



# FETAL ALCOHOL SPECTRUM DISORDER

## A Guide to Awareness and Understanding



### Letter to our Readers

FASD: A Guide to Awareness and Understanding includes a selection of materials gathered and prepared by the FASD Network of Saskatchewan. The intention of this guide is to provide basic information about Fetal Alcohol Spectrum Disorder for a variety of readers including parents, caregivers, family members, professionals, students, frontline workers and members of the general public. We hope that by increasing awareness and understanding of FASD, we will help to improve the lives of individuals and families living with FASD.

A list of suggested websites, organizations and print resources has been included to aid in your information gathering. We encourage you to please contact the Network if you are looking for further information or view our resources online by visiting us at [www.saskfasdnetwork.ca](http://www.saskfasdnetwork.ca).

Finally, we offer support and information to parents, caregivers, individuals with FASD and professionals on our toll free line at 1-866-673-3276. Feel free to contact us Monday to Friday, 9:00 a.m. to 4:00 p.m.

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## ABOUT THE NETWORK

The FASD Network of Saskatchewan is a provincial organization that works with families, children, and adults affected by Fetal Alcohol Spectrum Disorder. A group of dedicated parents came together in the early 1990s seeking support and understanding. They had common concerns about the challenges related to parenting children affected by prenatal exposure to alcohol. When the Network began, very little was known about FASD. Families faced stigma, lack of services, and misunderstanding.

Now, 20 years later, the Network is a community-based provincial organization with an office in Saskatoon. Over the years, the level of knowledge and understanding in Saskatchewan communities has grown along with the Network. The Network has expanded from a group of concerned parents into an organization led by a 12-member board of directors offering support, training, and events across the province.

Close ties and partnerships with community members, professionals, funders, and all levels of governmental departments aid the Network to accomplish activities aimed at improving the lives of individuals and families living with FASD.



Our vision is:  
“For individuals living with FASD and their families to recognize themselves as safe, supported, valued, included, and contributing members of the community”

## TRAINING

The Network offers a variety of tailored training sessions to organizations that work with individuals living with FASD.

These training sessions provide an in-depth knowledge of FASD presented by qualified instructors with a background in the disability. The Network continuously works on updating and developing curriculums for frontline workers, foster parents, educators, post-secondary students, and community organizations.

These sessions can be held anywhere in the province. By receiving training on the disability, organizations that work with individuals living on the spectrum can gain a better understanding of FASD and tailor supports to the individuals' needs.

## SUPPORT

The Support Program was created to give families direct support in their daily lives.

The program aims to work with families and circles of support to gain positive outcomes for those living with FASD. A Support worker will work to clarify the individual's short-term goals and determine a plan to reach these goals. The program provides assistance via case management, employment services, peer support, strategies, justice system navigation, referrals to community programs, and more.

Support workers have an in-depth understanding of FASD that can be shared to help individuals and families living with FASD achieve success.

## EVENTS

Along with our training sessions, the Network offers several annual events that provide education and training on FASD.

These events include an annual conference tailored to meet the needs of different sectors, Principles & Practices workshops that travel across the province to provide professionals with an introduction to the disability and strategies for success, as well as events created specifically for caregivers and individuals living with the disability.

The Network regularly updates its website to provide information on upcoming events and appreciates feedback on the types of events communities would like to see in Saskatchewan.

To access these services contact us at 1-866-673-3276 or visit [www.saskfasdnetwork.ca](http://www.saskfasdnetwork.ca)





# PROVIDING SUPPORT

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## Professionals

Those who choose careers in human services such as education, community or family support, health care, justice, social services, or mental health and addictions treatment will be in contact with individuals with FASD. If various professionals are aware of FASD and understand the signs, symptoms, and implications of living with FASD, they can modify their daily practice in order to better serve individuals and families. Through improved services and by making accommodations for a brain-based disability, the challenges of individuals and the professionals will be lowered and chances for success will be improved.

## Caregivers

Being a caregiver is one of the hardest jobs out there. Caring for an individual living with FASD comes with its share of struggles and frustrations as well as accomplishments and successes. Educating yourself about the disability is the first step. Understanding your child and how his or her brain works will help you understand what you can do to accommodate his or her needs. It is also important to be understanding towards birth parents, as no parents want to harm their babies; we need to have compassion when they share their stories. We encourage you to connect with other parents to learn new strategies and information and to share stories.

## Communities

We know that the rates of FASD are high. If 1 in 100 individuals are affected by prenatal alcohol exposure, think about the number of people you encounter each day in your personal, professional, or public life. People with FASD are members of our communities. They are friends, family members, neighbours, volunteers, students, and workers. It takes a community to raise an individual living with FASD. Each of us are unique and we each contribute to our communities in our own ways; we each have strengths, struggles, rights, and responsibilities. Acceptance of diversity, gained through improved understanding and awareness of FASD, will create strengthened and inclusive communities and improve individual lives.

# UNDERSTANDING FASD: BASIC INFORMATION

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## What is FASD?

The term Fetal Alcohol Spectrum Disorder is an umbrella term referring to the range of effects that can occur in children, youth or adults prenatally exposed to alcohol. The spectrum of effects includes four categories of primary disabilities: cognitive, behavioural, physical, and sensory. The disabilities caused by alcohol exposure are present from birth, but some are not noticeable until later in life. It is important to remember that with the right supports these individuals can and do succeed.

## How does alcohol harm a fetus?

Alcohol is a teratogen, meaning that this substance is toxic to, and can negatively influence, prenatal development. When a woman is pregnant and drinks, the alcohol passes freely through the placenta and enters the system of the developing fetus. Alcohol remains in the system of the fetus longer than that of the mother. The alcohol injures the body systems and organs that are developing at that stage of the pregnancy.

Our brains continue to develop after birth, so alcohol should also be avoided when breastfeeding. Many factors influence the amount of injury resulting from prenatal exposure, including the amount of alcohol consumed, how often alcohol is consumed,

the timing of consumption, the general health of the mother, stress levels, exposure to other substances and genetic makeup.

The central nervous system (CNS) is particularly vulnerable for two reasons:

- The CNS develops throughout the entire pregnancy so injury to neurological functions can occur over the entire nine months.
- Alcohol acts as a solvent on the rapidly developing cells of the CNS and causes significant injury, primarily to the brain.

## Can FASD be prevented?

We need to keep in mind the various factors surrounding the choice to drink during a pregnancy when we talk about prevention. The public requires clear and accurate information about the harmful effects of alcohol on a fetus. There is no known safe amount of alcohol or a known safe time during pregnancy to consume alcohol. For these reasons, it is best for women to abstain from alcohol throughout the entire pregnancy. This information and message needs to be widely available and consistent in communities and throughout the health-care field. We also need to understand that many people may be living with addictions or mental health issues. They may have a history of abuse

or lack of supports. Alcohol may also be a societal norm within some communities (statistics show that about 80% of society consumes alcohol and 50% of pregnancies are unplanned.) Women will need support from family, friends, partners, and communities to abstain from alcohol.

## How many people are affected by FASD?

In Saskatchewan, it is believed that 1 in 100 people may be affected by FASD. However, it is difficult to know just how many families are affected by FASD as a lot of individuals go undiagnosed their entire lifetime. The signs and symptoms of FASD often go unnoticed and are masked by other factors in the individual's life or are attributed to other causes. This is why FASD is often called an invisible disability. Individuals with invisible disabilities in many cases do not receive the support and accommodation they need to succeed in life. Many people with FASD have an IQ in the normal range, but the various cognitive processes have been altered. With appropriate supports and changes to their environment, individuals can be productive and successful members of society.



# DIAGNOSTIC TERMS

In 2005, a team of professionals developed the Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Diagnosis and assessment of prenatal exposure is a complex process best completed by a multi-disciplinary team of professionals that must include a physician specially trained in diagnosis and assessment.

Diagnostic and assessment services are available throughout the province but families continue to face barriers to these services. Barriers include long wait lists, services that are more widely available to children and youth rather than all age groups, lack of trained professionals, difficulty for families in remote and rural regions to access diagnostic and assessment services due to cost of travel and long distances to services.

We understand that there are difficulties accessing diagnostic and assessment services, but this is an important process that can improve outcomes for individuals and families.





A common area of confusion for families and professionals is the language used around diagnosis. The term Fetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term. FASD is an umbrella term used to describe the range of disabilities caused by drinking alcohol during pregnancy.

The following are the diagnoses that can be received within the spectrum of FASD. The criteria for diagnosis are those used across Canada.

Fetal Alcohol Syndrome FAS	Partial Fetal Alcohol Syndrome pFAS	Alcohol Related Neurodevelopmental Disorder ARND	Alcohol Related Birth Defects ARBD
<ul style="list-style-type: none"> <li>Confirmed maternal drinking</li> <li>Facial characteristics could include: smooth philtrum, short eye slits, thin upper lip</li> <li>Growth deficiency</li> <li>Central nervous system effects</li> </ul>	<ul style="list-style-type: none"> <li>Confirmed maternal drinking</li> <li>Some facial characteristics</li> <li>Either growth deficiency, central nervous system effects, behavioural or cognitive impairments</li> </ul>	<ul style="list-style-type: none"> <li>Confirmed maternal drinking</li> <li>Central nervous systems effects and behavioural or cognitive impairments</li> </ul>	<ul style="list-style-type: none"> <li>Confirmed maternal drinking</li> <li>Congenital anomalies</li> </ul>

A term used in the past that is no longer used as a diagnostic term is Fetal Alcohol Effects (FAE). This term has been replaced by the diagnostic terms pFAS and ARND.

It may take time for individuals to decide if they would like to seek a diagnosis. You can help by being patient and understanding throughout the entire process.

# PRIMARY DISABILITIES

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Fetal Alcohol Spectrum Disorder (FASD) describes a range of lifelong disabilities resulting from prenatal alcohol exposure. Maternal alcohol consumption injures the structure, function, and design of the brain resulting in a brain disability that is invisible to us. What is visible to us are the primary and secondary disabilities. It can be helpful to understand the various primary disabilities as well as the secondary disabilities associated with FASD.

Primary disabilities are those disabilities that are directly caused by the prenatal exposure to alcohol. Primary disabilities may impact physical, cognitive, behavioural, or sensory functioning.

## PHYSICAL DISABILITIES

Prenatal exposure to alcohol can affect how a body grows and develops. People with FASD can have differences in how their bodies are formed and how they move.

Physical disabilities can include:

- Slow to meet developmental milestones
- Problems with fine and gross motor control – things like throwing and catching a ball, holding a pencil, hopping on one foot, riding a two-wheel bike, or using scissors
- Poor balance and co-ordination – clumsy, bumping into things
- Lower height or weight
- Auditory impairments
- Weak heart, heart murmurs, frail bones, and other body system abnormalities

## COGNITIVE DISABILITIES

Cognitive functioning refers to intellectual tasks like thinking, reasoning, and remembering, which are crucial in our everyday functioning.

Cognitive disabilities can include:

- Difficulty with memory
- Confabulation – filling in gaps in memory with storytelling
- Slower to process information
- Short attention span
- Impaired executive functioning
- Difficulty setting and reaching goals
- Problems generalizing from one situation to another
- Problems connecting cause and effect
- Poor receptive language skills
- Trouble understanding abstract concepts like time, money, or math
- May have lower IQ



## BEHAVIOURAL DISABILITIES

Your brain controls your behaviour in social interactions. Individuals with FASD may seem to display strange or inappropriate behaviours because their brains do not process other people's actions and words in the same way.

Research on FASD has found learning and behavioural differences between people with FASD and others in relation to their developmental age. 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, the developmental age of a 16-year-old could be closer to that of an 8-year-old. In order to be appropriate and effective, expectations need to be based on developmental level rather than chronological age.

The behavioural symptoms of FASD may include:

- Impulsive actions
- Mood swings
- Inflexibility
- Lack of inhibitions
- Reacting poorly to changes in routine
- Poor understanding of ownership
- Poor understanding of personal space
- Poor ability to express and/or understand a range of emotions
- Repeated mistakes
- Vulnerable to peer pressure
- Easily overwhelmed
- Grandiose or unrealistic expectations
- Problems with social skills
- Problems with interpersonal skills
- Trouble reading social cues

## SENSORY DISABILITIES

Every day, your senses take in a huge amount of information from your environment. Receiving and interpreting this range of information is called sensory processing. Because the brain takes in so much information, the sensory system works best when all senses work together, which is called sensory integration.

Prenatal exposure to alcohol can damage the central nervous system and cause sensory processing or integration problems. Generally this looks like over- or under-sensitivity in taste, smell, touch, hearing, sight, vestibular input (movement sensation), and/or proprioception (a sense of where your body is in relation to your surroundings). This can result in sensory seeking behaviours such as unusual hyperactivity or avoidant behaviours such as shutting down to any responsive actions.

Sensory disabilities may look like:

- Poor sense of smell
- Trouble discerning objects in clutter
- Becomes carsick easily
- Hand on wall while walking
- Unusually low pain tolerance
- Craves touch
- Overwhelmed in noisy spaces
- Overactive gag reflex



FASD is a unique disability that affects each individual differently







# SECONDARY DISABILITIES

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Secondary disabilities are those difficulties that arise later in life 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. 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 disabilities.

Some common secondary disabilities and characteristics related to FASD are:

- Mental health problems
- Substance use
- Inappropriate sexual behaviours
- Emotional problems and violence
- Addictions
- Legal problems
- Employment problems
- Housing problems and homelessness

Let's see what this may look like:

At school, students are expected to learn quickly, follow along when the teacher is talking, sit still for long periods of time and remember things later during exams. However, students with FASD can have trouble with memory, process words more slowly than most people, or get headaches and pains under fluorescent lighting. This makes it difficult to succeed in school unless the teachers, educational assistants, and other students understand that FASD makes your brain work differently.

“With the right support, secondary disabilities can be prevented”

# PARADIGM SHIFTS

When families, caregivers, professionals, and community members change their own understanding or perception of the individual with FASD, this is called a “paradigm shift.”

Person first language puts the person before their disability. Person first language distinguishes an individual from the disability and emphasizes that FASD is not that person’s defining feature. For example, instead of referring to a client as “an FASD youth,” refer to that individual as “a youth living with FASD.” Person first language encourages us to get to know the individual first and then explore how the disability impacts his or her everyday life. In order to support individuals living with FASD, we need to understand them broadly (what do they want to achieve, what are their motivations, their likes and dislikes, their personalities, their strengths/weaknesses etc.) while also understanding the influence of FASD.

Strength-based approaches shift our understanding away from conventional practices and encourage us to think outside the box. A strength-based approach not only draws on the strengths of the individual but on the strengths of his or her support system, family, services provider, community, and friends. Strengths are resilient characteristics which can be built on in order to achieve success. Though people with FASD may face challenges, it is important to recognize the strengths, skills, and interests of each person. People with FASD are willing and able to learn when strategies match learning styles and build on strengths rather than deficits.







From seeing the child as:

Bad, annoying  
Lazy, unmotivated  
Lying  
Fussy  
Acting young, babied  
Trying to get attention  
Inappropriate  
Doesn't try  
Won't

To understanding them as:

Frustrated, challenged  
Trying hard, tired of failing  
Story telling, filling in the blanks  
Oversensitive  
Being younger  
Needing contact, support  
Behaviour of a younger child  
Exhausted or can't get started  
Can't

From personal feelings of:

Hopelessness  
Fear  
Chaos, confusion  
Power struggles  
Isolation

To feelings of:

Hope  
Understanding  
Organization, comprehension  
Working with  
Networking, collaboration

Professional shifts from:

Stopping behaviours  
Behaviour modification  
Changing people

To:

Preventing problems  
Modeling, using visual cues  
Changing environments



# COMMON BELIEFS ABOUT

Belief: All people who have FASD have below-average IQ. THIS IS NOT TRUE.

The truth is:

- Some individuals with FASD have below-average IQ.
- Some individuals with FASD have average or above average IQ.
- Because of the damage to the brain and central nervous system, individuals with FASD may have troubles learning in different environments.
- Individuals with FASD are usually at a lower developmental age than their chronological age.

Belief: Individuals with FASD will outgrow their difficulties. THIS IS NOT TRUE.

The truth is:

- FASD is a lifelong disability.
- With the right supports in place, they can learn to make adaptations to support their disabilities.
- Your child may need your support throughout adulthood as well.

Belief: The behaviour problems of individuals who have FASD happen because their parents are not doing a good job of parenting. THIS IS NOT TRUE.

The truth is:

- Brain damage can lead to primary disabilities. These primary disabilities can mean that an individual does not always behave as others expect them to.
- Individuals with brain damage can be challenging to parents, but by educating yourself, you can better understand your child.
- As a parent of a child who has FASD you need the support of your family, friends, and the community. It is very difficult to go it alone.

Belief: Because an individual with FASD has brain damage there is no point in helping them. THIS IS NOT TRUE.

The truth is:

- If individuals with FASD are supported throughout their lifetime they will succeed.
- We need to adjust our expectations to match their developmental age and redefine success.
- Advocating for your child will help family, friends, and professionals to better understand the individual's behaviour.



# FASD THAT ARE NOT TRUE

Belief: A diagnosis of FASD is a label that will make people want to give up on the individual. THIS IS NOT TRUE.

The truth is:

- A diagnosis tells you where their deficits are.
- A diagnosis helps you understand how to help your child.
- A diagnosis can help an individual to understand his or her own disability and help with feelings of being misunderstood.

Belief: Individuals with FASD are unmotivated or unwilling to take responsibility for themselves. THIS IS NOT TRUE.

The truth is:

- Individuals with FASD are not trying to be difficult. There is usually an underlying reason for the behaviour.
- Individuals with FASD may not understand cause and effect and therefore not understand the implications of their actions.

Belief: Mothers know that they could harm their babies by drinking during pregnancy but they still do it because they don't care. THIS IS NOT TRUE.

The truth is:

- Pregnant women do not purposely harm their babies.
- Family, friends, and the community all play a role in helping pregnant mothers to not drink while pregnant.
- Some women do not know that they are pregnant right away.
- Some women are dealing with addictions, trauma, abusive relationships, or mental health issues.
- Some individuals living with FASD may not understand the implications of their drinking because of their disability.



# STRATEGIES FOR SUCCESS

## Strategies for Success with Memory Deficits

- Individuals with FASD need more time to learn some things. You can help by being patient and explaining the same things multiple times.
- It is helpful if a person receives the same message in the same form from all of his or her support workers – it is important to repeat, repeat, repeat.
- Asking individuals with FASD to repeat instructions back does not ensure that they understand the meaning of what they are saying. Requesting that they “show you” or explain in their own words will more accurately demonstrate their level of understanding.
- Re-teach rules in different settings. Use visual charts and reminders.
- Communicate while being mindful of an individual’s ability to process information, be aware of the pace and tone of your speech.
- Use agendas, cell phones, computer calendars and anything else a client feels comfortable using to support the individual’s memory issues for important appointments and day-to-day activities.
- Use a series of notes, memos, pictures, or anything else that works around the home.
- Remind clients of the time they need to leave, the lunch they should bring and where they are going.

- Be patient, memory is a lifelong issue. However, years of practice and support can often result in self-sufficiency where otherwise you may not have expected it.
- Use concrete, visual reminders to support success

## Strategies for Success with Confabulation

- Understand the difference between confabulating and “lying.”
- Avoid asking questions you already know the answer to, like “Are you sure that’s what happened?”
- Ask only for the information needed at the moment.
- Ask short questions with definite answers.
- Ask the individual to tell you the story in a different way – for example, write it out or draw it.
- If the confabulations are not serious or indicative of danger, allow them to engage you with the story.
- If the confabulation indicates danger, examine the statements further.
- Use confabulations as social stories to teach lessons and explore otherwise unexplored issues.
- A client’s dignity is of foremost concern – always ensure your questioning is respectful and understanding.

## Strategies for Success with Cause and Effect

- Use clear and concrete words in short sentences. Say exactly what you mean with fewer words and you will find your messages are better understood.
- Try to have fewer distractions when individuals need to listen to instructions or make a decision. This could include environmental factors such as background noise, bright lighting, or the tone of your voice.
- Use a calm and clear voice. Messages can be lost when given in a highly emotional or excited tone. Simple gestures along with clear and direct language may be helpful.
- Since individuals with FASD have difficulty associating actions with consequences, make consequences as immediate and relevant as possible.
- Use positive reinforcements to encourage good behaviour.
- Create visual reminders of expectations and outcomes.
- Map out decision making so clients have a concrete visual to represent the proper path and consequences of each path.
- Use social stories that are age appropriate to describe the effects of possible actions and inactions.

### Strategies for Success with Time

- Digital clocks are easier to understand than a clock with hands.
- A person with FASD may need help being able to anticipate appointments or activities, so post calendars and schedules when possible. Pictures can be useful as well as words.
- Help to plan what to do and when by creating as much predictability and routine in one's schedule as possible.
- The use of timers is helpful for gauging time. These can be used when an activity is starting. They can also be sent with an individual if they need to take a break from a group setting to let them know when to come back.
- A simple phone call reminder can save a client from missing an appointment or being late to work. Finding caregivers willing to do this will create a lifelong support system.
- Advocate with school and employers for later start times and increased flexibility as time is an issue most clients will face their entire lives.

### Strategies for Success with Transitions

- Provide a predictable schedule. Having the schedule on a wall, phone, calendar, fridge or any other easily viewed location is helpful.

- Recognize the potential impact of life transitions before they happen (moving from a family home to a different home, being removed from cultural traditions).
- Prepare for transition and give plenty of forewarning.
- Practice the transition ahead of time.
- Use social stories that help to explain what will occur in future transitions. Repeat them regularly.
- Use strategies to make transitions in the day's activities. For example, use verbal prompts to initiate the end of one activity and shift to the next activity.
- Use times, activities, and television shows to indicate when a transition may happen.

### Strategies for Success with Ownership Issues

- Write names on items or colour-code property.
- Teach associations between specific items and their owners.
- Establish and implement appropriate consequences for taking other people's items. Ensure this is timely and consequences are swift but efficient.
- Practice borrowing. Have a client borrow a pen at your office and return it. Try this vice versa by borrowing a client's phone while he or she is in your office and return it before that person leaves.

- Explain what is safe to borrow and lend – use pictures, examples and social stories. Work with clients to understand monetary value. For example, the cost of a music player equals 15 hours of work.

### Strategies for Success with Impulse Control

- Individuals with FASD have trouble with impulse control in social situations, thus it may be helpful to develop “role playing scripts” or social stories for common situations.
- Cues and reminders can help individuals with FASD control impulses by interrupting the process between impulse and action.
- Identify a support person (family or friend) that the individual can call when he or she has a question. This person's role is to provide judgment-free guidance upon request only.
- Model impulse control out loud (say what you are thinking). For example: “I really want to buy a chocolate bar, but I also want to save money to buy a new t-shirt.”
- Develop a case plan that includes one-on-one support, wherein the individual can explore his/her perspective, discuss other perspectives and make informed decisions.
- Avoid situations in which clients have not been able to control their impulses before without supervision.







### Strategies for Success with Social Skills

- Build on strengths and interests that can engage them in social activities.
- Adjust expectations to fit a person's developmental age, not chronological age.
- Model good behaviour.
- Role play different social situations. Make sure to role play each scenario in different settings and involving different people.
- Teach examples of what healthy friendships look like and help to identify positive friends.
- Have open conversations about sex and sexuality, including contraceptives, regular sexual testing, and other issues pertaining to sexuality.
- Avoid large groups of people for social interactions. One or two friends is often much more significant than a group.
- If the opportunity for a mentor is available to your client, this can improve quality of life for both the client and the individual's family.

### Strategies for Success with Dysmaturity

- 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.
- Mentors and support workers are great resources to help individuals who are functioning at a lower level better understand and practice age appropriate behaviours and skills.

### Strategies for Success with Sensory Dysfunction

- Think accommodations: "How can I adapt the environment to support this person to succeed?"
- Recognize the potential sensory impact of noise, smells, environment, clothing, etc.
- Limit distractions.
- If the seams in socks are irritating, try turning socks inside out. Remove the tags from clothing, as well as strings, flaps, buttons, long shoelaces, etc. if they are too distracting.
- Scents may be bothersome to some people. Use scentless detergents.

### Strategies for Success with Sleep Issues

- Develop a calming sleep routine. This should include a slow transition from evening activities to getting ready for bed and going to sleep. Same bedtime every night. Avoid sleeping in. No television or computer an hour before bed. No sugar after 6 p.m. Warm bath before bed.
- Limit the amount of visual stimulation in the bedroom. Limit furniture and ensure that personal belongings can be stored out of sight.
- The introduction of relaxing music may be helpful for some individuals.
- For some individuals, taking a melatonin supplement can help to regulate sleep.
- Textured and weighted blankets may be helpful depending on an individual's sensory profile. If finances are an issue, try sleeping bags and/or heavy blankets such as wool fiber.

# MENTORS

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Being a mentor to someone with a cognitive disability is a service intended to bring greater quality of life and increased independence to the individual (mentee) you are supporting. A mentor's role is to build a relationship based on trust with the mentee, while presenting opportunities for that individual to learn, grow and be more self-sufficient in everyday life. A mentor acts as a positive role model, increases community involvement for the mentee, helps teach and improve daily life skills and offers a variety of other supports where needed.

Individuals with FASD require guidance more often and a level of guidance that is more structured and long term due to their disability. That being said, a mentor can be a perfect resource to provide extra support. The relationship between a trusted mentor and an individual with a disability, such as FASD, can result in a variety of positive outcomes. Over time the relationship can grow and reduce the feelings of isolation, loss, and failure that so often characterize the lives of individuals with FASD.

Young children with FASD tend to naturally receive support. Perhaps not as much support as they require, but the chances that parents, caregivers, family members, educators, coaches, and school peers create a circle of support around that individual are greater than that of teens and adults

with FASD. As a child with FASD becomes a teenager, the need for guidance actually may increase yet the guidance and support received decreases. Reasons for this vary, but it is likely that those within that youth's circle begin to have changing expectations. A coach or educator may be less willing to provide direction and guidance in decision-making and problem solving as they want to promote independence.

Many people do not understand that FASD is a lifelong disability and that life lessons need to be learned over and over again. The youth themselves may have changing needs and expectations. They might see their peers gaining autonomy or making decisions and, understandably, they want a degree of independence in their life. Peers may lack the knowledge or skills to support a friend affected by FASD because the issues faced become very serious. Issues such as violence, substance use, sexuality and dating are complex even for adults.

Due to these reasons, young people with FASD commonly begin to experience struggles during the teen and young adult years. In addition, by the time the teen years roll around, stress and frustration may be mounting for parents, family members, and caregivers. Members of the circle of support can become less resilient and feel that they have tried everything and have

no answers, thus the level of support decreases. It is also likely that families receive conflicting messages from professionals. The result is often confusion and self doubt about how to best guide their child. This can take quite a toll.

A mentor can make a difference in the life of a person with FASD, particularly during the teen and adult years. A mentor is a person who is willing to care about, guide, and support a young person or adult with FASD. Mentors share in the life of the individual, they provide opportunities for a variety of experiences, implement the necessary structure, assist with learning daily living skills, guide decision making, and support individuals when mistakes are made. The support is provided in a genuine and encouraging relationship. The mentor does not replace other members of the individual's circle of support; a mentor becomes one of the people in that circle. This is an important process for the youth with FASD and the parents or caregivers. The parents remain actively involved, as they know their child best, but the involvement, insight, and energy of the mentor can provide a different kind of support along with fresh ideas.

To find out more about mentoring or how to access a mentor for someone living with FASD please visit [www.saskmentors.com](http://www.saskmentors.com).

# RESOURCES

The FASD Network has a variety of resources that can be found on our website, [www.skfasnetwork.ca](http://www.skfasnetwork.ca). To order resources please contact the Network at 1-866-673-3276 or [fasdnetwork@sasktel.net](mailto:fasdnetwork@sasktel.net)

## Network publications:

- A Guide to Awareness and Understanding
- The FASD Network's Supports & Services
- The FASD Network's Training & Events
- Tips for Caregivers
- Tips for Employers
- Tips for Justice Workers
- Tips for Support Workers
- Tips for Teachers





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