



# FASD

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For Coaches

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FASD   
NETWORK

# ABOUT THE NETWORK

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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 1990's 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.

## TRAINING

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

## 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, as well as workshops and events created specifically for caregivers and individuals living with the disability.

## SUPPORT

The Network's support program was created to give families and individuals direct support in their daily lives. The program aims to gain positive outcomes for those living with FASD by working to clarify short-term goals and developing a plan to reach those goals.

For more information on the services provided by the FASD Network please contact us at:

1-866-673-3276

[info@fasdnetwork.ca](mailto:info@fasdnetwork.ca)

[www.saskfasdnetwork.ca](http://www.saskfasdnetwork.ca)

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# FASD FOR COACHES

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Sports can impact a child ‘beyond the game,’ teaching positive attitudes, life lessons, transferable skills, and instilling self-confidence and a sense of belonging. Everyone deserves the chance to become a valued and contributing member of a team but some children, such as those who live with FASD, face many challenges participating in recreational activities. Living with FASD is about more than a diagnosis. It is also about living with strengths and struggles. It is about living with a disability. All across Canada, people with FASD experience a range of primary disabilities that can affect their ability to function and participate as part of a team. Yet the life lessons learned from sports may be even more beneficial to children who live with disabilities, children who may feel different than their peers or children whose struggles impact their self-confidence and outlook on life.

The fact is, there are a lot of barriers to participating in sports for children with disabilities but finding the right team or the right coach can have a powerful influence on their lives. A coach who understands how FASD can affect a child and their ability to play sports can use strategies to support the often misunderstood needs of this child. Coaches who are aware of the disability can ensure that child is given the best chance to succeed. A coach who seeks education and understanding can make a difference, they can be the reason a child doesn’t get overwhelmed and frustrated to the point where they quit the sports they used to love. Continued participation on solo or team sports can help prevent some of the common secondary challenges that occur with FASD such as mental health issues, social isolation, withdrawal or even disrupted school experiences.

Becoming knowledgeable about FASD is the first-step to changing a person’s life. People are often frustrated or discouraged by the misunderstood behaviours and difficulties exhibited by individuals with FASD who are unsupported. Understanding how this unique disability impacts each individual can allow you to work effectively with all your team members. The goal of this resource is to equip coaches, physical educators or instructors of any kind with an understanding of FASD and practical strategies that can easily be utilized by anyone.

The FASD Network would like to thank our local coaches and instructors for the life lessons you help teach and the significant impact you can have on a child’s life.

# FASD 101

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## FASD & STIGMA

FASD is a disability that is relatively unknown and overlooked. Because we cannot see the disability there is often a barrier to acceptance and understanding. As a result, children, youth, and adults with FASD do not get the support they need.

People living with this disability face a lifetime of societal stigma and misconceptions. Society often assumes that everyone with FASD has below-average IQ, behaviour problems, an unwillingness to take responsibility for themselves and inevitable problems with the law. But these common beliefs are not true.

Mothers to children with FASD face shame & blame. Many people believe that mothers know they could harm their babies by drinking during pregnancy but they still do it because they don't care. Pregnant women do not purposely harm their babies. The reasons for alcohol use during pregnancy are complex and varied. Some women do not know they are pregnant or are dealing with addictions, trauma, abusive relationships or mental health issues. To prevent FASD, all women need the support of families and communities to have healthy, safe and alcohol-free pregnancies.

Stigma, stereotypes, prejudice, and discrimination can exist personally and structurally in today's society. Fortunately, there are many ways to combat stigma. Education and awareness are key. Informed individuals can become advocates to spread positive and correct information about the disability.

## PERSON-FIRST LANGUAGE

Person-first language puts the person before his or her 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 child 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 his disability impacts his 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.

# WHAT IS FASD?

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The term Fetal Alcohol Spectrum Disorder describes a disability that can occur in infants, children, youth or adults exposed to alcohol while in the womb. When a woman drinks alcohol while pregnant, her fetus is exposed directly to alcohol through her bloodstream. Alcohol can interfere with the growth and development of all fetal body systems. The developing brain and central nervous system (CNS) are especially at risk to the harms of alcohol.

The diagnoses are:

- FASD with sentinel facial findings
- FASD without sentinel facial findings
- At Risk for Neurodevelopmental disorder and FASD

These diagnoses include mild to severe disabilities. Even though alcohol can permanently damage the developing cells of every body system, the human brain is the organ most sensitive to the effects of alcohol exposure. Much of the injury linked with FASD occurs in the central nervous system which is comprised of the brain and spinal cord. The resulting physical changes and changes in brain functioning make FASD a brain-based physical disability.

## FASD IS LIFELONG

FASD is a disability that lasts through the entire lifespan. The primary disabilities linked with FASD are permanent. The damage caused to the brain does not lessen or improve, even as the person gets older. However, their behaviour may change with support, effective strategies and improved understanding.

## FASD IS MOSTLY INVISIBLE

Some primary disabilities like facial characteristics, poor growth or obvious changes in brain functioning are visible in people affected by FASD. For most individuals, FASD is a disability that is hidden from others. At birth and throughout life, it is often hard to see the range of permanent impairments caused by prenatal alcohol exposure. Because we cannot see the physical changes to the brain or the changes in brain functioning, FASD is called an invisible disability.

## FASD IS UNIQUE

FASD is a unique disability that affects each individual differently. Each person with the disability will have their own set of strengths and challenges.

# PRIMARY DISABILITIES

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Primary disabilities are caused directly by exposure to alcohol during pregnancy. There is a wide variety of primary disabilities. They are organized into the following four categories: physical, cognitive, behavioural, and sensory.

## 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.

What could this look like?

- Slow to meet developmental milestones
- Poor balance and co-ordination
- Auditory impairments
- Weak heart, frail bones and other system abnormalities
- Lower height or weight
- Problems with fine and gross motor control

## COGNITIVE DISABILITIES

Cognitive functioning refers to intellectual tasks like thinking, reasoning, and remembering, which are crucial to our everyday functioning. People with FASD can have trouble with many cognitive tasks.

What could this look like?

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

# BEHAVIOURAL DISABILITIES

The brain controls 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 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 their physical age, so they behave and think younger than they are.

What could this look like?

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

# SENSORY DISABILITIES

Every day, our senses take in a huge amount of information from our 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
- Touch
- Sight
- Proprioception - a sense of where your body is in relation to your surroundings
- Smell
- Hearing
- Vestibular input – movement sensation

This can result in sensory-seeking behaviours such as unusual hyperactivity, or avoidant behaviours such as shutting down to any responsive actions.

# REFRAMING PERCEPTIONS

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Supporting a child with FASD might not be easy but understanding the disability and shifting our perceptions from the child “won’t do something” to the child “can’t do something” makes an incredible difference (Diane Malbin, 2002). Understanding the child’s disability and how he functions is key to making sure you have the right interventions, supports and services in place for him.

Below is an example that Diane Malbin uses in her book, “Trying Differently, Rather than Harder” about shifting our perceptions (pg. 43).

From seeing the child as: | To understanding the child as:

Bad, annoying	Frustrated, challenged
Lazy, unmotivated	Trying hard, tired of failing
Lying	Story telling, filling in the blanks
Fussy	Oversensitive
Acting young, babied	Being younger
Trying to get attention	Needing contact, support
Inappropriate	Behaviour of a younger child
Doesn't try	Exhausted or can't get started
Won't	Can't

From personal feelings of: | To feelings of:

Hopelessness	Hope
Fear	Understanding
Chaos, confusion	Organization, comprehension
Power struggles	Working with
Isolation	Networking, collaboration

Professional shifts from: | To:

Stopping behaviours	Preventing problems
Behaviour modification	Modelling, using visual cues
Changing people	Changing environments

# THINK BRAIN, NOT BLAME

It is important to remember that if a child has FASD she has a disability. Behaviours she exhibits are quite often a result of the disability and her environment.

The child's behaviours are not intentional. She is not doing things to purposely make you mad or frustrated; her behaviours are a direct result of the prenatal alcohol exposure and often become a way of communication.

Once we understand and make sense of her behaviours it will be easier to put the proper supports and interventions in place.

## STRENGTH-BASED APPROACH

When supporting a child or youth living with FASD, it is crucial to take a strength-based approach. A strength-based approach not only draws on the strengths of the individual but also on the strengths of her support system – family, service providers, community and friends.

It is important to identify her strengths and understand her struggles, as this will help create a good fit in her environment and will make an incredible difference.

Strengths are resilient characteristics which can be built on to achieve success. Though people with FASD may face challenges, it is important to recognize the strengths, skills, and interests of each person. Always look for chances to help the child discover new talents. Every child is unique and will have a particular set of gifts. It is also important to remember that success looks different for everyone and the length of success may be shorter, but every individual has the right to know his or her strengths and to be as successful as possible. People with FASD are willing and able to learn when strategies match learning styles and build on strengths rather than deficits (Malbin, 2008).

Strength-based approaches shift our understanding away from conventional practices and encourage us to think outside the box.

# STRATEGIES

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## STRATEGIES FOR PHYSICAL DISABILITIES

- If a child needs additional practice to overcome some of the physical barriers of their disability try:
  - Partnering them with a close friend so they can practice without feeling embarrassed
  - Recommend ways the child can practice at home to build some of these skills.
- Be ready to demonstrate the skill as many times as needed so the child can see how it's done.
- FASD may affect how an individual feels pain, be aware of this if a child is injured while playing, it may be worse than the child says.

## STRATEGIES FOR 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 if needed.
- Provide more time to practice and learn new skills.
- Don't assume the child will remember how to do the things they were taught at the last practice, give them the option to go over things again to help their memory.
- Give the player time to process and retrieve information.
  - Slow down when speaking.
  - Allow extra response time.
  - An individual with FASD is a “ten-second child in a one-second world.”

# STRATEGIES FOR COMMUNICATION

- Use shorter sentences. Try to use fewer words so your message is better understood.
- Reduce unnecessary information. Expectations should be kept simple and to the point.
- Be consistent with the words and terms you use.
  - Try making a glossary of terminology for parents to go through with the child.
- Communicate instructions while being mindful of an individual's ability to process information, be aware of the pace and tone of your speech.
- Break down tasks.
  - Give step-by-step directions with simple language.
  - Visuals can be helpful but you may need to concretely explain how the visual is linked to the activity.
- Do not ask them to repeat the instructions back to you, ask them to either show you or explain it in their own words to be sure they actually understand.
- Individuals with FASD struggle to understand abstract concepts like jokes and figurative language, for example, "break a leg."
- Use statements that are specific to the desired behaviour you wish to achieve. For example, say "walk in this area" instead of "don't run in this area."
- A child with FASD may not realize they are supposed to follow instructions given to the group; you may need to repeat the instructions to them individually afterward.

# STRATEGIES FOR STRUCTURE

- Give the child plenty of forewarning before you move onto a new task.
- If possible, make the schedule predictable so transitions can be anticipated. For example, have a set warm-up or cool down routine.
- If there is a major change in routine, take the time to explain what is happening and then proceed.
- Monitor free time – if any part of practice is free time or unsupervised, give the child two options instead of unstructured time, for example: instead of telling the child to go warm up instruct them to do either jumping jacks or run laps.
- Allow them to consistently play one position so it becomes routine and they can master the skills or give them ample opportunity to practice/adjust to changes in their position if they have to switch.

# STRATEGIES FOR BEHAVIOURAL ISSUES

- Adjust your expectations for the child’s developmental level.
- Provide immediate feedback and recognition.
  - Encouraging words work well to reinforce positive behaviours.
- Traditional discipline techniques such as penalty boxes or being benched may not work, for these to be effective the child must remember what they did to get in trouble, understand the cause and effect of their actions and generalize an understanding that the consequence will happen again if they repeat their behavior. These types of punishments or consequences require a level of executive functioning that may not be possible at the child’s developmental level so you may need to repeatedly explain why consequences are happening.

Behaviour	What We Think	Thinking Brain, Not Blame
Not obeying rules	<ul style="list-style-type: none"> <li>• Doing it purposely</li> <li>• Attention seeking</li> <li>• Stubborn</li> </ul>	<ul style="list-style-type: none"> <li>• Struggles with translating directions into actions</li> <li>• Doesn’t understand</li> </ul>
Repeating mistakes	<ul style="list-style-type: none"> <li>• Not trying</li> <li>• Manipulative</li> </ul>	<ul style="list-style-type: none"> <li>• Doesn’t understand cause &amp; effect</li> <li>• Difficult generalizing from one event to another</li> </ul>
Not paying attention	<ul style="list-style-type: none"> <li>• Lazy, unmotivated</li> <li>• Doesn’t care</li> <li>• Seeking attention</li> <li>• Bothering others</li> </ul>	<ul style="list-style-type: none"> <li>• Sensory overload</li> <li>• Overwhelmed</li> <li>• Wrong learning style</li> <li>• Exhausted or tired of failing</li> <li>• Neurologically based need to move</li> </ul>
Poor social interactions	<ul style="list-style-type: none"> <li>• Poor parenting</li> <li>• May have experienced trauma</li> </ul>	<ul style="list-style-type: none"> <li>• Not able to interpret social cues</li> <li>• Does not know what to do in social settings</li> </ul>
Overly physical	<ul style="list-style-type: none"> <li>• Violent</li> <li>• Doing it to bother other people</li> <li>• Deviancy</li> </ul>	<ul style="list-style-type: none"> <li>• Hyper or hypo-sensitive to touch</li> <li>• Does not understand boundaries</li> </ul>

Table adapted from Diane Malbin.

# STRATEGIES FOR SENSORY ISSUES

- Think accommodations: “How can I adapt the environment to support this child to succeed?”
- If safe to do so, consider allowing the child to do the following during games or practice:
  - Wear sunglasses
  - Wear ear plugs
  - Wear weighted equipment like wristbands or vests
- Allow the use of fidget items (stress balls, spinners, etc) when the children are expected to sit and listen for long periods of time.
- A child may be acting up or refusing to participate in an activity due to sensory overload, they are not trying to be difficult – try asking them what they are feeling/experiencing.
- Let the child take breaks when the stimulus becomes overwhelming.
  - Show them a safe space to go when they need this break.

## CELEBRATE SUCCESS

Because children and youth living with FASD can struggle with so many things in their everyday lives, they may experience feelings of frustration, anger, and hopelessness. It is imperative for them to feel success to help build their self-esteem and self-confidence.

Celebrate their success no matter how big or small. Remember that success comes in many shapes and forms, and is different and unique to every individual.

# SUPPORTING FAMILIES

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Raising a child who lives on the spectrum is not easy; it is important to remember that caregivers need support too. Be aware of any preconceived ideas you may have about FASD and the kind of families it impacts.

Families with FASD are often under a great deal of stress. FASD is a complex disability and others don't always understand the issues they face every day. Be mindful that things like being late, forgetting equipment, or seeming stressed out can be a result of the greater challenges faced by families because of the influence of FASD.

Try to understand that some families' 'normal' may be different. The disabilities associated with FASD can sometimes cause behaviours or require accommodations that may not be 'normal' for other families.

Most importantly, listen to what the families have to say, they are the experts on how FASD impacts their children. If they have suggestions for what will or won't work for the child, take what they have to say into consideration.

## IF SOMEONE DISCLOSES

Disclosing a disability such as FASD is entirely up to the family. If they feel comfortable discussing their child's disability with you here are some things to keep in mind.

- Be respectful.
- Listen to what the parents have to say and consider any suggestions they have.
- Don't be shy to ask questions about the child's needs.
- Ask for the parents' advice on what strategies might work.

# RESOURCES

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The FASD Network has a variety of resources that can be downloaded from our website at [www.saskfasdnetwork.ca](http://www.saskfasdnetwork.ca) or ordered free-of-charge by contacting the Network at 1-866-673-3276 or [info@fasdnetwork.ca](mailto:info@fasdnetwork.ca)

## Printed 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
- Healthy Living Series

## Online publications:

- Advocacy: Successes & Struggles
- Transitions: Tips & Strategies
- Parent Retreat 2017: Strategies for Caregivers
- FASD Toolkit

# FASD NETWORK OF SASKATCHEWAN

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