



Health Care and Disease Management

Prevention of Fetal Alcohol Spectrum Disorder FASD

Who is Responsible?

Edited by Sterling Clarren,
Amy Salmon, and Egon Jonsson

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Preface

Research has well established that alcohol consumption during pregnancy may cause serious and irreversible brain damage to the fetus. Nobody would think of giving alcohol to a toddler; nevertheless, at least one in every 100 babies is born with a lifelong disorder resulting from the effects of fetal alcohol exposure. Fetal alcohol spectrum disorder – or FASD – is devastating for both the individual and the family, and its prevention is considered to be a high public health priority in many jurisdictions.

This book reviews evidence from research on the effectiveness of various strategies for the prevention of FASD. Considerable doubt continues to be raised about the effectiveness of some of the most commonly used prevention strategies, such as public media campaigns and printed information about the harm of alcohol use during pregnancy, as well as prenatal programs that educate pregnant women about the risks of drinking but do not address the root causes of drinking. There is, however, evidence that intensive interventions and other types of targeted support for high-risk mothers are both effective and cost-effective.

Every year, thousands of children are born with permanent brain injury resulting from exposure to alcohol during gestation. The response to that should be a forceful, determined, and sustainable effort to prevent this situation from occurring. It seems reasonable to suggest, therefore, that current approaches to prevention of FASD need to be reconsidered, and that a reallocation of resources to strategies that have a proven effectiveness should become a priority. Moreover, concerted efforts must be given to the development of new strategies for preventing this disorder.

But, who will take responsibility for FASD prevention? FASD falls across many areas of potential responsibility. It does

not have a home in any particular specialty of medicine – its implications are shared by ministries of health, education, children, and social services. To some extent, it also concerns departments and institutions responsible for correctional services, since individuals with FASD seems to be disproportionately represented among those in conflict with the justice system.

We argue that provincial, national, and international bodies need to work together to develop the multisectoral strategies required for the effective prevention of FASD. Moreover, we believe that the World Health Organization, in collaboration with member states, should take the initiative in formulating priorities in research and policy development for the prevention of FASD – in addition to its more general global strategy to reduce harmful use of alcohol.

Vancouver and Edmonton, February 2011

Sterling Clarren

Amy Salmon

Egon Jonsson

Note from the editors: This is the second of two books on FASD produced by the Institute of Health Economics in Edmonton, Canada, and published by Wiley-Blackwell. The first book, which focuses on FASD in a policy and management perspective, also contains several chapters that relate to the prevention of FASD (see *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD*, by Riley, E.P., Clarren, S., Weinberg, J., and Jonsson, E., Wiley-Blackwell, 2011, ISBN 978-3-527-32839-0).

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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.

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](#)).

Table 1.1 Cost of FASD in Canada, 2009.

Source: From Refs [3, 4] (adjusted to include all ages).

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.

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

Source: From Refs [3, 5–7].

Cost item	CAD
Medical	6 860
Education	5 443
Social services	4 217
Out-of-pocket	2 912
Total direct costs	19 432
Indirect cost	1 481
Total direct and indirect costs	20 912
Adjusted for severity of disability, age	22 393
Adjusted for estimated cost of correctional services	25 000

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.

Table 1.3 Annual direct cost of selected diseases and FASD in Canada in 2009^{a)}.

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

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.

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

Source: From Ref. [8] (discounted to 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

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