Fetal Alcohol Spectrum Disorders

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Who we are

AND WHY WE'RE HERE TODAY
TALKING ABOUT THIS

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Institute of Medicine report to Congress 1996

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

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Prevalence of Fetal Alcohol Spectrum Disorders

The CDC says "…up to one out of 20"; 5% is becoming commonly accepted. Conservative though:

However, FASD is estimated in 6.7% of U.S. schoolchildren in the May 2018 Journal of the American Medical Association.

This is the figure the author, Philip May, believes is more accurate, although still conservative, as children in care were not allowed to be included in these studies.

JAMA. 2018;319(5):474-482.

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Prevalence in Foster/Kinship Care

"A child with an FASD is 17 to 19 times more likely to be in child welfare than a child without an FASD."

Petrenko et al, 2019

Fetal Alcohol Syndrome found 10-15x as common in foster care as in the general population. Logical extrapolation to FASD.

Astley et al 2002

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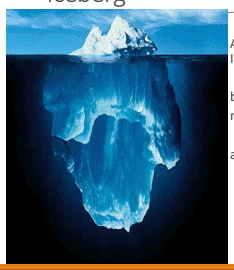
FAS-only the tip of the prenatal alcohol exposure Iceberg



Around 90% of people with FASD appear totally normal and have IQs in the normal range

but have a range of lifelong neurobehavioral challenges

and are rarely accurately diagnosed.
(except in LA County thanks to VIP!)

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What makes FASD so slippery?

- NOT a cookie-cutter presentation: Range from severe impairment—low IQ, explosive rages, obvious disabilities to high functioning (ARND = 3 areas 3rd %ile, but IQ can be high and all appearance normal)
- Wide variation in ability within one person
- Each person with FASD is different
- Change in functionality from day to day with little explanation
- Appearance of normalcy
- Most of the resulting behaviors look deliberate, or like bad parenting, or li like a mental health issue.

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Neurodevelopmental domains

- Executive functioning
- Broad range of cognitive functions
- Relational patterns
- Emotions
- Communication
- Sensory-Motor, Sensory Integration
- "Morals"

"…behavioral manifestations of a physical condition" D. Malbin

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Executive Function Impairment

- Problems with forethought, planning, sequencing
- Difficulty applying knowledge to daily skills
- Judgment
- Impulse control
- Poor organizational skills
- Lack of future orientation, inability to delay gratification
- Attention/concentration
- Cause and effect

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Cognitive

- Widely varying abilities
- Splinter skills
- Global deficits in intellect
- Learning problems
- Memory
- Reasoning and judgment impairments—"common sense retardation"
- Slow

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Relational Impact

- Poor ability to read social cues
- Lack of empathy
- Externalize blame
- Excessive demand for attention
- Inflexible/rigid/perseverative thinking
- Difficulty understanding consequences
- Lack of self awareness, reflection

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Emotional

- Little ability to recognize feelings in self or others
- Little ability to articulate feelings
- Sense of urgency and intensity
- Meltdowns frequent, over small things
- Anxiety
- Labile mood
- Low self-esteem

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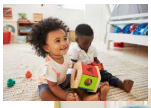
Speech/Language

- General delay in communication skills
- Much better talker than listener
- Superficial fluency
- Difficulty taking turns in conversation
- Often cannot connect with own real feelings or thoughts
- Slow processing speed!!!



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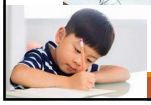
Sensory Motor Dysfunction



- Fine and gross motor function impaired (more often fine, poor hand-eye coordination)
- Often described as "clumsy" or "uncoordinated"
- Handwriting often a clue
- Perception can be off (auditory is the most studied but also visual and proprioceptive)

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Sensory Integration

- Hyper- or hyposensitive, or mixed.
- Some signs suggesting further investigation
  - tags on the backs of shirts, other clothing is uncomfortable
  - picky eaters
  - lights too bright; sounds too loud
  - upset by too much incoming stimuli—either shutdown or meltdown
  - hood over face

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"Moral"

Lying:
- confabulation—often unsuccessful
- often unaware
- partly a function of memory
- sometimes TOO truthful

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Where there is trauma AND FASD

- Symptoms mimic each other but FEAR is not central to FASD
- Trauma treatment must be modified to adapt to cognitive, sensory, memory, executive functioning gaps of FASD
- Attachment process doubly slow
- Calming is extra hard and extra important
- FASD symptoms do not go away, but can be managed.

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Secondary Disabilities

- Disabilities that an individual is not born with, but often develop when FASD is not identified or adequately treated
- Mental health issues >90%
- Problems in school: >60%
- Legal trouble or incarceration: 45-60%
- Alcohol and other drug dependence: at least 30-45%
- Dependent living: >80%

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Most Effective Intervention

Identification

Ann Streissguth, 1995
and everyone else since then.

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From the inside

- Constant hyperarousal (Cardiac Orienting Response) interspersed with exhaustion and/or shutdown
- Ongoing sense of dread—what will i screw up next?
- Craving to be normal—strong sense of being different
- Identity and thoughts often negative
- Little actual fun
- Others often angry or disappointed

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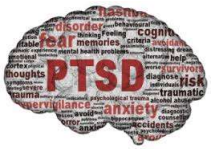
Fetal Alcohol Spectrum Disorders ALMOST ALWAYS MISDIAGNOSED AS:

- ADHD
- Bipolar Disorder
- Borderline Personality Disorder
- Autism
- Attachment Disorder
- Oppositional Defiant Disorder
- PTSD



The more of these diagnoses a person has collected, the more likely it is that prenatal alcohol is the culprit.

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A few principles of intervention

- Family resources/education/support/understanding!
- Sensory/Environment
- Communication
- Memory/patience/repetition
- Realistic expectations—age equivalent
- Support/scaffolding for success
- Remember brain damage
- THINK YOUNG in times of struggle
- The OT is your friend!
- FIND AND ENCOURAGE STRENGTHS AND JOYS

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