Jan. 2025 | www.neafan.ca

Advancing FASD Prevention And Care.

NEAFAN

Northeast Alberta FASD Network

Canada's Experience with FASD.

The study "Population-based Prevalence of Fetal Alcohol Spectrum Disorder in Canada" by Popova et al. is the first of its kind in Canada, providing population-based prevalence estimates for Fetal Alcohol Spectrum Disorder (FASD) among elementary school children aged 7–9 in the Greater Toronto Area.

Using a rigorous observational design and active case ascertainment, the researchers identified that the prevalence of FASD is likely between 1.8% (18.1 per 1,000) and 2.9% (29.3 per 1,000) among children in the region.

These findings suggest that FASD is more common than previous estimates and surpasses the prevalence of other significant conditions like Down syndrome, spina bifida, and autism spectrum disorder.

FASD, caused by prenatal alcohol exposure, results in permanent developmental, cognitive, and behavioral impairments. The study found that children with suspected FASD demonstrated deficits in IQ, memory, and processing speed, alongside higher rates of behavioral challenges such as attention and rule-breaking problems. Despite these serious impacts, none of the identified children had been previously diagnosed, highlighting widespread underdiagnosis and the critical need for improved diagnostic systems.

The authors emphasize the importance of prevention strategies, including awareness campaigns targeting alcohol use among women of childbearing age and improved access to early interventions. They advocate for national surveillance systems to monitor prenatal alcohol use and FASD, as well as integrating discussions about alcohol risks into routine health care.

This research underscores the pressing public health challenge posed by FASD in Canada and calls for coordinated efforts to address its prevention, diagnosis, and management. By recognizing FASD as a widespread but preventable disorder, the study makes a strong case for policy changes and enhanced support for affected individuals and their families.

Here is the link to this Study.

Addressing FASD Effectively.

The workshop report on Fetal Alcohol Spectrum Disorders (FASD) prevention and clinical guidelines research highlights the challenges and advances in addressing FASD within the U.S. military and broader healthcare systems. This 2023 event brought together experts from healthcare, academia, and advocacy to discuss the state of FASD research and initiatives aimed at improving prevention, diagnosis, and care.

FASD affects an estimated 1 in 20 people in the United States, yet it remains underdiagnosed and stigmatized. The report emphasizes that prenatal alcohol exposure (PAE), the primary cause of FASD, is preventable. Early diagnosis and comprehensive care are critical to minimizing the condition's lifelong impacts. The military population, with unique stressors and a higher prevalence of alcohol misuse, was a central focus of this research initiative.

" Innovations in FASD Diagnosis and Prevention hold promise."

Key discussions at the workshop revolved around implementing systems of care responsive to FASD, learning from implementation science, and leveraging data tools like electronic health records (EHRs). One highlight was the exploration of telehealth as a potential "hub-and-spoke" model for expanding FASD screening, diagnosis, and care in underserved areas.

This model could provide clinicians with remote access to training, resources, and case-based learning, enabling more consistent and timely care delivery.

Participants underscored the importance of reducing stigma associated with FASD. Stigmatizing language and punitive policies deter individuals from seeking diagnosis and care. Panelists advocated for a shift to compassionate, trauma-informed approaches. This includes training healthcare providers to engage in nonjudgmental discussions about alcohol use and fostering environments where families feel supported.

Practical innovations in FASD care were also highlighted. Emerging diagnostic tools, such as mobile apps and 3D imaging technologies, show promise for earlier and more accurate identification of FASD. The report also discussed integrating family-focused interventions, community education programs, and multidisciplinary care teams to address the complex needs of individuals with FASD and their families.

Finally, the workshop identified the need for continued research and policy improvements. Specific priorities include standardizing FASD diagnostic criteria internationally, increasing public awareness, and addressing systemic barriers to care access. By aligning military and civilian healthcare systems with evidence-based practices, the research aims to create a model for comprehensive FASD care that benefits all populations.

The findings underscore the necessity of collaboration across sectors to address FASD effectively. With advances in technology, policy, and care strategies, there is optimism that individuals affected by FASD can receive better support to lead fulfilling lives. The report sets the stage for future research and action to improve outcomes for individuals and families navigating the challenges of FASD.

Link to Report

The Family Doctor's Frontline Role in FASD Prevention.

GPs are positioned as frontline actors in both the prevention and management of FASD according to a 2024 study, based on a scoping review of 23 articles. Their responsibilities span from primary prevention and early identification to diagnosis, therapeutic intervention, and long-term follow-up. Prevention efforts focus on reducing alcohol consumption among women of childbearing age and ensuring informed decisions before pregnancy. Key interventions include motivational counseling and discussions about contraception and alcohol risks.

The scoping review "Role of the Family Doctor in the Prevention and Care of Patients with Fetal Alcohol Spectrum Disorder (FASD)" highlights the critical role that general practitioners (GPs) play in addressing FASD, which is recognized as the leading preventable cause of non-genetic mental disability. The research emphasizes that FASD is often under-diagnosed, leaving affected individuals without the necessary care and support. This condition encompasses a range of disorders caused by prenatal alcohol exposure, including Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorders (ARND), and Alcohol-Related Birth Defects (ARBD).

Early identification is emphasized as essential, as timely interventions can minimize developmental, social, and legal consequences for affected children. Diagnostic tools like CRAFFT and TWEAK are noted as effective, though their use in general practice remains limited. The review underscores the need for better training and resources to equip GPs with the knowledge and confidence to diagnose and manage FASD cases comprehensively.

Therapeutic education for patients, families, and communities forms another cornerstone of a GP's role. By fostering awareness about the harmful effects of prenatal alcohol exposure, GPs can mitigate societal stigma and ensure families are involved in care strategies. Furthermore, the GP's role extends to bridging gaps between medical, social, and educational services, particularly in underserved or rural areas.

> *"GPs are positioned as frontline actors in both the prevention and management of FASD."*

The review concludes with a call for more systematic training for GPs and the integration of specialized resources, such as interdisciplinary clinics, to address the complexities of FASD management. Future research, including randomized trials, is recommended to evaluate the impact of such training on prevention outcomes. The study underscores that empowering GPs with the right tools and knowledge is crucial to reducing the incidence of FASD and improving the quality of life for affected individuals and their families.

The Scoping Review link.

FASD Diagnosis

Insights from Lived Experiences.

The systematic review by Hayes et al. (2023), titled "Lived Experiences of the Diagnostic Assessment Process for Fetal Alcohol Spectrum Disorder (FASD)," offers a nuanced understanding of the diagnostic journey for individuals with FASD and their caregivers. This comprehensive study synthesizes qualitative evidence from various international sources, focusing on the challenges, emotions, and implications associated with the diagnosis of FASD. The findings are valuable for health professionals, policymakers, and service providers working in the health and social services industries.

The study highlights four key themes that define the diagnostic journey: concerns before assessment, the diagnostic process itself, receiving the diagnosis, and adjustments after the assessment. Challenges prior to assessment typically arise when caregivers notice behavioural or developmental problems in their children, leading them to seek professional assistance.

However, many caregivers reported feeling dismissed by health professionals, who often downplayed their concerns or attributed them to environmental factors. Additionally, FASD was frequently overlooked as a potential diagnosis, even when prenatal alcohol exposure was disclosed. These early dismissals contributed to delays in diagnosis and, consequently, in accessing necessary support services.

The diagnostic process itself was marked by significant barriers. Many caregivers faced long waitlists and limited availability of specialized diagnostic services. Some had to travel considerable distances to access qualified professionals, while others encountered a lack of knowledge and expertise among health providers. Despite these hurdles, caregivers who accessed specialized FASD services reported positive experiences. They described these environments as validating and empowering, appreciating the nonjudgmental and supportive attitudes of the staff. The comprehensive, multidisciplinary assessments provided clarity and validation for their concerns, which had often been dismissed elsewhere.

Receiving the diagnosis was a moment of mixed emotions for caregivers and individuals with FASD. On the one hand, the diagnosis brought relief, understanding, and a renewed ability to advocate for appropriate support. It helped caregivers and individuals reframe their expectations and understand the reasons behind specific behaviors or challenges. On the other hand, the diagnosis also brought grief, guilt, and a sense of loss, particularly for biological mothers who grappled with their role in their child's condition. Caregivers expressed concerns about the lifelong implications of the diagnosis and the complexities of managing co-occurring conditions.

Post-assessment, caregivers highlighted the need for ongoing support and tailored interventions. They valued diagnostic reports that emphasized strengths and provided practical strategies for managing challenges. However, barriers such as financial strain, family commitments, and limited availability of local services often impeded access to these resources. Caregivers also expressed aspirations for their children's futures, balanced by apprehensions about the uncertainties ahead.

This review underscores the importance of a person- and family-centered approach to FASD diagnosis.

Integrating the lived experiences of individuals and their caregivers into service delivery can refine the diagnostic process, improve access to support, and ensure that interventions address the specific needs of those impacted by FASD.

The systematic review link.

Let's Talk

The Prevention Conversation

It's time to talk about alcohol and pregnancy

Amy Tobin B.Ed

FASD Prevention Conversation Facilitator

amy.tobin@mcman.ca

780-750-9729

Amy Tobin, B. Ed, is the FASD Prevention Conversation Facilitator with NEAFAN (Northeast Alberta FASD Network) and an adoptive mother of two. Prior to motherhood, she was an elementary school teacher with the Fort McMurray Public School District for six years. Her passion for FASD, and its prevention, began nine years ago when she became a mother through adoption and was introduced, personally, to the beauty and perplexity of parenting those with prenatal alcohol exposure. Since then, she has dedicated much of her time to learning about, and educating others, on the effects of alcohol during pregnancy and Fetal Alcohol Spectrum Disorder. Her approach is one that takes into consideration the complexities that adoption, generational, and cultural trauma can play within FASD.

Prevention Conversation

The Prevention Conversation program aims to raise awareness of FASD and Prevention among target populations including Healthcare and Social Service Providers, Women of Childbearing Age(18-45), Partners, Families and Friends.

The Project is geared towards highlighting the importance of screening all women in child bearing age for alcohol use and risks associated with FASD, improve supports for these women and promote involvement of community members and primary care providers.

The Prevention Conversation is aimed at encouraging a community wide awareness of FASD and prevention, developing the skills within the community to engage in non-judgmental, empathetic conversations about alcohol use during pregnancy. The Prevention Conversation is centered around increasing our knowledge of FASD, training service providers on the use of screening tools to engage women in the Prevention Conversation.

To book a Prevention Conversation presentation, please contact:

Amy Tobin
FASD Prevention Conversation Facilitator

McMan Youth, Family and Community Services Assoc.
Fort McMurray, AB

amy.tobin@mcman.ca
780-750-9729

NEAFAN
Northeast Alberta FASD Network

Connect

Website: www.neafan.ca

Facebook: @neafanfasd

- Contact NEAFAN

Instagram: @neafanfm

Twitter: @neafanfm

- Contact NEAFAN