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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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?
The Old Laptop
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

- Cognition
- Memory
- Language
- Visual-motor
- Executive function
- ADHD
- Academics

- Sensory
- Motor
- Behavior
- Social Skills
- Adaptive
- Sleep
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
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

Behavior

Interpretation
Directions were too complex, abstract, for my clients ability

Response/ Accommodation
Reduce complexity of directions, provide visual support, teach how to ask for clarification

Individual Feels
Understood, less confused, calmer, respected, willing to try

Possible Outcome
Increased effort, success, more positive self image

Possible Outcome
Risk of secondary disabilities, avoiding, blaming, ignoring

Won't stop watching TV to start chores

Behavior

Interpretation
My client is willfully disobedient, only does what he wants

Response/ Accommodation
Punish, scold, give warnings

Individual Feels
Confused, frustrated, angry, unfairly treated

Possible Outcome
Increased effort, greater compliance, more adaptable

Possible Outcome
Unsurprised, calmer, more willing, more in control
Change the environment and expectations
Use positive behavior support strategies...
Antecedents, Behaviors, Consequences (FBA, BIP)

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<th>Irritable after a bad day at school</th>
<th>Being asked to do a chore</th>
<th>Setting Event/Circumstance » Immediate Predictor » Behavior » Ask for help » Realistic Behavior</th>
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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
Nutrition and Feeding
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 ...
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

www.chroniccare4sleep.org

www.adoptmed.org/topics/sleep-and-adoption.html

Feeding

www.feedingdoctor.com

www.adoPTIONnutrition.org

School education.alberta.ca/admin/supportingstudent/diverselearning/fasd.aspx

www.nichcy.org
Native American FASD Resources

Online Resources

www.ihs.gov/headstart/documents/
  FetalAlcoholSpectrumDisordersAmongNativeAmericans.pdf
www.comingoftheblessing.com (prevention booklet)

Journey Through the Healing Circle Video Series
  www.dshs.wa.gov/ca/fosterparents/journey.asp

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

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The FAS Clinic Team

Our Clinic and Study Families

Maria’s Children (artwork)