What I Wish Doctors Knew About Raising a Child with an FASD

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1. Understand that FASD is largely an invisible epidemic; state the prevalence of dysmorphic facial features in those with an FASD.

2. Understand that parents and children are under intense stress and need support.

3. Understand that diagnosis improves prognosis and reduces stress for the family.

4. Understand that traditional behavioral systems do not usually work for a child with an FASD.
FASD: An Invisible Epidemic

- A 2018 study by the NIH National Institute of Alcohol Abuse and Alcoholism revealed that conservatively as many as 5% of American children may have an FASD. “Estimated prevalence of fetal alcohol spectrum disorders among first-graders in 4 US communities ranged from 1.1% to 5.0% using a conservative approach.” (May, P. 2018, JAMA)

- FASD is 2.5 times more common than autism
“Families are desperate for support.” Yet many people with FASD haven’t even received an accurate diagnosis, let alone appropriate treatments. (Weir, K. 2022) www.apa.org
FASD is largely invisible; prevalence of facial features

Professionals still believe that dysmorphic facial features are necessary for an FASD to be present.

Less than 10% of those with an FASD have distinct facial features.
Objective 1- FASD is largely invisible; facial features

90% of those with an FASD “look” typical

Facial features are also on a spectrum of severity

“Our kids are slipping through the cracks and being failed by a system that does not recognize or support their disabilities.” Jurado, 2022

Abnormalities may be present but subtle
Objective 1 - FASD is largely invisible; lack of history

FASD is very prevalent among children who have been adopted or who are in foster care.

Conservatively, FASD affects ~70% of children in the foster care system (in my home, 2/2 adopted children have an FASD.)

There is often no documentation of exposure.
Objective 1-
FASD is largely invisible; stigma

- ~45% of pregnancies are unplanned.
- Most women do not know they are pregnant for several weeks.
- Anyone can have a child with an FASD if they consume alcohol at any time during their pregnancy.

- How to ask biological mothers about alcohol use?
  - Ask general questions regarding the pregnancy:
    - Was the pregnancy planned?
    - At what stage was the pregnancy confirmed?
    - Could you have consumed alcohol before you knew that you were pregnant?
Red Flags for FASD

- Self-Regulation Difficulties
- Neurocognitive Difficulties/Poor Executive Functions
- Poor Adaptive skills
- Prenatal History - not living with biological parents; born addicted to substances
- Hard behaviors not responding to traditional methods
- Sensory Processing Differences
Children with an FASD often have stronger expressive language than receptive language. This can further obscure their disability. “They can talk the talk but they can’t walk the walk.” (interpretation = defiance)

Children with an FASD often have an average IQ but all individuals will have impaired executive functions and adaptive skills. *Higher IQ is often harder to parent; but systems place more weight on IQ.*
Objective 2-
Parents and children are under intense stress and need support.

- FASD is an invisible, organic BRAIN INJURY!!!
- It is a life-long disability.
- Behaviors are symptoms.
- Appropriate supports are lacking.
Objective 2 - Parents and children are under intense stress and need support.

When you do not understand the cause, you may suspect that you are the cause and feel like a failure as a parent.

• Parents need to be equipped to understand that their child has a neurobehavioral disorder and need supports NOT:
  • That they are a bad child.
  • That they are bad parents.
Objective 2- Parents and children are under intense stress and need support

**Primary Characteristics of an FASD:**

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<tr>
<th>Irritability</th>
<th>Dysmaturity</th>
<th>Slower processing speed</th>
<th>Poor impulse control</th>
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<tbody>
<tr>
<td>Inconsistent performance</td>
<td>*Difficulty predicting outcomes (do not get cause-effect)</td>
<td>Over and under sensitive to stimuli</td>
<td>Often suffer from sleep disorders</td>
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Malbin, D., 2002
Objective 2-
Parents and children are under intense stress and need support.

Most schools are not set up to support children with an FASD.

Schools prioritize LEAST RESTRICTIVE ENVIRONMENT which sets children with FASD up for failure.

They need more supports not less.

If they are doing well with supports, DO NOT REMOVE THEM!

Most with an FASD are too high functioning for a traditional self-contained classroom but need more supports than resource alone.

These children are frequently kicked out of daycare and viewed as behavior problems once in school.
Objective 3-
Understand that diagnosis improves prognosis and reduces stress for the family.

A diagnosis brings understanding, empathy, and support from parent to child.

The earlier the better!

- Without a diagnosis there is no early intervention or school supports.
- Children and their parents are perceived as being the problem rather than having a problem.
Objective 3-
Diagnosis improves prognosis and reduces stress for the family.

When we see behaviors through the lens of a brain-based disability, we shift our perspective and our responses:

- View struggles as “can’t NOT won’t”
- Shift from punishment to support
- Move from reactive to proactive
- Prevent secondary characteristics
Objective 3-
Diagnosis improves prognosis and reduces stress for the family.

Secondary characteristics:

- Fatigue, frustration
- Anxiety, fear
- Rigidity, resistance
- Overwhelmed, shut down
- Acts out, aggression
- Family and school problems
- Truancy, run away, trouble with the law
- Poor self-concept, feelings of failure
- Depression, suicidal ideation

Malbin, D., 2002
Objective 4-
Traditional behavioral systems do not work for FASD.

Traditional systems are based on the “Learning Theory” which assumes that the child has normal cognition, specifically the ability to understand cause and effect.

Traditional Approaches:
- Time-Out
- Reward Charts
- Loss of Privileges

Schools largely reward children for performance not for individual effort. FASD’s are not well supported in the school system.
Objective 4-

Traditional behavioral systems do not work for children with an FASD.

FASD is a Neurobehavioral Disability and requires a Neurobehavioral Approach to parenting/caregiving.

The poor performance from inability to get cause-effect, poor memory, and inconsistent performance are traditionally viewed as DEFIANCE rather than due to a brain-based disability.

You cannot punish away a brain injury.
Practical Interventions:

• Relationship first (attachment disorder is common)
• Q-TIP: “Quite Taking It Personally” (Seale, R. 2022)
• Prioritize co-regulation (adult to child)
• Determine developmental age for skills (regardless of chronological age)
• Adjust expectations to fit their abilities
• Make accommodations for weaknesses
• Establish routines, predictability
• Parent/teacher coaching of the FASCETS Neurobehavioral Approach
• Strengthen self-regulation skills in the child
• Use bottom → top strategies (sensorimotor tools to calm the nervous system: yoga, mindfulness, sensory integration, deep breathing, progressive muscle relaxation, The Alert Program)
• Examine lifestyle habits (nutrition, exercise, time in green space, screen time)
• Strength-based learning strategies
• Teach, reteach, reteach
• “Interdependence” as the goal NOT independence
• Supervision, supervision, supervision! (Helicopter Parent!)

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In our clinic:

At least monthly, we are the first professional to mention FASD to a family when we see “Red Flags.”

Parents with children as old as 12, with foster/adoptive history, presenting with “Red Flags,” who have never been told to consider FASD.

Often these children were born addicted to substances (alcohol is the most damaging substance to the fetus, Stratton, et al. 1996.)

ALWAYS the parents are seeking support for hard behaviors.

ALWAYS they are tired, lonely, and frustrated.
In our clinic:

- Once parents consider that FASD could be the cause of their child’s problems, learn about the Neurobehavioral Approach, and begin to implement it, their stress level goes down, directly affecting the child positively.

- We teach that most hard behaviors are a result of a poor fit between the expectation and the child’s ability.
In order to change behaviors of the child, we must change the adults interacting with them.

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<th>Change</th>
<th>Assume</th>
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<td>Change the environment</td>
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<tr>
<td>Assume</td>
<td>Assume that most hard behaviors are reactional rather than planned/intentional</td>
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My children living with an FASD

- Are now 14 and 18 years old.
- My son has participated in public, private, and homeschool.
- My daughter has been homeschooled for the last 8 years.
- They both love theater and perform at their ability level.
- They are both amazing individuals and I have great hope for their future.
- They will both need life-long supports.
Questions?