Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

Fetal Alcohol Spectrum Disorder in Canada:

Summary Report

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Summary

This assessment was undertaken to better understand how to prevent Fetal Alcohol Spectrum Disorder (FASD) and support individuals with FASD and their families and communities, identifying challenges and opportunities to strengthen Canada's approach. The Public Health Agency of Canada charged the Canadian Academy of Health Sciences with answering the following four key questions:

- What is needed to support broader uptake of the Canadian FASD Diagnostic Guidelines in Canada?
- What are the clinical/community and federal/provincial/territorial challenges associated with case identification and data collection in Canada?
- How can FASD prevention activities be strengthened to support the overall objective of reducing the prevalence of FASD in Canada?
- What tools, resources and supports are needed to improve outcomes for those with FASD across the life course?

Our response is based on an updated literature review, an overview of the current FASD policy landscape in Canada, and an analysis of the policy in selected international jurisdictions, as well as an extensive engagement process. It also considers the implementation of the 2003 *FASD: A Framework for Action* report.

Overview

FASD presents a complex and important public health challenge. The issues of prevention, case identification and prevalence estimation, diagnostic approach and resources, and supports are interlinked. Prenatal alcohol exposure (PAE) is highly stigmatized, as are people with FASD and their parents. Stigma leads some people to avoid an FASD diagnosis and to seek alternative diagnoses. Diagnosis is resource intensive, there is limited diagnostic capacity, and confirmation of PAE can be difficult or impossible for some individuals. Difficulty in accessing interventions and supports in many parts of the country leads people to reject pursuing an FASD diagnosis for their child. The difficulty of accessing a diagnosis is a particular problem where formal diagnosis is required for accessing interventions and supports. Together these diagnostic challenges reduce accuracy in determining FASD prevalence; they also affect resource allocation for FASD prevention and supports. At the same time, adults with FASD often find their diagnosis to be highly valuable for self-understanding, building community, reducing blame and seeking treatment and accommodations.

There is currently a debate over the use of FASD as the primary or sole diagnostic category and the suggestion to shift toward a broader diagnostic term, complex neurodevelopmental disorder, with causal factors like PAE specified where known. Proposed advantages of this approach are that it would allow for diagnosis in cases where evidence of PAE is unavailable, and also address uncertainties about the relative contribution of the multiple pre- and post-natal risk factors that can affect brain development and that often co-exist along with PAE.

There is concern, however, that this approach might disincentivize FASD diagnosis. This would lead to underestimation of prevalence, hampering FASD prevention efforts and our understanding of FASD as an important public health issue requiring concerted action. For individuals with FASD this proposed approach might impede access to supports that depend upon an FASD diagnosis. There is also a risk of disrupting the sense of community and shared identity that some people with FASD have built around their common experiences. A possible way forward could be to use complex neurodevelopmental disorder diagnosis in conjunction with specific diagnoses such as FASD.

The legacies of colonial harm and trauma, as well as the health and well-being challenges associated with systemic racism and marginalisation, play a part in the picture of FASD in Canada. The Truth and Reconciliation Commission's Calls to Action draw attention to the impact of FASD for Indigenous peoples and communities. The report includes a separate chapter on Indigenous Peoples[1], communities and FASD, presenting the specific Indigenous literature review and engagement perspectives. We have integrated this within our responses to each question in this summary.

We now turn to the four questions specified by PHAC for this assessment.

1. What is needed to support broader uptake of the Canadian FASD Diagnostic Guidelines in Canada?

In addition to reducing stigmatization of PAE and FASD, and increasing certainty of benefits to people flowing from the diagnosis, the assessment found three overarching opportunities to support broader uptake of diagnosis: increasing FASD awareness among practitioners, expanding diagnostic capacity and regularly updating diagnostic guidelines.

Increasing understanding of FASD among professionals

Although public and professional awareness of FASD has increased since the publication of the *2003 FASD: Framework for Action* report, many health care, education, social, child welfare and justice system personnel lack confidence to identify when a person might have FASD in order to suggest assessment or other possible follow-up within their authority, and have limited

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[1] Canada's Constitution recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit Peoples. A distinction-based approach is important to be responsive to the unique needs and context of First Nations, Métis and Inuit Peoples. While the term Indigenous does not reflect the uniqueness of each group, it is used in this report with the intent to be inclusive.

understanding of the challenges associated with FASD. Helping professionals to understand the heterogeneous and hidden nature of FASD presentation could lead to more frequent recognition of FASD, with more people referred for diagnostic assessment.

A variety of resources exist across multiple professions, but their uptake is uneven or unknown and therefore steps to ensure this knowledge is recognized as standard of care would be helpful. Consolidating, updating, and sharing existing resources across jurisdictions would help increase their reach and uptake. In all these efforts, closely involving people with FASD and their families will ensure results are most useful and relevant to them.

Expanding diagnostic capacity

There is limited and uneven diagnostic capacity across Canada. Currently, FASD diagnosis relies on a relatively small number of specialized clinicians, teams and clinics that can accommodate only a small fraction of those likely to have FASD, and the wait list can be long in some locations. In many rural and remote regions, access to local assessment and diagnostic services is difficult or impossible. Capacity for young children and adult diagnosis is especially limited.

Increasing diagnostic capacity by helping a wider range of health professionals to build confidence in referral and assessment, improving provider incentives, and adopting new delivery models could help reduce this barrier to uptake. Examples include virtual delivery models and development of specialized FASD nurse practitioners. Culturally safe diagnostic practices would also support efficacy, trust and acceptance.

Regularly updating diagnostic guidelines

The development of the 2005 Guidelines, and their subsequent update in 2016, reflected the evidence available at that time and expanded the evolving understanding of FASD in Canada and internationally. Multidisciplinary FASD assessment as recommended by the guidelines is complex and resource intensive while diagnostic capacity across Canada is limited. Regularly updating guidelines to reflect current evidence, based on broad consultation, could support uptake and ensure their future relevance. It could be helpful to build consensus on the best way forward given recent questions raised about the use of a broader diagnostic category of complex neurodevelopmental disorder, along with specific diagnoses like FASD.

2. What are the clinical/community and federal/provincial/territorial challenges associated with case identification and data collection in Canada?

While some epidemiological studies on FASD prevalence exist, these data remain challenging to obtain due to diagnostic complexity, methodological challenges and variability in measurement approaches, as well as the stigmatization and underdiagnosis mentioned above.

Clinical challenges

Routine case identification and reporting of PAE through universal screening of all pregnant women[2] would contribute to improved data about the prevalence of the risk of FASD. However, health care providers may not ask pregnant patients about alcohol consumption, and pregnant patients may not disclose alcohol consumption because of stigmatization and fear of child apprehension. Health care providers could benefit from tools and advice on how to identify and counsel pregnant women who may be using alcohol; they would also benefit from a greater awareness of the importance of PAE screening and of giving clear, consistent yet non-judgmental messages about the risks and importance of avoiding alcohol during pregnancy.

Relying upon diagnosed cases of FASD significantly underestimates prevalence in Canada, as evidence suggests that only a small portion of cases are detected. Passive methods of data collection (using existing sources such as birth records, special registries for developmental disabilities and birth defects, physicians and school records) are useful for population-level surveillance, but may be impacted by the clinical challenges noted above. Active case ascertainment studies actively seek and find cases within a smaller sub-population and can be especially useful in establishing prevalence, although generalizability to a broader population may be a challenge.

Community challenges

Community-level data on FASD prevalence and risk factors in local or regional populations are rarely available. This disaggregated data would be helpful for understanding risk factors and directing supports to where they are most needed. For example, while FASD may be found in any community where alcohol is consumed, there is data available that suggests the prevalence of FASD in some specific sub-populations (e.g., children in care, people in prison, Northern remote communities) is estimated to be much higher than the general population.

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[2] Throughout our report we use the shorter term ‘women’ or ‘pregnant women’, and this should be taken to include women and all other gender-diverse people who are or could become pregnant, including trans men, non-binary, and two-spirited individuals. The rationale for this terminology is explained in chapter 1.

Reporting on prevalence in sub-populations or in local communities based on this disaggregated data runs the risk of stigmatizing affected groups, and fueling a perception that FASD is solely or primarily a problem of those groups. Working in collaboration with affected groups and their allies to contextualize FASD prevalence data, such as including data on the corresponding social determinants of health, helps to combat stigmatization and to support inclusion.

Many community-based initiatives are working to prevent FASD and support people with FASD and their families. However, they often rely on project-based funding and struggle to find sustained operational funding. Strengthening this local infrastructure through more reliable funding as well as mechanisms for performance assessment and improvement could help to maintain promising grassroots programs that are well positioned to help get community buy-in to support case identification and data collection. In Indigenous communities, robust community level data collection, consistent with data sovereignty principles, could meaningfully inform policy responses and resource allocation.

Federal and provincial/territorial challenges

Provinces and territories use inconsistent approaches to collect data on PAE and diagnosed cases of FASD, and in some jurisdictions, data are limited. Most administrative databases in education and health care provide little information about FASD prevalence due to a lack of FASD-specific codes or categories. Establishing FASD-specific codes could enhance prevalence information and aid understanding of service utilization within these systems.

A national data repository, to which all provinces and territories contribute consistent data, would improve our understanding of prevalence of PAE and FASD in Canada, and help facilitate coordinated and efficient policy. Mandatory data reporting at the clinical level could strengthen the data available on FASD and various approaches have been implemented in some jurisdictions, however, the contribution and collection of detailed data is resource-intensive and there are ethical considerations related to privacy and stigmatization. A broader data repository that captures complex neurodevelopmental disorder, along with FASD and other applicable diagnoses, might further improve understanding.

3. How can FASD prevention activities be strengthened to support the overall objective of reducing the prevalence of FASD in Canada?

Prevention activities take place at multiple levels across Canada, from universal public education and broad policy initiatives to targeted actions for at-risk groups. Both broad and targeted efforts, together with improved epidemiological data, can strengthen FASD prevention in Canada.

Universal and broad-scale prevention

The public's basic awareness of FASD has increased and is now quite high; however, understanding of the risks of PAE is not as high and media discourse may perpetuate stigma. At a population level, multi-pronged alcohol policies (such as increasing pricing/taxation, controlling marketing, reducing availability, and labelling about risks) can reduce the health risks of alcohol including FASD.

Most women stop consuming alcohol when they learn of their pregnancy. However, a significant number of pregnancies are unplanned, and alcohol consumption may occur until the pregnancy becomes known. Free, widely available, multiple-option birth control and emergency contraception is therefore part of an effective PAE prevention strategy.

Health care providers can help prevent PAE by educating and counselling people about alcohol and pregnancy, using a non-judgemental, supportive approach. During pregnancy, systematic screening for alcohol use can provide patients with information, counselling, and support, as well as referrals for more intensive interventions when needed.

School-based programs show promise in influencing alcohol consumption. Certain approaches such as programs that are interactive and focus on developing social resistance skills or targeted cognitive behavioural skills are associated with greater impact. For programs that try to raise awareness about FASD specifically, consideration of inclusiveness and respect, and the potential impacts on persons with FASD in the school population are important for any school-based programs seeking to raise awareness of FASD.

Concerns have been raised about young people's susceptibility to alcohol marketing, including youth with developmental challenges who can have unique vulnerabilities.

Targeted prevention

Effective prevention of FASD in at-risk subpopulations requires approaches that address the individual, social, cultural and environmental causes of problematic alcohol use, which frequently include a complex mix of risk factors such as trauma, abuse, poverty, and unmet mental health needs.

Effective prevention of FASD requires holistic, trauma informed, culturally safe wrap-around support that addresses risk factors. These supports implemented for prevention can be usefully continued postpartum to support early interventions for affected infants to reduce or prevent the harmful effects of alcohol on development. Continuity of care helps build the trusting relationships crucial to addressing problems with alcohol and substance use, as well as to diagnosing and supporting families affected by FASD.

Indigenous communities are best placed to determine the relevance and applicability of prevention strategies that respond to their own needs, culture, context, and objectives. Beneficial prevention models often include the above wrap-around supports and, in addition, are Indigenous-led and incorporate the Indigenous community's knowledge of healing and well-being. Developing and training Indigenous community-based health professionals and paraprofessionals could help to build local capacity, reduce turnover and provide culturally informed FASD health services.

4. What tools, resources and supports are needed to improve outcomes for those with FASD across the life course?

Access to timely and suitable interventions and supports can improve outcomes in relation to health and well-being, quality of life, education, employment, social relationships, and avoidance of problems with the justice system. A formal diagnosis is often not possible due to unconfirmed PAE or lack of diagnostic capacity, yet it is required for accessing many interventions and supports for people with FASD. Furthermore, people with FASD may be unable to access disability supports where they have an IQ above the cut-off point for eligibility despite experiencing significant challenges with adaptive functioning due to the symptoms of FASD.

Across Canada, the siloed operation of social services and systems increases complexity for people with FASD and their families and makes the delivery of supports less efficient and effective. Mechanisms to address system fragmentation and complexity include efforts to integrate service provision and the use of system navigators or key workers. Stability and consistency of community supports can be enhanced by moving to a system of longer-term and sustainable funding for models that have demonstrated success, rather than relying on time-limited project-based funding.

People with FASD are over-represented in the child welfare system, and involvement in the system is an additional risk factor affecting long-term outcomes. Supportive wraparound structures that aim to help and to preserve families are important. Other key elements to addressing this over-representation include ensuring that children and adolescents in the child welfare system are able to access diagnosis and supportive interventions as early as possible, and providing supports and training for kinship and foster care placements to enable continuity, stability and well-being. Youth with FASD transitioning out of the child welfare system benefit from stable supportive relationships and often need longer term, targeted supports that recognizes the slower pace with which the transition to adulthood occurs.

In Indigenous communities, evidence supports holistic Indigenous community-led FASD interventions; these communities are best placed to determine which tools, resources and supports respond to their own needs, cultures, contexts, and objectives.

Childhood and adolescence

Early FASD diagnosis and intervention is associated with improved outcome, but assessment in early childhood can be more difficult because some of the neurocognitive domains assessed as part of the process are difficult to accurately evaluate in pre-school age children. Family support and specific interventions for young children at risk of neurodevelopmental disorders can be offered prior to diagnosis on the basis of functional assessments which identify a child's strengths and needs in order to intervene and to help improve long-term outcomes.

As children enter school age and beyond, issues with social, behavioural and academic functioning may emerge as a result of the primary neurodevelopmental challenges caused by PAE. Earlier diagnosis, supportive, caring, consistent, stable environments, and interventions to prevent or reduce these issues are key for improved outcomes across the life span.

FASD-informed schools can meet the diverse needs of diagnosed as well as undiagnosed students with FASD. A tiered approach to school-based interventions offers different levels of support according to students' specific needs and strengths. Evidence-based interventions for school-aged children can ameliorate cognitive challenges, such as in mathematics and language acquisition, and can also support psychological and behavioural needs. Targeted educational interventions such as FASD-informed classrooms, small-group instruction, evidence-based FASD interventions, and access to educational assistants who facilitate the use of supports and strategies, are beneficial and are being used in some education systems.

Collaboration and wrap-around support among school teams, caregivers, and community organizations are beneficial to meeting the needs of students with FASD and promoting positive educational outcomes. Interventions are most effective when there is significant caregiver involvement. Outside of school, providing positive and engaging recreational and volunteer activities for youth with FASD can create pathways to school and employment success.

Currently, resources, supports, and training about FASD exist but are unevenly available and used within school systems. Educational leadership and institutional support is important to facilitate the uptake and implementation of FASD-specific training.

The transition to adulthood

The transition from late adolescence to early adulthood is a time of additional vulnerability for many people with FASD. Supportive, consistent, and stable relationships with people who have an understanding of FASD have been identified as being the most important factors in successful transition of youth with FASD.

Youth transitioning out of the child welfare system may have less developed natural support networks and would benefit from supports that allow for a slower and more deliberate transition from child and youth to adult programs. The objective of interdependence, rather than independence, is important for many people with FASD, highlighting the benefits of a natural support network.

Adulthood

Aging can bring added challenges impacting the quality of life of people with FASD including isolation, physical and mental health challenges, and difficulties with tasks of daily living. Limited research exists on evidence-based interventions for adults with FASD, but some elements include outreach support, strengths-based approaches, basic life skill learning in real contexts, and education for service providers.

Diagnosis improves adults' access to supports and accommodations, and also offers a range of benefits including information about potential physical and mental health issues, reduced blame and self-blame, and better self-understanding which builds self-esteem and confidence. Opportunities for peer support and networking can be a valuable source of information and support for adults with FASD.

People with FASD are at increased risk of a range of comorbidities. Evidence suggests that people with FASD can struggle to access care for these conditions, in part due to the effects of stigma, reduced awareness of the need to seek care, and also due to lack of accommodation for the particular challenges they may face in their interactions with healthcare providers. These challenges can include difficulties with schedules and following treatment recommendations.

Adults with FASD often face challenges with tasks of daily living, including employment, managing finances and securing stable housing. Life skills programs adapted to people with FASD are helpful and could begin in high school to support transition to adulthood. Ongoing coaching, mentoring, and support may also be needed to achieve the objective of interdependence. Support programs such as income assistance, vocational and employment programs, and affordable adapted housing programs can be difficult to navigate for people with FASD. Some people with FASD may require support in putting together applications, which may require them to assemble documentation and navigate procedures across multiple agencies. In addition, despite FASD being a lifelong disability, people with FASD can be required to repeatedly prove their eligibility. Adjusting and harmonizing eligibility criteria could improve outcomes.

Family and caregiver support

Parents and caregivers who support loved ones with FASD, including into adulthood and later years, play an important role in the creation of healthy environments conducive to positive outcomes. This includes caregivers in the child welfare system, foster and kinship caregivers as well as parents who have FASD themselves. Education, skill development, and supports that help them understand the impacts of FASD and how to support the development of life skills are beneficial. Other supports, such as opportunities for respite, peer networking opportunities, and broader social acceptance, understanding and inclusion, are key to family well-being.

Criminal justice system

People with FASD are over-represented in the criminal justice system, an outcome that early diagnosis and upstream supports and interventions can help to prevent. Once in the system, the challenges associated with FASD can affect their ability to navigate the justice system in their own defence, and can also put them at a disadvantage within carceral settings. Difficulties with following court orders can lead to escalating or compounding charges. Diversion programs and specialized FASD courts can help to achieve better outcomes in suitable cases. An understanding of the cognitive and behavioural challenges associated with FASD and the accommodation of these disabilities are key to achieving better long-term outcomes for justice-involved people with FASD as well as for society as a whole. Achieving this requires continued efforts to ensure that all sectors of the criminal justice system understand FASD; it also requires better access to FASD assessment and diagnosis. Structures for non-carceral support and supervision can better respond to the needs of people with FASD and the community and improve outcomes. Just as upstream supports can help to prevent involvement in the criminal justice system, properly tailored interventions and supports to reduce recidivism and to set people with FASD up for success when they leave the criminal justice system are essential. There are few specialized FASD courts or dockets in Canada recognizing these unique circumstances.

Analysis of the implementation of the 2003 *FASD: A Framework for Action* report

The 2003 Framework was a statement of shared commitment among the federal government, as represented by Health Canada and PHAC, and provinces and territories to address what was then becoming recognised as a significant public health concern.

Among the advances made since the 2003 Framework are the development of Canadian diagnostic guidelines, recommendations for systematic PAE screening, epidemiological research and the development of models of prevention. Several provinces and territories have developed FASD-specific strategies of their own. Internationally recognized research on FASD has been generated by Canadian research consortia.

Some of the progress made since 2003 can be directly attributable to federally-supported initiatives conducted because of the Framework. At the same time, the 2003 Framework's lack of concrete measures, clear roles and responsibilities, and evaluation and accountability mechanisms, limited resources, as well as intersectoral and jurisdictional complexities may have hindered progress that might have been made.

Peer countries are now adopting modernized FASD frameworks, and renewed national leadership on FASD could be helpful in signaling the importance of the issue, helping to coordinate and harmonize policy, and supporting the development of knowledge and tools that can be shared across the country, which assists jurisdictions with fewer resources.

Conclusion

There is diversity in the strengths and abilities of people with FASD, including strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges, hope for the future, independence, resilience, kindness and adaptability. People with FASD in our engagement process said they feel they can be more empathetic, and have a unique understanding of others with FASD; they feel they have to work so much harder at things that they can be more determined, creative, disciplined and hardworking; and they feel pride in what they've overcome, and in how they can offer hope for others with FASD.

And yet, many people with FASD and their families often experience social isolation and exclusion. Stigmatization of FASD harms health and quality of life for people with FASD and their families, creating barriers to accessing diagnosis, supports and accommodations.

There is consensus that with the provision of early assessment and adequate supports, people with FASD and their families can better face the challenges associated with FASD across many domains of life. Maintaining this common focus will help determine whether it is best to focus solely on increasing acceptance of and capacity for diagnosis of FASD, or to encourage a gradual shift to a broader approach of providing the diagnosis of a complex neurodevelopmental disorder and using this in conjunction with more specific applicable diagnoses including FASD. Committed and collaborative leadership and action will lead to ways forward to improve FASD prevention, as well as to improve services and supports for people with FASD.

The Public Health Agency of Canada funded the Canadian Academy of Health Sciences to undertake this evidence-based assessment.

An independent Panel of experts, including people with FASD and family members, provided the leadership for this assessment by reviewing the findings from the evidence, engagement input, and external peer review to prepare the report.

The conclusions expressed in this publication do not necessarily represent the views of the Panel members' organizations of affiliation or employment, or the sponsoring organization, the Public Health Agency of Canada.

Please visit https://cahs-acss.ca/ for the full report.