

Poll #1

What demographic of women are most likely to drink alcohol during pregnancy?

- A. College Educated
- B. High School Graduate
- C. High School Drop Outs



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How Prevalent FASD is in the U.S.



Up to 1 in 20 U.S. School Children are estimated to have an FASD.

(Centers for Disease Control 2016)



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FASD is not a Diagnosis

- FAS** Fetal Alcohol Syndrome
- PFAS** Partial Fetal Alcohol Syndrome
- ARND** Alcohol Related Neurodevelopmental Disorder
- ARBD** Alcohol-Related Birth Defects



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Poll #2



What is the approximate percentage of unplanned pregnancies in the United States?



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Poll #3

Which of the of the following substances has the most significant impact on the developing brain?

- A. Opioids/Heroin
- B. Crack/Cocaine
- C. Alcohol
- D. Methamphetamines



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Facial Features of FAS



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Challenges Identifying FASD

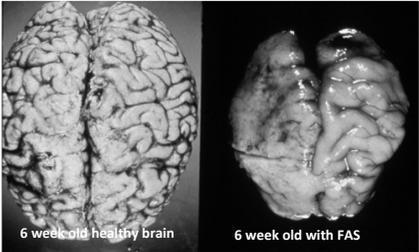


FASD is often referred to as an invisible disability.
Can you identify the youth with an FASD?

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FASD & the Brain

Autopsy Study



6 week old healthy brain 6 week old with FAS

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Symptoms of FASD



- Difficulty picking up on social cues
- Impairment in short-term memory and processing speed
- Difficulty understanding and remembering stranger-safety warnings
- Poor insight and judgment (concrete, rigidity, dysmaturity)
- Attention deficits
- Difficulty with abstract concepts (including concepts of time and space)
- Difficulty identifying dangerous people and/or situations
- Easily influenced by others
- Difficulty generalizing knowledge
- Difficulty understanding cause-and-effect relationships
- Sensory processing disorder



What FASD Can Look Like



Many Doors, No Master Key: Resources Needed for Brandan, Age 1-2 Years

Health	Education	Social and Community Services	Legal and Financial Services
Podiatrist	Feeding Specialist	Local Indian Child Welfare Advisory Committee	Dispute
Neurologist (2)	Neurologist	Tribal Social Worker	Div. of Child Welfare/Care Services and Family Resource Coordinator
Podiatrist/Ophthalmologist	High-Risk Infant Clinic	Child Welfare Case Worker	Substance Abuse Treatment (with mother)
Audiologist	FAS Diagnostic Clinic	Tribal Council	Mental Health Counseling (with mother)
Chiropractor	USA and Foreign Services	St-Isidore Program: Cooperative Services: Language, Social, Activity Therapy	Parenting Education (with mother)
Pharmacy	Biopsych	Respite Provider	Accounts for Birth Parents
Medical Supply Providers	Pulmonologist	Foster Care System	
Gastroenterologist	Respiratory Therapist		



— About 40 similar providers



Chronological vs. Developmental Age



What happens when you are working with a youth on the FASD spectrum that is operating at about half of their chronological age?





Case Study



Victimization and exploitation:

SAVING BOBBI: A TEEN'S SEX TRAFFICKING ORDEAL
StarTribune Series

In a 1996 study of individuals with an FASD it was found that 60% had been sexually victimized or experienced physical abuse.




Streissguth, et. al 1996



Case Study

Adverse Childhood Experiences

The story of Colton Harris-Moore is a case study of what may be seen in individuals on the spectrum that go undiagnosed for years and without the proper support.



Colton Harris-Moore, AKA the Barefoot Bandit, smiles after his 7-year sentencing

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Strategies

Thinking about Strategies

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Strategies not Solutions

There is no magic bullet!

- There is no magic bullet.
- Expect inconsistency. Celebrate consistency!
- Strategies are not always transferable from one person to another.



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Strategies

The most important strategy to remember when working with individuals with an FASD is to be patient and understanding.



Apply the maxim, "Seek first to understand, then to be understood."

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Modifying Interventions



Why we recommend screening for FASD

- Outcomes can be improved
- Individuals can be seen as having a disability
- Frustration and anger can be reduced
- Approaches can be modified
- Reframe poor self perceptions
- Prevent future alcohol-exposed pregnancies



Life Expectancy Study



Average Life Expectancy With FAS

34

Average Life Expectancy

82

A RECENT RESEARCH STUDY ESTIMATED THAT THE AVERAGE LIFE EXPECTANCY FOR SOMEONE WITH FETAL ALCOHOL SYNDROME IS 34.

Thanh et al., 2016



It is About Saving Lives



Suicide (1897)

- These are not new concepts. There are long-standing relationships that have been drawn between social exclusion and suicide.
- How integrated you are and how supported you are in your community matters!

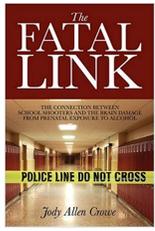




Eliminate Stigma



Stigma contributes to health disparities in our communities!









Change the Paradigm



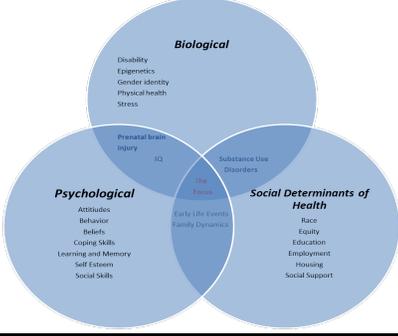
A toxic bundle of FASD and Trauma

Changing the paradigm:
Instead of asking “what is wrong with you?”, we should be asking “what happened to you?”

Physical Abuse	Sexual Abuse	Neglect	Divorce/Separation
Domestic Violence	Substance Use Disorders	History of Mental Illness	
Incarcerated Family Member			

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Understand their Profile

Biological
Disability
Epigenetics
Gender identity
Physical health
Stress

Psychological
Attitudes
Beliefs
Coping Skills
Learning and Memory
Self-Esteem
Social Skills

Social Determinants of Health
Race
Equity
Education
Employment
Housing
Social Support

The Person
Prenatal Brain Injury
IQ
Substance Use Disorders
Early Life Events
Family Dynamics

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Understand their Profile



- Reading and writing skill level
- Cognitive functioning
- Mental Health
- ACES and Trauma
- Social and communication skills
- Sensory Issues
- Self-Esteem
- Life Skills
- Areas for support
- Strengths

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Build on Strengths



- **Friendly, likable:** May be outgoing and sociable and have little anxiety about strangers.
- **Verbal, chatty:** May be very socially interested (but not necessarily socially-skilled).
- **Helpful, hard-working:** If you ask, they will do it. They can be very good workers with the right job and training.
- **Determined, resilient:** They don't hold grudges and will come back if rejected. Every day is a new day!
- **Want to be liked:** They will do whatever they can to have friends.

However, these strengths also may get them into difficulty.

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Strategies

Change the paradigm around IQ and intelligence!



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Strategies

The external brain concept coined by International FASD expert Sterling Clarren, MD

“The individual with disability caused by prenatal alcohol exposure will **always** need an **external** brain.”

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Strategies

Dispel the Myth:
Individuals with and without disabilities are more successful when the goal is **interdependence** rather than independence.



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Modifying Interventions

Understand and address the challenges inherent within group dynamics for individuals on the spectrum.



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Strategies



Understand the myriad of other factors to consider that can impact behavior and the way an individual presents:

- Dehydration
- Fatigue
- Missed Medications
- Additives in Diet
- Sensory Overload
- Confabulation
- Exercise
- Emotional Stress

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Modifying Interventions



More Intense Structure

- Individuals on the spectrum often function best in well controlled, predictable setting.
- Prepare individuals in advance for changes.
- Do not overschedule, but keep time consistent and productive.

Daily Routines

Redirect

Consistent Rules

Keep Calm

Create Goals

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Modifying Interventions



STRETCH.

the schedule and shorten meetings

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Strategies



Develop Self-Advocacy Skills



“We’re encouraging people to become involved in their own rescue.”

Strategies




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Strategies



A word on consequences..



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Modifying Interventions



Teach the individual positive and appropriate options using role play and social stories.

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Strategies



Adapt the Environment

- Reduce visual distractions and free classroom of unnecessary distractions
- Reduce the brightness of the lighting in the classrooms
- Pets and plants can help students to relax
- Give students responsibilities




Manitoba Healthy Child Initiative and Manitoba Child Care Association, What Early Childhood Educators and Caregivers Need to Know About Fetal Alcohol Syndrome Winnipeg, MB, 1999.

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Strategies



Adapt the Environment

- Visual boundaries can help kids organize themselves
- Mark visual boundaries on the floor using tape or carpet squares
- Assigned seats
- Labeled materials and personal spaces






Strategies



Adapt the Environment



Boyle Street Education Centre
Adapted High School Science Classroom



Strategies





Communication

- Allow extra time for processing and responding
- Simple, short directives
- Concrete and specific
- Simplify the materials
- Share the rules early and often
- Manageable tasks
- Importance of options
- Repeat, Repeat, Repeat
- Use the same verbiage
- Check for understanding/follow up
- Monitor for frustration



Strategies



Planning for Transition



VISUAL SCHEDULE

Sun	Mon	Tue	Wed	Thurs	Fri	Sat
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

To Do Today
Ride Bus Home
Track Absent








Help with Transitions



Planning for Transition

- Proactive transition plans are important and can help avoid melt downs.
- Research supports the use of visual timers with students with an FASD.



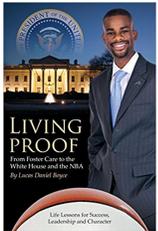

Research supporting Visual Timers:
 Kalberg, Wendy D. and David Buckley (2007). FASD: What types of intervention and rehabilitation are useful? *Neuroscience and Biobehavioral Reviews* 31, 278-285.
 Ohwang, Lesley B., Lisalotte Svensson and Susan Ashley (2010). Observation of Classroom Social Communication: Do Children with FASD Spend Their Time Differently Than Their Typically Developing Peers? *Journal of Speech, Language and Hearing Research* 53, 1687-1703.

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There is hope!



Set aside the myth that nothing can be done. While the brain injury is permanent individuals on the spectrum can survive and thrive!



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The goal is Equity





Equality doesn't mean **Equity**

<http://culturalorganizing.org/the-problem-with-that-equity-vs-equality-graphic/>

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Thank You!



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