

# Understanding Fetal Alcohol Spectrum Disorders

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# The Papillion Center

- ▶ **Mission Statement:** “Bringing Hope & Healing to Children and Families in Hard Places”
- ▶ **Vision Statement:** To provide quality services and therapies that will enhance the lives of clients who seek our assistance. We will specialize in those affected by Trauma, Fetal Alcohol Spectrum Disorders (FASD), Neonatal Abstinence Syndrome (NAS), and Attachment issues by addressing each of the five identified areas of need: social skills, emotional intervention, therapeutic parenting skills, nutritional and neurochemistry impact, education and support groups.
- ▶ **FASD United State Affiliates for Tennessee and Kentucky.** Serving all states to educate regarding FASD and how to best help those affected by FASD.

# Brief Explanation of FASD

- ▶ **What is fetal alcohol spectrum disorders (FASD)?**
- ▶ As defined by U.S. federal agencies, researchers, and other experts at the 2004 Fetal Alcohol Spectrum Disorders Terminology Summit sponsored by FASD United,
- ▶ “Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. 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.”

# What are the FASD diagnostic categories?

- ▶ FAS: Fetal alcohol syndrome
- ▶ pFAS: Partial Fetal Alcohol Syndrome
- ▶ ARND: Alcohol-Related Neurodevelopmental Disorders
- ▶ ARBD: Alcohol-Related Birth Defects
- ▶ ND-PAE: Neurobehavioral Disorders Associated with Prenatal Alcohol Exposure.

- ▶ Fetal Alcohol Spectrum Disorders is the leading cause of developmental disabilities, it affects approximately 1 in 20 school aged children (CDC#), yet it is often overlooked and misunderstood. FASD can include physical problems and problems with behavior and learning. This presentation is designed to help you understand FASD and gain skills to help those who have been affected.



# Brain Damage Resulting From Prenatal Exposure to Alcohol

Alcohol-Affected Brain vs Normal Brain

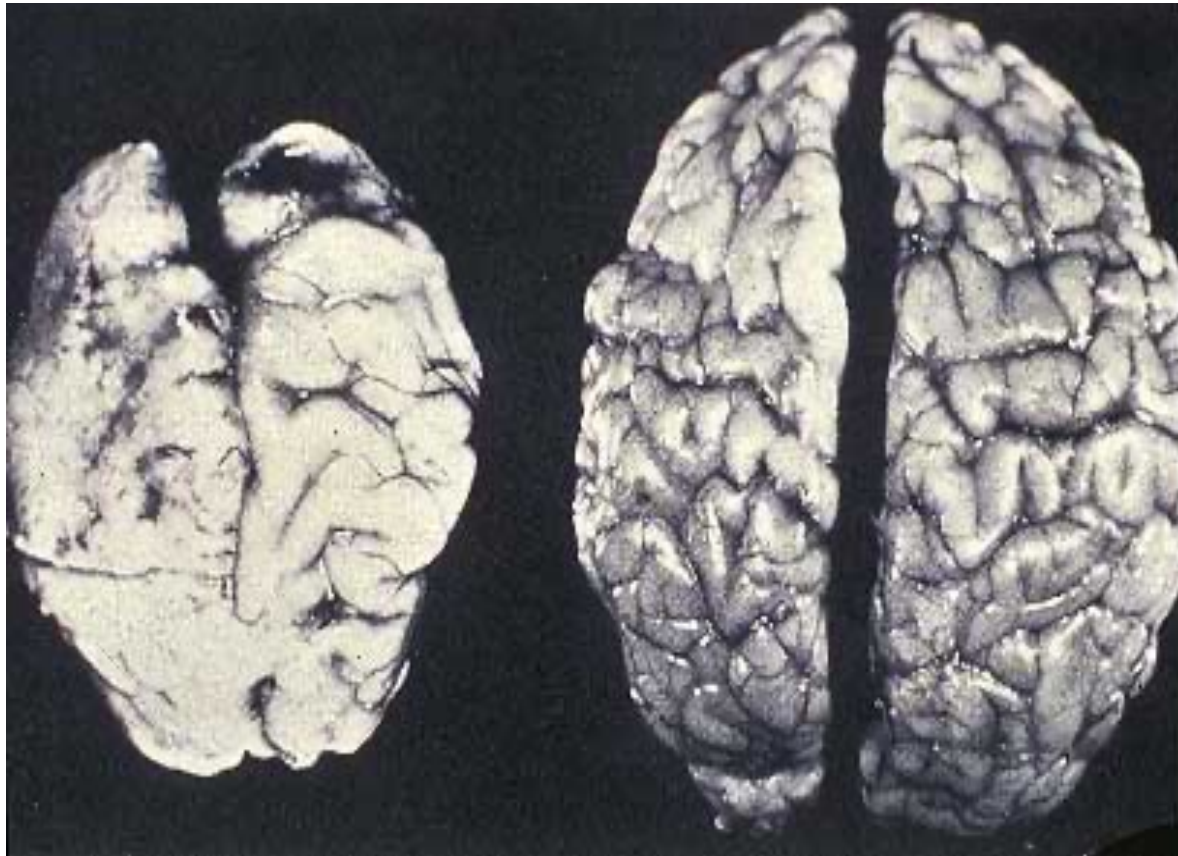
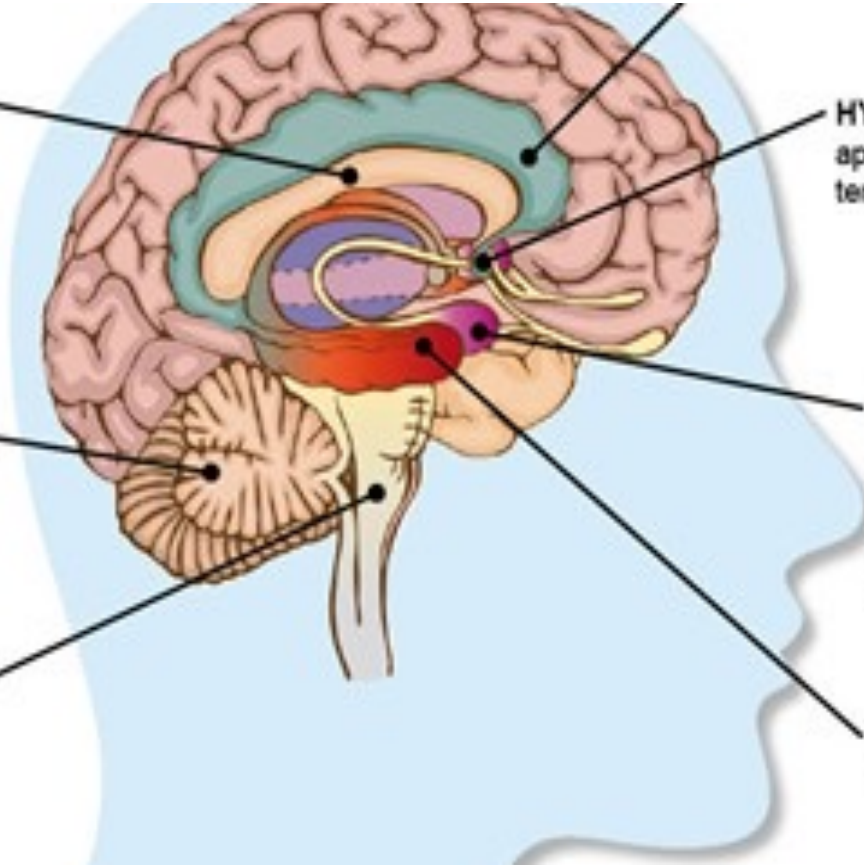


photo: Clarren, 1986

**CORPUS CALLOSUM**  
passes information from  
the left brain (rules, logic)  
to the right brain (impulse,  
feelings) and vice versa

**CEREBELLUM**  
coordination and balance

**BRAIN STEM**  
breathing and sleep



**HYPOTHALAMUS**  
appetite, emotions,  
temperature, pain sensation

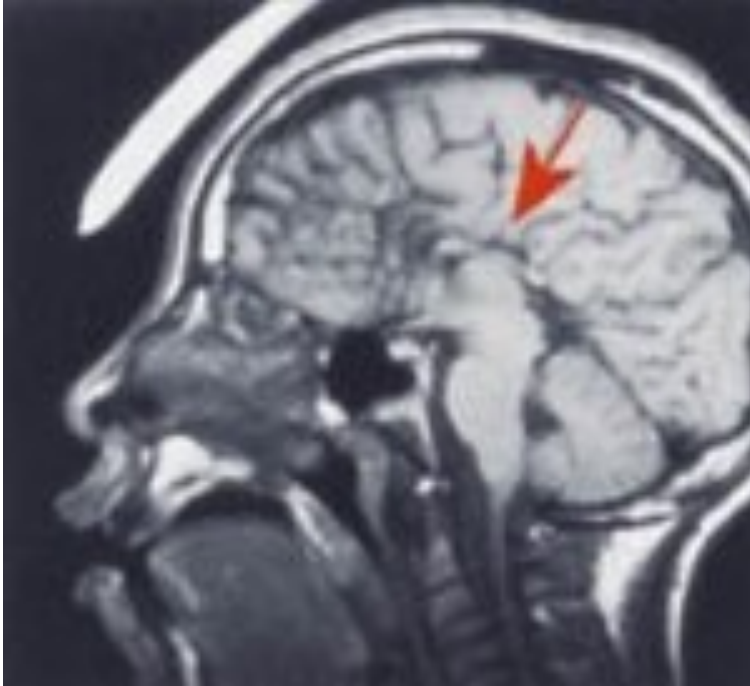
**AMYGDALA**  
senses danger/fear/anxiety,  
recognition of faces and  
facial expressions, social  
behaviour, aggression,  
emotional memory

**HIPPOCAMPUS**  
memory, learning, emotion

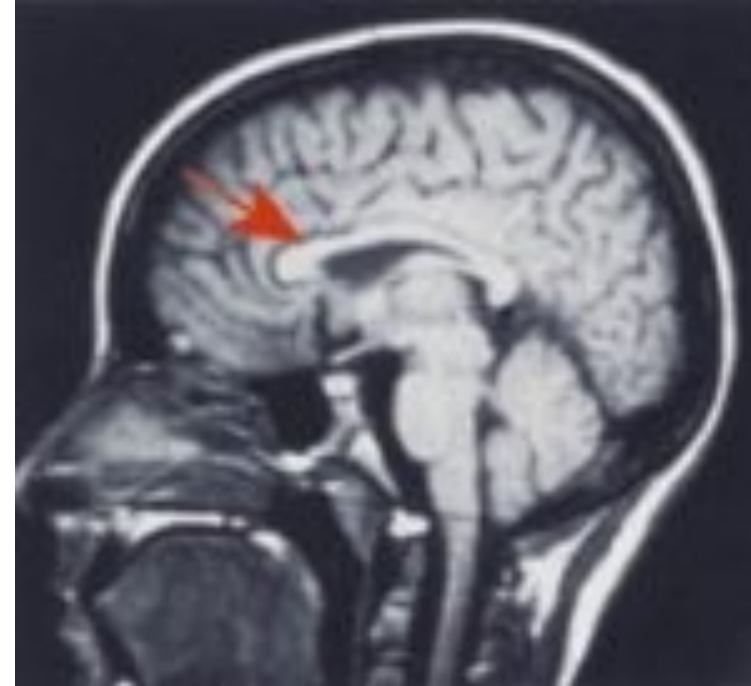
# Corpus Callosum



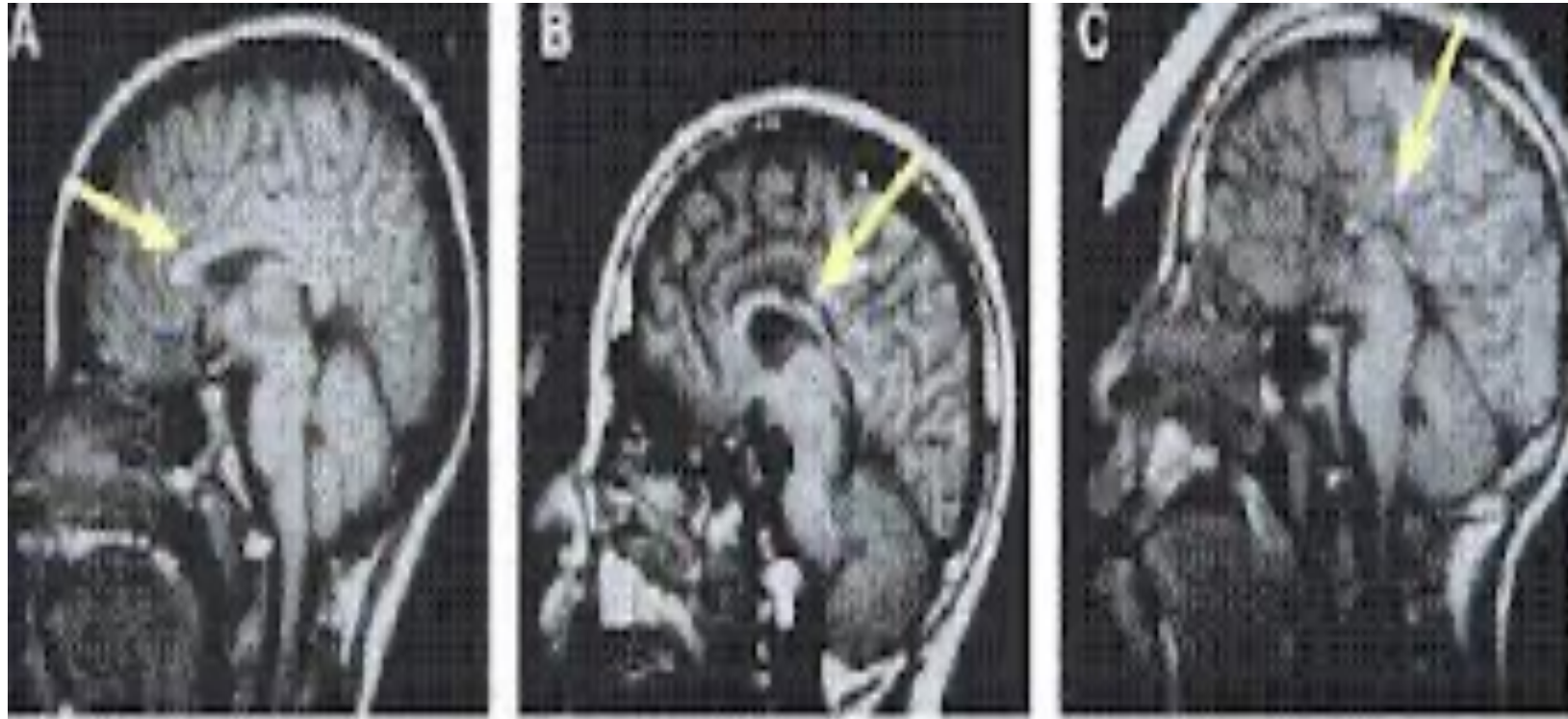
# MRI-Dr. Ed Riley

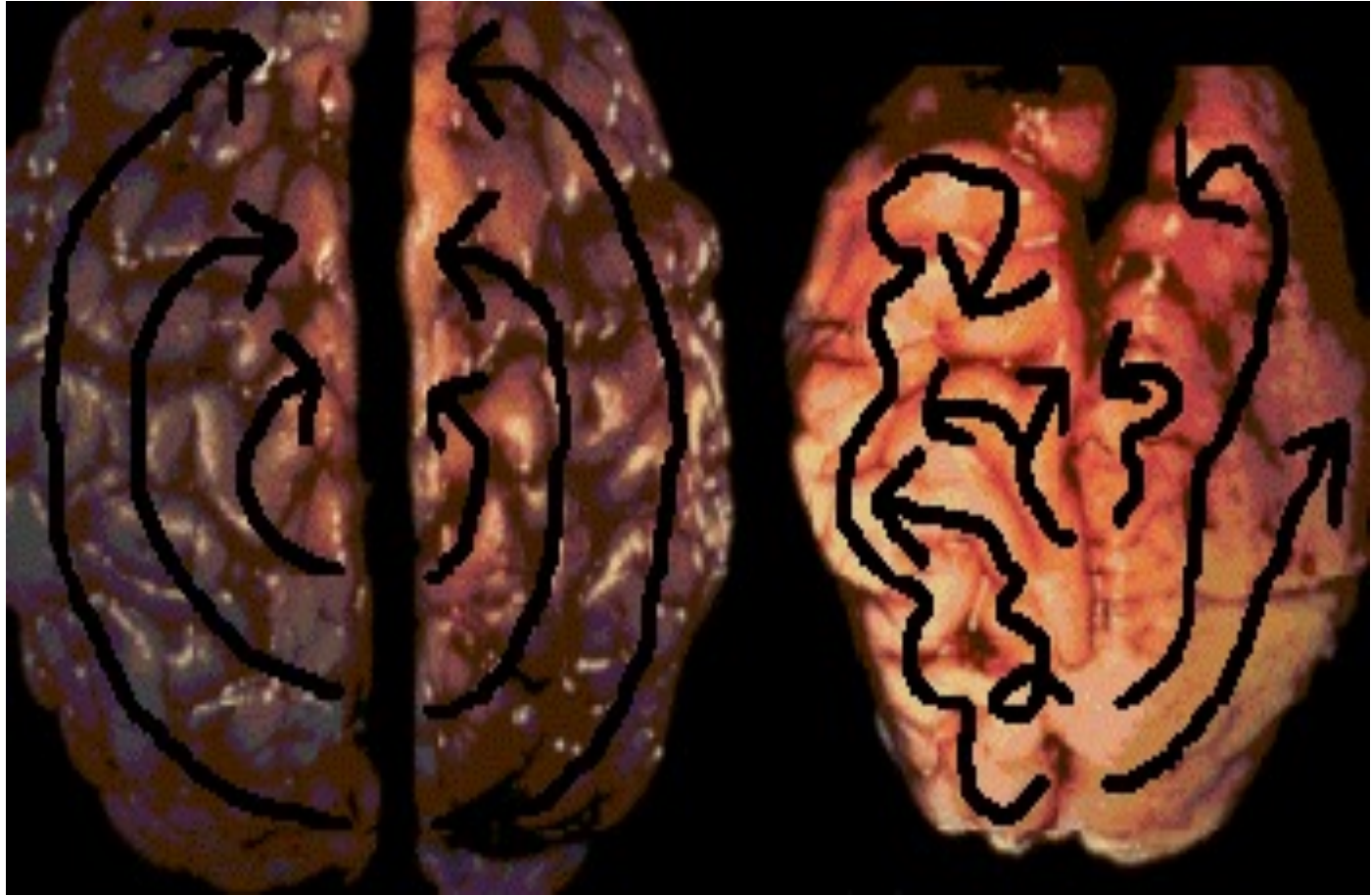


Red arrow points to corpus callosum of person with FAS



Red arrow points to corpus callosum of a normal individual





# Areas of Dysfunction/Symptoms

Source: FASD Center for Excellence<sup>10</sup>

## Central Nervous System Impairments

- ▶ Below average intelligence
- ▶ Delayed milestones
- ▶ Motor abnormalities
- ▶ Neurobehavioral disorders
- ▶ Perceptual problems

## Motor Abnormalities

- ▶ Poor gross motor skills
- ▶ Delays in fine motor skills
- ▶ Hand tremors

## Neurobehavioral Disorders

- ▶ Poor attention span
- ▶ Hyperactivity
- ▶ Perceptual problems
- ▶ Poor impulse control

## Language Disabilities

- ▶ Late onset
- ▶ Delayed use of sentences
- ▶ Uneven expressive and receptive skills
- ▶ Low quality masked by high fluency

## Behavioral Manifestations

- ▶ Social inappropriateness
- ▶ Persistent temper tantrums
- ▶ Excessive friendliness
- ▶ Fearlessness
- ▶ Poor response inhibition
- ▶ Processing deficits
- ▶ Input-output, integration deficits
- ▶ Short-term memory loss
- ▶ Sensory hypersensitivity
- ▶ Perseveration

# Typical Strengths of Persons With an FASD

- ▶ Friendly and cheerful
- ▶ Likable
- ▶ Verbal
- ▶ Helpful
- ▶ Desired to be liked



- ▶ Determined
- ▶ Have points of insight
- ▶ Hard working
- ▶ Every day is a new day!

# Typical Difficulties For Persons With an FASD

## Executive Function and Decision-Making:



- Repeatedly break the rules
- Give in to peer pressure

- ▶ Have difficulty entertaining themselves
- ▶ Naïve, gullible (e.g., may walk off with a stranger)
- ▶ Struggle with abstract concepts (e.g., time, space, money, etc.)

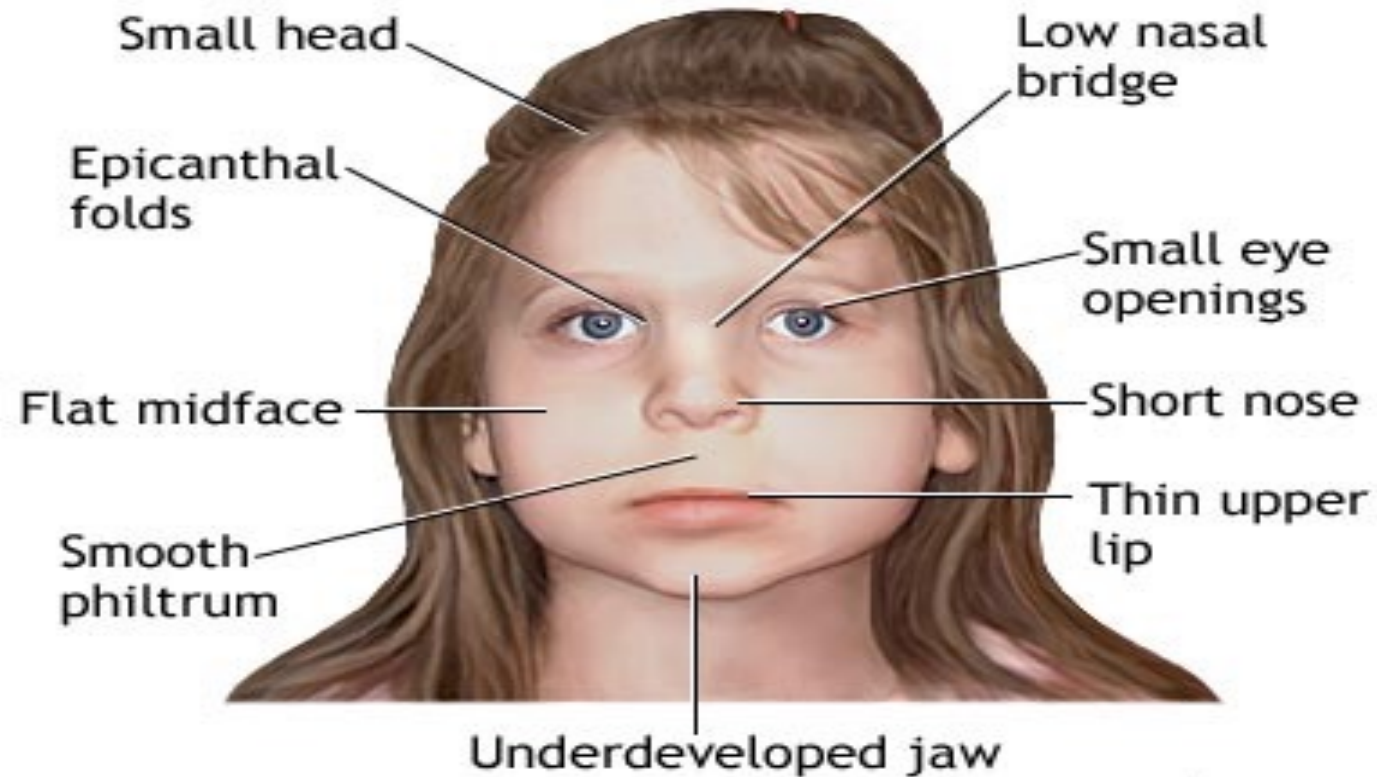
- ▶ Tend not to learn from mistakes or natural consequences
- ▶ Frequently do not respond to reward systems (points, levels, stickers, etc.)

I'm late!  
I'm late!



- ▶ **Executive Functions of the Prefrontal Cortex Effects of alcohol exposure on behaviors related to executive functions of the prefrontal cortex:**
- ▶ inhibitions: socially inappropriate behavior
- ▶ problem solving: inability to figure out solutions spontaneously
- ▶ sexual urges: inability to control sexual impulses, especially in social situations
- ▶ planning: inability to apply consequences from past actions
- ▶ time perception: difficulty with abstract concepts of time and money
- ▶ internal ordering: like files out of order, difficulty processing information
- ▶ working memory: storing and/or retrieving information
- ▶ self-monitoring: needs frequent cues, requires “policing” by others
- ▶ verbal self-regulation: needs to talk to self out loud, needs feed back
- ▶ motor control: fine motor skills more affected than gross motor
- ▶ regulation of emotion: moody “roller coaster” emotions, may withdraw or lash out
- ▶ motivation: apparent lack of remorse, need external motivators

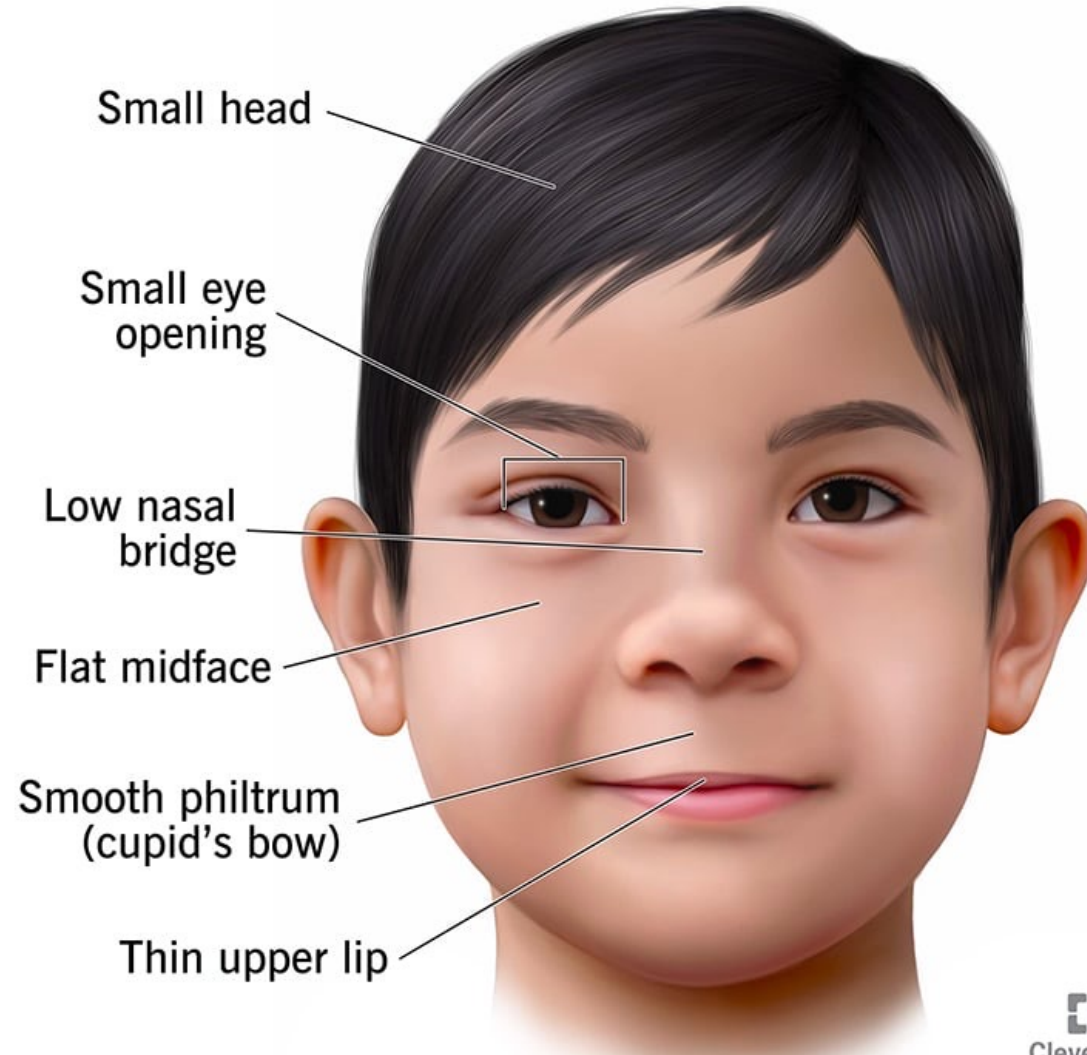
# Facial Signs of FAS



ADAM.



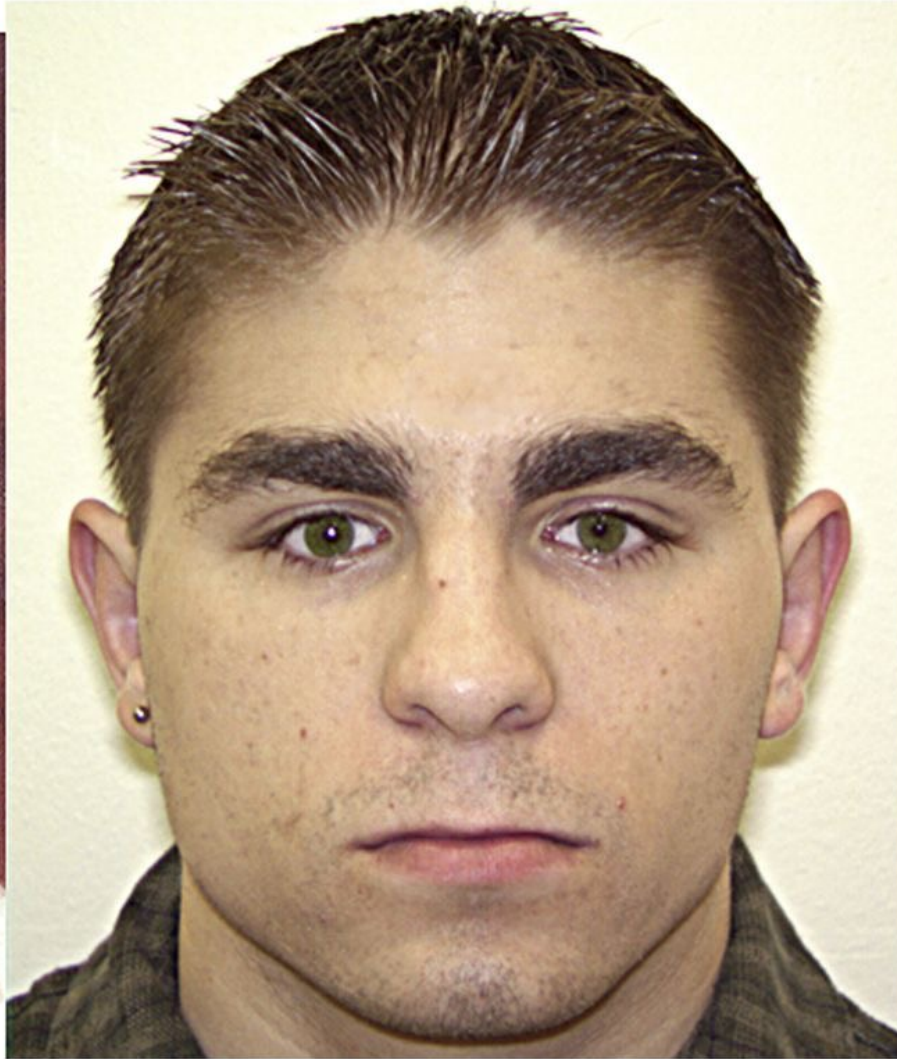
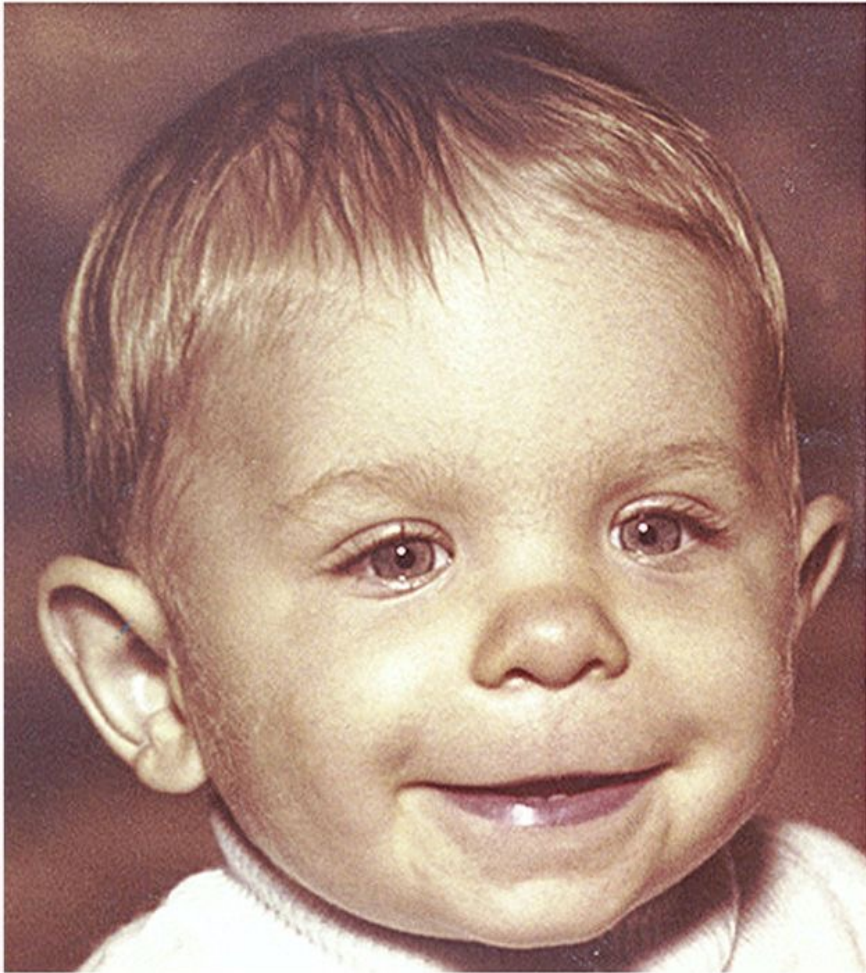
## Fetal alcohol syndrome



# Examples of Full FAS







# National Costs:

- ▶ According to a 2018 analysis of the economic impact of FASD, the annual cost for one individual, including health care, special education, residential care, and productivity losses, is as much as \$24,308.
- ▶ Adjusting the figure to include the costs associated with juvenile and criminal justice increases the figure to \$30,945 per individual with FASD per year. Based on an estimated US prevalence of 2% of the 2020 population of 331 million people the annual cost of FASD to society is as much as \$205 billion.

# People Aged 6-51 with FASD

- ▶ 94% Mental health problems
- ▶ 23% Mental illness requiring inpatient care
- ▶ 83% Adults experienced dependent living
- ▶ 79% Adults have employment problems
- ▶ 60% Have trouble with the law
- ▶ 50% Confinement (i.e., jail, prison, alcohol/drug/psych)
- ▶ 49% Repeated inappropriate sexual behavior
- ▶ 61% Disrupted school experience
- ▶ 35% Adults/Adolescents have alcohol/drug problems

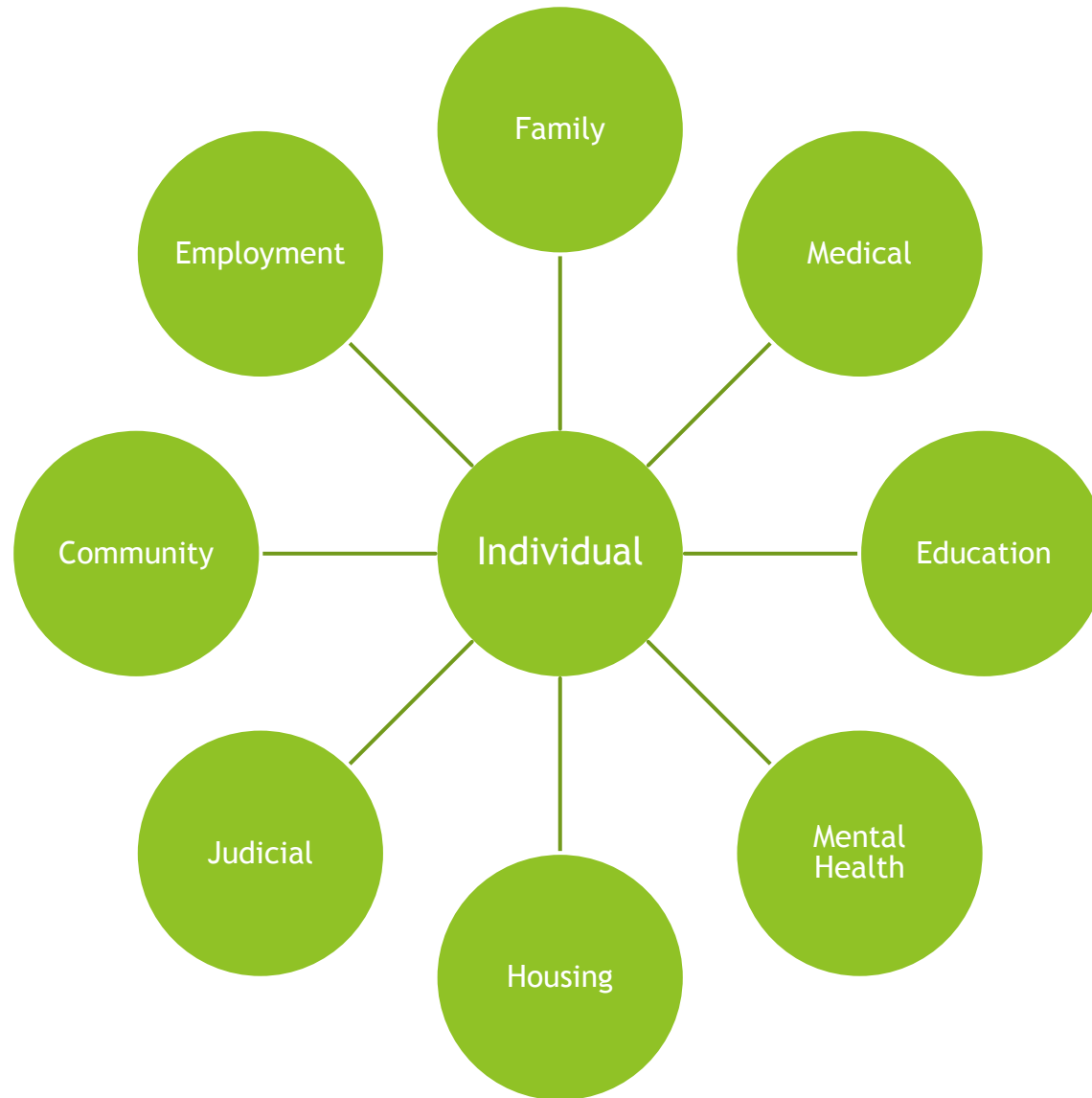
- ▶ Streissguth, AP, Bookstein, FL, Barr, HM, et al. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Develop Behavior Peds* 2004. 25-228-238

# Building Resources:

- ▶ Early Intervention is Critical
- ▶ Protective factors include:
  - ▶ Stable and nurturing environment
  - ▶ Early diagnosis (before age 6)
  - ▶ Absence of exposure to violence
  - ▶ Few changes in caretaking placements
  - ▶ Eligibility for social and educational services.

▶ Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK, Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004 Aug 25 (4) 228-38

# Creating a FASD Informed, TBRI Trained System of Support





# Tools for Success

- ▶ Set up an “External Brain”. Trusted family or friends that can help redirect as needed or go shopping to ensure correct money is exchanged. Understand that dealing with money can be difficult.
- ▶ Help set up resources to address any instances of using math, counting money, telling time or keeping track of time.
- ▶ Encourage independence but understand that individuals will likely need assistance.

# Give Them-12 Words or Less

- ▶ “Try that again with respect”
- ▶ “Gentle hands” “Gentle touch”
- ▶ “Match my voice” (modeling volume control)
- ▶ “Are you asking or telling?”
- ▶ “Make it right” (forgiveness and restitution)
- ▶ “Let me see your beautiful eyes”
- ▶ “Would you like to ask for a compromise?” “Let me hear it, what’s your compromise?”
- ▶ “Take a deep breath, give me words”

▶ Purvis & Cross; Trust Based Relational Intervention ®

# IDEAL<sup>©</sup> Response

- ▶ I- Immediate; in 3 seconds or less
- ▶ D- Direct; with proximity & eye contact
- ▶ E- Efficient; A measured response, don't use a Level III when a Level I will work.
- ▶ A- Action-based; Opportunity for a re-do, "let's fix it"
- ▶ L- Leveled at the behavior, not the child/person
- ▶ Pay attention to your body language and tone of voice.

▶ Purvis & Cross; Trust Based Relational Intervention <sup>®</sup>

# Sensory Input

- ▶ Pay attention to Sensory Input
  - ▶ Overwhelming and/or calming?
- ▶ Deep Breathing- “Pizza Breathing”
- ▶ Utilize sensory activities to calm the brain. Think proprioceptive or deep joint pressure.
  - ▶ Wall pushes
  - ▶ Hallway lunges
  - ▶ Chair pull-ups
  - ▶ Jumping Jacks
  - ▶ Tip-toe breathing

# Good News- Felt Safety

- ▶ The Brain responds well to the following:
- ▶ Physical Activity-sensory input (2 hrs)
- ▶ Meeting nutritional needs (2 hrs)
- ▶ Safe Touch- often-new child-ask first
- ▶ Playful engagement-”Whoa Nellie”
- ▶ Practice asking for needs (puppet play)
- ▶ Practice understanding feelings (chart)

# Case Management across the Lifespan

- ▶ Medical and health care
- ▶ Early intervention and education
- ▶ Proactive mental health services
- ▶ Increased supervision throughout adolescence and early adulthood
- ▶ Proactive preparation for adulthood
- ▶ Juvenile justice and corrections assistance
- ▶ Plan for supported living and employment

# Now What?

- ▶ I suspect a child has an FASD, what next?
  - ▶ Refer to a pediatrician who can diagnose
  - ▶ Get additional services involved, i.e., Early Intervention, OT, PT, Speech & Language Pathologist
  - ▶ Every 2-3 years request that a Vineland Adaptive Scale be administered and scored in years and months. The school psychologist can often do this.
  - ▶ Help parents, bio & foster, to understand that the child's brain works differently.
  - ▶ Refer to FASD United -Circle of Hope, if you have a birthmother who is struggling with the fact that her child has an FASD.

# Trust Based Relational Intervention

- ▶ Techniques to bring Hope and Healing to children and families.
- ▶ Disclaimer: Derived or reproduced from Trust-Based Relational Intervention® resources (Purvis & Cross, 1999-2011)
- ▶ The Connected Child, Purvis & Cross, 2007
- ▶ [www.papillioncenter.org](http://www.papillioncenter.org)
- ▶ [www.child.tcu.edu](http://www.child.tcu.edu)
- ▶ [www.fasdunited.org](http://www.fasdunited.org)



Q & A

