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# Supporting Clients with Fetal Alcohol Spectrum Disorder

## Workshop for Support Workers

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This presentation is for informational purposes only and does not constitute clinical or legal advice. Follow up with a BCcBA/BCBA/BCBA-D is recommended to develop a specific plan for your child or student.



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## Confidentiality Agreement

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## Objectives

After this workshop, you will know:

- What Fetal Alcohol Spectrum Disorder (FASD) is
- Stigma associated with FASD
- Strategies for Working with Someone with FASD

We will also discuss several case scenarios.

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What is Fetal Alcohol Spectrum Disorder (FASD)?

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CanFASD describes FASD as

“a lifelong disability that affects the brain and body of people who were exposed to alcohol in the womb. Each person with FASD has both strengths and challenges and will need special supports to help them succeed with many different parts of their daily lives.”

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Physical

Medical

**Prenatal Alcohol Exposure (PAE)**  
may cause deficits in the 4 following areas:

Behavioural

Cognitive

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## Rates of FASD

CanFASD currently estimates the rate of FASD in the general Canadian population to be:

# 4%

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## Canadian Diagnostic Guidelines

Diagnoses available:

- Fetal Alcohol Spectrum Disorder with Sentinel Facial Features
- Fetal Alcohol Spectrum Disorder without Sentinel Facial Features

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## Sentinel Facial Features

The sentinel facial features often associated with FASD are:

- Short palpebral fissures
- Smooth philtrum
- Thin upper lip

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**Sentinel Facial Features are Rare**

- CanFASD reports that **less than 10% of people with FASD have recognizable facial features**
- Facial features become less noticeable as an individual becomes older

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**FASD is INVISIBLE**

You cannot tell if someone has FASD:

- By the way they look
- By the way they talk

**You'll likely only know if someone has FASD if someone tells you.**



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**Stigma Associated with FASD**



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## There is stigma attached to FASD

- 1**  
Birth family may feel blamed
- 2**  
Caregivers may not want their child "labelled"
- 3**  
Families/individuals may see FASD as a disability with a "perpetrator" and a "victim"

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## Working with Someone with FASD

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## Areas that may require your help

- Memory
- Communication
- Social Skills
- Cognitive and Auditory Processing
- Abstract Thinking
- Sensory Processing
- Self-Regulation
- Executive Functioning

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# Memory

Remembering information, making use of information, making connections between bits of information

### Difficulty with:

- Remembering what someone said to them
- Repeating a mistake (either from challenges with memory or with impulsivity)
- Expressing themselves in a way that appears "untruthful"



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# Memory – Strategies

- Use reminders
  - Help them to place visual reminders in easy-to-see locations



- Prompt them to ask you for help
  - This shows them that asking for help is okay!
- Use repetition when teaching a skill

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# Repetition

- Short-term memory is often impaired in FASD
- Repetition strengthens skills in everyone's brain
  - Even those with issues with memory and/or impulsivity
- The more you do something, the less taxing it is on your brain
  - "The hands just know what to do - I don't have to think about it anymore"

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## Repetition can be a positive experience

- When it isn't forced
- When it occurs naturally
  - When the task is needed – e.g., tying your shoes only when they need to be tied
- Also when it is:
  - **Structured** (built into a routine)
  - **Consistent** (built into a regular routine)
  - **Supported** (help someone through a new skill/task many times before you, as support, do less and less over time)

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## “Lying” (it's not really lying)

Due to problems with memory, there may be confusion about what really happened

- May retell events in an incorrect order
- May feel ashamed for not remembering so "make it up" to cover
- May confabulate to fill in pieces they've forgotten or misunderstood
  - The brain automatically fills in blanks with things they've imagined, heard, or have seen on screens – to make sense of the event
  - Happens to us too at times

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## “Lying”

- Struggles with **communication** may also affect the ability to properly explain a past event
- Struggles with **impulsivity** may also cause someone to tell you what they think you want to hear, so as not to disappoint you – without thought to the possible **consequences** of not telling the truth

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## Confabulation – Strategies

Reduce opportunities to confabulate:

- Instead of asking if they did something, ask them to show you
  - E.g., "Show me what you picked up in your room"
- Just ask what you really need to know
  - Avoid unnecessary questions
- Give them time to process questions
  - They may give a response for the question you asked a while back, from earlier in the conversation

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## Confabulation – Strategies

Stay connected and do not punish for confabulation or storytelling:

- They may have short-term memory problems, or challenges controlling impulsivity, or see things differently when under stress, or not able to catch every word someone said to them
- Consequences will not decrease the confabulation, it will only frustrate
  - Learning through consequences involves "cause and effect" and abstract thinking – both areas which may be affected by FASD
- Focus on supporting their deficits with memory, attention, language, and/or inability to always control their impulses

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## Communication

Sending or receiving information

Difficulty with:

- Complex, abstract, symbolic language (e.g., metaphors, sarcasm)
- Understanding instructions, the meaning of words, even when appearing to be highly skilled verbally
- Agreeing to something they don't understand, and then not following through



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# Communication

They may struggle with:

## Expressive Language

Communicating thoughts with words and sentences

## Receptive Language

Understanding the meaning of words and sentences

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# Communication – Strategies



- Say their name first, and make eye contact
- Say what you mean
- State exactly what to do
  - Show them how, do it alongside them

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# Communication – Strategies

- Break everything down to simple pieces
- Give time to process



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## Working with a Person with FASD

Do not ask leading questions:

- They can easily take your lead and agree to any version of what happened
- The more you say/hear a certain version – the more your brain commits to it

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## Social Skills

Interacting and Communicating with others

**Difficulty with:**

- Developmental age
  - May act/think younger than peers
  - Therefore, they can easily be taken advantage of
- Gaining attention inappropriately
- Being teased or rejected
- Being bullied or told by peers to do things they are not allowed to do



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## Social Skills – Strategies



Teach by practicing these scenarios:

- Managing bullies
  - Walk away
  - Talk to an adult
  - Play in school yard near supervisors
- Handling rejection, or frustration with peers
- Personal boundaries
- Turn taking / sharing

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## Cognitive and Auditory Processing

### Cognitive Processing:

Taking in information and transforming it, storing it, recovering it, and putting it to work

### Auditory Processing:

Taking in sound through the ear and having it travel to the language area of the brain to be interpreted



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## Cognitive and Auditory Processing

### An individual may:

- Be slow to answer
- Give an answer right away, any answer, to "save face"
- "Jump down your throat" before they've understood what is being asked
- Be aloof / apathetic in certain social situations
- Follow through on instructions improperly



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## Cognitive and Auditory Processing – Strategies

Give them time to process:

- Be patient
- Avoid rapid-fire orders
- Be aware of overloading or overwhelming



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## Abstract Thinking

Thinking about things that aren't physically right in front of you (e.g., concepts, time, money)

### Difficulty with:

- Managing money, time
- Understanding cause and effect (consequences)
- Planning for the future
- Complex, symbolic language (e.g., metaphors, sarcasm)
- Concepts and systems (e.g., token systems, justice system)



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## Abstract Thinking – Strategies

- Use concrete objects to teach concepts (e.g., real money)
- Avoid complex language
- Say what you mean
  - Don't assume they'll understand hints, eye-rolls, sarcasm
- Say what you want
  - Don't assume they'll know what is expected of them because of what happened in the past, or what is customary, or because they've seen you do it

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**“It is crucial that caregivers understand that they will likely be handling their child’s money for the rest of their child’s life.”**

— FASD Strategies Not Solutions Handbook, EFAN (Edmonton and Area Fetal Alcohol Network)

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## Money

- Money is an abstract concept, more so for individuals with FASD
- They may have challenges about understanding the value of money (i.e., they might agree to pay \$10 for gum, or sell their iPhone for \$10)

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## Money – Strategies

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- For children and youth, suggest to parents that they give a small weekly allowance by giving the child **physical money**
- Plan with them what they will spend their money on
- Suggest 2 Piggy Banks – 1 for spending, 1 for saving

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## Money – Strategies

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Teach grocery shopping to youth:

- Always bring a list
- Move through the store in a set routine
- Bring a calculator (phone) to not overspend



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## Sensory Processing

Making sense of information/input processed through senses such as sight, hearing, touch, smell and taste, and also through balance, movement, and what our internal organs feel

### Difficulty with:

- Responding effectively to different types of sensory input, or too much sensory input coming at once
- Managing the input consistently (i.e., good one day, and not so good the next)
- Appropriately communicating sensory difficulty, and this, in turn, might look like a "bad behaviour" to us



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## Sensory – Strategies



- Choose a time to talk / Ask questions / Ask caregivers
- When they are upset, keep your talking at a minimum
- If you want someone to be calm – you must work on being calm yourself

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## Sensory – Strategies

- When shopping with a child, go during off-hours and be aware that stores/malls/movie theatres are designed to overstimulate
- Have a back-up plan if an environment/activity becomes too much
- Choose activities to wind them down before bed
  - Avoid screens – their light affects your ability to fall asleep

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## Sensory – Strategies

- Consult with an **Occupational Therapist (OT)**



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## Self-Regulation

Managing and controlling your emotions, thoughts and behaviours in a way that best helps you navigate the world around you

**Difficulty with:**

- Encountering a stressor, and then recovering
- Misconstruing events as threats
- “Fight / Flight / Freeze / Fawn” response



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## Self-Regulation

- We all get “caught up” in a wave of emotions and thoughts that lead to behaviours that don't help us
- Our bodies naturally produce “bursts of energy” to better respond to danger (or what we perceive as danger)
  - > The “Fight / Flight / Freeze / Fawn” response

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## Fight / Flight / Freeze / Fawn

- Your body's natural reaction to danger
- Helps you react to perceived threats
  - "He came at me, and I don't know... I just pushed him to the ground"
  - "I didn't have to think, I just jumped out of the way"
  - "I froze... and then I knew exactly what to do"
  - "I just gave them what they wanted"
- It's automatic, can't control it, like a reflex
  - Some of us, over time, have just become better at judging what really is danger and what is not
  - Someone with FASD may misconstrue events as serious threats

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## Fight / Flight / Freeze / Fawn

- Threats of punishment increases the level of this response
- Brain short-circuits, decision making worse
  - Very difficult to process information
  - It's like a computer when all its resources are being used up
- With FASD, Fight/Flight/Freeze/Fawn is much harder to manage
  - May view events as serious threats to their safety (such as someone else receiving a compliment)
  - This physiological "reflex" may be much more intense with FASD
  - They may have more "reactivity" to start with

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They may have more "reactivity" to start with



Same amount of stressor

**Person A**



Same amount of stressor

Higher level of physiological arousal / reactivity before stressor

**Person B (with FASD)**

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### Regulation – When Upset – Strategies

- Show them they are safe
  - Their brain is not able to find safety right now
- Keep talking to a minimum
  - Talking is just more information (noise) for the brain to process, to work on
- Use a calm and neutral tone
  - Co-regulate - children rely on us to know how to feel in certain situations
  - Mirror the emotion you want to receive back (e.g., calm)

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### Regulation – When Upset – Strategies

- No threats
- Ahead of time, ask caregivers if there is a safety plan in place, or known “triggers” and/or sensory issues
- Involve the client in the safety plan when possible
  - During calm times, come up with a plan (e.g., go to a quiet room)
  - Practice - such as a visual cue to signal plan to the child/youth

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### Regulation – When they are on “the verge”– Strategies

- Reduce expectations / give them an easier step
- Don't give their brain work to do
- Redirect




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**“Show me that asking for help is okay.”**

— The Asante Centre

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### Executive Functioning

Managing yourself and your resources to achieve a goal

**Difficulty with:**

- Being on time
- Knowing how long something will take
- Knowing what to do first, and in what order
- Following through on what was agreed upon



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### Executive Functioning – Strategies

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**Simple Schedules**

- Create schedules for routines that they can easily refer back to (e.g., visuals)
  - You can also use visual schedules for plans
- Lessen the amount of steps
- Don't assume that they already know how to do something (i.e., step) within a plan/routine; you might have to teach a new skill (supported many times) before moving forward with a plan/schedule

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### Visual Sequence for Toothbrushing



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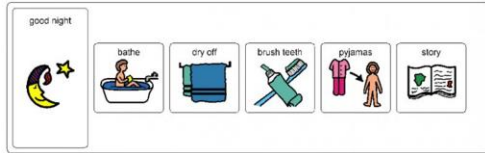
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### Visual Schedule for Nighttime Routine



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### Visual Schedule

- You can adjust visuals depending on the client's age/development
- Add text to visuals



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## Executive Functioning – Strategies

- Plan Together (for routines, scheduled events, important events, etc.)
  - Include them as much as possible (e.g., ask, “What are your concerns?” “What kind of help do you need?”)
  - Take the shame out of not knowing something – child/youth is then more likely to ask for help (appropriately)

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## Executive Functioning – Strategies

The individual may require many reminders, especially closer to the event.




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## Self-Care – Strategies



- Teach each step of a personal hygiene routine
- Hang visuals to aid with routines
- Create a mini-checklist for hygiene routines for sleepovers, vacations

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**Case Scenarios**



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**Scenario #1 15-year-old Male**

**Profile:**

- Neglecting to do household chores
- Forgetting to hand in school assignments
- Plays hockey and loves it, however he is always late to practice
- Works part time at hardware store chain but usually arrives 15 minutes late for his shifts

**Support Strategies:**

- Develop/practice/support schedule for chores
- Develop "end of school day" review routine, develop to do list, support him through both on a regular basis
- Set reminders / visual schedule for the different stages of hockey prep. Have equipment ready in consistent space
- Reminders / visual schedule / organized closet for work

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**Scenario #2 14-year-old Female**

**Profile:**

- Struggles to make friends
- Will try to "impress" others
- These same people may take advantage of her

**Support Strategies:**

- Circle of Support
- "Hangouts" with 1 or 2 peers, supervised from afar
- Peer role model
- Supervised Internet use

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Scenario #3 21-year-old Male

Profile:

- Has "friends" in the community that usually ask him to do things that get him into trouble

Support Strategies:

- Circle of Support
- Support interests / Facilitate strengths
- Support young man through any legal process – consequences are an abstract concept
- Talk to legal counsel before talking to the police

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Scenario #4 25-year-old Female

Profile:

- Working full time as a server in a restaurant, doing well
- Cannot manage his money, does not know how to budget and generally runs out of money before his next paycheck

Support Strategies:

- Circle of Support (likely requires lifelong support with money)
- Teach "pay bills first"; use a "budgeting" notebook
- Set reminders for bills
- Manage money together; make sure he gets to "reward" himself with a small purchase after being paid (or set money aside for large purchase)

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Thank you!

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