Landscape Paper
Fetal Alcohol Spectrum Disorder (FASD) in Newfoundland & Labrador

Executive Summary

Fetal alcohol spectrum disorder (FASD), caused by prenatal exposure to alcohol, permanently impairs cognitive, behavioural, social and emotional development. Individuals with FASD often live with lifelong challenges such as impulsive behaviours, poor time and money management, and difficulty thinking through sequential consequences of actions. In Canada, people *diagnosed* with FASD – representing only a fraction of people actually living with the condition – are overrepresented in the foster care system and as repeat offenders in the correctional system, and there is a disproportionately higher rate of diagnosis in Aboriginal communities.

Prevalence studies suggest that the most conservative estimates for people living with FASD are 1% of the general population, making FASD the leading cause of developmental disability with lifelong effects in Canada. The social stigmas associated with FASD for both the birth mother as well as the person diagnosed, however, is one of the primary reasons few people seek a diagnosis. Additional reasons include the lack of screening policies and training that would facilitate a diagnostic referral, the lack of places to refer someone for an assessment, and the uncertainty that an FASD medical diagnosis will improve access to supports and services.

Effectively addressing FASD requires a multi-pronged approach. FASD prevention work is critical to reduce the number of people living with FASD in the future; FASD diagnoses are valuable in informing how people can interpret behaviours, create nurturing environments, and set realistic expectations; and effective FASD interventions and supports from infancy to adulthood can dramatically improve one's chances at participating and contributing more fully in community.

This landscape paper provides a brief overview of what is known about best practices in FASD prevention, diagnoses, and interventions. There is FASD work being done in different pockets of Newfoundland and Labrador (NL) and the fasdNL Network is the first organization that has been formed to better collaborate and share ideas, resources, and projects across the province. By building on existing relationships with other Atlantic and national FASD working groups and networks, NL can benefit from being involved in national initiatives and partnerships.

Three recommendations moving forward related to FASD responses in Newfoundland and Labrador are:

1. Establish a permanent part-time consultant position with the fasdNL Network to coordinate pan-provincial FASD training, initiatives, support, resource sharing, and other interdisciplinary collaborations.
2. Identify a Mental Health and Addictions Consultant at the Department of Health & Community Services to join the fasdNL Network as a board director.
3. Expand FASD teams responsible for conducting diagnostic screening/assessment and providing supports similar to that offered through the Labrador Grenfell Regional Health Authority. These teams should be accessible to all residents of NL.

1. What is FASD?

Fetal alcohol spectrum disorder (FASD) is the leading known cause of developmental disability with lifelong impacts in Canada[1]. Alcohol contains teratogens that disturb the development of a fetus, affecting the central nervous system (CNS) cell growth that is necessary for normal fetal development[2 3]. *Primary disabilities* from FASD include language comprehension deficits, impaired adaptive skills, poor impulse control and judgment, poor executive functioning, and restricted physical growth[4-6]. *Secondary disabilities* associated with FASD result from prolonged discrepancy between societal expectations imposed upon an individual with FASD and their inability to meet these expectations without support – most common among youth and adults with FASD – and include mental illness, substance use, involvement with the law, housing and job insecurity[6-8].

1.1 Diagnostic Categories

FASD is a diagnostic term related to the effects of alcohol on fetus and includes FASD with sentinel features, FASD without sentinel features or at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. This replaced the previous criteria which included the following four specific diagnosis: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD)[12 58].

1.2 Prevalence of FASD

There are currently no confirmed statistics on the number of people who have FASD in Canada. The most commonly cited estimate is 9.1 per 1000 live births or roughly 1% of the population[9]. The Centre for Addiction and Mental Health (CAMH) is currently conducting a prevalence study to estimate the number of Canadians living with FASD. Determining the prevalence is a challenging and complex undertaking for a number of reasons:

- Currently, there are few FASD screening policy for newborns[10].
- Individuals are usually diagnosed later in life when symptoms such as learning disabilities and challenging behaviours emerge[11].
- Diagnostic assessments include disclosure from birth mothers that alcohol was consumed during their pregnancy[12].
- FASD diagnostic teams are not available in many parts of Canada[13].
- How an FASD diagnoses will improve access to needed supports and services is highly varied.
- Most people who have been diagnosed (to date) are children in care, adults in the correctional system, and targeted Aboriginal communities that have self-identified FASD as an area to address[1 14-17].

1.3 Cost of FASD

Based on the currently accepted and conservative prevalence rate of 1%, the annual cost of FASD in Canada has been estimated at approximately $2 billion[18]. The highest cost drivers are the direct health care costs, law enforcement, children and youth in care, supportive housing, long-term care, special education, addiction treatment, and loss of productivity[19 20].

2. Summary of Research & Best Practices on FASD

2.1 FASD Prevention

FASD prevention research shows that effective strategies must be aimed at different groups including pregnant and non-pregnant women at risk of an alcohol exposed pregnancy (AEP); medical and allied professionals that can screen and support people in (or at risk of) an AEP; policy makers; and the general population[21]. It is estimated that approximately 40% of all pregnancies in Canada are unplanned and approximately 52% of women of childbearing age consume alcohol[22 23].

***Best Practices in FASD Prevention*:** Research evidence supports addressing FASD prevention at four levels: 1) broad awareness, 2) dialogue on alcohol and related risks with women of *all* childbearing age, 3) specialized support of pregnant women who are drinking alcohol, and 4) support for new mothers[24 25]. A 2010 Canadian consensus paper also outlines the following 10 evidence-informed fundamental components to FASD prevention from a women's health determinants perspective: respectful, relational, self-determining, women-centred, harm reduction-oriented, trauma-informed, health promoting, culturally safe, supportive of mothering, and using a disability lens[26].

2.2 FASD Diagnoses

The Canadian FASD diagnostic guidelines outline the need for FASD screening and referrals, physical examination, neurobehavioural assessments, maternal alcohol history in pregnancy, and using the 4-digit Diagnostic Code. To adequately and confidently make a diagnosis, a multidisciplinary team approach – comprising a coordinator for case management, a physician and/or developmental pediatrician specifically trained for FASD diagnosis, a psychologist/neuropsychologist, an occupational therapist, a speech language pathologist, and a nurse and/or social worker - is necessary[12 27 58].

***Best Practices in FASD Diagnoses*:** Best practices for FASD diagnoses are largely dependent on the availability of screening and assessment referral training for healthcare professionals; access to multidisciplinary team members; and collaborative partnerships, including those between provincial governments and local, community-based agencies. Several Canadian provinces/territories have implemented these strategies.

Alberta and British Columbia developed progressive and comprehensive 10-year plans in 2008 to address FASD[60]. As part of the supports available, the Asante Centre in British Columbia and the Lakeland Centre for FASD (LCFASD) in Alberta are two not-for-profit organizations that have been recognized for their comprehensive approaches to FASD diagnostic assessments that include ongoing case management and intervention assistance for children, youth, and adults before and after a diagnosis is made[29-31]. The Government of Alberta's 10-year FASD strategy involves multiple provincial ministries (e.g., Children and Youth Services, Health and Wellness, Education, Seniors and Community Supports) and federal agencies (e.g., Health Canada) to improve awareness/prevention, assessments/diagnosis, research/evaluation, and access to supports[59].
In the Yukon, there is the Fetal Alcohol Syndrome Society Yukon (FASSY), a collaboration

between the Child Development Centre and Yukon Education through the Child and Youth Diagnostic and Support Team, as well as ongoing research supported by the provincial government. In the Northwest Territories, there is the FASD Family and Community Support Program with an FASD Diagnostic Clinic offered through the Stanton Territorial Health Authority[63 64].

The province of Saskatchewan offers services and funding for FASD support through its Cognitive Disabilities Strategy and designated Cognitive Disabilities Consultants, and also has its own FASD Network that provides FASD-related support for families, among other community-based programming; all of which have been externally evaluated[61]. In Manitoba, The Manitoba FASD Network employs Diagnostic Coordinators, and in collaboration with the Manitoba FASD Centre, assists in the provision of assessment referrals and assessments for five health regions across the province. Various governmental departments (e.g., Education and Training, Families, Manitoba Indigenous and Municipal Relations, Justice) support these efforts as part of the provincial FASD Strategy[62].

The Centre for Addiction and Mental Health (CAMH) in Ontario is a renowned mental health and addiction hospital that employs researchers specializing in FASD and offers an Alcohol Research and Treatment Clinic (ARTC), providing out-patent and pharmacotherapy abstinence support. There are also numerous diagnostic clinics and support groups situated across the province[19]. Québec opened its first FASD diagnostic clinic in 2013 and members of the FASD Network of Québec comprise healthcare professionals, diagnostic experts/practitioners, criminal justice personnel, and youth service employees.

In Moncton, New Brunswick, the FASD Centre of Excellence was established through a joint partnership between the provincial Department of Health, several regional health authorities, and Family Service Moncton[28]. The Centre offers bilingual and culturally sensitive services from prevention to diagnosis to follow up. The FASD Centre of Excellence hosted its launch upon the completion of the updated Canadian guidelines for FASD diagnosis. As discussed in greater detail in section 3, since 2014, the Labrador-Grenfell Regional Health Authority has had a devoted, interdisciplinary FASD diagnostic team comprised of specially trained professionals who utilize FASD-specific assessment tools and data system to support the diagnosis and provision of services related to this condition. There is now an FASD diagnostic team in Happy Valley-Goose Bay and St. Anthony, conducting a combined 12 annual assessments on average.

2.3 FASD Interventions and Supports

Interventions and supports for individuals with FASD vary depending on a wide range of factors, including access to an FASD diagnosis; the age of the person (with FASD); parental support in caring for a child/youth; FASD-informed approaches in early childhood development and schooling; access to FASD-informed support and services; as well as confounding issues such as trauma, mental health, and access to nurturing home environments[14 32-37]. Due to the social stigma associated with FASD and birth mothers, it is often the case that those who are diagnosed are children 'in care' or adopted or, in the case of adults, incarcerated[17 38-40]. As such, it is common for people diagnosed within the FASD spectrum that there are comorbid diagnoses such as attention

deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD), autism spectrum disorder (ASD), and other mental health issues[41 42]. It is also common for people with an FASD diagnosis to have lived through trauma - trauma that led to foster or adoptive care, trauma as the result of FASD behaviours that were not understood, and intergenerational trauma that may negatively affect parental capacity to provide a nurturing environment for their children[15 32 35 43 44].

***Best Practices in FASD Interventions and Supports*:** Interventions and supports for people living with FASD vary on how profoundly they are impacted by FASD and their developmental stage of life (e.g. early childhood, school-age, young adult, adult). Current research suggests that best practices for children living with FASD are to provide parents, caregivers, teachers, and other service providers with FASD awareness training, supports, and skills[35 37 45 46]. There is clear evidence that early interventions are necessary to mitigate challenges that have a cascading effect and often result from misunderstanding of children's behaviours[47 48]. For adults living with FASD, it is critical that employers, service providers, and social supports use trauma and FASD-informed approaches to programs, policies, communication, routines, and expectations[8 15 49]. Common interventions and supports that are often effective for people with FASD, for example, are to break tasks into fewer steps; use visual reminders of time and daily tasks; use literal and explicit language; provide daily routine and structure; use repetitive instructions; provide supports for caregivers/mentors; and provide 'life coaches' for adults with FASD[7 8 50 51].

3. Current FASD Work in NL and at the National Level

FASD is a public health issue that can be complex to address for a number of reasons. These include its relationship to social drinking cultures, stigma and mental health and addictions, as well as limited diagnostic capacity, and the varied areas of disciplines (e.g. health, education, corrections, child welfare, and more) that should be involved in diagnoses and service provision. Despite these challenges, there have been efforts by various stakeholders in NL and across Canada to deliver much needed services for individuals with FASD.

3.1 Significant FASD-related events in NL over the last decade

In Newfoundland and Labrador there have been a number of significant FASD initiatives in the last decade. They include:

- In 2005 Dr. Rosales, pediatric geneticist (now retired) at the Janeway Hospital, was funded by Health Canada to conduct FASD assessments; train physicians, other health professionals, and allied health workers in FASD screening and diagnoses; and establish a data collection system[9].
- In 2006, an NL interdepartmental consultation and Aboriginal governments led to a report that highlighted FASD-related needs for the province with the goals of securing financial support from the provincial government for the development of programs and services[52].
- In 2008, there was a provincial multi-stakeholder conference in St. John's that brought together people from justice, health care, education, housing, child welfare, foster/adoptive families, community-based organizations, FASD specialists and municipal/provincial/federal government department representatives. This conference led to the *Out of the Basement Report*[53].

- In 2013, a provincial not-for-profit organization called fasdNL Network was established; a national FASD conference (organized by people in NL) and the FACE Research Meeting were held in St. John's.
- In 2014, two teams (Happy Valley-Goose Bay and St. Anthony) were trained by Lakeland Centre for FASD to conduct FASD diagnoses; fasdNL Network received provincial Wellness Grant funds to facilitate FASD education and training across the province; and on September 9 (FASD Awareness Day) of 2014, the NL Liquor Corporation donated $10,000 to fasdNL Network to further its efforts to build provincial capacity to address urgent issues.
- In 2015, fasdNL Network hired its first consultant (part time) as a Capacity Building Network Assistant to manage the Network's website, social media accounts, and manage initiatives. fasdNL Network was the recipient of the Wellness Grant for a second year, providing FASD training to professionals across the province.
- In 2016, fasdNL Network created a Virtual Support Group for parents and caregivers of individuals with FASD across the province to meet through telephone or video and share resources and supports. fasdNL Network launched its first annual Heart & Sole 3k Walk & Family Fun Run in various municipalities across the province to raise awareness and funds for the Network.
- In 2017, fasdNL Network received a Community Healthy Living Fund to pursue further initiatives and FASD training.

3.2 Thumbnail sketch of current FASD work in NL

The Labrador Innu and Inuit governments have prioritized having a staff person dedicated to FASD prevention, diagnostic referral, and community supports. Sheshatshiu and Natuashish each have an FASD Liaison position; Nunatsiavut Government has an FASD coordinator responsible for NG beneficiaries in HVGB and coastal Inuit communities. Labrador-Grenfell Regional Health Authority (LGH) has an FASD Coordinator to organize FASD assessment referrals, diagnostic clinic, and case management after a diagnosis. The LGH holds an FASD assessment clinic every 2 months; a team (in Happy Valley Goose Bay or in St. Anthony) will assess two individuals per clinic.

Unfortunately, on the island portion of NL (except St. Anthony's diagnostic clinic), there are no paid FASD positions. There are two active FASD committees in Newfoundland: the Central FASD and St. John's Regional FASD Committees. Both committees are comprised of diverse stakeholders ranging from parents, family resource centre staff, psychologists, child welfare workers, mental health and addictions social workers, non-profit community groups, and researchers. The work of both committees are largely driven by project funding to do FASD awareness and education, facilitate parents support groups, and holding knowledge exchange events to facilitate dialogue around best practices on FASD prevention work. Some members on FASD committees are connected to national FASD working groups.

3.3 Brief overview of current FASD work at the national level

Canada is a leader in the research field of FASD, particularly around FASD prevention work and establishing medical FASD diagnostic guidelines. Canada FASD Research Network is an organization that works closely with Health Canada, Public Health Agency of Canada, and NeuroDevNet to translate FASD research knowledge for community and policy makers. The Network has three main "network action teams" – referred to as NATs – on FASD prevention, diagnostics, and intervention. Every two years, there is a well-attended international FASD conference in Vancouver that always attracts leading researchers from around the world.

The Centre for Excellence in Women's Health (in BC), the Centre for Addiction and Mental Health, and the Institute for Health Economics have also produced a few key documents in the recent years. These organizations have evaluated prevention programs; calculated the economic cost/burden of FASD; estimated costs associated with prevention work versus supportive services and interventions; established low-risk drinking guidelines; and calculated the incidence and prevalence rates in specific geographic areas[18 20 54-57].

3.4 Integrating FASD/alcohol policy and the Mental Health and Addictions Action Plan for Newfoundland and Labrador

The Government of Newfoundland and Labrador's recently released *Towards Recovery: the Mental Health and Addictions Action Plan* outlines several short-term, medium-term, and long-term recommendations to be completed within the next five years. The fasdNL Network is encouraged to see that the four outlined policy directions align well with the present and future goals of fasdNL, as well as several of the recommendations put forth in this paper. There are clear connections related to promotion, prevention and early intervention (e.g., "prevent […] substance use and addiction problems"); focusing on the person (e.g., "reduce harms associated with substance use and mental health problems"); improving service access, collaboration and continuity of care (e.g., "create provincial policies and programs applied consistently and equitably across all regional health authorities"); and including all people everywhere (e.g., "eliminate stigma and discrimination"; "support Indigenous people with their mental wellness goals"; "incorporate accessibility and inclusion requirements into all services").

The "Building on Ongoing Work" section acknowledges the need and potential opportunities for collaboration between the government and existing agencies/organizations, such as the fasdNL Network, in moving forward with both parties' recommendations.

4. Recommendations: Priority Areas

4.1 Establish a permanent part-time consultant position with the fasdNL Network to coordinate pan-provincial FASD training, initiatives, support, resource sharing, and other interdisciplinary collaborations.

Currently there is no full-time staff person to do FASD work. A permanent part-time position would allow for facilitation of effective pan-provincial initiatives, connected to Atlantic and other Canadian networks so that the work is informed by best practices, current research, and national initiatives.

4.2 Identify a Mental Health and Addictions Consultant at the Department of Health & Community Services to join the fasdNL Network as a board director.

The fasdNL board currently does not have representation from the DHCS. This would facilitate better understanding of and connection to provincial government efforts related to mental health and addictions that might inform the work of fasdNL Network members. This representation would also connect mental health and FASD-related efforts throughout the province with the new '*Towards Recovery: The Mental Health and Addictions Action Plan for Newfoundland and Labrador'.*

4.3 Expand FASD teams responsible for conducting diagnostic screening/assessment and providing supports similar to that offered through the Labrador Grenfell Regional Health Authority. These teams should be accessible to all residents of NL.

Currently, only residents of Labrador-Grenfell Regional Health Authority have access to a diagnostic team. A multidisciplinary team approach is necessary, comprising a coordinator for case management, a physician and/or developmental pediatrician specifically trained for FASD diagnosis, a psychologist/neuropsychologist, an occupational therapist, a speech language pathologist, and a nurse and/or social worker. It is imperative that these teams be made available in more health regions across the province to increase accessibility to all NL residents.

This landscape paper was jointly prepared by the following organizations, institutions, and experts that work collaboratively to advance the work of FASD prevention, diagnosis and supports in Newfoundland and Labrador.

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fasd Central Committee

fasdNL Board of Directors*

**At the time of release of this paper, the fasdNL board of directors included representation from the following organizations:*

Sheshatshiu Innu First Nation
Nunatsiavut Government
Provincial Perinatal Program
Newfoundland and Labrador Foster Families Association
Key Assets
Exploits Valley Community Coalition
Central Regional Health Authority
Labrador-Grenfell Regional Health Authority
Labrador Correctional Centre
Community Action Committee for Southwestern Newfoundland
Stella's Circle
Memorial University of Newfoundland and Labrador
Public Health Agency of Canada (Ex-Officio)

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