

Submission prepared by the Canada Fetal Alcohol Spectrum Research Network

In advance of

Federal Budget 2022

Recommendation:

That the government provide funding in the amount of \$15 million, over 3 years, and with \$1 million a year ongoing thereafter, to the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) to develop and implement a National FASD Strategy for Canada.

Context: The Prevalence and Impact of FASD in Canada

Fetal alcohol spectrum disorder (FASD) is the leading cause of neurodevelopmental disability in Canada, affecting 4% of the population – with rates being even higher in populations with compromised social determinants of health. With over 1.4 million Canadians with FASD today, there are more Canadians with FASD than autism, cerebral palsy, and Down syndrome combined.

FASD is a lifelong disability that impacts the brain and body of someone who was exposed to alcohol during fetal development. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

The impact of FASD on Canadians is astounding. 90% of those with FASD will struggle with at least one mental health challenge over their lifetime, and people with FASD are 20 times more likely to face substance use challenges. Their risk of suicide is 5.5 times higher than the general population.

Individuals with FASD are also disproportionately represented in the child welfare and criminal justice systems – and when they do end up in the criminal justice system, they usually end up in facilities that are not structured to support or remediate someone with a brain injury such as FASD.

These individuals struggle in school, and at work if they are able to find appropriate employment. Finding and maintaining housing or some form of assisted living arrangement are challenges for people with FASD and their families, as they are for those living with other disabilities, although due to the social issues that sometimes accompany individuals with FASD (children, substance use, criminal records), these are often greater.

The intangible and unmeasurable costs of having FASD, such as pain, suffering, stress, and stigmatization, are very difficult to quantify, but are significant. These intangible costs are borne not only by the individuals with FASD themselves, but by family members and their community.

Individuals with FASD and their caregivers experience stigma on a daily basis. Despite the fact that FASD affects approximately 4% of Canadians, the disorder is not well understood by the majority of the population. As a result, the challenges individuals with FASD face with emotional regulation and social interaction are often seen as “bad behaviour” and “poor life choices” by our society. This stigma impacts every aspect of their lives, from employment and education to involvement with the justice system and everything in between. Additionally, as mental health issues and substance use disorders frequently co-occur with FASD, individuals with FASD face stigma in a number of different forms.

Whereas the Government of Canada has invested \$1.46 million to develop a National Autism Strategy, which is certainly required to ensure that Canadians living with Autism and their families have the supports they need, the prevalence of FASD in Canada is far greater than Autism Spectrum Disorder, but Canada does not yet have a National FASD Strategy.

In 2003, the Government of Canada released *FASD: A Framework for Action* which was based on national consultations and stands as a vision for how jurisdictions can work together to improve outcomes for those impacted by FASD. In 2006, the Standing Committee on Health issued a report entitled *Even One is Too Many: A Call for a Comprehensive Action Plan on Fetal Alcohol Spectrum Disorder*, which called on the government to develop a comprehensive FASD action plan with clear goals, objectives, and timelines. Despite these reports and recommendations, little progress has been made at the national level to coordinate prevention, diagnostics, and supports.

Why do we need a National FASD Strategy in Canada?

FASD is a unique disability that requires a multi-disciplinary approach and support. FASD is not only a health care issue – but intersects with homelessness, substance use, education, criminal justice, mental health, child welfare, social services, family health and more. Despite its significant prevalence in Canada FASD remains largely unrecognized by public policy and programs, and individuals’ and families’ needs remain unmet.

Right now, the FASD community in Canada relies heavily on both informal and formal supports, whose effectiveness and availability are dependent on the knowledge of FASD across professions and within communities. Access to support varies – with some provinces and municipalities not recognizing FASD as a disability, disregarding the need for diagnostic capacity, or failing to provide tailored supports to those with FASD and the families supporting them.

Many researchers acknowledge that FASD often goes undiagnosed or misdiagnosed, especially at an early enough age where interventions can be most impactful. Although CanFASD’s National Database seeks to include as much information as it can, it cannot currently provide accurate prevalence rates as it only captures diagnostic information at time of assessment and the number of diagnoses are limited by capacity of the clinics. Additionally, some provinces (such as Nova Scotia and PEI) do not currently have diagnostic clinics or support services for individuals and families. Other provinces such as Newfoundland and New Brunswick have one

or two clinics to serve the entire province. Manitoba has limited diagnostic capacity but has extensive supports. A National FASD Strategy would seek to use evidence and best practices to standardize prevention, diagnostic assessment and interventions so that all Canadians have equal access to information and support and have the best chance at success.

People with FASD deserve to have concrete, individualized supports that reduce the risk of mental and physical health challenges, substance use, child welfare involvement, and interaction with the criminal justice system, and that provide opportunities for improved health and wellbeing, stable employment, safe housing, healthy relationships, and meaningful contributions within their communities.

Women across the country deserve equitable access to information to reduce and/or stop alcohol use during pregnancy, and receive non-stigmatizing, trauma-informed and holistic supports for the alcohol and other health issues they may face. While the Government's new mandate to provide affordable, accessible, inclusive and high-quality childcare is welcome, it will also heighten the need for providers to understand FASD, be able to identify children at risk of being born prenatally affected by substances, including alcohol, and implement early interventions to improve outcomes.

Caregivers deserve evidence-based information and practices to best support their child with FASD and deserve unblocked access to a skilled workforce, trained in FASD, that is prepared to effectively address their child's unique needs. They also deserve ongoing supports and services to improve their own mental health and wellbeing in the face of the unpredicted levels of stress they experience.

As such, we are calling for a National FASD Strategy that would work with partners to co-develop evidence-based prevention programs, diagnostic services and interventions to reduce the prevalence of FASD by preventing new cases and improve outcomes for those living with this life-long disability. A National FASD Strategy is needed to ensure that Federal and provincial governments have a coordinated and informed response when seeking to prevent instances of FASD, as well as to support Canadians with FASD and their families.

What would a National FASD Strategy look like?

Canada needs a coordinated, national, evidence-based approach to address FASD that provides federal leadership and builds on the work that has already been done at the provincial, regional and community levels. This strategy should be person-centered, include first-person perspectives, be culturally appropriate for the diversity of Canada's population, and reflect the needs of Canada's northern, rural, and remote communities.

A National FASD Strategy would also ensure that critically needed multilevel supports are available for pregnant women and new mothers and their children, so that prevention of FASD that is effective, respectful and addresses social determinants of health. Diagnostics for FASD in Canada are currently lacking, despite the fact that early diagnosis and the identification of appropriate interventions can help mitigate the onset and/or severity of adverse health and

psychosocial outcomes. A National Strategy would help enforce a coordinated approach to early and accurate diagnoses. This would also provide for a mechanism for entry into intervention and support services, and ensure that access to this is equal across the provinces and territories.

As Canada's first and only comprehensive national FASD research network, which currently collaborates with national entities, researchers, graduate students and practitioners across the country, the Network is uniquely positioned to lead the development of a National FASD Strategy. Our Network is committed to working with the federal government to leverage our current system with better coordination and learning across Canada, to ensure that Canadians from coast-to-coast can access a continuum of quality supports throughout their lives.

Four Areas of Focus for a National FASD Strategy

- A federal/provincial/territorial cross-governmental approach that ensures action is coordinated across ministries, agencies, and programs, including health, education, justice, child welfare, employment, housing, and research with a focus on screening and identification in early childhood.
- Federal funding to develop and implement a pan-Canadian FASD Prevention and Support Helpline to provide people, including pregnant women across Canada, with access to multi-lingual, culturally appropriate, 24/7 support from trained responders, using the technology of their choice (voice, text, or chat).
- Federal leadership in areas of federal jurisdiction to ensure FASD-informed knowledge exchange, dissemination, policy, and practice.
- Recognition of, and funding to, CanFASD as the only national organization that has the capacity, experience, network, and data to do this work on behalf of families, individuals, service providers, and researchers, and in partnership with federal, provincial, and territorial governments.

About the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD)

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) is a collaborative, interdisciplinary research network, with collaborators, researchers and partners across the nation. It is Canada's first comprehensive national FASD research network, which started as an alliance of seven jurisdictions.

CanFASD's primary focus is on supporting work that sets the foundation for the development of effective, evidence-based programs and policies. By bringing together invested stakeholders, including Canada's top FASD researchers, parents and caregivers, clinicians, front line service providers, community advocates, civil servants, political leaders, and people with FASD, CanFASD is fostering the development of high impact initiatives around prevention, diagnosis, and intervention for FASD as well as the knowledge exchange activities to support and promote them.

We believe that CanFASD is the only organization in Canada equipped with the expertise and resources to coordinate the development and implementation of a National FASD Strategy, and to do so effectively, efficiently, and equitably.