



FASD Prevalence in Special Populations

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Issue:

Based on the most current research, the estimated prevalence of Fetal Alcohol Spectrum Disorder (FASD) in the general Canadian population is 4%. However, rates of FASD are believed to be much higher in certain groups. The goal of this issue paper is to take a closer look at the research on special populations that may be at greater risk for FASD, including children in care, individuals involved in the justice system, and Indigenous communities. This examination is critical to understanding the demographic, social, geographical, and cultural factors that underlie drinking during pregnancy, and which groups may warrant additional support to ensure healthy outcomes.

Background:

Numerous social factors are known to influence the overall health of Canadians, including income/socioeconomic status (SES), social support, education, employment, social and physical environments, personal health practices/coping skills, child development, gender, and culture. Many of these social determinants of health (SDH) overlap with the environmental risk factors for alcohol use during pregnancy. For instance, a woman's nutrition, SES, depression, other substance use, and social connections are all related to the risk of her having a child with FASD. These factors suggest that communities and populations with compromised SDH may show disproportionately higher rates of FASD. Although few studies have been conducted to specifically explore the relationship between SDH and FASD prevalence, researchers have examined different risk factors and suggested that FASD may be more common in low-income and low-SES populations compared to the general population. 3,4

Many of the social determinants of health are known to influence a woman's likelihood of consuming alcohol during pregnancy, and overlap with the risk factors for FASD.

Children in care. Children in the welfare system, foster care, and orphanages around the world have been the focus of much of the FASD prevalence research to date. Because many children who are removed from their biological homes experience parental substance use,⁵ it is believed that they are at a higher risk for prenatal alcohol exposure (PAE) and FASD.⁶ Researchers have previously shown that the majority of children assessed for FASD do not live with their biological parents.⁷

In a 2013 meta-analysis, Canadian researchers⁸ reviewed published studies on FASD prevalence in child care settings around the world. Studies were identified from Brazil, Canada, Chile, Eastern Europe, Israel, Russia, Spain, Sweden, and the USA, and a pooled FASD prevalence of 18% among children in care was estimated. The highest rates were found in Sweden (52% among adoptees from Eastern Europe) and Russia (40% in orphanages for children with special needs), and the lowest rates were found in Israel (among foster and preadoption children) and the USA (among adoptees from Eastern Europe) – both 4%.

In Canada specifically, a number of studies have been conducted with children in care, and rates of FASD have been reported at 3% in Ontario, 4% in Alberta, 7% in Quebec (adoptees from Europe), 10 and 6% and 11% in Manitoba. Notably, these numbers are thought to be an underestimate, and the percentage of children in care with *suspected* FASD is significantly higher. 6

Researchers estimate the prevalence of FASD among Canadian children in care to be at least 3-11%.

Justice populations. Legal issues are a commonly experienced adverse life outcome for people with FASD, as victims, witnesses, and offenders. Researchers have noted that 60% of adolescents and adults with FASD reported contact with the justice system and 35% reported incarceration for a crime at some point during their lives.¹¹

Most FASD prevalence research in justice contexts has been conducted in Canada and the USA, though studies are emerging in other countries, such as Australia, Brazil, and Sweden. Among young offenders, Canadian researchers have estimated that youth with FASD are 19 times more likely to be incarcerated than youth without. ¹² In British Columbia (BC), rates of FASD have been reported between 11%-23% in forensic settings. ¹³⁻¹⁵ Australian researchers have estimated the rate of FASD among detained youth to be as high as 36%. ¹⁶ In the adult offender population, Burd and colleagues surveyed directors of correctional facilities in Canada¹⁷ and the USA¹⁸ in the early 2000s and found that only 0.9% of offenders in Canada, and 1 in over 3 million in the USA, were reported to have a diagnosis on the spectrum. More recently, Canadian researchers noted that 10% of adult inmates in Manitoba¹⁹ and 18% in the Yukon²⁰ meet the criteria for FASD. The contrast between these results may be due to study methodology, as questionnaires yield low numbers whereas higher rates are derived from active case ascertainment (ACA). This research indicates that FASD is a significant concern in justice settings, warranting practice and policy consideration to address the vulnerability of this group who may experience increased susceptibility to justice involvement and victimization.

The estimated prevalence of FASD in Canadian offenders is 11-23% for youth and 10-18% for adults.

Indigenous communities. One of the common myths about FASD is that it is an "Aboriginal issue." In fact, there is little high-quality evidence to support this claim, but because of mixed research findings, ²¹ it is difficult to derive clear conclusions.

In a recently conducted meta-analysis of FASD prevalence studies in Canada and the USA, researchers revealed that only three studies exist in Canada, which are outdated and have numerous acknowledged methodological limitations. Based on these studies, a pooled FASD prevalence was estimated to be higher in Canadian Indigenous compared to non-Indigenous populations, but the authors noted that existing data are not applicable for decision-making purposes, and rigorous ACA studies are urgently needed.²² Another review was conducted in 2013, and researchers reported that there is high variability among studies, and rates of FASD *are not* substantially different between Indigenous and non-Indigenous populations in Canada, USA, or Australia.²¹ There is limited Canadian evidence on the rates of FASD in Indigenous groups, and results range widely and depend on the population: 0.7% of young children living off-reserve in Western provinces,²³ 3.3% of children in the Yukon and northwestern BC,²⁴ 5-10% of children from a Manitoba First Nations community,²⁵ 19% of children from an isolated BC First Nations community,²⁶ and 27% of young offenders in a BC.¹³

Importantly, the continued surveillance, stigmatization, and stereotyping of Indigenous populations may contribute to the misbelief that FASD is over-represented in these communities, ²⁷ and pursuing this dialogue without sound research evidence could further perpetuate the marginalization experienced by Indigenous children, women, families, and communities.

Due to limited and mixed research findings, there is not enough evidence to conclusively say that FASD is over-represented in Indigenous populations.

New Canadians. With almost a quarter (22%) of the Canadian population comprising landed immigrants or permanent residents, ²⁸ it is important to consider the attitudes, beliefs, and behaviours related to PAE and FASD among this unique group. Although very little research exists on FASD prevalence among new Canadians specifically, some work has been done to explore drinking patterns among immigrant women. In one of the few Canadian studies, women who immigrated were less likely than native-born women to consume alcohol prenatally; however, 6% of immigrant women still reported drinking during pregnancy. ²⁹ Contrarily, some researchers in the USA have reported that foreign-born women were at a similar risk of consuming alcohol during pregnancy compared to native-born women. ³⁰ Researchers have also reported that immigrant women tend to adopt poorer health habits, including increased drinking during pregnancy, after moving to their new country. ³¹

Because the literature in this area is scarce, researchers conducting future FASD prevalence studies should consider the question of new Canadians to ensure that this significant portion of the population is best understood and supported. Additional research is also needed to understand whether or how SDH and FASD risk factors experienced in this group may differ from native-born Canadian women and may change with the process of acculturation.

Recommendations:

- 1. Routine screening protocols should be designed for use in child welfare and justice settings in order to quickly identify individuals in need of assessment and FASD-informed support.
- 2. Comprehensive training on FASD awareness, recognition, and intervention, including strengths-based approaches should be provided for service providers who work with individuals known to be at a heightened risk for FASD in order to foster the best possible outcomes.
- 3. Continued research that is culturally sensitive as well as gender- and trauma-informed is needed to better understand the risk factors for PAE and FASD among people of various backgrounds.
- 4. Although we know that FASD prevention is important for all women of childbearing age, special attention should be paid to ensuring that higher risk and marginalized populations are well-supported to have healthy pregnancies. As well, interventions should strive to improve SDH and risk factors underlying prenatal alcohol consumption for all women.

Conclusions:

The sole cause of FASD is alcohol exposure during pregnancy, thus FASD can affect individuals of all ages, genders, and cultural and socioeconomic backgrounds. However, because of a complex combination of personal and environmental factors, some populations may be at a higher risk for FASD. There is sufficient evidence to conclude that individuals in the child welfare and correctional systems experience disproportionately high rates of FASD. Although accurate prevalence rates in these groups have yet to be determined, researchers estimate ranges of 3-11% among Canadian children in care, and 10-23% among Canadian offenders. It is commonly believed that Indigenous communities also experience higher rates of FASD, but because the evidence in this area is conflicted, it is not possible to support this claim. The literature on FASD prevalence is relatively young, and researchers face methodological challenges and varied results. Therefore, rigorous studies are needed to better understand who is at risk for FASD and where specialized resources should be targeted.

References:

- I. Public Health Agency of Canada. (2018). Social determinants of health and health inequities. Retrieved from https://www.canada.ca/en/publice health/services/healthe promotion/populatione health/whate determinese health.html
- 2. May, P. A., & Gossage, J. P. (2011). Maternal Risk Factors for Fetal Alcohol Spectrum Disorders: Not As Simple As It Might Seem. *Alcohol Research & Health*, 34(1), 15e 26.
- 3. Bell CC, Chimata R. Prevalence of neurodevelopmental disorders among lowe income African Americans at a clinic on Chicago's South Side. *Psychiatr Serv.* 2015;66(5):539e 542.
- de Vries MM, Marais AS, Buckley D. Epidemiology of fetal alcohol spectrum disorders in rural communities in South Africa: prevalence, child characteristics, and maternal risk factors. Alcohol Clin Exp Res. 2014;38(s1):251A.
- 5. Semidei, J., Radel, L. F., & Nolan, C. (2001). Substance abuse and child welfare: clear linkages and promising responses. *Child Welfare*, 80(2), 109e 128.
- 6. Fuchs, D., & Burnside, L. (2014). Study on the prevalence of FASD in Canadian child welfare settings: Final report. A Tri-Province Initiative to Expand Understanding of Costs, Services & Prevention of a Public Health Issue: Fetal Alcohol Spectrum Disorder & Children/Youth In Care [2010-2014]. Public Health Agency of Canada, Ottawa, ON.
- 7. Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*, *17*(1), e132e 164.
- 8. Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of Fetal Alcohol Spectrum Disorders in child care settings: A metae analysis. Pediatrics, 132(4), e980e 995. doi:10.1542/peds.2013e 0066
- Burge P. Prevalence of mental disorders and associated service variables among Ontario children who are permanent wards. Can J Psychiatry. 2007;52(5):305–314
- 10. Robert M, Carceller A, Domken V, et al. Physical and neurodevelopmental evaluation of children adopted from Eastern Europe. Can J Clin Pharmacol. 2009;16(3): e432–e440
- 11. Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). *Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): Final report to the Centers for Disease Control and Prevention*. Seattle, WA: University of Washington, Fetal Alcohol and Drug Unit.
- 12. Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm J. (2011). Fetal Alcohol Spectrum Disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health, 102*(5), 336e 340.
- 13. Rojas, E. Y., & Gretton, H. M. (2007). Background, offence characteristics, and criminal outcomes of Aboriginal youth who sexually offend: A closer look at Aboriginal youth intervention needs. Sexual Abuse: Journal of Research and Treatment, 19(3), 257e 283. doi:10.1177/107906320701900306
- 14. Murphy, A., Chittenden, M., & The McCreary Centre Society (2005). Time Out II: A Profile of BC Youth in Custody. Vancouver, BC. The McCreary Centre Society.
- 15. Fast, D. K., Conry, J., & Loock, C. A. (1999). Identifying Fetal Alcohol Syndrome among youth in the criminal justice system. *Journal of Developmental and Behavioral Pediatrics*, 20(5), 370e 372.
- 16. Bower, C., Watkins, R. E., Mutch, R. C., Marriott, R., Freeman, J., Kippin, N. R., Giglia, R. (2018). Fetal alcohol spectrum disorder and youth justice: A prevalence study among young people sentenced to detention in Western Australia. *BMJ Open, 8*(2), e019605.
- 17. Burd, L., Selfridge, R., Klug, M., & Bakko, S. (2004). Fetal alcohol syndrome in the United States corrections system. *Addiction Biology*, *9*(2), 169–176.
- 18. Burd, L., Selfridge, R., Klug, M., & Juelson, T. (2003). Fetal alcohol syndrome in the Canadian corrections system. Journal of FAS International, 1(14), 1–10.
- 19. MacPherson, P. H., Chudley, A. E., & Grant, B. A. (2011). Fetal Alcohol Spectrum Disorder (FASD) in a correctional population: Prevalence, screening and characteristics. Ottawa, ON: Correctional Service of Canada.
- McLachlan, K. (2017). Fetal Alcohol Spectrum Disorder in Yukon corrections: Final report to Yukon Justice: Estimating the prevalence of FASD, mental health, and substance use problems in the justice system. Retrieved from http://www.justice.gov.yk.ca/pdf/Corrected McLachlan Final Report to Yukon August 2017.pdf
- 21. Ospina, M, & Dennett, L. (2013). Systematic review on the prevalence of Fetal Alcohol Spectrum Disorders. Edmonton, AB: Institute of Health Economics.
- 22. Popova, S., Lange, S., Probst, C., Parunashvili, N., & Rehm, J. (2017). Prevalence of alcohol consumption during pregnancy and Fetal Alcohol Spectrum Disorders among the general and Aboriginal populations in Canada and the United States. *European Journal of Medical Genetics, special issue on updates in "Teratology and The Fetal Alcohol Spectrum Disorders"*, 60(1), 32e 48. doi: 10.1016/j.ejmg.2016.09.010
- 23. Werk, C., Cui, X., & Tough, S. (2013). Fetal Alcohol Spectrum Disorder among Aboriginal children under six years of age and living off reserve. First Peoples Child & Family Review, 8(1), 7e 16.
- 24. Asante, K.O., Nelmse Maztke, J., 1985. Report on the Survey of Children with Chronic Handicaps and Fetal Alcohol Syndrome in the Yukon and Northwest British Columbia. Council for Yukon Indians, Whitehorse, YT.
- 25. Kowlessar, D.L., 1997. An Examination of the Effects of Prenatal Alcohol Exposure on Schoole age Children in a Manitoba First Nation Community. A Study of Fetal Alcohol Syndrome Prevalence and Dysmorphologies (Masters). University of Manitoba, Winnipeg, MN.
- 26. Robinson GC, Conry JL, Conry RF. Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. CMAJ. 1987;137(3):203e 207.
- 27. Tait, C. (2003). "The tip of the iceberg": The "making" of Fetal Alcohol Syndrome in Canada (Doctor dissertation). Retrieved from http://www.namhr.ca/media/docs/lega4eb233149a533e taite 2003.pdf
- 28. Statistics Canada. (2017). *Immigration and ethnocultural diversity: Key results from the 2016 census*. Retrieved from https://www150.statcan.gc.ca/n1/dailye quotidien/171025/dq171025be eng.htm
- 29. Walker, M. J., Ale Sahab, B., Islam, F., & Tamim, H. (2011). The epidemiology of alcohol utilization during pregnancy: An analysis of the Canadian Maternity Experiences Survey (MES). *BMC Pregnancy and Childbirth*, *11*. doi:10.1186/1471e 2393e 11e 52
- 30. Perreira, K. M., & Cortes, K. E. (2006). Race/ethnicity and nativity differences in alcohol and tobacco use during pregnancy. *Am J Public Health, 96*(9), 1629e 1636. doi:10.2105/ajph.2004.056598
- 31. Hawkins, S. S., Lamb, K., Cole, T. J., & Law, C. (2008). Influence of moving to the UK on maternal health behaviours: prospective cohort study. *BMJ: British Medical Journal*, 336(7652), 1052e 1055. doi:10.1136/bmj.39532.688877.25