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The Invisible Struggle: Parents with FASD, the Courts and the Child Intervention System

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Abstract: Fetal alcohol spectrum disorder (FASD) encompasses a range of complex neurodevelopmental challenges that arise because of maternal alcohol use during pregnancy. Contrary to previous beliefs, FASD is a wide-ranging condition that is mostly invisible, affecting cognitive, social, and daily living skills. Furthermore, living with FASD may present other challenges, such as mental health issues, substance abuse, and engagement in criminal behavior. FASD is a long-term disability that requires support across the lifespan. The main objective of this research was to determine what, if anything, has changed since a prior review in 2020 of parents with FASD appearing in child intervention courts in Canada. We found eleven relevant reported cases throughout Canada from 2020 to 2024 where parents had a confirmed diagnosis or a potential FASD to be eligible for our study. Within these cases, only one parent was able to reunite with their children because of the strong and supportive system they had. There were four cases where ongoing contact between parent and child(ren) was permitted, Additionally, we found that professionals lack education regarding the potential skills that people with FASD may demonstrate. A person with FASD is seen through the lens of their diagnosis rather than a strengths-based approach, creating stigma, fear, and power imbalance. Stigma has an impact not just on how professionals see people and make decisions but also on policymakers, funding, and support from governments or other social groups. Individuals or parents with FASD are often reluctant to report their diagnosis for fear of being judged or having their children taken from their care. Thus, parents are unable to obtain access to services, and even when they do have access, they must navigate the system on their own. Parents with FASD who are involved in child intervention may be required to participate in many programs simultaneously, potentially resulting in an overwhelming experience.

Keywords: fetal alcohol spectrum disorder; FASD; child protection; child intervention; child protection court; parents living with FASD

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1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) affects individuals exposed to alcohol in utero across the lifespan. Domains impacted include cognitive, emotional, physical and behavioral realms of functioning. It is vital to note that FASD exists across a spectrum from mild to severe, meaning there is no one expression of the disorder (Popova et al. 2023). Incapacity is often seen as inherently linked to FASD overstating limitations while understating capacity (Abadir and Ickowicz 2016).

Approximately 1.5 million individuals in Canada are affected by FASD, accounting for roughly 4 percent of the general population. According to Flannigan et al. (2018) and Popova et al. (2019), the prevalence rate of FASD surpasses that of trisomy 18, Down syndrome, anencephaly, spina bifida, and autistic spectrum disorder in Canada.

FASD is subject to significant stigma which can be thought of as the targeting of a group although both the group and the individual will pay the price. Stigma negatively stereotypes, lowers the power position of the group and separates through labelling (Andersen et al. 2022). Adding to the stigma is that FASD is seen as the byproduct of the mother's decision to use alcohol during the pregnancy, thus harming their child (Thomas and Mukherjee 2019; Bell et al. 2016; Badry 2008).

As social workers and/or child intervention workers, lawyers, and judges working with vulnerable populations in the courts, there is an obligation to be educated and be aware of the strengths and weaknesses of individuals with FASD (Choate et al. 2024; Badry et al. 2023; Binnie 2018). Ultimately, it is the judiciary that makes the determinations, although social workers gather the case data and develop the case management plan. This research paper will examine any improvements in the treatment of parents with FASD within the child intervention system (CIS) court decisions in Canada over the last four years. Additionally, it will explore the gaps in the representation of parents with FASD within the child intervention system.

The object of this work was to follow up on Choate et al. (2020) and to ascertain if newer cases showed shifts in how courts are considering issues related to parents living with FASD.

2. Literature Review

Persons living with FASD present with a range of complex neurodevelopmental impacts arising from maternal alcohol use during pregnancy. Diagnosing FASD is challenging and requires assessment by a multidisciplinary team that will consider cognitive ability, social functioning, and impairments in everyday living skills. Individuals with FASD may encounter mental health difficulties, engage in substance abuse, and have a higher likelihood of being involved with the justice system as well as being victimized in childhood (Hargrove et al. 2024; Cook et al. 2016; Gault et al. 2023).

Expression of FASD can vary depending upon when, and if, a diagnosis occurs and what, if any, supports have been offered over time. Popova et al. (2023) stated that FASD is a permanent disability that needs ongoing support in healthcare, social services, education, and employment. Early leads to better possible health outcomes, particularly given the increased risks of several early onset physiological disorders (Himmelreich et al. 2020).

A literature review by Flannigan et al. (2021) stated that viewing FASD through the lens of disability reduces the ability to see the strengths of a person. These authors also found several studies on adults with FASD that, "described many of the adults' successes, including completing post-secondary school, maintaining stable employment, engaging in volunteer work and community outreach, and balancing the competing demands of parenthood with school and employment" (p. 2454). The strengths perspective is less often part of the dialogue about persons living with FASD (Kautz-Turnbull et al. 2022).

The more common deficit view which emphasizes impairments, reinforces the stories of shame, victimization, and distress and may increase the risks of self-stigma as a less capable person (Hargrove et al. 2024). Such views impact how individuals living with FASD are seen (as burdens, criminals, or objects of pity), but also on policymakers, funding, and support from governments or other social groups (Flannigan et al. 2021; Choate and Badry 2019).

A systemic review conducted by McCormack et al. (2022) revealed knowledge gaps throughout many systems including child intervention, education, justice, and community services (see also Binnie 2018). The gaps have led to a lack of knowledge among professionals regarding FASD, thereby impeding their capacity to provide appropriate interventions, particularly over time as opposed to episodic efforts (Gilbert et al. 2021). Badry et al. (2023) identified that child intervention workers lack significant knowledge regarding FASD which impacts CI intervention planning (Badry and Harding 2020).

The lack of understanding about FASD has been reinforced by the work of McLachlan et al. (2021) who stated that several researchers have shown medical care, social services, and legal/criminal justice professionals lack an understanding of people with FASD and their abilities. To improve their practice, these experts require supplementary training (Choate et al. 2024).

Parents with FASD lacking appropriate support can potentially risk the well-being of their children as FASD impacts parenting skills, including, “problems with memory and organization; perseveration; planning; generalizing from one situation to another; using consequences effectively; understanding the concept of time; registering and integrating sensory cues such as hunger, temperature, and pain; and temper/patience and impulsivity” (Rutman and Van Bibber 2010, p. 356; see also Badry et al. 2023). FASD is a broad-spectrum condition that is mostly invisible. Therefore, the needs and strengths of the individual differ depending on the expression of the disorder across their lifespan. The strengths are often missed or dismissed due to the stigma (Choate and Badry 2019).

Parents with FASD feel that CI workers misinterpret their behavior, seeing them as non-compliant and unmotivated instead of recognizing that these are the consequences of their FASD which may interfere with communication, memory and follow through on agreed actions. CIS work needs to contextualize and understand how a person with FASD may interact and process information (Rutman and Van Bibber 2010). Professional training is needed (McCormack et al. 2022; Howlett et al. 2019).

Survey data with adults living with FASD show they are often not seen as credible witnesses within legal systems, which would include family courts (Hargrove et al. 2024; Flannigan et al. 2020; Choate 2013). Individuals living with FASD will face significant discrimination in judicial systems, including family, child intervention and criminal (Choate et al. 2020, 2024; Dunbar Winsor 2021; Mutch et al. 2020; Sessa et al. 2022). There is a paucity of research looking at the capacity of a parent living with FASD and fulfilling the parenting role alone or with support.

In a previous review (Choate et al. 2020), the courts were seen as a poor place to address the needs of parents living with FASD and also seeking to parent. The cases reviewed had complex factors including difficulty accessing social determinants of health and lacking expert evidence about FASD. Has that changed?

3. The Legal Structure for Child Intervention in Canada

Within the current legal context in Canada, CIS is the responsibility of the 10 provinces and three territories. There are differences in the laws yet the fundamental notion of protecting the best interests of the child is a common feature. Most legislation also makes specific reference to Indigenous children which is relevant as they are the most common population in CIS across Canada. The 2021 Canada census notes that 53.8% of children 14 and under in foster care are Indigenous, but account for only 7.7% of the child population according to Census 2021 (Indigenous Services Canada 2024). This under reports the data as the upper age is 14 years and it is related to foster care. This matters as current data indicate that FASD is more commonly identified in Indigenous populations (Samaroden 2018). However, given the history of colonization in Canada, it is probable that trial decisions do not capture this population as they are far less likely to contest a matter in court (Quinn et al. 2022) which compounds the bias felt by persons living with FASD (Hargrove et al. 2024).

Canada (2019) passed legislation designed to give First Nations, Inuit and Metis people the opportunity to manage their own CIS through their own legislation. The Supreme Court of Canada has held that legislation to be fully valid (2024 SCC 5). According to Canada, 58 Indigenous Governing Bodies (IGB) have served notice to exercise their legislative authority. Forty IGBs have requested to enter into coordination agreements with Canada regarding their own laws with 13 of them having implemented their own laws (Canada 2024). This will create space for Indigenous ways of knowing and being when working with parents affected by FASD within their own cultural systems. Indigenous caring systems tend to see children as gifts to be cared for and nurtured regardless of the presence of disabilities (Choate and Lindstrom 2023; Lindstrom and Choate 2016).

4. Methodology

Reported Canadian court cases were sought through the Canadian Legal Information Institute (CanLII) database for cases of parents with FASD involved in the child intervention system. There were 11 relevant cases found throughout Canada from 2020 to 2024 by using key terms (Parents with FASD, Parent with Fetal Alcohol Spectrum Disorder, Fetal Alcohol Spectrum Disorder). (KT (Re), 2023; KS v. BC Ministry of Children and Family Development, 2023; JM (Re), 2022; British Columbia (Child, Family and Community Service) v. S.H; Catholic Children's Aid Society v. J.B., 2022; Catholic Children's Aid Society v. J.B. and P.S., 2022; KS v. BC Ministry of Children and Family Development, 2023 Alberta (Child, Youth and Family Enhancement Act, Director) v M.L., 2020; The Children's Aid Society of Ottawa v. C.V. and J.H., 2022; Children's Aid Society of Toronto v. S.C.M.K., 2021 ONCJ 347; British Columbia (Child, Family and Community Service) v. R.L.T., 2020). Parents were required to have a confirmed diagnosis or believed to have FASD according to the decision to be eligible for inclusion. A thematic analysis was conducted of the 11 decisions based upon the prior work (Choate et al. 2020) as well as searching for any new themes arising from the current data.

Academic literature was searched using EBSCO, SocIndex, CINAHL, Social Services Abstracts, PubMed, MedLine, Sociological Abstracts, Cochrane Review, Policy Commons and Google Scholar. Search terms were birth alert, high-risk mother alert, birth alert and Canada, expectant mother alert, expectant parent alert, newborn apprehension system, child apprehension system, infant apprehension system, child apprehension at birth, child at risk alert and emergency or electronic records and birth alert. In total 56 distinct articles were identified. A content analysis was conducted in respect of the reported cases as well as the research identified. Following each researcher's review, consensus was achieved in a group review of the relevant data.

5. Results

5.1. Case Dispoistion

We found eleven cases of parents with FASD who were involved in the child intervention system. Figure 1 illustrates the outcomes: eight court cases resulted in a Permanent Guardianship Order (PGO) which terminates parental rights, one case in a Temporary Guardianship Order (TGO), one instance where the child was placed with a father who did not have FASD, and one case where the children were returned to a mother with FASD.

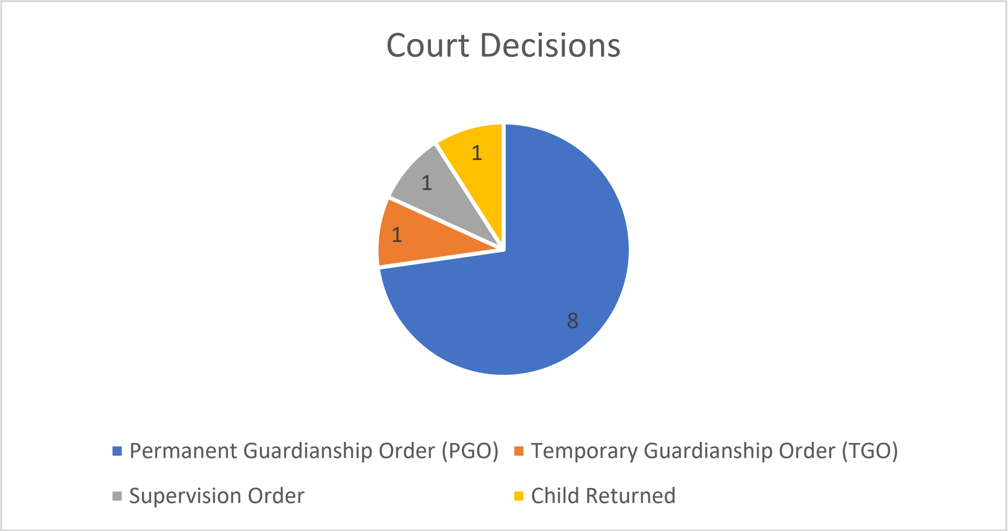

Figure 1. Outcomes from the Canada-wide decisions based on the 11 child intervention court cases involving parents with FASD.

We looked at the prior research (Choate et al. 2020) and combined the results with the current study. The most significant results were that out of 52 cases, only two parents had their child returned to their care. This means that parents with FASD, or suspected FASD, are highly likely to lose custody of their children when involved with the child intervention system and their cases come to trial. Caution is needed in that no case is decided solely on the FASD issue but also on the related issues noted earlier that exist within the living experience of FASD (Hargrove et al. 2024; Wilson et al. 2024).

Of the two cases where a child was returned, one case went in front of the British Columbia Human Rights Tribunal (RR v. Vancouver Aboriginal Child and Family Services Society 2022). It concerned an Afro-Indigenous woman who had her children apprehended because of the Vancouver Aboriginal Child and Family Services Society's (VACFSS) perception that she was unfit to parent. The Human Rights Tribunal found that the VACFSS discriminated against the complainant by wrongfully removing her children when there was no basis for removal, stating that the VACFSS did so because of stereotyping, and did not consider all possibilities. This decision is significant because it shows a step in the right direction when it comes to the courts honoring the rights of individuals with a disability, and those with Indigenous heritage.

While this parent had some comorbid concerns such as trauma, depression, anxiety, learning disabilities, drug, and alcohol use, and was experiencing homelessness, she was participating in community supports such as drug and alcohol counselling, completed a four-week Indigenous-based program for parenting and a trauma workshop. This parent was also regularly active in her community and was working alongside Elders. She was able to secure stable housing and her children were returned to her, and they were reported to be thriving in their community and actively engaging in cultural events and activities. This case illustrates the types of support systems needed for a parent raising their children.

In the other case where the child was returned to the care of the parent, the mother had shown active engagement with services and had a mild cognitive impairment but did not experience interpersonal violence or drug use (Choate et al. 2020). Again, an effective support system was in place which is an important lesson arising from this review.

5.2. Diagnosis and Co-Morbidity

Of the 11 cases in the current review, there were nine cases in which parents with FASD or suspected FASD also experienced mental health disorders, such as depression, anxiety, borderline personality disorder, post-traumatic stress disorder (PTSD), attention-deficit/hyperactivity disorder (ADHD), and dependent personality disorder. There were seven cases involving substance use including marijuana, cocaine, methamphetamine, and/or alcohol abuse. There were seven cases identified as having experienced interpersonal violence (IPV). There were seven instances of parents with confirmed or potential FASD that were impacted by intellectual impairments (see Figure 2). These issues were often intermixed as opposed to stand-alone concerns. (Popova et al. 2016). In other words, comorbidity represented a crucial element in these cases.

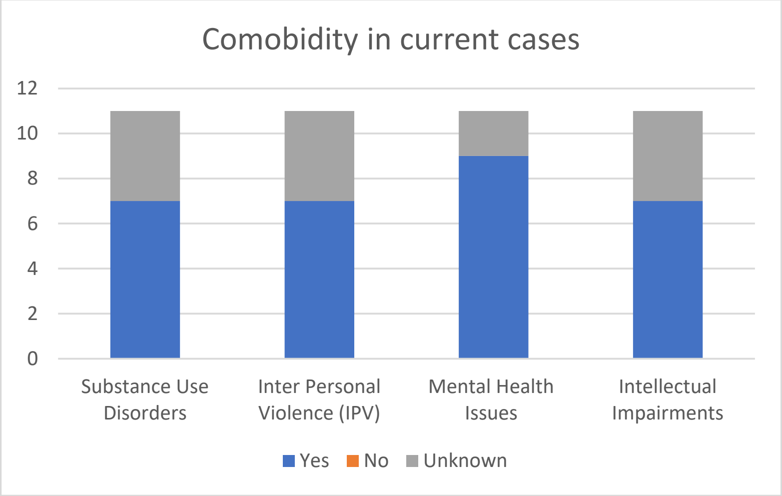

Figure 2. Presence of comorbid issues in the 11 cases in the current study.

6. Thematic Discussion

During the research process, four key themes were identified: stigma, power, and fear as well as pathways for hope. These themes helped to guide the research and identify areas of need. The significance of these themes relates directly to how parents with FASD are perceived and treated within the CIS. Stigma creates a power imbalance, which breeds fear; fear can be both a cause and consequence of stigma and power dynamics. Also considered is the question of an ongoing relationship between a parent with FASD and the children after the termination of parental rights.

6.1. Stigma

Stigma is one of the biggest barriers for individuals living with FASD (Hargrove et al. 2024). It creates a discourse in which people with FASD are seen as less deserving of support because of the public perception of the disability as being preventable and resulting in permanent disability which leads to a framing of stigmatized incapacity (Roozen et al. 2020; Choate and Badry 2019). Often, the perception of people with FASD is that they are incapable of contributing to society, incapable of parenting, and they are not seen as multi-faceted with strengths and challenges, rather, they are only seen through the lens of their diagnosis. This creates considerable distress because not only do they experience external stigma from society, but they also experience self-stigma and struggle with their perception of self and their abilities (Hargrove et al. 2024; Roozen et al. 2020).

Stigma is reinforced by a lack of training, education, research, and support programs for people with FASD. Child intervention workers, lawyers, and judges are not adequately educated on FASD, nor is there any significant evidence of mandatory training for these professionals (Choate et al. 2024; Wilson et al. 2024). These current cases, as with those in Choate et al. (2020), were marked by a lack of expert evidence in FASD that would act as a mechanism to inform courts.

In CIS parents with FASD are seen by professionals as unable to parent, uncooperative, unmotivated, or unwilling to follow directions. This may be more an issue of difficulty comprehending what is expected of them and lack of effective support for follow-through (Choate et al. 2020; Rutman and Van Bibber 2010). Professionals may also expect too much of people with FASD and fail to appreciate the unique challenges that they face daily (Rutman and Van Bibber 2010). Part of dealing with stigma is to recognize the various ways in which FASD can be expressed along with the specific and unique challenges and strengths of the parent living with FASD. Such understanding aids in effective case planning (Hargrove et al. 2024; Himmelreich et al. 2020).

Individual biases that professionals hold toward people living with FASD are a significant contributor to the stigma that many people with FASD face (Roozen et al. 2020; Corrigan et al. 2018). Since FASD is a spectrum, there is a broad range of impairments (Brown et al. 2021; Popova et al. 2023) and it is important for professionals working with FASD to understand there is no one-size-fits-all intervention. Rather, a focus on the individual and their strengths is key to supporting these individuals. A review by Flannigan et al. (2021) illustrates that strength-based dialogue is severely wanting. A more in-depth guide to working with these individuals will be addressed in the recommendations section.

FASD research is an area that is significantly lacking, especially among people with FASD acting in the role of parent (Flannigan et al. 2020). This could be due to stigma and the unwillingness of funders and researchers to explore this area because of the discourse that FASD is preventable and therefore the fault of the women who drank during pregnancy (Gomez et al. 2022). Mothers also self-stigmatize which is a further barrier (Binder et al. 2024).

The lack of research contributes to stigma because there is not enough information about the complexity, realities, challenges, and strengths of living with FASD (Dunbar Winsor 2021; Roozen et al. 2020). This also means there is a gap in data available to courts on how successes occur.

Information presented to the public, such as through awareness or prevention campaigns, is often deficit-based and places blame on the individual. There remain questions about the extent to which prevention programs are effective (Erng et al. 2020; Choate et al. 2019). In the case of CIS, this stigma can negatively impact parents because of the assumption that a person with FASD cannot effectively parent their children (Tortorelli et al. 2024). In the cases considered here, the prior work (Choate et al. 2020) was confirmed in that there did not appear to be expert evidence provided to the court regarding FASD and its impacts on strengths and challenges.

Stigma can also prevent a person from obtaining a diagnosis of FASD given that the mother needs to disclose she drank during the pregnancy. What price must the mother pay for disclosing this information (Matebese et al. 2021; Oni et al. 2022; Dunbar Winsor 2021). As was discussed, the public perception of women who drink during pregnancy is quite negative and they are typically blamed for their child's diagnosis (Roozen et al. 2020). This creates an environment of fear because the woman who drank during pregnancy may not want to disclose this information due to the risk of having her children removed from her care. This leaves many children without a proper diagnosis and leaves them vulnerable to challenges across their lifespan. Without a positive diagnosis, individuals with FASD will be left without access to formal support and their symptoms could be misinterpreted. There is also a lack of availability of diagnostic clinics and, where they are available, there are long waiting lists (Dugas et al. 2022). Popova et al. (2024) suggest that 98% of impacted individuals are either undiagnosed or misdiagnosed. Wait times for diagnoses can range from 1 month to 4.5 years. Popova et al. (2024) go on to note that, to address the need for assessment, Canada requires a 67-fold increase in diagnostic and assessment services. This has significant implications for parents with FASD in the child intervention system as the lack of access to diagnostic services means they are unlikely to have the needed support which can in turn increase the risk of CIS involvement. This leads to case decision-making not being based upon an understanding of the true needs of the parent but rather upon the more visible limitations that brought the parent to the attention of child intervention (see also Harding et al. 2024).

Lack of funding for support programs for parents with FASD is also a consequence of stigma. A literature review by Roozen et al. (2020) discussed a study in which participants were asked to distribute funding to different social services programs. The participants in the Roozen et al. (2020) study distributed much less funding to the FASD programs, which shows that people are far less willing to support and fund FASD services. Additionally, this study found that people's attitudes and perceptions about FASD were more negative towards women who have children with FASD than they were towards women with mental illness or other disorders. Gatekeeping of these services is also a concern for those with FASD because they are unable to access certain services due to the complexity of the disorder. For example, many programs use IQ-based qualifications, where an IQ under 70 is needed for services (Rutman and Van Bibber 2010). This is an issue because IQ does not consider the unique challenges that individuals with FASD face with daily functioning, and often, those who are parents need much more support. Given the nature of FASD as a spectrum disorder, IQ is a poor predictor of how a given individual with FASD may express strengths or challenges (Hyland et al. 2023). Therefore, professionals in CIS must be educated and trained on the effects of FASD and develop strategies tailored to each individual they are working with.

6.2. Power Imbalances

The stigma of FASD has far-reaching effects, not only on the people with FASD but also on those working with them and among the broader public (Choate and Badry 2019). Stigma creates power imbalances for parents within the CIS by influencing perceptions of their capabilities as parents and affecting their legal rights and advocacy opportunities (Curran and Danbrook 2023). CIS workers hold a lot of power over individuals involved in child intervention and they have the power to decide whether a child needs protection and whether that need should supersede the rights of the parents (Saar-Heiman 2023). As was shown in the results of this research, parents with FASD are very likely to have their children removed from their care if their case comes before the courts, bearing in mind that FASD may be one but not the only factor considered by the courts. The cases reviewed suggested stigma related to the diagnosis along with evidence showing that these parents do not have the tools or support to properly care for their children. It makes one wonder if these parents, who are at the extreme end of the spectrum, could have kept their children if they had intervention and adequate support early on. Bearing in mind that courts and child intervention systems hold the balance of power, parents with FASD are likely to perceive themselves as powerless within the systems. Social workers also struggle with how to advocate for the needs of children and families with FASD (Curran and Danbrook 2023).

We do not have the information on how many parents consent to a guardianship order without going to court because this information is not publicly available; however, due to the nature of the disorder, individuals with FASD tend to be agreeable, easily manipulated and possibly do not understand what they are agreeing to (Hargrove et al. 2024; Brown et al. 2021). Some limited research tells us that parents with disabilities face barriers to being allowed to parent which can result in consenting to orders (Gould and Dodd 2014). Indeed, they may feel they have little choice but to consent (Libesman et al. 2023). Knowing this, we can speculate that perhaps the number of parents with FASD having their children removed from their care is much higher than what we have seen after reviewing the publicly available trial decisions.

Given that estimates in Canada suggest 3–11% of children have FASD and that it is an over-represented population in CIS, the fact that we can find very few reported cases suggests parents do not believe they have the probability of success keeping their children (Badry and Harding 2020). However, more work needs to be carried out trying to uncover the experience of parents whose cases do not go to trial. There is a paucity of data on parents consenting to the termination of their parental rights when involved with CIS. This needs to be explored and better understood.

There is also a significant lack of data regarding parents who may decide to forgo their right to counsel and represent themselves, which as one might assume, is unlikely to go well. Alarmingly, individuals with FASD will sometimes take the stand and are subjected to harsh cross-examination by the lawyer. Due to memory problems and cognitive delays, parents with FASD are at a significant disadvantage on the stand and are unlikely to be believed by judicial systems (Hargrove et al. 2024). Perhaps they believe that taking the stand could help their case, but often it has the opposite effect. How can an individual with FASD properly advocate for themselves if they do not fully understand their rights? How can a child intervention worker, lawyer, or judge properly support these individuals if they do not understand the nature of the disorder? Such is the dilemma, and such is the basis for the need for more expertise on FASD in the CIS. Malbin (2004) has pointed out these gaps, although they have not been well documented in child intervention although there is a more vibrant literature related to the criminal justice system (Pei et al. 2023).

6.3. Fear

Stigma and power both contribute to the fear that is present in many parents with FASD involved in the child intervention system. Because of the power that this system holds over parents, many individuals with FASD avoid being diagnosed or are hesitant to disclose their diagnosis for fear of having their children removed from their care. Individuals may also avoid pursuing a diagnosis because they fear discrimination and being labelled a bad parent, or incompetent. They may worry about facing unfair treatment or biased decisions from child intervention workers, lawyers, or judges. The stigma surrounding FASD may lead child intervention agencies to prioritize removal rather than providing appropriate support services, intensifying this fear (Badry et al. 2023).

In summary, the intersection of stigma, power, and fear presents challenges for parents with FASD navigating the child intervention system. The stigma surrounding FASD intensifies power imbalances, leading to discriminatory practices and perpetuating a cycle of fear among affected parents. Overcoming these obstacles requires concerted efforts to challenge stigma, promote inclusivity, and provide tailored support services that recognize and accommodate the unique needs of parents with FASD. By addressing these systemic issues, we can work towards a more equitable and compassionate child intervention system that upholds the rights and dignity of all individuals, regardless of disability. The next section will discuss our recommendations for working with parents with FASD, including ways to support and advocate for these unique individuals.

6.4. Pathways for Opportunity

The cases reviewed offered some insights into how opportunity may exist. For example, in KT, permanent guardianship was granted. The rationale was related to a lack of a support system, meaning that the parents, the father with FASD and the mother with low IQ, were seen as not capable. While the court did not state what might have been carried out had such a system been available, it invites this as a factor for consideration. The SH decision took the permanent removal pathway while also offering an ongoing connection between the mother and the children. This has the advantage of sustaining relationships while also ensuring protection. This was also carried out in ML, JB and CV. This creates pathways for biological parents living with FASD to sustain a relationship with their children while not holding primary responsibility. These cases invite consideration that, even if a parent is not deemed capable of acting in the primary role, there are opportunities for an ongoing relationship (Iles-Hernandez 2016).

7. Recommendations

Badry and Harding (2020) conservatively estimate there is likely something in the order of 6000 children with FASD in CIS care in Canada. Yet, we are only able to find 52 reported cases. While this research does not shed light on how, why and under what circumstances these care decisions are not being contested, it is probable that the factors of not being believed, stigma, and perceptions of incapacity will be important drivers. In order to shift this, practice needs to change.

Considering the barriers that people with FASD face in the court system and beyond, we compiled recommendations for different demographics to use as guidance (See Table 1). While these recommendations are specific to supporting those with FASD, they might also be applied to other disabilities. It is necessary for policymakers, funders, professionals, the public and the media to be educated and informed on how to assist and support someone with a disability. Considering the widespread impacts of stigma, we should all play our part to ensure that we are upholding the dignity and worth of all people.

Table 1. Recommendations for working with parents involved with child intervention having or suspected of having FASD.

Action.	Policymakers and Funders	Professionals	Public and the Media
Education	Create a policy for mandatory education and training for child intervention workers	Keep up with and continually educate yourself on FASD	Advocate for proper training, and education, and create prevention campaigns that reduce stigma
Research	Allocate funding for more research on FASD. Develop a comprehensive assessment that accounts for daily functioning rather than IQ	Keep up to date on the latest research and ensure interventions are research-based	Keep up to date on the latest research
Ongoing Support	Allocate funding to create more programs to support individuals with FASD and their families	Use clear, concrete language; offer reminders; set realistic goals; individualized and flexible approach. Support must be ongoing (years not months). Use a mix of formal and informal supports	See the person, not the diagnosis

Table 1. *Cont.*

Action.	Policymakers and Funders	Professionals	Public and the Media
Human Rights	Implement strict policies that ensure the rights of people with FASD are upheld	Honour dignity and worth and ensure rights are upheld	Advocate for the human rights of people with disabilities and focus on raising awareness of FASD rather than creating stigmatizing prevention campaigns
Strengths-based Approach	Reframe the narrative of FASD from a deficit view to a strengths view by allocating funding for research of success stories of people with FASD	Focus on the strengths, rather than the limitations, while also offering support in areas of need. Use non-judgmental, non-stigmatizing language, patience, and flexibility	Reframe the public perception by focusing on what a person can do rather than what they cannot
Legal System	Create judicial processes that recognize people with disabilities such as FASD so they can fully participate in judicial processes.	Ensure judicial education on the intersection of FASD with CIS and other judicial systems.	Allow stories of success showing parents living with raising or significantly involved with their children via enabling court orders.

8. Conclusions

This research is a follow-up to the work of Choate et al. (2020). The focus of this work was on parents with FASD involved in the child intervention system and whether there were any changes to how parents with FASD were treated within the CIS since the prior work. The results of this review found that there do not seem to be any significant changes in how FASD is seen in the court system. There is a lack of information on what happens in the lives of these parents before child intervention becomes involved. When child intervention does become involved, it is apparent that a parent with FASD has no chance to keep their child.

The intersection of parents with FASD and the child intervention system presents a complex scenario fraught with stigma, fear, and power imbalances. The publicly available cases represent the extreme end of the spectrum considering that many of these cases involve parents who have significant mental health and addiction concerns. This presents a narrative to the public that people with FASD are unable to parent, a narrative that further research could serve to disrupt. This also indicates a need for more targeted interventions and ongoing support for parents living with FASD who also have comorbid concerns. This is also an access to justice issue (Choate et al. 2024). Important considerations for both clinical and legal practice, as this research suggests, is that there is not a single approach to deciding whether a parent living with FASD should parent their child. Rather, a careful understanding of the unique expression of FASD that parents experience is crucial along with access to support systems including social determinants of health. Children deserve to be raised in a healthy environment but denying access to a biological parent is not necessarily the best solution if a parent living with FASD can offer a constructive presence. This is not universally true but is so often enough that it should be a case management consideration (Gerdts-Andresen et al. 2024; Ruiz-Romero et al. 2022).

9. Limitations and Directions for Future Research

It is important to highlight to the reader that our study is restricted to examples that are publicly available. Cases that are resolved by a parent consenting to losing guardianship of their children are not publicly reported. Thus, there is an unknown number of parents living with FASD who are not included in any data presently available, but this is an area that should be researched. While data are not publicly available, given the number of children in permanent care in Alberta (5582 children are in permanent care as of 31 December 2023 (Alberta 2024)), only a small fraction of those cases were resolved through trial.

Since this research was conducted by searching only publicly available cases, there is a need for further research in this area. We need to better understand cases that do not go to trial or are settled through consent agreements. Additionally, further research on success stories of parents living with FASD is imperative to disrupt the deficit narrative and reduce the stigma associated with FASD. A crucial question is in what way is a parent living with FASD fully aware of the implications of going to trial and/or consent to the permanent removal of their child from a relationship with them. There is simply no research currently available, to our knowledge, that helps to understand this. It is a significant gap that needs to be addressed.

There is a substantial gap in the experience of adults with FASD in their role as parents (Choate 2013). This affects data that can be presented to the courts. Research needs to catch up with the reality that children with FASD grow up and become parents. Accessing diagnosis in Canada remains challenging (Tortorelli et al. 2024).

A further caution is that no case is decided upon a single factor such as a FASD. Parenting and the care of a child are multifaceted with courts having to make decisions on the specific facts of a case and the relevant legislation and, at times, precedence. This and the prior work (Choate et al. 2020) help to place FASD within that analytical framework.

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