

AN INTERSECTIONALITY-BASED POLICY ANALYSIS OF CANADIAN CHILD ADVOCATE REVIEWS OF INFANTS, CHILDREN, AND YOUTH WITH FETAL ALCOHOL SPECTRUM DISORDER IN CHILD WELFARE CARE

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ABSTRACT

Background and Objective

Care providers in the child welfare system often support children with Fetal Alcohol Spectrum Disorder (FASD). Women who give birth to children with FASD face many multi-dimensional socio-structural challenges, including prenatal substance use, that lead to their children being placed in care. Alcohol use disorders have strong associations to trauma histories, psychiatric problems, adverse experiences in life, and other substance use. Children with FASD experience abuse and neglect along with other forms of adversities in childhood and adolescence at higher rates than other children, and are often kept in the care of the child welfare system. Risks of harm for children and youth with FASD exist due to distinct vulnerabilities associated with the disability. Even with child welfare intervention, adverse outcomes remain for children and youth with FASD. Our objective was to examine reports generated from Child Advocate offices in Canada on deaths and serious injuries where FASD was identified to gain a deeper understanding of the experiences of this population in the child welfare system.

Material and methods

We employed an intersectionality-based policy analysis (IBPA) framework to analyze child welfare reports from 1989 to 2019 available online publicly from Child Advocate (or equivalent jurisdiction) Offices across Canada. An underpinning theoretical framework in this research was life course theory, as it is critical to recognize the connection that exists between early decisions made for infants and children with FASD and later outcomes in life. Reports were included when there was evidence of FASD or prenatal substance exposure in the report. Sequential Excel spreadsheets were employed for data extraction, and individual word documents were generated for each report specific to the IBPA framework. Thematic analysis was employed to identify themes related to serious injuries or deaths in child and youth, report summaries, and recommendations.

Results

A total of 61 reports were reviewed, and deaths of 17 children or adolescents with FASD were reported. Four categories of reports existed, including investigative death reports, investigative serious injury

reports, special reports, and annual reports. Key themes from these reports for this population included: (1) challenges to stability and permanency, (2) challenges to FASD-informed service provision, (3) overrepresentation of Indigenous children and youth, and (4) presence of concurrent mental health challenges. Recommendations within reports addressed needs of individuals, families, care providers, systems, and policies. There were many consistencies across time and jurisdictions. One notable concern was that FASD, while possible, was often not diagnosed, and therefore supports and services specific to this disability were not provided. It is critical to note that these reports served to document both a child's history and make key policy and practice recommendations to inform a differential response in the child welfare system in the case of FASD.

Conclusion

This analysis illuminated the risks and vulnerabilities for this population in the child welfare system and has implications for assessment, diagnosis, and practice interventions in responding to the needs of this population. This analysis also identified that many opportunities exist to improve practice and service delivery for individuals with FASD and their families. It is critical to recognize that a connection exists between early decisions made for infants and children with FASD and later outcomes in life.

Keywords: fetal alcohol spectrum disorder; prenatal substance exposure; opioid; foster care; child welfare; child advocate

INTRODUCTION

Problematic substance use, including alcohol, prescription medication and illicit substances, during pregnancy remains a significant health and social concern in Canada and many other countries around the world.^{1,2} A systematic review conducted by Popova et al. (2017) found that about 10–15% of women in the general Canadian population consumed alcohol during pregnancy.³ Additionally, use of polysubstance is prevalent and increasing, with approximately 4–7.4% of women reporting illicit substance use during pregnancy.⁴ Prenatal substance exposure (PSE) can result in significant maternal, fetal, and neonatal morbidity, which is typically compounded by multiple determinants of health, including poverty, trauma and violence, and mental health challenges.^{5–8} One significant outcome of prenatal alcohol exposure is Fetal Alcohol Spectrum Disorder (FASD).

A critical awareness driving this research was our theory that unrecognized FASD poses specific risks for those in the child welfare system. Despite FASD being identified globally as a leading cause of

developmental disability,^{3,9} it is frequently framed as a hidden disability receiving less attention and resources than other mental health, behavioral, or relational issues.¹⁰ A key challenge in accepting FASD is awareness and professional development within child welfare services despite assertions that individuals with FASD are overrepresented in child welfare, disability, youth justice, and mental health areas of practice.^{11–13} This overrepresentation has contributed to the development of negative and misrepresentative public stereotypes and thus stigmatization of these children and youth, their mothers, and families.^{14,15}

Researchers have established that many individuals diagnosed with FASD experience trajectories of early and multiple adversities and were raised in family and community environments where substance use, mental health, violence, abuse, and trauma often emerged from complex intergenerational contexts.^{16–19} In 2013, more than 62,000 children were reported to be in foster care in Canada.²⁰ Children in care (including adoptees and foster children) have been identified as a “special subpopulation” in 36 of the 69 FASD prevalence studies.⁹

Although true prevalence is difficult to estimate due to underreporting and lack of access to assessment and diagnosis, approximately 16.9% of children in care in Canada are estimated to have a condition along the spectrum of FASD.²¹

The goal of this research was to identify the way in which children with either diagnosed or possible FASD involved with child welfare were represented in publicly available Child Advocate reports on child deaths and serious injuries across Canada. There are currently 12 independent statutory offices in Canada operating with the titles of Child and Youth Advocate (Alberta, Saskatchewan, Yukon, New Brunswick, Newfoundland, and Prince Edward Island), Advocate for Children and Youth (Manitoba), Representative for Children and Youth (British Columbia and Nunavut), Ombudsman (Ontario, Nova Scotia), and Youth Commission (Quebec). Presently, there is no role of Child Advocate in the Northwest Territories. For the purposes of reporting, we utilize the common term Child Advocates.

Child Advocates are responsible under what are broadly known as Child and Youth Advocate Acts to report on their activities directly to their legislative assemblies.^{22,23} Child Advocates in Canada work on behalf of children involved in the child welfare system. Child Advocates have published reports regarding their work for many years. However, these reports often remain an untapped source of data and information to broaden our understanding of adverse events such as serious injuries and deaths of infants, children, and youth in care. Child Advocates utilize their reports to make recommendations in relation to policy and practice of child serving organizations to promote changes to systems in order to support better outcomes for children and youth.²⁴ Although Child Advocates across Canada have legislative mandates to make recommendations for system and policy change, they may not always have the power to enact or enforce these changes.

Infants, children, and youth with FASD have specific health, socio-emotional, and cognitive requirements emerging along the life course and

also have requirements in relation to service delivery. The specific research questions generated for this analysis of reports of Child Advocates were as follows:

1. How are infants, children, and youth in foster care affected by PSE and FASD represented in Child Advocate reports?
2. What recommendations have been made specific to this population?
3. What patterns are observed in these recommendations related to this population across the life course and other intersecting social locations?
4. What socio-structural factors influenced if and how recommendations were implemented?

METHODS

We conducted a policy analysis employing the intersectionality-based policy analysis (IBPA) framework developed by Hankivsky.²⁵ This method was developed for “understanding the varied health equity-relevant implications of policy and for promoting equity-based improvements and social justice within an increasingly diverse and complex population base” (p. 33).²⁵ The IBPA framework is considered a form of critical, multi-dimensional analysis of policy discourse and differs from policy approaches that start with one identity (such as gender or race), to which others are added.²⁶ Additive approaches may not be analytically adequate for exploring layered interrelationships in social locations; thus, IBPA can potentially lead to a more sophisticated and complete analysis of systemic experiences of inequity and inequality across all stages of the policy process.²⁷ This framework has two core components—a set of guiding principles and a list of 12 overarching questions to guide the analysis.²⁸ Guiding principles were developed to ground the questions. Examples of guiding principles included equity, power, and intersecting categories. The questions were both descriptive and

transformative and aimed to strengthen critical policy analysis and assist with the identification of alternate policy responses. Following are the examples of questions: (1) How have representations of the “problem” come about? (2) What are the current policy responses to the “problem”? (3) What inequities actually exist in relation to the “problem”?²⁵ This framework has utility in exploring the complex intersections intertwined in the construct of FASD, including stigma related to addiction, culture, disability, and child welfare engagement.

THEORETICAL PERSPECTIVE

Elder’s (1998) life course theoretical perspective was also employed to inform data analysis.²⁹ A life course perspective when applied considers biological, psychological, and sociocultural factors that are independent, cumulative, and interactive, creating and contributing to complex and unique life journeys. It is critical to recognize strengths of individuals with FASD and how those unique qualities, characteristics, and capabilities can positively influence the trajectory of life.

This perspective incorporates the following four major themes: (1) human lives are intertwined with and defined by significant historical life events; (2) the timing of these events in people’s lives; (3) the interdependence of human relationships across the lifespan; and (4) human agency, or the way people make choices when encountering structural constraints.²⁹ Two additional life course themes—diversity in trajectories, and developmental risk and protection—were advanced by Shanahan (2000)³⁰ and offer an interdisciplinary perspective to the core constructs developed by Elder (1998).²⁹ Further, Hutchison identified that the life course perspective “looks at how biological, psychological, and socio-cultural factors act independently, cumulatively, and interactively to produce great diversity in journeys and shape people’s lives across family generations” (p. 351).³¹ The infants, children, and youth who are most likely to enter and stay in child welfare care are those who are the most vulnerable population

because of complex family backgrounds and social contexts, including belonging to marginalized or minority identity groups and having experiences of trauma and violence, addiction, abuse and neglect, and developmental and intellectual disability.^{13,32} The life course of children and youth with FASD is often inextricably linked to the child welfare system because of the social conditions that contribute to prenatal alcohol exposure and the ongoing risks associated with parental addictions.

INCLUSION CRITERIA

We searched for reports developed and published by the Child Advocates across Canada from 1989 to 2019. As noted earlier there are Child Advocates in one form or another across all provinces and territories in Canada with the exception of the Northwest Territories, although not all jurisdictions provide reports to the public on child deaths and serious injuries. The three criteria for inclusion of a report in this analysis were as follows: (1) the focus of the report was on individuals in child welfare care; (2) there was evidence of FASD or other PSE in the report; and (3) reports were publicly available on websites. Our search identified a total of 472 documents. The list of key terms included: prenatal substance exposure, fetal alcohol spectrum disorder, drug, opioid, opioid exposure, substance, foster care, caregiver, parent, child protection, neonatal opioid withdrawal syndrome, neonatal abstinence syndrome, and fetal alcohol syndrome. After screening titles, abstracts, and full text, a total of 61 relevant reports were included in this analysis. A list of all reports with full details is provided in the Supplementary File: “Included Sources of Child Advocate Reports across Canada.”

DATA TRACKING, EXTRACTION, AND ANALYSIS

A detailed stepwise process was followed in this analysis as described below. Sequential Excel spreadsheets were developed to ensure that

all reports were tracked during the screening and inclusion process and to organize data extraction. The initial spreadsheet tracked the name of the office, province or territory, background information about the office, and the total number of reports available online through their website, including annual reports, business plans, position statements, and investigation reports. A second spreadsheet tracked selected data from each included report, including name of the report, year, focus, summary comments, recommendations that were specific to FASD, and life course stage (e.g., infant, toddler, child, or youth).

Individual word documents were completed for each included report using the IBPA framework. A final spreadsheet summarized key data points within the IBPA framework, using data from individual report analysis. Using a deductive approach to thematic analysis,^{33,34} key themes were identified that related to the focus of the reports, specifically in relation to FASD and policy recommendations. A graduate student conducted data extraction and initial analysis in consultation with two lead researchers (Dorothy Badry and Lenora Marcellus). Key themes were developed by the graduate student and one researcher (Dorothy Badry) and confirmed by the second researcher (Lenora Marcellus). Revising and editing of the manuscript were completed by Peter Choate.

RESULTS

Description of sources

Table 1 displays the number of reports generated by each office and the number of documents included in this analysis. Although the first Child Advocate office in Canada was launched in 1989, the earliest report meeting inclusion criteria was published in 2009. Despite over 60% of the Canadian population living in Ontario and Quebec, the greatest proportion of publicly available Child Advocate reports was produced in British Columbia and Alberta, potentially reflecting provincial, territorial, and Child Advocate office differences in responding to child welfare issues in each jurisdiction.

Overall, this analysis included 16 investigative death reports, 4 investigative serious injury reports, 30 special reports, and 10 annual reports. Within these reports, 98 deaths and 227 serious injuries were reported, with 17 individuals described as being diagnosed with FASD and 7 were identified as possibly having FASD (Table 2).

Specific to children and youth with identified FASD, the reports indicated that four of the child deaths and one of the recorded injuries were for children aged less than 4 years. We observed that with this younger population, the terms of PSE, neonatal abstinence syndrome, and neonatal opioid exposure were more likely to be employed rather than FASD. This reflects the pattern of FASD not necessarily being identified in the early years. We have employed the term FASD throughout this article for clarity of terminology and to reflect this pattern. Two of the recorded deaths and none of the recorded injuries were for children aged between 5 and 13 years. Nine of the recorded deaths and six of the recorded injuries were for youth aged between 13 and 17 years. Two of the recorded deaths were for youth aged 18 years and older. The following themes were generated from the analysis of the Child Advocate reports, representing integration of child experiences and social intersections.

Themes in child and family experiences

Challenges to stability and permanency

Many children experienced some level of placement disruption during their stay in care. Multiple disruptions to primary attachment were frequently noted across reports of Child Advocates, including reciprocal moves between foster and birth/kin families, across foster homes, and between foster homes, residential treatment, and incarceration for youth. The average number of moves was eight, with some children and youth moving more than 30 times. Youth with complex behaviors and requirements were even more likely to experience placement breakdown, resulting in multiple placements, including hotels.

TABLE 1 Summary of Included Reports.

Province Year child advocate office opened	Total reports screened	Investigative: deaths reports	Investigative: serious injury reports	Special reports	Annual reports	Total number of reports
New Brunswick (2006)	31			3 R. 23, 37, 49		4
Ontario (2007-2019)	78	3 R. 26, 50, 53		2 R. 51, 52		4
Manitoba (1999)	65	2 R. 32, 33		8 R. 21, 22, 25, 27, 29, 31, 34, 35	1 R. 36	11
Saskatchewan (1999)	46	2 R. 58, 59		1 R. 61	4 R. 55, 56, 57, 60	7
British Columbia (2007)	211	5 R. 7, 8, 11, 16, 54	1 R. 12*	12 R. 3, 4, 5, 6, 9, 10, 12,* 13, 14, 18, 19, 20	2 R. 15, 17	19
Alberta (1989)	20	4 R. 2, 30, 45, 48	4 R. 40, 41, 44, 46,	5 R. 1, 24, 28, 39, 43	3 R. 38, 42, 47	16
Newfoundland and Labrador (2002)	0	–	–	–	–	0
Nunavut (2015)	9	–	–	–	–	0
Yukon (2010)	12	–	–	–	–	0
Total:	472	16	5	31	10	61

Note: No office in Nova Scotia. Ontario—under legislative changes, advocate position was eliminated, and investigative function transferred to the Ontario Ombudsman, through a child and youth unit. Quebec (1976)—not included as not translated. NWT does not have a child advocate.

R: refers to reports reviewed in Supplementary File of the 61 reports reviewed.

**Report 12 is not counted twice as the report of the serious injury to Peter is included in Special Report 12 given in the Supplementary File.*

An example of one such report reviewed in our research is “Into focus: Calling attention to youth opioid use in Alberta (2018),”²⁸ reporting on the deaths of 12 young people aged between 15 and 19 years involved with the child welfare system, all of whom died from an opioid overdose. One young man identified in this report was 19-year-old Bruce who was diagnosed with FASD at the age of 15 and was in care under a Permanent Guardianship Order. Bruce’s history indicated that he had moved 33 times during his time in care, and as a disabled adult

he qualified for the Assured Income for the Severely Handicapped (AISH). Bruce spent time in and out of corrections and went to a shelter after custodial release, only to die of a fentanyl overdose after 28 days of finishing of his child intervention status.

Bruce’s story reveals a profound lack of placement stability for an individual where this stability is considered a critical intervention for promoting optimal outcomes. Recommendations focused on advocating for placement stability included: enhancing the quality and availability of placements;

TABLE 2 Number of Deaths and Serious Injuries with Possible or Diagnosed FASD.

Province	Number of deaths	Number of serious injuries
Ontario	28 (3)	–
Manitoba	2 (2)	–
Saskatchewan	2 (1)	–
British Columbia	40 (2)	5 (1)
Alberta	26 (9)	3 (3)
Total	98 (17)*	8 (4)*

Note: Bracketed numbers refer to children who were either diagnosed with FASD or identified as possibly having FASD within the report. The role of the Child Advocate is to investigate the systemic issues related to serious injuries and deaths of children who are receiving services in the child welfare system. Serious injuries are generally considered to be life-threatening.

**Diagnosed or possible FASD (Reports on Dillon, Lee, and Tony).*

developing innovative models of care; ensuring plans of care are being developed and followed; focusing on permanency planning; monitoring the number of placement moves; taking additional care when disrupted attachment has been noted; placing individuals with supported family members when possible; developing hotel reduction strategies; providing intensive sustained support plans for families when their children are returned; and developing consistent guidelines and policies for youth transitioning out of care. In addition to placement instability, the quality of placements at times was negatively influenced by overcrowding, which often resulted in reduction or elimination of therapeutic benefits. For example, consistent attachment and attentive caregiving, noted as critical for mental and developmental well-being, are interrupted by these challenging placement situations.³⁵

Challenges to FASD-informed service provision

Fetal alcohol spectrum disorder-informed approaches are based on the understanding that FASD is a brain-based permanent disability that affects multiple facets of life and health, is often associated with adversities such as violence, trauma,

and victimization, and likely to be linked to many gaps in determinants of health.^{5–7} Rutman (2016) has noted that programs where there is a higher likelihood of serving clients with FASD, such as child welfare and justice, have been designed in a manner that often presents barriers to success.³⁶ Across the reports of Child Advocates, lack of awareness and knowledge gaps of FASD were observed at the levels of individual foster care providers, health and social care professionals, and within policies. An overall lack of recognition of FASD contributed to limitations in communication and information sharing at multiple levels, and a lack of knowledge on how to support children with FASD was evident as were gaps in supervision, follow-up, and integrated case planning processes. Recommendations were made that included professional development and mandatory training; partnering with FASD organizations to provide learning opportunities; developing parenting resources; and integrating information about FASD into early childhood, education, and justice system strategic policy plans.

Many children and youth placed in care have unrecognized FASD and are misdiagnosed with cognitive challenges or developmental delays, with no formal assessment for FASD ever taking place. In this analysis, there were 17 children that were diagnosed with or who possibly had FASD. Of these 17 children and youth, five had a formal FASD diagnosis. Of those 12 who were noted as possibly having FASD, there was important documentation in the reports to support this finding. It is important to pay attention to the possible cases of FASD that were identified in reports of deaths of children and youth, as screening for FASD is critical for delivery of optimal child welfare services.

For example, in the 2018 report of the expert panel on the deaths of children and youth in residential placements from the Office of the Chief Coroner in Ontario, two cases were clearly identified as possible FASD (Supplementary Files; report 53). Anaya committed suicide at the age of 11 in a residential treatment program for youth with cognitive disabilities. Although she was never diagnosed of having

FASD, it was indicated as a possibility by health professionals but no investigation was conducted. Anaya was reported to be a victim of sexual abuse, started using substances at the age of 8, engaged in self-harming behavior, and had suicidal thoughts. She was reported to have an “executive function disability” (Supplementary File; report 53, p. 20) and was identified with significant cognitive delays. Parental substance use, mental health concerns, and domestic violence were noted as contributing factors to her involvement with the child welfare system at the age of 10. Anaya committed suicide after 10 weeks in a residential treatment care program.

Anaya’s story illuminates the context that problematic substance use in families is observed as a reason for children coming into care, and her family history provides clues to the potential for FASD. Other challenges observed included gaps in referral processes and a lack of access to diagnostic services. Yet for many children and youth, the linkage is never made that a child may have FASD, which can result in the care necessities of a child with a disability being chronically unmet. Underdiagnosis appears to contribute to the risk of early death for this population.

The transition from youth in care to adult services, or “aging out” of care, for individuals with limitations in adaptive functions was also noted to be a significant vulnerability, as expectations of independent living and employment were raised. It is also noted that the 15–24-year-old age group was at the highest risk for harm from substance use, thus compounding the impact of FASD. Recommendations were made throughout the reports to expand eligibility and increase funding for life skills training, personalized support initiatives, and extended transition programs.

Finally, the FASD-related neurobehavioral impairments that contributed to poor functional and adaptive outcomes were also likely to reduce abilities in dealing with legal problems.³⁷ Youth with FASD are estimated to be 19 times more likely to be incarcerated than youth without FASD.³⁸ This rate may be even higher due to underdiagnosis of FASD.

Gretton and Clift, cited by the Manitoba Advocate for Children and Youth (2012), noted that females had consistently higher proportion than males in relation to mental health problems overall, including substance use, conduct disorders, ADHD, depression, childhood abuse (both physical and sexual), and suicide ideation.³⁹ Recommendations identified in the reports of Child Advocates related to the justice system included developing diversion strategies; increasing funding; providing community mentoring; ensuring measured responses for early and first offenders; providing community-based wrap-around programs; and developing FASD-informed justice processes.

Overrepresentation of Indigenous children and youth in care

In included reports, 67 of the 98 children, or almost 64% of children, were Indigenous. In Canada, the impact of colonialism, assimilation efforts, and institutional racism continues to be reflected in the disproportionate number of Indigenous infants, children, and youth who are in foster care.⁴⁰ While 7% of children in Canada are Indigenous, they account for 52.2% of children in foster care.⁴⁰ It was observed in Manitoba that 90% of children in care in the child welfare system were Indigenous, representing the highest percentage of Indigenous children in care across Canadian provinces and territories.^{39,41} This research also emphasized that alcohol use in these populations needs to be understood within the socio-historical context of colonization, residential schools, and economic and social marginalization. In one report from the Northwest Territories, it was observed that Indigenous children represented 95% of children in care, with issues such as poverty contributing to cumulative disadvantages and leading to overrepresentation of Indigenous children in the child welfare system.⁴²

The Truth and Reconciliation Commission (TRC) of Canada: Calls to Action⁴³ and the United Nations Declaration of the Rights of Indigenous People (UNDRIP)⁴⁴ are compensates and principle-based frameworks for addressing the impact of

colonialism, and are the key documents highlighting the rights of Indigenous people in Canada and globally. The Calls to Action report (2015, p. 1 and 4) specifically addresses the issues of overrepresentation of Indigenous children in care (#1–5),⁴³ Indigenous individuals with FASD in the justice system (#34), and development of culturally appropriate FASD prevention programs (#33).⁴³

Children and youth placed in care were observed to be inconsistently connected to culturally based care practices. For example, a British Columbia file audit published in 2013 reported that culturally based care plans were mostly absent.⁴⁵ Recommendations from reports of Child Advocates applying to Indigenous children in care included ensuring that Indigenous parenting norms are incorporated into parenting capacity assessments; placing Indigenous children in Indigenous family foster care settings when possible; recognizing poverty and access to resources as system challenges rather than individual risks requiring removal of children; ensuring that child welfare services are culturally safe and trauma-informed; removing constraints, empowering and funding Indigenous and reserve-based child well-being organizations; developing clear legislative frameworks and accountability structures across provinces, territories, and the federal government; and providing opportunities for including Indigenous youth in decision-making processes.

Presence of concurrent mental health challenges

Infants, children, and youth in foster care experience multiple risk factors impacting their mental health, including separation from their family, violence and abuse, neglect, and cultural disconnection. The British Columbia Representative for Children and Youth indicated that almost 50% of case files mentioned children that had a mental health or special need diagnosis and were receiving some form of treatment or therapeutic support.⁴⁵ However, 40% of these children did not have a child and youth mental health worker and over half of the children and their families were not supported by a special

need or FASD key worker. Across reports, providers indicated that it was increasingly challenging to deal with the impact of mental health challenges and other compounding difficulties, including substance use, trauma, family, and sexualized violence, within the context of poverty.

Mental health issues were highlighted for youth and Indigenous youth. A report of British Columbia Representative for Children and Youth (2012) found that more Indigenous females than males committed suicide, but more non-Indigenous males than non-Indigenous females committed suicide.⁴⁶ For self-harm behaviors, females overwhelmingly were represented in the statistics; however, Indigenous females were shown to engage in self-harm behaviors more than their non-Indigenous female peers.

A key recommendation across the Child Advocate reports was to provide mental health services from a life course perspective, for example, promoting attachment in infants and developing systems of social support for youth aging out of the child welfare system. Recommendations included were as follows: implementing system-wide trauma- and violence-informed approaches; ensuring ongoing assessment and early detection of suicide risk; increasing access to confidential psychological counseling; developing strategies related to promoting mental health and reducing substance use; increasing clarity, transparency, and information-sharing across services related to the mandate for and provision of mental health services; strengthening prenatal support related to mental health and substance use; and developing practice standards for caring for children or youth who are assaulted sexually.

Clusters of recommendations identified across reports

We identified 12 clusters of frequently identified recommendations provided throughout the reports (Table 3). The need exists to provide theoretically grounded care in practice for infants, children, and youth with FASD. It is well established that children, youth, adolescents, and young adults

TABLE 3 Key Clusters in Recommendations in Death, Serious Injury, and Special and Annual Child and Youth Advocate Reports (1989–2019).

Cluster	Specific recommendations
Support families as a whole Stay connected to family	<ul style="list-style-type: none"> Engage the whole family in interventions and recognize the impact that alcohol and drug addiction has on families, including multiple generations.
Address multiple moves and placements in care	<ul style="list-style-type: none"> Recognize the impact of multiple placements on children and youth.
Use a disability-informed lens in case reviews	<ul style="list-style-type: none"> Recognize FASD as a disability and track and record in Child Advocate reviews and investigations.
Address issues around FASD diagnosis	<ul style="list-style-type: none"> The need exists for screening and referrals for assessment and diagnosis. FASD training is critical for children serving professionals to develop meaningful interventions and case plans. If FASD is possible, refer for assessment.
Create environments that support collaboration between agencies and families	<ul style="list-style-type: none"> Include children and their families in discussions around how policy could change as well as implementation of supports to meet their needs. Work collaboratively with communities and work toward reforming the criminal justice system. Promote better communication between child welfare, support workers, service providers, and families.
Build and create supportive relationships	<ul style="list-style-type: none"> Build relationships that can be sustained over time and across sectors. Work on developing a sense of trust as this will support early identification and intervention.
Tailor case planning to specific individual needs	<ul style="list-style-type: none"> Ensure that we are not taking a one-size fits all approach when creating policy and procedure. Case planning must include a continuum of residential services for children and youth whose needs cannot be met in a traditional foster home or group home setting.
Provide ongoing supports that benefit children with FASD and their families	<ul style="list-style-type: none"> Supports need to be sustained and tailored to the developmental and lifecourse perspective of the child and family.
Plan proactively to provide the family with support prior to birth in cases of prenatal substance exposure	<ul style="list-style-type: none"> It is critical to implement supports early and provide supportive interventions and early interventions. Recognize challenges for Indigenous families in accessing disability supports. Use Jordan’s Principle for services and support.
Address the gap between child welfare system and Indigenous communities	<ul style="list-style-type: none"> Provide culturally appropriate supports. Address barriers, including housing, finances, historical relationship, and jurisdictional issues. Honor the rights of Indigenous children and youth. Confront institutionalized mechanisms that work against meeting the needs of Indigenous children.
Provide public education and awareness of FASD and how to support expectant mothers as well as persons with FASD.	<ul style="list-style-type: none"> Creation of a tangible framework for increasing awareness and education around FASD. Address problems regarding the ability to receive prenatal supports in smaller communities. Increase awareness of FASD and the supports offered throughout the provinces and territories.

(continues)

TABLE 3 Continued.

Cluster	Specific recommendations
Training on FASD for all child serving professionals in child welfare	<ul style="list-style-type: none"> • Provide training on FASD and disability and promote FASD-informed practice and care. • Standardize continuing education programs that are cross-sectoral whenever possible.

FASD: Fetal Alcohol Spectrum Disorder.

with FASD experience difficulties in daily living because of neurodevelopmental disability as well as varying experiences of trauma.⁴⁷ A major challenge in the child welfare system is whether FASD is recognized or unrecognized, and the impact it has on practice interventions with a child or youth.

Based on the recommendations identified in the reports, in case FASD is recognized, the following should become standard practices: FASD is routinely screened for in child protection with appropriate referrals for assessment and diagnosis being made; FASD diagnosis is the gold standard measure for appropriate intervention; FASD-informed care underpins sound practice and routine; structure and stability become requirements for quality care across all environments; FASD is treated as a disability with appropriate supports and interventions provided; and children/youth and their families are more effectively supported.

Alternatively, in case FASD is unrecognized, the following concerns are evident: there are no referrals for assessment and diagnosis and children/youth live an unsupported life where systems repeatedly fail to offer effective interventions; children/youth are not able to meet expectations across care and educational environments which increase frustration and a sense of failure; behavioral concerns escalate, which increase risk and vulnerability; the risk of involvement with child protection and the justice system increases; families experience stress and burnout; and children and youth are lost in systems.

DISCUSSION

Our review and analysis of reports of Child Advocates provided a framework to critically

evaluate the status of children with FASD in the foster care system in Canada. An outcome of this analysis was the construction of a portrait of children and youth with diagnosed or possible FASD in the child welfare system and recognition of their complex requirements. System response to children with FASD requires being more proactive in providing FASD-informed disability supports that recognize the challenging mental health problems experienced by young people, particularly adolescents. The 17 children and youth we have reported on did not receive the required support and services and had less than optimal outcomes. The value of applying an IBPA framework was to highlight the interrelatedness of multiple intersections in children’s lives that influenced the ways in which they were cared for in the child welfare system. While many children are effectively supported, it is critical to recognize that children and youth with FASD have exceptional requirements that often are not addressed. Their care requirements are distinct often because of the social roots from which the disability of FASD emerges. These children and youth faced many challenges in their families where substance misuse contributed to the overall portrait of risk in their lives. In fact, these early adverse childhood experiences predispose these youth to greater risk in adolescence.

Overall, it is critical to observe that in these reports, FASD was diagnosed or mentioned as a possible reason in 17 of the 98 deaths, which clearly contributed to the continued level or risk of injuries and deaths reported for infants, children, and youth. Children and youth were injured or died in multiple ways either through sudden unexplained infant death, child abuse and neglect, suicide, or

through behaviors that put their lives at risk, particularly including high-risk drug use in adolescence. The safety and well-being of children with FASD in care requires further exploration to understand contributing factors and enhanced requirements more fully for integrated and focused case planning, service delivery, and monitoring. Well-educated and supported health and social system workforces and caregiving networks, along with enhanced policy in relation to the specific care requirements of children and youth with FASD, are required to promote safer quality care that optimizes the future child development, and thus potential. This requirement is demonstrated in Helton et al. (2019), who explain that in the United States almost half of the child welfare cases referred for child abuse and neglect investigation involve children with disabilities, including significant intellectual disability and severe emotional or behavioral problems and impairments.⁴⁸

Policy inertia or failure is common in large systems.^{49,50} Moran (2001, p. 210) defines persistent policy failure as “the same type of policy failure repeated across time periods, policy sectors, and countries, despite the availability of many opportunities for policy learning and the detrimental consequences of such failures to government.”⁵¹ Even though health and child welfare services are increasingly considered to be complex systems, policy implementation is still often seen as top-down, reductionist, technical, and linear, with lack of exploration of deeper intersecting organizational, sociopolitical, and economic dynamics.⁵² In particular, when policies require a long-term vision and plan, successful implementation is challenging.

Ilott et al. (2016) described three-phases of long-term policy-making, including: (1) a period of rising salience (significance); (2) a building blocks phase; and (3) embedding, with less political interest yet continued importance of delivering positive outcomes.⁵³ Continued generation of reports from Child Advocates highlight the salience and urgency of these issues. However, with varied implementation powers across jurisdictions, it is challenging to gain and sustain the attention and commitment of

provincial, territorial, and federal decision makers to “convert political will into action” (p. 7).⁵³ In fact, there may be a risk of diminishing political interest or avoidance in the face of a high number of reports that identify continued deficits or challenges when reporting on child deaths and serious injuries. For example, in British Columbia, the production of multiple reports criticizing the child welfare system was framed at one point in the media as “an utterly broken relationship between the province’s child advocate and the government she serves”.⁵⁴ When action was reported to move forward, it was often dependent on regional politics and resources that appeared project-oriented and reactive versus proactive, and often was not sustained or expanded.

Both policy-making and implementation are intersectional. Intersectionality-based analysis provides the opportunity to better understand how certain persons or populations get labeled as “different, troubled and in some instances, marginalized” within public policy, thus influencing policy intent and direction (p. 101).⁵⁵ Individuals with FASD have been constructed as both victims and dangerous, and their parents, particularly mothers, as neglectful and immoral.^{55,56} Individuals have been observed to shift from being seen as victims as younger children to being perceived as dangerous as they approach adulthood. For example, adolescents and young adults can be increasingly criminalized, and if pregnant and using alcohol during pregnancy, the risk increases for perpetuating the intergenerational cycle of FASD. Possibilities for options and outcomes thus risk being framed from within this increasingly narrow and negative labeling or stigmatization.¹⁰ Hence, IBPA offers an analytic framework to examine the problems within systems that contribute to the problem. In this research, unrecognized FASD posed a substantial risk to children in care. Finally, although we set out to examine the impact of FASD for children in care, a simultaneous yet unsurprising finding was the overrepresentation of Indigenous infants, children, and youth in the reports of Child Advocates.

TABLE 4 Reports on Child Deaths with Possible or Diagnosed FASD.

Report title and province	Child name	Age	FASD diagnosed (D) or possible (P)	Report synthesis and cause of death
A Critical Time: A Special Report on Emerging Adults Leaving Children's Services Care, 2019, Alberta	Joel	19	D	Joel, 19 years old, PGO since age 2, had FASD diagnosis (ARND) and qualified for Supports and Finance Assistance Agreement as a young adult. Placement with children's services ended and Joel incarcerated at age 18, actively using substances and became a father. At age 19, Joel was hospitalized for a suicide attempt and died at age 20. Experienced suicidal thoughts and behaviors. Cause of death: not identified. Unknown whether death was intentional or accidental.
A Place Where it Feels Like Home: Tina Fontaine, 2019, Manitoba	Tina	15	P	Indication of psychological assessment completed stating that she had ADHD and FASD, but no formal assessment attached to her file. In 2005, FASD was suspected by grandma, who requested that youth be assessed but no assessment documented (p. 22). Cause of Death: homicide.
In Need of Protection: Angel's Story, 2018, Manitoba	Angel	17	P	Psychological assessment completed, determined she had ADHD and FASD, but no formal assessment on file. History marked by trauma, sexual assault, suicide attempts, sexual exploitation, and drug and alcohol use. Frequently missing person. Cause of Death: accidental overdose.
Into Focus, 2018, Alberta	Bruce	19	D	Moved to Alberta at the age of 13. Diagnosed with FASD at 15. Severe substance use recorded—alcohol and marijuana. Incarcerated at 17 and 18. Lived in a shelter at 18. Cause of death: ethanol and acetyl fentanyl poisoning.
17-Year-Old Susan, 2018, Alberta	Susan	17	P	Possible FASD indicated by foster parent, teachers raised concerns of academic delay. Had two older brothers in care. Stepmother died by suicide. Susan displayed self-harm behaviors, was intoxicated outside in the cold and cutting at 13. Teen years marked by alcohol use, thefts. Cousin died by suicide when she was 16. Boyfriend died in a car accident. Heard voices telling her to kill herself. Cause of death: suicide.
Three Young Children, 2017 Alberta	Mikwan	1	P	Youngest of 7 children. Mother tested positive for illegal drugs during a prenatal check-up (lived outside of Alberta at this time). Mikwan tested positive for benzodiazepines and opiates at birth, induced after a car accident (parents were intoxicated). Mother charged with his death a year later, determined suspicious. Cause of Death: acute blunt head trauma.

(continues)

TABLE 4 Continued.

Report title and province	Child name	Age	FASD diagnosed (D) or possible (P)	Report synthesis and cause of death
Mandatory Reviews into Child Deaths, April–Sept 2018, Alberta	Jaxon	17	P	Possible FASD and ADHD. Reports of parental substance use and violence at the age of 19 months. Had three siblings, mother died when he was 11, not much contact with father. Displayed suicidal thoughts and behaviors prior to his death. Cause of death: suicide.
Mandatory Reviews into Child Deaths, April–Sept 2018, Alberta	Darian	16	D	FASD confirmed at the age of 12. Possible ADHD. Had six siblings also in care from parent DV and substance use. Mother used drugs and alcohol throughout pregnancy. Six incarcerations, said he could not see his life free from addictions, gangs, and criminal activity. Cause of death: car accident (in stolen car).
Mandatory Reviews into Child Deaths, April–September 2018, Alberta	Andy	15	P	Worked with FASD workers and other case workers. Diagnosed with Neurobehavioral Disorder Unknown Exposure to Alcohol. Foster parent was emotionally abusive, restricted food and hygiene. Attended residential addictions treatment at the age of 15 . Cause of death: fentanyl overdose.
Safe with Intervention, 2018, Ontario	Brooklyn	16	D	Five siblings. Diagnosed with FASD, a mild developmental disability, reactive attachment disorder, learning disabilities, developmental trauma disorder. Left her group home without permission on several occasions to be involved in illegal activities. Pushed her mattress against her bedroom door and set fire to it, blocking her safe exit and staff from being able to reach her. Cause of death: smoke inhalation.
Safe with Intervention, 2018, Ontario	Anaya	11	P	Youngest of four daughters. Two sisters died by suicide before Anaya’s death. Physical abuse noted, but not verified. Assessed having an executive function disability and significant cognitive delays. Not formally diagnosed with FASD but noted as possible by health professionals. Experienced at least two incidents of sexual abuse. Suicide attempt history. Cause of death: suicide (hanging).
Safe with Intervention, 2018, Ontario	Amy	13	P	Parental substance use, DV. History of cutting, solvent and alcohol use, suicide attempts, sexual abuse, sexual assault, and suicidal thoughts and behaviors. Had siblings, including one with a suicide pact with Amy. Possible FASD identified, but no investigation completed. Diagnosed with adjustment disorder and depression. Cause of death: suicide (hanging).

(continues)

TABLE 4 Continued.

Report title and province	Child name	Age	FASD diagnosed (D) or possible (P)	Report synthesis and cause of death
Broken Promises, British Columbia	Alex	18	P	Neurodevelopmental disorder diagnosis, did not meet FASD diagnostic criteria. Cause of death: suicide.
15-Year-Old Tony, 2014, Alberta	Tony	15	D	Parents—DV and alcohol/drug abuse reports. Teenage sister died by suicide when he was 3 years old. Expressed suicidal thoughts and behaviors. Diagnosed with alcohol-related neurodevelopmental disorder (report says also known as FASD). Displayed aggression and violence in his kinship homes. Attempted suicide at 14. Cause of death: suicide (hanging).
Lost in the System, 2014, Saskatchewan	Jake	1	P	History of DV between mother and father. Jake had an older brother, and both were taken into care when Jake was 5 months. Mother misused alcohol. Jake had a fractured femur 2 months prior to death that was healing properly. Was unable to talk and had suspected delays in other areas. Possible FASD noted from public health nurse, but no assessment/plan made. Cause of death: At 1 year and 11 months Jake was found unresponsive face down in bed—cause: undetermined - no evidence of foul play.
Investigative Review: Baby Annie, 2014, Alberta	Annie	2 weeks	Prenatal substance exposure confirmed	Annie died at 2 weeks of age. Mother used large amounts of prescription drugs for anxiety, sleep problems, and pain. Both parents have a history of alcohol and drug use, and family violence was a concern. Cause of death: undetermined.
Fragile Lives, Fragmented Systems, 2011, British Columbia	No name recorded	3 months	P	Parents had a lack of access to resources to learn about caring for infants and caring for infants with high medical needs, parents did not have a crib for the infant, prenatal substance use while pregnant was documented in report. Cause of death: Untreated kidney infection, viral infection, and aspiration pneumonia.

FASD: Fetal alcohol spectrum disorder; ADHD: Attention deficit hyperactivity disorder; ARND: Alcohol-related neurodevelopmental disorder; PGO: ponto-geniculo-occipital.

Table 4 provides details, including the recorded name (or pseudonym) of the child or youth, the title of the report, age at the time of death, and a brief synopsis of each report. We included this information to draw attention to the deep human toll experienced by children, youth, and their families, underscoring the critical requirement for referrals

for assessment and diagnosis where FASD is possible. FASD is a critically influencing condition relevant to the work of Child Advocates across Canada. Their important work has illuminated the tragic circumstances that relate to the serious injury or early death of an infant, child, or young person that warrants public attention. This information is critical in

bringing about change in policy, practice, and intervention with children and families and is crucial in a deeper understanding of the child welfare necessities of this population.

The opportunity to effectively intervene with children and youth with FASD in the child welfare system hinges on the ability of child welfare workers to recognize and respond to FASD and its many complexities within families. Owing to the substantial number of children with FASD in care, we suggest that an FASD-informed approach to practice is essential and fundamental to child welfare practice. It is observed in our analysis that 17 of the 98 or 16% of the reported deaths of infants, children, and youth connected to the child welfare system have either diagnosed or possible FASD. Moreover, it is critical to note upon further analysis of the reports of Child Advocates that 67 of the 98 or 64% of the reported deaths involved Indigenous children.

For Indigenous people in Canada and other countries, the long history of colonization has negatively influenced child welfare involvement because of the creation of enduring structural disparities contributing to overrepresentation in child welfare. As most child death reports in this analysis involved Indigenous infants, children, and youth, it is critical that adequate and culturally sensitive training and knowledge about FASD-informed care is provided not only to those who deliver frontline care and services to Indigenous children and youth but also to those having the responsibility for policy and program development and implementation.

LIMITATIONS

While this research was limited to publicly available Child Advocate reports, it is recognized that there are many other cases that could potentially be applicable to this analysis, such as reports from Coroner's offices or other health organizations, that were not within the scope of this research. Further, there is no requirement in Canada that this information be made public. We included reports where

it was indicated in the record that children or youth possibly had FASD. In cases where FASD was possible, it was not known whether follow up for assessment was completed. We highlighted the fact that FASD was mentioned in the report of a child or youth's death or serious injury, as it was potentially a contributing factor based on our knowledge of the risks and vulnerabilities associated with this disability. Finally, no reports were included from two provinces—Quebec, as translation was required from French, and Nova Scotia.

CONCLUSION

Utilizing and IBPA framework, a life course perspective and an FASD lens to analyze child deaths as reported by Child Advocates in Canada offers new insights into risks and opportunities for children involved in the child welfare system. Analysis of individuals or regional critical incidents is often conducted in isolation, resulting in solutions and actions that are not shared more widely and thus have limited influence on broader system structures and policies.⁵⁷ This analysis highlights the concern that FASD, while possible, is often not diagnosed, suggesting that greater awareness of the requirements of this vulnerable population of children and youth involved with child protection is essential. For those who have FASD, a diagnosis can be life-changing as it contributes to charting a course that recognizes the child or youth has a disability and distinct care requirements. Children and youth with FASD require extensive care and support because of the risks and vulnerabilities associated with the disability, including mental health support, and critical periods of risk for death and injuries were identified in the early years, in adolescence, and in the transition to adulthood.

Our review of three decades of reports from Canadian Child Advocates highlights the concern that infants, children, and youth with FASD are represented in both death and serious injury reports. An intersectional perspective can guide further focus on this population through integration of

disability-informed, gender-specific, and culturally informed approaches. Infants, children, and youth with FASD remain at significant risk in the child welfare system, suggesting the need to review policy and practice for this population from a disability lens.

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DECLARATION OF INTEREST STATEMENT

No potential conflict of interest was reported by the authors.

DATA AVAILABILITY STATEMENT

All data used were from public reports.

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SUPPLEMENTARY FILE

Sources of Child Advocate Reports across Canada

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