Fetal Alcohol Spectrum Disorders: A Foundation

Implications and Supportive Interventions

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Laura Burger Lucas
My brain is different.

But the thoughts and emotions in it are as real, as valid, as beautiful, and as important as anyone’s.
FASD basics

• A specific, yet variable, combination of abnormalities seen in some individuals who were exposed to high levels of alcohol during gestation.

• FASD is the leading cause of developmental disabilities in the US.

• FASD is a cluster diagnosis. Associated disorders: FAS, PFAS, ARBD, ARND, ND-PAE.

• Severity of effects are determined by three factors: Dose, pattern, timing

Some information from:
Streissguth, Alcohol, Pregnancy and the Fetal Alcohol Syndrome, 1994
How prevalent is it?

• Approximately 18% of women report drinking, and 6.9% report binge drinking in the 1st trimester of pregnancy. (SAMHSA, 2013)
• Prevalence is a moving target. Latest study indicates 1 in 20 US children (Nedelman, 2018)
• Cuts across racial and ethnic boundaries; however married, Caucasian women appear to be at higher risk.
• FASD is much higher in the foster care system (10-15% than the general population). 73-80% of youth who have full blown FAS are in foster care or adoptive homes.
Prevalence Comparison

Prevalence of Birth Defects Per 1,000 Live Births

- Cerebral Palsy: 2 in 1,000
- Spina Bifida: 0.7 in 1,000
- Down Syndrome: 1.4 in 1,000
- Fetal Alcohol Syndrome (FAS): 9 in 1,000
- Autism: 14 in 1,000
- Fetal Alcohol Spectrum Disorders (FASD): 24-48 in 1,000
Impact of Alcohol During Pregnancy

• Alcohol causes more harm than illegal drugs
  • “Of all the substances of abuse including cocaine, heroin and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus” - Institute of Medicine
• Alcohol is a neurotoxin
• A developing baby can’t process alcohol
• There is no safe amount or type of alcohol to consume during pregnancy

www.mofas.org
<table>
<thead>
<tr>
<th>Age of Embryo (in weeks)</th>
<th>Fetal Period (in weeks)</th>
<th>Full Term</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
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<tr>
<td>2</td>
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<tr>
<td>3</td>
<td>C.N.S.</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>heart</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>eye</td>
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<tr>
<td>6</td>
<td>heart</td>
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<tr>
<td>7</td>
<td>ear</td>
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</tr>
<tr>
<td>8</td>
<td>palate</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>external genitalia</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>brain</td>
<td></td>
</tr>
<tr>
<td>20-36</td>
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<td>38</td>
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</table>

- Indicates common site of action of teratogen.

**Critical Periods in Human Development**

- Red indicates highly sensitive periods when teratogens may induce major anomalies.

- Yellow indicates minor congenital anomalies.

- Not susceptible to teratogens.
FAS:

- Facial features
- Confirmed prenatal exposure to alcohol
- Cognitive impairment
- Growth delays
Typical challenges

• Physical
• Intellectual
• Social
• Emotional/Behavioral
Potential physical challenges

- Facial dysmorphia
- Heart defects
- Cleft palate
- Poor motor coordination
- Lung and respiratory problems
- Vision and hearing challenges

- Sleep disturbances
- Sensory challenges
- Delayed development
- Organ displacement, malformation
- Musculoskeletal differences
- Differences in brain formation/structure
Primary challenges: cognitive, developmental and behavioral

- Inconsistent memory and recall
- Difficulty with generalizing skills
- Difficulty expressing and applying abstract concepts
- Impulsivity and judgement concerns
- Resistant to change
- Inability to predict outcomes
- Inability to see another person’s perspective
- Inability to recognize indirect social cues
- Confabulation

Centre for Addiction and Mental Health, Toronto, Ontario, Canada
Secondary challenges: cognitive, developmental and behavioral

- Co-occurring mental health problems (90% have mental health dx)
- Poor academic achievement
- Inability to live independently
- Alcohol and other drug problems
- Problems with employment
- Incarceration and confinement (50%, confinement of all types)
- Repeated law violations (60%, avg start at 12.8 yo)
- Disrupted school experience (60% for adolescents)
FASD & the Criminal Justice System

• Lack of impulse control, difficulty thinking of future consequences of current behavior

• Difficulty planning, connecting cause and effect, empathizing, taking responsibility

• Vulnerability to peer pressure

• Confabulation and false confessions
Potential risk factors

- Family estrangement (80% not primarily raised by bio parents)
- Lack of friendships, other supportive relationships
- Victimization, abuse
- Withdrawal and isolation
- Inappropriate sexual behavior (50%, adolescents and adults)

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Rationale for intervention
A few ideas for supporting people with FASDs (there are LOTS more!)

- Understand the implication of executive function-related challenges.
- Understand the perspective that people do well when they can.
- Highlight and build strengths.
- Avoid idioms, abstract language.
- Use the Life History Screen to assess for FASD in adults.
What are executive functions?

- Executive functions are a set of cognitive processes that are necessary for cognitive control of behavior. They are skills we all use every day to plan, organize and complete tasks.

- Executive functions are thought to be developed and regulated in the prefrontal cortex, which is located deep within the limbic system of the human brain.
Understanding executive function

- Impulse control
  - blurts things out, engages in risky behavior
- Emotional control
  - overreacts, has difficulty with criticism
- Flexible thinking
  - can’t roll with the punches
- Working memory
  - has trouble remembering directions, even if written
- Self monitoring
  - can’t evaluate, surprised by bad grades
- Planning and prioritizing
  - unable to determine what’s most important
- Task initiation
  - freezes up, has no idea where to begin
- Organization
  - frequent loss of thoughts or things

Morin, understood.org
What’s in Your Toolbox?

- Strengths are attached to all behavior.
- Strengths are skills, relationships, characterological traits, resources, etc.
  - Executive functioning skills, Language processing skills, Emotion regulation skills, Cognitive flexibility skills, Social skills
- Strengths can be used to address challenges
- Strengths can be discovered by exploring an individual’s history of solution-finding.
Toolbox Affected by FASD

- Difficulty shifting from one task to another
- Slower information processing
- Memory deficits
- Poor organizational & planning skills
- Concrete thinking
- Poor judgment
- Poor impulse control
- Immaturity
- Difficulty with friendships and social cues
Shifting perspective

In wraparound, we make specific assumptions about behavior:

Skill not will
Not won’t, but can’t
<table>
<thead>
<tr>
<th>People do well if they want to.</th>
<th>People do well if they can.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpretation:</strong> Big behavior is an intentional manipulation designed to coerce others into giving in.</td>
<td><strong>Interpretation:</strong> Big behavior occurs when the demands of an environment or situation exceed the person’s ability to cope or adapt.</td>
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<tr>
<td><strong>Intervention goal:</strong> Compliance.</td>
<td><strong>Intervention goal:</strong> Competence.</td>
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<tr>
<td><strong>Approach:</strong> Person-centered.</td>
<td><strong>Approach:</strong> Systemic.</td>
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<tr>
<td><strong>Strategies:</strong> Rewards and consequences designed to provide incentive for improving behavior.</td>
<td><strong>Strategies:</strong> Teach skills to reduce stress and address unmet need.</td>
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<td><strong>Emphasis:</strong> Reactive focus on management of behavior <em>after</em> it has occurred.</td>
<td><strong>Emphasis:</strong> Proactive focus on resolving and preventing behavior <em>before</em> it occurs.</td>
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What can providers do?
## Avoid abstract language

<table>
<thead>
<tr>
<th>Abstract Idiom</th>
<th>Actual Meaning</th>
<th>Concrete Misunderstanding</th>
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</thead>
<tbody>
<tr>
<td>“A chip on your shoulder”</td>
<td>You think you know a lot</td>
<td>What? There are no chips (potato) on my shoulder</td>
</tr>
<tr>
<td>“As high as a kite”</td>
<td>You are drunk or on drugs or very very happy</td>
<td>What? I am standing on the floor.</td>
</tr>
<tr>
<td>“Out of the blue”</td>
<td>Something unexpected happened</td>
<td>Huh?</td>
</tr>
<tr>
<td>Abstract</td>
<td>Concrete</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Justice</td>
<td>Police Officer</td>
<td></td>
</tr>
<tr>
<td>Fled</td>
<td>Drove away in a car</td>
<td></td>
</tr>
<tr>
<td>Advised</td>
<td>Said or told</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>Bus, car, train, canoe</td>
<td></td>
</tr>
<tr>
<td>Criminal</td>
<td>Girl who stole my purse</td>
<td></td>
</tr>
<tr>
<td>Golfer</td>
<td>Tiger Woods</td>
<td></td>
</tr>
<tr>
<td>Idea</td>
<td>John’s idea</td>
<td></td>
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</tbody>
</table>

- Be aware that persons with organic brain injury may have trouble filtering out distractions, fighting their impulses and make poor decisions sometimes by obeying “EXACTLY WHAT YOU SAID!”
- Be aware of what you are saying – all the time.
- Understand that if they are doing something that you have expressly told them not to – go back over your instruction and see if they have translated what you said literally.
Strategies

• Be consistent with appointment times, locations and providers.

• Set reasonable goals (remember the person’s functional age and abilities are lower than chronological age).

• Learn the person’s language patterns and present information strategically.

• Communicate concretely and repetitively.

• Reduce distracting stimuli in the environment.
SHOUT OUT TO ALL OF US FIGHTING A BATTLE THAT MOST PEOPLE DON'T UNDERSTAND.

~ KEEP HANGING IN THERE ~
About the author

Megan French is a Children’s Intensive Services Program Manager at Lutheran Community Services Northwest, located in Kennewick WA. She is a Certified Fetal Alcohol Spectrum Disorder Trainer, through the University of Madison-Wisconsin.

Megan has a Master’s degree in Social Work and is a Child Mental Health Specialist. With over ten years of experience working in wraparound programs and watching families find success, Megan is passionate about the principles and process of wraparound. As a Program Manager, Megan is intentional about the recruiting, hiring and training of the staff who will accompany families through their journey in Wraparound. Megan is the Training Director of the 3 Rivers Wraparound Learning Center, which provides wraparound specific trainings locally and statewide.

In her free time, Megan can be caught spending time with her husband, 2 children and Australian Shepherds. She enjoys camping, boating, and hiking in the sunshine.
Laura Burger Lucas is a professional child and family team coach with experience in behavioral health, child welfare, juvenile justice, and education. She is the creator of over 200 curricula and training materials on wraparound and other empowerment models, and has been an invited speaker and workshop presenter at regional and national conferences for the last 25 years.

Laura has worked as a care coordinator, supervisor, manager, and agency administrator. She is the co-founder of the 3 Rivers Wraparound Learning Center, which offers training and strategic coaching support to wraparound providers in Washington and across the country. The parent of a young adult with a life-long history of multi-system involvement, Laura has experienced helping systems as both a provider and a consumer. She draws from lived experience to inform her work as an advocate, trainer, coach and consultant in nine states and the District of Columbia.

Laura’s particular interest is in the development, support and oversight of direct service providers in integrated systems of care. Her business is based in beautiful Bellingham, Washington. In her free time Laura enjoys traveling, gardening, quilting and spending time with her dogs, Clarence and Bella.