



**Written Submission for
Pre-Budget
Consultations in
Advance of the 2021
Budget**

By: Kathy Unsworth, Managing Director
August 2020

Recommendation

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

Executive Summary

Fetal alcohol spectrum disorder (FASD) is the leading cause of neurodevelopmental disability in Canada, affecting 4% of the population. This means that **over 1.4 million Canadians are living with FASD today.**

The **economic impact of FASD** across sectors in Canada, including health, justice, social services, and education, is estimated at **\$9.7 billion.**

This proposal outlines how a National FASD Strategy will provide an **economic opportunity** to reduce the resource burden on taxpayers in Canada while also addressing the government's commitments to improving the health and social status of vulnerable Canadians.

The National Alcohol Strategy Advisory Committee recently updated its strategy and identified **FASD as a priority**; a letter sent to the Minister of Health in January 2020 included these recommendations.

Canada can do a better job supporting people with FASD and their families. Currently, **individuals with FASD experience significant adverse outcomes and disabilities.** Ninety percent of individuals with FASD also have mental health issues. These individuals struggle in school, at work if they are able to find appropriate employment, and often end up in and out of corrections facilities that are not structured to support or remediate someone with a brain injury such as FASD.

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. FASD is a Canadian responsibility.

A National FASD Strategy should be person-centred, 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.

The federal government has an opportunity to provide strong leadership to address FASD in a way that reduces the high costs associated with the disability. **CanFASD 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.**

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol.

FASD is a lifelong disability.

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.

Why Does Canada Need an FASD Strategy?

A National FASD Strategy is a pathway to address the complexities of FASD by involving multiple sectors and partners, governments, clinicians, practitioners, researchers, community-based support organizations, and businesses. It inspires government organizations from health, mental health, education, social services, children's services, justice, employment, and housing to work together around common understandings and goals. A National FASD Strategy is a statement of leadership and commitment to Canadians and particularly those with compromised social determinants of health.

FASD is the leading cause of neurodevelopmental disability in Canada and a major health and social issue, affecting 4% of the population or over 1.4 million Canadians. The prevalence of FASD is greater than Down Syndrome, Cerebral Palsy, and Autism *COMBINED*. The rates of FASD are even higher in populations with compromised social determinants of health (i.e., children in care, Indigenous peoples, and justice and corrections populations) and families are in dire need of support. Despite these increased numbers, FASD remains largely unrecognized by public policy and programs and individuals' and families' needs remain unmet.

The economic impact of FASD across sectors in Canada is \$9.7 billion, of which the criminal justice system accounts for 40%, health care 21%, education 17%, social services 13%, and others 9%. This cost places a large burden on both families and taxpayers.

The highest contributor to the overall cost of FASD across all sectors is the lost productivity due to morbidity and premature mortality. The second highest cost is from corrections (not including costs of policing and courts) and the third highest contributor is health care. Other costs include children and youth in care, supportive housing, long-term care, the need for special education, and community or personal support.

The annual cost per case of FASD is estimated at \$27,000 and the incremental cost per case of FASD over a lifespan is estimated at \$1.1 million, suggesting the social return on investment in the prevention of FASD to be \$1.1 million for each prevented case.

Intangible costs, such as pain, suffering, stress, and stigmatization, are very difficult to quantify, but are also significant. These intangible costs are borne not only by the individuals with FASD themselves, but also by other family members, and the community.

Many of the costs associated with FASD can be reduced with the implementation of effective leadership for social policies and intervention and support programs.

Investing in a National FASD Strategy that includes evidence-based best practices in the areas of prevention, diagnosis, and intervention supports and services will provide an economic opportunity to reduce the resource burden on taxpayers in Canada and provide vulnerable Canadians with the support they need.

Why Now?

Canada cannot afford to wait any longer to address FASD at a national level. COVID-19 has reminded Canadians about the critical role of public health and prevention in maintaining our health and well-being. COVID-19 has also raised awareness of the link between mental health and substance use, including alcohol. The government must now continue to uphold these public health standards and principles, while developing and implementing a plan for economic recovery. A National FASD Strategy can support both of these goals.

Individuals with FASD experience significant adverse outcomes and disabilities. Ninety percent of individuals with FASD also have significant mental health issues, which often includes multiple co-occurring conditions. These individuals struggle in school, at work if they are able to find appropriate employment, and often end up in and out of corrections facilities that are not structured to support or remediate someone with a brain injury such as FASD. A National FASD Strategy would provide the provinces and territories with evidence-based standards to support Canadians with FASD to reach their full potential and achieve better outcomes. Without this strategy, we are leaving individuals with FASD and their families out of our social contract, hurting health, education, and economic outcomes for them and for all Canadians.

FASD has been recognized as a priority by the National Alcohol Strategy Advisory Committee. A letter sent to the Minister of Health in January included the following recommendations:

- The federal government should provide leadership on FASD by funding research and providing evidence-based messages about FASD.
- The federal government should provide new funding to develop strategies to address risk factors associated with FASD, and to improve interventions for those at higher risk of FASD because of compromised social determinants of health.

What would a National FASD Strategy look like?

Vision: That Canada becomes a global leader in the prevention of FASD and that Canadians with FASD and their families have full and equitable access to the resources they need across the lifespan to reach their full potential and achieve healthy outcomes.

A National FASD Strategy would name the partners, what their role would be, and how they need to work collaboratively to comprehensively and effectively address the complexities of FASD. The Strategy would recognize the federal, provincial, and territorial jurisdictions, and the areas of collaboration. It would give meaning to the important scientific research and Canadian evidence being generated by the FASD research community, and specifically by CanFASD. It would identify gaps in policy and funding and highlight best practices in all the multi-sectors to effectively address them.

Principles to guide a National FASD Strategy:

- Evidence-based to reflect current best practices
- FASD- and trauma-informed to reflect needs over a spectrum and lifespan
- Inclusive of pan-Canadian stakeholders
- Inclusive of individuals with lived experience.
- Inclusive of a unique and self-determined Indigenous approach
- Reflective of regional needs and differences, including language, especially rural, northern, and remote communities and vulnerable Canadians

Four Areas of Focus

- 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.
- 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.

Plan for Immediate Action

CanFASD to work with federal, provincial, and community FASD stakeholders to: establish a National FASD Strategy Think Tank; to identify key issues, gaps, and strengths in the current system; to identify the roles and requirements of partners and stakeholders at each level and; to use this information to inform a National FASD Strategy.

Establish an FASD research and training fund through the Canadian Institute of Health Research (CIHR) in partnership with CanFASD to further develop the evidence for policy and practice.

Translate research and evidence into knowledge and information for all Canadians that supports work across disciplines and programs and builds consensus on preventing and supporting individuals with FASD effectively.

What has been done so far?

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. These documents and recommendations are still relevant today and CanFASD would build on this important foundational work.

Who is the Canada FASD Network (CanFASD)?

The Canada FASD Network (CanFASD) is Canada's first and only comprehensive organization to support this country's leadership in addressing the extraordinary complexities of FASD. CanFASD is a national, charitable organization with a mission to produce multidisciplinary, collaborative evidence that can be shared with all Canadians, leading to prevention strategies and improved outcomes for people affected by FASD.

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 living 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.

Many countries follow the work of CanFASD, use our resources, and build on our research. Key projects have included the development of a National FASD Database that is the only one of its kind in the world, a recent national social media campaign regarding the risks of increased alcohol use and unprotected sex during the COVID-19 pandemic, and the development of the only prevention and intervention frameworks that are used around the globe. CanFASD's excellent reputation with provincial and territorial policy makers for being responsive, thoughtful, and for producing quality work demonstrates our capacity to lead this proposed initiative.

CanFASD is the only organization in Canada equipped to do this critical work, effectively, efficiently and equitably.