Practical Strategies for Supporting a Loved One with FASD

WEBINAR

Presented by Barbara Clark, NACAC
Hosted by Formed Families Forward
January 16, 2019
Who we are…

Formed Families Forward's mission is to improve developmental, educational, social, emotional and post-secondary outcomes for children and youth with disabilities and other special needs through provision of information, training and support to adoptive and foster parents, and kinship caregivers. We provide:

- In-person trainings (we sponsor and we come to you!)
- Webinars
- Fact sheets and other resources
- Youth/YA peer support group; parent/caregiver support group
- Direct support- calls and meetings
- Connecting families to resources

www.FormedFamiliesForward.org
Upcoming Trainings

• FASD Webinars: Jan 28 (Improved outcomes through Screening & Diagnosis of ND-PAE in Patients with FASD w Dr. Susan Rich) and Feb 7 (Schools & FASD)
• Trauma & Resilience in Alexandria (Jan 23) and in Loudoun (Feb 25)
• Spring Forward Foster, Adoptive and Kinship Family Fun Day and Professional Conference, April 27 at GMU Manassas
Fetal Alcohol Spectrum Disorders
-Practical Strategies for Supporting a Loved One w/FASD

Formed Families Forward - Part 1

Barb Clark, Parent Support Specialist
North American Council on Adoptable Children (NACAC)
Framing: 3 Types of Trauma

-Bruce Perry

• Intrauterine insult- prenatal alcohol or drug exposure, stress during pregnancy

• Early neglect; mother who is inattentive due to stress, depression, domestic violence, etc., Orphanage

• Classic trauma such as abuse, witnessing violence, etc.
What is FASD?

Remind yourself constantly...

Brain Injury
or
Brain Damage
# FASD & Developmental Timeline

## ACTUAL AGE OF INDIVIDUAL: 18

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

We recommend you take the age of an individual with an FASD, and cut their age in half. This is the age they are probably functioning at in most areas of life.

*Adapted from research findings of Streissguth, Clarren et al, Diane Malbin 1994*
# Developmental Quadrant

<table>
<thead>
<tr>
<th>Physical/Chronologic</th>
<th>Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social</th>
<th>Cognitive</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>11</td>
</tr>
</tbody>
</table>
# My daughter at 18

<table>
<thead>
<tr>
<th>Physical/Chronologic</th>
<th>Parent to this age</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional</strong></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide support and guidance with and about peers &amp; safety measures</td>
<td>Advocate at school regarding this age</td>
</tr>
<tr>
<td>Social</td>
<td>Cognitive</td>
</tr>
<tr>
<td>10</td>
<td>11</td>
</tr>
</tbody>
</table>

**Parent to this age**

- Advocate at school regarding this age

**Provide support and guidance with and about peers & safety measures**
Symptoms
Typical symptoms/challenges

- Difficulty with abstract concepts
- Impulse control
- Inability to manage money
- Difficulty generalizing
- Do not have the abstract feeling of the passage of time
- Difficulty with telling time
- Poor problem solving skills
- Sleep Issues
- Stubbornness/perseveration
  - Very similar to children with autism
- Attention deficits & hyperactivity
- Struggle with delayed gratification
- Pattern of lying/confabulating
ANXIETY

- Heart rate Increases
- Body temp rises
- Body tenses
- All tied to brain function
- Keep anxiety as low as possible through sensory breaks, interventions, relaxed testing (if any), etc.
4th-6th Grades

Around the ages of 9-11, difficulties in academic performance and behavior in the school setting become more apparent.

It is important to consider screening for an FASD if parents are expressing concerns over new behavioral issues and/or academic struggles particularly around the 4th to 6th grade level.
Strategies
Fingledobe and Pribin

Last serny, Fingledobe and Pribin were in the nerd-link treppering gloopy caples and cleaming burly greps.

Suddenly a ditty strezzle boofed into Fingledobe’s tresk.

Pribin glaped and glaped.

“Oh Fingledobe!” He Chifed, “That ditty strezzle is tunning in your grep!”
Top strategies…

- Remember it is brain damage!!
- Be patient and give grace!!
- Change the environment!!
- Don’t ask why!!
- Work on connection/relationship
Reframe

- Move away from constant consequences which produce anxiety
- Child is more likely to learn skills when not anxious & angry
Escalations/Raging- What not to do

- Remove others if possible or remove the individual from the area. Ensure safety.
- **Do not tell the child to calm down more than once!!!**
- Stay calm, and try to talk as little as possible.
- Avoid using the child’s name over & over.
- Do not point out consequences- perceived as threat when child is in the red zone
- Do not respond to cursing
Escalations/Raging- What to do

- Remember that when a child is on the way to the red zone, or is already there, their auditory processing is off.

- Talk as little as possible in a calm voice.

- Use phrases like:
  - What do you need from mom (or dad) right now?
  - How can I help you?

- Know that often once a rage has started, it is just a matter of waiting it out and keeping yourself calm.
Recovering from a rage or escalation

- It takes at least 2 hours for our bodies and brains to recover from an escalation to the point where we are calm and can process the situation.

- It takes 24 hours or more for a child with an FASD to recover from an escalation to the point where they are calm and can process the situation.

We are often expecting the child to process and make amends for an escalation when they are not yet capable of doing so.
Holidays

- Might need to change traditions- make new ones
- Don’t plan on staying as long as you would like. Stay as long as you know your child can handle
- Take two vehicles if possible
- Make a picture schedule of the day
Shopping

- If causes issues, avoid
- Make a list before you go and have them be responsible for part of it.
- Make clear only buying what is on list
- Have exit strategy
- If stealing is an issue, check their pockets when leaving
Advise

- Supervision is IMPORTANT!!
- De-clutter as much as possible.
- Don’t give multi step directions. Keep it simple.
- Remember our individuals often use the wrong words when it comes to feelings.
- Water and snacks every two hours is important.
- Resolve sleep issues as much as possible.
- Remind yourself: BRAIN DAMAGE!
- Expect inconsistency and celebrate it when you are wrong!
Homework

Homework may need to be reduced or eliminated if it is causing stress in the family setting.
Security

- Install locks on doors
- Buy safe/lock boxes
- Use door alarms
- Might need security system
- School: Keep valuables locked up, things of interest out of sight
Confabulation
(otherwise referred to as “lying”)

• “a memory disturbance, defined as the production of fabricated, distorted or misinterpreted memories about oneself or the world, without the conscious intention to deceive”

• We need to look at the “lying” or “confabulation” while we acknowledge the anxiety, whether visible or hidden, that is going on within the child.

• When under pressure, it is almost a given the correct story will not come out.

• Filling in the “holes” in the working memory. Would rather look “bad” than “stupid”.

Confabulation

How to handle

• If the child seems worked up, wait until later or a different day to confront the story.
• Need to wait until they are in a good, clear mind (or as clear as the child ever gets), to talk about it and process it
• When processing, do not shame, blame or embarrass the child. This is a part of their brain damage/disability
• Talk calmly and respectfully about the importance of truth and having the right facts
False Allegations

How to handle (often not a matter of if but when)

• Document history of confabulation/lies/stories in order to protect the child, professionals, peers and family.

• Do not tell the child that they could get a parent, friend, or teacher in trouble by saying something that isn’t true. This makes them more likely to do this when upset with an individual.

• Point out the individual impact the allegation could have on them, their social life, and peer relationships.
Set up an Occupational Therapy (OT) Evaluation

-request an OT who is trained in Sensory Integration techniques who can give you a “Sensory Diet” for your child
Sensory Strategies

- mini trampoline or large trampoline.
- Have an area where they may retreat if overloaded.
- Ear protection/noise cancelling head phones can be worn to reduce auditory stimulation.
- Have a variety of fidgets available.
- Frequent opportunities throughout day for physical activity.
- Snack and water break every two hours.
- Be sensitive to sensory issues.
Visual Timers

www.timetimer.com
Sand Timers

30 seconds
1 minute
3 minutes
5 minutes

www.schoolspecialty.com
Teach the difference between fair & equal
Websites

- National Organization on Fetal Alcohol Syndrome
  - www.NOFAS.org

- MN Organization on Fetal Alcohol Syndrome
  - www.MOFAS.org

- SAMHSA FASD Center for Excellence
  - Fasdcenter.samhsa.gov

- Centers for Disease Control and Prevention FAS Prevention Team
  - www.cdc.gov/ncbddd/fas
Books

- **Try Differently Rather Than Harder, Diane Malbin**
- Damaged Angels, Bonnie Buxton
- The Best I Can Be, Liz Kulp
- When Rain Hurts, Mary Evelyn Greene
- Fetal Alcohol Syndrome, Ann Streissguth
- The Braided Cord, Liz & Jodee Kulp