

Stigma against fetal alcohol spectrum disorder

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Stigma against fetal alcohol spectrum disorder (FASD), a leading cause of developmental delay in North America, can lead to prejudice and discrimination or impact self-esteem for individuals with FASD and their families. A recent study by IRCM neuroethics experts, published in the journal *Public Health Ethics*, suggests that public health practices or policies may inadvertently increase the stigma experienced by those affected by FASD.

Alcohol use during pregnancy is a significant public health issue, and a number of strategies, both supportive and punitive, have been used to prevent alcohol consumption that has the potential to harm a fetus. However, concerns have been raised about the effectiveness of some of

these strategies, as well their potential negative effects on underlying beliefs about FASD and the experiences of those affected, including children and adults with FASD, biological and adoptive parents, and foster caregivers.

"Very little research has been conducted on the factors that contribute to stigma for FASD individuals and how it impacts their lives," says Eric Racine, PhD, Director of the Neuroethics research unit at the IRCM.

"Yet, stigma can act as a barrier to acceptance, social interaction, health care or adoption, and can become an important ethical consideration for assessing public health practices and policies for FASD."

To better understand the nature of stigma in FASD, IRCM researchers, in collaboration with leading Canadian experts in FASD, propose a descriptive model based on three themes: personal responsibility and blame towards biological mothers; felt and enacted stigma experienced by children and families; and anticipated life trajectories for individuals with FASD.

"We suggest that three main categories of stigma exist in FASD," explains Emily Bell, PhD, the study's first author and Research Associate at the IRCM. "The first is about directing all blame and responsibility towards the mothers, despite the fact this simplifies by leaps and bounds the context that often surrounds and influences women who drink. The second stigma, towards the child and families, is similar to that associated with autism and is based on assumptions that a child with FASD is a troublemaker. Finally, stigma is linked to negative stereotypes about the life path destined for youth with FASD and perceptions that they are likely to encounter trouble with the law."

To address concerns associated with inadvertent stigmatization by public health initiatives for FASD, the Montréal ethics experts examined public awareness campaigns and diagnostic practices.

"Awareness campaigns aim to prevent the only known cause of FASD, drinking during pregnancy," says Dr. Bell. "In doing so, however, they may also unintentionally increase the blame towards biological mothers and impact the broader experiences of all those affected by FASD. For example, if such campaigns fail to address social factors surrounding alcohol and neglect circumstances surrounding the behaviour (i.e., when a woman drinks before realizing she is pregnant), they could cause anxiety for women and increase reluctance to seek medical care for their pregnancy or drinking."

"As for diagnostic practices, Canadian guidelines developed in 2005 were a good starting point for the standard diagnosis of FASD across the country, but our research suggests clinicians must strive to minimize biases in diagnosis, despite the fact that the label might knowingly be stigmatizing," adds Dr. Bell.

"We recommend further analyses to examine whether public [health policies](#) and practices inadvertently stigmatize and impact the success of [public health](#) initiatives and programs for FASD," concludes Dr. Racine. "Nevertheless, we believe public awareness campaigns should explicitly work to avoid increasing [stigma](#). In addition, to address potential biases in clinical practices, training about FASD prevention, diagnosis, interventions and lifespan trajectory should be incorporated into professional education. "

Fetal alcohol spectrum disorder (FASD) describes a range of adverse developmental outcomes resulting from exposure to alcohol during pregnancy. Individuals with FASD can face a range of physical and mental health issues, which can include difficulties with organization, planning and cognitive flexibility that are important for adapting to the demands of daily adult life. The secondary effects of FASD (such as difficulties at school, trouble with the law, challenges living independently) influence the life experiences and quality of life for

persons with FASD and their families. The primary prevention of FASD has been challenged by a lack of consensus, particularly around what policies to adopt in advising women about acceptable levels of alcohol during pregnancy. International FASD Awareness Day is observed on September 9.

More information: *Public Health Ethics*:
[phe.oxfordjournals.org/content ... 5/17/phe.phv012.full](https://phe.oxfordjournals.org/content/5/17/phe.phv012.full).

Provided by University of Montreal

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