

Individuals with Fetal Alcohol Spectrum Disorder and Experiences of Stigma

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KEY MESSAGES

Stigma can negatively impact individuals with Fetal Alcohol Spectrum Disorder (FASD) and can decrease individuals' capacity to access services and supports, while perpetuating feelings of shame and contributing to social isolation. Increased access to information about FASD must be shared with and amongst health and social service providers, teachers, and the media in order to reduce discrimination and other effects of stigma on individuals with FASD.

Issue:

Stigma can be defined as a set of damaging attitudes, stereotypes, and discriminatory behaviours [1] while **stigmatization** is the product of these attitudes, stereotypes, and behaviours. Individuals with Fetal Alcohol Spectrum Disorder (FASD) are often stigmatized because of their diagnosis, identified behaviours, and other possible traits that may be seen as different from others [2]. Although a great deal of stigma surrounds mothers and women who use substances during pregnancy (in part because of FASD as a diagnostic term being named after the cause and nature of the condition), public stereotypes and prejudicial attitudes often follow individuals with FASD even in the absence of their mother [3, 4].

The purpose of this issue paper is to explore the ways in which individuals with FASD experience stigma, identify the implications of stigma on individuals and their families, and provide recommendations to reduce stigma.

Background:

Stigma can compound the cognitive, physical, behavioural, and social issues associated with FASD by reducing the services and support individuals with FASD receive. In turn, individuals with FASD who are not connected to support services may face additional problems, such as social isolation. Due to discrimination, and negative attitudes and beliefs about FASD, individuals with FASD often experience feelings of shame regarding the problems they face in

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life because of their disability. In turn, the stigma associated with FASD is both external – emerging from public viewpoints – and internal – emerging from within. This dual layer of both external and internal pressures adds to the complexity of FASD and can contribute to a perception that people with FASD are unable to care for themselves or lead positive, healthy, and successful lives. These attitudes can further decrease individuals' independence and their perceived future potential, and can impact the family and extended community networks who support individuals through ongoing advocacy and adaptive strategies [3, 5-7].

Stigma and discrimination can be experienced across different sectors, including from the public, the education system, the workplace, the child welfare system, the health and social service systems including disability services, and the media. Individuals with FASD often experience similar stigma to those with Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, or intellectual disabilities [8]; however, negative attitudes and beliefs about individuals with FASD are often further spread by the media, including ideas that FASD is the result of individual behaviour or that it is entirely preventable [9]. Improving public perception and messaging, thereby reducing stigma and discrimination towards individuals with FASD, is fundamental. As one individual with FASD shared, without stigma,

"I would feel freedom, inclusion, equality, a sense of belonging, a willingness to speak up and/or seek out help/support (without the cost of sacrifice as once required). We would build one another up, there would be less fighting, more accommodations, more diagnoses and families coming together" [10] – Participant, Changing the Conversation Symposium, Winnipeg, 2018.

1. Stigma, the Individual, and the Family

Using incorrect or stigmatizing language to describe individuals with FASD can shame those with FASD and cloud individuals' identities with unfounded stereotypes and perceptions [11]. Social isolation is a unique component of having an FASD diagnosis, as many individuals in the general public hold a strong stigma towards mothers and the disability itself [7, 12]. Children with FASD are often stereotyped as different from the norm, lazy, and even violent, with difficulties relating to attention, learning, and social relationships [2, 6, 13, 14]. As adults, these perceptions lead to the belief that individuals with FASD will be crime and substance use involved [3]. These views and the uniquely stigmatizing nature of FASD can also impact the entire family unit including caregivers, siblings, and extended family who are advocates and supports for their relatives with FASD [2, 6, 13, 14].

2. Stigma and Health and Social Services

Recent evidence shows that stigmatizing attitudes from health care providers towards people with intellectual and developmental disabilities can impact their ability to support individuals with FASD [15, 16]. Health care and social service providers may misdiagnose or fail to diagnose children because of stigmatization and the fear of stigma that often accompanies an FASD diagnosis [17, 18]. Other health care providers may feel unprepared to diagnose or support

children with FASD [19]. Failing to accurately diagnose an individual with FASD or refer individuals with FASD to necessary services and supports can further impede individuals from receiving the assistance and intervention that they need [16].

Often an individual's choice to disclose their diagnosis is based on the discrimination they think they will receive or have already experienced. There are both positive and negative effects of disclosing a diagnosis for both individuals with FASD and their families. Many people who work or interact with individuals with FASD do not understand that it is not that they will not control their behaviours but that it is often that they cannot control their behaviours. For this reason, the blame placed on individuals with FASD is not easily changed. While disclosing a diagnosis can often help individuals access necessary supports, both in school and workplace environments, revealing a diagnosis can also lead to stigma from co-workers, classmates, teachers, extended family members and friends, and school administration [11, 20]. Moreover, while a diagnosis of FASD should facilitate a child or adult receiving necessary supports and accommodations, in both the school system and the health care system, stigma can result in inadequate service or support plans for the child [2] or further the perception that children with FASD have poor and uncontrollable behaviours [3].

3. Stigma and the Media

The public and media's representation of individuals with FASD can exaggerate individuals' behaviours, suggesting that all individuals with FASD are the same, and detract from the effectiveness of interventions and supports [21]. For example, when an individual is in the justice system, the media then suggests all individuals with FASD are criminals. Behaviours, such as hyperactivity, challenges controlling emotions, and difficulty paying attention, coupled with the belief that individuals with FASD will have a poor life trajectory or are unable to parent, can attract unwanted negative attitudes and perceptions, whether individuals' have chosen to disclose their diagnosis or not [3, 22]. Social media can further perpetuate stigma, as inaccurate and often misleading information about individuals with FASD can be shared on a public and viral scale [4]. This rapid sharing of incorrect information is especially of concern because the media is often a go-to source of information for many people. The public, media, and social media representation of FASD and individuals with FASD can have lasting impacts on individuals with FASD and their families.

Implications and Recommendations:

- The media has the capacity to shape public perception of FASD, effecting both individuals with FASD and women who use substances in pregnancy. By widening the focus of reporting, the media can help highlight information and positive stories about people with FASD, emphasize opportunities for prevention and support, and help shift public opinion [23]. Using resources, such as *Language Matters... Talking about Fetal Alcohol Spectrum Disorder*, can be used to challenge stereotypes about FASD and frame reporting for the media [9].
- Health and social service providers should access evidence-based materials about FASD to help improve their capacity for referral, diagnosis, and support. Integrating

information about FASD into medical, nursing, social work, and teaching curricula can further professional support for individuals with FASD [24-26].

- Educational pamphlets and resources with local supports for individuals with FASD and their families can help families in accessing diagnostic and support services.
- Increasing providers' confidence and competence to have non-judgemental conversations about substance use can increase mothers' ability to seek support in pregnancy and when mothering [27].
- Educators should be provided with better information about how to support individuals with FASD in and out of the classroom. For example, the Canada FASD Research Network offers *FASD for School Level Staff*, a series of online courses that provide teaching strategies and characteristics for an FASD-friendly school and classroom. Educators also require appropriate resources to support individuals with FASD and their families, including time to meet with parents and to plan for the child's needs in the classroom.
- For First Nations and Inuit children 18 and under anywhere in Canada, health and social service providers can apply to Jordan's Principle to facilitate access to FASD diagnosis and supports, including educational assistants, recreation programs, occupational therapy and child counselling, and psychiatric services [28, 29].
- Policy makers are encouraged to review their own policies for the use of person first and identity first language and to review their FASD prevention materials to ensure that these informational materials are unlikely to further increase stigma experienced by individuals with FASD and their families.

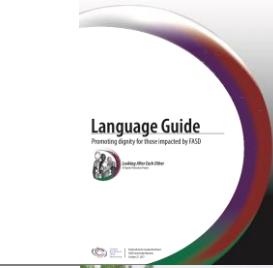
Note that this paper does not discuss the stigma experienced by mothers or women who use substances during pregnancy. For additional information, please refer to our companion issue paper on mothers' experiences of stigma which is expected be released in Fall 2019.

Conclusion:

Negative attitudes and perceptions of individuals with FASD can impact individuals with FASD and their families as a result of discrimination and a lack of access to supports and services. Reducing stigma through ongoing training and education for educators and health and social service providers can facilitate increased support for individuals with FASD and help reduce misconceptions and stereotypes perpetuated about individuals with FASD and their families.

Recommended Resources:

The following resources are existing examples that you can refer to in writing, learning, and talking about FASD in a supportive and non-stigmatizing way:

	Common Messages: Guidelines for Talking & Writing About FASD https://canfasd.ca/wp-content/uploads/sites/35/2019/01/Common-Messages-FINAL-Dec-14-2018.pdf
	Language Matters: Talking about Fetal Alcohol Spectrum Disorder (FASD) https://canfasd.ca/media/media-resources/?fbclid=IwAR0arcm5nghC9-8VGR9ENLI3CfIrwFS9L6WIGA2VHz4l956pQzM7x6-Qn8
	FASD Language Guide: Promoting Dignity for Those Impacted by FASD http://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/
	FASD Awareness Month Toolkit https://canfasd.ca/wp-content/uploads/sites/35/2019/07/CanFASD_FASDMonth_Toolkit.pdf
	Policy Action Paper: Toward a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada https://canfasd.ca/wp-content/uploads/sites/35/2019/07/Toward-a-Standard-Definition-of-FASD-Final.pdf
	Foundations in FASD (Online Training Course) https://estore.canfasd.ca-foundations-in-fasd
	FASD for School Staff Level II: Practical Strategies for the School Environment (Online Training Course) https://estore.canfasd.ca/fasd-for-school-staff-level-ii

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