Beyond the Diagnosis:
Effective Interventions for Children and Adolescents with Fetal Alcohol Spectrum Disorders

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Disclosure: Julian Davies, MD

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I do not intend to discuss an unapproved/investigative use of any commercial product/device in my presentation.
Why this talk? Why me?
Making this work for you and yours
How does prenatal alcohol exposure damage the brain?
How can alcohol impact the child/adolescent brain?
Cognitive/Behavioral Phenotype?

Not yet (or ever?), but FASDs seem to involve:

a generalized deficit in processing complex information

(such as diminished intellectual function, slow processing, relative difficulty with complex tasks)

variability

(for the child and the spectrum)

adaptive gaps that widen with age

(can the gaps close with intervention?)
### Impacted Brain Domains in FASD

<table>
<thead>
<tr>
<th>Cognitive Domain</th>
<th>Sensory Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>Sensory</td>
</tr>
<tr>
<td>Memory</td>
<td>Motor</td>
</tr>
<tr>
<td>Language</td>
<td>Behavior</td>
</tr>
<tr>
<td>Visual-motor</td>
<td>Social Skills</td>
</tr>
<tr>
<td>Executive function</td>
<td>Adaptive</td>
</tr>
<tr>
<td>ADHD</td>
<td>Sleep</td>
</tr>
<tr>
<td>Academics</td>
<td></td>
</tr>
</tbody>
</table>
Secondary Disabilities from Streissguth et al, 1996
FASD Interventions
FASD Challenges

Uneven
Complex
Life-Long
Stressful
Key Concepts

Leverage
Turning Points
Invisible Disabilities
Reframing
Scaffolding
Mixing Metaphors
Brain Development Timeline

Casey, 2005
A problem has been detected and Windows has been shut down to prevent damage to your computer.

BAD_POOL_HEADER

If this is the first time you've seen this stop error screen, restart your computer. If this screen appears again, follow these steps:

Check to make sure any new hardware or software is properly installed. If this is a new installation, ask your hardware or software manufacturer for any Windows updates you might need.

If problems continue, disable or remove any newly installed hardware or software. Disable BIOS memory options such as caching or shadowing. If you need to use Safe Mode to remove or disable components, restart your computer, press F8 to select Advanced Startup options, and then select Safe Mode.

Technical information:

*** STOP: 0x00000019 (0x00000020, 0xA8EBB8B0, 0xA8EBC008, 0xA8EBB880)

*** csatd1.sys - Address A8EBB8B0 base at A8E8A000, DateStamp 444947b7
*** csatd1.sys - Address A8EBC008 base at A8E8A000, DateStamp 444947b7
*** csatd1.sys - Address A8EBB880 base at A8E8A000, DateStamp 444947b7

Beginning dump of physical memory
Physical memory dump complete.
Contact your system administrator or technical support group for further assistance.
Protective Factors Against Development of Secondary Disabilities

Early diagnosis and intervention

A caregiving environment (in middle childhood) that is:

• Nurturing, stable
• Appropriately structured & stimulating
• Geared to the child’s developmental needs
• Free from caregiver substance abuse
• Safe from violence

Appropriate social services

[Adapted from Streissguth et al., 1996]
Recent FASD Intervention Research Projects

Self-Regulation & Sensory Strategies

• The Alert Program (Children’s Research Triangle)

Learning How to Learn - “Cognitive Habilitation”

• Math Interactive Learning Program (Marcus Institute)

Social Skills Interventions

• Children’s Friendship Training (UCLA)

Behavioral Support

• Families Moving Forward (UW research)

PCIT vs Parent Support and Management

• University of Oklahoma
Pillars of Parenting
Kids with FASD

Structure
Supervision
Simplicity
Steps in sequence
Situational
Pillars of Parenting, Part I

Map your child’s strengths and weaknesses. Start early, and repeat as they grow, as new gaps may emerge.

Be their “external brain” in areas of challenge, for as long as they need it.

Model and support self-regulation, self-calming.

Use sensory strategies to help kids maintain focus and an even keel.

Provide “scaffolding” for lagging skills.

Learning may require a lot more repetition, and since learning may not generalize to a new environment or situation, relearning may be necessary.
Pillars of Parenting, Part II

Reframe challenging behaviors as “can’t” (yet) vs “won’t”.

Change the environment, when you can’t change the child. Provide accommodations at home and school that reduce stress, sensory overload, help children regulate their behavior, and support their learning styles.

Use positive behavior support strategies, finding ways to prevent problem behaviors, and ways to respond that don't reinforce them.

Make “invisible disabilities” visible to teachers and other caregivers.

Practice self-advocacy with your child.

Parental support and self-care is not optional.
Map, and re-map, their developmental profile
Be their “external brain” ...
Model and support self-regulation.

Daily practice, grasshopper.
Use sensory strategies
Use scaffolding for lagging skills
Learning
Relearning
Learning to learn
Reframe challenging behaviors
**DIDN’T FOLLOW DIRECTIONS**

- **My client is willfully disobedient**
- **Interpretation:** Directions were too complex, abstract, for my client’s ability
- **Response/Accommodation:** Reduce complexity of directions, provide visual support, teach how to ask for help/clarification
- **Individual Feels:** Understood, less confused, calmer, respected, willing to try
- **Possible Outcome:** Increased effort, success, more positive self-image
- **Feels:** Confused, frustrated, angry, unfairly treated
- **Risk of secondary disabilities, avoiding, blaming, ignoring**

**WON’T STOP WATCHING TV TO START CHORES**

- **My client is willfully disobedient, only does what he wants**
- **Interpretation:** My client has difficulty with transitions, poor impulse control
- **Response/Accommodation:** Give him a “heads up” or warning that a change is coming to give him time to adjust
- **Individual Feels:** Confused, frustrated, angry, unfairly treated, defensive
- **Possible Outcome:** Increased effort, greater compliance, more adaptable
- **Feels:** Unsurprised, calmer, more willing, more in control
- **Risk of secondary disabilities, avoiding, yelling, ignoring**
Change the environment and expectations
Use positive behavior support strategies ...
### Antecedents, Behaviors, Consequences (FBA, BIP)

<table>
<thead>
<tr>
<th>Setting Event/Circumstance</th>
<th>Immediate Predictor</th>
<th>Behavior</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irritable after a bad day at school</td>
<td>Being asked to do a chore</td>
<td>Following directions the first time</td>
<td>Finish task more quickly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ideal Behavior</td>
<td>Consequence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not following directions</td>
<td>Escape task</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ask for help</td>
<td>Escape task</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Realistic Behavior</td>
<td>Consequence</td>
</tr>
</tbody>
</table>
The ABCDs? The D is for Dance ...
Make “invisible disabilities” visible
Practice self-advocacy
Parent support and self-care is not optional
Sleep

Impact on child & family

Entrenched habits

Consistency and routine

Sleep associations

Safety

Diagnoses

Sleep specialists
Other Problem Areas

Social Skills & Bullying
Safety
Sexuality
Substances
FASD Parenting Ages & Stages
Ideal School?
Tools of the Mind

A promising preschool
Advocating for School Needs

Birth-to-3, then Child Find

504 Plan vs IEP

Develop an ally/advocate

IEP Meetings

• Check your own pulse
• Stack the deck in your favor
• Build a succession of YES’s
• Make the bureaucracy work for you

If things still aren’t going well ...

NICHCY.org
Medications?

- Stimulants
- Alpha-agonists
- SSRIs
- Mood stabilizers
- Atypical anti-psychotics

BIG Cautions
Treatments of the future?

Nootropics
Choline
Thyroid
L1 adhesion targets
Neurofeedback
Executive skills training
Newer medications

Most of these are far from proven
Consultation for Treatment

FASD team or neurodevelopmental clinic for “developmental home”?

PT, OT, and SLPs are frequently involved in assessment and treatment

School-based or private psychologists and behavioral specialists/therapists can be invaluable

Psychiatrists for med management

Social skills groups, Special Olympics, etc

Online and local support groups for caregivers
Key Points for Caregivers and Professionals

FASDs are too often an “invisible disability”

Refer alcohol-exposed kids for early evaluation

Thorough testing is so important

Expect deficits in complexity, integration

Individualized, longterm interventions

  • Reframe behaviors, adjust expectations and child’s environment
  • Behavioral consultation, self-regulation, social, learning to learn
  • Targeted medication evaluations
  • Anticipate adolescent and adult transitions

Caregiver education, support groups, linkage, school advocacy, respite
FASD Resources

UW Publications, Diagnostic Tools, Guides and Training:

fasdpn.org
(including an online course in 4-Digit Code)

adoptmed.org/fas

Other Online Resources

cdc.gov/fasd/

fasdcenter.samhsa.gov

nofas.org/ (with national resource directory)
More Resources

Sleep
- chroniccare4sleep.org
- adoptmed.org/topics/sleep-and-adoption.html

Feeding
- www.feedingdoctor.com
- adoptionnutrition.org

School
- education.alberta.ca/admin/supportingstudent/diverselearning/fasd.aspx
- nichcy.org
Native American FASD Resources

Online Resources

fasdcenter.samhsa.gov/nativeinitiative/resources.aspx

ihs.gov/headstart/documents/FetalAlcoholSpectrumDisordersAmongNativeAmericans.pdf

comingoftheblessing.com (prevention booklet)

Journey Through the Healing Circle Video Series

dshs.wa.gov/ca/fosterparents/journey.asp

Gifts from the Sacred Circle (parenting curriculum)
Thank You!

Susan Astley, PhD
Julia Bledsoe, MD
Julie Gelo
Heather Olson, PhD
Allison Brooks, PhD
The FAS Clinic Team
Our Clinic and Study Families
Maria’s Children (artwork)