

FASD Prevention Program Webinar Series

“Supporting Health Care Providers to
Prevent Fetal Alcohol Spectrum Disorder”

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Welcome

- First time using WebEx?
 - You can type in questions in the **Chat Box** and we'll answer them throughout the webinar.
 - You can **raise your hand** and we'll pause to let you speak if we have time.
- Today's webinar will be **recorded and archived** on the our project website. Please keep this in mind when sharing information and experiences during the webinar.

New to The Arc?

- Founded in 1950, nation's leading and largest community-based organization
- Network of 140,000 members in almost 640 state and local chapters serving more than 1.4 million people with I/DD* and their families
- National headquarters in Washington, DC with strong federal-level public policy advocacy and program services department (currently over \$10 million in funding)
- Provide “birth to grave” services and advocacy in areas such as: prevention, early intervention, special education, self-advocacy, health care and employment
- *FASD prevention and awareness at local, state and national levels*



* *Intellectual disability* is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates **before the age of 18**.

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What Do You Think?

FASD is entirely preventable if women do not drink alcohol while pregnant, nevertheless, survey data show that women are drinking alcohol during their pregnancies. What percentage of women do you think drink alcohol during pregnancy?

- a. 1 in 5
- b. 1 in 10
- c. 1 in 13
- d. 1 in 15
- e. 1 in 20

What's the Issue?

- FASD is entirely preventable if women do not drink alcohol while pregnant, but survey data show that 1 in 13 women continue to drink*, even so...
- Many health care providers advise women that light drinking is safe and do not use screening tools or intervention strategies
- FASD is the single most common cause of intellectual and developmental disabilities that is 100% preventable
- Drinking alcohol while pregnant can harm a developing fetus and cause Fetal Alcohol Spectrum Disorder or FASD (which is a life-long, disorder)

http://www.cdc.gov/mmwr/preview/mwrhtml/mm6128a4.htm?s_cid=mm6128a4_e%0D%0A

FASD Prevention Project

Problem: Many health care providers don't talk about alcohol, even when patients drink too much. **Why Not?**

- Time Limitations
- Patient/client sensitivity or denial of issue
- Discomfort or unsure how to discuss issue with patient/client
- Lack of clarity on who is responsible for screening/discussion issue
- Need for additional training
- Lack of referral resources
- Lack of financial reimbursement
- Unsure about/disagree with research



Fetal Alcohol Spectrum Disorder
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Overview of FASD

- Umbrella term describing the range of effects in a person whose mother drank alcohol during pregnancy
- Alcohol passes through the placenta and enters the embryo or fetus through the umbilical cord (affecting size, shape and function of cells that form brain, heart, kidneys and other body organs)
- Effects include physical, behavioral and mental and/or learning disabilities; no cure
- CDC studies have shown that 0.2 to 1.5 cases of fetal alcohol syndrome (FAS) occur for every 1,000 live births in certain areas of the United States.

FASD Prevention Project

- \$1.3M cooperative agreement from the U.S. Department of Health Resources and Services Administration (HRSA)
- Goal is to increase health care providers:
 - Knowledge about the risk that alcohol poses to the fetus
 - Use of FASD prevention strategies, including use of screening and assessment methods
 - Use of consistent messaging with their patients: drinking while pregnant can cause FASD

Project Partners

- Association of Reproductive Health Professionals (ARHP)
 - CME Course
- The Association of American Indian Affairs (AAIA)
- Association of Women's Health, Obstetrics and Neonatal Nurses (AWHONN)
- The National Association of City and County Health Officials (NACCHO)
- Dave Garry, D.O., Albert Einstein College of Medicine, Chair of FASD Task Force for ACOG District II, NY

** Partners will review materials and disseminate information via their networks*

Federal Collaborators

- Health Resources and Services Administration (HRSA) - project funder
<http://www.hrsa.gov>
- Centers for Disease Control and Prevention (CDC)
<http://www.cdc.gov/ncbddd/fasd/index.html>
- SAMHSA (Substance Abuse and Mental Health Services Administration)
FASD Center for Excellence:
<http://www.fasdcenter.samhsa.gov/>
- National Institute on Alcohol Abuse and Alcoholism (NIAAA)
Interagency Coordination Committee on FASDs
<http://www.niaaa.nih.gov/ICCFASD>

Target Audiences

- Family Practitioners
- Internists
- Pediatricians
- Obstetricians and Gynecologists
- Physician's Assistants
- Midwives
- Nurse practitioners
- Registered Nurses / Licensed Practical Nurses
- Mental Health Therapists
- Substance Abuse Therapists
- Community Health Representatives

Health Care Providers to the Rescue

- Experts believe there are many more cases of FASD in the U.S. than are actually diagnosed (FASD is both underdiagnosed and misdiagnosed)
- Health care providers have the unique position in a person's life to provide education that could impact a child and his or her family for their rest of their lives
- Patients will often listen to their health care provider's advice over the advice of others, and for good reason

What Do You Think?

According to recent data from CDC, how many adult patients say a health care provider has ever discussed alcohol use with them?

- a. 1 in 2
- b. 1 in 4
- c. 1 in 6
- d. 1 in 8
- e. 1 in 10

Welcome Dr. DeJoseph

- Adjunct faculty member at Philadelphia College of Osteopathic Medicine
- Licensed in Family Medicine in PA, clinical experience in General Practice and Geriatrics
- Works with NJ/NE FASD Education and Training Center
- Serves on the NJ and Philadelphia Task Forces on FASD, as well as the National FAS/FAE Task Forces
- Recipient of Ambassador Award in the area of Health Care from NJ Governor's Council on Mental Health Stigma
- Member and regional coordinator in SAMHSA's Birth Mother Network
- Provides education and training on a variety of addiction and mental health topics

“My Doctor Said It’s Ok for Me to Have a Few Drinks”

Screening as Prevention
ARC US Webinar
March 2014

Overview

- Screening and prevention- definitions and universal screening recommendations
- The problem: Lack of a clear prevention message
- Medicine as a culture and what is the language of physicians?
- What surveys tell us
- Progress and resources

National Alcohol Screening Day®

April 10, 2014

- Screening for Mental Health offers alcohol screening programs for the military, colleges and universities, community-based organizations and businesses.
- Held annually on Thursday of the first full week of April, National Alcohol Screening Day is an outreach, education, and screening program that raises awareness about alcohol misuse, offers online screening, and refers individuals with alcohol problems for further treatment.
- Thousands of colleges, community-based organizations, and military installations provide the program to the public.



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<http://www.mentalhealthscreening.org/events/national-alcohol-screening-day.aspx>

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Possible Fetal Effects of Prenatal Exposure to Alcohol

- **Fetal Alcohol Syndrome (FAS)** is a life long birth defect caused by maternal consumption of alcohol during pregnancy.
- Diagnostic criteria include
 - Dysmorphic facial features
 - Growth delay
 - Brain dysfunction
 - Maternal history
- Genetic syndromes must be ruled out
- **Fetal Alcohol Spectrum Disorders** is a descriptive term used for the broad spectrum of disorders caused by prenatal exposure to alcohol including:
 - FAE (Fetal Alcohol Effects)
 - ARND (Alcohol Related Neurodevelopmental Disorders)
 - ARBD (Alcohol Related Birth Defects)
 - FAS (Fetal Alcohol Syndrome)
 - PFAS (Partial FAS)
 - NDD-PEA (DSM5)

****FASD IS NOT A DIAGNOSIS**



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The Challenges: Who is the Woman at Risk?

Consider Behavioral Risk Factor Surveillance System (BRFSS) 2006-10




The Arc

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Prevention: Universal Screening and Appropriate Intervention

- NIAAA 2007-Helping Patients Who Drink Too Much; AUDIT screen
- ACOG Toolkit (2006) phone app (2012); SBIRT; AAP Toolkit
- Self- report: TACE; TWEAK; 4P's Plus; CRAFFT
- Laboratory, Ultrasound, Meconium (FAEEs), Neonatal hair
- Brief Interventions-Ask, Advise, Assist, Monitor, Re-Assess; use motivational strategies
- Referral to CHOICES or treatment as indicated

The Problem has Cultural Roots

- *“My doctor said it was fine for me to have a few drinks”*
- Health care providers aren’t routinely advising “no alcohol during pregnancy.” Only one in six adults say a health care provider has ever discussed alcohol use with them even though drinking too much is harmful to health, (CDC 1/14)
- Health care is a culture in and of itself, with it’s own language, beliefs, values, challenges, customs, traditions, habits
- The office visit is a cultural exchange
- We live in a drinking culture in America, no matter what our ethnicity

The Culture and Language of Medicine:

What do you identify with?

- If I find something, I want to fix it (don't have resources/referral sources/proof that light drinking is a problem)
- My patients and I work better if they understand and appreciate my screening efforts
- I like to get paid for my work
- If I upset my patients, I'm more likely to get sued
- I need clear diagnosis, prevalence, and interventions
- Unspoken values-it's the drug addicts who cause the damage, not the social drinker

What surveys tell us*

- 66% Ob-gyns believe that occasional alcohol consumption is not safe during any period of pregnancy
- Top barrier- patient denial, sensitivity, and resistance to treatment. Other: time, finances, confidentiality, need for training
- Top resource needed- referral resources for patients with alcohol problems
- Personal consumption of alcohol affects doctors opinions about women at risk, safety threshold, and feeling prepared to conduct brief intervention to reduce alcohol use by women

*(Britta 2010; Anderson 2010)

Challenges to Diagnosis: Women's Views and Experience*

- More women are informed about risks of drinking during pregnancy; information alone may not translate into behavioral change
- Still many misconceptions about type of alcohol and timing during pregnancy when alcohol may cause harm
- Media and health care provider messages cause confusion
- Partners, family and friends influence women's decisions about drinking during pregnancy

Ending on a positive note: *Progress*

- Validated tools
- Widespread discussion and controversy
- Task forces, Regional Training Centers, Diagnostic centers, State Coordinators, Prevention research
- Neuroimaging, genetics, epigenetics
- DSM5- Neurodevelopmental Disorders- Prenatal Alcohol Exposure (ND-PAE)
- Educational materials
- Birth Mother's Network (NOFAS) and SAFA (The Arc)
- Practical strategies and interventions

Resources: The Fetal Alcohol Spectrum Disorders Toolkit—American Academy of Pediatrics/CDC

- About FASDs
- The Toolkit
- The Facts/ Common Definitions
- Frequently Asked Questions
- Identification, Diagnosis, and Referral
- Patient Management/Practice Management
- Sample Forms
- In-Depth Provider Training
- Resources

<http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit>

Drinking and Reproductive Health: Toolkit for Clinicians*

Drinking and Reproductive Health: a fetal alcohol spectrum disorders prevention tool kit is developed for women's health care clinicians. It includes screening and brief intervention tools for the clinician and one-page patient education handouts for download.

Tool kit components include:

- FASD Clinician Guide
Additional Screening Tools
Assess Readiness
Evaluation and CME guide
Standard drink pocket card
Strategies for change



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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

- **Phone app:**

<http://www.womenandalcohol.org/steps.html>

*(acog.org; womenandalcohol.org)

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Resources

- Announcing the new IDToolkit website for health care providers 2/7/2014 American Academy of Developmental Medicine and Dentistry (AADMD):

<http://aadmd.org/articles/announcing-new-iddtoolkit-website-health-care-providers>

Includes checklists on general, physical, behavioral, and mental health issues. Useful resource for individuals with FASD, including birth mothers with FASD themselves

- CDC RTC trainings available, info @ <http://www.cdc.gov/NCBDDD/fasd/training.html#RTCs>



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How to Get Involved

- Participate in focus groups to guide FASD prevention educational materials for healthcare providers
- Serve as an FASD prevention education materials reviewer
- Serve as a webinar presenter and/or recommend webinar presenters
- Distribute electronic communications via social media about FASD prevention materials to colleagues or health care providers
- Distribute and/or present FASD prevention materials to your colleagues and/or health care providers in my local community
- Suggest that your research or a resource be added to the website
- Share information with us about your FASD prevention efforts

I Have A Question



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Contact Us

EMAIL:

FASDinfo@thearc.org

WEBSITE:

<http://www.thearc.org/FASD-Prevention-Project>



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