raising children with fetal alcohol spectrum disorders (FASD) tips

about

Parenting a child with Fetal Alcohol Spectrum Disorders (FASD) is a journey. It can sometimes be very challenging and very rewarding at the same time. You cannot parent a child with an FASD without having it change your life and most often, for the better. You will meet some amazing people, make some amazing friendships, and see a beautiful child work really hard to be the best person they can be with your love and support.

on fasd

• Know that you will go through periods of grief that never fully go away. The brain damage from the prenatal alcohol exposure is a lifelong disability, one that makes a child’s future uncertain. It is hard to see them struggle. This will hit you at times when you are least expecting it. This is normal.

• Learn as much as you can about FASD. Read books, attend trainings, conferences, and support groups. Not just at the beginning of the journey, but all throughout.

• Get accustomed to educating many people on FASD, including professionals. It is a very misunderstood disorder.

remember

• Take your child’s age and cut it in half. That is the age you can expect them to act.

• It is a spectrum disorder. Children and adults with an FASD function at different levels.

• FASD is brain damage. Permanent brain damage.

• Don’t blame yourself (or the birth mom if your child is adopted). FASD is usually a result of either an addiction issue, or a lack of knowledge and understanding about what prenatal exposure can do to a developing fetus. No mom goes into their pregnancy willfully intending to hurt their child.
patience

- Be patient. Children with an FASD can tell you a rule, but that does not mean they can always follow it. This is very frustrating.

- Re-teach everything. Don’t get irritable or short tempered when you have to teach your child the same things over and over again — sooner or later (likely later) they will get it.

- Know that conventional parenting techniques often don’t work with children with an FASD. A sticker chart may work well with one child and not another. Time-outs rarely work with our kids. We have to be creative and find alternative strategies. And know that when we find one that works, it might not work for more than a few weeks (or less, or more).

routine

- Keep to a routine when possible and let the child know ahead of time what the plan is for each day. Post a daily calendar and run through the routine with the child each morning.

- Prepare for transitions such as getting in and out of the car or bathtub, waking up, going to sleep, settling for dinner, a change in television programs. Children with an FASD don’t always have the natural ability to make transitions from one emotional state, or one activity level, to another. Be prepared to help them every time.

- Break all tasks down to one step at a time. Children with an FASD can’t always see the parts of a whole nor can they always understand a sequence — help them to see the parts and the order of an activity or task.

- Know that our kids often have a hard time discerning the difference between what one minute, five minutes, or 30 minutes feel like. Visual times can help to alleviate many meltdowns that are due to this challenge. There are two different timers I recommend and they are both available on a website called www.abilitations.com Search “audible countdown timer” and “sand timers.” The sand timers are offered in various times and are pretty sturdy.

- Learn to distinguish between flexibility and chaos. You will have to allow for spontaneous change but that doesn’t mean that you can’t have a schedule that is mostly followed; you will know when to let go.

health

- Keep complex carbohydrates and proteins (e.g. whole wheat crackers, string cheese, etc.) around for regular snacks to keep blood sugars stable. Varying blood sugars will impact the child’s mood so keep it stable.

- Our children need lots of exercise. Try individual sports like swimming or biking. This helps with large muscle development and keeps them out of team sports that can create confusion or peer alienation.
developmental age equivalent

With most kids with an FASD, we should cut their age in half, and that is often the age they are functioning in most areas. Imagine sending a 9 year old into the real world with little to no support...

<table>
<thead>
<tr>
<th>Skill</th>
<th>Developmental age equivalent</th>
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<tbody>
<tr>
<td>Actual Age</td>
<td>18 years</td>
</tr>
<tr>
<td>Expressive language</td>
<td>20 years</td>
</tr>
<tr>
<td>Comprehension</td>
<td>6 years</td>
</tr>
<tr>
<td>Money and time concepts</td>
<td>8 years</td>
</tr>
<tr>
<td>Emotional maturity</td>
<td>6 years</td>
</tr>
<tr>
<td>Physical maturity</td>
<td>18 years</td>
</tr>
<tr>
<td>Reading ability</td>
<td>16 years</td>
</tr>
<tr>
<td>Social skills</td>
<td>7 years</td>
</tr>
<tr>
<td>Living skills</td>
<td>11 years</td>
</tr>
</tbody>
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relationships

- Negotiate with the teacher for a reduced, or non-existent, homework load. This will reduce household tension in the evenings and respect the child’s exhaustion level.

- Get use to feeling like you are being judged by everyone: people, other family members, medical professionals, school staff, neighbors, etc. People will give you advice that will often seem very condescending. Learn to smile and know that people mostly are just trying to help. Say something when appropriate.

- Be aware that some relationships in your life may change. You may very well be raising “that child,” the one that others don’t want around their children. Some families experienced not being invited to certain activities. Work on educating your family and friends on FASD, with hope that they will be patient and understanding.

- Find other families raising children with an FASD to form relationships with. This is by far the most common desire that caregivers have, to talk with another parent who “gets it.”

have fun

- Create some fun in every day. FASD symptoms can create a lot of tension and stress in the family, so make sure you find something positive and fun in each day. It can be simple and short, but it needs to happen.

- Lots of cuddling and hugging! Your child needs the physical contact that re-enforces attachment.

- These kids are precious. They can be really frustrating, really often, but they are typically really fun kids who just want love and acceptance. Accept them for who they are. Consider their developmental age, instead of their chronological ages when setting expectations.

- Learn to expect chaos, issues, and challenges. Have fun and celebrate when you are wrong!
books

- *Damaged Angels* by Bonnie Buxton (good basic info)
- *Trying Differently Rather Than Harder: Fetal Alcohol Spectrum Disorders* by Diane Malbin (good practical ideas)
- *Broken Cord* by Michael Dorris (one of the first books written on the subject)
- *Braided Cord* by Liz and Jodee Kulp (wait until you are farther along on the journey)
- *Fetal Alcohol Syndrome* by Anne Streissguth (very research and medical based, but good info)

websites

- Minnesota Organization on Fetal Alcohol Syndrome: www.mofas.org
  - MOFAS calendar for activities and educational opportunities: www.mofas.org/calendar
  - MOFAS Resource Guide for education, social services, health care, and family or community related topics and services you may qualify for: www.mofas.org/resources/guide
  - MOFAS Resource Directory to search for FASD-friendly professionals and programs in your area: www.mofas.org/directory
- National Organization on Fetal Alcohol Syndrome: www.nofas.org
- Center for Diseases Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- Reach to Teach, booklet on teaching children with an FASD: http://www.thewhole9.org/pdfs/Reach_To_Teach_Final_011107.pdf