Workshop

F5: Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder: The Invisible Disability

FAS/FASD PowerPoint Handout

Presenters

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Objectives

1. To provide a general overview on the following topics:
   - FASD definitions
   - Historical and epidemiological information as it relates to prenatal alcohol exposure
   - FAS Diagnosis
   - Prevalence of FASD
   - Screening of women and alcohol consumption
   - Brain damage associated with prenatal alcohol
   - Case study (Fred)
   - Developmental disabilities
   - Help for individuals with FASD

7. But he said to me, ‘You will become pregnant and have a son. Now then, drink no wine or other fermented drink,...

   Judges 13: 7
Terms – Acronyms

- Fetal Alcohol Spectrum Disorders (FASD) is a descriptive term used for the broad spectrum of disorders caused by prenatal exposure to alcohol including:
  - FAS (Fetal Alcohol Syndrome)
  - PFAS (Partial FAS)
  - FAE (Fetal Alcohol Effects)
  - ARND (Alcohol Related Neuro-developmental Disorders)
  - ARBD (Alcohol Related Birth Defects)
  - ND-PAE (Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure) DSM-V

Fetal Alcohol Spectrum Disorders and Fetal Alcohol Syndrome

Modern concept of FAS was first identified in 1968 by the French (Lemoine et al)

The term FAS was coined by Smith and Jones in the U.S. in 1973 to describe a constellation of characteristics noted in children examined by Dr. Ulleland
FAS Diagnostic Criteria

- Growth Restriction:
  Babies are born smaller than anticipated for the gestational age at birth, and usually remain so throughout life.

- Central Nervous System:
  Any or all of the following conditions may be present—intellectual disabilities, developmental delays, short attention span, impulsivity, perceptual problems, hyperactivity, poor coordination & learning disabilities.

- Facial Anomalies:
  Babies have the following distinctive facial features—small widely spaced eyes; a short, upturned nose; a smooth philtrum (no notch between the nose and lips); abnormally thin upper lip; and small flat cheeks.

What is a teratogen?

- any substance, agent, or process that interferes with normal prenatal development, causing the formation of one or more developmental abnormalities in the fetus.... Among the known teratogens are chemical agents, including such drugs as thalidomide, alkylating agents, and alcohol; infectious agents, especially the rubella virus; .......
Thalidomide is a Teratogen

Alcohol Myths and Facts
• Less than one drink/day when pregnant is OK (no safe time);
• Beer and wine are not alcohol (no safe alcohol);
• FAS/FASD is curable (it is a lifelong disability)
• Alcohol, esp wine, is good for you (you would need to drink 20-30 glasses for the antioxidants to be effective)

What does the Woman at Risk Look Like? Observe your own reactions
FAEEs in meconium as a screening tool for fetal alcohol exposure

Which substances affect women and their fetuses the most?

- Alcohol
- Tobacco
- Heroin/Methadone/Buprenorphine
- Cocaine/crack
- Marijuana-THC
- Prescription Abuse
- OTC Drugs
- Inhalants/Hallucinogens
- Internet Pharmaceuticals
- Methamphetamine

Alcohol Crosses the Placenta

- Alcohol passes freely from the mother to the fetus
- The fetal liver cannot metabolize alcohol efficiently
- Blood alcohol levels are equivalent between the woman and fetus by 1 hr. (Cohen-Kareem, 2002)
- Alcohol levels in amniotic fluid are lower but persist for longer (Burd, L. 2007)
Maternal Risk Factors (May 2011)

- Dosage (blood alcohol level)
- Pattern of drinking (1/4 Americans binge drink [SAMHSA, 2011])
- Timing during the gestation (all three trimesters)
- Advanced Age (older women [30+] more likely to drink more, and the fetus is more at risk for an FASD [Chiodo, 2010])
- Genetic sensitivity and epigenetic factors
- Maternal metabolism/Nutrition/Parity
- Active teratogenic metabolites
- Synergy with other agents (environmental/other drugs)
- Mental health issues and supports

Fetal Development Chart

Brain Regions Affected by Alcohol
Corpus Callosum

- Prenatal exposure can cause thinning of or malformation (sometimes absence of)
- Damage has been linked to deficits in attention, intellectual functioning, reading, learning, verbal memory, executive function and psychosocial functioning.

A. Magnetic resonance imaging showing the side view of a 14-year-old control subject with a normal corpus callosum; B. 12-year-old with FAS and a thin corpus callosum; C. 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.


FASD demographics and statistics (general population)

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The data and analysis for this slide was provided by Dr Alla Gordina of GlobalPediatrics.net and is used here with express permission.
**FASD demographics and statistics**  
*(special populations)*

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**Prevalence**

- Experts estimate that an FASD occurs in at least 1 in 100 live births (1% of all births).

**Defining the Standard Drink**

Alcohol Consumption Among Women (CDC)

- 1 in 8 women 18 yrs and older and 1 in 5 high school girls binge drink. Women who binge do so frequently-about 3 times a month and have about 6 drinks per binge(CDC Vital Signs, 1/2013);
- 45% of women reported consuming alcohol in the three months before finding out they were pregnant;
- 2/3 of women do not learn they are pregnant until the 4th-6th week of gestation;
- Woman more likely to drink if: hx of trauma, Major Depressive Disorder or PTSD, heavy drinking by male partner, poly-drug/cigarette smoker
- CDC encourages a pre-conceptual approach to alcohol screening (CHOICES, 2011)

Screening for alcohol use among women of childbearing age

- All women of childbearing age should be screened
- Levels of use for non-pregnant women: 7 or less per week; 3 or less on any one occasion (more than 3 is a binge); no drinking when pregnant, breast feeding, taking medication that may interact with alcohol

Clinical Implications of Impairments for Individuals with FAS/FASD

- Impulsivity and poor self-regulation, which decreases tolerance for frustration, and makes them quick to anger
- Poor habituation which results in drowning in stimulation, emotional overload, shutting down and behaving irrationally
- Perseveration which leads to doing the same thing over and over again
Clinical Implications of Impairments for Individuals with FAS/FASD (cont)

- Poor judgment which leads to trusting anybody and behaving irrationally
- Difficulty with self reflection which leads to not being able to express ones’ needs and not getting help

**FRED part 1**

- Fred is 7 yrs old, foster placement, traumatic abuse
- Diagnoses: Failure to thrive, PTSD, ADD, Serious Emotional Disturbance, ODD, LD IQ=75
- Described as: explosive, controlling, avoidant, resistant, socially inappropriate, easily frustrated

**INTERVENTIONS (Fred’s)**

- Classroom aide
- Individual Therapy
- Behavioral class room placement
- Medications
- Verbal warnings
- Timeouts
- Isolation

Nevertheless he had daily melt-downs, temper tantrum & application of 4 pt restraints
THE TEAM TOOK ANOTHER LOOK

- Fred has a known history of prenatal alcohol exposure
- A multidisciplinary Neuro-Developmental Assessment

FASD is a brain-based physical disability with behavioral symptoms.

WHAT DOES THIS MEAN

- Brain functions:
  - Fred’s brain is wired differently
  - Typical brain functions are invisible
  - Your normal brain
    - Listening, decoding, formulating arguments, managing your emotions, comparing what you are hearing with what you know, wondering where all this is going, thinking about what your going to have for supper.
  - We proceed on the basis of pre-verbal assumptions that “others’ brains work like our brains.”

WHAT TO LOOK FOR

**Primary Characteristics**

Accumulated diagnoses could indicate that a brain dysfunction has not been considered

- Primary Characteristics:
  - Dysmaturity: functioning @ half of chronological age
  - Sensory processing: easily overwhelmed, lights, noise
  - Language: hears every third word
  - Memory storage and retrieval
  - Executive functioning: planning, abstract thinking
Common Disorders Identified with FASD

- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder (ADHD)
- Borderline Personality Disorder
- Conduct Disorder
- Anxiety
- Reactive Attachment Disorder
- Depression
- Learning Disability
- Oppositional-Defiant Disorder
- Post Traumatic Stress Disorder (PTSD)
- Receptive-Expressive Language Disorder
- Eating Disorders

SECONDARY BEHAVIORS

1. Fatigue
2. Anxiety, low self esteem, social isolation, self destructive behaviors
3. Avoidance, frustration, anger
4. Aggression, destructiveness
5. Depression, suicidal thinking or actions
6. Feeling overwhelmed

TERTIARY PROBLEMS

1. Trouble in school, suspensions, dropping out
2. Mental health problems
3. Arrests
4. Alcohol and drug involvement
5. Trouble at home
6. Social services involvement
**WHAT CAN WE DO?**

Neuro-Behavioral Model (N-B) Informed Interventions

–Explores problems & solutions by linking brain function & dysfunction with Behavioral Symptoms

From superficial Symptoms to underlining causation

From trying to change a person to providing accommodations

From punishing weakness to building on strengths

From Immaturity to Dysmaturity

From fighting to ending the downward spiral

Brain trumps behavior

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**10 Strategies**

1. Prepare them for transitions
2. Chunking their work
3. Frequent movement breaks
4. Scribing, using computers to write
5. Activity based learning
6. Resistance work
7. Gum
8. Activity before and in-between classes
9. Adjust expectations
10. Repeat. repeat, repeat ......

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Punishment does not cure
Neurological Damage

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*Trying Differently: Rethinking Juvenile Justice Using a Neuro-Behavioral Model*

By Diane Malbin, David Boulding, and Susan Brooks – July 2010
Secondary Disabilities Resulting from the Primary Disabilities of Individuals with FAS/FASD

- 60% have trouble with the law
- 50% will be confined in prison, mental institutions and/or treatment centers
- 35% have alcohol and/or drug problems
- 61% have disrupted school experience
- 49% exhibit inappropriate sexual behavior
- Other: joblessness, homelessness, inability to demonstrate effective caretaking and parenting, and increase potential for victimization, need for lifelong supervision
- Odds of escaping secondary disabilities are increased 2-4 fold with a DX before age 12

Streissguth 2004

Fred (part 2)

- Significant Dysmaturity: 7 yr old functioning like a 3 yr old
  - Instead of punishment - adjust expectations
- Memory problems
  - Repeat, repeat, repeat.
- Slow auditory processing
  - Slow down – fewer words, simple instructions
- Rigidity & perseveration – poor transitions
  - Fewer task – less frustrations
- Sensory integration dysfunction
  - Instead of insisting he sit still – give him breaks & opportunity to move

Rethink program, write age appropriate goals to reflect his developmental age. Identify and teach to his strengths.

Fred’s temper tantrums and 4 pt restraints ended within a week

Universal Protective Factors

- Early diagnosis
- Stable, nurturing home environment
- Good attachment, bonding with a caring adult
- No violence/victimization
- Early Intervention services
- DDD services

Streissguth, 2004
Reconceptualizing the Behavior of the Individual with FASD

Professionals, family members, and caretakers need to re-conceptualize how we view the behavior of an individual with FAS/FASD (D. Malbin, fascetsofg.org)

From seeing: → To understanding:

✓ Won’t → Can’t
✓ Lazy → Tries hard
✓ Lies → Fills in
✓ Doesn’t try → Exhausted or can’t start
✓ Doesn’t care → Can’t show feelings
✓ Refuses to sit still → Over stimulated
✓ Fussy, demanding → Oversensitive
✓ Resisting → Doesn’t “get it”

Common Positive Characteristics of Individuals with FASD

✓ Many individuals with FASD are:

✓ Caring, kind, loyal, nurturing and compassionate
✓ Trusting, loving, determined, committed and persistent
✓ Curious, involved, fair and cooperative
✓ Energetic, hard working and athletic
✓ Artistic, musical and creatively intelligent

Treatment Across The Lifespan

✓ Unique challenges at each age
✓ Increase supervision as the child matures
✓ Proactive preparation for adulthood
✓ Plan for possible need of supervised living and employment (60-70% need some type of supervision)
✓ Proactive mental health services
✓ Family support and care
In NH very few children are identified as having been exposed prenatally to alcohol. Therefore very few children are identified as having FAS/FASD. Most of these children have another diagnosis ADHD, ODD, CD, Depression, Autism etc... and are treated for these conditions. Often the system fails these children because treating a child with an FAS/FASD as if the child had ADHD does not work. So, what can we do?

• Prevention is obvious, right?
• Child protection can screen for prenatal exposure to alcohol.
• Once behaviors are identified, use our knowledge of the exposure to ask for the right interventions.
• Educate people, especially potential mothers about this issue.

Final thoughts

Be good to me...
Stay alcohol free!

A few drinks can Last forever
No safe time. No safe amount. No safe alcohol. Period....

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References

• http://depts.washington.edu/fasdpn
• www.nofas
• www.cdc.gov
• www.fasdcenter/samhsa.gov
• www.fascets.org
• www.womenandalcohol.org
• CDC Vital Signs: Binge Drinking, Jan/2013

• Our thanks to the Texas OPDD and the FASD Center for use of some of their slides
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