



Fetal Alcohol Spectrum Disorders:

History, Prevalence, Diagnosis and Effective Interventions

Presenter Information:

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Objectives

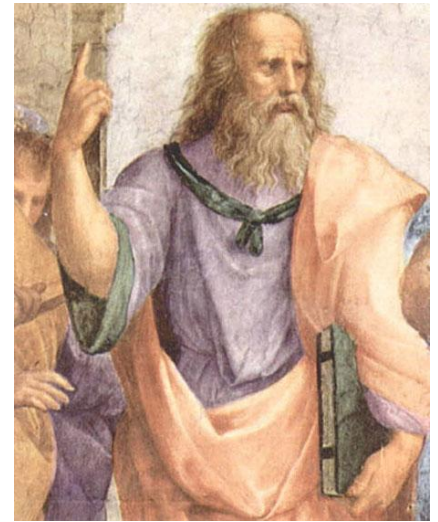
- To review historical information and recent developments regarding prenatal alcohol use
- To present recent epidemiological information
- To present basic FASD definitions
- To explain the diagnostic process
- To provide an overview of FASD affects and interventions throughout the lifespan
- To review the use of Screening, Brief Intervention and Referral to Treatment (S-BIRT) with all women of childbearing age



Historical Perspectives & Recent Developments

History of Prenatal Alcohol Exposure

- Alcohol was originally used in religious ceremonies and rituals dating as far back as 7000 B.C.



- Alcohol is the oldest and most widely used drug in the world and it has been considered a risk to pregnancy since at least 300 B.C.

Early Research

“Chronic alcoholism can be appropriately added to the list of maternal factors that create an unhealthy intra-uterine environment for the developing fetus - the consequences which are lifelong”

-Christie Ulleland, MD (1972)

Recent Developments

“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 (IOM) Report to Congress, 1996*





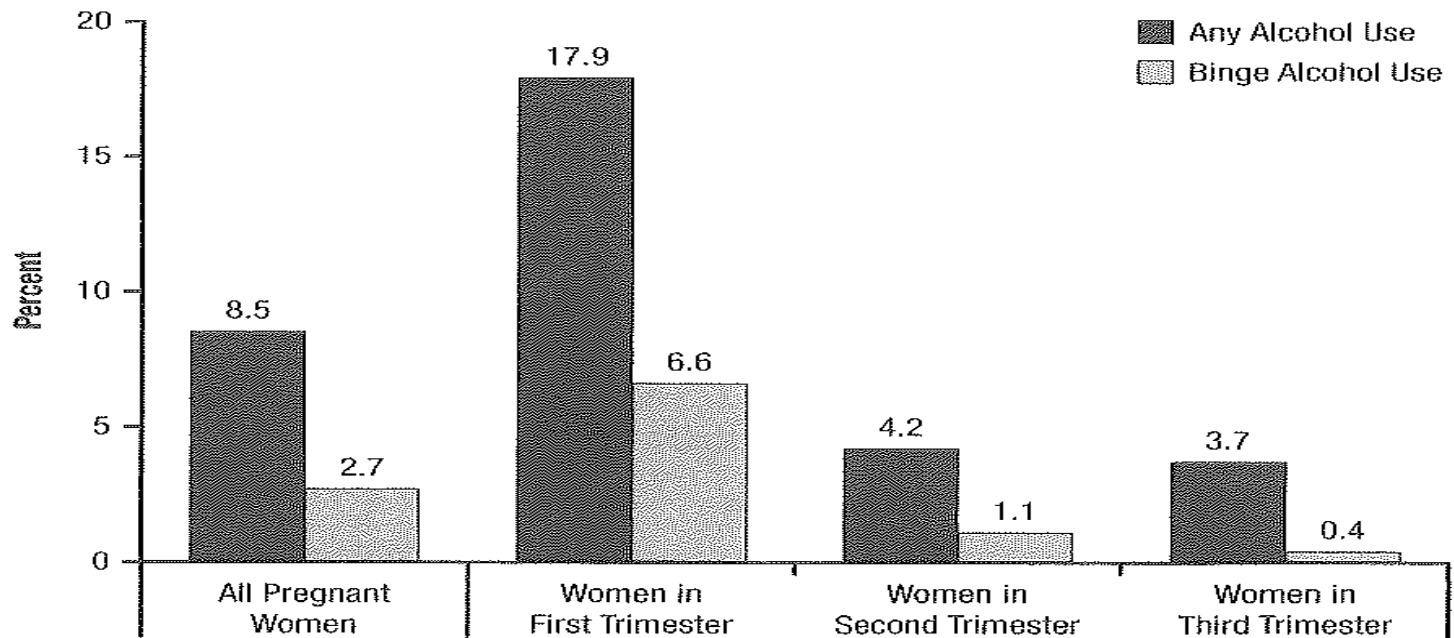
Women, Alcohol & FASD Epidemiology

Women & Alcohol Use in the U.S.



Pregnancy & Alcohol Use in the U.S.

Past Month Alcohol Use and Binge Alcohol Use among Pregnant Women Aged 15 to 44, Overall and by Trimester*: 2011 and 2012

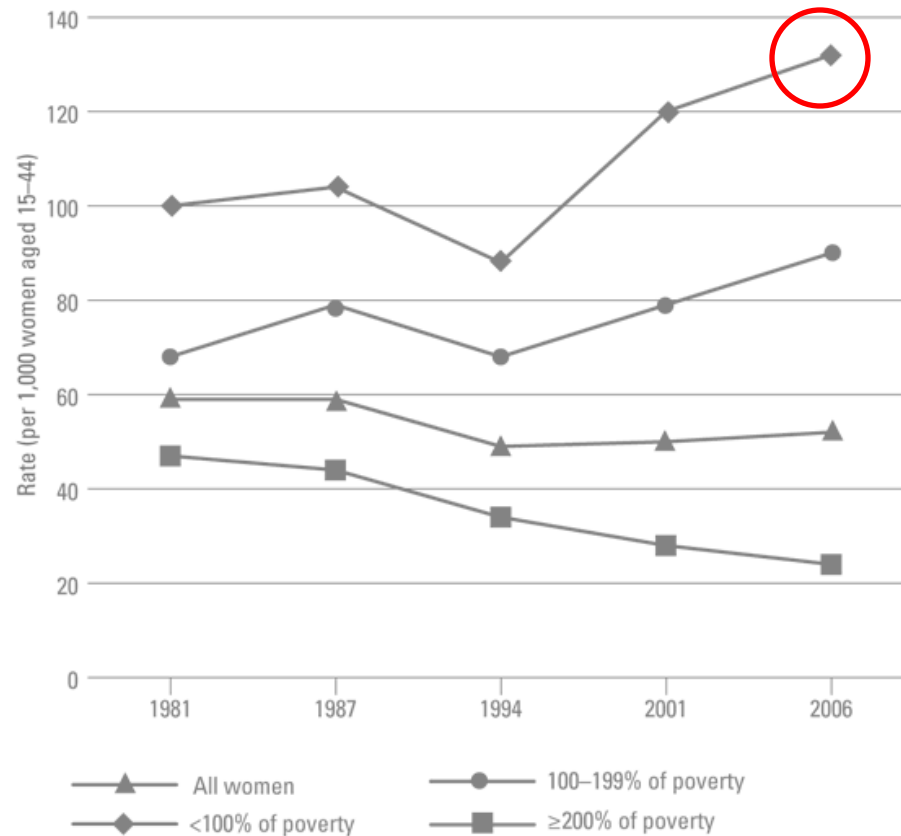


* Pregnant women are defined as women aged 15 to 44 who reported that they were pregnant at the time of the survey interview. Pregnant women aged 15 to 44 not reporting trimester are excluded.

Unintended Pregnancy

Unintended Pregnancy Rates, 1981–2006

Unintended pregnancy has become increasingly concentrated among poor and low-income women



FASD Prevalence In the U.S.

- Each year in the United States, an estimated 40,000 babies are born with an FASD.
- Prevalence of FAS in the United States is estimated to be between 0.5 and 2 per 1,000 births.
- It is very difficult to determine prevalence.
- Symptoms are often not detected until after child starts school.



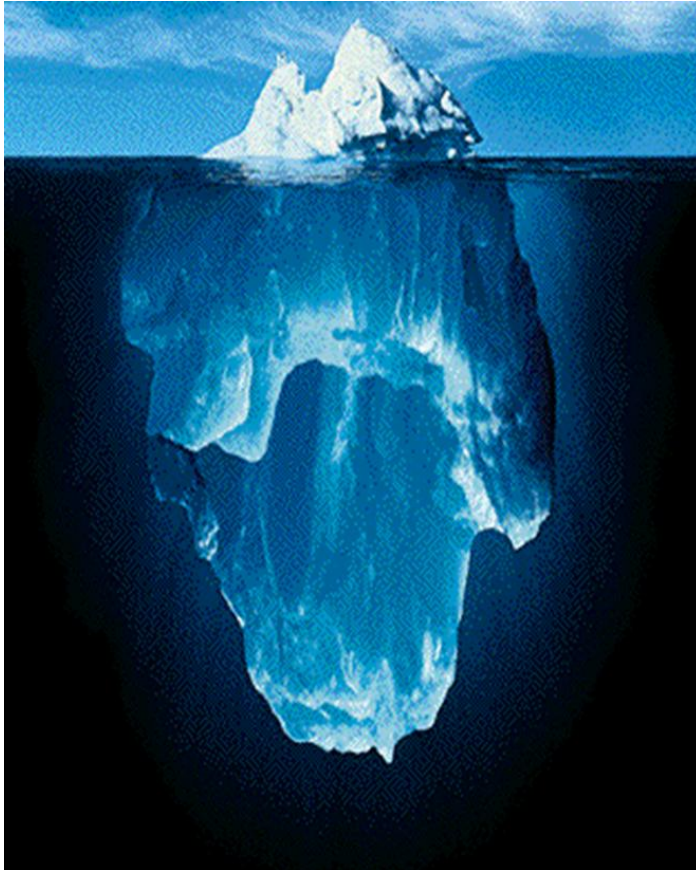
FASD Definitions and Diagnoses

What is FASD?



- FASD is NOT a diagnosis.
- Impacts of FASD can include physical, mental, behavioral, and/or learning disabilities.
- FASDs last a lifetime.
- Early detection and referral to services greatly improves the outcomes of people who have an FASD.
- FASD's are 100% preventable

FAS – Only the tip of the iceberg



✓ FAS (Fetal Alcohol Syndrome)
Only the tip of the iceberg!

- ✓ PFAS (Partial FAS)
- ✓ ARND (Alcohol Related Neuro-Developmental Disorders)
- ✓ ARBD (Alcohol Related Birth Defects)

FASD Diagnosis

- The four diagnoses related to prenatal alcohol exposure are currently:
 - Fetal alcohol syndrome (FAS)
 - Partial fetal alcohol syndrome (PFAS)
 - Alcohol related neuro-developmental disorder (ARND)
 - Alcohol related birth defects (ARBD)

Fetal Alcohol Syndrome

- The term “FAS” was first used in 1973.
- FAS represents the severe end of the FASD spectrum.
- Three diagnostic criteria must be met.
 - Facial anomalies
 - Growth retardation
 - Central nervous system abnormalities

FAS Facial Features

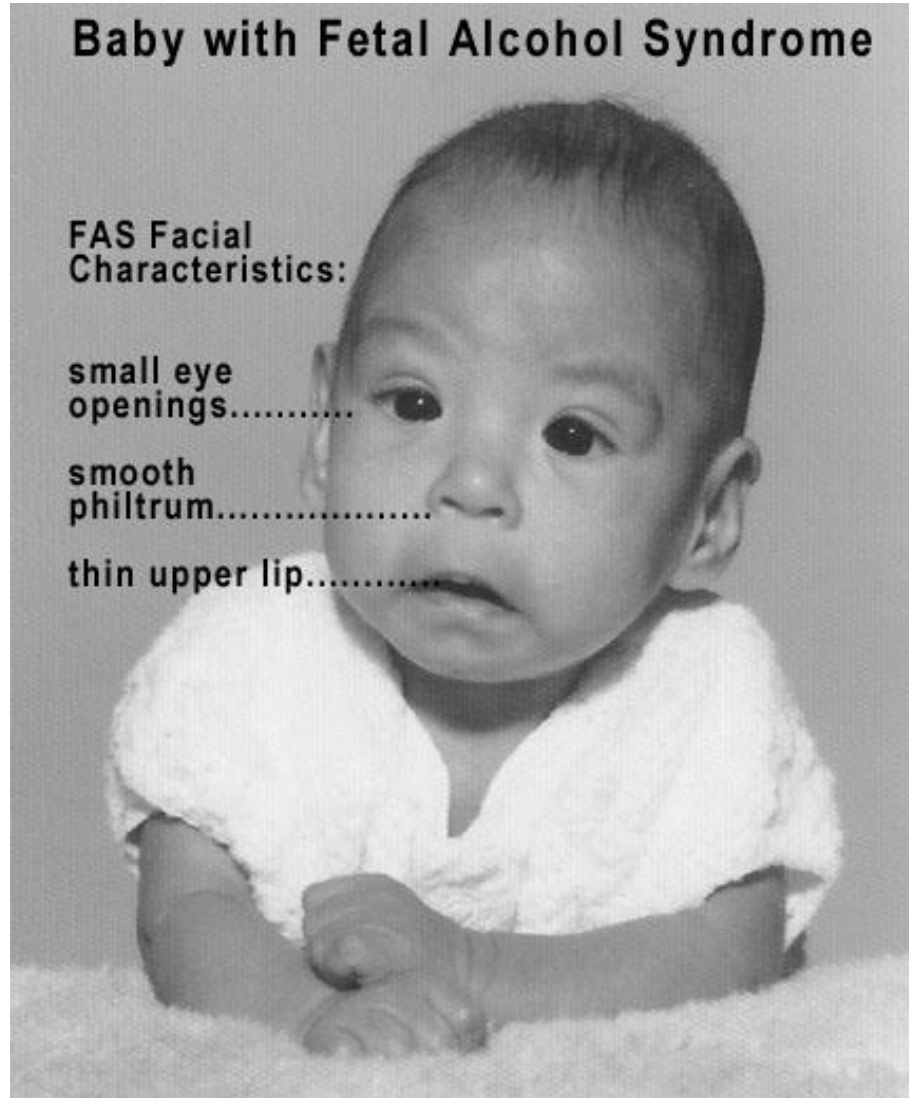
Baby with Fetal Alcohol Syndrome

FAS Facial Characteristics:

small eye openings.....

smooth philtrum.....

thin upper lip.....



Other FASD Diagnoses

- Partial Fetal Alcohol Syndrome (PFAS)
- Alcohol Related Neuro-developmental Disorder (ARND)
- Alcohol Related Birth Defects (ARBD)

Common Disorders Identified with FASD

- ✓ Asperger's Disorder
- ✓ Attention Deficit Hyperactivity Disorder (ADHD)
- ✓ Autistic Disorder
- ✓ Borderline Personality Disorder
- ✓ Conduct Disorder
- ✓ Reactive Attachment Disorder
- ✓ Anxiety
- ✓ Depression
- ✓ Learning Disability
- ✓ Oppositional-Defiant Disorder
- ✓ Post Traumatic Stress Disorder (PTSD)
- ✓ Receptive-Expressive Language Disorder
- ✓ Eating Disorders

Secondary Disabilities Resulting from the Primary Disabilities of Individuals with FAS/FASD

- ✓ 60% have trouble with the law
- ✓ 50% will be confined in prison, mental institutions and/or treatment centers
- ✓ 35% have alcohol and/or drug problems
- ✓ 61% have disrupted school experience
- ✓ 49% exhibit inappropriate sexual behavior



FASD Throughout the Lifespan – Affects and Interventions

FASD in Childhood



Poor habituation, sleep-wake cycles, irritability



Failure to thrive, poor sucking response



Fidgeting (meal time or other structured event)



Usually high maintenance-24/7



Difficulties determining body language and expressions



Difficulties separating fact from fantasy



Difficulty understanding cause and effect



Boundary issues



Attention problems/Impulsive/poor impulse control



Easily frustrated/tantrums

FASD's and Adolescents



Still need limits and protection due to deficits in reasoning, judgment and memory



High risk of being drawn into anti social behavior



Unable to distinguish between friends/enemies;



Struggle to accept their own disability while trying to prove ability to be independent



Negligent of normal hygiene



Unable/unwilling to take responsibility for actions; egocentric

FASD's and Adults



- 🧒 Vulnerable to anti-social behavior
- 🧒 Unlikely to follow safety rules
- 🧒 Social/sexual/financial exploitation; social isolation
- 🧒 Vulnerable to panic, depression, suicide, psychosis (Huggins, et.al-2008)
- 🧒 Need sheltered environment
- 🧒 Can't see the big picture/other points of view

*** Chudley, et al(2007): Adults with FASD have higher rates of social problems, executive functioning and psychopathology when compared to general population**

Comprehensive Assessment and Management of Individuals with FASD

Use a TEAM approach

- ✓ **Multi-discipline assessment**
 - Psychosocial history
 - Physician
 - Disciplines (Mental health, speech, OT/PT, education system)
 - Parents/caregivers
 - Social service agencies (DDD, SS, Child protective, drug treatment)

- ✓ **Case management**
 - Diagnosis
 - Early intervention and tracking
 - Stable home environment
 - Medication
 - Case manager/mentor in school/home/communities
 - Support services-family community, educational, vocational
 - Supervised housing/residential facility
 - Special education and vocational rehabilitation

Challenges for Providers

- People with an FASD are often challenging to work with.
- Recognizing an FASD challenges some of the basic tenets of treatment and interactions with people.

Reconceptualizing the Behavior of the Individual with FASD

From seeing: → To understanding:

- | | |
|------------------------|--------------------------|
| ✓ Won't | Can't |
| ✓ Lazy | Tries hard |
| ✓ Lies | Fills in |
| ✓ Doesn't try | Exhausted or can't start |
| ✓ Doesn't care | Can't show feelings |
| ✓ Refuses to sit still | Over stimulated |
| ✓ Fussy, demanding | Oversensitive |
| ✓ Resisting | Doesn't "get it" |

(D Malbin, fascets.org)

Guiding Principles

- ✓ Support: Self-esteem.
- ✓ Understand: That FASD is not “Chicken Pox.”
You can’t catch it and it never goes away.
- ✓ Shift: From a “non-compliance” model to a “non-competence” model.
- ✓ Accept: Individuals with FASD do the best they can with what they’ve got at that time.

Guiding Principles

- ✓ Acknowledge: Interventions must be useful to, and usable by the individual in order to be an intervention.
- ✓ Foster: Inter-dependence
- ✓ Reflect: Respect
- ✓ Promote: Self-worth
- ✓ Believe: You can make a difference.

Best Practice

One model contains seven basic components, that form the acronym **SCREAMS**

Structure

Cues

Role models

Environment

Attitude

Medications

Supervision

Strategies to Use

DO!

- Give clear directions, one at a time.
- Use short-term consequences that are as closely linked to the behavior as possible.
- Use a variety of communication tools – verbal, visual, symbolic, hands on communication.
- Be understanding. Any lack of progress, shutting down, isolation, or emotional outbursts are not under the individuals volitional control.



Universal Screening for ALL Women of Childbearing Age

Why screen: Alcohol can have deleterious effects in women

- Health Risks
- Pregnancy risks
- High risk lifestyle



Screening for Prenatal Alcohol Use

- Use a valid screening tool, such as the T-ACE, TWEAK, or 5 Ps Plus
- Document any prenatal alcohol use:
 - What trimester?
 - How often?
 - How much?
- If alcohol/drug use during pregnancy is suspected or confirmed, refer for screening for medical issues, disabilities, etc. and refer for full evaluation.



Knowledge, Opinions and Practice Patterns of OB-GYNs Re: Patients' Use of Alcohol

- 66% believe that occasional alcohol consumption is not safe during any period of pregnancy
- 82% ask all pregnant patients about alcohol use during initial visit only
- 78.5% advise abstinence when women report alcohol use
- 71.9% felt prepared to screen for risky drinking

Britta,L et al JAddMed June 2010



Drinking and Reproductive Health: Toolkit for Clinicians

(acog.org; womenandalcohol.org)

Tool kit components include:

- FASD clinician guide
- Additional screening tools
- Assess readiness
- Standard drink pocket card
- Strategies for change

Patient education handouts:

- Before you get pregnant
- If you are pregnant
- If you are not planning a baby
- If someone is having a baby
- My plan for alcohol
- My plan for birth control
- Drinking contracts

To access toolkit, go to:

<http://www.acog.org/~media/Department%20Publications/FASDToolkit.pdf?dmc=1&ts=20140103T1332149786>

FASD in women and in offspring may contribute to relapse

- Women that have used during pregnancy often have severe guilt and shame.
- Women that have children with undiagnosed FASD risk relapse for a number of reasons.
- Women prenatally exposed to alcohol themselves will need extra support to prevent relapse and engage in treatment and Recovery
(K. Mitchell NOFAS)



The Circle of Hope - Birth Mother's Network

- Utmost level of confidentiality
- Values honesty and integrity of all members
- Core group of passionate, strong, and empowered women
- Safe environment-welcomes all women without fear of judgment, shame, or ridicule
- Contact: Kathy Mitchell (Mitchell@nofas.org)
National Organization on Fetal Alcohol Syndrome
<http://www.nofas.org/join-the-circle-of-hope/>

The Final Word: Key Points

- Many Maine women drink alcohol.
- Women are not always aware when they first become pregnant. Alcohol can cause damage in early pregnancy.
- Screening, brief intervention and referral to treatment (SBIRT) are effective in identifying women in need of support.
- FASD's are caused by prenatal alcohol exposure and are life-long.
- Early diagnosis and effective intervention can help reduce secondary disabilities related to FASD.
- Remember that FASD causes problems with memory, emotional regulation, sensory integration, abstract thinking and decision-making, and creates social challenges. It is the brain damage, not the person, that you are seeing in these behaviors.

**Remember: there is no safe time, no safe amount,
and no safe kind of alcohol during pregnancy.**

**NO AMOUNT OF ALCOHOL CONSUMPTION DURING
PREGNANCY IS PROVEN TO BE SAFE.**



Questions

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Program Info & Contact Information

- SAMHS FASD/DAB Task Force
- FASD/DAB Trainings & 2014 Conference
- Prenatal alcohol use prevention campaign – rollout spring 2014

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