

FETAL ALCOHOL SPECTRUM DISORDERS

The Basics



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



Fetal Alcohol Spectrum Disorders (FASD): The Basics

This presentation is broken into five sections:

1. Understanding Fetal Alcohol Spectrum Disorders (FASD)
2. Individuals With An FASD – Strengths, Difficulties, and Approaches
3. Prevention and Risk Reduction
4. Resources
5. Conclusion



Section 1: Understanding Fetal Alcohol Spectrum Disorders (FASD)

Section 1 includes:

- Fetal Alcohol Spectrum Disorders (FASDs)
- Diagnostic Terminology
- Facts About FASDs
- Facts About Alcohol Use Among Pregnant Women
- Cause of FASDs
- What's a Standard Drink?
- Economic Costs of FAS

Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.
- Not a diagnosis.





Diagnostic Terminology

- Fetal Alcohol Syndrome (FAS)
 - The term FAS was first used in 1973 by Dr. David Smith and Dr. Ken Lyons Jones at the University of Washington.
 - While FASD describes a *range* of disorders, FAS is a *specific* birth defect caused by alcohol use while pregnant.
 - FAS *is* a diagnosis: It is medical diagnosis Q86.0 in the International Classification of Diseases (ICD-10).

Other Diagnostic Terminology



Pregnancy



Alcohol



+

May result in



- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)
- Fetal alcohol effects (FAE)
- Alcohol-related birth defects (ARBD)
- Static encephalopathy (an unchanging injury to the brain)

Facts About FASDs



- FASDs are the leading known cause of preventable mental retardation.¹
- FASDs effect an estimated 40,000 newborns each year in the United States.²
- FASDs are more common than autism.³
- The effects of FASDs last a lifetime.
- People with an FASD *can* grow, improve, and function well in life with proper support.
- **FASDs are 100% preventable.**

Facts About FASDs



- No amount of alcohol consumption during pregnancy is proven to be safe.¹
- FASDs are not caused by the biological father's alcohol use.
- **FASDs are not caused intentionally by the mother:** Many women simply may not know when they are first pregnant or may not be aware of the harm that alcohol consumption during pregnancy can cause.



Facts About Alcohol Use Among Pregnant Women

- Nearly 12 percent of pregnant women report using alcohol in the past month.
- Past-month alcohol use among pregnant women and recent mothers aged 15 to 44 did not change significantly between 2002-2003 and 2006-2007.
- Nearly 16 percent of pregnant women aged 15 to 17 used alcohol in the past month, and they consumed an average of 24 drinks in that month (i.e., they drank on an average of 6 days during the past month and had an average of about four drinks on the days that they drank).



Cause of FASDs

- The sole cause of FASDs is the fetus being exposed to alcohol during the pregnancy.
- Alcohol is a *teratogen*: A drug or other substance capable of interfering with the development of a fetus, causing birth defects.

“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”

—IOM Report to Congress, 1996



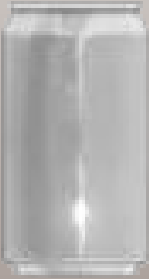
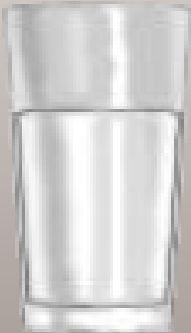




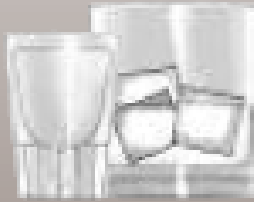
Cause of FASDs

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.*
- While it's true that not every woman who drinks during pregnancy will have a child with an FASD, that does not mean that these disorders are rare or random.
- **Any time a pregnant woman consumes alcohol, it becomes possible that her baby will have an FASD.**

* Binge = 4 or more standard drinks on one occasion for women

What's A Standard Drink?



<p>12 oz. of beer or cooler</p> 	<p>8–9 oz. of malt liquor 8.5 oz. shown in a 12-oz. glass that, if full, would hold about 1.5 standard drinks of malt liquor</p> 	<p>5 oz. of table wine</p> 	<p>3–4 oz. of fortified wine (such as sherry or port) 3.5 oz. shown</p> 	<p>2–3 oz. of cordial, liqueur, or aperitif 2.5 oz. shown</p> 	<p>1.5 oz. of brandy (a single jigger)</p> 	<p>1.5 oz. of spirits (a single jigger of 80-proof gin, vodka, whiskey, etc.) Shown straight and in a highball glass with ice to show the level before adding a mixer*</p> 
<p>~5% alcohol</p>	<p>~7% alcohol</p>	<p>~12% alcohol</p>	<p>~17% alcohol</p>	<p>~24% alcohol</p>	<p>~40% alcohol</p>	<p>~40% alcohol</p>
<p>12 oz.</p>	<p>8.5 oz.</p>	<p>5 oz.</p>	<p>3.5 oz.</p>	<p>2.5 oz.</p>	<p>1.5 oz.</p>	<p>1.5 oz.</p>



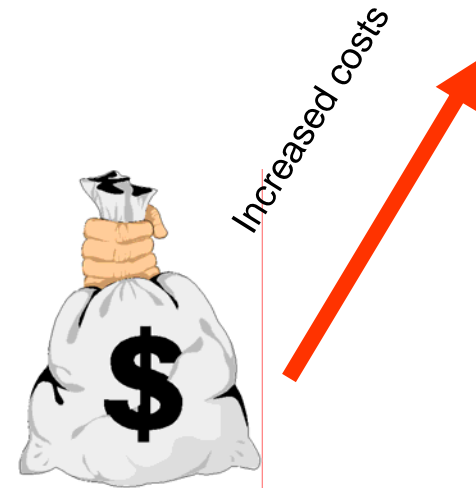
What's a Standard Drink?

In recent research, frequent drinkers and the majority of women reported drinking larger-than-standard drinks:

- Daily drinkers were consuming drinks that were anywhere from three to six times the size of a standard drink.
- The majority of drinkers underestimated the number of fluid ounces they were consuming by about 30%.

Economic Costs of FAS

- FAS alone is estimated to cost the United States nearly \$4 billion each year.
- The average lifetime cost for each child with FAS is almost \$3 million.



Economic Costs of FAS

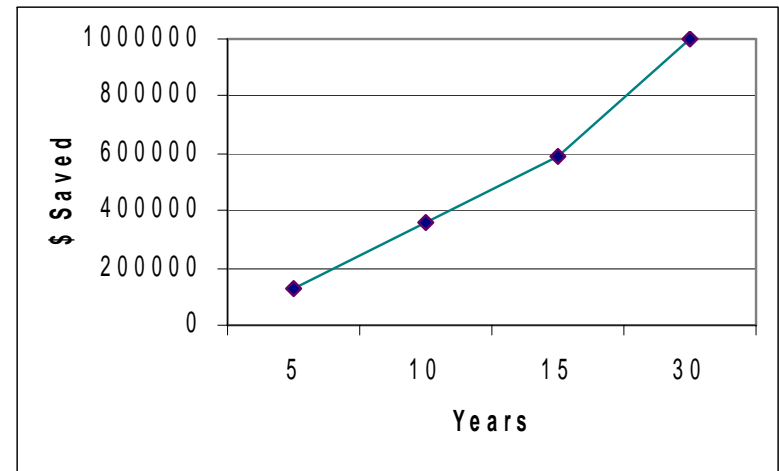
- One prevented case of FAS saves:

- \$130,000 in the first 5 years

- \$360,000 in 10 years

- \$587,000 in 15 years

- More than \$1 million in 30 years



Increased savings
through prevention



Section 2: Individuals With an FASD – Strengths, Difficulties, and Approaches

Section 2 includes:

- Primary Disabilities That Can Occur in Persons With an FASD
- Typical Strengths of Persons With an FASD
- Typical Difficulties for Persons With an FASD
- Risks of Not Accurately Identifying and Treating an FASD
- Factors Associated With Reduced Life Complications
- Identifying an FASD
- Possible Signs of an FASD
- Trends in Treatment

Primary Disabilities That Can Occur in Persons With an FASD

- Lower IQ
- Impaired ability in reading, spelling, and arithmetic
- Lower level of adaptive functioning



Typical Strengths of Persons With an FASD



- Friendly and cheerful

- Likable

- Desire to be liked

- Helpful

- Verbal



- Determined

- Have points of insight

- Hard working

- Every day is a new day!

Typical Difficulties For Persons With an FASD

Sensory: May be overly sensitive to bright lights, certain clothing, tastes and textures in food, loud sounds, etc.

Physical: Have problems with balance and motor coordination (may seem “clumsy”).



Typical Difficulties For Persons With an FASD



Information Processing:

- Do not complete tasks or chores and may appear to be oppositional
- Have trouble determining what to do in a given situation
- Do not ask questions because they want to fit in
- Have trouble with changes in tasks and routine



Typical Difficulties For Persons With an FASD

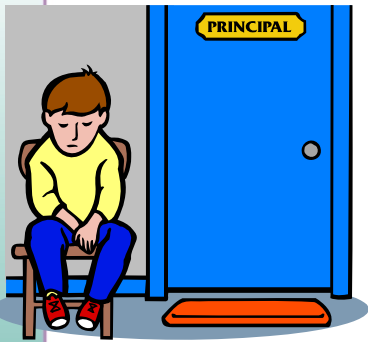
Information Processing:

- Have trouble following multiple directions
- Say they understand when they do not
- Have verbal expressive skills that often exceed their verbal receptive abilities
- Cannot operationalize what they've memorized (e.g., multiplication tables)
- Misinterpret others' words, actions, or body movements



Typical Difficulties For Persons With an FASD

Executive Function and Decision-Making:



- Repeatedly break the rules
- Give in to peer pressure
- Tend not to learn from mistakes or natural consequences
- Frequently do not respond to reward systems (points, levels, stickers, etc.)
- Have difficulty entertaining themselves
- Naïve, gullible (e.g., may walk off with a stranger)
- Struggle with abstract concepts (e.g., time, space, money, etc.)

I'm late!
I'm late!





Typical Difficulties For Persons With an FASD

Self-Esteem and Personal Issues:

- Function unevenly in school, work, and development – Often feel “stupid” or like a failure
- Are seen as lazy, uncooperative, and unmotivated –Have often been told they’re not trying hard enough
- May have hygiene problems
- Are aware that they’re “different” from others
- Often grow up living in multiple homes and experience multiple losses



Risks of Not Accurately Identifying and Treating an FASD

For the individual with an FASD:

- Unemployment
- Loss of family
- Homelessness
- Jail
- Premature death
- Increased substance abuse
- Wrong treatment or intervention is used

For the family:

- Loss of family
- Increased substance use
- Premature death
- Financial strain
- Emotional stress



Factors Associated With Reduced Life Complications

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life



Identifying an FASD

Only trained professionals can diagnose a disorder from the FASD spectrum. Ideally, diagnosis is done by a team that may include:

- › Geneticists
- › Developmental pediatricians
- › Neurologists
- › Dysmorphologists (physicians specializing in birth defects)
- › Education consultants
- › Psychologists, psychiatrists, and social workers
- › Occupational therapists
- › Speech and language specialists



Possible Signs of an FASD

Signs that may suggest the need for FASD assessment include:

- › Sleeping, breathing, or feeding problems
- › Small head or facial or dental irregularities
- › Heart defects or other organ dysfunction
- › Deformities of joints, limbs, and fingers
- › Slow physical growth before or after birth
- › Vision or hearing problems
- › Mental retardation or delayed development
- › Behavior problems
- › Maternal alcohol use



Trends in Treatment

Strategies to assist persons with an FASD and their families continue to increase dynamically:

- SAMHSA's FASD Center for Excellence provides a variety of materials for families, providers, and educators:
<http://fasdcenter.samhsa.gov>
- In addition to materials, the National Organization on Fetal Alcohol Syndrome (NOFAS) provides a directory of FAS resources: www.nofas.org/resource/directory.aspx
- The Centers for Disease Control and Prevention (CDC) are currently researching new approaches to FASD at sites across the country.



Section 3: Prevention and Risk Reduction

Section 3 includes:

- Prevention Starts With Asking!
- Brief Interventions Can = Prevention
- Public Health Messaging
- We Can All Talk About Alcohol Use
- Who Needs To Know
- Raise Awareness in Schools
- Raise Awareness in the Community

Prevention Starts With Asking!



Ask all women of childbearing age about alcohol use:

- Ask routinely at every medical appointment.
- Ask at appointments in various systems.
- Ask in a nonjudgmental manner.
- Use effective screening tools.
- Ask about possible prenatal exposure.
- Imbed questions about alcohol use in general health questions (e.g., wearing seat belts, taking vitamins, smoking, etc.).





Brief Intervention Can = Prevention

- Research shows that brief interventions can help reduce alcohol use among women of childbearing age, whether pregnant or non-pregnant.
- Typical brief interventions include outreach, screening, referral, and other activities that promote the health of the mother (and, among pregnant women, the fetus).
- Brief interventions have been effectively implemented by health professionals in primary care, emergency, and substance abuse treatment settings, and also on campuses.



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NOW IS A GOOD TIME
TO STOP DRINKING.

Did you know Minnesota women of childbearing age drink more frequently than women in nearly every other state? If you're a woman who's drinking and pregnant, you're increasing the chance that your baby will be born with alcohol-related birth defects – such as mental retardation, delayed development or lifelong behavioral disorders. Remember, one drink is one too many. Call 1-800-728-5420 for more information.

DON'T TAKE THE RISK. DON'T TAKE THE DRINK.

This message brought to you by the State of Minnesota.

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We Can All Talk About Alcohol Use



Talk about the effects of alcohol on an individual and on a fetus:

- Begin at an early age, such as elementary school.
- Indicate that stopping drinking at any time during pregnancy will help the fetus.

The father can play an important role in preventing FASD by helping the mother avoid alcohol.

We Can All Talk About Alcohol Use



**Convey the message to women:
Say No to Alcohol.
For You, and for Your Baby.**

Who Needs To Know

EVERYONE!

While FASD awareness may seem like it's just about women who are pregnant, it's not. Anyone who can help a woman remain alcohol-free during pregnancy should know: Men, women, family, friends, health care providers, educators...

EVERYONE!



Raise Awareness in Schools



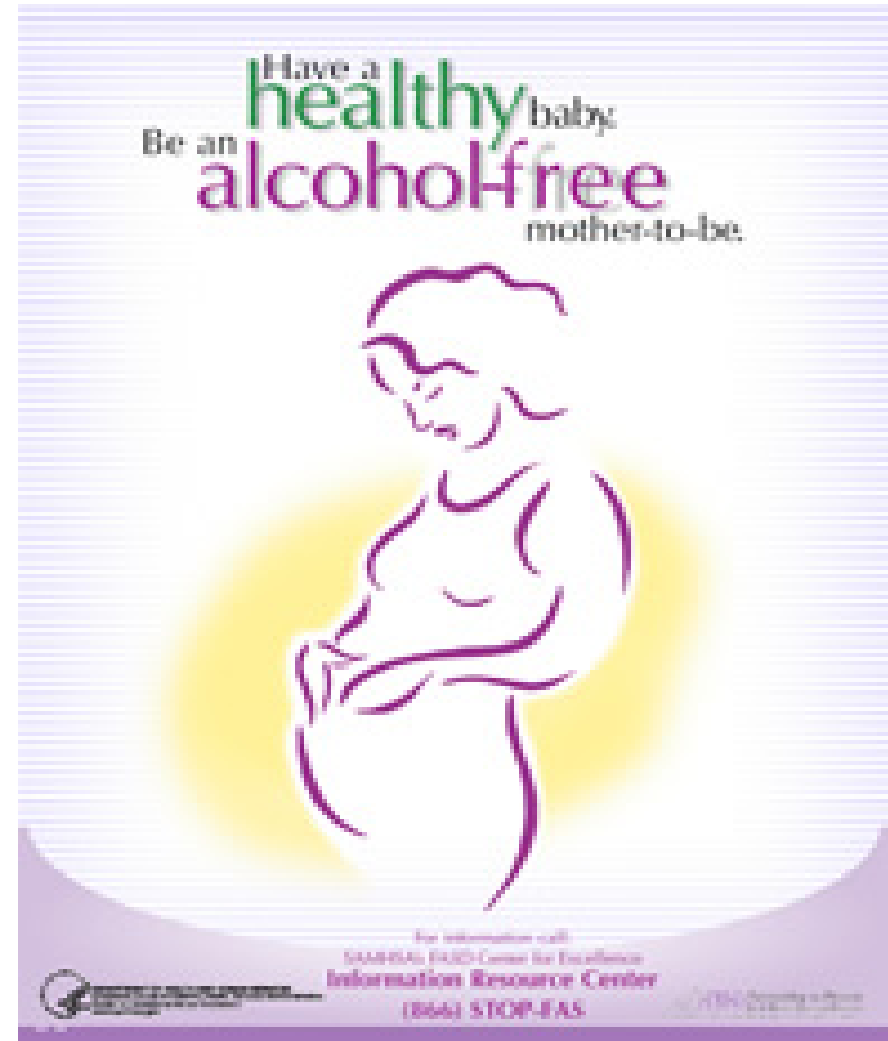
- Ask the school to put up posters about drinking and pregnancy.
- Include information about FASDs in health, science, and physical education classes.



- Hold an assembly to talk about the effects of alcohol on a person and on a baby.

Raise Awareness in the Community

- Post FASD information in doctors' offices, treatment centers, and community centers.
- Promote FASD Awareness Day (September 9). Visit the Web site www.fasday.com for information.
- Discuss FASD in your community; at work, at church, anywhere. Awareness can have a positive impact on everyone.



Section 4: Resources

- SAMHSA FASD Center for Excellence:
fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
 - › NOFAS Resource Directory:
www.nofas.org/resource/directory.aspx
- National Clearinghouse for Alcohol and Drug Information (NCADI): ncadi.samhsa.gov



Section 5: Conclusion



Section 5 includes:

- The Benefits of Identification and Treatment of FASDs
- What is Needed

The Benefits of Identification and Treatment of FASDs

- Helps decrease anger and frustration for individuals, families, providers, and communities by helping them understand that negative behavior results from the disability and is not willful.
- Helps people with an FASD succeed by focusing on their strengths and what will help them, not on their ‘weaknesses’ and what they’ve done ‘wrong.’
- Helps improve outcomes.
- Helps prevent future births of children with an FASD.



What is Needed

What is needed to adequately address FASDs is a paradigm shift in how we think:

“We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

—Dubovsky, 2000



Thank you for taking time to learn about FASDs!

For more information about FASDs, including topics such as diagnosis and treatment, please visit <http://www.fascenter.samhsa.gov>.