

Fetal Alcohol Spectrum Disorders (FASD): A Policy Perspective

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The link between alcohol use and poor pregnancy outcome may have been observed for thousands of years, as described in a contribution to this issue of the journal by Brown et al.¹ Although scientific evidence of the teratogenic effects of alcohol was published 45 years ago, and the awareness about this has increased since then, little has been achieved to effectively prevent the harms of alcohol use during pregnancy. Moreover, as is shown in another article in this issue by the same authors, there is still no universally accepted diagnostic tool available for the range of syndromes named fetal alcohol spectrum disorders (FASD). The slow pace of actions in the field is blamed on the relative scarcity of research on FASD, which may have serious implications for appropriate planning, policy, and practices in the field.²

There are probably few if any diseases or disabilities with such broad and appalling consequences in humanitarian, social, and economic terms as FASD. It can affect the whole body including a range of deficiencies from lifelong brain trauma and from disabling physical conditions.³⁻⁶ Its burden not only is seen in health care but also stretches into many other sectors of the society, such as the educational, social, and legal systems for which the economic implications are huge. In Canada, there are an estimated 350,000 people living with FASD and about 4000 babies born with FASD annually based on a conservative prevalence rate of 1% at the population level. The total annual cost of FASD in Canada has recently been estimated at about \$9.4 billion, most of which falls within criminal justice: the police, the courts, the correctional, and victim services.⁷

The reason for FASD is known and preventable. It is caused by alcohol exposure to the embryo/fetus during pregnancy. Alcohol easily crosses the placenta and may cause cell damage and interfere with developing organs, for example, the brain and the spinal cord. Several organs are sensitive to alcohol exposure during all stages of pregnancy. However, a spectrum indicates varying degrees of severity. The most severe alcohol-induced birth defects, which may shorten the average life expectancy to about 34 years, are a result of very heavy prenatal exposure.⁸ However, the

volume of alcohol consumed during pregnancy does not seem to be the only factor determining whether trauma is caused to the developing child. As stated by a prominent researcher in FASD cell biology and physiology, the “variability from individual to individual with respect to genetic background, as well as in exposure to other predisposing or protective environmental factors makes it difficult, if not impossible, to define a universally safe maternal dose of alcohol. . . . With much of embryogenesis occurring prior to the time that pregnancy is typically recognized, unintended alcohol exposure is common” (p. 38).⁹

A developing child who has been exposed to alcohol during pregnancy may experience neurological disorders including cognitive deficiencies such as problems with memory, learning, attention, and social communication. FASD is in general not visible; however, for a fraction of the disorders (fetal alcohol syndrome [FAS] accounting for between 10% and 30% of all FASDs in most studies), there are often specific signs, such as malformations of the face and growth retardations. People born with FASD may also experience several physical diseases and impairments during the life span, such as, for example, heart defects, kidney failure, hearing loss, gastroenteritis, pneumonia, bronchitis, epilepsy, sleeplessness, and bone and joint problems. FASD is also related to a higher risk of secondary disabilities such as dropping out of school, disrupting family and placement, becoming unemployed or homeless, abusing alcohol and drugs, and, not least, being involved with the criminal justice system.¹⁰ Without appropriate support for people with FASD, it can be devastating for the individual, the family,

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other caregivers, and society. With strong and structured support of individuals with FASD, many of the secondary implications may be prevented or at least reduced.¹¹

In Canada, like in many other jurisdictions, the prevalence of FASD at the population level is not known. Most older studies of prevalence focused on FAS in certain geographical areas and in specific population groups, such as those in foster care, in correctional systems, in schools, and among indigenous peoples. The challenge of establishing a true frequency of FASD is more complicated than for most other conditions. Early diagnosis is usually not possible before school age. Resources for and training in diagnosing FASD are limited, and it may become difficult, or sometimes impossible, to follow up with mothers to get confirmation of alcohol use during pregnancy. Above all, FASD does not have an ICD code for administrative and billing purposes and therefore does not show up in administrative databases or in other statistics.

For decades, there has been a consensus in the research community (partly based on findings from research published about 40 years ago) that a conservative estimate of about 1% prevalence rate of FASD at the population level may be safely used until a true prevalence is determined by appropriate research methodology. However, this rate of 1% has often been considered underestimated in the research community, and it is clearly beginning to be challenged by findings from new studies on the prevalence of FASD.

A study from the province of Alberta in 2015 found that the prevalence rate of FASD might be in between 1.42% and 4.38%, if FASD cases, possibly misclassified into a diagnosis that mimics FASD, such as attention-deficit hyperactivity disorder, learning disability, oppositional defiant disorder, mental retardation, nervous system defects, and so forth, are included.¹² A study from a representative state in a Midwestern US community published in 2014¹³ showed a prevalence rate of FASD among first-grader school children of 2.4% to 4.8% (midpoint 3.6%), and another prevalence study from four communities in the US (Rocky Mountain, Midwestern, Southeastern, and Pacific Southwestern) published in 2018 showed an FASD prevalence rate also among first graders ranging from 1.1% to 5%.¹⁴ Even higher prevalence rates, approximately 2% to 6%, have been reported in studies from the Lazio Region, including Rome in Italy.¹⁵ Several studies from provinces in South Africa reported that 6% to 8% of school children are affected by the most severe forms of FASD, namely, FAS and partial FAS.¹⁶

Despite the fact that the cause of FASD is known, is in principle preventable, and requires significant societal resources, it receives substantially less attention and funding for research than many other diseases and disabilities, such as, for example, stroke and other cardiovascular diseases, diabetes, kidney diseases, and lung cancer. In general, there is inadequate support of most people with FASD, particularly of those who come into conflict with the law (60% of all with FASD) and end up in jail. Although it ought to be acknowledged that Canada, the United States, and Australia

seem to be ahead of most other countries in frameworks and infrastructure for actions in FASD, there are relatively small amounts of funding available for much needed basic and applied research in the field.

It is increasingly important, for many reasons, to more effectively prevent FASD. We are already not able to appropriately deal with all the challenges of FASD, and at some stage of a higher prevalence, already signalled from a study of schoolchildren in Ontario¹⁷ showing that the prevalence (2-3%) might be 3 times higher than ever thought before, we may need to discuss FASD also from a macroeconomic perspective, including potential threats to the supply of the nation's workforce and overall societal affordability of preventable syndromes costing about \$10 billion per year in Canada. There are numerous innovative and other thinkable strategies to reduce the rate of FASD in Canada, for example, emphasizing maternal health; making use of technology in prevention; making use of artificial intelligence to link data in several databases in different areas of society, both for prevention and support; focusing strategies for prevention on specific and crucial parts of the social determinants for health rather than on its entire spectrum; to assess the potential of the growing number of Mental Health Courts in assisting in this orientation; and making use of available findings from research not only in health care but also in all other relevant sectors of the society.

It is suggested here that a National Institute for Prevention and Research on FASD should be established, that the equivalent of 1% of the current total cost of FASD (\$100M) be invested in this Institute, and that it might be funded by the gaming and liquor commissions in Canada in proportion to their respective populations – a 2 cents increase of the price or markup of a can/bottle of beer would deliver this significant investment for prevention of FASD for which the rate of return is high indeed. The overall aim of this Institute would be to achieve a significant reduction in the incidence and prevalence of FASD in Canada.

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