

UNDERSTANDING

Fetal Alcohol Spectrum Disorder (FASD)

*A Resource for
Service Providers*

This booklet was first created through the Canadian FASD Mentoring Project. The purpose of the Project was to raise awareness of Fetal Alcohol Spectrum Disorder (FASD) by providing workshops to Aboriginal Head Start sites in Urban and Northern Communities (AHSUNC) across Canada. The Saskatchewan Prevention Institute was the lead organization for this Project.

The booklet has been adapted for use in Saskatchewan.

This booklet includes information about:

- Alcohol, Pregnancy, and Fetal Alcohol Spectrum Disorder (FASD)..... 1
- Strengthening Services for Children and Families 21
- Children with FASD: Their Strengths, Their Challenges, and Strategies to Support Success 31
- Supporting Healthy Families 49
- Supporting Wellness 55



Alcohol, Pregnancy, and Fetal Alcohol Spectrum Disorder (FASD)

Alcohol is the most commonly used drug in Canada. About 8 out of 10 Canadians over the age of 15 drink alcohol. Alcohol is a legal drug. Alcohol can also cause long-term health problems such as high blood pressure, cancer, diabetes, and liver disease.

Canada's Guidance on Alcohol and Health

Choosing not to drink any alcohol is the healthiest choice for everyone, regardless of age, sex, gender, ethnicity, alcohol tolerance, or lifestyle. For people who drink alcohol, experts created Canada's Guidance on Alcohol and Health. The guidance gives recommendations for alcohol use to help prevent health risks.

Before talking about Canada's Guidance on Alcohol and Health, it is important to understand what a standard drink size is, and how much alcohol is in different types of drinks. In Canada, a standard drink has about 14 grams (about 0.5 fluid ounces) of pure alcohol (ethanol). Although the drinks in this picture are different sizes, each one has the same amount of pure alcohol.



Beer	Cider, Cooler	Wine	Rye, Gin, Rum, etc.
341 mL (12 fl oz)	341 mL (12 fl oz)	142 mL (5 fl oz)	43 mL (1.5 fl oz)
5%	5%	12%	40%
alcohol content	alcohol content	alcohol content	alcohol content

For people who use alcohol, reducing how much and how often they drink may help reduce the risk of health problems.

When pregnant or planning to be pregnant, driving a vehicle, or when responsible for the safety of others, zero alcohol is the only safe option.

Overall health risks associated with alcohol consumption per week:

- **No risk** - for those who do not consume any drinks
- **Low Risk** - for those who consume 2 standard drinks or less per week;
- **Moderate Risk** - for those who consume between 3 and 6 standard drinks per week;
- **Increasingly high risk** - for those who consume 7 standard drinks or more per week.



Pregnancy

It takes about 9 months for a baby to develop and be ready for birth. A healthy pregnancy includes:

- not drinking alcohol
- taking a daily prenatal vitamin with folic acid
- visiting a health clinic regularly
- making sure immunizations are up to date
- eating healthy food
- exercising and getting enough rest
- reducing stress
- being a healthy weight (talk to your doctor)
- getting tested for Sexually Transmitted Infections (STIs), Human Immunodeficiency Virus (HIV), and Sexually Transmitted Blood-Borne Infections (STBBIs)
- avoiding medications that may harm an unborn baby
- treating any medical conditions, such as diabetes and high blood pressure
- having healthy relationships
- not smoking cigarettes, not using cannabis, and not vaping products
- not using street drugs

How the Unborn Baby Gets What it Needs to Grow

At first, a yolk sac is attached to the unborn baby. The yolk sac has many jobs. One of the jobs is to provide nourishment (food) to the baby until a placenta and umbilical cord grow and do this job. The placenta is attached to the wall of the uterus and linked to the pregnant person. The umbilical cord runs from the placenta to the unborn baby's tummy.

Whatever the pregnant person drinks, eats, inhales, or injects goes into their system and then through the placenta and umbilical cord to the unborn baby. Alcohol goes through the placenta and umbilical cord and gets to the baby.

Fetal Development

Throughout pregnancy, different organs, limbs, and body parts are developing. There are times during pregnancy when a certain body part is quickly developing. This is called a sensitive or critical period of development. For example, the heart has a rapid period of development between the 4th and 8th week and continues to grow until the 11th week of pregnancy. During this time, the development of the heart is most at risk of harm or changes from substances, like alcohol.

Alcohol can affect any part of the developing body. The brain and central nervous system grow for all 9 months of pregnancy. This makes the brain very vulnerable to being impacted by alcohol at any time during pregnancy.



Alcohol and Pregnancy

Alcohol is the most commonly used drug in Canada. People who are pregnant may use alcohol for a variety of reasons, including the following:

- They do not know that they are pregnant. Research has shown that approximately 50% of pregnancies are unplanned.
- Some people who are trying to get pregnant do not quit drinking until their pregnancy is confirmed.
- They may not know that alcohol can impact their baby.
- They may have received unclear messages about whether alcohol is safe during pregnancy.
- Drinking may be normal in their family and community.
- Drinking behaviours of partner(s), family members, or friends may influence their drinking.
- Drinking alcohol may be a habit, or they may have an alcohol dependency or addiction.
- They may drink alcohol to cope with stress, violence, or trauma.

Although people who are pregnant may drink alcohol for many reasons, it is important to know that there is no known amount of alcohol that is risk-free for an unborn baby (fetus). That is why researchers and doctors recommend that during pregnancy, or when trying to get pregnant, not drinking alcohol is the only safe option. It would be ideal if everyone who can get pregnant avoid alcohol (i.e., those who are sexually active and not using effective birth control). This would protect unborn babies from being exposed to alcohol.

A person's life circumstances do not suddenly change the day they learn they are pregnant. (Fond et al., 2017). For pregnant people who are unable to stop using alcohol, reducing how much and how often they drink may help reduce the risk of health problems for them and their baby. This is called harm reduction. “Risky” drinking (drinking 4 or more drinks on one occasion) may be particularly harmful to a fetus. Supporting a harm reduction approach may reduce the impact on both the pregnant person and their unborn baby. If someone wants help to stop drinking, they can talk to:

- Doctor or healthcare provider
- Addictions services in their area
- Saskatchewan HealthLine 811
- First Nations and Inuit Hope for Wellness HelpLine
1-855-242-3310

The Impact of Stigma

Stigma refers to shame, judgement, and negative attitudes (prejudice) or behaviours (discrimination) toward others who may be seen as different from the “norm” or “status quo”. * Judgement can make people feel like failures or like they are being blamed. When a pregnant person is judged for using alcohol, they may not go for health appointments or seek support to reduce their drinking.

Support, not judgement, is better for helping people make changes. Acceptance and understanding will help a pregnant people to consider a change in their drinking.

*FASD Okanagan Valley Assessment and Support Society, 2018

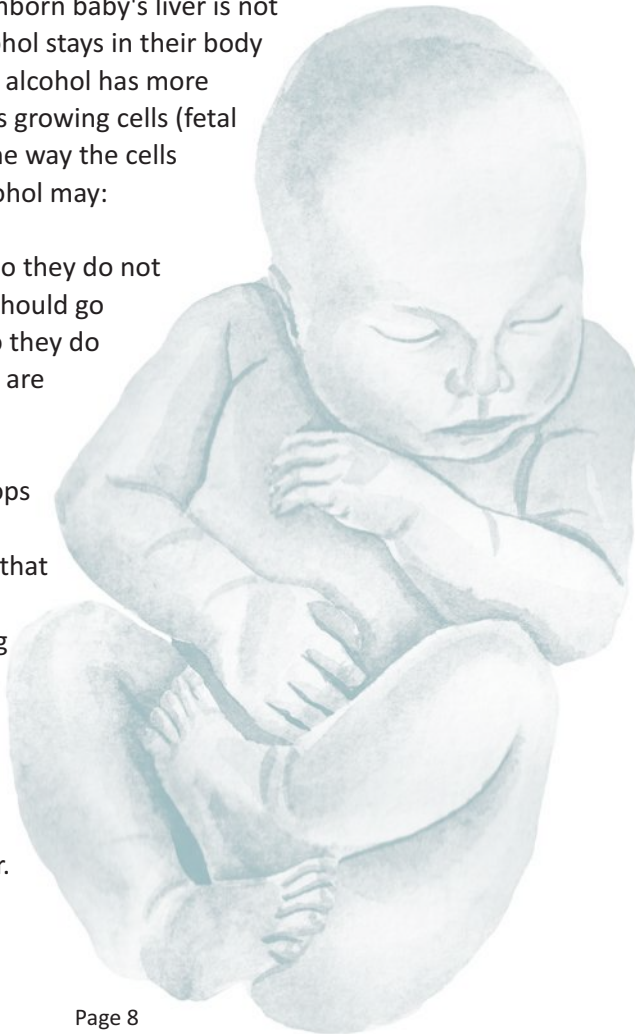
Alcohol and Unborn Babies

When someone who is pregnant uses alcohol, the alcohol goes to their stomach and then into their bloodstream. Once it enters the bloodstream, it travels through the body to the brain (which is how the effects of alcohol are felt) and to the liver (so it can be moved out of the body). The alcohol reaches the unborn baby through the umbilical cord and placenta.

While an adult's liver can process alcohol to move it out of the body, an unborn baby's liver is not fully developed, so alcohol stays in their body longer. This means that alcohol has more time to harm the baby's growing cells (fetal cells). Alcohol affects the way the cells grow and function. Alcohol may:

- kill the cells
- interrupt the cells so they do not get to where they should go
- confuse the cells so they do not do the job they are supposed to do

The baby's brain develops throughout the entire pregnancy. This means that alcohol can affect the brain at any time during pregnancy. Alcohol's impact on the brain can result in challenges with things such as social skills, learning, and behaviour.



FASD

When alcohol is used in pregnancy, it can cause Fetal Alcohol Spectrum Disorder (FASD). This is because alcohol can harm fetal cells while the unborn baby is developing. Alcohol is the leading cause of preventable developmental disability in Canada. Although it is a preventable disability, FASD is not 100% preventable because where there is alcohol, there is a chance that an unborn baby can be exposed. Also, birth control is not 100% effective.

Each unborn baby can be impacted differently by alcohol in pregnancy. This is affected by:

- the amount of alcohol that is used at one time
- when alcohol is used in the pregnancy
- genetics of the parents
- the pregnant person's health, including their nutrition and stress levels
- other drugs used during pregnancy

FASD is primarily a brain-based disability. Depending on alcohol's impact on the developing brain, someone with FASD will have a range or spectrum of abilities. This means that one person might be very impacted and another may function more typically. Regardless of the degree of impact, **FASD is a lifelong disability**. Although children do not outgrow FASD, the impacts can be lessened with supports that work for the individual.

As well as the impacts on the brain, alcohol can affect the body while it is developing in the uterus (womb). For example, a child with FASD may have digestive problems or heart problems.

Based on research, the current best estimate is that as many as 4 out of 100 people in Canada have FASD (4% or 1 in 25 people). FASD can be found in all ethnic groups, cultures, and socio-economic groups (rich and poor people). Some communities may have more people with FASD. Some communities may have less people with FASD. It can depend on the drinking habits and access to effective birth control in the community.

Diagnostic Terms

FASD is the medical diagnosis used to describe a range of effects caused by prenatal alcohol exposure. The diagnostic terms for FASD have changed over the years. This is based on researchers learning new information and working to make diagnosis as sensible and helpful as possible. Old terms that are no longer used include Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND).

Can someone who is not pregnant cause FASD?

Many people ask if men can also cause FASD. The answer is no. Remember, FASD is caused by alcohol passed to the unborn baby through the placenta and umbilical cord. A partner's drinking can cause some harms, but not FASD.

Perhaps most importantly, a partner's drinking has a strong influence on the pregnant person's drinking. It is harder to stop drinking if the partner does not stop drinking or does not support them to stop drinking. Fighting and abuse can make it harder to not use alcohol. Drinking can also be related to:

- reduced fertility; damaged sperm
- learning and memory problems in the child

Can Communities Cause FASD?

Family, friends, and community can influence a pregnant person's alcohol use when:

- drinking is normal for family, friends, and other people in the community
- families and friends encourage them to drink
- there are community events where alcohol consumption is encouraged (e.g., having a beer tent.)

Diagnosis of FASD

In 2016, Canada released new guidelines and terms for the diagnosis of FASD. A diagnosis of FASD is a complex process. It requires a team of professionals (such as a pediatrician or physician, speech language pathologist, occupational therapist, psychologist, and social worker). This team varies depending on the age of the patient and the clinic. During the diagnosis process, the team asks about alcohol use during pregnancy, examines 10 brain domains (e.g., motor skills, brain structure and functioning, language, memory), and looks for 3 distinctive facial features.

The current possible diagnoses are:

1. **FASD without Sentinel Facial Features.** This diagnosis replaces FAE and ARND. For this diagnosis, an individual will have the following:
 - Confirmed prenatal alcohol exposure
 - 3 areas of neurodevelopmental function (brain domains) that are significantly below typical

2. **FASD with Sentinel (Characteristic) Facial Features.** This diagnosis replaces FAS and pFAS. For this diagnosis, an individual will have the following:
 - All three distinctive facial features: small palpebral fissures (eye width), flat philtrum (groove between the base of the nose and the border of the upper lip), and thin upper lip
 - Three areas of neurodevelopmental function (brain domains) that are significantly below typical
 - Prenatal alcohol exposure (can be confirmed or unknown)

3. Infants and children with confirmed prenatal alcohol exposure, but who do not meet the criteria for a diagnosis of FASD, may be termed **At Risk for Neurodevelopmental Disorder and FASD**. A complete assessment is recommended at a later time. Sometimes, young children are difficult to assess; this designation recognizes that and aims to re-assess them later.

10 Brain Domains* Associated with FASD Diagnosis

Domain	Example
<p>1. Motor skills How the muscles move and act</p>	Fine motor skills (small muscles), gross motor skills (large muscles), muscle tone, reflexes, balance, coordination
<p>2. Neuroanatomy/ Neurophysiology How the brain and nervous system are built and work</p>	Brain structure, head size, seizure activity
<p>3. Cognition How one learns, understands, and gains knowledge</p>	Thinking, perception, and reasoning
<p>4. Language How one uses and understands language</p>	Ability to hear and interpret language and communicate to others (verbal or nonverbal)
<p>5. Academic achievement How one progresses in school subjects</p>	Includes measures of math, reading, and writing
<p>6. Memory How one stores information and remembers it when needed</p>	Remembering what is heard (auditory) and what is seen (visual) Remembering information over time
<p>7. Attention How one focuses and stays on task, including with those tasks that are less enjoyable or more challenging</p>	Ability to ignore or tune out distractions

Domain	Example
<p>8. Executive function (“Boss of the Brain”) How mental skills are used to get things done</p>	<p>Impulse control, planning, problem solving, organizing, controlling one’s thoughts, following instructions, understanding abstract concepts (e.g., time, value of money)</p>
<p>9. Affect regulation How one controls emotions, reacts to stress, and reacts to different situations</p>	<p>Includes current or possible mental health diagnoses (e.g., depression or anxiety)</p>
<p>10. Adaptive behaviour, social skills, social communication How one manages everyday life and social situations</p>	<p>Ability to take care of oneself (everyday life skills), and respond age-appropriately to others</p>
<p>*Sensory How one responds to different sensations like touch, movement, sound, smell, sight, and taste</p> <p>When someone is being assessed for a diagnosis of FASD, the person’s response to different sensations such as touch, movement, sound, smell, sight, and taste is not included in the assessment; however, the sensory response can impact all brain domains.</p>	

The information in this chart is adapted from the Provincial Training Handbook on Fetal Alcohol Spectrum Disorder (n.d.) from Healthy Child Manitoba.

Access to Diagnosis

There is an issue in some communities with access to a diagnostic team. Even if there is a diagnostic clinic, the professionals may not have the capacity to see everyone. This can mean being put on waiting lists or not being seen at all. Another barrier to diagnosis is the stigma and shame parents feel when confirming that they drank while pregnant. Some people are afraid to get a diagnosis because it might label a child.

There are many benefits to getting a diagnosis, including the following:

- It can rule out other medical concerns/disabilities.
- The results can guide support plans that can help a child be successful.
- It may provide access to services or funding that might not have been available before the diagnosis.
- It can provide caregivers and parents with knowledge about why a child is experiencing challenges and how to help with supports.
- Individuals with FASD are often relieved to know that they are not “stupid” or “bad”. The diagnosis provides an explanation for their behaviour.
- When people working with a child who has FASD understand the diagnosis, they are typically more patient, and outcomes for the child improve.
- A diagnosis can promote early intervention. This can make the biggest difference in terms of outcomes for the child. Working with a child while their brain is still being wired (neuroplasticity) can mean new pathways are formed in the child’s brain and new ways of learning are found.

The guidelines for diagnosis, as well as frequently asked questions and information about where to find diagnostic clinics, can be found on the Canada FASD Research Network’s website at www.canfasd.ca.

Diagnosis in Saskatchewan

Regina Qu'Appelle
Health Region Child and
Youth Services
Regina
306.766.6700

Prince Albert Health
Region Child and Youth
Services
Prince Albert
306.765.6068

Alvin Buckwold Child
Development Program
Saskatoon
306.655.1070

Saskatoon
Genetics/Teratology
Clinic Royal University
Hospital
Saskatoon
306.966.8112

**Adult FASD
Assessments**
Dr. Gerald Block
Saskatoon
306.373.3110

Onion Lake FASD
Diagnostic Team
(*only for Onion Lake*)
306.344.2330

Strengths and Challenges

Children with FASD have many strengths. They work hard. They are resilient. They grow and develop. They are friendly and helpful. They may be good at art, telling stories, or sports.

Sometimes when people talk about FASD, they forget about the strengths and concentrate on the challenges. Remembering children's strengths is very important when working with them. It helps build their self-esteem.

In all cases of FASD, impacts on the brain are part of alcohol's effect. Areas of functioning that can be affected include:

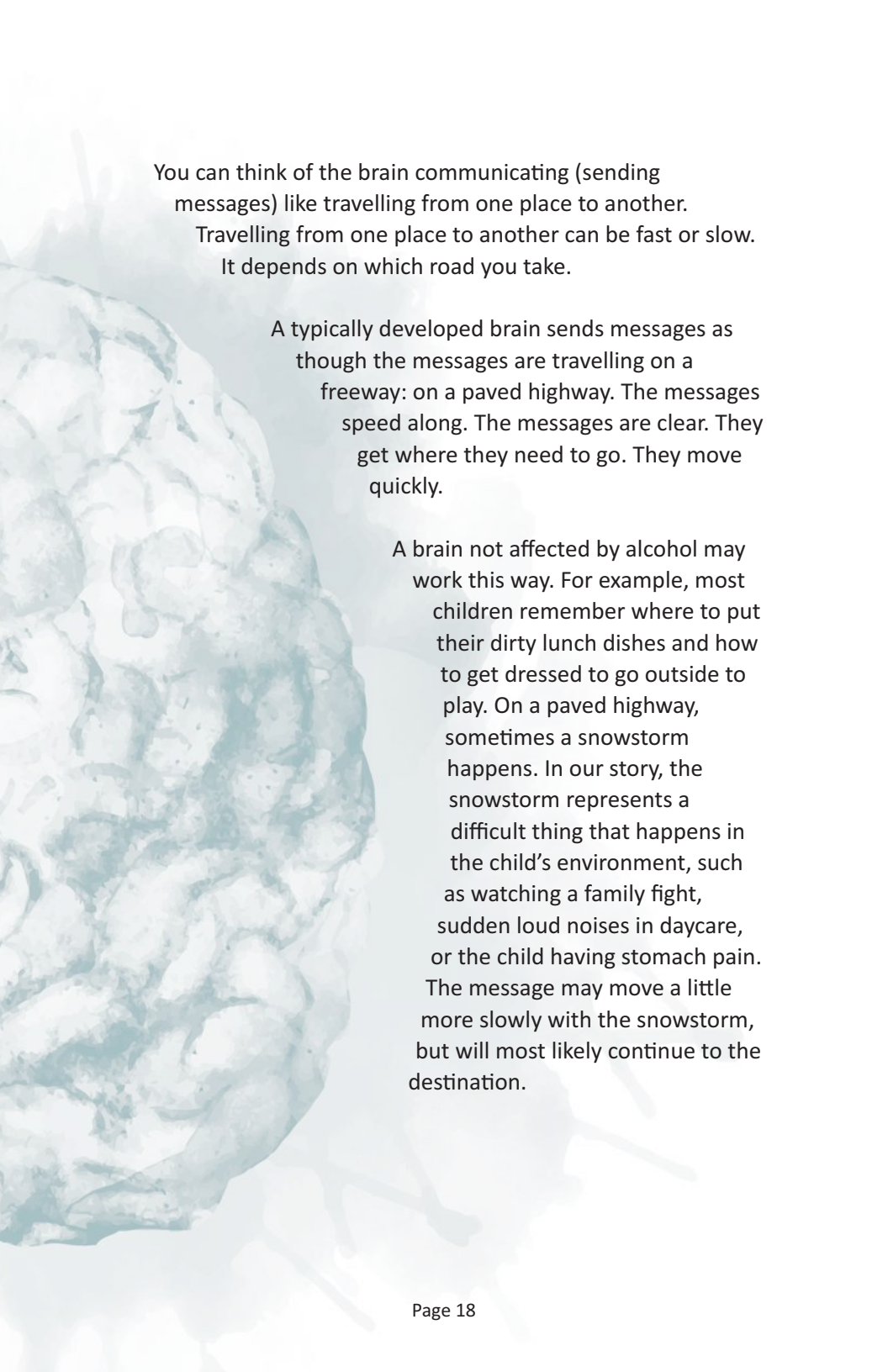
- cognitive (thinking, remembering, speaking, reasoning, perceiving, problem-solving)
- behavioural (actions and reactions)
- physical (body organs, skeletal and muscular systems, motor development)
- sensory (taste, smell, touch, hearing, vision)

Individuals with FASD experience high rates of mental health issues. It may be that alcohol has changed their brains (i.e., they are born with mental health issues), or that difficult life experiences have brought on mental health issues. Appropriate preventative services and early treatment can help.

People with FASD may have significant struggles in some areas of functioning and have significant strengths in other areas. No two people with FASD will have the same strengths or the same challenges. This is because alcohol affects each fetus differently.

Understanding the Brain of Someone with FASD

Sometimes, using a story helps us to understand how something works. Using different roads is one way to think about the way a brain works for a typical person and for a person with FASD.

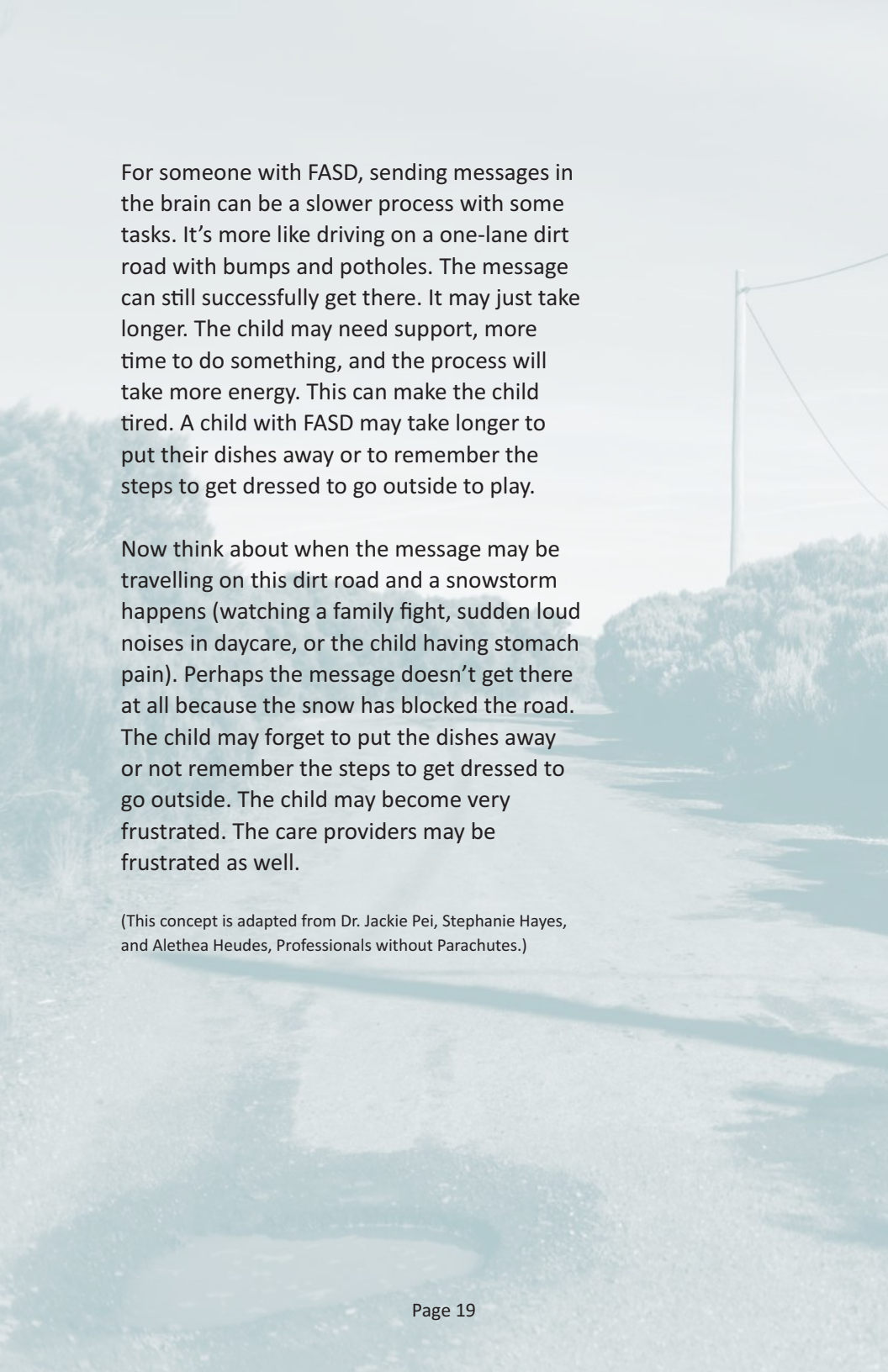


You can think of the brain communicating (sending messages) like travelling from one place to another.

Travelling from one place to another can be fast or slow. It depends on which road you take.

A typically developed brain sends messages as though the messages are travelling on a freeway: on a paved highway. The messages speed along. The messages are clear. They get where they need to go. They move quickly.

A brain not affected by alcohol may work this way. For example, most children remember where to put their dirty lunch dishes and how to get dressed to go outside to play. On a paved highway, sometimes a snowstorm happens. In our story, the snowstorm represents a difficult thing that happens in the child's environment, such as watching a family fight, sudden loud noises in daycare, or the child having stomach pain. The message may move a little more slowly with the snowstorm, but will most likely continue to the destination.



For someone with FASD, sending messages in the brain can be a slower process with some tasks. It's more like driving on a one-lane dirt road with bumps and potholes. The message can still successfully get there. It may just take longer. The child may need support, more time to do something, and the process will take more energy. This can make the child tired. A child with FASD may take longer to put their dishes away or to remember the steps to get dressed to go outside to play.

Now think about when the message may be travelling on this dirt road and a snowstorm happens (watching a family fight, sudden loud noises in daycare, or the child having stomach pain). Perhaps the message doesn't get there at all because the snow has blocked the road. The child may forget to put the dishes away or not remember the steps to get dressed to go outside. The child may become very frustrated. The care providers may be frustrated as well.

(This concept is adapted from Dr. Jackie Pei, Stephanie Hayes, and Alethea Heudes, Professionals without Parachutes.)

Adverse Outcomes

People with FASD will be born with some challenges. They might also have some challenges that they are not born with, but can happen over time depending on their environment or experiences. Things such as poverty, an unstable home life, trauma, bullying, difficulty making friends, and a school teacher who does not understand the disability can make life more difficult and create more challenges. Some individuals with FASD struggle with challenges that develop over time because of the relationship between their disability and the environment around them.

These outcomes may include:

- dropping out of school
- getting in trouble with the law; going to jail
- making friends with the “wrong” people and being taken advantage of
- being homeless
- problems getting a job or keeping a job
- not being able to live independently
- having mental health problems (may be primary disabilities, but could also come from experiences)

Sometimes it is the simple things that can make a difference in whether a person can be successful. If they are receiving appropriate help and the environment they are in is meeting their needs, they may not experience as many challenges. For someone with FASD, caregivers and others who understand the disability and provide the right type of supports can help to avoid further struggles and impacts.



Strengthening Services for Children and Families

The beliefs, attitudes, and approach of service providers can make a big difference for the children and families that they serve. It helps to recognize and remember that FASD is a brain-based disability. The challenges that children with FASD have are because of the changes in their brains caused by alcohol when they were developing inside the uterus. They are not necessarily misbehaving or not trying; it is just how their brain works.

All children want to, and can, learn and grow. No child wants to fail. It feels good to succeed. Our job as parents, caregivers, and service providers is to adapt routines and activities to help children succeed.

All behaviour has a purpose. It is driven by a need. Sometimes a basic need can be the trigger, like hunger, fear, feeling cold or hot, or being tired. Sometimes it is things in the environment, like being annoyed by the feeling of scratchy clothing, buzzing lights, smells, or too many distractions. Sometimes behaviour is communication; it is a child's way of saying "I've had enough", or "This is exciting. I want more." Our job is to be "behaviour detectives" and figure out what the trigger or need is and how to help.

The information in the following chart shows how responses to behaviour are different based on how the behaviour is understood. Using the example of a child not sitting still – if you think a child won't sit still, you may see this behaviour as attention-seeking or bothering others. When you understand that this is a brain-based behaviour, you realize that perhaps the child just cannot help moving or that there is too much stimulation in the environment for the child to sit still and focus. Then you can help the child be successful by adjusting how they can participate.

Child Behaviour	If we think “Won’t”, we assume	If we think “Can’t”, we assume	If we think “Can, But Differently”, we assume
Makes the same mistakes over and over	<ul style="list-style-type: none"> • Willful • Manipulative 	<ul style="list-style-type: none"> • Can’t link cause to effect 	<ul style="list-style-type: none"> • Can, with visual cues and positive prompts
Not sitting still	<ul style="list-style-type: none"> • Seeks attention • Bothering others 	<ul style="list-style-type: none"> • Can’t sit still while learning • Sensory overload 	<ul style="list-style-type: none"> • Can, with fidget toy or weighted blanket
Hits other children	<ul style="list-style-type: none"> • Poor parenting • Willful • Mean 	<ul style="list-style-type: none"> • Can’t interpret social cues • Doesn’t know what to do 	<ul style="list-style-type: none"> • Can, with social practice and coaching, or social story

Chart adapted from Diane V. Malbin, MSW, FASCETS (www.fascets.org)

Changing the way people think can help individuals with FASD. If people change from *they won’t* to *they can’t*, it means that they understand that FASD is a brain-based disability, and they adjust their expectations. If people change their thinking to *they can, but differently*, they are even more motivated to find ways for people with FASD to be successful. Children with FASD can learn and grow, but often differently than other children. For example, they may be able to sit still at group time if they have fidget toys, if the lights are dimmed, if they have a weighted blanket, if they have a fuzzy matt to sit on, or if they can face away from the group.

Thinking *they can, but differently* can help families and service providers understand that obstacles may be overcome. Days run smoother. Everyone is happier. Other children may also benefit from some of the changes to the environment.

Service providers, children, and families also benefit from programs and services that are family-centred and strength-based, culturally-informed, and trauma-informed.

Family-Centred and Strength-Based

A family-centred and strength-based program recognizes that:

- All families are unique. Taking time to get to know each family will help service providers to understand what is going on and what support is needed. Families also need time to build relationships with service providers.
- All families have strengths. Recognizing those strengths and using them in a family's program will encourage success, hope, and motivation to succeed.
- Families are the experts on themselves. Families know what has worked in the past and what will not work for them. They know their children best. They know what their unique strengths and challenges are.
- All families deserve to be treated with respect and dignity. It sends a message that they are worthy and on equal footing with you. When people give respect, they will generally get respect in return.
- All families have the right to make their own decisions, even if sometimes service providers do not agree. Parents want what is best for their children and for their family. Service providers have lots of knowledge to share and may offer a solution or some advice.

- Families can make well-informed decisions about keeping their children safe when they are supported. Providing information in a respectful way can support families to make decisions and move forward. When families are involved in decision-making, outcomes can improve.
- Children are part of a family, a community, and a culture. Including culture in programming can help to build relationships. All children, including children with FASD, respond to culture with great interest. It provides familiarity, builds self-confidence, and instills hope for the future.

Trauma and Trauma-Informed Practice

Bruce Perry is an expert in trauma and trauma-informed practice. He writes that “trauma is a psychologically distressing event outside the range of usual human experience. It involves a sense of intense fear, terror, and helplessness, and may lead to a variety of effects, depending on the child or person.” Trauma in children may be caused by:

- neglect
- abuse
- domestic violence
- neighbourhood violence
- forced disconnection from home or culture
- a parent being in jail
- a parent abandoning the child
- parental substance use or mental health issues
- medical trauma
- other psychologically intense experiences (e.g., disasters, war)



Childhood trauma affects about 1 in 4 children. Many children with FASD have experienced trauma. Their parents or caregivers may also have experienced trauma. Many adults still feel the impact of childhood trauma. Trauma can have many impacts in children and adults, including:

- The body – fight, flight, or freeze reactions; sensory challenges; unusual responses to pain; physical symptoms (stomach aches)
- Emotions – hypervigilance (being on high alert for danger), distress, problems regulating themselves, trouble talking about feelings or needs, possible dissociation
- Actions – poor impulse control, aggression, participating in dangerous actions, oppositional behaviour (anger, irritation, non-cooperation), self-harm, overly compliant, sleeping or eating problems, substance abuse
- Thinking – learning and processing problems, language development problems, trouble paying attention, planning and organizational problems, not understanding cause and effect
- Self-concept – low self-esteem, feelings of worthlessness and self-hatred, problems understanding what is real or possible (grandiose ideas), bragging, blaming, body image problems, self-sabotaging behaviours
- Relationships – lack of trust for others, overly dependent, clingy, withdrawn, problems with friends and peers, overly helpful, works hard to get attention, lack of empathy



Getting services and support from people trained to deal with trauma, and learning to work through traumatic experiences, can improve the situation for children and adults who have experienced trauma. A child who has experienced trauma needs:

- trusting relationships
- adults who figure out the child's trigger(s) and ways to help the child cope
- help and support when things get out of control
- an environment that allows them to feel safe
- adults who are calm, patient, and accepting
- sensory items to use or opportunities for movement
- help to learn to self-regulate
- routines and limits
- adults who understand that perhaps they can't do something; it's not that they won't do it
- empathy from others

Trauma can affect every part of children's health. For example, they may begin to have nightmares or night terrors, they may have physical complaints (stomach aches), or they may seem to be always aware of everything that goes on around them (hypervigilance). This may happen without the children or adults being aware of why it is happening. Children who have experienced stress or trauma may begin to think that normal everyday events are threatening. Sometimes, the behaviours of children who have experienced stress or trauma may be hard to deal with, such as impulsivity, tantrums, aggressiveness, frequent crying, and irritability.

The effects of trauma continue throughout a person's life. For example, children who have been abused are more likely to have physical and mental health concerns in adulthood. Inter-generational trauma happens when families and communities have been impacted by trauma, and future generations are affected. Trauma is literally passed on to children and grandchildren. Colonization and residential schools are examples of events that have caused inter-generational trauma.

People have many responses to trauma. One of the ways that some people cope with trauma is using substances. Getting support to deal with the trauma can lessen some of these effects and can potentially change the situation for the next generation.

Being trauma-informed is thinking "Something's happened to them" instead of thinking "Something's wrong with them". Service providers can re-traumatize people by insisting on gathering details about past trauma. Understanding that something happened is important, but understanding the details is not.

Agencies and service providers can take a trauma-informed approach. Trauma-informed practice is built on the following principles:

- Being aware of and understanding how trauma can impact individuals throughout their lives
- Having safe, supportive attitudes, policies, and programs that help to build trusting, compassionate relationships
- Working in partnership with families and allowing them to make choices that work for them
- Supporting children and families to build skills by focusing on strengths

Organizations can offer trauma-informed services in the following ways:

- Providing welcoming spaces (welcome sign instead of lists of rules, a parent lounge, opportunity to meet with staff)
- Offering choice, voice, and control to all who use services
- Working to create physical, emotional, and cultural safety for everyone
- Offering opportunities to learn key coping skills
- Being aware of and understanding how trauma can impact individuals throughout their lives (something has happened to them)
- Having safe, supportive attitudes, policies, and programs that help to build trusting, compassionate relationships
- Working in partnership with families and allowing them to make choices that work for them
- Supporting children and families to build skills by focusing on strengths
- Providing links to services, such as counsellors, to help people deal with trauma

Building Resilience in Children

Resilience is the ability to adapt and grow in the face of stress or adversity. A common reason for children doing well is a stable and ongoing relationship with a parent, caregiver, or other adult. When there are positive relationships, children can learn to adapt to different events and control their behaviour. Positive experiences also help children build resilience. Resilience is associated with longer life, better health, school and work success, happier relationships, and less depression.





Children with FASD: Their Strengths, Their Challenges, and Strategies to Support Success

Strategies are tools and ideas to support a child to cope, learn, progress, and grow. Strategies:

- sometimes require a shift in the way we think
- can be developed in partnership with children and families
- can be learned by children with FASD
- can be applied to learning and behaviour
- can be helpful for children with other disabilities (e.g., Autism) and for typical children

Strategies suggested in the following pages are aimed at supporting early learning and child care centres. These strategies can also be adapted by families to use at home.

Common Strengths

Every child is unique. Every child with FASD is also unique and has individual strengths and challenges. It is important to think about what the child does well, what the child enjoys, and what the child's best qualities are. You can broaden your perspective by asking the child's parents and caregivers, as well as the child. The following are some common strengths seen in children with FASD:

- Generous and helpful
- Friendly and affectionate
- Value fairness
- Determined
- Athletic
- Talkative
- Care takers (drawn to animals, small children)
- Often average or above-average intelligence
- Can memorize to movement or song
- Learn by multiple ways (by doing, by observing, in relationship to others)
- Remember what they see (long-term visual memory)
- Curious
- Artistic and musical
- Good with their hands (gardening, building, mechanics)

The following section covers common challenges that young children with FASD may experience and strategies to help them succeed. Common challenges include information processing, memory, executive functioning, social skills, emotional regulation, language, and sensory integration.

Challenge: Information Processing

The human brain is a complicated information processing system. We use our senses to take in information, turn it into messages, understand the messages, and figure out what to do. All of this typically happens very quickly.

When alcohol impacts the fetal brain, it can be more difficult for the brain to send messages. Using the analogy in the story of roads on pages 17-19, sometimes it is like travelling on a one-lane dirt road compared to a freeway. This means it can take longer to process information and will take a lot more energy. Children with FASD may have the following challenges.

- Talk well, but not understand everything that they have said
- Be unable to predict outcomes
- Misinterpret other people's words, actions, facial expressions, or body movements
- Have trouble following more than one direction at a time
- Have difficulty making decisions
- Have meltdowns when over-stimulated (too much happening in the environment)
- Have trouble connecting an action to a consequence
- Have trouble generalizing something they have learned in the past to the present

Strategies: Information Processing

The following are possible strategies to support a child to process information.

- Use clear communication. Say exactly what you mean. Use a calm and clear voice.
- Limit distractions. Check to see what is around that is taking the child's attention.
- Check for understanding. Ask them to show you instead of tell you, or ask them to tell you in different words.
- Break down tasks into small steps. Give one direction at a time.
- Slow down, allow more time, count to 10 (or maybe even 30) before expecting a reply. This allows the child time to process what you said and respond.



Challenge: Memory

Processing information also involves using memory. We store information in a number of ways (sensory memory, working memory, and long-term memory). You can think of your brain as a storage unit that is like a filing cabinet. Information is organized in categories and is relatively easy to retrieve. This helps us to recall information when it is needed. Everyone struggles with memory sometimes.

People with FASD typically struggle with memory. These struggles are a direct result of structural changes in the brain functioning due to alcohol exposure. Instead of a filing cabinet system of memory storage, they may have a box with everything thrown in. The information is there, but it is not always easy to find what they need. As a result, the following challenges may arise.

- Memory can function one day and not the next, so it is not consistent.
- A child with FASD may not be able to generalize information from one situation to another. For example, they learn to follow a nap-time routine at home but cannot do the same at grandma's house.
- A child with FASD may "lie" (called confabulation). It is not that they are NOT telling the truth; instead, they are having problems with her memory and is trying to fill in the blanks. Their story can be influenced by something heard or seen, or by a memory of another event.

We all have different ways of learning. Some people are auditory and learn best by hearing. Some people are visual and learn best by seeing. Some people are kinesthetic and learn best by moving or touching. Someone with a brain impacted by alcohol will likely need to interact with material to learn. Also, they will benefit from having more time. Remember that memory is fluid and what is remembered one day may not be remembered the next.

Strategies: Memory

The following are possible strategies to help a child remember things.

- Visual reminders can help; ideas include the following:
 - A visual schedule with line drawings or real photos to help a child remember what comes next in the day
 - Photos of the staff in the preschool or daycare centre
 - Pictures showing where toys get put away (e.g., picture of blocks on the shelf where the blocks get put away)
- Repetition
- Reminders and prompts
 - To promote success, start with a question to start memories. Try to start general and lead to more specific questions. Count to 10 (or maybe even 30) after you ask a question and before you expect a response. Here is an example:
 - “Where do we put our lunch dishes?”
 - “Remember, we put away our dishes together yesterday.”
 - “Lunch dishes go in a place near the kitchen.”
 - “Lunch dishes go in the bbb... (bin).”
- Consistent messages – using the same words to announce an event helps a child remember (e.g., time to wash your hands in the sink).
- Consistent routines – set a daily schedule where things generally happen in the same order (meals, group times, work times, nap). Use visuals, timers, and verbal prompts. Calmly explain unexpected changes and support children through the change.
- Sensory memory – let a child touch, explore, hold, and do. Sensory memory can support remembering.
- More time is needed to practice and learn new tasks.
- Teach ownership, borrowing, and sharing:
 - Write names or have photos on items (photos on cubbies or lockers)
 - Colour code property (child only uses books with yellow sticker that belong to them)
 - Teach associations between owners and items (photos, social stories)
 - Securely store valuable items to avoid problems



Challenge: Executive Functioning

Executive functioning describes a set of cognitive abilities that control and regulate other abilities and behaviours. Executive functioning is like the “Boss of the brain” or Manager of the workplace – directing and organizing tasks. Children with FASD may have some of the following challenges.

- Not understand or learn from mistakes
- Not understand consequences
- Have trouble with abstract concepts, like time and money
- Not respond to reward systems
- Give in to peer pressure
- Have trouble with judgement (e.g., will go with strangers, easily taken advantage of)
- Have trouble staying organized
- Shut down and appear unmotivated
- Difficulty making decisions
- Difficulty transitioning to something new and when schedules change
- Difficulty understanding ownership (might take something they want without understanding it is stealing)



Strategies: Executive Functioning

The following are possible strategies to help children organize their thinking, their activities, and their day.

- Consistent routine
- Repeat things often, as many times as needed, calmly, patiently
- Visual schedules or visual decision-making tools
- Physical exercise before quiet work
- Provide things for the child to fidget with to help the child when it is time to listen (story time)
- Hands-on, interactive learning
- Support child to control impulses: model impulse control, talk out loud, use of cues and reminders, role play, avoid some situations that stress the child, teach social skills (I'm sorry; Can I have the bike when you are done?), provide one-on-one support when needed
- Build upon a child's strengths: for example, for a child who loves to paint, you can use painting to learn many things (increase numeracy by painting dots to count; increase social skills by taking turns with another child to add to a large painting; increase language by describing his painting to someone)



Challenge: Social Skills

Children develop social skills over time, as they grow older, and as they practice getting along with others.

Children with FASD might experience the following challenges.

- Get into someone else's space
- Be overly friendly with strangers
- Hit someone
- Not understand social rules or boundaries
- Not understand ownership and may take toys and other belongings
- Not be able to generalize from one situation to another
- Not be able to read facial cues, body language, and other social cues
- Stare at someone or say inappropriate things
- Have trouble showing empathy (understanding how someone is feeling)

Strategies: Social Skills

The following are possible strategies to help a child make friends and get along with peers.

- Teach kids to play with other children. Model, show, and practice. Pre-teach with an adult, and then coach during play with peers.
- Provide positive simple rules.
- Speak openly about peer behaviour – “They are crying because they are hurt” helps the child to label and identify what they see. This also helps to build empathy.
- Help a child identify social space with boundaries. For example, put out individual mats at group time to support children to keep their own social space and not invade another’s space.
- Teach the “rules of touching” and appropriate friendship skills.
- Teach turn-taking.
- Avoid larger groups, if needed and possible.
- Build on strengths.
- Use social stories.

Social Stories

Social stories are written and told over and over again to a child to support them to learn how to behave in a situation. They are typically used for children with Autism or FASD, and the stories teach them the nuances (expected behaviours) of social interactions. A parent, caregiver, or staff member might read a social story to a child many times so they have an opportunity to “get it”.

Challenge: Emotional Regulation

Emotional regulation means being able to name your emotions, show your emotions, and control your emotions in a healthy way. All children are learning to do this. Children with FASD may struggle more with this and may need support to calm down after losing control. It is important to remember that there are no bad emotions. We just have to learn how to decrease their intensity and show them in a way that doesn't hurt others or ourselves. It is okay for children to feel anger, but they may need support to show anger in a healthy way.

Children with FASD may do the following.

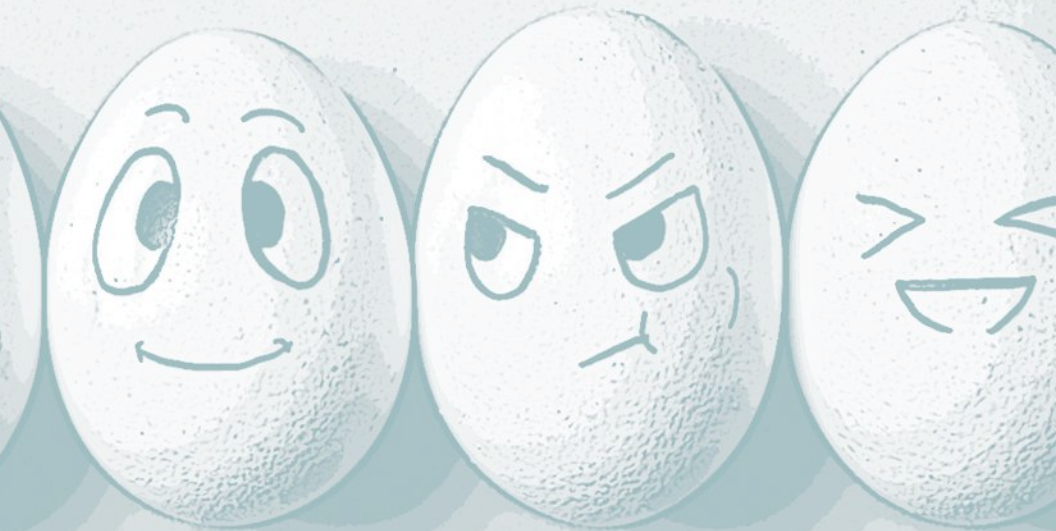
- Have tantrums
- Zone out
- Fight with others
- Have uncontrolled laughter that does not fit the situation
- Become overexcited



Strategies: Emotional Regulation

The following are possible strategies to help children regulate their emotions.

- Have calming places that children can go to calm themselves down.
- Teach calming behaviours, such as taking deep breaths, counting, stretching, and playing with sensory materials such as sand or water or using techniques such as blowing bubbles or tearing paper.
- Model the same calming behaviours you want the child to learn.
- Supply fidget toys for whenever you want a child to sit and pay attention.
- When things are out of control, use distraction to draw their attention away.
- Anticipate (plan for) and intervene (get involved) at times when a child might struggle.
- Use a social story.



Challenge: Language

Language has two parts: 1) what we say, and 2) what we understand others are saying (words, facial expressions, body language, tone of voice). All children are learning language in their early years. Children with FASD may experience the following challenges.

- Not understand verbal language, facial expressions, body language, and tone of voice
- Not understand jokes, sarcasm, phrases, and popular expressions; these are often abstract or are a play on words (beat around the bush, cry over spilled milk, something costs an arm and a leg)
- Not understand words that have different meanings (waive your rights)
- Not develop language skills at the same rate as other children the same age
- Ability to use words (expressive language) may not be at same level as ability to understand those words when someone else is saying them (receptive language)
- Have hearing impairments and/or speech and language impairments (diagnosed or undiagnosed)



Strategies: Language

There are many strategies that can help to support a child who has language difficulties. These may include the following:

- Use specific, descriptive, simple language and short phrases (e.g., put your coat in the blue basket).
- Talk about what you see or what they are doing. A running commentary can support language learning for children.
- Explain and demonstrate at the same time so that the child can see it as you say it.
- Say what you want instead of what you don't want (e.g., say "walk" instead of "don't run").
- Break down instructions into simple steps. Give 1 to 3 instructions at a time, depending on the child.
- Consider getting support from a speech-language pathologist.

Challenge: Sensory Integration

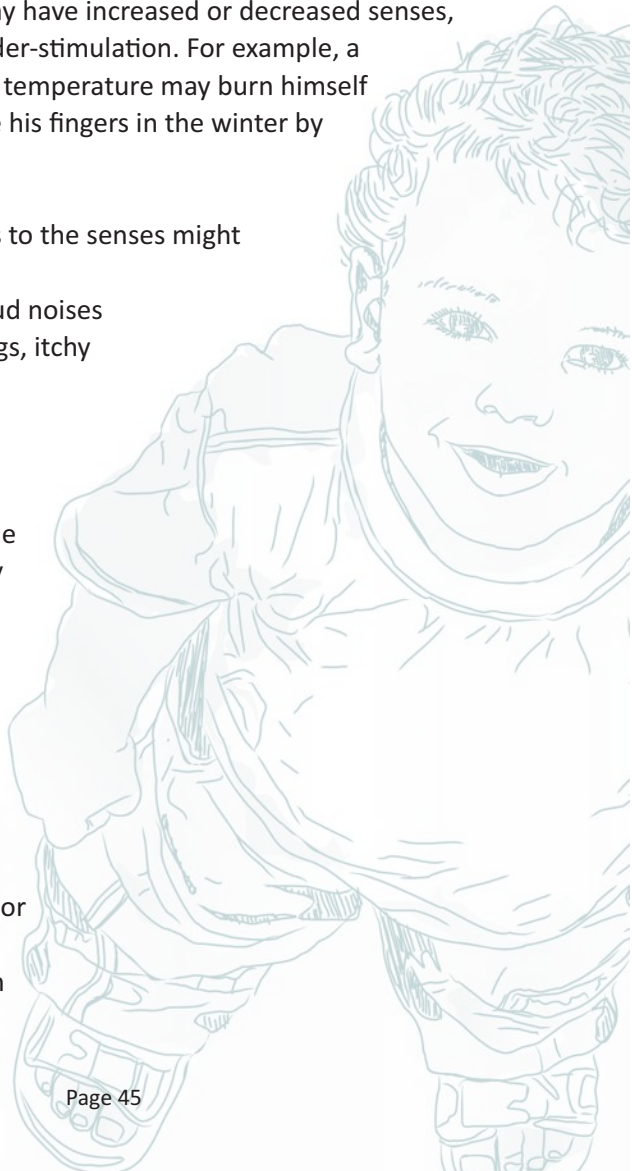
We take in information using all of our senses: touch, taste, sight, smell, hearing, proprioception (awareness of the position and movement of the body), and vestibular (sense of balance). All of the information we get from our senses has to go to the brain.

Someone with FASD may have increased or decreased senses, resulting in over- or under-stimulation. For example, a child who does not feel temperature may burn himself in the bathtub or freeze his fingers in the winter by not wearing mittens.

Things that cause stress to the senses might include the following:

- Bright lights and loud noises
- Clothing (seams, tags, itchy material)
- Textures of food
- Smells
- Temperature
- Bumping into people or things frequently (not being able to sense where their body is in space)
- Physical touch

Noises and activities around us can interfere with our learning and ability to concentrate. For someone with FASD, sensory distractions can be even more extreme.



Strategies: Sensory Integration

The following are possible strategies to help support children with sensory difficulties.

- Reduce visual distractions. Declutter walls and bulletin boards. Use curtains to cover distractions or shield child from busy parts of the room.
- Think about what colours are used and the number of colours used – the walls, furniture, etc.
- Consider lighting (lights that might flicker or hum) and sound (adding some fabric will help absorb sound).
- Cover open shelves with cloth or cupboard doors so children do not get distracted looking into them. Limit the number of toys available.
- Provide a place where children can be alone. This is not for a time out, but as a place to be calm. Some children may need an adult to be with them or nearby during this time.
- Have quiet spaces available (bean bag chairs in a quiet corner of a room, sensory-free tent), and provide headphones so children can tune out sounds.
- Consider children's clothing, towels, and blankets. Are there scratchy tags, seams, rough materials? Observe and ask.



Success is Possible

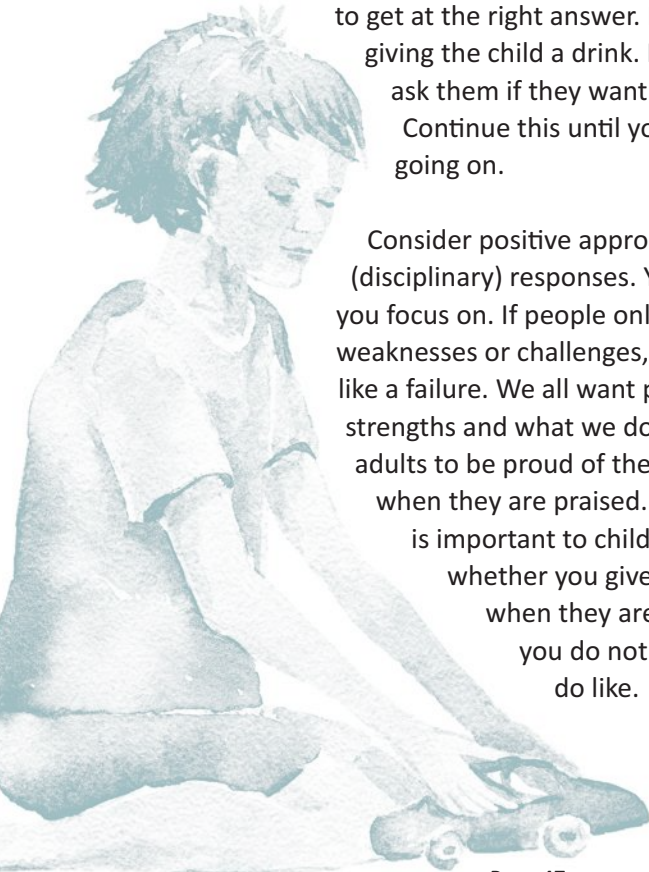
Research is clear: success is possible for every child. When we think in different ways and support learning and mastery, success can happen. Setting realistic goals is key. Our beliefs matter. We will get what we expect. We often set children up for failure, because we believe that they will fail. Therefore, we may not go that extra step to help ensure success. When we believe that children will succeed, chances are greater that they will. A positive attitude pays off.

It is important to remember that all behaviour has a purpose. Figure out what the child needs (food, drink, bathroom, attention, quiet). You may have to test your theories

to get at the right answer. For example, try giving the child a drink. If that does not work, ask them if they want a hug or cuddle.

Continue this until you figure out what is going on.

Consider positive approaches versus punitive (disciplinary) responses. You strengthen what you focus on. If people only focus on your weaknesses or challenges, you can begin to feel like a failure. We all want people to focus on our strengths and what we do well. Children want adults to be proud of them and they thrive when they are praised. Remember, attention is important to children. Think about whether you give them more attention when they are doing something you do not like or something you do like.



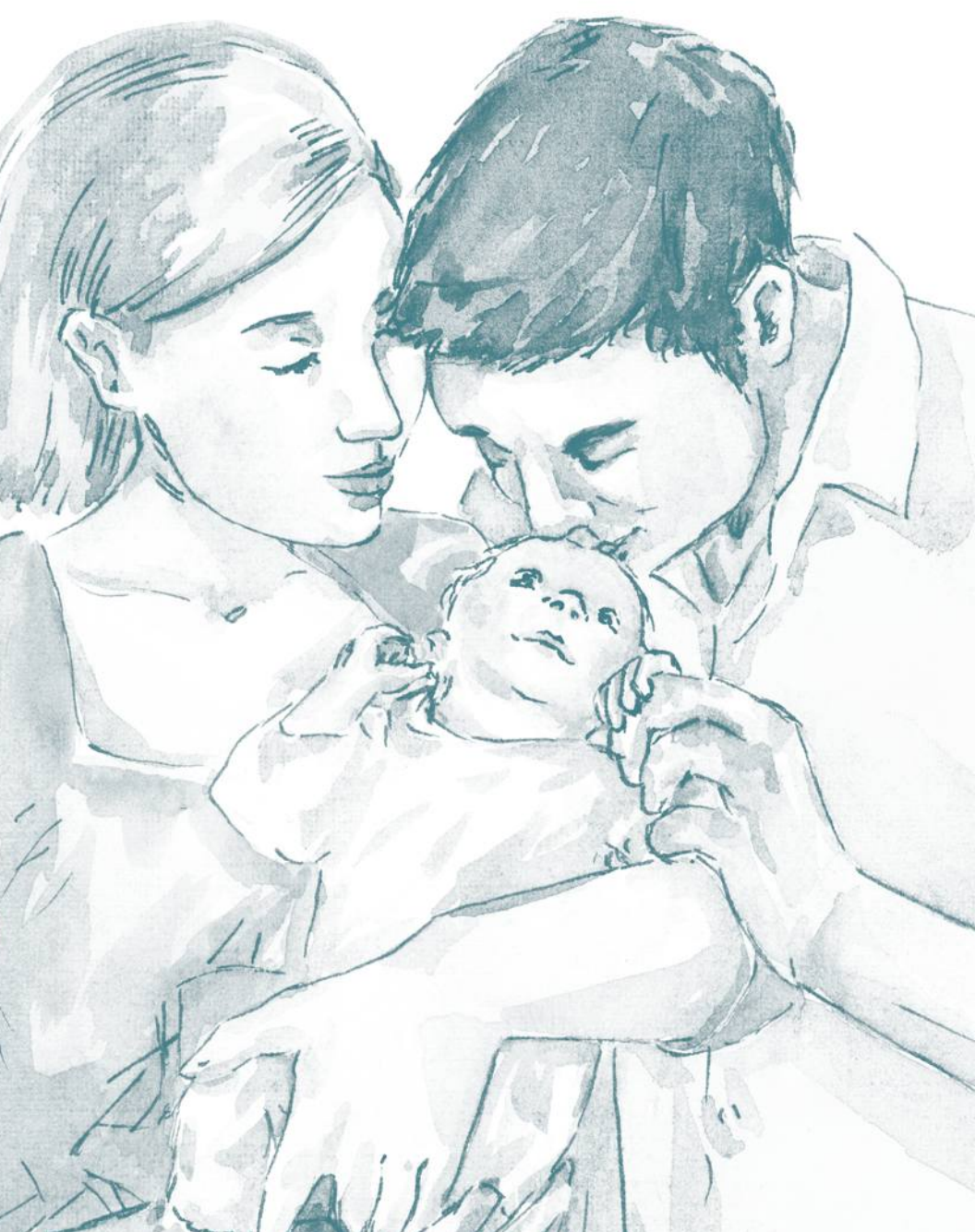
Create meaningful opportunities for children. Include something they might be interested in (trains, dinosaurs, kittens). Make sure they have opportunities to make friends, and include their family and culture. Follow the child's lead.

Things to Remember About Children's Responses

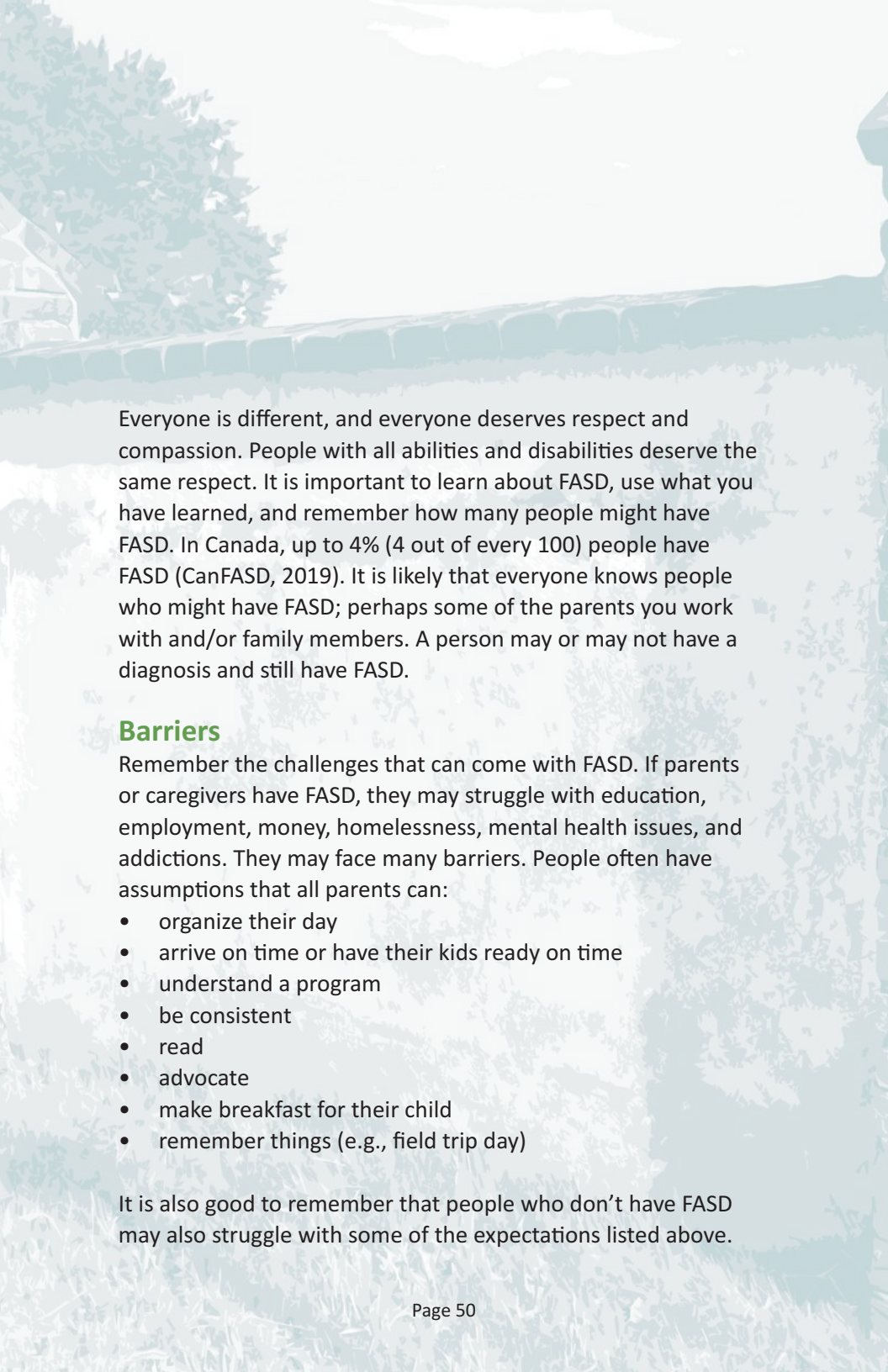
Keeping the following in mind will help when working with a child with FASD.

- The effort the child makes to complete a task is important. Recognize that the child is trying even though they may not "succeed" at the task. Don't expect perfection and accuracy.
- We set the tone. If we are in a bad mood, the child may join us. If we expect a child to fail, they may fail. If we have positive expectations, they may too.
- Memory is not consistent. Remember, one day they may know something and the next day they may not.
- Ask "Why?" or "Tell me how ...". These questions help you figure out how a child learns and what they are thinking. They can also help the child figure out how they learn and why they think like they do.
- Give time. Remember the 10 to 30 second guideline.
- Encourage the child to "show you" to convey their understanding. They may not be able to verbally communicate that they understand. They might repeat what They heard, but not really understand what it means.
- Be innovative. Be willing to try. Think outside the box. However strange or simple an idea might seem, it might be the best strategy for that moment. There are many different ways to support learning.

Children with FASD can learn and grow in many ways. It is up to parents, caregivers, and service providers to find a way that works for each child.



Supporting Healthy Families



Everyone is different, and everyone deserves respect and compassion. People with all abilities and disabilities deserve the same respect. It is important to learn about FASD, use what you have learned, and remember how many people might have FASD. In Canada, up to 4% (4 out of every 100) people have FASD (CanFASD, 2019). It is likely that everyone knows people who might have FASD; perhaps some of the parents you work with and/or family members. A person may or may not have a diagnosis and still have FASD.

Barriers

Remember the challenges that can come with FASD. If parents or caregivers have FASD, they may struggle with education, employment, money, homelessness, mental health issues, and addictions. They may face many barriers. People often have assumptions that all parents can:

- organize their day
- arrive on time or have their kids ready on time
- understand a program
- be consistent
- read
- advocate
- make breakfast for their child
- remember things (e.g., field trip day)

It is also good to remember that people who don't have FASD may also struggle with some of the expectations listed above.

Strategies for Supporting Parents

The following are ways to support all parents, including those who might have FASD.

- Ask parents what is helpful. Collaborate with them to come up with solutions.
- Use communication tools that the parent prefers (e.g., send notes home; pin important notes to child's shirt or use a label; phone or send a text or email; use a communication book).
- Find out if they need help to read forms and other communication.
- Post visual schedules.
- Access or link to outreach worker for home support.
- Watch for parent strengths and mention them (e.g., "You always remember to bring their snow pants, mitts, and hat so they are warm when we go out to play.").
- Ask "how" and "why" questions to understand the parents and also to help the parents understand themselves (e.g., "How do you remember to bring his snow pants every day?").
- Accept them for who they are. Work with them when they need support.

Do not limit service based on the following behaviours:

- Missed appointments
- Discomfort with formal institutions
- Lack of transportation
- Location of residence (homelessness)
- Inability to understand expectations
- Inability to follow through
- Literacy issues



Support for Avoiding Alcohol During Pregnancy

There are many ways to support people to avoid alcohol during pregnancy.

- Provide non-judgemental acceptance and respect.
- Provide information about alcohol and pregnancy (conversations, brochures, posters).
- Support each person as an individual, considering the whole person. Take into account their age and specific needs. Support them mentally, physically, emotionally, and spiritually, and within the context of their family, community, and culture (holistic support).
- Build compassionate relationships.
- Validate and reflect back their experiences, thoughts, and feelings (reflective listening).
- Build on strengths to increase confidence.
- Link them to supports online, in the community, or in the province.

If it is appropriate to your role:

- Ask every pregnant person, or person who can get pregnant, about their alcohol use
- Have a discussion about birth control



What Can You Do to Prevent FASD in Your Community?

In addition to supporting people to avoid alcohol during pregnancy, there are a number of other ways that you can help prevent FASD in your community.

- Include the topics of alcohol, pregnancy, and FASD as part of conversations.
- Link people to supports.
- Show compassion and respect.
- Post and share information about alcohol, pregnancy, and FASD.
- Share information about birth control and how to access it.
- Get involved in FASD Awareness Day (held on September 9 each year).
- Host a community event where someone talks about their experiences with FASD. This personal story has been shown to reduce stigma (National Academies of Sciences, Engineering, and Medicine, 2016).
- Attend or host alcohol-free events, such as a family dance.

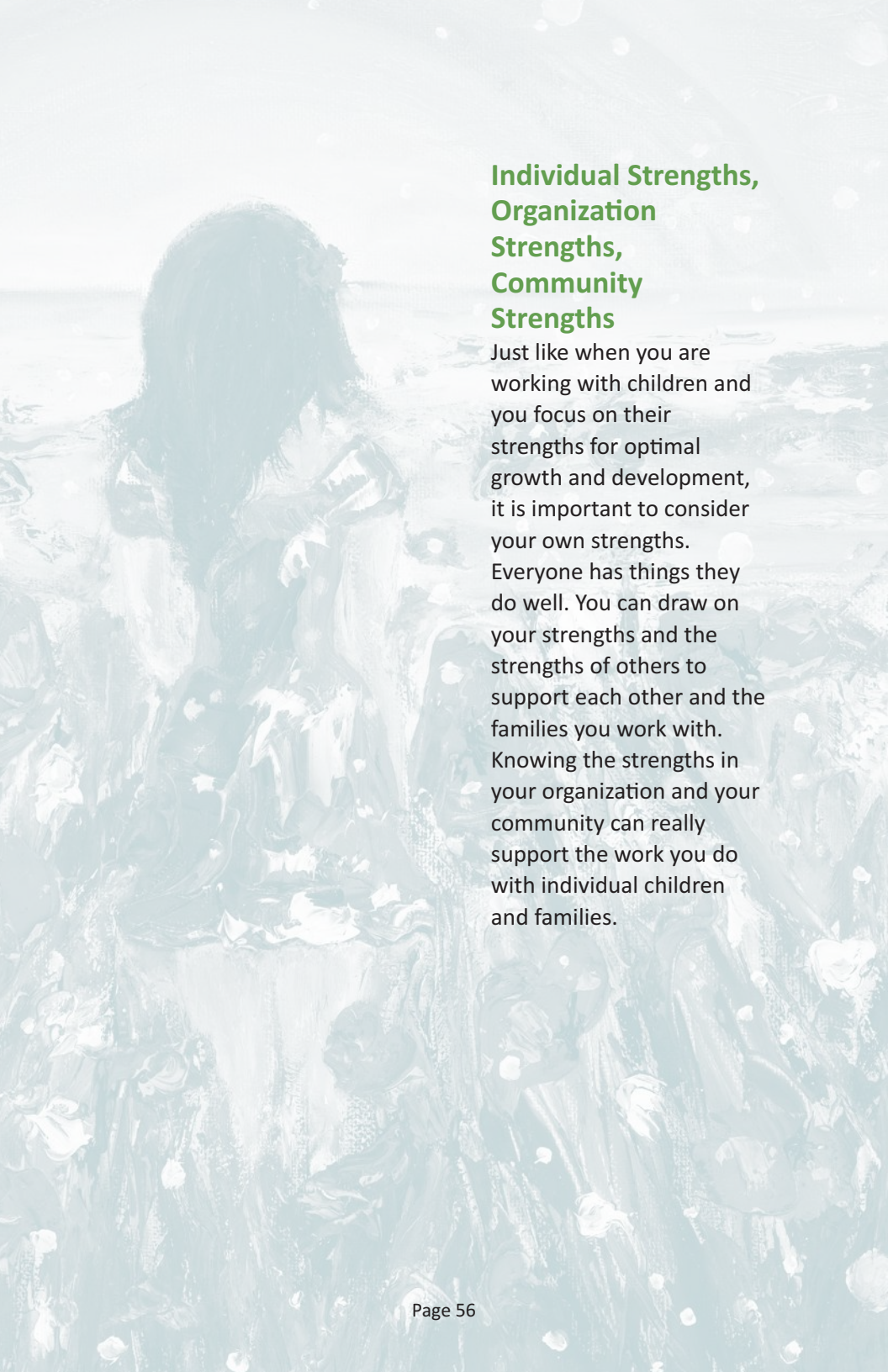
- Serve mocktails (cocktails/drinks without alcohol) in a local liquor store, bar, or at an event.
- Find or choose non-drinking locations within your community.
- Participate in, or host groups for people that provide positive non-drinking social environments (sewing, beading, cooking, drumming, dancing, or painting).

Cultural connections are important for many people. It is important to acknowledge that culture can play a role in the prevention of FASD. Talk with families to determine which cultural components will be of significance to them in their journey to health and well-being.

Working with children and families, including those with FASD, can be both rewarding and challenging. People cannot continue to take care of others unless they take care of themselves too. Recognizing, using, and building upon individual strengths, organization strengths, and community strengths is an important part of wellness.



Supporting Wellness

A woman with long dark hair, wearing a light-colored dress with a floral pattern, is seen from behind, looking out at a vast ocean under a bright sky. The scene is peaceful and contemplative.

Individual Strengths, Organization Strengths, Community Strengths

Just like when you are working with children and you focus on their strengths for optimal growth and development, it is important to consider your own strengths. Everyone has things they do well. You can draw on your strengths and the strengths of others to support each other and the families you work with. Knowing the strengths in your organization and your community can really support the work you do with individual children and families.

Knowing Yourself

If you are working with families, it is important to understand your own assumptions, beliefs, and values. How you feel about some sensitive topics that might come up with families (abortion, birth control, family planning, drinking alcohol during pregnancy) may impact your ability to be supportive and non-judgemental. When you understand where you are coming from, you can think about how you offer services, how you interact with people, and how you make them feel. Although it can be difficult, work to challenge your assumptions. Empathy is trying to understand someone else's perspective or feelings, often described as "walking in their shoes". Empathy helps you to be accepting and non-judgemental.

If you work with families, it is important to be clear about your professional boundaries with families. It is a way to protect yourself and a way to ensure that you are not doing something for the family that they can do themselves. Some families can struggle knowing the difference between workers and friends. Keeping your role professional will support these healthy boundaries.

Your values are important, and it is okay that you might value different things than the people you work with or the people you serve. However, when values cloud people's vision, it can be difficult to see people for who they are. This makes it harder to accept them as they are, and this makes it harder to act in ways that are non-judgemental. Learn what your values are. Think about how they might cloud your vision. Put your values aside. Accept people for who they are and what they value. This will support the development of trusting relationships.

Self-Care Toolkit

It takes commitment and strength to develop relationships and care for families in your community. It can also cause feelings of burnout. It is vital that you care for your mental, emotional, physical, and spiritual well-being. The following are examples of ways to care for yourself.

- Think about, talk about, or write down your own feelings and thoughts (e.g., journaling).
- Take time for yourself and learn about self-care options.
- Consider setting healthy boundaries with the families you work with.
- Ask for help when you need it.
- Meet with a counsellor.
- Exercise, meditate, or spend time on a hobby you enjoy.
- Hang out with friends and family who make you feel good about yourself.
- Laugh.

Supporting Each Other

You and the people you work with can also support each other. This will help to improve your own wellness and the wellness of the staff you work with. Some examples include the following.

- Brainstorm and solve problems as a group.
- Ask for help when you need it, and ask others when you think they may need help.
- Use reflective practice. This involves an environment that promotes self-reflection among staff. Staff are able to come together to talk about the day, question their practice, and learn from experiences and from each other. This involves openness and trust among the staff.
- Have fun together. Celebrate a birthday or special event. Share a laugh.

Growth

Be open to growth – keep an open mind and be curious. Identify areas where you, your program, and your community can grow and learn. Take small steps to work toward your goals. Lifelong learning means being open to learning new things beyond formal education. It involves taking workshops, reading books, watching videos, learning from each other, and learning from the children in your care.

Recommended Resources

If you have questions or would like more information, including recommended resources and websites, you can visit the Saskatchewan Prevention Institute at www.skprevention.ca.

saskatchewan
preventioninstitute
our goal is **healthy** children

1319 Colony Street, Saskatoon, SK S7N 2Z1

Bus. 306-651-4300 Fax. 306-651-4301

Email: info@skprevention.ca

Website: www.skprevention.ca

© Copyright 2020, Saskatchewan Prevention Institute

RESOURCE 3-013

Revised 08/2023