

Caring for Children and Youth With Fetal Alcohol Spectrum Disorder

As a parent or caregiver, you may encounter various diagnoses for the children and youth in your care. Prenatal exposure to substances can be especially damaging to a developing brain. Fetal Alcohol Spectrum Disorder (FASD) is the umbrella acronym meant to describe the group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These can range from mild to severe, affecting each person differently. The impact of alcohol usage during pregnancy varies based on when, how much, and how often the mother drank.

If you are caring for a child with possible FASD, remember that behaviors, abilities, and physical

characteristics vary greatly from one child to another. Also, keep in mind that, when discussing behaviors, trauma and FASD share some similarities.

Getting a diagnosis for FASD is not a

simple or straightforward process most of the time. A medical FASD diagnosis currently requires confirmed alcohol use by the birth mother and specific physical features. This may be hard to get, particularly in a child welfare setting. Regardless, you can learn more about how the FASD brain works—and you may find some answers that could help dramatically improve the children's behaviors and the atmosphere in your home.

If you believe that the child in your care may be affected by FASD, talk to your worker and doctor. They may refer the child for genetic testing to get an FASD exam, which includes taking specific physical measurements and testing cognitive abilities and functioning. You may find that a neuropsychological evaluation is more helpful in learning where the child's challenges arise.

Some Types of FASD

• Fetal Alcohol Syndrome (FAS): People with FAS are at the severe end of the spectrum of FASD. They may have facial and physical characteristics and issues

affecting their central nervous system. Facial features are only present in about 10% of children affected by prenatal alcohol exposure, and drinking must occur at a specific time in the pregnancy to affect facial features. This



is the hardest diagnosis to get.

- Alcohol-Related Neurodevelopmental Disorder (ARND): People with ARND have neurological system issues but do not have any facial characteristics. ARND was formerly known as FAE or ND-FAE, Neurodevelopmental Disorder Fetal Alcohol Effect.
- Alcohol-Related Birth Defects (ARBD): People with ARBD have physical medical issues with their vision, hearing, heart,

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kidneys, or bones. ARBD used to be known as FAE (Fetal Alcohol Effects).

Characteristics of FASD

Caring for a child with FASD may be a difficult journey for many parents. They may notice some of the following characteristics that affect the child or youth's neurological system:

- **Difficulty understanding abstract concepts** such as time, money, or math.
- Poor short-term memory affects the ability to connect behavior to a consequence and often leads to academic problems.
- **Inability to make predictions** can lead to safety issues and poor social skills.
- **Poor impulse control** can lead to a child doing a specific behavior but not having the desired result.
- Poor judgment skills. The "correct" choice isn't always obvious, especially when children with FASD have poor memory, prediction, and impulse control skills.
- Poor boundaries. A child with FASD might be too friendly with strangers and not understand personal space and property.
- Hyperactivity and attention deficits, which are seen in a large percentage of children with FASD.
- Developmental delays can affect a child in social, academic, and physical areas of development.
- Sensory issues can affect the child's mood or behavior in specific environments, as well as their personal likes/dislikes for food, clothing, lighting, or noise.

Strengths of FASD

Children with FASD also have incredible qualities, including the tendency to be caring, creative, determined, and eager to please the adults around them. They do best with routine, clear communication, and close

supervision.

- Children with FASD who struggle often want to please; remember, children do well if they can.
- A child with FASD is sometimes very motivated by helping and positive adult feedback. They function well in oneon-one settings, such as yard work projects, giving good sensory input.
- Children with FASD typically are incredibly compassionate and protective. Give them opportunities to care for something, such as a pet, with proper supervision.

Physical Characteristics of FASD

Keep in mind that some studies indicate that as few as 10% of children with FASD have physical characteristics and may only display emotional, behavioral, and cognitive concerns. A child will only have facial characteristics if the mother drank alcohol when the child's midface was developing during pregnancy.

Facial characteristics may include:

- Small eye openings
- Thin upper lip
- Smooth, wide philtrum (area between your upper lip and nose)
- Smooth, wide bridge of nose

Other physical characteristics can include:

- Low birth weight
- Small head circumference
- Shorter-than-average height
- Low body weight
- Poor coordination
- Vision or hearing concerns
- Sleeping or sucking concerns as a baby
- Concerns with heart, kidneys, or bones

Creating a Calming Environment

Because this alcohol exposure is not reversible, the best success is achieved by

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changing the external environment and expectations to help your child. Many parents of children with FASD talk about the role that environmental factors play in how a child behaves. For example, a calm, plain room, free of bright colors and background noise, will provide a much more relaxed environment.

Remember that their initial reaction isn't necessarily their true response; give them a minute to respond. They may initially respond "no" to a direction, but given another 10 seconds, may then say, "I need help with that" or, "I can't do that yet; I'm hungry."

Here are a few additional suggestions that you may find helpful:

- Have a plain-looking bedroom and things that are not easily broken.
- Use digital clocks to help the child read the time more easily, but know that they may need help understanding the concept of time.
- Post house rules specific to each room, in each room.
- Have a toy chest in a specific place for personal items out of the child's sight.
- Keep your furniture and the child's basic self-care items in the same place daily.

The above tips are also valid for the child's classroom, if possible.

Parenting Tips and Suggestions

Parenting strategies for children with FASD usually revolve around structure, routine, clear rules, and increased awareness of environmental factors. If a parenting technique isn't working, replace it with another method. Don't try harder. Not every

technique is going to work all the time.

- Parent the child by the developmental age versus the chronological age. Children with FASD have a hard time connecting consequences to a behavior. Punishment or removal of privileges will not make sense to them and will typically cause escalation. Stay positive and focus on the desired outcome rather than correcting negative behavior.
- Repetition is your friend. Role-play appropriate behavior before some situations and after an inappropriate situation. The more you do this when they are calm, the more likely they will have it as a tool when upset.
- Be consistent with rules and routines,

including following through every time and everywhere.

- Visual support is key! Create schedules at home and make signs for desired tasks such as cleaning their room or brushing their teeth.
- Do not give more than one direction at a time. For example, "clean your room" will not have
- the desired effect. Begin with, "Put your clothes in the hamper." Once that is completed, follow up with, "Please put your toys on the shelf." This may seem tedious, but remember, your child is not trying to be defiant. Instead, you are working with the effects of a traumatic brain injury.
- Anticipate situations where the child's safety may be at risk, such as a parking lot or a busy street. Many kids with FASD aren't good at multitasking and may be thinking about shopping rather than shopping and watching for traffic. The part of the brain that controls judgment and impulsivity is also often damaged in kids with FASD.

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- Give rewards immediately following good behavior.
- Ensure you enforce the rules for everyone in the home every time. Consistency is crucial.
- Remember that a skill can be learned and forgotten a day or a week later. This is not defiance; it is a symptom of their brain injury. Frequently review expectations for behavior and rules with the child.
- Avoid problem situations where the child may be overwhelmed, such as long lines, crowded places, and other unstructured environments.

Finding Balance

One Wisconsin foster parent talks about having a teen in care who had possible FASD, possible Oppositional Defiant Disorder, and possible Reactive Attachment Disorder.

"I did my research, only to find that techniques for FASD were contrary to those for RAD," she says. "I was a little stuck. With RAD, you should keep kids off balance and not do the expected thing. With FASD, you're supposed to be structured and predictable."

She says, "What I figured out with my daughter was that she has to have some choices and control. But she also needs the basic structure of having reminders to flush the toilet and wash her hands, and she needs a lot of simple reminders about what the plan is on days when we might have an appointment after school."

What this mom says is a good reminder for all parenting children and youth touched by foster care and adoption: remember there are no one-size-fits-all answers. Each family needs to seek their own balance and what works best for them.



Resources

From the Resource Library

- Fetal Alcohol Syndrome: Lifelong Effects (DVD)
- Adoption & Prenatal Alcohol and Drug Exposure: Research, Policy, and Practice by Richard Parth, Madelyn Freundlich, & David Brodzingsky
- Understanding FASD: Cause, Effects, and Interventions, by Academic Edge
- Fetal Alcohol Syndrome and Fetal Alcohol Effects, by the Minnesota Department of Health
- Recognizing and Managing Children with Fetal Alcohol Syndrome, by Brenda McCreight
- Fantastic Antone Succeeds!, by Judith Kleinfeld
- The Best I Can Be, by Liz Kulp

Additional Resources

- Families Moving Forward Program
- <u>Fetal Alcohol Spectrum Disorders</u> (FASDs)
- Study of First-Graders Shows Fetal Alcohol Spectrum Disorders Prevalent in U.S. Communities
- FAS Community Resource Center
- Fetal Alcohol Exposure Fact Sheet
- Cognitive Supports
- FASD United
- Trying Differently Rather Than Harder, by Diane Malbin



