

Current state of knowledge on Fetal Alcohol Spectrum Disorder

Key points

Foreword

Prepared by Marie-Alexia Masella for the Association pour la santé publique du Québec (ASPQ) as part of an action research project supported by the Public Health Agency of Canada,* this scientific review outlines the current state of knowledge on Fetal Alcohol Spectrum Disorder (FASD) in Québec, in Canada, and around the world. It identifies the key points from five documents produced on behalf of the ASPQ:

- **Revue de la littérature sur la stigmatisation que subissent les femmes en matière de consommation d'alcool** (2019), by Marianne Paquette, B.Sc. Nursing and candidate for a specialized graduate diploma (DESS) at the École de santé publique of Université de Montréal;
- **La consommation d'alcool chez les femmes au Québec** (2020), by Marianne Dessureault, B.A. L.L.B., Attorney at law, project manager, ASPQ;
- **Connaissances actuelles sur le TSAF** (2019), by Yves G. Jalbert, Ph.D., ASPQ;
- **Recension des écrits sur les problèmes éthiques liés à la prévention de la consommation d'alcool chez les femmes et à la détection du trouble du spectre de l'alcoolisation fœtale** (2019), by Marie-Alexia Masella, M.A, Ph.D. candidate in bioethics, Université de Montréal;
- **Alcool : stratégies marketing ciblant les femmes au Québec** (2020), by Marianne Dessureault, B.A. L.L.B., Attorney at law, project manager, ASPQ



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Introduction

Pregnancy is a special time for a woman and her loved ones. It is also a period of close medical follow-up, during which women are advised to adopt or avoid certain behaviours for their own health and that of their unborn child. One of these recommendations is to abstain from drinking alcohol, because prenatal exposure to alcohol is the leading preventable cause of intellectual disabilities and birth defects. The consequences of prenatal exposure to alcohol are complex and variable and most are grouped under the name Fetal Alcohol Spectrum Disorder (FASD).

The Association pour la santé publique du Québec conducted five literature searches on various topics related to FASD prevention. The first section of this scientific review presents the main facts about alcohol consumption in Québec and the current state of knowledge about FASD. The next section outlines ethical issues and potential stigma against pregnant women, mothers of children with FASD, and people living with FASD. This is followed by a discussion of the factors that can also influence alcohol consumption by pregnant women. The conclusion presents the lessons learned from previous FASD awareness campaigns. It will allow to develop effective, beneficial awareness campaigns that respect the autonomy of individuals directly concerned by this problem.



01. Alcohol consumption in Québec

Quebecers and alcohol

In Québec, drinking alcohol is socially well accepted. Although alcohol is considered to be a psychoactive substance, the general public does not perceive it as such (unlike cannabis, for example). Drinking is associated with relaxation, good times and celebrations, and alcohol is easily accessible and affordable — one of the reasons why 84% of Quebecers drink and 92% feel it is acceptable to drink alcohol occasionally [1]. The 2019 CROP–Éduc’alcool survey [2] found that **one in six alcohol drinkers (16%) in Québec think their drinking is harmful to their physical health**. This proportion drops to 13% in women.

This same survey breaks down alcohol consumption by Québec administrative region. The provincial average is 84%. Certain regions have a higher rate of drinkers:

- Chaudière-Appalaches (88%)
- Montérégie (87%)
- Capitale-Nationale (87%)
- Centre-du-Québec (86%)
- Estrie (85%) [2]

While others have a lower rate:

- Côte-Nord (76%)
- Gaspésie—Îles-de-la-Madeleine (79%)
- Saguenay—Lac-Saint-Jean (81%) [2]

Moreover, according to the 2017 *Canadian Tobacco, Alcohol and Drugs Survey* [1], close to one in five drinkers do not respect Canada’s Low-Risk Alcohol Drinking Guidelines (LRDG)¹. Compliance with the LRDG also fluctuates according to age. The largest number of drinkers who do not follow these guidelines are among young Canadian adults aged 20–24 [1]. Young Québec adults aged 18–24 are also proportionally more likely to drink alcohol compared to other age groups [3]. In fact, 83.5% of respondents aged 20–24 said they had consumed alcohol in the previous 12 months, compared to 56.8% of people aged 15–19 and 79.4% of people aged 25 and over [3].

1. These guidelines recommend a maximum of two drinks at a time for women and three drinks at a time for men.

Alcohol consumption among women

The gap between men and women of alcohol consumption tends to narrow over the years, with their drinking habits becoming similar [1]. It is thought that at least 8 in 10 women aged 12 and over in Québec drink alcohol and that close to half of them are frequent and regular drinkers [1]. Alcohol abuse is seen especially in women **aged 18–34**, and **wine appears to be the alcoholic beverage of choice** among women, while men prefer beer [2]. Women also drink more often **at home** (their own or a friend's) rather than at bars or clubs [2].

Alcohol consumption among adolescents

Adolescents are especially prone to drinking, especially in large quantities. Their circle of friends, lack of parental supervision and support, low self-esteem, and academic performance are factors that influence excessive alcohol consumption in adolescents [4]. The proportion of adolescents drinking alcohol is lower among those who live in a two-parent family (48%) than among those who live in a blended family (66%) [4]. The alcohol consumption of teenage girls is very similar to that of teenage boys. The prevalence of drinking among adolescents aged 11–17 has been decreasing for roughly the past decade [3].



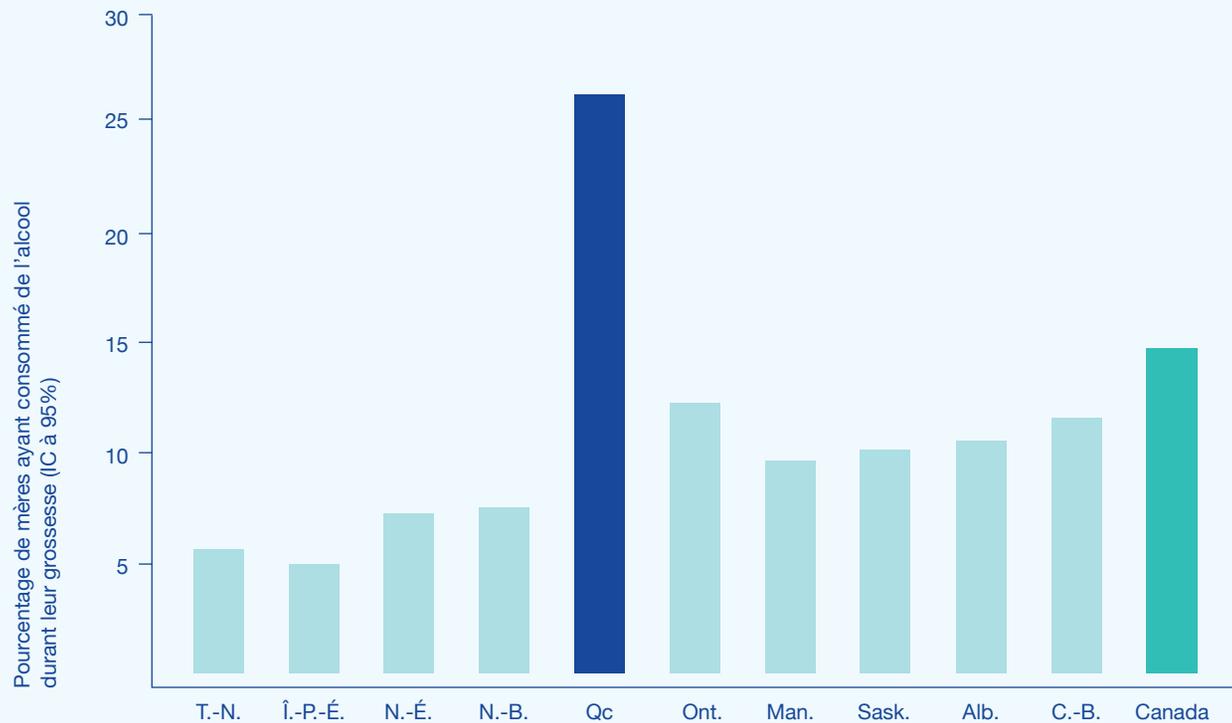
Alcohol consumption among pregnant women in Québec

The lack of recent data makes it impossible to draw up a current, representative portrait of alcohol consumption among pregnant women in Québec. In 2006, the 2005–2006 Survey on breastfeeding in Québec found that 34.1% of women had consumed alcohol during their pregnancy [5]. According to another Canadian survey, in 2006–2007, the proportions of women in Québec who drank alcohol while pregnant (21%) and in the months preceding their pregnancy (67%) were higher than the Canadian averages of 10.5% and 62%, respectively [6]. Three-quarters (73%) of Quebecers say they completely agree with the guideline to abstain entirely from drinking during pregnancy and 21% say they somewhat agree (76% of women completely agree and 24% of men somewhat agree) [7]. The more often a person drinks, the less likely they are to support complete abstinence during pregnancy [7].

The data in a 2013 Public Health Agency of Canada document reveal a high percentage of Québec mothers between 1993 and 2008 who drank alcohol while pregnant (25–30%). Also note that the Canadian average increases due to the Québec average, without which the national average would be much lower [8].



La consommation d'alcool durant la grossesse selon la province de résidence, Canada, 1993-2008



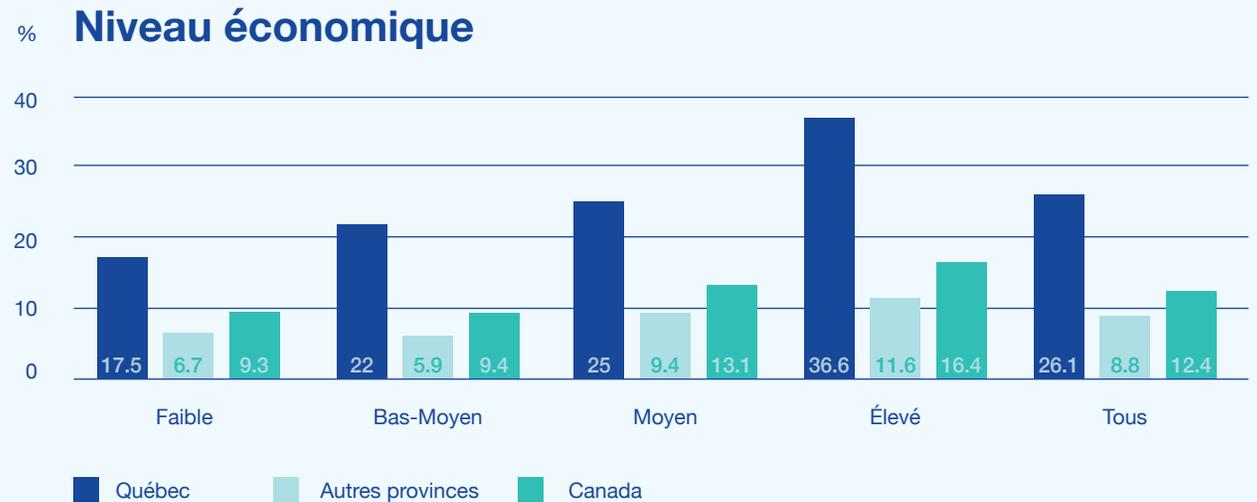
Source : Statistique Canada, Enquête longitudinale nationale sur les enfants et les jeunes
 Les dénominateurs excluent les réponses «ne sais pas» et les refus de répondre.
 Les territoires ont été exclus, car l'enquête n'y a pas été réalisée.
 IC — Intervalle de confiance

Based on these data and in light of the existing data on alcohol consumption among women, the following are the profile of adult women who are most likely to drink alcohol while pregnant [9]:

- **born in Québec;**
- **live in the administrative regions of Chaudière-Appalaches, Montérégie, and Capitale-Nationale²;**
- **aged 20–24;**
- **have a post-secondary degree;**
- **earn a high income.**

2. <http://www.stat.gouv.qc.ca/statistiques/sante/enfants-ados/alimentation/stat-allaitement.pdf>

The following figure represents the alcohol consumption rates by pregnant women in 2013, according to the socio-economic level. It is interesting to note that women from **higher socio-economic levels drink more, and that the average rate for Québec is higher than the national average, for all socio-economic levels** [10].



To obtain an accurate portrait of the situation, more recent data are needed on drinking habits before and during pregnancy.

In short

- Most Quebecers drink alcohol.
- Slightly more men than women drink alcohol, but the gap with women is small and tends to narrow over the years. More than 8 in 10 Québec women drink alcohol.
- There are no recent, reliable data on the prevalence of alcohol consumption among pregnant women or women who want to become pregnant in Québec. In 2006–2007, this prevalence was estimated at **21%** and **67%**, respectively. According to the *Survey on breastfeeding in Québec*, **34.1%** of women drank alcohol while pregnant.
- The more a person drinks, the less likely they are to support complete abstinence during pregnancy.

02. Current knowledge about FASD

History and nomenclature

The consequences of prenatal alcohol exposure have been known for several centuries, and even in Antiquity pregnant women were advised not to drink wine and fermented beverages (Old Testament, Diogenes, 400 BCE). The term Fetal Alcohol Syndrome (FAS) has been used since 1973, although Fetal Alcohol Spectrum Disorder (FASD) has been recommended since 2015 to encompass all manifestations of prenatal alcohol exposure, including FAS and Alcohol-Related Neurodevelopmental Disorder (ARND) [11] (see Table 1)

Prenatal alcohol exposure is the leading preventable cause of birth defects, developmental disorders, and intellectual disability in children [12]. The harmful effects of alcohol consumption on the mother and the child include [13]: stillbirth³, miscarriage, premature birth, intrauterine growth restriction, and low birth weight. These effects depend on the frequency of alcohol consumption, the amount consumed, and the stage of pregnancy during which the alcohol was consumed.

Acronym	Definition
FAE	Fetal Alcohol Effects: Children who present with some of the known dysmorphic features related to maternal alcohol consumption during pregnancy.
PAE	Prenatal Alcohol Exposure
SE/AE	Static Encephalopathy/Alcohol-Exposed
FAS	Fetal Alcohol Syndrome: One of the most severe birth defects caused by PAE, it is a persistent and irreversible syndrome characterized by a set of distinctive facial features, growth retardation, and central nervous system dysfunction.
pFAS/PFAS	Partial Fetal Alcohol Syndrome: Confirmed history of alcohol exposure and presence of facial abnormalities with or without other cardinal features of FAS.
FASD	Fetal Alcohol Spectrum Disorder: Encompasses the wide range of deficits associated with PAE. It is a highly variable phenotype sometimes accompanied by neurological deficits and intellectual disability.
ARBD	Alcohol-Related Birth Defects: Confirmed history of alcohol exposure and presence of birth defects potentially related to alcohol.
ND-PAE	Neurobehavioural Disorder associated with Prenatal Alcohol Exposure
ARND	Alcohol-Related Neurodevelopmental Disorder (formerly FAE): Confirmed alcohol exposure, presence of central nervous system abnormalities and cognitive disorders.

▲ **Table 1: Terms that refer to the effects of alcohol consumption during pregnancy on the fetus and the child**

3. Stillbirth occurs when the fetus dies after 20 weeks of gestation but before delivery. Spontaneous abortion, or miscarriage, is when the fetus dies before 20 weeks of gestation.

Prevalence of FASD

The prevalence rate of FASD is difficult to measure due to methodological limitations with some studies. It varies according to culture, definitions used, and socio-economic status [14]. The prevalence rate for the past few years is estimated between 7.8 (low estimate) and 29.3 (high estimate) per 1,000 births, according to a Canadian study conducted in Toronto in 2018 (children aged 7–9 in Toronto-area public elementary schools) [13]. According to a new U.S. study of 6,639 students aged 6 and 7, conducted between 2010 and 2016, conservative prevalence estimates for FASD ranged between 1.1% and 5% [15]. The same study found a weighted prevalence ranging from 3.11% to 9.85% in children with FASD [15].

There are no representative prevalence data for Québec. The incidence is also higher in certain subpopulations: Aboriginal peoples [16], prison inmates, [16–19] and psychiatric patients [16,20]. Therefore, depending on the environment in which it was assessed, the prevalence of FASD varies (with higher estimates for intake systems, such as youth centres and the justice system) [21].

The **difficulty in making a diagnosis** is also a factor that influences incidence and prevalence estimates. Most children affected by alcohol present with only a few or even none of the physical markers of FASD (fewer than 10% of them) [12]. As a result, they are more difficult to identify, especially without any specific information about their alcohol exposure. The possible effects of prenatal alcohol exposure are in fact heterogeneous and variable, as illustrated in the following diagram:

Developmental problems

Growth retardation	Speech impairments
Lower overall intelligence than their peers	Attention deficit (impulsiveness, difficulty concentrating and understanding instructions)
Psychomotor problems (difficulty with fine motor skills, balance, coordination)	Executive function deficits (difficulties with concentration, problem-solving, planning, conceptualization, verbal fluency)
Visual-spatial skill impairments	

Behavioural problems

Difficulty establishing relationships and social interactions	Increased risk of being classified as hyperactive, impulsive or delinquent
Frequent tantrums	Erratic behaviour
Increased risk of psychiatric disorders, run-ins with the law, drug addiction problems	Decreased ability to be independent

Physical health problems

Distinctive physical features (thin upper lip, smooth ridge between the upper lip and nose, small and/or wide-set eyes)	Physical deficits (vision/hearing problems; heart, bone and kidney defects; digestive disorders; central nervous system abnormalities; reduced brain size)
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Diagnosis of FASD

On the one hand, infants, children and adults with FASD who have access to care will benefit from that care — not because they have been diagnosed with FASD, but because they meet other criteria for medical treatment or early childhood/special education programs, by virtue of their symptoms and not their FASD diagnosis. Incidentally, FASD diagnosis enjoys no special status in Québec that would give people with the disorder access to medical care specifically related to their condition. On the contrary, many people living with FASD do not meet the existing criteria and fall through the cracks in the healthcare system [27].

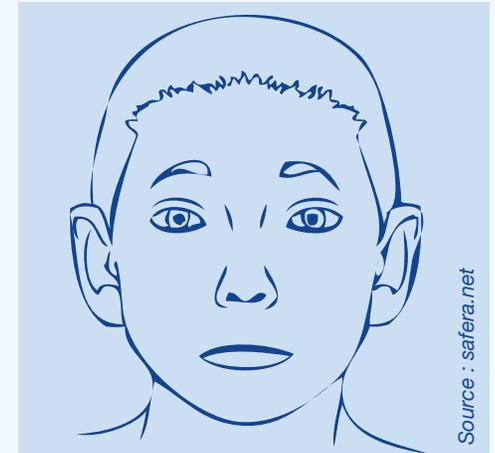
On the other hand, FASD is very often confused or lumped in with other disorders, such as autism spectrum disorder, attention deficit hyperactivity disorder, oppositional defiant disorder, behavioural disorders, and reactive attachment disorder. These diagnoses will take precedence over FASD diagnosis, because some of them benefit from social/medical programs and related services, whereas no such resources are in place for FASD⁴.

The absence of a diagnosis or the presence of a misdiagnosis will therefore adversely affect the life of a child who does not receive the care they truly need, not to mention the negative effects on their family, who provide most of their care [22].

In Canada, the clinical diagnosis of FASD is based on national guidelines published in 2015, and the nomenclature proposes the following diagnoses [28]:

FASD with sentinel facial features

Children who present with three sentinel facial features (i.e., short palpebral fissure length, smooth philtrum, and thin upper lip) and in whom three areas of neurological development (learning disabilities, inattention, social skills gaps, executive functioning) are affected. Prenatal alcohol exposure may or may not be confirmed.



FASD without sentinel facial features

People whose mother consumed alcohol during pregnancy and who present with significant neurological development disorders, but who have no specific physical signs. (Most people with FASD fall into this category).

At risk of neurodevelopmental disorder and FASD associated with prenatal alcohol exposure

People with prenatal alcohol exposure who present with certain neurological development disorders, but who do not meet the diagnostic criteria for FASD.

4. <https://www.journaldequebec.com/2019/10/21/de-faux-diagnostics-pour-obtenir-des-services>

The complexity and chronicity of the effects of FASD **impact both the individual affected and their family**. According to a study conducted in the United States of America, those who generally live with a child or an adult with FASD are foster families (31%), adoptive parents (20%), the biological mother (19%), the extended family (often grandparents, 12%), the biological father (9%), and other settings (group homes, rehabilitation centres, 8%) [29].

In Québec, children with FASD are often found in foster families, adoptive families, extended biological families, rehabilitation centres, and with their biological parents [29]. **In many cases, individuals with FASD will need lifelong help and a wide range of care and services.** While the level of autonomy varies from person to person and depending on the tasks undertaken, these individuals will never be totally independent (help needed with activities of daily living, work, managing finances, etc.). The figure below outlines the various impacts and challenges for families taking care of a child or an adult with FASD.

Problems at home

Lack of autonomy in adulthood

Constant issues with sleeping, eating, dressing, socializing, etc.
Altered family dynamics

Children who are highly reactive, frequent tantrums
Parents who are strained, do not always know how to react

Problems affording the costs related to FASD

Annual cost of \$24,000 per child

Parents assume 21% of the costs

Impacts of a diagnosis before age 6

Allows siblings to be screened and preventive measures to be taken for any future children

Increases parents' and children's sense of competence

Helps parents work through the “grieving” process of a “normal” child

Prevents secondary consequences (e.g. depression, drug abuse, legal problems)

In conclusion, no specific programs or action plans exist, and no formal coordination mechanisms are in place in Québec for FASD [31]. A recent study [13] showed that FASD must be considered a concerning public health problem in Canada for which improvements are needed in prevention initiatives related to alcohol consumption among women aged 12–29, but also among pregnant women and women of childbearing age, while supporting people with FASD and their families.

In short

- The effects of prenatal alcohol exposure are unpredictable, multiple and chronic.
- Prenatal alcohol exposure is the leading preventable cause of birth defects, developmental disorders, and intellectual disability in children, even if most have an IQ within normal limits.
- The prevalence of FASD is difficult to accurately assess due to the lack of representative data, the variable definitions, and the possible subdiagnoses.
- The absence of a diagnosis or the presence of a misdiagnosis therefore adversely affects the life of a child who does not receive the care they truly need, not to mention the negative effects on their family, who provide most of their care.
- Canadian guidelines were issued in 2015 to adequately diagnose people with FASD. Three diagnoses were described:
 1. FASD with sentinel facial features,
 2. FASD without sentinel facial features,
 3. At risk of neurodevelopmental disorder and FASD associated with prenatal alcohol exposure.

03.

Stigma associated to FASD

Definition

Women who drink alcohol during pregnancy, and children and adults living with FASD, are very often exposed and subjected to stigma [32–35].

The *Chief Public Health Officer's Report on the State of Public Health in Canada 2019* ([36], p. 22) defines stigma as follows: “Stigma begins with the labelling of differences and negative stereotyping of people, creating a separation between “us” and “them.” (...) This can lead to disadvantage and inequitable social and health outcomes. Stigma happens in institutions (...), at a population level (...), through interpersonal relationships (...) and internally (...).”

Stigma against pregnant women

Pregnant women who drink alcohol are the target of **social stigma** [37]. Society frowns on these mothers-to-be for acting in their own interests, by making choices that may adversely affect their fetus. Their alcohol consumption is therefore **attributed to deviance and irresponsibility** on their part [33].

Stigma against people with FASD

Children with FASD are often described as victims of their mother's actions [33]. Nevertheless, they are judged or ridiculed because they are not and do not act like a “normal” person.

The physical, developmental and behavioural consequences of prenatal alcohol exposure also lead to stigma against these people, who are sometimes qualified as villainous and deviant, and labelled and stereotyped as being inherently criminal [32]. Certain short cuts and society's stereotypes and derogatory names are not necessarily related to the FASD diagnosis, but rather to its obvious effects. As a result, some individuals with FASD report problems ranging from social exclusion to discrimination at work [33].



Health promotion and stigma

Public discourse, the media, and health messages shape social norms and “can influence what is considered to be ‘normal’ and ‘acceptable’” ([36], p. 22). As for drinking during pregnancy, these messages in Canada too often **emphasize blame, shame, and a mother’s individual responsibility** [32,33]. By disregarding any external factors potentially at play, this emphasis can feed into stereotyped portrayals of women who drink while pregnant as unfit, irresponsible, and even criminally negligent [32,33].

Certain health professionals can also demonstrate stigmatizing attitudes and behaviours. When this happens, it is generally associated with a **lack of knowledge and competence** by these professionals, causing them to have stereotyped, moralistic and accusing opinions about their patients [38].

Consequences of stigmatization

This stigmatization **has harmful effects** on the management of these women and children, and on their health as a result [36]. Pregnant women may isolate themselves, refuse to seek help, and not disclose their drinking, which can have the effect of depriving them **of adequate medical care** [33,39–41]. Often, women who know they are pregnant and continue to drink hold back from disclosing their drinking and from seeking help for **fear of losing custody of their child** and of having the child taken away by child protective services [40,41].

The stigma associated with FASD can also prevent certain health professionals from accurately diagnosing children with the condition. In fact, they fear the stigmatizing label that an FASD diagnosis could involve for their young patient, in addition to being embarrassed to question the pregnant mother about her drinking [42].

Here is a figure who illustrates how the stigma pathways to health outcomes model can be applied to substance use, including alcohol.



Drivers of stigma

Belief that substance use disorders are evidence of a lack of willpower or of moral failure

Intersecting stigmas

Social identity stigmas (racism, sexual stigma, gender identity stigma, etc.) and/or health-related stigmas (mental illness stigma, etc.)

Stigma practices

Negative portrayals, discrimination, social avoidance, demeaning and inappropriate language (including from health professionals)

Experiences of stigma

Enacted stigma (the experience of unfair treatment), internalized stigma (shame and embarrassment), anticipated stigma, secondary stigma for the family

Outcomes and impacts

Reduced seeking of services, concealment of the drinking problem, increased risk of homelessness, adjustment strategies, and health harming coping strategies

▲ Figure 1: Application of the stigma pathways to health outcomes model to substance use (including alcohol), taken from the Chief Public Health Officer's Report on the State of Public Health in Canada [36]

Recommendations to minimize stigma

A helpful strategy for reducing stigma and its negative consequences is to **encourage and bolster self-esteem and self-efficacy⁵ in mothers and people with FASD** [36]. There is also a need for increased awareness and training among health professionals and social workers [34,36]. Professionals must be encouraged to take a comprehensive, patient-centred approach steeped in tolerance, understanding and non-judgment. This positive, therapeutic communication method is relevant not only with women who are considered at risk, but also with all women, and even the population as a whole [34].

When it comes to public health campaigns, **potentially stigmatizing and blaming discourse is to be avoided**. Preference must be given to **uplifting messages that do not infantilize women and that convey clear, precise information about the topic** [33,39,40]. These campaigns must target not only pregnant women who are at risk of drinking or who are dependent on alcohol, but also women in general (especially during the pre-conception stage) and their loved ones (spouse, family, friends, etc.) [43]. In order to help and support women and stop condemning them, campaigns need to be developed that target their family members [44,45]. Women will also be encouraged to talk about their drinking, and

any changes they make will be more effective with help and support from their family and community [46].

Some also suggest creating and using a so-called neutral diagnosis ,e.g. congenital neurodevelopmental disorder, to avoid compounding the guilt and judgment levelled at mothers, and to help preserve their dignity, thereby avoiding any stigma against the child associated with the word *alcohol*, which necessarily alludes to their mother's drinking [35].

5. Self-efficacy is a theory developed by Canadian psychologist Albert Bandura. Self-efficacy is one's belief in one's ability to succeed in specific situations or accomplish a task.

In short

- Several pregnant women who drink or have drunk alcohol are victims of stigma, as are people with FASD.
- People with FASD report issues ranging from social exclusion to discrimination at work because of their diagnosis or the consequences of prenatal alcohol exposure.
- Preventive health messages can fuel prejudice and stereotypes.
- Some health professionals sometimes adopt a blaming or stigmatizing approach, which often stems from a lack of knowledge about FASD.
- The stigma is likely to lead to an increased prevalence of FASD, in particular by discouraging women from talking about their drinking and denying them access to appropriate medical treatment.
- Awareness about drinking during pregnancy among women in general, and among their loved ones, needs to be prioritized and widespread.

04.
Ethical issues
surrounding the prevention of FASD

The prevention of alcohol consumption during pregnancy and of FASD is associated with several ethical issues related to over-responsibilization, stigmatization, and misinformation, which are presented in the diagram below.

Over-responsibilization

Mothers are victims of standards, stereotypes, and pressure in terms of what constitutes a good person, a good woman, and a good mother.

Beliefs (sometimes conveyed by awareness campaigns) occasionally support the notion that pregnant women who drink are personally and solely responsible for the situation.

The lack of consideration for the social determinants of health and for the reasons that motivate women to drink is a key factor.

Infringes on:

- The woman's autonomy
 - The beneficence
- + Presence of paternalism

Stigmatization

Pregnant women are judged, criticized, made to feel guilty, and sometimes even shamed in public or by their health professional.

This stigma triggers in women shame, depression, low self-esteem, fear that their child will be taken away from them, and reluctance in seeking help and treatment.

The consequences on children and people living with FASD are significant: presumption that they are unhappy and a potential burden, ultimately leading to their isolation and marginalization.

There is a risk of increased condemnation and judgment toward certain populations with a higher reported rate of drinking during pregnancy.

Infringes on:

- The woman's autonomy
- The beneficence
- The non-maleficence
(harm caused to people affected)

Misinformation

The various messages and information for women about drinking during pregnancy are contradictory and unclear.

Health professionals lack knowledge, awareness, and training on preventive measures.

Misinformation is propagated by the alcoholic beverage industry.

Women have difficulty making voluntary, informed decisions.

Infringes on:

- The woman's autonomy
(alteration of voluntary,
informed decision-making process)

Factors to consider for ethically acceptable awareness campaigns

Several recommendations can be made for the purpose of avoiding situations that infringe on the autonomy (capacity for self-determination and freedom of choice) of pregnant women and people with FASD and that run counter to the principles of beneficence (acting for the good of others), nonmaleficence (not causing harm), and justice (fair treatment of all women) sought by public health agencies in their fight against drinking during pregnancy. The *international charter on prevention of Fetal Alcohol Spectrum Disorder (ETCAF)*, produced, endorsed and adopted by more than 700 people from 35 countries worldwide at a conference in 2013, encompasses most of the following recommendations [55]:

- 01.** Since many pregnancies are unplanned (estimated at approximately 40% in Canada) [56], prioritize **prevention and awareness during the preconception stage**. Emphasize the **importance of contraception** to prevent an unwanted pregnancy, especially if a woman wants to drink alcohol. It is best not to impose contraception on women. If they do not want to use feminine contraception or a specific type of contraception, we must avoid a paternalistic approach of imposing contraception on all women under the pretext of wanting to reduce the incidence of FASD. Likewise, the burden of preventing FASD through the use of contraception should not be placed solely on women [44,55,57–60].
- 02.** Women of childbearing age may be **adolescents**. This population is especially prone to drinking, sometimes in large quantities. Prevention measures also need to be adapted to this population and to the challenges associated with it. Several authors point out that it is preferable to associate information about FASD and pregnancy with drinking prevention initiatives in adolescents [45,55,61].
- 03.** It is important to **manage the factors** that can lead to alcohol consumption: mental illness, addiction, socio-economic status, marital problems, etc. [55,62].
- 04.** It is important to consider the **diversity of women** targeted by the public health campaigns: age groups, socio-economic status, ethnic groups, cultures, religions, etc. [40,62–64].

Promoting ethically acceptable clinical management

It is essential to educate health professionals about the importance of preventing FASD and to provide practical tools to discuss the topic with their patients [58,65].

To help women play an **active** role in changing their drinking behaviours, it is necessary to make them the main focus during medical consultations and **listen to them in an open, helpful, and judgment-free way** [66].

The use of alternative or complementary therapeutic methods (occupational therapy, meditation, sociotherapy, art therapy, etc.) can also be beneficial because of their potential influence on the factors that can lead women to drink during pregnancy (stress, anxiety) [67].

Therefore, when developing awareness campaigns or clinical interventions, it is essential to consider these ethical issues and to maximize the **principles of beneficence, autonomy, non-maleficence, and justice** (helping everyone on a fair and equal basis, including women who are marginalized or already stigmatized for other reasons).

05.

**Factors that influence
alcohol consumption among women**

Factors that influence alcohol consumption among women

The various literature searches revealed several factors that can influence alcohol consumption among women, in particular among pregnant women.

Factors related to the woman's current condition

Stress (related to pregnancy, financial problems, relationship problems with the father)

Pre-existing alcoholism

Unwanted pregnancy

Wanting an abortion

Physical and psychological trauma

Childhood trauma (abuse, rape, etc.)

Toxic conjugal relationship

Misinformation

Lack of clear guidelines on drinking during pregnancy (contradictory sources, lack of a scientifically proven safe limit, contradictory messages)

Individual characteristics

Age

Ethnicity

Level of education

Socio-economic status

Parity

Social environment

Family support

Substance use by partner and loved ones (which can make it more difficult for the woman to stop drinking)

Beliefs

Social and cultural norms

Historic community environment

Historic impacts of abuse suffered by certain communities

It is also worth noting that the alcoholic beverage industry developed a code of ethics in 2006 [71]. However, this code of ethics states that “there is such a thing as a safe level of alcohol consumption,” which can be misleading for the general population, including pregnant women [71].

Marketing also plays a non-negligible role in influencing alcohol consumption among Quebecers, in particular, young girls, women, and pregnant women. The goal of marketing is to attract and retain new consumers by offering them products that respond to their needs and wants [72]. The following table outlines the current trends in the promotion of drinking by alcohol producers and their impacts on alcohol consumption by the general population. ▶

Product

Sweet and flavoured products (coolers)

The taste of alcohol is masked, leading consumers to believe these products contain less alcohol and are therefore not harmful and will not cause intoxication (very popular with adolescents and young people, especially young girls).

Wine

Per capita increase in consumption in Québec
(+21% between 2007 and 2018)

Spirits

Increase in consumption in response to the current craze for homemade cocktails (mixology and local distillers)
(+7,44% between 2016 and 2018 in Québec)

Beers

Increase in consumption, with sales almost doubling (from \$1B in 2014 to \$1.9B in 2018); blonde beers are preferred in the non-craft beer category, while ales are the top choice in the craft category

Price

Use of **cross promotions** by alcohol producers (giving away another product with the purchase of alcohol) to decrease the price of alcohol.

For **women aged 18 and over**, options abound for them to **drink for free 6 out of 7 nights** at certain bars and restaurants that hold promotions such as Ladies' Night, 2-for-1, or Happy Hour events.

Price has a **major influence on purchasing behaviour** (raising the price is one of the most effective ways to reduce consumption), especially among young people.

Price-change policies: **floor prices** (increase in prices, therefore decrease in availability of cheaper alcohol, preferred by at-risk drinkers) AND **pricing on alcohol content** (increase in the price of products with a higher alcohol content to reduce overall per capita alcohol consumption).

In Québec, the government determines the price of alcohol, to a certain extent, by taxing products and setting minimum prices.

Advertising

Alcohol is one of the most widely advertised consumer goods on the market.

Use of the following communication methods by the industry: television, print, social media, websites, advertising signage, product placement in television shows and movies.

This exposure to advertising **leads young people to an early exposure to drinking** when they did not previously drink and **increase the amount they drink** if they already drank.

Despite the restrictions or laws in place, adolescents are still **highly exposed to advertising** for alcoholic beverages (as much as, or more so than adults).

Young girls are more exposed to **magazine and radio** advertisements, while young boys are more susceptible to television advertisements.

Use of **social media** by the industry to disseminate more varied content to a maximum of young people.

Targeting women

Feminization of consumer and advertising practices.

Development of products aimed at adolescent girls and women: fruit-flavoured beers, premixed beverages, low-calorie/carbohydrate drinks, low-alcohol products.

Use of female stereotypes in advertising messages: focus on slimness, pink packaging, motherhood, sexuality, accessory giveaways (jewelry, makeup).

Recently, use of messages of empowerment, sexual affirmation, promotion of equality between the sexes, celebration of women.

Nevertheless, a recent Léger marketing poll, commissioned by the Retail Council of Canada (RCC), estimated that **17%** of Quebecers would participate in an alcohol-free month initiative, a proportion that increases to **24%** in people under age 35, or close to one in four young people [87].

As such, according to one study, organizations funded by the alcohol industry were statistically less likely than public health websites to provide information about FASD and less likely to state that no amount of alcohol is safe during pregnancy [88]. These results suggest that the organizations funded by the alcohol industry can increase the risks for pregnant women by disseminating incorrect or biased information. The

public should be made widely aware of the risks related to obtaining health information from sources funded by the alcohol industry [88]. As such, there is a need to develop potential applications for social marketing in terms of campaigns to prevent drinking during pregnancy.

Conclusion

Drinking is socially acceptable and widely practised, in particular among people aged 20–24. Adolescents (age 11–17) are the age group that most drinks to excess. In Québec, in 2005–2006, 34.1% of pregnant women drank alcohol, although there are no data on the frequency of their consumption. Drinking can have severe consequences on the fetus.

Several terms are used to describe some of the consequences in children linked to prenatal alcohol exposure. FASD encompasses most of these consequences. According to a Toronto study, FASD is estimated to affect between 7.8 children (low estimate) and 29.3 children (high estimate) per 1,000 live births in Canada, or 0.8% to 2.9%. For example, this study found that the prevalence of FASD in elementary school students in Ontario is likely between 2% and 3% [16]. According to a 2018 California study of 6,639 children, the proportion of newborns whose brain is affected by alcohol abuse during pregnancy is between 3.1% and 9.85% (according to weighted estimates) [15].

However, there is a lack of available data in Canada, because these people are difficult to diagnose. In fact, FASD is broad and non-homogeneous and is often confused with other behavioural disorders. To avoid this situation, guidelines proposing three possible diagnoses were issued in 2015.

This congenital abnormality is hard on the person living with FASD and on their family and community. Some of the obstacles to overcome include the lack of autonomy by people with FASD (although their autonomy varies, they are generally dependent on family to some extent), disruptions to family life, ignorance about the condition and the costs associated with managing it, and social opinion and judgment.



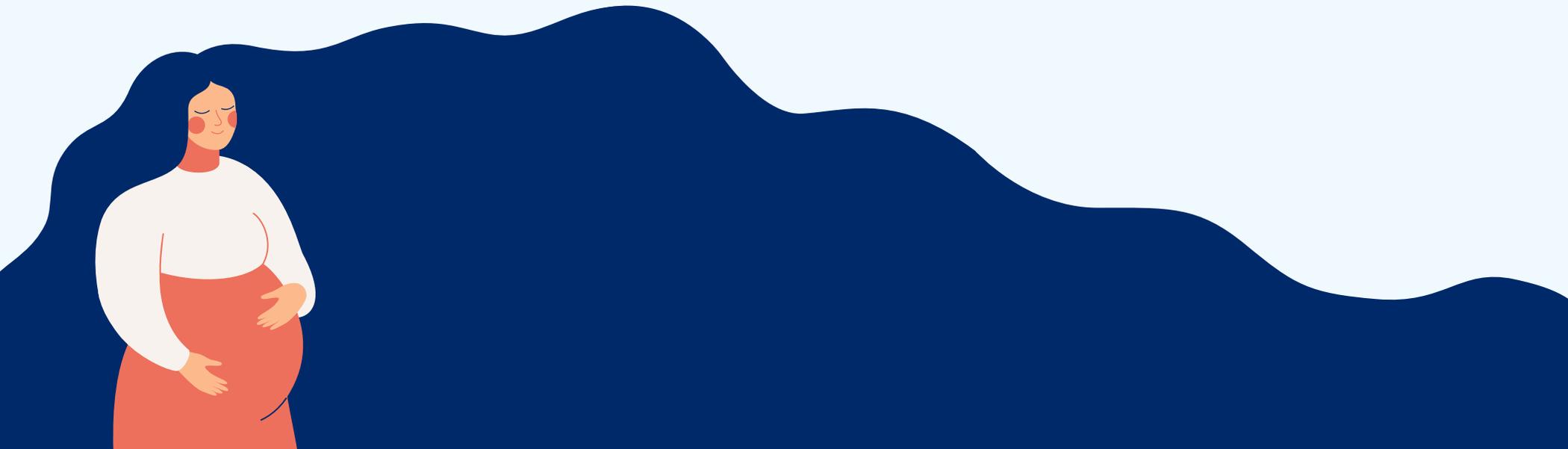
Conclusion (suite)

As several studies have shown [32,33], stigma is a fact of life for pregnant women who drink, who are labelled as irresponsible and selfish, and for people with FASD, who are mocked for their sometimes immature behaviour and labelled as deviant and criminal.

This stigma, added to the over-responsibilization of women, and the misinformation of pregnant women about the consequences of drinking during pregnancy, are all factors that compromise the autonomy of these people, and that run counter to the principles of beneficence and non-maleficence sought by the various stakeholders involved in the prevention of FASD.

As such, prevention campaigns should strive to convey “blaming and shaming” messages, which can stigmatize these populations, as well as avoid placing full responsibility on pregnant women. Instead, they should focus on:

- Raising awareness among the public and the woman’s community, which plays an important role in prevention, through the support it can provide to the woman.
- Informing women during the preconception stage and recommending contraception if they drink and do not want a child.
- Encouraging women to seek help to manage the factors that could lead them to drink during pregnancy.
- Encouraging women to talk to health professionals without fear (and encouraging professionals to seek out the information and training they need to provide helpful, open support and beneficial case management).



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