

Why Doesn't This Kid Do What I Ask?

Part I -Brains, Behavior, and Prenatal Alcohol Use

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Hosted By the Texas Office for
Prevention of Developmental Disabilities

Overview

- Case Presentation
- Prenatal alcohol use and effect of alcohol on brain development
- Overview of the brain as interpreter and navigator
- The challenges in working with an individual whose brain has been affected by alcohol prenatally
- Strategies for success and peace of mind

Which Substance Has The Most Long-lasting Neurobehavioral Effects On The Fetus ???

- Alcohol
- Heroin/ Methadone
- Cocaine/ Crack/ Methamphetamine
- Prescription Abuse
- Inhalants/ Hallucinogens
- Internet Pharmaceuticals
- Tobacco
- Marijuana
- OTC Drugs



What About Alcohol Use With Other Substances During Pregnancy?

- Women's beliefs about alcohol, tobacco and other drugs during pregnancy
- Barriers to screening, identification, and intervention for alcohol use
- Other commonly used substances during pregnancy

“Of all the substances of abuse (including cocaine, heroin and marijuana), alcohol produces, by far, the most serious neurobehavioral effects in the fetus”

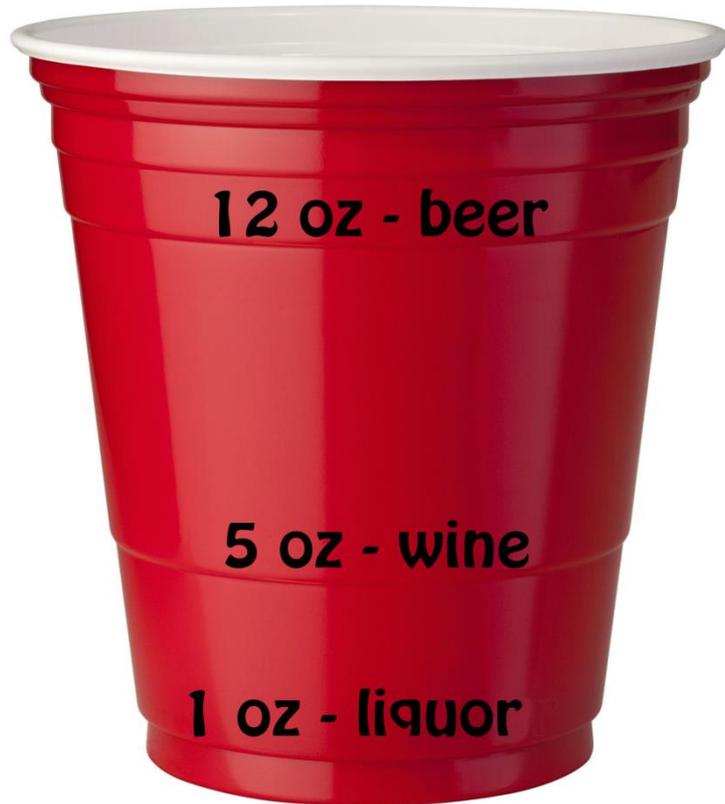
- IOM Report to Congress, 1996

DSM5: Substance Use Disorders

- Essential feature is a cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues to use the substance despite significant substance related problems
- Changes in brain function occur during the course of the disease and may persist even after detoxification (NIDA: drugabuse.gov)
- ***The developing fetus can be affected by any substance a woman is using, whether or not she meets the criteria for a substance use disorder***

What Is A Standard Drink?

Red Solo Cup Measurements



How much are you
REALLY drinking?

At-Risk Drinking (Women):

- 3 drinks/ occasion
- 7 drinks/ week
- Any drinks/ during pregnancy



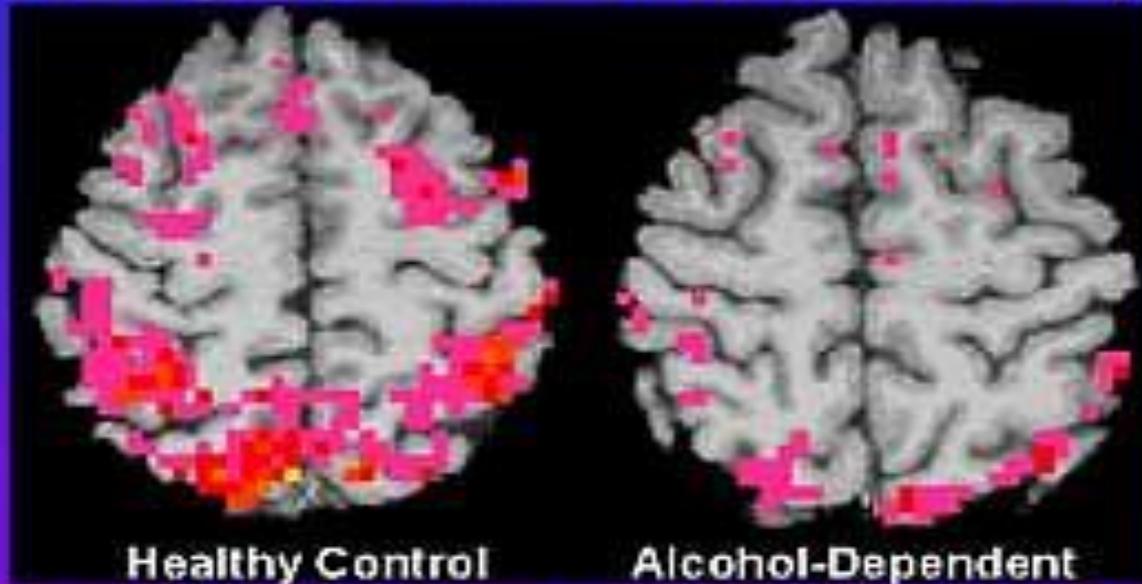
Categories Of Alcohol Use In Women

- 1) Abstainers
- 2) Low Risk Drinkers
- 3) At Risk/ Heavy Drinkers
- 4) Alcohol Use Disorders (DSM5 changes)
- 5) Alcoholism
- 6) Binge Drinkers - more than 3 per drinking occasion

- *Alcohol can be harmful to the fetus, regardless of the category*
- *Binge drinking is highest risk pattern for developing fetus*
- ***Women do not have to be categorized as an alcoholic to have a child with effects from prenatal exposure***

Drinkers: Less Active Brains

Two 20 year old females. Top view of brain, two inches above ears



Note differences in back of brain

Colored areas show active brain areas during memory task.

Source: Tapert SF, Brown GG, Kindermann SS, Cheung Eh, Frank LR, Brown SA (2001). MRI Measurement of Brain Dysfunction in Alcohol-Dependent Young Women. Alcoholism: Clinical and Experimental Research, 25 (2): 236-245

Chronic alcohol use affects women's ability to follow directions, abstain, and recover.

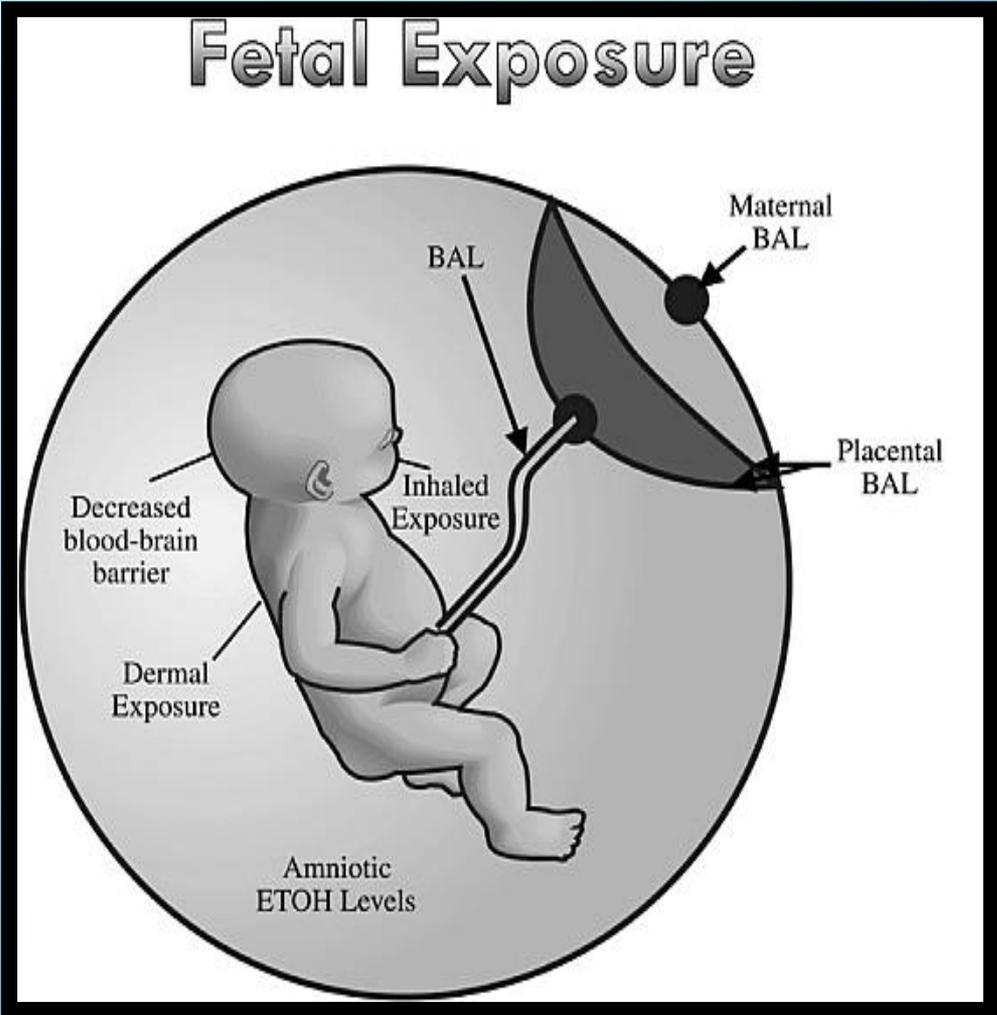
What Does A Woman At Risk Look Like? Observe Your Own Reactions.



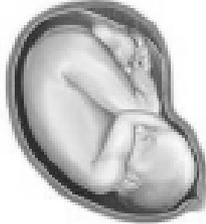
How Can We Find Out If Women Are Using? What Can We Do About It?

- ✓ _ Comprehensive Perinatal Risk Assessment (PRA)
- ✓ _ ACOG Toolkit (2006) and phone app (2012); SBIRT
- ✓ _ Self- report: TACE; TWEAK; 4P's Plus; CRAFFT and Perceived Benefits for adolescents; Timeline Follow-Back (TLFB)
- ✓ _ Laboratory, Ultrasound, cord blood, Meconium (FAEEs), Neonatal hair
- ✓ _ Brief Interventions-Ask, Advise, Assist, Monitor, Re-Assess; use motivational strategies
- ✓ _ Referral to treatment as indicated

How Does Alcohol Get To The Fetus?



The Effects of Alcohol Consumption on a Developing Baby

Months 1, 2, & 3	Months 4, 5, & 6	Months 7, 8, & 9	Birth – 18 months
<ul style="list-style-type: none"> • The major organs develop (heart, lungs, kidneys, etc.) • The basic structure of brain is laid down 	<ul style="list-style-type: none"> • Body grows rapidly • Movement increases 	<ul style="list-style-type: none"> • The brain grows very rapidly and organizes itself so it can work properly • The lungs mature 	<ul style="list-style-type: none"> • The brain continues to grow rapidly as the baby learns new things every minute 
<p>Drinking alcohol during the first 3 months can result in problems such as heart defects and facial changes.</p>	<p>Drinking alcohol during the second 3 months can slow a baby's overall growth and change the way cells in the brain develop.</p>	<p>Drinking alcohol during the last 3 months can greatly reduce brain growth and hurt overall brain development.</p>	<p>A mother who drinks alcohol while breastfeeding will pass some of that alcohol along to her baby. Babies drink less milk when there is alcohol in it.</p>
<p><u>Stopping</u> drinking during the first 3 months can help prevent organ damage and changes to the way the face looks.</p>	<p><u>Stopping</u> drinking now can improve a baby's birth weight and growth and prevent the most severe effects on the brain.</p>	<p><u>Stopping</u> drinking now can prevent the most severe effects on the brain (early in the 3rd trimester) and prepare the mother to handle the challenges of raising a child.</p>	<p><u>Stopping</u> now means that a baby will get the nutrition that he or she needs, and a mother can be a better parent, more prepared to deal with the ups and downs of raising children.</p>

When you stop drinking, you have a better chance of having a healthy baby!

Neonatal Withdrawal From Alcohol: Non-opiate NAS

- Alcohol is a CNS depressant like the opiate drugs. The fetus develops tolerance to CNS depressant effects and makes natural stimulant compounds to balance out those effects.
- When alcohol is withdrawn by delivery or cessation of use, the fetus/ newborn has to metabolize those natural stimulants and accommodate to living and developing without the alcohol. Initial over-production of these natural stimulant neurochemicals after delivery is what we see as neonatal alcohol withdrawal (non-opiate withdrawal on the Finnegan NAS scale)
- ***NAS (opiate or non-opiate) is a treatable condition of variable duration. The effects of alcohol on the brain are permanent.***

Clues To Neonatal Alcohol Withdrawal

(Coles et al; Gleason et al)

- Tremors, hypertonia, restlessness, excessive mouthing movements, inconsolable crying, reflex abnormalities, poor suck-swallow reflex and feeding, unusual sleep patterns, poor mother- infant interaction and bonding
- May be slower on their orientation toward auditory and visual stimuli, motor performance, habituation, and autonomic regulation
- Look for alcohol withdrawal signs in mother- hypertension, tachycardia, nausea, vomiting, sweating, tremor, anxiety, insomnia
- Alcohol withdrawal may be masked by other medical conditions or withdrawal from other substance

The Challenge Of Diagnosis

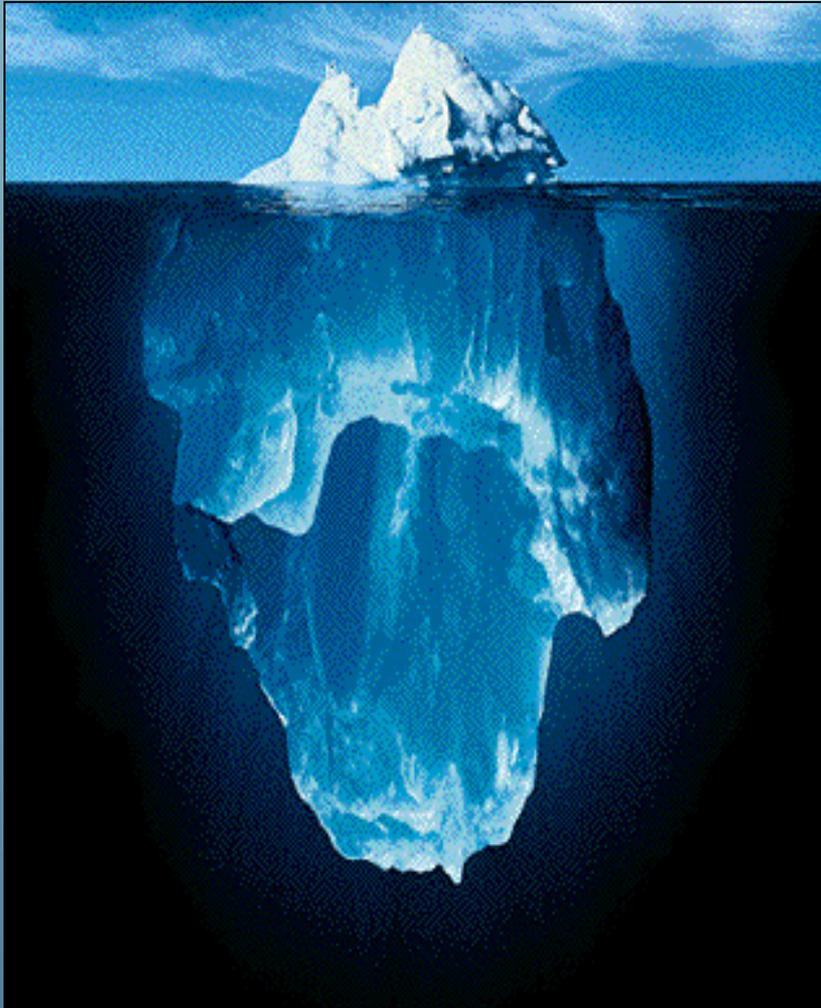
- **Fetal Alcohol Syndrome (FAS)** is a lifelong birth defect caused by maternal consumption of alcohol during pregnancy.
- **Diagnostic criteria** includes:
 - Dysmorphic facial features
 - Growth delay
 - Brain dysfunction
 - Maternal history
- **Genetic syndromes must be ruled out**
- **Co-occurring issues are common**

Fetal Alcohol Spectrum Disorders (FASD) is a *descriptive term* used for the broad spectrum of disorders caused by prenatal exposure to alcohol including:

- **FAE** (Fetal Alcohol Effects)
- **PFAS** (Partial FAS))
- **ARND** (Alcohol Related Neurodevelopmental Disorders)
- **ARBD** (Alcohol Related Birth Defects)
- **FAS** (Fetal Alcohol Syndrome)
- **ND-PAE**- Neurodevelopmental Disorder-Prenatally Alcohol Exposed (DSM5)

****FASD is NOT a diagnosis**

Fetal Alcohol Syndrome (FAS) Is Just The Tip Of The Iceberg



Visible Disabilities:

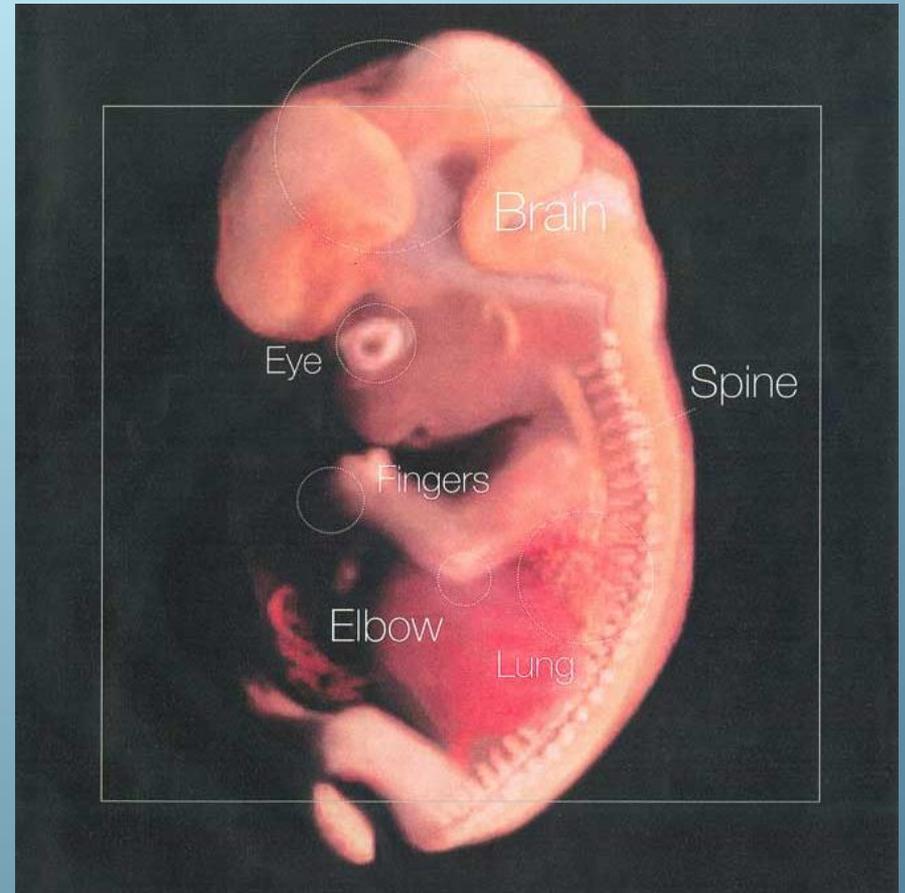
- **FAS** (Fetal Alcohol Syndrome)

Invisible Disabilities:

- **PFAS** (Partial FAS)
- **FAE** (Fetal Alcohol Effects)
- **ARND** (Alcohol Related Neurodevelopmental Disorders)
- **ARBD** (Alcohol Related Birth Defects)
- **ND-PAE** (Neurodevelopmental Disorder-Prenatally Alcohol Exposed DSM5)

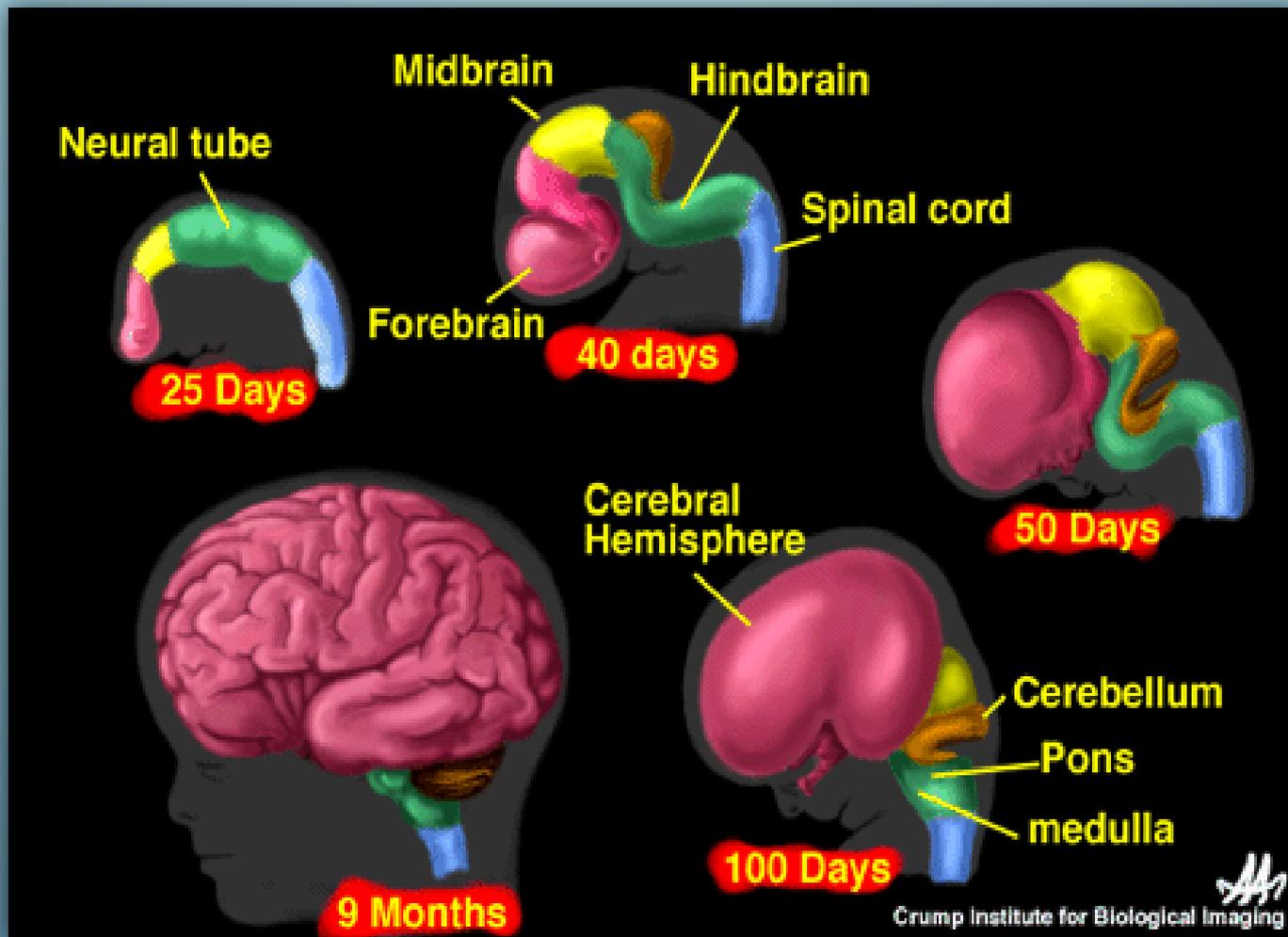
How Does Alcohol Affect The Brain? Can We Prevent Any Of These Effects?

- Alcohol affects brain development throughout pregnancy
- Brain structure, pathways, communication, and function can all be affected by alcohol exposure during gestation
- Some of these primary changes may be ameliorated with nutritional and other interventions



Brain Development Influences Lifelong Behavior

(Yang, et al, 2012)



Challenges

- ❑ “I can’t get him to eat or sleep”
- ❑ “I can’t leave him alone for a second”
- ❑ “He won’t stop hitting the other kids in school”
- ❑ “His teacher says he knew it in school!”
- ❑ “He won’t even try”
- ❑ “She’s always late.”
- ❑ “He is never prepared.”
- ❑ “She is so irresponsible with money.”
- ❑ “He never follows through.”
- ❑ “She keeps picking the worst friends.”
- ❑ “He makes the same mistakes over and over.”

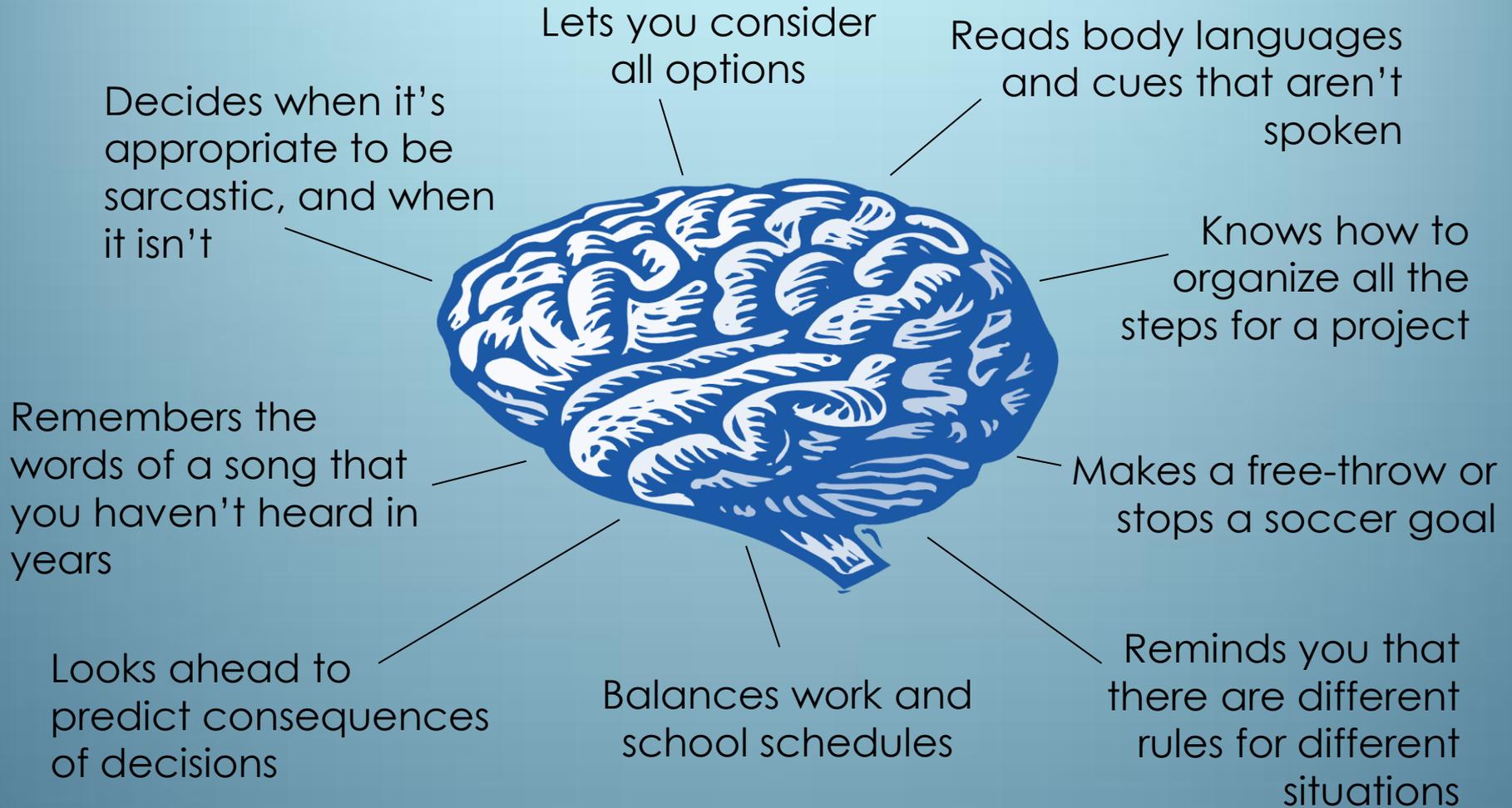
What Might The Individual Experience?

- Confusion
- Anxiety
- Frustration
- Anger
- Defeat
- Hopelessness
- Fear
- Stress
- Symptoms of mental illness
- Higher rates of infections
- Decreased and increased response to sensory stimulation
- Poor body awareness i.e. hunger, thirst, bodily functions

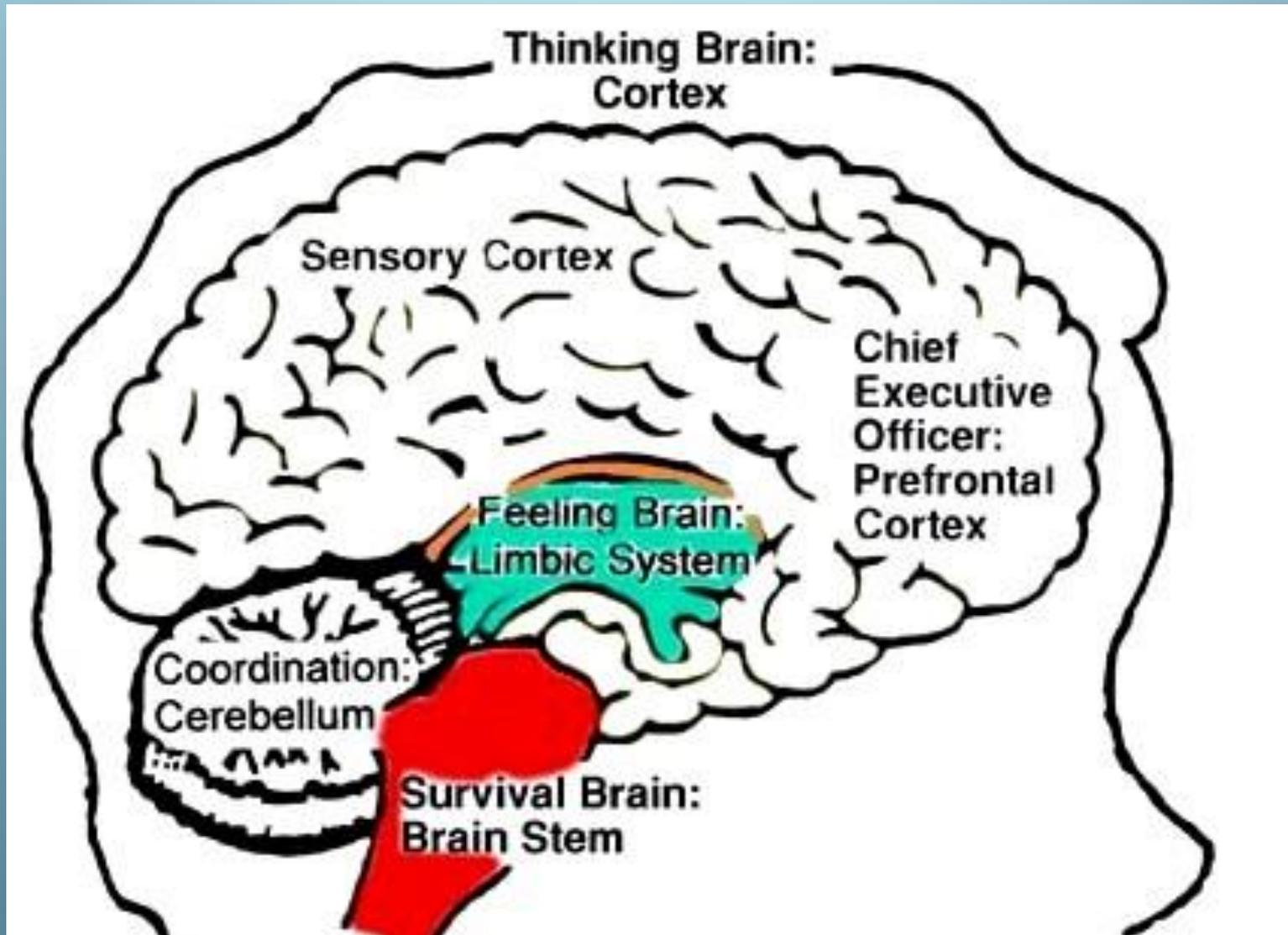
Things We Have Tried (How'd That Work Out?)

- Explaining
- Reasoning
- Cajoling
- Bribing
- Begging
- Therapy
- Meds for ADHD
- Meds for Bipolar Spectrum
- Meds for psychosis
- Discipline
- Consequences
- Grounding
- Taking away privileges
- Ignoring
- Frustration
- Anger
- Impatience
- Desperation
- Change in placement

What Does Your Brain Do For You?



Tour of the Brain: Geography

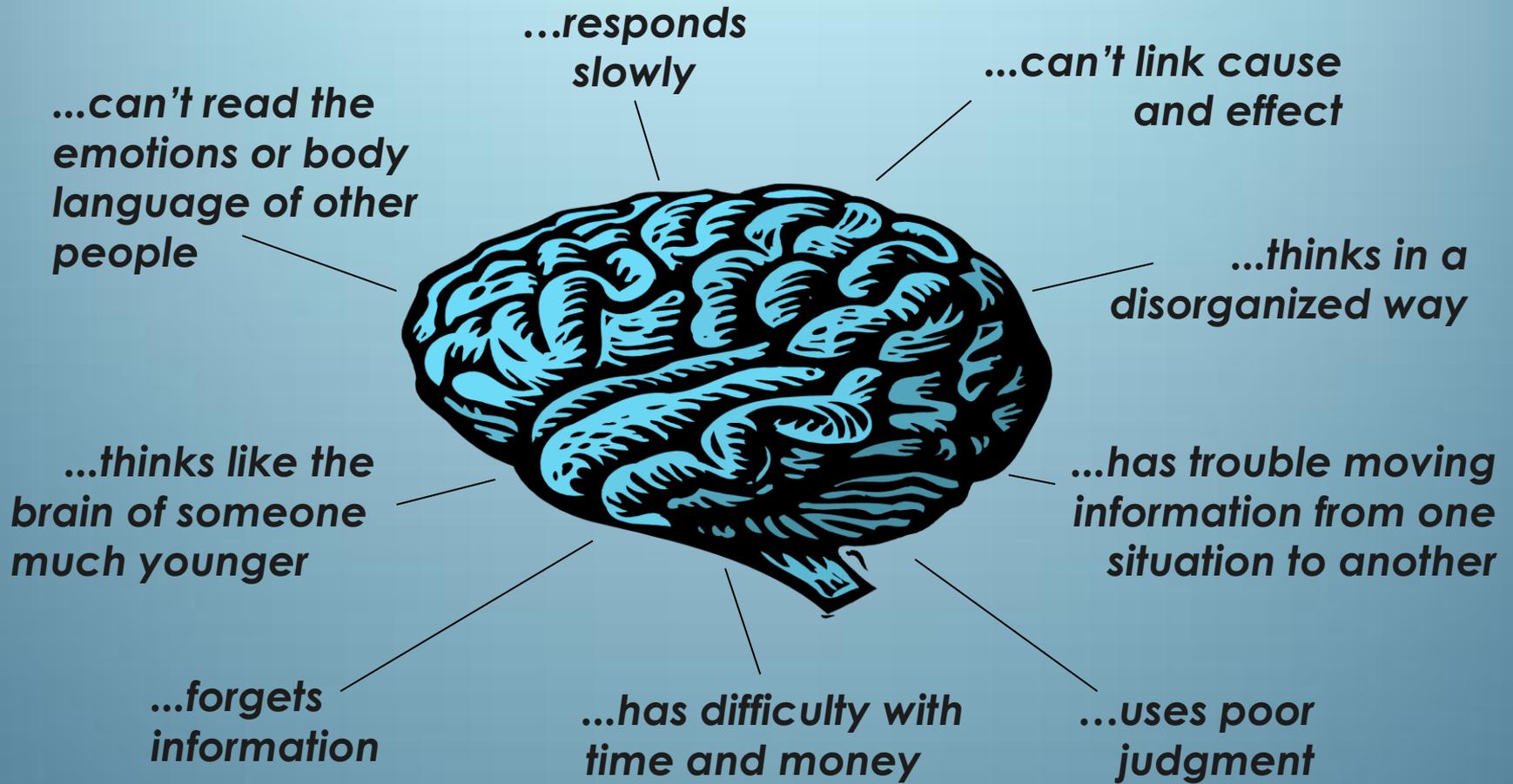


Alcohol Affects Information Processing

- **Input**-recording information
- **Integration**-interpreting input
- **Memory**-storing input for later use
- **Retrieval**- access to stored information
- **Output**-appropriate use of language and motor skills based on information



Alcohol During Pregnancy Can Create A Lifelong Brain That:



Problem Domains of Individuals with Prenatal Alcohol Exposure

- Cognition/ intellectual functioning
- Executive functioning
- Activity and attention
- Learning and memory
- Processing abilities
- Language
- Motor abilities
- Sensory integration
- Social skills and adaptive behavior
- Mental health issues

Common Challenges For Individuals With Prenatal Alcohol Exposure

- ***Very literal thinking.*** May not understand abstract concepts (Money, time) or language (“Clean up your act.” “Act your age.”)
- ***Slower brain pace.*** May take longer to respond because the brain needs more time to process information.
- ***Difficulty Learning From Experience.*** May have a hard time moving information from one situation to another. Every situation may be brand new because the brain might not have the benefit of learning from previous experiences.
- ***Disruption in Cause / Effect Thinking:*** Inability to look ahead and predict what might happen in a new situation. May be very impulsive and then seem surprised at the outcomes.

Common Challenges For Individuals With Prenatal Alcohol Exposure

- ***Rigid Thinking.*** Once something is learned, may be difficult to re-learn, apply, or change it.
- ***Difficulty Reading Body Language:*** Non-verbal communication might not be understood, which leads to misunderstandings.
- ***Memory Problems:*** Short-term memory may be inconsistent. Might be able to repeat something and then forget it a second later.
- ***Sensory Integration:*** Senses may be experienced differently than most people. A slight touch may feel like a slap or normal lights may look like strobe lights.
- ***Poor judgment.*** May have difficulty responding to new or unexpected situations or using common sense in everyday life.

What Can We Do: Interventions

(<http://www.cdc.gov/ncbddd/fasd/treatments.html>)

- **Medical care/ health maintenance-** Special health risks in people with FASD include growth, nutrition, specific deficiencies, immune competence, stress management
- **Medications-** Psychiatrist may suggest stimulants, neuroleptics, antidepressants, antianxiety drugs
- **Alternative Approaches**
- **Behavior and Education Approaches**
 - CDC flyer: Families Moving Forward; Best Buddies; MILE Program; Neurocognitive Habilitation
- **Parent and Caregiver Training**

“I think he’s doing it on purpose...”

Behavior Is A Window To Brain Function

- Picks inappropriate friends / partners
- Says it but doesn’t do it
- Is financially irresponsible
- Inflexible thinking and no common sense
- Says socially inappropriate things
- Responds slowly to questions or requests
- Reads fine but doesn’t understand or remember
- Says “I don’t know” a lot; acts younger than age
- Seems motivated but doesn’t follow through
- Is disorganized, late, unprepared

“So what can I do with him?” Start With Changing Yourself

- Put your own oxygen mask on first....
- You as the caregiver or service-provider will need to take care of yourself physically, mentally, emotionally, spiritually to get yourself and an individual with FASD through the day. That starts with basics like healthy nutrition and sleep.
- You will need to have a sense of curiosity, creativity, open-mindedness, exploration, and shared responsibility.

Consider Your Own Attitudes And Responses

- Do I ask, “what is causing this behavior?”
- Do I ask, “what age behavior does this feel like?”
- Am I resistant to specific strategies? Often they go against the grain of what families have been told for years. Fair ≠ equal
- Am I thinking strengths first?
- Do I remember to utilize other members of the individual’s success team?

Then Consider The Individual With An FASD And The Environment

- Remember that brain differences are only visible to us as an individual's behavior
- ***Think non-competence before non-compliance:*** Did he understand what I said? Can he act on it? What if this behavior is coming from a brain difference?
- Use behavior as a guide for accommodations
- Every day is a new day-don't assume skills will carry over.
- Have the courage to admit defeat, appreciate effort and save a task for another time and another strategy

“I know he understands because he can repeat what I said, but then he just doesn’t do it...”

- **Expressive language skills** better than receptive language skills (“talks better than he thinks”, doesn’t comprehend even though he can repeat the words back to you)
- **Difficulty generalizing information** (Can’t move information from theory into practice; Can say it but doesn’t know how to do it)
- **Can’t organize and sequence** the information and steps (details get lost or are unknown)
- **Poor memory** (forgets the steps required)
- **Lacks ability to solve unexpected problems**, even small ones (may get confused or halted if anything unexpected happens during the process)
- **Doesn’t know where to start** (task may feel overwhelming)

What we see	What we think	What may be really going on	What we can do
<ul style="list-style-type: none"> ▶ Doesn't follow rules 	<ul style="list-style-type: none"> ▪ Noncompliance ▪ Attention Seeking ▪ Stubborn ▪ Purposeful 	<ul style="list-style-type: none"> ● Difficulty translating verbal directions into action ● Cognitive deficit 	<ul style="list-style-type: none"> ◆ Check for understanding ◆ Repeat instructions ◆ Simplify tasks
<ul style="list-style-type: none"> ▶ Repeatedly makes the same mistakes 	<ul style="list-style-type: none"> ▪ Manipulative ▪ Doing it on purpose ▪ Willful 	<ul style="list-style-type: none"> ● Not able to link cause and effect ● Difficulty generalizing 	<ul style="list-style-type: none"> ◆ Provide assistance with organization ◆ Structure choices
<ul style="list-style-type: none"> ▶ Poor social judgment 	<ul style="list-style-type: none"> ▪ Attention Seeking ▪ Poorly parented ▪ Impulsive 	<ul style="list-style-type: none"> ● Not able to interpret social cues ● Desire to be liked 	<ul style="list-style-type: none"> ◆ Role play ◆ Identify safe external support/s ◆ Safety planning
<ul style="list-style-type: none"> ▶ Easily agitated 	<ul style="list-style-type: none"> ▪ Poor self control ▪ Deviant 	<ul style="list-style-type: none"> ● Frustrated ● Disappointed ● Mental health issue 	<ul style="list-style-type: none"> ◆ Teach self advocacy ◆ Identify and practice coping techniques

“Where do I begin?...” Think About What Might Be Going On In The Brain

- Ask yourself questions like –
 - How does this child do with abstract language?
 - Is it possible that she struggles to go from theory (words) into practice (action)?
 - Does this child process auditory information more slowly?
 - How does this child respond to changes in routine?
- And then ask yourself — **What can I do to provide more support in these areas?**
- You can come up with ideas to meet the needs of this child by investigating the brain-based causes of behaviors.

What To Do: Concrete And Multi-sensory Communication

- **It takes time and a sense of humor to develop this habit. Consistency in language is essential.**
- Rather than saying “Keep your hands to yourself!”, say and demonstrate with his hands “Put both your hands on your own knees like this and keep them there”.
- Rather than saying “Be a good girl while I make dinner”, say and supervise “Sit in this chair and draw me a picture of our home while I’m cooking” or “Would you like to learn how to make pancakes?”
- Rather than “Watch your mouth!” be specific with words you encourage or don’t allow.

What To Do: Pace Your Verbal Communication

- **Speak slowly and use fewer words** Typically when a child isn't understanding something, we try to explain it "better" - which means using more words.
- This can overwhelm a brain that works at a slower pace. Slow down and use fewer words to allow for better understanding. Give the child extra time to respond, even to simple questions and requests.

Problems with Speech and Language

Try these activities:

-  _ Language stimulation/skills
-  _ Get individual's attention before speaking to her
-  _ Target speech production
-  _ Reduce competing auditory stimuli
-  _ Look at writing samples for clarity, grammar, etc.
-  _ Use voice activated computers

**** Differential with ASD: FASD may have difficulty in receptive; ASD has difficulties in BOTH receptive and expressive**

Problems with Social/ Emotional

Try these activities:



_ Therapy



_ Social skills group



_ Anger management



_ Address issues of loss and grief (loss of secure future, dreams, etc)



_ Understand limitations (do not blame for what they cannot do)



_ Address hygiene issues (may not know how, may not remember to use soap/change dirty clothes, etc)



_ Frequent praise

****Differential with ASD: ASD has restricted emotional expression/ ASD has difficulty relating to others meaningfully**

Problems with Friendships

Try these:



Identify a sport/activity the child/adolescent is successful in



Use weekends for social activities when individual is more rested



Use role plays for situations the person may find himself in



Help individual learn facial cues by looking at magazines, or photos



Practice body language by turning off sound of TV and guessing what is happening

-Morse and Weiner, 1993

What To Do: Memory Struggles

- **Expect to reteach, reteach, reteach.**
- Don't punish for forgetting—poor or inconsistent memory will likely be a lifetime issue.
- Instead, find ways to help the child remember. Teach something as many times as a child needs to hear it—10, 20, 300 times if necessary.
- Teach differently! Not harder, louder or with more words.
- **Provide external memory tools.**
- Lists, cue cards, pictures—be creative in coming up with ideas for external memory tools. This is not enabling—it is filling in the gaps of what this brain cannot do on its own.

What To Do: New Or Unexpected Situations

- **In new or unfamiliar situations**, an individual with FASD may have a very hard time knowing how to react and anxiety.
- Having an “external brain”—**someone who understands the brain difference and is ready to provide guidance without judgment or frustration**—can help a child successfully navigate the world.
- **Provide extra supervision, support, mentors**
- **Understand the importance of structure and routine:** schedules, boundaries, language, expectations

What To Do: Multi-step Tasks

- **Be as specific as possible.** An individual with FASD may have a hard time figuring out all the steps that need to be done, and in what order to do them. (For example, the instruction to “clean out your locker” may be too broad)
- **Help organize and break tasks into small parts**—and write it down, use pictures. Don’t forget technology- is there a phone app for this? A youtube video we can watch first?
- **Help eliminate physical and mental clutter** whenever possible

Instead Of Defiance, What If This Is A Brain Challenge?

- **Ask concrete questions** to find out how much a person understands (“What does it mean to clean the kitchen?” “What is the first thing you will do?”)
- **Practice behaviors and actions multiple times** (Using a checklist, practice going through all the steps of applying for a job, scheduling an appointment, going through a morning routine, cooking a meal, etc.)
- **Provide external structure** (reminder phone calls, postcards, checklists)

Instead Of Defiance, What If This Is A Brain Challenge?

- **Don't require a person to rely on their memory.** Write everything down, including each step a person needs to complete to be successful.
- **Think younger.** Imagine structures, supports and explanations for someone half their age.
- **Teach self-advocacy** (“I don't know where to start. Can you help me?” “I'm confused.” “I can't remember what to do next.”)

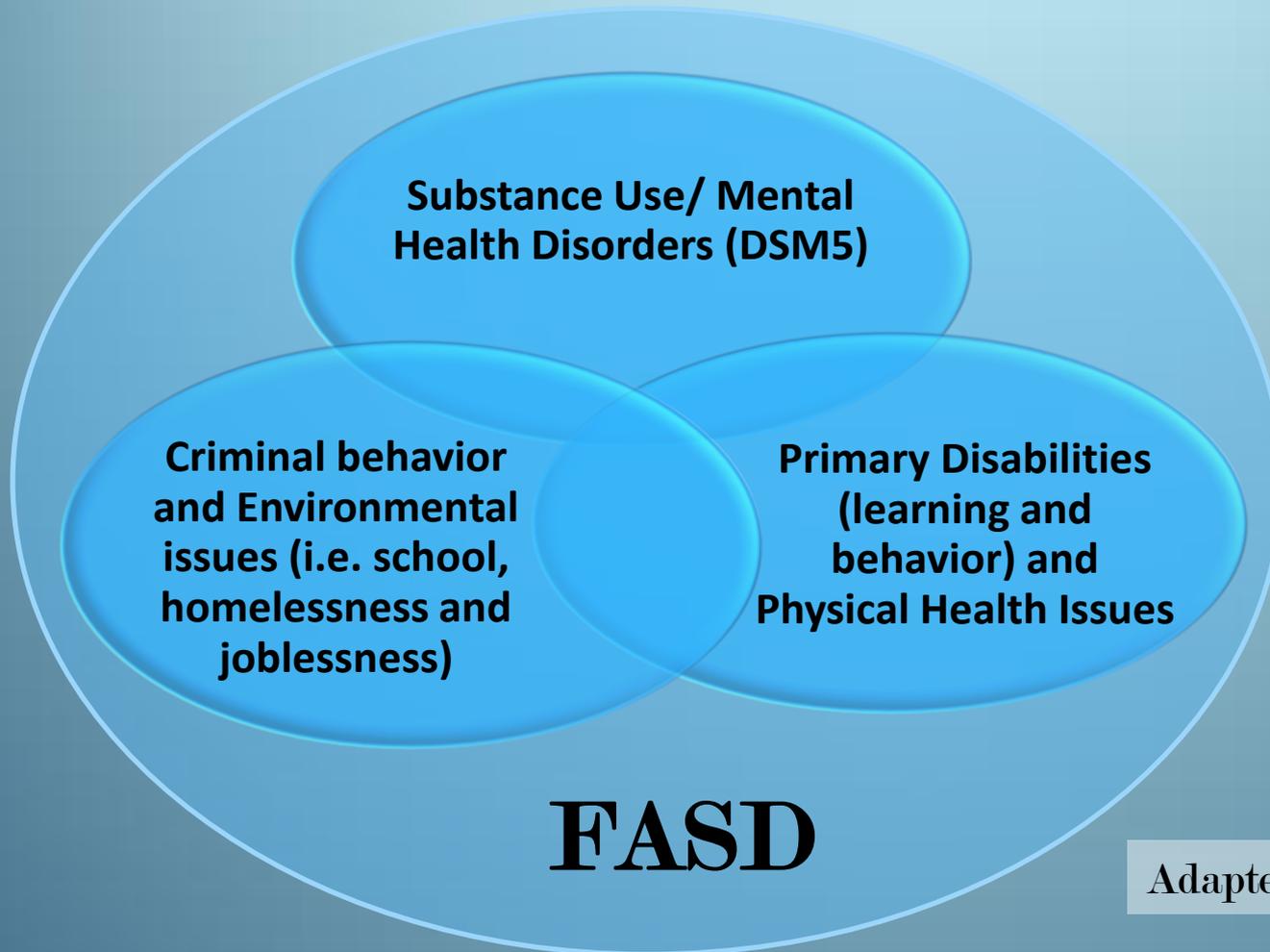
What Strengths Might The Individual Have (Despite Appearances)?

- **Survival skills** (May look manipulative)
- **Verbally expressive** (Talks, doesn't listen)
- **Curious** (Doesn't focus on task in front of him)
- **Wants to please** (Vulnerable to peer pressure)
- **Sense of humor** (Laughs inappropriately)
- **Persistence** (Repetitive behavior; of a particular task)
- **Patience** (Standing around)
- **Passion** (Anger)

Obtaining A Diagnosis: Multidisciplinary Assessments

- **Health care: Physician (pediatrician, developmental pediatrician, family practitioner), nursing, psychiatry, genetics**
- **Allied Health- OT, PT, Speech**
- **Neuropsychological; psychology**
- **Education and Learning specialists**
- **Social work, Family Protective Services, Child Welfare**

FASD Informed Care: FASD Impacts Evaluation And The Success Of All Interventions



Adapted from D Dubovsky, 2010

Online Resources

- nofas.org
- cdc.gov
- fasdcenter.samhsa.gov
- <http://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/preface>
- <http://www.kyfasd.org>
- <http://www.youtube.com/watch?v=mMDPP-Wy3sl>

Or search **YouTube** using keywords “**prenatal brain development elearning centralia**”

**This Concludes Part 1,
presented by Dr. Mary DeJoseph**