

Provincial and Territorial Strategies for Fetal Alcohol Spectrum Disorder in Canada

Jessica Burns, MA; Kelly Harding, PhD; Katherine Flannigan, PhD; Kathy Unsworth, MPH, MBA; Audrey McFarlane, MBA

Canada FASD Research Network

KEY MESSAGES

Given the unique complexities of FASD, there is a need for provinces and territories to address and support the needs of people with FASD and their families through FASD-specific strategies. Currently in Canada, four provinces and territories have an operating strategy or framework in place to address FASD. Other existing provincial and territorial strategies could be updated, indirectly refer to FASD as part of a larger framework, or do not explicitly refer to FASD. Provincial and territorial strategies that are specific to FASD allow for a greater appreciation and exclusive focus on the multifaceted nature of the disability. The development and implementation of an evidenced-based national FASD strategy would serve to guide the provinces and territories on how to implement region-specific FASD strategies, while promoting national consistency of FASD research and practice. The focus of this paper was on FASD as a disability and not on FASD prevention strategies exclusively, though prevention was a recurring aspect of the FASD-specific strategies discussed (e.g., non-stigmatizing FASD prevention messaging, providing information, non-judgmental support, and services to pregnant women and women of child-bearing age).

Issue:

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe the lifelong impacts on the brain and body when an individual is prenatally exposed to alcohol [1]. An estimated 4% of the Canadian population has FASD, with impairments being widespread and unique to each individual [2]. The variation and complexity of needs associated with FASD require both a multidisciplinary diagnostic approach to identify individuals with the disability, and a comprehensive and tailored system of support across the lifespan to foster positive outcomes [3]. Despite the identified needs among this population, such as deficits in cognitive function, difficulties with activities of daily living, and mental health concerns [e.g., 4, 5], it is unclear whether and to what extent each province and territory in Canada addresses FASD through strategic plans and frameworks to best support individuals with the disability. Having provincial and territorial plans in place to strategically address public health concerns, such as FASD, allows for clear direction and goals to achieve desired outcomes. With respect to FASD, these outcomes include early diagnosis and ongoing intervention for individuals with the disability, as well as the prevention of future alcohol-exposed pregnancies.

Several provinces and territories, specifically those with FASD strategic plans, were invited to review and respond to this paper. The authors would like to thank the provincial and territorial governments who provided feedback on this paper.

The purpose of this issue paper is to share information about existing provincial and territorial strategies targeting FASD, including which provinces have (or have not) developed a strategy specific to FASD, and what these strategies include.

Background:

In Canada, four provinces and territories (Alberta, Manitoba, Ontario, and the Yukon) currently have a specific strategy or framework in place to address FASD. British Columbia and Saskatchewan previously had FASD-specific strategies; however, these are now outdated. A separate Inuit FASD strategy involving community representatives from Newfoundland and Labrador, Quebec, Nunavut, and the Northwest Territories also exists, but is similarly outdated. Though not specific to FASD, Nova Scotia incorporates FASD into its broader provincial strategy in an intersecting area (e.g., alcohol), while the Northwest Territories acknowledge a facet of FASD (i.e., research and prevalence) as part of “other related initiatives” in their disability action plan. Prince Edward Island (PEI), New Brunswick, Quebec, and Newfoundland and Labrador have existing mental health and wellness strategies; however, none of these directly refer to FASD. Nunavut is working towards a strategic disability plan. Additionally, New Brunswick is building on the experiences of other provinces and territories within the CanFASD Research Network, and is currently developing an interdisciplinary provincial strategy for FASD. Each strategy is discussed below, along with an overview of the similarities and differences across these plans.

1. Current FASD-Specific Provincial and Territorial Strategies

Alberta’s current FASD strategy is comprehensive in its approach to FASD, focusing on five strategic pillars that include public awareness and understanding, prevention, diagnosis and assessment, supports for individuals with FASD, their families, and caregivers, and organizational learning, and is built on the success and learnings of the [Alberta FASD 10-Year Strategic Plan 2007-18](#). In addition to providing detailed definitions of what is included in each area of focus, the Alberta strategy delineates the target population, the desired outcomes of the plan, and existing gaps in services and supports related to each specific area. The *Alberta FASD 10-Year Strategic Plan 2007-2017* underwent two formative evaluations: [one at 5 years](#) and [one at 7 years](#), and one final summative evaluation. These evaluations provided key findings and recommendations which have helped to further guide policies and practices for supporting Albertans with FASD while improving Alberta’s strategic model and the supports and services available across the province. The vision of a coordinated response to prevent future alcohol exposed pregnancies and a continuum of culturally informed supports across the lifespan is achieved through cross-ministerial collaboration and twelve FASD Service Networks. The strategy continues to evolve to include initiatives to support employment for individuals with FASD, explore the use of a telehealth model, development of an FASD Workforce Development Framework to enable an FASD-informed workforce across sectors, and an FASD policy framework.

The province of Manitoba first implemented an FASD strategy in 2007 and has continued to invest and expand on this strategy since its inception. Developed within an interdepartmental partnership, the Manitoba FASD Strategy functions across a wide range of areas (e.g., health, education, employment, justice, housing). Employing a lifespan approach to FASD, and guided by five main goals (i.e., Knowledge, Prevention, Intervention, Evidence, and Quality), the province outlines numerous successes across each sector from these ongoing strategic efforts in the [Together we are Stronger: Continuing the Success of Manitoba’s FASD Strategy](#)

document. Manitoba has indicated its desire to include evidence-based prevention strategies, in addition to the strategies which focus on post-diagnosis.

Informed by foundational initiatives and sources, [The Yukon FASD Action Plan](#) aims to address FASD and support families and communities using a holistic approach. The action plan identifies key contributors, guiding vision statements, principles, and seven priority areas. Each area of priority outlines an overarching goal, followed by immediate and/or intermediate actions, as well as desired outcomes. Given the recent execution of the action plan, a separate plan delineating lead persons, partners, resources (both human and financial), and timelines to further support the implementation of the action plan is being created.

Ontario's Provincial FASD Efforts

In 2017, the Ontario provincial government announced that it was committed to investing over \$26 million dollars over four years to increase awareness and prevention of FASD in the province. Six initiatives were outlined in the [budget](#) including: funding for FASD support workers; investing in parent support networks; increasing access to Indigenous-led FASD initiatives; establishing a consultation group to provide advice and feedback to inform implementation planning and prioritization efforts; and creating a research fund and investing in knowledge mobilization. Despite these commitments, as well as recognized funding in some of these areas, no formal Ontario FASD strategy has been released to the public to date.

2. Previous FASD-Specific Provincial and Territorial Strategies

British Columbia's (BC) [Fetal Alcohol Spectrum Disorder: Building on Strengths \(2008-2018\)](#) plan built upon its previous 2003 strategy and clearly described its goals for the province pertaining to FASD including guiding principles, values, and cross-government strategic objectives. As an additional layer to the BC strategic plan (2008-2018), and to ensure progress within each objective, the 2008-2018 strategy further highlighted the efforts and priorities that should take place at the levels of individual/community, professionals and service providers, policy, and research and evaluation. Importantly, the BC strategy lacks information regarding revisions to the 2008-2018 plan or development of a new strategy.

Grounded in the *Levels of FASD Prevention Framework* [7], which characterizes FASD prevention activities under four key levels to promote a comprehensive approach, [Saskatchewan's FASD Prevention Framework 2014](#) aimed to guide and facilitate FASD prevention initiatives across human sector services throughout the province. The framework primarily targeted awareness, education, and support to women of childbearing age, pregnant and postpartum women, and their support networks. For each Level, the framework outlined the target population, described the intended outcome of efforts in the specified area, addressed current gaps in service delivery relevant to each area, and indicated strategies for how to achieve desired outcomes. No information regarding revising the now outdated framework or developing a new provincial strategy was stated, but Saskatchewan maintains that their cognitive disabilities strategy continues to function, providing diagnosis and individualized support.

The [Inuit Five Year Strategic Plan for FASD \(2010-2015\)](#) was developed by Pauktuutit Inuit Women of Canada in partnership with representatives from Inuit communities in Newfoundland and Labrador, Quebec, Nunavut, and the Northwest Territories. This plan served to address FASD in the context of Inuit knowledge, attitudes, and behaviours regarding prenatal alcohol use, while acknowledging the ongoing northern health, social, and economic environmental changes. Guided by the wisdom gained from Pauktuutit member focus groups,

the Inuit plan was comprehensive, inclusive, holistic, and community-based. Its mission was to enhance FASD prevention, diagnosis, and to support the needs of individuals and families living with FASD in Inuit communities. To achieve these objectives, the plan outlined a vision, guiding principles, and eight specific goals. The plan also provided a review of Pauktuutit strengths, challenges, opportunities, and limitations to demonstrate the organization's potential in meeting priority objectives, and to better strategize for successful outcomes.

3. Strategies that Indirectly Address FASD

In addition to their prevention plan, Saskatchewan also has a cognitive disability plan which addresses FASD. Saskatchewan's *Action Plan for Citizens with Cognitive Disabilities* [6] includes FASD as a main element in this framework, which aims to support individuals (aged 0 to 24 years) with cognitive disabilities who have behavioural and developmental concerns. In an effort to address existing service gaps, the strategy identified areas of priority that required attention and financial investment. FASD was included as one of the three priorities of action described in this plan (i.e., strengthening FASD prevention and intervention), highlighting the province's commitment to FASD prevention, support, assessment, and diagnosis. For each of the three priorities of action outlined in the plan, an overview of the priority, followed by in depth discussions of the various initiatives that were to be launched, and where these would take place, were presented. Saskatchewan's cognitive disability strategy continues to function, providing access to diagnosis and individualized supports.

In its broad population-based strategy for reducing alcohol-related harm, Nova Scotia's [*Changing the Culture of Alcohol Use \(2007\)*](#) targets high risk drinking patterns, such as drinking and driving and alcohol consumption during pregnancy. The strategy acknowledges the importance and need to shift public awareness to recognize FASD as a community responsibility, though no specific steps on how this will be achieved are described. Drinking during pregnancy is addressed in specific areas within the strategy, including in the priorities for action (e.g., address alcohol consumption when planning a pregnancy or during a pregnancy). One of the strategy's intermediate outcomes (3-7 years) is to reduce alcohol consumption among women who are planning a pregnancy or who are pregnant. Beyond these specific areas, there is no direct mention of efforts to address or support individuals in the context of prenatal alcohol exposure or FASD.

[*The Government of the Northwest Territories Disability Action Plan 2018/19- 2021/22*](#) addresses the multifaceted nature of "disability" by providing a wide scope of strategic objectives and actions across multiple areas (e.g., physical and cognitive disabilities). Within each objective, the main lead, specific activities and timelines, and the related outputs and outcomes are presented. The action plan speaks specifically to research in the area of FASD (i.e., risk factors and incidence rates) in relation to initiatives that coincide with the action plan's vision, principles, and goals, but the facilitation is deemed better suited through other ongoing work within the province. More specifically, the FASD-related initiative outlined in the action plan is associated with the province's ongoing Early Childhood Development Action Plan 2017-2020 [8].

4. Provincial and Territorial Strategies Lacking an FASD Focus

Newfoundland and Labrador, PEI, New Brunswick, and Quebec all have existing mental health or wellness strategies that lack explicit reference to FASD. These strategies more broadly include overarching visions, guiding principles, goals, and strategic priorities for mental health and wellness. Although none of these strategies acknowledge FASD explicitly, it is possible that

individuals with FASD may be indirectly targeted through the strategies' general definitions of "mental health/wellness" or "disability" and the related priorities and objectives. For example, in PEI's [Mental Health and Addiction Strategy \(2016-2026\)](#), mental health is considered a range of "more common mental health problems and illnesses to less common mental health problems and illnesses" (p. 1). While certain facets of FASD (e.g., mental health concerns) may be addressed within strategies that are lacking explicit acknowledgement of FASD, the multifaceted nature and needs of this specific population may be overlooked.

Thematic Similarities and Differences between FASD-Specific Strategies:

Although there are differences in the structure and execution of FASD-specific strategies between regions, there are also similarities among the visions, goals, and objectives of these strategies. Areas of common focus include FASD awareness and prevention (including maternal health), assessment and diagnosis, intervention and support, mental health, caregivers and families, education and training for service providers, research, and culturally-informed and community-based practices. The breadth of these targeted areas highlights that the provinces and territories employing comprehensive FASD-specific strategies have the potential to facilitate FASD prevention, as well as identify and support individuals with FASD, their caregivers and families, and communities.

The majority of strategies that explicitly target FASD still refer to it as an "umbrella term," a now outdated definition that was used prior to the implementation of the 2015 FASD Diagnostic Guideline [9]. New research and practice refer to FASD as a *diagnostic* term in and of itself, which was reflected in the release of Yukon's FASD Strategy in 2019. Knowledge of this distinction is important to ensure shared and accurate language among service providers working with individuals with FASD and their families [10]. It is important to note that many of the strategies using this outdated language were initially developed before the establishment of the 2015 Guideline, though revisions or modifications to these strategies have not been made to reflect this change in terminology.

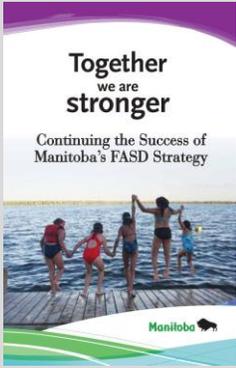
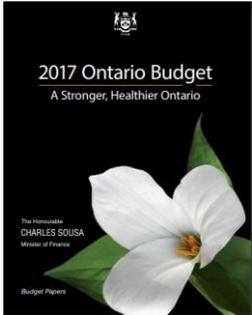
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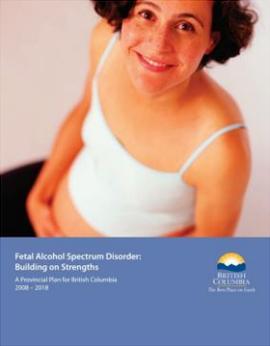
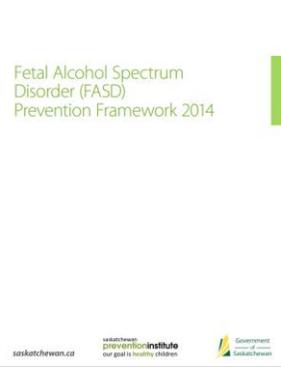
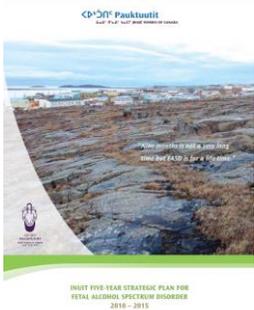
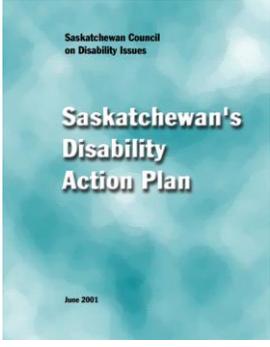
- Provincial and territorial strategies for FASD are needed across the country to ensure a comprehensive, tailored, and intentional approach to preventing FASD and supporting individuals, families, and communities with the disability.
- An evidence-based national FASD Strategy for Canada should be created and implemented to promote national consistency of FASD research and practice.
- Existing FASD strategies should be continually revised and updated to align with current, evidence-based FASD information to ensure consistent and proper knowledge translation and best practices for support and intervention.
- Existing provincial and territorial FASD strategies should be evaluated to determine their efficacy.
- For provinces and territories without an FASD-specific strategy, it is recommended that an FASD-specific strategy be created and implemented. Where this is not feasible, it is recommended that FASD is incorporated into other existing frameworks.
- Provinces and territories that are not currently members of CanFASD are encouraged to join to promote and ensure a pan-Canada perspective in research, and to inform leadership and evidence-based policy and practice across the country. CanFASD can assist with developing provincial/territorial FASD specific strategies.

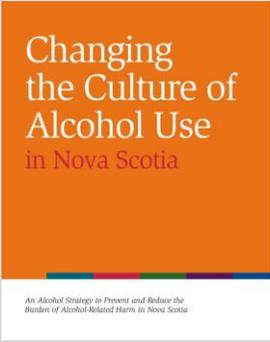
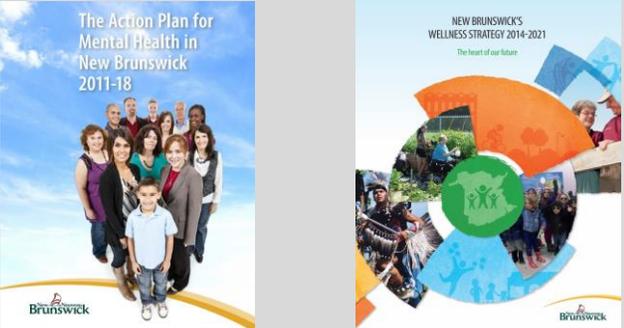
Conclusion:

FASD is a unique and prevalent disorder that warrants specialized provincial and territorial attention and efforts. When FASD is embedded within larger provincial strategies and plans, it is often linked to one specific area (e.g., alcohol-related harm), which excludes and overlooks other key components related to the disability (e.g., prevention). Furthermore, when FASD is missing from existing provincial and territorial strategies altogether, it is unclear whether or how individuals with FASD and their families will receive much-needed services and supports. An all-encompassing strategic approach to FASD will allow for high-level attention to the various facets and complexities of this disability.

Recommended Resources:

Province	Strategy Title and Year
Current FASD Specific Strategies	
<p>Alberta</p> 	<p>Fetal Alcohol Spectrum Disorder 10 Year Plan 2008</p> <p>Year 5 Evaluation of the Government of Alberta's FASD 10 Year Strategic Plan</p> <p>Year 7 Evaluation of the Government of Alberta's FASD 10 Year Strategic Plan</p>
<p>Manitoba</p> 	<p>Together We Are Stronger: Continuing the Success of Manitoba's 2007 FASD Strategy</p>
<p>Ontario</p> 	<p>Ontario's 2017 Budget</p>
<p>Yukon</p> 	<p>Yukon FASD Action Plan (September 2019)</p>

Previous FASD-Specific Strategies	
<p>British Columbia</p> 	<p>Fetal Alcohol Spectrum Disorder: Building on Strengths 2008-2018</p>
<p>Saskatchewan</p> 	<p>Fetal Alcohol Spectrum Disorder (FASD): Prevention Framework 2014</p>
<p>Inuit</p> 	<p>Inuit Five-Year Strategic Plan for Fetal Alcohol Spectrum Disorder 2010-2015</p>
Strategies that Indirectly Address FASD	
<p>Saskatchewan</p> 	<p>Saskatchewan's Action Plan for Citizens with Cognitive Disabilities (not publicly available)</p> <p>For an earlier iteration, please refer to: Saskatchewan's Disability Action Plan (2001)</p>

<p>Nova Scotia</p> 	<p><u>Changing the Culture of Alcohol Use in Nova Scotia (2007)</u></p>
<p>Northwest Territories</p> 	<p><u>Government of the Northwest Territories Disability Action Plan (2018/19- 2021-22)</u></p>
<p>Strategies Lacking an FASD Focus</p>	
<p>Prince Edward Island</p> 	<p><u>Mental Health and Addiction Strategy 2016-2026</u></p> <p><u>Health PEI: Strategic Plan 2017- 2020</u></p>
<p>New Brunswick</p> 	<p><u>The Action Plan for Mental Health in New Brunswick 2011-2018</u></p> <p><u>New Brunswick's Wellness Strategy 2014-2021</u></p>

Quebec



[Working Together and Differently: 2015-2020
Mental Health Action Plan \[French\]](#)

Newfoundland and Labrador



[Towards Recovery: The Mental Health and
Addictions Action Plan for Newfoundland and
Labrador \(2017-2022\)](#)

[Healthier Together: A Strategic Health Plan for
Newfoundland and Labrador](#)

References:

1. Harding, K., Flannigan, K., & McFarlane, A. (July, 2019). *Policy Action Paper: Towards a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada*. Canada: Canada FASD Research Network. Retrieved from <https://canfasd.ca/wp-content/uploads/2019/08/Toward-a-Standard-Definition-of-FASD-Final.pdf>
2. Flannigan, K., Unsworth, K., & Harding, K. (July, 2018). *CanFASD Issue Paper: The Prevalence of Fetal Alcohol Spectrum Disorder*. Canada: Canada FASD Research Network. Retrieved from <https://canfasd.ca/wp-content/uploads/2018/08/Prevalence-1-Issue-Paper-FINAL.pdf>
3. Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S., Baldwin, M. E., Chudley, A. E., ... Temple, V. (2018). A response to "A critique for the new Canadian FASD diagnostic guidelines". *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 27, 83-87.
4. Temple, V. K., Cook, J., Unsworth, K., Rajani, H., & Mela, M. (2019). Mental health and affect regulation impairment in fetal alcohol spectrum disorder (FASD): Results from the Canadian National FASD database. *Alcohol and Alcoholism*, 1-5. doi: 10.1093/alcalc/agz049
5. Mukherjee, R. A. S., Cook, P. A., Norgate, S. H., & Price, A. D. (2019). Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. *Alcohol*, 76, 23-28. doi: <https://doi.org/10.1016/j.alcohol.2018.06.002>
6. Saskatchewan Ministry of Health. (n.d.). *Communities Working Together. Saskatchewan's Action Plan for Citizens with Cognitive Disabilities*. Regina: Saskatchewan Ministry of Health.
7. Poole, Nancy A. (2008). *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives*. Ottawa: Public Health Agency of Canada. Retrieved from: <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/cp-pc/index-eng.php>
8. Government of Northwest Territories. (2018). *Government of the Northwest Territories Disability Action Plan 2018/19-2021/22*. Northwest Territories: Ministry of Health and Social Services.
9. Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., ... Rosales, T. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188, 191-197. doi: 10.1503/cmaj.151425
10. Canada FASD Research Network. (January, 2019). *Common Messages: Guidelines for Talking & Writing about FASD*. Canada: Canada FASD Research Network. Retrieved from <https://canfasd.ca/wp-content/uploads/2019/01/Common-Messages-FINAL-Dec-14-2018.pdf>