

# FASD Update

Building FASD State Systems Conference  
Nashville TN  
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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
[www.samhsa.gov](http://www.samhsa.gov)



SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence



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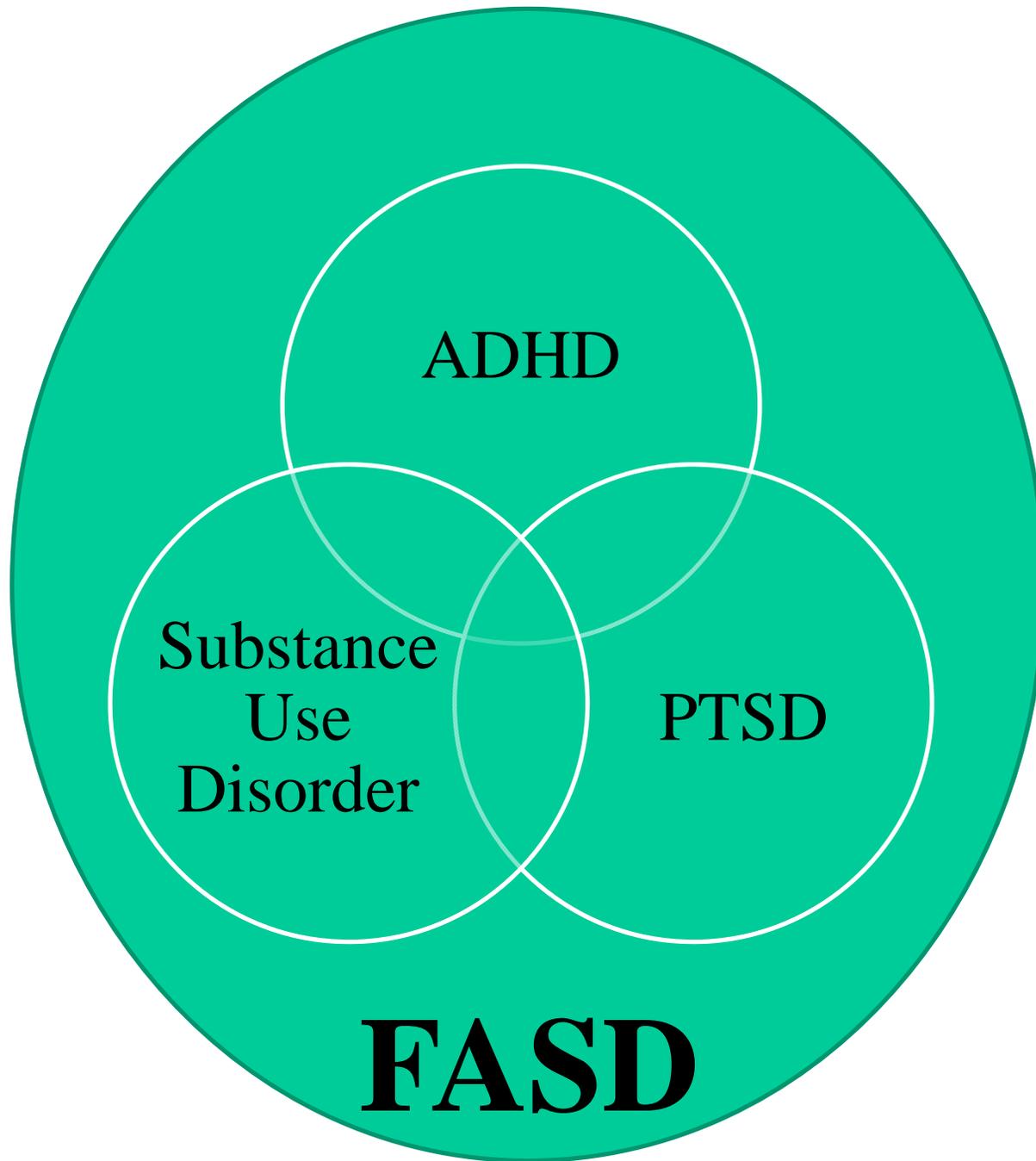
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ADHD

Substance  
Use  
Disorder

PTSD

**FASD**

# Diagnostic Update on Facial Features

(Clarren, Chudley, et al 2010)

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- Normal palpebral fissure lengths
  - › Grow with age until about 16 years old
  - › Boys' are slightly larger than girls'
  - › Should be stable in adults
  - › Blacks and South Asians > Caucasians and First Nations > Asians and Southeast Asians
  - › All are within 1 mm or each other and can be placed on the same graphs

\* Canadian J of Clinical Pharmacology Vol 17, 67-78, 2010

# Brain Research

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- Some brain changes due to prenatal alcohol exposure are extreme
- Brain changes are often microscopic
  - › Typical CAT Scans and MRIs will not pick them up
  - › Many people with this level of brain damage might well have “normal” MRIs
  - › Research magnetic resonance imaging techniques such as fMRI and MRS are better able to pick up these changes
- New research shows the trigeminal nerve is smaller in mice with prenatal exposure
  - › Responsible for sensory facial responses
  - › May explain poor sucking reflex



# Diagnostic Capacity

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- There is a crisis in the lack of diagnostic capacity
- In Canada, about 15000 people have been diagnosed with an FASD since 1980 out of an estimated 332,000 people living with an FASD
- U.S. statistics are not as easy to gather
- Diagnostic capacity for ARND and pFAS lag behind capacity for diagnosing FAS
- Diagnostic capacity for adults is woefully lacking
- Perhaps a triage model needs to be established

# MRI, MRS, and fMRI Study Findings

## Susan Astley (2009)

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- Study conducted at the University of Washington
- Frontal lobes were found to be disproportionately smaller in those with the facial features of FAS
- The caudate was significantly smaller even in those without the facial features of FAS
- MRIs previously done were mostly read as normal
- Even those with mild ARND had structural brain damage by scan
  - › We need to determine whether these structural differences have functional consequences with population based norms

# MRI, MRS, and fMRI Study Findings

## Susan Astley (2009)

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- Those with prenatal alcohol effects scored similarly to controls on a one-back test (does this picture match the last one you saw)
- Those with prenatal alcohol exposure scored significantly poorer on the two-back test (does the picture match one that you say two back)
  - › The level of activation in the Dorsolateral Prefrontal Cortex is significantly less in those with an FASD
  - › This is a measure of working memory

# Stress and Anxiety

Joanne Weinberg (2010)

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- Two systems mediate the stress response
  - › Sympathetic nervous system (fight or flight)
  - › Hypothalamic-Pituitary-Adrenal axis (HPA)
- The neurobiology of the stress system plays a role in vulnerabilities to mental health disorders
- In the late 1990s, S Jacobson did a study with 13 month olds that demonstrated that those who were prenatally exposed to alcohol showed an overreaction to a heel stick
  - › Infants exposed prenatally to cigarettes or cocaine did not have this response

# Recent Animal Studies on Stress and Anxiety

Joanne Weinberg (2010)

- Studies examine how prenatal alcohol exposure and other early nutritional or environmental insults affect neurobiological systems in an animal model and implications for intervention
- Liquid diet with alcohol at about twice the level of drunk driving (but not extremely high) were given
- Alcohol changed the endocrine system
  - › Altered hormonal, immune, and behavioral function
  - › Special focus on stress



# Recent Animal Studies on Stress and Anxiety

Joanne Weinberg (2010)

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- Initial findings include:
  - › Maternal alcohol consumption increases HPA (hypothalamic-pituitary-adrenal) activity and alters HPA regulation in the mother and the offspring
  - › HPA releases cortisol from the adrenal glands, which causes a cascade of hormonal responses that have metabolic effects on the body
  - › Alcohol exposure causes an increase in HPA activity and alters HPA regulation
    - Greater activity under minor stressors
    - Increased time to readjust after stress



# Possible Protective Factors

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- Animal research on choline as a possible protective factor
- In pregnant mice who have been given ethanol, choline appears to mitigate the effects of the ethanol
- Early animal studies are showing that 2 peptides are able to mitigate the effects of prenatal alcohol exposure on mouse offspring
- Women who drink in a study in the Ukraine have low levels of copper and zinc
- Anecdotal reports point to exercise helping improve some of the disabilities associated with prenatal alcohol exposure

# Possible Protective Factors

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- Research on exercise
  - › Exercise can increase neuronal plasticity
  - › Exercise can improve functioning of the hippocampus
  - › Exercise can improve learning in children prenatally exposed to alcohol
- Enriched environments can increase neuronal plasticity
- Studies have shown that people who play the keyboard or juggle before the age of 7 develop larger corpus callosums
  - › Anything that utilizes bimanual coordination may help

# Possible Protective Factors

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- This *does not* mean that a woman can drink and take choline and have a healthy baby
- This *does* mean that women who drink during pregnancy need to get good prenatal care and take their prenatal vitamins
  - › Ensure that levels of vitamins and minerals are normal
  - › As long as stigma remains, women who are drinking during pregnancy are less likely to seek prenatal care



# Issues in Diagnosing an FASD

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- No consensus in diagnostic terms
  - › We are getting closer
- No consensus in diagnostic criteria
  - › We are getting closer
- Lack of diagnostic capacity
  - › Especially for diagnosing those without full FAS and adults
- Some physicians still feel there is no reason to diagnose because there is nothing that can be done
  - › Not true



# Adult Diagnosis

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- Recent research by Dr. Sterling Clarren and Dr. Albert Chudley found that palpebral fissures are set by age 16
- The first adult diagnostic team was formed at the Lakeland Centre for FASD in Alberta Canada in 2002
  - › One adult seen per month with a waiting list
- Increased diagnostic capacity for adults is necessary
- Even if no adults were diagnosed, the children diagnosed in the 1970s and 1980s are now adults

# Importance of Preventing FASD: Facts to Consider

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- FASD is one of the few birth defects that is 100% preventable
- There is no known safe amount of alcohol to use during pregnancy
- There is no known safe time to drink during pregnancy
- Most women do not know when they become pregnant
- The only proven safe amount of alcohol to drink during pregnancy is **none**
- Fetal alcohol spectrum disorders can occur in any community where women drink

# Lessons from the Field: Center Subcontracts 2008-2012

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- The Center is funding 15 State and local organizations to integrate evidence-based FASD prevention practices into existing systems of care
  - › Nine community subcontracts
  - › Six State subcontracts
- Subcontractors are utilizing one of three prevention approaches
  - › Screening and brief intervention
  - › Project Choices (adapted)
  - › Parent Child Assistance Program (PCAP)

# Screening and Brief Intervention

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- Addresses consequences of drinking during pregnancy and benefits of stopping
- Reviews risky drinking situations and coping strategies
- Asks for a commitment to not drink in the next month
- For those not willing to stop drinking, discusses cutting down



# Screening and Brief Intervention Program Developed at UCLA

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- Mary O'Connor and Shannon Whaley
- Randomized clinical trial of current drinkers (N=345) in WIC clinics in Southern California
- At 36 weeks of pregnancy, control group 5 times more likely to be drinking than intervention group
  - › Assessment only control: 8.7% drinking
  - › Brief intervention: 1.7% drinking
- 24 of 369 (6.5%) referred to alcohol treatment program



# Project CHOICES

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- CDC intervention study for non-pregnant women
  - › Phase 1 clinical trial initiated in 1997
  - › Randomized controlled trial of motivational intervention underway
- Dual intervention focusing on alcohol-use reduction and effective contraception for women of childbearing age at high risk for an AEP
- Maximum of 4 motivational counseling sessions and one visit to a family planning provider



# Parent-Child Assistance Program (PCAP)

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- 36 month paraprofessional home visitation model targeted to high-risk women who abuse substances
- Goals:
  - › Assist mothers in obtaining treatment, maintaining recovery, and resolving problems associated with substance abuse
  - › Guarantee that children are in a safe environment and receive appropriate health care
  - › Link families with community resources
  - › Demonstrate successful strategies for preventing future births of alcohol- and drug-affected children
- Average caseload of 10-15
- Cost averages \$5000-\$6000 per woman per year

# Parent-Child Assistance Program (PCAP)

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- Intake questions used by PCAP to determine possible prenatal alcohol exposure:
  - › Did your mother ever have a problem with alcohol?
  - › Did she drink alcohol when you were young?
  - › Did she drink alcohol when she was pregnant with you?
  - › Is your birth mother alive?
  - › Were you raised by someone other than your birth mother?



# State of the Art Prevention in FASD

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- Screening all women at risk for alcohol use
  - › Ask specifically about alcohol use
    - Especially examine further if other drug use
  - › Imbed questions in general health screening
  - › Ask questions in a manner that promotes honest responses
  - › Ask open-ended questions and ask repeatedly
  - › Be careful about how questions are asked
    - Be sure they are literal
- Include questions about prenatal alcohol exposure in all assessments in substance abuse and mental health treatment

# FASD and Sexually Transmitted Infections

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- People with an FASD are at risk for HIV and sexually transmitted infections
  - › Difficulty avoiding dangerous situations
  - › Difficulty negotiating safe sex
  - › Difficulty remembering to use safe sex techniques
- For people with an FASD, the approach to prevention of HIV and sexually transmitted infections must be different
  - › Literal
  - › Repeated
  - › Role playing of situations the person might find him or herself in

# FASD and Sexually Transmitted Infections

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- For people with a co-occurring FASD and a sexually transmitted infection or HIV, treatment approaches need to be altered
  - › Treatment needs to be broken down to one step at a time
  - › Medication schedules need to be simplified
  - › Direct one-to-one support needs to be provided to attend appointments and follow treatment regimen
  - › Discussions about the importance of treatment and issues regarding re-infection need to be repeated
    - Always check for true understanding

# Importance of Recognizing an FASD for Successful Intervention

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- Women with an FASD are often not diagnosed
  - › PCAP identified 131 women who were heavily prenatally exposed to alcohol
  - › Only 15 of those women had a diagnosis of an FASD
- Women with an FASD need more intensive services
- Women with an FASD are at high risk for suicide
  - › 44% of mothers who were prenatally exposed to alcohol had suicide attempts
  - › 33% of mothers who were not prenatally exposed to alcohol had suicide attempts
  - › 5% of the U.S. population has had suicide attempts

# Importance of Recognizing an FASD for Reducing Suicide Risk

T Grant, J Huggins (2009)

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- Recognize increased risk of suicide in individuals with an FASD
- Suicide assessment and intervention protocols need to be modified for those with an FASD taking into account cognitive differences and communication impairments
  - › Don't use suicide contracts due to impulsivity issue
  - › Check for possible disconnect between lethality of method and intent to die
  - › Obtain input from family and others

# Importance of Recognizing an FASD for Reducing Suicide Risk

T Grant, J Huggins (2009)

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- To lower suicide risk
  - › Address basic needs and increase stability
  - › Teach distraction techniques
  - › Remove access to lethal means
  - › Increase social supports
  - › Treat depression
  - › Build reasons for living
  - › Monitor closely
  - › Strengthen positive relationships



# Issues to Keep in Mind

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- FASD is not a diagnosis
  - › No one can be diagnosed with FASD
- When referring to alcohol use, it is important to say “alcohol and other drugs”
  - › We need to clarify that alcohol is a drug of abuse
  - › We should refer to “alcohol use” rather than “drinking alcohol”
- It is essential to use person first language
  - › No one is FAS or FASD
  - › We need to model person first language for others
- We need to utilize a true strengths based approach to FASD



# A Strengths Based Approach to FASD

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- Faith
  - Ability
  - Strength
  - Determination
- > Developed by young people with FASD at 2010 Vancouver FASD conference