

Fetal Alcohol Spectrum Disorders from a Trauma Lens

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FASD within a Trauma Lens

3 Categories of Trauma (according to Dr Bruce Perry)

1. **Intrauterine insult**; prenatal alcohol or drug exposure, stress during pregnancy
2. **Early neglect and/or seperation**; mother who is inattentive due to stress, depression, domestic violence, etc., orphanage; but also a child who isn't with his birth mother whether voluntary or involuntary
3. **Classic trauma**; abuse, molestation, witnessing violence, etc.




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“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”
—IOM Report to Congress, 1996

Alcohol or drugs:

Which is more damaging to a developing fetus?


ALCOHOL!!



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Varying impact of exposure to substances

	Alcohol	Opioids	Marijuana	Meth	Cocaine	Nicotine
Facial anomalies	Strong	Effect	None	None	None	None
Behavior Challenges	Strong	Effect	Effect	Effect	Effect	Effect
Cognitive Impairment	Strong	Effect	Effect	Effect	Effect	Effect
Growth Issues	Strong	None	None	None	Effect	None
Physical/Medical Effects	Strong	Effect	None	Effect	Effect	None
Withdrawal	None	Strong	None	Maybe*	None	None
Birth Weight	Strong	Effect	None	Effect	Effect	Effect



Prenatal Substance Abuse: Short- and Long-term Effects on the Exposed Fetus; Marylou Behnke, MD, Vincent C. Smith, MD, [Pediatrics](#), 2013 Mar;131(3):e1009-24. doi: 10.1542/peds.2012-3931. Epub 2013 Feb 25.

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Fetal Alcohol Spectrum Disorders- FASD



- Most people have heard of FAS, Fetal Alcohol Syndrome. It became a spectrum disorder in 1996.
- FASDs are a set of physical, behavioral and cognitive disorders affecting people who were prenatally exposed to alcohol.
- FASDs are permanent disabilities that result in lifetime brain injury/damage.



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Fetal Alcohol Spectrum Disorder is an umbrella term.

- Fetal Alcohol Syndrome -FAS. (1973): 3 facial features, growth deficits, meet the cognitive profile
- Partial Fetal Alcohol Syndrome- pFAS (1996): Have some of the physical features but not all. Match the cognitive profile
- Alcohol Related Neurodevelopmental Disorder- ARND (1996)- new name for FAE (Fetal Alcohol Effect): No physical features but brain was impacted by the alcohol. Must have confirmation of alcohol exposure in utero and match the cognitive profile.

The FASD Umbrella

- DSM 5 (2013): Can list any FASD as: "other specified neurodevelopmental disorder" [315.8] Then add the specifier: "neurodevelopmental disorder associated with prenatal alcohol exposure" (ND-PAE)



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Fetal Alcohol Syndrome - facial features



- Smooth philtrum
- Thin upper lip
- Short palpebral fissures

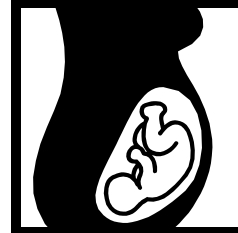
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**Only 10% of
people on the
spectrum have the
facial features**

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Factors that impact the degree of brain injury to the developing fetus

- Timing of exposure
- Resiliency of fetus
- Metabolism and diet of the mother
 - If mom's iron level is low, more likely fetus is damaged
 - Alcohol is absorbed into the amniotic fluid which acts as a reservoir and increases the exposure time
- Blood alcohol concentration of the mother



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Twin research

- Identical twins had virtually identical results of injury from Prenatal Alcohol Exposure (PAE).
- Fraternal twins had vastly different outcomes from the prenatal alcohol exposure.
- Conclusion: **Fetal Genetic factors into the level of damage that a fetus receives from the PAE**



(Hemingway et al., Twin study confirms virtually identical prenatal alcohol exposures can lead to markedly different fetal alcohol spectrum disorder outcomes fetal genetics influences fetal vulnerability. Advances in Pediatric Research, 2019)

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Prevalence

- ▶ 2018 research estimates that 1 out of 20 children have an FASD, but mostly go undiagnosed or are misdiagnosed. (May, 2018).*
- ▶ The prevalence of Fetal Alcohol Syndrome in the foster care system is 10 times higher than in the general population**
- ▶ 1 out of 40 children have an autism diagnosis according to 2018 research.** autism and FASD have many similarities.

*May, P.A., et al. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. JAMA. Online February 6, 2018.

**S. J. Atley, PhD, J. Stachowiak, RN, MN, S. Clarren, MD, Ch Clausen, RN, MN, (2002) Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population, Journal of Pediatrics, Volume 141, Number 5.

***Guifeng Xu et al. Prevalence and Treatment Patterns of Autism Spectrum Disorder in the United States, JAMA, December 3, 2016



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FASD- the missed diagnosis

- 86.5% missed diagnosis rate for children in foster care and adoptive families
- Minnesota is the first (and so far only state) to require that all children who go into foster care be screened for prenatal alcohol use (2020)



*Ira J. Chasnoff, Anne M. Wells and Lauren King, Pediatrics February 2015, 135 (2) 264-270

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Red flags

questions to consider...



- Was the child in foster care or is he/she adopted?
 - FASD United estimates that 70-80% of children in foster care were prenatally exposed to alcohol
 - 29-68% of Russian adoptions are estimated to show severe alcohol-related damage
- Is there history of chemical dependency issues for child or for their parents?
- Is child is easily distracted, hyperactive, inattentive and impulsive?
- Have they been involved with the criminal justice system?
- **Does the child continue to make the same mistakes and not learn from consequences?**



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Red flags



- Are there multiple diagnoses like bi-polar depression, ADHD, reactive attachment disorder (RAD), autism, conduct disorder, etc.?
- Does the child consistently display extreme behaviors (i.e. aggression, emotional instability)?
- Are there sleeping and/or eating Issues?
- Does the individual have an average IQ but functions at a much lower capacity?
- Can the child repeat a rule, but cannot follow it and seem unaware of what they have done or why they are in trouble?



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Early intervention is CRUCIAL



- Diagnosis before age 6 is a protective factor
- Choline supplements before age 5 can help repair some of the brain injury (Wozniak, J.R., Fink, B.A., Fuglestad, A.J. *et al.* Four-year follow-up of a randomized controlled trial of choline for neurodevelopment in fetal alcohol spectrum disorder. *J Neurodevel Disord* 12, 9 (2020). <https://doi.org/10.1186/s11689-020-09312-7>)
- Parents can use more effective techniques if they understand the infants brain – therefore not unintentionally causing more trauma



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4th-6th grades

Around the ages of 9-11, difficulties in academic performance and behavior in the school setting become more apparent.

It is important to consider screening for an FASD if parents are expressing concerns over new behavioral issues and/or academic struggles particularly around the 4th to 6th grade level.



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Diagnosis

- ❖ Confirmation of alcohol consumption during pregnancy is needed in order to diagnosis everything under the spectrum except for FAS (if they have the facial features, confirmation of exposure is not required).
- ❖ **FASD: Focus of diagnosis**
 - ❖ Growth deficits
 - ❖ Central nervous system problems
 - ❖ History of prenatal alcohol exposure
 - ❖ Facial abnormalities (FAS, pFAS only)



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10 brain domains

- Cognition
- Attention
- Achievement
- Motor
- Adaptation
- Executive function
- Memory
- Sensory and soft neurological signs
- Language
- Social communication



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Why do you need a diagnosis?

- Decreases anger/frustration for all
- Helps to know the negative behaviors result from a disability and ARE NOT willful
- Helps the individual receive appropriate services early
- The individual will need a lifetime of external supports.
- Set realistic expectations
- Decreases risk of secondary disabilities (law/school)
- Provides better self awareness and acceptance
- Prevents next pregnancy exposure
- Increases understanding that FASD is a lifetime disability based on permanent, irreversible brain damage



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How to ask...



- Hard questions
 - Do not just ask if they used alcohol while pregnant
 - “Is there anyway you could have been using alcohol before you knew you were pregnant?”
 - Empathize – “This has happened to several of my friends and family” (It probably actually has!)



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Strengths

- ▶ Highly verbal
- ▶ Energetic, hard working
- ▶ Caring, kind and loyal
- ▶ Curious and involved
- ▶ Friendly/ likeable
- ▶ Talkative
- ▶ Strong desire to be liked
- ▶ Don't hold a grudge
- ▶ Good with younger children
- ▶ Not malicious
- ▶ Every day is a new day!



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Most common strength -

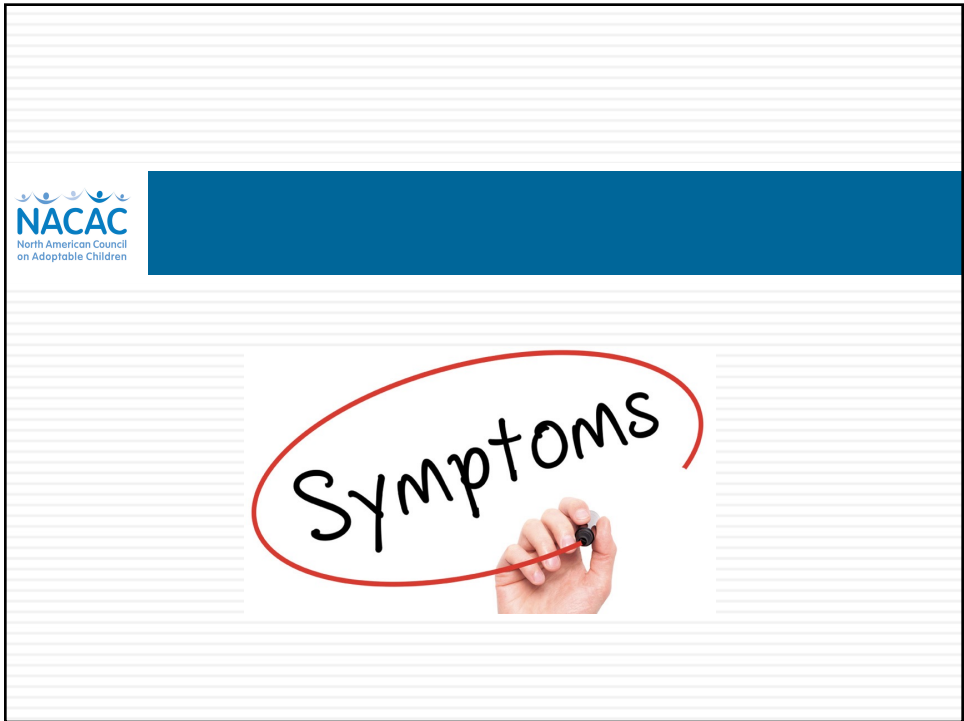
Good with younger children



Most should not babysit younger children without adult supervision



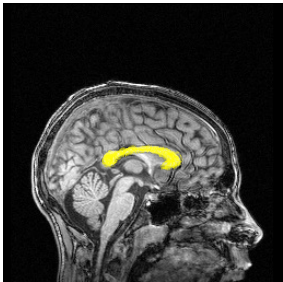
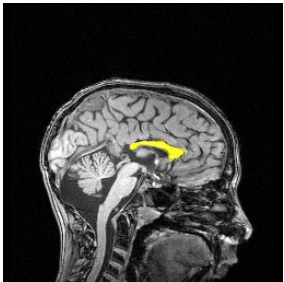
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Corpus callosum damage

Inconsistency is symptom of corpus callosum damage

Typical	FAS
	

 * Images courtesy of Dr Jeffrey Wozniak, University of Minnesota, 13 year old boys

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Impulse control



- Frontal lobe, part of executive function skills
 - Stealing
 - Sexual choices
 - Cursing/verbal aggression
 - Physical aggression



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Memory struggles



- There is a difference between short term and long term memory.
- Short term memory is what is called working memory
- Working memory is almost always a deficit in people with an FASD




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Sensory Issues

SIGHT

Can be sensitive to bright or fluorescent lights



TASTE

Can struggle with textures of foods or be very fussy eaters

TOUCH


Fright or Flight response. Can be incredibly sensitive to being touched

HEARING

Sometimes are able to hear every little humming and buzzing noise

SMELL

Odors can have huge impact, leading to explosions




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Difficulty generalizing

- Struggle to transfer skills to different situations, with different people, different places, etc.

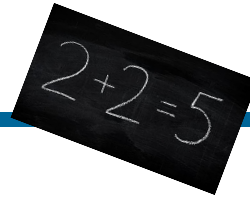
- $4+4=8$
- 4
- $\underline{+4}$
- 8

**** This is also what makes them so vulnerable**



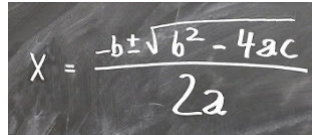
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Math struggles



$$2+2=5$$

- When FASD children were imaged by a technique called DTI (Diffusion Tensor Imaging), the 5 areas in the brain important in mathematical ability showed damage—and the amount of damage correlated highly with their math scores on standardized tests.



$$x = \frac{-b \pm \sqrt{b^2 - 4ac}}{2a}$$

Sleep challenges



- Sleep is directly related to brain function
- Important to not get upset with our impatient with the person/child if they are not sleeping well

ANXIETY

- Heart rate Increases
- Body temp rises
- Body tenses up
- All tied to brain function
- Keep anxiety as low as possible through sensory breaks, interventions, relaxed testing (if any), etc.



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Typical symptoms/challenges



- Poor executive function skills
- Inability to manage money
- Difficulty with understanding the feeling of the passage of time
- Poor problem solving skills
- Stubbornness/perseveration
 - Very similar to children with autism
- Struggle to find right words



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Social skills lag behind their peers

Social skills are abstract and most children pick them up by watching and listening with some guidance and direction from adults.

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Consequence Based Parenting

- Often causes further trauma to the child
- Slows down and often stops attachment
- Can impede felt safety for the child
- Increases anxiety

So many of these kids have **ALREADY** experienced some of the most severe consequences imaginable

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Trauma Responsive Parenting



- focuses on the relationship
- does not shame or blame
- understands the neurobehavioral aspect of behaviors
- is not instinctive or intuitive
- acknowledges developmental ages, not birth age



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FASD Developmental Timeline- Dysmaturity

ACTUAL AGE OF INDIVIDUAL: 18

Skill	Developmental age equivalent
Expressive Language	> 20
Comprehension	> 6
Money, time concepts	> 8
Emotional maturity	> 6
Physical maturity	> 18
Reading ability	> 16
Social skills	> 7
Living skills	> 11

WE RECOMMEND YOU TAKE THE AGE OF AN INDIVIDUAL WITH AN FASD, AND CUT THEIR AGE IN HALF. THIS IS THE AGE THEY ARE PROBABLY FUNCTIONING AT IN MOST AREAS OF LIFE.



ADAPTED FROM: RESEARCH FINDINGS OF STREISSGUTH, CLARREN ET AL, .DIANE MALBIN 1994

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Top strategies...



- ❖ Remember the BRAIN!!
- ❖ Be patient and give grace!!
- ❖ Change the environment!!
- ❖ Don't ask why!!
- ❖ Forgive, forget, and move on!!
- ❖ Throw logic out the door!!



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Sometimes
strength comes in
knowing you are
not alone

Connect with other parents who have similar children
~give support groups a try



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FASD Resources



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Podcast- FASD Success Show – Jeff Noble



www.fasdsuccess.com	www.fasdsuccess.com
<ul style="list-style-type: none">▶ Multiple adults on the spectrum are interviewed▶ Mindfulness▶ Housing▶ Managing anxiety	<ul style="list-style-type: none">▶ Diagnosis▶ Rages▶ MRI research▶ Choline research▶ Sleep▶ Online issues



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Websites

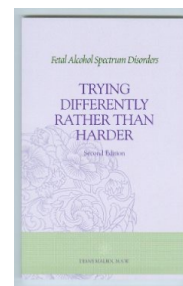
- ▶ Proof Alliance (formerly MOFAS)
 - ▶ www.proofalliance.org
- ▶ FASD Toolkit
 - ▶ www.fasdtoolkit.com
- ▶ FASD United (formerly NOFAS)
 - ▶ www.fasdunited.org
- ▶ Centers for Disease Control (CDC)
 - ▶ <https://www.cdc.gov/ncbddd/fasd/facts.html>
- ▶ Oregon Behavioral Consultants YouTube Series
 - ▶ <https://www.youtube.com/channel/UCQ6qtXeMCZ-vgC9tG7LokNw/videos>



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FASD Books

- Trying Differently Rather Than Harder, Diane Malbin
- Damaged Angels, Bonnie Buxton
- The Best I Can Be, Liz Kulp
- Fetal Alcohol Syndrome, Ann Streissguth
- The Braided Cord, Liz & Jodee Kulp
- FASD & the Online World, Ira Chasnoff
- Children's Friendship Training, Fred Frankel
- FASD & the Online World, Ira Chasnoff



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