

1 in 20: What to know about working with students with Fetal Alcohol Spectrum Disorders

Michelle Trager

# SUPPORT HR 4151/SB 2238

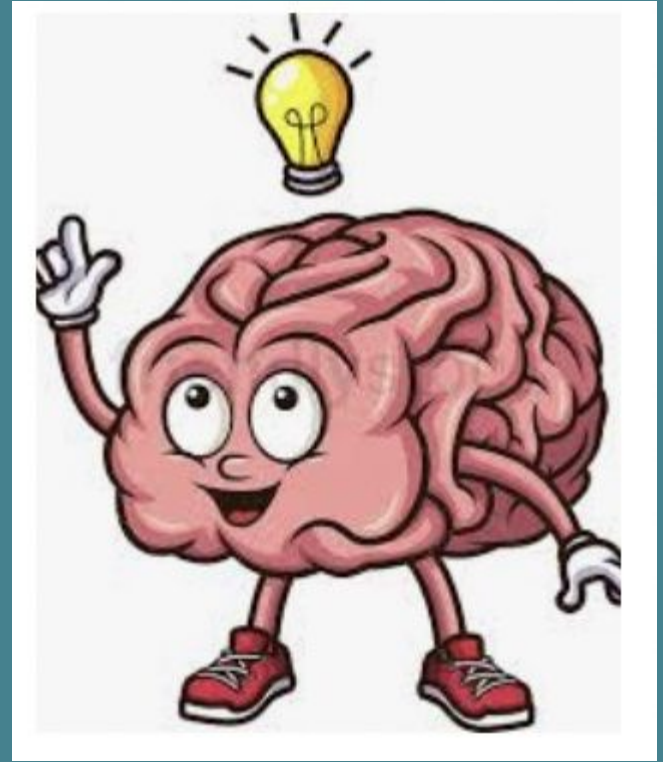
The FASD Respect Act

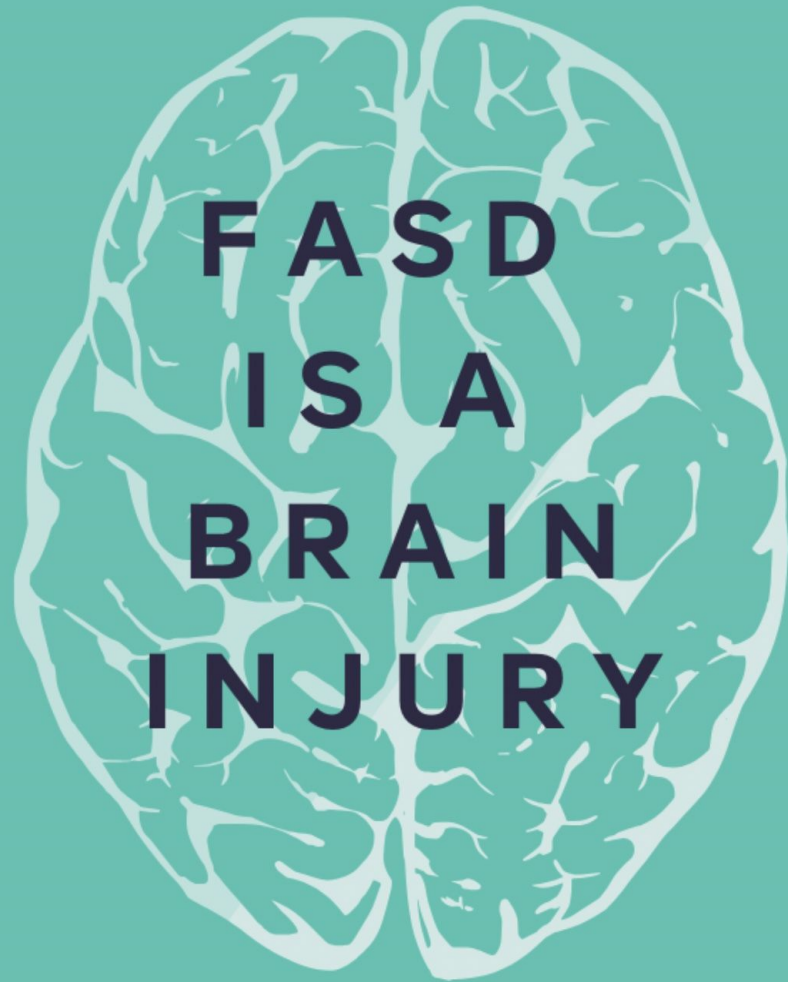


## 1 IN 20

As many as 1 in 20 people have a Fetal Alcohol Spectrum Disorder, they deserve support. Find out more at <https://bit.ly/FASDRespect>

*What did your  
brain do today?*





**FASD  
IS A  
BRAIN  
INJURY**

# What is FASD?

CanFASD: FASD is a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb. Each person with FASD has both strengths and challenges and will need special supports to help them succeed with many different parts of their daily lives.

FASD United: Fetal alcohol spectrum disorders is an umbrella term describing a range of effects that can occur in an individual prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

# ALCOHOL AND PREGNANCY

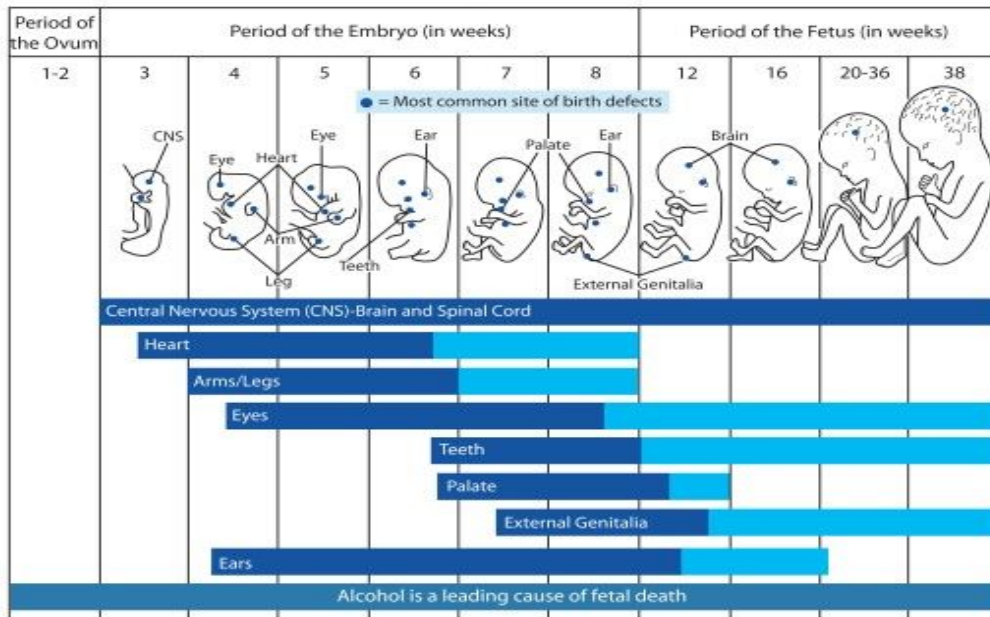
**NO SAFE  
Time.**

**NO SAFE  
Amount.**

**NO SAFE  
Alcohol.**

# PERIOD.

## Your Baby in Weeks



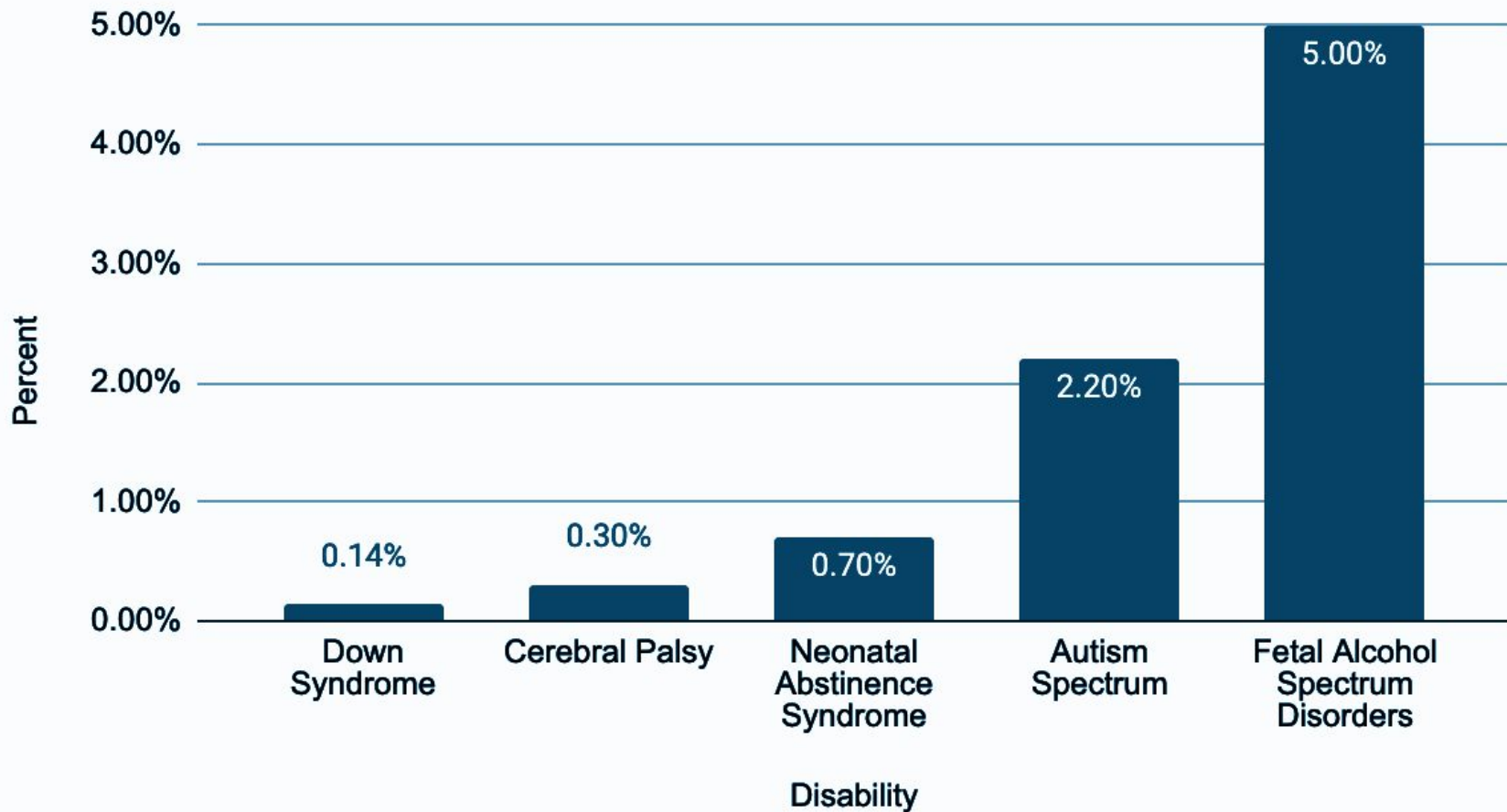
Adapted from: Jacobson, S. Assessing the impact of maternal drinking during and after pregnancy. *Alcohol Health & Research World* 21(3), 1997.

The chart shows your developing baby's vulnerability to alcohol-related defects during specific periods of development. The dark blue segments represent the most sensitive periods.



ONLY 10% OF THOSE AFFECTED BY PRENATAL ALCOHOL EXPOSURE HAVE THE SENTINEL FACIAL FEATURES.

# FASD Prevalence Comparison



Of the over 140,000 babies born annually in Illinois, almost 7000 babies are estimated to have FASD.

Of the 1.95 million students in Illinois schools, as many as 97,850 may have FASD, yet far fewer are diagnosed.

An estimated 633,000 of the 12.76 million people living in Illinois may be affected by FASD.



Even at lower prevalence rates, the estimated average annual cost to Illinois for FASD is over \$7.84 billion in health care, special education, residential care, productivity losses, and corrections costs.



Most people with FASD will not qualify for disability services, even with a diagnosis.

FASD is not tracked in special education under IDEA. Most schools lack training and supports for students with FASD.



In 2018 NIAAA supported a prevalence study of 6,639 first graders in four US geographically separated communities found 222 children (3.3%) had FASD. The study's conservative prevalence estimate ranged up to 5%. The weighted prevalence estimate ranged from 3.1% to 9.85%. Only 2 youths had a previous diagnosis of FASD.

A study published in 2015 indicated that among the population of foster and adopted children the rate of missed diagnosis for FASD was 80%.

Over 90% of individuals with FASD will develop co-morbid mental health conditions. A 2019 study found that the rate of adolescent males with FASD who reported a serious suicide attempt was 19.5 times higher than for adolescent males in the general population.

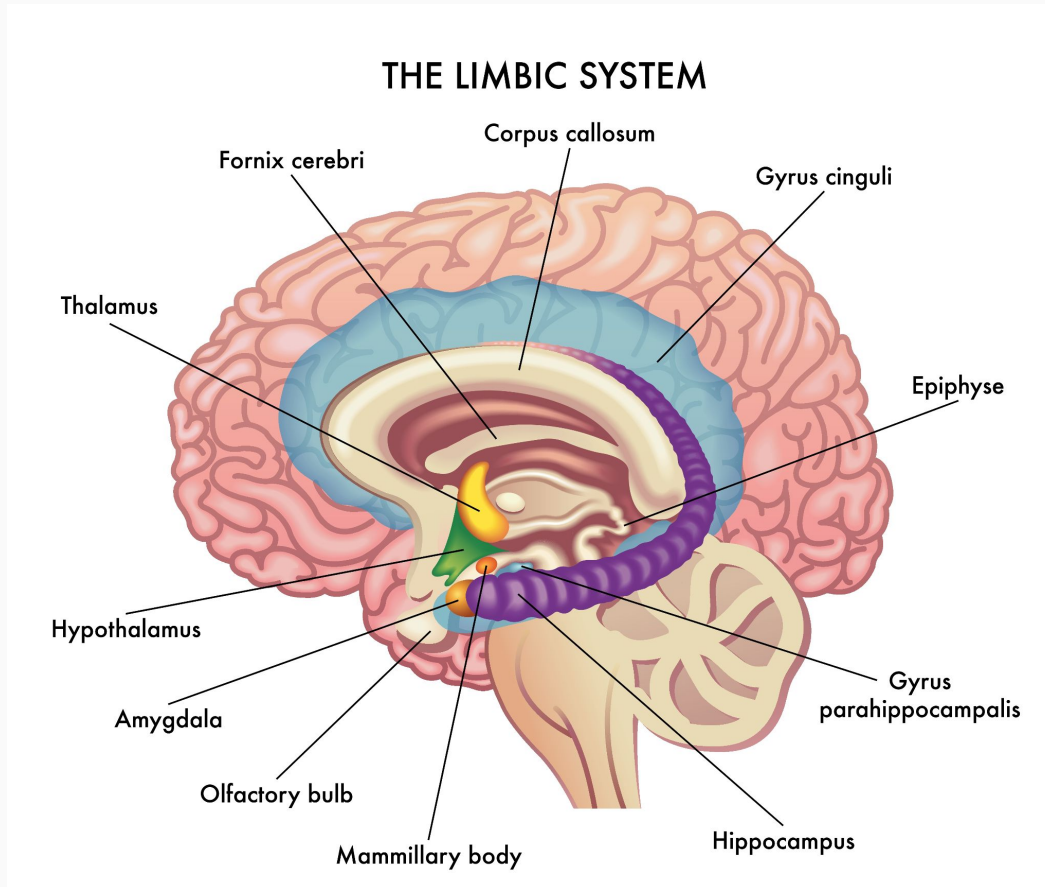
A 2015 review of studies on FASD in the juvenile justice system found that adolescents affected by FASD are 19 to 40 times more likely to become involved in the juvenile justice system. The average age that children with FASD begin having trouble with the law is 12.8 years.

A study published in September 2020 found that the rate of binge-drinking by women of child-bearing age during the pandemic had increased 41%.

In 2020 an Adolescent brain Cognitive Development Study found 25.9% (or 1 in 4) youths had been exposed to alcohol in utero.

In January of this year CDC researchers published an article that stated about 1 in 7 pregnant people (nearly 14%) in the United States reported drinking alcohol, and 1 in 20 pregnant people (5%) reported binge drinking. The dates of the reports were 2018-2020.

# Section Title



Primary characteristics of FASD are directly related to brain differences and vary from person to person.

slow processing

impulsivity

memory problems

sensory differences

difficulty with abstract thought and predicting

difficulty with language and communication

may be rigid in thinking

Secondary characteristics of FASD are behaviors that result when the primary characteristics are misunderstood by others as intentional.

frustration

tantrums

demanding

disruption

resistant

excessively irritable

anxious or fearful

shutting down

argues with everyone

low self-esteem

truancy/running away

may be socially isolated

sexual acting out

many physical complaints because they cannot identify their feelings

Tertiary characteristics of FASD happen as a result of chronic of chronic misunderstanding and frustration over time.

trouble at home

disrupted foster placement

trouble with the law

addictions and substance abuse

self-harm and hospitalizations

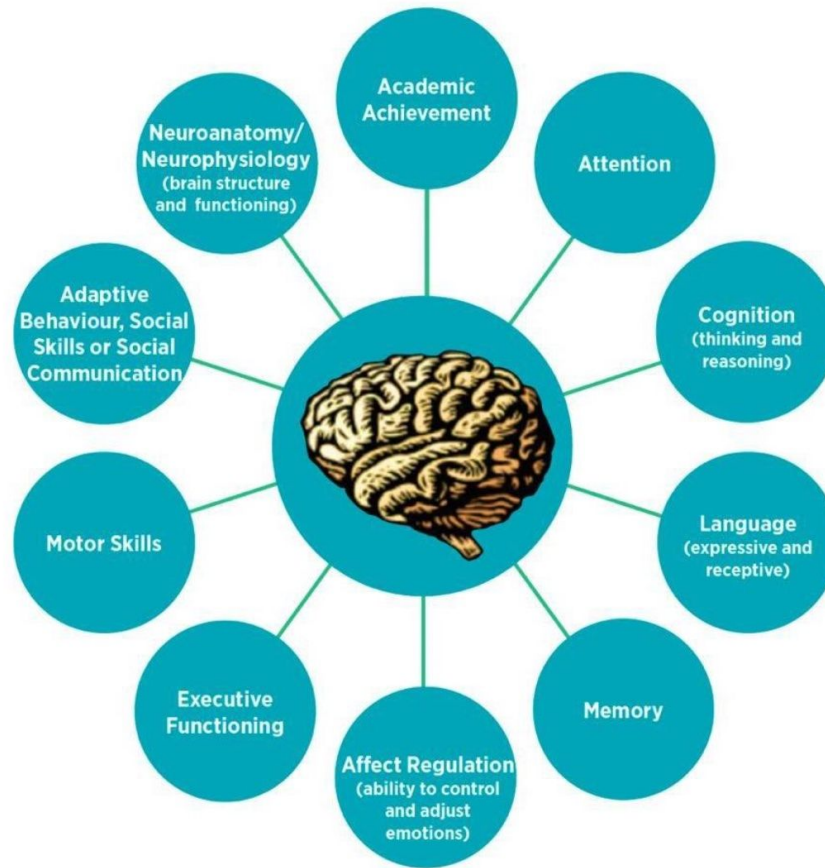
at risk of being victimized

trouble at school

disrupted school experience

incarceration

homelessness



# IQ and Executive Functioning

“Executive functions are a set of cognitive processes that are necessary for the cognitive control of behavior: selecting and successfully monitoring behaviors that facilitate the attainment of goals.”

--Wikipedia

“Executive function and self-regulation skills are the mental processes that enable us to plan, focus attention, remember instructions, and juggle multiple tasks successfully.”

<https://developingchild.harvard.edu>



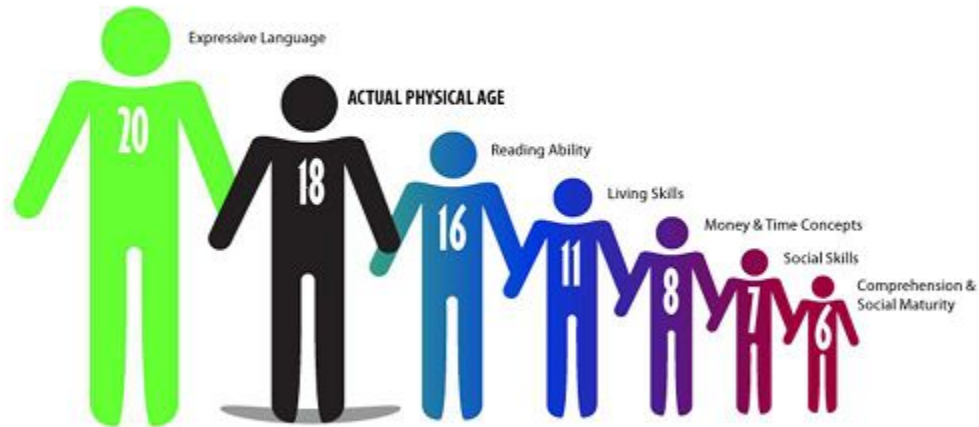
# Executive Functions

judgment, initiating, set-shifting, inhibition, impulse control, mental flexibility, sequencing, planning, problem-solving, organizing, abstract reasoning, self-monitoring, regulating emotional responses, working memory



## What you see is NOT what you get...

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Actual &  
Physical age  
18 years

Expressive language  
of 20-year-old

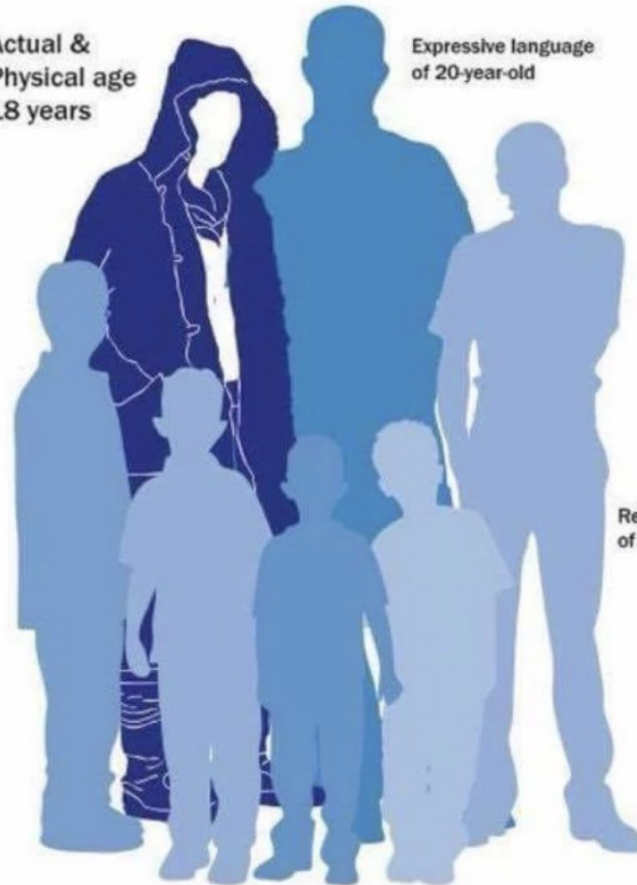
Living skills  
of 11-year-old

Reading ability  
of 16-year-old

Money & time  
concepts of  
8-year-old

Comprehension &  
Emotional maturity  
of 6-year-old

Social skills  
of 7-year-old

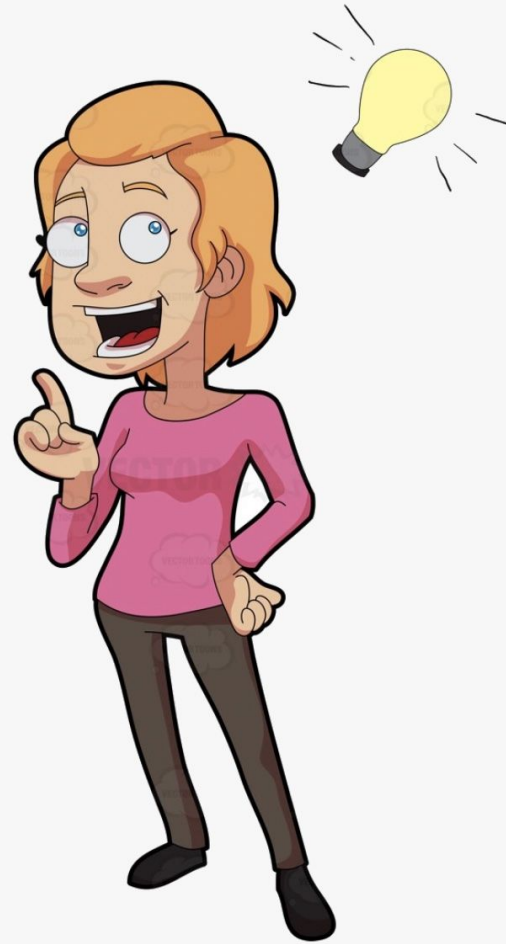


XX%

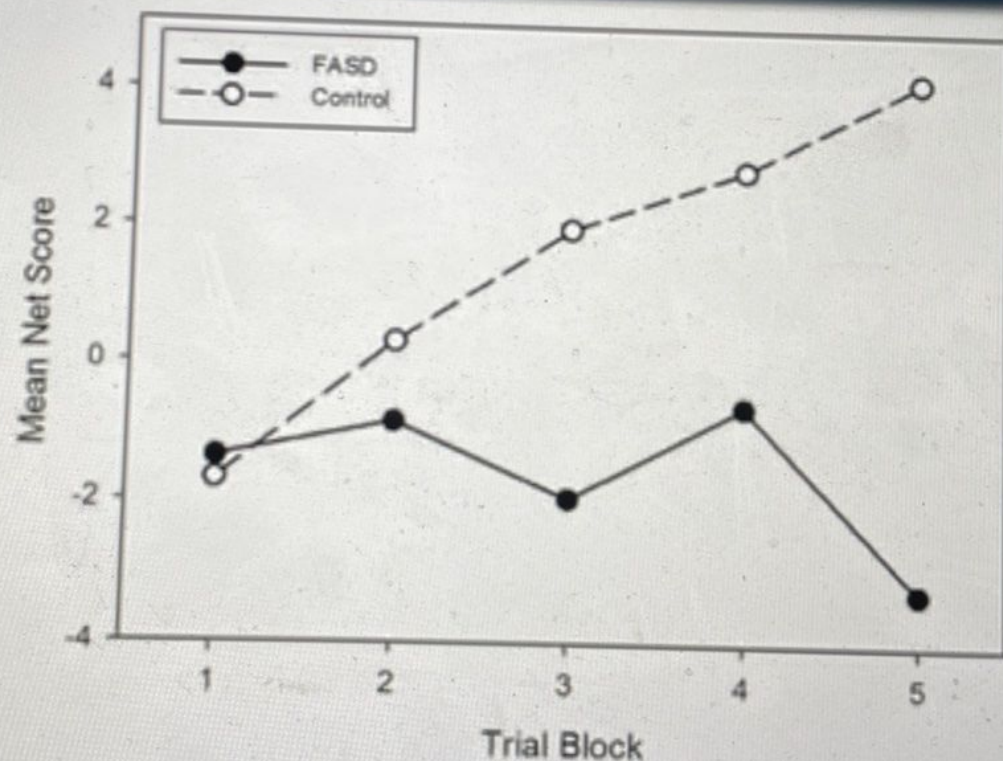
## WISC Scores on Evaluation from Children's Research Triangle

<u>Index</u>	<u>Score</u>	<u>Percentile</u>
Verbal Comprehension	108	70
Visual Spatial	102	55
Fluid Reasoning	88	21
Working Memory	67	1
Processing Speed	77	6
Full Scale IQ	94	34
General Ability Index	100	50

AHA! MOMENT

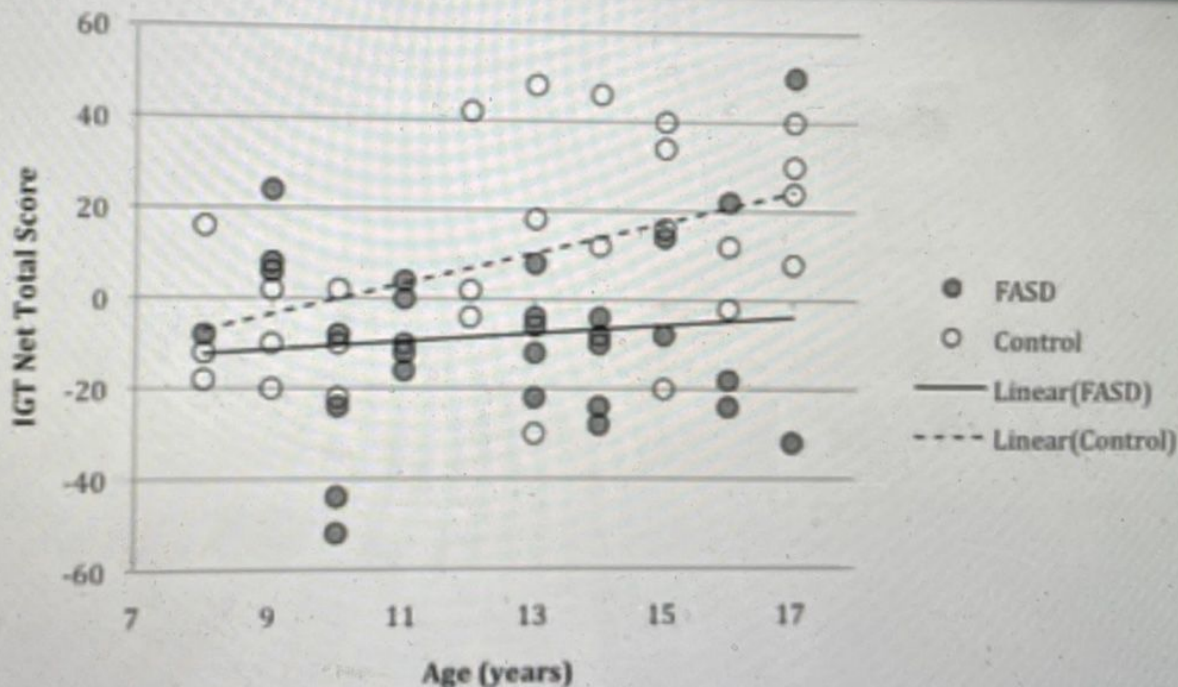


# Performance on IGT – decision making



From: Kully-Martens, K., Treit, S., Pel, J., & Rasmussen, C. (2012). Affective Decision-Making on the Iowa Gambling Task in Children and Adolescents with Fetal Alcohol Spectrum Disorders. *Journal of the International Neuropsychological Society*

# Age Effects on IGT – decision making



From: Kully-Martens, K., Treit, S., Pel, J., & Rasmussen, C. (2012). Affective Decision-Making on the Iowa Gambling Task in Children and Adolescents with Fetal Alcohol Spectrum Disorders. *Journal of the International Neuropsychological Society*

## Fetal Alcohol Spectrum Disorders

Living every day like a lamp with a short in it



Some days, the FASD brain works like a bright, shining lightbulb. Symptoms are minimal. They are able to do common tasks with little or no help. They remember things they've learned with few, if any, difficulties.



Some days, the FASD brain's bulb seems to have a short in it. Symptoms come and go- they seem to be misbehaving more. They can sometimes do common tasks and sometimes they can't. They sometimes remember things they've learned, but forget other things.



Some days, the FASD brain's bulb won't turn on at all. Symptoms show up throughout the day and what seem to be misbehaviors are nearly non-stop. Tasks they can often do alone, they now are completely unable to do. They can't remember things that they've demonstrated mastery of in the past.



# Common interventions that typically do not work for individuals on the FA Spectrum

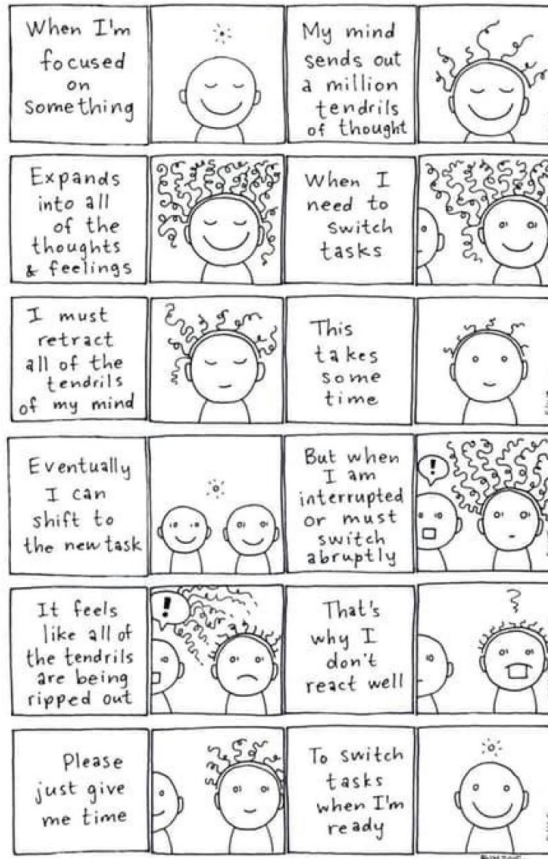
time out, “natural” consequences,  
lecturing/yelling, contracts, reasoning/logic, star  
charts/sticker charts, points/levels, “store,”  
taking something away

call parents to pick the child up (again),  
detention, isolate, suspend, incarcerate



# Why it's hard to switch tasks

(Let's call it Tendril Theory)



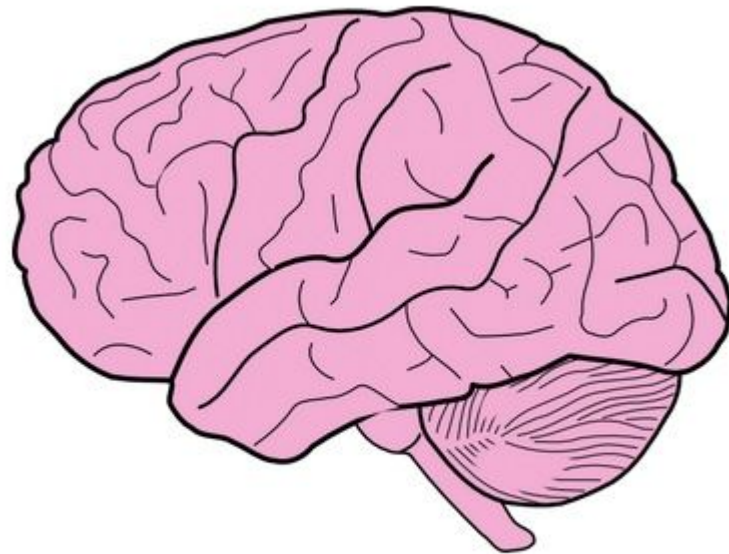
# Values Clash



**You can't convince some people with Fetal Alcohol that their thinking is off because their thinking is off. Thinking is their disability. Save your energy for interventions, not lectures.**

FASD CAREGIVER  
*Success*

Bring it back  
to the brain!



**AN EXPLOSIVE OUTBURST—  
LIKE OTHER FORMS OF  
MALADAPTIVE BEHAVIOR—  
OCCURS WHEN THE  
COGNITIVE DEMANDS BEING  
PLACED UPON A PERSON  
OUTSTRIP THAT PERSON'S  
CAPACITY TO RESPOND  
ADAPTIVELY.**

**ROSS W. GREENE, THE EXPLOSIVE CHILD**

# Comparing ODD, ADHD and FASD

(D Dubovsky 2002)

	ODD	ADHD	FASD
<b>Behavior</b>	Does not complete tasks		
<b>Underlying cause for the behavior</b>	<ul style="list-style-type: none"><li>• Takes in the information</li><li>• Can recall the information when needed</li><li>• Chooses not to do what they are told</li></ul>	<ul style="list-style-type: none"><li>• Takes in the information</li><li>• Can recall the information when needed</li><li>• Gets distracted</li></ul>	<ul style="list-style-type: none"><li>• May or may not take in the information</li><li>• Cannot recall the information when needed</li><li>• Cannot remember what to do</li></ul>
<b>Interventions for the behavior</b>	Provide positive sense of control, limits, and consequences	Limit stimuli and provide cues	Provide one direction at a time

# What might work? Some Ideas:

NOT talking when they are escalated (no matter how quiet and calm we are and don't say their name over and over

Roleplay: we show them what we want them to do and then they roleplay what they saw us do

Repetition, repetition, repetition, much more than we think we should need to do (especially if they are older or have a high IQ); we have to get past the damaged working memory to get it into long term memory



# What else works?

Modifying the environment, visual cues, preparing for transitions, structure and habits, supervision, distractions, humor, break it down into fewer and smaller steps, “less is more” in their environment, food/sleep/exercise, bribery, “enabling,” giving them time to respond (sometimes at least 30 seconds), verbal cues such as “we’re going to talk about this question, don’t answer it right now, just think about it and we’ll talk after we finish this page.”





# Any other ideas?

External support person who can co-regulate them

Focus on Interdependence rather than Independence

Don't point out consequences in the heat of the moment; don't tell them it's no big deal; don't take away things they like; don't use logic in the heat of the moment; don't respond to cursing in the moment

“

Every time you think of calling a kid 'attention-seeking' this year, consider changing it to 'connection-seeking' and see how your perspective changes.

— Dr. Jody Carrington  
PSYCHOLOGIST

edutopia

# Some common areas of strengths for individuals with FASD

Very friendly and engaging (which is also a risk factor when no one is a stranger to them); love to be helpful; love to have a job/hard workers; often creative (music, dance, art, crafts); might be good in sports; good with animals; they do worry about others (but can't see how their own words and actions impact others); determined; may be very good with elderly or young children (caveat is sexually inappropriate behaviors, which are not uncommon); every day is a new day—they don't hold grudges (the flip side is that re-teaching is needed and consequences carried over from the day before probably won't work)



*Find each individual's unique strengths and build on those!*



“FASD doesn’t excuse behavior, but it explains behavior. And if it explains behavior, then it tells us how we respond to it. It doesn’t mean we ignore challenging behaviors, but our focus is on building strengths and abilities and changing the environment so they can be more successful.”

–Dan Dubovsky on the FASD Success Show  
podcast with Jeff Noble



Learn more and advocate

- Education In Schools
- FASD Informed Interventions
- Research
- Services for Adults with FASD
- Education in Medical and Mental Health Systems
- Increased Diagnostic Capacity
- Education in the Justice System
- Building FASD Systems of Care in States
- Prevention

**SUPPORT  
HR 4151  
AND  
SB 2238**

## **THE FASD RESPECT ACT**

People with Fetal Alcohol Spectrum Disorders  
need our support.

Find out how you can help at  
<https://bit.ly/FASDRespect>

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"If you've told a child a thousand times, and the child still has not learned, then it is not the child who is the slow learner." --Walter Barbe

# RESOURCES

FASD United

<https://fasdunited.org/>

<https://nofaspolicycenter.org/>

Canada FASD Research Network

<https://canfasd.ca/>

Jeff Noble

<https://www.fasdsuccess.com/>

(podcasts, trainings, support group)

Jeff Noble

Making Sense of the Madness: An FASD Survival Guide (2012)

Diana Malbin

Trying Differently Rather Than Harder (1999)

Dr. Ira Chasnoff and Ron Powell

\*\*Dr. Chasnoff is a Chicago doctor

Guided Growth: Educational and Behavioral Interventions for Children and Teens with Fetal Alcohol Spectrum Disorders and Early Trauma (2020)

<https://www.ntiupstream.com/>

Ellen Rodger and Rosie Goswell

Understanding Mental Health: Fetal Alcohol Spectrum Disorder

Dr. Carl Bell

\*\*Dr. Bell was a doctor who practiced in Chicago

Fetal Alcohol Exposure in the African-American Community (2018)

Dr. Vanessa Spiller

Explained by Brain

<https://www.jumpstartpsychology.com/>

Adrienne Bashista and Families Affected by Fetal Alcohol Spectrum Disorder

<https://fafasd.net/index.php/2021/02/25/oppositional-behavior-and-fasd/>

Fetal Alcohol Spectrum Consultation Education and Training Services

<https://fascets.org/>

Collaborative Initiative on Fetal Alcohol Spectrum Disorders

<https://cifasd.org/>

<https://www.facebook.com/groups/FASDaFlyingwithbrokenWings/>

<https://redshoesrock.com/>

Excellent YouTube videos of trainings:

Nate Sheets

Dan Dubovsky

Documentary: <https://thefasdproject.org/>

# Sources

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<https://nofaspolicycenter.org/the-fasd-respect-act/strategic-advocacy/il-respect/>

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