

FETAL ALCOHOL SPECTRUM DISORDERS (FASD) SOCIAL WORK CHAMPIONS

Fetal Alcohol Spectrum Disorders: What Social Workers Need to Know and Do**

BACKGROUND

Prenatal exposure to alcohol is one of the leading preventable cause of birth defects, intellectual disability, and neurodevelopmental disorders. The non-diagnostic umbrella term "fetal alcohol spectrum disorders (FASD)" is used to characterize the range of physical, mental, behavioral and/or learning disabilities that can result from alcohol-exposed pregnancies.

With support from the CDC's National Center on Birth Defects and Development Disabilities, FASD Practice and Implementation Centers (PICs) at the University of Missouri and the Baylor College of Medicine, along with partners at The University of Texas at Austin and National Association of Social Workers, are collaborating to develop and disseminate FASD curricula, training, and evidence-based practices to social work practitioners, students, and practice settings. This collaboration is part of CDC's national cross-discipline initiative to promote evidence-based clinical practices to prevent FASD; promote proper treatment and support services for those with FASD; and facilitate sustainable practice change for primary prevention of alcohol-exposed pregnancies. Building on CDC's two decades of FASD-related efforts, these strategic partnerships strengthen "research to practice" linkages with the overall goal of improving, implementing, and sustaining evidence-based practice behaviors — practice- and systems-level practice change — around prevention, identification and treatment of FASD.

Key outcomes of the FASD PIC program include the following:

AWARENESS OF THE PREVALENCE OF FASD

- Recognize the prevalence of FASD
- Recognize the social worker's own bias around FASD-related issues as a barrier to recognition and access to medical care

ADOPTION OF BEST PRACTICES FOR PREVENTION OF ALCOHOL-EXPOSED PREGNANCIES

- Alcohol screening and brief intervention for adolescents and adults
- Identification and referral of individuals with suspected FASD

REINFORCE THE ROLE OF THE SOCIAL WORKER WHEN WORKING WITH FASD

- Employ strategies that promote workforce development of social work clinicians
- Promote the value of FASD identification and referral to assure appropriate care

KNOWLEDGE ACQUISITION AND PRACTICE CHANGE

- Implement screening of alcohol use in practice settings
- Embrace family engagement and communication
- Operationalize behavioral health into primary care

ROLES AND RESPONSIBILITIES OF FASD SOCIAL WORK CHAMPIONS

Practitioners play a critical role in identifying effects of prenatal alcohol exposure in individuals. The FASD Social Work Champions program will focus its effort on enhancing practitioner education and awareness, development of capacity building tools and resources, and cultivation of partnerships focused on the promotion of both primary prevention and early identification, referral, and management of individuals who have or may have FASD.

To achieve the program objectives, the project will utilize a network of FASD Social Work Champions to raise awareness and educate clinicians and decision makers to facilitate practice and systems change. Champions will be identified throughout the United States.

The role of the FASD SW Champion is completely voluntary and diverse, therefore the time commitment will vary. The FASD SW Champions are required to gain experience or expertise in FASD-related issues to serve in this role. Champions are dedicated, eager, and energetic; they are committed to the dissemination of knowledge about and prevention of FASD, as well as improving outcomes of individuals with FASD, and affecting systems change at the local, state and regional levels.

The responsibilities of the SW Champions are varied and include the following:

- Utilizing regional and local communication channels to raise awareness of educational and capacity building resources that enhance the adoption of evidence-based interventions.
 - Disseminating educational materials through regional, chapter and other local communication channels (including writing articles for newsletters, social work student education, and grand rounds and hospital- and office-based presentations)
 - Responding to media inquiries
- Serving as advocates for change at practice and health systems levels to overcome stigma and bias as a barrier to screening for prenatal alcohol exposure.
 - Supporting efforts to create and pilot practice-based resources
 - Collaborating with peers to influence state-level policy and programs related to preventing FASD, and supporting and intervening with individuals who have or may have an FASD
- Providing training and technical assistance within their respective region/state to support prevention programs and the early identification, referral, and care for individuals who have or may have FASD.
 - o Participating on working groups both at a national and regional/state level
 - o Providing leadership, guidance and education to healthcare providers in their region/state; serve as faculty for training at the state and regional levels
 - o Promoting training available within the region at both the national and state levels. This includes both in person and the online training modules developed by CDC
 - Responding to technical assistance questions
 - Collaborating with regional and state government agencies on FASD-related activities and initiatives

**Adapted from materials of the Am. Academy of Pediatrics (AAP), provided by Josh Benke, 2016



FETAL ALCOHOL SPECTRUM DISORDERS (FASD) SOCIAL WORK CHAMPIONS

Preventing alcohol-exposed pregnancies and improving health outcomes for individuals diagnosed with FASD

FASD is Common

A recent school based study found an estimated 2-5% (I in 50 to 1 in 20) of school-aged children to have FASD, which can affect their physical, mental, behavioral and cognitive development for a lifetime¹. Individuals diagnosed with FASD can experience growth restriction, cognitive and behavioral disabilities, and dysmorphic facial features.

Recognizing FASD is Critical

Social work practitioners play an important role in identification, diagnosis and treatment of individuals who may have FASD. Social workers should consider FASD when working with individuals with developmental problems, behavioral concerns, school failure, mental health/substance use disorders, and involvement with the justice and child welfare systems. Like other people with complex medical/behavioral disabilities, persons with FASD need coordinated care for their medical, behavioral, social, and educational services. FASD is a lifelong disability, and services need to change as the child develops into adulthood.

The Public Health Impact of FASD is costly

Alcohol-related birth defects are completely preventable when pregnant women abstain from alcohol use. Prenatal alcohol exposure is the leading identifiable cause of intellectual disability in the US. Annual costs in the US for drinking while pregnant are estimated to be more than \$5.5 billion².

Neurocognitive and behavioral problems resulting from prenatal alcohol exposure are lifelong. All too often children who present with objective signs of neurocognitive damage consistent with prenatal alcohol exposure are not identified. This may lead to misdiagnosis, adverse life outcomes, greater need for special education services and/or a higher risk of being involved in the legal system. Early recognition, diagnosis, and appropriate intervention and supports can improve outcomes throughout the lifespan.

**Adapted from materials of the American Academy of Pediatrics (AAP), provided by Josh Benke, 2016

FASD Social Work Champions Program

In 2014 the Centers for Disease Control and Prevention (CDC) funded FASD Practice Implementation Centers and National Partners to prevent FASD and to improve outcomes for individuals with FASD by improving practitioners' capacity for screening and brief intervention for problem alcohol use, early identification of children at-risk for FASD, intervening with those identified with FASD, and addressing the role of stigma and bias as it relates to prenatal alcohol exposure. The Social Work Champions Program is being executed in partnership with CDC-funded FASD Practice and Implementation Centers at the University of Missouri, Baylor College of Medicine, and their National Partner, the University of Texas at Austin.

The overarching goals of the program are the following:

- to prevent alcohol-exposed pregnancies
- to improve outcomes for all individuals who have or may have an FASD and their families by improving social worker capacity to recognize, assess, and coordinate care; and
- to address the role of stigma, bias, and other attitudes that contribute to health care provider reluctance to screen for prenatal alcohol exposure.

To achieve these goals, a network of *FASD Social Work Champions* will be established to raise awareness and enhance education to facilitate practice and systems change.

Social Work Champions will do the following:

- Utilize regional and local communication channels to raise awareness of educational and capacity building resources that enhance the adoption of evidencebased interventions.
- Serve as advocates for change at the practice and health systems levels to overcome stigma and bias as a barrier to screening for prenatal alcohol exposure.
- Provide training and technical assistance within their respective region to reinforce the early identification and care for those who have or may have an FASD**

¹May, PA, Baete, A, Russo, J, et al (2014). *Pediatrics*, 134:855-866.



COMMON MYTHS ABOUT FETAL ALCOHOL SPECTRUM DISORDERS**

MYTH: PHYSICAL FEATURES MUST BE PRESENT TO MAKE A DIAGNOSIS OF A FETAL ALCOHOL SPECTRUM DISORDER (FASD).

FACT: Fetal Alcohol Spectrum Disorders (FASD) have a range of effects. Many individuals with an FASD have no defining physical effects, but have developmental and/or behavioral impairments. Fetal Alcohol Syndrome has the most recognizable physical effects including distinct facial features. Not all people with an FASD have distinct facial features; trained physicians should examine individuals for below normal growth and central nervous system problems to diagnose FASD.

MYTH: ALL THOSE WITH AN FASD HAVE A LOW I.Q.

FACT: Individuals with an FASD have a wide range of disabilities. Studies have identified an I.Q. range of 29 to 142 for those with an FASD.

MYTH: A DIAGNOSIS OF FASD DOES NOT CHANGE THE TREATMENT PLAN.

FACT: A diagnosis of an FASD can help explain why a child learns, develops and behaves the way he or she does. Therapeutic interventions tailored to the specific challenges of the young child may improve long-term outcomes and mitigate the progression of adverse life outcomes as s/he develops. These services may include social support, parenting strategies, and developmental and educational interventions that take into account the cognitive, adaptive function, executive function, memory and/or behavioral issues resulting from prenatal alcohol exposure.

MYTH: THERE ARE NO INDIVIDUALS WITH FASD IN MY PRACTICE.

FACT: Prenatal alcohol exposure is common in all socioeconomic and demographic groups. About 1 in 10 pregnant women in the United States report drinking alcohol in the past 30 days, and about 1 in 33 pregnant women report binge drinking (having four or more drinks at one time) in the past 30 days (MMWR, 2015). Studies of grade school children suggest that up to 2% to 5% have an FASD (May, 2014). Although the risk is higher with higher levels of exposure, during pregnancy no amount of alcohol intake should be considered safe.

FASD may be misdiagnosed, or a diagnosis can be missed, for multiple reasons:

- Stigma is a major barrier to diagnosis. Many health care professionals are uncomfortable with considering an FASD diagnosis and many parents are uncomfortable with labeling their child with an FASD.
- There is not a specific test for diagnosing FASD.
- Mothers may not share information about drinking during pregnancy, due to stigma, judgmental responses, and the risk of having her children removed from her care.
- The individual may not have facial features associated with some types of FASD.
- Mental health conditions can be present in FASD, without other symptoms.

- FASD may be misdiagnosed as a mental health condition.
- The biological mother's history of drinking may not be known for those individuals who are in foster care, or have been adopted.
- Mothers who have known histories of opioid or other drug use may not be asked about their alcohol use.
- FASD is an under-recognized condition that is usually hidden.
- The terminology and the many acronyms of FASD can be confusing.

MYTH: IT IS NOT HELPFUL TO THE FAMILY TO GIVE A CHILD A DIAGNOSIS OF AN FASD.

FACT: More often than not, parents and caregivers recognize that a diagnosis of an FASD opens the door to hope because it can help explain why the child learns, develops and behaves the way he or she does. Healthcare professionals should be sensitive to the ways that a diagnosis of an FASD can impact biological and adoptive/foster families differently. A diagnosis can help a person realize that he or she learns differently because of the way their brain works and not because they are not smart enough or are lazy or unmotivated. A diagnosis may also help individuals and their families receive the right services and treatment to help them be successful and improve outcomes as they age.

MYTH: FASD IS A CHILDHOOD DISORDER.

FACT: Everyone with an FASD, across the IQ span, has brain damage. It may range from mild to severe and there are a number of brain structures that are typically damaged by prenatal alcohol exposure. As such, this is a brain-based disorder that is lifelong. Therefore, you may well encounter adults with an FASD as well as children and adolescents, including parents. Due to the difficulties as individuals with an FASD age, especially if they are not correctly identified, they will be represented in every system of care, including substance use treatment, corrections, vocational services, education, and child welfare.

MYTH: THE MENTAL HEALTH ISSUES ASSOCIATED WITH FASD ARE OUTSIDE THE SCOPE OF PRACTICE FOR HEALTHCARE PROFESSIONALS.

FACT: Most healthcare professionals, especially social workers, are in a unique position to identify mental health issues and initiate care. Because individuals with FASDs have special health care needs, healthcare professionals should apply chronic care principles, regardless of whether they are providing mental health services alone or collaboratively. When a higher level of mental health care is required, social workers can support families by connecting them with community services, linking individuals and their families to social security disability benefits and advocating for those benefits if needed, helping families find appropriate therapy services that understand FASD and how to treat it, and remaining involved in their care, when possible. Social workers are a key part of the care team that can optimize health outcomes for families living with FASD.

MYTH: LIGHT DRINKING DURING PREGNANCY IS OKAY.

FACT: Alcohol is a known teratogen that can cause adverse reproductive outcomes for women, and serious, lifelong problems for a person exposed to alcohol prenatally. No amount of alcohol has been proven to be safe to drink at any time during pregnancy. All types of alcohol, including beer, wine and liquor, equally put babies at risk of being born with an FASD.

MYTH: HEALTHCARE PROVIDERS AND PUBLIC HEALTH PROFESSIONALS KNOW EVERYTHING THERE IS TO KNOW ABOUT FASD.

FACT: There is a lot we still do not know about the effects of prenatal alcohol exposure and FASD. Because most people consider FASD to be under-diagnosed, we do not have accurate prevalence data on FASD in the United States. Why alcohol seemingly affects one fetus and not another is also unknown. Researchers have shown that genetic differences, epigenetic factors, as well as the mother's health and nutrition, may play a role. While much remains unknown about FASD, it is clear that abstaining from alcohol while pregnant is a 100% effective method to prevent FASD.

MYTH: ASKING A MOTHER ABOUT PRENATAL ALCOHOL EXPOSURE WILL TRIGGER UNDUE SCRUTINY BY CHILD WELFARE AGENCIES.

FACT: The Child Abuse Prevention and Treatment Act (CAPTA) does not require clinicians to report to Child Protective Services if a child has been prenatally exposed to alcohol. Referral to Child Protective Services is required if the child has been diagnosed with an FASD in the period between birth and three years. The intent of this referral is to develop safe care and possible treatment plans for the infant and caregiver if needed, not to initiate punitive actions. Although CAPTA requires referral, not reporting, states are able to establish their own statutory definitions and practices related to child abuse and neglect. A small number have included the presence of FASD in their state abuse and neglect codes. All healthcare professionals, including social workers, are encouraged to be aware of their respective state laws on this matter.

References

- Tan, C.H., Denny, C.H., Cheal, N.E., et al. (2015) Alcohol Use and Binge Drinking Among Women of Childbearing Age United States, 2011–2013. Morbidity and Mortality Weekly Report (MMWR). 64(37);1042-1046. Atlanta, GA: CDC Online article:
 - https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6437a3.htm?s_cid=mm6437a3_w
- May, P. A., Baete, A., Russo, J., et al. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*, 134(5), 855-866.
- **Adapted from materials of the American Academy of Pediatrics (AAP), provided by Josh Benke, 2016



FREQUENTLY ASKED QUESTIONS **

Note: The term "safety" in this document refers to the health of the fetus.

What is Fetal Alcohol Spectrum Disorders?

Fetal Alcohol Spectrum Disorders (FASD) is the umbrella term used to describe any diagnostic category related to adverse effects from alcohol exposure in utero. **The term is NOT a clinical diagnosis**. Diagnoses under the FASD umbrella can include: Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD). The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM 5) includes two additional terms. The term, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), is outlined in Section Three (syndromes for further study). It is not yet an official diagnosis with an ICD-10 CM code. In the body of the DSM -5th ed "Other specified Neurodevelopmental Disorder," with an ICD -10 CM code of F88, utilizes the example of Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure. Diagnoses under FASD include a range of physical, behavioral and learning issues for the individual throughout the lifespan. Prenatal alcohol exposure and any effect should be diagnosed as early as possible so that appropriate case management and other services can begin.

How common is FASD?

It is difficult to calculate the exact number of individuals who have been diagnosed with an FASD. The Center for Disease Control and Prevention (CDC) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) have conducted studies throughout the United States and internationally. Worldwide pooled estimates are higher than assumed, so far, but rates vary widely, depending on methodology used (passive or active surveillance). What is agreed is that future research needs to be more comprehensive and more consistent regarding methodology and guidelines (Roozen, et.al, 2016).

Estimates of the prevalence of FASD among US children range from 2% to 5% (May, et al., 2014). Some groups are known to have higher documented rates of FASD. FASD can be found in ALL socioeconomic and cultural groups.

How do I know who needs to be seen for an FASD evaluation?

Any individual, regardless of age, should be screened if there is confirmation of prenatal alcohol exposure, a clear possibility of alcohol exposure during pregnancy, or cognitive/behavioral symptoms that may indicate FASD. For child welfare agencies, documented proof is not needed. You can receive information of possible or confirmed prenatal alcohol use by the mother from any reliable informant. In addition, all women should be screened for alcohol use as part of their routine care.

Which women should be screened for alcohol use?

All women should be screened for alcohol use as part of their routine care.

How is FAS diagnosed?

There currently are 4 models of diagnosis in use in the United States: Canadian Guidelines for FAS, CDC Guidelines, Clinical Guidelines for diagnosing FASD (Hoyme, 2016) and the Four Digit Code (Astley, 2009). All look for facial dysmorphology (smooth lip and philtrum and a short palpebral fissure), growth restriction, and central nervous system dysfunction. What differs is the terminology used in diagnosing,

and the degree to which an individual shows problems in any of the three areas. Clinicians should know which model is used by their state or clinic to provide further guidance in how to refer an individual for diagnosis.

What treatment is best for FASD?

There is no one treatment that is used to treat FASD because prenatal alcohol exposure effects differ for every person. For example, although there are no medications specifically indicated to treat FASD, some individuals do well on medication; others, however, may have severe effects and sometimes become even more symptomatic. Research has shown some effective interventions for individuals with FASD; it is recommended that one look for evidence-based interventions. However, if there are no such programs available in your region, this should not deter you from finding appropriate services that are available, and treatment shown to be successful for individuals affected by prenatal alcohol. The best approaches are based on an understanding of the brain damage caused by prenatal alcohol exposure.

For families living with FASD, parent education and training can help parents in working with their child as he develops, and to help them advocate for needed services. It is essential to identify family members who may have an FASD so they can receive services and treatment they need to be successful.

There is no one treatment modality that works with all individuals. Individualized interventions and services must be developed. Careful monitoring and follow-up is critical for on-going adjustment and additions to the individual's care.

Can FASD Be Prevented?

Yes! FASD is 100% preventable if a woman completely avoids all alcohol while she is pregnant — this is the only way to prevent FASD. Since damage from prenatal alcohol exposure can begin before most women know that they are pregnant, women who are trying to become pregnant should not drink.

If a woman drinks alcohol, is sexually active but doesn't want to get pregnant, she should use an effective form of contraception to prevent FASD. She can talk to her health care provider to choose the most appropriate form of contraception and, if needed, get support to stop drinking.

Three promising practices that have been shown to be effective in reducing the incidence of alcohol-exposed pregnancies include:

- 1. Screening and Brief Intervention (SBI): It is currently recommended that health care providers routinely screen patients for risky alcohol use. If a woman is drinking at risk levels or while pregnant, the health care provider delivers a brief intervention targeting risky drinking and risk of alcohol-exposed pregnancy (AEP).
- 2. CHOICES: Developed with the support of CDC, CHOICES is an evidence-based intervention targeting non-pregnant reproductive age women who drink at risk levels, are sexually active and not using effective contraception (Floyd et al., 2007). The intervention uses motivational interviewing to help women make decisions around risk behaviors. Women can decrease their risk of AEP by using effective contraception, decreasing their alcohol use, or both. CHOICES has been successfully adapted for delivery in 2-4 sessions in primary and specialty care settings.
- 3. Parent-Child Assistance Program (PCAP): This is a 3-year advocate model with women at high risk of having an alcohol-exposed pregnancy to provide them with support for the mother and her children, encouragement to enter treatment, and transportation (Grant, 2013).

Can a woman safely drink any alcohol when she is pregnant?

No. There is no known safe amount of alcohol use during pregnancy or while trying to get pregnant. There is also no safe time during pregnancy to drink. All types of alcohol — including all wines and beer — are equally harmful to a developing fetus. It is recommended that women do not drink alcohol if they are pregnant or may be pregnant.

<u>Is there a safe level of alcohol that women can drink while trying to get pregnant?</u>

No. It is recommended that women abstain from drinking alcohol while trying to conceive because there is no safe time during pregnancy to consume alcohol. This will prevent a potential alcohol-exposed pregnancy.

Is it safe to drink alcohol when breastfeeding?

No. Alcohol passes through the breast milk to the child, so it is recommended that a woman not drink if she is breastfeeding her child. Drinking alcohol during this period may decrease breast milk production, change the taste of breast milk, and has been shown to cause early sleep, motor and developmental problems for the child. If a woman chooses to drink while she is still breastfeeding, it is recommended to do so after she has nursed, or expressed her breastmilk, allowing at least 2 hours per drink before the next breastfeeding or pumping session.

<u>Is drinking alcohol while pregnant safer than consuming other substances such as cocaine, heroin, opioids or pot during pregnancy?</u>

None of these substance are "safe" to consume while pregnant. Using alcohol, drugs, marijuana — or even tobacco — during pregnancy are all known to be harmful to a developing child. Prenatal exposure to any of these substances can adversely affect prenatal growth, development, and/or birth outcomes, as well as the mother's health.

Prenatal exposure to alcohol remains the leading preventable cause of birth defects and intellectual and neurodevelopmental disabilities. It can include physical, mental, behavioral, and/or learning disabilities (broadly known as FASD) — and these problems are lifelong (Williams, et al, 2015).

It is for this reason that the CDC, US Surgeon General, and leading medical organizations all recommend that women do not drink alcohol while pregnant. There is no safe type of alcohol, no known safe amount of alcohol consumption, and no safe time to consume alcohol during pregnancy. FASD is completely preventable if a woman does not drink during her pregnancy.

REFERENCES

- CHOICES: A program for women about choosing healthy behaviors to avoid alcohol-exposed pregnancies. Counselor Manual and Client workbook. National Center for Birth Defects and Developmental Disorders, Center for Disease Control and Prevention. Atlanta, Georgia. 2011.
- Floyd RL¹, Sobell M, Velasquez MM, et al. **Preventing alcohol-exposed pregnancies: a randomized controlled trial**. American Journal of Preventive Medicine, 2007; Apr;32(4):360. DOI: 10.1016/j.amepre.2006.08.028.
- Grant TM, Novick Brown N, Dubovsky D, et al. **The Impact of prenatal alcohol exposure on addiction treatment**. *Journal of Addiction Medicine*, 2013; 7(2) 87-95.
- Grant TM, Novick Brown N, Graham JC, et al. Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress. *International Journal for Alcohol and Drug Research*, 2013; 2(3) 37-49.
- Hoyme HE, Kalberg WO, Elliott AJ, et al. **Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders.** *Pediatrics*, online, July 27, 2016; DOI: 10.1542/peds.2015-4256.

- May PA, Baete A, Russo J, et al. **Prevalence and characteristics of FASD**. <u>Pediatrics</u>, 2014; 134(5); 855-866. Morbidity and Mortality Weekly Report: September 25, 2015. **Alcohol use and binge drinking among women of childbearing age- United States**, **2011-2013**. *MMWR* 2015: 64(37); 1042-1046 CDC.
- Roozen S, Peters GJ, Kok G, et al. **Worldwide prevalence of fetal alcohol spectrum disorders: A systematic literature review including meta-analysis.** *Alcohol clin exp res:* 2016 Jan; 40(1): 18-31. Doi:10.1111/accr.12939.
- SAMHSA Curriculum for Addiction Professionals (CAP) Level 1. 2007.

 http://fasdcenter.gov/SAMHSA.gov/educationTraining/courses/FASD-Center-CAP

 Curriculum/index.cfm
- Williams, Janet F. & Smith, Vincent C. (2015). **Fetal Alcohol Spectrum Disorders**: **Clinical Report.** *Pediatrics, 136(5).* e1395-e1406. DOI: 10.1542/peds.2015-3113

^{**}Adapted from materials of the American Academy of Pediatrics (AAP), provided by Josh Benke, 2016

Fetal Alcohol Spectrum Disorders (FASD)

Selected Resources for Social Work Practitioners

Practitioner / Patient Education on FASD & Alcohol Use during Pregnancy

- Williams, Janet F., Smith, Vincent C. & AAP Committee on Substance Abuse (2015). Fetal Alcohol Spectrum Disorders. Clinical Report. *Pediatrics*, 136(5). e1395-e1406. DOI: 10.1542/peds.2015-3113.

 Downloadable PDF: http://pediatrics.aappublications.org/content/pediatrics/early/2015/10/13/peds.2015-3113.full.pdf excellent clinical overview summarizing FASD, its impact, identification and prevention.
- National Organization on Fetal Alcohol Syndrome (NOFAS) -- http://www.nofas.org/
 NOFAS offers a national/state-by-state resource directory with information on FAS diagnostic specialists; support groups for families; support for birth mothers; materials for educators, mothers, persons with FASD, and patient advocates.
- Centers for Disease Control and Prevention. Fetal Alcohol Spectrum Disorders (FASDs) -- https://www.cdc.gov/ncbddd/fasd/CDC's FASD website provides research-based information, tools, and patient education and training materials. Download or order CDC's free materials (posters, brochures, fact sheets, and practice resources) about FASD and alcohol use during pregnancy: https://www.cdc.gov/ncbddd/fasd/freematerials.html
- Centers for Disease Control and Prevention. (2016). CDC Vital Signs: Alcohol and Pregnancy. Website: http://www.cdc.gov/vitalsigns/fasd/index.html
- Centers for Disease Control and Prevention. (2016). Vital signs: Alcohol-exposed pregnancies—United States, 2011-2013. *Morbidity and Mortality Weekly Report (MMWR)*, 65(4); 91-97. doi: 10.15585/mmwr.mm6504a6

 Online article: http://www.cdc.gov/mmwr/volumes/65/wr/mm6504a6.htm
- Centers for Disease Control and Prevention. (2013). CDC Vital Signs: Binge Drinking: A Serious, Under-recognized problem among women and girls.

 Website: http://www.cdc.gov/vitalsigns/bingedrinkingfemale/
 Downloadable PDF: http://www.cdc.gov/vitalsigns/pdf/2013-01-vitalsigns.pdf
- Edwards, W. J. (Ed.). (2010). Special Issue: Fetal Alcohol Syndrome. *Journal of Psychiatry & Law, 38* (4), 367-618. Articles on FASD in court and criminal justice, forensic assessment, diagnosing juvenile offenders, neurology and adaptive behavior, interventions, and more. Check availability electronically or through your local library.

Stigma

National Organization on Fetal Alcohol Syndrome. (no date). NOFAS Statement on the Stigma of FASD. Website: http://www.nofas.org/2015/08/24/nofas-statement-on-the-stigma-of-fasd/

Circle of Hope: A Mentoring Network for Birth Mothers (NOFAS). http://www.nofas.org/circleofhope/

Practice and Implementation Resources for FASD Prevention

- Centers for Disease Control and Prevention. (2016). CDC's Alcohol Screening and Brief Intervention Efforts. Website with downloadable resources: http://www.cdc.gov/ncbddd/fasd/alcohol-screening.html
- Centers for Disease Control and Prevention. (2015). The FASD Competency-Based Curriculum Development Guide for Medical and Allied Health Education and Practice. Atlanta, GA: CDC.

 Downloadable PDF:
 - http://www.mpfasdpic.org/wp-content/uploads/2016/12/Competency-Based-Curriculum-Guide July.2015.pdf
- Centers for Disease Control and Prevention. (2014). Planning and Implementing Screening and Brief Intervention for Risky Alcohol Use: A Step-by-Step Guide for Primary Care Practices. Atlanta, Georgia: National Center on Birth Defects and Developmental Disabilities.

Downloadable PDF: http://www.cdc.gov/ncbddd/fasd/documents/alcoholsbiimplementationguide.pdf

- Centers for Disease Control and Prevention. (2011). CHOICES: A Program for Women about Choosing Healthy Behaviors.

 Atlanta, Georgia: National Center on Birth Defects and Developmental Disabilities.

 CHOICES Curriculum CD package and/or Counselor manual, client workbook and facilitator guides are available to order/download at: http://www.cdc.gov/ncbddd/fasd/freematerials.html
- Substance Abuse and Mental Health Services Administration [SAMHSA] (2014). *Addressing Fetal Alcohol Spectrum Disorders (FASD)*. Treatment Improvement Protocol (TIP) Series 58. Rockville, MD: SAMHSA. Downloadable PDF: http://store.samhsa.gov/shin/content//SMA13-4803/SMA13-4803.pdf
- U.S. Preventive Services Taskforce. (2013). Alcohol Misuse: Screening and Behavioral Counseling Interventions in Primary Care.

 Website: http://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/alcohol-misuse-screening-and-behavioral-counseling-interventions-in-primary-care Provides screening instruments, clinical summary for physicians, evidence summary, and consumer guide.
- Adubato, S.A. & Cohen, D. E. (Eds). (2011). *Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment*. Oakpark, IL: Bentham eBooks. doi: 10.2174/97816080503141110101.
- American College of Obstetricians and Gynecologists. (2006). *Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Toolkit*. Washington, DC: ACOG.

 Downloadable PDF: https://www.acog.org/-/media/Departments/Tobacco-Alcohol-and-Substance-Abuse/FASD-Clinician-Guide.pdf
- Hagan, J.F., Balachova, T., Bertrand, J., et al. (2016) Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure. *Pediatrics*, 138(4), e20151553.
- Hoyme, HG, Kalberg, W, Elliott, AJ, et al. (2016). Updated Clinical Guidelines for Diagnosing Fetal Alcohol Spectrum Disorders. *Pediatrics*, *138* (2), e20154256. DOI: 10.1542/peds.2015-4256. Downloadable PDF: http://pediatrics.aappublications.org/content/pediatrics/early/2016/07/25/peds.2015-4256.full.pdf
- Levy, S. J., Williams, J. F. & AAP Committee on Substance Use and Prevention. (2016). Substance Use Screening, Brief Intervention, and Referral to Treatment. *Pediatrics, 138* (1), e20161211. doi: 10.1542/peds.2016-1211. Downloadable PDF: http://pediatrics.aappublications.org/content/pediatrics/138/1/e20161211.full.pdf "Clinic Report: Guidance for the Clinician in Rendering Pediatric Care" specifically addresses SBIRT for adolescents; provides excellent overview on issue of adolescent substance use and clinical response.
- Paley, B. & O'Connor, M.J. (2009). Intervention for Individuals with Fetal Alcohol Spectrum Disorders: Treatment Approaches and Case Management. *Developmental Disabilities Research Reviews, 15* (3), 258-267. doi: 10.1002/ddrr.67. Downloadable PDF: http://onlinelibrary.wiley.com/doi/10.1002/ddrr.67/epdf
- SBIRT App for Screening, Brief Intervention, and Referral to Treatment –

 Free app available at https://itunes.apple.com/us/app/sbirt/id877624835?mt=8

 Provides steps to complete a brief intervention and/or referral to treatment based on motivational interviewing.

 Provides screening questions for alcohol, drugs and tobacco use; includes CRAFTT, AUDIT, and DAST instruments.
- Velasquez, M. M., Ingersoll, K., Sobell, M., & Sobell, L. C. (2016). Women and Drinking: Preventing Alcohol-Exposed Pregnancies. Series: Advances in Psychotherapy Evidence-based Practices, vol. 34. Boston, MA: Hogrefe Press. Describes CHOICES, CHOICES-like and other promising interventions; provides implementation resources.

Position Statements/Recommendations on Preventing Alcohol Use During Pregnancy

- American Academy of Pediatrics. (no date). Joint Call to Action on Alcohol and Pregnancy: Eliminating the Risk for Fetal Alcohol Spectrum Disorders.
 - Downloadable PDF: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Documents/FASD_AAP%20Joint%20Statement_FINAL_1.pdf
- Office of the Surgeon General, U.S. Dept. of Health and Human Services. (2005). Advisory on Alcohol Use in Pregnancy. Downloadable PDF: http://www.cdc.gov/ncbddd/fasd/documents/surgeongenbookmark.pdf



FETAL ALCOHOL SPECTRUM DISORDERS SOCIAL WORK CHAMPIONS

TALKING POINTS - FASD**

What is FASD - Fetal Alcohol Spectrum Disorders?

- Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual who was exposed to alcohol before birth.
- There are several different types of FASD. The most well-known FASD (though not the most common) is Fetal Alcohol Syndrome (FAS) which is characterized by specific physical features, growth restriction and developmental impairment.
- FASD most commonly manifests as a neurobehavioral developmental disability with no physical features. One new term for this type of FASD is ND-PAE, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure.
- Children with FASD can have lifelong physical, mental, behavioral and/or learning problems.
- A study funded by NIAAA to determine the prevalence of FASD among 1st graders from a Midwestern town found that 2-5% of them have FASD.
- Prenatal alcohol exposure is associated with an increased risk of miscarriage, stillbirth, prematurity and SIDS, as well as a range of lifelong physical, behavioral, and intellectual disabilities.

Is FASD preventable?

- FASD is completely preventable if a developing fetus is not exposed to alcohol before birth.
- Exposure to alcohol from all types of beverages, including beer and wine, is unsafe for the developing fetus at every stage of pregnancy.
- High amounts of alcohol from binge drinking during pregnancy put a fetus at higher risk for FASD and for these effects to have greater physical & neurodevelopmental characteristics.
- Is light to moderate drinking ok while pregnant? No! The Surgeon General states that No amount of alcohol use is known to be safe for a developing baby before birth.
- Alcohol exposure is unsafe for the developing fetus at every stage of pregnancy.

What is the role of the Social Worker in preventing alcohol-exposed pregnancies?

- When talking with teens, social workers can start teaching that drinking even a little alcohol during pregnancy may bring serious, damaging, lifelong effects to the developing fetus.
- Social workers can help prevent FASD by educating mothers about the risks of drinking alcohol during future pregnancies.
- Social workers can clear up misconceptions that occasional alcohol use or certain types of alcohol (e.g., wine) are safe during pregnancy.
- Social workers can screen for alcohol use, perform brief interventions, and treat, or refer, for treatment for problem drinking.

How is FASD diagnosed?

- Experienced clinicians look for specific symptoms to diagnose an FASD since there are no medical tests alone that can provide a diagnosis.
- Small size, certain facial features or central nervous system problems may signal FASD; all 3 criteria must be present for a diagnosis of Fetal Alcohol Syndrome.

- Facial features of FAS are a thin upper lip, a smooth philtrum, and short palpebral fissures.
- Those with FAS comprise a small portion of the spectrum of FASD.
- Fetal alcohol exposure can cause brain damage, affecting intellect, speech, language, memory, attention, behavior, coordination, judgment, socialization, and many other areas of functioning.
- There are many mental health issues associated with FASD, such as ADHD, anxiety, depression, substance use, addiction and suicide.
- FASD symptoms, which range from mild to severe, can vary for each person and can appear at different times in different manners.
- Social workers should look for FASD symptoms if they believe that a baby was prenatally exposed to alcohol and refer for an assessment if the symptoms are present.

What is the role of the Social Worker in recognizing FASD, referring for a diagnostic evaluation, and supporting persons with FASD?

- Social workers can engage families in a discussion about the effects of prenatal alcohol exposure, establishing a sense of trust and reducing stigma.
- Social workers need to document prenatal alcohol exposure and screen for FASD.
- Social workers can recognize FASD, manage treatment and refer individuals for special services that may improve their outcomes.
- Social workers can advocate for appropriate services for individuals with an FASD.
- Social workers can provide information to service systems about FASD and why traditional approaches of case management and care need to be modified for those with an FASD.

What are the benefits of an FASD diagnosis to the individual/family?

- A diagnosis can help explain why a person learns, develops and behaves the way he or she does.
- A correct diagnosis can reduce frustration and anger on the part of families and professionals.
- Medications and treatments for FASD effects can be tailored to meet individual needs.
- People with FASD have better medical, psychological and job outcomes with lifelong intervention and treatment.
- Identifying strengths of people with FASD and building on those can improve outcomes.
- A diagnosis of an FASD should inform all systems (including families) in how best to support the person and their family.
- A correct diagnosis of one of the FASD can lead to a network of healthcare providers who will design effective, appropriate interventions.

What is the role of the Social Worker in lifelong care for individuals with FASD?

- To ensure individuals achieve optimal outcomes, social workers can plan treatment in partnership with the individual, family and care team.
- Social workers can case manage, and refer to medical and health specialists, risk assessment services, and legal and community resources.
- Social workers can direct families to resources to enroll in developmental and educational services.
- Social workers can raise questions when appropriate as to the validity of diagnoses given to the individual over their lifetime, once an FASD is recognized.
- Social workers can advocate for services that the individual and family need in order to be optimally effective.

- FASD may qualify children for Supplemental Security Income, which can provide income and insurance aid into adulthood.
- Using electronic health records can help coordinate care and eventually transition children and adolescents to adult care for FASD.

What are the therapeutic interventions that improve outcomes for individuals and families living with FASD?

- FASD cannot be cured but special therapies and treatment may improve outcomes for individuals and families.
- Due to the brain damage caused by prenatal alcohol exposure, typical treatment modalities that rely on verbal receptive learning processes, working memory or abstract thinking are often ineffective unless modified.
- Individuals with FASD and their families often benefit from home and school modifications, parenting strategies, social support, occupational and developmental therapy.
- Developmental, learning and behavioral difficulties associated with FASD often qualify children and adolescents for special education or school accommodations.
- There are no specific medications to treat FASD but medication may treat the individual symptoms of FASD and help improve associated mental health issues.
- The effects of FASD vary for each person, so treatments should be tailored to meet individual needs throughout the lifespan.

What resources for FASDs are available to the Social Worker and health care practitioner?

- Centers for Disease Control and Prevention (http://www.cdc.gov/ncbddd/fasd/)
- NOFAS Resource Directory (http://www.nofas.org/resource-directory/)
- SAMHSA TIP # 58 Addressing Fetal Alcohol Spectrum Disorders (FASD). HHS Publication #13-4803. Published, 2014.
- SAMHSA webpage for FASD- www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center
- American Academy of Pediatrics, Fetal Alcohol Spectrum Disorders Toolkit (https://www.aap.org/fasd)

What resources for FASDs are available to the family?

- National Organization on Fetal Alcohol Syndrome (NOFAS) (http://www.nofas.org/)
- Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) (http://www.mofas.org)
- Centers for Disease Control and Prevention (http://www.cdc.gov/ncbddd/fasd/)

^{**}Adapted from materials of the Am. Academy of Pediatrics (AAP), provided by Josh Benke, 2016