

Addressing Fetal Alcohol Spectrum Disorders (FASD)  
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## Fetal Alcohol Spectrum Disorders (FASD)

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

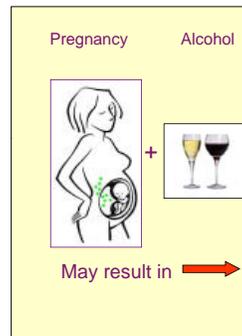
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## Fetal Alcohol Syndrome (FAS)

- Term first used in 1973 by Drs. Smith and Jones at the University of Washington
- One of the diagnoses used to describe birth defects caused by alcohol use while pregnant
- Characterized by certain facial features
- Only represents a small group of individuals and is not necessarily more severe than other levels of prenatal alcohol exposure
- Is a medical diagnosis (760.71) in the International Classification of Diseases (ICD)

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## FASD Terminology



- Fetal Alcohol Syndrome (FAS)
- Fetal Alcohol Effects (FAE)
- Alcohol-related birth defects (ARBD)
- Alcohol-related neurodevelopmental disorder (ARND)
- Partial FAS (pFAS)

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## FASD: What We Know

- 100 percent preventable
- Leading known cause of preventable mental retardation
- Not caused on purpose
- Can occur in any community where women drink
- Not caused by paternal alcohol use



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## Number of People With an FASD

- No one knows for certain how many individuals are born each year with an FASD or living with an FASD.
- It is estimated that 1 in every 1,000 births has FAS.
- It is estimated that 1 in every 100 births has an FASD.

NOTE: the NYS DOH Birth Defects Registry tracks FAS births only up to age 2

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## Economic Costs of FAS

- Fetal alcohol syndrome alone cost the United States cost \$5.4 billion in the U.S. in 2003.
- The average lifetime cost for each child with FAS is \$2 million.
  - \$1.6 million for medical care services
  - \$0.4 million for loss of productivity
- Potential savings from preventing the birth of one child with FAS is \$850,000

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*Lupton, Burd, and Harwood (2004)*

## FAS Annual Costs by State, 2004 (\$ in millions)

Alabama	\$59.0	Kentucky	\$26.1	North Dakota	\$13.2
Alaska	\$11.3	Louisiana	\$54.3	Ohio	\$178.5
Arizona	\$98.5	Maine	\$26.5	Oklahoma	\$43.7
Arkansas	\$29.7	Maryland	\$71.5	Oregon	\$68.3
California	\$581.3	Massachusetts	\$125.3	Pennsylvania	\$207.3
Colorado	\$78.8	Michigan	\$182.9	Rhode Island	\$20.5
Connecticut	\$52.0	Minnesota	\$107.4	South Carolina	\$61.1
Delaware	\$17.6	Mississippi	\$26.0	South Dakota	\$17.9
Dist. Columbia	\$14.8	Missouri	\$95.7	Tennessee	\$43.7
Florida	\$259.4	Montana	\$17.1	Texas	\$330.3
Georgia	\$96.7	Nebraska	\$30.7	Utah	\$27.0
Hawaii	\$10.4	Nevada	\$46.0	Vermont	\$9.9
Idaho	\$18.3	New Hampshire	\$23.1	Virginia	\$118.3
Illinois	\$226.3	New Jersey	\$97.4	Washington	\$99.3
Indiana	\$102.9	New Mexico	\$22.1	West Virginia	\$15.4
Iowa	\$65.2	New York	\$361.0	Wisconsin	\$133.8
Kansas	\$40.3	North Carolina	\$81.4	Wyoming	\$9.3

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## What Causes FASD?

- Sole cause: mother drinking alcoholic beverages during pregnancy
- Alcohol is a teratogen



**“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.  
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## FASD and Alcohol

- All alcoholic beverages are harmful.
- Binge drinking is especially harmful.
- There is no proven safe amount of alcohol use during pregnancy.



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## Why do women drink alcohol during pregnancy?

- Uninformed or misinformed
- Addiction
- Denial
- Unaware that they are pregnant





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## Drinking Among U.S. Women (age 15 - 44)

- 1 in 2 reports any alcohol use during the past month
- Approximately 1 in 4 reports binge drinking (defined for women as four or more drinks on one occasion)
- About 1 in 20 reports heavy alcohol use (binge drinking on at least 5 days in the last month)



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### State Rates of Female "At Risk" Drinking

Females age 18-44 years, Past Month Binge or Heavy Drinking

Alabama	12.6%	Kentucky	6.0%	North Dakota	20.7%
Alaska	16.9%	Louisiana	11.3%	Ohio	15.3%
Arizona	17.1%	Maine	20.4%	Oklahoma	12.2%
Arkansas	10.7%	Maryland	12.1%	Oregon	18.8%
California	15.3%	Massachusetts	18.2%	Pennsylvania	17.0%
Colorado	16.0%	Michigan	17.7%	Rhode Island	17.8%
Connecticut	14.8%	Minnesota	20.0%	South Carolina	14.0%
Delaware	20.0%	Mississippi	8.4%	South Dakota	23.6%
Dist. Columbia	21.1%	Missouri	16.1%	Tennessee	7.0%
Florida	15.5%	Montana	19.2%	Texas	13.7%
Georgia	9.9%	Nebraska	17.3%	Utah	10.0%
Hawaii	8.6%	Nevada	19.2%	Vermont	16.1%
Idaho	12.9%	New Hampshire	17.3%	Virginia	15.0%
Illinois	17.0%	New Jersey	11.0%	Washington	15.2%
Indiana	16.2%	New Mexico	11.5%	West Virginia	8.7%
Iowa	22.0%	New York	17.7%	Wisconsin	23.6%
Kansas	14.5%	North Carolina	9.1%	Wyoming	18.7%

Estimated from 2002 BRFSS; U.S. average was 14.9%, or 8.4 million females

### Drinking Patterns in Youth

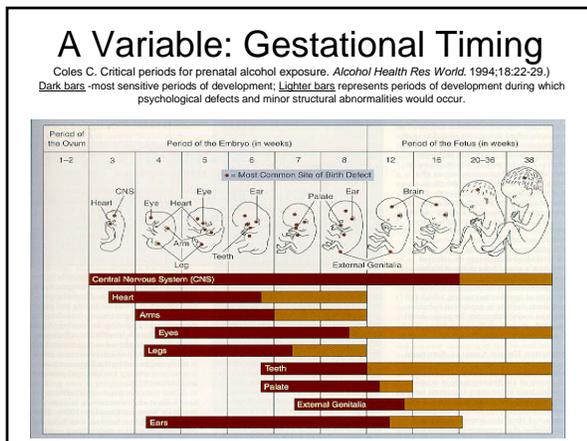
- More than 80 percent of youth have tried alcohol by grade 12 (National Center on Addiction and Substance Abuse: CASA).
- Thirty percent of students had more than five drinks on more than one occasion in the past 30 days (Youth Risk Behavior Surveillance Survey: YRBSS).
- Teens tend to drink larger amounts of alcohol per sitting (CASA).

### Sexual Activity by Youth

- Adolescents who drink are more likely to binge drink in early pregnancy compared to adults (Cornelius, et al., 1997).
- Twenty-three percent of sexually active youth report having unprotected sex as a result of alcohol or drug use (CASA).
- Forty-six percent of all high school students in the U.S. have had sexual intercourse (YRBSS).
- Teenagers tend to recognize their pregnancies later than adults (Cornelius, et al., 1997).

### Unplanned Pregnancies Pose A Great Challenge for FASD Prevention

- An estimated 40% of the 60 million US women in their childbearing years do not practice contraception
- Half of all pregnancies in the US are unplanned
- Often women do not know they are pregnant for several weeks (or even months) during which time they may drink alcohol



### Prevention Is the Best Cure

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, respectful manner.
- Use effective screening tools.
- Ask about possible prenatal exposure.

## Screening Tools to Help Women

Problem drinking and binge drinking can be determined by screening. Interview-based or self-administered screening tools are the most effective. Can take 5-10 minutes or less. Screening Materials are available on the web.

Examples:

- CAGE
- TWEAK
- T-ACE
- AUDIT
- 4 P's



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## Talk About Alcohol Use

- Talk about alcohol's effects 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.



Convey the message: If you're pregnant, don't drink. If you drink, don't get pregnant.

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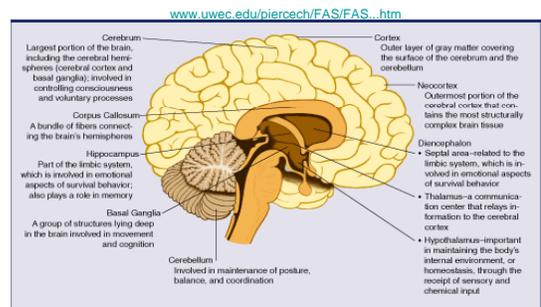
## FASD and the Brain

- Prenatal alcohol exposure causes brain damage.
- Effects of FASD last a lifetime.
- People with an FASD can grow, improve, and function well in life with proper support.

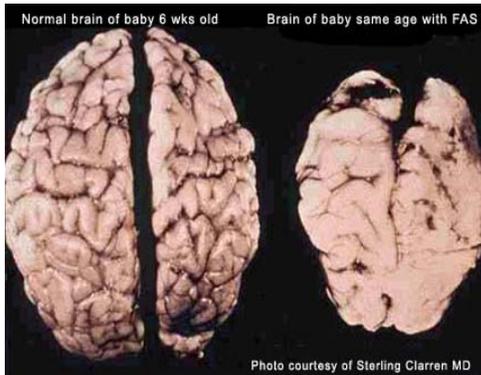


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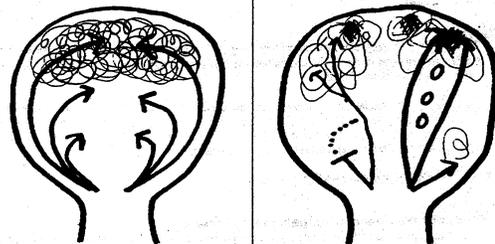
## Brain areas that can be affected by alcohol exposure



## FAS and the Brain



## Visual Model of Brain Differences



Normal brain development is complex, orderly, and sequential. Rich neural networks provide mechanisms for basic abilities: Storing, remembering, integrating, and retrieving information.

FAS/ARND: There is often undergrowth, overgrowth, gaps and tangles. Fewer cells, the brain structure and chemistry may be altered affecting basic cognitive abilities and sensory responses.

Adapted from Malbin (1999)

### Identifying FAS: What to Look For

- Growth deficiency in height and/or weight
- Specific differences in facial characteristics
- Damage to the central nervous system
- Evidence of mother drinking while pregnant<sup>5</sup>



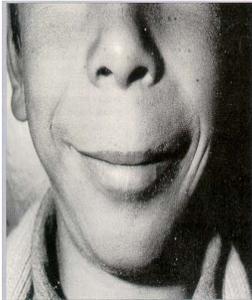
Photo courtesy of St. Louis Arc

### Short Palpebral Fissures




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### Smooth Philtrum, Thin Upper Lip




Lip-Philtrum Guide 1 Lip-Philtrum Guide 2

### Developmental Skills

Developmental Skills Adapted from research findings of Streissguth, Clarren, et al., by Diane Malbin, 1994

Skill Equivalent	Developmental Age
Comprehension.....	6 years
Emotional maturity.....	6 years
Social skills.....	7 years
Money and time concepts.....	8 years
Living skills.....	11 years
Reading ability.....	16 years
Physical maturity.....	18 years
<b>Actual age.....</b>	<b>18 years</b>
Expressive language.....	20 years

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### Primary Disabilities in Persons With an FASD

- Lower IQ 
- Impaired ability in reading, spelling, and arithmetic 
- Lower level of adaptive functioning; more significantly impaired than IQ

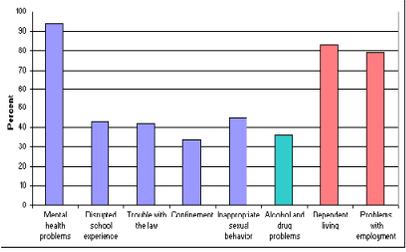
Age 21: Graduation from high school  
Photo courtesy of [www.fasstar.com](http://www.fasstar.com)

*Streissguth, et al. (1996)*

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### Secondary Disabilities of Persons With an FASD

Percent of Persons With FAS or FAE Who Had Secondary Disabilities



Category	Age 6+	Age 12+	Age 21+
Mental health problems	~90%	~90%	~90%
Disrupted school experience	~40%	~40%	~40%
Trouble with the law	~40%	~40%	~40%
Confinement	~30%	~30%	~30%
Inappropriate sexual behavior	~40%	~40%	~40%
Alcohol and drug problems	~35%	~35%	~35%
Homeless living	~80%	~80%	~80%
Problems with employment	~80%	~80%	~80%

◆ = Age 6+    ◆ = Age 12+    ◆ = Age 21+

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## Overall Difficulties for Persons With an FASD

- Taking in information
- Storing information
- Recalling information when necessary
- Using information appropriately in a specific situation



### Typical problems for individuals with an FASD:

Sensory Integration  
Memory Problems  
Executive Functioning  
Self-esteem and personal issues  
Information Processing functions

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## Infancy & Early Childhood, birth-5 *Challenges*



- Sensitivity to light, sounds, & touch
- Poor sucking response
- Failure to thrive
- Sleep disturbances
- Delays in walking, talking, toilet training
- Hyperactive
- Irritable
- Temper tantrums

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## Childhood, 6-11 years old *Challenges*

- Easily influenced
- Attention & memory problems
- Difficulty with cause & effect, consequences
- Easily distracted
- Delayed physical & cognitive development
- Poor understanding of social rules & expectations
- No sense of boundaries
- Easily victimized by peers



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## Adolescence, 12-17 years old *Challenges*



- Attention & memory problems
- Impulsive
- Inappropriate social skills
- Faulty logic
- Low self-esteem
- Easily victimized
- Depression, anxiety
- Risk of substance abuse
- Good expressive language/poor comprehension

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## Adulthood, 18+ years *Challenges*

- Poor comprehension of social expectations
- Social, sexual &/or financial victimization
- Increased expectations by others
- Withdrawal & social isolation
- Daily obstacles—housing, employment, transportation, money



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## New Northrop Grumman Funding Award to OASAS

- Seven states in USA were awarded State subcontracts;
- Project period is February 1, 2008 - May 31, 2012;
- Funding level totals \$1.2 million over the subcontract period (dependent upon available funding)
- Our initiative seeks to implement an evidence-based approach called "Project CHOICES," which utilizes Motivational Interviewing to prevent alcohol-exposed pregnancies;
- Three women's residential treatment sites in the Greater NY Metropolitan area will be selected initially, with plans to expand to eight sites by end of the project period; and
- Funding is provided to establish a FASD Task Force to guide the project.

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## FASD Resources: Web Links

- **NYS Office of Alcoholism & Substance Abuse Services (NYS OASAS):** [www.oasas.state.ny.us/fasd](http://www.oasas.state.ny.us/fasd)
- **SAMHSA FASD Center for Excellence:**
  - [www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov)
- **Centers for Disease Control and Prevention FAS Prevention Team:** [www.cdc.gov/ncbddd/fas](http://www.cdc.gov/ncbddd/fas)
- **National Institute on Alcohol Abuse and Alcoholism (NIAAA):** [www.niaaa.nih.gov/](http://www.niaaa.nih.gov/)
- **National Organization on Fetal Alcohol Syndrome (NOFAS):** [www.nofas.org](http://www.nofas.org)

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## “Recovering Hope” video

- For use by women in treatment and/or recovery programs
- Is developed in two ½ hour parts
- Comes with Facilitator’s Discussion Guide and brochures
- Can be ordered on-line for free from: <http://www.ncadi.samhsa.gov> (there is also a link from the OASAS web site)

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## Any questions?

### Contact me:

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