Fetal Alcohol Spectrum Disorders:
History, Prevalence, Diagnosis and Effective Interventions

Presenter Information:
Andrea Pasco, FASD/DAB State Coordinator
Department of Health & Human Services
Office of Substance Abuse and Mental Health Services
Phone: 207-287-2816
Email: Andrea.Pasco@maine.gov
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.
“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.

State-Specific Weighted Prevalence Estimates of Alcohol Use (Percentage of Any Use/Binge Drinking) Among Women Aged 18 – 44 Years — BRFSS, 2008

[Map showing state-specific weighted prevalence estimates of alcohol use by percentage of any use/binge drinking among women aged 18 – 44 years.]

CDC
SAFER • HEALTHIER • PEOPLE™
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 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

-Streissguth 2004
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.

( FASD Support Network of BC)
Best Practice

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

Structure
Cues
Role models
Environment
Attitude
Medications
Supervision

- Teresa Kellerman, 2012
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

???
Program Info & Contact Information

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

Andrea Pasco, FASD/DAB State Coordinator
Department of Health & Human Services
Office of Substance Abuse and Mental Health Services
Phone: 207-287-2816
Email: Andrea.Pasco@maine.gov