

# MODULE TWO

## What is FASD?

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# What is FASD?

## DEFINING FASD

Fetal Alcohol Spectrum Disorder (FASD) is recognized as the leading known cause of developmental disability in Canada (Poole, 2008). Prenatal alcohol exposure can also lead to vision and/or hearing impairments, growth restriction, and damage to the brain that results in challenges in regards to attention, memory, reasoning, and judgement (Poole, 2008). FASD is a lifelong condition that has individual, family, social, economic and health system costs. FASD crosses all boundaries, and it is not confined to any particular race, socioeconomic status, or other demographic group/subpopulation. The financial costs of FASD in Canada are profound at a total annual amount of \$5.3 billion. The costs were calculated for individuals from the day of birth to 53 years of age. They are dependent on the severity of the individual's condition, age, and relationship of the individual to their caregiver. At the individual level, the annual cost is \$21,642.00 (Stade et al., 2009).

FASD occurs as a result of alcohol use during pregnancy. Alcohol is a teratogen that interferes with the normal development of the fetus. The majority of the damage caused by alcohol occurs in the central nervous system (CNS); however, birth defects have been seen in all organ systems. The impact that alcohol will have on the fetus is not uniform and is influenced by a number of factors (e.g., timing, amount, pattern of consumption, nutrition, and genetics). This permanent damage to the developing brain leads to the disabilities faced by individuals with FASD throughout the lifespan.

Prenatal alcohol exposure can cause a broad range of disabilities. These can range from mild to severe, and can result in a constellation of primary disabilities. Specific areas of functioning that are affected can include: learning, memory, attention, problem solving, social interactions, and mental health. The effects of alcohol exposure are unique to the individual, and each person will have different struggles and different strengths. Children will not “outgrow” FASD as brain damage is permanent and causes lifelong disabilities. By identifying and focusing on the strengths of individuals with FASD, they can be supported to lead fulfilling lives.

## FASD: AN INVISIBLE DISABILITY

FASD is often referred to as an “invisible disability” because there is no visible sign of the central nervous system damage caused by prenatal alcohol exposure. It is the behaviours associated with the disability that are evident, not the disability itself. This can make it even more difficult for those who have FASD, because if people do not know or understand that the individual has FASD, they might attribute the person's behaviours or difficulties to the person rather than the disorder.

Unfortunately, it is widely believed that only a small fraction of the people affected by FASD have been diagnosed as such (Chudley et al., 2005).

## 100% PREVENTABLE?

FASD is a preventable disease but saying it is 100% preventable may not be realistic. While the statement “if no alcohol is consumed during pregnancy there is no chance that FASD will occur” is true, it does not take into account the many variables present in the “real” world. In the “real world”, a woman may drink alcohol before she knows that she is pregnant or she may be dealing with addictions issues.

Prevention messages such as “FASD is 100% preventable” tend to suggest that stopping drinking is easy and that women who don’t stop are “bad” or “deliberately hurting their baby” (Poole & Urquhart, 2006). The message conveys a sense of judgment or evokes guilt in the women who drank before they knew they were pregnant or have issues with addictions. Media’s portrayal of mothers who drink as bad parents can also increase women’s anxiety and guilt levels. In turn, this can lead to further isolation and alcohol use (Mothering Under Duress Research Team, 2008).

The message to women should be that the only way to be certain their baby will not have FASD is to avoid alcohol during pregnancy. There is: **No Safe** kind of alcohol; **No Safe** amount of alcohol; **No Safe** time to drink alcohol during pregnancy.

## FASD: THE TERMINOLOGY

There are various terms that are used to describe individuals who have been affected by prenatal alcohol exposure. The use of so many different terms can be very confusing.

Since 2001, the term Fetal Alcohol Spectrum Disorder (FASD) has been used as a descriptive term to encompass the many disorders resulting from prenatal alcohol exposure (Chudley et al., 2005). FASD is *not* a diagnosis. It is an umbrella term. The diagnoses that fall beneath this umbrella and represent the spectrum of effects include:

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)

***For the purpose of this teaching package, the term FASD will be used unless discussing a specific diagnostic category within the spectrum.***

A person does not have to have a formal diagnosis of FASD to be living with the effects of prenatal alcohol exposure. Many people living with prenatal alcohol exposure remain undiagnosed throughout their lifetimes. Even without a diagnosis, an individual who has been affected may require additional support and the attention of health professionals.

## THE HISTORY OF FASD

It is important to be aware of the many other terms that have been used to refer to prenatal alcohol exposure. As some people and resources still use dated terminology, it is important to understand these terms and be able to explain their significance to others.

## 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. The idea that drinking during pregnancy can negatively affect the fetus is not new and has been documented throughout history. For example, in ancient Greek and Roman culture (500 BC), it was commonly believed that consuming alcohol at the time of conception would produce a "damaged" or "defective" child (Jones & Smith, 1973).

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 two and a half times the rate of their non-drinking female relatives. Interestingly, scientific research into the relationship between alcohol use and birth defects did not become popular again until late in the 20th century.

## FETAL ALCOHOL EFFECTS (1978-1995)

As research continued, there came an awareness among researchers that the outcomes of prenatal alcohol exposure were highly variable. To accommodate this, US researchers Clarren and Smith (1978) suggested the term "Fetal Alcohol Effects" to be applied to cases where there were more minor effects. This term was widely adopted, and incorporated into the diagnostic criteria by the Fetal Alcohol Study Group of the Research Society on Alcoholism (US) in 1980 (Calhoun & Warren, 2007).

However, the use of the term FAE to distinguish between different types of alcohol effects was not entirely successful. Instead of offering clarity, the term FAE was used by health professionals to "label any child with behavioural problems coming from families with suspected alcohol abuse" (Calhoun & Warren, 2007, pp. 169). In 1995, in order to decrease confusion, it was suggested that this term not be used as it caused misdiagnosis to occur (Aase, Jones, & Clarren, 1995).

## INSTITUTE OF MEDICINE (IOM) CLASSIFICATION SYSTEM (1996)

In 1996, the Institute of Medicine (IOM) in the United States created a committee to develop a more precise classification system for the spectrum of effects of prenatal alcohol exposure. This system distinguished between five diagnoses (Stratton, Howe & Battaglia, 1996):

- Fetal Alcohol Syndrome (FAS) with a confirmed history of alcohol exposure
- Fetal Alcohol Syndrome (FAS) without a confirmed history of alcohol exposure
- Partial FAS (pFAS)
- Alcohol-Related Neurodevelopment Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)

## THE 4-DIGIT DIAGNOSTIC CODE (2000)

Astley and Clarren (2000) developed a different diagnostic system, known as the “4-Digit Diagnostic Code” in the late 1990s. This code provides a system for making diagnoses utilizing a well-defined rating scale for four areas:

- Growth deficiency
- FAS facial phenotype
- Central nervous system damage/deficiency
- Gestational alcohol exposure

## CANADIAN GUIDELINES FOR FASD DIAGNOSIS (2005)

The Canadian Guidelines for FASD Diagnosis were developed in 2005 (Chudley et al., 2005). These guidelines use features of both the 4-Digit Code and the IOM categories and detail all elements of the diagnostic process (Calhoun & Warren, 2007). A multidisciplinary team approach is emphasized. More detailed information on these guidelines can be found in Module Seven: Referral and Diagnosis.

## THE INCIDENCE AND PREVALENCE OF FASD

Two of the most common terms used in the field of epidemiology are prevalence and incidence. These are also the terms that are most frequently confused (Shields & Twycross, 2003).

In epidemiology, *incidence* is “the number of instances of illness commencing, or of persons becoming ill during a *given period in a specified population*” (Last, 2001). Incidence is most relevant to understanding the number of *new cases* or how patterns in a specific population change over time. Incidence rates are also very useful for making comparisons (Shields & Twycross, 2003).

*Prevalence* provides information about the *percentage of a population* that is affected by a particular disorder at a *particular time* (Shields & Twycross, 2003). It is different from incidence, because it measures the overall occurrence of a disease at a certain point in time versus new cases occurring during a certain time period.

## WHAT IS THE PREVALENCE OF FASD?

There is a wide range of information available on the prevalence of FASD in Canada. These numbers can vary widely, depending on the research methods used and the population studied. Currently, the consensus states that the prevalence for FASD is at least 9.1 per 1000 live births (approximately 1 in 100 live births) (Sampson et al. 1997).

## THE IMPORTANCE OF UP-TO-DATE STATISTICS

The importance of up-to-date, accurate statistical information on the prevalence of FASD cannot be overlooked. Unfortunately, in Canada, it is not yet mandatory to report when a diagnosis of FASD is made. Without this statistical information, it is difficult for provincial and federal governments to budget for the necessary supports and services.

## FASD AND THE ABORIGINAL POPULATION

Historically for many Aboriginal cultures, the forces of colonization, residential school experiences and government institutions, including the child welfare system, created mass incidents of mistreatment and widespread abuse to Aboriginal children.

As families were fragmented and scattered, so was the foundation of traditional societies. FASD exists in the context of this history (First Nations, Inuit, and Aboriginal Health, 2007). Aboriginal people in Canada experience high rates of FASD because of this loss of family connections and culture and not because of any racial or cultural characteristics (Wemigwans, 2008).

It is recognized that Aboriginal traditions and beliefs vary from community to community. It is important to familiarize yourself with communities and individuals that you are working with in order to better understand their traditions. See Module Nine: Prevention of FASD for more information.

There has been a disproportionate amount of research in Canada on Aboriginal women's use of alcohol during pregnancy and the incidence of FASD (Masotti et al., 2003). The research often focuses on communities where there is known high rates of alcohol and substance abuse. The prevalence of FASD in these communities is then generalized to the entire Aboriginal population (Tait, 2004). Aboriginal communities are especially sensitive to the stigma associated with FASD because it is often seen as a racial problem versus a societal one. This stigma can be reduced through education and awareness. See Module Three: Alcohol, Women, and Pregnancy for more information on the factors that influence women's drinking during pregnancy.

## DISCUSSION QUESTIONS

### 1. What is Fetal Alcohol Spectrum Disorder?

- Occurs as a result of maternal alcohol use during pregnancy
- Leading known cause of developmental disability in Canada
- FASD is an umbrella term for Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND)

### 2. What does it mean to have an FASD?

- Lifelong condition that encompasses a broad range of disabilities that range from mild to severe
- Specific areas of functioning that are affected can include: learning, memory, attention, problem solving, social interactions, and mental health
- The effects of alcohol exposure are unique to the individual – each person will have different strengths and struggles

### 3. If FASD can only occur when a mother drinks alcohol during pregnancy, why do we avoid saying that it is 100% preventable?

- In an ideal world, FASD is preventable - if NO alcohol is consumed during pregnancy, there is NO chance that FASD will occur
- Consider these facts about the “real” world:
  - high percentage of women of childbearing age consume alcohol regularly
  - about 40-50% of pregnancies are unplanned
  - women often don't know they are pregnant until a few weeks into the pregnancy
- Saying that FASD is 100% preventable conveys a sense of judgment and doesn't account for these (and other) real life factors
- The message to women should be that there is no safe kind of alcohol, no safe amount of alcohol, and no safe time to drink during pregnancy

## References

Aase, J. M., Jones, K. L., & Clarren, S. K. (1995). Do we need the term “FAE”? *Pediatrics*, 95, 428-430.

Astley, S.J., & Clarren, S.K. (2000). Diagnosing the full spectrum of fetal alcohol exposed individuals: Introducing the 4-digit diagnostic code. *Alcohol and Alcoholism*, 35(5), 509-519.

Calhoun, F., & Warren, K. (2007). Fetal alcohol syndrome: Historical perspectives. *Neuroscience and Biobehavioral Reviews*, 31, 168-171.

Chudley, A. E., Conry, J., Cook, J. L., Looch, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172(Suppl. 5), S1-S21.

Clarren, S. K., & Smith, D. (1978). The fetal alcohol syndrome. *New England Journal of Medicine*, 298, 1063-1067.

First Nations, Inuit, and Aboriginal Health, (2007). Fetal alcohol syndrome/Fetal alcohol effects. Retrieved May 29, 2009, from <http://www.hc-sc.gc.ca/fniah-spnia/famil/preg-gros/intro-eng.php>.

Jones, K. L., & Smith, D. W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *Lancet*, 2, 999-1001.

Last, J.M. (2001). *A dictionary of epidemiology* (4<sup>th</sup> ed.). Oxford: Oxford University Press (APA).

Masotti, P., Szala-Meneok, K., Selby, P., Ranford, J., & Van Koughnett, A. (2003). Urban FASD interventions: Bridging the cultural gap between aboriginal women and primary care physicians. *Journal of FAS International*, e7 (1).

Mothering Under Duress Research Team (2008). How do the media represent mothers with substance use problems? *Highs and Lows. Canadian Perspectives on Women and Substance Use*. Toronto, ON: Centre for Addiction and Mental Health.

Poole, N. A. (2008). Fetal alcohol spectrum disorder (FASD): Canadian perspectives. Retrieved February 10, 2009, from <http://www.phac-aspc.gc.ca/fasd-etcaf/pdf/cp-pc-eng.pdf>.

Poole, N., & Urquhart, C. (2006). Pregnant women and alcohol: We need to move from stigma to support. *Visions Journal*, 2(9), 16-17.

Sampson, P. D., Streissguth, A. P., Bookstein, F. L., Little, R. E., Clarren, S. K., Dehaene, P., et al. (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology*, 56, 317-326.

Shields, L., & Twycross, A. (2003). Research update: The difference between incidence and prevalence. *Paediatric Nursing*, 15, 50.

Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S. & Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Canadian Journal of Clinical Pharmacology*, 16(1), e91-e102.

Stratton, K., Howe, C., Battaglia, F. C. (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment*. Washington, DC: Institute of Medicine and National Academy Press.

Sullivan, W. C. (1899). A note on the influence of maternal inebriety on the offspring. *Journal of Mental Science*, 45, 489-503.

Tait, C. (2004). *Fetal alcohol syndrome and fetal alcohol effects: The 'making' of a Canadian aboriginal health and social problem*. Unpublished dissertation. McGill University, Montreal, PQ.

Wemigwans, J. (Revised 2008). *FASD tool kit for Aboriginal communities*. Toronto, ON: Ontario Federation of Indian Friendship Centres.