



Fetal Alcohol Spectrum Disorders



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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.
- FASDs are 100% preventable and the number one known cause of intellectual disability.

3 Types of Trauma

-Bruce Perry

1. Intrauterine insult; prenatal alcohol or drug exposure, stress during pregnancy
2. Early neglect; mother who is inattentive due to stress, depression, domestic violence, etc., Orphanage
3. Classic trauma; abuse, molestation, witnessing violence, etc.

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)

Fetal Alcohol Syndrome

-Facial Features



- Smooth Philtrum
- Thin upper lip
- Short palpebral fissures

Only 10-20% of
people on the
spectrum have the
facial features

“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!!

Prenatal Substance Abuse: Short- and Long-term Effects on the Exposed Fetus

TABLE 2 Summary of Effects of Prenatal Drug Exposure

	Nicotine	Alcohol	Marijuana	Opiates	Cocaine	Methamphetamine
Short-term effects/birth outcome						
Fetal growth	Effect	Strong effect	No effect	Effect	Effect	Effect
Anomalies	No consensus on effect	Strong effect	No effect	No effect	No effect	No effect
Withdrawal	No effect	No effect	No effect	Strong effect	No effect	*
Neurobehavior	Effect	Effect	Effect	Effect	Effect	Effect
Long-term effects						
Growth	No consensus on effect	Strong effect	No effect	No effect	No consensus on effect	*
Behavior	Effect	Strong effect	Effect	Effect	Effect	*
Cognition	Effect	Strong effect	Effect	No consensus on effect	Effect	*
Language	Effect	Effect	No effect	*	Effect	*
Achievement	Effect	Strong effect	Effect	*	No consensus on effect	*

* Limited or no data available.

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.

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
- Blood alcohol concentration of the mother

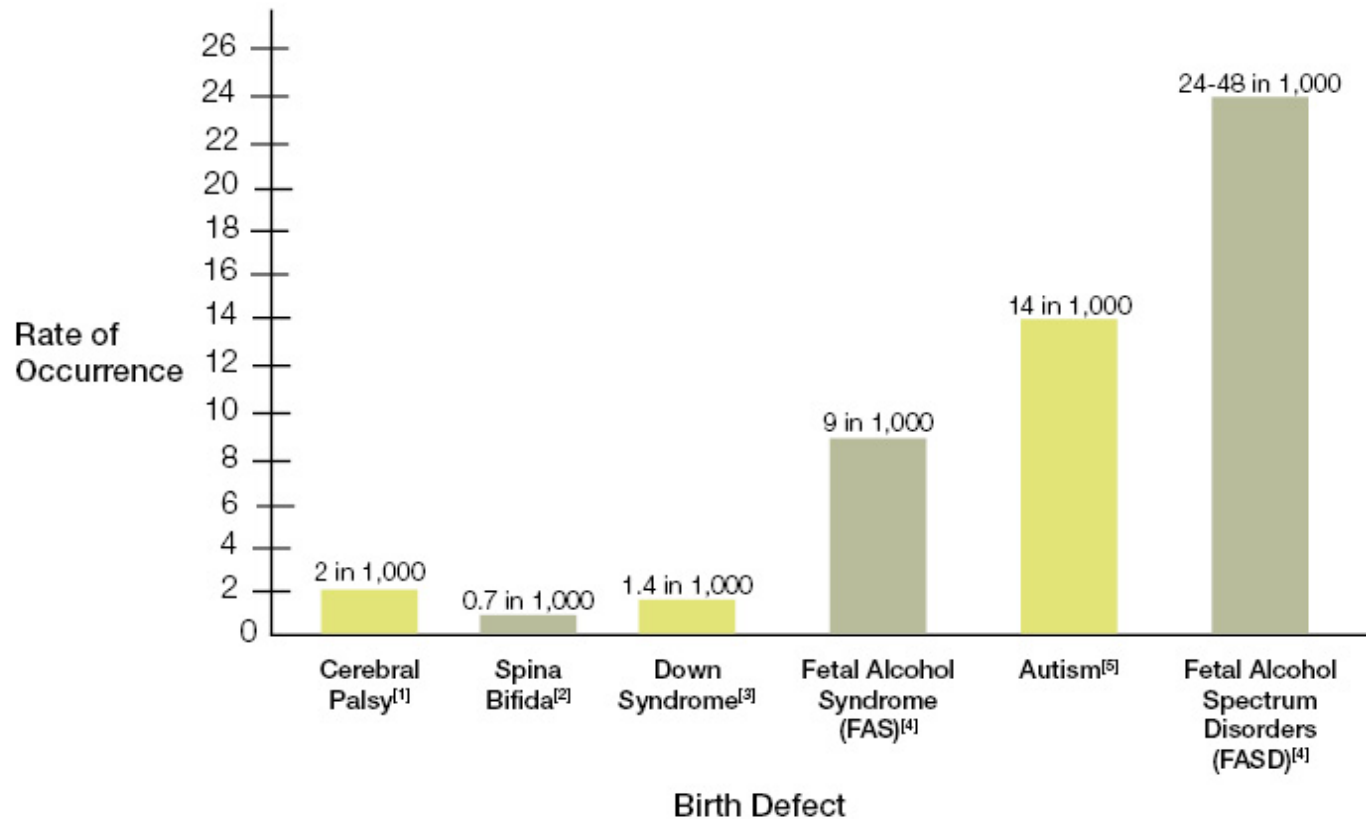


Prevalence

- ▶ 2018 research estimates that 1 out of 20 children have an FASD, but mostly go undiagnosed or are misdiagnosed. (May, 2018).
- ▶ 1 out of 59 children have an Autism diagnosis according to the CDC. 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.*

Prevalence of Birth Defects Per 1,000 Live Births



[1] My Child™ at Cerebral Palsy (<http://cerebralspalsy.org/about-cerebral-palsy/prevalence-and-incidence/>)

[2] American Pregnancy Association (<http://americanpregnancy.org/birth-defects/spina-bifida/>)

[3] March of Dimes (<http://www.marchofdimes.org/baby/down-syndrome.aspx>)

[4] Philip A. May, et al., "Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders," *Pediatrics*, Volume 134, Number 5, November 2014.

[5] Center for Disease Control and Prevention (<http://www.cdc.gov/ncbdd/autism/data.html>)

Graphics and info put together by Proof Alliance

Red Flags

question to consider



- Was the child in foster care or is he/she adopted?
 - It is estimated that 70-80% of children in foster care were prenatally exposed to alcohol and have an FASD.
 - 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?
- Does the child appear to not learn from consequences?

Red Flags



- Can the child repeat a rule, but cannot follow it?
- Are there multiple diagnoses like Bi-Polar, ADHD, Reactive Attachment Disorder, Autism, Conduct Disorder, etc.?
- Does the child Consistently display extreme behaviors (aggression, emotional instability)?
- Are there Sleeping and/or eating Issues?
- Does the individual have an Average IQ but functions at a much lower capacity?
- Are Vivid fantasies and perseveration problems present?
- Does the individual seem unaware of what they have done or why they are in trouble?

4th-6th Grades

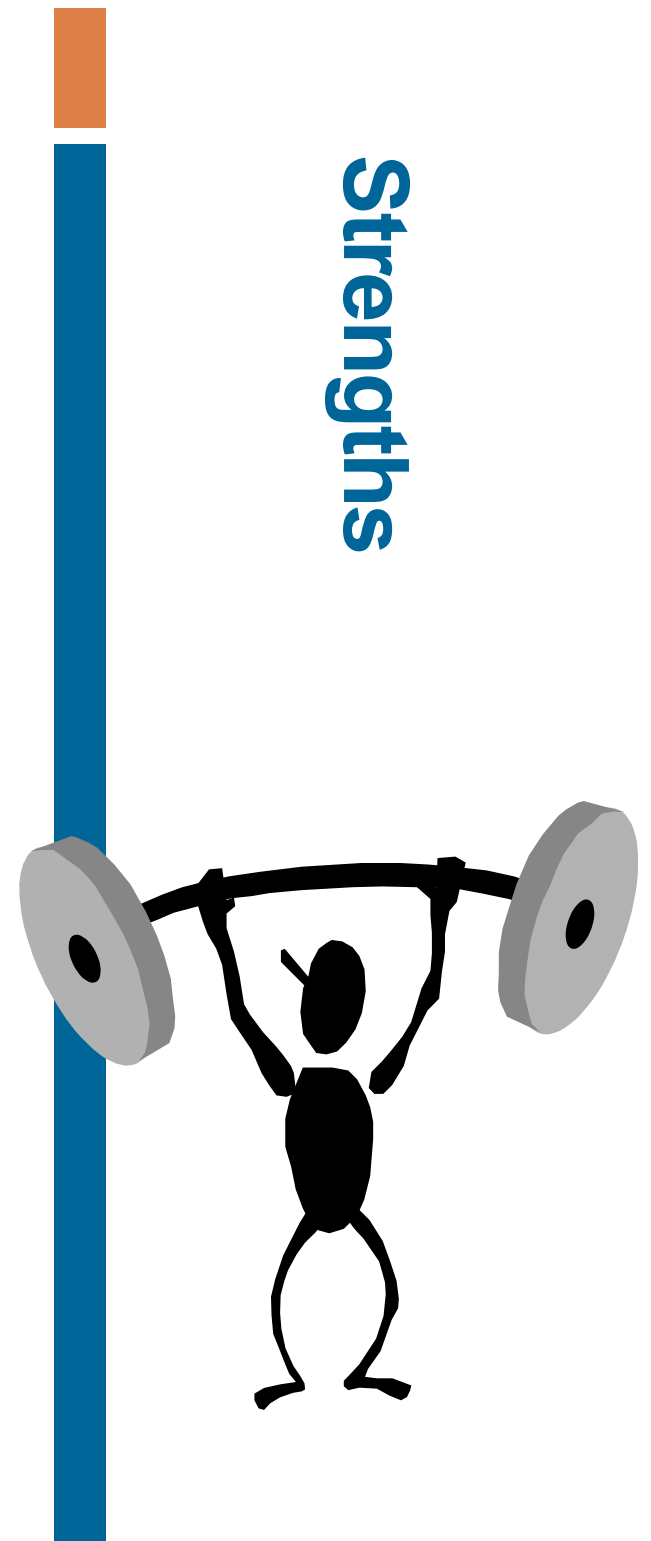


Around the ages of 9-11, difficulties in academic performance and behavior in the school setting become more apparent.

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.



- ▶ 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!



Most common strength-

Good with younger children

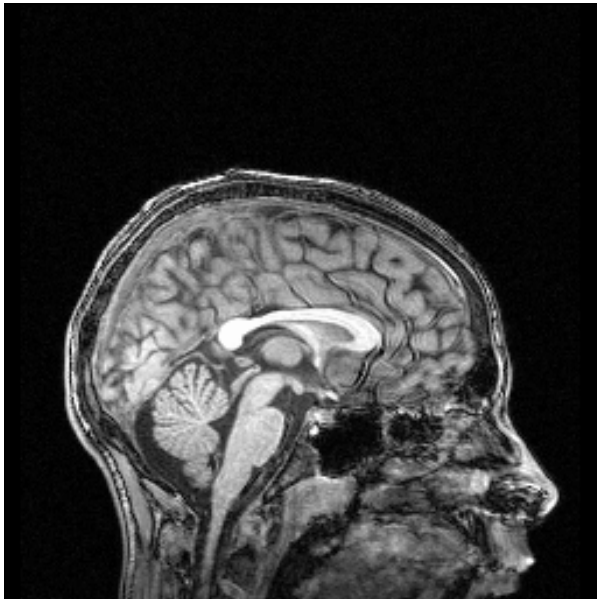


Most Should not babysit younger children without adult supervision

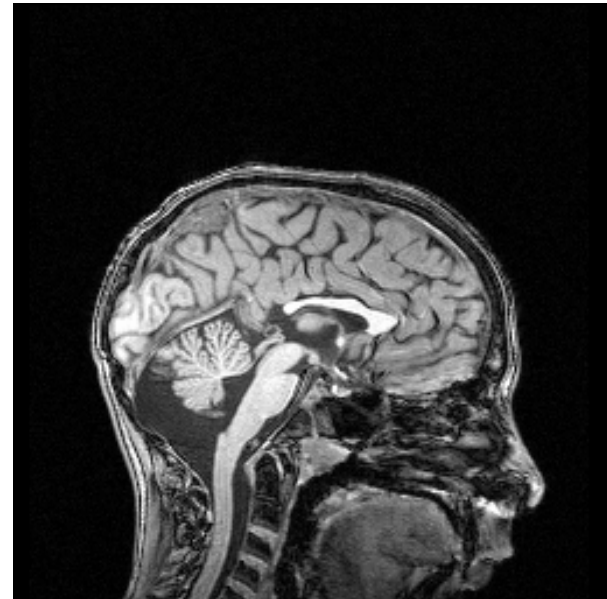


Corpus Callosum

- Typical



- FAS



Impulse Control

- Frontal Lobe, part of Executive function skills
- Impacts anger response, taking things (stealing), sexual choices, cursing or verbal aggression



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



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 bussing
noise

SMELL

Odors can have huge
impact, leading to
explosions

Difficulty Generalizing



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

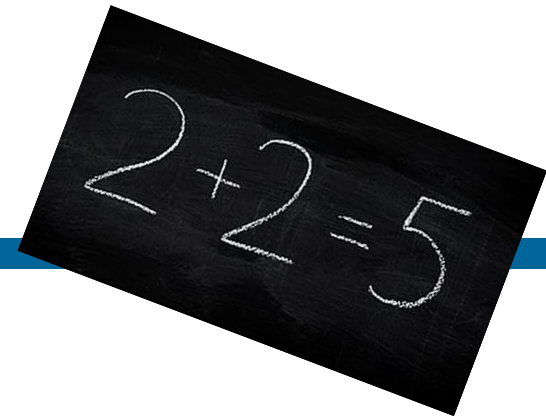
- $4+4=8$

- 4

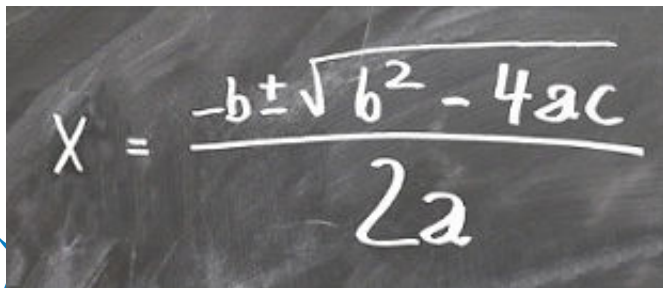
$$\begin{array}{r} +4 \\ \hline \end{array}$$

$$8$$

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.



Typical symptoms/challenges



- Difficulty with abstract concepts
- Inability to manage money
- Difficulty understanding the passage of time & telling time
- Pattern of lying
- Poor problem solving skills
- Stubbornness/perseveration
 - Very similar to children with autism
- Attention deficits & hyperactivity
- Struggle with delayed gratification

FASD Developmental Timeline



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.

Developmental Quadrant



Physical/Chronologic

14

Emotional

4

Social

6

Cognitive

9

My daughter at 18



Physical/Chronologic

14

Parent/teach to this age

Emotional

4

*Provide support and guidance
with and about peers & safety measures*

Social

6

Advocate at school regarding this age

Cognitive

9



Strategies



Top strategies...



- ❖ Remember it is brain injury!!
- ❖ Be patient and give grace!!
- ❖ Change the environment!!
- ❖ Don't ask why!!
- ❖ Don't match fire with fire!!
- ❖ Forgive, forget and move on!!

Reframe

- Move away from constant consequences which produce anxiety
- Child is more likely to learn skills when not anxious & angry



Security

- Install locks on doors
- Buy safe/lock boxes
- Use door alarms
- Might need security system
- School: Keep valuables locked up, things of interest out of sight



Escalations/Raging- What not to do



- Remove others if possible or remove the individual from the area. Ensure safety.
- Do not tell the child to calm down more than once!!!
- Stay calm, and try to talk as little as possible.
- Avoid using the child's name over & over.
- Do not point out consequences- perceived as threat when child is in the red zone
- Do not respond to cursing



Escalations/Raging- What to do



- Remember that when a child is on the way to the red zone, or is already there, their auditory processing is off.
- Talk as little as possible in a calm voice.
- Use phrases like;
 - What do you need from mom (or dad) right now?
 - How can I help you?
- Know that often once a rage has started, it is just a matter of waiting it out and keeping yourself calm

Recovering from a rage or escalation



Neuro-typical person

- It takes at least 2 hours for our bodies and brains to recover from an escalation to the point where we are calm and can process the situation.

Neuro-diverse person

- It takes 24 hours or more for a child with an FASD to recover from an escalation to the point where they are calm and can process the situation.

We are often expecting the child to process and make amends for an escalation when they are not yet capable of doing so.

Confabulation

(otherwise referred to as “lying”)



- “a memory disturbance, defined as the production of fabricated, distorted or misinterpreted memories about oneself or the world, without the conscious intention to deceive”
- We need to look at the “lying” or “confabulation” while we acknowledge the anxiety, whether visible or hidden, that is going on within the child.
- When under pressure, it is almost a given the correct story will not come out.
- Filling in the “holes” in the working memory. Would rather look “bad” than “stupid”.

Confabulation

How to handle



- If child seems worked up, wait until later or a different day to confront the story.
- Need to wait until they are in a good, clear mind (or as clear as the student ever gets), to talk about it and process it
- When processing, do not shame, blame or embarrass the child. This is a part of their brain damage/disability
- Talk calmly and respectfully about the importance of truth and having the right facts

False Allegations

How to handle

- Document history of confabulation/lies/stories in order to protect the student, staff, peers and family.
- Do not tell the student that they could get a staff, friend or parent in trouble by saying something that isn't true. This makes them more likely to do this when upset with an individual
- Point out the individual impact the allegation could have on them, their social life, and peer relationships.

Occupational Therapy is one of most effective interventions

Ask for a
"Sensory
Diet"

Request an OT eval with a sensory integration focus.

Choline in early development



Research at the University of Minnesota is showing promising results of choline in children ages 2-5. It is helping to improve their neuro-cognitive functioning. Consult with your Pediatrician.

Introduce choline rich foods to children when they start taking solid foods, after figuring out potential allergens.

What Is
CHOLINE?
Benefits, Sources & Signs of
CHOLINE Deficiency

Dr. Axe
FOOD IS MEDICINE

Sensory Strategies

- mini trampoline or large trampoline.
- Have an area where they may retreat if overloade
- Ear protection/noise cancelling head phones can be worn to reduce auditory stimulation.
- Have a variety of fidgets available.
- Frequent opportunities throughout day for physical activity.
- Snack and water break every two hours.
- Be sensitive to sensory issues.

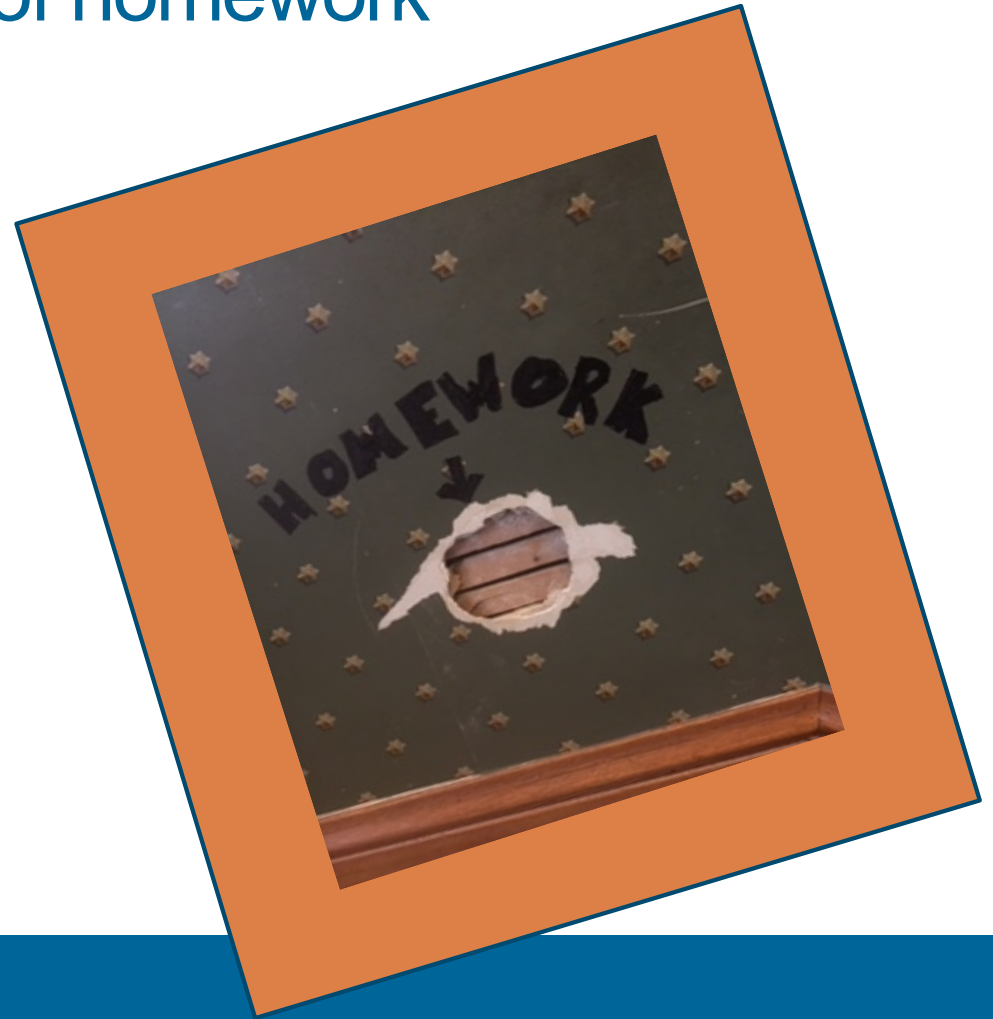


Advice

- ▶ Supervision is IMPORTANT!!
- ▶ De-clutter as much as possible.
- ▶ Be patient. Re-teach. Change expectations.
- ▶ Don't give multi step directions. Keep it simple.
- ▶ Remember our individuals often use the wrong words when it comes to feelings.
- ▶ Water and snacks every two hours is important.
- ▶ Resolve sleep issues as much as possible.
- ▶ Remind yourself: BRAIN DAMAGE!
- ▶ Expect inconsistency and celebrate it when you are wrong!

Homework:
a reduction or elimination of homework
might be necessary

Especially if there is a
trauma history outside of the womb



Visual Timers



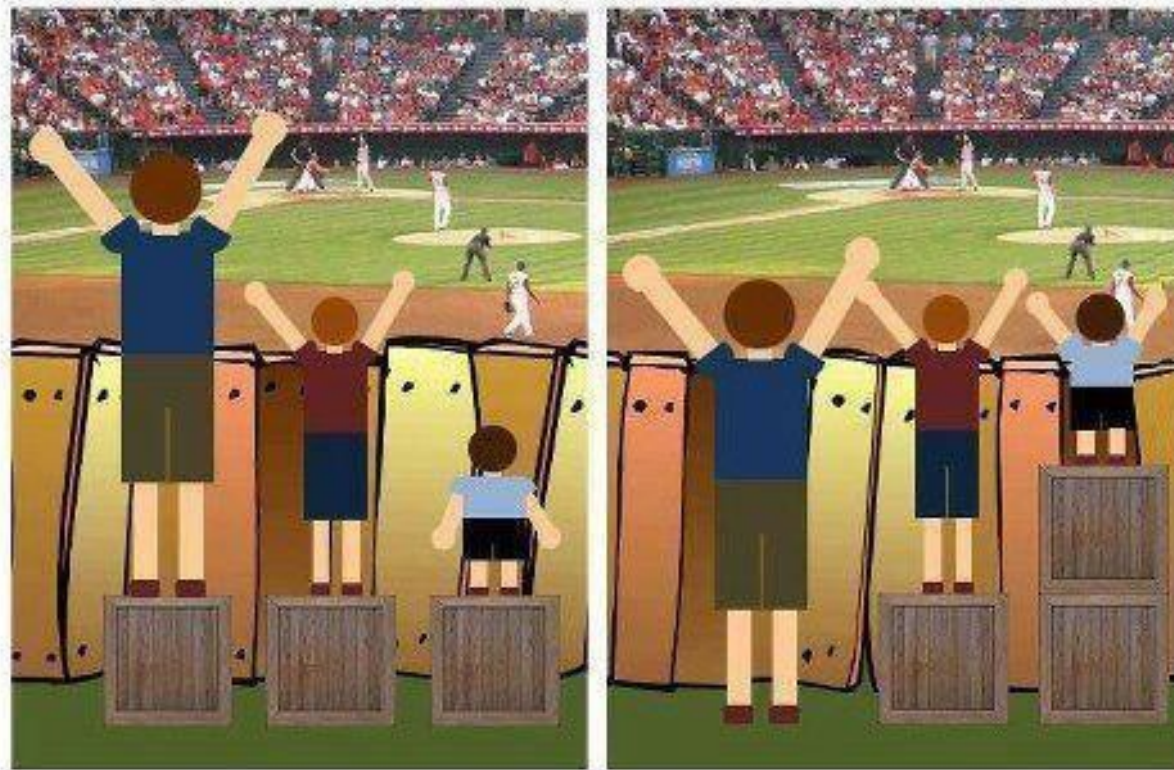
www.timetimer.com

Sand Timers



www.schoolspecialty.com

Teach the difference between fair & equal



NACAC Upcoming Webinars



- FASD from a Trauma Lens
 - Thursday, May 9, 6:30-8 pm
 - <https://www.nacac.org/resource/fasd-from-a-trauma-lens/>
 - \$15 members, \$20 non-members

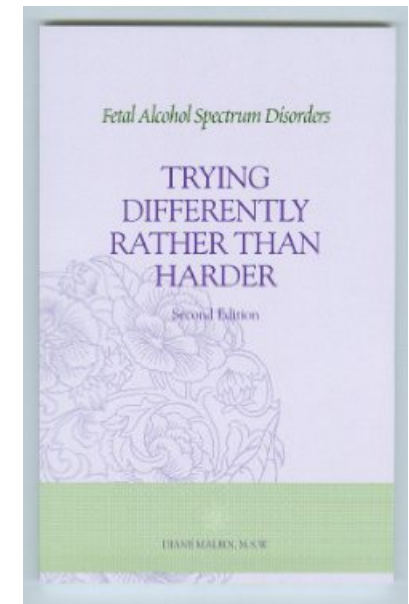
- Parenting from the Trenches
 - Monday, June 24, 2019, from 6:30-8:00 pm
 - <https://www.nacac.org/resource/fasd-from-a-trauma-lens/>
 - \$15 members, \$20 non-members

Websites

- ▶ Proof Alliance (formerly MOFAS)
 - ▶ www.proofalliance.org
- ▶ FASD Toolkit
 - ▶ www.fasdtoolkit.com
- ▶ National Organization on Fetal Alcohol Syndrome
 - ▶ www.NOFAS.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>

Books

- Try Differently Rather Than Harder, Diane Malbin
- Damaged Angels, Bonnie Buxton
- The Best I Can Be, Liz Kulp
- When Rain Hurts, Mary Evelyn Greene
- Fetal Alcohol Syndrome, Ann Streissguth
- The Braided Cord, Liz & Jodee Kulp



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