

**RESEARCH ARTICLE**

WILEY

Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database

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Funding information

Canada FASD Research Network; Public Health Agency of Canada; Kids Brain Health Network

Abstract

Aims: The current study aimed to explore differences in adverse outcomes between youth and adolescents with fetal alcohol spectrum disorder (FASD) living in child welfare care (i.e., foster care or group home) with those living with their biological parent(s) or with adoptive or other family member(s) in Canada.

Methods: Data gathered from the Canadian National FASD Database were used for analysis. A total of 665 youth and adolescents with a clinical diagnosis of FASD under the age of 18 living in child welfare care, with biological, adoptive or other family members, were included in the sample. Key areas examined included living situation, legal problems, experience of sexual or physical abuse, mental health (anxiety, conduct disorder, mood disorder and post-traumatic stress disorder) and suicidal ideation. Descriptive statistics and chi-square comparisons were utilized to explore these differences.

Results: Results revealed a significantly higher rate of reported sexual and physical abuse among individuals in child welfare care compared with those living with biological parents or with adoptive or other family member(s). Rates of difficulty with the law were also higher among those in child welfare care compared with adoptive/other family members. Conversely, the rate of mood disorders was significantly higher among those living with adoptive/other family members compared with child welfare care. Results highlight similar rates of reported suicidal ideation/attempts across all living situations, as well as mental health concerns.

Conclusions: Results offer rare insight into the lives of youth and adolescents under age 18 with diagnosed FASD who reside in child welfare care in contrast to those living with biological parent(s) or with adoptive or other family members. These findings increase our awareness of the complexity of mental health concerns and suicide risk across all living environments. Results have further implications for policy, practice and clinical intervention.

KEYWORDS

Canada, child welfare, fetal alcohol spectrum disorder, living environments, national database, prenatal alcohol exposure

1 | INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe the lifelong impacts on the brain and body of individuals prenatally exposed to alcohol (Harding, Flannigan, & McFarlane, 2019). To reach their full potential, individuals with FASD require ongoing support in the areas of physical health, daily living skills, motor skills, learning, memory, attention, communication, emotional regulation and social skills (Cook et al., 2016). Approximately 4% of individuals in Canada are estimated to have FASD (Flannigan, Unsworth, & Harding, 2018), with a noted elevation in special populations, including the child welfare system (Fuchs, Burnside, Marchenski, & Mudry, 2010; Popova, Lange, Burd, & Rehm, 2014). This overrepresentation in the child welfare system aligns with research indicating that children and youth with disabilities, including those with FASD, are at an increased risk for experiencing adversities such as abuse, neglect and exposure to substance use (Badry, 2009; Fagerlund, Autti-Ramo, Hoyme, Mattson, & Korkman, 2011; Kambeitz, Klug, Greenmyer, Popova, & Burd, 2019). The degree and severity of difficulties associated with FASD have been reported to be significant predictors of apprehension from biological homes and connection to child welfare (Popova et al., 2014). Compared with typically developing children and those with other disabilities, children with FASD come into the child welfare system at an earlier age, become permanent wards more quickly and remain involved in child welfare for a longer period of time (Fuchs et al., 2010). The earlier children with FASD come into care, the greater the likelihood of adverse childhood experiences and the higher the impact on adult health outcomes (Felitti et al., 1998; Pearce, Murray, & Larkin, 2019).

Researchers have suggested that individuals with FASD function more adaptively and experience fewer adverse life outcomes when their living environments are stable, provide structure, are free from violence and when their basic needs are met (Badry, 2009; Petrenko, Alto, Hart, Freeze, & Cole, 2019). It is clearly documented that contact with the child welfare system is associated with poor outcomes among the general population, including poor educational attainment, mental health concerns and legal issues (Fuchs, Burnside, Marchenski, & Mudry, 2009; Rangmar,

Key messages

- The living arrangements of youth and adolescents with clinically diagnosed FASD in Canada vary, highlighting the need for targeted and accessible supports.
- The rate of reported sexual and physical abuse was significantly higher among youth and adolescents with FASD living in child welfare care compared with other living arrangements, suggesting a need for further research in this area.
- Over 30% of youth and adolescents in our sample had reported suicidal ideation or a past suicide attempt, supporting the elevated risk that exists among individuals with FASD and the importance of targeted intervention and support.
- Further research is needed to identify potential protective factors specific to different rearing environments to inform policy and practice.

Sandberg, Aronson, & Fahlke, 2016; Ringel et al., 2018), and that these risks are inflated for individuals with FASD as a result of pre-existing vulnerabilities (e.g., cognitive and behavioural impairments; Fuchs et al., 2010).

Other problems among the FASD population include difficulties in the educational system, mental health concerns, suicidal thoughts and behaviour, substance use issues, legal system, unemployment and homelessness (Badry, Walsh, Bell, & Ramage, 2018; McLachlan, Flannigan, Temple, Unsworth, & Cook, 2020; Wyper & Pei, 2016). Poorer outcomes are directly correlated with adverse environmental factors including frequent changes in living situation as well as exposure to violence and abuse (Peled et al., 2014). Children and youth with FASD have complex and variable needs and are vulnerable to becoming involved in the child welfare system, highlighting the focus of our research in delineating the experiences of children and youth with FASD through our national database.

1.1 | National FASD Database

In an effort to explore the population characteristics and needs of individuals assessed for FASD in Canada, the National FASD Database project was established, which collects assessment and diagnostic information across FASD clinics in Canada. Currently, 26 clinics in Canada across seven provinces and territories are participating in the database project, representing a pan-Canadian perspective of FASD assessment and diagnosis. The database captures a host of information pertaining to demographics, family history, prenatal exposures, mental health concerns, presenting concerns and adverse outcomes being experienced by individuals presenting for assessment. Participating clinics enter records into an online questionnaire through the secure website, REDCap (Harris et al., 2009), hosted at the University of Alberta. A detailed description of the National FASD Database project, variables included and the data collection procedures have also been described elsewhere (see Clarren et al., 2015, and more recently, Temple, Cook, Unsworth, Rajani, & Mela, 2019).

1.2 | Purpose

The current study aimed to compare outcomes of Canadian children and youth with a clinical diagnosis of FASD living in child welfare care (i.e., foster care and group home) with those living in other settings, including with biological families (mother or father), adoptive parent(s) or other family member(s). This study further explored whether the outcomes among living situations differed according to the age of individuals (<12 [youth] and 12–17 [adolescents]). In relation to age, we examined the data for youth <12 and ages 12–17, anticipating that many were living in out of home care. The purpose of this research was to highlight the experiences of children and youth with FASD in varied living situations. It is our hope that gaining a better understanding of the intersection of FASD, child welfare and the living situation can offer meaningful information to inform the child welfare sector about the needs of this population. A key policy and practice consideration emerging from this research relates to keeping individuals with FASD with *extended* families or in other supportive child-rearing environments and limiting involvement in the child welfare system, where possible.

2 | METHODS

Specific variables included in the National FASD Database were chosen as outcome measures in the current study. Using a subset of available records from the larger database, a secondary data analysis was employed, which compared the experiences of children and youth with FASD living in different settings (i.e., child welfare, biological parents and adoptive/other family members). Specific outcomes measured in the current study included legal problems (offender, victim or general difficulties), sexual or physical abuse and various mental health or other diagnoses (anxiety disorder, mood disorder,

autism spectrum disorder [ASD], conduct disorder, post-traumatic stress disorder [PTSD], substance use disorder and suicide attempt(s)/ideation).

Ethical approval for the National FASD Database was obtained by the principal investigators through the Ottawa Health Science Network Research Ethics Board (REB#20160423-01H). Ethical approval for the secondary data analysis conducted in this study was obtained from the Laurentian University Research Ethics Board (REB#6020681).

2.1 | Participants

A total of 665 children and youth under the age of 18 with clinically diagnosed FASD in Canada were included in this study. Individuals were, on average, 10.6 years old. The sample consisted of a greater number of males (60.5%) compared with females (29.6%). Children and youth in this sample were most commonly living in foster care (27.7%), with other family members (22.7%), in adoptive care (20.5%), with their biological mother (15.9%) or biological father (8.1%) or in a group home (5.1%). Additional sample demographic characteristics are outlined in Table 1.

2.2 | Data analysis

Data were analysed using SAS 9.4. Descriptive analyses were determined for the overall sample characteristics, and chi-square comparisons were performed to determine statistical significance (set at $p \leq 0.05$) to explore the differences between children in child welfare (i.e., foster care and group home; $n = 218$) compared with children living with their biological mother or father ($n = 160$), as well as those living with adoptive caregivers or other family members ($n = 287$). The overall sample was subsequently grouped according to age (<12 and 12–17), and the same analyses were run to examine whether the experiences across living situations differed with age. The results presented here reflect a subset of available records in the National FASD Database. Therefore, results should be interpreted with caution, as it is possible that the sample included here may be experiencing increased rates of adverse outcomes compared with the overall population of the database or among individuals with FASD in general.

3 | RESULTS

3.1 | Child welfare care in comparison with biological parent care

We examined the experiences between children and youth with FASD in child welfare care compared with those living with their biological mothers or fathers (p 's > 0.05). Children and youth with FASD living in child welfare care did not differ from those living with a biological parent regarding legal problems as an offender or victim, general

TABLE 1 Overall sample characteristics

Demographic characteristics	
Gender, n (%)	
Male	399 (60.5)
Female	261 (29.6)
Average age (SD)	10.6 (3.9)
Age variability, n (%)	
<12	395 (59.4)
12–17	270 (40.6)
Living situation, n (%)	
Biological mother	106 (15.9)
Biological father	54 (8.1)
Other family member	151 (22.7)
Foster care	184 (27.7)
Adoptive care	136 (20.5)
Group home	34 (5.1)
Province/territory, n (%)	
Alberta	201 (30.3)
British Columbia	3 (0.5)
Manitoba	162 (24.4)
New Brunswick	99 (14.9)
Northwest Territories	6 (0.9)
Ontario	192 (28.9)
Yukon	1 (0.2)
Source of referral, n (%)	
Social services agency	264 (40.1)
Medical referral	136 (20.6)
Education system	48 (7.3)
Legal system	17 (2.6)
Self-referral	8 (1.2)
Family referral	175 (26.6)
Other	11 (1.7)

difficulties with the law, all mental health and other diagnoses, as well as reported suicide attempt(s)/ideation (all p 's > 0.05). Though not statistically significant, it is notable that the rates of children who were assessed and diagnosed with a suicide attempt and/or ideation were higher among children living with a biological parent (27.3%) compared with those living in the system (21.7%).

However, there was a statistically significant difference between children and youth with FASD living in the system and those living with a biological parent for experiencing sexual or physical abuse, with those in child welfare (30.7%) having a higher rate of reported abuse compared with those living with a biological parent (5%), $\chi^2(1, n = 378) = 12.4974, p = 0.0004$. For more information, see Table 2.

3.2 | Child welfare care in comparison with adoptive/other family members

Children and youth with FASD living in child welfare did not significantly differ from those living in adoptive care or with other family members regarding legal problems as a victim, having a diagnosis of anxiety disorder, ASD, conduct disorder, PTSD and substance use disorder, as well as reported suicide attempt(s)/ideation (all p 's > 0.05). There was a statistically significant difference between children and youth with FASD in child welfare and those living with other/adoptive family member(s) regarding legal problems as an offender. Those in child welfare had a higher rate of legal problems (13.3%) compared with those living with other/adoptive family members (5.7%), $\chi^2(1, n = 490) = 8.52, p = 0.0035$.

The rate of general difficulties with the law was higher among children and youth in child welfare (11.0%) compared with those living with other/adoptive family members (4.9%), $\chi^2(1, n = 505) = 6.6928, p = 0.0097$. Sexual or physical abuse was also significantly higher among those in child welfare (30.7%) compared with those living with adoptive/other family members (14.3%), $\chi^2(1, n = 505) = 19.9367, p < 0.0001$. There was also a statistically significant difference

Outcome	Child welfare	Biological parent	p value
Legal problems (offender)	28 (13.3)	20 (12.7)	0.8490
Legal problems (victim)	9 (4.5)	4 (2.6)	0.3789
General difficulties with the law	24 (11)	15 (9.4)	0.6058
Sexual or physical abuse	67 (30.7)	24 (15)	*0.0004
Anxiety disorder	30 (30)	21 (29.2)	0.9060
Mood disorder	18 (22.5)	15 (27.8)	0.4867
ASD	7 (8.4)	5 (8.1)	0.9364
Conduct disorder	17 (19.8)	9 (17.3)	0.7203
PTSD	13 (18.1)	3 (8.6)	0.1968
Substance use disorder	8 (9.9)	5 (10.9)	1.0000
Suicide attempt(s)/ideation	21 (21.7)	15 (27.3)	0.4333

TABLE 2 Summary of outcomes for children and youth with fetal alcohol spectrum disorder in child welfare and those living with a biological parent

Abbreviations: ASD, autism spectrum disorder; PTSD, post-traumatic stress disorder.

*Denotes a statistically significant difference between groups ($p < 0.05$).

TABLE 3 Summary of outcomes for children and youth with fetal alcohol spectrum disorder in child welfare care and those living with adoptive care/other family members

Outcome	Child welfare	Adoptive/other family members	p value
Legal problems (offender)	28 (13.3)	16 (5.7)	*0.0035
Legal problems (victim)	9 (4.3)	4 (1.4)	0.0523
General difficulties with the law	24 (11.0)	14 (4.9)	0.0097
Sexual or physical abuse	67 (30.7)	41 (14.3)	*<0.0001
Anxiety disorder	30 (30.0)	36 (22.4)	0.1674
Mood disorder	18 (22.5)	53 (37.9)	*0.0191
ASD	7 (8.4)	15 (14.0)	0.2327
Conduct disorder	17 (19.8)	27 (20.9)	0.8360
PTSD	13 (18.1)	9 (14.5)	0.5813
Substance use disorder	8 (9.9)	8 (7.8)	0.6286
Suicide attempt(s)/ideation	21 (21.7)	24 (17.8)	0.4619

Abbreviations: ASD, autism spectrum disorder; PTSD, post-traumatic stress disorder.

*Denotes a statistically significant difference between groups ($p < 0.05$).

between groups regarding a reported mood disorder. In this case, children and youth in child welfare (22.5%) had a lower rate of mood disorders compared with those living with other/adoptive family members (37.9%), $\chi^2(1, n = 220) = 5.4931, p = 0.0191$. For more information, see Table 3.

3.3 | Age differences

When comparing the experiences of children and youth with FASD living in child welfare with those in other settings while considering age, statistically significant differences were found. Youth with FASD <12 in child welfare (23.3%) had a significantly higher rate of reported sexual or physical abuse compared with those living with a biological parent (12.8%), $\chi^2(1, n = 227) = 3.9865, p = 0.0459$. Conversely, children and youth with FASD <12 in child welfare (10.3%) had a statistically significantly lower rate of reported mood disorders compared with children and youth with FASD <12 living with adoptive/other family members (24.7%), $\chi^2(1, n = 122) = 4.0037, p = 0.0454$.

Adolescents with FASD between the ages of 12–17 in child welfare (42.4%) had a significantly higher rate of reported sexual or physical abuse compared with those living with a biological parent (18.2%), $\chi^2(1, n = 151) = 10.0105, p = 0.0016$. Sexual or physical abuse was also significantly higher among adolescent youth 12–17 years old in child welfare (42.4%) compared with those living with adoptive/other family members (11.8%), $\chi^2(1, n = 204) = 25.0735, p \leq 0.0001$.

A statistically significant difference between adolescent youth aged 12–17 with FASD in child welfare (32.0%) and those living in the care of adoptive/other family members (12.1%) was found regarding legal problems as an offender, $\chi^2(1, n = 194) = 11.5944, p = 0.0007$. Similarly, the 12–17 age cohort living in child welfare (11.5%) also had a significantly higher rate of legal problems as a victim compared with those living with adoptive/other family members (2.6%), $\chi^2(1, n = 193) = 0.0114, p = 0.0153$. Rates of general difficulties with the law were higher among these groups (child welfare:

25.9%, adoptive/other family members: 10.1%), $\chi^2(1, n = 204) = 8.9103, p = 0.0028$.

4 | DISCUSSION

In this Canadian sample of individuals with FASD, 32.8% were living in child welfare care at the time of FASD assessment, whereas the remaining 67.2% were living with biological parent(s), adoptive families or extended family members. Overall, our results revealed significant differences between children living with their biological family in comparison with those living in care, whereas more significant differences were noted between children in child welfare care compared with those living with adoptive/other family members. For other examined outcomes, children living in child welfare did not differ from those living with biological families or with adoptive or other family members, suggesting some similar experiences between groups. Although results were presented for each analysis performed, the main study findings are discussed here.

4.1 | Sexual and physical abuse

The results revealed a major difference between individuals with FASD living in child welfare care and those living with a biological parent, and those living in adoptive care or with other family members, with respect to reported sexual and physical abuse. This finding also remained significant when groups were examined by age. The finding that abuse was higher among individuals in care may be explained by abuse being a common reason for involvement with the child welfare system (Badry, 2009; Kambeitz et al., 2019). A concerning finding was that when considering *all* living situations of individuals in our sample, over 30% experienced abuse. Previous researchers have suggested that children with FASD are vulnerable to abuse across various living situations (Fagerlund et al., 2011), including

among child welfare (Mukherjee, Cook, Norgate, & Price, 2019). The results of this study support previous research that speaks to the high rate of abuse experienced by children and youth within the child welfare system (Mukherjee et al., 2019) and points to the need for further research that explores the protective factors for children with FASD in care who may have a history of abuse. Although this finding is of concern, we are unable to speak to further details about the type of abuse, when it was experienced and how it came to be reported for individuals in our sample. This limitation highlights the need for more descriptive and detailed data to be gathered in these categories to gain a comprehensive understanding of the experiences of physical and sexual abuse in this population. However, this study is the first interrogation of the National FASD Database specifically in relation to child welfare issues, and we recognize both the strengths and limitations of the data collected.

4.2 | Mental health

Those in the child welfare system had a much lower rate of mood disorders than those living with other family or adoptive family members. Individuals in care who are already predisposed to mental health concerns are generally considered higher users of mental health services, based on their histories of trauma, which precipitate their involvement with child welfare (Larsen, Baste, Bjørknes, Myrvold, & Lehmann, 2018). Researchers have previously suggested that child welfare acts as a 'gateway' to mental health services for children, even when the need for service is controlled for. Therefore, it is possible that the mental health concerns and needs of individuals in the child welfare system are more closely monitored and subsequently identified, which may contribute to lower rates of mood disorders (Leslie et al., 2005).

4.3 | Suicide risk

Finally, the risk of suicidal ideation, suicide attempts and completions for children and youth with FASD has emerged as an area of concern. Suicide is a leading cause of premature death specifically among individuals with FASD (Thanh & Jonsson, 2016), with high estimations of suicidal ideation and attempts across studies (O'Connor, Portnoff, Lebsack-Coleman, & Dipple, 2019; Streissguth, Barr, Kogan, & Bookstein, 1996). Approximately 13%–26% of individuals with FASD have reported a history of suicide attempts (Dirks et al., 2019; Streissguth et al., 1996), with adolescents with FASD being 5.5 times more likely to make a serious attempt compared with their age-matched peers (O'Connor et al., 2019).

Specifically, we discovered that 39% of individuals in this sample experienced suicidal attempts/ideation. Though not statistically significant, our results indicated that the rate of suicide was higher among children and youth with FASD living with a biological family member (27.3%) compared with those in child welfare care (21.7%). Additionally, a comparison of youth in care with those living with

adoptive families (17.8%) also indicated that the risk of suicide may be highest among those in care. Although behaviour and psychiatric concerns are often present among individuals in care (Fagerlund et al., 2011), it is important to note that although the rate may be higher for those in child welfare care, the rate was not significantly different among either group. This finding may speak to the increased risk of suicidal ideation and suicide attempts among individuals with FASD in general, identifying an important area for targeted intervention and support.

4.4 | Limitations and considerations

The use of the National FASD Database for this study on individuals involved with the child welfare system and living with biological or adoptive families offers new insights into their experiences. A major limitation of this study relates to the variable of abuse, which is defined on the questionnaire as a singular variable. It would be important in future studies to be able to distinguish between physical and sexual abuse as distinct categories and to consider broader aspects of child protection including neglect and emotional abuse. The database also relies on diagnostic and assessment data that are entered by participating clinics across Canada. For the purposes of this study, we were able to examine the data for children aged <12 and youth 12–17 from Alberta, Ontario, Manitoba and New Brunswick (98.5%). Only 1.5% of the data came from British Columbia, the Northwest Territories and the Yukon. It is anticipated that more provinces and territories will contribute to database and increased records will support further analyses.

5 | CONCLUSION

Our examination of the National FASD Database in relation to 665 children and youth under the age of 18 with clinically diagnosed FASD in Canada has provided the opportunity to gain insight into the mental health challenges, including mood disorders and suicidal ideation, involvement with the law and experiences based on their current living situation. Our research reveals some positive findings about aspects of life within various living situations and recognizes the notion that, with support, families of children with FASD can have some measure of success. However, our findings reveal areas of critical concern, including the increased risk of suicidal ideation and attempts among individuals with FASD, which have important clinical implications for practice among those working in child protection and also those supporting caregivers of individuals with FASD. It was noted that mental health concerns, including anxiety, mood and conduct disorders, are more pronounced for individuals in adoptive families versus biological families. Children in child welfare care may represent a challenging population in relation to clinical intervention and support. Further research is required to explore the experiences of individuals with FASD who remain in family care and the potential protective factors associated with these relationships. The

information gathered through the National FASD Database offers critical insights into the lives of children, youth and families with confirmed FASD diagnoses and provides a reliable clinical platform for identifying areas of meaningful intervention into child welfare placements and community-based populations.

ACKNOWLEDGEMENTS

The National FASD Database was supported by grants from the Kids Brain Health Network, a contribution agreement from the Public Health Agency of Canada, and the Canada FASD Research Network. The authors would like to thank all of the participating diagnostic clinics contributing to the National FASD Database.

AUTHOR CONTRIBUTIONS

This paper has six contributing authors. D.B., K.H. and K.U. originally conceptualized the paper and the intended focus on child welfare. J.B., D.B., K.H. and K.U. collaboratively cowrote and edited the manuscript. As the statistician and analyst consultant for the larger National FASD Database project, N.R. ran the initial data analysis for this paper and contributed to the ongoing data analysis and drafting of Section 3. K.U. and J.C. are the Managing Director and Principal Investigator, respectively, for the larger National FASD Database project. Both K.U. and J.C. were responsible for the conception and design of the overall database. All authors contributed to the analysis and interpretation presented in this paper. In line with the ICMJE authorship criteria, all authors have reviewed and approved the final version of the manuscript for submission.

CONFLICT OF INTERESTS

None.

DATA AVAILABILITY STATEMENT

The data presented in this study are not publicly available due to privacy or ethical restrictions. The data that support the findings of this study are available on request from the corresponding author or by contacting the Principal Investigator and Managing Director of the National FASD Database. For more information, please visit <https://canfasd.ca/topics/diagnosis/#nationaldatabase>.

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How to cite this article: Burns J, Badry DE, Harding KD, Roberts N, Unsworth K, Cook JL. Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database. *Child Care Health Dev.* 2021;47:77–84. <https://doi.org/10.1111/cch.12817>