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Introduction

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This book is about the prevention of a disability that does not need to exist: fetal alcohol spectrum disorder (FASD). Alcohol use during pregnancy is the direct cause of this disability, which the baby must live with for the rest of its life. The damage caused to the brain of the fetus by exposure to alcohol is irreparable. Who is responsible for this?

For almost 40 years, FASD has been said to be entirely preventable, and ever since the cause of the disorder was established, women who drink while they are pregnant have been made to feel fully responsible for perpetuating this "entirely preventable" condition. But, the more we learn about FASD and the challenges to its prevention, the more we realize that investing only pregnant women with the responsibility for FASD prevention is misguided, ineffective, and punitive. Yet, if the responsibility for FASD prevention does not lie only with women who drink when they are pregnant, who else is responsible?

That question is not as easy to answer as it may seem, since there are many reasons for alcohol use during pregnancy. Men who are violent at home, who abuse alcohol themselves and who encourage or demand their pregnant partner to drink with them are responsible for the syndrome. The social determinants of health, such as poverty, poor housing, poor nutrition, along with other complicating social circumstances, may also be implicated in the alcohol use that causes FASD. Healthcare and social service providers who fail not only to ask pregnant women about their alcohol use but also to provide meaningful support to women at risk, may be seen as responsible. Governments who do not adequately fund the programs, services, and infrastructure necessary for providers to reach families who are struggling also hold responsibility for FASD.

Pregnant women who drink are, of course, also responsible. Some women drink before they know that they are pregnant; some may believe that only heavy drinking will endanger their baby, and that consuming a moderate amount of alcohol is harmless; some may drink in conformance with cultural norms and beliefs. It is well known from several scientific studies that many women drink during their pregnancy simply to cope with their difficult living circumstances and relationships – to lessen their fear, anxiety, depression, and loneliness.

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Not only women, but also their male partners, their social support networks, and society at large are responsible for FASD, and must also be held responsible for its prevention. At least one in every 100 babies born has to live with this permanent disability. In Canada alone, with a population of 33 million, there are about 300 000 individuals living with this injury. If the same incidence holds for the United States, with its population of 307 million, there are about three million people in that country forever incapacitated by having been exposed to alcohol during their most vulnerable time in life – their first nine months. In Europe, with a population of more than 500 million, there may be as many as five million people living with this preventable syndrome.

When thousands of babies are born every year with permanent brain injury of known cause, the response to that ought to be a forceful, determined, concerted, compassionate, sustainable and effective effort to prevent such an occurrence.

1.1 The Content of This Book

This book presents findings from research on different strategies to prevent FASD. Although prevention of this syndrome is challenging, promising results have been obtained from many studies, demonstrating that certain prevention programs are effective in reducing alcohol use during pregnancy.

Chapters 2 and 3, which form the core of the book, are systematic reviews of a large number of studies on the prevention of FASD that have been published in the scientific literature. Chapter 2 also includes a review of the effectiveness of different strategies for diagnosis and treatment, which also are relevant in FASD prevention. Maria Ospina and colleagues have examined the strength of the evidence in each of the studies, and have found some prevention strategies that have clearly been shown to work. But, perhaps more importantly, they have also identified other programs that may not be effective.

It seems self-evident that ineffective strategies for prevention should not be used. However, the reviews show, for example, that widely used and comparatively expensive strategies – such as alcohol-related warning messages, alcohol bans, and some other social marketing strategies implemented on a massive scale – have a limited effectiveness. They do not seem to increase knowledge of FASD, nor to change attitudes toward alcohol use during pregnancy.

On the other hand, focused multimedia education programs aimed at youth in school settings show some evidence of effectiveness, as do health education programs directed at women of childbearing age and pregnant women. Some screening programs for the prenatal use of alcohol have proven effective in identifying high-risk women, and there is strong evidence of the effectiveness of several types of intervention in reducing alcohol use during pregnancy.

The most important finding from the systematic reviews may be that comparatively few FASD-prevention programs have been evaluated. Moreover, among those that have been assessed, only a small fraction have employed a rigorous

scientific methodology. The authors argue for more evaluation and for research into the broader social and systemic causes of alcohol use during pregnancy. They also point to the importance of promoting strategies for which there is empirical evidence of effectiveness.

Chapter 4 includes five presentations made at a consensus development conference on FASD. Lola Baydala, from the University of Alberta, presents strong evidence for school-based substance use-prevention programs and, in particular, for the Life Skills Training program initially developed at Cornell University. That program has been shown to be highly effective with students from different geographic regions and with different socioeconomic, racial, and ethnic backgrounds.

Robin Thurmeier from the Saskatchewan Prevention Institute reviews the evaluations of Canadian primary prevention campaigns for FASD. This review is based on an inventory of FASD primary prevention resources, which included campaigns such as "Be Safe; This is Our Baby"; "Alcohol and Pregnancy"; "Born Free"; "Mother Kangaroo"; and "With Child, Without Alcohol." Some of these programs have been found to have had a high impact on the awareness of what FASD is, and that it is linked to alcohol use during pregnancy. However, little is known about how effective these campaigns are in promoting behavioral change. Robin concludes that a behavioral change model needs to be employed to guide the creation of materials and interventions, and she offers "Protection Motivation Theory" as one potential theoretical framework for guiding future prevention campaigns.

June Bergman, from the University of Calgary, discusses the role of primary healthcare in the prevention of FASD, and points out that primary care not only addresses a large majority of personal healthcare needs but also has numerous other dimensions. These include prevention and attention to the social determinants of health, as well as creating community capacity as needed. For example, primary care physicians could be more involved in screening for alcohol use during pregnancy; however, June points out that there are currently a number of barriers to that, such as lack of time and training, shortages of resources, and lack of access to the services of trained counselors when alcohol use is identified.

Nancy Whitney, from the University of Washington, discusses mentoring programs for mothers at risk and, specifically, the Parent–Child Assistance Program (PCAP), which is an intensive three-year home visitation program. The PCAP originated in Washington State some 20 years ago, and has since been replicated all over the United States. The program is tailor-made for each woman, many of whom live in poverty and with domestic violence and untreated mental health problems. The aim is to motivate these women to stop drinking before and during pregnancy, and to help those women who cannot stop drinking to avoid becoming pregnant by using family planning. Several assessments of the program have demonstrated that most women in the PCAP go from chaos to stability, become sober, live in permanent housing, become less dependent on social welfare, and use family planning. The program also seems highly cost-effective. The author recommends this type of intensive case-management program aimed at the highest-risk mothers in the community, along with the support of specialized

addiction treatment centers that welcome the women and their children. Unfortunately, such programs continue to be few in number, and are under enormous pressure to meet demands for their services.

Amy Salmon, from University of British Columbia, reminds us of our common assumption that healthy women have healthy babies, and underlines the importance of looking beyond biological factors and genetic endowment to support good health in women. She stresses the need to focus on the social determinants of health in the prevention of FASD. This requires attention to income and social status, social support networks, education, employment and working conditions, social environments, personal health practices, healthy child development, culture, and gender – all of which are unevenly supported in different jurisdictions. Findings from research have shown that those women who give birth to children with FASD are also most likely to have their own health and well-being compromised by addictions, depression, anxiety, high stress levels, and experiences of violence, trauma, grief, and loss. Clearly, the messages in FASD prevention must not build on shame and blame, which stigmatizes, discriminates and isolates women from exactly the kinds of care that they need. Increasing the system capacity for effective FASD prevention, focused on the root causes of alcohol use during pregnancy, requires a full recognition of women's health issues in its broadest sense.

1.2 What is FASD?

The notion that alcohol consumption during pregnancy might be harmful to a developing fetus has been occasionally considered since antiquity. Seminal studies conducted in France and in the United States during the late 1960s and early 1970s brought a more concerted attention to the possibility. In both places, physicians detected a specific, recognizable pattern of physical traits that were consistent in some children who had been exposed to alcohol during gestation. David W. Smith and his group called this syndrome "fetal alcohol syndrome" (FAS) [1], even though they were not sure that alcohol was the true etiologic agent. Nevertheless, they were convinced that the syndrome's prevention included the elimination of alcohol from the embryo–fetal milieu. FAS was soon defined to include structural brain damage (or, at least, clinical evidence of significant brain dysfunction), a typical set of specific minor facial anomalies, and slower prenatal and/or postnatal growth. There was also evidence of problems in other organs, such as the skeleton, kidneys and heart, although these were considered to be associative rather than necessary for defining the syndrome.

Over time, the results of studies conducted with animals have proved that alcohol is indeed capable of producing embryonic and fetal damage (teratogenic). These studies have also shown that the mechanisms of teratogenesis are complex and multifaceted, so that a simple medical approach to blocking a pathway and reducing harm has not been forthcoming. The original human observations have also been confirmed, that the most common impact of fetal alcohol exposure is found in the brain. Those children who were first described with FAS had obvious

brain problems typified by severe structural malformations, significantly smaller heads than normal for their age and gender (microcephalus), neurologic problems such as seizures or cerebral palsy, and intellectual handicap. However, these severe manifestations of alcohol's effect were found over time to be only the most extreme examples, not the most common. It is now understood that alcohol primarily alters the microscopic structure and the neurochemistry of the brain, and that this can lead to global, diffuse problems with memory, executive function, social communication, complex learning tasks, attention and other processing dysfunctions.

Affected individuals have different degrees of challenge within and among functions. Among those children initially identified, tests of intellectual quotient (IQ) were frequently within the normal range. However, clinical findings from all measures would sum to a final common pathway of poor adaptive function in society, school and at home that could not be explained by any single deficit alone. The patterns and severity of the functional components were the same in children exposed to alcohol who had the facial and/or growth abnormalities, and those who did not. This led ultimately to the term "fetal alcohol spectrum disorder" (FASD), which was meant to include those with FAS and all those exposed to alcohol who demonstrated the neurobehavioral deficits without the more easily identifiable physical signs. The term FASD was meant to de-emphasize the importance of the physical findings in making a diagnosis, and to re-emphasize the "hidden" nature of this neurodevelopmental condition.

1.3 How Common is FASD?

The incidence and prevalence of FASD is poorly established because of the limited ability to detect the condition. This is itself a multifaceted problem. First, there is no full agreement on what term should be used to describe the level of brain structural abnormality found in FASD. Should this be called "prenatal brain damage," "prenatal traumatic brain injury," "diffuse brain dysfunction," "adaptive brain functional disorder," or something else? Without a uniformly recognized term and then a clear definition of severity, it has been difficult to propose or define a functional severity score that could appropriately be used to define who has been affected to the point of a disability. To date, the recognition of brain differences has been through a broad battery of cognition and performance measures that are not usually sensitive and therefore predictive of dysfunction until children are over four years of age (unless the patient has a more severe intellectual handicap as a component). This type of diagnosis is generally possible only through the work of specialized multidisciplinary teams that are in very short supply. Indeed, probably fewer than 2000 diagnoses can be made annually in all of Canada.

The study of newborns can detect babies with FAS based on growth abnormalities, the facial features, and the most severe forms of prenatal brain injury. Active case-finding studies conducted primarily during the 1970s and early 1980s found that the features of the full syndrome and a confirmed history of gestational alcohol exposure occurred in 1 to 3 per 1000 live births in the United States and

Europe [2]. Later studies suggested that the population of those with FASD might be 1 in 100 individuals, or more, depending on the levels of brain dysfunction and physical findings required by the researchers and the level of proof needed to establish the history of gestational alcohol exposure.

At the present time, there is no evidence that the rate of FASD has changed in Canada during the past two decades; nor do we know the rate at which individuals with FASD emigrate from and immigrate to other countries through adoption or immigration, nor if those with FASD have a higher death rate. However, assuming that 1 in 100 is a valid estimate of FASD prevalence, over 330 000 people in Canada have this condition right now. Far fewer than 20 000 of them have had a full FASD evaluation in a clinic that routinely uses the Canadian Guidelines for FASD Diagnosis. In fact, diagnostic capacity cannot keep pace with new cases, let alone deal with the backlog of older children, youth, and adults. While more active surveillance and case finding could be carried out at this time, the clinical capacity to make final diagnoses is the limiting factor in establishing the true prevalence of this condition in Canada, and elsewhere.

1.4 What is the Economic Burden of FASD?

The economic burden of FASD is substantial by any measure. The total cost of the disorder in Canada in 2009 has been conservatively estimated at CAD7.6 billion, based on a prevalence of nine cases per 1000 births. This amount includes the cost of medical care, education, social and correctional services, as well as out-of-pocket costs and indirect costs due to caregivers' productivity losses. The direct cost of FASD in Canada for healthcare alone was CAD2.1 billion in 2009 (Table 1.1).

1.4.1 Annual Cost Per Person with FASD

While the annual cost of healthcare for a person with FASD is estimated at CAD6860 (Table 1.2), the annual total of all direct and indirect costs is about CAD25 000 per person. The total lifetime cost of services per person with FASD in Canada was CAD1.8 million in 2009.

Table 1.1 Cost of FASD in Canada, 2009.

Total annual direct and indirect costs	CAD7.6 billion
Total annual direct costs[a)]	CAD4.9 billion
Total annual direct cost of healthcare for people with FASD	CAD2.1 billion

a) Includes the cost of healthcare and educational and social services, but excludes out-of-pocket costs and the cost of correctional services. Source: From Refs [3, 4] (adjusted to include all ages).

Table 1.2 Annual costs per person with FASD, aged 0–53 years, in Canada 2009.

Cost item	CAD
Medical	6860
Education	5443
Social services	4217
Out-of-pocket	2912
Total direct costs	19432
Indirect cost	1481
Total direct and indirect costs	20912
Adjusted for severity of disability, age	22393
Adjusted for estimated cost of correctional services	25000

Source: From Refs [3, 5–7].

Table 1.3 Annual direct cost of selected diseases and FASD in Canada in 2009[a].

Cost item	Annual cost (CAD)
Direct healthcare costs of respiratory diseases	4.8 billion
Direct healthcare costs of all forms of cancer	4.7 billion
Direct healthcare costs of FASD	2.1 billion

a) Includes cost of hospitalization, physicians, and drugs for each item.
Source: From Ref. [8] (discounted to 2009).

Table 1.4 Direct annual cost of selected diseases and of FASD in Alberta, 2009.

Cost item	Annual cost (CAD)
Direct cost of healthcare of cardiovascular diseases (CVD)	773.8 million
Direct cost of healthcare of FASD	229.8 million
Direct cost of healthcare of type 2 diabetes	155.1 million
Direct cost of lung cancer	121.6 million

Source: From Ref. [8] (discounted to 2009).

1.4.2 Comparing Costs

A comparison of the costs associated with FASD and those associated with other conditions and types of care at the macroeconomic level, helps to shed light on the economic magnitude of FASD. In order to put the cost of FASD into perspective, Tables 1.3 and 1.4 show the cost of FASD in relation to the costs of various forms of healthcare, selected on the basis of available data.

The total direct yearly cost of healthcare for FASD is almost half of the equivalent cost of all forms of cancer (Table 1.3). However, healthcare for FASD (CAD2.1 billion) is significantly more costly than, for example, the yearly cost of breast cancer and colon cancer, which are CAD380 million and CAD449 million, respectively. In fact, FASD requires more than twice the resources for healthcare alone as these two forms of cancer combined.

Another comparison at the macro level shows that the annual cost of FASD is significant also in relation to the cost of drugs. In the Canadian province of Alberta, for example, the total direct and indirect cost of FASD was CAD520 million in 2009, an amount equivalent to 25–30% of the cost of all pharmaceuticals used in the province that year [9]. The provincial healthcare costs of cardiovascular diseases, FASD, type 2 diabetes, and lung cancer are shown in Table 1.4.

1.4.3 Cost of Prevention versus Cost of Inaction

There are many competing priorities in healthcare, as in other sectors of society. Whilst it is common to place a higher priority in public policy on health conditions that have significant economic implications, the relative neglect of FASD shows that this is not always the case. While some countries or individual provinces do make considerable investments in FASD prevention, it is not known precisely how much any jurisdiction spends on FASD prevention; neither is it known precisely what the results of those investments have been.

In Canada, the provincial and territorial funding provided for all areas of activity in FASD (including, but not limited to, prevention) amounted to CAD26.8 million in 2007. Although funding may have increased in Canada during the past few years, it remains far short of the estimated CAD125.6 million required annually ([10], discounted) to ensure that all women receive the level of support necessary to assist them in abstaining from alcohol use during pregnancy. Conversely, the theoretical maximum cost savings of preventing FASD in Canada, which is equivalent to the total incremental cost of FASD, is approximately CAD2.6 billion annually.

What does it cost to leave FASD without prevention? The answer to this question is, to a certain extent, illuminated above. It can be further demonstrated by, for example, comparing the economic benefit of preventing one case of FASD with the cost of certain specific interventions in healthcare. For such a comparison, it is important to make use of the lifetime incremental cost per person with FASD, which is the added cost attributable to FASD alone, over and above the cost of healthcare, educational, social and correctional services for the general population. The lifetime incremental cost of one case of FASD is CAD742 000 in Canada (at 2009 cost levels). This figure may be regarded as the theoretical maximum that could be spent on preventing one case of FASD. Looked at another way, it is the revenue that becomes available for other purposes when one case of FASD is prevented, or the opportunity cost for leaving FASD without prevention. The benefit of preventing one single case of FASD would amount to, for example, the

Table 1.5 Opportunity cost of preventing *one case of FASD* in Canada in 2009.

Procedure	Average cost (CAD)[a)]	Number of procedures that could be performed by preventing one case of FASD
Repair of inguinal hernia	4938	150
Appendectomy	5505	135
Cesarean section	5303	140
Hysterectomy	6317	117
Cholecystectomy	6985	106
Discectomy	7601	98
Knee replacement	10903	68
Hip replacement total and partial	13182	56
Coronary artery bypass graft	24966	30

a) Excluding atypical and long-stay cases.
Source: From Ref. [11] (discounted to 2009 cost level).

opportunity to repair about 150 inguinal hernias, or to perform 135 appendectomies, or 68 knee replacements, or 56 hip replacements (Table 1.5).

The above calculations and comparisons are all based on the costs of FASD, with little attention having been paid to what it would cost to *prevent* this disorder. Currently, many potential strategies have been proposed for the prevention of FASD, some of which are presented in Chapters 2 and 3 of this book.

Ideally, any assessment of programs focused on FASD prevention would include a formal cost–benefit or cost–effectiveness analysis. Preferably, this would be based on the incremental costs so that the cost of achieving each additional unit of the outcome measured could be determined.[1)] Such formal analyses would provide valuable information about the extent to which prevention is cost-saving, in addition to achieving its other targeted outcomes.

1.5 Approaches to FASD Prevention

1.5.1 Universal Prevention

Public health education campaigns directed towards mothers and aimed at improving infant and child health have been key features of the Canadian public health

1) In a cost–benefit analysis, both costs and benefits are expressed in monetary terms. In a cost–effectiveness analysis, the outcome is not expressed in monetary terms, but rather in, for example, lives saved, years of lives saved, or number of cases intervened, counselled, or otherwise supported. In a so-called cost–utility analysis, the cost per quality-adjusted years of lives saved is calculated.

landscape for over 100 years. Indeed, they represent a relatively inexpensive and uncontroversial means of showing that some policy attention is being paid to health inequities [12, 13]. To date, the FASD-prevention activities most commonly undertaken by governments in Canada have been those aimed at changing an individual woman's alcohol use during pregnancy. For the most part, this has taken the form of primary prevention campaigns intended to increase public awareness of the risk posed by prenatal alcohol exposure, and urging pregnant women to abstain from drinking [14].

In Canada, most pregnant women whose pre-pregnancy drinking falls into "low-risk" patterns abstain from alcohol for the duration of their pregnancy. According to the most recent Canadian data, 11–15% of women consumed alcohol during their last pregnancy [15, 16]. In some countries, it is reportedly widely believed that drinking during pregnancy is good for the fetus. For example, a survey conducted in 1998 under the auspices of the Australia National Drug Strategy reported that 73.1% of pregnant women had consumed alcohol recently, and 17% of all pregnant respondents reported drinking at least three standard drinks when they drank [17]. A recent UK study [18] reported that, among the 83% of mothers who consumed alcohol prior to pregnancy, 54% continued to drink while they were pregnant.

Overall, both the incidence and prevalence of alcohol use in pregnancy seem to be changing. Most of this change is due to the fact that those women whose drinking patterns were low-risk to begin with are now abstaining completely. In Canada, although an overwhelming majority of women (98%) are aware that there is a link between alcohol use during pregnancy and harm to the fetus, a large fraction of women (62% in 2006) believe that a small amount of alcohol use during pregnancy is safe [19]. Confusion over the safety of small amounts of alcohol is evident in the conflicting guidance provided by health professionals and professional bodies. While Health Canada Report 2009 [20], the US Surgeon General [21], the Royal Australian and New Zealand College of Obstetricians and Gynaecologists [19], and the British Medical Association [22] have all taken a cautionary approach in advising women to abstain from alcohol completely while they are pregnant, others – such as the British Royal College of Obstetricians and Gynaecologists [23] – counsel that "… it remains the case that there is no evidence of harm from low levels of alcohol consumption, defined as no more than one or two units of alcohol once or twice a week." Moreover, rates of episodic high-volume and high-frequency drinking (often referred to as "binge drinking") among pregnant women and nonpregnant women of childbearing age have remained relatively stable [16, 21]. It is these drinking patterns that are most closely associated with the likelihood of having a child with FASD [24–26].

Primary prevention campaigns tend to be aimed either directly at women, or at those who might be in a position to influence a woman's alcohol use (such as partners, family members, friends, or the broader community). Such campaigns have been in existence since the mid-1970s; indeed, over 350 direct-messaging campaigns have been used in northwestern Canada alone since 2000 [27]. The presentations vary greatly from "soft" recommendations for having a healthy baby

to negative ads warning about the lifelong problems faced by children affected by alcohol. Awareness-raising materials that depict male partners, friends and family rarely provide direct suggestions on how these concerned persons might effectively help a woman to stop drinking, and no evaluations of the utility or success of these indirect messaging campaigns have yet been found. More often, the visual image is that of a lone pregnant woman or, in an attempt to make the message more universal, sometimes the focus is on the pregnant torso. However, such images may reinforce notions that FASD prevention is confined to the womb of an individual woman, thus negating the role of social, political, and economic conditions that so profoundly shape a woman's risk for having a child with FASD.

While these direct-messaging campaigns are extensive and expensive, few research data have been published that has evaluated their effectiveness in changing the behavior of pregnant women and their supporters. In fact, the materials raise many new questions:

- What harm may come from showing such messages to pregnant women, who might then worry about the potential injury to which their fetus has already been exposed?
- What is needed to ensure that primary prevention campaigns are effective across different communities, age groups, or economic or social circumstances?
- How can primary prevention campaigns avoid "blaming and shaming" women who drink while pregnant?
- Since drinking is legal and socially condoned, what written warnings would be most effective in helping women know when and how to stop?
- How can primary prevention campaigns account for relative risk?

In summary, both general and focused public awareness campaigns advising women of the harm of the gestational use of alcohol are common. Yet, remarkably few campaigns have been evaluated (see Chapters 2 and 3), and therefore little is known about their impacts. Without serious and sustained efforts to understand this social marking experiment, improvements will not be possible. Epidemiological research on the prevalence of drinking during pregnancy indicates that while public education campaigns seem to have increased the awareness of FASD – and, by extension, have encouraged abstinence among those women whose drinking patterns place them at lowest risk – these campaigns alone have not been sufficient to support women in the highest-risk groups to abstain from alcohol during their pregnancies [2].

1.5.2 Screening for Prenatal Alcohol Exposure in Obstetric Settings

At present, two forms of screening for prenatal alcohol use are employed in obstetric settings: biomarkers (in the form of meconium testing; see below) and

maternal self-reports of alcohol use using direct or indirect questioning (which may involve the use of standardized screening instruments).

1.5.2.1 **Meconium Testing**

Meconium testing involves screening samples of a newborn's first stool for the presence of fatty acid ethyl esters (FAEEs), which confirm exposure to alcohol during the last two trimesters of fetal development. Some advocates have suggested that a targeted implementation of meconium screening may be useful. For example, a recent study in a high-risk obstetric unit indicated that infants born in this unit had a 12-fold higher risk of screening positive for second- and third-trimester alcohol exposure than infants born in the general population of the referring community [28]. However, while an FAEE-positive screen can provide an indication that a woman was drinking alcohol during her pregnancy, a number of concerns regarding meconium testing as a tool for prevention and intervention in FASD exist. First, the predictive value of FAEE-positive meconium with regard to neurodevelopmental delays has not yet been established [29]; thus, in the absence of other evidence of compromised fetal development or neurobehavioral symptoms, an FAEE-positive screen itself cannot confirm that an infant has been negatively affected by prenatal alcohol exposure. Moreover, screening for alcohol (and other drug) use is different from all other types of newborn screening. In most cases, diagnostic tests reveal information that is not known to the patient or anyone else. In this case, the mother knows that she consumed alcohol in volume, and has decided not to reveal that information voluntarily. This may be because substance use during pregnancy is often interpreted as a form of abuse or neglect, which may trigger the apprehension of the infant by child welfare authorities [30]. Therefore, the implementation of meconium screening may have an unintended consequence of discouraging high-risk women from accessing obstetric care for fear of losing their children to foster care.

1.5.2.2 **Maternal Self-Reporting**

Evidence suggests that women accurately and willingly describe their prenatal substance use when asked, provided that safety is assured. An accurate identification and assessment of alcohol-related pregnancy risk factors can be enhanced through the use of reliable screening tools [24]. Indeed, Chang [31] argues that the routine use of screening questionnaires in clinical practice may reduce the stigma associated with asking women about their alcohol use, and result in a more accurate and consistent evaluation (see also Ref. [32]). At present, there is no consensus in Canada on which standardized screening tools to use: each province and territory, healthcare organization, and healthcare provider uses a variety of formal and informal screening tools [33]. However, previous systematic reviews have demonstrated that using *any* standardized screening tool tends to make it more likely that pregnant women will disclose their alcohol use than when "standard care" practices are followed (which typically involve no direct questioning on alcohol use at all) [32]. While there are often concerns that fear, stigma, and shame can influence women to under-report their alcohol use, studies have shown that

"... there is no systematic tendency for women generally to understate the amount they drink during pregnancy" [34]; indeed, antenatal maternal reports of high-risk alcohol use tend to predict infant neurodevelopmental delay better than do postpartum maternal self-reports, most likely due to compromised recall [34]. Accurate maternal self-reporting can be improved by offering strong assurances of confidentiality,[2] conducting the screening in a community setting, inviting women to complete a printed questionnaire rather than to undergo direct questioning, using more than one alcohol-consumption measure, and wording the questions clearly [35].

However, at least in maternity care settings, it appears that women are not asked as frequently as they should be. In addition, there are inconsistent processes across Canada for recording alcohol use in a woman's medical chart, and for transferring this information to the child's health records [33]. In 2007, only three Canadian provinces (British Columbia, Yukon, and Newfoundland) included questions in their prenatal records inquiring about pre-pregnancy alcohol use. Only two provinces (which use the same reporting form) included prompts to elicit additional information regarding women's usual, pre-pregnancy alcohol consumption patterns (such as average amount of alcohol consumed per drinking session) [36]. Given that Pregnancy Risk Assessment Monitoring System (PRAMS) data show high rates of unplanned pregnancies – especially among young women who are the most likely to drink in binge patterns – this represents a missed opportunity for providing education, counseling, and referral for women who may be experiencing a pregnancy complicated by alcohol use.

1.5.3 Selective Prevention

Most selective prevention approaches to FASD combine some form of brief intervention and motivational interviewing. This approach has been best studied among women aged 18 to 44 years, who do not meet the criteria for alcohol dependency or a substance-use disorder, and among younger women who drink in binge patterns (i.e., Refs [35, 37]). For example, a randomized controlled trial (Project CHOICES) conducted in six community-based settings in the United States found that women who received a brief motivational intervention, consisting of four counseling sessions and a contraception consultation delivered over 14 weeks, significantly reduced their risk of having an alcohol-exposed pregnancy (as measured by decreased risky drinking and/or effective use of contraception) compared to women who received information only [24, 38].

2) It is important to note that research on maternal self-reporting has tended to involve studies with an experimental design, in which researchers were able to assure the women participating that their responses would be treated as confidential and would not be forwarded to their treating physician. This, in itself, may have mitigated the woman's fear of possible negative reprisals resulting from her disclosure, but would significantly limit the generalizability of these findings to the clinical setting [24].

Although, the efficacy of paired brief intervention and motivational interviewing approaches in reducing alcohol-exposed pregnancies has not been extensively researched in Canadian settings, a range of initiatives has drawn on these findings to provide FASD-prevention supports to women. In British Columbia, Healthy Choices in Pregnancy (a component of the provincial government's healthy living initiative that included FASD-prevention targets) provided training to healthcare and related service providers to incorporate brief intervention and motivational interviewing into coordinated, informed, respectful responses to substance-using pregnant women.[3)] Similarly, the Alberta Alcohol and Drug Abuse Commission's Enhanced Services for Women has incorporated both motivational interviewing and brief intervention techniques into a wide range of resources to encourage the identification and referral of pregnant women with substance-use problems.

1.5.4 Indicated Prevention

It is now abundantly clear that women who give birth to children with FASD are most often those whose own health and well-being are also significantly compromised. The lives of birth mothers of children diagnosed with FASD are frequently imbued with violence, isolation, poverty, mental ill health (including diagnosed psychiatric conditions, very high stress levels, and trauma), addictions, and lack of supportive health and social care before, during, and after their pregnancy [10, 39, 40]. Undoubtedly, the complexity of these issues demands a timely and coordinated approach to care that addresses social determinants of women's health.

Despite increasing acknowledgment that isolation and a lack of social support are common among pregnant women and mothers with substance-use problems, women who are most vulnerable to having a child with FASD often have difficulty accessing timely and supportive services for addictions treatment [41]; for parenting support [40, 42]; and support for issues related to violence and trauma [43]. While public health messaging campaigns exhort pregnant women to identify their drinking as problematic, and to seek professional help if they cannot stop drinking on their own, health systems and services are often unprepared to provide help when women seek it. More often than not, pregnant women facing concurrent problems with violence, mental health, and addictions will be shuffled between uncoordinated systems of care with competing and contradictory service mandates and access criteria. To illustrate this, women presenting to addictions services are often told that they need to get treatment for their mental health issues before they can enter addictions treatment, while mental health services often require abstinence from alcohol and (nonprescribed) drugs before women can be admitted into their care. Likewise, transition houses and other services for women experiencing violence have often been unprepared to provide service to women with untreated mental-health and substance-use problems [44, 45].

3) See www.hcip-bc.org for more information.

Thus, women who seek help often find themselves bounced around and between systems of care, until they are bounced out of them entirely [46].

While multiple barriers to care continue to exist, evidence is also accumulating that interventions to increase social support for pregnant women and new mothers by addressing social determinants of women's health can improve outcomes for mothers and children, and also reduce the likelihood of future substance-exposed pregnancies [32, 47–51]. For example, mentoring programs built upon the Parent–Child Assistance Program (PCAP) model (see Chapter 4) offer women who have had a previous substance-exposed pregnancy practical assistance with meeting their basic needs for food, housing, transportation, childcare, advocacy, and parenting skills/teaching. Once engaged in a supportive relationship with their PCAP mentor (many of whom are women with their own experiences of being pregnant and/or parenting with an addiction), women may begin to request birth control, mental healthcare, addictions treatment, employment readiness training, or help in fleeing from a violent relationship. PCAP mentors are able to help make referrals and facilitate the needed interventions. The program has demonstrated success in reducing alcohol-exposed pregnancies [49] and has been replicated in many communities in Canada. Currently, there are as many as 40–50 programs in western Canada alone working with high-risk women in this way.

The findings from programs such as PCAP have shown that efforts to prevent FASD must extend beyond a singular focus on alcohol use in pregnancy. Research is increasingly demonstrating the complex roles of social determinants of health in mediating the outcomes of alcohol-exposed pregnancies for women and their children. For example, Bingol *et al.* [52] were among those to document the effect of socioeconomic status in the development of FAS. In a population-based sample of women who admitted to drinking three or more alcoholic beverages per week during pregnancy, 71% of low-income women gave birth to children who were diagnosed with FAS by school age, whereas only 4.5% of women of higher socioeconomic status had children diagnosed with FAS. This study identified nutritional status during pregnancy (which is directly related to poverty) as the key variable accounting for these disparate outcomes (see also Ref. [53]). Elsewhere, the teratogenic effects of alcohol have been shown to be compounded by maternal smoking, stress, and exposure to environmental toxins [54].

Focusing only on alcohol (and other drug) use may limit the effectiveness of prevention efforts, particularly among the most marginalized women, by eclipsing opportunities for addressing factors beyond an individual woman's control that influence the likelihood of having a child with FASD. While FASD, by definition, occurs only in individuals exposed prenatally to alcohol, researchers, clinicians, and other front-line service providers are increasingly recognizing that equally important in mediating outcomes of such pregnancies are considerations such as whether a pregnant woman has access to good nutrition, pre- and post-natal medical care, safe and stable housing, support from partners, family, and friends, and other factors that help her to care for herself and her child(ren) [55]. These observations suggest an urgent need for ways to consider FASD prevention that extend beyond an individualized "alcohol awareness" approach to acknowledge the

conditions in which women negotiate and experience the complexities of substance use, pregnancy, and mothering.

Research to define and examine the roles of social determinants of women's health in mediating the risk and protective factors for FASD is still in its infancy, as are strategies for embedding timely, respectful, and appropriate FASD prevention into systems that might serve women and children for other initial, linked needs. Studies demonstrating the effectiveness of this approach are urgently needed in order to assist governments to develop policy and funding frameworks that can enhance these collaborative approaches. Regardless of the circumstances in which they become pregnant, give birth to, and raise their children, mothers in contemporary western societies are still invested with the primary responsibility of ensuring that their children achieve an optimal level of health and well-being. When mothers are unable to do so, they become objects of derision, particularly if this outcome is understood to be the result of "poor choices" rather than of circumstances beyond their control [56]. Although they are common, shame-and-blame approaches to FASD prevention have been repeatedly shown as ineffective at reducing drinking among women at highest risk of having a child with FASD, and have resulted in many missed opportunities for providing supportive care [39, 40, 57].

1.6 FASD Prevention in Aboriginal Communities

FASD has been described as a "crisis situation" among Aboriginal peoples in Canada, among whom both the incidence and prevalence of FASD are believed to be much higher than in the general population ([58, 59]; see also Ref. [60]). Data derived from individual First Nation communities in Canada suggest that the incidence in these locales varies from 25 per 1000 [61] to 190 per 1000 [62]. However, these data were collected in response to concern from community leaders that FASD incidence appeared to be high, in order to demonstrate unmet needs that would garner support for implementing intervention and prevention activities. No representative data on FASD incidence or prevalence are available from Canadian Aboriginal communities in which FASD has not been locally identified as a priority issue. Moreover, there are presently no population-level data available showing the extent to which Aboriginal women in Canada drink (or abstain) during pregnancy, or exhibit patterns of alcohol use that are (or are not) distinct from other of those of other Canadian women. There is also a lack of data describing how Aboriginal women's alcohol use varies by age, income or education level, employment status, place of residence, cultural affiliation, or any other factors which have been shown to differentiate alcohol use patterns in other populations [63].

FASD prevention efforts undertaken in First Nations communities must account for the specific cultural, historic, political, and social contexts in which pregnant women drink [59, 60]. Accordingly, these prevention initiatives often take different

forms, from "mainstream" approaches to prevention. The incidences and experiences of FASD in Aboriginal communities are mediated by the contemporary legacies of state-sponsored activities designed to dismantle Aboriginal cultures, languages, spiritualities, families, and social and political institutions. In particular, the intergenerational impacts of residential schooling policies, forced relocations, and other government policies which resulted in trauma, violence, and disrupted family structures have been identified as among the most salient "root causes" of FASD among indigenous people [59, 60]. Thus, efforts undertaken at the community level to support cultural revitalization and strengthen families have provided a foundation on which to build programming aimed at improving the health and well-being of Aboriginal women, children, families, and communities, which incorporate specific initiatives to prevent FASD.

1.7 Main obstacles to Preventing FASD

Efforts undertaken at all levels of prevention activity have yielded substantive increases in public awareness of the importance of avoiding alcohol use in pregnancy, and of the challenges faced by children with FASD. These are clearly important developments to be celebrated. However, a consequence of these efforts has also been to construct FASD in the public (and political) imagination as a *children's* health issue. This has inspired reductionist approaches to FASD prevention as primarily a problem of maternal ignorance and/or malfeasance. In other words, the task of preventing FASD has come to be understood by many as an effort to improve children's health by intervening with their mothers, to ensure that women who drink are aware that they are "hurting their babies," and to "protect" those babies whose mothers continue to knowingly put them at risk. Moreover, in Canada, there remains a salient belief that FASD is a problem that is particularly attributable to specific groups identifiable by race (i.e., Aboriginal peoples) and class (i.e., women living in poverty). These beliefs about who is "at risk" for FASD may encourage inappropriate intervention in some cases (in which an individual woman or specific community is wrongly identified as being "at risk"), and lack of intervention in others where "no risk" is believed to be present. In so doing, opportunities have been missed to understand that FASD and its prevention are directly related to women's health status, and to act to reduce FASD prevalence at a population level by improving social, economic, and political contexts which give rise to problematic substance use among women and compromise maternal and child health [64].

Beliefs about who is "responsible" for preventing FASD, and who is "at risk" have also constrained the availability and distribution of resources to support prevention initiatives, with many groups remaining underserved. Among the barriers to preventing FASD at the population level has been the difficulty and discomfort experienced by health professionals when asked to discuss alcohol use with pregnant women. For example, a 2002 survey of physicians and midwives in

Canada conducted by Tough *et al.* [65] found that, while 94% of providers had knowledge about FASD and its causes, only 45% frequently discussed alcohol or other drug use, or addiction history, with women of childbearing age, and only 54% felt prepared to care for pregnant women who had substance-use problems. Here, a primary concern cited by care providers was a lack of confidence that they could make an appropriate referral to specialist services, indicating a lack of strong cohesion between primary care, maternity care, and addictions services, as well as a potential belief among those outside of the addictions field that maternal substance use and FASD are not among the required competencies for their field. This may also reflect a well-documented concern among maternity care providers that they are becoming overwhelmed by a perception of increasing expectations that they screen women for a range of issues (such as smoking and intimate partner violence), without having access to additional resources to provide appropriate supports to those who screen positive [66].

1.8 Challenges in Measuring Effectiveness of FASD Prevention Initiatives

One reason that so much basic work still needs to be done seems to be related to a failure of FASD to be incorporated into the general cloth of medical work, or easily addressed and accommodated in systems like education, social services, mental health, justice, and so on. To improve that situation, we need solid research to evaluate what we are doing; we need to determine how it might be done better; and we need to implement change where and when it is most needed.

Effective, integrated policy responses are clearly and urgently needed to prevent FASD and to improve the outcomes for those affected. This gives rise to a critical question: What evidence is needed by policymakers to garner sufficient political will for supporting FASD prevention?

Much of the activity being undertaken to prevent FASD is happening at the community level, in small, frequently under-funded and over-extended programs. Overall, there has been a lack of funding and support for designing and implementing projects at the community level that are tied explicitly to evaluation. Often, when an evaluation of prevention initiatives occurs, it will be in an opportunistic fashion, because a program provider happens to have resources that can be earmarked for evaluation, or because a partnership evolves between a researcher and a service provider which is successful in attracting research funds to examine a specific set of outcomes for clients. In some cases, program funders actively discourage evaluation by excluding evaluation activities from funding agreements, or by restricting the collection of data within programs.

When such evaluations are conducted, a key challenge lies in identifying evaluation methods, outcome measures, and indicators of "success" that are appropriate for research undertaken in programs that are delivered in community settings. This is particularly true for intensive intervention services that are focused broadly on preventing FASD through acting on the social determinants of women's health. In such programs, the traditional medical model for outcome research, which

holds blinded, controlled trials as the "gold standard" for evidence, does not fit well, and may in fact be highly problematic on ethical and humanitarian grounds. How, for example, could the randomization of high-risk, marginalized, alcohol-dependent pregnant women into a "usual care" arm of a trial of a comprehensive support program be justified when "usual care" often results in irreversible, lifetime disadvantage for both mother and child? How could the assignment of participants to a control or intervention condition be double-blinded under these circumstances?

The end outcome in FASD prevention would be a reduction in the number of babies born with FASD. However, due to the difficulty of diagnosing FASD (particularly the neurodevelopmental aspects of this condition that are not found on physical examination at or near birth), it may not be possible to determine such an outcome until long after birth. Another methodological challenge in assessing the effectiveness of FASD prevention is that the benefits of preventive programs may accrue gradually over time, and therefore may not appear to be significant in the short term. Prevention programs that require behavioral, social, and cultural changes are thus forced to focus on intermediate outcomes of different types, measured by both quantitative and qualitative techniques. Such outcomes may include increases in knowledge about the effects of alcohol use in pregnancy, increases in self-reports of intention to abstain from alcohol in future pregnancies, decreases in binge drinking, increases in the effective use of contraceptives, or improvements in conditions that increase the risk for developing alcohol-related problems, such as stress, depression, or social isolation. Such outcome measures are common in studies of primary and indicated prevention interventions, and are amenable to study using experimental designs with short-term follow-up and comparisons of pre- and post-intervention measures. This problem could be solved by the findings obtained from well-designed longitudinal studies. However, the funding for such studies is typically difficult to secure, particularly in the Canadian research context where research grants normally extend for no more than five years. Thus, no results from such studies are available to date.

Although, high-quality data from qualitative studies may provide useful insights into these issues (for example, by documenting women's changing relationships with health and social care providers that decrease barriers to care, or by illuminating social contexts in which women negotiate issues surrounding alcohol use in pregnancy), such data are rarely included for consideration in systematic reviews, and most systematic review methodologies lack the criteria to allow for accurately assessing the strength of evidence generated through the analysis of qualitative data. These data would, however, be difficult to use in an expression of the cost–effectiveness or cost–benefit of an FASD-prevention program.

1.9 Who is Responsible for the Prevention of FASD?

FASD prevention is simple in theory: if pregnant women abstain from alcohol, their children will not develop FASD. In practice, however, FASD prevention is

nearly unparalleled in its complexity, requiring not only changes in beliefs and culture but also major political interventions that address the inequalities and social determinants of women's and children's health.

In resource-constrained environments where health, social service, and educational systems must constantly seek ways to reduce costs and to cut back on the delivery of expensive and time-consuming services, mother-blaming discourses may be more readily invoked to offer a rationale for shifting responsibility away from governments and systems and onto individual women and their families. As a result, individual women have been stigmatized, shamed, blamed and, in some contexts, also prosecuted when they are unable on their own to reduce their alcohol use in response to public health warnings or brief interventions. These mother-blaming discourses have resulted in public opinions and policy responses that artificially separate women's alcohol use from the broader social, economic, and political conditions in which they live [57]. These beliefs about FASD as a disability caused to children by the actions of their mothers have also frequently served to marginalize mothers raising children with FASD, who often hear that "the problem is at home" when they attempt to advocate for additional supports for their child.

An important obstacle for the prevention of diseases and disorders in general – and the prevention of FASD in particular – is the fact that effective prevention usually requires attention to the social determinants for health. Although this might be well known among different professions in healthcare, there is no particular mandate, responsibility or financial incentive, nor are there enough resources allocated to approaching these effectively from the health sector perspective at any level of intervention.

As shown above, FASD is accompanied by considerable costs and opportunities lost, in particular for health services, although the overall economic implications of FASD are visible also in educational, social, and correctional services. The provincial governments in Canada seem to deal with FASD mainly through their departments of children and youth and their departments of health. The health implications of FASD are most likely given the same priority as any other condition when acute healthcare is needed. Educational and social support may also be provided to the same extent as other needs in these fields. Consequently, data must be collected systematically to demonstrate the support needs of pregnant women, mothers, families, and people living with FASD: this could also demonstrate gaps in service provision that could subsequently render governments accountable for ensuring that such needs are met

Problems of the complexity of FASD prevention require a long-term commitment to improvement and change. Although it is usually thought that government will provide this commitment, because of competing interests a consistent government response to any problem with adequate funding and incremental policy improvement will require ongoing advocacy. In the medical fields, this advocacy usually involves a partnership between professional groups who work with the condition, and patients and families. In the case of FASD advocacy, both groups are hard to find.

Who, in medicine, is "in charge" of FASD? Should it be the professional organizations that represent pediatrics, obstetrics, genetics, neurology, psychiatry, addictions treatment and/or family practice? They all play a role, but none has taken up the mantle of speaking for the condition as a whole, let alone for its prevention. Can any of them do so? Who, too, should speak for the legal, psychological, social, and educational intervention aspects? Since no one has volunteered, perhaps the job needs to be assigned, but who would – or could – do that? When a condition does not fall squarely into a field that is ready to catch it, the condition is dropped. That may not be unique to FASD, but it has happened to FASD.

Where, too, is the parent group? The social stigma associated with giving birth to a child with FASD has unfairly made it difficult for birth mothers who may still have active alcohol-dependency issues to advocate for their children. But where are the fathers, the mothers now in recovery, the extended families and adoptive parents? As individuals they arrive in the clinic deeply concerned about their children, frustrated at the lack of services and the poor coordination of services that do exist. Individuals have effectively represented themselves and their families. Some degree of organization has been tried (e.g., the National Organization of Fetal Alcohol Syndrome [NOFAS]), but a politically vibrant family-driven voice has not emerged. Neither have disability-rights organizations run by people with disabilities incorporated the concerns of people with FASD meaningfully and systematically into their social justice work.

FASD also falls within and between every ministry in government that deals with people: health, mental health, social services, education, justice, and so on. No single ministry has taken the lead on FASD, nor has been asked to do so. The structure of government and funding works against conditions that require such vast inter-ministerial cooperation and coordination.

The "natural experiment" conducted since this condition was first identified 40 years ago has made it apparent that the systems will not become organized, as they need to be organized spontaneously. However, this extensive, expensive, and devastating condition should not be held captive to organizational structures that work well for so many issues, but not for FASD.

Clearly, in Canada a conference should be called as soon as possible, bringing together professional leadership, family advocates, and government representatives with the aim of establishing a leadership approach for the long run.

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