

The Prevalence of Fetal Alcohol Spectrum Disorder

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KEY MESSAGES

Research on the prevalence of FASD is critical for understanding the scale of the disability in our communities and for identifying opportunities for supporting healthy pregnancies. This research can inform decisions about allocating resources and services to support healthy families, and aid in monitoring the effectiveness of prevention efforts. Emerging evidence on FASD prevalence suggests conservative rates of 8% in the North American general population, and at least 4% in Canada. It is possible that higher rates of FASD will be identified with further research.

Issue:

Since fetal alcohol syndrome was first defined in North America in the 1970s, researchers have been working to determine prevalence rates of the disability. Now referred to in Canada as fetal alcohol spectrum disorder (FASD), the social, health, and economic impacts of FASD for families and communities are profound, thus understanding its scope is critical. Over the years, researchers have used various methodologies in a range of geographical regions and populations around the world in their efforts to establish prevalence rates. Because of these differing approaches, FASD prevalence findings have not always been consistent.

The purpose of this issue paper is to share the most up-to-date findings of FASD prevalence research and provide clarity around the question “How many people have FASD?”

Background:

FASD prevalence research began nearly five decades ago, though early studies were limited to specific populations and small geographical regions such as isolated communities.¹ In the last 20 years, there has been a significant increase in worldwide attention to FASD, and consequently a rise in the number of more robust prevalence studies. Acknowledging the important contributions of early prevalence work, the current issue paper focuses primarily on research published in recent years.

Approaches to Establishing Prevalence Rates. *Prevalence* is defined as the proportion of a population who has a specific characteristic, health condition, or diagnosis at a given point in time or across the lifespan.² It differs from *incidence*, which refers to the number of *new cases* of a specific characteristic that develops within a population during a specific period of time.² FASD prevalence is inherently

difficult to measure due to challenges with recognition, screening, and diagnosis. The hidden nature of FASD, as well as factors related to the social determinants of health that often influence prenatal alcohol consumption and FASD, complicate our ability to establish accurate rates. Symptoms of FASD are often complex and may not manifest fully in early life, thus individuals with FASD may not come to the attention of service providers until the school years or beyond. Because of the stigma and shame attached to the disability, prenatal alcohol exposure (PAE) is also likely underreported. Together, these issues mean that many individuals with FASD may be incorrectly diagnosed with other disabilities or missed altogether.³⁻⁶ For these reasons, FASD prevalence estimates reported in existing studies are believed to be conservative.

There are several approaches commonly used by researchers to estimate prevalence rates of diagnoses or disabilities.² *Passive surveillance* is the least expensive approach, involving reviewing files that already exist, such as birth certificates and hospital charts, and recording the number of individuals with a documented diagnosis (e.g., Burd et al.⁷). *Clinic-based studies* are a more common approach and are typically conducted in prenatal settings, where researchers track maternal alcohol use and later follow up with child outcomes (e.g., Bloch et al.⁸). Finally, in *active case ascertainment (ACA) studies*, the ‘gold standard’ in estimating prevalence rates, researchers actively seek out and assess participants in large geographical regions who may have FASD (e.g., May et al.^{9,12-15}; McLachlan et al.^{10,30}). ACA is the most reliable way to establish prevalence rates, however it is also the most cost- and time-intensive, and the most challenging to conduct. Not surprisingly, prevalence estimates vary widely depending on the research approach, with passive surveillance generally yielding more modest results, and clinic-based and ACA studies indicating higher rates.² Each approach has its own strengths and limitations that add to the challenge of establishing true prevalence.

North American Studies. Most studies on FASD prevalence to date have been conducted in the United States (US) and Canada. One of the first studies was published in the US in 1997 by researchers who reported a prevalence rate of 9.1 out of 1000, or 1% of the population.¹⁸ Since then, May and colleagues have conducted a series of studies in the US with school-aged children suggesting conservative rates of 4 to 8%, which replaces the long-standing estimate of 1%.¹¹⁻¹⁵

In Canada, research on FASD prevalence in the general population is scarce. Most of this previous work has been done with specific groups (e.g., forensic populations) or in limited geographical regions (e.g., specific provinces). In one 2014 study of the general population in Alberta, researchers used a passive surveillance method to establish an estimated prevalence rate of 1.4-4.4%, depending on the length of follow-up (i.e., 1.4% of the population being diagnosed in their first year of life and 4.4% being diagnosed later in life).¹⁶ Another population-based ACA study was more recently conducted with elementary school students in Ontario, where researchers estimated a prevalence rate of 2-3%.¹⁷

Based on existing evidence showing conservative estimates ranging from 1% to 8%, our current best estimate for the prevalence of FASD in the general population of North America is 8%. In Canada, the FASD prevalence rate is likely at least 4%, and as research evidence grows, this minimum estimate could continue to rise.

Research Across the World. With increased worldwide attention to FASD, researchers around the globe have examined prevalence in their local regions. Estimates vary widely across countries, but several international research reviews have recently been conducted.¹⁸⁻²³ Findings from these studies indicate a global FASD prevalence of 0.8% among children and youth, with the highest rates reported

in South Africa (11.1%), Croatia (5.3%), Ireland (4.8%), and Italy (4.5%), and the lowest rates in the Eastern Mediterranean region (0.01% in one study from France).²¹ There are many possible reasons for these regional differences, including differing awareness and attitudes toward alcohol use in pregnancy, varied diagnostic practices and terminology, and differences in prioritization and availability of resources to conduct FASD prevalence research.

The current estimate for global FASD prevalence rate is 0.8% with wide variability depending on region and country.

Special Populations. In addition to general population research, several targeted FASD prevalence studies have been conducted among special groups,^{6,24} including individuals in criminal legal settings,^{10,26-28} child welfare,^{29,30} and Indigenous communities.³¹⁻³³ Among several studies of children in care as well as youth and adults in correctional settings, rates of FASD have been shown to be higher than in the general population. Prevalence studies with Indigenous communities are limited and have produced conflicting results because of continued surveillance, stigmatization, and stereotyping in these populations.^{24,34,35} Considering these findings, there is an ongoing need for additional exploration of the social determinants of health related to PAE and FASD to identify and support groups who may experience extra layers of inequity.

Setting the Context. FASD is one of the leading known causes of developmental disability in the western world. Compared with other disabilities, at an estimated prevalence of **at least 4%** in Canada, FASD more than:

- 2 times more common than autism spectrum disorder (2%³⁶)
- 17 times more common than cerebral palsy (0.23%³⁷)
- 29 times more common than Down syndrome (0.14%³⁸)
- 40 times more common than Tourette's syndrome (0.10%³⁹)

Conclusions:

FASD is highly prevalent, vastly outnumbering other common developmental disabilities. However, by comparison, FASD receives relatively little public recognition or understanding. Current research points to a much higher rate of FASD than was initially estimated, and with improved methods of detection, even these conservative estimates continue to rise. Although FASD prevalence rates vary widely across countries and populations, the current best estimate in the general North American population is 8%. In Canada, the minimum best estimate is 4%. There are significantly higher rates in special groups, such as those involved in the child welfare and criminal legal systems. FASD prevalence research is important not only for understanding the scale of the disability in our communities, but also for making decisions about funding and resource allocation, and for monitoring the effectiveness of prevention efforts. As well, with improved knowledge about special populations that may be particularly impacted with respect to PAE or FASD, intervention efforts may be targeted to reduce the number of new exposures and to support healthy outcomes for individuals and families who are already affected.

Recommendations:

- FASD needs to be recognized by government, policy and decision makers, service providers, and society as a serious social and public health issue in Canada connected to the social determinants of health.
- Building on FASD prevalence research, there needs to be increased acknowledgement at the government and policy levels that FASD is a common disability, and more attention needs to be given to improving interventions, training, and support.
- FASD surveillance efforts should be expanded to cover broader geographical regions, leading to a more representative estimate that is applicable across Canada. Prevalence research efforts should be expanded to include larger populations in diverse contexts to better understand trends and needs across environments.
- More research is needed on high quality screening methods to improve the identification and diagnosis of FASD, along with training provided for front-line service providers in all contexts to implement these screening practices.
- A universal sampling strategy to assess individuals from the global population is needed to better capture FASD prevalence rates.
- Service providers across sectors should enhance their understanding of FASD and inquire whenever feasible and appropriate about the possibility of prenatal alcohol exposure as a pathway to FASD-informed care and support.
- Most previous prevalence work has been conducted with children and youth, therefore more studies are needed to examine rates of FASD into adulthood and across the lifespan. Groups of people who experience marginalization and social and health inequity should continue to be considered in FASD prevalence research, with special attention paid to assessing whether and how FASD prevention and support are impacting these groups.

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