

FETAL ALCOHOL SPECTRUM DISORDERS

Panel Presentation

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FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

Fetal Alcohol Syndrome (FAS): Facial malformations visible at birth (thin upper lip, small eye openings from inner corner to outer corner, absent philtrum, microcephaly); Brain damage invisible at birth and throughout life. Less than 15% of children born with an FASD have FAS.

Partial FAS: Has some of the malformations but not all.

Alcohol Related Neurodevelopmental Disorder (ARND): No visible damage; invisible brain damage from mild to severe.

STATISTICS

Current prevalence thought to be 2.4-4.8% of children in the US. Based on the 2014 number of live births, that would mean between 3,373 and 6,747 babies were born in PA with FASD in 2014.

40-60% of individuals born with an FASD will spend some time in their life incarcerated, whether as an adult or an adolescent. Many re-cycle through the correctional system.

About 85% of the children with an FASD are in foster care or adopted.

Over 90% of these individuals have mental health and/or substance abuse disorders.

Over 80% of these individuals have an IQ of 80 or more. There are people with FASDs who have IQs as high as 140. It is their verbal skills that negatively impact their IQs. Otherwise they tend to perform as well or almost as well as the average person.

PREGNANT WOMEN DRINKING

As of the 12th day after conception, alcohol in the mother's bloodstream can cause damage to the newly developing placenta and a week later can cause damage to the newly developing fetus.

About 10% of pregnant women in the US admit to drinking at some time during their pregnancy. We know that this figure is significantly higher than 10%. Many women drink before they realize that they are pregnant. Women who are binge drinkers or alcoholic are at very high risk for producing a child with an FASD.

CDC, American College of OB/GYN, American College of Pediatrics Recommend:

Tell women who want to drink and to be sexually active to use reliable contraception to avoid producing a child with an FASD.

Tell women who want to become pregnant to stop drinking alcohol BEFORE trying to conceive and throughout the pregnancy.

Infants Born With an FASD

Symptoms:

Irritable –do not respond to holding, rocking, soothing. Cannot self-soothe. Some do not like physical contact, others do.

Poor sucking reflex

Decreased muscle tone, floppy, motor delays

Jitter, tremors, increased startle response

Problems eating and sleeping

Hypersensitivity to stimuli – noise, light, touch, activity

Absence of babbling, speech delays

Lack of response to pain

Lack of eye contact

Suggestions:

Swaddle to soothe and calm

Limit stimulation- keep in calm, quiet surroundings as much as possible

Refer to Early Intervention for full evaluation and further recommendations.

In a friendly, non-judgmental way, try to find out from mother if she smoked, used alcohol or other drugs at any time just prior to realizing she was pregnant and during her pregnancy.

Stay with a specific schedule as much as possible. Limit the child's caretakers to 2 or 3 at the most.

Use the same words to communicate with the child. If "night, night" means time for bed, then all caretakers should use the words "night, night."

Limit caretakers to only 2 or 3 at most.

Early Childhood, Toddlers with an FASD

Symptoms:

Sensory issues – tags, seams in socks, clothing too snug, clothing too loose, hate loud noises, Hate being in groups/crowds, over or under sensitive to pain, hate wet diaper.

Food issues – cannot deal with textures and some tastes; might gorge themselves or might barely eat.

Tantrums and rapid onset of outbursts with excessive or intense crying or behaviors

Peer Relationships – have difficulty playing nicely with other children. Have difficulty with the concept of what “play” is. Don’t want to share. Might not want to be around other kids. Move quickly from one activity or toy to another, cannot remain focused.

Sleep – difficulty falling asleep and/or staying asleep. Might have night terrors and be restless during sleep.

Communication – Slow to develop speech or have speech impairment. Some children chatter endlessly, even without meaning to their words.

Immaturity – demonstrate behaviors that are not as advanced as their age in years would indicate. Act younger and might choose to play with younger children and the toys of younger children.

Inconsistent behaviors. Behaviors and moods can change quickly.

Suggestions:

Refer to Early Intervention for full evaluation and more specific recommendations.

As much as possible, limit the stimuli around them for as much of the day as you can.

Cut tags out of shirts and back of pants; purchase clothes that child finds comfortable.

Limit play with other children to only one or two at a time. Don’t get too many toys out at one time.

Provide a “get away place” for them to go to calm down or get away from over stimulation or to just rest in a favorite place of their own. (Set up a pup tent, throw a blanket over a table, use a large cardboard box as their get-a-way, hang a soft, light colored, sheer curtain from the ceiling and allow them to get behind it.)

Allow child to sleep in sleeping bag or use weighted blanket to make child feel safe and comfortable.

Be consistent in the words you use, be consistent in how you respond to the child.

Have a set schedule for weekdays and one for weekends and stick with them as much as possible.

Build a quiet rest time into their schedule at least 2 times a day.

Limit the number of caretakers for the child. Use 2 or 3.

When giving the child choices, offer only 2 choices.

When giving instructions state only one step at a time. Two steps can be overwhelming to a child with an FASD. **Most children will have some difficulty with remembering rules and instructions. This is not willful.**

If a child becomes upset or unruly, consider – could they be sick, hungry, thirsty, or in pain? Often they are not able to communicate this to a caretaker verbally. **They communicate with their behavior.**

Use constant repetition to teach them.

Find reasons to praise them for their behavior.

PARENT EDUCATION

Explain what you notice about the child to the parent and that the child should be evaluated so that the child can receive the services he/she needs. Explain to the parent what is normal for a child at age 6 months and why you have concerns about the child’s development.

If the child is identified as having an FASD, link the parents to an organization that specializes in improving the lives of children and adolescent with an FASD. (NOFAS, MOFAS, etc.)

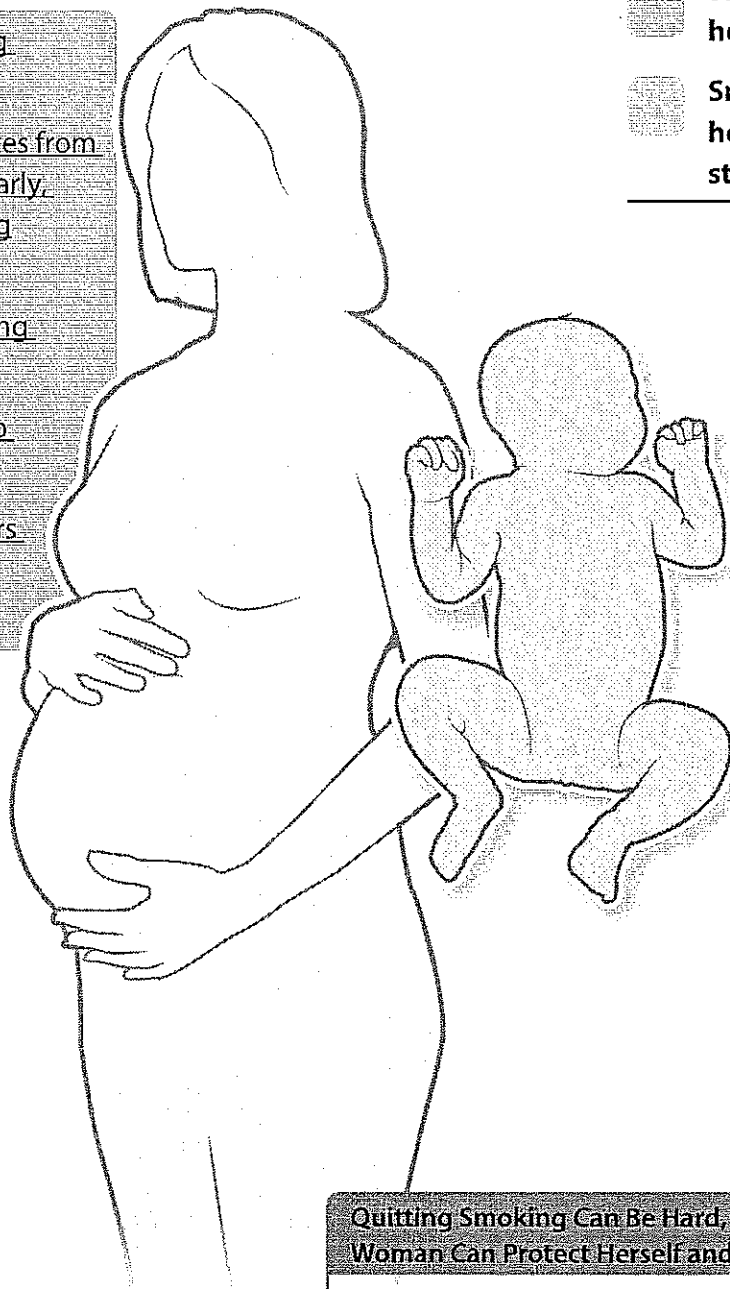
If the biological mother knows that she drank alcohol that caused the child's disorder, consider referring her for grief/guilt counseling.

Smoking and Pregnancy

Smoking can cause problems for a woman trying to become pregnant or who is already pregnant, and for her baby before and after birth.

Effects on Women

- Difficulty getting pregnant
- Placenta separates from the womb too early, causing bleeding
- Placenta covers the cervix, causing complications
- Water breaks too early
- Pregnancy occurs outside of the womb



Smoking causes these health effects.



Smoking could cause these health effects, but more studies are needed to be sure.

Effects on Babies

- Baby born too small
- Baby born too early
- Sudden Infant Death Syndrome
- Stillbirth
- Infant death
- Cleft lip/palate
- Certain birth defects, such as:
 - Clubfoot
 - Gastroschisis
 - Some heart defects
- Attention Deficit/Hyperactivity Disorder (ADHD)
- Miscarriage

Quitting Smoking Can Be Hard, But It Is One of the Best Ways a Woman Can Protect Herself and Her Baby's Health.

If you or someone you know wants to quit smoking, talk to your healthcare provider about strategies. For support in quitting, including free quit coaching, a free quit plan, free educational materials, and referrals to local resources, please call **1-800-QUIT-NOW** (1-800-784-8669); TTY 1-800-332-8615.

For additional resources to help quit smoking, visit www.cdc.gov/reproductivehealth/TobaccoUsePregnancy/Resources.htm



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Updated based on 2014 Surgeon General's Report

PROTECT YOUR UNBORN BABY. DON'T DRINK ALCOHOL WHEN YOU'RE PREGNANT.

1 IN 5 PREGNANT WOMEN REPORT DRINKING
ALCOHOL DURING EARLY PREGNANCY

THERE IS NO PROVEN SAFE AMOUNT OF ALCOHOL TO DRINK DURING PREGNANCY.
DRINKING ALCOHOL WHILE PREGNANT MAY PUT YOUR BABY AT RISK FOR FETAL
ALCOHOL SPECTRUM DISORDERS (FASD).



FASD IS 100% PREVENTABLE. STOP AND THINK. IF YOU'RE PREGNANT OR COULD BE PREGNANT, DON'T DRINK.

SOURCE: Center for Behavioral Health Statistics and Quality. (2014). Behavioral health trends in the United States: Results from the 2013 National Survey on Drug Use and Health. <http://www.samhsa.gov/data/>

SAMHSA's mission is to reduce the
impact of substance abuse and mental
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Substance Abuse and Mental Health Services Administration
SAMHSA



General Facts and Recommendations

FACING ADDICTION IN AMERICA

*The Surgeon General's Report on
Alcohol, Drugs, and Health*

How do we define substance use problems?

Substance misuse is the use of any substance in a manner, situation, amount, or frequency that can cause harm to users or to those around them. Prolonged, repeated misuse of a substance can lead to a **substance use disorder**, a medical illness that impairs health and function. Severe and chronic substance use disorders are commonly referred to as **addictions**.

Why have substance misuse and substance use disorders become a public health crisis in the United States?



**1 in 7
people**

will develop
a substance
use disorder
at some
point in their
lives.

Source: Kessler et al., 2005.

- Over 66 million people (25% of all people) reported binge drinking. Binge drinking is defined as having 5 or more standard drinks for men, and 4 or more standard drinks for women, on the same occasion on at least 1 day in the past 30 days.¹
- Nearly 48 million people (18% of all people) said they used an illicit drug or misused prescription drugs in the past year.¹
- Illicit drug use and its consequences are increasing. More than 47,000 people died from a drug overdose in 2014,² and nearly 30,000 of these deaths involved prescription drugs.³ Alcohol misuse contributes to 88,000 deaths in the United States each year.⁴
- One in 7 people in the United States is expected to develop a substance use disorder at some point in their lives.¹ Only 1 in 10 people with a substance use disorder receive any type of substance use treatment.¹

¹ Center for Behavioral Health Statistics and Quality (CBHSQ), 2016.

² Rudd et al., 2015.

³ National Institute on Drug Abuse (NIDA), 2015

⁴ Stahre et al., 2014.

How must we change our attitudes about substance misuse to successfully address this crisis?

- Substance use disorders have a neurobiological basis. They should be treated as a medical issue like any other.
- We must change social attitudes, shifting how we think, talk, and act towards people with substance use problems.
- We have a moral obligation and economic imperative to provide access to high quality care for those suffering from substance use disorders.

What can we do to solve this public health crisis?

- This public health crisis requires a public health solution, marshalling all the resources needed to address substance misuse and substance use disorders in our communities.
- Prevention works, treatment is effective, and recovery is possible for everyone.



Prevention Works

- Strong positive family ties, social connections, emotional health, and feelings of control help people avoid substance misuse.
- Evidenced-based prevention programs and policies are available for communities, schools, health care organizations, and other settings.



Treatment is Effective

- Substance use disorders can be effectively treated with behavioral therapies.
- Medications are also available for treating alcohol and opioid use disorders, and when combined with behavioral therapies, can effectively help people manage their symptoms and achieve recovery.



People Recover

- Many people are able to make significant changes in their lives and maintain remission through social networks and recovery-supportive environments.
- Recovery supports, including mutual aid groups (like Alcoholics Anonymous), recovery coaches, and peer recovery services, can help.

Every spent on...

Implementation of **evidence-based interventions** can have a **benefit of \$58**



substance use disorder treatment **Saves \$4** in health care costs.



Saves \$7 in **criminal justice** costs.

Source: Ettner et al., 2006.

How can you help reduce substance misuse and substance use disorders?

- **Individuals and families:** Reach out, talk to your children, be supportive of those who have a substance use disorder and those in recovery.
- **Educators and academic institutions:** Teach accurate, up-to-date scientific information and enhance training of health care professionals. Implement evidence-based prevention interventions in schools and universities.
- **Health care professionals and professional associations:** Address substance-related health issues with the same sensitivity and care as any other chronic health condition and support high-quality, integrated care for substance use disorders.
- **Health care systems:** Promote efficiency and high-quality care through primary prevention, evidence-based treatments, and effective integrated and coordinated care. Work with payers to develop and implement comprehensive billing models and leverage health information technologies to improve access to and quality of care.
- **Communities:** Build awareness and invest in evidence-based prevention interventions and recovery supports.
- **Private sector:** industry and commerce: Encourage adults who use legal substances to be responsible and support youth substance use prevention.
- **Federal, state, local, and tribal governments:** Provide leadership, guidance, and vision in supporting an evidence-based approach.
- **Researchers:** Focus on implementable, sustainable solutions; consider how scientific research can inform public policy and programs, and promote rigorous evaluation of policies and programs.

How can you find out more?

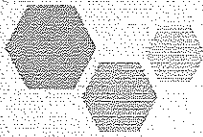
The Surgeon General's Report on Alcohol, Drugs, and Health provides evidence-based information on effective and sustainable strategies for addressing alcohol and drug problems. The Report offers hope, practical solutions, and resources for communities, which play a critical role in prevention, treatment, and recovery for those affected by substance use disorders and their consequences. To read the Report, visit <http://addiction.surgeongeneral.gov/>



Substance Abuse and Mental Health Services Administration
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For Providers SAMHSA


Fetal Alcohol Spectrum Disorders




Tips for Providers
on Fetal Alcohol Spectrum Disorders

How to
help your
clients or patients
be alcohol-free mothers-to-be.



 U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Share the truth.

Alcohol and pregnancy can be an unfortunate mix. Many people don't know that like a pregnant woman's use of tobacco or drugs, her use of alcohol can hurt her fetus.

The truth is, drinking alcohol while pregnant is risky.

- **There is no known safe amount** of alcohol use during pregnancy.¹ Yet, many pregnant women who drink-to-moderate amounts of alcohol think it cannot harm their babies.
- **There is no safe type** of alcohol to use during pregnancy. A bottle of beer, a glass of wine, home brew, a "forty," hard lemonade, or "alcopops"—even some energy drinks—all carry the same risk as drinking a shot of hard liquor or a mixed drink made with liquor. They all contain about the same amount of alcohol.
- **There is no safe time** to drink alcohol during pregnancy. Drinking alcohol at any time during pregnancy can permanently damage the fetal brain and other parts of the body. Some research indicates that the brain is especially vulnerable to alcohol during the first few weeks of fetal development.

Because most pregnancies are unplanned, women and girls usually are not aware that they have become pregnant and may continue to drink alcoholic beverages. Data on past month alcohol use among women in the United States, indicate that—

- 12.2 percent of pregnant women (about one in eight) drank alcohol. This rate remained stable over the 15-year period 1991–2005.²
- 19 percent drank alcohol during their first trimester; 7.8 percent in the second trimester; and 6.2 percent in the third trimester.³

Many caring professionals, including social workers, doctors, nurses, and other clinicians do not discourage all drinking by pregnant women, so it is one reason it is important that you tell your clients that a pregnant woman or girl who drinks alcoholic beverages can cause damage to her baby, possibly including **fetal alcohol spectrum disorders**.

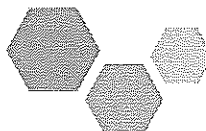
¹National Institute on Alcohol Abuse and Alcoholism. 2003. Alcohol: A Women's Health Issue. NIH Publication No. 03-4956. Rockville, MD. National Institutes of Health. pubs.niaaa.nih.gov/publications/brochurewomen/women.htm.

²CDC. MMWR Weekly, May 22, 2009. "Alcohol Use Among Pregnant and Nonpregnant Women of Childbearing Age—United States, 1991–2005."

³SAMHSA, Office of Applied Studies. May 21, 2009. The NSDUH Report. Substance Use among Women During Pregnancy and Following Childbirth. Rockville, MD.

*Alcopops are the popular name for sweetened, flavored alcoholic beverages usually sold in single-serving cans or bottles. They are the preferred alcoholic beverage of underage girls. Teens also call it "cheerleader beer" and "chick beer."





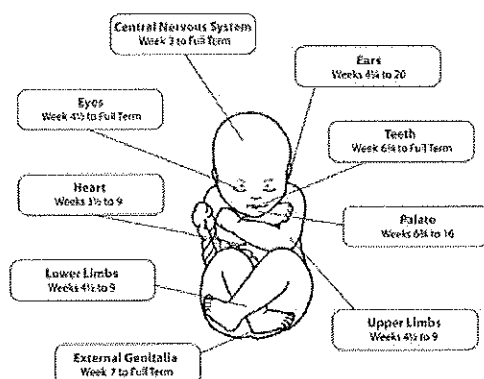
Expose the consequences.

A woman or girl who drinks alcohol during pregnancy risks causing her child to be born with a fetal alcohol spectrum disorder.

Fetal alcohol spectrum disorders (FASD) is an umbrella term for the range of abnormal effects that can occur in an individual whose mother drank alcohol while pregnant. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

Research shows that drinking alcohol during pregnancy is the number one known preventable cause of mental retardation.⁴

Alcohol is a teratogen—a substance that can cause abnormalities in a developing fetus. Because alcohol can affect so many sites in the brain and body, it can cause more harm to the developing fetus than heroin, cocaine, or marijuana.⁵



Use of alcohol by a pregnant woman or girl can cause her baby to have brain damage, defects in internal organs such as the heart or liver, abnormal facial or physical features, and/or behavioral and learning disabilities.

⁴Abel, E.L., and Sokol, R.J. 1987. Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies. *Drug and Alcohol Dependency* 19(1):51-70.

⁵Stratton, K., Howe, C., and Battaglia, F., eds. 1996. *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention and treatment*. Rockville, MD: National Academy Press. <http://books.nap.edu/html/fetal>.

Ask about alcohol use.

Tools are available to screen for alcohol use, to detect risky drinking, binge drinking, and alcoholism. Studies have shown that some screening tools are very effective with women. For instance, you would ask your client:

"I have a few routine questions for you about when you use alcohol. Have you ever had a drink containing alcohol?"

If she answers "yes," you might use one of several validated screening tools, such as the T-ACE and ask:

Tolerance:

T How many drinks does it take for you to feel high?
(2 or more drinks = 2 points)

Annoyed:

A Have people annoyed you by criticizing your drinking?
(Yes = 1 point)

Cut down:

C Have you ever felt you ought to cut down on your drinking?
(Yes = 1 point)

Eye-opener:

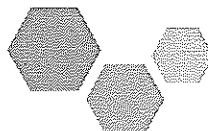
E Have you ever had an eye-opener (a drink first thing in the morning) to steady your nerves? (Yes = 1 point)

It takes about 1 minute to ask the T-ACE questions. A score of 2 points or more may indicate the need for intervention.

Whether a woman or girl is pregnant, not pregnant, or even not trying to become pregnant, if her T-ACE score is 2 points or more; or if she has more than 3 standard-sized drinks at one sitting/occasion, or more than 5 standard-sized drinks a week, she is engaging in risky drinking; 4 standard-sized drinks at one sitting or 7 drinks a week is binge drinking. If your conversation reveals either level of drinking, she should be counseled and/or referred for follow up.

Note: Screening tools also proven to be reliable and valid with women who are pregnant or not pregnant include the 5P's, the Alcohol Use Disorder Identification Test (AUDIT), CAGE, and TWEAK. Some of these instruments are available in Spanish and other languages. For more information, refer to Treatment Improvement Protocol TIP 51, Substance Abuse Treatment: Addressing the Specific Needs of Women at www.store.samhsa.gov/product/TIP-51-Substance-Abuse-Treatment-Addressing-the-Specific-Needs-of-Women/SMA09-4426.





Help, using proven strategies.

***Screening and Brief Intervention (SBI)** models in which counselors have more than one contact with the client have proven effective at stopping or reducing alcohol use in women and girls, whether pregnant or not pregnant, in a wide range in age, and from a variety of racial and ethnic groups, socioeconomic and educational levels, geographic locations, and substance use status.

One successful SBI model uses a simple written assessment and 10- to 15-minute intervention with pregnant women who report drinking. This intervention has been integrated by providers into their existing health care and social services systems. They are reaching women and girls through the Women, Infants, and Children (WIC) Program and Healthy Start programs, as well as community clinics and residential and outpatient treatment centers.

SBI models have two primary components: an assessment, such as the T-ACE, and motivational interviewing.

****Motivational interviewing (MI)** is not just a counseling technique: It is a way of relating to your client that can help them resolve their ambivalence around stopping behaviors they know are dangerous, such as drinking while pregnant and risky or binge drinking. MI-based interventions—

- Focus on client strengths.
- Use empathy more than authority.
- Recognize co-occurring disorders.
- Center the encounter on the individual.
- Respect the client's autonomy.

The keys are to collaborate with rather than confront a client and to forge mutual understanding; to draw out the client's true motivations, rather than impose your assumptions and ideas; and to de-emphasize your authority and recognize and convey that the client has the power and responsibility for changing her behavior.

*To obtain information on SBI programs successfully used with pregnant and non-pregnant women and girls, visit <http://www.fasdcenter.samhsa.gov>.

**For more information on motivational interviewing, see Enhancing Motivation for Change in Substance Abuse Treatment, SAMHSA/CSAT TIP Series, No. 35, <http://www.ncbi.nlm.nih.gov/books/NBK64967/>.

Leverage your relationship.

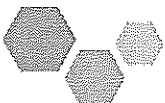
You are a trusted source of advice and information. If you learn that your client is drinking alcohol, your close relationship makes you a good person to give advice in a supportive way. Here are some tips for starting the conversation:

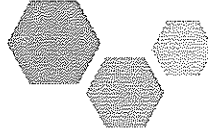
- Begin by telling her that you care about her and her baby.
- Ease into the subject with talk about plans for the birth, such as getting a crib, clothes, and toys.
- Ask her if she has been to a doctor or clinic for prenatal care and if she is taking prenatal vitamins, and is following other medical advice.
- Tell her that drinking alcohol at any time during her pregnancy can hurt her unborn baby. Give her important facts:
 - Any alcohol she drinks goes into her bloodstream and passes to the unborn baby.
 - Unborn babies cannot process alcohol as adults can, so if she drinks any alcohol, she risks causing permanent damage to her baby.
- Give her the companion booklet for pregnant women and girls.
- Ask if there are problems in her life that cause her to want to drink alcohol.
- Offer to find support services to help her stop drinking, if needed. If she is a heavy drinker, ensure that she stops drinking under professional supervision.

If your client says she drank during another pregnancy and the baby was okay, tell her that—

- Just because she drank alcohol during a previous pregnancy without harming the baby, there is no guarantee that she can drink alcohol and not affect the child in her current pregnancy.
- The effects of alcohol on an earlier child may be mild or unrecognized. For women and girls who are pregnant or nursing, no alcohol is the best practice for them and their babies.

An FASD lasts a lifetime. It cannot be cured, but it can be prevented.





Show your concern.

Encourage a pregnant woman or girl to see a medical provider to get good prenatal care. Emphasize the importance of taking prenatal vitamins, folic acid and only drugs or substances as prescribed or approved by the health care provider. Ask whether she has a physician, access to a clinic, or needs help to find someone to provide prenatal care.

You can provide pivotal guidance at prenatal visits or whenever you meet with a pregnant woman, her family members, or her friends.

Concern about alcohol abuse should not stop with pregnant clients.

Talk with all women and girls of childbearing age about alcohol use and, if needed, intervene to assist them in changing their behavior to help prevent FASD. To help a woman or girl, use the “5-A’s” approach, which is consistent with successful SBI methods:⁶

- **Assess:** Ask her about alcohol use.
- **Advise:** Advise her to take appropriate action—to stop drinking if she is trying to become pregnant or if she is drinking and not using a contraceptive.
- **Agree:** Ask her to agree to take specific actions to change her drinking behavior. For instance: “Can we agree that you will try to avoid the people and situations usually associated with your drinking?”
- **Assist:** Assist her in taking the actions.
- **Arrange:** Arrange for follow-up, monitor progress, and repeat the intervention.

Your approach with women and girls of childbearing age who engage in risky drinking or binge drinking may influence them to change their behaviors and reduce the risk for an alcohol-exposed pregnancy and other health problems in the future.

⁶O'Connor, M.J., and Whaley, S.E. 2007. Brief intervention for alcohol use by pregnant women. *American Journal of Public Health* 97(2):252-258.

Speak up.

Experts estimate that each year at least 40,000 babies are born with an FASD, costing the Nation up to \$6 billion annually in institutional and medical costs.⁷

Advise your clients that the best time to stop drinking alcohol is when they start to think about getting pregnant. You can also reassure women and girls who are already pregnant that, if they **stop drinking now**, they will reduce the potential for harm to the fetus.

Prevention is the only cure.

You may request companion pamphlets for mothers-to-be, family, and friends through the SAMHSA Store. Available in English and Spanish, they include:

- How to have a healthy baby: Be an alcohol-free mother-to-be
- Tips for Women: How to help your family member or friend
- Tips for Men: How to help your family member or friend

To order publications, call 1-877-SAMHSA-7 (1-877-726-4727) or access the Web site <http://www.samhsa.store.gov>.

If you want more information and training on FASD, visit the SAMHSA FASD Center for Excellence Web site <http://www.fascenter.samhsa.gov/>.

⁷Popova, S.; Stade, B.; Bekmuradov, D.; et al. 2011. What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism* 46(4):490-497.



Help a patient or client
have a
healthy baby.
Help her
to be an
alcohol-free
mother-to-be.