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# Gap Analysis: Sexual Orientation, Gender Identity, Gender Expression, and Fetal Alcohol Spectrum Disorder

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# **KEY MESSAGES**

There has been an increase in the awareness of disabled people who identify with a diverse sexual and/or gender identity. Although this area has been minimally explored within the context of FASD, this issue is frequently broached by caregivers and service providers as an area of increased need and support. FASD is complex, and the combination of diverse gender identities and sexual orientations with FASD can increase the vulnerability of people with FASD. Therefore, approaches to care and service provision should identify and dismantle heteronormative and binary structures to reframe inclusivity. Absent societal perceptions of these intersecting identities raise human rights and equity concerns as many people with diverse gender and sexual identities experience stigmatization, discrimination, unmet health needs, and suicidality. Thus, an intersectional and human rights-based lens must be applied in research, policy, and practice to aid social transformation toward an inclusive society, including for persons with FASD.

#### Issue:

Internationally, there has been an increase in people identifying outside of the gender binary or with diverse sexual orientations. In 30 countries worldwide, an average of nine percent of adults identify as LGBTQIA2S+, demonstrating diversity on a global scale [1]. The acronym LGBTQIA2S+ refers to lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual, and Two-Spirit; the plus highlights that diverse gender and sexual identities and forms of expression continue to expand outside of heteronormalcy [2]. In Canada, the 2021 Census reported that 100,815 Canadians aged 15 and over identified as transgender or non-binary, representing 0.33 percent of the total population or about one in 300 people [3]. Specifically, 0.19% of Canadians aged 15 and older identified as transgender and 0.14% as non-binary [4]. Furthermore, a 2023 IPSOS poll found that 10% of Canadians identified as LGBTQIA2S+, including 4% as lesbian or gay, 4% as bisexual, and 1% as pansexual or omnisexual, asexual, and transgender, non-binary, gender non-conforming, or gender fluid, respectively [1].

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Despite increased awareness of diverse gender identities, expressions, and sexual orientations, disabled people remain overlooked or unheard in the discussions, including persons with FASD [5]; therefore, to be inclusive of all persons with FASD, it is important to ensure that the intersection between FASD, gender expression, gender identity, and sexual orientation is understood. Among disabled people, *The National Survey on Health and Disability* in the United States reported that 39% of the nearly 28,000 respondents with diverse gender and sexual identities reported having one or multiple disabilities [6]. In Australia, over a third of people who identify as LGBTQIA2S+ reported having a disability [7]. In the largest study to date, transgender and gender-diverse persons were 3–6.4 times more likely to have an autism diagnosis than people who were cisgender [8]. These findings highlight that the experiences of gender and sexuality among autistic and disabled persons appear to be beyond the binary and are less heteronormative [9].

Unfortunately, there is currently limited evidence regarding the prevalence and experiences of people with FASD who identify as having diverse sexual orientations, gender identities, and gender expressions. However, preliminary data is beginning to emerge that provides an understanding of gender diversity among people with various disabilities, including among those with FASD [10]. Newer FASD initiatives have considered these diverse experiences as part of their demographic data collection [11-14]. Drawing on recent data from CanFASD's National FASD Database, 23 persons (or 0.6%) presented at the time of assessment with a diverse gender identity [15]. However, it is important to note that gender-related data collected in the Database is based on two categorical variables – "gender identity (male/female/other)" and "gender identity issues (yes/no)". Therefore, it is likely that this number is not an accurate representation of the general population given the small sample size to date. While this rate provides us with some preliminary information that gender diversity exists among a clinically referred sample of individuals with prenatal alcohol exposure (PAE), it does not represent all individuals who may have PAE and/or FASD and does not fully capture the complexities of the intersection of FASD with diverse gender identity and sexual orientation experiences [16].

#### **Context Setting and Language Use**

It is important to note that we write this paper at a time of intense global backlash against the LGBTQIA2S+ community. For example, in 2023, 562 bills were introduced in the United States that negatively impacted and targeted communities based on sexual orientation and gender identity (e.g., anti-trans legislation that discriminates against those who identify as transgender or gender diverse). Of those, 354 bills are active and 79 have passed [17]. In Canada, there has also been a rise in anti-LGBTQIA2S+ sentiments and subsequent policy changes [18, 19]. In 2022, 580 hate crimes were reported against members of the LGBTQIA2S+ community, with 491 targeting those from diverse sexual orientations and 89 targeting those with diverse sexual and gender identities [20]. Internationally, some countries still have laws that criminalize forms of gender expression and sexual orientation [21]. These laws are quite concerning because, based on where a person lives, the policies and political agendas that are in place can impact an individual's safety, access to services and support, and quality of life.

The lack of recognition of the intersection between disability, mental health, sexual orientation, and gender identity can further lead to health inequities, primarily due to stigma and discrimination. These perceptions can also result in exclusion from accessing resources through multiple pathways [22]. For example, societal norms about sexual orientation and gender identity, as well as norms around ability, often work to deny LGBTQIA2S+ people and people with disabilities opportunities that others enjoy in their daily lives [23]. This disparity highlights the possibility of human rights and equity concerns because it means that current social practices do not align with the *Convention on the Rights of Persons with Disabilities*, the *United Nations Standard Rules on the Equalization of Persons with Disabilities*, and the *Canadian Human Rights Act* – all of which emphasize the need to ensure that services are provided without discrimination based on disability, sexual orientation, and gender identity [24-27]. For this reason, it is important to highlight and challenge the current inequalities. To truly advocate for and move toward a society that embraces diversity, equity, and inclusion, we must raise the recognition, representation, and inclusion of people with diverse intersections of disability, including FASD, and LGBTQIA2S+ identities.

It should also be noted that the language used throughout this paper includes both disability-first and person-first language to recognize that members of this community may choose either form of representation to identify themselves [28]. Disability-first language demonstrates that disabled people accept, take pride in, and celebrate their disability and do not want to be separated from it, whereas person-first language acknowledges that disabilities are a natural part of being human and do not define the person [29]. Additionally, the focus of this issue paper includes sexual orientation, gender identity, diverse sexual and gender identities, and LGBTQIA2S+ people, and therefore it is important to define these terms to ensure shared understanding. Sexual orientation refers to a person's physical, romantic, and/or emotional attraction toward others [30, 31]. Gender identity refers to each person's internal and individual experiences of gender, which may or may not correspond with their sex assigned at birth. As noted above, the acronym LGBTQIA2S+ refers to lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual, and Two-Spirit; the plus highlights that our conceptualizatons of gender and sexual identities and forms of expression continue to evolve and expand outside of heteronormalcy [2].

The purpose of this paper is to describe the prevalence of disabled people with diverse gender and sexual identities, as well as to describe the common experiences and outcomes faced as a result of the intersections between disability and diverse gender and sexual identities. Recommendations are outlined that highlight how an intersectional and health rights-based lens can be applied in research, policy, and practice to provide inclusive services.

#### **Background:**

There has been a dearth of research on LGBTQIA2S+ identities among people with FASD. However, inferences from the diverse sexual and gender identities seen within broader disability literature emphasize the importance of this area as an area of focus. In this gap analysis, we describe what is currently known about LGBTQIA2S+ issues among people with FASD and highlight key themes of intersectionality, stigmatization, discrimination, unmet health needs, and mental health concerns (i.e., suicidality). We conclude by providing research, policy, and practice recommendations.

#### 1. Intersectionality, Stigma, and Discrimination

As coined by Kimberly Crenshaw [32], *intersectionality* and an intersectional framework can be used to recognize and emphasize the compounding impact of multiple marginalized identities as they layer and intersect to experiences of social inequity [33]. Therefore, social inequalities due to intersectional identities of disability and queerness can result in stigma, discrimination, and oppression based on ableist, homophobic, and transphobic ideologies [34, 35]. Ableist ideologies exist when disabled people are seen as lacking or of lesser value in comparison to the "ideal" or "typical" human body [36]. These ideologies draw on a medicalized understanding of disability, which emphasizes treatment and prevention to "fix" disabled people so that they can participate in the world around them while the environmentt is considered unproblematic [37]. Transphobic and homophobic ideologies exist when the diverse gender and sexual expressions of people are viewed as "abnormal" by those with traditional and norm-confirming identities (e.g., a heterosexual male/man or female/woman) [35]. When viewing identity with an intersectional lens, the shared and often complex ways that disability, sex, and gender interact can become apparent; being a member of multiple marginalized social identities can increase the likelihood of being an outsider.

As it stands, those who are disabled with diverse gender or sexual identities experience dual marginalization and minority stress. This stress includes proximal stress (i.e., internal feelings based on a negative experience), internal experiences of rejection or internalized homophobia or transphobia and distal stress (i.e., external experiences resulting in an oppressive action), and environmental experiences of harassment, discrimination, and assault, which showcase the negative experiences faced by disabled people within the LGBTQIA2S+ community [35]. These stressors also refer to the subjugation felt when occupying multiple minority identities and having to navigate the disabling effects caused by disablism and homophobia/transphobia due to their sexual identity or gender identity and expression [8, 34, 35, 38, 39]. While the goal of this paper is to highlight the impacts of disability and gender, it is critical to note that further marginalization can also occur with additional layers of disadvantaged identities, such as those with diverse ethnic or cultural identities or those with lower socioeconomic status [40-42]. Thus, these negative experiences and the complex ways disability and diverse gender and sexual identities intersect can result in health inequalities.

#### 2. Unmet Health Needs

Disabled people, including persons with FASD, experience many inequalities across multiple sectors such as justice, housing, education, and health care [43]. These inequalities are highlighted by many articles in the United Nations *Convention on the Rights of Persons with Disabilities*, also known as the UN CRPD [25]. However, our primary focus in this paper is on the unmet health needs experienced by persons with FASD and those belonging to the LGBTQIA2S+

community, given the increased attention in the literature to these unmet needs and the significant intersectional challenges of accessing appropriate health care services. Disabled people with diverse sexual and gender identities experience higher rates of unmet health needs than those without disabilities, leading to harmful outcomes and highlighting barriers to access and health equity [34].

Those with FASD often face specific barriers when accessing services. For example, support is primarily offered reactively during a crisis, FASD can be seen as exclusionary criteria making it difficult to qualify for services, there may be a lack of existing FASD- and traumainformed care, and stigmatization may occur when an FASD diagnosis is disclosed [43]. Additionally, those with diverse sexual orientations face feeling negatively judged by a physician because of perceptions of their identity or feeling like their physician is not competent in addressing their concerns, creating barriers to accessing appropriate care [44]. The combination of these intersecting identities can create even narrower gaps for access to services leading to unmet health needs. Heteronormative treatment exists when accessing services, such as health care, which can lead to disabled patients with non-normative sexuality and gender identities being invisible or dismissed [42]. Thus, when there is a lack of recognition and education about the diverse sexual orientations and gender identities of disabled people, it can inhibit their ability to access health resources, impacting their overall wellbeing [45].

While evidence regarding LGBTQIA2S+ identities is limited among people with FASD, some published anecdotal evidence provides insight into the experiences of people with FASD. The Alberta Mandatory Reviews Into Child Deaths report from 2021-2022 reports the story of Gemma, a thirteen-year-old diagnosed with gender dysphoria who was perceived as being unable to consent to gender-affirming care (e.g., hormone therapy) because of possible FASD. A psychological report concluded that Gemma had a learning disability and experienced anxiety and depression. Gemma expressed thoughts of suicide and used substances to cope and died as a result of drug toxicity [46]. Additionally, in a medical case study, "Ms. A" was a 23-year-old transgender woman with fetal alcohol syndrome, intellectual disability, and borderline personality disorder seeking support for a time of crisis related to her mental health concerns. "Ms. A" received treatment that focused on her borderline personality disorder without consideration of her gender identity concerns [47]. "Ms. A" had developmentally consistent frustrations over her gender expressions which were treated as poor coping responses, consistent with borderline personality disorder [47]. Focusing on one diagnosis or presenting concern can create conditions that may force a disabled person to accept treatment for one area of need over another. In "Ms. A's" case, despite familial support for her gender confirmation, she could not find appropriate gender-affirming care [47].

Additionally, as part of the Government of Canada's *2SLGBTQI+ Action Plan* [48], a survey was conducted with LGBTQIA2S+ people living in Canada. The results of the 2021 survey focused on health and wellness and identified that only 15% of survey respondents reported having access to LGBTQIA2S+-specific mental health services [48]. Respondents with a disability reported that they were less likely to have access to gender-affirming health services and related products, more likely to experience discrimination, or were treated unfairly within the

health care system based on their sexual orientation [48]. Combined, these cases and results highlight the challenges and complexities in formulating, treating, and providing services for people experiencing disability, mental health concerns, and sexual and gender identity needs [46, 47].

#### 3. Suicidality

Unfortunately, because of these othering experiences perpetuated by stigmatization, discrimination, and unmet health needs, it is not uncommon for disabled people with diverse sexual and gender identities to experience mental health challenges, including suicidality. The authors of the National Centre for Transgender Equality's 2015 U.S. Transgender Survey reported that transgender people with disabilities were substantially more likely to experience suicidal thoughts and behaviours, with 12% of disabled respondents reporting a suicide attempt in the past year and 54% of disabled respondents reporting a suicide attempt in their lifetime [6]. These results are troubling, especially when considered alongside recent data on suicidality among people with FASD that demonstrated how the complexity and uniqueness of FASD, life stages, and biopsychosocial factors can increase vulnerability to suicidality among people with FASD [49]. The highest rates of suicidality were found amongst adolescents ages 13-17 (34.7%) and emerging adults aged 18-24 years (35.2%). Furthermore, substance use and mental health concerns (e.g., anxiety, depression) were seen to have strong associations with experiences of suicidality among persons with FASD [49]. Though the authors did not examine the impacts of gender on suicidality in this study, given the high rates of suicidality in LGBTQ2IAS+ youth, this may also be an important consideration.

As demonstrated in the previously discussed cases from the *Mandatory Reviews Into Child Deaths* report and a published clinical case study, Gemma expressed thoughts of suicide and used substances to cope. She died by overdose a week after her 18<sup>th</sup> birthday [46]. "Ms. A" made frequent self-harm gestures, such as cutting herself and threatening suicide [47]. Similarly, a recent media report highlighted the plight of Sam, a transgender teenager with FASD who experienced severe depression and suicidal thoughts due to his struggles getting his gender identity needs met. During puberty, these struggles manifested as anxiety and depression due to bodily changes and increased his feeling of being trapped [50].

In a recent qualitative study reporting on caregivers' experiences and perceptions of suicidality among their children and youth with FASD, caregivers identified that gender identity and related bodily challenges, particularly relational-level concerns including transphobic bullying and attacks, were contributing factors in their youth's suicidality [51]. The lack of research involving people with FASD means that very little is currently known about their experiences of being transgender [52]. However, these preliminary findings speak to the potentially heightened risk for youth with FASD who are already highly marginalized and experience significant adversity in their daily lives [51].

#### Implications for Research, Policy, and Practice:

In this section, we offer both theoretical and pragmatic recommendations for considering LGBTQIA2S+ issues in the context of FASD. We present these recommendations with recognition of the current context in which LGBTQIA2S+ issues are addressed and discussed, both in Canada and globally. We also recognize that best practices in language use and terminology regarding LGBTQIA2S+ identities are evolving and ongoing and therefore what is relevant today may rapidly change in the future. Given the dearth of available literature on LGBTQIA2S+ issues among disabled people in general, and among people with FASD specifically, we also draw attention to the significant need for more information in these areas, leveraging the benefits of both evidence-based research and living experience wisdom.

### **1. Implications for Research:**

- Conduct more research regarding the experiences of LGBTQIA2S+ people with FASD. Experiences of diverse sexual orientations and gender identities and expressions are significantly understudied in people with disabilities broadly, let alone among people with FASD specifically. Thus, there is a need to conduct more research. For example, research is needed to explore how many people with FASD identify as members of the LGBTQIAS2+ community. Additionally, their experiences as members of multiple intersectional identity groups should be captured in research to highlight the relationship between FASD and neurodiversity and to increase understanding of complex disabled identities beyond the binary of heteronormativity.
- **Consider diverse identities in research design**. Research designs should intentionally be constructed as disability-informed and LGBTQIA2S+-informed, as it is important to illustrate the uniqueness of people at the intersections of gender identity, sexual orientation, and disability [53]. There is diversity within the broader LGBTQIA2S+ community that should be recognized. Thus, gender identity should not be conflated with sexual orientation.
- Disaggregate data, where appropriate, by relevant identities. Disaggregated • data is necessary to account for both LGBTQIA2S+ identities and disability to inform policy development and implementation [53]. Many researchers and data sources still rely on the traditional constructs that comprise and define human sexuality (e.g., gender and sex-assigned at birth) that can act to maintain underrepresentation and erasure of non-identifiable groups within these preconceived labels [27]. Researchers should ask questions in a way that obtains diverse information when collecting demographic information, creating surveys, conducting interviews, etc. One way this can be done is by avoiding options that present the dominant sex and gender binary (e.g., male, female, other; man, woman, other) and presenting options for people to self-report their diverse identities by asking questions like "How do you identify" and leaving a blank space for a response. When gender options fail to make space for all possible identities, we continue to perpetuate harm against those whose identities fall outside of heteronormative binaries [54].
- **Recognize the expertise of people with lived experience.** It is essential to include people with lived and living experiences to identify ecologically valid and

meaningful research; people with lived experiences have the most knowledge about their own lives and circumstances. This participation includes being involved in the entire research process from setting the research agenda, choosing a methodology, collecting and interpreting data, and guiding the knowledge translation process [55]. People with lived experience are most familiar with what is relevant in their own lives and should be provided with the opportunity and platform to share their wisdom regarding the lived realities of being members of multiple equity-seeking groups.

 Make the research process accessible, trauma-informed, and FASD-informed. People with FASD who identify as LGBTQIA2s+ may experience additional barriers that prohibit or limit their involvement in research. Safe and traumainformed spaces need to be created to provide a welcoming environment for participation. FASD-informed approaches are useful to identify the various barriers disabled people face and the potential solutions to those barriers; knowledge of impairment-related needs is essential [55]. The day-to-day functioning, evolving needs and strengths, and the unique developmental trajectories of people with FASD should be considered when presenting research information and processes [55]. Additionally, for the research process to be truly accessible, opportunities should be given to those with FASD to dictate their accessibility needs.

#### 2. Implications for Policy:

- Consider intersectionality and human-rights-based lenses in policy. It is of utmost importance that the rights of disabled people are understood. The UN CRPD can be used as a guideline or reference marker of a human-rights-based lens [56]. Additionally, policies must recognize that disability is one of several layers of intersecting identities that can result in negative outcomes (e.g., discrimination). They need to implement measures to embrace and protect those in this community during the policymaking process [53]. Ensuring that the rights of disabled people are respected and upheld while considering the multidimensional layers of identities, statuses, and life realities that inseparably intersect with each other emphasizes non-discriminatory practices and approaches toward equality [53].
- Increase the visibility of people with lived experience in policy. The experiences
  of people with FASD who identify as LGBTQIA2S+ should be acknowledged to
  generate real-world impact and relevant knowledge for action or change [55].
  Providing an active role in policymaking can increase the engagement,
  empowerment, and protection of those with FASD [55]. However, to ensure
  diverse representation and reduce burnout, it is important to utilize a wide range
  of people with vested interests/interested parties, voices, and perspectives [55].
- Reduce policies that approach sexuality from a medicalized and heteronormative lens. Heteronormative assumptions can reproduce stereotypes and expectations for conformity to the norms of the male/female binary [16, 42].

Approaches to policy and decision-making should recognize and celebrate the fluidity of gender and sexuality [57].

• **Combat discrimination at the systems level.** Examining the complex interplay of individual rights versus the institutionalized and systemic inequalities deeply embedded in societal practices is crucial [53]. Systemic responses that enforce protection and anti-discrimination are required where LGBTQIA2S+ members of the disability community are subjected to systemic violence, discrimination, and stigmatization [53]. Systemic discrimination and institutionalized oppression can be eradicated by utilizing conceptual approaches, such as the *Convention on the Rights of Persons with Disabilities*, in which those from this community are supported [53].

## **3. Implications for Practice:**

- Resist the idea of "normal." As highlighted throughout this paper, the assumption of heterosexuality and the traditional sex/gender binary leads to the false categorization of people as 'normal' and 'abnormal,' which remains a fundamental challenge in health care institutions, services, curricula, and training [22, 58]. Therefore, we must continue to deconstruct and challenge normalization mechanisms and ableism because normalcy is a socially constructed ideology [58, 59]. People must re-engineer their perceptions of what types of people deserve or can have different gender expressions than their biological sex and explore their sexualities [59]. One way to do this would be to utilize a crip theory approach, a radical critique of the concept of normalcy, which emphasizes disability and diverse sexual and gender identities as part of the human experience, one to embrace and respect [60].
- Embrace diversity and provide access to individualized support. Disabled people without access to information and resources are disadvantaged when making important decisions about their own lives [61]. People with FASD should be supported on their sexual and gender diversity journies through adequate awareness raising, education, social protection and housing, and access to health care and rehabilitation services [53]. These resources should capture their diverse needs and strengths.
- Include people with lived and living experience in decision-making. It is imperative to emphasize "nothing about us without us" which forces political-economic and cultural systems to incorporate disabled people into decision-making and recognize that their experiential knowledge is pivotal in making decisions that affect their lives [55, 62]. Including the voices and perspectives of those with FASD, including those with diverse sexual and gender identities, when creating informed resources and services can be done so by including caregiver in-home perspectives and the voices of people with in-body lived experiences of FASD [55].
- Provide appropriate accommodations to enhance participation and access to both LGBTQIA2S+ and disability events. The social model of disability recognizes that environmental factors act as barriers to access and inclusion [37]. Thus,

community event organizations and service providers should plan to ensure that events, spaces, and places are inclusive for all bodies and minds. Individualized accomodations should be provided to ensure equity regarding access, and people with lived experience should be consulted to understand what accommodations may be required [63].

 Focus on enhancing LGBTQIA2S+ membership within broader disability organizations and committees and build connections and partnerships between disability organizations and LGBTQIA2S+ organizations. It is critical that LGBTQIA2S+ people with disabilities, including people with FASD, are visible and active within the disability community so that their issues are recognized and addressed. Enhancing the in-body experiences of people with FASD can create a balanced narrative through which people may be increasingly humanized and seen for their contributions, strengths, and resiliencies [55]. This humanization includes recognizing the contributions of having people with FASD participate on committees aimed at addressing disability rights and those addressing gender and sexuality diversity.

#### **Conclusion:**

Little research has been conducted to understand the prevalence and experiences of gender and sexual diversity within the disability community. However, it is evident that the intersectionality of disability and diverse LGBTQIA2S+ identities can result in experiences of stigmatization, discrimination, unmet health needs, and mental health concerns. More research is needed to better understand this community's experiences and to identify gaps in service provision, policy, and practice. When conducting research, it is essential to include diverse people with lived experience to identify meaningful research and appropriate methodologies. Policies should be approached from an intersectional and human rights-based lens to make the multidimensional layers of identities visible. Furthermore, like other emerging identity categories relevant to the disability and FASD communities, such as neurodiversity, practices should emphasize disability and diverse sexual and gender identities as part of the human experience, one to embrace, respect, and support.

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