



Evaluation of the Public Health Agency of Canada's Fetal Alcohol Spectrum Disorder Program 2017-18 to 2021-22

Prepared by the Office of Audit and Evaluation
Health Canada and the Public Health Agency of Canada

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List of Acronyms

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| AHSUNC | Aboriginal Head Start in Urban and Northern Communities |
| CAPC | Community Action Program for Children |
| CHP | Centre for Health Promotion |
| CPNP | Canada Prenatal Nutrition Program |
| CSAR | Centre for Surveillance and Applied Research |
| FASD | Fetal Alcohol Spectrum Disorder |
| ISC | Indigenous Services Canada |
| HPCDPB | Health Promotion and Chronic Disease Prevention Branch |
| NSPF | National Strategic Projects Fund |
| OGD | Other Government Departments |
| PHAC | Public Health Agency of Canada |
| P/Ts | Provinces and Territories |

Executive Summary

Background

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that describes the impact that prenatal alcohol exposure has on the brain and body. People with FASD will experience lifelong challenges with their motor, social and cognitive skills; physical health; and emotional regulation¹. The Public Health Agency of Canada (PHAC) is one of many players that addresses FASD in Canada. Other key players include local public health authorities, provincial and territorial (P/T) governments, other government departments (OGDs) and many community-based organizations.

The goal of the FASD Program is to provide strategic federal leadership and coordination, to prevent FASD, and to promote positive health and social outcomes for those with FASD. Through the FASD Program, PHAC manages grants and contributions funding, conducts policy, and undertakes surveillance activities.

Within PHAC, the Centre for Health Promotion (CHP) leads policy efforts and manages the FASD National Strategic Projects Fund (NSPF). This fund allocates \$1.5 million annually to national projects that support FASD prevention, education and knowledge exchange, capacity building, coordination, and data collection and research. PHAC's Centre for Surveillance and Applied Research (CSAR), in collaboration with key stakeholders, conducts surveillance and monitoring to progress toward building national FASD surveillance data. Together, these activities form the FASD Program, which is the focus of this evaluation.

The evaluation covered activities from 2017-18 to 2021-22 and used several lines of evidence to assess PHAC's role and the effectiveness of its activities.

What we found

To date, PHAC has undertaken activities to address FASD that are well aligned with its federal public health role. Despite having ambitious objectives, FASD-dedicated funding is limited. Important gaps remain and some appear to align with the federal public health role in the areas of strengthening surveillance, national strategic planning, stakeholder engagement and collaboration, documenting promising practices, and supporting guideline development and dissemination.

All NSPF funded projects have developed and shared relevant information to raise awareness and improve knowledge at various levels of the four-part FASD prevention model, and appear to be mainly focused on prevention. The public, childbearing or pregnant women and their network, and several professionals, including healthcare professionals, were all target populations of the NSPF funded projects. Most projects had to adapt to the COVID-19 pandemic by shifting toward virtual delivery. The performance data required from funded projects covered mostly outputs and reach, however, some projects were able to demonstrate that participants had acquired awareness and new knowledge. There would be value in collecting additional data to determine project achievements like knowledge, use, or behaviour change, as with other PHAC grants and contributions programs.

Some funded projects also helped enhance FASD surveillance data while PHAC's surveillance activities examined various data sources to establish national FASD surveillance. However, the lack of national FASD prevalence data continues to represent a gap, which is further exacerbated by the under-diagnosis and under-reporting of FASD cases.

Recommendations

Recommendation 1: Continue strengthening surveillance efforts with a focus on establishing the building blocks for FASD surveillance, including national prevalence estimates.

Current exploratory activities are necessary precursors to building a national surveillance system. Gathering the necessary data to inform decision making, particularly regarding equity-deserving populations, will require identification of investment in surveillance and collaboration with provinces and territories (P/Ts). This would also align with the Truth and Reconciliation's Call to Action regarding the need to understand and close the gaps in health outcomes between Indigenous and non-Indigenous communities.

Recommendation 2: Strengthen the integration of FASD efforts across PHAC, from awareness and prevention to a response that adopts social determinants of health and harm reduction lenses which would improve connection with PHAC's broader substance use approach.

The evaluation found that some gap areas in FASD could be filled by PHAC given its federal public health role; however, not all activities are integrated. A few teams across PHAC are responsible for FASD-related activities (within CHP, CSAR and in the regional offices), but there is no overarching structure currently to coordinate these efforts. Moreover, FASD is a complex issue that requires considering social determinants of health beyond traditional public health programming. It is also related to issues such as alcohol consumption in pregnant women, which also falls under substance use, and alcohol consumption. Both issues are addressed by other groups in the health portfolio. Better understanding how current activities are structured and how to coordinate them both internally and externally is a preliminary step for a more consistent approach

to facilitate national approaches to FASD policy and planning. While the previous FASD evaluation recommended improving stakeholder engagement, further work is still needed to enhance coordination.

Recommendation 3: Enhance the FASD program's performance measurement approach with a focus on impact.

Once activities and roles are mapped and better defined, FASD-related activities should be clearly articulated in a logic model that would highlight FASD program objectives and the respective ways to achieve them. The four-part FASD prevention model may help frame efforts by target populations. It would also clarify where the FASD program is best positioned to serve each population while clarifying boundaries with children's programs. By using this framework, synergies could also be found across funded projects geared toward the same goals and at the same level. Once the logic model is clarified, relevant and realistic indicators should be identified and collected to monitor progress. In the case of NSPF, PHAC should ensure that funded projects plan and commit to monitoring efforts early on. While enhancing performance measurement was recommended in the previous FASD evaluation, progress in data collection was limited and therefore more refined and comprehensive performance measures would benefit the program.

Management Response and Action Plan

Evaluation of the Public Health Agency of Canada's Fetal Alcohol Spectrum Disorder Program 2017-18 to 2021-22

| Recommendation 1 | | | | |
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| Continue strengthening surveillance efforts with a focus on establishing the building blocks for FASD surveillance, including national prevalence estimation. | | | | |
| Management response | | | | |
| <p>Agree. Building on past and present activities, CSAR will continue to pilot promising methods and options for national FASD prevalence estimation. CSAR will continue to commit limited resources to pursue these activities, including having dedicated FTEs to lead these projects.</p> <p>We agree that collaboration with both internal and external stakeholders will be key to ensure that PHAC has the data and information to inform decision making around equity-deserving populations. Leveraging existing tables will be key to achieve this goal. Through the Interdepartmental FASD Working Group we will not only ensure that ongoing surveillance activities serve to inform PHAC policy needs, but the Truth and Reconciliation's Call to Action as well.</p> | | | | |
| Action Plan | Deliverables | Expected Completion Date | Accountability | Resources |
| PHAC continues to explore options for the estimation of the national prevalence of FASD through a multi-sourced approach. This includes continued reporting on FASD using existing data sources such as pan-Canadian surveys as well as, | 1.1 Using the Canadian Health Survey on Children and Youth (2019 and 2023), develop an analytic plan in preparation for the continued reporting on FASD. | March 2024 | Executive Director, Centre for Surveillance and Applied Research (CSAR) | Existing Resources |

| | | | | |
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| feasibility assessments of existing P/T health administrative databases. | 1.2 Develop a summary report of the available P/T specific health administrative databases and their usefulness in estimating the prevalence of FASD. | March 2025 | Executive Director, CSAR | Existing Resources |
| In partnership with other Government departments and external organizations, PHAC will ensure it has the data and information to inform decision making around equity-deserving populations. | 1.3 By leveraging the Interdepartmental FASD Working Group, develop a consultation plan to seek guidance on a strategy for collecting, reporting, and disseminating information on equity-deserving populations. | March 2024 | Executive Director, CSAR | Existing Resources |

| Recommendation 2 | | | | |
|---|--|--------------------------|--|---|
| Strengthen the integration of FASD efforts across PHAC, from awareness and prevention to a response that adopts a social determinant of health and a harm reduction lens which would be better connected with the broader substance use approach. | | | | |
| Management response | | | | |
| Agree. Opportunities to strengthen integration and coordination of FASD efforts across PHAC will be identified to support a more consistent approach to facilitate national approaches to FASD policy and planning. | | | | |
| Action Plan | Deliverables | Expected Completion Date | Accountability | Resources |
| Examine and determine how to strengthen collaboration and integration of FASD efforts across PHAC. | 2.1. Inventory documenting current activities and leads across PHAC pertaining to alcohol use and related harm reduction (including mental health and family and gender-based violence), and FASD. | September 2023 | Director General, Centre for Health Promotion (DG, CHP) Director General, Centre for Mental Health and Wellbeing (DG, CMHWP) Executive Director, Centre for Surveillance and Applied Research (ED, CSAR) | Existing Resources in CHP, CMHWP and CSAR |
| | 2.2. Development of a governance structure and/or information sharing strategy to coordinate alcohol, harm reduction and FASD-related program, policy and surveillance activities and stakeholder engagement (includes clarification of roles and responsibilities). | April 2024 | Vice President, Health Promotion and Chronic Disease Prevention Branch (VP, HPCDPB) | |

| Recommendation 3 | | | | |
|---|--|--|---|---|
| Enhance the FASD program's performance measurement approach with a focus on impact. | | | | |
| Management response | | | | |
| Agree. As part of efforts to strengthen collaboration and integration of FASD efforts across PHAC, a renewed program logic model will be developed that better articulates the linkages between awareness and prevention, and that incorporates performance measures related to the broader social determinants of health and harm reduction. | | | | |
| Action Plan | Deliverables | Expected Completion Date | Accountability | Resources |
| Update the FASD program logic model and performance measurement strategy based on clarification of program objectives and outcomes, including those related to alcohol use, harm reduction and surveillance. | <p>3.1. Updated Program Logic Model</p> <p>3.2. Updated Performance Measurement Strategy that includes:</p> <ul style="list-style-type: none"> • Relevant and realistic indicators for projects undertaken through the FASD National Strategic Projects Fund; as well as consider additional indicators related to alcohol use, harm reduction and surveillance. • Improved project-level data collection to monitor progress, including project performance measurement | <p>June 2024</p> <p>September 2024</p> | <p>DG, CHP</p> <p>DG, CMHWP</p> <p>DG, CSAR</p> <p>VP, HPCDPB</p> | Existing Resources in CHP, CMHWP and CSAR |

| | | | | |
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| | <p>capacity to collect data on project achievements (e.g., knowledge, use or behavior change)</p> <ul style="list-style-type: none"> • Opportunities for knowledge sharing across projects, and more broadly across the Agency. | | | |
|--|--|--|--|--|

Purpose of the Evaluation

The purpose of the evaluation was to provide guidance and information to PHAC on the relevance and effectiveness of the FASD program.

This is the third evaluation of the FASD program:

- The purpose of the previous evaluation, the *Evaluation of the Fetal Alcohol Spectrum Disorder (FASD) Initiative 2008–2009 to 2012–2013*, was to assess the relevance and performance of the NSPF for the period of 2008-09 to 2012-13. It found that significant progress was made regarding stakeholder collaboration and developing tools and resources, but also emphasized a need for a continued federal focus.
- The purpose of the first evaluation, the *Summative Evaluation: Fetal Alcohol Spectrum Disorder Initiative*, was to assess the relevance, impact and effect, design and delivery, and cost-effectiveness of the NSPF and policy activities for the period of April 2004-05 to 2007-08. It also examined upcoming projects carried forward into 2009. It revealed that the NSPF and policy activities should continue and that it was in line with current federal and provincial objectives. The evaluation also helped identify key areas that stakeholders wanted to see addressed by PHAC, including working with OGDs, coordination and collaboration to avoid duplication of efforts, and ensuring a holistic approach.

Evaluation Scope

The evaluation covered activities from 2017-18 to 2021-22. The evaluation drew on evidence from multiple data collection methods including interviews, document and file review, literature review, and financial data review. See Annex A for detailed methodology, limitations, and mitigation strategies.

The following questions guided the evaluation:

1. What should PHAC's role be as it relates to FASD? Is PHAC investing in areas that are consistent with its federal public health mandate and to achieve maximum impact? Are there unmet needs?
2. Is the program achieving its expected results related to the NSPF and policy activities?
3. To what extent are funded projects able to scale up to increase their impact and better serve the needs of Canadians in a sustainable way?
4. Is there an integrated and collaborative approach between surveillance and policy teams to support FASD-related decision-making? Are there any gaps?

While regional offices do not play a direct role in delivering the FASD program, the evaluation considered the link between regional FASD-related activities and the FASD program, but did not assess regional activities per se.

Program Profile

PHAC's FASD program seeks to reduce alcohol-affected births and address the underlying conditions that make Canadians vulnerable to consuming alcohol during pregnancy. The goal of the FASD program is to provide strategic federal leadership and coordination, to prevent FASD, and to improve the health and social outcomes for those with FASD. In 2016, PHAC developed a five-year FASD Strategic Plan (2016-2021) to identify its priorities for enhancing its FASD programming, which includes grants and contributions funding, policy, and data. The strategic plan also defines the objectives of the NSPF grants and contributions solicitations for this time period.

The program is composed of the funding and policy activities led by CHP and surveillance activities led by CSAR. CHP and CSAR both

operate within the Health Promotion and Chronic Disease Prevention Branch (HPCDPB).

CHP Key Activities

- manage the NSPF;
- convene FASD partners and stakeholders; and
- oversee FASD-dedicated content on the PHAC website.

CSAR Key Activities

- develop surveillance information and evidence on FASD; and
- explore the feasibility of a multi-source FASD surveillance system.

PHAC allocates \$1.5 million annually in grants and contributions funding under the NSPF to help organizations develop knowledge products, tools, and resources to address FASD issues and advance awareness, prevention, and intervention activities. Since 2017-18, PHAC has supported ten organizations among P/Ts and NGOs in developing and evaluating innovative projects meant to improve the health and social outcomes of those living with FASD. The last call for proposals was initiated in August 2018.²

Context

There are a few key elements to consider when it comes to understanding PHAC's activities in addressing FASD. To set the stage, the section below provides a quick overview of the prevalence and societal costs of FASD in Canada, which is then followed by a short history of programming within the health portfolio and the federal government writ large. Some more recent government policies and priorities are then presented because they all have some implication on FASD and its programming. Finally, the impact of the recent COVID-19 pandemic is acknowledged as a factor to consider including with regards to the delivery of activities for the period under review.

The prevalence and societal cost of FASD in Canada

In 2019, it was estimated that 0.1% of Canadian children and youth aged 1 to 17 years had been diagnosed with FASD, including 1.2% of off-reserve Indigenous children³. In 2015-16, the prevalence of FASD among First Nations children living on-reserve was estimated to be 0.5%⁴.

In 2017, a meta-analysis revealed that, among the general population, about 10% and 15% of pregnant women consume alcohol in Canada and in the United States, respectively. This prevalence is approximately three to four times higher in Indigenous peoples.⁵ Moreover, overall alcohol consumption has increased during the pandemic, and this may have also affected pregnant women.⁶ This unfortunate trend is due to contextual factors beyond the program's control. Nonetheless, addressing this increasing problem might be relevant to COVID-19 recovery efforts.

The economic costs of FASD, including costs derived from health, special education, employment, social services, and the criminal justice system range from \$1.3 billion to \$2.3 billion per year in Canada⁷. The highest contributor to the overall FASD-attributable

costs is productivity loss due to morbidity and premature mortality, ranging from about \$532 million to \$1.2 billion. This represents 41% of the total FASD-attributable cost in Canada. Other contributors include the cost of corrections, not including costs of policing and courts, which is \$378.3 million and 29% of the total cost of FASD, and the cost of health care, ranging from \$128.5 million to \$226.3 million, representing 10% of the total cost⁸.

FASD programming in the federal government

While federal FASD-related activities have been managed by Health Canada's Health Promotion and Program Branch and the First Nations and Inuit Health Branch (FNIHB) since 1999, they were transferred to PHAC and Indigenous Services Canada (ISC), for First Nations on-reserve and Inuit populations specifically, upon the creation of these OGDs (2004-05 and 2017-18 respectively). PHAC has been addressing FASD through national leadership, using previous strategies, the NSPF for grants and contributions, and surveillance. In addition, PHAC regional offices, located within the Health Security and Regional Operations Branch, play a liaison role with local FASD partners and stakeholders and deliver three children- and youth-dedicated programs which at times cover FASD aspects: Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP), and Aboriginal Head Start in Urban and Northern Communities (AHSUNC).

While PHAC focuses mainly on FASD prevention activities, other departments within the federal government, including Justice Canada and Correctional Services Canada, serve people living with FASD. ISC works on both prevention and services for those living with FASD while Employment and Social Development Canada (ESDC) holds the mandate for disabilities and inclusion, including the Disability Inclusion Action Plan (DIAP).

Government policies and priorities affecting FASD

FASD fits within, or may help to address, numerous Government of Canada policies and initiatives. As part of the Canadian Drugs and Substances Strategy and more recently in its response to the opioid crisis, PHAC has adopted a harm reduction approach to reduce the harmful health, social and economic effects of substance use on individuals, their families and communities. Moreover, the Government of Canada is also engaged in reducing alcohol related harm by supporting the Guidance on Alcohol and Health that was released by the Canadian Centre on Substance Use and Addiction in early 2023.

Given that FASD is particularly prevalent among Indigenous peoples, there are specific FASD actions directed towards the federal government and P/Ts in the Truth and Reconciliation Commission of Canada's Calls to Action:

- Call to Action 33: "develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner."

- Call to Action 34: "undertake reforms to the criminal justice system to better address the needs of offenders with FASD".

Finally, the *Accessible Canada Act* and the *Accessible Canada Regulations* <https://laws-lois.justice.gc.ca/eng/regulations/SOR-2021-241/index.html> came into force in 2019 and 2021 respectively and implicitly include FASD. Their main objective is to realize a barrier-free Canada by 2040. The Disability and Inclusion Action Plan released by ESDC in 2022 focusses specifically on economic inclusion and financial support to people with disability.

COVID-19 pandemic and FASD

Finally, the impact of the COVID-19 pandemic on those with FASD is not yet known. Some activities carried out under PHAC's FASD program were readjusted for online delivery, and in some cases, timelines had to be shifted as a result of internal staff temporarily joining the COVID-19 response efforts. A few sections in the report acknowledge these challenges.

Key Findings: Role

To assess the relevance of the program, the evaluation examined alignment of PHAC's current FASD role with federal priorities and mandate. Gaps to address FASD were also determined with a focus on gaps that may fall under the federal public health role.

Alignment of PHAC's current FASD role with federal priorities and PHAC's mandate

PHAC's current FASD activities fall within its federal public health role: PHAC supports community-based projects and public health guidelines, conducts surveillance, supports, and undertakes knowledge transfer and exchange initiatives, and acts as a convenor. PHAC's FASD work is well aligned with the current priorities of the Government of Canada; however, the integration of FASD efforts across PHAC is currently a gap.

PHAC's mandate regarding FASD

While public health in Canada is a shared responsibility between the federal and P/T governments, PHAC plays a leadership role in promoting and protecting the health of Canadians. As per PHAC's mandate, this includes strengthening intergovernmental collaboration on public health and facilitating national approaches to public health policy and planning.^{ix} PHAC's areas for action in health promotion and disease prevention programming include program development, community capacity building, public education, inter-sectoral collaboration, and information synthesis and exchange.

Although funded for more than 20 years, FASD is not a priority stated in key federal government documents (e.g., Speech from the Throne, Minister of Health (or Associate Minister) mandate letters, federal budgets) except in Budget 1999. Thus, PHAC's mandate as it relates to FASD is defined in its program authority and includes prevention, public education, capacity building and coordination. More recently, the FASD Initiative 5-Year Strategic Plan 2016-2021 articulated the program's mission as "providing federal leadership in the prevention of further alcohol-affected births and promote

positive health and social outcomes for people already impacted by fetal alcohol spectrum disorder." Two important objectives were added to those of the 1999 program authority: *improving health and social outcomes for those affected by FASD* as well as *improving FASD data on prevalence and use of alcohol by women of child-bearing age*^x.

The initial funding allocated in 1999 included \$1.5 million in grants and contributions. This budget has remained the same and has not been corrected for inflation, similar to the CAPC and CPNP programs^{xi}. Using a similar calculation to the one used in the CAPC and CPNP evaluation, \$1.5 million in 1999 would amount to approximately \$2.45 million in 2022, when corrected for inflation. FASD-related surveillance activities were not included and remain unfunded.

Alignment with PHAC's role

For FASD, PHAC has been carrying out a federal public health role that aligns with its broad mandate in the areas of stakeholder engagement, policy, and surveillance, in addition to addressing more specific commitments outlined in the FASD program authority

through the ongoing management of the NSPF. The 1999 program authority clarified the roles played by Health Canada's branches regarding FASD, which remain the same to this day. As such, PHAC is responsible for addressing FASD among Indigenous peoples living off-reserve and FNIHB, or ISC, the FASD program managed by FNIHB offers prevention programming for pregnant women as well as screening and case management services for children in on-reserve and Inuit communities.

Roles played by Other Government Departments

In addition to the role played by ISC, other government departments contribute to supporting adults living with FASD such as Employment and Social Development Canada, the Department of Justice Canada, Public Safety Canada, and Correctional Service Canada by leading efforts to better understand the perspectives of those living with FASD in specific settings, raising FASD awareness in these settings, and providing FASD specific resources. Finally, the Canadian Institutes of Health Research (CIHR) invests in FASD-focused research through the Kids Brain Health Network and other neuroscience programs.^{xii}

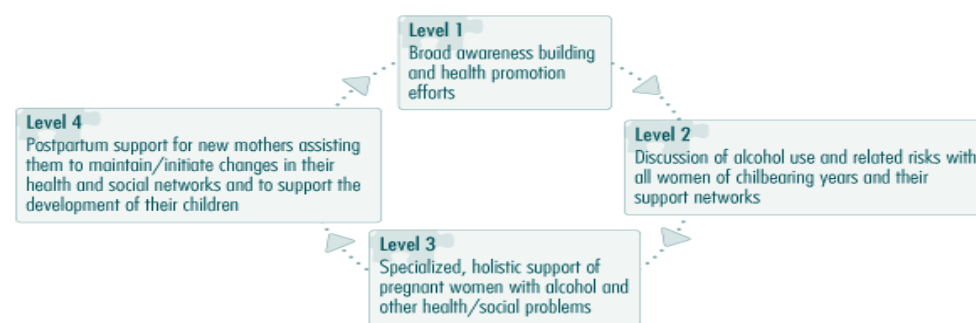
FASD prevention continuum across PHAC

The evaluation looked at the four-part FASD prevention model to understand where, in the prevention continuum, PHAC is focusing its efforts and which results have been achieved along this continuum. This model depicted below (see Figure 1) describes the four-levels of mutually reinforcing prevention approaches in addressing FASD prevention, linked to overall policy strategies. The four levels span from general to specific practices that assist women to improve their health and the health of their children, with support from family, support networks, services and community.

While projects funded through NSPF focused mainly on raising the awareness of the general public and women of childbearing age

(levels one and two), PHAC-funded children's programs focus mainly on providing support to pregnant women and mothers in a holistic way, including FASD aspects (level 3 and 4). Children's programs are well positioned to address level three and four issues, due to their community-based nature and ongoing funding status. Currently, the children's programs fall under CHP; however, PHAC's regional offices also play a role in delivering and managing program funding. The regional offices, organizationally, fall under a separate Branch – the Health Security and Regional Operations Branch. The integration of FASD efforts across PHAC is currently a gap, as highlighted by several interviewees from non-governmental organizations and PHAC regional offices.

Figure 1 – The Four-Part Model of Prevention



Source: Poole, N. (2008). *Fetal alcohol spectrum disorder (FASD) prevention: Canadian perspectives*. Public Health Agency of Canada.

Gaps and opportunities

The remaining gaps to address FASD in Canada are well documented and mostly reside within the P/Ts' mandate. A few gaps that may be filled by PHAC include better defining roles and responsibilities across PHAC, enhancing FASD surveillance, convening stakeholders, and contributing to consistent messaging and greater uptake guidelines related to FASD.

As outlined above, FASD is a complex issue requiring efforts from multiple jurisdictions. The evaluation found many remaining gaps to address FASD and some of these gaps and opportunities fall under P/Ts or other government departments' jurisdictions (e.g., consistent diagnostics and resourcing across the country, or

screening in schools)¹³, or are broader than FASD, such as the need for a national alcohol policy, similar to tobacco.¹⁴ However, some other gaps appear to align with the federal public health role, as indicated below:

| Gaps | Potential alignment with PHAC's role |
|---|--|
| PHAC developed the FASD Framework for Action in 2003 to guide its FASD work and priorities. The strategic plan is the last guiding document for PHAC's specific work in FASD. However, there is no national approach or strategy that defines the roles and responsibilities of all FASD key partners and stakeholders to help coordinate efforts. ¹⁵ Many recipients, NGOs and regional offices interviewees envision a more integrated approach from awareness and prevention to a response that adopts social determinants of health, and a harm reduction lens that would be better connected with the broader substance use approach and ensure consistent services for Indigenous peoples on- and off-reserve. They also suggested a more dynamic and collaborative strategic planning approach. | This is aligned with the broad PHAC mandate to "facilitate national approaches to public health policy and planning". As per the above-noted context, however, PHAC would need to consider how this role can be undertaken while other related issues are considered (e.g., substance use strategy). |
| There is limited and fragmented national-level stakeholder engagement for sharing updates, best practices, and funding opportunities. Currently, efforts are not well coordinated across the country. Some convening mechanisms such as pNAT and CanFASD are led by NGOs while the Canada Northwest FASD partnership has been gathering P/Ts since 1999, except Ontario, Quebec, and the Atlantic provinces. ¹⁶ Since 2019, the strengthening of stakeholder engagement in the Atlantic provinces has been supported by PHAC (see section below). | This is aligned with the broad PHAC mandate to "facilitate national approaches to public health policy and planning" and would be appropriate for FASD, as PHAC does with other program areas. |

| | |
|--|---|
| The national FASD prevalence is unknown because reliable national level surveillance data is not available for determining the magnitude of the population affected by FASD. This gap has a trickledown effect in a few spheres such as government funding allocation decisions. | Surveillance is part of PHAC's main role in collaboration with others, such as P/Ts, who are responsible for collecting data to support surveillance efforts. See the section on surveillance for more details. |
| NGOs and internal interviewees have highlighted the lack of consistency in prevention messaging, the application of diagnostic guidelines across sociodemographic groups, and the absence of a harm reduction lens in screening approaches. ^{17 18} Some experts suggested integrating these aspects in the 2016 guidelines for diagnosis and broadly disseminating this update to encourage its uptake, in collaboration with professional associations. | Although diagnostics services fall under P/T jurisdictions, PHAC has either developed or supported the development, or update, of many public health guidelines. PHAC continues to do so for issues similar to FASD, like dementia. Although this role is not formally documented, PHAC supported the first Canadian FASD guidelines for diagnosis in 2005 and its update in 2016 released by SOGC. ¹⁹ |
| Despite the clear mandate split between PHAC and FNIHB regarding Indigenous peoples, these populations are not siloed, and transits between areas may also generate coverage gaps. | Offering a more integrated approach between PHAC and ISC coverage would align with the 2015 Truth and Reconciliation Commission's Calls to Action #33 and #34 including the need for trauma-informed and culturally safe approaches. ²⁰ |
| Most recipients and NGOs highlighted that the federal government needs to focus on how FASD intersects with many social determinants of health beyond prevention. This may also include documenting societal costs such as those incurred in the justice system for example. | Although this is beyond PHAC's scope, coordinating with other departments (e.g., Justice Canada or Correctional Services Canada) and P/Ts would be essential for addressing these complex issues. |

Guidelines available abroad

The renewal of the FASD guidelines is identified as a potential area for action above. Keeping guidelines up to date and broadly disseminated among practitioners is necessary for consistent messaging and practices. The status of comparable countries may serve as a benchmark. Similar diagnostic approaches to the Canadian guidelines have been adopted internationally, but they differ regarding recommendations, criteria and clinical cut-offs.²¹ As a comparison, the United States' Centers for Disease Control and Prevention refers to the 2004 Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis to educate medical and allied health professionals on FASD.²² Germany released their own FASD diagnosis guidelines in 2013.²³ The Australian Guide to the Diagnosis

of Fetal Alcohol Spectrum Disorder was developed in 2016 in response to limited training opportunities on FASD, a lack of a nationally adopted diagnostic instrument, and confusion over diagnostic criteria.²⁴ In 2019, Scotland became the first country in the UK to publish guidelines on diagnosing fetal alcohol spectrum disorder (FASD)²⁵ and the United Kingdom's National Institute for Health Care Excellence released guidelines on how to improve the diagnosis, assessment, and prevention of FASD in 2022.²⁶ The Scottish and Australian guidelines explicitly mention being largely informed by the 2016 Canadian guidelines on the diagnosis of FASD, which were perceived to give a comprehensive and transferable set of recommendations.^{27 28}

Key Findings: Effectiveness

The evaluation assessed progress against achievement of outcomes for PHAC's main activities – community-based funding through the NSPF and surveillance. To do so, the outcomes identified in the following performance information profiles were used, where appropriate:

- Health Promotion Program (NSPF)
- Evidence for Health Promotion, Chronic Disease and Injury Prevention (surveillance)

NSPF achievements

All NSPF funded projects offered a solid representation of Canada, with some projects being national in scope and others focusing in on specific P/Ts or communities. Projects spanned across the four-part FASD prevention model, displaying successful dissemination of relevant information and a strong focus on prevention. Projects were collaborative, creating new partnership opportunities, and incorporating those with lived experience into their work. Most projects adapted to pandemic restrictions and shifted successfully toward virtual delivery of activities. Due to the nature of the NSPF, the program was unable to determine if there had been a reduction in alcohol-affected births.

Access to, and use of, relevant information to prevent FASD and support those living with FASD

All funded projects have shared relevant information to raise awareness at various levels and appear to be focused on prevention. The general public, targeted populations, and professionals in health and other relevant sectors were all target populations that were reached by NSPF funded projects. Depending on the delivery format, some projects were national in scope while others focused on the Atlantic Provinces, Quebec, areas in western provinces or the Inuit Nunangat. As such, the program offered a good geographical coverage across Canada.

Most projects had to adapt to pandemic restrictions and shift toward virtual delivery of activities. This transition occurred at different rates depending on the nature of the content to be delivered and the target population.

Project achievements are presented below according to the four-part FASD prevention model. Projects may cover more than one level.

Building awareness and increasing prevention

Level 1: Three projects focused on the general population and raised awareness about the risk of drinking while pregnant. They used social media and radio in the Atlantic Provinces, advertisements directed at those aged 18 to 44 in specific cities across the country, and other awareness materials. A community-based campaign across the Inuit Nunangat and other northern areas with concentrations of Inuit was put in place to reduce stigma associated with FASD. In total, those projects have reached around 500,000 Canadians.

Level 2: Four projects focused specifically on women of childbearing age and their networks and implemented social media campaigns. In addition, an FASD dictionary was built and released to teach the

basics of FASD and what to do to help reduce FASD stigma among marginalized populations in the metropolitan Vancouver area. Finally, a mix of in-person and pre-recorded lessons and other virtual formats were created and disseminated among teenagers in schools in Ontario and Quebec. After the media campaign in Quebec, 70% of surveyed young women had an excellent retention of the main messages, and 48% had the intention to talk about the risks of drinking while pregnant to family and friends. In total, these projects have reached approximately 900,000 Canadians.

Level 3: One project examined the implementation and performance of a PHAC program's (AHSUNC) funded projects that were related to FASD and helped them determine lessons learned on project implementation. The eight funded projects provided services to Indigenous pregnant women, including addressing alcohol consumption. Results were shared with other community-based programs and more broadly through conferences and publications.

Building capacity to support those with FASD

Level 4: Eight projects, focused on health professionals and allies, included the dissemination of PHAC-funded diagnosis guidelines released in 2016, the delivery of an online course on best practices and resources to discuss alcohol use with women in 2018, and the release of new guidelines for 'Screening and Counselling for Alcohol Consumption during Pregnancy' in 2020. Clinicians trained through the online course demonstrated improved knowledge and understanding when tested before and after attending the course. In total, the 2020 guidelines received 54,000 hits in the few months following its release.

In addition, justice and police professionals in the Atlantic Provinces received virtual FASD training sessions and material to be shared with colleagues. Finally, AHSUNC staff were trained to increase

awareness and knowledge of FASD in Indigenous communities. Some AHSUNC staff mentioned applying an "FASD lens" when approaching clients and others were able to notice "FASD signs" in children and adapt their approach accordingly. In total, those projects have reached around 2,000 professionals.

Building data

Finally, in addition to awareness building and knowledge sharing efforts, one project focused on updating CanFASD's database that registers FASD cases detected by affiliated diagnostic clinics while another project estimated the population-based prevalence of FASD among elementary school students, aged 7 to 9 years, in the Greater Toronto Area in 2019. According to this study, the FASD prevalence among elementary school students in this area was likely to range between 2 and 3%.²⁹

Alcohol-affected births

The reduction of the incidence of alcohol-affected births is an aspirational ultimate outcome, but it is too early in the project life cycle to discuss this goal in this evaluation. Projects (level one, two and four) were not required to track this result among their participants. If possible, following up with project participants could provide additional information. This is discussed more fully in the performance measurement sub-section.

On the other hand, PHAC-funded AHSUNC projects (level three) provide direct support to pregnant women and this funding is ongoing. The NSFP provided some evaluation support to eight AHSUNC-funded projects by helping them document their implementation and results. For example, this support enabled projects to demonstrate that, among women seeking support from holistic projects for problematic substance use or trauma, 84% managed to quit, reduce substance use or do it more safely.³⁰

Opportunities for collaboration

To carry out their activities, recipients built on existing partnerships, by engaging with a broad range of partners to inform and tailor their deliverables, including awareness tools and resources. All projects were rooted in fostering collaboration to plan and deliver their activities. Some projects included people with lived experience, which proved to be an important aspect because it ensured that the project was designed and delivered appropriately, meeting the needs of their target populations.

During the pandemic, the increased need to raise awareness of the risk of drinking during pregnancy led to several projects implementing similar efforts. Although cumulative efforts might have been beneficial, there is no evidence that collaboration and synergies were sought across these pandemic-specific projects. Of note, while projects funded through the NSPF and children's programs are separate, two of them have demonstrated fruitful interactions: one helped to document AHSUNC sites' achievements in supporting pregnant women with alcohol issues,³¹ the other offered mentoring support to AHSUNC sites to increase knowledge and awareness of FASD in Indigenous communities.³² For this project, PHAC regional offices provided support for improving enrollment, when necessary.

Scalability and sustainability of funded projects

Applicants for NSPF funding have to demonstrate the potential scalability and sustainability of their project as PHAC funding is time limited. According to recipients, successful sustainability strategies included the maintenance of relationships, the monetization of training programs, and the creation of subscription services. The short-term nature of PHAC funded projects (two years) has led recipients to look for alternative funding sources, such as grants and

partnerships, to maintain programming and continue pursuing their goals.

Performance measurement challenges

Projects funded by the NSPF were required to provide performance data, focussing on deliverables and reach, as part of their evaluation plan. Short- and medium-term outcomes like overall access and use of information by target population to prevent FASD or reduce harm cannot be appropriately measured given that those types of outcomes would require following-up with target populations following the completion of the project. Follow-ups are not currently covered as part of the current program design, nor is it required under the funding agreements.

Some projects, like the one from the Saskatchewan Prevention Institute, managed to document such achievements. The mentorship program trained mentors who raised FASD awareness among AHSUNC sites' staff and parents. A formal evaluation documented knowledge acquisition and use through follow-ups, several months after the training was offered. Although collected through testimonials rather than a structured and systematic manner, the project collected strong evaluation data and could inspire other projects.

Many other grants and contributions programs require more rigorous performance measurement data in their contribution agreements, including PHAC's HIV and Hepatitis C Community Action Fund, the Multisectoral Partnerships Program, and the Mental Health of Black Canadians. Enhancing performance data is important for PHAC's accountability and decision-making as well as for projects' ability to attract other funding to sustain their efforts once PHAC funding ends.

Surveillance achievements

FASD data is available from several sources that all provide information on varying aspects of FASD in Canada. FASD is under-diagnosed and under-reported, which is a major challenge for measuring accurately the FASD prevalence in Canada. PHAC is currently exploring data sources that could feed into FASD national surveillance.

Surveillance and Monitoring Data Availability

Surveillance consists of tracking and forecasting health events and determinants through the collection, analysis and reporting of data. As mentioned earlier, national surveillance is an important role played by PHAC and it continues to be the case with FASD.

However, for FASD, surveillance activities have been dependent on the availability of staff and other internal financial resources.

In the absence of well-established national data on FASD prevalence at the beginning of the scoping period, PHAC funded the Centre for Addiction and Mental Health (CAMH) for the 2017 to 2021 period. CAMH conducted an environmental scan of existing surveillance data sources for FASD and prenatal alcohol exposure in Canada. A final report was made public on the CAMH's website in 2021 and helped to describe what data sources were available.³³

FASD data is available from different sources that provide information on certain aspects of FASD in Canada, including:

- The Canadian Health Survey on Children and Youth (CHSCY) is a national survey that identifies respondents with FASD via a self-reported questionnaire administered to the person most knowledgeable about the selected youth/child. PHAC has been financially contributing to the 2019 and 2023 editions. Based on this survey data, PHAC published an estimation in 2021 of the prevalence of FASD among children and youth aged 1-17 in Canada, and discussed the challenges associated with FASD prevalence estimation.³⁴ This is the main source of data used at

PHAC at the end of the evaluation's scoping period for informing policy and program activities.

- PHAC's Canadian Congenital Anomalies Surveillance System captures only severe FASD cases.³⁵
- PHAC's Canadian Perinatal Surveillance System includes alcohol consumption during pregnancy.³⁶

Beyond the work on the CHSCY, the surveillance team is presently exploring data that could feed into national FASD surveillance or complement FASD data, including the readiness of the CanFASD database and other existing surveillance platforms and initiatives to help assess FASD prevalence and incidence, as well as inform diagnostic practices and care trajectories for children with FASD.

Other Sources of FASD Data

The CanFASD database, put in place in the fall of 2016, collects information and characteristics of the FASD population in Canada including the functional profile, comorbidities, intervention needs and difficulties in daily living experienced by individuals assessed for FASD across the lifespan. It does not capture all jurisdictions. This database was partially funded by PHAC during the period covered by this evaluation.

Data challenges

The national surveillance of FASD is affected by many challenges, for example:

- An FASD diagnosis requires a multidisciplinary assessment and knowledge of prenatal alcohol exposure.
- There are variations across Canada between diagnosed versus self-reported FASD prevalence partially due to the stigma associated with the consumption of alcohol during pregnancy.
- Only a select number of P/Ts capture codes used by physicians that are specific enough to identify FASD.³⁷
- The diagnostic practices and accessibility to those services (especially during the pandemic) vary across jurisdictions.³⁸

As a result of these challenges, complete, accurate and comparable surveillance data, and FASD prevalence estimates across the country remain a gap. These challenges trickle down to gathering and estimating prevalence among equity-deserving populations such as Indigenous communities. The United States and Europe also experience these surveillance challenges.³⁹

International FASD data

Prevalence estimates of FASD are also limited in most countries. Several countries, such as the United States, Australia, England and France, use generic hospital surveillance systems to identify major birth anomalies or birth defects. However, these systems have diagnostic accuracy and collection issues; they are passive surveillance systems that are not sufficient to obtain prevalence figures for complex diagnosis such as FASD.^{40 41} Internationally, the global standard for disease reporting is the World Health Organization's International Classification of Disease. The 10th version (in use from 1990 to 2021) coding structure is a challenge for FASD data acquisition.⁴² The 11th version (used since 2022) includes a term for neurodevelopmental disorders associated with prenatal alcohol exposure, but it does not include an FASD-specific code.⁴³

Use of surveillance for decision-making

One of the main outcomes associated with the surveillance function is the uptake of data to inform policy and programming. Given the limited surveillance data available on FASD and the lack of internal documentation on policy work, this evaluation was not able to document whether and how surveillance data is used to inform policy and programming. However, since 2021, CHP has been collaborating with CSAR on projects focusing on addressing knowledge gaps through national prevalence estimation of FASD or FASD components in addition to collaborating with key partners and stakeholders.

The following examples provide an overview of external use and internal coordination:

- Partners and stakeholders use high-level CHSCY data for raising awareness, requesting funding, or lobbying for policy development in their own jurisdiction or organization. Many external interviewees do not use the current data because of its major limitations.
- Internal interviewees indicated that while information sharing between surveillance and policy was limited during the scoping period, this has greatly improved since 2021-22, although no formal communication channels are in place. Unlike other CHP programs (i.e., ASD) where the building of a national strategy includes intensive consultations, there are fewer opportunities for the surveillance team to engage with external stakeholders along with the policy team. Quantitative data are shared with the policy team when available. There is, however, no collaborative or joint planning among both policy and surveillance teams, which limits the opportunities for both teams to benefit from each other's work.

Other areas

Beyond project funding and surveillance activities, the FASD program shares information with regional colleagues, meets with other government departments annually, and has deployed communication efforts through awareness activities during the pandemic and as part of FASD Awareness Day. Policy activities include a funding request attempt to better support FASD activities.

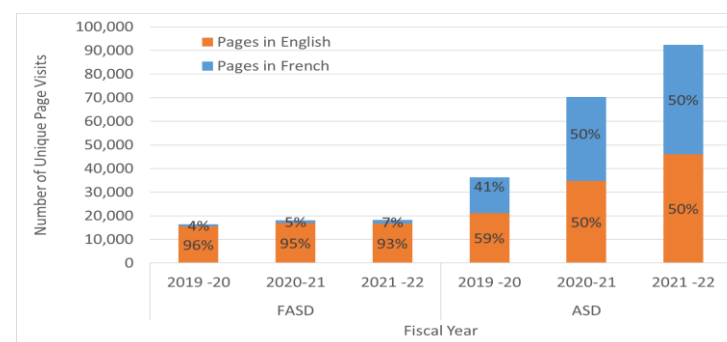
As noted previously in the report, the only program element funded for FASD is the NSPF. Regardless of this, PHAC has been able to carry out numerous other activities to support FASD. In addition to NSPF activities and surveillance, the FASD program has undertaken the following activities:

- **Stakeholder engagement** activities – where meetings are organized several times a year between the FASD program and those in PHAC regional offices who liaise with local FASD stakeholders (regional FASD leads). The interdepartmental working group also meets once a year for the purpose of information sharing. Interviewees indicated that, prior to COVID-19, meetings with funding recipients were organized for sharing updates; however, these meetings no longer occur. There is currently no governance or engagement table involving P/Ts beyond broader existing tables such as the Pan-Canadian Public Health Network.
- **Policy** activities, where CHP tried to leverage the renewal of the Canadian Drug and Substance Use Strategy as a new funding opportunity for FASD but was unsuccessful due to other high priority competing areas. More recently, on October 19, 2022, *Bill S-253: An Act respecting a national framework for fetal alcohol spectrum disorder* was introduced in the Senate of Canada. The second reading in the Senate is in progress. Should this act pass, it will have an impact on PHAC's future work. Please note that recent policy activities in response to this bill fall outside of the scope of this evaluation.
- **Communication** activities included updating the PHAC webpages dedicated to FASD (in 2018 and 2022), and PHAC's

participation in the International FASD Awareness Day campaign (September 9). In 2020, PHAC funded a prevention awareness campaign to address specific needs in the context of the COVID-19 pandemic by providing complementary amounts to grants and contributions funding recipients.

The web traffic generated by PHAC's ASD communication activities is illustrated in Figure 1 – views of FASD pages have remained stable over the past three years. This trend is different to other similar issues, such as ASD. The ASD pages received more views, which may be explained by the public interest generated by the upcoming ASD national strategy. Moreover, FASD-dedicated pages in French account for about 5% of all traffic to these pages in Canada over the three-year period, which is very low compared to Canada's linguistic representation. The traffic on the ASD pages is well balanced between English and French contents.

Figure 1: PHAC website views in Canada: FASD versus ASD pages



Source: Communications and Public Affairs Branch, Digital Communications Division.

Conclusions

To date, PHAC has undertaken activities to address FASD that are well aligned with its federal public health role. Despite having ambitious objectives, FASD-dedicated funding is limited. Important gaps remain and some appear to align with the federal public health role in the areas of strengthening surveillance, national strategic planning, stakeholder engagement and collaboration, documenting promising practices, and supporting guideline development and dissemination.

All NSPF-funded projects have developed and shared relevant information to raise awareness and improve knowledge at various levels of the four-part FASD prevention model, and appear to be mainly focused on prevention. The public, childbearing or pregnant women and their networks, and several professionals, including healthcare professionals, were all target populations of the NSPF funded projects. Most projects had to adapt to the COVID-19 pandemic by shifting toward virtual delivery. The performance data required from funded projects covered mostly outputs and reach, however, some projects were able to demonstrate that participants had acquired awareness and new knowledge. There would be value in collecting additional data to determine project achievements like knowledge, use, or behaviour change, as with other PHAC grants and contributions programs.

Some funded projects also helped enhance FASD surveillance data while PHAC's surveillance activities examined various data sources to establish national FASD surveillance. However, the lack of national FASD prevalence data continues to represent a gap, which is further exacerbated by the under-diagnosis and under-reporting of FASD cases.

Recommendations

Recommendation 1: Continue strengthening surveillance efforts with a focus on establishing the building blocks for FASD surveillance, including national prevalence estimates.

Current exploratory activities are necessary precursors to building a national surveillance system. Gathering the necessary data to inform decision making, particularly regarding equity-deserving populations, will require identification of investment in surveillance and collaboration with provinces and territories (P/Ts). This would also align with the Truth and Reconciliation's Call to Action regarding the need to understand and close the gaps in health outcomes between Indigenous and non-Indigenous communities.

Recommendation 2: Strengthen the integration of FASD efforts across PHAC, from awareness and prevention to a response that adopts social determinants of health and harm reduction lenses which would improve connection with PHAC's broader substance use approach.

The evaluation found that some gap areas in FASD could be filled by PHAC given its federal public health role; however, not all activities are not integrated. A few teams across PHAC are responsible for FASD-related activities (within CHP, CSAR, and in the regional offices), but there is no overarching structure currently to coordinate these efforts. Moreover, FASD is a complex issue that requires considering social determinants of health beyond the traditional public health programming. It is also related to issues such as alcohol consumption in pregnant women, which also falls under substance use. Both issues are addressed by other groups in the health portfolio. Better understanding how current activities are structured and how to coordinate them both internally and externally is a preliminary step for a more consistent approach to facilitate national approaches to FASD policy and planning. While

the previous FASD evaluation recommended improving stakeholder engagement, further work is still needed to enhance coordination.

Recommendation 3: Enhance the FASD program's performance measurement approach with a focus on impact.

Once activities and roles are mapped and better defined, FASD-related activities should be clearly articulated in a logic model that would highlight FASD program objectives and the respective ways to achieve them. The four-part FASD prevention model may help frame efforts by target populations. It would also clarify where the FASD program is best positioned to serve each population while

clarifying boundaries with children's programs. By using this framework, synergies could also be found across funded projects geared toward the same goals and at the same level. Once the logic model is clarified, relevant and realistic indicators should be identified and collected to monitor progress. In the case of NSPF, PHAC should ensure that funded projects plan and commit to monitoring efforts early on. While enhancing performance measurement was recommended in the previous FASD evaluation, progress in data collection was limited and therefore more refined and comprehensive performance measures would benefit the program.

Appendix 1- Data Collection and Analysis Methods

The scope of the evaluation included PHAC activities related to Fetal Alcohol Spectrum Disorder from April 2018 to March 2022. The evaluation was designed to address the intended outcomes of PHAC's FASD activities and provide insight on the evaluation questions.

The evaluation team collected data using various sources and methods, including the following:



Document and File Review

Program staff at CHP and CSAR provided documents for evaluators for review. In total, the evaluation team screened approximately 120 documents and reviewed 30 of them in details.



Web Analytics

FASD web analytics data was available from 2019-20 to 2021-22. The data measures the number of visits to FASD-related pages on PHAC's website. Each page was counted once per session, which is the time between accessing and leaving the website. Data prior to 2019-20 is not stored on Health Canada-PHAC servers.



Interviews

Evaluators conducted interviews with 49 individuals. This included nine interviewees internal to PHAC, six P/Ts, ten recipients and 24 other external stakeholders from OGDs and NGOs or experts. The evaluators used NVIVO qualitative analysis software to identify emerging themes from these interviews.



Financial and Human Resources Data

PHAC's Chief Financial Officer and Corporate Management Branch

provided financial data on planned and actual program expenditures for the evaluation period. Human resources data was also collected to document program turnover.



Academic and Grey Literature

A focused review of academic and grey literature was conducted to inform evaluation findings.



Performance Measurement Data

PHAC provided performance measurement data, which the evaluation team analyzed to look for key trends and assess outcomes.

The evaluation team used triangulation to analyze data collected by these various methods in order to increase the reliability and credibility of the evaluation findings and conclusions. Still, most evaluations face constraints that may affect the validity and reliability of evaluation findings and conclusions.

The table below outlines the limitations encountered during the implementation of the selected methods for this evaluation, and the mitigation strategies put in place to ensure that evaluation findings are sufficiently robust.

| Limitation | Potential Impact | Mitigation Strategy |
|---|--|--|
| Interviews are retrospective in nature, providing only a recent perspective on past events. | This can affect the validity of assessments of activities or results that may have changed over time. | Triangulation with other lines of evidence substantiated or provided further information on data captured in interviews. Document review also provided corporate knowledge. |
| Some interviewees were not available for interviews due to extended leave post-funding. | Some potential interviewees were unable to contribute their insight. The evaluation could be missing important views and perspectives. | Contacted other potential interviewees from the same category to ensure that there was representation from the range of stakeholders or partners that collaborate with PHAC. |
| PHAC performance measurement data was limited to a small number of indicators. | Assessment of progress towards outcomes that do not have associated performance measurement indicators can be more challenging. | Triangulation of other lines of evidence was used to provide further information where there were gaps in performance measurement data. |
| Financial data structure is not linked to outputs or outcomes. | There is limited ability to assess efficiency using quantitative methods. | Used qualitative lines of evidence, including interviews and document reviews. |
| There was limited data related to medium- and long-term outcome due to funding timing. | Assessment of progress towards related outcomes is challenging. | The evaluation focused on other outcome areas and used triangulation of other lines of evidence to the extent possible. |

The evaluation applied an SGBA+ lens in its assessment of FASD activities, including discussions on which disaggregated data was available and needed. Official languages were examined in the deliverables of funded projects as well as FASD-related webpages on the PHAC website.

Furthermore, the Sustainable Development Goals did not apply to this evaluation and therefore were not examined.

The scope for this evaluation was presented at the Performance Measurement and Evaluation Committee (PMEC) on June 21, 2022, and the final report in March 2023.

Appendix 2- Program spending and internal challenges

Program Spending

PHAC's planned spending on FASD-related activities for the period of the evaluation was approximately 9.9 million dollars.

Table: CHP planned versus actual spending, by fiscal year

| CHP | | | | |
|------------------|---------------------|---------------------|---------------------|---------------------------|
| Fiscal Year | Planned Spending | Actual Spending | Variance | % of planned budget spent |
| 2017-18 | \$ 2,106,346 | \$ 1,861,684 | \$ -224,662 | 88% |
| 2018-19 | \$ 2,122,749 | \$ 1,346,148 | \$ -776,601 | 63% |
| 2019-20 | \$ 2,082,327 | \$ 2,176,415 | \$ 94,088 | 105% |
| 2020-21 | \$ 1,820,591 | \$ 1,651,808 | \$ -168,783 | 91% |
| 2021-22 | \$1,820,591 | \$1,096,866 | \$-723,725 | 60% |
| TOTAL CHP | \$ 9,952,603 | \$ 8,132,921 | \$-1,819,681 | 80% |

Internal challenges hindering results

Human resources turnover affected the FASD program at least twice over the scoping period. Those working on the FASD file were also mobilized to support the COVID-19 pandemic, like many employees across PHAC. According to interviewed stakeholders, the program's staff turnover and loss in expertise led to a disconnect with stakeholders. In addition, issues with information management, when combined with human resources turnover, has led to the loss of corporate memory. Historical program knowledge is unavailable, and new staff have difficulty accessing relevant information and building upon the work done by former staff.

Appendix 3- Alignment of desired outcomes with the Four-part prevention model

Desired outcomes as per the FASD strategic plan 2016-2021 align with the four-part FASD prevention model, shown in Figure 1. See the corresponding levels in the table below. The mapping between desired outcomes and the prevention model are presented in the table below. In addition, the last desired outcomes “increasing the understanding of the magnitude and burden of FASD in Canada to support planning and decision making” complement this model.

| Level | Four-part prevention model | Desired outcomes of the 2016-2021 strategic plan |
|-------|--|--|
| 1 | Broad awareness building and health promotion efforts | Raising public awareness |
| 2 | Discussion of alcohol use and related risks with all women of childbearing years and their support networks | Preventing alcohol use in pregnancy through the provision of consistent messaging on its impact |
| 3 | Specialized, holistic support of pregnant women with alcohol and other health or social problems | Relevant resources for service providers to assist women who have difficulty stopping or reducing alcohol use during pregnancy |
| 4 | Postpartum support for new mothers assisting them to maintain or initiate changes in their health and social networks and to support the development of their children | Supporting those affected by FASD through evidence-based and culturally appropriate FASD interventions, training opportunities and sharing of best practices |

Appendix 4- FASD National Strategic Fund: Project Description and Results

Five projects targeted the general population and raised awareness about the risks of drinking while pregnant (Level One).

- The project “Toward Prevention: An Atlantic FASD awareness and collaborative action-building initiative” managed by **Fetal Alcohol Spectrum Disorder Newfoundland and Labrador Network (fasdNL)** developed FASD prevention and awareness messaging and resources for the general public in the Atlantic Provinces. These activities included a social media campaign with 14 posters in English, French and Inuktitut, and a Mi'kmaq translation was planned as per most recent report. The campaign reached over 477,000 individuals, incorporated feedback from partners and those living with FASD, and will continue until 2023. In addition, two radio advertisements aired across Atlantic Canada in January 2021. Finally, during FASD Awareness month 2021, fasdNL held a free webinar about the project and the work being done in Atlantic Canada.
- The project “Using Diagnosis and Data to improve Outcomes in FASD”, managed by **CanFASD**, included multiple components, one of which was to develop and make available online a caregiver's guide to FASD diagnosis. The guide reached over 11,000 people via a Facebook post while posts on Twitter and LinkedIn resulted in some impressions: over 4,000 and 240 respectively.
- **Association pour la santé publique du Québec** developed “FASD: Talking about it for better action” a bilingual awareness campaign to prevent alcohol consumption during pregnancy and to address stigma associated with FASD in Québec. The program aimed to increase knowledge

and understanding about alcohol consumption during pregnancy and FASD among the general population, change public perceptions, reduce FASD stigma and evaluate bilingual resources and best practices to support community action. The campaign resulted in approximately 11 million ‘impressions’ from individuals through its various platforms, including social media, web, TV and other means like printed materials.

- The project “FASD Prevention School-Based Program for Children and Adolescents in Select Urban, Rural and First Nation Schools in **Ontario**” is the second project currently being managed by the **Centre for Addictions and Mental Health**. This pilot project will culturally adapt, translate, deliver, and evaluate the effectiveness of the National Organization on Fetal Alcohol Syndrome’s (NOFAS) school-based FASD Education and Prevention Curriculum in select Ontario schools for children aged 12 to 18 years in urban, rural, and First Nations communities. An interdisciplinary steering committee was convened in fall 2019. Collaboration with advisory committees and advocacy groups have so far included Shkaabe Makwa, CanFASD, FASD One, NOFAS, substance use prevention experts, educators and those with lived experience. By the end of 2022, the first objectives had been met to culturally adapt the NOFAS curriculum for implementation in select Ontario schools and to encourage non-stigmatizing language and tolerance. Implementation of the pilot tool began in March 2022 and would continue until January 2023. The final

objectives include evaluating the tool and, if it is found to be effective, providing a toolkit to guide its implementation.

- **The Pauktuutit Inuit Women of Canada's** Fetal Alcohol Disorder: Supporting Our Inuit Families and Communities Campaign was a community-based awareness campaign based in Inuit Nunangat, which includes parts of Yukon and Northwest Territories, Nunavut, Québec, Labrador, Ontario and Alberta that aimed to promote FASD prevention in Inuit communities, reduce stigma associated with FASD, and improve maternal and infant outcomes. To do so, the project looked to enhance FASD Inuit-specific data, and inform resource development through in-person and virtual focus groups and telephone interviews. In September 2021, the steering committee summarized the research findings from the first phase of the project via the release of two reports: the Environmental Scan and Research Report, and the Community Report (plain language version). Both reports provided an overview of knowledge, attitudes, and understanding of FASD in the communities in addition to highlighting certain Inuit-led and culturally-safe FASD services available in the region.

Four projects targeted women of childbearing age and their support networks (Level Two).

- The project "Using Diagnosis and Data to improve Outcomes in FASD", managed by **CanFASD**, expanded its activities in the early stages of the COVID-19 pandemic to address the surge in alcohol consumption. CanFASD developed a one-page document to increase awareness of the risks associated with alcohol use during pregnancy and to increase awareness of resources to support women and families during isolation. The document was featured on a CanFASD blogpost, and promoted through multiple channels, reaching about 2,400 individuals on Facebook, as

well as 18,000 people through partners' social media platforms (such as SOGC's).

- The **Association pour la santé publique du Québec** managed "FASD: Talking about it for better action". One of the target populations for the awareness campaign was women aged 12 to 25. According to the post-campaign survey among young women of the target age group, the retention of the main messages on FASD and alcohol consumption was excellent (70%), and almost 90% found the campaign to be understandable and caring. Approximately 48% had the intention to talk about the risks of drinking while pregnant with family and friends.
- The **YWCA Metro Vancouver** managed 'Culturally Sensitive Awareness to Prevent FASD in Marginalized Communities', a community-driven pilot project from 2019-20 to 2022-23 that ended in May 2022. The project focused on building awareness for women of child-bearing age with regards to alcohol consumption during pregnancy, and on developing resources to teach the basics of FASD. It targeted those in marginalized and underserved communities, including immigrants, refugees, low-income individuals, and Indigenous and non-Indigenous peoples in Vancouver, British Columbia. The project relied on the input of various experts, individuals with lived experience, and organizations to plan, develop and test its project materials. The project resulted in key deliverables like a literature review on the FASD context, an FASD Dictionary to teach the basics of FASD and what to do to help reduce FASD stigma, and a toolkit to help other organizations replicate the project's prevention campaign. The project also held two conferences. An evaluation concluded that the project's successful factors were the inclusion of those with lived experience, establishing protocols for working together as a collective, generating the content for the FASD Dictionary,

the accessibility of the dictionary, and the overall passion, time and caring that went into the development of this resource.

- The **Saskatchewan Prevention Institute Inc.** managed the “National FASD Mentoring Project” which provided training to Aboriginal Head Start in Urban and Northern Communities (AHSUNC) sites to staff and partner organizations’ staff through FASD mentors. The goal of the project was to increase awareness and knowledge of FASD for those who work with families in Indigenous communities so that they can, in turn, strengthen their skills and tools, and develop appropriate services. Using a “train-the-trainer” approach, 17 mentors who were identified to facilitate workshops received training and resources over the course of three days. In total, the mentors delivered 63 workshops to 84 AHSUNC sites which were attended by over 600 individuals, 50% of which were AHSUNC staff). The evaluation of the project noted that it was successful in building capacity in Nunavut to address FASD and that lessons learned from the workshops were being implemented well after the conclusion of the project.

One project supported a PHAC-funded AHSUNC project to help them document their achievement of supporting pregnant women in a holistic manner including alcohol consumption (Level Three).

- The **Nota Bene Consulting Group’s** “Multi-Site Evaluation on FASD Prevention, with Holistic Programs Reaching Pregnant Women at Risk” project consisted of conducting a multi-site evaluation of Level Three FASD holistic prevention programming from eight sites across Canada. The programs were guided by a similar set of approaches, which included being ‘trauma-informed, relationship-based, women-centred, culturally-grounded, and harm-reducing.’ The organization formed an advisory committee of individuals

with FASD expertise in various activity areas. The evaluation contributed to increasing the knowledge base to help current and future holistic programs succeed. It did so by publishing three articles over the course of the project and presenting results at various conferences. Findings were related to or focused on some of the evaluation results such as perspectives of women on seeking help and their most significant changes. In addition to sharing its evaluation report, Nota Bene also produced a series of online information sheets focusing on various aspects of the evaluation findings. Outcomes of the various programs found that participants experienced the biggest changes in substance usage, such as reducing or quitting consumption, increased support from programs, and stronger connections with personal support systems⁴⁴.

Five projects targeted health professionals and allies and provided them with guidelines and tools to screen FASD and support those living with this syndrome (Level Four).

- The project “Toward Prevention: An Atlantic FASD awareness and collaborative action-building initiative” managed by **Fetal Alcohol Spectrum Disorder Newfoundland and Labrador Network (fasdNL)** described above also released training materials and sessions for supporting professionals. This includes a virtual training entitled “FASD 101 and the Justice System”, delivered in October 2021 and March 2022 to 143 justice professionals and 20 facilitators. In addition, in April 2022, a training session was also delivered to 43 members of the Royal Canadian Mounted Police and the Newfoundland and Labrador provincial police force. Participants received copies of the training material for further dissemination.
- The **Association pour la santé publique du Québec** as part of its “FASD: Talking about it for better action” bilingual

awareness campaign reached professionals and decision makers. Nineteen presentations were delivered to school boards and medical professionals, with audiences ranging from 80 to 800 attendees and toolkits were disseminated to other organizations that were more difficult to reach.

- The **Saskatchewan Prevention Institute Inc.** managed the “National FASD Mentoring Project” which provided training to Aboriginal Head Start in Urban and Northern Communities (AHSUNC) sites to staff and partner organizations’ staff through FASD mentors. The goal of the project was to increase awareness and knowledge of FASD for those who work with families in Indigenous communities so that they can, in turn, strengthen their skills and tools, and develop appropriate services. After the workshops, attendees and site directors confirmed that teachings and strategies from the workshop were already being implemented. Some attendees mentioned having used an ‘FASD lens’ when thinking about situations, and others were able to notice ‘FASD signs’ in some children, allowing them to better support families and clients.
- The project “‘Dialogue + Action: Women and Substance Use’ – was led by the **British Columbia Centre of Excellence for Women’s Health**. The project aimed to identify and summarize screening tools, approaches and practices that can be used by health care providers to discuss alcohol use with women. The project looked to supplement this information and then completed a scan of the literature that was later compiled into a report for PHAC. They also looked to modify existing delivery platforms to identify and promote best practices related to discussing and screening for alcohol use. Findings from the literature review and regional sessions were compiled into several documents, with distribution reaching almost 500 copies, among English and French readers, and almost 150 attending the

accompanying webinar. The projects were highly collaborative, with partnerships including healthcare professionals, research bodies and provincial government offices.

- The project “Using Screening, Training and Data to Address Women’s Alcohol Use during Pregnancy” was developed and managed by the **Society of Obstetricians and Gynecologists of Canada**. The project developed clinical practice guidelines, training programs, and toolkits. In addition, the project updated current screening tools and treatment protocols. In its first year, SOGC’s project drafted two surveys, completed a literature review and evidence synthesis, and conducted a needs assessment of women’s healthcare providers to determine barriers and facilitators regarding alcohol use during pregnancy. Various approaches were undertaken to promote guidelines and train professionals, including using a guideline toolkit, an interactive web forum, virtual workshops, and an e-course. Preliminary results indicated that there were 646 guideline downloads, 200 participants at the workshops and 54,000 hits on their website. SOGC’s update of risk factors resulted in an awareness campaign that attracted 1 million impressions on social media, and 60,000 visits to the website over 5 weeks.
- The project “Using Diagnosis and Data to Improve Outcomes in FASD” was managed by **CanFASD**. The Towards Improve Practice (TIP) course was launched online on the CanFASD e-learning platform in 2018 and a total of 71 individuals completed the course. However, since TIP had limited uptake, with only 71 learners, it was incorporated into a new course titled ‘Identifying Best Practices for Fetal Alcohol Spectrum Disorder’. This course has been taken by 336 online learners at the time of the project completion, and it was further promoted in a

webinar attended by 96 service providers. The online training is the first training offered to all new clinicians in an FASD diagnostic clinic team or for those starting a new clinic. Pre- and post-test results indicate that the 613 learners who completed the “Multidisciplinary Team Training for Diagnosis of FASD” have improved knowledge and understanding.

Finally, two projects advanced the understanding of the magnitude of the FASD prevalence.

- **CAMH** conducted a screening study using a cross-sectional, observational design to determine the population-based prevalence of FASD among elementary school students in the Greater Toronto Area (GTA) in Ontario, Canada. This study provides the first population-based estimate of the

prevalence of FASD among elementary school students aged 7 to 9 in Canada. It was published in BMC Public Health, a peer-reviewed, open-access scientific journal, on the CAMH and CanFASD websites. The journal has at least 50 citations according to ResearchGate and this does not include those who accessed the article via other websites.⁴⁵

- **CanFASD** managed the “Using Diagnosis and Data to improve Outcomes in FASD” project from 2016-17 to 2020-21. The project looked into expanding and updating its web-based collaborative forum and information on prenatal exposure in its database. The National FASD database held by CanFASD was also updated. Almost 300 records were recoded and added and significant data on demographics and risk factors was also collected as a result of a survey with clinics.

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