Submission to Standing Committee on Health in regards to its study on children's health
On behalf of the Canada Fetal Alcohol Spectrum Disorder Research Network

Fetal Alcohol Spectrum Disorder (FASD) affects 4% of Canadians, more than autism, cerebral palsy, and Down syndrome combined. Approximately 300,000 children in Canada have FASD, and this number is higher in populations with trauma and compromised social determinants of health. FASD is a lifelong disability that impacts the brain and body of someone who was exposed to alcohol during fetal development. People with FASD have areas of both strengths and challenges and will need supports to help them succeed in their daily lives.

Children with FASD often have problems with learning, attention, memory, and problem solving, along with poor coordination, impulsiveness, and speech and hearing impairments. As children with FASD grow up, school behaviors, emotional, and social problems often get worse, which exacerbates the mental health challenges they are predisposed to. Early assessment, diagnosis, and intervention are critical protective factors against these adverse outcomes. Recent studies show, when unsupported, 90% of people with FASD will experience mental health issues. They are over 20 times more likely to face substance use challenges. And 35% of teens with FASD report suicidal ideation, with 13% reporting at least one serious suicide attempt in the past year. Individuals with FASD are also disproportionately represented in the child welfare and criminal justice systems.
Individuals with FASD function more adaptively and experience fewer adverse life outcomes when their living environments are stable, provide structure, are free from violence and when their basic needs are met. The COVID-19 pandemic created an ongoing sense of instability, stress, and social isolation for children across Canada, including those with FASD. Without dedicated interventions, it is the Network's concern that these tensions will have long-term impacts on children with FASD and their families and exacerbate the challenges they already face.

Background

Researchers have suggested that the global prevalence of FASD among elementary school students may be underestimated. FASD can be difficult to diagnose in early and middle childhood for many reasons, such as challenges in accessing diagnostic services and difficulty detecting impairments across multiple domains of functioning at an early age. Also, many features impacted by FASD, such as executive functioning and verbal reasoning are not seen in typically developing children until at least 12 years of age. Additionally, there are reports of high rates of comorbidities in children with FASD. For instance, overlapping symptoms between FASD and Attention Deficit Hyperactivity Disorder (ADHD) and FASD and Autism Spectrum Disorder (ASD), have been documented.

It is crucial to understand the early presentation and distinguishing components of FASD in order to have networks in place prior to school entry to optimize current supports, alert educators and families to future assistance that may be warranted, provide information to facilitate long-term planning, and ensure access to funding, as appropriate. Combining these supports set children with FASD up for success in learning and other aspects of their life and development. Further research to inform policy and practice in developing analytical methods that distinguish FASD characteristics at a young age can contribute to more effective and timely diagnostic approaches and early intervention initiatives.

Early detection of FASD, as with other disabilities, has been associated with reduced risk for adverse outcomes. In general, detection is crucial prior to entering school as this influences the accommodation and special education opportunities, that helps to create a healthy educational trajectory of a child, as well as affecting health into adulthood. There is a lack of a clear understanding about certain neurodevelopmental disabilities, such as FASD, especially regarding their presentation or unique characteristics early in life. This is due in large part to limitations in neuropsychological assessment measures and the range of adverse environmental factors that impact development such as multiple foster placements and history of abuse.

Identifying and diagnosing FASD in young children is complicated by the high rates of early life adversity noted for this population. Experiencing early life adversities, such as exposure to abuse, neglect, and household dysfunction tends to predict poor physical and mental health outcomes in the general population. The deleterious neurodevelopmental outcomes associated with early life adversity tends to be more severe for children with prenatal alcohol exposure, placing them in “double jeopardy.”

The presence of these factors and the associated stigma may make diagnosis of FASD even more difficult, thereby further elevating the vulnerability of this population—underscoring the importance of early detection. For example, compared to patients with FASD from stable home environments, patients with FASD who live in unstable homes are at a greater risk for disrupted school experiences, trouble with the law, and alcohol and drug problems. Early identification creates opportunities for early intervention that may mitigate these risks.

Waiting lists for diagnostic assessment are long, with children and families in some provinces and territories waiting as long as 2 years before the pandemic, if they have a diagnostic clinic within their vicinity. If they don’t, they are forced to travel outside their province to seek answers and support. Post pandemic, waitlists will be even longer, with healthcare services that were not available trying to catch up on over 2 years of unserved case load.

Clinicians may be hesitant to undertake FASD assessments in young children as a result of inherent clinical challenges, however, failing to identify children at an early age may limit their developmental potential.

An uninformed workforce means that children struggle and often go unidentified and the opportunity for early intervention to optimize outcomes is missed. Training for clinicians and front-line service providers, including social workers and mental health and addictions support workers, to screen for, diagnose and develop plans for interventions and support would begin to address this gap in the FASD system.

Gaps in funding, training, policy and practice, are preventing children with FASD and their families from reaching their full potential. Although children across the country have suffered from increased stress and social isolation due to the COVID-19 pandemic, the impacts on children with FASD are difficult to estimate. The creation and implementation of a comprehensive National FASD Strategy is critical to address all of these issues, and ensure that children with FASD receive the supports they need.

Recommendations

Putting children first means meeting the growing and urgent demand for timely access to FASD diagnosis so that children and youth do not suffer lifelong consequences as the result of delayed assessments, diagnoses and interventions. It means positioning Canada as a world leader with respect to children's health and FASD research.

While many Canadians believe our country is one of the best in which to raise a child, UNICEF reported in 2020 that the health and wellbeing of Canadian children ranked 30th of 38 OECD countries. Not only is our performance relatively poor, Canada's ranking continues to drop. Countries who invest in their children reap tremendous long-term economic and social payoffs. The time has come for Canada to invest in the future, and to invest in the health of all children and youth, including those with FASD.

As such, the Canada Fetal Alcohol Spectrum Disorder Research Network recommends that the Government:

1. Fund the creation and implementation of a comprehensive National FASD Strategy, with a scope that includes:
   -a trained workforce to detect children at risk of having an FASD through screening and improving diagnostic capacity across the country; and
   -evidence-based supports for these children and their families to improve outcomes.
2. Recognize the unique needs of children with FASD, and the impact of the COVID-19 pandemic on their wellbeing, by providing tailored supports for children with FASD and their families.