



Fetal Alcohol Syndrome and Developmental Disabilities

***Matrix of Other Emerging Research: “Priming
for Prevention” Teleconference 10-17-2007***

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Fetal Alcohol Syndrome (FAS) ***With or without confirmed Maternal Alcohol Exposures***

- *Facial Anomalies*
- *Growth Retardation*
 - *Low birth weight*
 - *Deceleration in weight over time*
 - *Disproportional low weight to height*
- *CNS neurodevelopment abnormalities*



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Statement of the Problem



- 58.8% of women age 15-44 drank alcohol
- **10% of pregnant women drank; 2% binged**
 - Of those who drank during pregnancy
 - 65.8% drank in the 1st trimester
 - 56.6% in 2nd trimester, and
 - 53.9% in 3rd trimester consumed alcohol

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NIAAA Council Approves Definition of Binge Drinking

A "binge" is a pattern of drinking alcohol that brings blood alcohol concentration (BAC) to 0.08 gram percent or above. For the typical adult, this pattern corresponds to consuming 5 or more drinks (male), or 4 or more drinks (female), in about 2 hours.

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Statement of the Problem

- **FAS**
 - Diagnosed in 1/ 600-700 live births
(5-12,000 babies/ year)
 - Leading Preventable cause of mental retardation in the world!--100% preventable
- **FAE**
 - Diagnosed in 1/ 300-350 live births

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Statement of the Problem

- Live births (US)
- 1996 = 3,899,000
- 1997 = 3,882,000
- 1998 = 3,941,553
- 1999 = 3,959,417
- 2000 = 4,058,814
 - 5,798 to 6,764 with FAS;
 - 11,597 to 13,529 with FAE;
 - Altogether, 17,395 to 20,293 per year.



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FAS Prevalence Rate – FASS Net States, 1995-97 (MMWR 2002;51:433-5)

Black	30/27,358	1.1/1,000
White	49/266,443	0.2/1,000
Hispanic	24/107,127	0.2/1,000

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Economic Costs of FAS

- *FAS alone cost the United States more than \$4 billion in 1998.*
- *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*



Increased costs

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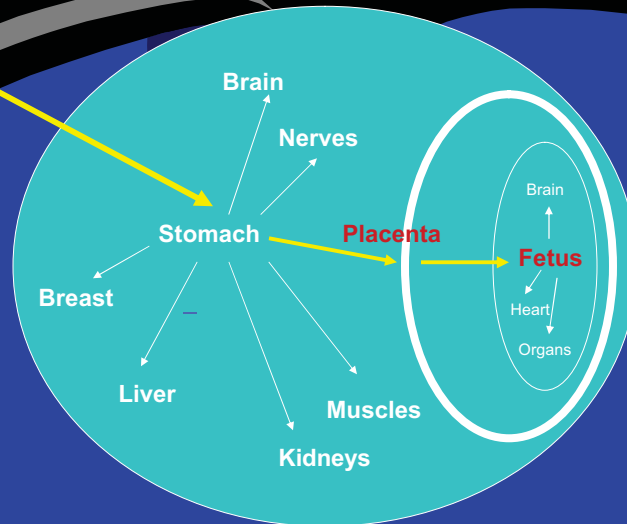
Lupton, Burd, and Harwood (2004)

*So, I'm Pregnant and I drink...
or any Pregnant Woman
Drinks...*

Then What Happens?

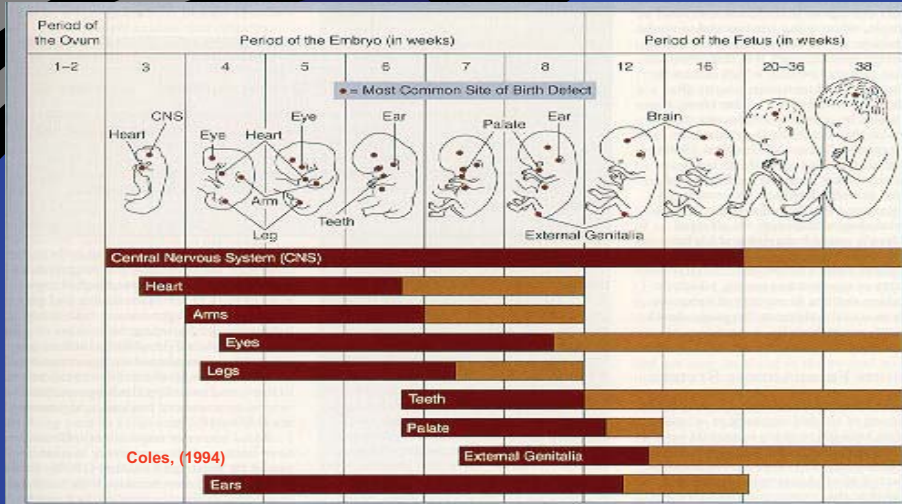
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No Safe Level of Alcohol



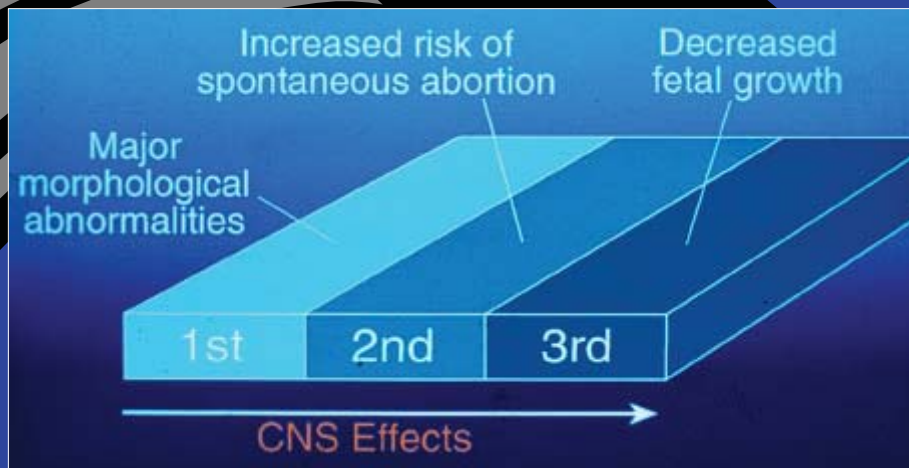
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No Safe Time to Drink Alcohol During Pregnancy



2.10 11

Major Effects of Ethanol by Trimester of Pregnancy



The most prudent advice you can give to *all* women is to **stop drinking before conception and to maintain abstinence throughout pregnancy and during breast feeding.**

(UCLA RTC)

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Additional Factors Associated With Women Who Drink During Pregnancy

- Moderate to High alcohol use prior to pregnancy
- Early initiation of alcohol use
- High parity (> 3)
- Late entry into prenatal care and fewer visits
- Lower Body Mass Index (BMI) and poor nutritional status overall

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Clinician, Parental, or Community Observations and Intervention Opportunities

- *Other children given up for adoption*
- *Foster parenting of children with behavioral problems*
- *History of Intimate partner violence (IPV)*
- *Use of other substances (cigarettes, other drugs)*
- *Issues of household instability*

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Preventing Alcohol-Exposed Pregnancies



- Reduce risk drinking

or



- Prevent pregnancy

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Reality Check...

Neonatal diagnosis is not a hopeless prognosis

Appropriate intervention +

Community support =

*Minimized (though not eliminated)
impact of alcohol related birth injury and
neurodevelopmental disabilities*

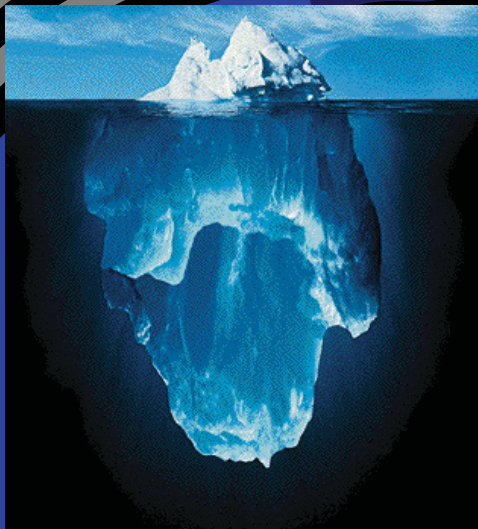
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Tip of the Iceberg



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FAS – Only The Tip Of The Iceberg



- *Fetal alcohol syndrome*
- *Fetal alcohol effects*
- *Clinical suspect but appear normal*
- *Normal, but never reach their potential*

Adapted from Streissguth
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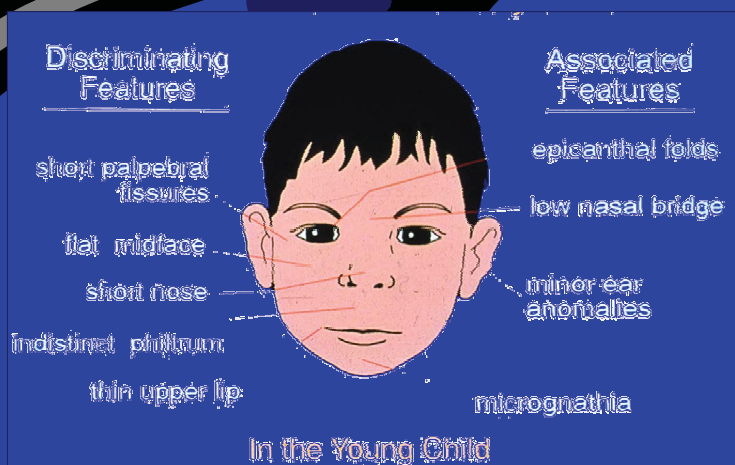
Characteristic facial anomalies of FAS (First Criterion)

- *Short palpebral fissures*
- *Flat upper lip*
- *Flattened philtrum*
- *Flat midface*



Photo courtesy of Teresa Kellerman

Facies in Fetal Alcohol Syndrome (First Criterion)



Streissguth, 1994

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**Six-year-old boy with flattened facial profile
unusual ear cartilage ("railroad track" ear)**

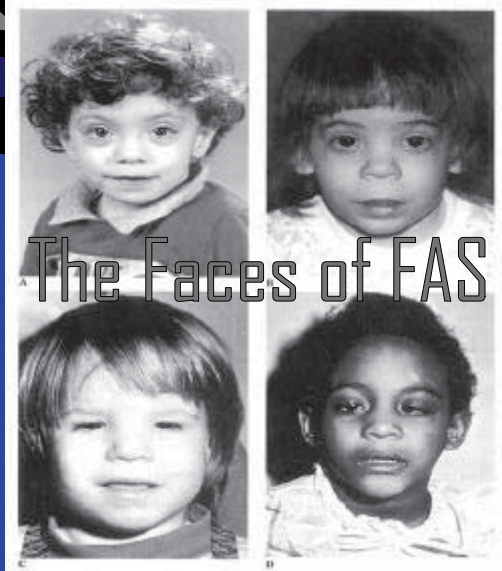


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Specific Patterns of Facial Anomalies

These children exhibit FAS findings such as:

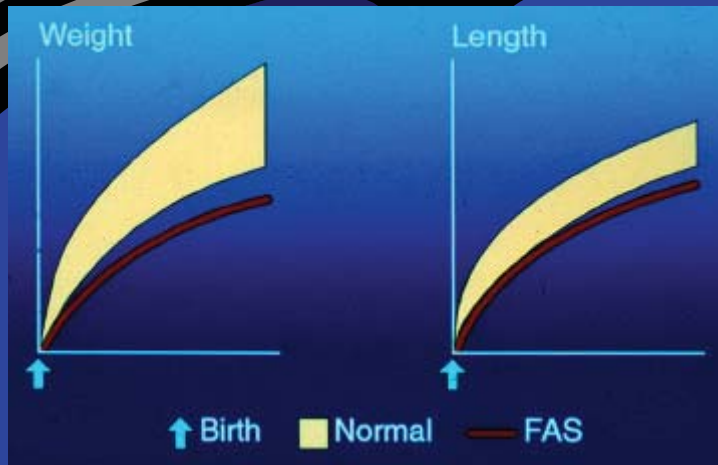
- flat philtrum
- lid lag
- thin upper lip
- Short palpebral fissures



Photos courtesy of UCLA

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Growth Deficiency in Fetal Alcohol Syndrome (2nd Criterion)



UCLA RTC

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Postnatal Growth Deficiency (2nd Criterion)



Fetal Alcohol Syndrome (FAS) (3rd Criterion)

- **Brain Abnormalities**
 - *Decreased cranial size at birth*
 - *Structural brain abnormalities*
 - *Soft or hard neurological signs*
(Gait; Coordination)

Brain Damage Resulting From Prenatal Alcohol

Evidence of CNS dysfunction

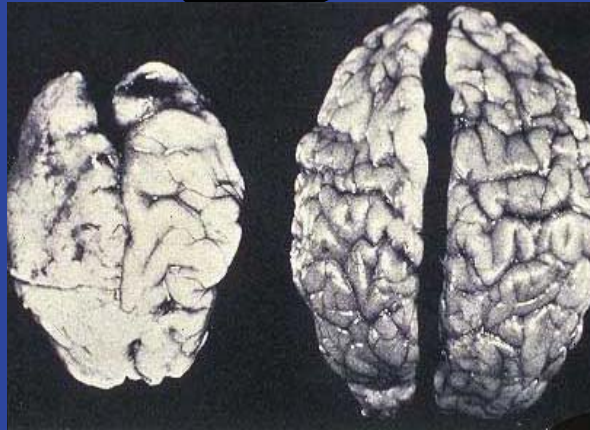


photo: Clarren, 1986 27

Fetal Alcohol Syndrome (FAS) (3rd Criterion)

CNS Neurodevelopment Abnormalities

- Structural, Neurological, or Functional
 - **Structural** brain abnormalities (decreased cranial size at birth; neuro-imaging abnormalities)
 - Soft or hard **neurological** signs (gait; coordination; seizures)
 - **Functional** (test performance substantially lower than expected for age, educational level, etc.)

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Brain Damage Resulting From Prenatal Alcohol

Prenatal alcohol exposure

- disrupts the normal structure and function of the developing brain.

“Intermittent exposure of the developing fetus to a bolus of alcohol producing a high Blood Alcohol Concentration (BAC) is considered to be one of the most powerful determinants of the severity of developmental brain damage and possibly damage to areas involved in regulating attention”.

(Paula J. Lockhart, M.D. Kennedy Krieger Institute)

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Brain Structures Most Sensitive to Prenatal Alcohol Exposure



Brain Structure	Function	Prenatal alcohol exposure may result in problems with:
Corpus Callosum	Communicates motor, sensory and cognitive information between the two hemispheres of the brain	Storing and retrieving information, problem solving, attention and verbal memory
Cerebellum	Processes input from other areas of the brain to coordinate motor and cognitive skills	Controlling movements, maintaining balance and fine motor skills

National Organization on Fetal Alcohol Syndrome (NOFAS)
1.800.66NOFAS or visit www.nofas.org



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Brain Damage Resulting From Prenatal Alcohol

Single exposure to high levels of ethanol can kill nerve cells in the developing brain” (Science, February 11, 2000)

- *Based on study with infant rats...synaptogenesis is when the brain cells are forming connections, and time when alcohol most toxic.*
- *Aptosis—cells died post single exposure of brain cells to alcohol*
 - *Rate of cell death 30x that expected spontaneously*

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Fetal Alcohol Effect (FAE)

- *Look “normal”*
- *Usually have higher IQ’s*
- *Life skills not consistent
With higher IQ*

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Effects of Alcohol on Developing Fetus

Absence of physical features of FAS does not indicate that serious neurodevelopmental damage has not occurred.



Alcohol Related Neurodevelopment Disorder (ARND)

Mental impairments consistent with FAS, but without abnormal facies and growth deficiencies

- *Mental (Low IQ)*
- *Learning Deficits*
- *Behavior Problems*

Alcohol Related Neurodevelopment Disorder (ARND)

- **Intelligence**
 - IQ scores range from 20-110
 - Average IQ—60's
 - "Talk the talk" ...
 - Adult Q: What would you do in an emergency...
 - ARND child A: "Call 911"
 - Can't "Walk the walk" ...
 - Adult Q: "What is an emergency?"
 - ARND child: "????"
- (Too difficult...higher level of thought processing)

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Primary Central Nervous System Disabilities



- Decreased I.Q.
- Specific deficits in reading, spelling and math
- Fine and gross motor problems
- Executive functioning deficits
- Communication and social interactions problems
- Attention problems and/or hyperactivity
- Memory deficits



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Alcohol Related Birth Defects (ARBD)

*Physical abnormalities of the
skeleton
and major organs*

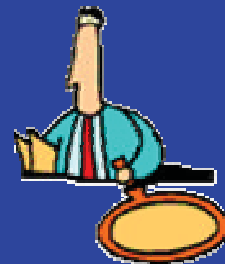


- **Heart Problems**
 - Atrial Septal Defect
 - Ventricular Septal Defect
 - Aberrant Great Vessels
 - Tetralogy of Fallot

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Alcohol Related Birth Defects (ARBD)

- **Ocular**
 - Strabismus
 - Refractive problems secondary to small globes
 - Optic nerve hypoplasia
 - Posterior haze of the cornea
 - Decreased visual acuity in infancy



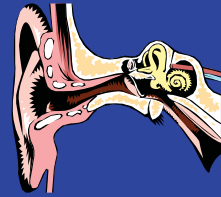
(J Pediatrics, Oct 2005)

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Alcohol Related Birth Defects (ARBD)

Chronic ear infections & Hearing loss

FAS affected children must
receive periodic hearing
tests



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Alcohol Related Birth Defects (ARBD)

- *Dento-facial*
 - *TMJ and malocclusion*
- *Immune system*
 - *An apparent relationship between alcohol exposure and a reduction in t-cells*

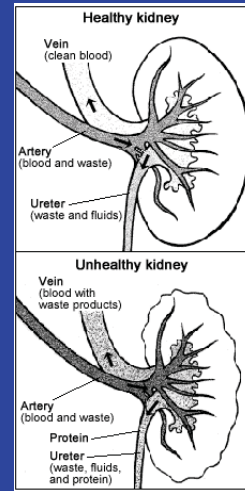


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Alcohol Related Birth Defects (ARBD)

Renal

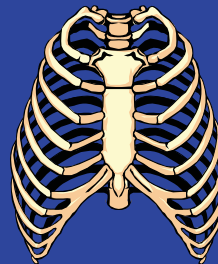
- Aplastic, dysplastic, hypoplastic kidneys
- Horseshoe kidneys
- Ureteral duplications
- Hydronephrosis



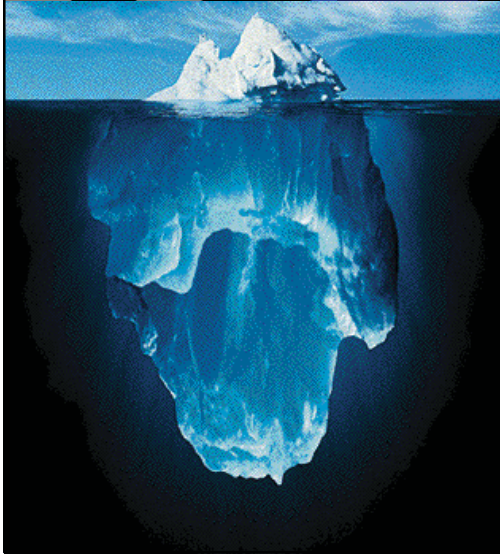
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Alcohol Related Birth Defects (ARBD)

Skeletal



FAS – Only The Tip Of The Iceberg



Fetal Alcohol Effect (FAE)
Alcohol Related
Neurodevelopment Disorder
(ARND)
Alcohol Related Birth Defects
(ARBD)
Fetal Alcohol Spectrum Disorder
(FASD)

Adapted from Streissguth 43

So, I Drank While Pregnant...

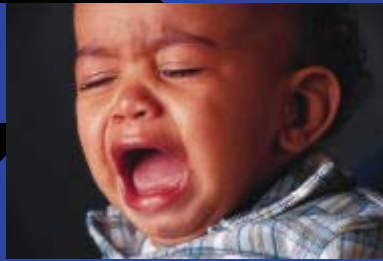
I had an Affected Baby...

Then What Happens?



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Signs/Symptoms of Withdrawal



Most infants with FAS/FAE exhibit

- Irritability
- Poor suck and feeding
- Don't sleep well
- Extra sensitive to sensory stimulation, and
- A strong startle reflex
 - Hyperextend their heads or limbs,
 - hypertonia or hypotonia, or both

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Socialization Issues



- Excessive body contact
 - (Don't understand personal space)
- Impulsiveness
- Intrusiveness
 - (Miss social cues for making/keeping friends)
- Lack of stranger anxiety
 - (Easily victimized/sexually abused)

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Disrupted Schooling

- **43% of teens affected by alcohol use in utero (FAS/FAE/FASD) are at risk of having schooling interrupted by**
 - Suspension
 - Expulsion, or
 - Dropping out



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Learning Problems

- **Problems with information processing...**
 - *Input—receiving signals from senses*
 - *Integration—interpreting the signals*
 - *Memory—storage of information*
 - *Output—translating the information to action*

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Fine Motor Skill Abnormalities

- ARND child called...
 - “Clumsy”
 - “Accident prone”
- Child has difficulty with hand-eye coordination
- Handwriting is frequently illegible!

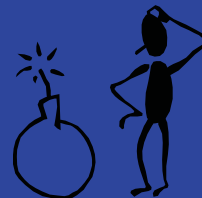


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Conduct Problems

“The girls get knocked up...
and the boys get locked up.”

- Lying/ Stealing/ Antisocial Behaviors
- Poor Judgment
- Inappropriate Sexuality
- Can't follow rules



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Inappropriate Sexual Behavior

Touching is a major issue...

- *Animals*
- *Phone calls*
- *Incest*
- *Public masturbation*
- *Voyeurism*
- *Compulsions*
- *Exposure*
- *Promiscuity*
- *Sexual touching*
- *Sexual advances*

Employment Problems

- *Holding a job*
- *Getting a job*
- *Being fired*
- *Losing job without explanation*



a supervised living environment
improves the employability of the
FAS adult.

Legal Problems Community Impact



- *FASD/FAS/FAE/ARND persons are very gullible... easily manipulated by others (especially criminals)*

- *Common crimes committed...*
 - *Crimes against property*
 - *Shoplifting*
 - *Theft*

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Legal Problems Community Impact



- *Common crimes committed...*
 - *Crimes against persons*
 - *Assault*
 - *Run away*
 - *Child molestation*

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Front of Card

MEDICAL INFORMATION FOR POLICE CARD

I have the birth defect Fetal Alcohol Syndrome/Fetal Alcohol Effects, which causes brain damage. If I need assistance, or if you need my cooperation, you should contact the person listed on the back of this card. Because of this birth defect, I do not understand abstract concepts like legal rights. I could be persuaded to admit to acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my Miranda rights. Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting with an attorney. I do not consent to any search of my person or property.

Back of Card:

For information or assistance regarding:

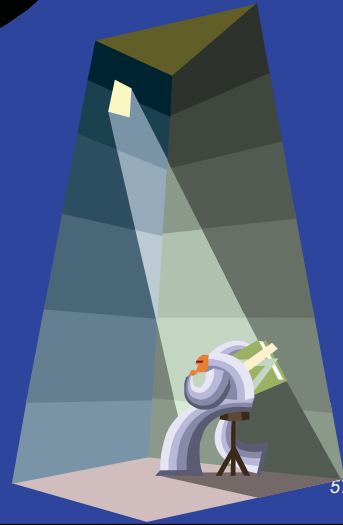
Please contact:

Doctor or diagnostician:

faslaw@u.washington.edu
<http://depts.washington.edu/fadu/legalissues/>

Confinement Community Implications

- *Mental health in-patient*
- *Substance abuse centers*
- *Jail*
- *Prison*



Common Differential Diagnoses

- *ADHD/ add*
- *Borderline personality disorder*
- *Conduct disorder*
- *Depression*
- *Learning disability*

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Common Differential Diagnoses

- *Receptive-Expressive Language Disorder*
 - *Problems with*
 - *Articulation*
 - *Stuttering*
 - *Interrupting*
 - *Understanding humor*

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Common Differential Diagnoses

- *Mental retardation*
- *Epilepsy*
- *Sleep disorder/ night terrors*
- *Dyslexia*

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Treatment/Management (Policy Implications)



- *Pregnant women receive priority in obtaining state and federally funded treatment slots*
- *Early intervention and special education services*
 - *Individuals with disabilities education act (idea)—birth through-two-year-olds, early intervention services for developmentally delayed children; Special education at 3+ years*

Birth Defects and Disabilities Can be Prevented

Risk Factor

Action

Thalidomide

Removal from market

Paralytic Polio

Polio Vaccine & Eradication

Congenital Rubella Syndrome

Rubella vaccine & Eradication

Lead

Lead Removal

Birth Defects and Disabilities Can be Prevented

Risk Factor

Action

Fetal Alcohol Syndrome

Abstain from Drinking while pregnant; Educate MD's and Allied Health Care Providers on Prevention and Recognition

Rh incompatibility

Rhogam

MR caused by Hib meningitis

Conjugated Hib vaccine

Spina Bifida

Folic Acid fortification & Supplementation

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Fetal Alcohol Spectrum Disorder may present to Clinicians or Educators...

- With the various problems of attention which greatly impact the daily lives of affected patients and their communities*
- Referrals for psycho-pharmacotherapy of the attention or other behavioral issues in FASD and other prenatal alcohol related disability*

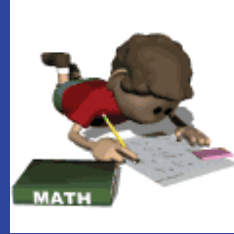


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Referral for Evaluation of...

Cognitive or Developmental Deficits or Discrepancies

- *Specific learning disabilities*
 - *Math*
 - *Visual-spatial deficits*
- *Uneven profile of cognitive skills*



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Recommendation for Evaluation of...

Cognitive or Developmental Deficits or Discrepancies

- *Poor academic achievement*
- *Discrepancy between verbal and nonverbal skills*
- *Slowed movements/reaction to people and stimuli (poor information processing)*



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Educators and Parents, Request Evaluation of...

Executive Functioning Deficits

- *Poor organization, planning or strategy use*
- *Concrete thinking*
- *Lack of inhibition*
- *Difficulty relating cause and effect*
- *Inability to delay gratification*

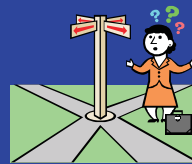


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Educators and Parents Please request Evaluation of...

Executive Functioning Deficits

- *Perseveration (Difficulty changing strategies or rethinking things)*
- *Poor judgment*
- *Inability to apply knowledge to new situations*



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Providers Please Provide Evaluation of...

Motor Functioning Delays

- *Delayed motor milestones*
- *Difficulty with writing or drawing*
- *Clumsiness*
- *Balance problems*
- *Tremors, poor dexterity*
- *Poor suck in an infant*



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Strongly Recommend Beyond Minimal Evaluation of...

Attention Issues or Hyperactivity

- *Parents or teachers c/o “busy” child*
 - *Inattentiveness*
 - *Easy distractibility*
 - *Difficulty calming down*
 - *Hyper-active*
 - *Can’t complete tasks*
 - *Difficulty with transitioning*
- *Parents c/o “on” and “off” days of child*

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Red Flags—consider FASD

Social Skill Deficiencies

- *No stranger fear*
- *Naiveté and gullibility*
- *Immaturity...preferring younger friends*
- *Clinically significant inappropriate interactions and initiations with others*
- *Adaptive skills significantly below cognitive potential*

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Clinicians and Parents, Please Recognize and Evaluate...

Other significant issues/limitations

Sensory problems

Tactile defensiveness

Upset by bright lights or loud noises

Annoyed by tags in shirts or seams in socks

Oral sensitivity

Bothered by certain textures of food

Pragmatic language problems

Difficulty reading facial expressions

Inability to understand others perspectives on issues

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Seek Clinical Evaluation of...

Other significant issues/limitations

Memory deficits

- *Forgetting well learned information*
- *Multiple trials to achieve memory*

*Inability to relate cause and effect
(discipline issues with parents/police)*

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Policy Opportunities for Intervention

Improve the screening of women to identify those with alcohol usage of concern

- *Refer for treatment*
- *Provide reproductive counseling and provide contraceptive services to women who are substance abusers*



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So, How to use knowledge of FASD?

- Advocate for, and facilitate women of childbearing age getting the message not to drink...
- Insist that if a woman drinks while pregnant, she acknowledges it, and is directed to and accepts help...



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Selective Prevention: Examples of Media Materials Targeting Diverse Groups

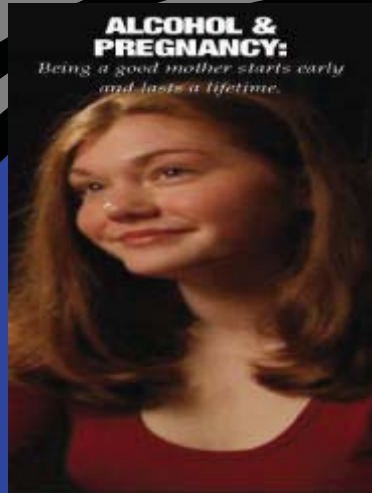


Los Angeles
County, California

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Selective Prevention

Iowa



St. Louis,
Missouri

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Community Impact ...Policy

- *Ensure that the woman using ETOH while pregnant is handled in a culturally sensitive, non-judgmental manner by health care professionals*
- *Mother is not stigmatized and outcast, but assisted in the care and raising of her special child*
- *That if a child is adversely affected by alcohol in utero...they are identified early*

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Policy Issues...

- *Child affected by ETOH in the womb gets into early intervention programs*
- *Educational system works optimally with parent(s) and child throughout childhood*
- *Child's potential is maximized/ reached*
- *Community develops understanding, and a village approach to care of the child/impacted adult*

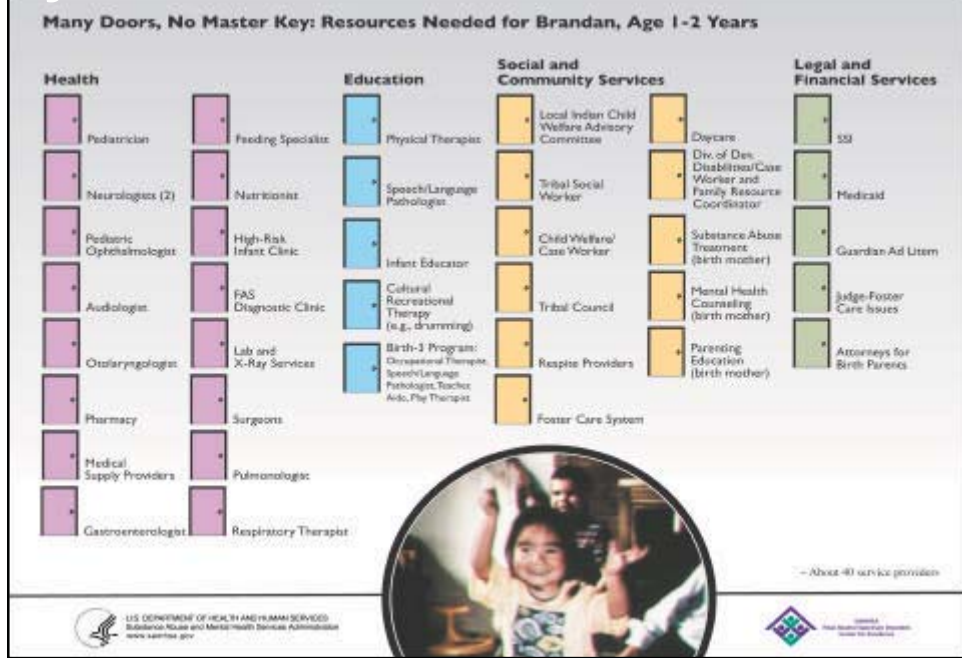
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Community Considerations for Persons with FASD

- *Legal system/ police departments become familiar with the issues of FASD*
- *Affected individuals not taken advantage of by others*
- *Employment opportunities are developed in communities to assist mainstreaming of these disabled individuals*

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Systems of Care-Potential Resources



Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Sensory Integration Issues

- Simplify the individual's environment.
- Provide a lot of one-to-one physical presence.
- Take steps to avoid sensory triggers.



SAMHSA⁸²

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Memory Problems

- Provide one direction or rule at a time and review rules regularly.
- Use a lot of repetition.



SAMHSA

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Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Information Processing Problems

- Check for understanding.
- Use literal language.
- Teach the use of calculators and computers.
- Look for misinterpretations of words or actions and discuss them when they occur.

Tell me what you just heard me say.



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SAMHSA

Strategies To Improve Outcomes for Individuals With an FASD

Strategies for Executive Function Deficits

- Use short-term consequences specifically related to the behavior.
- Establish achievable goals.
- Provide skills training and use a lot of role playing.



Photo property of SAMHSA.

Resources

- Southeastern United States Center for the Prevention of Fetal Alcohol Syndrome (Morehouse, Meharry, Tennessee State University) www.sefasrtc.org
- SAMHSA FASD Center for Excellence: fasdcenter.samhsa.gov
- Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncebd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- National Clearinghouse for Alcohol and Drug Information: ncadi.samhsa.gov
- These sites link to many other Web sites.

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Website Intervention

about FAS | research | advocacy | resources in southeast | event calendar | links | about us

Southeast Fetal Alcohol Syndrome Regional Training Center

11th Annual Maternal and Child Health Epidemiology Conference
December 7-9, 2005 Wyndham Hotel
 Miami, Florida
[Event Details](#)

Article Alert:
Jailing Women who used drug sparks a debate
[Read More](#)

Fact: 58.8% of women age 15-44 drink while pregnant

tools and templates

continuing education

Publications
 Articles
 Photo Gallery
 Research Studies

FAS Training Centers
 Participating Schools
 Background
 Our Team

translating research into practice

Welcome to the Southeast Fetal Alcohol Syndrome Regional Training Center

Medical and Allied Health Providers

This site is designed by you and for you! Use this site as a resource to aid you in understanding and preventing Fetal Alcohol Syndrome. We have made great efforts in gathering resources, links, articles, and information that will be valuable in conducting your job. Our aim is to "translate research into practice. Please feel free to contact us with questions or concerns.

Dr. Yvonne Gray Johnson

Tip of the Week

Mental impairments consistent with FAS, but without facial anomalies or growth deficiencies include: Low IQ, Learning Deficits, Behavior Problems

Email Signup:

Stay informed about upcoming Medical and Allied Health Providers news and events!

Email

<http://www.sefasrtc.org/main.asp>

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Meharry Medical College | Morehouse School of Medicine
 National Center for Primary Care

West Basic Sciences Building

TENNESSEE STATE UNIVERSITY
 Two Campuses. One University.

Fetal Alcohol Syndrome Regional Training Centers
(funded by the Centers for Disease Control)

Saint Louis University
 School of Health Professions

DAVID GEFEN SCHOOL OF MEDICINE
 UCLA

UNIVERSITY OF MEDICINE & DENTISTRY OF NEW JERSEY
 UMDNJ

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Common Community and Clinician Questions

What if I only drink a little while pregnant?

I don't drink the hard stuff...
is that okay?



Will I be okay if I stop the last few months.



Beer doesn't count, does it?

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Maternal Take Home Message "Keep It Simple"



- Drinking alcohol during pregnancy will damage the child...
- There is *no safe level of alcohol consumption during pregnancy...*
- Fetal Alcohol Syndrome is 100% preventable!



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Fetal Alcohol Syndrome is 100% preventable!

- *An alcoholic father does not make a FAS baby (unless mom drinks too)*
- *A mom with FAS does not a FAS baby make (unless mom drinks while pregnant)*

DON'T ASK MY CHILD TO FLY

Don't ask my child to fly,
for he has not wings.
Don't ask my child to see the glint on the eagle's beak,
for his vision has been diminished.
Don't ask my child to remain calm amid the din,
for her ability to screen out the noises has been taken away.
Don't ask my child to be careful with "strangers",
for he is affectionate with everyone and prey for the unscrupulous.
Don't ask my child to "settle down",
for the clock which works for you and I, does not exist for her.
Don't ask my child to not play with the toys of others,
for he has no concept of property.
Don't ask my child to remember you tomorrow,
although you met today.
Don't ask my child to heal your wounds,
for her hands cannot hold a scalpel or sutures.
Don't ask my child to meet the challenges set by society,
for you have denied her the tools.
Don't ask my child to forgive you for standing idly by,
while he was being tortured in his mother's womb,
for he will,

but He may not.

Bruce Ritchie 1997



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Thanks!

Questions, Comments, or Concerns?

Keep your babies happy. Keep your babies healthy.

Think Before You Drink.