FASD – A Caregiver's Learning Series

# Participant Material:

# Session 1:
# What is FASD?

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Ministry of Children and Family Services

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What is FASD?
Workforce Development Branch

For more information regarding this content visit: https://open.alberta.ca/dataset/3e4bccf4-6758-4e4a-bfb9-f7f063b83962/resource/d3739e94-9dd4-4514-8ba3-67ca1ebff81b/download/GoA-Publications-Guideline.pdf

*Workforce Development respectfully acknowledges that we are located on Treaty 6, 7 and 8 territories, traditional gathering places for diverse Indigenous peoples including the Cree, Blackfoot, Metis, Nakota Sioux, Dene, Ojibway/Anishinaabe, Inuit, and many others whose histories, languages, and cultures continue to influence our community and how we train, learn and work.*

# Acknowledgements

## What is FASD?

This session is part of the *FASD: A Caregiver's Learning Series* and was updated from the *What is FASD (2018)* Caregiver Training module. The session is informed by the Caregiver Competency profile and input from Subject Matter Experts. Workforce Development (WFD) recognizes the people who helped develop this session:

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# What is FASD?

In this session, you will learn what FASD is and how prenatal alcohol exposure (PAE) can impact the whole body, most importantly, the central nervous system, the brain and their many functions. You will also learn about how diagnosis, assessment, and ongoing support improve developmental outcomes for an individual with FASD.

## Learning Objectives

At the end of this session, you will be able to:

- Describe FASD as a lifelong disability.
- Define the words used to describe FASD.
- Explain how brain development and function is impacted by PAE.
- Describe FASD as a brain-based disability rather than a set of *difficult* behaviours.
- Explain the importance of an FASD diagnosis.
- Explain how assessment and providing lifelong supports improve outcomes for a child/youth with FASD.

## Icon Summary

✎ Individual exercise / reflection

👥 Small group activity

💬 Large group discussion

▶ Video

✓ Checklist

## Exercise: Learning about FASD

What do you hope to learn about FASD?

How do you think this information will help you in your caregiving role?

## Why Learn About FASD?

All the current research points to the same conclusion:

**Knowledgeable and skilled caregiving can help those with an FASD “do better.”**

Caregivers can learn about FASD and strategies to support children/youth with FASD. This will make life better for the child/youth with FASD, for caregivers, and for other family members.

With a deeper understanding of FASD, caregivers can:

- Recognize possible traits of PAE in a child/youth. (Caregivers should be aware but cannot make a diagnosis. The traits of FASD overlap with other factors, such as trauma, insecure attachment, and grief.)
- Modify caregiving based on the child/youth’s capacity.
- Work more effectively with CFS staff, specialists, and family members.
- Help the child/youth to achieve positive developmental outcomes.
- Help the child/youth to avoid negative outcomes of FASD.

Alberta recommends the **FASD Language Guide** to give dignity to people with FASD and their families.

## What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body. Prenatal exposure to alcohol is the cause of FASD.

Each person with FASD has both strengths and challenges. People with FASD need special supports to help them succeed with many different parts of their daily lives (CanFASD, n.d.).

- FASD is a permanent, lifelong neuro-developmental **disability.** Neuro-developmental means it affects brain development.
- There is no cure or “growing out of it”. A child with FASD will become a youth with FASD and grow up to be an adult with FASD.

### The Language of FASD

As you learn about FASD, it is important to be aware of the different words that are used.

In this training we use the terms PAE and FASD. These are Canadian terms and definitions.

- **FASD** (fetal alcohol spectrum disorder) is a diagnostic term. It describes the range of disabilities and birth defects that result from **PAE.**
- **PAE** (prenatal alcohol exposure) describes the events that can lead to FASD, which is exposure to alcohol in the womb. Not every person who has disabilities resulting from PAE has a diagnosis of FASD.

## Three Categories for Diagnosis

In Canada, three categories are used for the diagnosis of FASD:

- FASD with Sentinel Facial Findings (SFF). This means that the three facial features associated with PAE are present: short palpebral fissures, smooth philtrum, and thin upper lip.
- FASD with no sentinel facial findings (SFF). This means that the three facial features associated with PAE are NOT present.
- At risk for Neurodevelopmental Disorder and FASD associated with PAE.
  - This is NOT a diagnosis; it is a designation.
  - This means the child/youth needs ongoing monitoring and assessment.

If you research FASD you will likely come across different language, including:

- FAS (Fetal Alcohol Syndrome)
- PFAS (Partial Fetal Alcohol Syndrome)
- ARBD (Alcohol Related Birth Defects)
- ARND (Alcohol Related Neurodevelopmental Disorder)

These terms may be used in other countries. In caregiver training we use the Canadian definitions and terms as outlined above.

***You Cannot See FASD***

Decades ago, the facial features of FASD received a lot of attention in the press. However, most people with FASD are not visibly different. Facial features are present ONLY when exposure to alcohol happened at a very specific time very early during pregnancy. You cannot see FASD.

## How Many People Have FASD?

Prenatal alcohol exposure (PAE) and FASD are the leading known causes of developmental disability in the Western World (CanFASD, 2018).

Emerging studies show 4% of the general population have FASD (Popova, 2018). That's 1.4 million Canadians!

This also means that:

- There are approximately 174,000 Albertans with FASD.
- Each year, about 600 babies born in Alberta will eventually meet criteria for an FASD diagnosis (Government of Alberta, n.d.).

### Children/Youth with FASD in Care

- An estimated 3-11% of children/youth in care in Alberta have an FASD diagnosis (Popova, Lange, Burd, & Rehm, 2014). Since not all children/youth with FASD have a diagnosis, the real number may be higher.
- Children/youth with a diagnosis of FASD in Alberta are more likely to be involved with Child Intervention.
- From 2005-2011, Child Intervention Services were accessed more by those with FASD (32-37%/year) than those that did not have a FASD diagnosis (1-2%/year) (CYDL, 2016).
- In a six-year period (2005-2011), nearly half (48%) of children/youth with a diagnosis of FASD were involved with Child Intervention at some point (CYDL, 2016).

### Not Everyone with FASD is Diagnosed

These estimates are probably low because not everyone with FASD gets a formal diagnosis. **FASD is "hidden disability."**

PAE must be confirmed to make a diagnosis of FASD. This is not always possible. There are many other reasons a diagnosis may be missed. These include (but are not limited to):

- Lack of resources
- Systemic challenges
- Waitlists
- Racism

***Cost of FASD***

The estimated annual cost of FASD in Alberta is **$927.5 million**. This includes the cost of health, social, and correctional services. It also includes productivity losses and other costs (fasd.alberta.ca).

## Video: PAE and the Developing Brain

Jot down key messages and/or questions you have from this video.

**Check it out!**

If you want to watch the PAE and the Developing Brain video again or share it with others, you can find it here:

https://www.engagingalllearners.ca/il/supporting-students-with-fasd/

# PAE and Fetal Development: What Happens?

Alcohol passes easily from a pregnant person's body to a developing fetus. Alcohol that enters the developing fetus' bloodstream affects the whole body. Alcohol may interfere with brain development and with development of other critical organs, structures, and systems.

Alcohol molecules can enter developing cells in the fetus and:

- Change the growth and migration of cells
- Reduce the number of pathways or connections between cells
- Dehydrate cells
- Change structure of cells
- Delete cells

***This happens because the alcohol molecules enter the cell which is mostly made of water. When alcohol molecules leave the cell, they take the water out of the cell with them. Alcohol dehydrates cells.***

## FASD is Different for Every Person

Several factors influence the type and extent of injury that PAE causes, including:

- When was alcohol consumed during pregnancy, in relation to fetal development?
- How often was alcohol consumed during pregnancy?
- How much alcohol was consumed at a time? Binge drinking is more likely to affect the fetus.
- Is the pregnant person's metabolism fast or slow? How does their body tolerate alcohol? What medical conditions do they have? Are they already dehydrated or malnourished?
- It the fetus's metabolism fast or slow?
- What social and emotional factors affect the pregnant person? For example:
    - Access to medical care
    - Family violence
    - Poverty
    - Homelessness
    - Challenges with employment
    - Mental health

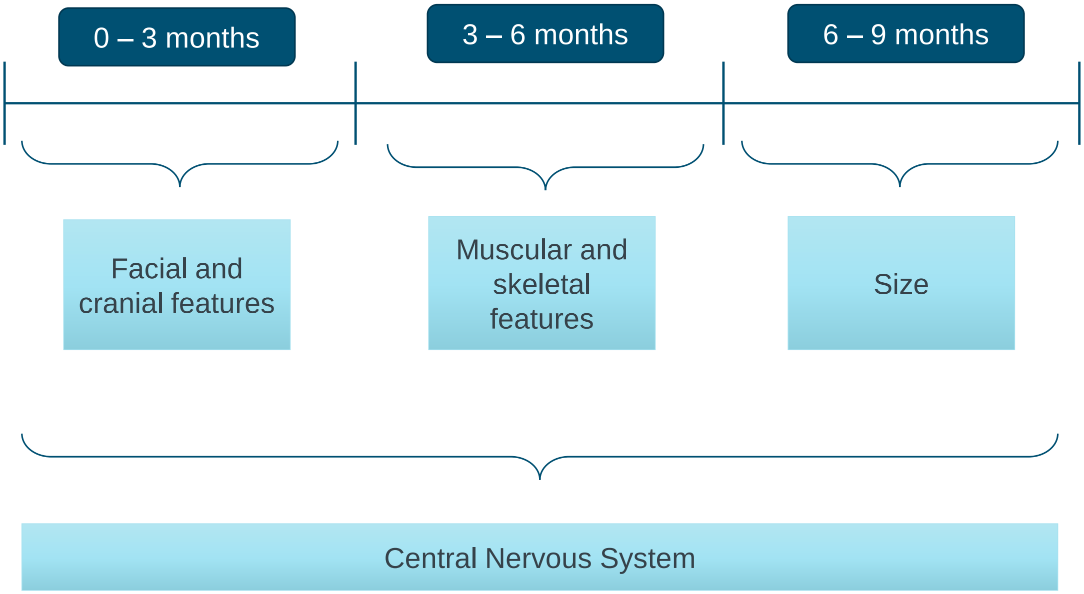
These factors are different for every pregnant person and every pregnancy. Therefore, prenatal alcohol exposure impacts every fetus differently. This is why PAE can cause many different types of disabilities.

## Timing of Alcohol Exposure

The organs, structures and systems that are most at risk of injury from PAE are the ones that are under development at the time of alcohol exposure. For example:

- The facial and cranial (skull) features are most at risk during the first three months of pregnancy.
- The **brain and spinal cord** (i.e., the central nervous system) **are developing throughout the entire pregnancy**. This means that the brain and spinal cord are most vulnerable to potential injury caused by prenatal alcohol exposure.
- While no two people with FASD experience the same disability to the same degree, all people with FASD have some brain dysfunction resulting from PAE.

***What is Developing During Pregnancy?***



***FASD is a Hidden Disability***

Most people with FASD do not have facial features that make them look different. Research suggests that these facial features only occur if alcohol is consumed on days 19-21 of the pregnancy.
**That's only 3 days!**

# Executive Function

During pregnancy, the brain of the fetus is constantly developing. Thus, the brain is at risk at all times when alcohol is consumed during pregnancy.

The brain grows from the bottom up – which means the parts of the brain that are the most vulnerable to PAE are those that develop last. The front of the brain is especially vulnerable. This part of the brain is responsible for executive function.

Executive function is a set of complex thinking processes. Executive function gives us the ability to plan ahead, meet goals, use self-control, follow multi-step directions, and stay focused despite distractions. These skills help our brains prioritize tasks, filter distractions, and control impulses.

Executive function uses several thinking processes at the same time. These thinking processes include:

- Working memory
- Impulse control
- Flexible thinking
- Organizational skills
- Temporal ordering and sequencing (keeping track of the order and sequence of events)
- Internalizing language (so that you can speak naturally without thinking about it)
- Attention and effort

People with FASD often have challenges with some or all of these brain functions.

## Video: Executive Function

Jot down key messages and/or questions you have from this video.

**Check it out!**

You can access the video at:

https://www.albertafamilywellness.org/resources/watch/executive-function

## Primary Disabilities

PAE causes a range of disabilities. **Primary disabilities** are the disabilities and characteristics directly caused by PAE. They are permanent and will last a lifetime.

Dr. Anne Streissguth describes a primary disability as “*a functional deficit that is the result of permanent brain injury*.” Primary disabilities are permanent and last across the person’s lifetime.

There are several primary disabilities that may commonly result from PAE. However, it is important to remember that every individual with FASD is unique. This means that every person with FASD:

- Has a unique set of disabilities
- May experience their disability differently from others with the same disability
- May function higher or lower on a spectrum for each disability
- May function differently in different settings

There is no such thing as a typical FASD diagnosis. It will look and be experienced differently for every person with FASD.

Below is a list of some common primary disabilities that may result from PAE. The disabilities are organized by the four areas of development (although listed separately, these areas of development overlap):

Thinking

Social

Emotional

Physical

While it is important to be aware these challenges may occur, don’t look for them. As you know, every person with FASD is different and even though these challenges are common, not every person with FASD will experience them or experience them to the same degree.

## Thinking

Thinking

While these differences may be present, it is important to remember that not all people with FASD experience these challenges with thinking. Not all people with FASD have low intelligence; many are within or above the normal range of intelligence.

### *Challenges with Abstract Concepts*

Abstract thinking requires the ability to understand relationships and ideas that are not tied to physical objects. Abstract concepts can change or vary in different situations. Abstract thinking helps us to recognize patterns and relationships. This helps with understanding our world. Abstract thinking is important for executive function, which we will talk about later.

People with FASD often have challenges with abstract concepts and they may demonstrate the following characteristics:

- Does not understand consequences
- Does not apply learning to new situations
- Does not understand cause-and-effect
- Has challenges understanding similarities and difference

### *Challenges with Working Memory*

Working memory allows us to hold information in mind temporarily and use it to complete tasks. For example, your working memory allows you to hold a phone number in mind and dial it at the same time.

Individuals with FASD often struggle with working memory. This can result in challenges making judgements, making the “right” decisions, and following through with plans.

Working memory is different from short-term memory and long-term memory. A child/youth with FASD may remember tiny details from years ago. They may remember where you parked your car this morning. This is because their long-term memory works fine. However, they may have trouble using information in the moment because of limitations with working memory. This can make it hard to follow a long conversation, complete chores, and many other tasks.

### *Challenges with Judgement*

Judgement is the ability to consider information to make a decision. It is also the ability to come to sensible conclusions. “Sensible” means how most people with healthy thinking would decide.

Judgement is an abstract concept that requires coordination of many executive functions. FASD can make it challenging to predict outcomes that will occur because of someone’s action.

### ▶ *Challenges with Math*

Many ordinary things in life require math skills. This includes telling time, using money, setting and following schedules and routines, and many others.

Math is very abstract and requires a higher level of thinking and reasoning. Math is challenging for many people with FASD.

### ▶ *Challenges Paying Attention*

The ability to pay attention means we can focus on a task and not be easily distracted. It means we can concentrate on one part of our environment and keep other parts in the background.

Someone with FASD may be very easily distracted. They may not have the ability to filter out environmental or emotional distractions. They may be very sensitive to sensory stimuli (noise, sound, movement, touch, etc.)

### ▶ *Learning Differences*

Children/youth generally learn at a rate that is similar to other children/youth of the same age. Children/youth with FASD, however, often experience learning differences.

Learning differences don’t just happen at school. Learning differences can occur in any area of life. Learning differences can be the result of slower, inconsistent cognitive and auditory processing or decreased mental stamina. Thinking and learning can be tiring for those with FASD!

## Social

Social

### *Challenges Communicating (Receptive Language)*

Communication can be broken down into two main skills:

- Receptive language is the ability to understand the language of others
- Expressive language is the ability to use language

Individuals with FASD often have good expressive language skills but limitations understanding others/what is being said to them (receptive language).

As a result, they may be able to “talk the talk” and sound more capable than they are. For example, they may be able to repeat an instruction but cannot complete the task. They may also have trouble understanding subtle jokes, statements with two meanings, slang, sarcasm or cliches. Individuals with FASD may take things very literally.

### *Social Perception Challenges*

Social perception means being able to read the reactions of other people and change your behaviour responses to “fit”. It means recognizing and responding to subtle social cues.

For example, you realize that your actions are making someone angry, and you decide to stop what you are doing.

Individuals with FASD may not understand another person’s perspective (this is abstract thinking). They may struggle to understand social demands in relationships and in society.

### *Challenges with Impulse Control*

Impulse control is the ability to stop ourselves from certain behaviour responses. Impulses are short, quick feelings and may feel like the “urge” to do something. Impulse control is related to executive function.

Individuals with FASD often have challenges with impulse control They may react immediately to emotional or involuntary impulses. They tend to “act on a whim” rather than thinking things through.

Prenatal exposure to alcohol can reduce the brain’s ability to control impulses. This combined with memory and judgment challenges means that individuals with FASD may look like they are doing the wrong thing much of the time.

## Emotional

Emotional

### Challenges with Emotional Regulation

Many of the challenges with behaviour responses that happen for individuals with FASD result from challenges they have gaining and maintaining control of their emotions. That is, they have challenges regulating their emotions. Emotional regulation is the ability to put a brake on our emotions so we can make an intentional choice on how to respond in an emotional situation rather than reacting immediately.

### Mental Health Concerns

Mental health concerns and diagnoses are more common among persons with FASD.

According to a study by Streissguth et al. (1996), more than 90% of people with FASD had mental health challenges. The most common mental health challenges found in the study were:

- Depression
- Anxiety
- Panic disorder
- Attention deficit hyperactivity disorder (ADHD)
- Post-traumatic Stress Disorder (PTSD)
- Obsessive-Compulsive Disorder (OCD)
- Conduct Disorder
- Self-harm
- Suicide
- Bipolar Disorder

> “The nature of mental health issues in this population may change across the lifespan with alcohol and drug abuse being a serious concern for adults. Compounding this risk is the fact that adults with FASD rarely access mental health services.” ~Dorothy Badry

## Physical

Physical

### *Sensory-Motor Function Differences*

People with FASD might experience challenges with how their senses and motor functions work. This is even more noticeable in younger children.

Sensory-motor differences could be over-stimulation or under-stimulation of any of the senses, such as sight, touch, taste, hearing, and smell. It might also affect balance, knowing the position of our head and body, and being aware of the strength of our muscles.

The following are some examples of sensory motor challenges people with FASD may experience:

- Speaking too loudly or not loudly enough
- Stomping around or tiptoeing around
- Being extremely sensitive to anything on the skin
- Everything being too loud for them
- Apparent clumsiness and poor balance
- Challenges with food selection
- Getting into another person’s space
- Filling mouth too full of food
- Sensitive to bright light

### *Sleeping/Eating Differences*

Sleeping and eating are controlled by the brain. If the brain has a disordered pattern of thinking, sleeping and eating can be affected.

Individuals with FASD may have trouble regulating their eating or sleeping patterns. They may not understand why good sleep and nutrition are important. They may eat or sleep too much or too little.

Sleeping differences may include:

- Nightmares
- Wakefulness
- Inability to fall asleep and/or stay asleep
- Too much sleep
- Falling asleep too easily

It’s not that they won’t! It’s that they can’t!

When it comes to eating, individuals with FASD may not receive messages from their brain that say, “You’re full, it’s time to stop eating or Hey, you’re hungry, time to eat”.

Individuals with FASD are often trying to keep up with an unrealistic world of expectations. This can be tiring and affect sleep.

Challenges with brain regulation are often misunderstood as poor behaviour choices. With FASD it’s important to understand it is not that they won’t, it’s that they can’t!

## Video: FASD for Caregivers

In this video, Christine Duteau shares her experience caring for children/youth with FASD.

Note key messages, insights, or questions you have from the video.

**Check it out!**

You can access the video at:

https://vimeo.com/757411940

## Exercise: Through the Disability Lens

Behaviour responses are often very noticeable to others. But remember **behaviour responses are actually “function”**. Individuals with FASD are not choosing their behaviour response. Their behaviour responses come from differences in the brain that result in the disabilities we’ve talked about.

The behaviour response can cause challenges for the individual themselves, but they can also cause challenges for caregivers, peers, teachers, siblings, and any other individuals living or working with that individual. To help children/youth with FASD be successful, we must shift how we think about FASD. We must recognize FASD as a brain-based disability instead of labelling children/youth with behavior *problems*.

What are the benefits to a child/youth with FASD when we view it as a disability?

## Adverse Outcomes

Due to the primary disabilities, people with FASD may experience complex challenges in life. Daily living can be a struggle and negative life experiences may happen more often. Individuals with FASD have a greater risk for adverse outcomes, for example, substance use or trouble with the law.

Adverse outcomes are sometimes called **secondary disabilities**.

Adverse outcomes may include (CanFASD):

- Disrupted school attendance (suspension, expulsion, and/or drop-out)
- Inappropriate sexual behaviour
- Involvement with the law (charged and/or convicted of a crime)
- Confinement
- Challenges with independence
- Housing challenges
- Challenges with employment
- Substance use
- Aggressive behaviour responses
- Rigid or resistant behaviour responses
- Low self-concept or low self-esteem
- Victimization

Adverse outcomes can be prevented, reduced, or improved with appropriate supports.

## Protective Factors

Unlike the primary disabilities which are permanent, research shows challenges with daily living and adverse outcomes can be mitigated and perhaps even prevented with appropriate supports.

There is never a guarantee that a person with FASD will not experience these challenges. However, people with FASD have better outcomes when the following protective factors in place (Streissguth et al., 2001):

- Living in a stable and nurturing home and having basic needs met
- Being protected from harm, violence, and trauma
- Being diagnosed and assessed
- Having supports as early as possible

When caregivers understand FASD, it helps reduce or prevent adverse outcomes.

As you can see, caregivers have an important role to play. You can help reduce or even prevent adverse outcomes for children/youth with FASD in your care.

# The Importance of Diagnosis and Ongoing Assessment

**Diagnosis** is the process of determining if an individual has FASD. It is critical for improving outcomes for children/youth with FASD. Diagnosis:

- Opens doors to supports; Helps children/youth with FASD get lifelong services and supports for their unique needs.
- Provides hope for the child/youth and their families and caregivers.
- Helps caregivers and other people in the child/youth's life understand the child/youth's responses to their environment and challenges. (If the child/youth becomes involved with the legal system a diagnosis may help with the understanding of Judges, Lawyers and others involved; can change the conversation in these settings).
- Helps provide supports for transitions such as: starting school, progressing from elementary to junior high and junior high to high school, as well as high school into adult life.
- Helps prevent or reduce adverse outcomes
- Helps with pre- pregnancy counseling to prevent future FASD cases (Guidelines Journal, CMA).

### Early Diagnosis Means Better Outcomes

Research has found that individuals with FASD have better outcomes when they are diagnosed younger (Streissguth, 2004). However, diagnosis often does not happen until a child is in elementary school. This is when the signs and symptoms of FASD become more apparent.

A diagnosis may or may not change the caregiver family's response or day-to-day care of the child/youth. Caregivers may already be aware of the child/youth's struggles. They may also suspect the reason for the child/youth's struggles. However, what **will** change is how others respond to the child/youth and access to supports, both now and as the child/youth grows up and becomes an adult.

## How FASD is Diagnosed

Diagnosing someone with FASD can be a long and complex process. Diagnosis is based on a collaborative approach.

While early diagnosis is ideal, individuals are not usually diagnosed with FASD until they are in elementary school or even later. Reasons for delayed diagnosis include: long waitlists for diagnosis, accessibility challenges, community isolation, lack of resources, the parents also have FASD, or concerns were not apparent until the child entered school.

There is not one single test that is used to diagnose FASD. A diagnosis of FASD requires:

- A multidisciplinary team that may include a physician, psychologist, social worker, occupational therapist, speech and language specialist.
- A complex physical and neurodevelopmental assessment.

## Ongoing Assessment

The signs and symptoms of FASD will continue to change throughout an individual's life. Ongoing assessment makes sure the individual has the right supports at different life stages.

Diagnosis can open doors for additional supports. Assessment is the key to understanding and supporting a person with FASD.

**Assessment** provides insight into a person's strengths and gaps. It is ongoing and required throughout the lifetime of an individual with FASD to **understand where gaps are widening and where to focus supports**.

Assessment:

- Informs caregivers and other members of the child/youth's support network (e.g., caseworkers, teachers) about the child/youth's strengths and challenges.
- Helps the network identify the best ways to support and encourage the child/youth.
- Helps the network know how to best shape the child/youth's environment. The key to positive outcomes is in providing a supportive environment for the individual with FASD.
- Provides recommendations to address the child/youth's unique challenges and strategies to build on their strengths.

Ongoing assessment helps caregivers to provide supports on a day-to-day basis as well as during times of transition such as when a child starts school, a youth progresses from junior to high school, or when a youth transitions to adult life.

## Video: FASD for Caregivers

In this video, Christine Duteau shares her experience caring for children/youth with FASD.

Note key messages, insights, or questions you have from the video.

**Check it out!**

You can access this video at:

https://vimeo.com/757422950

# Action Plan

As a result of this session, I will . . .

### *Start*

### *Continue*

### *Stop*

### *Skill Development*

I will develop my skills in the following areas:

# Resources

## Websites and References

- CanFASD: Canada FASD Research Network - https://canfasd.ca/
- Dry9 - https://dry9.drinksenseab.ca/
- Edmonton Fetal Alcohol Network – https://edmontonfetalalcoholnetwork.org/
- Edmonton Regional Learning Consortium - https://www.engagingalllearners.ca/il/supporting-students-with-fasd/
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- FASD Network, Saskatchewan - https://www.saskfasdnetwork.ca/
- FASD Alberta Network – www.fasdalberta.ca
- FASD United - https://fasdunited.org/
- Fetal Alcohol Spectrum Consultation, Education and Training Services (FASCETS) - https://fascets.org/
- Fetal Alcohol Spectrum Disorder (FASD), Government of Alberta - https://www.alberta.ca/fetal-alcohol-spectrum-disorder-fasd.aspx
- Language Guide Promoting dignity for those impacted by FASD - https://www.fasdcoalition.ca/wp-content/uploads/2016/10/LAEO-Language-Guide.pdf
- Language Matters: Talking about Fetal Alcohol Spectrum Disorder (FASD) - https://canfasd.ca/wp-content/uploads/2019/11/3-LanguageImages-Matter-5.pdf
- Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD), British Columbia Ministry of Education - https://www.fasdoutreach.ca/
- The FASD Success Show – www.fasdsuccess.com

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FASD – A Caregiver’s Learning Series

# Participant Material:

# Session 2: FASD Across the Lifespan

Ministry of Children and Family Services

January 2023 | WORKFORCE DEVELOPMENT

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Children and Family Services, Government of Alberta
January 2023
FASD Across the Lifespan
Workforce Development Branch

For more information regarding this content visit: https://open.alberta.ca/dataset/3e4bccf4-6758-4e4a-bfb9-f7f063b83962/resource/d3739e94-9dd4-4514-8ba3-67ca1ebff81b/download/GoA-Publications-Guideline.pdf

*Workforce Development respectfully acknowledges that we are located on Treaty 6, 7 and 8 territories, traditional gathering places for diverse Indigenous peoples including the Cree, Blackfoot, Metis, Nakota Sioux, Dene, Ojibway/Anishinaabe, Inuit, and many others whose histories, languages, and cultures continue to influence our community and how we train, learn and work.*

# Acknowledgements

### Caregiver Training: FASD Across the Lifespan

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Every effort has been made to provide acknowledgement of original sources. If there is content that has not been acknowledged accurately, please notify WFD so appropriate corrective action can be taken.

# Table of Contents

# FASD Across the Lifespan

In this session, you will learn how prenatal alcohol exposure (PAE) impacts development across the lifespan. You will explore the concept of dysmaturity, the importance of interpreting behavior, and why traditional caregiving strategies may not work with children/youth with FASD. To optimally support an individual with an FASD, our perspectives require a shift to understanding FASD as a brain-based disability. This shift in perspective will set the stage for Session 3.

## Learning Objectives

At the end of this session, you will be able to:

- Explain how prenatal alcohol exposure (PAE) impacts a child/youth's developmental path.
- Define dysmaturity and describe its impact.
- Discuss how our interpretation of a child/youth's behaviour responses impacts how we support them.
- Use strengths-based and growth-oriented language when communicating with others about children/youth with FASD.
- Identify ways to improve developmental outcomes for children/youth through the lifespan.
- Describe the systems that caregivers work with, the challenges that can happen, and how to advocate for the needs of the child/youth.

## Icon Summary

Individual exercise / reflection

Small group activity

Large group discussion

Video

Checklist

## Exercise: Review of *What is FASD?* session

List three key things you learned and one outstanding question you have from Session 1: *What is FASD?*

Share and discuss with your group and from the lists you shared, work together to identify one key take away and one question your group wants to share with/ask the large group.

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## Exercise: FASD video review

How did you feel while watching the videos? What was your reaction?

How did you feel while answering the questions?

How did your feelings impact your ability or desire to answer the questions?

## Video: FASD for Caregivers

In this video, Heather Kleckner shares her experience caring for children/youth with FASD.

Note key messages, insights, or questions you have from the video.

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## FASD Across the Lifespan

As children/youth get older, they are expected to be able to do more and to need fewer supports. As children/youth with FASD get older, though, there is often a gap between what people expect them to do and what they are able to do. Typically, they cannot meet the increasing expectations in the same way that children/youth of the same age without FASD can.

This can be confusing for adults who don’t have knowledge of FASD. Thus, when their expectations for “age-appropriate” behavior responses aren’t met, they may begin to see the behaviour responses of a child/youth with FASD as challenging.

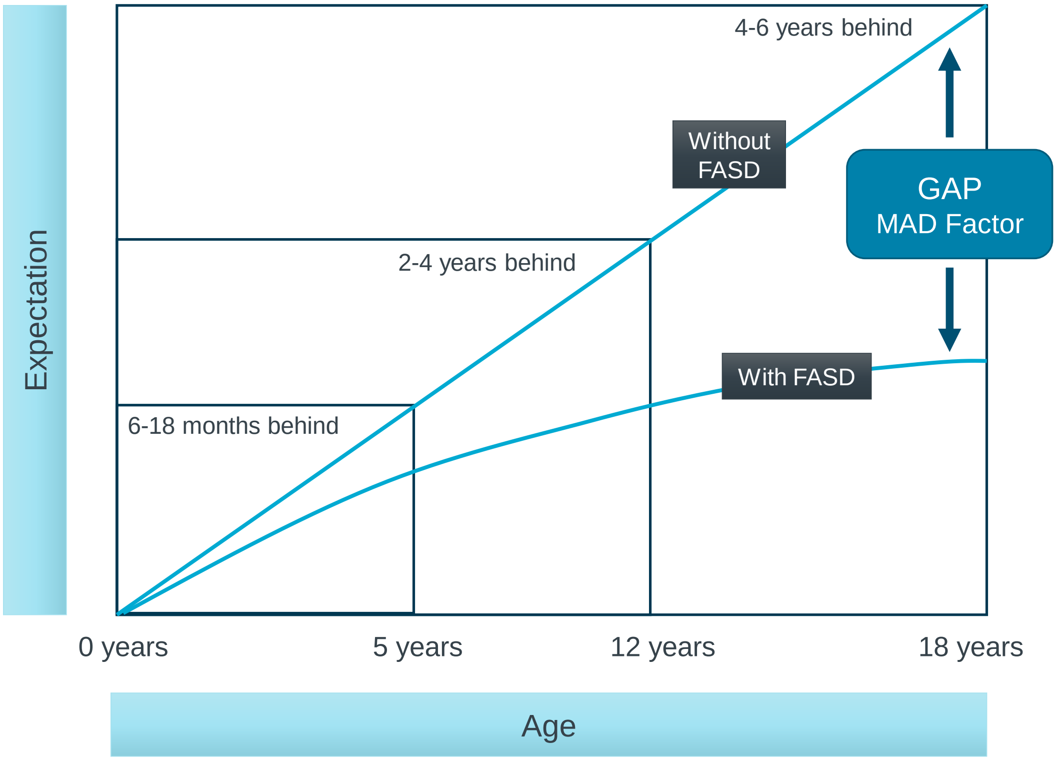
### Dysmaturity

This gap between age-based expectations and developmental abilities is known as **dysmaturity**.

- Typically, as a child/youth with FASD grows up, their disabilities become more apparent.
- Children/youth with FASD may appear to fall further and further behind when compared with their peers.
- The gap between the child/youth’s abilities and other people’s expectations can cause a lot of stress for the child/youth with FASD as well as those around them.

**Dysmaturity**

When a person’s chronological age is higher than their developmental capacity.



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### MAD Factor

The MAD factor (on the right of the chart) happens when we expect children/youth with FASD to “act their age”. They get frustrated, overwhelmed, and MAD, and so do their caregivers. They cannot meet our expectations because of their disability.

We would never expect a child/youth in a wheelchair to just try harder to walk! And we would never tell a child/youth with a hearing impairment to smarten up and listen like everyone else!

**MAD Factor**

The MAD factor describes what happens when we don’t have an understanding of FASD and our expectations do not match the individual’s abilities. The individual and the people around them get overwhelmed, frustrated and MAD!

### Knowledge of FASD

The more we know about FASD, the more we understand the unique developmental path of a child/youth with FASD.

## Primary Disabilities

### Thinking

- Challenges with abstract concepts
- Challenges with working memory
- Challenges with judgment
- Challenges with math
- Challenges paying attention
- Learning differences

### Social

- Challenges communicating (receptive language)
- Social perception challenges
- Challenges with impulse control

### Emotional

- Challenges with emotional regulation
- Mental health concerns

### Physical

- Sensory motor function differences
- Sleeping/eating differences

## Infancy and Early Childhood: 0 – 5 Years

During this stage, children with FASD often behave like children of the same age.

In the early years, it's normal for some children to be ahead of or behind others in accomplishing tasks. We also have fewer expectations of young children. As a result, developmental delays are harder to diagnose and may be missed.

Diagnosis may also be missed because the developmental delays seen in FASD overlap with those seen in children who experience abuse, trauma, and neglect. As a result, caregivers may feel the child's challenges will improve with time and love.

By the end of early childhood, children with FASD may show more obvious signs of developmental delays. They may be 6 to 18 months behind other children in some of their abilities.

We might see the following among children 0-5 years old:

**Areas of Development**

Disabilities and challenges associated with FASD can be described across the following four areas of development:

- Thinking
- Social
- Emotional
- Physical

### Thinking

- Language delays
- Challenges making transitions
- Challenges making simple choices

### Social

- Charming
- Friendly
- Overly attention seeking

### Emotional

- Excessive crying
- Irritability – babies may be difficult to soothe and comfort
- Easily overwhelmed by sound and/or light

### Physical

- High need for touch
- Challenges with coordination
- Small head circumference
- Low muscle tone
- Sleep disturbances
- Delays including walking and toilet training

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## Middle Childhood: 6– 12 Years

When children begin school, the disabilities associated with FASD may become more noticeable. This is because expectations on children begin to grow at this age. Also, school-age children with FASD are seen in relation to their peers without PAE.

Typically, we raise expectations and lower supports at this age and stage.

The gap between expectations and ability starts to become wider in about grade 3. This is when we expect children to apply what they have learned instead of just remembering information.

We might see the following among children 6-12 years old:

### Thinking

- Challenges with expressive and receptive language
- Challenges initiating and ending activities
- Daydreaming
- Makes up imaginary experiences to compensate for loss of memory
- Challenges making good choices
- Gets stuck or gives up easily
- Disorganized
- Challenges with time and money
- Challenges making simple choices
- Confuses fantasy and reality
- Forgets the rules

### Social

- Challenges understanding subtle facial expressions.
- No sense of personal space/boundaries.
- Plays with younger children
- Often accused of lying and stealing.
- Easily influenced
- Challenges sharing or cooperating
- Challenges with social skills
- Passive in response to challenging situations.

### Emotional

- Easily over-stimulated
- Can tune out
- Easily discouraged
- Irritable
- Nervous
- Cries often
- Very quiet and withdrawn
- Mental health challenges

### Physical

- Easily tired
- Hyperactive
- Delayed growth
- Bone, joint, muscle differences
- Small height and/or weight

## Adolescence: 13 – 18 Years

By the time a youth with FASD reaches adolescence, they may be 4 or more years behind the developmental level of their peers. They may have a range of challenges in social, cognitive, and emotional skills.

We might see the following among youth 13-18 years old:

It is important to “think younger” when setting expectations for a child/youth in your care.

### Thinking

- Challenges managing time, money, relationships, hygiene, and schedules.
- Challenges with logic
- Focused on self (egocentric).
- Does not learn from modeled behaviours.
- Does not learn from experiences.
- Limited judgment.
- Blames others.
- Cannot balance the present with the future.

### Social

- No fear of strangers
- Take things at face value
- May be used as a scapegoat or manipulated by others.
- Limitations with self-awareness.
- Limitations with awareness of or empathy for others.
- Challenges with boundaries
- High demand for attention

### Emotional

- May get “stuck” in arousal.
- Absorbs the emotion in the room.
- May overreact.

### Physical

- Malformation of joints, limbs, and fingers
- Limitations with coordination or balance
- Small is size/weight
- Challenges with vision and hearing
- Heart defects and problems with kidneys and bones
- Sexualized behaviours without sexualized understanding

## Video: FASD for Caregivers

In this video, Heather Kleckner shares her experience caring for children/youth with FASD.

Note key messages, insights, or questions you have from the video.

Classification: Protected A

## Adulthood: 18+

**FASD is a lifelong disability**. Children/youth with FASD grow into adults with FASD. They will continue to struggle with the same kinds of challenges. As adults, they will need ongoing support if they are to survive and thrive.

Although people will view them as independent adults, they will continue to have all the challenges of living with a brain injury.

The sooner supports are provided to a person with FASD the more effective they will be at reducing the adverse outcomes of the disability. Supports help to create a positive path to the future.

Providing supports early helps to normalize the experience of receiving supports. This can help to reduce feelings of stigma and isolation.

We might see the following among adults with FASD:

- Does not make transition to adulthood without support
- Language skills hide lack of understanding
- Easy to influence or manipulate
- Cannot get things done – appears unmotivated and lazy
- Challenges with memory
- Unable to make simple predictions
- May not understand humour
- “Talks the talk” but cannot follow through
- Challenges with self-direction, self-control, motivation, and discipline
- At high risk for adverse outcomes: mental health challenges, addictions, etc.
- Employment challenges

**Check out this video: Morgan Fawcett on Living with FASD (7:04)**

https://www.youtube.com/watch?v=K0VrkLQfkFg

In this video, Morgan reflects on his experiences as an adult living with FASD.

Note: Morgan speaks negatively about his mother at one point. Acknowledge this is his perspective but as caregivers it is important for us to always be respectful of birth parents.

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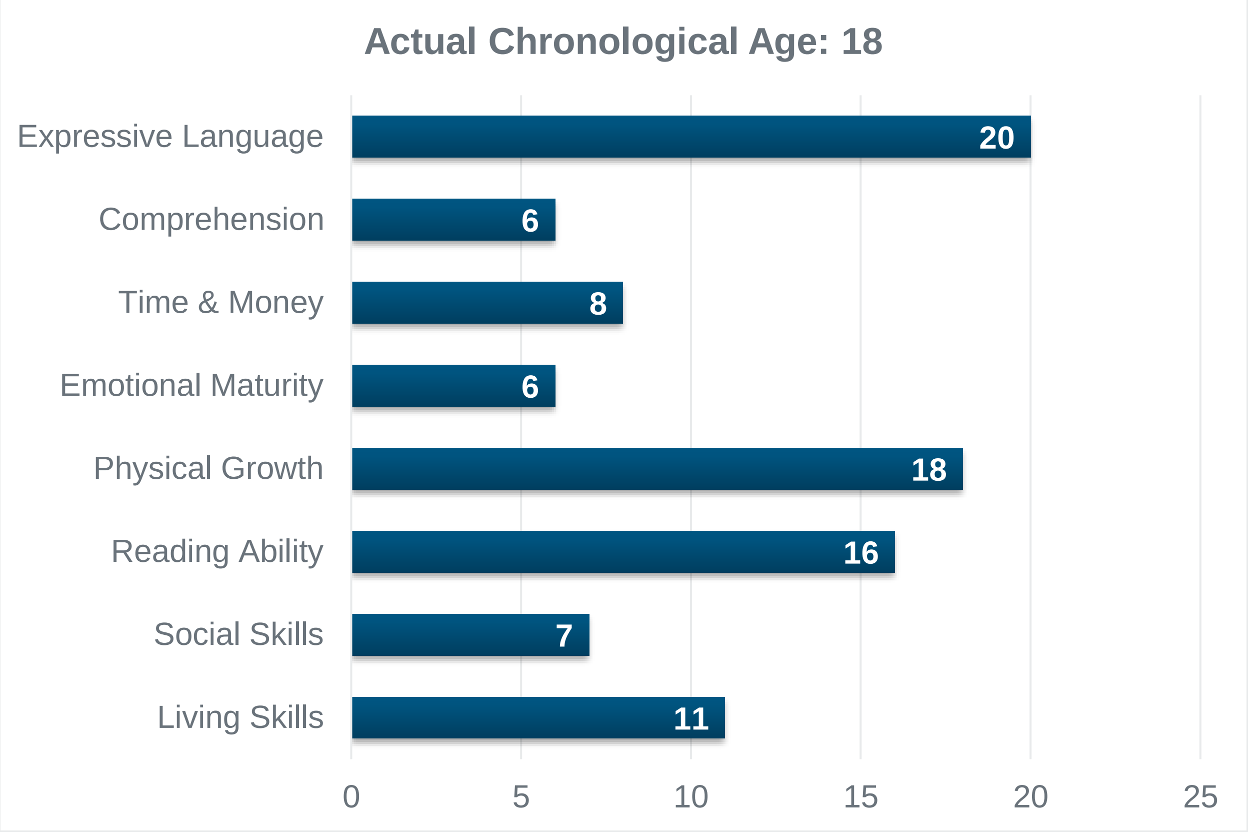
## Exercise: Dysmaturity in Adulthood

The following graph (from Dr. Anne Streissguth) provides an example of the developmental abilities of an 18 old youth with FASD. The numbers on the bottom represent the developmental age level.

With your group, discuss the impact of the gap between the young adult’s actual age and the developmental age for each skill.



## Shifting Perspectives: An FASD Informed Lens

How we think about people with FASD is important. As a caregiver there are some shifts in thinking that will help you to be more successful. These shifts are:

- Brain not blame (focus on the function of behaviour responses)
- Use strength-based language

### Brain Not Blame[1]

The first shift is to move from focusing on the child/youth's behaviour responses to focusing on how the child/youth's brain works.

Instead of judging the behaviour response, ask yourself:

- What is the child/youth's brain doing?
- What needs or goals does the behaviour response express?
- How can we work with the child/youth to find solutions?

Behaviour is communication

The FASD Support Network of Saskatchewan (2007)[2] suggests the following shifts in interpretation:

| Behavioural Interpretation | Could be interpreted as… |
|---|---|
| Bad, annoying | Frustrated; challenged |
| Lazy, unmotivated | Trying hard; tired of failing |
| Lying | Storytelling; filling in the blanks |
| Fussy | Oversensitive |
| Trying to get attention | Needing contact; support |
| Inappropriate | Displaying behaviours of a younger person |
| Not trying | Exhausted or not able to get started |

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[1] Used with permission of Professionals without Parachutes.

[2] "Fetal Alcohol Spectrum Disorder: A guide to awareness and understanding," FASD Support Network of Saskatchewan, Inc., 2007, accessed February 14, 2018. http://www.skfasnetwork.ca/pdf%20files/fasd_guidecomplete.pdf

## Video: Brain Structure Versus Brain Function

Jot down key messages and/or questions you have from this video.

**Check it out!**

If you want to watch the Brain Structure Versus Brain Function video again or share it with others, you can find it here:

https://www.engagingalllearners.ca/il/supporting-students-with-fasd/index.php?id=2

## Use Strengths-Based Language

How we talk about people with FASD shapes the way we think about them. Our language changes our perception. If we are always talking about challenges, we will find mostly challenges. However, if we are also talking about solutions, we can find those too.

How we talk about people with FASD also influences the people who support the child/youth.

| From | To |
|---|---|
| FASD child | Child with FASD |
| Bad | Hurt |
| Won't | Can't (to "How could they do it?") |
| Acting out | Expressing a need |
| Oppositional | Facing a roadblock |
| Change the person | Change the environment |
| Problems | Solutions |
| Deficit | Growth |

An important language shift is to focus on the child/youth's strengths and ability to grow. This shifts us away from thinking only about what is missing.

This does not mean we ignore the disabilities. However, we will be more successful when we build on strengths and identify solutions.

Talking about strengths and growth helps everyone feel more positive about the child/youth. It also helps the child/youth feel better about themself. Use strengths-based language when talking to professionals (e.g., teachers, psychologists), family and friends, and the child/youth.

Informed by challenges; built on strengths.

Classification: Protected A

## Exercise: Communicating about a Child/Youth with FASD

Review the following scenario with your groups and identify suggestions for how you would respond to Josh's teacher. Use strength-based language. Focus on function instead of Josh's behaviour response.

*Josh is 8 years old. He has been in your care for 8 months.*

*You get a call from Josh's grade 3 teacher. He is concerned that Josh does not focus in class. The teacher says Josh frequently daydreams. He ignores directions; he constantly seeks attention by acting silly. He often falls out of his desk and fumbles with his pencil. This makes the other kids laugh.*

*The teacher has tried different strategies with Josh. He has given Josh quiet time in the reading nook. He has sent Josh to the office. He has taken away Josh's tablet time. But Josh still doesn't pay attention or behave appropriately.*

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## Exercise: Interpreting Behaviour Responses Through a Disability Lens

Sometimes parents, grandparents, teachers, and others do not understand FASD; it's easy for them to misinterpret the behaviour response of a child/youth with FASD. For each of the behaviour responses below, identify how someone might misinterpret them if they don't know about FASD.

| Behaviour Response | Might be interpreted as… | Disability lens interpretation |
|---|---|---|
| Does not sit still, very physical | | |
| Trying to get other's attention | | |
| Taking objects that belong to others | | |
| Saying things that others do not think are true | | |
| Missing social cues, focuses on self | | |
| Strong emotional reactions | | |

Classification: Protected A

## Fostering Interdependence: The Snow Plow Caregiver

Understanding FASD allows you to be proactive instead of reactive. Knowing the individual strengths and needs of a child/youth with FASD helps you to have realistic expectations. Solutions to challenges lie with you and the environment rather than with the child/youth.

Interdependence means being able to accept support. Interdependence is a protective factor that will help children/youth with FASD transition to adulthood. With interdependence, the individual knows how and when to ask for help.

To encourage interdependence:

- Look for ways to “do with” rather than “do for.”
- Provide snow plow caregiving when the child/youth faces obstacles.

### The Snow Plow Caregiver

As you have learned, traditional caregiving approaches are often not effective with children and youth with FASD. Remember: *it is not that they won’t, it is that they can’t*. Our approach to caregiving must take this into consideration.

With snow plow caregiving, the caregiver gets in front of the child/youth with FASD and makes their journey safer and easier. Like a snow plow, the caregiver clears a path through the deep snow, ensuring a safe journey. By limiting obstacles in this way, the child/youth’s feelings of competence increase.

A snow plow caregiver knows the child/youth well enough to recognize potential obstacles. They get in front to clear the way as much as possible. They understand a child/youth with FASD may never be fully independent. However, with someone clearing the path for them, the chance of success increases, and the risk of adverse outcomes decreases.

**Remember:**

You have the opportunity to pave a safe, reliable, path to success for the child/youth.

Classification: Protected A

## Action Plan

As a result of this session, I will . . .

### *Start*

### *Continue*

### *Stop*

### *Skill Development*

I will develop my skills in the following areas:

Classification: Protected A

# Resources

## Websites and References

- CanFASD: Canada FASD Research Network - https://canfasd.ca/
- Dry9 - https://dry9.drinksenseab.ca/
- Edmonton Fetal Alcohol Network – https://edmontonfetalalcoholnetwork.org/
- Edmonton Regional Learning Consortium - https://www.engagingalllearners.ca/il/supporting-students-with-fasd/
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# Appendix: Common Behaviours, Misinterpretations and Characteristics of Students with FASD

The following has been reproduced from *Understanding and addressing the needs of children and young people living with Fetal Alcohol Spectrum Disorders (FASD): A resource for teachers.* This is a reproduction and thus the language does not always align with strengths-based language.

| Behaviour observed | Could be misinterpreted as | Accurate interpretation for FASD |
|---|---|---|
| **Non-compliance** | Doing it purposely and maliciously<br>Attention seeking<br>Stubborn | Difficulty translating verbal directions into action<br>Doesn’t understand<br>May need to have words/processes taught explicitly and repeatedly<br>Needs to become familiar with ways of operating within the school culture to understand expectations |
| **Repeatedly making the same mistakes** | Doing it on purpose<br>Manipulative | Cannot link cause to effect<br>Cannot see similarities<br>Difficulty generalising from one event to another<br>May require screening for hearing difficulties |
| **Often late** | Lazy, slow<br>Poor parenting<br>Doing it on purpose | Cannot understand the abstract concept of time<br>Needs assistance getting organised<br>Limited access to resources such as clocks, phones and other time keeping devices |
| **Not sitting still** | Seeking attention<br>Bothering others<br>Doing it on purpose | Neurologically based need to move while learning<br>Sensory overload<br>Needing alternatives that help calm them while concentrating |
| **Poor social judgment** | Poor parenting<br>Abused child<br>Doing it on purpose | Not able to interpret social cues from peers<br>Not sure what social conventions are appropriate in different contexts<br>Not understanding the implications of actions, so having difficulty with empathy |
| **Overly physical** | Doing it to bother other people<br>Deviancy | Hyper- or hypo-sensitive to touch<br>Does not understand social cues regarding boundaries |
| **Does not work independently** | Poor parenting/caregiving<br>Doing it on purpose | Chronic memory problems<br>Cannot translate verbal directions into action<br>Does not fully understand the task or expectations |
| **Stealing** | Deliberate dishonesty<br>Lack of conscience | Does not understand the concept of ownership over time and space<br>Immature thinking<br>Unable to generalise what is wrong from one setting to another |
| **Lying** | Deliberate dishonesty | Problems with memory/sequencing<br>Unable to accurately recall events |

| Behaviour observed | Could be misinterpreted as | Accurate interpretation for FASD |
|---|---|---|
| | Lack of conscience | Trying to please by tell you what they think you want to hear |
| **Egocentric** | Selfishness<br>Only cares about self | Only seeing the superficial or concrete level of social behaviour<br>Does not link cause and effect |
| **Volatile** | Poor parenting/caregiving<br>Aggressive nature<br>Short tempered | Exhausted from stress of trying to keep up<br>Extremely over-stimulated |
| **Inconsistent performance** | Not trying hard enough | Chronic short-term memory problems<br>Inability to generalize learning from one situation to another |

FASD – A Caregiver's Learning Series

# Participant Material:
# Session 3: Caring for Individuals with FASD

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Ministry of Children and Family Services

January 2023 | WORKFORCE DEVELOPMENT

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Children and Family Services, Government of Alberta
January 2023
Caring for Individuals with FASD
Workforce Development Branch

For more information regarding this content visit: https://open.alberta.ca/dataset/3e4bccf4-6758-4e4a-bfb9-f7f063b83962/resource/d3739e94-9dd4-4514-8ba3-67ca1ebff81b/download/GoA-Publications-Guideline.pdf

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# Acknowledgements

## Caregiver Training: Caring for Individuals with FASD

This session was updated from the *Caring for Children/Youth with FASD (2018)* module from Caregiver Training. It was informed by the Caregiver Competency profile and input from Subject Matter Experts. Workforce Development (WFD) would like to acknowledge the contributions of the following:

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Every effort has been made to provide acknowledgement of original sources. If there is content that has not been acknowledged accurately, please notify WFD so appropriate corrective action can be taken.

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# Caring for Individuals With FASD

Research shows that a stable home with caregivers who are supported, and who have an understanding of FASD and the importance of community advocacy, can have the most positive influence on a person with FASD. In this final session, you will learn how emotional regulation, building good habits and building competence support better outcomes for children/youth with FASD. You will also learn how the five pillars of stability are necessary to support you and the children/youth with FASD in your care.

## Learning Objectives

At the end of this module, you will be able to:

- Describe some common strengths of children/youth with FASD.
- Discuss the attitudes and approach to caregiving that support better outcomes for children/youth with PAE.
- Identify how connections to culture can support resilience and wellbeing in a child/youth with FASD.
- Identify and apply the most successful caregiving strategies when caring for a child/youth with FASD.
- Apply the five pillars of stability to help a child/youth with FASD succeed.
- Explain why caregiver self-care is important when caring for a child/youth with FASD.
- Develop a personal action plan for self-care.

## Icon Summary

Individual exercise / reflection

Small group activity

Large group discussion

Video

Checklist

## Review: Learning Successes

What is one success you have had applying your learning from these sessions so far?

What is one question you have about caring for children/youth with FASD?

# Caring for Individuals with FASD

Children/youth with FASD may never become fully independent adults, but they can live healthy, happy, and productive lives with the right support.

Caregivers can make a big difference in the lives of children/youth with FASD. When caregivers understand FASD and use caregiving strategies they can help children/youth with FASD develop skills needed to grow into adulthood while also helping to reduce the risk of adverse outcomes.

The following are the key caregiving strategies for children/youth with FASD that we will discuss:

- Building on strengths
- Supporting emotional regulation
- Creating structure and habits
- Building competence
- Connecting to culture
- Planning for transitions

## Video: Strengths of Children/Youth with FASD

What are some strengths Dan Dubovsky identifies in the video?

Why is it important to look for and use the strengths of a child/youth with FASD?

What questions or thoughts do you have from the video?

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## Building on Strengths

While no two people with FASD are the same, there are some **common strengths** among people with FASD that include the following:

- Friendly
- Likeable
- Kind
- Caring
- Cuddly
- Loyal
- Faithful
- Helpful
- Deep sense of fairness
- Want to do a good job
- Don't hold a grudge
- Persistent
- Highly verbal
- Trusting
- Creative/Artistic
- Musical ability
- Mechanical skills
- Love animals

**Check out this video: Tania Peterman on Living with FASD (4:16)**

https://www.youtube.com/watch?v=_Pe1acd0CHI

In this video, Tania reflects on her experiences as an adult living with FASD.

Even with these common strengths, no two people will experience them in the same way. Each person's personality, temperament, and life experiences shape their unique character.

### Exercise: Building on Strengths

Getting to know the unique strengths of the children/youth in your care is important. If you know their strengths, you can build on them. Building on strengths increases competence and strengthens your connection with the child/youth.

Think of a child/youth in your care (or think of yourself). What are their strengths?

**Remember:**

Won't is often Can't.

Find a way to help them be able to!

How can you use this knowledge to help them build competence in their daily skills (e.g., hygiene)?

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## Supporting Emotional Regulation

Many individuals with FASD have challenges gaining and maintaining control of their emotions. In other words, they have challenges regulating their emotions. This can lead to challenging behavior responses.

Emotional regulation is the ability to manage our emotions so we can choose how to respond in an emotionally-charged situation. Without emotional regulation, our emotions drive our reactions in such situations.

Caregivers must help children/youth with FASD to develop awareness of their emotional state. Caregiver must also teach them how to respond to challenging situations.

A tool that is helpful for caregivers is the green, amber, and red model (or go, wait, stop). This tool helps caregivers identify the best (and worst) times to teach emotional regulation skills.

## Zones of Emotional Regulation

1 **RED ZONE – STOP**
Remove all expectations
Make safety a priority for individual, yourself, and others (the person is in fight or flight and cannot think or reason)

2 **AMBER ZONE – WAIT**
Lower expectations
Make emotional regulation a priority (the person has been triggered and is not available to think or reason clearly)

3 **GREEN ZONE – GO**
Maintain expectations
Build skills and habits (the person is in a positive state of mind and is available for thinking and support)

1 **RED/STOP:**

While in the red zone, people are emotionally driven and unable to think clearly. This is not a time for teaching, threatening, arguing, debating, discussing consequences, or trying to reason.

Do not join the person in the red zone.

Make sure everyone around the person is safe, including yourself. Suggest a calming activity that the person likes to do. Be patient, calm, quiet, and loving.

2 **AMBER/WAIT:**

If a person is in the amber zone, their emotions are rising. Their ability to think clearly decreases. This is when you should focus on quiet, calm relationship building.

3 **GREEN/GO:**

When a person is in the green zone, they are calm, able to think at their best and open to learning. This is the best time to build skills and habits. This is when teachable moments can happen.

Check in on your own emotions and don’t go to the red zone with a child/youth. There can be a danger of physical abuse or allegations of mistreatment when both the caregiver and the child/youth with FASD are in the red zone.

## Exercise: Caregiving in the Zone

For each zone, list behaviour responses (signs or indicators) that tell you a child/youth might be in the:

- Green zone
- Amber zone
- Red zone

How can we help someone move from the amber zone to the green zone?

How can we help someone move from the red zone to the amber/green zone?

Before we can teach an individual with FASD to regulate emotions, we must learn how to do it ourselves. How do you know when you are in the amber zone or red zone?

Be sure your responses to a child/youth's behaviour responses BUILDS relationship rather than DAMAGES it!

How do you get yourself back to the green zone?

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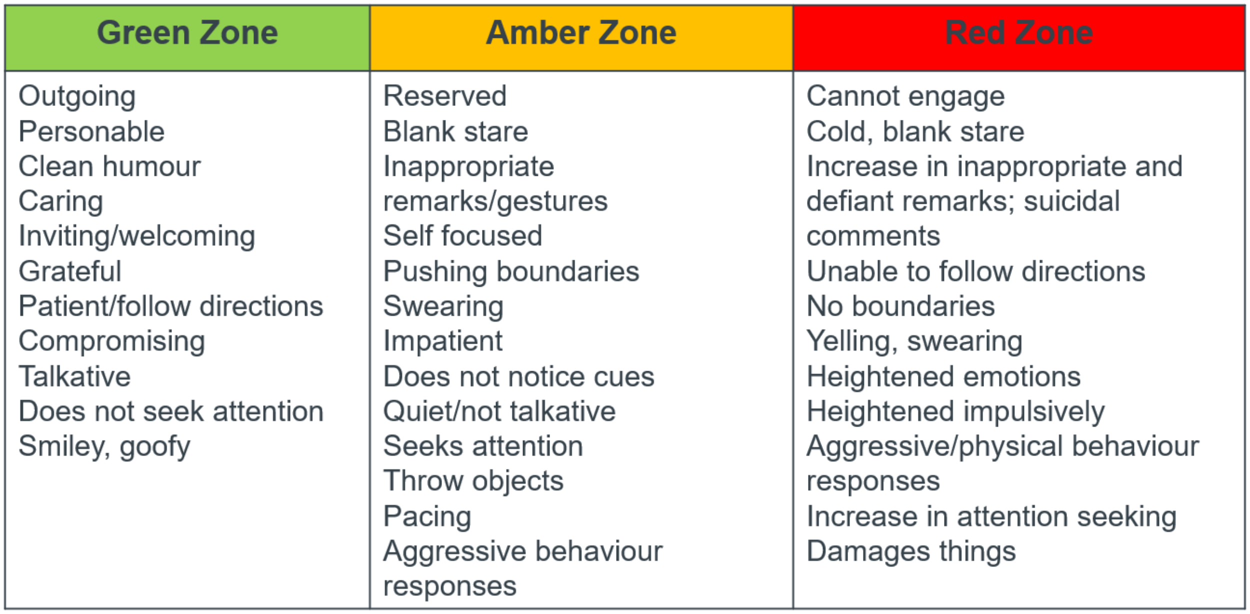

| Green Zone | Amber Zone | Red Zone |
|---|---|---|
| Outgoing<br>Personable<br>Clean humour<br>Caring<br>Inviting/welcoming<br>Grateful<br>Patient/follow directions<br>Compromising<br>Talkative<br>Does not seek attention<br>Smiley, goofy | Reserved<br>Blank stare<br>Inappropriate remarks/gestures<br>Self focused<br>Pushing boundaries<br>Swearing<br>Impatient<br>Does not notice cues<br>Quiet/not talkative<br>Seeks attention<br>Throw objects<br>Pacing<br>Aggressive behaviour responses | Cannot engage<br>Cold, blank stare<br>Increase in inappropriate and defiant remarks; suicidal comments<br>Unable to follow directions<br>No boundaries<br>Yelling, swearing<br>Heightened emotions<br>Heightened impulsively<br>Aggressive/physical behaviour responses<br>Increase in attention seeking<br>Damages things |

## Creating Structure and Building Habits

*“He doesn’t know what to do when he doesn’t know what to do”.*

Children/youth with FASD benefit from a structured environment with clear routines. Structure, routines, and habits help prevent adverse outcomes.

In a structured environment, the “rules” are set. We do the same things in the same order, in the same manner, with the same cues and prompts. Structured routines create strong habits. This leads to better outcomes for children/youth with FASD. Habits reduce the needs for decision-making and setting priorities.

### Key Skills in Adulthood

There are five key skills that are important for adults to be successful:

- Time
- Schedules
- Money
- Hygiene/Health
- Relationships

Many young adults with FASD struggle with these key skills. Each of these skills involves abstract concepts. We know abstract concepts can be challenging for those with FASD.

Children/youth with FASD may require more support and training to learn these skills. Many will require support maintaining these skills as adults.

It is *never* too early to begin to support children/youth with FASD (or any child/youth) to learn these skills. They need consistent support that is appropriate for their age and development level. Skills can build and grow with the child/youth.

Remember that every child, youth, and adult with FASD has unique disabilities. Some may not have challenges with all five skills. Others may struggle with all of them.

## Exercise: Structure and Habits to Develop the Key Skills in Adulthood

Note examples of structures and habits you might use to help a child/youth in each age category develop the key skill (time, schedules, money, hygiene/health, and relationships)

| Age | Structure and Habit |
|---|---|
| **0-5 years** | |
| **6-12 years** | |
| **13-18 years** | |

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## Building Competence: The 3 C’s

***The following was developed by Donna Debolt.***

When teaching children/youth who don’t have FASD, we start by building a connection with them. When a child/youth feels connected, they are more likely to be compliant with their caregiver. With more compliance, we can help them build and strengthen competencies that will last.

This process does not work the same for children/youth with FASD. Here we need to start by helping the child/youth build social, emotional, and/or physical competencies. As these improve, the child/youth will feel more comfortable with an activity or situation. With more comfort comes compliance and their connection with you builds. They develop a love and trust for you.

When supporting the growth and development of children/youth with FASD:

- Start where they’re at right now.
- Start with what they’re good at.
- Introduce requests and new tasks when they are feeling competent, calm, and successful.
- Always pay attention to their emotional state.

Choose CONNECTION over CORRECTION

Over time, this linear model – Build Competence > Create Compliance > Make a Connection -- can become a cycle. A cycle where the positive relationships based on success and skills, creates greater compliance.

## Building Good Days

There are four elements that contribute to building a “good day” for children/youth with FASD.

- Literacy / Numeracy
- Life Skills
- Job Skills
- Service / Volunteering

## Exercise: Good Days

For your assigned element, what are ways you can incorporate it to make a good day child/youth with FASD?

A “Good Day” means good for the child/youth and good for the family.

# Connecting to Culture

## Video: Connecting to Culture

In the video Christian Duteau and Heather Kleckner share their experience caring for children/youth with FASD and discuss the benefits of connecting to culture.

Note key messages, insights, or questions you have from the video.

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## Planning for Transitions

Experts used to believe the impacts of FASD would worsen as a child/youth got older. We now know this is not true.

With the right supports, primary disabilities can have much less impact on the child/youth’s life. When we reduce the impacts of primary disabilities, we also reduce the likelihood and severity of adverse outcomes.

If we understand FASD and its impacts, we can build on the child/youth’s abilities. We can access the right supports at the right time.

As a caregiver for a child/youth with FASD, it is important to understand the impact our caregiving may have later in life. Our role is to consider how we can make positive changes now to help the child/youth in the future.

## Exercise: I Can Do This!

Review each item and check off each item you feel ready to do!

- ☐ **Shift my perspective:** Understand that “I won’t” means “I can’t.” Help other people understand this.
- ☐ **Anticipate developmental needs**: Understand the child/youth’s developmental level. Support their development based on current needs.
- ☐ **Promote interdependence vs. dependence**: Let the child/youth know they can count on me to be there. That makes the child/youth feel more secure and confident.
- ☐ **Practice prevention:** Draw from past successes or failures to predict how well the child/youth can handle a situation. Manage triggers that cause the child/youth frustration.
- ☐ **Provide supervision**: Recognize there are places the child/youth cannot go and things they cannot do without some supervision. Supervise yourself or find another responsible person.
- ☐ **Manage expectations:** I don’t set my expectations too low **or** too high for the child/youth. I always look for their comfort zone. I help the child/youth make steady gain while remaining calm. I don’t assume that all expectations need to be lowered.
- ☐ **Limit experiences:** I select experiences within their comfort level. I avoid experiences that cause frustration, shutdown, or rage. I limit distractions as much as possible. I pay attention to things that overwhelm the child/youth. I know what they are capable of and what challenges them. I remember that new experiences overwhelm more quickly.
- ☐ **Build habits:** I do things the same way every time to build habits. I know that routines and habits build confidence and self-esteem. I am careful because I know this applies to bad habits, too!

## Exercise: Do’s and Don’ts of Caring for Individuals with FASD

Brainstorm lists of things caregivers should do and should not do when caring for a child/youth with FASD.

| Do’s | Don’ts |
|---|---|
| | |

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### Do’s

- Make sure someone else is around and take a break for yourself! Stay calm!
- Anticipate needs, get there before the behaviour response becomes challenging.
- Provide positive attention
- Set realistic expectations and increase expectations slowly.
- Make goals achievable, let them master a goal and do well with it before you increase.
- Teach slowly, give many opportunities to learn, be patient, demonstrate, review, re-teach.
- Break skills into small steps, remind often.
- Give lots of positive praise.
- Give down time; not as something negative, like a time out, but as a rest and break.
- Be encouraging. Believe the child/youth really does want to do well.
- Offer help even when not asked for it.
- Maintain support at all times.
- Encourage positive adult relationships.
- Use simple, concrete, specific language.
- Use routines so that everyone gets used to them; structure makes the world make sense.
- Use a timer for transitions.
- Give visual supports such as picture cues.
- Begin conversations with the child/youth’s name and make eye contact.
- Use humour.
- Teach and practice social skills.
- Be careful with your nonverbal communication.

### Don’ts

- Talk, lecture, try to reason.
- Argue, debate, negotiate.
- Get angry or become too authoritarian.
- Be frustrated that you dealt with the same behaviour responses yesterday.
- Ask “why?”
- Increase expectations too fast.
- Moralize, compare, criticize.
- Tell them to calm down.
- Expect the child/youth to be reasonable or to “act their age.”
- Set your expectations too high, or too low.
- Be disappointed or feel frustrated.
- Ask for an explanation of what they were thinking or assume the child/youth is responding out of defiance or non-compliance.
- Use group directions.
- Try to analyze the behaviour responses.
- Expect the child/youth to remember what you said, what happened last time, etc.
- Ignore the child/youth when they start to become anxious.
- See the child/youth as being manipulative, lazy, or sneaky.

# Working with the Systems

## Exercise: Working with the Systems

What have you found that works well when advocating for children/youth with FASD in your care?

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## Stability in Caregiving: Five Key Pillars

We know that stability is very important for the success of children/youth with FASD. This includes a stable home.

Dorothy Badry suggests two main things about stability:

- Stability does not mean just staying in the same place and never leaving.
- For caregivers to provide a stable placement, five key pillars of stability are needed:

1. Training
2. Coaching
3. Respite and Relief
4. Collaboration
5. Grief and Loss

Let’s explore these five key pillars of stability that support caregivers…

## Training

FASD is complex. Research continues to bring us new information. Ongoing training helps caregivers understand the complexities of the disability and keep up with new information.

Training helps caregivers:

- Understand how children/youth with FASD develop.
- View children/youth with FASD positively.
- See how a child/youth's disability creates both strengths and challenges.
- Increases awareness of what works and why.
- Helps caregivers to be effective advocates for children/youth with FASD.

**Caregivers are the keepers of success**

More training = increased understanding = successful, happy children/ youth = happy caregivers

Caregivers that receive ongoing training about FASD feel more confident about their abilities to:

- Parent children/youth with FASD.
- Manage daily routines.

Never be afraid to take training, and never feel that you know all you need to know. You often don't know what you don't know!

**What resources are available to support you in learning more about FASD?**

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## Coaching

Living with a child/youth with an FASD involves unique challenges and opportunities. Caregivers need to know who they can call when facing a challenge. They need effective, nonjudgmental coaching from someone who understands:

- FASD
- The child/youth with FASD
- The stress of caregiving for a child/youth with FASD

Don't ever be afraid or ashamed to call for their help!

There are agencies that specialize in providing **in-home** support and training for families caring for children/youth with FASD. These agencies assess and understand the needs and strengths of caregivers. They also teach and advise family members.

## Respite and Relief

Caregivers often express how challenging it is to parent a child/youth with FASD. It can be physically and emotionally exhausting. Researchers, social workers, and family support workers recognize the emotional, social, and financial costs of caring for a child/youth with FASD.

All caregivers need meaningful respite and relief. Respite and relief decrease burnout, exhaustion, stress, and isolation. Respite and relief increase caregiver well-being.

Asking for respite or relief doesn't look bad, it looks responsible.

### Respite

- Is planned in advance.
- Caregivers feel reassured when they know respite is scheduled.
- Respite workers are on TAP: Trained, Available, Pleasant, and Positive.

### Relief

- Meets emergency situations but can be planned for.
- Is available when needed.
- Planning for relief gives caregivers actions they can take when they feel they can't go on.
- Ensure stability of the placement when things get hard.

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## Exercise: Respite and Relief

What happens to children/youth when caregivers can’t cope?

What happens to caregivers?

What options for respite and relief are you aware of?

What do you do to take a break and care for yourself?

What are you committed to doing to care for yourself?

## Collaboration

- Working with teachers, medical professionals and others in a team approach improves outcomes for children/youth with FASD.
- Structure, consistency, and routine are easier when everyone helping the child/youth are working together.
- Caregivers need to build a community of service providers who understand FASD.
- Open communication, shared goals, and clear roles help to build a strong community of support.
- Everyone helping the child/youth must have the same expectations of what “good outcomes” will look like for that child/youth.

## Loss and Grief

There are many things, events or feelings that might cause caregivers to feel loss and grief. Loss and grief are normal and natural for caregivers. You need permission from yourself and others to do the work of grieving. Loss and grief support work is an ongoing need for caregivers.

***“What will it take to give up what you wish this was to take on what it really is? What might we grieve?”***

- Hopes and dreams
- Self-esteem and competence
- A balanced family system
- Support from family, friends and community
- Companionship – shared caregiving purpose
- Faith
- Financial security
- Privacy (everyone knows your story)
- Freedom
- Social network
- Ability to share in accomplishments
- The loss of affected loved ones through separations, suicide, leaving the family

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## Exercise: Loss and Grief

Think about the losses we discussed. What are the impacts of these losses?

Ask yourself, “How will I let go of “what was”, so I can take care of “what is?”

What support do you need to move through the grief you feel?

## Video: FASD for Caregivers

In these videos Christian Duteau and Heather Kleckner share their experience caring for children/youth with FASD.

Note key messages, insights, or questions you have from the video.

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## Action Plan

As a result of this module, I will . . .

### *Start*

### *Continue*

### *Stop*

### *Skill Development*

I will develop my skills in the following areas:

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# Resources

## Websites and References

- CanFASD: Canada FASD Research Network - https://canfasd.ca/
- Dry9 - https://dry9.drinksenseab.ca/
- Edmonton Fetal Alcohol Network – https://edmontonfetalalcoholnetwork.org/
- Edmonton Regional Learning Consortium - https://www.engagingalllearners.ca/il/supporting-students-with-fasd/
- FASD clinic card https://canfasd.ca/wp-content/uploads/publications/AB-FASD-Clinic-FAQ-card.pdf
- FASD Network, Saskatchewan - https://www.saskfasdnetwork.ca/
- FASD Alberta Network – www.fasdalberta.ca
- FASD United - https://fasdunited.org/
- Fetal Alcohol Spectrum Consultation, Education and Training Services (FASCETS) - https://fascets.org/
- Fetal Alcohol Spectrum Disorder (FASD), Government of Alberta - https://www.alberta.ca/fetal-alcohol-spectrum-disorder-fasd.aspx
- Language Guide Promoting dignity for those impacted by FASD - https://www.fasdcoalition.ca/wp-content/uploads/2016/10/LAEO-Language-Guide.pdf
- Language Matters: Talking about Fetal Alcohol Spectrum Disorder (FASD) - https://canfasd.ca/wp-content/uploads/2019/11/3-LanguageImages-Matter-5.pdf
- Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD), British Columbia Ministry of Education - https://www.fasdoutreach.ca/
- The FASD Success Show – www.fasdsuccess.com

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