

TIPS

For Support Workers



FASD
NETWORK

FETAL ALCOHOL SPECTRUM DISORDER

Fetal Alcohol Spectrum Disorder (FASD) is a disability that can occur in children, youth, and adults when alcohol is consumed during pregnancy. It is a lifelong, brain-based, and often invisible disability.

Primary disabilities are caused directly by exposure to alcohol during pregnancy. There is a wide variety of primary disabilities. They are organized under the following four categories: physical, cognitive, behavioural, and sensory. For most individuals, FASD is a disability that is hidden from others. Because we cannot see the physical changes to the brain or the changes in brain functioning, FASD is called an invisible disability. What is most problematic is that the invisibility of FASD creates a barrier to acceptance and understanding. As a result, people with FASD do not get the support they need.

When learning about the risks of alcohol use and FASD most people want to know what the scope of the problem is. They want to know the rates of FASD. We do not have national statistics on the rates of FASD in Canada although the Public Health Agency of Canada suggests that 9 in 1000 births are affected. Another way to understand this is that up to 300,000 people are living with FASD in our country. What we do know for sure is that FASD can affect anyone. FASD can occur in families from any culture, ethnicity, or socio-economic background. During your career, you may support individuals who are diagnosed with FASD and many who will not be formally diagnosed. Developing an understanding of FASD will help you recognize the diverse needs of all your clients.

FASD is a unique disability that affects everyone differently. Each individual with FASD is born with a unique set of primary disabilities and characteristics. While there are some common disabilities that are described in this resource, it is important to understand that every person with FASD will have different needs. A strategy that works for one individual may not be the best fit for another. As support workers, the first step to supporting individuals with FASD is to learn about the disability and the potential impact it can have on those affected. Then get to know each person's unique needs.

One of the biggest challenges for individuals and families impacted by FASD can be advocating for the education, health, social services, and other systems to understand people with FASD and understand that their brains work differently. The following pages are tips and strategies that can be implemented to help understand and make adaptations to fit the common needs of individuals with FASD.

Adapting and accommodating environments to suit the needs of people with FASD is the best way to prevent secondary characteristics of the disability such as mental health issues, disrupted education, substance use disorders, etc. Reframing our perceptions from the individual "won't" do something to understanding that they live with a brain-based disability and "can't" do something is the best starting point for identifying poor fits between a person's abilities and the expectations being placed on them.

TIPS FOR COMMUNICATING

Prenatal alcohol exposure changes the way the brain is able to process information. As a result, individuals living with FASD may require more time to understand the world around them. A lack of comprehension can be caused by a variety of primary disabilities such as poor receptive language skills, confabulation, dysmaturity, sensory disabilities, and a lack of understanding of cause and effect. If you try to ensure communication is understood, consistent, and done in a way that supports the individual, you will have more success with communicating.

- Always start by using plain language first, and then adjust your communication style to meet the individual's needs.
- Each individual processes information in a way that is unique to his or her skill set. It is important to recognize that even though an individual might talk fast, have an incredible vocabulary, and seem as though they are processing information quickly, they may still struggle when receiving information.
- Allow extra response time. An individual with FASD is a “ten-second child in a one-second world.”
- You can stop during communication to check for comprehension. Even if a client can repeat things back to you word-for-word that doesn't necessarily mean they understand, try asking them to explain things in their own words.
- Simplify:
 - Use shorter sentences.
 - Reduce unnecessary information.
 - Rather than providing lengthy instructions, provide a point form list of how to complete a task.
- Be Direct:
 - Say what you want rather than what you don't want.
 - Use the person's name to direct their attention to you.
- Be clear and make sure that the information you are providing is organized. If you are talking about the steps required to complete a task, list them in the order they should be done.
- Individuals living with FASD can struggle to understand abstract concepts like jokes, figurative language, and sarcasm. Avoid intonations and verbal tones that are attached to abstract meaning.
- Use plain language to explain legal and medical information.
- Ask what word the individual prefers to use, or what he or she used in the past (jacket vs. coat, sneaker vs. shoe, cash register vs. till, etc.).

TIPS FOR MEMORY IMPAIRMENTS

One way FASD can impact cognitive functioning is memory impairment. You may see these memory difficulties when a client is unable to complete a task they've done several times before, when meetings or appointments are repeatedly forgotten, or when a client seems to have a good understanding of a concept one day but not the next. Finding ways to aid their memory or accommodate their deficits by using their strengths will allow your clients to be successful despite their memory impairment.

- Repeat, repeat, repeat. Routine, repetition, and consistency can be effective strategies for addressing memory issues.
- Give the client time to process and retrieve information – slow down when speaking.
- Don't assume the individual will remember. Do not put unreasonable expectations on them.
- If it's an 'off' day, don't pressure the individual, wait for a better day.
- Use reminders like notes, follow-up emails/phone calls, etc. to help your clients remember appointments and meetings.
- Help them develop a system for recording the important things they need to remember.
 - Use agendas, cell phones, planners, or any other item the client is comfortable with.
- Keep instructions simple without unneeded details or words. Say exactly what they need to know so there's less to remember.
- Re-teach things as needed, in a patient and respectful way.
 - Memory deficits and issues generalizing lessons learned in one scenario to the next may mean a client will need to be retold things in new environments.
- Most importantly, be patient. Memory is a lifelong issue, however, practice and support can often result in self sufficiency.
- You can help your client create visual reminders such as reminder pictures, chore charts, calendars, task lists, and a ready for work chart, these are easy and cost-effective ways to create reminders that individuals with FASD can utilize to aid their memory deficits.
- Memory deficits can result in story telling or confabulating. Confabulations are a disturbance of memory, defined as the production of fabricated, distorted, or misinterpreted memories, without the conscious intention to deceive. Sometimes confabulation can be misunderstood as lying, but often this exaggeration makes sense or becomes true in the moment to those who are saying it. Confronting a person about a story can lead to a blow-up. If they are approached without negativity, accepted, and not confronted or rejected, some individuals with FASD are able to recognize or end a confabulated story. You can help your client to recall the real story by asking them to describe what took place, rather than interpret events.

TIPS FOR EXECUTIVE FUNCTIONING

FASD can cause deficits in an individual's executive functioning, meaning they may be unable to plan and guide their behaviour. Typical executive functioning refers to the ability to identify goals, plan how to reach them, and then effectively implement these plans. In order for an individual's brain to follow this process several abilities need to integrate such as a working memory, organizational skills, future planning, impulse control. etc. These are all cognitive abilities that are commonly impaired by FASD.

Executive dysfunctions can hinder an individual's ability to perform tasks that require attention, concentration, or control.

- Give one instruction at a time.
- Create a reasonable timeline or due date for tasks.
- Have a routine when you meet with your client that doesn't change. For example, meet on consistent days at the same location, begin the meetings by talking about topics in a certain order each time.
- Help your clients to set and monitor short/long-term goals.
- Break large or complicated tasks down into simple, step-by-step parts.
- Help teach them skills by thinking through the process aloud.
- When giving your client paperwork, use highlighters to emphasize important parts.
- Use computers or technology as much as possible for ease of completing tasks.
- Help your client develop the skills needed for executive functioning:
 - Planning - making lists, developing routines, writing out goals, etc.
 - Organization - show them how to systematically organize their lives, give extra time before/after tasks so they can get organized.
 - Time management - help set specific, time-based goals, teach them how to prioritize tasks.
 - Task initiation - help them make a specific plan for how to do tasks.
- While working with clients who have FASD you may discover that behaviour modification strategies and consequences do not work; the individual may be unable to relate or generalize consequences to the actions that caused them. This can lead to continuous involvement with the justice system because the individual may not remember what they did to get into trouble, understand the cause and effect of their actions, or generalize an understanding that the consequence will happen again if they repeat their actions.
 - You may need to repeatedly explain why consequences are happening to ensure your client understands.
 - Advocate for restorative justice for your client. Restorative justice works as a mechanism to provide the individual with a consequence that fits the original mistake, while also giving back to the victim or community. This can allow the individual to make mistakes, correct the mistakes, restore relationships and, perhaps, learn from their mistakes.

TIPS FOR DYSMATURITY

Dysmaturity is when someone's developmental age is younger than his or her physical age, so they act and think younger than they are. For example, an individual may be 18 years old but developmentally they may have the living skills of an 11 year old, the social skills of a 7 years old, and the comprehension of a 6 year old. In other areas, the individual may be developmentally on time or ahead of their years. The behaviours of children and youth with FASD are often perceived as inappropriate for their age but when dysmaturity is understood as a symptom of FASD, it can be seen that they are actually acting fittingly to their developmental age.

Most of us, whether professionals or caregivers, expect children to develop and grow according to an accepted chronological schedule and for physical, cognitive, and psychological development to occur at about the same rate. Unfortunately for individuals affected by prenatal alcohol exposure, these assumptions about development create a poor fit between abilities and the expectations placed upon these individuals. Research shows that as children with FASD grow, the gap between their chronological age and developmental abilities can actually widen. It is important to "think younger," when supports are appropriate to an individual's development age, frustrations and behaviours are often prevented.

- Take a step back to consider your client. What age do their abilities and behaviours suggest?
- Adjust expectations to the level the individual is functioning at.
- Utilize strategies targeted at the level of functional, not chronological, age.
- Set up opportunities for the individual to have positive experiences ensuring appropriate supervision and boundaries are in place.
- Advocate to others when the individual needs to be treated their developmental age rather than their chronological age.
- Mentors and support workers are great resources to help individuals who are functioning at a lower level to better understand and practice age appropriate behaviours and skills.
- Give them responsibilities that are appropriate to their developmental age, this will help them develop life skills and give them confidence.
- As people with FASD grow older and reach the legal age of adulthood they will experience increased expectations and responsibilities along with a decrease in the services available to them. Instead of the drop-off in supports, as individuals age out of school and other systems, they may require even more intensive supports to ease the transitions and assist with the expectations of adult life.

TIPS FOR SENSORY DISABILITIES

The senses take in enormous amounts of information. Sensory processing and sensory integration help with successful functioning, responding, and making sense of the world. With the presence of a brain injury resulting from exposure to alcohol in the womb, individuals may experience a variety of sensory issues. Disordered sensory processing and integration can create difficulties for individuals with FASD, they may be unable to filter out stimuli and get overwhelmed, or unable to concentrate on one stimuli, they may seek out sensory information through movement, or they may avoid sensory inputs like bright lights and noisy crowds. Sensory disabilities can impair learning, physical functioning, and behavioural development.

- Speak to your client about any sensory issues they may have. Most individuals will be able to tell you when certain things bother them or the tips and tricks they have developed over the years to deal with their sensory impairments.
- Be aware of the sensory input in the meeting spaces you arrange with your client. Is there clutter in the room? Bright posters? Flickering lights? Are there distracting noises?
 - Try to find meeting spaces with little activity or noise, especially when the individual needs to focus.
- Recognize that an individual may be shutting down or refusing to participate due to the sensory stimuli in an environment, they are not trying to be difficult.
- The use of things like headphones, earplugs, sunglasses, or hats can help tune out overwhelming sensory input. Allow your client to wear these things while you're working with them and advocate for them to be allowed to use these items as aids for their sensory disability in other places where it might not be deemed appropriate such as school, meetings, court, etc.
- Try to understand that your client may need body breaks during lengthy appointments like getting up to stretch or a quick walk around the block.
- Fidget tools can help individuals with FASD pay attention. It may take more sensory input than typical for them to pay attention so the movement involved in manipulating fidgets can help the brain focus and attend.
- If your client is having consistent 'meltdowns' in certain places, do an audit of that environment to see what may cause issues.
- Help your client gain access to the services of an Occupational Therapist who can provide methods to deal with unique sensory impairments.

TIPS FOR ISSUES WITH OWNERSHIP

Ownership is an abstract concept that can be difficult for children and adults with FASD to understand. There are many factors that can make individuals with FASD struggle with the concept of ownership, they may be 'living in the moment,' they might not remember that there are consequences for taking things, or, if no one is around, it can be difficult to understand that an object belongs to someone else. Deficits in an individual's impulse control can lead to many circumstances of 'stealing,' it is possible that they do not intend to steal an object, they simply see something they like so they pick it up with no thought about who it may belong to or what they actually plan to do with the object.

It can be hard to know what to do when an individual with FASD takes something that belongs to someone else, are they intentionally stealing or do they even understand that taking the object was stealing? Each case will be different but ownership is a concept that may need to be repeatedly taught.

- If there are issues with ownership, have conversations with your client and explain why it's a problem.
- The concept of ownership may need to be retaught in different environments.
- Help your client to understand ownership by asking how they would feel if their favourite things were taken by someone else.
- If ownership is a consistent problem at home or in school, try suggesting that belongings are marked with a sticker. For example, everything with blue stickers belong to the individual. If something doesn't have a sticker then they should not take or use those objects.
- Try to practice borrowing with your client, this is an area where they may experience problems.
 - You can start by asking your client to hold on to something for you for safe keeping, such as a lucky pen, be sure to explain that they will have to return the item. This will help them understand what borrowing looks like.
 - It is important that individuals with FASD also learn about the concept of lending out their own belongings. Look for ways to borrow something from your client. Try to teach them what is appropriate to lend out and what is not.
 - Individuals with FASD are often visual learners so try to use pictures or examples to teach what is safe to borrow and lend.
- If a client begins to have legal repercussions for taking things advocate for restorative justice instead of consequences. For example, if they shoplift from a store have them return the items and do community service at the store so they can learn there are consequences for taking things and gain some work skills.

TIPS FOR APPOINTMENTS

When you have an appointment or meeting scheduled with a client there are certain assumptions made about the client's abilities. For example, you may assume they should be able to remember the meeting, that they can figure out how to get to the appointment on their own, or that they understand why they are having this meeting. For individuals with FASD these abilities (memory, executive functioning, comprehension) may be directly impacted by their disability. Here are some quick tips to help you have successful meetings with your clients who have FASD.

- Remind them of any meetings or appointments they have scheduled with you.
 - Don't just remind them of when/where the meeting is. Be sure that they understand not only what time the meeting is but what time they will have to leave their house, how they will get to the meeting, and what they need to bring with them.
- Help your client understand the expectations of the appointment. Some expectations will be provided, for example that they bring their paperwork to the meeting, while other expectations will be implied, for example the expectation that they wear presentable clothing to an appointment instead of their pajamas or that they eat their lunch before the meeting.
- Sleep can be an issue for many people with FASD so scheduling appointments with your client for the afternoon rather than the morning may be a good strategy to help them make it to the appointment on time and be alert.
- FASD is a full body disorder so you may need to address what is going on with your client in terms of their physical disabilities before their minds will be able to concentrate on the meeting. See page 06 on sensory disabilities.
- If your client has a mentor or a support person, suggest they come to meetings as well. They will be able to help the client understand what is being said, remember it after the meeting, and begin any tasks that need to be done.
- Be aware of your expectations for the meetings.
 - Try not to schedule a lot of information to be covered.
 - Be sure the meeting moves at a pace that gives your client enough time to process and understand the information being discussed.
- Schedule time after important meetings to debrief with your client and ensure they understand all the information that was covered during the meeting.

TIPS FOR SECONDARY CHALLENGES

Secondary challenges are those difficulties that arise due to a poor fit between the individual's needs, level of functioning, and the environment. Complications arise most often because of undiagnosed primary disabilities, lack of intervention, lack of services, ineffective strategies or unrealistic expectations. Many organizations and people are not educated on FASD and the brain differences that influence behaviours. Repeated failure and continued high expectations in an environment that is confusing, overwhelming, and frustrating contributes to secondary challenges. Having FASD doesn't mean that these things will definitely happen, just that it is more likely. If we put the right supports in place early on, we can help to avoid secondary challenges.

Some common secondary challenges and characteristics related to FASD are mental health issues, relationship issues, healthy sexuality, disrupted education, substance use disorders, justice issues (victims or offenders), employment problems, and homelessness. Secondary challenges such as mental health can often be more troubling than the primary disabilities. They often carry a greater risk to the child, youth, adult, and family.

- It is very important to recognize a poor fit and work towards making accommodations to help your client succeed. Early intervention can lead to better outcomes for individuals and families impacted by FASD.
 - Identifying strengths is a great starting point. A good fit for an individual with FASD must be based on strengths, abilities, and interests while addressing their struggles.
 - People with FASD are willing and able to learn when strategies match learning styles and build on strengths rather than deficits.
 - Use strength-based approaches such as implementing different learning styles and kinds of intelligence (visual, auditory, hands-on, etc.) based on the individual's strengths.
 - Ask the client, their caregiver, or other support workers where they have succeeded in the past. What has worked well? What is the client good at?
- Try to explain to your client how dealing with the disabilities associated with FASD can impact their mental health.
- You may also want to explain how emotions can cause physical responses. For example, anxiety can feel like an upset stomach.
- Should treatment be required, advocate for a program which recognizes the needs of individuals with FASD or is willing to adjust their programs to increase success.
- You may need to explain the disability to some mental health professionals as they may not have extensive knowledge on FASD.

TIPS FOR ADVOCATING

FASD is a disability that remains relatively unknown, so you may have to advocate for your client to receive the supports and services they require. Educating others about FASD and teaching them to put the person before their disability is the first step in advocacy. This can include providing resources, involving the individual's support team in meetings, or explaining the specific struggles and strengths that an individual has.

One of the hardest parts of supporting someone with this disability can be helping them navigate complicated systems that may not be designed to accommodate the needs of individuals with FASD.

- The first step to advocating for a client with FASD is becoming educated on the many facets of this unique disability so you are able to explain how their needs are a direct result of FASD.
 - Individuals with FASD and their caregivers have to advocate to countless people in almost every system they encounter, by becoming educated about FASD you can help alleviate some of this burden by being one less professional they will need to advocate to.
- Try to involve other members from the client's support team. Their family members, mentors, or other professionals in their lives will be able to reiterate what you are saying.
- Maintain open and constant communication with the other members of your client's support team.
- Help your client learn their own style of self-advocating by finding them ways to learn about their disability and how it affects them.
 - You can also learn from the individual by determining what they are comfortable disclosing to others. Some clients may not want to openly discuss their disability with others. Always advocate in a way that supports dignity and respect.
- Be sure to involve the client in your advocacy efforts. Individuals living with FASD should be involved in the decisions being made for them or about them. They know what has worked for them and what hasn't in the past so involving them in advocating for accommodations to be made on their behalf can result in more effective ideas and strategies.

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