

Who has to change? Trying their hardest, doing their best!  
*What it is like to live with Fetal Alcohol Spectrum Disorder*

by  
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*This information applies to any individual who is functionally dependent on others in some specific areas, and who does not learn from correction, or who does not 'get' why people are distressed with their behavior.*

Parents, teachers and support persons of individuals with fetal alcohol spectrum disorder (FASD) are sometimes faced with episodes of extreme behavior. The first instinct we all follow is to use 'common sense' methods for controlling the disruptive behavior of any child.

In many ways, children with FASD think and learn in a different manner than "normal" children. When a child with FASD acts out in some excessive or violent manner those of us who support them need to ask ourselves several questions.

Whose problem is this? Who has to accommodate? Who has to learn something new to be able to solve these problems?

When we are raising our children, our role as parents is to have our own cultural standards for behavior, and to teach our children how to conform and to share in those cultural expectations.

Things like "Do unto others as you would have them do unto you", "Don't interrupt while someone is speaking", or "It's polite to share..." we are all familiar with them. They are those slogans on the poster about "Everything I need to know in life I learned in kindergarden."

The child is expected to accommodate and to learn. We set the standard. We model correct social behavior. We remind and caution about the "rules".

We often make it fun to follow the social rules by offering positive consequences (rewards) for cooperation ("Whoever can use the quietest voice gets an extra book", "Whoever is the most polite gets to go on the computer first, etc.) When necessary we control a child who will not accommodate by removing them from social opportunity. If they are just too tired to get along we may put them down for a nap or have them sit out a turn till they are calmed down and ready to cooperate. Often this is all that is required. These are the methods that we use to elicit voluntary cooperation and to socialize our children to grow up to become responsible, caring adults.

Some children still don't get the polite message that the world has boundaries and external expectations. We may use negative consequences (punishments) to teach them that they do not have the right to be omnipotent, to always have their own way, or to bully others.

We may use consequences such as sending them to their room. We may briefly take away privileges (bed time, television), or even “ground” them from certain activity. When needed to maintain order and control, these are ways we educate our kids that their freedoms are related to their level of personal responsibility. Until they show a level of responsibility someone else will maintain control in their world.

In Western culture, using these methods, children learn that there are boundaries. We teach children that they are expected to act in a socially responsible manner, be accountable and responsible for their actions, and that they must accommodate some of their own behavior to be able to fit into the social norm.

And this works just fine for the greatest majority of our children. If we did not follow these cultural traditions our children would grow up “spoiled”, expecting everything to be their way, whenever they want, and not become caring about the rights of others.

Here is the dilemma. For a person with FASD, their mind often does not perceive the other point of view. They can sometimes see the meaning of what is being explained to them through a social story. Even then, it is bringing the information to them, in story form, so that it can become their point of view. They process, as through blinders, only what is concrete, and immediately apparent, in the immediate moment.

Many children with FASD are not able to learn from correction. They may not have a long enough attention span to connect what they did just before with the correction that was offered. If they are reminded about what is expected ahead of time they may be self-controlled and know exactly what to do. But if they are brought into a problematic situation without re-educating them about the expectation each time, they may be unaware of what is expected and unable to self-monitor their own behavior.

Such children do not generalize a “lesson” learned from past experience. If you admonish them about their behavior they may not know what to do to self-correct because they can’t make the connection. All they “process” when they hear “no”, “don’t” and “stop” is “you don’t like me”, or “I’m bad”.

Children growing up with these types of differences in their thinking and learning processes often become very emotionally fragile. They don’t ‘get it’ about why people are distressed with them. They experience that others are distressed with them and often mirror or reflect back the very emotion that is being shown towards them. For these children, it is very important to really like them when you are speaking to them. They work more off the emotions of those around them than the words and actions of those who are guiding them. Being emotionally angry towards them always further escalates their behavior.

For some children, each time they have an experience is like the very first time, no matter how many times they have been through it before. These children may always have to be coached and reminded. When they become frustrated or confused they often become very anxious.

Most such children “telegraph” their anxiety by first becoming slightly agitated. Such behavior must be interpreted by their parents/teachers/caregivers as communicative. The message is ‘come rescue me before I go out of control’. If the early signs of anxiety are not responded to the child will often escalate to a point of self-injury or aggression until someone else intervenes to assist them to calm themselves down.

The only point of view they have is their own, immediate perspective. They don’t know what to do to “correct” their own behavior until an understanding caregiver reminds them that now is the moment when they have to remember to apply a social rule. (“What do you do with your hands?” “Use your soft voice”). Criticising or challenging these children does not assist learning, is counter-productive and always makes things worse.

So here is the crux. Imagine an individual with FASD who can do exactly what you expect, perfectly well, each time you organize the situation and remind them of expectations. Yet each time you fail to put this much effort into anticipating what could possibly go wrong and trying to remedy every possible failure and reaction ahead of time they become agitated, aggressive, self-injurious, withdrawn, etc.

With such a child, no matter how much you use negative consequences, this only makes the child more reactive. No matter how much you use positive consequences, they still remain dependent on you to structure and remind them about what to do. Such a child may never become independently able to be responsible for their own actions.

So back to the original question: Who has to change? Whose problem is this? Who has to accommodate? Who has to learn something new to be able to solve these problems?

This is not a child that is “spoiled” by the parent or caregiver who is accommodating to their special needs. Living with their FASD frame of mind they need someone else to make the connections for them and to keep their world orderly and structured. The child may not be able to achieve our cultural expectation for eventual independent functioning, but the child is clearly showing that they are willing and able to follow expectations when someone is present to assist them to navigate through their life.

Most of these reactive kids are very emotionally fragile. When they have a smile on their face they can be happy, cooperate, focus and work within their familiar repertoire. When they are distressed, confused, frustrated or anxious they tend to lose their ability to function and become very reactive.

Another big dilemma is “outsiders” who don’t see how much effort it takes to keep these kids “glued together” so that they can function at all. “Outsiders” see the accommodations made to protect these kids from “suffering consequences” of their actions. For kids who are unable to learn from their mistakes, accommodation must be made to protect them from negative consequences which lead to self-injurious and anxious, regressed behavior.

“Outsiders” may unknowingly blame caregivers for “spoiling” the child. They may give generalized “advice” that “the child has to learn”, and “the world isn’t always going to protect them.” Or, ‘No one is going to do that for them when they get to high school.’ But

when children are capable when they are properly supported, yet unable to learn from negative experience, the world may have to always offer them protection.

These are not bad kids. Often they are working heroically to overcome their learning disabilities and to participate in the world wherever they are able.

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