



Framing Fetal Alcohol Spectrum Disorder Policy, Practice, and Research Using the United Nations *Convention on the Rights of Persons with Disabilities*

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KEY MESSAGES

The purpose of this report is to identify how the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) can be used to improve service provision and government policies for persons with Fetal Alcohol Spectrum Disorder (FASD). It includes recommendations for how the CRPD could be used to advocate for improved outcomes and as a framework for future research, policy, and practice.

Human Rights and the United Nations *Convention on the Rights of Persons with Disabilities*:

Human rights have been accepted as a universal standard for ensuring that all people are provided with the opportunity to live with dignity and freedom from fear of harassment or discrimination [1]. Since the inception of the *Universal Declaration of Human Rights* in 1948, the United Nations (UN) has developed a number of other instruments to strengthen and promote the human rights of all people [2]. One such example is the UN *Convention on the Rights of Persons with Disabilities* (CRPD) [3] – the first human rights treaty of the 21st century [1]. The CRPD was adopted by the UN on December 6, 2006 and subsequently has had 164 signatories and 182 ratifications by nation-states, including Canada [4].

The preamble and the first five articles in the CRPD outline the universal standards, such as anti-discrimination, proportionality, and intersectionality, that inform subsequent articles in the Convention [5]. Based on the social model of disability, in which disability is viewed as an interaction between individual impairment and environmental barriers [6, 7], the CRPD recognizes the importance of not only ensuring that civil and political rights (e.g., equality and anti-discrimination) of individuals with disabilities are met, but also that social, economic, and cultural rights, such as shelter, education, and cultural participation, are met as well [5, 8]. It is because of the inclusion of these social, economic, and cultural rights that many advocacy groups, such as the Council of Canadians with Disabilities, have suggested that policy

frameworks take into account the CRPD and a human rights-based approach to ensure genuine inclusion of people with disabilities in society [9].

By ratifying the CRPD in 2010, Canada consented to be bound by this convention and has agreed to develop national policies that provide persons with disabilities with opportunities for protection, provision, and participation [5]. As such, all levels of government are required to ensure that they are implementing policies, legislation, programs, and services to accommodate individual differences while maintaining respect for each person's inherent dignity [1]. In addition, Canada is required to report to the Committee on the Rights of Persons with Disabilities ("the Committee") every four years regarding the implementation of the CRPD and to make improvements in identified areas of concern [4]. In the most recent concluding observations made by the Committee, they expressed concern that Canada has yet to provide a national framework for how provinces should incorporate the CRPD appropriately into legislation and policies across sectors and levels of government [sec. 9(a)] [10]. Moreover, they recommended that governments seek feedback and input from self-advocates and organizations representing persons with disabilities to ensure that their actions meet the needs of persons with disabilities and align with the principles and values of the CRPD [sec. 12(a)] [10]. Consequently, there is a need for on-going implementation and monitoring of legislation, policies, and supports and services to ensure that Canada is supporting the full and effective participation of people with disabilities in society on an equal basis, including individuals with Fetal Alcohol Spectrum Disorder (FASD).

In Canada, provincial and territorial advocates for children and youth collect data about complaints and common issues. This collection of data is informed by varying foundational principles and practices across the country, including the CRPD, the UN *Convention on the Rights of the Child*, and the UN *Declaration on the Rights of Indigenous Peoples*, as well as children and youth first principles. Unique to Alberta is the *Advocate for Persons with Disabilities* ("the advocate"), whose role is to help individuals with disabilities resolve concerns regarding the availability and provision of services, to provide education that promotes the rights, interests, and well-being of people with disabilities, and to inform the community of issues faced by persons with disabilities including identifying gaps in programs and services [11]. The mandate of the advocate aligns with the CRPD, given that it promotes the participation and inclusion of persons with disabilities in society and endorses the values of respect for difference, acceptance of persons with disabilities, and equality in opportunity and accessibility [12].

Despite the ongoing monitoring of service provision to persons with disabilities by the advocate, one group of individuals that have remained notably absent are persons with FASD. In reviewing the recent findings of the advocate [12], the Alberta FASD Service Networks [13] have raised concern that the needs of the FASD community were not being adequately identified and addressed in the report. Since the inception of the advocate role in Alberta almost three years ago, there have been few reported cases of rights violations or exclusion of persons with FASD. This concern is not unique to Alberta, as other provinces have also identified that children and youth with FASD and other complex needs have not been well

supported and are largely invisible from collected data of publicly funded support [14]. Collectively, these findings are concerning given recent research indicating that identified supports and services for persons with FASD are still lacking and FASD remains a low priority in Canada for research and policies informing resources and services [15]. However, a human-rights based approach to supporting persons with FASD is important, given the complexity of FASD [16], including the diversity of impairment and the potential for experiences of social inequality (e.g., access to diagnosis, the need for on-going FASD-informed support across the lifespan, and the lack of awareness and education for professionals and service providers).

Considering FASD Within the Context of the CRPD:

Some researchers have explored how the CRPD can inform service provision for persons with disabilities, including advancing self-determination and advocacy [17], quality of life [18, 19], social inclusion [20], and dignity [21]. It is possible that these recommendations could be used to inform improved services that are provided to persons with FASD. Though limited, some researchers have also explored how particular Articles of the CRPD can be used to address the unique needs of specific disabilities, including inclusive education for autistic young persons [22] and consent and capacity for persons with psychiatric disorders [23-25]. It is for this reason that it is important to consider how the Articles of the CRPD can be used to empower self-advocates with FASD and their care providers.

Recently, other countries have considered how a human rights-based approach could be used to develop, implement, and monitor a framework for service provision to address FASD. For example, an inquiry into FASD by the Australian Human Rights Commission [26, 27] highlighted how several human rights treaties, including the CRPD, could be used to address FASD within communities. They identified that any framework that is implemented needed to be community-led and community-focused and should be informed by the social model of disability [26]. Moreover, they recommended that the Australian government undertake significant law reform to ensure that supports and services provided to persons with FASD were aligned with the provisional rights in the CRPD [26].

Notably, although persons with FASD share some commonalities with other disability groups and complex populations, FASD is linked to a number of factors that distinguish it as a distinct disability with unique considerations [15, 16]. Unique to this disability are the high levels of adverse outcomes frequently reported [28, 29], including high rates of mental health issues and substance use challenges [30, 31], justice system involvement [32], unique developmental and environmental considerations, and experiences of stigmatization [33-35]. The incorporation of individuals with FASD into existing systems of service delivery [15] is further compounded by the lack of evidence-based practices to support or guide the use of the CRPD in advocating for persons with FASD. Therefore, more consideration and evidence are needed to understand how the CRPD can be used to advocate for the needs of people with FASD. A cursory glance at the identified areas of need for individuals with FASD overlap with the provisional articles in the CRPD, including the need for individualized services, accommodations, and trauma- and culturally-informed approaches. Below are a few examples of how the identified areas of need for persons with FASD overlap with some of the CRPD Articles. This overlap suggests areas for

how the provisional articles of the CRPD can be used to advocate for accommodations, supports, and services provided to persons with FASD.

Example Identified Areas of Need for Persons with FASD	Relevant CRPD Articles
Access to diagnostic services, appropriate interventions, and increased public awareness of FASD [31, 36-38]	Article 1: Purpose Article 8: Awareness-raising; Article 25: Health
Housing [39-42]	Articles 19: Living independently and being included in the community; Article 23: Respect for home and the family; Article 28: Adequate standard of living and social protection
Overrepresentation of individuals with FASD in the criminal justice system [32, 43, 44]	Article 12: Equal recognition before the law; Article 13: Access to justice; Article 14: Liberty and security of the Person

1. Diagnosis

The second paragraph of Article 1 of the CRPD identifies that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [45]. Given the known impairments associated with FASD across the lifespan, it would fall well within the definition of disability provided by the CRPD. That being said, the inability to secure a diagnosis because of limited diagnostic resources has meant that persons with FASD may not be able to access the necessary supports and services and may continue to experience on-going mental health effects of discrimination and stigma [46]. Furthermore, even when there is recognition of FASD as a disability, persons with FASD are often required to meet the diagnostic criteria for an intellectual disability (i.e., an IQ below 70) to receive support and services despite evidence of the scope and severity of needs [47].

Researchers have long advocated for policy development and coordination that spans across the lifespan and across interdisciplinary settings such as health, children and family services, education, and justice for persons with FASD [48]. This coordinated care includes assessment and diagnosis to facilitate identification and understanding of unique needs, particularly given the high levels of diversity in both behavioural presentation and needs for supports and services. Researchers have identified that any policies, supports, or interventions for persons with FASD need to be aligned with the values of fairness, equality, and respect for family members, kinship caregivers, and community partners [48]. Furthermore, recognizing the role that intersectionality plays in the experience of persons with FASD, any services or interventions provided need to be supportive (and not blame) of birth families and culturally

informed [49-51].

Critical policy considerations for FASD include the identified need for comprehensive assessment and diagnosis capacity in communities (including remote communities) across Canada. This comprehensive service provision includes respectful public health media campaigns regarding alcohol consumption during pregnancy, widely available FASD diagnostic services, and ongoing supportive case management across the lifespan [27, 52]. In recent years, there has been greater attention paid to the relationship between FASD and how information about alcohol-consumption during pregnancy is portrayed in public health media campaigns. It is recognized that when women are made to feel shame about alcohol consumption during pregnancy, they are less likely to disclose consumption when asked [53]. Article 8 (Awareness-raising) ensures that portrayals of persons with disabilities are respectful and do not provide a negative image of persons with disabilities, which extends to the messages that are provided about FASD prevention. Messages regarding the prevention of disability need to be carefully constructed to ensure that they do not imply that disability is something wrong or in need of being fixed [5]. Although the Committee has not explicitly addressed the needs of persons with FASD in their recommendations, they did reinforce the importance of adopting public campaigns that promote the inclusion of persons with disabilities and that combat negative stereotypes about persons with disabilities [sec. 9(a)] [10]. Furthermore, Article 25 (Health) of the CRPD ensures that persons with disabilities are provided the provisional right of “enjoyment of the highest attainable standard of health without discrimination on the basis of disability” [45]. Specifically, subsection (b) provides individuals with disabilities the opportunity for health services required for early identification and intervention, recognizing that early support can prevent further disabilities later in life [45]. Previous research has demonstrated that early diagnosis of FASD is associated with more positive outcomes, including reduced contact with the criminal justice system [54].

2. Persons with FASD in the Criminal Justice System

The involvement of individuals with FASD in the criminal justice system, including the associated negative outcomes associated with justice involvement and incarceration, remain one of the most significant areas of interest in FASD for both researchers and policy makers alike. Persons with FASD are overrepresented in the criminal justice system [32, 55]; however, more research is required to understand the relationship between FASD and justice-involvement [43]. In addition, the lack of knowledge and training for justice professionals has meant that persons with FASD are not properly accommodated at multiple points in the criminal justice system, including at the time of arrest and during court proceedings, potentially creating more barriers and risk of criminalization [56, 57].

Ideally, the justice-involvement of persons with FASD is addressed through better service provision that prevents it from happening. Therapeutic jurisprudence, a relational approach to law that emphasizes the role of empowerment, human rights, and psychological/emotional well-being in legal matters [58], may provide a framework for ensuring that the rights of persons with FASD who are justice-involved are respected. One of the most significant developments in the therapeutic jurisprudence movement has been the international

proliferation of therapeutic courts, such as mental health courts and drug courts, that resolves to “divert individuals away from the criminal courts in exchange for an agreement to participate in community treatment that reduces the likelihood of future offending” [58].

Diversion to therapeutic courts is consistent with several of the rights/articles in the CRPD, including the right to equal recognition before the law (Article 12), the right to access to justice (Article 13), and the right to habilitation/rehabilitation (Article 26). In addition, these diversion courts are consistent with the recommendations made by the Committee in their Concluding Remarks regarding the need for Canada to increase the accommodations for justice-involved persons with disabilities as diversion courts tend to include specially trained staff and focus on including the accused in proceedings [10, 58]. Although most people with FASD who are eligible can be diverted to mental health courts, the province of Manitoba opened the first FASD diversion court in Winnipeg to provide young persons with FASD in contact with the law the opportunity to be diverted to a court that is supported by specialized staff and justice professionals knowledgeable about FASD. This court has also developed partnerships with community agencies to provide training to increase capacity for supporting persons with FASD and to provide community-based interventions [59]. Finally, this court resolves to reduce the criminalization of persons with FASD by ensuring that the young person who is suspected of having FASD receives a formal diagnosis (if they do not already have one), by providing FASD-informed recommendations to justice professionals for sentencing, and by developing an individualized support plan that addresses factors contributing to the offence for the individuals with FASD [60]. At this time, one of the identified barriers to effectively providing diversion to justice-involved persons with FASD is securing a diagnosis, particularly for adults [61].

3. Persons with FASD and Housing

The right to living independently in the community is arguably one of the most important rights as it predicates all other provisional rights [5]. Unfortunately, it has been well established that individuals with FASD are at a higher risk of housing instability [39, 62, 63]. Service providers, individuals with FASD, and caregivers have all described the challenges of navigating conventional housing support systems for individuals with FASD [39, 64]. Additionally, unhoused individuals with FASD often negatively experience other social determinants of health that result from being homeless, including trauma, prior transient housing including involvement with child welfare, substance use, and continued experiences of victimization while unhoused [39].

When individuals with FASD are able to find housing in the community, it is often short lived as agencies may not be FASD-informed resulting in termination of services or voluntary discharge. Canadian researchers have indicated that current housing models are not meeting the ever-changing needs of people with FASD and the lack of FASD-informed practices may lead to individuals with FASD facing additional challenges and adverse outcomes [39]. Yet, this population does not need to be characterized by adversity and vulnerability. Stepping beyond this potentially stigmatizing pre-deterministic thinking, healthy outcomes are possible when supports provided are well suited to the unique needs of people with FASD [39]. Although current housing models are not consistently meeting the complex needs of people with FASD,

there have been programs and families that have experienced success.

One program that aligns with a rights-based approach to supporting persons with FASD to secure housing is the *Housing First* model, a recovery-based approach that focuses on “provid[ing] housing first and then combin[ing] that housing with supportive treatment services in the areas of mental and physical health, substance abuse, education, and employment” [65]. Housing First is consistent with a rights-based approach to housing given that it emphasizes core principles of human rights, including the right to choose a place of residence, adequate standards of living (including adequate food, clothing, and housing), and ensuring social and community integration [65]. Using this approach to supporting persons with FASD will help to provide them with safe, supportive, and stable housing that is consistent with the right to live independently and be included in the community (Article 19), have respect for the home and family (Article 23), and provision of an adequate standard of living and social protection (Article 28). Further community-based work in which the voices of individuals with FASD and their families are incorporated into housing initiatives, and whereby programs are supported in implementing FASD-informed approaches to support housing successes, are greatly needed.

Recommendations for Research, Practice, and Policy:

There is an urgent need to use a human rights-based approach in research, practice, and policy for persons with FASD. Some key recommendations based on what is known at this time include:

1. Persons with FASD should be educated about the CRPD and the rights enshrined within it. As recommended by the Committee in their most recent Concluding Observations of Canada’s implementation of the CRPD 2017 [10], persons with FASD should be supported to advocate for their rights, using language that is most meaningful for them. Education should also include providing training about how to self-advocate and exercise rights at local, provincial, and federal levels. Example programs that could be used to teach persons with FASD include the materials developed by self-advocates and their support systems (e.g., *We Have Human Rights* [66]) and other Rights-based education (e.g., the *3Rs Education Program* [67] or the *Respecting Rights - My Voice, My Choice* self-advocacy curriculum [68]).
2. Supports and services should be tailored to meet the needs of persons with FASD. Aligned with changes in the broader disability community for more self-advocates and persons with lived experience involved in the development of policies influencing their supports and services [69], persons with FASD should also be provided with the appropriate accommodations and opportunities to participate in their communities and to provide their perspectives and opinions regarding policies and implementation.
3. The unique needs of persons with FASD need to be considered in approaches and interventions. Although impairment is part of the spectrum of human variation [8], it is still important to recognize how the unique neurological profiles of persons with FASD influence social and behavioural outcomes [16]. It is also important to recognize that these impairments alone do not create the experience of disability; rather, it results from the environmental and attitudinal barriers that prevent equal participation (i.e., the social model of disability).

4. Existing frameworks (e.g., quality of life, therapeutic jurisprudence, housing first) that are aligned with the CRPD should be considered in policy development and service delivery for persons with FASD. Existing policies should be examined with a human-rights lens to ensure that persons with FASD are provided with opportunities for protection, provision of services, and participation aligned with the Articles in the CRPD.
5. A comprehensive FASD framework needs to take into account prevention and the impact of the social determinants of health on alcohol consumption in various marginalized populations. Therefore, a complete FASD framework will need to take into consideration other intersectional and international human rights conventions and declarations in addition to the CRPD, including the *Universal Declaration of Human Rights* [2], the *Convention on the Rights of the Child* [70], the *Convention on the Elimination of all Forms of Discrimination against Women* [71], and the *UN Declaration on the Rights of Indigenous Peoples* [72, 73].
6. The unique experiences of persons with FASD needs to be captured in the data to fully understand how persons with FASD are being supported by current service provisions and policies. In the Concluding Observations made by the Committee on Canada's implementation of the CRPD, they recommended the need for better collection of data regarding persons with disabilities including statistics broken down by type of disability and barriers encountered (sec. 54) [10]. Following through on this recommendation by the Committee and ensuring that specific data about FASD is captured in this monitoring will provide an opportunity to understand the strengths of current interventions and to highlight gaps for future intervention.
7. Article 35 of the CRPD requires countries to submit reports every four years regarding the efforts made to conform with the articles of the CRPD [5, 45]. As part of the process, disability organizations, civil society organizations, and human rights commissions are invited to submit reports to the UN Committee providing feedback regarding the Rights of Persons with Disabilities in Canada [74]. In the 2017 review by the Committee, information was provided by several Canadian advocacy groups including Autistic Self Advocacy Network Canada and Disabled Women's Network of Canada. To ensure that the concerns of persons with FASD regarding the implementation of the CRPD are heard, submissions should be made identifying the strengths and challenges faced by persons with FASD in Canada as they relate to the CRPD. Submissions by individuals invested in the human rights of individuals with FASD can provide a more holistic picture of how rights-based approaches are implemented in Canada and ensure that future policy development includes persons with FASD.

Conclusion:

The political and symbolic power of the CRPD should not be underestimated [1] as the CRPD provides a valuable tool to advocate for change. The articles in the CRPD provide targeted areas that can be leveraged to empower advocates (including self-advocates, substitute decision-makers, families and caregivers, and organizations) to speak up on behalf of persons with FASD to ensure that their human rights are respected and that their full participation in society is supported. The urgent need to implement a human-rights based approach in research, practice,

and policy for persons with FASD can only be realized when resources are allocated to these identified needs.

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