FETAL ALCOHOL SPECTRUM DISORDERS

WHAT WE ALL NEED TO KNOW

MARY SCHALK FASD PROGRAM DIRECTOR PARTNERS IN PREVENTION

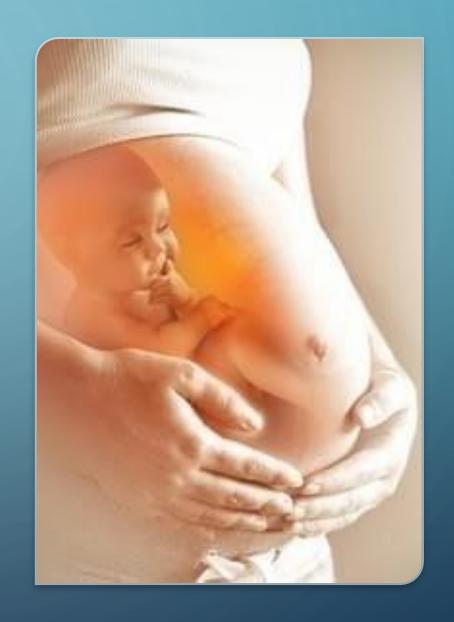
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SERVING ALCONA, ALPENA, MONTMORENCY AND PRESQUE ISLE COUNTIES

ETHANOL CROSSES THE PLACENTA FREELY





A "Standard" Drink

12 fl oz of 2-3 fl oz of 1.5 fl oz shot 8-9 fl oz of 5 fl oz of 3-4 fl oz of 1.5 fl oz of regular beer table wine cordial, liqueur, brandy or of 80-proof malt liquor fortified wine distilled spirits (shown in a (such as sherry or aperitif cognac (a 12-oz glass) or port; 3.5 oz single jigger (2.5 oz shown) shown) or shot)



About 5% Alcohol



About 7% Alcohol



Alcohol



About 17% Alcohol



About 24% Alcohol

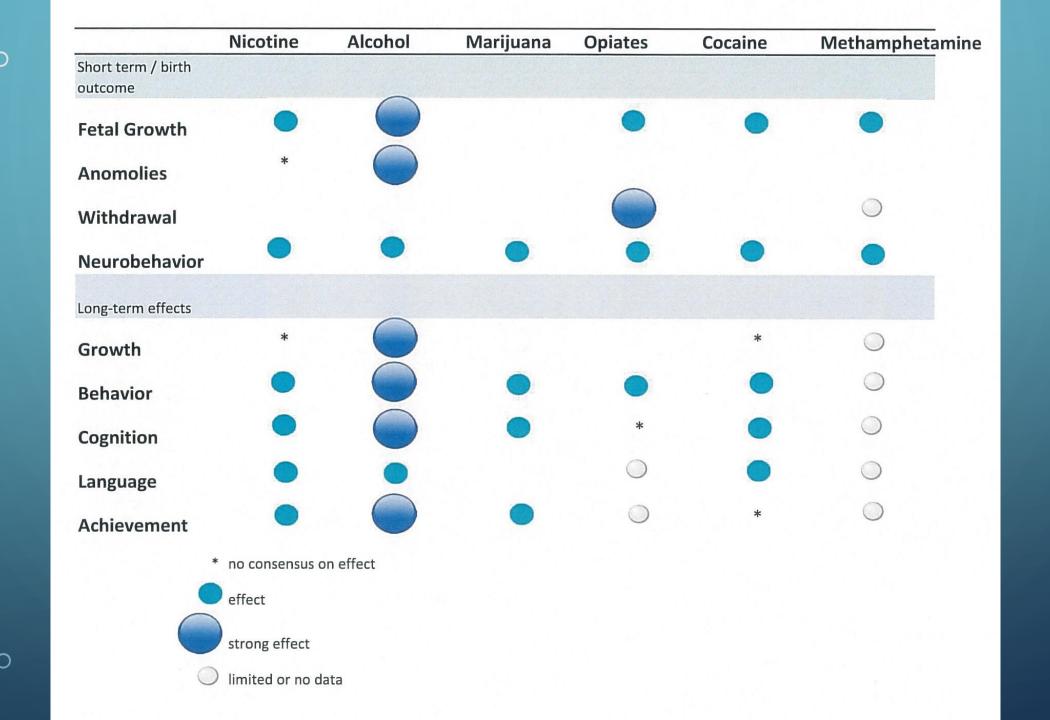


About 40% Alcohol

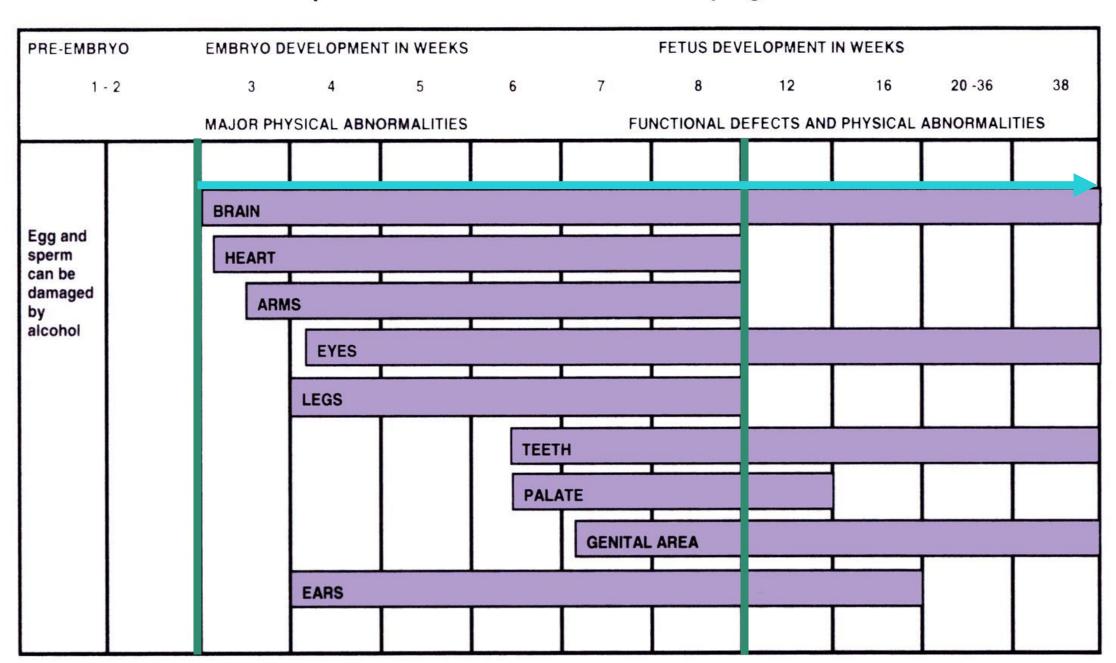


About 40% Alcohol

"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



Impact of Alcohol Use on the Developing Fetus



NO KNOWN SAFE

- Type
- Time
- Quantity
- Frequency





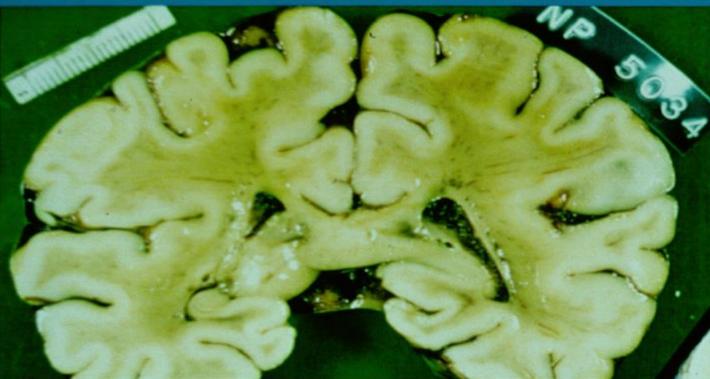
DIFFERENTIATION AND MIGRATION

- Cell proliferation
- Determination
- Differentiation
- Migration

```
• What am I doing here?

• What am I doing here?
```

Coronal Sections of Brain



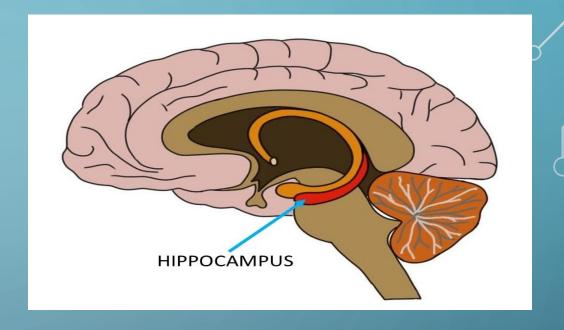
FAS

Normal

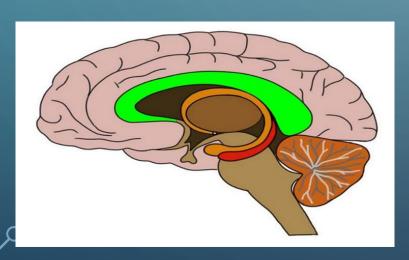


HIPPOCAMPUS

- Learning
- Memory



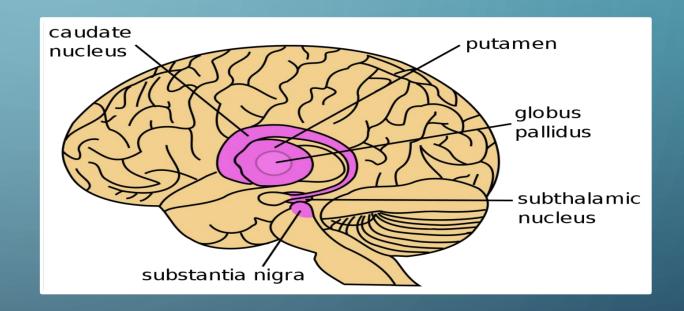
CORPUS CALLOSUM



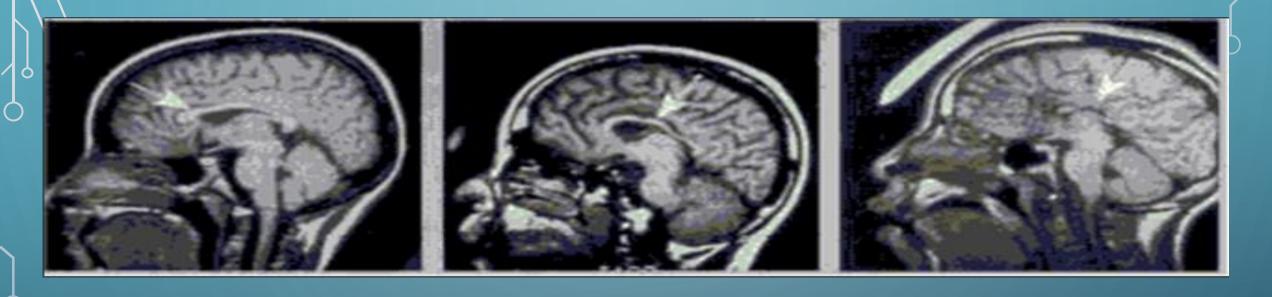
Processes information between the Right and Left brain

BASAL GANGLIA

- Processes memory
- Predicting outcomes
- Time perception
- Setting goals



CORPUS CALLOSUM DAMAGE



Left: 14 year old control subject: normal

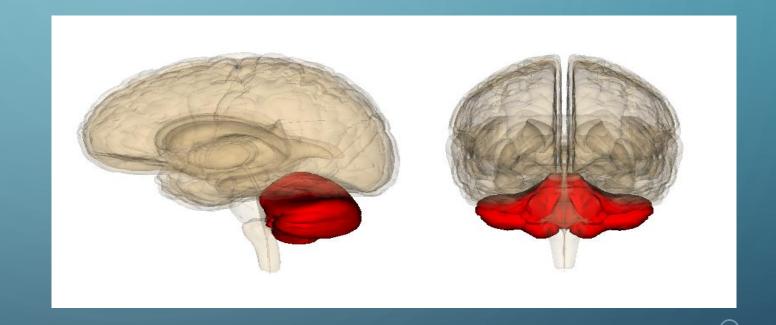
Center: 12 year old with FAS: thin

Right: 14 year old with FAS: agenesis

Mattson, Jernigan and Riley, 1994

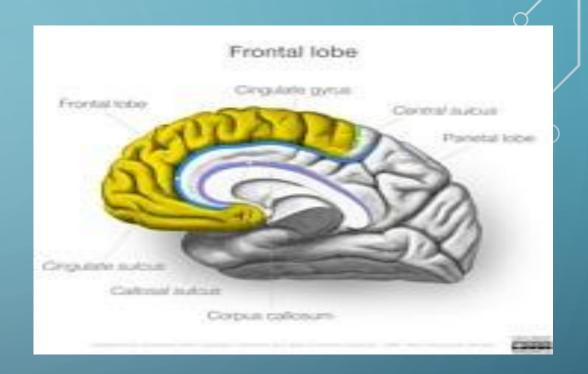
CEREBELLUM

- Coordination
- Movement
- Behavior
- Memory



FRONTAL LOBES

- Executive functions
- •Impulse control
- Judgment



"By the time I figure out what I'm gonna do ...



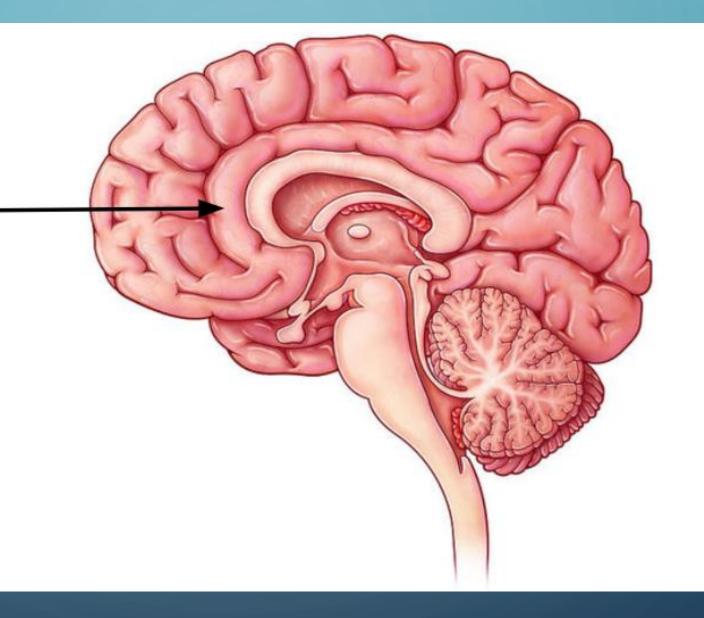
I've already done it!"



INSULA

Located deep within the cerebral cortex, under the many folds in the brain.

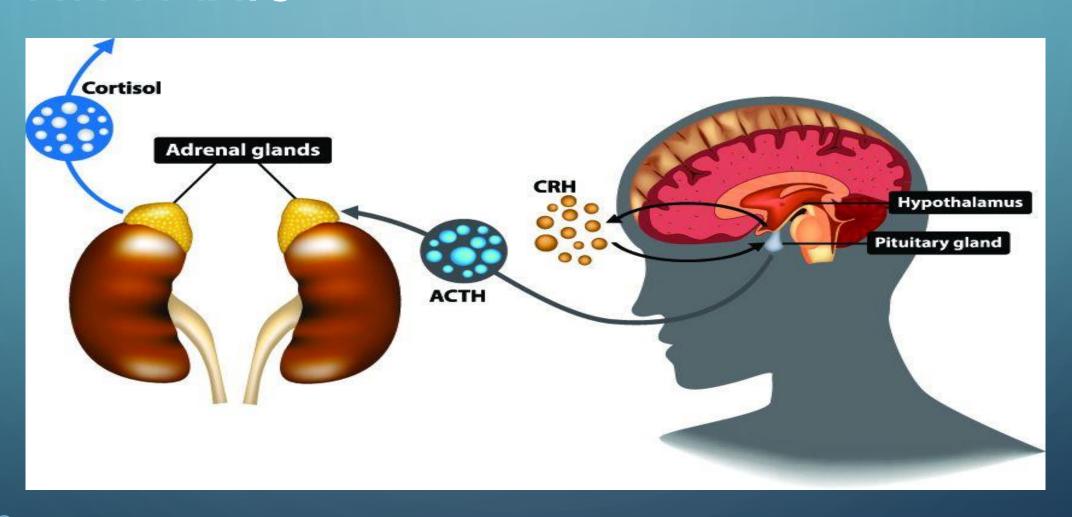
Receives and decodes interoceptive input from sensory receptors in our body - tissue, organs, bones, etc.

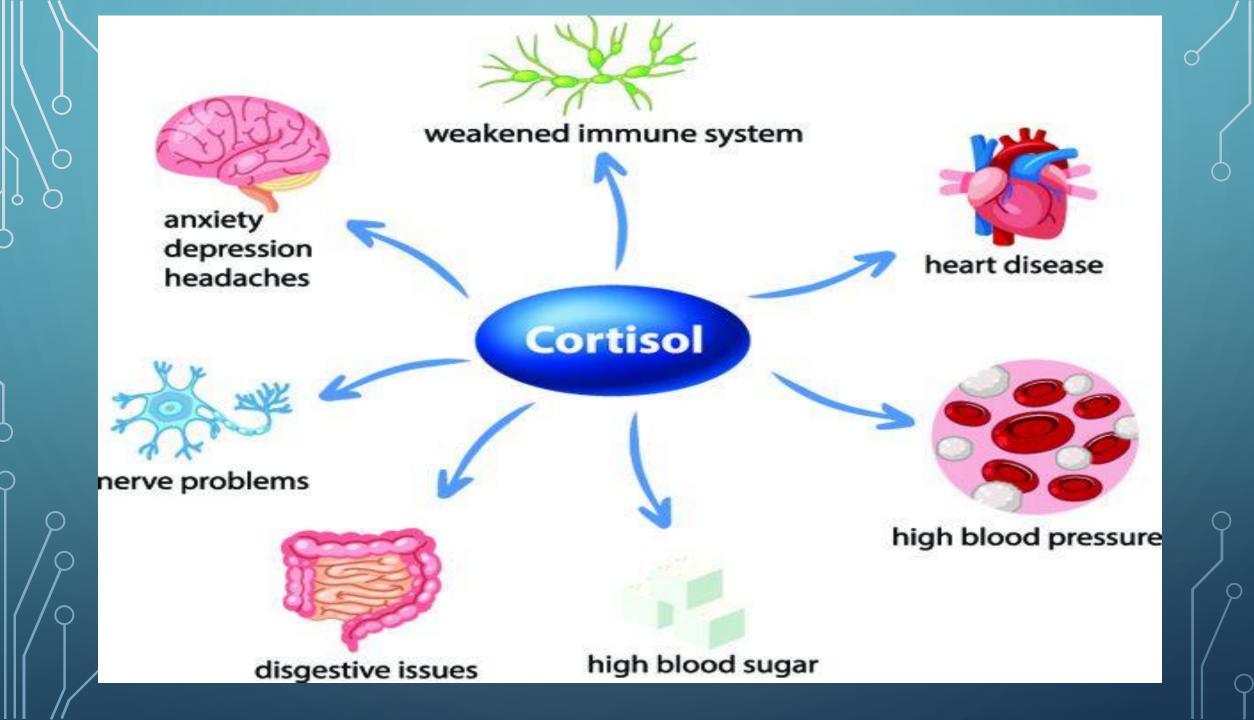


NEUROCHEMICALS

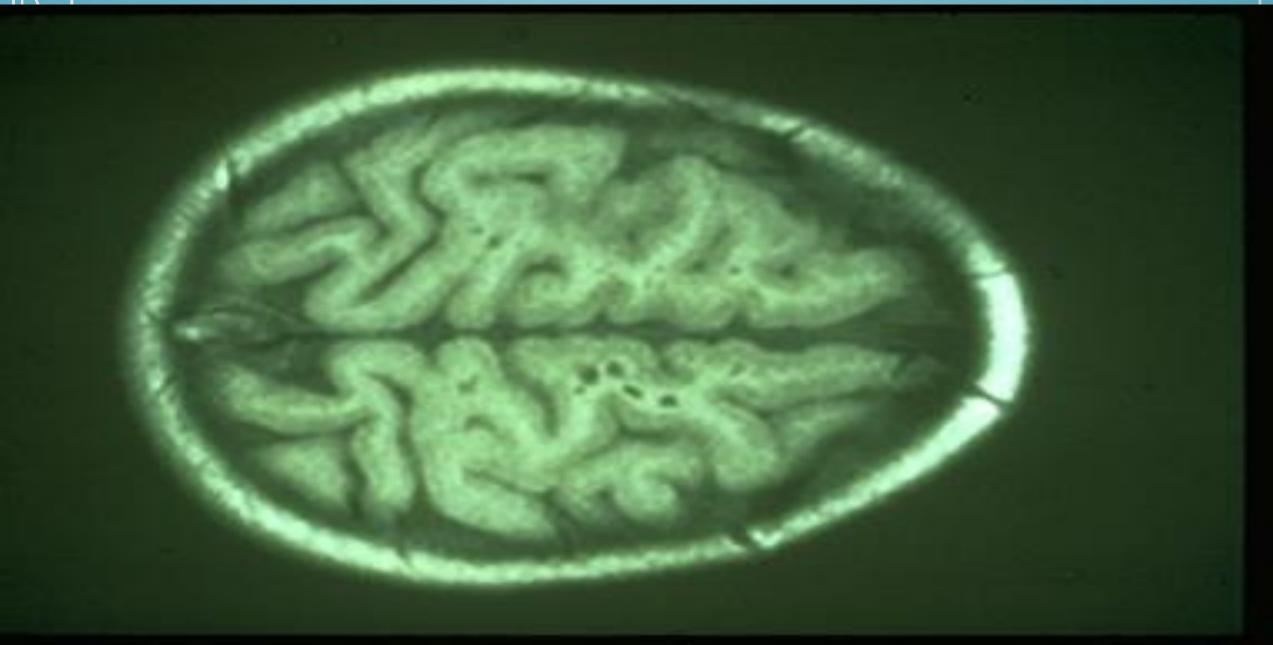
- Oxytocin production
- Dopamine
- Glutamate

HPA AXIS









IQ

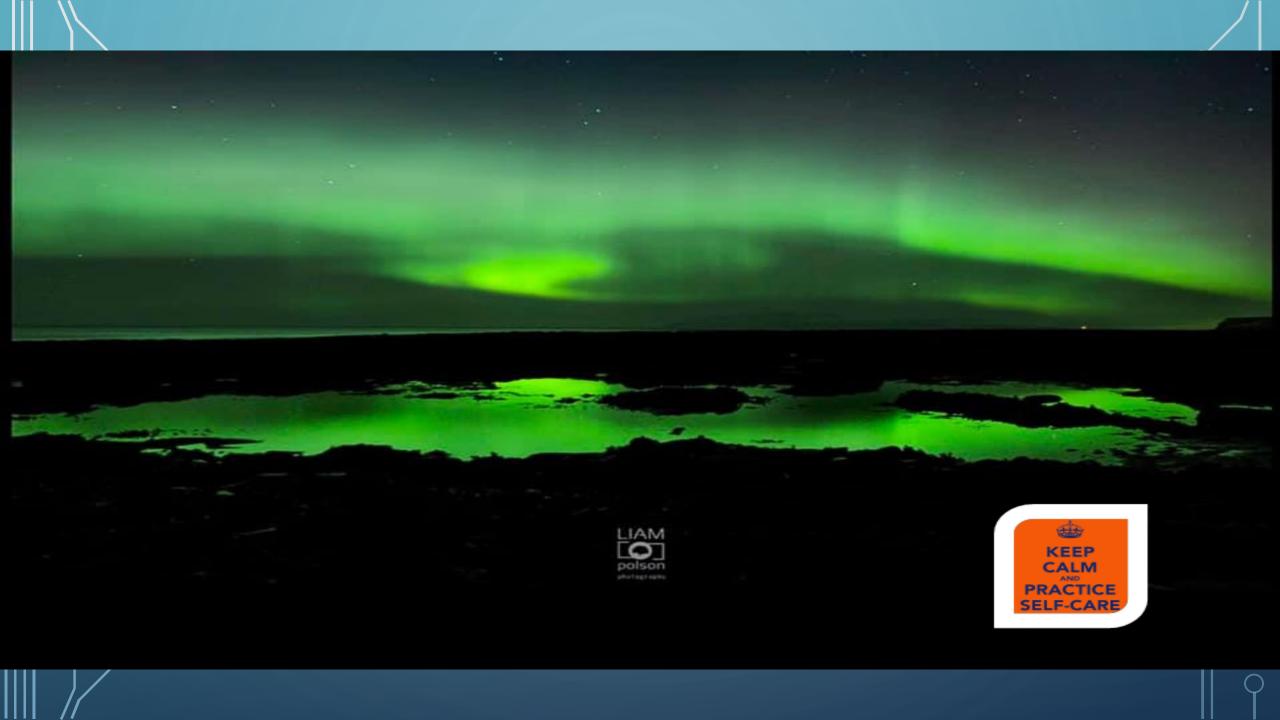
- Generally in the borderline to low average range
- Large range from very high to very low
- Strength or deficit in verbal or visual domains
- More difficulty giving non-verbal responses
- More difficulty with social behaviors and thoughts, attention, delinquency, and aggression

EXECUTIVE FUNCTION

- Planning
- Problem solving
- Monitoring own thought processes
- Cognitive flexibility
- Rapidly producing responses
- Controlling responses & impulses
- Use of feedback



WHEN A CHILD TAKES ITS FIRST DRINK BEFORE ITS FIRST BREATH...





Variability of consequences

- ► Tremendous range of potential impacts
- Variability in severity
- No person has all the impacts we will describe
- Impact is responsive to dose and timing of exposure
- ▶ What if?

Primary
Performance
Domains

Categories described by Diane Malbin as a means to group the myriad consequences of prenatal alcohol exposure

Additional physical details

Executive Functioning

Planning

Organizing

Prioritizing

Sequencing

Initiating

Following through

Executive Functioning continued







SETTING GOALS



COMPLYING WITH EXPECTATIONS



BEING ON TIME



ADHERING TO A SCHEDULE

Impaired Judgement

- Unable to make decisions
- Difficulty recognizing safety or danger
- ► Differentiating reality from fantasy
- Recognizing friend or stranger

Impulsivity

- ► Ready, fire, aim!
- ► Words, actions, decisions
- May be able to see the problem after the fact

Memory

Information input

Integration

Forming associations

Retrieval

Output

Memory continued

- Difficulty learning from past experiences
- Repeats same mitsakes over and over
- Confabulation
- Suggestibility



Inconsistent Performance

- Here today, gone tomorrow
- ► But then it is back again
- ►Or not
- "I am consistently inconsistent" RJ Formanek

Abstract Concepts

- **►**Time
- Money
- **▶**Ownership
- **►**Math



Deficits in math typically more pronounced than other academic areas

Math



Occur even with normal IQ



Related to processing speed and efficiency, executive functions, and working memory

Concrete thinkers



Perseveration

- ▶ Rigid
- ► Get stuck
- Difficulty switching gears
- Difficulty transitioning
- ► Difficulty stopping



Why it's hard to switch tasks (Let's call it Tendril Theory)

When I'm My mind sends out focused a million on Something tendrils of thought Expands When I into all need to of the Switch thoughts tasks & feelings I must This retract takes all of the tendrils some time of my mind

Inability to Generalize

- Difficulty forming links and associations
- Unable to apply a rule in a new setting
- Difficulty applying learning to new application

Communication Challenges

Appears to understand more than they truly comprehend

Repeats (rules, instructions) verbatim, but fails to apply them

Verbal skills much better than comprehension, appear competent

Language Problems

- ► Difficulty comprehending meaning
- Confabulation
- May agree inappropriately
- May talk excessively, yet unable to engage in meaningful way



May think more slowly

Slow Cognitive Pace



Make require time to generate a response



"ten second people in a one second world"

Slow Auditory Pace

- Language processed more slowly
- Needs more time to comprehend
- May only grasp every second or third word in normally-paced speech

Dysmaturity



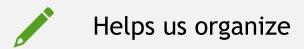
Sensory Integration Dysfunction

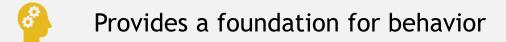
- May overreact or underreact to sensory stimulation
- May be easily overwhelmed
- Unable to filer out extraneous stimuli
- 5 senses?

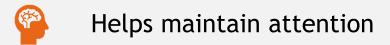




Proper Sensory Integration







Supports positive relationships



Vestibular System

- Sense of balance and movement
- First system to develop in utero
- Close relationship to gravity, safety, survival, arousal and attention
- Awareness of yourself in relation to space around you (with input from eyes and ears)

Proprioceptive System



Sensory input from muscles and joints



Position, weight/pressure, stretch, movement



Detects body parts in relation to each other



Detects relation to objects in environment

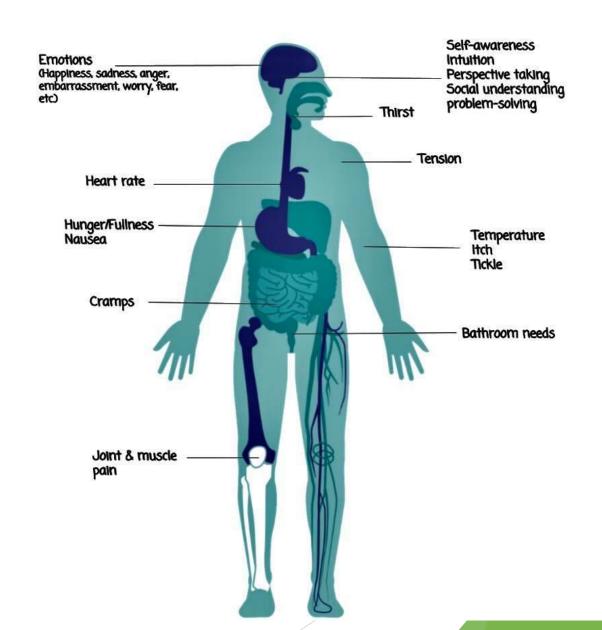
Interoceptive System

- ► Tells what is happening inside the body
- Hunger or thirst
- ► Cold or warm
- ► Tired or alert
- Urinate, defecate
- Seeks homeostasis



INTEROCEPTIVE AWARENESS

HOW WE KNOW WHAT'S HAPPENING, AND HOW WE FEEL INSIDE OUR BODIES



Hypersensitive

- Overreacts
- Attempts to block out stimulation
- Orients to anything new in environment
- Notices things others don't notice
- Easily distracted
- Picky eater

Hyposensitive

- Rough behavior
- ► Chews or mouths non-edible items
- ► Touches things excessively
- Poor safety awareness
- Seeks opportunities for deep pressure
- ► Grinds teeth
- Self-harming behaviors

>50% of people with FASD report a high pain tolerance

30% report low pain tolerance

Includes oral tactile

Avoids being close to others

Touch

Eating

- Lack of coordination between sucking (chewing) and swallowing
- Easily distracted
- May not feel hungry, may not feel full
- Sensory overload

Social Challenges

- Inability to read non verbal cues
- Improperly recognize emotion in others
- Trouble with problem solving in social situations
- Difficulty showing empathy
- Poor understanding of others' mental states









Social Challenges continued

- Poor understanding of boundaries
- Dysmaturity
- Moral chameleon
- ► Vulnerable to manipulation
- May easily make friends, but can't maintain

Motor Skills

- ► Poor muscle tone rigid or flaccid
- ► Both fine and gross impacted
- Unstable posture
- Delayed reaction time
- Poor hand eye coordination
- ► Trouble coordinating two hands together

Affect and Emotional Regulation

- Less ability to maintain focus
- ► Mood swings, unpredictable mood
- Trouble recognizing, understanding and responding to emotions of others
- Increased mood and anxiety disorders

Sleep

- Difficulty getting to sleep, staying asleep or waking up
- ► Circadian rhythms disrupted

Dysgraphia

- Trouble forming letters or shapes
- Awkward pencil grip
- Trouble with sentence structure
- Difficulty organizing or articulating thoughts on paper
- Impacted by motor skills, special perception and language processing

Inappropriate Sexual Behavior

- Sexual development not delayed
- Misunderstanding of personal space
- Desire to fit in and be accepted
- Impulsivity
- Perpetrator or victim of inappropriate behavior



Metabolic Disorders

- ► Type 2 Diabetes
- ► Lower HDL
- Elevated triglyceride levels
- Increased risk of stroke and heart attack

Secondary Disabilities

- Early school dropout
- Alcohol and other drug problems
- ► Having children they can't care for
- Joblessness
- ► Homelessness
- ► Trouble with the Law
- Mental Health problems
- Premature death

Mental Health Concerns

- ▶ 83% 94% of people with FASD across the age span
- **ADHD**
- Depression and mood disorders
- Anxiety disorders and Obsessive Compulsive Disorder
- ► Conduct Disorder
- ► Higher suicide rates
- Alcohol and other drug dependence

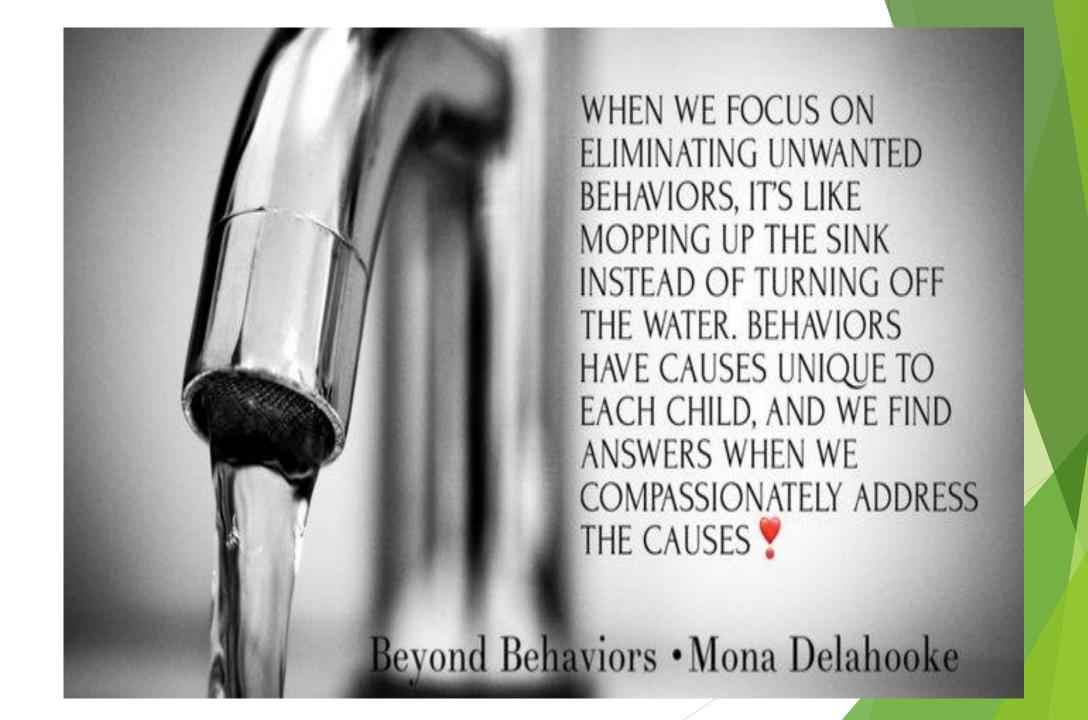
Adaptive Functioning / Daily Living

- Personal hygiene
- Personal finances
- Navigating social interactions
- **Employment**
- **►**Safety

Prevalence of 12 ACEs among children with FASD compared to non-FASD controls.

In FASD, ACEs are often underway before birth.

ACE	FASD %	Non-FASD %
Parents Divorced/Separated	72.5	45.7
Drinking/Drugs in Home	84.7	22.9
In Foster Care	90.8	16.2
Neglect	86.7	14.3
Unloving Family	68.4	11.4
Parental Depression	32.7	35.2
Physical Abuse	50.0	9.5
Verbal Abuse	46.9	7.6
Parent in Prison	35.7	7.6
Mother Abused	32.7	8.6
Sexual Abuse	23.5	5.7
In Residential Care 🛑	19.4	2.9
None or One Year	6.1	58.1
Two to six Years	39.8	35.2
Seven to Twelve Years	54.1	6.7



Invisible Gap

Expectation is here

Ability is here



The person has limited ability to change





EXPECTATIONS MUST CHANGE

ENVIRONMENT MUST CHANGE

EIGHT MAGIC KEYS

ekwien562

PLANNING FOR STUDENTS WITH FETAL ALCOHOL SPECTRUM DISORDER



CONCRETE

TALK IN CONCRETE TERMS AVOID ABSTRACT LANGUAGE

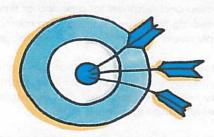


P. ROUTINE HELP REDUCE ANXIETY



SPECIFIC

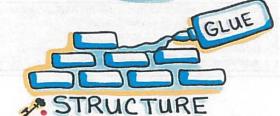
SAY EXACTLY WHAT YOU MEAN GIVE STEP BY STEP DIRECTIONS



* CONSISTENCY

PARENTS & EDUCATORS USE THE SAME WORDS & STRATEGIES





THE GLUE THAT MAKES THE WORLD MAKE SENSE ... THEIR FOUNDATION



REPETITION

RE-TEACH MANY TIMES TO RETAIN IN LONG - TERM MEMORY



SIMPLICITY



SUPERVISION
SCAFFOLD INDEPENDENCE

Kristin Wiens 2017



Concrete

- **►** Concrete terms
- No double meanings
- No idioms
- It helps to think younger

Abstract to Concrete



I'm going to run to the store.



You need to get your act together.

Structure

- This is the glue that holds everything together!
- Make expectations clear
- Provide written (pictorial) guides, checklists and schedules

9 REASONS TO USE VISUALS

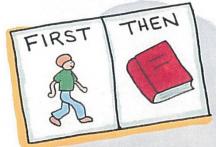
www.northstarpaths.com



· VISUALS ARE PERMANENT (SPOKEN WORDS DISAPPEAR)



· VISUALS ALLOW TIME FOR LANGUAGE PROCESSING



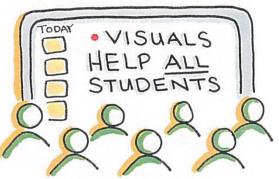
@kwiens 62

· VISUALS PREPARE STUDENTS FOR TRANSITIONS

> I DIDIT MYSELF!



· VISUALS HELP KIDS SEE WHAT YOU MEAN



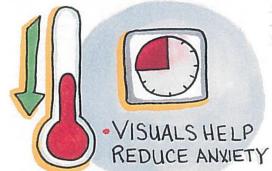
· VISUALS HELP BUILD INDEPENDENCE

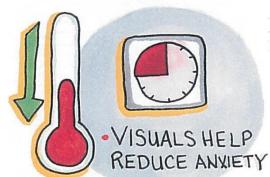


· VISUALS ARE TRANSFERABLE BETWEEN ENVIRONMENTS AND PEOPLE



· VISUALS HAVE NO ATTITUDE · NO TONE · NO FRUSTRATION . NO DISAPPROVAL





WHY IS REPETITION IMPORTANT?

MEMORY DEFICITS

Individuals with FASD may live with short-term and long-term memory deficits which means, without reminders and repetition they may be unable to recall information.

PROCESSING TIME

FASD may also impact processing speed which means it may take longer to take in and respond to information. When things are repeated it provides another chance to process the information.

GENERALIZING

Difficulties generalizing means information learned in one setting is not readily transferred to another which is why it can be helpful to repeat instructions and expectations, especially in new settings.

INCONSISTENCY

An individual may have varying learning abilities or personal changes from day-to-day, so something they could easily do yesterday may have to be repeated or retaught today

COMMUNICATION PROBLEMS

Individuals may struggle with speech and language problems or issues with comprehension so repeating the communication can provide multiple opportunities for them to understand what is being said

SENSORY DISTRACTIONS

Sensory issues can impact every one of an individual's senses which can be very overwhelming. It is difficult to focus on instructions when your senses are overloaded so being given the instructions again can be very helpful.



Routine

- Know what to expect
- Decreases anxiety
- >Allows for learning
- You may find it boring get over it and do it!

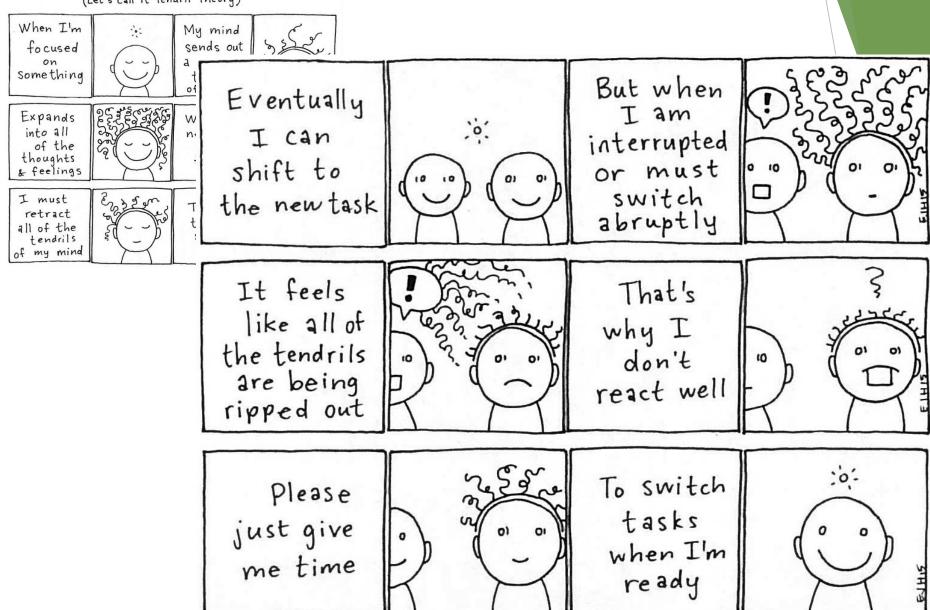
Routines and Transitions

- ► Keep the same schedule
- Use visuals to reinforce the schedule
- Develop rituals
- ► Give alerts in advance of changes
- Make clear how much longer

Transitions

- Explain what is coming next
- Use an auditory signal for changes
- Use tool to signal time for change
- ► Don't rush
- Take a sensory break
- Reduce "wait" time

Why it's hard to switch tasks (Let's call it Tendril Theory)



Consistency

- Same expectations/routines over time
- Same language at home, school, work and elsewhere

Simplicity

- Keep it Short and Simple
- As few words as possible
- Simple environment





Specific

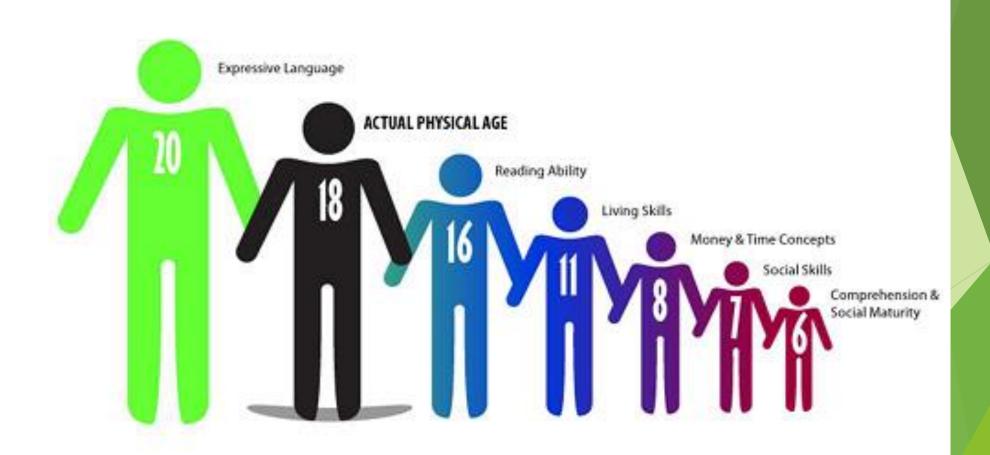
- Say exactly what you mean
- Step by step instructions one at a time
- ► Can't generalize

Supervision

- Yes, even adults
- ► Think younger
- ► Naïve
- Poor judgement

Think younger

What you see is NOT what you get...



Organizing the Physical Space

- Reduce visual and auditory distractions
- "calm corner" or "quiet place"
- ▶ Define boundaries rug, tape, etc.
- Lights low, voice calm
- ► Furniture that fits
- Consistency and predictability

Improve Behavior

- Give a fidgety child a job that requires movement
- Learn the signs of building frustration & teach strategies to diffuse
- Use visual cues of good behavior
- Use visual cues to signal deteriorating behavior
- Immediate rewards for good behavior
- Reduce opportunities for frustration

Sensory Integration / Overload

- Sensory behaviors serve a purpose
- Be a detective watch for signs of overload - note environmental factors
- Accumulation factor
- Plan for sensory breaks
- Food and drink to moderate arousal water bottles, pretzels, jerky, gum

Sensory Integration / Overload

- Replace inappropriate sensory behavior with an acceptable behavior
- Appropriate seating
- Quiet retreat
- Large muscle stimulation heavy work weighted tools
- Occupational Therapy is fabulous!

Walk **Nature** Tear paper Time away Blow up balloon Play dough Cold drink Swing Spin Hum



Stress and Rage

- Stop fighting, step back, observe
- ▶ Don't hug or try to contain
- Spinning / tickling at the beginning
- ► Movement, music, dance
- Self-soothing behaviors rocking, drumming, singing
- Angry area
- Manage your own reactions, Cover face when stressed
- Praise for regaining control

Stress and Rage

- ► Tactile objects to play with
- Warm bath after a stressful time
- Lots of exercise, periods of calm
- Monitor environment for over stimulation
- Monitor for low blood sugar
- Needs lots of rest
- Don't paint him or her into a corner

If someone with FASD is aggressive, it's usually because they are in over their heads.

When you match your expectations with their ability, you'll see less aggression.

You would be aggressive to if you

constantly could not understand things.

Ever try putting something together from IKEA?

facebook.com/FASDSuccess





Teach Self-Regulation

- Help identify emotional state
- Stop and breathe
- ► Stop and think
- Rehearsal and selftalk

Teach Social Skills

- ► Teach personal space
- ► Teach specifically who to touch/hug
- ► Role play appropriate skills
- Use a timer as a reminder to take turns
- Model proper skills in various settings
- ► Clearly define unacceptable behavior

Teach Social Skills

- Public and private behavior
- Inability to meet social expectations increases risky behaviors
- Practice appropriate behavior never demonstrate improper behavior

Support Memory

- ► Use all the senses in learning
- Use picture reminders
- Encourage use of checklists
- Have the child repeat back in their own words
- One thing at a time

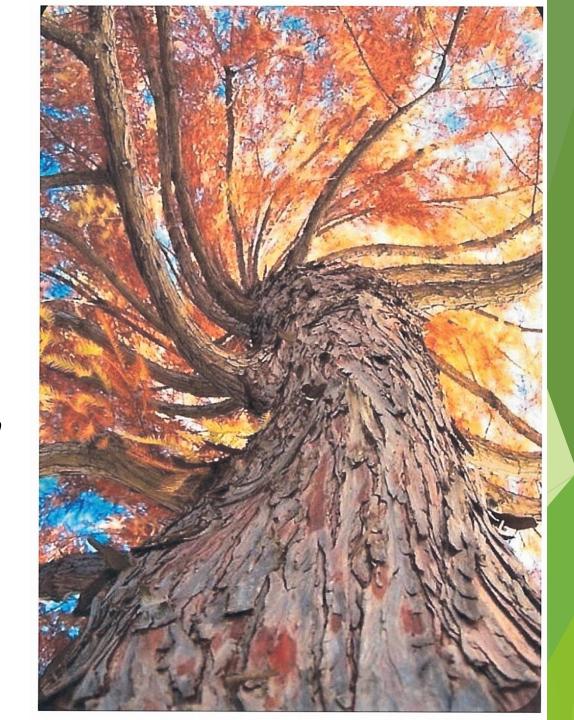


Good judgment comes from bad experience, and a lot of that comes from bad judgment

...but people with an FASD often do not learn from their mistakes

Take a new perspective

Understand it is can't, not won't



Strengths of Persons With an FASD

- Friendly
- ▶ Likable
- Desire to be liked
- Helpful
- Loving, caring, kind, sensitive, loyal, and compassionate

- Determined
- Have points of insight
- ▶ Not malicious
- Energetic and hard working
- Spontaneous, curious, and involved

Identify Strengths to Build On

- **Music**
- **Arts**
- Reading
- **▶** Computers
- Mechanics
- Writing & Poetry
- **▶** Creative

Questions to ask ourselves

- ▶ What is their developmental age?
- ▶ What are their challenges?
- ▶ What is it they don't understand?
- ► What strengths can we draw on?
- ► Who are their supports?
- ► How can we help develop appropriate habits or learned patterns of behavior?