



# **Fetal Alcohol Spectrum Disorder and Child Welfare**

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#### **KEY MESSAGES**

Children, youth, and young adults with Fetal Alcohol Spectrum Disorder (FASD) are a key population in the child welfare system. Responding to FASD requires skills and knowledge in the many areas that intersect with FASD. Social workers and other professionals who work in the child welfare system require increased education, training, and support to address the needs of individuals with FASD and their families.

#### Issue:

In Canada, there are an estimated 47,885 children in foster care, 29,590 of which are under the age of 15 [1]. More recent estimates of the number of children in care in Canada also suggest that these numbers may be even higher, with an estimated 62,428 children in out of home care in Canada [2]. Children with Fetal Alcohol Spectrum Disorder (FASD) are known to be overrepresented in the child welfare system, both in Canada and internationally [3]. In Canada, researchers have conservatively estimated the prevalence of FASD among Canadian children in care to be *at least* 3-11% [4-6]. Most children with FASD in care are not formally diagnosed, particularly when they enter the child welfare system.

Children, youth, and young adults with FASD are a key population in the child welfare system. The goals of the public and private services that make up the child welfare system are to safeguard children from abuse and neglect and to promote the well-being of children, youth, and young adults by ensuring their safety and strengthening families [7]. However, youth with FASD represent a particularly vulnerable population within the child welfare system and often experience poor outcomes. Outcomes for children in care in general are often poor in comparison to the general population, and may include homelessness, drug and alcohol use, mental health issues, and lower educational attainment [8, 9]. Children and youth in care may also experience early life abuse and neglect, among other adverse childhood experiences.

Children with FASD are often placed in the care of child protection service agencies and frequently end up in permanent foster care waiting to be adopted [10]. Individuals with FASD and their families may also seek services from social workers and human service professionals across various settings, including health, corrections, disability, education, mental health, and

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social services [11]. Therefore, social workers and social service providers who encounter individuals with FASD must be knowledgeable about the disability [11], yet the limited research on social workers indicates that while they report feeling knowledgeable about the consequences of alcohol consumption during pregnancy, they are less familiar with the characteristics of FASD or existing diagnostic guidelines [12]. Given the significant proportion of children with FASD in care, as well as the complex nature of their needs, it is imperative to understand the best practices and key areas of challenge facing the child welfare system and to understand the relationship of this population to child welfare agencies.

The purpose of this issue paper is to provide a brief background on the state of FASD and child welfare in Canada.

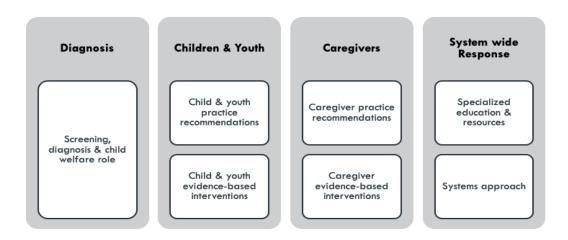
## **Background:**

In general, children with disabilities are at a greater risk of maltreatment and/or neglect than children without disabilities. Children with disabilities, including FASD, experience all forms of abuse and neglect more often than other children, and conversely are more vulnerable to the impacts of this adversity [13-16]. Researchers have suggested that individuals with behavioural disorders face the greatest risk, at seven times the rate of children without disabilities [17]. Children with disabilities are more likely to experience multiple incidents of abuse from multiple perpetrators over a longer period of time. Furthermore, children and youth with FASD have significantly poorer outcomes compared to those with other disabilities including educational challenges, involvement with the criminal justice system, comorbid mental health conditions, and alcohol and substance use [18-20].

A report called *Mandatory Reviews into Child Deaths* from April 1, 2018 – September 30, 2018 prepared by the Office of the Child and Youth Advocate in Alberta reported on the deaths of nine young people involved in Child Intervention Services in Alberta [21]. It is critical to note that at least four of these nine young people shared a common thread of prenatal exposure to alcohol, which formulated part of their history and was a clear factor in their involvement with the child welfare system.

As a child welfare issue, FASD is a serious concern for child protection authorities. Children and youth with FASD have distinct vulnerabilities that need to be well understood by all facets of child protection care so that outcomes may be improved. Yet, meeting the complex and variable needs of children with disabilities such as FASD creates significant challenges for child welfare agencies. The child welfare system is primarily responsible for many children with disabilities, including FASD, in care and in the community, but gaps in the system present challenges [22-26]. There is no national policy or framework to support children with disabilities as services are delivered on a provincial and territorial basis.

Based on the results of a recent scoping review, the following section summarizes the four core thematic areas pertinent to child welfare in Canada [27].



### 1. Diagnosis

Diagnosis addresses the importance of early screening and diagnosis, early intervention, communication of diagnosis, challenges to diagnosis, and implications for child welfare. Early FASD screening and diagnosis has been emphasized as a critical first step for supporting individuals and families [28-30], as well as an important component in the prevention of FASD via improved diagnostic capabilities [31]. To optimize this step, it has been emphasized that there is a need for individuals and families to have a better understanding of FASD prior to assessment [32] and that ongoing assessments should be implemented (beyond the initial diagnosis) to monitor developmental trajectories and evolving needs, especially among children with FASD who frequently have multiple placement changes [33].

Upon receiving a diagnosis, early support and planning for family stability is essential. In particular, a stable, nurturing home is a well-known protective factor among children and youth with FASD [34]. Children in foster care who are placed early into stable home environments, and those who are adopted at an earlier age, often experience fewer behavioural problems in later childhood [35] and may express fewer behavioural and cognitive challenges as a result of not experiencing a significant number of traumatic or adverse childhood experiences [36]. Early life stability appears to have an influence into adulthood and is a critical factor in promoting a more positive lifecourse trajectory.

Early diagnosis is key in arranging and maintaining successful appropriate placements, facilitating better preparation and improved parenting capabilities for foster and adoptive parents in meeting their child's needs, and increasing overall caregiver and caseworker understanding of the consequences of prenatal alcohol exposure and FASD [27]. Therefore, social workers and those working within child welfare systems should be aware that children receiving their services may be impacted by prenatal alcohol exposure. Child protection workers should have training that equips them to screen for FASD as part of case assessment, familiarity with the FASD diagnostic process, and knowledge of how to obtain a diagnosis for their clients.

#### 2. Intervention and Supports

The second key thematic area addresses child and youth specific practice- and intervention-

based recommendations, including strength-based and ecological approaches to mental health, education, transition planning, self-regulation and emotional control, social skills, and outreach. There are a number of child and youth-specific practice recommendations and interventions that emphasize the importance of child welfare workers and foster parents adopting a strengths-based approach when working with children [33, 37-40]. Interventions should be specifically tailored to meet the needs of each child and should take into account the environmental context [41]. For example, the recently released *Towards Healthy Outcomes* model for individuals with FASD supports interventions across the lifespan and is based on core beliefs that integrate research evidence with wisdom from communities and caregivers, as well as the lived experience of individuals with FASD [42]. This model is one example of a mapping tool that may help enact these principles in alignment with evidence-based research.

Although researchers have highlighted the significance of strength- and ecological-based approaches for children and youth with FASD, significantly less work has been done addressing the needs of youth and adolescents with FASD transitioning out of care or into emerging adulthood [43-45]. The transition to adulthood is a critical period of time that warrants particular attention, especially regarding life planning.

#### 3. Supporting Caregivers

The third key thematic area involves supporting a diverse range of caregivers of children with FASD in the child welfare system, including biological and kinship parents, foster and adoptive parents, and parents with FASD themselves [46], to support child placements and to facilitate caregiver adaptation. Research on parents and caregivers of children with FASD reveals that biological, foster, and adoptive parents have considerable worries for the future of their children [47-52]. Furthermore, risks to the family unit can vary depending on family structure, as biological, foster, kinship, and non-kinship adoptive families appear to respond differently to the care needs of a child with FASD. Although historically research on caregiving for children with disabilities has emphasized negative family outcomes, more recently the positive and strength-based outcomes have been described. Seeing positive developmental and behavioural changes in the child and wanting to make a difference in the child's life have been suggested as crucial motivators for fostering a child with FASD [38]. Social support, particularly parent peer support, was identified as the foremost factor in maintaining successful placements of children with FASD in foster care, and in facilitating successful family adaptation among a diverse population of caregivers [53, 54].

Children in care need to feel safe and secure in their home environment [55]. If families are not provided with effective support, including respite in caring for children with FASD, the risk exists for repeated placement breakdowns that can reinforce patterns of insecure attachment [56] and make it difficult for children to trust others [41]. For adoptive parents, the lack of information and access to post-adoption services has been suggested as a significant challenge for caregivers. Adoptive parents reported that social workers often did not provide them with sufficient information on FASD to make informed pre-adoption decisions [57], and caregivers expressed the need for post-adoption emotional and financial support. Therefore, those working in child welfare systems should be aware of, and respond to, the significant need for respite and related supports for caregivers of children with FASD to prevent burnout and

placement breakdown [37, 38, 58, 59]. It is critical to care for caregivers of children and youth with FASD.

#### 4. Engagement with Other Systems

Lastly, the fourth key thematic area addresses the specialized education and resources, as well as systems-level approaches [42], that are required to support individuals with FASD and their families in the child welfare system. Importantly, there is a clear need for improved and increased training of professionals who work in the health and social service fields who may come into contact with individuals with FASD and their families [60, 61]. Specific, specialized training in FASD supports for caseworkers, foster parents, and others is greatly needed [62]. When professionals are not adequately trained, it may lead to a lack of professional knowledge about FASD, the blaming of caregivers for "poor parenting" [54, 57], making caregivers feel as though they have nowhere to turn for help [57], and increased stigmatization and discrimination towards individuals with FASD and their families [63, 64].

## **Implications and Recommendations:**

The need to provide supports that focus on the lifecourse are a critical part of diagnosis, intervention, and support. Creating and maintaining stability across all systems is crucial for the well-being of the child and the family unit.

- Early screening, assessment, and diagnosis are required for individuals with prenatal alcohol exposure or those suspected of having FASD. Child protection workers need to have training and knowledge on screening and referral for FASD diagnosis.
- Increased specialized education and training is needed for caregivers (e.g., foster parents, adoptive parents, group homes, and other residential care providers) to help them to effectively support children and youth with FASD.
- Permanent, early, and long-term stable placements are necessary to protect against the adverse childhood experiences, and the vulnerability to these adverse experiences, often associated with FASD.
- Interdisciplinary, collaborative, systems-based, multi-level approaches are needed to support children and youth with FASD who often have many professionals involved in their lives. Case coordination and high-quality case management is essential from early childhood through emerging adulthood and into adulthood.
- A lifecourse approach is warranted to recognize the impact of various transitions and developmental pathways that may impact the life trajectories of children and youth with FASD, particularly the removal from parental care and placement in foster, adoptive, or residential care.
- There is a need for increased research and evidence informed policies for youth aging out of care and transitioning from the child welfare system. Supports well into adulthood are often required for youth with FASD who need increased support to successfully navigate the responsibilities of young adult life.
- Social work has a key role and responsibility in the field of child welfare and needs to take a strong leadership role in advocating for mandatory, FASD-informed education for students and practitioners.

## **Summary or Conclusion:**

FASD is one of the most critical issues in child welfare practice today given the high vulnerability of children and families where prenatal alcohol exposure is a concern. Responding to FASD requires skills and knowledge about FASD regarding ways to foster strengths, improve lifecourse outcomes, and address areas of concerns such as problematic alcohol and substance use, the developmental and behavioural challenges of living with FASD, and the often-complex psychosocial needs of families. Legacies of historical trauma are often present in families where FASD is present. Child welfare workers are more likely than any other human service professional to encounter FASD, yet much of the workforce has not received training on this topic. When FASD is not recognized, the child's needs are not effectively met, contributing to cumulative disadvantages that can impact lifecourse outcomes. Early recognition, diagnosis, and intervention offer the best chance for success for children with FASD. Social workers and allied health workers are key professionals in child welfare practice and are well positioned to provide FASD informed care with training and knowledge of the care needs of children and families. Each province and territory would benefit from the adoption of a national strategy on effective case management, consultation, and responses to FASD for children, youth, and families.

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