Fetal Alcohol Spectrum Disorder in Education

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What is FASD?

FASD Is…..

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol during pregnancy.

FASD is a lifelong disability. Individuals with FASD may experience challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, emotional regulation, and social skills.

Each individual with FASD is unique and has areas of both strengths and challenges.
What Do The Experts Say?

Dr. Sterling Clarren, one of the world’s leading researcher’s into FASD states that, “Fetal Alcohol Spectrum Disorder is the most difficult disability that an individual can have”.

The Institute of Medicine reports that, “of all the substances (including cocaine, marijuana and heroin), alcohol produces by far, the most serious neurobehavioral effects to the fetus”.
Causes of FASD

- All alcoholic beverages are harmful. There is No Safe Time, No Safe Amount, No Safe Kind.

- Binge drinking is especially harmful.

- Binge drinking is defined by 4 drinks or more on one occasion.

- While it’s true that not every woman who drinks during pregnancy will have a child with an FASD, that does not mean that these disorders are rare or random.
Being honest with yourself, what are your thoughts or impressions of FASD?
Stigma and FASD

- Involving individuals living with FASD in the conversation
- Providing community with accurate information
- Ensuring language is inclusive and judgement free

For birth mothers
- FASD is NOT caused intentionally by the mother
- May be unaware they are pregnant
- Upwards of 61% of pregnancies are unplanned
- May be poorly informed of the dangers of alcohol during pregnancy
- Mom wants to stop but she find she can’t due to dependency and/or poor supports.

FASD IS NOT 100% PREVENTABLE
A Woman’s Relationship with Alcohol

Increasingly women are drinking more.

Binge drinking increases the risk.

Women over the age of 35 who hold a university degree are fastest growing group of women drinking during pregnancy.

Does not discriminate.

61% of pregnancies are unplanned.

Alcohol is more accessible (i.e., grocery stores, hair salons, etc.)
Why is Alcohol Considered Harmful to the Fetus?

- Neurotoxin and Teratogen.

- Alcohol crosses the placenta and is water soluble - no barrier.

- Alcohol combines with the amniotic fluid and can remain there for up to 3 days.

- A fetus does not have a functioning liver so it is unable to eliminate alcohol from the environment.

- Impacts the brain and body.
How Does Alcohol Impact the Brain?

https://www.youtube.com/watch?v=8753eb1U0
Fetal Alcohol Spectrum Disorder

The Prevalence of Fetal Alcohol Spectrum Disorder (July 2018) Canada FASD Network

FASD is recognized as one of the leading known causes of developmental disability in the western world. Compared with other common disabilities, at an estimated prevalence of 4%, FASD is:

- 2.5x more common than Autism (1.52%)
- 19x more common than Cerebral Palsy (0.21%)
- 28x more common than Down’s Syndrome (0.14%)
- 40x more common than Tourette’s Syndrome (0.10%)
The costs of FASD to society are high - without taking into account the lost potential and opportunity, direct costs associated with FASD over a lifetime have been estimated at about $1.5 million per person with FASD. (Public Health Agency of Canada)
Identification, Assessment and Diagnosis
FASD is a medical diagnosis that requires a multidisciplinary team assessment (Physician, Psychologist, Occupational Therapist, Speech and Language Pathologist, and Social Worker or Child and Youth Worker).

- Physical Assessment
- Cognitive Assessment
  - No unique profile identified for FASD
  - Brain dysfunction, substantial deficiencies or discrepancies across multiple areas of brain performance.
Facial Features

Only 10% of individuals with FASD have facial features.
Facial features occur when the alcohol exposure happens during days 17-21 of pregnancy
50% of pregnancies are unplanned
No safe time, no safe amount.
<table>
<thead>
<tr>
<th>FASD with sentinel facial features</th>
<th>FASD without sentinel facial features</th>
<th>At risk of ND and FASD (designation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirmed of unconfirmed exposure</td>
<td>Confirmed prenatal alcohol exposure</td>
<td>Confirmed prenatal alcohol exposure</td>
</tr>
<tr>
<td>3 facial features</td>
<td>3 domains impaired</td>
<td>Clinical concern about development</td>
</tr>
<tr>
<td>3 domains impaired</td>
<td>3 domains impaired</td>
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</tbody>
</table>
Brain Domains

- Motor Skills
- Neuroanatomy/neurophysiology
- Cognition
- Language
- Executive Function
- Memory
- Attention
- Affect Regulation
- Adaptive behaviour, social skills or social communication
Other Features Commonly Associated with FASD

- Sleep problems
- Sensory sensitivities – sight, smell, touch, taste, hearing, vestibular, processing, proprioception
- Other physical and medical challenges
- Growth (small stature)
So What Do We Do?

- Key is understanding the disability
- We need to make a paradigm shift in our views and attitudes
- Understand that this shift is hard and we fall back on traditional interventions
- Know there is no “magic” answer or cure – knowledge and creativity are the key.
Sensory and Motor Concerns

- Their sensory channels do not have filters.
- Sensory information comes in at the same intensity.
- Gross motor coordination can be an area of strength.
- Fine motor skills are often an area of difficulty.
Strategies for Sensory Concerns

- Allow movement.
- Adjust temperature, lighting and sound in the environment.
- Use sunglasses, ear plugs when you can’t control the environment.
- Use heavy work or wear heavy items to feel grounded in space.
Communication and Language

- Develop language skills at a slower rate.

- Expressive language skills may appear stronger than their receptive language skills.

- Receptive language: have difficulty receiving information, interpreting information and remembering information accurately.

- Because they are highly verbal they present with a thin veneer of competence.
Strategies for Communication and Language

- Give instructions one step at a time. Repeat as needed.
- Check for understanding by asking for repetition of directions in own words.
- Use rhythm such as slow rhythmic clapping to focus attention, and to reinforce learning.
- Use multi-modal strategies (visual, auditory, tactile, kinesthetic). For example, expose students to letters in a variety of situations.
- Use art projects to make abstract concepts more concrete.
Many people with FASD have an IQ within the normal range and is not a good indicator of brain damage.

- IQ is what you know.

- Adaptive and Executive Functioning is how you use it.
Cognition - Intelligence and Brain Differences

INFORMATION IS EASILY ACCESSIBLE

INFORMATION IS DISORGANIZED.....IT'S ALL THE SAME AMOUNT OF INFORMATION
Executive Functioning

The CEO of the brain. This is the system that is in charge of making sure things get done form the planning stages of the job until the final deadline:

1. Analyze the task and figure out what needs to be done.
2. Plan how to handle the task.
3. Get organized and break down the plan into steps.
4. Figure out how much time is needed to carry out the plan.
5. Make adjustments and changes as needed.
6. Finish the task in the time allotted.
7. And manage emotions while doing all the above.....
Spoon Theory
https://youtu.be/7DQgO1OE
Strategies to Support Executive Functioning

- Teach the individual to use “self-talk” to help stay focused
- Use concrete reinforcements or reminders
- Consequences for inappropriate behaviour need to be immediate.
- Arrange a quiet area to use when distractions are too great
- Make each activity brief.
Strategies to Support Executive Functioning

- Speak face-to-face; use their name.
- Keep the number of instructions and the explanations short.
- Stop at key points to check for comprehension: be alert to “losing them” (that glazed-over look).
- Use lists, such as a checklist for daily routine or a checklist for daily work.
- Reminders on cell phones.
Strategies to Support Executive Functioning

- Prepare in advance for changes in routine.
- Plan for transitions between activities by letting them know how much time is left.
- Verbal reminders, sand timer, watch with an alarm.
- Watch for signs of irritability and fatigue—usually looks like behaviour.
Memory

- Inconsistent memory and recall.

- Slower, inconsistent cognitive and auditory processing.

- Make things up due to gaps in memory. This often leads adults to thinking that they are lying.

- Needs to be taught over and over again in different modalities (visual, verbal, kinesthetic)
Strategies to Support Memory

- Provide one instruction at a time until the student can remember two instructions
- Chunk information into appropriate number of words
- Concepts presented in a concrete fashion (i.e., with examples) will be easier to learn and retain than abstract concepts
Strategies to Support Memory

- Pair concepts with visuals
- Provide practice in sequencing events, such as creating a photo story
- Use recognition questions rather than open ended ones
- Use cuing (i.e., hinting) or prompting to help the student recall details
- When giving verbal instruction, write down the main points that student can refer back to
Confabulation: When Lying Isn’t Lying

https://youtu.be/UR8n5EECb4
Adaptive Skills

- Affects employment, managing money, healthy use of non-structured leisure time.
- Impaired social judgement.
- Highly susceptible to manipulation, easily led.
- Abused by others.
- Unable to learn from experience.
- Poor life skills, such as hygiene, personal relationships, independence, and judgement in social/work situations.
Strategies to Support Adaptive Skills

- Decide what is within the control of the child; ignore the rest.
- Be consistent in imposing consequences – make them immediate and remind what the consequences are for.
- Help problem solve: “Where did the problem start?”, “What did I do?”
- Help student take another person’s point of view
Strategies to Support Adaptive Skills

- Supervision and acceptance of support person.
- Fill free time with activities that are strength based.
- Monitor friendships and social media feeds.
- Use filters for internet access.
- Identify safe person that they can ask any questions of.
Predictable Areas of Difficulty

- Time - predicting and/or having conscious control over time spent on activities
- Money - spend frivolously, vulnerable to being taken advantage of, difficulty budgeting
- Relationships - poor boundaries, poor understanding of reciprocity, immaturity, naïve and gullible
- Hygiene - difficulty understanding and meeting expectations with regard to hygiene and physical appearance.
- Schedules - difficulty getting where they need to be, when to be there.
Anxiety and depression are often co-occurring issues for individuals with an FASD.

We need to think of anxiety and depression as a symptom of the brain damage and not necessarily a separate entity or caused because of their experiences.

Dysregulation.

Treatment can be difficult.
Common Mental Health Challenges
90% of individuals with FASD have mental health concerns

Mental Health professionals can assist in the identification of individuals with FASD.

Is it a secondary challenge of FASD?

Is it a poor fit between the brain damage and the environment?

Is it biological?

Higher cortisol baseline level (Hellemans, 2014)

Persistent changes to normal stress pathways and brain function- these changes may lead to the development of mental health disorders

Trauma in children with and without PAE revealed that children with PAE and postnatal traumatic experiences had: lower intelligence scores and more severe deficits in language, memory, visual processing, motor skills and attention than those without PAE (Henri, 2007)
Developmental Trauma and FASD

Remember the brain develops bottom to top

- Relationship problems and attachment
- Identity and self concept
- Medical problems
- Cognitive and learning problems
- Emotion Regulation
- Understanding of the world
- Dysfunctional behaviour
- Reflective function
Self Regulation

- Self-regulation can be defined in various ways. In the most basic sense, it involves controlling one's behavior, emotions, and thoughts in the pursuit of long-term goals. More specifically, emotional self-regulation refers to the ability to manage disruptive emotions and impulses.
Co-Regulation

- Articles speak about co-regulation being the stepping stone to self-regulation
- This may not be the same for individuals with FASD
- They may ALWAYS need co-regulation
- Self-regulation is really internalized co-regulation!!!!

‘This is especially important to remember with children. Yes, we can teach them skills to help calm and regulate. Yes, this is important. But skills live in the neocortex- the highest part of the brain. Dysregulation lives in the limbic system and brainstem- lower parts of the brain. The cortex can help to regulate the lower parts of the brain, but it is much more effective to regulate those lower parts without involving the ‘thinking brain.’”

Robin Gobbell, LCSW
We need to be mindful of our own triggers and how we can be “derailed” by the behaviors of our students.

Kristin Souers in Education Week Teacher
## Strengths

<table>
<thead>
<tr>
<th>Visual</th>
<th>Kinesthetic</th>
<th>Artistic</th>
<th>Musical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creative</td>
<td>Eager to Please</td>
<td>Eager to Help</td>
<td>Good with Animals and Young Children</td>
</tr>
<tr>
<td>Determined</td>
<td>Articulate</td>
<td>Comedic, good sense of humour</td>
<td>Energetic</td>
</tr>
</tbody>
</table>
What We Know

Placement Stability - with a family or caregiver that is trained (through all developmental hurdles) and supported

Early identification - Before age 6

Appropriate service planning with specialized training to agency/school staff, families and caregivers

Appropriate accommodations

Effect transition to adult services
#1 Protective Factor

Number one goal for intervention is PLACEMENT STABILITY

- Parents and Caregivers need:
  - Training
  - Coaching
  - Respite and Relief
  - Grief and Loss
Understanding FASD

- FASD is a DISABILITY of thinking
- There will be a consistent pattern of inconsistency
- Our job is to explain these individuals to the world, not the world to these individuals
Focus on the Environment
Key Concepts
## Developmental Dysmaturity
### What if?

A 5 year old….

<table>
<thead>
<tr>
<th>A 5 year old….</th>
<th>…..has a brain of a 2 year old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Go to school for a full day</td>
<td>Takes naps</td>
</tr>
<tr>
<td>Follow three instructions</td>
<td>Follow simple instructions</td>
</tr>
<tr>
<td>Sit still for 20 minutes</td>
<td>Active, sit still for 5-10 minutes</td>
</tr>
<tr>
<td>Interactive, cooperative, play, share</td>
<td>Parallel play</td>
</tr>
<tr>
<td>Take turns</td>
<td>Defiant</td>
</tr>
</tbody>
</table>
### Developmental Dysmaturity
#### What if?

<table>
<thead>
<tr>
<th>A 13 year old....</th>
<th>Had the brain of an 8 year old?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be responsible</td>
<td>Needs reminding, even for daily tasks</td>
</tr>
<tr>
<td>Organize themselves; plan ahead and follow through</td>
<td>Impatient, waiting is very difficult</td>
</tr>
<tr>
<td>Meet deadlines with minimal prompting</td>
<td>Requires adult organization, structure and guidance</td>
</tr>
<tr>
<td>Appropriate social boundaries</td>
<td>Tends to be active, lots of touching</td>
</tr>
<tr>
<td>Establish and maintain friendships</td>
<td>Friendships are in the moment</td>
</tr>
</tbody>
</table>
### Developmental Dysmaturity
**What if?**

<table>
<thead>
<tr>
<th>A 18 year old...</th>
<th>Had the brain of a 9 year old...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be fully independent</td>
<td>Start to become independent with self-care</td>
</tr>
<tr>
<td>Maintain a job and graduate from high school</td>
<td>Add and subtract 2 digit numbers</td>
</tr>
<tr>
<td>Drive</td>
<td>Can start to plan ahead for play dates</td>
</tr>
<tr>
<td>Have a plan for their life</td>
<td>Curious about relationships but may not admit it</td>
</tr>
<tr>
<td>Relationships, safe sexual behaviour</td>
<td>Needs structure, guidance and organizational help from adults</td>
</tr>
<tr>
<td>Budget their money</td>
<td></td>
</tr>
</tbody>
</table>
Create a “Thinking Free Day”

- Routines
- Schedules
- Building Habits
- Repetition
- Consistency
Supported Dependency

- Teach individuals to accept HELP
- Seeing support as a good thing
<table>
<thead>
<tr>
<th>OLD WAY OF THINKING</th>
<th>NEW WAY OF THINKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour is seen as</td>
<td>Behaviour is a clue that the person’s needs are not being met.</td>
</tr>
<tr>
<td>• Negative</td>
<td></td>
</tr>
<tr>
<td>• Purposeful</td>
<td></td>
</tr>
<tr>
<td>• Voluntary</td>
<td></td>
</tr>
<tr>
<td>Onus of change is on the individual</td>
<td>When there is a pattern of negative behaviour there is missing information</td>
</tr>
<tr>
<td></td>
<td>Onus of change is on the environment and caregivers</td>
</tr>
</tbody>
</table>

**Behaviour vs. Function**
Things you should know....

WWW.FASDWATERLOOREGION.CA

SUBSCRIBE TO UPDATES AND BECOME A MEMBER OF OUR FASD COMMUNITY OF PRACTICE.
THANK YOU!