

The Unique Complexities of Fetal Alcohol Spectrum Disorder

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KEY MESSAGES

Fetal Alcohol Spectrum Disorder (FASD) is a multifaceted disability, associated not only with complex brain- and body-based challenges, but also with high rates of environmental adversity, diverse sociocultural contexts, and lifelong difficulties with daily living. It is important to consider the complexities of FASD, and the ways in which FASD requires unique considerations to develop and employ specialized research, practice, and policy initiatives in support of positive outcomes for individuals with FASD and their families.

Issue:

With an estimated 4% of individuals in Canada living with Fetal Alcohol Spectrum Disorder (FASD), this disability is more common than most other neurodevelopmental disabilities combined. However, knowledge and awareness of FASD among both the general public and service providers continues to lag behind that of other disabilities [1-3]. FASD is a highly complex disability. With increased knowledge of the complexities associated with FASD, researchers, service providers, and policy makers will be better equipped to *identify* individuals with FASD, *support* success for individuals with FASD and their families and caregivers, and *develop* meaningful policy initiatives that foster well-being and positive outcomes.

The goals of this paper are to: 1) discuss contributing factors to FASD that distinguish the disability in terms of complexity, co-occurrence, and magnitude, and 2) emphasize the importance of adapting practice and policy approaches to account for these factors.

In this paper, we will discuss the literature related to FASD as a socially-rooted disability that has intergenerational impacts, multiple layers of stigmatization, and high rates of mental health comorbidities; is exacerbated by experiences of adversity across the lifespan; and presents unique challenges for caregivers and families.

1. FASD as a socially-rooted disability

FASD is caused by prenatal alcohol exposure (PAE), and it is therefore theoretically preventable. However, the simplification of FASD as a preventable disability can be misleading and even harmful. There are many factors that influence why a pregnant woman may consume alcohol, many of which parallel the social determinants of health [4]. For example, experiences of early life trauma [5]; stressful life events [6]; conflict with family members [7]; intimate partner violence [8]; societal and peer pressures [9,10]; having a partner who uses substances [11,12]; a history of child welfare involvement; and mental health challenges [13] are all associated with increased risk for drinking during pregnancy. Additionally, nearly half of all pregnancies in Canada are unplanned [14], and not all women recognize that they are pregnant during early stages. Women may also have limited awareness about the harms associated with drinking while pregnant [15], or they may have received conflicting information from the media and/or health care professionals about alcohol use during pregnancy [16]. It is important to recognize that, although PAE can have profoundly damaging impacts on a developing fetus, the social determinants of health play a fundamental role in increasing the likelihood of alcohol use during pregnancy [17].

Informed prevention and intervention initiatives are needed to reduce the risk factors associated with drinking during pregnancy. Holistic supports should be leveraged to promote women's health and wellness in a way that is respectful and responsive to high levels of complex vulnerability [18,19].

2. FASD as an intergenerational disability

Researchers have identified multi-generational contributions to the development of FASD [20-23]. For example, grandmothers of children with FASD are more likely to have histories of trauma, injuries, and alcohol use than grandmothers of children without FASD [21]. Similarly, individuals with FASD report high rates of intergenerational trauma [24], and some have an increased likelihood of substance use [25,26] and risky sexual behaviour [27,28]. When all of these factors are combined, and in the absence of adequate services and supports, individuals with FASD may be at increased risk of having future alcohol-exposed pregnancies.

The specific mechanisms underlying the intergenerational nature of FASD are not fully understood, but researchers have begun to unpack possible genetic and epigenetic contributors [22,29-31]. PAE is an early life stressor that can damage the developing brain and cause neurological alterations leading to a heightened vulnerability to stress, mental health problems, and substance use [32-34]. Researchers working with animal models of PAE have reported that this alteration of the brain's stress response system and the resulting epigenetic impacts can be carried on for at least three generations [23]. This research highlights the complex and multifaceted nature of the causal pathways of FASD [35], which involve biological, behavioural, sociocultural, historical, and interpersonal factors. Together, these factors can increase the risk of trauma, health and economic disparity, substance use, and other risk factors that perpetuate the intergenerational cycle of FASD [10,20,36].

Given the intergenerational impacts of FASD, practice and policy initiatives should address the broader social and systemic inequities that place multiple generations of families at risk for FASD. To be as comprehensive and effective as possible, FASD interventions should contextualize the needs and challenges of the individual within their larger family system.

3. FASD and stigma

Individuals with mental health challenges experience stigma that is pervasive [37] and damaging to their quality of life [38,39]. The literature on stigma surrounding neurodevelopmental disabilities is relatively scarce, however, there is some evidence to suggest that stigma associated with FASD in particular is multi-layered and magnified in several ways.

Individual and familial stigma. Similar to other disabilities, stigma affects the individual with FASD, their families, and their care providers through experiences of marginalization, negative stereotypes, lower self-esteem, and misperceptions about the individual's abilities [40]. Negative attitudes related to the life trajectories and anticipated outcomes of individuals with FASD are prevalent. The positive potential of individuals with FASD is often overshadowed by a public perception that negative outcomes are inevitable [40]. This stigma can create significant barriers to service delivery for individuals with FASD and their caregivers by undermining their willingness to seek supports [40]. Moreover, these barriers may be compounded by misperceptions or a lack of knowledge of FASD among professionals, and the disqualification of individuals with FASD from mainstream services [41]. Even among service providers who are knowledgeable about the disability, there may be hesitation to diagnose an individual with FASD due to concerns about how stigma will impact the individual and their family [42-45].

Maternal stigma. An additional layer of stigma, which is unique to FASD, is the "shame and blame" that is targeted specifically toward mothers [46]. FASD has been inextricably linked to maternal behaviour, and mothers are often held responsible for "causing" harm to their child [40]. This maternal stigma can be particularly harmful by impeding women from seeking support or discussing alcohol consumption with health and social care providers out of fear of judgement, child removal, or incarceration [19]. The well-intentioned claim that FASD is "100% preventable" is misleading and can further stigmatize and marginalize women who consume alcohol during pregnancy, as well as individuals with FASD and their caregivers and family members [47], who are likely already be experiencing significant challenges and adversity.

Cultural stigma. Another unique layer of stigma exists at the sociocultural level, whereby FASD is commonly, and incorrectly, misperceived to be an "Indigenous issue" [48,49]. In fact, there are no recent or rigorous prevalence studies to support this misconception [50]. Although cultural factors are certainly relevant to FASD insofar as they can help to guide efforts toward FASD prevention, diagnosis, and intervention [20,24,51-53], cultural stigma can cause numerous harms. For example, incorrectly assuming that FASD only affects Indigenous communities can lead to Indigenous children with other disabilities being overlooked [54,55] and non-Indigenous children with FASD being under- or mis-diagnosed. It is critical to address the harms of cultural stigma to reduce marginalization of Indigenous communities and ensure the provision of appropriate and effective intervention approaches.

The multiple layers of stigma associated with FASD can be deeply harmful, and thus targeted efforts are needed to reduce it at the individual, familial, community, and societal levels. These efforts are critical for ensuring that individuals with FASD and their families, as well as women who use alcohol during pregnancy, are better understood, respected, and have access to a wide range of services and supports systems that will help to increase quality of life and foster positive outcomes.

4. FASD and adversity

Individuals with FASD experience disproportionately high rates of prenatal and postnatal adversity, with complex impacts on neurodevelopment [56]. Beginning early in life, exposure to adverse experiences, such as caregiving disruption, death of a parent, abuse and neglect, as well as exposure to parental, caregiver, and/or familial substance use, violence, mental health problems, and criminal justice system involvement, are well-documented in this population [57-63]. Adverse life experiences continue throughout the lifespan for individuals with FASD, with high rates of problems related to school and employment, challenges attaining housing and independence, victimization, and trouble with the law [28,64-66]. Although adversity is common for individuals across disability groups [67] such as those with physical [68] and developmental disabilities [69,70], it is especially pervasive, chronic, and complex among those with FASD [60,62,64]. The high rates of adversity in this population can further exacerbate the brain-based vulnerability due to PAE and increase this risk of negative outcomes [71].

Exposure to adversity, particularly in the early years, can have a profoundly damaging and cumulative effect on an individual's long-term health and well-being [72,73]. Given the increased vulnerability of individuals with FASD, supports and services for these individuals and their caregivers should be delivered early, and incorporate a holistic, family-focused, and long-term approach to promoting safety, stability, and well-being.

5. FASD and mental health

Although mental health comorbidity is not uncommon across disability groups, such as individuals with Autism Spectrum Disorder [74] or Intellectual Disabilities [75], the rates of comorbidity tend to be higher among those with FASD. In fact, it is estimated that 90% or more of individuals with FASD struggle with comorbid mental health challenges including Attention Deficit Hyperactivity Disorder (ADHD), Intellectual Disability, Learning Disorders, Oppositional Defiant Disorder, and depressive and anxiety disorders [28,66,76,77]. Other common mental health concerns in this population include substance use [25,26] and suicidality [58,78-81]. Compared with the general population, individuals with FASD are reported to be 10 times more likely to have ADHD, 20 times more likely to have substance use problems, and 25 times more likely to be diagnosed with a psychotic disorder [77,82]. However, there is a critical lack of mental health and substance use interventions for individuals with FASD [83].

Mental health challenges among individuals with FASD occur alongside complex biopsychosocial vulnerabilities, which may obstruct a clear understanding of the underlying needs of the individual. FASD is a heterogeneous disability and the varying ways in which FASD and comorbid conditions can manifest and are interpreted have serious implications for

diagnosis and treatment [84]. The presence of multiple health conditions can make it difficult for service providers to identify the root cause of concerning symptoms or behaviours, to assign an accurate diagnosis, and to apply effective interventions. Moreover, the majority of individuals with FASD show no obvious physical signs of impairment [85], and the “hidden” nature of the disability can further compound the challenges of accurate identification. Importantly, inadequate appreciation of the potential for wellness and resilience among individuals with FASD may create barriers to service access where mental health and substance use treatments are denied because of service provider misperceptions about the disability [41].

The clinical complexities of FASD underscore the multifaceted needs of individuals with this disability and highlight the importance of effective communication, professional education strategies, as well as comprehensive and needs-driven services and supports.

6. Caregiver and family experiences

A growing body of literature explores the experiences of caregivers of individuals with FASD [86], many of whom struggle to manage the complex challenges associated with the disability [87,88]. Caregivers experience high rates of distress, isolation, grief and loss [88-92], and feel under-supported, misunderstood, and at times, blamed by service providers for the challenges of their family member with FASD [90,93,94]. Although these challenges may be present for families of individuals with *any* disability [95-98] there is emerging evidence to suggest that caregivers of those with FASD experience stressors that are unique, and in some cases more severe, than those of children with other disabilities. For instance, parents of children with FASD have reported significantly higher levels of pessimism, dysfunctional parent-child interactions, difficult child characteristics, and lower levels of hope for the future compared to parents of children with Autism Spectrum Disorder [99,100]. Because of the sharp decrease in service availability for individuals with FASD as they transition to adulthood [101], many caregivers will play a long-standing role in supporting, advocating, and assisting their family member to navigate service systems. Caregiver challenges become more complicated when situated in the broader context of stigmatization, intergenerational impacts, and chronic adversity that is associated with FASD.

Specific and evidence-based interventions to support caregivers of individuals with FASD are essential [86]. Comprehensive networks of support that leverage caregiver strengths and community resources are needed to support well-being and positive outcomes for individuals with FASD and their care providers.

Recommendations:

FASD should be recognized as a common disability with many complex features that are best understood and addressed through an FASD-informed lens. This recognition should be acknowledged across programs, policies, and sectors, and serve as an important first step in fulfilling the following recommendations.

1. **FASD awareness and prevention.** There is an ongoing need to identify and address the individual and biopsychosocial factors that contribute to alcohol use during pregnancy, and develop effective and targeted supports for women who are experiencing these risk factors.
 - Initiatives are needed to improve public awareness of FASD and to reduce the stigma, shame, and blame experienced by individuals with FASD, their mothers, other family members, and the broader community.
 - Resources are needed to better support women’s overall health and well-being, as these have the potential to reduce the likelihood of PAE, and ultimately improve outcomes for women, children, and families.
2. **Caregiver and community-based supports.** Supports for caregivers are urgently needed, especially those caring for adults with FASD. Caregiver resources should emphasize self-care, respite, social connection, support for grief and loss, advocacy, and multi-generational considerations. The role of supporting individuals with FASD across the lifespan should not fall solely on caregivers, and community-based supports should be developed and enhanced to include natural networks that meaningfully foster interdependence for individuals with FASD and their families.
3. **Professional training.** Continued efforts are needed to increase knowledge of FASD among service providers. This improved knowledge will help to increase access for individuals with FASD to all programming, ensure that services are well-informed of the unique brain-based differences of FASD, and provide opportunities for individuals to experience success.
 - Knowledge and sensitivity to FASD and alcohol use during pregnancy among service providers should be increased to facilitate the willingness of women who are or may become pregnant to seek out support for alcohol use. Training should involve a prevention focus and emphasize empathic and compassionate approaches to facilitating safe discussion about alcohol use.
 - Service providers should be given specific training on the complexities and nuances of FASD to be better able to effectively identify and support clients with FASD and their families. Training materials should incorporate the perspectives of professionals regarding practices that have been helpful in working with this population.
 - FASD training would be especially useful at the postsecondary level, so that professionals are equipped at the outset of their careers with knowledge and strategies specific to FASD.
4. **FASD-informed services.** Funding and resources are needed to develop and provide tailored supports and FASD-specific services for individuals with FASD across the lifespan, especially for adolescents and adults when needs become more complex and services are particularly scarce. FASD services should be individualized, interdisciplinary, trauma-informed, culturally appropriate, family-centered, and life-long to ensure comprehensive systems of support.
 - More targeted work is needed to explore the ways in which FASD is distinct from other disabilities, as well as common or shared needs between groups, which will inform the development of specialized and informed supports.
 - FASD-specific work at the research, practice, and policy levels must draw upon the lived experiences of individuals with FASD and their families to ensure that their perspectives and realities are meaningfully acknowledged.
5. **Recognizing and building potential.** Much of the literature on FASD is focused on the challenges associated with the disability and of women who use alcohol during pregnancy.

There is a critical gap in the literature on the unique strengths, successes, and resiliencies of these groups. Strengths-based work is important for reducing the stigma associated with FASD, as well as identifying and leveraging the positive potential of individuals with FASD and their caregivers. In spite of the complexities of FASD, individuals with FASD are capable of growing and experiencing success, and there is a need for opportunities that support them to do so.

Conclusion:

FASD is a multifaceted disability, characterized by exceptional clinical complexity, multiple layers of stigma, and wide-ranging impacts on individuals and their families across generations. Although these issues in and of themselves can apply to various disability groups, FASD is distinct in that these complex factors are often experienced in combination, at greater magnitudes, and with compounding and exacerbating effects. This disability represents the intersection of complicated biological, family, community, and societal circumstances that increase risk for social inequity, intergenerational trauma, and health disparity. To fully understand FASD and its associated challenges, as well as to effectively identify and support individuals with FASD and their families, it is necessary to contextualize the disability within this complex web of risk and vulnerability. Working with individuals with FASD and their families requires empathy, flexibility, creativity, resourcefulness, and cross-disciplinary collaboration. FASD is a significant social and health issue, and targeted work is needed to better address the unique challenges, recognize and build strengths and resiliencies, and promote the long-term well-being of individuals with FASD, their families, and their communities.

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