. Office follow-up provides opportunities to monitor progress, give feedback and encouragement, and adjust the therapeutic course as needed.

[Going the Extra Mile: Improving Math and Behavior in Alcohol Affected Kids](#)

The Math Interactive Learning Experience or MILE program uses adaptive materials and tutoring methods. MILE improves math knowledge and graphomotor (handwriting) skills in children. MILE includes teaching methods and manuals for caregivers, teachers, and tutors.

Parents and Children Together (PACT) uses group formats to teach children how to identify arousal and other states (e.g. hunger, fatigue) using a "How is your engine running?" metaphor. Group training for parents and caregivers is part of the program so that they have ready strategies for dealing with arousal states. The PACT method provides constructs adaptable to the pediatric setting and training for parents and caregivers to improve behavior regulation skills, executive functioning, and parent effectiveness for children with an FASD.

[GoFAR: An Intervention for Affective and Metacognitive Control in FASD](#)

The GoFar program focuses on disorders of affective and cognitive control that are central to behavioral and adaptive disorders from infancy through young adulthood. GoFar brings together computer game technology and behavioral techniques for affective and cognitive control to manage impulsive and problematic behavior. The methodology also includes parenting strategies to improve child behaviors.

[Good Buddies](#)

Good Buddies uses a group format for children with an FASD and their parents that improves peer relationships, social skills, and parental understanding of FASD-related disabilities. This intervention teaches age-appropriate social skills over 12 weekly sessions for parents and children. Training is focused on small steps toward the child and family setting up and having a successful play date. The Good Buddies training uses explicit instruction of social skills (e.g., slipping into a group).

[The Zones of Regulation](#)

The Zones of Regulation is a framework to promote self-regulation and emotional control. Zones of Regulation uses a group format to teach children how to identify their internal states with the use of a color mapping paradigm. The method teaches children strategies and skills to manage states through activities and incorporates parent education and skill building. The concepts and parenting methods of Zones of Regulation are adaptable for individual children in pediatric office settings.

[Families Moving Forward](#)

Families Moving Forward is an intervention that is most appropriate for children with severe, clinically significant behavior problems. Based on positive behavior support techniques, the model uses supportive consultation with a parent or caregiver rather than directly with a child. Mental health providers with specialized training lead the consulting sessions that last 9 to 11 months, involving semi-weekly meetings with parents and caregivers. The Families Moving Forward program has developed a large number of brief handouts for parents, caregivers, educators and service providers.

[Triumph Today](#)

Triumph Today is a parent training/advocacy program. It is a 16-segment online training series that gives parents the tools and techniques to understand a child with an FASD. It helps to create structures and strategies to bring success to family members with the disability. There is a cost associated with Triumph Today training.

[The Alert Program](#)

The Alert Program is an occupational therapy program that has been adapted for use for individuals with an FASD. The method has shown to improve executive function skills, emotional problem-solving, inhibitory control, and social cognition. The program is the basis for the PACT and Zone of Regulation interventions previously described.

Do2Learn

Do2Learn is a resource for individuals with special needs. The intervention has a virtual reality game that can teach fire and street safety skills to individuals with an FASD. The Do2Learn site also provides an FASD ToolBox where supportive education and behavior materials are available for download.

View [additional resources](#) at the National Organization on Fetal Alcohol Syndrome

View [FASDs: Treatments](#)

Behavioral Intervention Availability

Formal programs for particular behavioral interventions may be unavailable in a community. If your practice has the capacity, key elements and adaptations of some of the behavioral interventions can be provided in the pediatric medical home setting or in consultation with an appropriate professional (e.g., psychologist).

Provider Education: Appropriate Referral for Families

- FASD United- Family Navigator Program

The FASD United Family Navigator program provides individuals living with fetal alcohol spectrum disorders (FASD), their family members, caregivers and supporters with expert, confidential support and referrals;

<https://fasdunited.org/family-navigator/>

- CDC FASD Homepage

- County of Santa Clara Behavioral Health;

<https://bhsd.sccgov.org/information-resources/substance-use-prevention-services/fetal-alcohol-spectrum-disorder-fasd>

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What is the FAS DPN?

The Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FAS DPN) started out as a single FASD diagnostic clinic at the University of Washington in Seattle in 1993. It was sponsored by the CDC as a [FASD primary prevention study](#). The clinic expanded into a statewide network of interdisciplinary FASD diagnostic clinics led by the core clinical/research/training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, WA. Susan J. (Astley) Hemingway, Ph.D., Professor of Epidemiology/Pediatrics, is the Director of the FAS DPN. The network was established in 1995 through Washington State [Senate Bill 5688](#) and [RCW 71.24.605](#). Over the years it has received support from the CDC, March of Dimes, Chavez Memorial Fund, and WA State Department of Social and Health Services.

Each clinic in the network uses the same interdisciplinary approach to diagnosis and the same systematic diagnostic method-the 4-Digit Diagnostic Code. The mission of the FAS DPN is primary and secondary prevention of FAS through screening, diagnosis, intervention, training, education, and research. The WA State FAS DPN began diagnosing patients in 1993 and has diagnosed over 3,000 patients to date.

The WA State FAS DPN has expanded both nationally and internationally through the training of interdisciplinary teams. Several hundred interdisciplinary teams have been trained around the world. Major accomplishments of the FAS DPN include:

[Home](#)[FAS DPN](#)[Screening](#)[Diagnosis](#)[Surveillance](#)[Intervention](#)[Prevention](#)[Training](#)[Research](#)[Literature](#)[Links](#)[Order Forms](#)[Russia](#)[Search](#)

Screening

- Creation of a computerized FAS Facial Photographic Screening Tool.
- Ten-year, population-based FAS screening in foster care confirming, 1 out of every 100 children in WA foster care has FAS.
- Juvenile Justice FASD Screening/Diagnostic Initiative.

Diagnosis

- Creation of the FASD 4-Digit Diagnostic Code.
- Creation of the FAS Facial Photographic Analysis software.
- Creation of the interdisciplinary model for FASD diagnosis.
- Establishment of the WA State FAS Diagnostic & Prevention Network.
- Diagnosis of over 2,000 patients to date.

Prevention

- Publication of a lifetime profile of birth mothers of children with FAS and factors that enhanced and hindered their ability to achieve sobriety and practice effective family planning.

Surveillance

- Discovery that the prevalence of FAS among children in foster care born between 1993 and 1998 has significantly declined in King County. This is correlated with a significant decline in maternal drinking during pregnancy in the same years.

Intervention

- CDC-sponsored randomized control trial to assess an individualized, supportive, behavioral consultation intervention for parents and school staff of children with FASD.
- CDC-sponsored observational study of school-based social communication deficits among children with FASD.
- NIAAA-sponsored motor-sensory intervention research for children with FASD.
- Affiliation with NOFAS Washington State providing family support to children/adolescents with FASD.

Training

- FASD training of community professionals from WA State (1,000s trained).
- FASD training program to establish interdisciplinary FASD diagnostic teams worldwide (>150 teams trained).
- Worldwide distribution of FASD diagnostic tools and software.
- Online training course for use of the FASD 4-Digit Diagnostic Code.

Research

- NIAAA: Alcohol teratogenicity studies, 1984-92.
- GE: FAS MRS study, 1991-92.
- Establishment of the FAS DPN database on over 7,000 patients, 1992 to present.
- Establishment of the FAS DPN Photographic Image Analysis Laboratory for clinical and research analysis of facial photographs, 1992 to present.
- Establishment of a FAS DPN Patient Registry as a resource for invitation of patients into FASD research studies, 1992 to present.
- CDC: FAS Primary Prevention study, 1992-97.
- CDC: FASD Social Communication Intervention study, 2001-2006
- CDC: FASD Behavioral Consultation Study creating the Families Moving Forward intervention program 2001-2010..
- NIAAA: FASD MRI/MRS/fMRI study, 2002-07.
- NIAAA: FASD Motor-sensory Intervention study 2009-14.
- NIH: National Children's Study Dysmorphology Assessment Instrument, 2010.

Literature

- Publication of over 200 research articles by the FAS DPN clinical/research team.

Summary

- FASDs result from *in utero* alcohol exposure, they are not hereditary
- FASDs are difficult to diagnose, require a multidisciplinary approach, and have no cure
- Certain indigenous populations have a higher rate of binge drinking in pregnancy; the use of alcohol is complex and likely has roots in history
- Provider education, funding, and multidisciplinary approach/clinic will allow improved medical, psychological, and vocational outcomes through longitudinal intervention and treatment that maximize protective factors and build capacity in identified strengths (*e.g.*, vocational training and life skills development, long-term outcomes include optimizing environmental modifications, parenting strategies)



Questions

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