

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.

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.

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.

Secondary challenges, sometimes referred to as adverse outcomes, are not caused directly by prenatal exposure to alcohol, but they develop throughout later childhood, adolescence and during adulthood. Children, youth and adults living with FASD live in a world that often does not fit them very well. Most people around them do not recognize that their behaviour and limitations are in fact linked to the primary disabilities of FASD. The poor fit between a person with FASD and her or his environment is not on purpose. It is the result of gaps in understanding and missing information. When a disability is not recognized, demands and expectations that cannot be met because of brain differences are placed on individuals with FASD. These individuals experience failure over and over. Repeated failure and continued high expectations in an environment that is confusing, overwhelming and frustrating contributes to secondary challenges.

Secondary issues are interconnected. They tend to stack up over and above the struggles linked with the primary disabilities. Families and professionals see several types of secondary challenges such as mental health problems, disrupted school experiences, addictions, social isolation, struggles with employment, homelessness, as well as victimization and involvement in the justice system.

Often the best way to support children and adults with FASD is to adapt our way of thinking, to understand that they have a disability that will require thinking outside of the box to make the necessary accommodations they need to succeed. More information and resources are available from the FASD Network.

TIPS ON COMMUNICATION

When you have a client who has FASD, or you suspect to have FASD, there are a couple of quick tips for communication that will help you obtain information and maintain appointments.

- It's important to remember that when you call someone, you don't have a view of what is taking place on the other end of the phone. If clients are on the bus when they take your call, they will likely forget what you tell them because they have no paper or pen in front of them and taking the bus requires a certain level of cognitive ability; therefore, they are required to multi-task.
- · Consider ways that will allow the client to access the information, and retrieve it when necessary. Sometimes this will be texting, other times a simple e-mail can be very helpful. Different instant messaging services or social networking sites may work as well.
- Be sure to follow up with a friendly phone call the day before or the morning of an appointment, reminding them to check their messages, or look at the map you sent.
- As service providers, it can be easy to assume that a missed appointment means the individual does not want help or that the person will come to us when they are ready. Remember, this may not be the case for an individual with FASD as he or she may simply have a hard time remembering and managing the time that it takes to get to an appointment.
- · Try setting meetings somewhere the person already frequents (at school, home, work, coffee shop etc.).
- · If a client is always late, see how the individual gets to appointments (bus? car? taxi?). Work out a new plan on how to get to the appointment on time.
- · See if the individual has better luck getting to appointments in the morning or afternoon.
- · When sending a text, ask that they save it in their memo or text box with an appointment reminder.
- · With the client's permission, call the client's support worker, so he or she can remind the client of appointment times as well.
- · Send a letter with a reminder of any upcoming appointments

TIPS ON COMMUNICATION

When individuals with FASD participate in the court process, they may struggle with poor memory functioning, impaired executive functioning, slower processing pace, poor problem-solving skills, lower concentration levels and lack of sequential thinking. These issues can be aggravated when compounded with the intimidation and low self-esteem felt throughout the court process.

It is important to accommodate clients as much as possible to ensure the best outcome for the court proceedings and the client's overall well-being.

- · Including a client's support worker or family in the court process will increase the level of understanding within the client's circle of support. An engaged and knowledgeable circle of support will help to initiate better outcomes for those individuals living with FASD who come into contact with the justice system.
- · A client may demonstrate an understanding of the charges, but comprehension may be lacking. Inviting a family member or support worker into privileged conversations can help to increase a client's willingness to ask questions and truly understand consequences.
- Having a family member or support worker present will help to ensure that a client understands any consequences that counsel may be unaware of or has assumed the client is aware of. For instance, a client may agree to plead guilty to avoid further proceedings. A support worker can remind a client that pleading guilty may interfere with the client being present at an important family event.
- Ensuring that a client's support circle is informed regarding all legal matters ensures that the client has access to support outside typical counsel appointment times. This will help the client by alleviating the anxiety and tension that accompany not remembering parts of their conversation with counsel. Clients are better able to refer to notes or conversations with a support worker.
- The support person must be fully aware of the dangers of giving legal advice. Counsel must be sure to advise the client and support person of the dangers and complications that could result from following advice provided by anyone other than a legal professional.
- Trial can be especially difficult for an individual with FASD because many of the typical court procedures require memory and patience. The presence of a support person will provide the client with an opportunity to be given reminders and potential calming during times of anxiety and frustration.

TIPS ON COMMUNICATION

- · Involving a support person in case preparation may allow counsel the opportunity to access additional information about the client and his or her disability. The support person can provide a firm understanding of the client's strengths and weaknesses, highlighting what part of the court process may be most difficult and where the client's understanding may be lacking.
- The support person may be able to help ensure the client presents the best version of themselves in court. This can mean that the support person encourages a client to dress professionally, adhere to appropriate conduct, come on time, and participate willingly.
- · Including a support person may help to ensure the client has supports after court proceedings have ended. Abiding by extrajudicial sanctions and conditions can be difficult for clients with FASD and having a support person may increase the client's chances of fulfilling the court's requirements.
- Legal professionals often carry heavy workloads with little time available for special circumstances. Accommodating a client and their support person can sometimes cause communication issues and require additional time. Both the legal professional and the support person must strive to maintain a healthy working relationship that allows them to balance representing the best interests of a client and supporting the client through the justice system.
- Both a legal professional and a support person function as a support to the client, but in very different capacities. Being able to maintain one's role and provide the client with specific services will work towards providing the absolute best outcome in each given circumstance.

TIPS ON PRACTISING FOR COURT

FASD is becoming more and more recognized in courtrooms all across Canada. With more understanding of the disability by all parties involved in the courtroom process clients are better able to work with their strengths and present themselves and their disability in a way that is better accommodated during the trial and sentencing process.

- Taking the time to work with a client who may require extra time to comprehend or process instructions can be difficult due to time constraints and heavy workloads. However, the time you take to work with clients will lessen their anxiety of what is to come and better prepare them to be participating members of their defense.
- · Having to recount an incident or enter a plea in court can be very overwhelming for anyone, especially for someone living with FASD who has trouble with memory and comprehension.
- · Practise with your client where they will stand in the courtroom and how they will give their statement, especially for trial court or sentencing.
- Advocate for the client by explaining the correlation between poor memory functioning and FASD. Ask the courts to allow the client an opportunity to read a statement they wrote and deliver it to the courtroom. By asking the courts to allow clients to read their statements, you are advocating on behalf of their disability, and allowing fewer opportunities for clients to confabulate, forget or change their original statement.
- · Work with your client to understand some of the normal social cues displayed in the courtroom. This may mean giving the client some practice hearing normal courtroom instruction, in which things like "please take your seat" means "go sit down." "Crown" is the lawyer that represents the province or the country, etc.
- Take the time to develop a template for understanding legal terms and courtroom expectations. Share this with the client's family or support worker so they may practise before appearing in court.
- Be sure a client is truly comprehending what is being asked of him or her. Try asking them to describe what a plea of guilty means, rather than simply asking if they understand.
- · Immediate consequences can be easier to understand rather than those consequences that happen further down the road. Try asking the client to explain how his or her charges will affect them in two or five years. This will tell you a lot about levels of comprehension.
- · Request the courts take into consideration a client's IQ (if lower), FASD assessment, or co-occurring mental health diagnosis. Although this is rarely successful in turning the courts opinion during trial, it does assist in sentencing.

TIPS ON PRACTISING FOR COURT

Although different courtrooms look different in size and cosmetic appearance, they follow the basic principles of respect and tradition. Understanding these traditions and respecting the court's authority can be a confusing process without proper support. Be sure to work with a client on some of the basic courtroom manners expected of them when they appear in court. For instance:

- Be sure the client understands his or her responsibility to bow when entering and exiting the courtroom. It is not always as important they understand the history behind why we bow, but more that it is an important tradition that they should be following. Don't forget to demonstrate this for the client and ask them to show you how they will bow when they enter the courtroom.
- Ask the client to wear clothes that are clean and don't have writing on them. Not every client will have a dress shirt and pants to wear, but being very clear that a clean pair of cotton or polyester pants with a clean t-shirt or sweater will go a long way compared to your favorite band's t-shirt and sweat pants.
- · Wearing a hat or sunglasses has become a more socially acceptable norm for young people at work and at school. It is important to reiterate that no hat should be worn and that sunglasses should be tucked into a pocket or purse and not worn on your head.
- Just like the airport, it is important not to bring anything that could be considered hazardous to court. This should be explained in very plain language: for instance, no wine bottle openers, no pocket knives, no drug paraphernalia, one or two lighters, only prescription drugs still in the bottle with the label, and no food or drink in the court room.
- · Clients should be told not to chew gum or tobacco or have a toothpick in their mouths when they enter the courtroom.
- · Clients should be told to only bring people who are supportive and understand the same rules apply to them as they do to you in a court room.

TIPS ON DESCRIBING AN EVENT

Many individuals living with FASD experience memory problems that can make it hard to recall how an event happened. If an individual is asked to recall what happened, but is struggling to remember, they may tell a story that doesn't reflect the actual occurrence. Instead, the story they tell may reflect what they wanted to happen, what they think happened or something they saw happen on television. This is known as a confabulation. However, by asking careful questions, you can compile a more accurate account of what took place and avoid confabulations.

- Every question should encourage the client to describe the event rather than reflect on it. This will minimize their need to process how or why it happened and any emotions connected to the event.
- Be specific with your questions, for example: Instead of asking 'what happened?' Ask 'how did it happen?,' 'where did you go?,' 'who was there?,' or 'where did you go next?'
- · Instead of asking 'why did it happen?,' Ask 'how did you get involved?,' 'who was there?,' or 'how did John get involved?'
- · Give plenty of time for the individual to process the question and then formulate a response. Individuals living with FASD have a slower processing speed; what feels like ten seconds to us can feel like just one to them.
- · Practise active listening; repeat what you have heard back to the person periodically for clarification.
- · To help you organize the individual's thoughts, you can use a genogram to map what the individual is saying.
- · Be aware of your ability to influence the individual's response.
- · Remove any distractions, sounds, smells or unnecessary people from the interview space.
- · Give the individual a pen and paper so that they can write down the sequence of events.
- · Avoid asking redundant questions.
- · Use plain language

TIPS ON CLIENT MEETINGS

- · Before meeting with a client, it is important to ask if he or she would like anyone else to join the meeting for note-taking, support or just an extra ear. Try suggesting the individual ask a support worker or parent to be present to write down what is talked about in the meeting.
- Having a support person or parent present can often put a client at enough ease that the individual will hear more of what you are saying. It is also helpful for you to meet the support person or parent attached to your client as they will be a powerful ally in getting the client to appointments and prepared for future meetings.
- Try using a smaller room that has a door that can close. If a meeting is held in a larger room, or even an open space, clients will have trouble focusing on the meeting, as they will be processing their surroundings.
- · Provide the clients and their support people with an agenda and notes about what you will be talking about. This is especially important for legal matters that involve following specific guidelines and expectations.
- If meetings will be taking place on a regular basis, knowing the support person will be an asset to maintaining regular appointments and having someone to contact when appointments become irregular.
- · Be sure to always take into account processing speed, allowing for a client to fully comprehend what you explain to him or her before moving on.
- Make your best effort to remember the person has a cognitive disability. Individuals may appear to "talk the talk," but always be sure they can "walk the walk" before they leave your office. Ask questions to reinforce concepts and ensure understanding.
- · Don't forget that where you sit in a room can become confrontational or oppressive. Sit in an open space, with no desk between you.
- · A room for meetings should have plain walls and comfortable chairs. A client can spend the entire meeting reading posters on the wall and when the meeting is over have no memory of what was talked about.

TIPS ON PROVIDING CONDITIONS

Conditions are a set of court mandated guidelines handed down by a judge after someone has broken a law. The idea behind conditions is to help youth or adults avoid areas where they may be tempted or pressured to break laws and put themselves or others at risk. Without the proper understanding of what conditions entail, the youth or adult is unable to adhere to them and therefore begins a cycle of involvement with the criminal justice system.

- The youth or adult may still have difficulty following a condition due to memory issues, lack of impulse control and poor problem solving, but with supports, they will be more likely to succeed.
- Taking a set of conditions and breaking them down further into simple and plain language with several examples will help the individual place the conditions in the different contexts he or she encounters every day.
- Use the comprehension guide to be sure the individual truly understands what a condition entails. For example, if a youth is to abstain from going to the corner store, they are also not allowed to hang out in the parking lot of that corner store.
- Print the conditions and give them to support workers and family the more people aware of the conditions, the more reminders and help the individual will receive.
- · Try using social stories to explain conditions.
- · With permission email conditions to family, friends and support workers. They can use positive reinforcement to encourage the youth or adult to follow the conditions.
- · Give the youth or adult several copies of their conditions as they will be lost, or forgotten somewhere.
- · Tell the individual to make a memo on his or her phone of the conditions.
- · Make sure the youth or adult understands they are liable for whatever they choose to share on social networking sites.

TIPS ON RESTORATIVE JUSTICE

Restorative justice is not just for legal matters — it is for the home as well. Applying appropriate consequences can be a source of tension for many parents. Applying a method of restorative justice at home, in school, with friends, and in the community allows the individual to make mistakes, correct the mistakes, restore relationships and, perhaps, learn from their mistakes while maintaining dignity.

- It can be personally embarrassing to make mistakes that other people your age have already learned from, and it can also be embarrassing for parents, friends, and siblings. Providing a consequence that fits the issue is an important component to alleviating the tension a problem has caused.
- 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. Starting this in the family home is the best way to instill a sense of community obligation and respect for others. When started later in life, it can be difficult to instill to the same degree.
 - · For example: In the community, this can look like a child who knocks over someone's mailbox (for fun) being required to build a new mailbox and shovel the neighbour's driveway for the week.
 - · For example: A good example of how restorative justice works is with stealing or breaking things in the family home. When something is stolen and the child is without a doubt responsible for the stolen item, a house meeting could be called to discuss what should be done to make up for the stolen item. If the item can be produced, the child may only be required to do the victim's chores for that week. However, if the item cannot be given back, the child may be required to give up one of his or her own toys and still do the victim's chores for the week.
- It is very important for neighbours, friends and family to understand the individual's disability and still be given the choice of calling the police if the incident warrants police involvement. In some cases, a neighbour has seen a child grow up and is well aware of that child's weaknesses and is happy to participate.
- To impose proper consequences, all affected parties should be involved in the development and follow-through of the consequences. This will work best when the family begins utilizing restorative justice practices at a young age.
- · Consequences should not have to be demeaning and a parent can help if a child is struggling. The point is to restore previous relations between the victim and the individual.

TIPS FOR REFRAMING PERCEPTIONS

It is important to remember that FASD can cause behavioural impairments. Some of the behaviours that may be exhibited by clients with FASD are a result of the disability; they are not intentional. Reframing perceptions means viewing the person's conduct with an understanding that brain damage can cause disordered behaviours.

Explaining the need to interpret behaviours as a direct result of FASD can change how others view your client during legal processes and procedures.

Behaviours	Misinterpretation of behaviours	Accurate interpretation of primary disabilities
Non-compliance (failure to appear, missing meetings, not abiding with conditions of release)	Willful misconduct, stubborn, disregard for rules of court, indifference, disrespect	Memory issues, a lack of understanding, struggles with abstract concepts (such as time), having difficulty getting organized, communication problems
Repeating the same mistakes (recidivistic actions, correction does not work)	Willful misconduct, manipulative, doesn't care, hopeless	Cannot link cause to effect, cannot see similarities or generalize, memory issues, poor judgement, lack of impulse control
Disruptive behaviours (fidgeting, talking, not paying attention)	Seeking attention, bothering others, willful misconduct	Sensory disabilities, over or under reactive to stimuli, sensory seeking behaviours, overwhelmed, short attention span
Lack of reactions (appears to have no remorse, disregard for seriousness of situation)	Lack of remorse, doesn't care, not pay- ing attention, negative attitude	Impaired ability to recognize or articulate emotions, dysmaturity, tendency to shut down when overwhelmed
Inappropriateness (improper attire, unsuitable language, overly physical)	Disregard for rules of court, disrespect, defiant, attention seeking	Dysmaturity, poor judgement, lack of understanding, poor receptive language skills, concrete thinker
Lying (giving inaccurate information, changing stories, false admissions of guilt)	Willfully lying, attention seeking, attempting to avoid punishment, unreliable	Confabulation, memory deficits, lack of understanding, poor receptive language skills, issues communicating

TIPS ON SAFETY NOTIFICATIONS

Individuals living with FASD may be stopped by the police or required to answer questions if they are a witness, victim or accused of committing a crime. A wallet card and the Vulnerable Person Registry are two strategies for safety notifications that will let the police know that the individual lives with FASD. These notifications can provide the police with personalized information about their disability, need-to-know information about behaviours, and the information of whom to call if the individual is non-compliant or simply uncomfortable.

- A wallet card is a simple wallet-sized piece of paper that an individual can carry around with them. It list numbers of support people who the police, lawyers, etc. can call to support the individual. It also has the individual's identifying information. This card is incredibly useful when the individual is in a stressful situation where their processing speed and ability could be further impaired.
 - · Hospitals can also find wallet cards helpful when clients come to them injured, frantic, inebriated, unconscious or simply overwhelmed. Wallet cards can contain whatever information an individual is comfortable with. This may include the client's name, date of birth, health card number, contact people, and information pertaining to their disability.
 - · A wallet card does not have a template that must be used, but be sure to keep it short and simple.
 - · Practise when and how to use the wallet card with the individual.
 - · Wallet cards can be used in a variety of situations not just within the justice system; they can be used to advocate for oneself.

The Vulnerable Person Registry is a voluntary service offered by the Saskatoon Police Service for the City of Saskatoon. Go online to register at: http://saskatoonpolice.ca/vulnerable/. The Registry provides critical information to the Saskatoon Police Service that may be used during situations requiring police interactions such as information about their physical appearance, the most likely places they would go if missing, as well as triggers, stimulants and de-escalation techniques can be utilized by police.

- · There is no cost to register and the information is only accessed when needed.
- · The information on the Vulneral Person Registry must be renewed annually.
- · Other police jurisdictions will not have access to the Saskatoon Police Service Vulnerable Person Registry. Please contact your local police agency to learn their procedures.

FASD NETWORK OF SASKATCHEWAN

510 Cynthia St Saskatoon, SK 1-866-673-3276 www.saskfasdnetwork.ca