

FASD Prevalence in Special Populations

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KEY MESSAGES

Emerging evidence on FASD prevalence suggests conservative rates of 8% in the North American general population, and at least 4% in Canada. However, researchers report substantially higher rates in certain groups. This knowledge is important for researchers, practitioners, and policy makers to help us to better tailor FASD-informed services and support healthy outcomes across communities and populations.

Issue:

Based on the most current research, the estimated prevalence of fetal alcohol spectrum disorder (FASD) in the general North American population is at least 8%. However, rates of FASD are believed to be higher in certain groups. Examining the varying rates of FASD across different groups is critical to understand the demographic, social, geographical, and cultural factors that underlie alcohol consumption during pregnancy, and which groups may benefit from additional or tailored support to promote healthy outcomes.

The purpose of this issue paper is to take a closer look at the research on special groups thought to experience higher rates of FASD, including children in care, individuals involved in the criminal legal system, and Indigenous communities.

Background:

Numerous intersectional 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.¹ Many of these social determinants of health (SDH) overlap with the environmental risk factors for alcohol use during pregnancy. For instance, a person's geographic location, SES, nutrition, educational attainment, mental health, maternal depression, other substance use, and connections with family and community are all related to the risk of them having a child with FASD.²⁻⁴ This overlap suggests that communities and populations with compromised SDH may show disproportionately high rates of prenatal alcohol exposure (PAE) and 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 groups with low-income and low-SES compared to the general population.⁴⁻⁷

Many social determinants of health influence a person's likelihood of consuming alcohol during pregnancy and overlap with the risk factors for having a child with FASD.

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For further reading on rates of PAE, refer to [the prevalence of alcohol use during pregnancy in Canada](#).

Children in care. Children in the child welfare system, foster care, and orphanages around the world have been the focus of much FASD prevalence research to date. In a recent Canadian study, Popova and colleagues^{8,9} reported that 75% of adolescents and adults with FASD had some form of previous involvement in child welfare services.¹⁰ This finding is similar to another study from Sweden, where 81% of individuals with FASD had prior involvement with child welfare.¹¹ Because many children who are removed from their birth homes are exposed to parental substance use,¹² and because polysubstance use during pregnancy is common, it is believed that children who are apprehended into the child welfare system may also be at risk for PAE and FASD.¹³

In a 2013 meta-analysis, Canadian researchers¹⁴ reviewed published studies on FASD prevalence in child welfare settings from numerous countries, including Brazil, Canada, Chile, Israel, Russia, Spain, Sweden, and the United States (US). Based on the studies included in this meta-analysis, a pooled global FASD prevalence of 18% among children in care was estimated. The highest rates of FASD were found among adoptees from Eastern Europe in Sweden (52%) and in orphanages for children with special needs in Russia (40%). The lowest rates were found among foster and pre-adoption children in Israel and among adoptees from Eastern Europe in the US (4% in both studies). In another recent study with Eastern European children adopted in Spain, researchers reported that 50% had FASD.¹⁵

In Canada specifically, several studies have been conducted with children in care and rates of FASD have been reported at 3% in Ontario,¹⁶ 4% in Alberta,¹³ 7% in Quebec (adoptees from Eastern Europe),¹⁷ and 6%-11% in Manitoba.¹³ Notably, these numbers are thought to be an underestimate, and the percentage of children in care with *possible* FASD is likely much higher.¹³

The estimated prevalence of FASD among Canadian children in care is at least 3-11%.

Criminal legal system. People with FASD commonly experience legal issues as victims, witnesses, and individuals who offend.¹⁰ In one early US study, researchers noted that 60% of adolescents and adults with FASD reported contact with the criminal legal system (CLS) and 35% reported incarceration for a crime at some point during their lives.¹⁸ Researchers later reported that 28% of adults with fetal alcohol syndrome in Sweden had been convicted of a crime.¹¹ New findings in a Canadian context were recently reported, where 30% of youth and adults with FASD had experienced problems with offending and 3% had experienced incarceration.¹⁹

Most FASD prevalence research in criminal legal contexts has been conducted in Canada and the US, though studies have recently emerged in other countries, such as Australia, Brazil, and Sweden. Among youth involved in the CLS, Canadian researchers have estimated that youth with FASD are 19 times more likely to be incarcerated than youth without.²⁰ In early research from British Columbia (BC), rates of FASD were reported at 11%-23% in a youth forensic population.²¹⁻²³ Australian researchers more recently estimated the rate of FASD among detained youth to be as high as 36%.²⁴

Adults with FASD are also overrepresented in the CLS. In the early 2000s, Burd and colleagues surveyed directors of correctional facilities in Canada²⁵ and the US²⁶ and found that only 0.9% of CLS-involved adults in Canada, and 0.0003% in the US, were reported to have a diagnosis of FASD. In later research, Canadian researchers found that 10% of men in a Manitoba correctional facility,²⁷ 17% of women in a small study who were incarcerated,²⁸ 18% of incarcerated men in the Yukon,^{29,30} and 46% of adults in a forensic mental health setting³¹ met the criteria for FASD. Importantly, in several of these studies, researchers suggested that FASD prevalence rates could be much higher than estimated. For example, in the Yukon study, McLachlan and colleagues noted that 31.2% of participants had possible FASD but there was insufficient information to confirm a diagnosis.³⁰

The wide range of estimates in CLS settings is likely due to differences in study methodology, sample,

and context. However, across studies, researchers indicate that FASD is a significant concern in CLS settings, warranting practice and policy considerations to address the complex needs of this group who may experience increased susceptibility to criminal legal involvement and victimization.

The estimated prevalence of FASD in criminal legal system settings in Canada is up to 23% among youth and 46% among adults.

Indigenous communities. A common, and problematic, misconception about FASD is that it is an “Indigenous issue.” In fact, there is little high-quality evidence to support this claim, and because of mixed research findings, as well as referral bias, and historical and ongoing racism against Indigenous Peoples,^{32,47} the claim is unfounded and harmful. In a 2017 meta-analysis of FASD prevalence studies, researchers noted only three studies with Indigenous communities in Canada, which were conducted in the 1980s and 1990s and had numerous acknowledged methodological limitations. Based on these studies, a pooled FASD prevalence was estimated to be higher in Canadian Indigenous communities compared to non-Indigenous populations, but the authors noted that existing data are not applicable for decision-making purposes and more rigorous studies are urgently needed.³³

In reviews conducted in 2013 and 2019, researchers demonstrated a high variability among FASD prevalence studies with Indigenous communities around the world.^{32,43} In these studies, the pooled prevalence of FASD in Indigenous populations in Australia was reported to be 1.48%,^{34,35} in Canada it was reported to be 4.36%,³⁶⁻³⁹ and in the US it was reported to be 0.4%.⁴⁰⁻⁴³ Specific to the Canadian context, findings range widely and depend on the study population: estimates include 0.7% among young children living off-reserve in Western provinces,⁴⁴ 3.3% among children in the Yukon and northwestern BC,³⁶ 5-10% among children from a Manitoba First Nations community,⁴⁵ 19% among children from an isolated BC First Nations community,⁴⁶ and 27% among CLS-involved youth in BC.²¹

Importantly, alcohol use in Indigenous communities is inextricably linked to colonialism and intergenerational trauma,^{33,43,47,48,52} and the continued surveillance, stigmatization, stereotyping, and racism toward Indigenous populations contributes to the misbelief that FASD is over-represented in these communities.⁴⁷ Pursuing this dialogue without sound research evidence further perpetuates the inequity experienced by Indigenous children, parents, families, and communities.

There is not strong evidence to say that FASD is over-represented in Indigenous populations. In fact, this misconception is rooted in racism, over-surveillance, and stereotypes, and perpetuates ongoing harms against Indigenous communities.

New Canadians. With almost a quarter (23%) of the Canadian population comprising landed immigrants,⁴⁹ 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 Canadian-born women to consume alcohol prenatally; however, 6% of immigrant women still reported drinking during pregnancy.⁵⁰ Contrarily, some researchers in the US have reported that foreign-born women were at a similar risk of consuming alcohol during pregnancy compared to native-born women.⁵¹

Because the literature in this area is scarce, researchers conducting future FASD prevalence studies should consider the potential unique needs and experiences of new Canadians related to PAE and FASD to ensure that this community is best understood and supported. Additional research is also needed to understand whether or how the risk factors related SDH and FASD that are experienced in this group may differ from native-born Canadians and may change with the process of acculturation.

Conclusions:

Although prenatal alcohol use is the sole necessary cause of FASD, it is insufficient to consider alcohol use during pregnancy without considering the social and systemic contexts within which PAE and FASD occur. FASD can affect individuals of all ages, genders, and cultural and socioeconomic backgrounds. Because of a complex combination of personal, relational, environmental, and systemic factors, some groups of people may be at a higher risk for PAE and FASD. There is growing evidence that individuals in the child welfare and correctional systems experience disproportionately high rates of FASD. Accurate prevalence rates in these groups have yet to be determined, though researchers estimate ranges of 3-11% among Canadian children in care and 10-46% among Canadians involved in the CLS. Although it is commonly believed that Indigenous communities may experience higher rates of FASD, evidence in this area is conflicted and does not support this claim, and continued use of this unfounded messaging can perpetuate harm. The literature on FASD prevalence is relatively scarce 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. More research is needed across these contexts to understand the scope and the prevalence of FASD which is critical for resource allocation, training development, and policy considerations to support healthy outcomes for people with FASD, their families, and their communities.

Recommendations:

- Alcohol consumption during pregnancy and FASD need to be recognized by government, policy, and decision makers, social service providers, and the public as serious social and health issues with global implications.
- There is a need for a global effort to collect more data on alcohol consumption during pregnancy using a universal sampling strategy and consolidating information into a centralized database for confirmed FASD diagnosis.
- Routine screening protocols should be designed for use in child welfare and criminal legal settings to quickly identify individuals who may benefit from assessment and FASD-informed support.
- Comprehensive training on FASD awareness, recognition, and intervention, including strengths-based approaches, should be provided for service providers who work with individuals who may be at a heightened risk for PAE/FASD to foster the best possible outcomes.
- 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.
- Create and non-judgmental initiatives are needed that reduce the stigma experienced by women who disclose alcohol consumption during pregnancy to increase safety in reporting alcohol use and assist in FASD assessment and diagnosis.
- Health promotion and intervention efforts should be strengthened to support the needs of individuals with FASD and people who consume alcohol during pregnancy across contexts by implementing multidisciplinary care teams.
- Although we know that FASD prevention is important for all people of childbearing age, special attention should be paid to ensuring that populations experiencing higher levels of inequity are well-supported to have healthy pregnancies. As well, interventions should strive to improve the SDH and risk factors underlying prenatal alcohol consumption for all people.

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