

Understanding a Child with Fetal Alcohol Spectrum Disorders

By Lynn Tanner, R.N. BS

It has been my privilege to work with adoptive parents in a support group setting in Davis County for over 10 years. I have been impressed with the dedication and care shown by these remarkable people, kudos to all of you for opening your hearts and homes to children in need.

I have been asked to write about prenatal exposure to alcohol. My hope is to help readers understand what it might feel like to be a child with Fetal Alcohol Spectrum Disorders (FASD), often an invisible disability, as well as suggest ideas about how to work differently with this child. Much of the information I share in this article comes from Laura Nagle, Coordinator of Kentucky's FASD Center. I am extremely grateful to Laura for giving me permission to share her work. (1)

Have you ever known a child living with the effects of prenatal exposure to alcohol? Chances are good that you have known many. A child with prenatal alcohol exposure may look like any other child, have a typical IQ but still have invisible brain dysfunction that causes confusing, disruptive and challenging behaviors.

Some adoptive parents I know have said that they were puzzled by their child's behaviors and inconsistent performance. Keep in mind that most alcohol exposed children are not identified or diagnosed as having an alcohol-related brain disorder. You might not know whether or not your child was exposed prenatally to alcohol. An important thing to remember is this; children can have brain-based disabilities that look like willful misbehavior, non-compliance, defiance or lack of effort. You can make a difference in your child's life whether or not a medical diagnosis has been made. If you think or know that your child was prenatally exposed to alcohol I will provide referral information at the end of the article.

Fetal Alcohol Spectrum Disorders are caused when alcohol in a pregnant woman's bloodstream circulates to the fetus by crossing the placenta. This alcohol use during pregnancy can create a brain that: can't link cause and effect, responds slowly, uses poor judgment, can't read the emotions or body language of other people, thinks like the brain of someone much younger, forgets information, has difficulty with time and money, thinks in a disorganized way, and has trouble moving one situation to another.

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Please visit: <http://fasdcenter.samhsa.gov> for a detailed definition of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders.

According to the Institute of Medicine's 1996 Report to Congress: "Of all the substances of abuse, (including cocaine, heroin and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus." A logical question is to ask why alcohol is more damaging to the brain than other substances of abuse. The answer is very complex – therefore I will share with you something that is understandable to me – just realize it is not a comprehensive answer. The molecules of alcohol are so small that they pass freely through the blood-brain barrier. Alcohol can disrupt the way nerve cells develop, travel to form different parts of the brain and function. Also toxic byproducts of alcohol metabolism may become concentrated in the brain and contribute to the development of an FASD. (2)

It is important to know that no amount of alcohol consumption can be considered safe for the unborn child. The good news is that Fetal Alcohol Spectrum Disorders are completely preventable if a woman does not consume alcohol during her pregnancy. (3)

Children with an 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 the child is being stubborn and defiant, but the child's brain might be having a hard time processing input quickly, leaving them unable to keep up with more than one small instruction at a time.

Ask yourself a few questions; What if my child's behavior is pointing to a disability that no one can see? What if the things he does wrong show us exactly what they need from us? What would it feel like if you are doing your very best and still fail at everything? 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.

Brain dysfunction is the primary disability of FASD. It manifests itself in behaviors, such as the following, which are common among children living with prenatal alcohol exposure.

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- Very literal thinking
- Slower brain pace
- Difficulty learning from experience
- Disruption in cause/effect thinking
- Rigid thinking
- Difficulty reading body language
- Memory problems
- Sensory integration problems
- Poor judgment and impulse control

Sometimes as a parent you may feel like giving up because you've explained the rules again – and she keeps breaking them. She can complete the task 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 she WON'T do it? What if it's that she CAN'T do it?

There are many factors that influence pregnancy outcomes, consequently there are no clear-cut instructions or fail-proof methods. That being said many parents have found strategies that have helped them manage more effectively from day to day. Following a few simple principles and changes to the environment can make a difference. A few suggestions:

- Keep all communication on a concrete and literal level
To better understand literal thinking consider reading one of the children's books featuring Amelia Bedelia
- Expect to reteach, reteach, reteach
- Provide external memory tools – lists, cue cards, pictures
- Speak slowly and use fewer words
- Provide extra supervision
- Understand the importance of routine and structure
- Reduce the stimuli in the environment to prevent sensory overload
- Support your child during transitions using a constant signal – visual or auditory

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Develop your own strategies – think about what might be going on in the brain – ask yourselves questions like:

- How does this child do with abstract language?
- Is it possible that they struggle 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?
- When given more than one instruction at a time do they fail to perform the tasks?
- What are the precursors to a meltdown?
- Which elements of the environment might be interfering with my child's ability to focus? (sound, light, noise, smells)
- Are there things that seem to soothe my child that could help frustration and avoid meltdowns?

You may want to keep a log or journal and document your observations to help you find answers and provide more support in these areas. Focus on their strengths – What do they do well? What do they like to do? What are their best qualities?

A wise mother once said, “Instead of trying to change my child, I now try to change the environment.”

From the experts – the parents of course.

- Find something your child likes to do and does well (that is safe and legal) and arrange to have them do that regardless of behavior.
- Deep breathing accomplished by blowing bubbles – inexpensive and fun – now known as ‘relaxing bubbles’
- Pictures on drawers showing contents of the drawers
- Self soothing activities – swinging, walking and rhythmic chanting
- Develop a protocol for loss of control – i.e. if you need to leave our church meeting – put your hand on my knee and squeeze like this – demonstrate

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- Role play a new situation to help your child know how to handle the unexpected
- Pictures in the bathroom showing, brushing teeth, combing hair, etc.
- Color code textbooks and notebooks for each subject
- Define boundaries at the kitchen table with place mats
- To reduce stimuli in their bedroom - less on the walls, less out around the room, and avoid suspending materials from the ceiling

Realize that techniques, even good ones do not work for everyone. Even though a strategy has worked in the past if it is no longer working, stop doing it, put it on the shelf for awhile and try a different approach. Think outside the box, easier said than done right? For fresh ideas I recommend connecting with other parents raising children who are living with the effects of prenatal exposure. One way to do that is to visit the Utah Fetal Alcohol Coalition's website. www.utahfetalalcoholcoalition.org. Our coalition has a Facebook page where you can ask questions or find other families in your community - perhaps you could start your own support group. Adoptive parent Theresa Kellerman shares ideas on her website how to do just that. Visit her website: www.come-over.to/FASCRC

Information about the support group held at Davis Behavioral Health every other month September through May is also found on our website along with good national websites, upcoming events and local resources.

For Diagnosis of FAS in Utah

Division of Medical Genetics
The University of Utah
50 North Medical Drive
Salt Lake City, Utah 84132
801-213-3599*

Physicians at the Division of
Medical Genetics
Dr. Alan Rope
Dr. David Stevenson
Dr. David Viskochil
Dr. John Carey

St. George
Dr. Ellen Arch, Pediatric Geneticist
Dixie Regional Medical Center
435-688-4841

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* You will first need a referral form from your family practice doctor or a pediatrician.

Fax the referral to 801-581-8986

*Upon receipt of the referral, they will send you a packet to complete. After the packet is turned in, the wait is typically around six months.

For a Neuropsychological Assessment

A Neuropsychologist is a licensed psychologist with additional specialized training in “brain behavior relationships”. A neuropsychologist examines the neuropsychological strengths and weaknesses that are exhibited through specialized evaluation.

Utah Fetal Alcohol Coalition <http://www.utahfetalalcohol.org>

Contact Lynn Tanner – lynnt@dbh.utah.gov

1. Kentucky Fetal Alcohol Spectrum Disorders Center: www.kyfasd.org
2. Fact Sheet – Effects of Alcohol on a Fetus, FASD Center For Excellence www.fascenter.samhsa.gov
3. Centers for Disease and Prevention www.cdc.gov/ncbddd/fas

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Lynn has worked in the addiction field for twenty-nine years in clinical and administrative settings with both adolescent and adult clients. Currently she works as a Program Coordinator for the Davis Family Advocate Program. This program service women who need to access treatment services and women who are pregnant and using substances.

Lynn is the co-founder of the Utah Fetal Alcohol Coalition and was the first Chairperson for the organization. She also served for two years as the Team Leader for the Prevention Team with the Utah Fetal Alcohol Coalition.

Lynn has had the opportunity to teach adoptive and foster parents, at risk pregnant women, DCFS employees, mental health and substance abuse providers, school teachers, head start workers and hospital staff members about Fetal Alcohol Spectrum Disorders.