



From the Inside Out: A Guide for Understanding a Child with Fetal Alcohol Spectrum Disorders

Have you ever known a child living with the effects of prenatal exposure to alcohol? Chances are good that you have known many.

A lot of people were taught that all kids with FASD have mental retardation or can be identified by their distinct facial features. This isn't true. Only a small percentage of people with alcohol-related brain dysfunction have mental retardation and a recognizable face.

A child may look like the rest of the children, have a typical IQ but still have invisible brain dysfunction that causes confusing, disruptive and challenging behaviors.

This short guidebook will provide some insight about what it might feel like to be a child with an invisible disability, as well as give you some ideas about how to work differently with this child. Remember—most kids are not identified or diagnosed as having an alcohol-related brain disorder. You probably won't know whether or not a child was exposed to alcohol prenatally. The most important thing is this: children can have brain-based disabilities that look like willful misbehavior, non-compliance, defiance, or lack of effort. You can make a tremendous difference to a child whether or not a medical diagnosis has been made.

You may find this information overwhelming at first. More resources and technical assistance are available to you.

INSIDE YOU'LL FIND

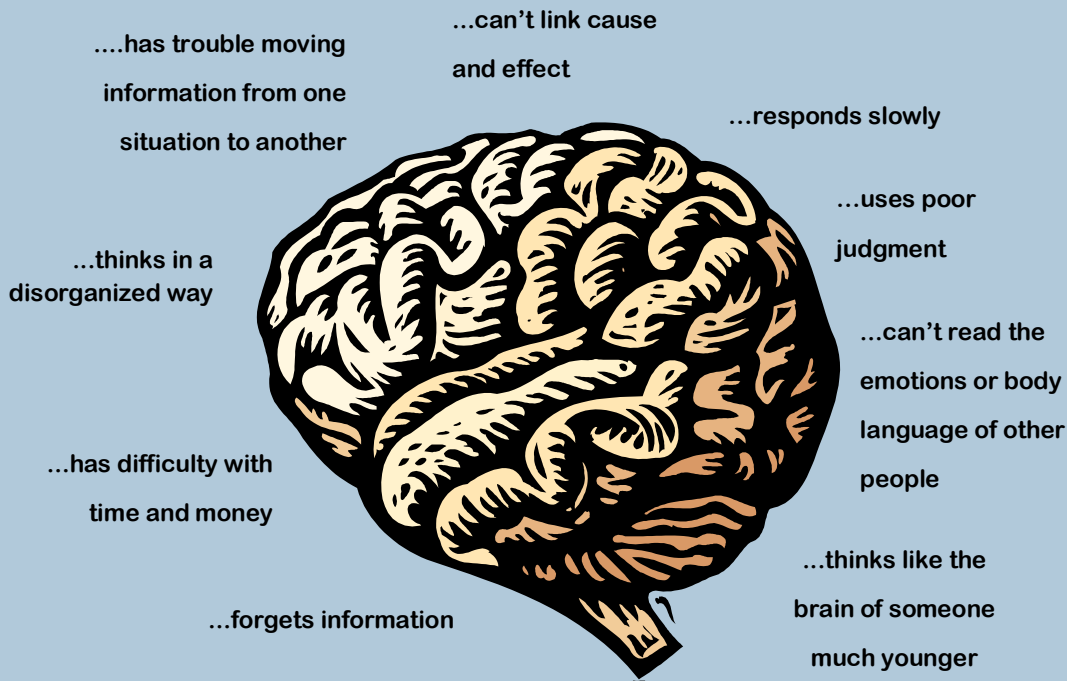
- ALCOHOL AND THE BRAIN
- CAN'T VS. WON'T
 - TYPICAL CHARACTERISTICS OF FASD
- STRATEGIES TO GUIDE INTERACTIONS
- TALKING ABOUT ALCOHOL AND PREGNANCY
- FOR MORE INFORMATION
- TEN SIMPLE REMINDERS

What if.... her behavior is pointing to a disability that no one can see?



What if.... the things he does wrong show us exactly what he needs from us?

Alcohol During Pregnancy Can Create A Lifelong Brain That:



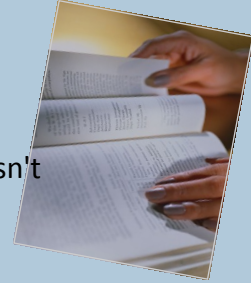
According to the Institute of Medicine's 1996 Report to Congress: "Of all of the substances of abuse, alcohol produces by far the most serious neurobehavioral effects in the fetus." Why is alcohol more damaging to the brain than crack, meth, tobacco, heroin or other illicit substances? The molecules of alcohol are so small that they pass freely through the blood-brain barrier. The brain is highly vulnerable to the effects of alcohol at all stages of pregnancy. There is no safe TIME, no safe TYPE and no safe AMOUNT of alcohol if a woman is pregnant or could become pregnant. Many women stop drinking as soon as they learn of their pregnancy, but early alcohol exposure can damage the developing brain without a woman even knowing that she's pregnant.

Effects of Prenatal Exposure: Institute of Medicine's Report to Congress

	Alcohol	Heroin	Marijuana	Tobacco	Cocaine
Subnormal IQ	x				
Developmental delays	x		x	x	
Sensory deficits	x			x	
Fine motor deficits	x				
Attention deficits	x		x	x	
Hyperactivity	x			x	
Gait abnormality	x				
Neonatal withdrawal	x	x		x	x
Prematurity	x			x	x

The United States Surgeon General, the Centers for Disease Control and the American College of Obstetrics and Gynecology state that there is **NO AMOUNT of alcohol that has been proven safe** for an unborn child. Research now shows that even small amounts of alcohol can have neurobehavioral effects on the brain.

From the Outside. Jessica's third-grade teacher is becoming more and more frustrated with her. Jessica could do her classwork if she would just apply herself, but she refuses to pay attention or complete her work. It is obvious that she is bright and capable. Every day she gets angry when she isn't allowed to play outside, but she won't work harder in order to get her assignments done.



From the Inside. Jessica sees the rest of her classmates opening up their desks, finding their books and remembering which page to start the assignment. Jessica opens up her desk too but there is so much in there that she can't remember which book she's looking for. After a wrong try, she finds the book but can't remember what to do. Everyone already thinks she's stupid and Jessica doesn't want to ask someone for help. She opens the book to any page and starts copying numbers. Her paper has as many numbers written on it as the girl next to her, and it isn't fair that Jessica is the only one who has to miss recess again.

Brain Differences: An Excuse or a Context?

Every aspect of our day is navigated by our brain: getting out of bed on time so that we won't be late, reading the body language of peers and knowing when joking is not appropriate, remembering a verbal instruction and translating it into immediate action, planning ahead to get homework done, managing impulses.

Are all brains created equal?

No.

The brain is an extremely complicated organ that is not yet well understood. A child can have a typical IQ, read well, speak well and still have significant dysfunction in their ability to manage life in the same way as their peers. Our response tends to be TRY HARDER! Would we say this to a student who can't read a textbook because she is blind? Of course not. Blindness isn't an excuse to avoid responsibility; rather, it is a context that provides an explanation and points toward supportive adaptations. With invisible brain differences like FASD, behavior provides us with a valuable clues in which to understand the brain and provide support.



What would it feel like to do your very best and still fail at everything?

She won't do what
I ask her to do.

Children with FASD often have a hard time following instructions with more than one step, especially when instructions are given verbally. From the outside it appears that she is being stubborn and defiant, but her brain might be having a hard time processing input quickly, leaving her unable to keep up with more than one small instruction at a time.

Sometimes you feel like giving up because you've explained the rules again —and she keeps breaking them. He completes his tasks perfectly on Monday — but on Tuesday you're back to square one. You try reasoning, explaining, inspiring, cajoling. Nothing works. You get frustrated.

WAIT. Step back and ask yourself this question:

What if it's not that he **WON'T** do it?

What if it's that he **CAN'T** do it?

BRAIN DYSFUNCTION IS THE PRIMARY DISABILITY OF FASD, AND IT IS INVISIBLE. IT MANIFESTS ITSELF IN BEHAVIORS, SUCH AS THE FOLLOWING, WHICH ARE COMMON AMONG CHILDREN LIVING 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.
- **Rigid Thinking.** Once something is learned, may be difficult to re-learn or change it.
- **Difficulty Reading Body Language:** Non-verbal communication such as tone of voice, facial expressions and body language 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. This makes it more difficult to get through the day.
- **Poor judgment.** May have difficulty responding to new or unexpected situations or using common sense in everyday life.

Even if a problem APPEARS to be purposeful and deliberate misbehavior, ask yourself this question: WHAT IF this problem is coming from an invisible disability? You may be the only person who has taken the time to question the assumption that all behavior is on purpose.

Strategies to Guide Interactions

Just like with all children, there are no clear-cut instructions or fail-proof methods. However, remembering some simple principles and using these strategies to shape your interactions and the environment around the child can make a tremendous difference. First and foremost, keep all communication on a concrete and literal level. (For example, instead of saying “Keep your hands to yourself”, say “put your hands on your knees.”)

Expect to reteach, reteach, reteach.

Memory may be a constant struggle. 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.

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.

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.

Provide extra supervision.

In new or unfamiliar situations, this child may have a very hard time knowing how to react. 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.

Understand the importance of routine.

Since a child with this kind of brain difference often has trouble looking ahead, routine is the thing that brings security. When a routine is disrupted, this brain will likely experience high anxiety. Help this child prepare for changes in routine, even changes that seem very small.

The best way to brainstorm strategies is to 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 — what can I do to provide more support in these areas? You can come with ideas to meet the needs of this child by investigating the brain-based causes of behaviors.

Be consistent with the words and phrases that you use. Use the exact same words and phrases so this brain can make easier connections between words and actions. (Instead of saying “slow down” “walk please” and “don’t run in the hallway”, pick one phrase and use it every single time.)

Be as specific as possible. A child with this kind of brain difference 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.

Provide structure. Typical brains are able to internalize structure and navigate through the day independently. A child with this kind of brain difference will need external structures in order to be successful. All children need consistent routines, boundaries, prompts and support - but this child likely cannot function independently without these things.

Help eliminate clutter. A messy space can be overwhelming, but this child may not know where to start or how to create order. Help develop a system of organization for the child and then practice it.

Use only concrete language. Don’t assume that a child is able to understand abstract instructions such as “Be good”, “do the right thing”, “take your seat”, “pick up your room”, “watch your mouth” and any language that doesn’t mean literally what it says. Choose words carefully to eliminate this language barrier.

For More Information

FASD Diagnostic Clinic: This clinic is a part of the Weisskopf Child Evaluation Center at the University of Louisville.

Contact: U of L FASD Clinic (502-852-5333)

Website: <http://louisville.edu/childevaluation>

<http://come-over.to/FASCRC>

“Fetal Alcohol Syndrome Community Resource Center” This website provides facts, resources and information including diagnostic tools, pictures, research / journal articles, strategies for intervention (in English and Spanish) and training opportunities.

www.nofas.org

“National Organization on Fetal Alcohol Syndrome” This website provides resources, frequently asked questions and other information from the national clearinghouse on FASD.

www.fasalaska.com

“FAS Alaska” This website provides a free manual for teachers, as well as strategies, developmental characteristics and information about the biological basis of FASD.

http://www.von.ca/fasd/_fasdtool_fullproof_final.pdf

“Let’s Talk FASD” This free, downloadable guidebook provides information, stories, examples and resources for people seeking to support a person with brain differences caused by prenatal alcohol exposure.

A Few Words: Talking About Alcohol During Pregnancy.....

Not everyone is in a position to develop a close, trusting relationship with a child’s family, but those who are may be responsible for having a very sensitive conversation: asking a biological mother whether or not she drank during pregnancy. Understandably, a woman may not feel comfortable answering this question right away. However, the fact that you were able to bring up the subject in a non-judgmental way may give her the courage to share information with you or someone else at a later time if she’s not able to disclose immediately.

Instead of saying: Did you drink when you were pregnant?

Ask: “Is there a chance that you might have had some alcohol before you knew you were pregnant? And when did you find out you were pregnant?”

Or Ask: “Lots of people drink alcohol. Before you got pregnant, how often did you drink? How much would you usually drink? After you found out you were pregnant, how often?”

Ten Simple Tools for You:

1. Use concrete language and ask “what” questions (not “why” questions) to check for understanding. (“What does it mean to be on time?” “What does it mean to follow the rules on the bus?”)
2. Speak more slowly and use fewer words.
3. Structure is the glue that holds the day together for this child.
4. Routine eliminates anxiety. When a child’s routine gets disrupted (even in a small way), the world doesn’t make sense any more and the future becomes frightening and unpredictable.
5. Never assume that a child is capable of doing something just because she can say the right words. A child with FASD often “talks better than she thinks”. This fools us into believing that she being disobedient on purpose.
6. Inconsistency is normal for a brain with prenatal alcohol exposure. Just because he did it right yesterday (or ten minutes ago) doesn’t mean that his brain can access that information again.
7. Instead of immediately assuming “willful disobedience”, assume “brain difference”, put some supports in place and see if it helps. Be curious about what this brain needs to be successful.
8. A child may need to hear something 100 times (or more) before it sticks in her brain.
9. Her developmental age is likely younger than her chronological age. A rule of thumb is to imagine that she is half her age, and then adjust your language and expectations accordingly.
10. Remember: this child is doing the best he can. Help him find ways to feel successful. He may not experience many natural successes - so go out of your way to give him a reason to feel good about himself.

Kentucky’s Prevention Enhancement Site for Fetal Alcohol Spectrum Disorders:

Funded by the Substance Abuse Prevention branch of Kentucky’s Division of Behavioral Health, this project provides technical assistance and resources to communities, agencies and individuals looking for information about Fetal Alcohol Spectrum Disorders:

Contact: Laura Nagle, Coordinator (Lmnagle@bluegrass.org)

Website: www.kyfasd.org