Module 2

Overview of Fetal Alcohol Spectrum Disorder (FASD)

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Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a result of prenatal alcohol exposure. FASD is complicated. Alcohol is an accepted part of Western culture, but people with FASD and their families experience stigma. This module will examine FASD, prevalence, terminology, conflicting messaging about alcohol and pregnancy, and demographics.

What is FASD?

> Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol.
>
> FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential.
>
> Each individual with FASD is unique and has areas of both strengths and challenges.
>
> (CanFASD, 2018)

Most infants prenatally exposed to alcohol look typical. Some may be smaller and grow more slowly. Some have distinctive (to FASD) facial features. These facial features only show that alcohol was used at a certain time in early pregnancy. They do not reflect the actual impact the alcohol has had on the brain. The facial features and growth effects are not found in all people with FASD (CanFASD, 2019).

What is a Teratogen?

Alcohol is a **teratogen** (poison) that interferes with the typical development of the fetus, resulting in lifelong impact. A teratogen is anything a woman is exposed to during pregnancy that can harm her unborn baby. Because the **central nervous system (CNS)** (brain and spinal cord) is developing throughout the nine months of pregnancy, it is the most vulnerable to damage from alcohol (Bonthius, 2015).

When alcohol is used in pregnancy, the fetus is exposed to a teratogen (poison) that impacts typical fetal development and has a lifelong impact.

The impact that alcohol will have on the fetus is not the same for all fetuses. It is influenced by a number of factors such as:

- timing of exposure (when)
- amount of alcohol (how much)
- pattern of drinking (Little & Streissguth, 1981; Flak, Su, Bertrand, Denny, Kesmodel, & Cogswell, 2014)
- nutritional status of mother (Lee, 2015; Shankar, Ronis, & Badger, 2007)
- genetics (National Institute on Alcohol Abuse and Alcoholism, 2019; May & Gossage, 2011; Warren & Li, 2005)

Alcohol's effect on the developing brain leads to the lifelong impacts experienced by individuals with FASD. The effects of alcohol on the fetus are discussed in detail in **Module 3: Fetal Development.**

Alcohol use in pregnancy can cause a broad range of disabilities. These can range from mild to severe, and can result in a unique mix of impacts that are present at birth, although the impacts may not be detected until later, such in school or during adolescence. The Canadian guideline for diagnosis of FASD, developed by Cook and Colleagues (2016), list specific areas of functioning that can be affected.

Table 2.1 Ten Brain Domains* Associated with FASD**

Domain	Example
1. **Motor skills** – How the muscles move and act	Fine motor skills (small muscles), gross motor skills (large muscles), muscle tone, reflexes, balance, coordination
2. **Neuroanatomy/Neurophysiology** – How the brain and nervous system are built and work	Brain structure, head size, seizure activity
3. **Cognition –** How one learns, understands, and gains knowledge	Thinking, perception, and reasoning
4. **Language –** How one uses and understands language	Ability to hear and interpret language and communicate to others (verbal or nonverbal)
5. **Academic Achievement –** How one progresses in school subjects	Includes measures of math, reading, and writing
6. **Memory –** How one progresses in school subjects	Remembering what is heard (auditory) and what is seen (visual) Remembering information over time
7. **Attention –** How one stores information and remembers it when needed	Ability to focus and keep attention including on tasks that are less enjoyable or more challenging Ability to ignore or tune out distractions
8. **Executive function** ("Boss of the Brain'') – How mental skills are used to get things done	Impulse control, planning, problem solving, organizing, controlling one's thoughts, following instructions, understanding abstract concepts (e.g., time, value of money)
9. **Affect regulation** – How one controls emotions, reacts to stress, and reacts to different situations	Includes current or possible mental health diagnoses (e.g., depression or anxiety)
10. **Adaptive behaviour, social skills, social communication –** How one manages everyday life and social situations	Ability to take care of oneself (everyday life skills), and respond age-appropriately to others
***Sensory** – How one responds to different sensations like touch, movement, sound, smell, sight, and taste 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. A person's **sensory** response can impact all brain domains.	

Research has shown that as the amount of prenatal alcohol exposure goes up, so do neuropsychological and neurobehavioural impacts, as well as difficulties with:

- attention
- math skills
- visual-spatial memory (using the visual information stored in the brain to process information; using ability to remember shapes and colours, as well as their locations and movements (Kulman,2015))
- IQ

(Streissguth, 2007)

Not all children who were prenatally exposed to alcohol are impacted. There are many other factors that may influence outcomes, such as early environment and parenting, and prenatal nutrition, smoking, and use of other drugs (Streissguth, 2007).

Individuals affected by prenatal alcohol exposure may also experience physical impacts such as:

- sleep problems (nightmares, wakefulness)
- sensory sensitivities
- other physical anomalies (differences)
- reduced growth
- attachment challenges
- proprioception (problems with motor skills and control [e.g., unintentionally breaks things])
- balance problems

(Cook et al., 2016)

Recent research has found that individuals with FASD are more likely than the general population to experience a long list of health conditions. The most common conditions include a wide range of birth defects and mental and behavioural disorders (Popova et al., 2016). It is suggested that healthcare providers be more aware of the link between these conditions and FASD so that they can explore the possibility of prenatal alcohol exposure when these conditions are identified (Popova et al., 2016). The five most common conditions of people with FASD include:

- abnormalities of the peripheral nervous system (parts of the nervous system outside the brain and spinal cord that are not typical)
- chronic serious otitis media (recurring middle ear infection)
- receptive language disorder (understanding others)
- expressive language disorder (expressing themselves)
- conduct disorder (serious behaviour and emotional problems)

Mental health issues are very common and show up as problems with behaviour and attention early in life. Research has shown that children with FASD can struggle with:

- overall ability to do something effectively (competence)
- internalizing and externalizing behaviours
- school competence

- rule breaking/delinquency
- aggressive behaviour
- attention problems
- social problems/competence

(Tsang et al., 2016)

Children with prenatal alcohol exposure/FASD experience many challenges. It is not surprising that problems with being with others in a social environment (psychosocial health) and mental health develop over time (O'Connor & Paley, 2009; Streissguth, 2007). As shown in **Table 2.2**, challenges experienced by children grow as the children age.

Table 2.2 Challenges experienced by individuals with FASD can grow over time

Infancy/Early Childhood	Middle Childhood	Adolescence/Young Adulthood
Irritability Insecure attachment Depressive symptoms	Social problems ADHD Anxiety Depression Intellectual and learning disability Psychotic disorders Bipolar disorder Antisocial and disruptive behaviours/delinquency	Suicide thoughts/attempts Alcohol misuse Aggression Antisocial personality Depressive, anxiety, and psychotic disorders

(O'Connor & Paley, 2009; Streissguth, 2007; Weyrauch et al., 2017).

There is growing evidence that when the fetus is exposed to alcohol, it can affect fetal programming (Hellemans, Sliwowska, Verma, & Weinberg, 2010; Raineki et al., 2014). Fetal programming links what the fetus is exposed to in the womb (environmental conditions) with the risk later in life of diseases, behaviour problems, and mental health issues (Institute of Medicine, 2015; Centre for Fetal Programming, 2019). Prenatal alcohol exposure can cause the brain system to be more sensitive to stresses in later life. That is because of changes to the brain structure and function (what is called neurobiology).

Adverse prenatal exposure can impact the ability to control stress and emotion. This makes it more likely that people with FASD experience mood disorders such as depression and anxiety (Hellemans, Sliwowska, Verma, & Weinberg, 2010; Raineki et al., 2014).

Children with prenatal alcohol exposure are more likely to see peer behaviours they find confusing as hostile. Because of this, they may have a hostile response, and because of poor self-regulation are more

likely to act on their aggressive impulse. This influences the development of disruptive disorders and delinquent behaviours (O'Connor & Paley, 2009).

It has been suggested that the term "secondary impact" may not be appropriate when describing the mental health problems experienced by individuals with FASD. This is because difficulties begin with the vulnerability of the stress and emotion regulation systems due to prenatal alcohol exposure (Pei, Denys, Hughes, & Rasmussen, 2011). Throughout life, there are many environmental factors that may affect the relationship between prenatal exposure and mental illness and behavioural disorders (Pei et al., 2011).

One of the most important environmental factors that can affect long-term functioning is an infant's early experience with the main caregiver (primary attachment relationship). This may be a mother or someone else who is looking after the baby. The relationship between prenatal alcohol exposure and the early caregiving environment is complicated. When infants have less ability to deal with stress and control negative emotions and mood, challenges can occur with the mother-infant interaction. These early relationship difficulties may later cause problems with the child's ability to control emotions and form positive and rewarding relationships with other people (Cohen, Onunaku, Clothier, & Poppe, as cited by California Department of Education, 2019). Women who used alcohol heavily during pregnancy had infants with higher levels of negative emotions in mother-infant interactions (O'Connor & Paley, 2009). These mothers were less sensitive in responding to their infants. Later, these infants had higher levels of insecure attachment (expecting to be abandoned or hurt) and eventually higher levels of depression (O'Connor & Paley, 2009). If babies who had been exposed to high levels of alcohol had mothers who could provide a supportive presence, the children developed a better ability to cope with stress and frustration and better attachment security.

The quality of the mother-child relationship appears to affect the relationship between all of the risk factors experienced (e.g., prenatal alcohol exposure, poverty, domestic violence, maternal mental health issues, etc.) and FASD-related brain-based behaviours for infants and young children (Motz et al., 2011). This effect may go both ways. Having a child with fewer neurobehavioural impacts likely improves the mother-child relationship, as these children may be relatively easier to parent. On the other hand, having a warm, sensitively responding parent likely contributes to improved neurobehavioral outcomes for all children.

Research suggests that a positive mother-child relationship can be a defense against the impact of prenatal and postnatal risks in early development. This includes prenatal alcohol exposure. When providing early intervention services, it is important to look holistically at both the child and her caregiver. There are many factors that can play a role in development and adjustment, like the caregiver-child relationship or a family that is experiencing multiple risks. Many mothers who are alcohol dependent likely experience challenging circumstances. It is important to keep these circumstances in mind when designing interventions to support the mother-child relationship. These include:

- unstable finances and housing
- legal problems
- physical and mental health problems
- lack of social supports, and the stress that these factors may place on the parenting role

(Conners et al., 2004)

FASD: An Invisible Disability

Often, there is no external evidence of the brain damage caused by prenatal alcohol exposure. In other words, the individual may show no obvious physical characteristics of prenatal alcohol exposure, although the effects of the damage are found in such things as behavioural differences and learning difficulties. For this reason, FASD is often called an "invisible disability." This is different from other disabilities. For example, if a person cannot hear, there will be signs (e.g., hearing aid,, use of sign language). The "invisibility" of FASD can increase the difficulties faced by those who have FASD, because others may believe the person's behaviours or difficulties are caused by the *person* and not the disability. Another challenge is that, most likely, only a small fraction of the people with FASD have been diagnosed. This is because of limited capacity and expertise and the need to involve several professionals in a comprehensive multidisciplinary diagnostic evaluation (Chudley et al., 2005).

FASD
is an "invisible" disability
because a person may show no
obvious physical signs
of the disability

Prevention of FASD

Current studies suggest that up to 4% of individuals in Canada have FASD. This means up to 1,451,600 people have FASD (CanFASD, 2018).

If alcohol is not used during pregnancy, there is no chance that FASD will occur. There are many reasons alcohol may be used in pregnancy. For example:

- a woman may not know she is pregnant (up to 50% of pregnancies are unintended)
- drinking is normal in her society/group/community/family/friends
- she may be living with violence
- a partner's or family's drinking behaviour influences her drinking

- she hears confusing messages about alcohol and pregnancy
- she may be coping with challenging life circumstances (determinants of health such as poverty, a difficult early life, discrimination)

Prenatal alcohol exposure is the leading known cause of preventable developmental disability in Canada (Abel, 1998; Poole, 2008; Popova, et al., 2018). Fetal Alcohol Syndrome (FAS), the first diagnosis, was named after the cause. The idea was that it would encourage prevention (Clarren, 2005). Unfortunately, one of the results of this diagnosis is shame, judgement, and stigma.

It is best **not** to say that FASD is 100% preventable.

It oversimplifies the issue.

Early messaging about FASD stated that FASD is 100% preventable and even now, some messages state that FASD is 100% preventable. This oversimplifies the issue (CanFASD, 2018). The statement may be true in an "ideal" world, but it does not take into account the many reasons for using alcohol in the "real" world, as previously listed. Statements using "100% preventable" can lead to shaming and blaming. Shame and blame (stigma) are often reasons people don't ask for help, talk about alcohol use, or go for prenatal care (Eggertson, 2013). It is preferable to make sure that people understand the reasons why women may drink when they are pregnant and learn how partners and communities can support healthy pregnancies. For more information on why women may use alcohol during pregnancy, see **Module 6: Prevention of FASD.**

FASD: The Terminology

In Canada, FASD is now a diagnostic term describing the wide range of effects and disabilities caused by drinking alcohol during pregnancy (Cook et al., 2016). In 2015, Canada released new guidelines and terms for the diagnosis of FASD. There are now only two diagnostic categories: FASD with sentinel facial features and FASD without sentinel facial features (Cook et al., 2016). As well, there is a non-diagnostic category known as At Risk for Neurodevelopmental Disorder and FASD, associated with prenatal alcohol exposure (Cook et al., 2016). This last category is considered to be a condition for future study and not a current diagnosis (Cook et al., 2016). Other acronyms (e.g., Fetal Alcohol Syndrome, partial Fetal Alcohol Syndrome) are no longer used for diagnosis since the term FASD includes any alcohol-related diagnostic terms previously used. The following are the diagnostic criteria and the non-diagnostic category.

<u>FASD without Sentinel Facial Features</u>

For this diagnosis, an individual will have the following:

- Confirmed prenatal alcohol exposure
- Three areas of neurodevelopmental (brain) function that are significantly below typical

FASD with Sentinel Facial Features

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)
  - Thin upper lip
- Three areas of brain function that are significantly below typical
- Prenatal alcohol exposure (can be confirmed or unknown)

At Risk for Neurodevelopmental Disorder and FASD

This is not a diagnosis. It is a designation (term) to identify individuals who may have FASD, but require further assessment (Cook et al. 2015). This is a designation that should be given to individuals when:

- there is confirmation of prenatal alcohol exposure, with the estimated dose at a level known to be associated with neurodevelopmental effects
- central nervous system criteria from the above two categories are not met
- there is some indication of neurodevelopmental disorder in combination with a plausible (reasonable) explanation as to why the neurodevelopmental assessment results failed to meet the criteria for substantial impairment (refer to **Module 7** for more information)

In Canada and Australia, FASD is no longer described as an umbrella term and is the diagnostic term. However, previous literature, international literature, and countries such as the United States, still use a variety of different diagnoses.

The Diagnostic and Statistical Manual of Mental Disorders - 5th edition (DSM-V) also categorizes FASD as a Neurodevelopmental Disorder, associated with prenatal alcohol exposure. However, researchers recommend that a comprehensive assessment conducted by a multidisciplinary team be used with both the DSM-V and the Canadian guidelines (Doyle & Mattson, 2015).

In this manual, the term FASD will be used in line with Canada's latest diagnostic guidelines.

Module 7: Referral and Diagnosis of FASD highlights some of the different categorizations and their overlap with latest Canadian diagnostic guidelines.

Not everyone affected by prenatal alcohol exposure has a diagnosis of FASD. Fetal alcohol exposure is routinely under-identified (Sokol et al., 2003). Even without a diagnosis, an individual impacted by prenatal alcohol exposure may require additional support and the attention of healthcare professionals.

Table 2.3: Canada's New Diagnostic Guidelines

FASD with Sentinel Facial Features	Replaces Fetal Alcohol Syndrome (FAS)
FASD without Sentinel Facial Features	Replaces Partial Fetal Alcohol Syndrome (pFAS) Alcohol Related Neurodevelopmental Disorder (ARND)
At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure	New Term A designation (term) to identify individuals who may have FASD but require further assessment

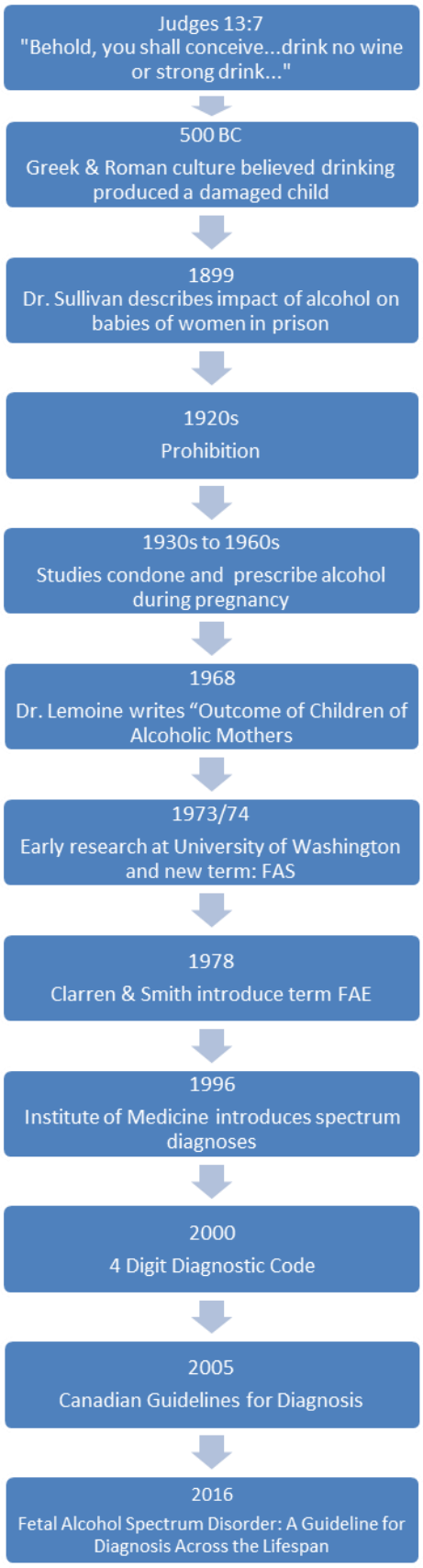
Table 2.4: Terms previously used in Canada (adapted from Saskatchewan Ministries of Health and Education, 2007)

Fetal Alcohol Syndrome (FAS)	• Maternal alcohol consumption may or may not be confirmed
	• Person has full set of symptoms:
	  ○ distinct facial features (small eye openings, little or no groove between the nose and upper lip [philtrum], and a flattened mid-face)
	  ○ slow growth (low birth weight, weight loss not due to poor nutrition, low weight-to-height ratio)
	  ○ damage to the central nervous system (small head size at birth or structural abnormalities of the brain, hearing loss development of fine motor skills, eye-hand coordination, walking)

Partial Fetal Alcohol Syndrome (pFAS)	• Describes those who don't have all of the characteristics of FAS, but there is knowledge of maternal alcohol consumption
	• Some of the facial features of FAS are present and at least one of the following characteristics is present:
	  ○ growth deficiency
	  ○ central nervous system impairments
	  ○ behaviour/learning problems (e.g., not age appropriate and cannot be explained by heredity or environment alone)
	• The term "partial" does not mean that the effects on the individual are less severe than FAS

Alcohol-Related Neurodevelopmental Disorder (ARND)	• This is the most common form of FASD
	• Person has no physical signs (invisible form) of FAS but has central nervous system abnormalities and/or a pattern of behavioural/learning impairments such as difficulty with:
	  ○ school performance
	  ○ abstract thinking
	  ○ impulse control
	  ○ social skills
	  ○ language and math skills
	  ○ memory
	  ○ attention
	  ○ judgement

Alcohol-Related Birth Defects (ARBD)	• Describes congenital abnormalities related to:
	  ○ the heart
	  ○ the skeleton
	  ○ the kidneys
	  ○ the eyes
	  ○ the ears
	• Maternal alcohol consumption must be confirmed



The History of FASD

Some people and resources still use dated terminology. It is useful to understand and be aware of the many other terms that have been used to refer to prenatal alcohol exposure and to be able to explain their significance to others. It helps to have an understanding of the history of Canada's response to FASD and related issues. In other words, to understand where we are and where we are going, it is important to have an understanding of where we have been.

Beliefs about Alcohol Use and Pregnancy

Fermented grain, fruit juice, and honey have been used to make alcohol (ethyl alcohol or ethanol) for thousands of years. This makes alcohol one of the world's oldest known drugs. Alcohol has been used as an anesthetic, painkiller, disinfectant, and a "cure-all." Alcohol has even been prescribed to pregnant women as a means of preventing premature labour. The manufacture of products containing alcohol has become big business in today's society, and the consumption (and abuse) of alcohol has become a major public health concern.

The idea that drinking alcohol during pregnancy can negatively affect the fetus is not new and has been documented throughout history. In ancient Greek and Roman culture (circa 500 BC), it was commonly believed that using alcohol at the time of conception would produce a "damaged" or "defective" child (Jones & Smith, 1973). This association was also part of the Judeo-Christian tradition, as shown in Judges 13:7 of the Old Testament, where it directs a pregnant woman not to drink alcohol or other strong drink (Calhoun and Warren, 2007). Although there has been some discussion about the exact nature of these beliefs, different cultures have incorporated these ideas into their belief systems.

There is also a long history of a more scientific-based association between alcohol use and harmful impacts for the child. In 1899, Dr. William Sullivan produced the first scientific report on the effects of drinking alcohol while pregnant (Sullivan, 1899). As a physician who worked with women in prison, he found the stillborn and infant death rate of the 600 children born to imprisoned alcoholic women was 56%. This

was much higher than the rate of their female relatives who did not drink. Sullivan concluded that maternal inebriety (drunkenness) is unfavourable to the vitality and normal development of offspring due in part to alcohol's toxicity to the embryo (Sullivan, 1899). Scientific research into the relationship between alcohol use and birth defects did not become popular again until late in the twentieth century. The issue was largely ignored because of the prohibition movement in the 1920s.

After Prohibition, researchers in the United States and Britain mainly conducted animal studies that ridiculed the moralizing studies from before prohibition on pregnancy and outcome. The earlier studies had condemned alcohol. Until the late 1960s, when FASD research resurged, medical literature condoned and even prescribed alcohol use in pregnancy (Warren & Bast, 1980).

History of FASD: Clinical Study and Terminology

In 1968, Dr. Paul Lemoine and his colleagues in France published a paper entitled "Outcome of Children of Alcoholic Mothers" (Lemoine et al, 1968). In this study, researchers examined 127 children from 69 families in which the mother drank heavily throughout her pregnancy. They determined that 25 of these children shared many of the facial characteristics, growth deficits, and neurological problems that are now known to be related to prenatal alcohol exposure. At the time, this study was not widely read and the findings had little impact on the field.

In 1973 and 1974, *The Lancet* published three articles that "laid the foundation for the new diagnosis of **Fetal Alcohol Syndrome (FAS)**" (Calhoun & Warren, 2007, p. 169). A team of researchers at the University of Washington in Seattle had found a number of similarities among children born to mothers who drank heavily during their pregnancies. These studies (Jones & Smith, 1973; Jones, Smith, Streissguth, & Myrianthopoulos, 1974; Jones, Smith, Ulleland, & Streissguth, 1973) included a number of case studies of alcohol-affected children. The similarities found amng these children included developmental delay, unique facial characteristics **(facial dysmorphology)** and growth deficiency.

Jones & Smith (1973) introduced the diagnostic term "Fetal Alcohol Syndrome" (FAS) to describe these similarities. FAS was named after the cause to encourage prevention. Dr. Smith believed that if people knew alcohol use in pregnancy caused the syndrome, education and awareness would prevent people from using alchol in pregnancy (Clarren, 2005).

Fetal Alcohol Effects (1978-1995)

The publication of *The Lancet* articles led to research in the area of FAS, and many articles and case study reports were published (Calhoun & Warren, 2007). Researchers became aware that the outcomes of prenatal alcohol exposure were highly inconsistent. To accommodate this, American researchers Clarren and Smith (1978) suggested the term **"Fetal Alcohol Effects" (FAE)** be applied to cases where there were more minor effects. At the time, they were believed to be minor. This term was widely adopted and was included in the diagnostic criteria used by the Fetal Alcohol Study Group of the Research Society on Alcoholism (US) in 1980 (Calhoun & Warren). However, this term was not well defined and was not always used appropriately. In 1995, in order to make it less confusing, it was suggested that this term no longer be used (Aase, Jones, & Clarren, 1995).

Since that time, the diagnostic criteria have changed many times:

- Institute of Medicine (IOM) Classification System (1996)
- The Four Digit Diagnostic Code (2000)
- The Canadian Guidelines for FASD Diagnosis (2005)
- The Canadian Guidelines for Diagnosis of FASD (2015)

Understanding FASD Research

In the last several decades, the amount of attention focused on FASD has greatly increased. It helps to be an informed reader when looking at research about FASD. Look at:

- the methods underlying the research
- ways to interpret the research
- implications of this research

One common question about FASD is how often it occurs. While this may seem like a simple question to answer, the answer actually depends on a variety of factors (e.g., methods used, population studied). This section will look at some of these methods and their results.

The Rates of FASD

The term "**rate**" describes the number of cases out of a set number of individuals in a group or population. Percentage is the number out of 100. Rate can also be per 1,000 individuals, or per 10,000 individuals. Rates can be presented in terms of prevalence or incidence. **Prevalence** is the number of **existing cases** at a particular time (Shields & Twycross, 2003).

Incidence is the number of **new cases** in a certain time period in a certain population (Last, 2001). Incidence helps us to understand the number of new cases or how patterns in a specific population change over time. Incidence also allows for making comparisons between time periods (Shields & Twycross, 2003).

Incidence helps us understand how patterns change in a specific population over time and allows comparison between time periods (Shields & Twycross, 2003).

Prevalence gives information about the number of people in the population who have a diagnosis.

Types of Research on the Rates of FASD

There are three types of studies commonly used to look at the rates of FASD:

- Passive surveillance studies
- Clinic-based studies
- Active case ascertainment (May & Gossage, 2001)

Each method has a different approach to measuring the occurrence of FASD. Each has strengths and weaknesses, and each produces different results. The rate of FASD varies considerably depending on

factors, such as the population researched, the research method or study type, and the study itself (May et al, 2009).

Passive Surveillance Studies

Passive surveillance studies use existing information from a particular area (e.g., province). The study can report either prevalence or incidence.

Different types of records are used, including birth certificates, medical charts, school records, and/or registries. More recent studies often use multiple records to identify as many cases as possible. A disadvantage of passive surveillance of FASD is that, unlike many other conditions, FASD is not as easy to recognize and diagnose at birth or within the first years of life (Clarren et al., 2001). Passive systems depend on the diagnoses and reporting from many different non-specialist professionals, so lack the rigour and consistency of other more active systems.

Due to these challenges, passive surveillance studies tend to report lower rates of FASD than other study methods. The Centers for Disease Control and Prevention (CDC) reported that the estimated birth rate of FASD was 2 per 10,000 live births (0.2 per 1,000) from 1979-1992 (CDC, 1993). This is quite a bit lower than the rates found using other methods.

Clinic-Based Studies

Until fairly recently, clinic-based studies provided much of the knowledge about rates of FASD. These studies used data from specific sites, such as prenatal clinics (May & Gossage, 2001). Clinic-based studies look at prevalence among only those who receive services at included clinics. Researchers collect data from women at various stages in their pregnancies, and from diagnosis at birth. They can obtain data about alcohol use and other important information (e.g., other drug and tobacco use, nutrition, and mental health, May & Gossage, 2001).

Advantages of this method are that it provides more detailed information, and allows for more control and rigour of measurement. Disadvantages include that women at the highest risk of drinking during pregnancy are less likely to go to prenatal clinics regularly, if at all. A reliance on diagnosis at birth excludes many children who do not start showing FASD-related issues until much later (between ages of 3 and 12). This may result in an underestimation of the prevalence of FASD in the populations studied (Clarren et al., 2001; May & Gossage, 2001).

Some researchers have combined many clinic-based studies to reach broad conclusions about the rates of FASD. For instance, Abel (1995) looked at 35 clinic-based studies in over 40 sites in the Western world. He concluded that the rate of FAS was 1.97 per 1,000 live births.

One widely quoted study (Sampson et al., 1997) looked at the prevalence of FAS and/or ARND (more similar to FASD). This is one of the first studies that looked at alcohol-exposed children more broadly than those with a diagnosis of FAS. Researchers concluded that the combined prevalence rate for FAS and ARND in North America was at least 9.1 per 1,000 live births (almost one in 100 births). This was believed to be an underestimate, since diagnosis is often delayed or missed entirely (Chudley et al., 2005).

Active Case Ascertainment

Active case ascertainment looks at prevalence in a specific population or area. Often these studies are conducted in schools, focusing on all children in a particular grade. In-school active case ascertainment studies "may be the most complete and accurate way of determining the epidemiological characteristics of FASD within a population and will come closest to determining the true prevalence and far-reaching effects of FASD in human populations" (May et al., 2009, p. 178). In-school studies represent the local population (e.g., race/ethnic group, socio-economic status, environmental factors). At this stage of development, neuropsychological tests that are used in FASD diagnosis start to show differences between children (from the same population).

The unique part of this method is that it takes a very *active* approach to research, by seeking to screen all children in the population examined within a particular age range in order to find and involve all children who have FASD (May & Gossage, 2001). Once potentially impacted children have been identified, they are assessed by a variety of professionals, and mothers are invited to provide information on maternal behaviour and risk factors. Final diagnosis is made in a case conference reviewing all diagnostic criteria.

Benefits of this methodology include:

- the focus on children who are of appropriate age for accurate diagnosis
- the involvement of a multidisciplinary team of specialists in diagnosis
- the comprehensive outreach to the general population, making it more likely that at-risk children will be detected and that the participants are more representative of the community

Disadvantages include that this approach is time consuming and costly, and that it is necessary to gain a high level of cooperation of the many groups within the community, including parents and the children, which may be difficult to achieve.

In the past, many active case ascertainment studies have been carried out in communities where alcohol use is problematic, potentially inflating the estimated rates of FAS for the general population and contributing to stigmatizing certain groups.

What is the Rate of FASD in Canada?

There is a wide range of information used to estimate the rate of FASD in Canada. These numbers can differ a lot, depending on the research method used and the population studied. In the 1980s and 1990s, there was a perception that FASD was an "aboriginal problem" (Mackenzie et al., 2016 as cited in CanFASD, 2018). Early studies were done in Indigenous communities and small areas (CanFASD, 2018).

A number of active case ascertainment studies have been done in Canadian communities. These small-scale studies took place in regions where a high need for FASD diagnosis and treatment had been identified. A study of an isolated Aboriginal community in British Columbia found a rate for FAS of 190 per 1,000 live births (Robinson, Conry, & Conry, 1987).

Another study in a First Nations community in Manitoba estimated the prevalence of FAS at 55-101 per 1,000 live births (Square, 1997). These findings are specific to the communities which were studied. The results should not be generalized to other aboriginal communities or the general population. "Findings in such small and unique communities cannot be compared to other populations unless there is evidence that similar social, cultural, behavioural, nutritional, and health conditions exist" (May et al., 2009, pp. 182).

Until recently, the most commonly quoted study was the Sampson et al. (1997) study, which states that the incidence of FASD in Seattle is at least 9.1 per 1,000 live births. Because of the assumption of under-reporting, this rate is often rounded up to approximately 1 in 100 live births.

More recently, May and colleagues (2014) conducted active case ascertainment in schools to examine the prevalence of FASD among first grade children in a representative (middle socioeconomic status) Midwestern US city. Active consent was obtained from children and mothers to participate. Diagnoses were made by a multidisciplinary team using Institute of Medicine (IOM) diagnostic guidelines for FASD. Confirmed maternal prenatal alcohol use (from mother or secondary, but reliable reports) was required for some, but not all, categories of diagnosis. This study estimated the prevalence rate of FASD to be 2.4% to 4.8%, which is substantially higher than previous estimates for general populations in the US, Canada, or Europe. Even though this is a much higher rate than has been previously estimated for a general population, it is likely an underestimate of the actual prevalence rate. A reluctance to participate in all aspects of the study, and underreporting of alcohol consumption during pregnancy were recognized as problems with this study and similar studies.

Similarly, Thanh et al. (2014) estimated an incidence rate of 1.4 to 4.4% using a passive surveillance method, based on the year and length of follow-up (with 1.4% being the population diagnosed within the first year of life, and 4.4% the population diagnosed by age eight). As acknowledged by the authors, these incidence rates are likely to be underestimated due to the relatively short follow-up time (10 years).

FASD has been recognized as a preventable disability. It is important to estimate the prevalence for prevention, early detection, diagnosis, and intervention. Knowing the prevalence also informs policy-makers and politicians of the impact of FASD. As well, prevalence estimates will help to set priorities for public health policy, funding for public health initiatives, and healthcare planning. Updated prevalence estimates are essential to effectively prioritize, plan, and deliver health care to high-needs groups such as children, youth, and adults with FASD. These estimates are also necessary for assessing the impact of FASD on individuals, families, and communities, and making sure there are resources for health care and prevention.

In order to provide an estimate of the prevalence of FASD in Canada, Popova and colleagues (2018) conducted an active case ascertainment study. Students from grades 2, 3, and 4 within the public school system of the Greater Toronto Area (GTA) were screened based on the 2005 Canadian guidelines for diagnosis (Chudley et al., 2005). The population-based prevalence of FASD was estimated to range between approximately **2% and 3%** among elementary school children, aged 7 to 9 years, in the GTA (Popova et al., 2018). The GTA provides an sufficient sample of Canadians, as it is home to approximately 18.3% of Canada's population (Statistics Canada, 2017). It is representative of the general population of Canada for sex, age, and drinking patterns (Popova et al., 2018). However, to increase our confidence in applying this estimated prevalence of FASD to Canada as a whole, it is important that similar active case ascertainment studies be conducted in all provinces and territories of Canada.

Even though this study provides the best estimate of prevalence in Canada to date, there are many challenges with this study. This is likely an underestimate of prevalence of FASD. The challenges include a lower than ideal participation at all levels (school boards, schools, parents, and children). Some parents may have declined having their child take part because of the fear of stigma and/or family conflict. They may not even have been informed of the study because the child did not deliver the information letter, or the parent did not understand the English-only information. As well, relying on teachers or parents/guardians to identify a child with suspected behavioural and/or learning difficulties may have resulted in some children being missed. Finally, requiring confirmation of alcohol exposure from biological mothers is difficult for a variety of reasons (including the mother being uninterested, unwilling, or unavailable). Because of the challenging nature of this sort of research, the estimated FASD prevalence of 2% to 3% is likely understating the problem.

Using the evidence from two recent studies (Thanh et al., 2014; Popova et al., 2018), the Canadian FASD Research Network (CanFASD) puts the current best estimate for the prevalence of FASD at 4% for the general population (CanFASD, 2018). That is 1,451,600 people in Canada. This is more than the number of people who live in Calgary, AB. It also means that approximately 1 in 25 people in Canada have FASD.

Worldwide, the proportion of FAS among all people with FASD was recently estimated to be 18.9%. That means approximately two out of 10 people with FASD will be diagnosed with FAS (Lange et al., 2017; Popova, Lange, Probst, Gmel et al., 2017).

The current best estimate for the Canadian prevalence of FASD is 4% for the Canadian general population. (CanFASD, 2018)

The Importance of Up-to-Date Statistics

As previously mentioned, to inform decisions around prevention, health services, and supports, it is important to have up-to-date, accurate statistical information on the rate of FASD. In Canada, it is not mandatory to report when a diagnosis of FASD is made, although it is mandatory for other diagnoses such as Down syndrome. Without statistical information, it is difficult for the provincial and federal governments to budget for the necessary supports and services.

Although reporting a diagnosis of FASD is not mandatory, Canada has the only comprehensive FASD database in the world (CanFASD, 2019). The database started as a project in 2010 (Hrvatin, 2019). It is led by CanFASD and is supported by Kids Brain Health Network and funded by the Public Health Agency of Canada and CanFASD (Hrvatin, 2019). As of 2019, more than 25 clinics from nine provinces and territories have volunteered to take part (CanFASD, 2019). As of 2020, Saskatchewan had not participated in the database, but one clinic had completed paperwork to participate (A. McFarlane, personal communication, January 26, 2020).

CanFASD (2019) notes that "the national database is important for understanding the relationship between diagnostic capacity and service availability for individuals with FASD. In-depth research will inform policy decision and resource allocations pertaining to health services provided to those with FASD" (p.1).

Alcohol Industry and Messaging

Messages about alcohol can be found almost anywhere:

- Television and radio
- Movies
- Billboards and bus ads
- Internet/social media/apps/blogs
- People's clothing
- Friends and family
- Sporting events
- Music events

The messages from advertisers may be different, but they have the same goal: to inform, educate, and influence people's thoughts and behaviours. There is not a lot of Canadian research on alcohol advertising (Public Health Agency of Canada, 2016). American research shows advertising reaches a large audience (Public Health Agency of Canada, 2016). This audience includes underage people. Some research suggests "the greater the exposure to advertising, the more youth drink." (Public Health Agency of Canada, 2016).

For the most part, advertisers show drinking alcohol as something fun, glamorous, cool, the "normal" way to celebrate any occasion, and with no consequences. It is in the advertisers' best interests to create excitement about their products in order to sell more. They can do this with alcohol by "normalizing" the drinking experience and presenting it as something that enhances the fun in any situation. Others may have different motivations, such as normalizing their own drinking habits, but still may present messages that do not accurately reflect current research.

It is important to think about all of these influences when talking about alcohol use with clients, students, and the public, as these messages both reflect and create the social situations of people.

Conflicting Messaging on Alcohol and Pregnancy

One challenge that can be faced when providing education on FASD is the existence of conflicting messages about alcohol use in pregnancy. It is not unusual to talk to people who have read or heard somewhere else that drinking alcohol during pregnancy is not that harmful. Often, this misinformation comes from peers, family, or from the media.

The messages from the media are especially challenging because:

- the media is viewed as a source of "trustworthy" information
- the media often misinterprets or overextends research findings
- the epidemic of "fake news" has increased the number of sources that are presented as reliable but have no basis in quality research

A good example of the misinterpretation/overextending of research is the controversy that occurred when an article called "Light Drinking in Pregnancy, a Risk for Behavioural Problems and Cognitive Deficits at 3 Years of Age?" (Kelly et al., 2008) was published in the International Journal of Epidemiology. The conclusions of the London (UK) researchers suggested that light alcohol use during pregnancy could result in positive cognitive and behavioural outcomes for these children at age three.

Although the study had a number of serious methodological issues (for a full critique, see Gijsen, Fulga, Garcia-Bournisse,n & Koren, 2008), “these results were rapidly repeated in the media. This led to a flurry of print and Internet articles discussing the potential benefits of light alcohol use during pregnancy” (pp. 782).

Gijsen et al. (2008) list some statements made in the media about these results. These show how the results of one study can be interpreted (or misinterpreted) in many ways. It was reported that the study:

- found that light drinking may lead to calmer babies - “Light Drinking when Pregnant may Lead to Calm Babies, Says Study” (Connor, 2008)
- found that light drinking may be good for babies - From: The Guardian: “Light Drinking in Pregnancy May be Good for Baby Boys, Says Study: Researchers Find Fewer Behavioural Problems and Higher Test Scores at Age 3” (Boseley, 2008)

In 2013, Emily Oster, an economist, wrote a popular book “Expecting Better: Why the Conventional Pregnancy Wisdom is Wrong and What You Really Need to Know”**.** Using her background as an associate professor of economics, she examined and interpreted the research behind pregnancy advice (CanFASD, 2013). Based on her research, she gave the "go ahead" for light drinking. This added to the confusion many people have around alcohol and pregnancy and caused great concern in the world of Fetal Alcohol Spectrum Disorder. CanFASD, National Organization on Fetal Alcohol Syndrome (NoFAS), and the Saskatchewan Prevention Institute were some of the organizations responding to media coverage which included statements such as the following:

- Daily Mail: “Pregnant women CAN drink alcohol and coffee, claims controversial new book that aims to dispel 'motherhood myths'” (Brown, 2013)
- Wellblogs, New York Times: “Pregnant, and Disputing the Doctor” (Louis, 2013)
- The Guardian: “Pregnancy: the hard facts – Economics professor Emily Oster's new book Expecting Better cuts through the myths and faulty data on pregnancy” (Flemming, 2013)
- News.com Australia: “New book, Expecting Better by Emily Oster, examines pregnancy myths” (News.com Australia, 2013)

In 2015, the American Academy of Pediatrics (AAP) issued a report that ended with this statement “There is no known absolutely safe quantity, frequency, type, or timing of alcohol consumption during pregnancy, but having no PAE (prenatal alcohol exposure) translates into no FASD”. Lindsay (2015) wrote that many media outlets accurately reported the conclusion of the AAP, but other media had headlines such as the following:

- Boston Globe: “Is drinking during pregnancy really so bad?” (Horowitz, 2015)
- NPR: “Why Do People Get So Bent Out Of Shape About Drinking While Pregnant?” (Shute, 2015)
- Slate Magazine: “Light Drinking While Pregnant Is Probably Safe: So why are women being told otherwise?” (Caplan-Bricker, 2015)
- Time USA “'No Alcohol' During Pregnancy Is Just Another Shame Battle in the Mommy Wars” (Oster, 2015)

There is much research about the negative impact of high levels of drinking during pregnancy and of binge drinking (Chudley et al., 2005). In contrast, the effect of light or moderate drinking does not have this level of empirical support (Gijsen et al., 2008). The media tends to focus on this lack of evidence, and often changes "lack of evidence about this type of drinking" into "it is acceptable to drink."

It has been widely established that:

- alcohol is a teratogen
- alcohol can harm the fetus
- FASD is only caused by prenatal alcohol exposure (Stratton et al., 1996)

Even if it has not yet been established that light drinking will definitely harm the fetus, it has also not yet been established that it *does not* harm the fetus. In recent animal studies, alcohol use as early as the time of conception has been linked to poor growth of the placenta, causing conditions such as fetal growth restriction and low birth weight (Limet al., 2019). The safest message is "It is safest to avoid alcohol during pregnancy".

It is safest to avoid alcohol during pregnancy.

Costs of Prenatal Alcohol Exposure

FASD is lifelong. It crosses all boundaries, and is not limited to any particular race, socioeconomic status, or any other demographic group/subpopulation. Prenatal alcohol exposure can affect physical, behavioural, learning, and adaptive areas of development (Cook et al., 2016), and is strongly associated with mental illness (American Psychiatry Association, 2013).

FASD is costly because of an increased need for services for individuals and families across sectors (CanFASD, 2018). There is conflicting evidence about the true total cost and there should be caution about describing FASD as a burden (CanFASD, 2018). That can increase stigma and shame for individuals and their families.

Some of the costs are difficult to measure. They include productivity loss for families, and stress/guilt for mothers (CanFASD, 2018). There is also no measurement of how costs may be affected when individuals and families receive the services and supports they need (CanFASD, 2018). Many studies show different costs, depending on what systems they measure, such as:

- medical
- education
- social services
- corrections
- prevention/research
- productivity loss

(CanFASD, 2018)

Popova and colleagues (Popova, Lange, Burd, & Rehm, 2015) estimate the cost associated with FASD in Canada in 2013 to be approximately $1.8 billion. When making this estimate, Popova and colleagues (2015) used the most commonly cited rough estimates of the prevalence of FAS (1 per 1,000; PHAC,

2003b) and FASD (9 per 1,000; Roberts & Nanson, 2000) in Canada. This estimate is considered conservative, since not all relevant cost data was available, and healthcare costs related to FASD are likely significantly underestimated for a variety of reasons.

- Data was only available for those with a diagnosis of FAS, which is thought to represent only 10-20% of all FAS cases (PHAC, 2003b; Roberts & Nanson, 2000).
- Since not all healthcare providers are familiar with FASD, it is often not recorded in the medical chart.
- There is a lack of reliable estimates of FASD prevalence.
- CanFASD (2018) estimates up to 4% of individuals in Canada have FASD.
- Some costs are not measurable (e.g., productivity losses for parents, stress/guilt of mothers [CanFASD, 2018])

FASD and the Indigenous Population

FASD is often still viewed as only an Indigenous issue. This view perpetuates stigma and disparity for a particular group in Canadian Society.

Historically, many Indigenous cultures experienced harm and widespread abuse of Indigenous children through:

- colonization
- residential school experiences
- mistreatment by government institutions (e.g., child welfare system)

Families and the traditional societies were broken up and scattered. FASD exists in the Indigenous population in the context of this history (First Nations, Inuit, and Aboriginal Health, 2007). The residential school era, in particular, left ongoing and devastating impacts on the health and well-being of Indigenous individuals, families, and communities through a legacy of shame, loss, and self-hatred (Aguiar & Halseth, 2015). The impact of historic trauma includes conditions of disadvantage, such as:

- lower levels of income and education
- lower quality of housing
- limited access to resources
- loss of cultural identity

Because of the impacts of intergenerational trauma on the health and well-being of Indigenous people, it is important to develop effective and culturally appropriate services that do not just treat the symptoms of trauma, but facilitate healing and restoration (Aguiar & Halseth, 2015). “Culture as treatment” activities have been suggested as an important component of restoring the lost pride and cultural identity (Gone, 2013). Indigenous traditions and beliefs vary from community to community and from family to family. Becoming familiar with communities, families, and individuals gives insight into beliefs and traditions. See **Module 13: Raising Awareness of FASD in the Context of Community** for more information.

In Canada in the 1980s and 1990s, the stereotype spread that FASD was an "Aboriginal problem" (McKenzie et al., 2016 as cited by CanFASD, 2018). There has been a disproportionate amount of research in Canada on Aboriginal women's use of alcohol during pregnancy and the incidence of FASD (Maloti, Sala-Manioc, Selby, Ranford, & Van Koughnett, 2003). The research often focuses on communities that are known for high rates of alcohol and substance abuse. The rate of FASD in these communities is then generalized to the entire Aboriginal population (Tait, 2004). Aboriginal communities are very sensitive to the stigma of FASD because it is often seen as a racial problem and not a societal one. This stigma can be reduced through education and awareness. FASD can occur in any community. See **Module 6**: **Prevention of FASD** for more information on the factors that influence drinking while pregnant.

In 2015, The Truth and Reconciliation Commission of Canada (TRC) released Calls to Action "in order to redress the legacy of residential schools and advance the process of Canadian reconciliation". Call to Action #33 was related to FASD and included the following (Truth and Reconciliation Commission of Canada, 2015):

- To recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD); and
- To develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.

More information on Truth and Reconciliation can be found at http://www.trc.ca/.

CanFASD, along with other groups, is working to develop strategies to address these recommendations (Stewart et al., 2018 cited by CanFASD, 2018). In May 2017, the Centre of Excellence for Women's Health, the Thunderbird Partnership Foundation, and the Canada FASD Research Network co-organized a dialogue event where experts on FASD from across Canada met to discuss TRC Call to Action #33 and how it could be met. A Consensus Statement was developed, which includes eight principles for enacting Call to Action #33.

1. Centering prevention around Indigenous Knowledge and Wellness
2. Using a Social and Structural Determinants of Health Lens
3. Highlighting Relationships
4. Community Based, Community Driven
5. Provision of Wraparound Support and Holistic Services
6. Adopting a Life Course Approach
7. Models Supporting Resiliency for Women, Families, and Communities
8. Ensuring Long-Term Sustainable Funding and Research

A result of this dialogue event is the development of a series of booklets "Indigenous Approaches to FASD Prevention". This series of booklets can be found on the canFASD website:

- Brief Interventions with Girls and Women
- Community Action
- Indigenous Mothering
- Reconciliation and Healing
- Wellness

Conclusion

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe the impacts on the brain and body of individuals prenatally exposed to alcohol. There are several systems that have been developed for diagnosing FASD. The most recent Canadian Guidelines for Diagnosis of FASD (2015) are used in this manual.

The rates of FASD are difficult to define because several different types of studies are used to determine them, and produce different outcomes. The exact rates of FASD in Canada are unknown. Previously the accepted prevalence of FASD was approximately one in every 100 live births. More recently, it has been estimated as four per cent in the Canadian population.

Alcohol is an accepted part of Western culture. This makes it a challenge to advocate for abstinence. The media often sends conflicting and inaccurate messages about alcohol during pregnancy, and must be viewed with caution.

Prenatal alcohol exposure can impact all demographic groups. When alcohol is consumed during pregnancy, there is risk of the child being impacted by FASD. Women use alcohol in pregnancy for many reasons, including not knowing they are pregnant, substance use challenges, and to cope with challenging circumstances. These challenging circumstances include the social determinants of health. It is important to recognize that many Indigenous communities are dealing with the impact of colonization, residential schools, and government mistreatment. This has caused intergenerational trauma, poverty, housing issues, and discrimination. The TRC Call to Action #33 highlighted the need to address and prevent FASD, and the importance of culturally appropriate FASD preventive programs being developed in collaboration with Aboriginal people as priorities.

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