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The Prevalence of Fetal Alcohol Spectrum Disorder

Katherine Flannigan, PhD; Kathy Unsworth, MA; and Kelly Harding, PhD
Canada FASD Research Network

Issue:

Since Fetal Alcohol Syndrome was first defined in North America in the 1970s, researchers have been working to determine prevalence rates of this disability. The social and economic impacts of Fetal Alcohol Spectrum Disorder (FASD) on families and the broader community are profound, thus understanding the scope of the issue is critical. Over the years, researchers have used various methodologies and examined 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 research findings, and to provide clarity around the question, "*How many people have FASD?*"

Background:

Although FASD prevalence research began more than four decades ago, early studies focused on specific populations and limited geographical regions (e.g., isolated communities in British Columbia[1]). However, in the last 10 years, there has been a significant increase in worldwide attention to FASD, and consequently a rise in the number of robust and high-quality prevalence studies. Acknowledging the important contribution of early prevalence work, the current issue paper focuses primarily on research published in recent years.

Approaches to Establishing Prevalence Rates. FASD prevalence is inherently difficult to measure, due to challenges with recognition, screening, and diagnosis. The "invisibility" of FASD, as well as factors related to the social determinants of health that are often at play for individuals with FASD, confound our ability to establish accurate rates. Because symptoms of FASD are often complex and may not manifest fully until later in life, individuals with FASD may not come to the attention of service providers until the school years or beyond. As well, because of the stigma and shame attached to the disability, prenatal alcohol exposure (PAE) is likely underreported. Because of these issues, many individuals with FASD may be incorrectly diagnosed with another disability or missed altogether. Therefore, estimates across all studies are believed to be conservative.

Three approaches are commonly used to estimate prevalence rates.[2] *Passive surveillance* is the least expensive approach and involves reviewing files that already exist (e.g., birth certificates, hospital charts) and recording the number of individuals with a documented diagnosis (e.g., Burd et al.[3]). *Clinic-based studies* are a more common approach and are typically conducted in prenatal settings, where researchers track maternal drinking and later follow up with child outcomes (e.g., Bloch et al.[4]). Finally, in *active case ascertainment (ACA) studies,* which are becoming increasingly more common, researchers actively seek out and examine participants in large geographical regions who may have FASD (e.g., May et al.[5]). ACA is the most reliable way to establish rates, however it is also the most cost- and time-intensive, and therefore the most challenging to conduct. Not surprisingly, estimates

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vary widely depending on the approach, with passive surveillance generally yielding more modest results, and clinic-based and ACA studies indicating higher numbers.[2] Each approach has its own set of strengths and limitations that add to the challenge of establishing true prevalence.

Researchers have also used innovative technologies to identify biomarkers of PAE, such as maternal saliva and hair testing, as well as infant hair, meconium, umbilical, and placenta sampling.[6] These methods typically demonstrate higher rates of PAE (16 to 44%) than are reported via questionnaire (0 to 37%).[7] It is important to note that rates of PAE cannot be equated to rates of FASD, as numerous biopsychosocial factors influence how alcohol affects a fetus (e.g., pattern, dose, and timing of exposure; genetics and epigenetics; maternal health, nutrition, and stress; fetal exposure to other substances), and not every baby born with PAE will necessarily be later diagnosed with FASD.

North American Studies. Most studies on FASD prevalence to date have been conducted in the United States. One of the first was published in 1997 by researchers who reported a rate of 9.1 out of 1000 live births, or 1% of the general population.[8] In more recent years, May and colleagues have conducted a series of studies with school-aged children and suggested a conservative estimate ranging from 2-5%,[5,9-11] which has replaced the original, long-standing estimate of 1%.

In Canada, research on FASD prevalence in the general population is scarce; most previous work has been with specific groups (e.g., forensic populations) or in limited geographical regions (e.g., western provinces, Indigenous communities). In one of the few Canadian studies in the general population, researchers in Alberta used a passive surveillance method to establish an estimated 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).[12] Very recently, a population-based ACA study was conducted with elementary school students in Ontario, and the researchers estimated a prevalence rate of 2-3%.[13] Both of these studies align with findings in the US.

Based on evidence in two recent studies reporting conservative rates of 1-4%[12] and 2-3%,[13] our current best estimate for the prevalence of FASD in the general Canadian population is 4%.

To build on this important Canadian work, researchers from CanFASD, the Centre for Addiction and Mental Health, and Canadian Centre on Substance Use and Addiction are currently embarking on a project funded by the Public Health Agency of Canada to develop a cross-jurisdiction surveillance system to monitor prevalence rates of both FASD and PAE. This project is a collaboration between researchers in three provinces and two territories and relies on multiple existing data sources. It will provide much needed insight into the scope and impact of FASD at a national level.

Research Across the World. With increased worldwide attention to the issue of FASD, researchers around the globe have begun to examine prevalence in their local regions. Estimates vary widely across countries, but several worldwide reviews of research in the general population have recently been conducted.[14-16] Findings of these studies indicate a global FASD prevalence of 0.8%[14,15] with the highest rates in South Africa (11%) and the lowest rates in eastern Mediterranean countries (0.01%).[16]

Special Populations. A number of FASD prevalence studies have been conducted in special groups, including individuals in forensic settings,[17-19] child welfare,[20,21] and Indigenous communities.[22-24] In many studies, rates of FASD in these groups have been shown to be higher than in the general population, particularly among children in care as well as youth and adults in correctional settings.[14]

However, prevalence studies with Indigenous communities in particular have produced conflicting results because of continued surveillance, stigmatization, and stereotyping in these populations.[25] There is an urgent need for additional exploration of these issues in order to properly identify vulnerable groups who may require specialized support.

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

- 2.5 times more common than Autism Spectrum Disorder (1.52%[26])
- 19 times more common than Cerebral Palsy (0.21%[27])
- 28 times more common than Down Syndrome (0.14%[28])
- 40 times more common than Tourette's Syndrome (0.10%[29])

Recommendations:

1. FASD needs to be recognized by government, policy and decision makers, social service providers, and the general public as a serious public health issue in Canada.
2. FASD surveillance efforts should be expanded to cover broader geographical regions, leading to a more representative estimate that is applicable across Canada.
3. High quality screening methods must be developed to improve our ability to detect cases of FASD, and training should be provided for front-line health care and service providers across sectors on the implementation of these screening practices.
4. Most previous prevalence work has been conducted with children and youth, therefore it will be important to conduct studies to examine rates of FASD across the lifespan.
5. High-risk populations should continue to be a focus of FASD prevalence research, with special attention paid to assessing whether and how interventions are impacting these groups.

Conclusions:

FASD is a prevalent disorder, vastly outnumbering other common developmental disabilities; however, FASD comes with relatively little public recognition or understanding. Recent research points to a much higher rate of FASD than was initially estimated, and with improved methods of detection, these numbers continue to rise. Although FASD prevalence rates vary widely across countries and populations, and are considered to be conservative, the current best estimate in the general Canadian population is 4%. There are significantly higher rates in special groups, such as those involved in the child welfare and justice systems. FASD prevalence research is important not only for understanding the scale of the issue 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 at a particularly high risk for PAE or FASD, intervention efforts may be targeted to reduce the number of new cases of FASD and to support healthy outcomes for individuals and families who are already affected.

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