



**Written Submission  
for Pre-Budget  
Consultations in  
Advance of the 2020  
Budget**

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## **Recommendation**

That a federal investment of \$20 million over 4 years, with \$1 million a year ongoing thereafter, be made to fund the Canada FASD Network to begin addressing the complexities of FASD from a national perspective through the development and implementation of 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).

\*Budget 2019 provided \$25 million over five years, starting in 2019–20, with \$5 million per year ongoing, to support a suicide prevention service. The Pan-Canadian FASD Prevention and Support Helpline will use a similar model and will benefit from the experience, technology and partners of the Suicide Prevention Service in order to best leverage and utilize past, present and future federal investments.

## Executive Summary

Fetal alcohol spectrum disorder is a major public health issue in Canada, affecting 4% of the population. This means **over 1.4 million Canadians are living with FASD today**. While other disabilities are also important, the prevalence of FASD is greater than autism, cerebral palsy and Down's syndrome combined.

The **economic impact of FASD** across sectors in Canada, including health, justice, social services and education is estimated at \$9.7 billion. 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 is \$1.1 million for each prevented case.

Investing in evidence-based best practices in the areas of prevention, diagnostic and intervention supports and services will provide an **economic opportunity** to reduce the resource burden on taxpayers in Canada.

FASD is preventable and women who consume alcohol during pregnancy need support to reduce their alcohol intake and reduce the number of cases of babies born with FASD. A **Pan-Canadian FASD Prevention and Support Helpline** will provide people across Canada with access to bilingual, 24/7, support from trained responders, using the technology of their choice (voice, text or chat). This service will leverage and build on existing services and experiences of partners and stakeholders dedicated to FASD prevention and support services.

**Individuals with FASD experience significant adverse outcomes and secondary disabilities.** Ninety percent of individuals with FASD also have mental health issues. These individuals also 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.

**Individuals who get early diagnosis and intervention and are well supported can be productive citizens.**

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 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.**

## 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.*

## Who is the Canada FASD Network (CanFASD)?

The Canada Fetal Alcohol Spectrum Disorder Network (CanFASD) is Canada's first comprehensive organization to support this country's leadership in addressing the extraordinary complexities of Fetal Alcohol Spectrum Disorder (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 research that sets the foundation for the development of effective, evidence-based programs and policies. By bringing together invested stakeholders—including researchers, parents and caregivers, clinicians, front line service providers, community advocates, program planners, 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.

## How Many Canadians Have FASD?

FASD is a major public health issue in Canada, affecting 4% of the population<sup>1</sup>. This means ***over 1.4 million Canadians are living with FASD today***. While other disabilities are also important, ***the prevalence of FASD is greater than autism, cerebral palsy and Down's syndrome combined***.

Binge drinking among women of child-bearing age is at an all-time high<sup>2</sup> and 61% of women have unplanned pregnancies.<sup>3</sup> Ten percent of Canadian women report drinking during pregnancy. Recent data from the Centre for Disease Control report that this number is increasing, and more women are drinking during pregnancy.<sup>4</sup> All of these conditions make the risk of having an alcohol exposed pregnancy higher than it has ever been. Awareness and support are key to reducing this risk.

The sole cause of FASD is alcohol exposure during pregnancy, thus FASD can affect individuals of all ages, genders, and cultural and socioeconomic backgrounds. However, because of a complex combination of personal and environmental factors, some populations may be at a higher risk for FASD.

### *Children in Care*

Children in the welfare system, foster care, and orphanages around the world have been the focus of much of the FASD prevalence research to date. Because many children who are removed from their biological homes experience parental substance use<sup>5</sup>, it is believed that they are at a higher risk for prenatal alcohol exposure (PAE) and FASD.<sup>7,8</sup> Researchers have previously shown that the majority of children assessed for FASD do not live with their biological parents.<sup>7</sup>

In Canada, researchers estimate the prevalence of FASD among Canadian children in care to be at least 3-11%.<sup>6,9-10</sup>

### *Justice and Corrections Populations*

Legal issues are a commonly experienced adverse life outcome for people with FASD, as victims, witnesses, and offenders. Researchers have noted that 60% of adolescents and adults with FASD reported contact with the justice system and 35% reported incarceration for a crime at some point during their lives.<sup>11</sup> Over representation of Indigenous people in the justice system in Canada is well documented and must be consciously considered in policy considerations to address this issue effectively and entirely.

Canadian researchers have estimated that youth with FASD are 19 times more likely to be incarcerated than youth without.<sup>12</sup> The estimated prevalence of FASD in Canadian offenders is 11-23% for youth and 10-18% for adults<sup>13</sup>, warranting practice and policy considerations to address the vulnerability of this group.

### *Indigenous*

There is limited Canadian evidence on the rates of FASD in Indigenous groups, and results range widely and depend on the population: 0.7% of young children living off-reserve in Western provinces<sup>14</sup>, 3.3% of children in the Yukon and northwestern BC<sup>15</sup>, 5-10% of children from a Manitoba First Nations community<sup>16</sup>, 19% of children from an isolated BC First Nations community<sup>17</sup>, and 27% of young offenders in BC<sup>18</sup>. Drawing conclusions based on these mixed research findings could further perpetuate the marginalization experienced by Indigenous children, women, families, and communities.

**Based on the Canadian prevalence rate of at least 4% of the population, there is an immediate and urgent need to address the prevention of FASD and the development of services and resources to support the high number of individuals living with this disability.**

**CanFASD will also use this funding and the evidence generated from this work to continue to address TRC Recommendations #33 and #34.**

## **The Economic Impact of FASD**

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%.<sup>19</sup> This cost places a large burden on both families and taxpayers.

The **highest** contributor to the overall cost was the cost of productivity losses due to morbidity and premature mortality. **Second highest** was the cost of corrections (not including costs of policing and courts) and the **third highest** contributor was health care. Other direct costs include children and youth in care, supportive housing, long-term care and the need for special education and support.

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 their parents/caregivers, siblings, and other family members.

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 is over a million dollars for each prevented case.

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

CanFASD believes that investing in evidence-based best practices in the areas of FASD prevention, diagnostic and intervention supports, and services will build competency and capacity, and provide an economic opportunity to reduce the resource burden on taxpayers in Canada.

CanFASD will work with Employment and Social Development Canada, Employment, Workforce and Labour and other federal departments to develop and implement training programs for individuals with FASD to provide them with skills and opportunities to become gainfully employed and to improve their social determinants of health and thereby their outcomes.

## **How Will a Pan Canadian Prevention Helpline Help to Prevent FASD?**

FASD is preventable and women who consume alcohol during pregnancy need support to reduce their alcohol intake and reduce the number of cases of babies born with FASD. A pan Canadian FASD Prevention and Support Service will provide people across Canada with access to bilingual, 24/7, support from trained responders, using the technology of their choice (voice, text or chat). This service will leverage and build on existing services and experiences of partners and stakeholders dedicated to FASD prevention and support services.

A systematic review of predictors of *any* drinking during pregnancy identified two consistent factors: previous exposure to abuse or violence and pre-pregnancy alcohol consumption.<sup>20</sup> Other risk factors for alcohol consumption during pregnancy identified over the past three decades

include increased maternal age, higher maternal education levels, and maternal smoking.<sup>21-22</sup> Evidence from hundreds of empirical studies, meta-analyses and systematic reviews have shown that brief intervention and support in a range of settings are an effective strategy for reducing harmful or risky alcohol use, other substance use, and related issues.<sup>23-26</sup>

These risk factors demonstrate a need for a Pan Canadian FASD Prevention and Support Helpline with trained health care professionals that can help identify women who are at higher risk of consuming alcohol during pregnancy through screening and provide non-judgemental information, brief counseling and support that is collaborative, recognizes women as experts in their own lives and supports health, safety and resiliency.

**A pan Canadian FASD Prevention Helpline will provide people across Canada with access to bilingual, 24/7 support from trained responders, using the technology of their choice (voice, text or chat) to reduce their alcohol intake and reduce the number of cases of babies born with FASD.**

**CanFASD will work with provincial, territorial and community counterparts, including First Nations, Inuit and Métis groups to ensure that all information and support is culturally appropriate and accessible for all Canadians.**

## **Diagnosis and Evidence-Based Interventions to Improve Outcomes**

Individuals with FASD experience significant adverse outcomes and secondary disabilities. Ninety percent of individuals with FASD also have mental health issues.<sup>11</sup> These individuals also 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. It is estimated young people with FASD are 19 times more likely to be incarcerated than those without.

Early diagnosis and the identification of appropriate supports can help mitigate the onset and/or severity of adverse health and psychosocial outcomes, while also eliminating many of the direct costs associated with FASD. Early and accurate diagnoses provide a mechanism for entry into intervention and support services, resulting in a higher return on investment for health systems and programs.<sup>27</sup>

**Individuals who get early diagnosis and intervention and are well supported can be productive citizens.**

**CanFASD will work collaboratively with stakeholders in the mental health field as well as the provinces and territories, to leverage the federal government's 2017 investment of \$5 billion over 10 years to support mental health initiatives, ensuring that the unique and complex needs of individuals with FASD are understood and met.**

**References available upon request.**