



Written Submission for the Standing Committee on Social Affairs, Science and Technology on the study of Bill S-253 *An Act respecting a national framework on fetal alcohol spectrum disorder*

On behalf of  
The Canada Fetal Alcohol Spectrum Disorder Research Network

April 2024

## **CanFASD strongly supports Bill S-253 *An Act respecting a national framework for fetal alcohol spectrum disorder.***

### **Context: Why do we need a National FASD Framework 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 1.5 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.

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.

***Bill S-253: The national framework must identify measures to promote research and intergovernmental information-sharing in relation to the prevention and diagnosis of fetal alcohol spectrum disorder and support measures for those who are impacted by it.***

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. Individuals with autism have much easier access to diagnostic and support services, allowing them to reach their full potential. Individuals with FASD do not. *“FASD diagnosis is a pathway to supports and all Canadians should have equitable access to the both.”* – FASD Caregiver and CanFASD 2023 Conference Attendee

***Bill S-253: The national framework must include measures to address the training, education and guidance needs of health care and other professionals regarding the prevention and diagnosis fetal alcohol spectrum disorder and support measures for those who are impacted by it.***

The National FASD Framework 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. *“We need knowledge and awareness of FASD in Nova Scotia in order to increase capacity for diagnosis and intervention in the province.”* – Allan Mountford, Fetal Alcohol Nova Scotia

***Bill S-253: The national framework must set out national standards for the prevention and diagnosis of fetal alcohol spectrum disorder and for support measures for those who are impacted by it.***

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. *“If I had a magic wand, everyone would know I have FASD and they would know how to support me.” – Individual with FASD*

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. *“Consistency is needed, in order to ensure that every province and territory receives the same message about alcohol use during pregnancy and FASD.” – CanFASD 2023 Conference Attendee*

***Bill S-253: The national framework set out a strategy to increase awareness of the risks of alcohol consumption during pregnancy and the consequences of fetal alcohol spectrum disorder, including by recommending changes to legislative and policy frameworks related to alcohol consumption and marketing.***

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.

***Bill S-253: The national framework must identify any other measures that the Minister considers appropriate to prevent fetal alcohol spectrum disorder, ensure that individuals with fetal alcohol spectrum disorder are properly diagnosed, and promote better outcomes for those individuals, their families and their caregivers.***

## **What has Canada done so far?**

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, or Framework of any sort.**

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.

Finally, in October 2022, Bill S-253 *An Act respecting a national framework for fetal alcohol spectrum disorder*, was introduced in the Senate. This Bill has brought hope to the FASD community in Canada.

CanFASD strongly supports this important Bill and recommends its swift passage.

## **What are other countries doing?**

### ***FASD in Australia***

With a foundation of Canadian research, the Australian government has committed more than \$75 million dollars to address FASD since 2012. In recognition of the need for improved diagnosis of FASD in Australia, the Australian Government funded the development and dissemination of The Australian Guide to the Diagnosis of FASD in 2016. These diagnostic guidelines were based heavily on the Canadian diagnostic guidelines. Since the release of the Guide in 2016, significant progress in Australia has been made towards consistent diagnostic practices and improving diagnostic capacity of FASD. Recently, \$24 million was invested in diagnostic and support services and Australia is now undertaking a review of the Guide that will also look at identifying opportunities for improvement that will maximise guideline uptake and impact in policy and practice.

### ***FASD in UK***

Finally, after many years of calls for policy engagement public health agencies are aligning on the seriousness of FASD. In 2021, the UK's first prevalence study from the University of Salford showed 2-4% of young people had FASD (a rate higher than autism). Across the general population these figures are thought to be higher (3.25-5%), and within specific vulnerable groups, such as those who are care experienced, it is understood that this could be much higher. For many, and for too long, FASD has been unrecognised or misdiagnosed.

In March 2022, the National Institute for Health and Care Excellence (NICE) published standards which set out how health and care services can improve the diagnosis, assessment, and prevention of fetal alcohol spectrum disorder (FASD). The introduction of the NICE quality standards for FASD marks a significant step change in recognising the condition in England and Wales.

NICE's quality standard, highlights five key areas for improvement:

- Pregnant women are given advice throughout pregnancy not to drink alcohol.
- Pregnant women are asked about their alcohol use throughout their pregnancy, and this is recorded.
- Children and young people with probable prenatal alcohol exposure and significant physical, developmental, or behavioural difficulties are referred for assessment.
- Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.
- Children and young people with a diagnosis of FASD have a management plan to address their needs.

### **FASD in New Zealand**

Again, using the Canadian Diagnostic Guidelines, New Zealand has recently elevated them to include cultural context for their Indigenous populations. While Canada has historically provided leadership, particularly around diagnosis, we are now falling behind while other countries use this evidence and work to move forward in addressing and supporting their entire population. The **Aotearoa FASD Diagnostic Guidelines** will be published and promoted shortly by the Government's Ministry of Health.

## **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.*