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Changing our approach when our children can't change

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What have I learned about parenting a child with a fetal alcohol spectrum disorder (FASD) over the past 22 years? I have learned that it was not her that needed to make changes. The change needed to come from me.

Did I learn this effortlessly? Quickly? Painlessly? No. Throughout the years, I kept trying to use the same traditional parenting strategies, even when they clearly weren't working. I watched our parent-child relationship nearly break under the constant strain. It was clear that I was not seeing the big picture.

Once I learned more about the brain differences that my daughter struggles with every day, I became a better parent and we were a happier family. These are a few of the many important things I've learned about parenting a child with FASD.

Children who have an FASD have a brain injury

They may have physical or medical issues, but the greatest challenges come in the form of damage to the brain as a result of prenatal alcohol exposure. It is vital to understand that the damage to the prefrontal cortex of the brain, which is responsible for executive function skills, is permanent and has many effects.

One significant challenge is that many children are never diagnosed with an FASD, in spite of the prevalence of the disorders in children in adoption and foster care. These children and their families may struggle without knowing what's wrong or without a diagnosis for which they can seek support.

Challenging behaviors are common for those who have an FASD

Many of our children have not only experienced the in-utero trauma of alcohol exposure. They may have experienced trauma after their birth as well.

Some of the behavioral concerns include:

- Poor impulse control
- Lying, stealing, and physical aggression
- A lack of understanding of cause and effect
- Struggles with abstract thinking
- Anxiety (often in response to authority figures), which can lead to behavioral challenges.

Most children with an FASD function at about half of their age

But for children with FASD, their verbal expressive skills are almost always a strength. This is why parents, schools, and other systems often have unrealistic expectations of what they are capable of and understand.

This disconnect between a child's capacity and an adult's expectations can have serious ramifications. The children may be treated as if they are willfully

disobedient, stubborn, or lazy, rather than as if they have a permanent brain injury. This leads to frustration and challenges at home, at school, and in the community.

There are many parts of their brain that are affected by the alcohol exposure, but it is common that their corpus callosum is damaged, which makes them very inconsistent. The corpus callosum helps the two hemispheres of the brain communicate with each other. Sometimes information has been stored in one side of the brain, but the child cannot get to it in the moments we need them to. This can lead to adults making assumptions that the child is not trying.

As many astute professionals in child behavior can attest, a child will do well if they can do well. We have to understand that in almost every case of a child with an FASD falling short of our expectations, it is not that they won't, but rather that they can't.

It's up to you to change your behavior—not the child

When parents are using typical consequence-based strategies, it often leads to bigger, more challenging behaviors, frustration, and feelings of failure for both child and parent, and relationship struggles between the child and adults in their lives.

“If you have told a child a thousand times, and the child still has not learned, then it is not the child who is the slow learner.”
—Walter Barbe

Would we punish a blind child for not reading a sign? Would we expect a child in a wheelchair to clean a ceiling fan? Would you take a toy away from a three-year-old child because they can't list all 50 states?

Of course not. So why do we punish a child who has an FASD when they have a behavior that is due to their brain injury? Why would we expect them to act like a 12-year-old when they are developmentally 5 or 6? Why would we send them off to post-secondary school or a job at 18 expecting them to succeed without supports if they are developmentally closer to a 9-year-old? This happens daily to hundreds of thousands of children and adolescents who have an FASD, and it is neither fair nor successful.

As a parent of a child with FASD, you must understand the brain more fully and how it is affected by in utero alcohol or drug exposure. There are many places you can go to learn more. For me, reading the groundbreaking book by FASD expert Diane Malbin, *Trying Differently Rather than Harder*, was life changing.

In Malbin's book, I learned an effective way to respond to my daughter's escalations or anxiety:

- I begin by taking a deep breath and reminding myself of her developmental age at that very moment, especially her emotional age.
- I then consider what might be making her anxiety so high. Does she feel overwhelmed? Is she experiencing sensory overload? Does she feel like the task I am asking her to do is too much? Is she being triggered by a similar situation that did not go well in her past? Did her brain just glitch?
- Then as I am trying to form my response, I consider the following: How can I avoid causing more escalation at this moment? What does she need from me right now?
- Finally, I think of ways I can change the environment so that she can best calm down. Repeating her name over and over will not help. Saying "calm down" will not work. Silence can be the best approach until you formulate your response.

Once everyone in my family started to understand the FASD brain and its unique characteristics, we realized that consequences were rarely if ever going to be an effective strategy. We adopted new ways of thinking and behaving:

- We learned to let go of the anger we had in response to my daughter's seemingly purposeful behaviors. We stopped taking things personally. Instead, we focused on relationships instead of punishments. We started having conversations instead of lecturing. And we remembered to give ourselves grace if we messed up and just promised to do better the next time.
- After a meltdown, in a calm later moment, we talked about how we all could have handled the situation differently. We gave lots of support and grace. We began to see changes in the behaviors that she had struggled with for years because we helped to bring her extreme anxiety down so that she could actually absorb the strategies we were trying to teach. There is hope for change. Hold on tight. You will find it.
- We learned that it was important for our daughter to understand her disability. She knew she was different. But, without appropriate words to put to the differences, she used the words she had heard out in the world. She called herself "dumb" and "crazy" and "mean." By talking to her about what was going on in her brain, she could learn to accept her differences. It is often such a relief for those with an FASD to

gain an understanding of their own brains, and that knowledge alone can start to take the pressure off. Once that happens, it reduces the pressure on everyone in the family.

Your child has to understand the effects of FASD too

It is typically best to give children information about FASD (or other disabilities) over time, rather than all at once, although this depends on their developmental age, not just their chronological age. Teenagers may not want to hear about their differences at a time when they just want to be the same as everyone else. Start young if you can and sprinkle information during calm and teachable moments. If your child is a teen already, they still hear you even if you think they are not listening. They will most likely come back to the words you give them. Choose them wisely.

Don't forget to give them hope during these discussions! Have them listen to podcasts that feature adults living with an FASD who are thriving—there are many! Seek out families who have young adults living on the spectrum and let your kids see them thriving. Attend conferences with adults with FASD who can share their stories. One thing you, and your child, may learn from these stories is that every journey is unique. For some young people with an FASD, college (or at least traditional college full time right after high school)

may not be the best option. Let them know there are other ways to succeed and help them find the education and career path that fits their strengths, skills, and abilities.

Last but not least: do not lose hope!

Just as our children need hope, parents do too. It's so important to understand FASD and parenting strategies that will make your children's journey more successful and less frustrating. Access expert training and support on FASD as early as possible—your child's life depends on it.

ABOUT THE AUTHOR

Barb Clark is a parent support and training specialist with the North American Council on Adoptable Children (NACAC).

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