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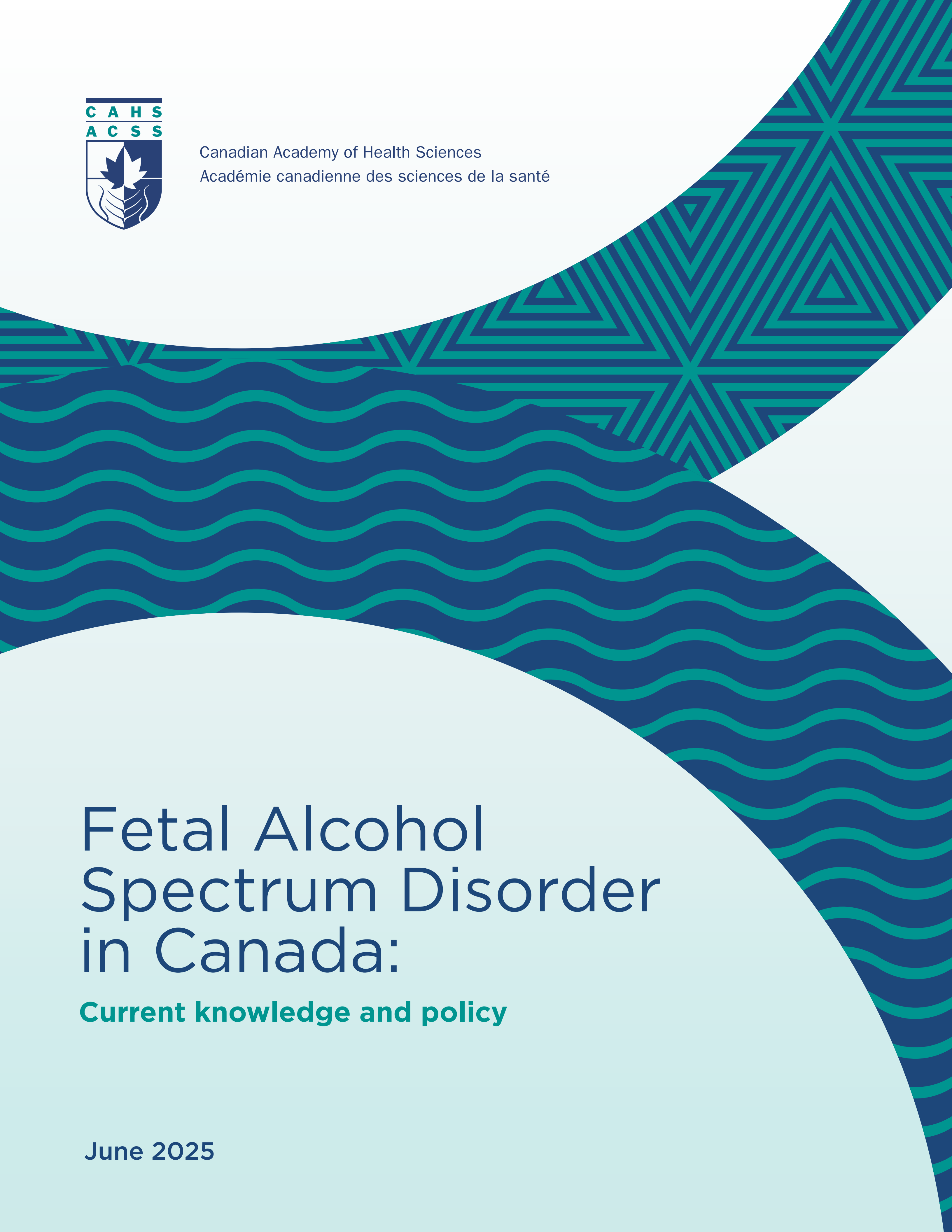

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

June 2025

The Canadian Academy of Health Sciences

78 George Street, Suite 204, Ottawa, Ontario, Canada, K1N 5W1

This report was prepared for the Government of Canada in response to a request from the Public Health Agency of Canada. The Board of Directors of the Canadian Academy of Health Sciences (CAHS) approved the work, the composition of the panel and the release of the report. The members of the Assessment Panel responsible for the report were selected by the CAHS for their expertise and competencies and with regard for diversity. Any opinions, findings, or conclusions expressed in this publication are those of the authors, the Assessment Panel, and do not necessarily represent the views of their organizations of affiliation or employment. The views expressed herein also do not necessarily represent the views of the Public Health Agency of Canada.

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The Canadian Academy of Health Sciences

The Canadian Academy of Health Sciences (CAHS) provides independent and timely assessments that inform policy and practice to address critical health challenges affecting Canadians. The CAHS helps put change into action for a healthier Canada.

The CAHS recognizes Canadians of great achievement in health sciences. Founded in 2004, CAHS now has almost 1,000 Fellows and elects new Fellows on an annual basis. The organization is governed by a voluntary Board of Directors and a Board Executive.

The CAHS brings together Canada's top-ranked health and biomedical scientists and scholars from all disciplines across our nation's universities and its healthcare and research institutes to make a positive impact on the urgent health concerns of Canadians. These Fellows reach out to other experts and engage with the public and key stakeholders to evaluate Canada's most complex health challenges and identify strategic, actionable solutions.

Since 2006, the CAHS has co-invested in rigorous, independent assessments that address key health issues with outcomes that have shaped its strategic policy and initiatives.

Acknowledgements

The Canadian Academy of Health Sciences (CAHS) established an expert panel to conduct this assessment on Fetal Alcohol Spectrum Disorder. The Panel included a diversity of expertise from across Canada. Their biographies are available on our website.

Panel members worked closely together reviewing documents, considering engagement participant input and discussing material related to this assessment. All of their work was done virtually. Their commitment to this project was remarkable. The Academy greatly appreciates their significant contribution.

The Panel Chair, Jennifer Chandler, provided overall leadership for this assessment. Leigh Wincott, Vice Chair and Chris Mushquash, Chair Indigenous Task Group contributed valuable expertise and additional leadership, to develop the assessment report with the Panel below:

- Shannon Butt
- Janet Carioni
- Peter Choate
- Patricia Conrod
- Lori Vitale Cox
- Maude Dubois Mercier
- Twyla Gilroy
- Kathy Kalinowsky
- Stacey Kelsh
- Neena Mackinnon
- Tanya Northcott
- Svetlana (Lana) Popova
- James Reynolds

The **Indigenous Working Group** provided guidance to the Assessment Panel on how best to reflect the unique perspective and experience of First Nations, Métis, and Inuit Peoples within the context of a pan-Canadian assessment. This group was chaired by Christopher Mushquash who is Anishinawbe (Ojibway) and a member of Pawgwasheeng (Pays Plat First Nation) and included Tanya Northcott, of Wabigoon Lake Ojibway Nation and of West Coast Indigenous descent, as well as Panel Members who work as allies to Indigenous people: Leigh Wincott, Lori Vitale Cox, Neena Mackinnon, and Jennifer Chandler (ex officio). Their work was supported by an Indigenous owned consulting group, the Firelight Group, who completed an Indigenous-specific literature review and engagement sessions.

Peer reviewers provided feedback on the objectivity and quality of a draft of the assessment report. Their submissions, which will remain confidential, were considered in full by the Panel, and many of their suggestions were incorporated into the report. They were not asked to endorse the conclusions, nor did they see the final draft of the report before its release.

- Ana Hanlon-Dearman, MD, MSc, FRCPC, FAAP
- Christine Loock, MD, FRCPC
- Marie-France Raynault, MD, MSc, FCAHS

A **staff team and consulting services,** led by Sonya Kupka, supported the overall process, enabling the work of the committee members and managing the engagement process.

Message from the CAHS President

On behalf of the Canadian Academy of Health Sciences (CAHS), I am pleased to introduce this Assessment Report on Fetal Alcohol Spectrum Disorder (FASD).

This important document will undoubtedly inform policy makers and all Canadians on this important issue.

The CAHS would like to express its sincere appreciation to the Chair of the Panel, Jennifer Chandler, as well as the members of the Panel for their immense contributions to this assessment.

This Assessment continues CAHS' approach to assessments by including lived experience individuals on the Panel to better inform the scientific process. Furthermore, the report was strengthened by the extensive consultations undertaken throughout the process.

I would also like to thank the peer-reviewers who provided excellent feedback on the draft report and the members of the CAHS Scientific Affairs Committee for their guidance throughout the process.

Finally, I would like to recognize the Public Health Agency of Canada (PHAC) who sponsored this assessment. We are grateful that PHAC turned to the expertise and experience of CAHS for this work, and we applaud its ongoing commitment to evidence-informed policy making.

Sincerely,

Trevor Young, MD, PhD, FCAHS
President, Canadian Academy of Health Sciences

Message from the CAHS Assessment Panel Chair

Fetal Alcohol Spectrum Disorder (FASD) affects all parts of Canadian society and represents a major public health challenge. Disadvantageous social determinants of health and the continuing legacies of colonialism result in disproportionate impacts for some. Responding to the challenge of FASD requires coordinated and integrated efforts locally, regionally and nationally, as well as across the many areas of knowledge, practice and expertise relevant to such a complex and stigmatized public health problem.

This Assessment benefited from the invaluable expertise and insights of a huge number of people and organizations who so generously responded to the invitations to participate in our multiple engagement mechanisms. In addition, our Panel reflected a broad geographic and subject-matter expertise, with each person bringing deep experience and commitment on one or more aspects of a multi-faceted public health issue. This allowed us collectively to access a more comprehensive view of how key social systems (health, justice, education, social supports), jurisdictional divisions, stigma and resource constraints combine to produce policy challenges and opportunities for a Canadian FASD response. A CAHS team of dedicated researchers and writers provided experience, wisdom and skilled support throughout this group effort.

In discussions with my co-Panelists, I learned that I was not alone in having learned a tremendous amount from everyone involved in this Assessment and in feeling grateful for the opportunity to work on it. Throughout this process, it was abundantly clear how much commitment and work there has been across the country at the grass-roots level as well as regionally and nationally. This effort - by people with FASD and their families, service providers, national research consortia, individual researchers and policymakers - has made Canada a recognized leader in the field in many ways, even if there remain important gaps, unmet needs and substantial room for improvement.

The constraints of the process mean that we will have missed or misinterpreted some voices, perspectives and evidence. Despite this, I hope that this report will be helpful for policymakers, as well as for the groups and communities working to support people through their pregnancies to prevent prenatal alcohol exposure, and for those working to support people with FASD and their families to build healthy and rewarding futures and to mitigate the consequences of FASD across the lifespan.

Jennifer Chandler, LLM, FCAHS

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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:

1. What is needed to support broader uptake of the Canadian FASD Diagnostic Guidelines in Canada?
2. What are the clinical/community and federal/provincial/territorial challenges associated with case identification and data collection in Canada?
3. How can FASD prevention activities be strengthened to support the overall objective of reducing the prevalence of FASD in Canada?
4. 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 understanding of the challenges associated with FASD. Helping professionals to understand

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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.

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 fromtools 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, 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 signalling 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.

Chapter 1:
Introduction

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

1.1 Introduction

Many people, families and communities across Canada are affected by Fetal Alcohol Spectrum Disorder (FASD). Named for its association with prenatal alcohol exposure (PAE), FASD is a lifelong, whole-body condition, affecting many spheres of life (Himmelreich et al. 2020). It is associated with a wide range of symptoms and co-occurring conditions, including physical, sensory, learning, behavior, and mental health concerns. These conditions interact with individual, environmental and societal factors and can produce substantial and continuing impacts on the lives of people with FASD and their families (Petrenko & Kautz-Turnbull, 2021).

When FASD is looked at primarily through a medical lens (e.g., CDC, 2023), it can lead to a deficit perspective which can result in stigma and social exclusion (Armstrong, 2015; Flannigan, Wrath, Ritter et al., 2021; Petrenko & Kautz-Turnbull, 2021). A strengths-based perspective recognizes the many adversities along with the diversity and contributions of people with FASD and seeks to improve the systems of services and resources around them (Flannigan, Wrath, Ritter et al., 2021; Petrenko & Kautz-Turnbull, 2021).

FASD is a complex condition. It results from many interlinked individual, social, economic, environmental and cultural factors (McQuire et al., 2020) situated at the intersection of some challenging aspects of past and current Canadian society. Addressing FASD fully involves multiple sectors, including health, social services, education, employment, housing, recreation, and justice. This in turn requires the engagement of multiple governmental jurisdictions: federal, provincial/territorial, Indigenous Nations and local communities. As FASD is a global health issue (Popova, 2017), there is also a benefit from international collaboration on research and promising practices.

1.2 About this assessment

To better understand how to prevent PAE and support individuals with FASD and their families and communities affected by it, the Public Health Agency of Canada (PHAC) asked the Canadian Academy of Health Sciences (CAHS) to undertake a comprehensive scientific assessment on FASD.

This assessment builds on progress made since PHAC's 2003 publication, *FASD: A Framework for Action.* Since then, there have been many significant developments related to FASD including the publication of the 2005 *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis* (Chudley et al., 2005) and the subsequent updated 2016 *Fetal Alcohol Spectrum Disorder: A Guideline for Diagnosis Across The Lifespan* (Cook et al., 2016). A call for a renewed framework, Bill S-253, was under consideration in the Canadian Senate since 2022, until the prorogation of Parliament in early 2025.

This assessment situates FASD as a form of neurodiversity, a framing that recognizes and embraces the diversity and strengths among people with FASD along with their challenges (Armstrong, 2015; Nobel, n.d.; Flannigan, et al., 2021; Petrenko & Kautz-Turnbull, 2021). It grounds FASD in a broad understanding of disability, where multiple factors interact to produce the experience of disablement, including biological, psychological, environmental and social factors (Shakespeare et al., 2017) and includes the experiences of individuals with FASD and their families. This inclusive approach, signaling the value of including people affected by FASD in the development and implementation of systems, policies, programs and services, is consonant with Canada's Disability Inclusion Action Plan (Employment and Social Development Canada, 2020), the 'Nothing About Us Without Us' principle in the Accessible Canada Act (Employment and Social Development Canada, 2019), and the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2008).

This assessment provides an updated review of existing data, policies, programs, and international best practices. It also analyzes the implementation of the 2003 *FASD: A Framework for Action*, identifying lessons learned and challenges. It considers the Truth and Reconciliation Commission's Calls to Action, especially 33 and 34 which reflect a high level of concern about the impact of FASD for Indigenous Peoples and communities (Truth and Reconciliation Commission of Canada, 2015). A multi-step Canada-wide engagement process provided important context and helped to identify emerging issues and promising practices.

The Charge

The Canadian Academy of Health Sciences was charged with answering the following questions:

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

1.3 About FASD

1.3.1 Definitions

The definition of the term Fetal Alcohol Spectrum Disorder (FASD) has evolved over time and is used differently across countries (Popova, Charness et al., 2023; Kachor, 2024). Currently, in Canada, based on the Canadian Diagnostic Guidelines (Cook et al., 2016), FASD is a diagnostic term covering a range of neurological and physical conditions linked to PAE. Because these conditions are concentrated in neurological and cognitive domains, in diagnostic terms FASD is considered to be a neurodevelopmental disorder.

Diagnostic systems differ in the criteria they use to define FASD and the subcategories within their spectra. Specifically, they vary in how they define, assess and include: confirmed PAE, facial features found in some people with FASD (sentinel facial features, SFF), growth deficiencies, and structural and functional brain abnormalities (Popova, Charness et al., 2023). Efforts to reconcile the different systems of defining and diagnosing FASD have found generally good consensus at the most severe end of the spectrum, but less agreement on the rest of the spectrum (Astley Hemingway et al., 2019; Brown et al., 2019; Myers et al, 2024). Lack of consensus and standardization has constrained comparability across knowledge bases, and hampered advances in FASD research, diagnosis, treatment care and policy (Brown et al., 2019; Astley Hemingway et al., 2019; Popova, Charness et al., 2023; Myers et al., 2024).

For example, the diagnostic categories Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS) and Alcohol-Related Neurodevelopmental Disorder (ARND) were previously used in Canada, and are still in use elsewhere. These terms are no longer used in the 2016 Canadian guidelines, which instead use two categories: FASD with Sentinel Facial Features (SFF) and FASD without SFF. A third possibility—at risk of neurodevelopmental disorder and FASD, associated with PAE—is not a diagnosis, but a designation that can be used when there is confirmed PAE and either suspected neurodevelopmental impairment or physical signs like SFF or microcephaly, but when severe central nervous system impairment cannot be confirmed.

In this Assessment Report, the term FASD is generally used when referring to the whole spectrum of conditions associated with PAE. This includes the two diagnoses related to neurodevelopmental impairments associated with PAE as defined in the 2016 Canadian Guidelines (FASD with SFF and FASD without SFF). FASD with SFF replaced the diagnostic category FAS in the 2016 Canadian Guidelines but the older term is sometimes used in the literature and in this report. Moreover, other distinctions are made where relevant, such as where research results are restricted to one of the other distinct diagnoses falling within the broader classification of outcomes associated with PAE.

In addition to diagnostic terminology, language related to FASD has evolved. In particular the Canada FASD Research Network maintains an annually updated guideline for writing and talking about FASD that offers useful analysis and suggestions, while recognizing sometimes that there are varying or conflicting views on some terms (CanFASD, 2023a). In this assessment, the term people with FASD is used, although some may prefer terms like 'living with FASD' or 'affected by FASD'. The report also recognizes the importance of gender-inclusive language in discussing women and other gender-diverse people who are pregnant or could become pregnant, including trans men, non-binary, and Two-Spirited individuals. CanFASD (2023a) notes that the possible general term 'pregnant people' may be ambiguous, and also that it is important to some people to be referred to as women and mothers; for example, 'mother' and 'mothering' are important terms in many Indigenous cultures. As a result, this report uses the terms 'women' or 'pregnant women'', and this should be taken to be inclusive of people of any gender identity who can become or are pregnant.

1.3.2 Prevalence

FASD is a relatively prevalent neurodevelopmental disorder affecting children's long-term outcomes (Popova, Charness et al., 2023; Flannigan, Unsworth & Harding, 2018). Prevalence estimates for FASD vary depending on the populations studied and the methods used.

Prevalence estimates are detailed in Chapter 4, along with the methodological limitations of those estimates. There is consensus that prevalence estimates based on the numbers of diagnosed cases substantially underestimates the presence of FASD in the population (Popova et al., 2024), in part because of the many factors that make it difficult to obtain or access an FASD diagnosis (Hayes et al., 2023) as well as the lack of international consensus on standardized diagnostic criteria described above. These factors are discussed in detail in Chapter 6, along with evidence regarding the current uptake of the 2016 Canadian Diagnostic Guidelines.

Although FASD occurs throughout the population regardless of socioeconomic status, educational attainment, or ethnicity, higher prevalence rates in several subpopulations reflect concentrations of risk factors and unfavorable conditions. For example, higher FASD prevalence is found in populations involved in child welfare, correctional, special education, and mental health settings (Popova, Lange, Shield, Burd, & Rehm, 2019). In Canada, as in some other countries with colonial histories, FASD is more prevalent in some Indigenous communities than in the general population, with root causes identified in ongoing intersectional risk factors flowing from colonialism and anti-Indigenous racism. These subgroup prevalences are discussed in Chapters 3 and 4.

1.3.3 Causes and risk factors

Prenatal alcohol exposure (PAE) is a direct cause of FASD. However, there are both protective and exacerbating factors that appear to affect the impact of alcohol on the fetus. About one in thirteen pregnancies with known PAE results in FASD, with many societal, environmental and individual factors increasing its likelihood (Popova, Lange, Probst, Gmel et al., 2017).

Maternal age, genotype, mental health, prenatal nutrition, stress, smoking, illicit drug use, and body mass index have all been shown to influence the impact of PAE and the likelihood of FASD. Many of these factors are in turn influenced by a host of more distal determinants: alcohol policy and guidance, health professionals' knowledge and attitudes, socioeconomic status, unplanned pregnancy, pre-pregnancy and family and friends' use of alcohol and other substances, social support, trauma and other adverse pre- and postnatal exposures and events (McQuire, et al., 2020). In other words, PAE intersects with a myriad of other factors and combinations of factors, to determine whether a child will or will not be born with FASD. In addition, early infancy and childhood experiences, particularly exposure to acute and chronic trauma, also influence brain development and the potential for meeting the criteria for FASD diagnosis (Price et al., 2017).

Alcohol consumption is in general influenced by social and environmental factors that determine its availability and cultural acceptability. Alcohol consumption during pregnancy may occur prior to awareness of a pregnancy. In addition, the exposure to physical, mental, social and environmental stress and distress are additional risk factors for alcohol consumption during pregnancy (Ninomiya et al, 2023; Muckle et al., 2011; Erng et al., 2023; Lyall et al., 2021; Popova et al., 2022; Shrestha, Weber, & Hanson, 2018). The timing and amount of alcohol required to cause FASD are not fully clear (Mamluk et al., 2017; Roozen et al., 2016), although it is suspected that there are multiple mechanisms involved at different points of fetal development (Samson et al., 2000). Consuming more drinks per occasion (a proxy for blood alcohol concentration) increases the risk for FASD. High blood alcohol concentration has been associated with physical characteristics of FAS and cognitive and behavioral deficits in children (May et al., 2016; May & Gossage, 2011). Smaller women, women with poor prenatal nutrition, and older women who do not metabolize alcohol as effectively as the young have a higher likelihood of having children with FASD diagnosis for equal quantity of alcohol consumed (May & Gossage, 2011).

Given this complex array of risk and causal factors, preventing FASD requires a multi-faceted approach that addresses alcohol consumption and other modifiable risk factors as well as systemic societal and health inequities, societal attitudes and stigmatization. Chapter 5 examines prevention in detail.

1.3.4 Variability and diversity

Individuals with FASD are a highly heterogeneous group (Flannigan, Pei et al, 2022; Cook et al. 2021). Many of its symptoms overlap with other neurodevelopmental disorders (Weyrauch, Schwartz, Hart et al., 2017).

Central nervous system issues are highly variable among individuals who have been exposed to alcohol in utero (Lang, 2006). These can be observed in both structural and physiological differences in the brain as well as in differences in brain function. Functional differences are present in the domains of cognition, executive functioning, learning/academic achievement, memory, language, visual-spatial ability, motor skills, attention, affect regulation (mood and behavioral regulation), and adaptive functioning, including daily living skills and social communication (Sanders et al., 2017).

FASD can also co-occur with a range of other physical, physiological, cognitive, and psychological conditions (Popova, Lange, Shield et al., 2016; Reid, Kent et al., 2023). Factors in the social and socioeconomic environment that can affect social development and integration may also be present (Lange et al., 2018). FASD is a spectrum that encompasses a range in severity, and the type and severity of co-occurring conditions can also multiply the diversity within the diagnosis (Flannigan, Pei et al., 2022). Early diagnosis of FASD with identification of these co-occurring conditions and the provision of appropriately adapted interventions and supports helps to respond to this diversity and to reduce the effects of FASD on other important areas of development. Chapter 5 identifies a range of such secondary prevention approaches.

Although much of the literature on FASD views it in terms of negative deviation from a “normal” state (Choate & Badry, 2019), there is also evidence of diversity in the strengths and abilities of people with FASD (Flannigan, Wrath, Ritter et al, 2021; Flannigan, Pei, McLachlan et al., 2022; Petrenko & Kautz-Turnbull, 2021). These strengths can include strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges, hope for the future (Flannigan, Wrath, Ritter et al., 2021), independence, resilience, kindness and adaptability (Petrenko & Kautz-Turnbull, 2021). Chapter 7 also outlines strengths-based intervention frameworks.

1.3.5 Stigmatization

The prevalent public discourse about FASD is typically negative (Choate & Badry, 2019; Flannigan, Wrath, Ritter et al., 2021; Skorka et al., 2020), and stigmatization of PAE and of FASD by healthcare providers, communities and the public is common (Aspler et al., 2022). According to one study, FASD is more highly stigmatized than serious mental illness, substance use disorder and jail experience (Corrigan et al., 2017). FASD stigmatization may have been perpetuated by the lack of strengths-based FASD research (Flannigan, Wrath, Ritter et al, 2021).

Stigmatization is experienced by an expectant or new parent as judgment and blame, even from providers who consider themselves compassionate and non-judgemental (Oni, Dreke, Dietze et al., 2022; Mitchell-Forster et al., 2022). For people with FASD, misunderstanding of the condition and all the ways it can present (Noble, n.d.) and lack of strategies adapted to their needs and strengths can lead to poor experiences in school and missed opportunities to focus on intellectual (Armstrong et al. 2015), social (Flannigan et al., 2021) and adaptive (Skorka et al. 2020) assets. Stigmatization is associated with the high levels of stress experienced by people with FASD and their caregivers, producing negative mental and physical health consequences (Skorka et al. 2020; Ilchena et al. 2023; Schwartz et al., 2017). Stigmatization has many consequences for efforts to understand and address FASD, including prevalence estimation (Chapter 4), assessment and diagnosis of FASD (Chapter 6), prevention (Chapter 5), and supports and intervention (Chapter 7). The erroneous assumption that FASD is primarily an Indigenous issue works together with anti-Indigenous racism and negative stereotypes of Indigenous parenthood to amplify the stigmatization of FASD with deleterious effects on all aspects of FASD: from prevalence estimation through assessment and diagnosis, prevention, and supportive interventions (Chapter 3).

1.3.6 Costs of FASD

People with FASD may require lifelong assistance in many dimensions of their lives, creating a long-term, multi-component economic impact (Himmelreich et al., 2020; Hargrove et al. 2024). The mean cost per person in Canada (all ages) with FASD has been assessed in one study at $12,470 USD per year (Greenmyer et al., 2018) and in another at $27,000 CND per year (Thanh & Jonsson, 2015).

Using a conservative 1% estimate of FASD prevalence, the estimated total annual costs associated with FASD in Canada were approximately $1.8 billion (range $1.3 - $2.3 billion; Popova, Lange, Burd et al., 2016). This study included direct costs of resources expended on all the major cost drivers, including: screening and diagnosis (Popova, Lange, Burd, Chudley et al., 2013); healthcare (Popova et al., 2012); specialized addiction treatment (Popova, Lange, Burd, Urbanoski et al., 2013); law enforcement (Popova, Lange, Burd, & Rehm, 2015b); supportive housing; long-term care; prevention and research; and services and programs such as children and youth in care (Popova, Lange, Burd, & Rehm, 2013), special education (Popova, Lange, Burd, Nam et al., 2016), speech and language services (Popova et al., 2014), and indirect costs of productivity losses due to morbidity (Easton et al., 2014) and premature mortality (Easton et al, 2015). Indirect costs of productivity losses due to morbidity and premature mortality accounted for 42% of total FASD-attributable costs. Correctional services accounted for about one-third, 30%, of FASD-related costs (see also Popova, Lange, Burd, & Rehm, 2015b; Andersson & Elliot, 2018). Direct healthcare costs accounted for 10% of the total cost (Popova, Lange, Burd, & Rehm, 2012).

In a study that included additional costs associated with the criminal justice system beyond correctional services (e.g. police, court and victims' services), the estimated total annual cost of FASD in Canada in 2014 was much higher than Popova, Lange, Burd, & Rehm's (2016) estimate, at $9.7 billion (Thanh and Jonsson, 2015). In Thanh and Jonsson's estimate, costs of FASD to the Canadian criminal justice system were approximately $3.9 billion (range $1.9 billion to $7.0 billion), accounting for 40% of total costs. In these estimates, healthcare costs were 21%, education 17%, social services 13% and others 9% of the total cost (Thanh and Jonsson, 2015).

In summary, although estimates vary according to which methods are used, which cost drivers are included and which prevalence estimates are used, studies of FASD's economic impact concur that its costs to Canada and Canadians are very high.

Another approach to economic impact analysis is to examine the relative cost and benefit of interventions. Another possible approach is the Social Return on Investment (SROI) methodology. Although not a study of FASD-specific policies, Hubberstey and Rutman (2020) used this methodology in a two-year program evaluation and found that for every dollar invested, a drop-in and outreach program for pregnant women and new mothers with a history of substance use created a social value of approximately $4.45. Considerable value was produced through reduced use of expensive hospital care, fewer infants and children being placed in foster care, and fewer children born substance-affected.

It has been argued that of the billions spent each year on FASD and its multiple consequences for people, families and communities, only a small fraction of this would be needed to provide accurate community-based assessment, diagnosis-informed interventions, and effective prevention initiatives that would reduce FASD's economic impact (Popova et al., 2020).

1.4 Our approach

The evidence collection and methodological approaches for this assessment on FASD were designed to ensure a comprehensive, multidisciplinary, and inclusive evaluation. The methodologies incorporated rigorous literature reviews, policy scans, and international case studies, and a multi-component engagement process to provide a holistic understanding of FASD in the Canadian context.

1.4.1 Guided by a diverse Panel of experts

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 and engagement input and preparing a report. External peer reviewers commented on the report independently and anonymously, providing final input for the Panel's consideration.

1.4.2 Evidence collection and methods

Evidence was collected for this assessment through an iterative process that combined a series of systematic searches and targeted scans of the published literature and policy documents, legislation, and reports. The results of this process are summarized in Table 1 and described below.

Table 1: Results of evidence collection process

Collection	Identified	Included in analysis
Systematic	462	93
Additional search	178	90
Engagement participants	60	60
Two stage policy database and web search	540	238
Indigenous-specific search	340	292
International case studies	875	343
TOTAL	**2455**	**1116**

Sequential literature searches

Sequential literature searches were conducted. A first systematic search of four key databases (PubMed, MEDLINE, Web of Science and CINAHL) identified systematic/scoping reviews (qualitative or quantitative or a combination of both) or meta-analyses, published in 2015 or after, that addressed different aspects of FASD and its intersections. Of the 462 non-duplicate results, 360 were excluded based on a review of abstracts against our screening criteria. The remaining 102 full texts were assessed for eligibility, and 93 studies were included in the analysis for this report.

In a second step, additional searches were conducted using the same keywords to identify studies that may have fallen outside the databases' journal inclusions, or were especially relevant, but neither systematic nor scoping reviews. An additional 178 non duplicate papers were identified, 90 of which were used for analysis through this process. In the writing of the report, the panel identified areas where additional targeted research was required and contributed relevant peer-reviewed articles.

Finally, in the engagement process, described below, survey respondents were asked to contribute any references they considered important to the field and as a result, an additional 60 sources were identified. These were almost all in the gray literature, such as program evaluations, government reports, factsheets or websites.

These references were evaluated, analyzed, and key information was extracted and developed into evidence summaries for the identification of key findings and integration into the report.

Policy scans

The charge to CAHS included an overview of the current FASD policy landscape, and we conducted a comprehensive scan for FASD-related policy across Canada.

The policy scan was conducted using an iterative approach with a combination of policy-focused databases and Web searches. Additionally, as noted above, engagement participants contributed documents, capturing community-level and non-governmental organization policy directions.

Three databases, Policy Commons, Government of Canada Publications Database and CanLII, identified a total of 403 policy documents, legislation, and reports. Of these, 178 were considered potentially relevant. Subsequently, searches were conducted through Google Scholar and targeted web searches of key federal bodies, provincial and territorial governments, health authorities and service organizations, and municipal/community-based agencies, as well as the websites of relevant specialized organizations. This web-based search identified another 60 government FASD-related policy documents and an additional 77 documents related to Indigenous communities. All potentially relevant documents were screened for duplicates and eligibility. Ultimately, 238 documents were included in the analysis. Content from all sources was thematically organized and main trends were identified for the Panel's consideration and integration into the assessment report.

Indigenous-specific scan

An Indigenous-led research firm, Firelight Group, was engaged to conduct a complementary review, adding Indigenous-specific and Indigenous-issue-associated search terms to those used for the general literature review. This involved searches on three databases (Web of Science, CINAHL, and OVID Medicine) and Google Scholar, a targeted web search of government and key organizations, and a hand search of eleven specialized Indigenous journals. Given the more specific focus on Indigenous Peoples, broader selection criteria were used, including primary research and gray literature which included policy documents. A total of 340 non-duplicate results were identified. Of these, 38 were removed for relevance and the remaining 292 documents were included in the analysis.

Policy scan specific to diagnosis process

While mapping the screening, assessment and diagnosis processes for FASD across the provinces and territories, 46 websites were reviewed. These included websites of regional, provincial, and territorial FASD networks, ministries of health, and local clinics and programs. Five academic publications were also included in the analysis after being identified from a broader literature review.

In the analysis of health professional availability/capacity, 12 health profession regulatory or organization websites were searched. Six academic publications were included in the assessment from a larger literature review and information from four regional or provincial FASD network websites was highlighted.

International case studies

Case studies on key FASD policy and practice initiatives implemented in various countries provided insights into the implementation of FASD initiatives and identified opportunities to strengthen Canada's approach to addressing FASD. Through an iterative web-based search, 875 documents were identified and reviewed, 343 of which were included in the case studies.

This search identified 25 countries with some level of activity related to FASD. Six countries were selected for an in-depth case study as they had documented national approaches, standards, guidelines, and initiatives relating to current strategies for FASD prevention, identification, and care. These countries were: Australia; New Zealand; Republic of Ireland; South Africa; United Kingdom; and the USA. A briefer review of 19 additional countries in each of the six WHO regions was also conducted. This included: Belarus, Belgium, Chile, China, Denmark, Ethiopia, Finland, France, Germany, India, Israel, Italy, Korea, Netherlands, Norway, Poland, Spain, Sweden, and Switzerland. The Panel reviewed these case studies and extracted policies and practices of relevance for the Canadian context. These insights are interspersed throughout this assessment report.

1.4.3 Engagement strategy and methods

The engagement process was conducted in two separate rounds, each with a specific purpose and each including multiple ways to participate. The first round collected information on barriers, challenges, and opportunities related to the four questions from the Public Health Agency of Canada. It also generated suggestions on strengthening Canada's approach to FASD. In the second round of engagement, we presented preliminary findings emerging from the draft literature review and policy scan material, and explored these with participants to validate, amend, and refine them.

To support broad and inclusive participation, we offered a variety of ways to engage: live virtual sessions, small group conversations for people with FASD, written surveys, asynchronous online discussions, Indigenous-led sessions, and several interviews with provincial and territorial government representatives. Each engagement mechanism was offered in English and French.

Reach

Across all engagements, we reached a total of 1622 participants. (Note that some individuals may have participated more than once across different engagement mechanisms, so this number does not necessarily represent the number of unique participants.)

Out of the 1622 total participants, 377 (23%) had living experience of FASD (defined here as people with FASD and people close to them, including family and caregivers). Figure 1 shows a breakdown of how many participants were reached through the different engagement mechanisms. Indigenous[3] and Indigenous-serving[4] persons and organizations were invited to all engagement mechanisms, and Indigenous participation was not limited to the Indigenous-led sessions held exclusively for Indigenous participants.

Figure 1: Outreach and engagement across both rounds

* At least 165 Indigenous and Indigenous-serving persons and organizations were also involved in the other engagement mechanisms.

The engagement process involved a broad spectrum of participants, contributing to a comprehensive and inclusive approach. Along with other representatives, we reached many groups key to understanding the challenges and opportunities related to FASD in Canada (Table 2).

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[3] "Indigenous" is defined here as an organization or individual self-identifying in response to survey/poll questions and/or a thorough web search into the organization's leadership, history, and mission.

[4] "Indigenous-serving" is defined here as an organization or individual that serves a large Indigenous population, has Indigenous perspectives integrated into the organization's mission and vision, and/or is strongly involved in services specifically designed for Indigenous individuals.

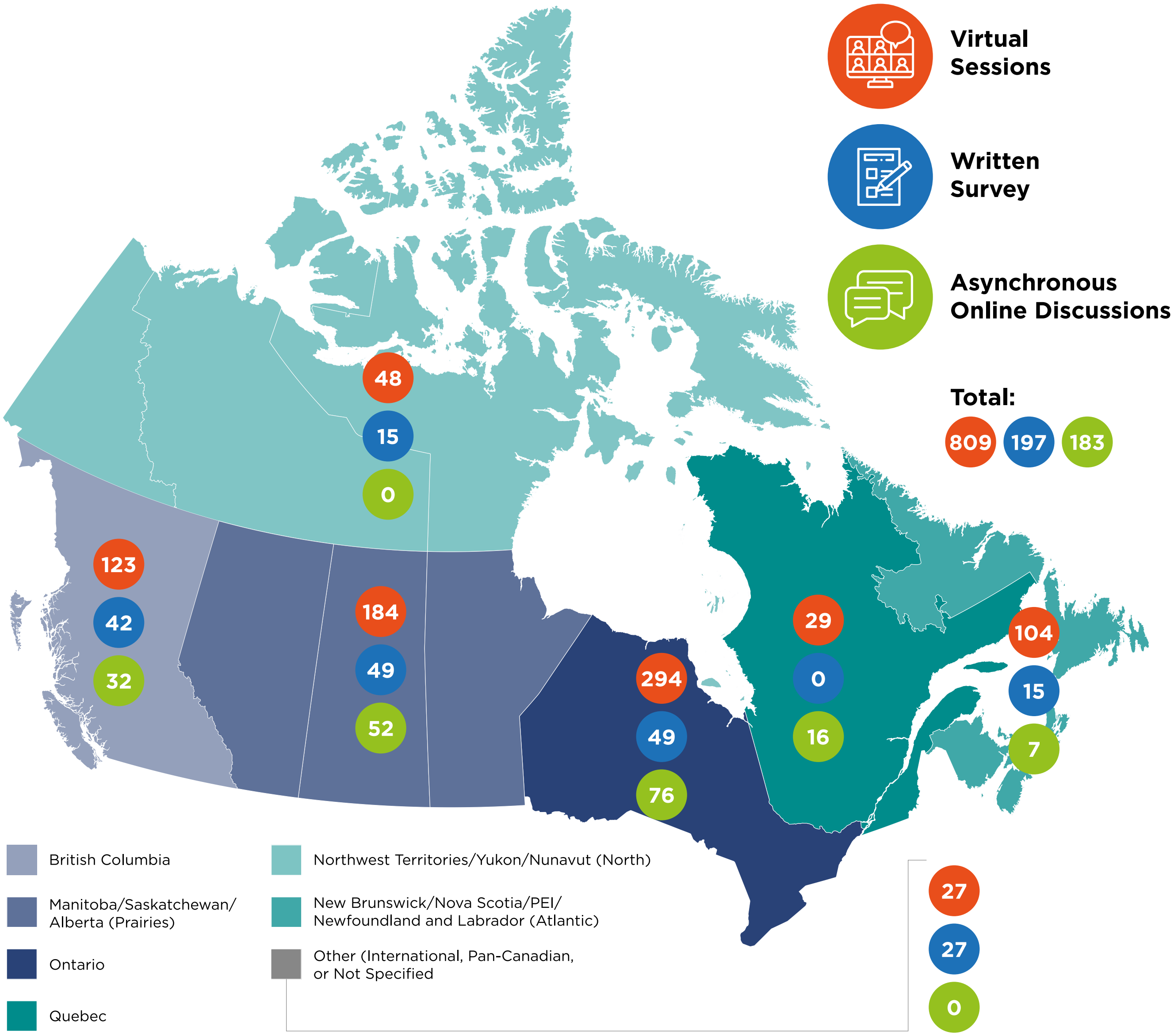
Table 2: Key groups represented in engagement

People with FASD	Adults living with FASD, providing firsthand accounts of their experiences, challenges, and needs
Family members and caregivers	Parents, grandparents, and other family members supporting people with FASD, sharing their insights on the support systems and resources required
Healthcare professionals	Physicians, nurses, allied health professionals, and other clinicians involved in the prevention of FASD, and in the diagnosis and support of people with FASD within Canada's health system
Education, service delivery, and other professionals	Teachers, justice system representatives, and members and leaders of organizations from various sectors involved in FASD prevention and in supporting individuals with FASD
Researchers and academics	Experts in the field of FASD and related research, providing insights based on their research and knowledge from peer-reviewed evidence
Policy makers and government representatives	Individuals involved in the development and implementation of policies related to FASD, contributing this perspective on systemic and policy-related challenges
Indigenous persons	Representatives from Indigenous communities and organizations, to ensure understanding of and relevance to the perspectives and needs of Indigenous communities
Non-government organizations (NGOs)	Representatives from organizations working in the field of FASD, providing insights into the practical challenges and opportunities for improving support and services

Geographic diversity

Participants joined from across Canada. Figure 2 shows a geographic breakdown of participants across different forms of engagement, where data was provided.

Figure 2: Participants across different forms of engagement by geographic region



The insights and data gathered through the engagement process were systematically analyzed and synthesized to inform the development of the final assessment report.

This engagement strategy allowed for iterative integration of community knowledge and living experiences with FASD, complementing the information gathered from the literature review and policy scans. By structuring the engagement in this manner, the process ensured a robust and comprehensive exploration of FASD-related issues, combining multiple forms of expert input and knowledge.

A separate Engagement Report provides further detail and accompanies this assessment report.

1.5 Structure of this report

After this introductory chapter, in Chapter 2 we present a high-level overview of the current FASD policy landscape across and within provincial, territorial and federal jurisdictions of Canada. Findings from the six international case studies are also integrated. Specific details about Canadian policy have also been incorporated into subsequent chapters as relevant and helpful to those discussions.

Chapter 3 reviews the situation of Indigenous Peoples and communities with respect to FASD. This separate chapter was meant to capture the specific issues pertinent to Indigenous Peoples, and is meant to be read alongside the other chapters which discuss aspects that are more generally applicable. The inclusion of this dedicated chapter was informed by the Truth and Reconciliation's FASD-related calls to action, and the current Indigenous self-government initiatives related to the delivery of health, education and social services.

Chapter 4, on prevalence data collection and management, summarizes the existing literature and the results of the engagement process on prevalence estimates and data collection, including limitations and challenges with current estimates and data collection systems.

In Chapter 5, findings on the prevention of FASD and its consequences are presented along with identification of practices that are most effective and promising.

Chapter 6 discusses FASD assessment and diagnosis. It includes an examination of the uptake of the 2016 Canadian Diagnostic Guidelines and barriers to their utilization, as well as examining the state of diagnosis in Canada and the causes and consequences of the current situation of underdiagnosis of FASD.

Chapter 7 presents literature, policy review and engagement findings on interventions and support for people affected by FASD, including attention to interventions throughout the lifespan - particularly healthcare; education; aging and transitions; essential needs such as income and housing; family and caregiver support; the child welfare system; criminal justice system, and stigmatization and inclusion.

Chapter 8 analyzes the implementation of the 2003 Canadian FASD Framework for Action, including barriers and challenges. It also considers the attributes of more recent national frameworks in other countries, and contains reflections drawn from the engagement process regarding the benefits and challenges facing national FASD frameworks. The chapter also includes assessment of current training, education, and guidance needs and opportunities.

Within the chapters, key themes emerging from the panel's analysis of the evidence and policy reviews and the engagement findings are summarized, integrating information from all of these sources. Actionable, policy-oriented key findings from the evidence are provided for each of the main themes. These key findings are presented in Appendix A.

The report includes relevant quotes from participants in our engagement process, in order to bring to readers these first-person perspectives. As per our commitment to participants, we have removed all personal and identifying information for those who provided input.

1.6 Scope and limitations of the report

The scope of this assessment focused on answering the specific questions put by PHAC by collecting and presenting an updated overview of existing knowledge and policy, informed by the key input of people with lived experience and other experts through the engagement process. This approach should be differentiated from other forms of review aimed at developing clinical or research guidelines. Although clinical and research issues, such as diagnosis and assessment and intervention programs, were included, the Panel's work focused on extracting robust knowledge from the best possible sources that could provide policy-relevant learning with an emphasis on meta-analyses and scoping/systematic reviews, rather than on critiquing the quality of single studies or comparing their methodological rigor, . Although a substantial number of primary studies were also gathered and are reflected in the report, it was not possible to conduct an exhaustive systematic review of all of the FASD-related literature.

Our findings focused on the Canadian context with some international information for comparative and inspirational purposes. We have specifically identified Canadian research where the findings provide context-specific information, such as prevalence or interprovincial/territorial or geographic variability. However, we did not directly compare provincial and territorial policies or service models.

As outlined in the charge and methodology, this was not an exhaustive assessment, but one focused on the questions selected by PHAC while aiming to provide adequate background information to contextualize the policy challenges and the strengths and limitations of current approaches.

The engagement process faced limitations which are described in this assessment's Engagement Report. While we received extensive input, these perspectives may not reflect the broader population of people with FASD, their families, and organizations working in this area. For example, despite concerted recruitment efforts, some groups were underrepresented among engagement participants. These include Francophone participants and people in remote areas.

Throughout this report we provide a sampling of policy, program and service examples to illustrate aspects of current and emerging best practices, demonstrating what may be possible in other contexts, with local adaptation. Due to the evolution of programs and policies, some of these examples may no longer be operational or have been updated. In addition, examples were surely missed.

There were some other general challenges in reviewing evidence on FASD. Critical disability approaches (e.g., Piepzna-Samarasinha, 2018) have begun to deconstruct what we may have thought about FASD in the past. There is an evolving realization that we need to better understand the lived experience of FASD and what contributes to the quality of life of people with FASD and their potential to participate in societal roles, as well as how to support and enable caregivers. While research is shifting in this direction, the earlier research tends to be biomedical in orientation, and research acknowledging the heterogeneity of people with FASD is just starting to appear.

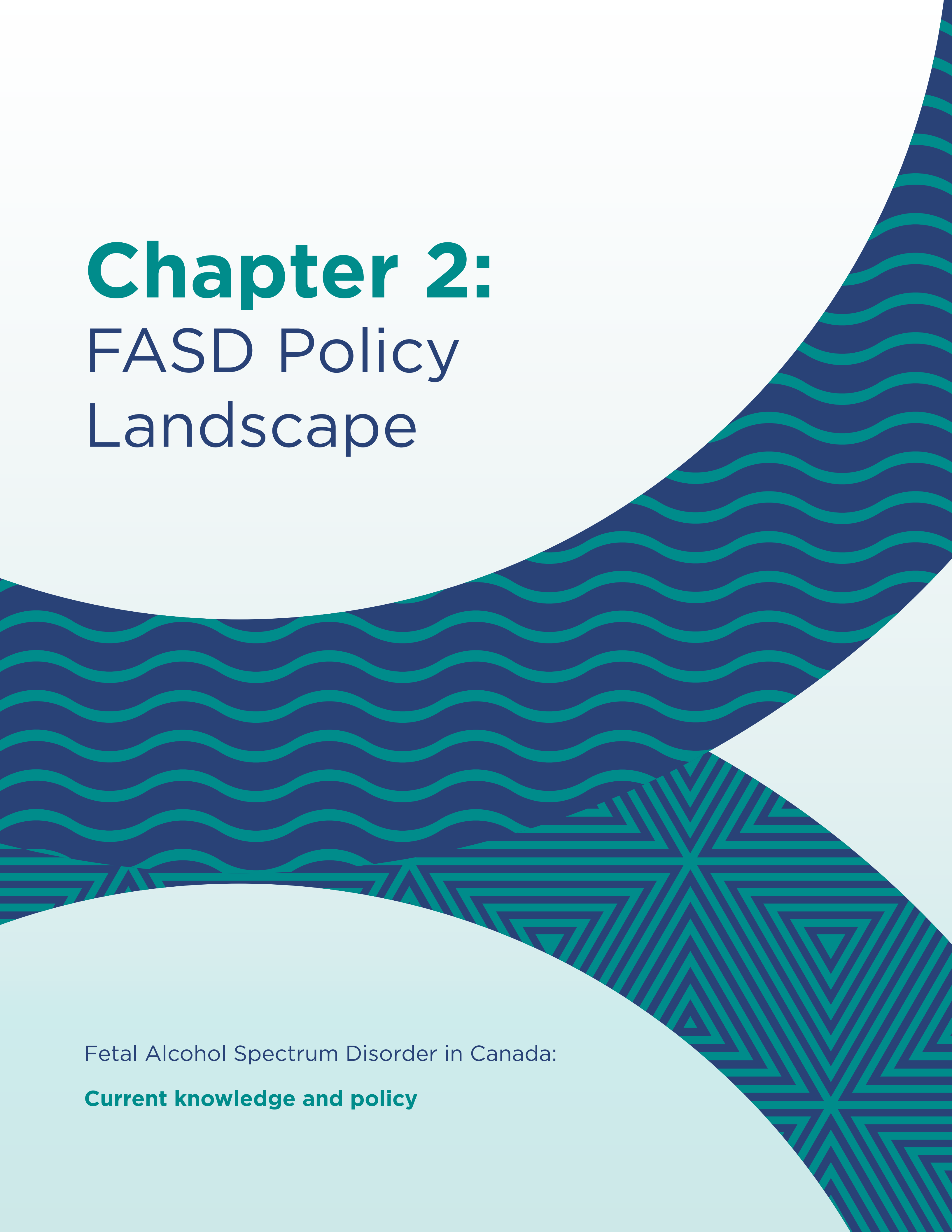
In adopting an intersectional and inclusive lens on Canadian health and social care systems, at times, systemic barriers faced by many Canadians emerged as highly relevant to the challenges faced by people with FASD. These barriers were particularly pertinent to the health inequities and systemic racism experienced by Indigenous Peoples (see Chapter 3). However, in keeping with the scope of the assessment, our analysis of potential solutions to these challenges was limited to evidence within FASD research and policy. As such, there are other possible systems-wide solutions -- movement toward Indigenous self-determination, justice system reform, among others -- that are not examined within this report. Yet, in aiming to create a more inclusive society that is sensitive to and accessible to the needs of diverse Canadians, there may also be broader applications of the information presented here in relation to FASD. Accordingly, while the scope of this assessment was specific to FASD, many of the conclusions may be applicable to other groups in Canada who face similar challenges and barriers.

With respect to Indigenous issues and FASD, there are limitations on what could be learned within the time frame of generating this report, such that the diversity of experiences and perspectives among Indigenous Peoples and communities may not be fully represented.

Moreover, as a Panel of individuals our personal experiences shape our perspectives on and interpretation of the information that was discussed and included in the report. We acknowledge that these unconscious biases may have resulted in errors of understanding.

Many people from diverse regions, contexts, and backgrounds participated in this assessment, sometimes under conditions that were less than ideal for them. We are grateful for the extraordinary input and support of our diverse leadership and contributing committee members and engagement participants.

Chapter 2:
FASD Policy Landscape



Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

2.1 Introduction

A key component for this assessment is an overview of the current FASD policy landscape across Canada, describing the present situation as well as evolution since the publication of *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action* (Public Health Agency of Canada, 2003).

For this assessment, "policy is broadly defined as what governments and other decision-making entities choose to do or not do that impacts persons with disabilities and their families" (Finlay, Ragot et al., 2023, p. 4).

Many government policies of general application affect FASD, including for example disability-related supports. In this chapter, we focus more narrowly on FASD-specific policy documents. The broader disability policy context was recently reviewed and published in reports on the federal (Finlay, Ragot et al., 2023) and provincial and territorial policies (Finlay, 2024).

In this chapter we describe current FASD legislation, strategies, standards and approaches adopted by various jurisdictions and civil society organizations in Canada. In addition, national approaches adopted by other countries that may be of interest in Canada are also presented.

This chapter offers an overview of policies; the details of specific policies, for example on screening in Assessment and Diagnosis (Chapter 6) or income supports in Interventions and Supports (Chapter 7), are provided in those chapters, along with relevant approaches adopted by other countries.

2.1.1 FASD: A Framework for Action (2003)

In 2003, concerned about the scope of FASD and its consequences, (Bacon, 2012) a unit of Health Canada, now housed in the Public Health Agency of Canada (PHAC), led a series of national consultations that informed the development of the *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action* (Public Health Agency of Canada, 2003). Public health is a broad field encompassing many areas of governmental activity and potential policy levers. In Canada, jurisdiction to legislate in relation to public health is a shared responsibility between the federal, provincial and territorial governments. Given the complexity of many public health issues, it is often the case that multiple levels of government have a role to play. The FASD Framework for Action was initiated by the federal government through Health Canada and shaped by the National Advisory Committee on FASD and an Interdepartmental Working Group on FASD. The Framework was intended as a foundation for action at community, provincial, territorial and federal levels.

The Framework outlined a shared vision and suggested ideas and options for further action for each of the federal, provincial, territorial and community levels. It identified five broad goals, with the intention that more specific and measurable objectives and action plans would be developed by all jurisdictions and sectors:

- increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy;
- develop and increase capacity;
- create effective pan-Canadian screening, diagnostic and data collection and reporting tools and approaches;
- expand the knowledge base and facilitate information exchange; and,
- increase commitment and support for action on FASD.

An analysis of the implementation of this framework will be presented in Chapter 8.

2.1.2 Evolution of federal FASD policy and research

The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women issued a report in 1992 – *Foetal Alcohol Syndrome: A Preventable Tragedy* – calling attention to this hidden health problem (Green & Wilbee, 1992). In 1996, this was followed by a *Joint Statement on the Prevention of Fetal Alcohol Syndrome/Fetal Alcohol Effects in Canada*, with Health Canada and 18 national professional associations recognizing the use of alcohol during pregnancy as a "national health concern" and committing to a collaborative approach to identify prevention strategies (cited in Bacon, 2012). Program authority for FASD was first conferred on Health Canada, and later PHAC, in the 1999 Budget as an expansion of the Canada Prenatal Nutrition Program, which targeted vulnerable pregnant women and infants (Government of Canada, n.d.-a). In the years following its launch, the 2003 Framework led to several milestones, including the development and publication of Canadian FASD diagnostic guidelines, which were updated in 2016 (Chudley et al., 2005, Cook et al., 2016) as well as FASD Initiatives within PHAC and in the First Nations and Inuit Health Branch, which is now a part of Indigenous Services Canada.

Following the evaluation of the FASD Initiative 2008/09-2012/13 (Public Health Agency of Canada, 2014), a Five-Year Strategic Plan 2016-2021 was developed to guide PHAC's role in supporting the framework. The Plan expanded the program authorities and had four strategic priorities:

- Raising public awareness
- Preventing alcohol use in pregnancy
- Improving health and social outcomes for those affected by FASD
- Improving FASD data (Government of Canada, n.d.-b)

Within PHAC, FASD activities are overseen by the Centre for Health Promotion, which manages the $1.5 million per year FASD National Strategic Projects Fund, and the Centre for Surveillance and Applied Research, which focuses on the development of FASD data systems and surveillance. The Centre for Health Promotion also funds three other community-based programs that support broader protective factors for child health and may include FASD elements: Canada Prenatal Nutrition Program, the Community Action Program for Children and Aboriginal Head Start in Urban and Northern Communities (Public Health Agency of Canada, 2023a).

The evaluation of the 2017/18-2021/22 FASD Initiative (Public Health Agency of Canada, 2023a) concluded that despite having ambitious objectives, FASD-dedicated funding is limited, and that important gaps to addressing FASD in Canada and opportunities for collaboration remain.

In 2022, Senator Ravalia introduced Bill S-253 entitled “An Act Respecting a National Framework for FASD” calling for a new national FASD framework (Ravalia, 2022). As of the writing of this assessment, Bill S-253 has had a second reading and has been referred to the Standing Senate Committee on Social Affairs, Science and Technology, but has not proceeded further.

As described in Chapter 1, PHAC approached the Canadian Academy of Health Sciences to conduct an evidence-based assessment on FASD “to identify challenges as well as opportunities to strengthen Canada’s approach to addressing FASD” (Public Health Agency of Canada, 2023b).

2.1.3 Clinical guideline development

The 2003 FASD Framework for Action outlined interdepartmental work needed to develop national guidelines for diagnosis of FASD, and the collection, analysis and reporting of incidence, prevalence and economic impact data through evidence-based research and consultations across sectors. This led to the development of national diagnostic guidelines (Chudley et al., 2005), reaching the first consensus on a Canadian standard. As will be discussed in detail in Chapter 6, the current Canadian Diagnostic Guidelines for FASD (Cook et al., 2016) updated the 2005 Guidelines and are currently in use across Canada (Brown et al., 2019; Coons-Harding, Flannigan et al., 2019, Flannigan, Coons-Harding et al., 2022).

2.2 Canadian FASD-specific policy landscape

Canada has interlocking federal, provincial, territorial and Indigenous health and social service systems (Health Canada, 2024). Canadian education and justice systems also function on multi-levels with important roles in federal, provincial and territorial governments. Some social service areas, such as subsidized housing, emergency shelters, and harm reduction, also have municipal components in some jurisdictions.

2.2.1 Federal policy

In addition to PHAC's leadership and program delivery roles (see Section 2.1), other federal government departments and agencies specifically contribute to the federal FASD policy landscape. These include:

- Indigenous Services Canada, which delivers the FASD Initiative through project-based funding in First Nations on-reserve and Inuit communities (ISC, 2024a);
- Employment and Social Development Canada, including the Canada-Nunavut Canada-wide Early Learning Child Care Agreement (Government of Canada, 2021);
- Justice Canada (2022a) provides programs for people with FASD in the criminal justice context, and Public Safety Canada, which has provided policy background (Public Safety Canada 2010); and
- Canadian Institutes of Health Research (CIHR), its Institute of Neurosciences, Mental Health and Addiction and the Network of Centres of Excellence through the Kids Brain Health Network (2022) and other neuroscience research programs.

Federal funding also contributes to other national and regional entities such as research and support networks. These are presented in Section 2.2.3.

2.2.2 Indigenous leadership and governance

Canada has embarked, in partnership with Indigenous Peoples, on a process to undo federally imposed systems of governance and administration, and to replace these with Indigenous control and delivery of these systems through self-government negotiations and other mechanisms to pursue greater self-determination (Government of Canada, 2024a). This rests upon the recognition of the inherent right to self-government of Indigenous Peoples in s.35 of the Canadian Constitution, as well as the fundamental Indigenous right and principle of Indigenous self-determination set out in the United Nations Declaration on the Rights of Indigenous Peoples. The ongoing Health Transformation Initiative is working to increase Indigenous control in the design, delivery and management of health services, and involves a tripartite process between First Nations-led health organizations (representing a number of communities), the federal and provincial governments (Government of Canada, 2024b). A new federal legislative framework, the *Act Respecting First Nations, Inuit and Métis Children, Youth and Families,* addressing child and family services for Indigenous children received Royal Assent in 2019 (Justice Canada, 2019). It recognizes Indigenous Peoples' rights and jurisdiction over child and family services, as part of an inherent and Aboriginal right to self-governance, and to establish national standards in this area (Fryer & Tiedemann, 2019). This provides important policy context for FASD.

As Indigenous communities progress toward self-governance and Indigenous sovereignty over health, education and social services, they are becoming key actors in the FASD policy response. British Columbia's First Nations Health Authority has implemented an FASD program to support the development of culturally appropriate evidence-based prevention, promotion and early intervention programs related to FASD (FNHA, n.d.). An Inuit-specific FASD strategy was developed by Pauktuutit Inuit Women of Canada (2010), in collaboration with representatives from Newfoundland and Labrador, Quebec, Nunavut, and the Northwest Territories. Known as the *Inuit Five Year Strategic Plan for Fetal Alcohol Spectrum Disorder 2010-2015*, the strategy sought to meet the unique needs of Inuit women and their families in order to enhance FASD prevention, diagnosis, and supports.

2.2.3 Provincial and Territorial policy responses

FASD Strategies

In addition to their general policies related to disability (Finlay, 2024), several provinces and territories have implemented specific FASD strategies.

Building on a previous 2003-08 strategic plan for FASD, the Government of British Columbia's 2008-2018 provincial plan *Building on Strengths* (2008) was developed with the involvement of nine provincial ministries in order to promote a coordinated and collaborative cross-ministry approach. It identified three high-level goals: ensuring that (1) women who can become pregnant have access to effective support and have healthy pregnancies, (2) children are born healthy and free of the effects of prenatal alcohol and substance exposure, and (3) people with FASD are supported to reach their full potential in healthy and safe communities. The plan articulated more specific cross-government objectives having to do with public awareness regarding PAE and FASD, support for women of childbearing age and their partners, focused interventions and supports for pregnant women with substance use problems and their partners, timely FASD diagnosis and assessment, comprehensive and lifelong interventions and supports for people with FASD and their families, and coherent, integrated and coordinated service systems that benefit from strong research and evaluation.

Alberta's *FASD 10-Year Strategic Plan* (Government of Alberta, 2008) focused on seven strategic objectives: public awareness and prevention, assessment and diagnosis, support for individuals with FASD and caregivers, training and education, strategic planning, research and evaluation, and stakeholder engagement. For each objective, it identified strategies as well as ministry leads and co-leads responsible for implementation. Like the BC plan, the Alberta plan recognized the need for coordination and collaboration across multiple policy sectors, noting that issues related to FASD are cross-jurisdictional and involve other levels of government. An FASD Cross-Ministry Committee that included participation of nine provincial ministries was ultimately responsible for oversight, and the plan provided for ongoing evaluation and monitoring to ensure targets were being met and outcomes were being realized. The strategy was evaluated in years five and seven and the final year 10 evaluation identified key achievements such as the development of an "FASD Learning Organization," referring to successful collaboration, coordination and cooperation amongst ministries and a high degree of cohesion in the FASD sector (Government of Alberta, 2017b). The evaluation identified the development of FASD services that are culturally-informed by Indigenous leaders and families as key to success. The creation of 12 FASD Service Networks was also identified as an important part of the successful model. A single portal links the 12 networks and serves as a navigation hub for FASD services in the province (Government of Alberta, n.d.-a).

Saskatchewan implemented the *Fetal Alcohol Spectrum Disorder (FASD) Prevention Framework 2014* to guide and facilitate FASD prevention initiatives across human services sectors. This is an example of a narrower framework than that adopted in BC and Alberta, where the framework focused on prevention as one of a broader set of goals. The Saskatchewan prevention framework was developed by the Saskatchewan FASD Coordinating Committee, working with a broad range of partners including the multiple provincial ministries, PHAC, FASD service organizations, Indigenous organizations, the provincial Liquor and Gaming Authority, among others. The framework was based on the four levels of prevention model (Poole, 2008) discussed in Chapter 5: (1) broad awareness and health promotion, (2) discussion of alcohol use and risks with all people in their childbearing years, (3) specialized, holistic support for pregnant women with alcohol and other health/social problems, and (4) postpartum support for new mothers and support for child assessment and development. The plan identified target populations, desired outcomes, current gaps and strategies to achieve those outcomes. It did not clearly assign responsibilities or provide a detailed plan to monitor progress, although the province's intent to support rigorous evaluation of the programs was stated. (Saskatchewan Ministry of Health, 2014). Saskatchewan's *Action Plan for Citizens with Cognitive Disabilities* also addressed FASD, allocating enhanced funds for strengthening FASD prevention and intervention, partnership with Saskatchewan Fetal Alcohol Support Network, and a Screening and Alternatives Measures Pilot Project (Government of Saskatchewan, 2005).

Manitoba's Fetal Alcohol Spectrum Disorder (FASD) Strategy was first implemented in 2007 to ensure coordination of programs and initiatives across all areas of government and with community partners (Government of Manitoba, 2024a). In 2024, Manitoba released its Renewed FASD Strategy 2024-2029. The renewed strategy prioritizes investments in community awareness, wrap-around supports for pregnant women and families, and increased specialized support for people with FASD across the lifespan. The Strategy notes the need for collaboration within government as the work on FASD intersects with other government priorities related to maternal and child health, gender-based violence, suicide prevention and reduced child mortality, public safety and the criminal justice system, homelessness, disability supports, child welfare and reconciliation (Government of Manitoba, 2024a). Like the Saskatchewan plan, the Manitoba plan does not assign specific responsibilities, but is overseen by the FASD Interdepartmental Committee which has the role of ensuring coordination among departments (Government of Manitoba, 2024a). A system for monitoring progress and evaluating outcomes is not described.

The Manitoba FASD network is a province-wide integrated diagnostic and short-term follow-up service, established in 2009 with the goal of facilitating FASD assessment, support and education closer to home. FASD Diagnostic Coordinators are located in five regions throughout the province (Manitoba FASD Network, n.d.-a).

Yukon's FASD Interagency Advisory Committee released the *Yukon FASD Action Plan 2019* (Government of Yukon, 2019a). It identified seven priority areas: supports for people with FASD, support for families and caregivers, awareness, prevention, assessment and diagnosis, knowledge exchange and mentoring, research and evaluation. For each priority area, the plan lists specific actions - immediate and intermediate - under each of these goals, as well as the desired outcomes. In only some cases are the specific entities responsible for these actions identified, but the plan also refers to the creation of a separate implementation plan that will identify leads, partners, resources and timelines. The plan also notes that an annual report will be developed to outline progress on new and existing initiatives and identify challenges impeding implementation. Among other existing initiatives, it builds on the 2019 *Yukon Forum declaration and joint Priorities action plan*, an agreement between Government of Yukon, Yukon First Nations and the Council of Yukon First Nations leaders, to work together on a shared set of priorities and actions, one of which is to continue to work collaboratively on prevention and enhancement initiatives with a focus on the wellbeing of Yukon First Nation children and families (Government of Yukon, 2019b).

FASD within other policy directions

Some jurisdictions address FASD within the context of other policy areas or programs, or they provide FASD funding in the broader context of their health systems:

- In 2017, Ontario invested $26 million over four years to expand FASD programs and supports with funding allocated to six initiatives (FASD ONE, 2017). Additionally, the province has dedicated funding for FASD diagnostic and other services which are implemented by community organizations in partnership with the government (Government of Ontario, 2023). To build the capacity of communities to respond to the needs of those impacted by FASD, FASD workers/coordinators within coordinating agency service delivery areas provide direct services to children, youth, and families with FASD, including consultation and system navigation support (Government of Ontario, 2023). FASD/TSAF Ontario offers an online, accessible and bilingual website that can orient people to services and supports (FASD/

TSAF Ontario, n.d.-a). Ontario’s programs include the Indigenous FASD/Child nutrition program, offered by 21 Indigenous service providers across 180 communities in Ontario (Government of Ontario, n.d.-a).

- Québec’s Public Health Institute released a report on the status of FASD in Québec in 2004 (Institut national de santé publique du Québec, 2014). FASD is not mentioned in Quebec’s 2015-2025 Provincial Public Health Plan, which orients the programming of the province’s 18 health regions. However, healthy child development based on a social determinants of health approach is a provincial priority (Axe d’intervention 1 – Le développement global des enfants et des jeunes; Ministère de la Santé et des Services sociaux du Québec, 2015). In 2016, the Ministère de la Santé et des Services sociaux [Ministry of Health and Social Services] issued a public health notice about alcohol consumption during pregnancy (Ministère de la Santé et des Services sociaux, 2016). Most recently, the Ministry released *Plan d’action 2023-2028 en périnatalité et petite enfance* [2023-28 Action plan in perinatal and early childhood health], which includes a review of FASD knowledge and an objective of sensitizing parents and future parents about PAE and supporting parents who have consumption problems (Ministère de la Santé et des Services sociaux, 2024).
- Nova Scotia recognizes FASD on its provincial website and includes FASD as part of a 2007 provincial alcohol strategy. A 2008 workshop report *Towards a Coordinated Approach to FASD* in Nova Scotia outlines potential strategies (Nova Scotia Department of Health Promotion and Protection, 2008).
- In 2021, PEI conducted a survey of needs of children with complex conditions, which, without naming any particular diagnosis, included children experiencing long term functional limitations due to a physical, developmental, behavioral or emotional condition (Health PEI, 2023a). This has resulted in the creation of a system navigator position for these families (Health PEI, 2023b).
- Newfoundland and Labrador’s *Provincial Alcohol Action Plan* (2022) prioritizes support to provincial FASD networks to improve capacity for prevention, screening and assessment and to increase understanding of the services required by individuals affected by FASD (Government of Newfoundland and Labrador, 2022).
- New Brunswick funds the FASD Centre of Excellence (Government of New Brunswick, 2022) to support FASD diagnosis, intervention and prevention, which is aligned with the government’s five-year *Inter-Departmental Addiction and Mental Health Action Plan* (Government of New Brunswick, 2021). This is the only bilingual diagnostic center in Canada (Vitalité Health Network, n.d.).

- The *Government of the Northwest Territories Disability Action Plan* 2018/19- 2021/22 resulted in the establishment of an Adult FASD Diagnostic Clinic to support adults with disabilities with access to assessment and diagnostics services as well as additional rehabilitation resources (physiotherapy, occupational therapy, speech-language pathology and audiology) within the Beaufort Delta and Stanton Territorial Hospital rehabilitation teams for children and families with complex needs, including FASD (Government of the Northwest Territories, 2023).

- Nunavut funds FASD assessments and services through its Department of Health (Legislative Assembly of Nunavut, 2019). In 2023, the Nunavut government announced the construction of an addictions and trauma recovery center in Iqaluit (Government of Nunavut, 2023). Support for people with suspected or confirmed FASD and their families is available through two Inuit-led centres: the Pirugatigiit Resource Centre in Iqaluit and the Kitikmeot Friendship Society in Cambridge Bay (Government of Nunavut, 2024a).

Regional FASD Networks and other organizations

Regional FASD networks and other types of resource-developing organizations are in place in many jurisdictions, allowing coordination, information sharing and sometimes fostering communities of practice. For example:

- FASD ONE (Ontario Network of Expertise) is a broad network of diverse provincial and local stakeholder groups working to better serve children, youth, parents, pregnant women, and families affected by FASD in communities across Ontario. It has also developed position papers on educational services (Duquette & Orders, 2010), respite care (Whyte, 2010), and effective service provider practices (Hall, Cunningham, & Jones, 2010).

- Also in Ontario, Health Nexus with funding from the Government of Ontario, offers three FASD programs: a bilingual website with resources for families and service providers; subsidies for FASD support groups; and training for families and service providers about how to locate events and learning material (Health Nexus Santé, n.d.).

- In BC, the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD) has been funded by the British Columbia Ministry of Education since 2006. Through training and resource sharing, it develops capacity within school systems to support learners with FASD (POPFASD, n.d.-a).

Legislation

Some legislation has been enacted at different jurisdictional levels to contribute to addressing FASD, through prevention with specific foci on general FASD awareness or on alcohol controls (both discussed more fully in Chapter 5) or on services and supports (Chapter 7).

Federally and with equivalents in provinces and territories (e.g., Manitoba (Government of Manitoba, 2022), the Fetal Alcohol Spectrum Disorder Awareness Day and Month are used to raise FASD awareness in the general population. The September date, the ninth day of the ninth month, honors the nine months of pregnancy (Government of Canada, 2024c).

Several jurisdictions have implemented legislation to support FASD prevention through education about PAE.

- Sandy's Law stipulates that establishments in Ontario that serve or sell liquor are required to display signs "cautioning pregnant women that the consumption of alcohol while pregnant is the cause of Fetal Alcohol Spectrum Disorder" (Government of Ontario, 2004). In 2019, the Build Ontario Together Act included the requirement that:
  - No person shall sell or supply liquor or offer to sell or supply liquor from prescribed premises unless a prescribed sign warning of the dangers of fetal alcohol spectrum disorder is displayed in accordance with the regulations (Government of Ontario, 2019).
- As part of its 10-Year Strategic FASD Plan, Alberta's Gaming and Liquor Commission introduced changes to regulations requiring Class A licensees (restaurants, bars, nightclubs, etc.) and Class D licensees (liquor stores) to post FASD prevention signage (Government of Alberta, 2017a).
- In Nova Scotia, the Public Education About Fetal Alcohol Syndrome Regulations require each Government store and agency store to periodically display a sign that warns pregnant women that the consumption of alcohol during pregnancy may cause fetal alcohol syndrome.

Local municipalities can play a key role through local legislation. In British Columbia, the Center for Excellence on Women's Health has developed signage and other material, including instructions on how to modify municipal bylaws, for use by municipal and local governments regarding alcohol use and FASD risk (Centre of Excellence for Women's Health, 2014).

Other types of legislation address the supports and services that governments commit to providing for people with FASD and their caregivers or educators:

- In British Columbia, the Community Living Authority Act and Regulations include persons with FASD in the offer of support and services to children and adults with developmental disabilities and the support and services to families to assist them in caring for a child or an adult with a developmental disability (Government of British Columbia, 2018).
- In Ontario, Bill 108, An Act in relation to Fetal Alcohol Spectrum Disorder (FASD) passed first reading in Ontario's legislature, but progress was interrupted with the calling of a

general election in 2025. It would have required boards of education to develop policies and guidelines with respect to FASD and teachers' colleges and early childhood education programs to provide training with respect to FASD (Bill 108, Ontario, 2023). A previous attempt to pass a bill proposing the same changes similarly did not succeed (Bill 172, Ontario, 2020).

In the three territories, regulations require mandatory reporting of Fetal Alcohol Syndrome (i.e., FAS - not FASD) as part of their public health or disease surveillance legislation (Yukon, 2000; Government of the Northwest Territories, 2009; Government of Nunavut, 2024b).

2.2.4 Partnerships, research consortia and professional associations

Partnerships

The Canadian Intergovernmental Conference Secretariat provides administrative support and planning services for the federal-provincial-territorial and provincial-territorial conferences of ministers throughout Canada. In 2016, the deputy ministers responsible for justice and public safety asked the Secretariat to produce the Fetal Alcohol Spectrum Disorder (FASD) Partnerships Inventory, identifying over 30 federal, interjurisdictional, and non-governmental organizations, networks and partnerships (Canadian Intergovernmental Conference Secretariat, 2016). While outdated as some of these partnerships have completed their work or evolved, it does illustrate the acknowledged importance of interjurisdictional collaboration for addressing FASD. A snapshot of current partnerships follows.

Alberta, British Columbia, Manitoba, the Northwest Territories, Nunavut, Saskatchewan, and Yukon are members of the Canada Northwest FASD Partnership, an interprovincial/territorial alliance that established and continues to help fund the Canada FASD Research Network (CanFASD, n.d.-b). The Canada Northwest FASD Partnership shares best practices and materials to support an efficient and effective FASD response (CanFASD, n.d.-b; Government of the Northwest Territories, 2015).

The Atlantic Intergovernmental FASD Partnership comprises provincial, federal, and regional government representatives from New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland and Labrador, Nunatsiavut, Health Canada (First Nations and Inuit Health), and PHAC. This partnership's mandate is to foster collaboration between the provincial and federal government in the Atlantic region, pool resources to provide public education on FASD, and promote FASD research in the region (Canadian Intergovernmental Conference Secretariat, 2016; Windsor & Ward, 2022).

Research consortia

Two main research consortia are highly active in FASD and related research across Canada:

- The Canada FASD Research Network (CanFASD) emerged from CNFASDP in 2005 to serve as a national research network informing prevention and support for people impacted by FASD (CanFASD, n.d.-a). Its cross-jurisdictional Research Leads and their respective networks focus on diagnosis, intervention and prevention, child welfare, justice and knowledge mobilization. The network also collaborates with the Public Health Agency of Canada and the Kids Brain Health Network. CanFASD, with funding from Kids Brain Health Network, operates the National FASD Database to facilitate research across all areas and produce evidence for policy decisions. Alberta, British Columbia, Manitoba, Saskatchewan, Northwest Territories, Yukon, Nunavut, and New Brunswick are currently jurisdictional members of CanFASD, and its affiliated researchers are involved in numerous ongoing research projects across Canada (CanFASD, 2023b).
- Kids Brain Health Network (formerly known as NeuroDevNet) has FASD as one of its research portfolios. In addition to having been the primary funder of the National FASD Database, it has funded research in the areas of detection, diagnosis, early intervention, and support for people with FASD and their caregivers (Kids Brain Health Network, n.d.). With funding from the Network of Centres of Excellence and now the Strategic Science Fund (Innovation, Science and Economic Development Canada, 2021), Kids Brain Health Network is focusing on research with the potential to begin implementation in the near term. Two projects selected are: a tutoring program called the Math Interactive Learning Experience (MILE) that addresses the FASD-associated cognitive deficits in visual-spatial processing, self-regulation, and working memory; and the Client-Oriented Mapping for Point of Care Access to Supports and Services (COMPASS) tool, which aims to facilitate clinicians' customized recommendations for families when a child is diagnosed with FASD. This project is using data from the National FASD Database (Kids Brain Health Network, 2024a).

Health professionals' associations

Health professions' clinical practice guidelines, policy positions, and publications can be an influential part of the FASD policy landscape. Their professional associations play an important role in standardizing care across Canada regarding preventing alcohol use during pregnancy, identifying or diagnosing FASD, and providing or facilitating access to interventions and supports. Examples that are relevant to FASD include:

- The Society of Obstetricians and Gynaecologists of Canada's *Guideline No. 405 Screening and Counselling for Alcohol Consumption During Pregnancy* (Graves et al., 2020), establishes national standards of care for screening and counselling pregnant women and women who could become pregnant regarding alcohol consumption and possible alcohol use disorder.

- The Canadian Medical Association published the 2005 and 2016 Canadian FASD Diagnostic Guidelines in the Canadian Medical Association Journal.

2.3 FASD policy in other countries

The international case studies conducted for this assessment identified several national policy approaches to FASD.

Australia's *National FASD Strategic Action Plan 2018-2028* is a comprehensive recent national FASD strategy. The Australian plan aims to reduce the prevalence of FASD and the impact it has on individuals, families, care providers, and communities and is built around the four key national priorities of:

- prevention
- screening and diagnosis
- support and management
- priority groups and people at increased risk (Government of Australia, 2018a).

Given Australia's similar structure to Canada's, with division of powers between federal and state governments, it is of interest to note that *Australia's National FASD Strategic Action Plan 2018-2028* (Government of Australia, 2018a) has overarching goals that are almost identical to Canada's but its approach is that of an Action Plan, with concrete directives on roles and activities, a governance structure, and a monitoring and evaluation framework. Moreover, the FASD Action Plan is a sub-strategy of the National Alcohol Strategy (Government of Australia, 2018a), which contains shared FASD prevention actions through alcohol policy, identifies performance indicators and sets measurable targets. It also aligns with the *National Drug Strategy 2017-2026*; the *National Aboriginal and Torres Strait Islander People's Drug Strategy 2014- 2019*; the 2017 *National Strategic Framework for Chronic Conditions* and the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*. The Action Plan does not identify Indigenous communities as priority groups directly, but notes that across Australia, a range of programs have been implemented in Indigenous communities where there is increased FASD risk (Government of Australia, 2018b).

Australia's FASD Action Plan specifies a governance structure with a National FASD Advisory Group at the helm, reporting ultimately to the Council of Australian Governments which enacts shared responsibility between the national and state/territory governments. Its membership includes a range of expertise including lived experience with government and non-government representation, co-chaired by government and non-governmental representatives. This body is responsible for oversight and reporting under a monitoring and evaluation framework requiring ongoing monitoring and formal evaluation after three years, at midpoint, and in the ninth year of implementation, with the evaluation questions and data sources identified in the Action Plan (Government of Australia, 2018b). The three-year evaluation found the Action Plan to be on track, while highlighting areas of good progress and those in need of bolstering (Curtis et al., 2022).

New Zealand implemented the *Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019: An action plan* (New Zealand Manatu Haurora Ministry of Health, 2016), which built on a number of existing health and social sector initiatives and encompassed support service recommendations related to various outcome domains, including education, awareness raising, research, advice, resources, and tools to support community action and strengthen the health and disability sectors across the country (Health New Zealand, 2023). The Plan aimed to foster collaboration to achieve collective impact, using a whole-of-government approach, and included success indicators with target dates (New Zealand Manatu Haurora Ministry of Health, 2016). Although the FASD Action Plan was formally from 2016-2019, it continues to be the foundation for an evidence-based, interagency approach to preventing and responding to FASD (Health New Zealand, 2023).

The United States' FASD policy landscape is complex and longstanding, with roles played by the federal and state governments as well as tribal authorities. Early federal legislative leadership included the 1988 Alcohol Beverage Labeling Act, which required warning labels on alcoholic beverages cautioning against use during pregnancy (US Senate, 1988). In 1993 the first interdisciplinary FASD diagnostic clinic sponsored by the Center for Disease Control was established in Seattle at the University of Washington (Astley Hemingway et al., 2023; FAS Diagnostic & Prevention Network, n.d.). In 1996, the United States Congress mandated the Institute of Medicine to conduct a study of FAS and related birth defects. In part, the objective was to develop diagnostic guidelines "…which could subsequently be used in epidemiologic, clinical, and basic research" (Stratton et al., 1966). These guidelines proved influential in Canada and worldwide. Most recently, the FASD Respect Act was reintroduced during the 2023-2024 118th Congressional Session (H.R.4151- 118th Congress, 2023-2024). The FASD Respect Act called for a prompt, coordinated response to all prenatal substance exposures to preserve the health and well-being of children and families across the nation (US Senator Amy Klobuchar, 2023). If it had passed, the Act would have reauthorized and strengthened existing federal FASD programs by increasing funding for FASD education initiatives, providing financial support to Tribal systems for FASD services, and establishing systems of care to enhance the awareness, training, and outreach on FASD (FASD United Policy And Training Center, n.d.).

Complementing this legislative and policy effort, the US Department of Health and Human Services has developed a number of research briefs and reports. For instance, the "State Responses to FASD: Effective Strategies and Ongoing Challenges" (US Department of Health and Human Services, 2022a) highlights how various states approach FASD through prevention, identification, and intervention strategies. Additionally, *The Role of Health and Human Service Providers in Preventing FASD* (US Department of Health and Human Services, 2022b) outlines the critical contributions of health and service providers, emphasizing the importance of education, support, and advocacy in managing FASD. In addition to these legislative and national initiatives, federal agencies in the US, particularly the National Institute of Alcohol Abuse and Alcoholism, within the National Institute of Health (the nation's primary medical research agency), support and conduct research on the effects of alcohol use on human health and wellbeing, including research on FASD that addresses prevention, diagnosis, treatment and etiology (National Institute on Alcohol Abuse and Alcoholism, 2023).

In the United Kingdom (England), prevention and awareness raising are carried out by Public Health England, NHS England, and NHS Improvement, with the responsibility for the commissioning of services with the clinical commissioning groups. The government recognizes the importance of FASD, and has developed *Fetal Alcohol Spectrum Disorder: Health Needs Assessment*, which focuses on current gaps in policy and services for persons with FASD, including recommendations for innovative approaches to support individuals with FASD and their families and caregivers (Department of Health & Social Care, 2021). Its National Institute for Health Care and Excellence (NICE) has also developed an FASD Quality Standard, outlining care quality standards for alcohol consumption in pregnancy, PAE, referral for assessment, neurodevelopmental assessment, and management plans (National Institute for Health and Care Excellence, 2022).

2.4 International treaties of relevance to FASD

The Canadian Government recognizes FASD as a lifelong disability (Government of Canada, 2023a). As such, the United Nations Convention on the Rights of Persons with Disabilities (United Nations, n.d.) has relevance for many of the issues faced by people with FASD and ensuring they are able to fully participate in society. It is important to consider FASD within the context of disability rights so that general disability policies are inclusive of people with FASD.

Canada adopted the United Nations Convention on the Rights of Persons with Disabilities, accepting the legal obligations contained within to uphold and protect the rights of persons with disabilities. This includes (Finlay, Ragot et al., 2023):

- ensuring there are national laws to prevent discrimination,
- eliminating barriers to accessibility, and
- working to promote the capabilities and contributions of persons with disabilities.

The United Nations Convention on the Rights of Persons with Disabilities provides a framework for the rights of people with FASD, as exemplified in a report by New Zealand's Disability Rights and Children's Commissioners (New Zealand Human Watch & Children's Commissioner, 2020). The report draws attention to the insufficient support available for people with FASD and their families and how this limits their ability to fully participate in society and to access essential health and social services, as required by the Convention on the Rights of Persons with Disabilities (New Zealand Human Watch & Children's Commissioner, 2020).

Without adequate resources, people with FASD are more vulnerable to adverse outcomes, including disproportionate interaction with the criminal justice system (Lansdell et. al., 2021; New Zealand Human Watch & Children's Commissioner, 2020). This trajectory is often exacerbated by neurodevelopmental impairments, which complicate comprehension and behaviour within legal settings (Lansdell et. al., 2021). The Convention on the Rights of Persons with Disabilities's mandate of equal access to justice highlights the need for procedural accommodations for individuals with disabilities, including those with FASD (Lansdell et. al., 2021). In line with this, policy discussions in Australia highlight the importance of training and accessibility within the justice system to ensure fair and equitable treatment for people with neurodisabilities, reflecting the Convention on the Rights of Persons with Disabilities's principles of non-discrimination and the right to equal participation in legal processes (Lansdell et. al., 2021).

In addition, and as noted in Section 2.2, Canada's adherence to the United Nations Declaration on the Rights of Indigenous Peoples (Justice Canada, 2021a), also provides important policy context for FASD. In line with the declaration as well as the United Nations' Convention on the Rights of Persons with Disabilities, Canada's 2023-2028 Action Plan commits to ensuring that the equality rights of Indigenous persons with disabilities are respected in the design and delivery of Government of Canada programs, policies, and services (Justice Canada, 2023a).

2.5 Conclusion

This assessment found that the overall policy landscape for FASD in Canada offers many strengths, contributions and innovations. There are examples of successful policy initiatives across the country as well as internationally. At the same time, there are significant gaps in FASD health service delivery and uneven attention to addressing the needs of people with FASD in Canada.

Several Canadian jurisdictions have developed and implemented FASD-related legislation, frameworks or strategies or embedded FASD initiatives at the provincial or territorial policy level since the 2003 Framework. However, there are inconsistencies within the country in terms of engagement in FASD policies, research and advocacy. This variable visibility of FASD across the country suggests differences in perceived urgency to addressing FASD and dedicating resources to it.

Similarly, while there has been substantial nation-wide achievement in development of clinical practice guidelines to diagnose people with FASD, provinces and territories vary as to whether there is a coordinated, sustained approach to implementing the guidelines.

A strong feature of some provincial and territorial and other nations' FASD strategies is the recognition of the critical importance of effective mechanisms to ensure coordination and collaboration among the many different sectors of government that need to work together, with explicit articulation of who will participate, the governance structure, and mechanisms for accountability.

Canada's obligations under the Convention of the Rights of Persons with Disabilities as well as under its own Constitution in relation to persons with disabilities are an important part of the FASD policy context. Recent advances in FASD policy in peer countries offer a useful point of reference for Canadian policy-making.

Chapter 3:

Indigenous Peoples, Communities and FASD

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

3.1 Introduction

FASD is a condition that affects people of all races and ethnicities. The Panel included a separate chapter on Indigenous Peoples[5], communities and FASD for multiple reasons. Processes now underway toward self-governance and Indigenous sovereignty over health, education and social services including child protection, among other areas, mean that Indigenous communities are becoming key authorities in FASD response through their own structures and policies. A chapter specific to Indigenous issues can support those responses, by providing a thorough examination of the existing research literature, interpreted through the critical lens of participants in the engagement process. This comprehensive review can help counter misinformation, stigmatization and stereotyping related to Indigenous Peoples, alcohol and FASD (as described in this and subsequent chapters), while offering examples of Indigenous approaches. As acknowledged in previous Canadian Academy of Health Sciences reports (2022, 2023), Indigenous Peoples face unique systemic challenges and special attention is needed to address the historical and contemporary inequities.

In addition, in deciding to include a separate chapter, we were informed by the Truth and Reconciliation Commission's Calls to Action 33 and 34 (2015) about FASD:

33. We call upon the federal, provincial, and territorial governments to recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD), and to develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.

34. We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:

    i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.
    ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
    iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.
    iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.

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[5] 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.

This chapter is organized in the same sequence as the charge to the panel (see Chapter 1) and the overall report. This is not to imply that this is the priority order for most effectively addressing FASD, nor to suggest that by beginning with prevalence, little is known about the extent of the problem.

Much of the evidence and discussion contained in the other chapters of this assessment report are also relevant to Indigenous Peoples and communities. We do not repeat those discussions in this chapter, but instead focus here on the distinctive situation of Indigenous Peoples and communities in Canada, and offer an analysis of the Indigenous-specific data, literature, policy and engagement results. This chapter should be read along with those other chapters.

3.1.1 Approach

The Panel's overall approach to this work aimed to ensure that Indigenous expertise was called upon in as many ways as possible.

The Panel's structure included a Working Group on Indigenous Peoples, Communities and FASD that included Indigenous Panel members and allies. This group developed and approved the issues to be addressed and the outline for this chapter, and most importantly, developed the key findings. An Indigenous-led consulting firm conducted the underlying review of literature and policy documentation. This firm also organized two virtual engagement sessions, one targeted to key Indigenous organizations across the country, and a second open to interested Indigenous members of the public. In the other engagement sessions (described in Chapter 1), there was extensive participation by self-identified Indigenous people, Indigenous organizations, and non-Indigenous organizations that serve a large Indigenous population and incorporate Indigenous knowledge and objectives (for example, district school boards with Indigenous curriculum). This broad Indigenous involvement is captured in Figure 3 and includes Indigenous[6] and Indigenous-serving[7] persons and organizations.

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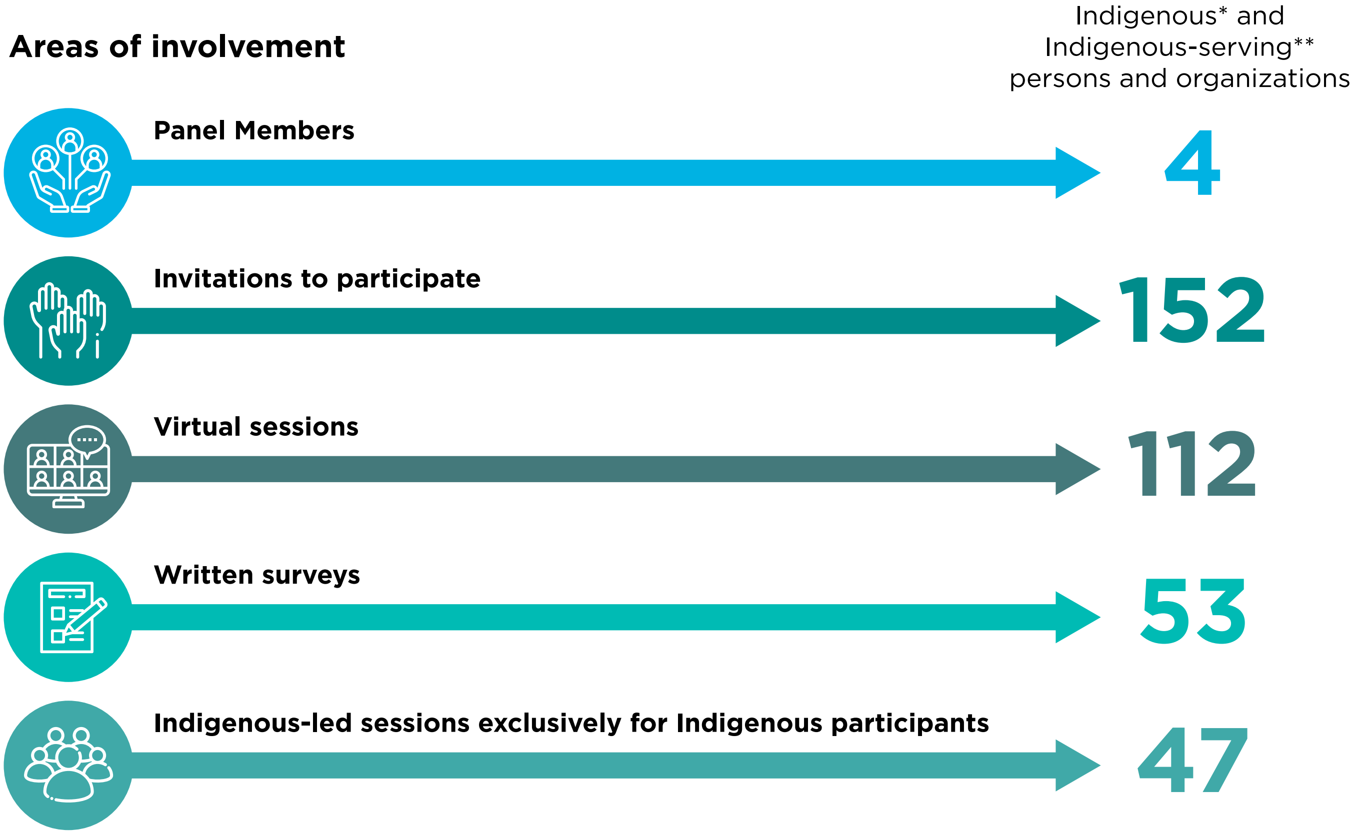
[6] "Indigenous" is defined here as an organization or individual self-identifying in response to survey/poll questions and/or a thorough web search into the organization's leadership, history, and mission.

[7] "Indigenous-serving" is defined here as an organization or individual that serves a large Indigenous population, has Indigenous perspectives integrated into the organization's mission and vision, and/or is strongly involved in Indigenous activities with services specifically designed for Indigenous individuals.

Figure 3: Indigenous and Indigenous-serving persons and organizations across the assessment process



* "Indigenous" is defined here as an organization or individual self-identifying in response to survey/poll questions and/or a thorough web search into the organization's leadership, history, and mission.

** "Indigenous-serving" is defined here as an organization or individual that serves a large Indigenous population, has Indigenous perspectives integrated into the organization's mission and vision, and/or is strongly involved in Indigenous activities with services specifically designed for Indigenous individuals.

There are many Indigenous perspectives on the issues covered, and the Panel cannot claim to have heard them all. The content of this section is not assumed to represent the perspectives of any one Indigenous community and certainly not all Indigenous Peoples.

3.1.2 Context

Historic and contemporary trauma and determinants of health

The trauma and resultant intergenerational effects from residential school experiences, the forced adoption system now known as the Sixties Scoop, and other colonial policies have been linked to many negative outcomes for Indigenous Peoples, including poor physical health, mental health problems, parenting and family challenges, ongoing over representation of Indigenous children in the care of child protection, family violence, justice system involvement, and lower educational attainment (Tait, 2003; Wolfson, Poole, et al., 2019).

Maternal risk factors are multidimensional, and factors related to socioeconomic status such as poor living conditions, inadequate nutrition and high levels of stress during pregnancy, enhance risk for FASD pregnancy outcomes (May & Gossage, 2011). Adverse childhood experiences, in particular exposure to drinking/substance misuse, domestic violence (Tan et al., 2022) and generational food insecurity (May & Gossage, 2011; Werk et al., 2013) are associated with FASD.

Indigenous Peoples also face the intersecting and compounding effects of FASD stigmatization, stereotyping and racism, and lack of access to culturally safe FASD health services (Aspler et al., 2019; Di Pietro & Illes, 2014). Engagement participants concurred, emphasizing that because of mistrust of the healthcare system, stigma, and fear of child apprehension, Indigenous people may avoid prenatal treatment and FASD diagnosis.

Consistent with the 2017 *Consensus Statement on developing Indigenous Approaches to FASD* prepared by CanFASD, the Thunderbird Foundation and the Centre for Excellence in Women's Health (2017), research has explored the wide set of determinants that contribute to substance use, addictions, prevention, and treatment from an Indigenous perspective, documenting risk factors and protective cultural factors and situating findings within a social determinants of health (SDH) framework (McKenzie et al., 2016; Shahram, Bottorff, Oelke, Dahlgren et al., 2017).

Distinctions-based approach

The Panel's work aligns with a distinctions-based approach to reconciliation, respecting and acknowledging First Nations, Métis, and Inuit Peoples as distinct Peoples with unique cultures, histories, rights, laws, and governments. With respect to FASD, the Panel understands that a distinctions-based approach may require different approaches or actions and result in different outcomes (Government of British Columbia, 2023a).

3.2 Prevalence

3.2.1 Prevalence estimates for FASD and PAE among Indigenous Peoples

In a global study, Lange, Probst, Gmel et al. (2017) found FASD prevalence in children and youth to be 15.6 (Australia) to 24.6 (Canada) times higher among Indigenous populations than the estimated global prevalence in the general population 7.7 per 1,000 population (95%CI: 4.9-11.7 per 1,000 population). Other epidemiological research estimates the prevalence of FAS and FASD among the Indigenous population in Canada to be 38 times and 16 times higher than in the general population, respectively (Popova, Lange, Probst, Parunashvili, & Rehm, 2017).

Elevated rates are also found in the Indigenous populations of countries with similar colonial histories, including the US (Popova, Lange, Probst, Parunashvili, & Rehm, 2017) and Australia (Popova, Lange, Shield et al., 2019).

However, research underscores the need to contextualize these figures, attributing FASD rates not to Indigenous status per se, but pointing to the causal role of past and ongoing colonial trauma flowing from the legacy of residential schools, the Sixties Scoop, and child apprehension, compounded by anti-Indigenous racism in producing the unfavorable social determinants of health identified in the research literature cited above (McKenzie et al., 2016; Shahram, 2015; Shahram, Bottorff, Oelke, Dahlgren et al., 2017;; Fournier, 2022).

Drawing pan-Indigenous conclusions from non-representative data on PAE and FASD obscures the diversity among Indigenous communities and pan-Indigenous approaches or solutions may not be appropriate in every community. Moreover, restricting data collection to small geographic areas such as reserves or to high risk individuals can produce inflated prevalence estimates if generalized to all Indigenous Peoples (Hanson et al., 2023). These can perpetuate the stigmatization and stereotyping of Indigenous Peoples (Flannigan, Unsworth et al., 2018; Aspler et al., 2019; Hanson et al., 2023). In an analysis of the discourse about FASD in Canadian print media, Aspler et al. (2019) found exaggerated, overgeneralized reports about FASD prevalence based on studies conducted in single, often remote, communities. Engagement participants noted that the perpetuation of stigmatization can then distort prevalence estimates further. As one participant stated:

> *...there is a bias towards race-based referral for assessment of young children. Indigenous children are directed to the FASD assessment stream more often than non-Indigenous children, leading to a wariness of parents to seek supports early on.*

Patterns of alcohol consumption among Indigenous communities vary widely with some Indigenous people consuming little or no alcohol (First Nations Information Governance Centre, 2018; Bélanger et al., 2020). Among those who drink alcohol, a proportion engage in heavy episodic consumption, which is defined as 4 (for women) or 5 (for men) or more drinks on a single occasion (First Nations Information Governance Centre, 2018; Bélanger et al., 2020); however, this data is not specific to pregnant women. Data on heavy episodic consumption among pregnant Indigenous women is old and limited. Based on two studies from Northern Canada in the 1980s and 1990s, pooled prevalence of heavy episodic drinking during pregnancy was estimated to be 22.1% (95% CI: 0.0-52.9; Popova, Lange, Probst, Parunashvili, et al., 2017). As a pattern of heavy episodic consumption is known to be associated with an elevated risk of FASD (May & Gossage, 2011), this may be one factor in the elevated FASD prevalence in some Indigenous populations as compared to the general population. Drawing conclusions from limited samples can reinforce historical stereotypes, while neglecting broader sociocultural and historical influences (Hanson et al., 2023).

Flannigan, Unsworth and Harding concluded in 2018 that existing data were not conclusive enough to assert that FASD is disproportionately represented in all Indigenous communities.

The comprehensive systematic review of FASD prevalence studies conducted by Popova, Lange, Shield et al. (2019) concluded that the reported prevalence figures for Indigenous populations are out of date and suffer from various methodological limitations, and are therefore "not applicable for decision-making purposes" (p.1168).

3.2.2 Improving data collection

Given the limitations of the existing FASD prevalence data for Indigenous communities (Flannigan, Unsworth et al., 2018; Popova, Lange, Shield et al., 2019), it is important to improve FASD data collection. However, the history of unethical and exploitative research involving Indigenous Peoples in Canada (Hayward et al., 2021; Interagency Advisory Panel on Research Ethics, 2022) may further hinder the development of the trust necessary for the collection, analysis, communication and stewarding of accurate prevalence data. Engagement participants expressed a desire for data collection by and for Indigenous communities, in order to support Indigenous- and community-specific responses. Where community capacity for data initiatives can be strengthened, the importance of developing relationships with supportive non-Indigenous research allies was also highlighted.

The concept and principles of Indigenous data sovereignty assert that Indigenous communities are encouraged to have control over data collection in their communities, as well as ownership and control over the use and sharing of that data. Principles of Indigenous data collection and management are set out in the First Nations OCAP Principles of ownership, control, access and possession (OCAP; First Nations Information Governance Centre, 2020a); the Inuit Tapiriit principles of access, ownership, and control (OCA; Inuit Tapiriit Kanatami, 2018) and the Manitoba Métis principles of ownership, control, access, and stewardship (OCAS; Martens et al., 2010, University of Manitoba, 2021). As one survey respondent recommended:

> *Allow for Indigenous communities to collect and analyze their own communities' data and share it externally if desired and without obligation.*

The recent federal government process to develop distinctions-based Indigenous health legislation as part of its response to the Truth and Reconciliation Commission's Calls to Action identified the theme: "Indigenous Peoples control their data and information is available to support wellness" (Government of Canada, 2023b; Government of Canada, 2024d). With respect to FASD, engagement participants also suggested that FASD data collection be led by Indigenous researchers, be separated from political processes, use tools and strategies that align with Indigenous ways of knowing that recognize Indigenous Knowledge Keepers and forms of knowledge, and ensure that Indigenous communities can access and use the data. Providing support for community-based research would entail increased training of Indigenous health professionals and health researchers as well as community access to health research literature (Canadian Academy of Health Sciences, 2023). A reconciliatory approach also includes the offer of substantive and ethical support by non-Indigenous research partners, which requires capacity among non-Indigenous researchers to meet community needs and address their research questions in contextually and culturally appropriate processes, in line with the federal Transformational Approach to Indigenous Data (Government of Canada, 2023c; Indigenous Services Canada, 2024b).

FASD prevalence data at the community level is aligned with a distinctions-based approach and would provide more precise and relevant data helpful to Indigenous leadership in policy-making and resource allocation. However, the Indigenous-specific literature review found few studies that consider variants such as culture, local policies, and history. For example, Metis- or Inuit-specific studies are scarce (Allen et al., 2023; Pauktuutit Inuit Women of Canada, 2010) although some data are available for the Inuit population of Nunavik (Moisan et al., 2021; Fortin et al., 2016). A relative lack of research in Eastern Canada may mean that many Nations and cultural groups in that region may have been poorly represented in the available FASD prevalence estimates (Pacey, 2009).

3.2.3 Indigenous-led and collaborative prevalence assessments

The First Nations Regional Health Survey has collected data on FASD prevalence using respondent reports of health professionals' diagnosis of FASD in repeated cross-sectional surveys. These surveys report that diagnosed FASD prevalence in First Nations children decreased from 1.8% in 2002-2003 to less than one percent (0.5%) in 2015-2016 (First Nations Information Governance Centre, 2018).

Local, Indigenous-led initiatives in Australia have produced FASD prevalence data used to inform policy and prevention. These examples could inform further efforts in Canada. The Lililwan Project, in the remote Fitzroy valley of Western Australia, aimed to support community-led FASD prevention and management initiatives by providing quantifiable data on FASD prevalence. The study was implemented with the collaboration and guidance of the communities to collect high-quality data on FASD prevalence. This included using a community-based participatory research approach, conducting extensive community consultation, convening an expert advisory group, and employing local Indigenous community navigators. It produced a sizable body of published literature and data on rural and remote FASD prevalence rate (Fitzpatrick et al., 2017).

Based in north Queensland in Australia, the Yapatjarrathati project aimed to "co-design" a culturally-safe tiered neurodevelopmental assessment process that could identify FASD in primary healthcare. It was developed with Indigenous leaders, local health providers, and community members and aimed to expand capabilities of practitioners in the remote region while ensuring that the assessment process aligned with the specific concerns of the local community, including cultural practices and knowledge (Shanley et al., 2023; Miller et al., 2022).

In Canada, an Indigenous led initiative in a M'ikmaq First Nation has produced prevalence data to inform the development and implementation of a Two Eyed Seeing community based FASD healing model (Cox, 2023).

Key Findings:

Patterns of alcohol consumption among Indigenous communities vary widely and drawing general conclusions from limited samples can reinforce historical stereotypes, while neglecting broader sociocultural and historical influences. Correcting these stereotypes can help foster conversations at community and individual levels that are key to progress on responding to FASD.

Many Indigenous Peoples and communities face inequities in social determinants of health and have experienced historic and contemporary trauma and resulting intergenerational effects (e.g. adverse childhood experiences) due to the effects of colonialism and racism. These factors increase risk for PAE and FASD.

Some data suggests that prevalence rates of FASD and PAE are significantly elevated for some Indigenous communities. Accurate, up-to-date data on FASD and PAE prevalence and risk factors among Indigenous communities would help to inform policy responses and resource allocation for prevention and support. This includes robust Indigenous-led community level data collection methods, consistent with data sovereignty principles.

3.3 Prevention, interventions and supports

The peer-reviewed and grey literature highlight a consistent set of best approaches for prevention, intervention and support initiatives for Indigenous Peoples and communities, informed by the historical and current factors underpinning FASD and their interplay with the social determinants of health. Eight tenets have been synthesised and endorsed in several consultations on enacting the Truth and Reconciliation Commission's Call to Action 33 (Wolfson, Poole, et al., 2019):

- centering prevention around Indigenous knowledge and wellness;
- using a social and structural determinants of health lens;
- highlighting relationships;
- community-based and community-driven;
- provision of wraparound support and holistic services;
- adopting a life course approach;

- models supporting resilience for women, families, and communities; and,
- ensuring long-term sustainable funding and research.

In the sections below, we summarise the research evidence framing these tenets in two main groupings: culturally- and community-informed, and community-specific programming; and holistic, integrated, wrap-around forms of prevention and care. We also integrate context and nuance obtained through our engagement process.

3.3.1 Culturally- and community-informed, and community-specific programming

Evidence has been accumulating on the need for and the effectiveness of culturally informed diagnosis, prevention, and interventions (Badry & Felske, 2013a; 2013b; 2013c; Symons et al., 2018). Such programming, whether for prevention, assessment, intervention or support, acknowledges Indigenous communities' desire and intent to move beyond a medical model perceived as colonial (Allen et al., 2023; Hayward et al., 2020). It aims to create safer spaces for acceptance, disclosure and collective healing (Cox, 2023; Hellard, 2018), often by asking those affected to identify their own definitions of health and safety and work with them toward achieving their own goals or ideal conditions (Cox, 2023; Badry & Felske, 2013c).

Social and Indigenous determinants of health

Effective FASD programs take into consideration social and Indigenous determinants of health, as mapped or identified by the individuals, communities and groups concerned (McKenzie et al., 2016; Shahram, Bottorff, Oelke, Kurtz, et al., 2017; James et al., 2021). The *Integrated Life Course and Social Determinants Model of Aboriginal Health (ILCSD)* developed by the National Collaborating Centre for Aboriginal Health (Reading & Wien, 2009) provided a framework for subsequent studies, identifying distal determinants (i.e., social, political and historical contexts, such as history with residential schools), intermediate determinants (i.e., health, education and community infrastructure and systems, environmental stewardship and cultural continuity) and proximal determinants (i.e., physical, mental, emotional or spiritual health resources and impacts; Reading & Wien, 2009). Some of these determinants may constitute protective factors: for example, the intermediate-level determinant of accessible and safe systems for sharing experiences of trauma may be beneficial to addressing substance use among young Indigenous women who are or were pregnant (Shahram, Bottorff, Oelke, Kurtz et al., 2017).

Trauma-informed

To be effective in reaching, engaging and helping people affected by FASD, prevention and intervention programming considers and addresses historical structural and root causes of the condition (Gonzales et al., 2021). This is facilitated by the use of trauma-informed practices, including: 1) awareness of historical and allied trauma among practitioners (Spillane et al., 2023); 2) safety and trustworthiness of the intervention encounters, attempting to erase the judgmental and accusatory narrative around alcohol use in pregnancy; 3) avoidance of re-traumatization and supporting clients' safety, choice, and control in service delivery; and 4) strengths-based approach and skill building (Morton Ninomiya et al., 2023; Spillane et al. 2023). The engagement sessions also emphasised the importance of cultural safety, for example, suggesting that FASD diagnostic processes are not always experienced as culturally safe, which may impede disclosure or create new barriers to diagnosis.

With respect to trauma awareness among practitioners (Spillane et al., 2023), studies have found that practitioners may be unaware of existing relevant resources about FASD and its determinants (Williams et al., 2018). To enhance culturally-aware interprofessional practice, Reid, Liu et al. (2023) have demonstrated the potential of co-design approaches, building on communities' and professionals' respective ways of knowing and knowledge bases. In this context, the lived-experience perspective of formal and informal caregivers is also important (Williams & Badry, 2023).

For example, a Two-Eyed Seeing approach for FASD services is used in New Brunswick, and includes providing culturally informed FASD diagnosis (Cox, 2023).

Strengths-based

Strengths-based approaches contribute to effective FASD prevention and interventions. An Indigenous worldview on FASD, and on disability more broadly, in contrast to a deficit-focused medical model "accepts diversity and embraces the whole person, recognizing the strengths that difference brings to the community" (Williams & Badry, 2023, pp. 63). In strengths-based interventions, the focus is on the strengths of individuals affected by FASD in connection to the sources of meaning in their lives that are rooted "in tradition, culture and connection to the land" (Badry & Felske, 2013c, p. 14; Di Pietro & Illes, 2016). This can include a focus on protective factors (Jorda et al., 2021).

Indigenous FASD interventions that recognize and use the strengths of communities and individuals are being developed and evaluated. In a scoping review of culturally safe, strengths-based parenting programs for FASD, Ritland et al. (2020) found several factors contributing to positive outcomes across studies, many of which echo those already noted above:

- self-determination of parents, families, and communities;
- connection to culture and traditional values;
- healing from intergenerational, historical, and lifetime trauma;
- building trust through cultural safety; and
- pregnancy as a critical period to offer substance use treatment.

Similarly, engagement participants indicated that Indigenous-led prevention efforts and programming at the community level offered with local community resources would be most appropriate.

Alberta's PCAP (Parent Child Assistance Program) is a trauma-informed and community-based approach to FASD prevention providing three years of home visitations by mentors. A qualitative, participatory evaluation in rural and remote First Nations communities (Pei, Carlson et al., 2019) concluded that the program improved clients' social and emotional well-being, positive community experiences and independence, while reducing stigmatization, isolation and stress. Impacts were also observed in the domain of addictions and mental health. The program led to some participants accessing health and addictions services, with positive family outcomes such as healthy births, regained child custody and improved parenting practices (Pei et al., 2017). An economic evaluation showed the program to be cost-effective (Thanh et al., 2015). Engagement participants in this assessment concurred that PCAP has been highly successful, but noted that its availability within and outside of Alberta as limited.

Community-specific cultural teachings

The integration of community-specific cultural teachings into FASD prevention and intervention programming is regarded as a best practice for enhancing engagement and effectiveness (Lyall et al., 2023; Espiner et al., 2022; Otter-Conroy & Sweeney, 2022; Koptie, 2013). Because Indigenous communities vary in myriad historical, cultural, geographic, and resource dimensions, their mixtures of assets, strengths, and needs will differ. Programs that systematically tailor their messaging to specific Indigenous communities can be more effective (Montag et al., 2017; McIlduff et al., 2023). Some engagement participants observed that initiatives developed in and effective for one context may not be suitable for other local conditions, and importing them without adaptation is sometimes interpreted as a lack of care and comprehension.

Our literature reviews found community and culturally specific FASD services and programming for numerous First Nations communities, and some for other Indigenous groups as well. As part of Alberta's FASD strategy, all eight Métis settlements in Alberta can access FASD diagnostic services through a specialized Service Network that incorporates the Métis way of life (Flannigan, Wrath, McFarlane et al., 2021). Hayward et al. have documented studies describing FASD interventions, in some Inuit regions (Hayward et al., 2020), and Pauktuutit Inuit Women of Canada reported on FASD prevention activities undertaken in Nunatsiavut and Nunavut (Pauktuutit Inuit Women of Canada, 2010).

Wolfson, Poole, et al. (2019) underscore the importance of culturally rooted programming, providing several examples of programs that integrate community-specific traditional knowledge about healthy practices for pregnancy; for example, emphasizing the cultural and spiritual importance of honouring kinship relations and centering prevention around the knowledge of Elders (Wolfson, Poole, et al., 2019). An example of a culturally informed program is Wilp Dim Gaymaxghl Laaxws Ahl Majagaleehl Gitxsan, which works to prevent FASD using the Gitxsanayookw (Gitxsan laws and Code of Conduct) in Hazelton, British Columbia. The program adapts the PCAP home visiting and mentoring program cited above, including a longer follow-up, and culture-driven programming including learning the Gitxsan language (documented in Wolfson, Van Bibber, et al., 2019).

The engagement sessions provided insights from those working on the ground in Indigenous communities and organizations to address FASD, which echo the research findings. Participants supported community-building and culture-promoting activities in FASD programs, including speaking with Elders and participating in land-based activities. For example, a participant indicated:

> *Connecting to culture and ceremony will naturally create a supportive environment for moms and utilizing our Elders and women who have lived experience.*

The Nogemag Lodge, a healing on the land educational program, provides students with FASD/complex neurodevelopmental disorders and significant behavioral problems an alternative setting until they can manage in the regular school environment (Eastern Door, n.d.-a). Individualized support is available for adolescents with FASD/complex neurodevelopmental disorders who are in crisis: suicidal, in trouble with the law or experiencing high levels of family adversity.

A tension in the practices of incorporating traditional knowledge into FASD programming is noted by Salmon (2007), based on a study of young Indigenous women whose life experiences included FASD. The study identified a tension between adaptation approaches, which assimilate traditional knowledge into official knowledge, and decolonizing approaches, which aim to counter the effects of colonization by encouraging revitalization and renewal of traditional cultural practices and teachings. On the topic of culturally-informed care, engagement participants stressed the importance of supporting options that recognize the diversity of spiritual beliefs including, where desired, for culture based, and land-based approaches. They also indicated that many traditional teachings were lost through colonization and their revitalization could benefit communities, perhaps as a form of upstream strengthening.

Diagnosis within an Indigenous context

Although assessment and diagnosis of FASD will be addressed in Chapter 6, it is important to mention here that Indigenous engagement participants have expressed concern about the cultural sensitivity and safety of FASD diagnostic guidelines and diagnostic process. An Australian study also identified the importance of cultural considerations with respect to the content of their diagnostic guidelines and suggested ‘alternative culturally appropriate assessment tools and clinical decision-making processes’ (Hayes et al., 2022, p. 12). Considerations for more culturally appropriate diagnostic guidelines and processes would include ensuring that: assessment tools are both culturally appropriate and rigorously grounded in distinctions-based Indigenous knowledge and practices; benefits of an FASD diagnosis are real and accessible; upstream access to equitable front-line care is improved so that Indigenous people access assessment as early as possible; and cultural norms around healthy child development are respected. Involving Indigenous Peoples in the development and design of FASD diagnostic guidelines would help to ensure the cultural sensitivity and safety of FASD diagnosis and contribute to a decolonizing methodology.

3.3.2 Holistic, integrated, wrap-around forms of prevention and intervention

Holistic approaches to FASD prevention, intervention and support have received support in the research literature (Stoner et al., 2023; Pei, Carlson et al., 2019; Rutman, 2013; Rutman et al., 2021) and can be seen as a natural extension of strengths-based approaches (Ritland et al., 2020). Consistent with Indigenous ways of relating to the overall environment, holistic approaches centre the person affected by FASD in the intervention design and delivery, understanding their situation, strengths and needs within their unique personal and social contexts. Programs can be holistic in multiple complementary ways, such as including family, caregiver and community support circles around the person; looking at a person’s entire life course; and linking multiple service constellations around each individual’s unique needs. We summarise evidence on these dimensions below.

Inclusion of family, caregivers and community

Regarding involvement of the broader family and kinship system in FASD prevention, studies of the determinants of PAE consistently find that social drinking patterns and norms among friends, families and partners before pregnancy are strongly associated with PAE (Muckle et al., 2011; Erng et al., 2023; Lyall et al, 2021; McBride & Johnson, 2016; Popova et al., 2022), suggesting that social influences are important considerations to address PAE. In prevention programming, Choate and Badry (2019) underscore the role of fathers, families and social circles. In the provision of intervention and support, McRae et al., (2019) highlight the value of including the wisdom of parents or other caregivers. However, other research suggests that family relationships in FASD may be complex, with negative elements stemming from recent and intergenerational trauma, along with the positives of unbreakable bonds and unconditional support (Allen et al., 2023; Shahram, Bottorff, Oelke, Kurtz et al., 2017).

Culturally-informed resources for men, grandmothers, aunts and other kinship caregivers may be less available than those for health professionals (Williams et al. 2018). Choate and Badry (2019) note that fathers can play a crucial role in supporting decisions to reduce or stop alcohol consumption during pregnancy, yet their involvement is often overlooked. Doyle et al. (2023), looking at Aboriginal and Torres Strait Islander communities in Australia, emphasize the insufficient inclusion of men in FASD research, prevention, screening, and diagnosis. This underscores the potential benefits of greater involvement of men in Indigenous FASD prevention efforts. An engagement participant highlighted this issue, also pointing to how current support systems are not necessarily designed to accommodate family participation. Speaking about treatment programs for individuals with alcoholism to support them during their pregnancy, the participant argued for:

> *Allowing their partners to also reside there and providing education and support to help through their pregnancy.*

Life-course approach

In a life-course approach, efforts to address FASD start from pre-conception prevention strategies and extend through every stage of life to provide support for families, caregivers, children, teens, adults, and Elders living with and affected by FASD (Lemon et al., 2022). This can include specialised supports for women who have FASD, who have been shown to be at risk for concurrent substance use, violence and trauma experiences, mental health problems, and of having a child with FASD (Rutman, 2013).

Wrap-around programs

Wrap-around programs, discussed in more detail in Chapter 5, have been shown to be effective in FASD prevention, intervention and support in Indigenous contexts. Offering multiple services in one location, including health, child welfare and addiction services, they also provide support for basic needs such as housing and food security (Rutman et al., 2020; Hubberstey et al., 2022). The Parent-Child Assistance Program (PCAP) is a wraparound program aimed at preventing future alcohol- and drug-exposed births by supporting women and birthing people who are at risk of substance use. It targets people who are pregnant, at risk of becoming pregnant, or postpartum (University of Washington School of Medicine, 2024; Gander et al., 2023; Alberta Parent-Child Assistance Program Council, n.d.). In an evaluation of PCAP in Alberta First Nations Communities, PCAP was found to be successful in respectfully and flexibly responding to women's diverse needs, interests and readiness (Pei, Carlson et al, 2019). Consistent with proposed evaluation frameworks for FASD prevention programming (Rutman et al., 2016; Hubberstey et al., 2015), the evaluation intended to assess program impacts on client outcomes, including substance use, social support, birth control, pregnancy, income source, employment status, use of mental health counseling, and use of physician healthcare; however, community-disaggregated data were not available (Pei et al., 2017). Wilp Dim Gaymaxghl Laaxws Ahl Majagaleehl Gitxsan, mentioned above, is also an example of a wraparound program; it adapts the Parent-Child Assistance Program model to include a longer follow-up and culture-driven programming (Wolfson, Van Bibber, et al., 2019).

Blending Western and Indigenous knowledge systems

Some FASD prevention, intervention and support programming integrates Indigenous and Western approaches to FASD. In some cases, programming is co-developed or co-designed by Indigenous community representatives and practitioners and non-Indigenous professionals representing national or regional health services.

For example, in Elsipogtog First Nation, New Brunswick, a comprehensive, culturally- and scientifically- informed model of multi-disciplinary FASD service delivery including primary prevention, screening, diagnosis and support is offered (Cox, 2023). This model incorporates key tenets of the 2019 FASD collaborative action statement. (Wolfson et al., 2019). It uses a life-course approach that includes prevention of the effects of PAE in young children, prevention of secondary conditions in youth, prevention of generational FASD in families, and prevention of misinformation in the community. Preliminary data showed that the estimated FASD prevalence in the community reduced by approximately 50% from pre-2006 levels to 2020 (Cox, 2023).

The Australian Fetal Alcohol Spectrum Disorder (FASD) Indigenous Framework blends Indigenous wisdom (strengths-based, healing-informed approaches grounded in holistic and integrated support) and Western wisdom (biomedicine and therapeutic models) in relation to FASD, identifying changes needed for these worldviews to coexist for the benefit of Indigenous people with FASD and their families (Hewlett et al., 2023).

Although accounts of co-design have been positive (Williams et al., 2024; Hanson & Pourier, 2016; Miller et al., 2022), increased Indigenous professional engagement (Williams et al., 2024) and assurance of decolonising power sharing (Fiske & Brown, 2008) have been called for. In the engagement sessions, participants emphasized the importance of open communication without judgement as the basis for community input, stressing that community members must feel both safe and valued in order to offer input into service delivery design.

3.3.3 Research on prevention, intervention and supports

Evidence of FASD program effectiveness for Indigenous communities in the peer-reviewed academic literature is limited. In a 2018 systematic review of English-language prevention initiatives in Indigenous communities globally, Symons et al. (2018) identified 170 FASD prevention projects targeting Indigenous populations but found only three peer-reviewed, published evaluations. This is reflected in the findings of our literature review focussing on prevention initiatives; while several articles focused on principles of prevention or described prevention initiatives, few provided controlled evaluations of the effectiveness of interventions. Our Indigenous-specific literature review identified the following peer-reviewed articles that assessed and evaluated the impact of prevention efforts in Indigenous communities, none of which were based in Canada. Examples are:

- Hanson et al. (2017) looked at the effects of an American, tribally-run intervention program called the Oglala Sioux Tribe (OST) CHOICES. The study showed a significant decrease in risk for PAE based on reduced risky drinking and increased contraceptive use. Surveys conducted 3 months after the intervention showed that risk reduction mostly came from the use of birth control (67.7%), rather than the reduction of episodic drinking (9.8%).
- Also working in the Oglala Sioux Tribe, Montag et al. (2015a; 2015b) randomized women to either an assessment or a Screening, Brief Intervention and Referral to Treatment (SBIRT) intervention. Both groups reduced risky drinking (Montag et al., 2015a; Montag et al., 2015b) but the effect of the SBIRT was greater among depressed than non-depressed women (Montag et al., 2015a).
- Symons et al. (2020) assessed the community-led Marulu FASD Prevention Strategy initiated in 2010 in remote Indigenous communities in Western Australia with promising results, finding that alcohol use was reduced significantly from 2010 to 2015, and that first-trimester use of alcohol was reduced significantly from 2008 to 2015.

However, some important gray literature on the efficacy of Indigenous-centred FASD initiatives in Canada exists. A key example is the Co-Creating Evidence project, discussed above (Rutman et al., 2021). Another strong example is Pei et al.'s 2017 evaluation of the PCAP program, also cited above (Pei et al., 2017). In Elsipogtog First Nation, 20 years after implementing a community based FASD initiative, community prevalence data indicates a significant reduction in FASD (Cox, 2023).

One of the reasons behind the dearth of published evaluations may be a lack of resources. Engagement participants identified that funding for appropriate evaluation is generally limited, despite the emphasis of the Truth and Reconciliation Commission on ensuring evaluation evidence is available to verify the extent of progress (Truth and Reconciliation Commission of Canada, 2015). Participants also noted challenges in finding researchers or evaluators able to conduct strong evaluation locally, with appropriate credentials and field skills for work on sensitive topics in Indigenous communities.

The engagement sessions identified that while information is valuable, research and evaluation can contribute to stigmatization of Indigenous people. Notably, if research is focused on communities with the largest problems and documents only deficits, there is a risk that negative findings will inevitably be generalized to all Indigenous communities. These concerns have contributed to the development of respectful, co-led protocols such as that used in the Co-Creating Evidence project, discussed above (Rutman et al., 2021).

Guidance and guidelines

Several resources are available to guide the evaluation of FASD programming, including wraparound (British Columbia Centre of Excellence for Women's Health, n.d.) and justice interventions (Bell et al., 2019). Hubberstey et al. (2015) have developed common evaluation frameworks for use in all types of FASD programming, informed by programs in Indigenous communities.

More general guidance is also available about research with Indigenous communities, in addition to counsel that can be sought from Elders and Knowledge Keepers. Hyett, Marjerisson and Gabel (2018) outline major ethical guidelines in Indigenous health research in Canada. These include:

- the Tri-Council Policy Statement's (2022) Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada;
- the First Nations OCAP (Ownership, Control, Access, and Possession) Framework (First Nations Information Governance Centre, 2020a; 2020b);
- Assembly of First Nations' (2018a) Ethics Guide on Research and Aboriginal Traditional Knowledge;
- Inuit Tapiriit Kanatami (ITK) National Inuit Research Strategy, which sets out principle of Inuit access, ownership, and control (OCA) over data and information (Inuit Tapiriit Kanatami, 2018);
- Inuit Qaujimajatuqangit statement on the role of Indigenous knowledge in supporting wellness in Inuit communities (Tagalik & National Collaborating Centre for Aboriginal Health, 2010);
- Manitoba Métis principles of OCAS (Ownership, Control, Access, and Stewardship; Martens et al., 2010; University of Manitoba, 2021).

In addition, advances have been made in developing decolonizing research methodologies that address inherent researcher–participant power imbalances and connected concerns of trust and cultural safety, enabling participants to share in-depth insights from their lived experiences and cultural knowledge on their own terms (e.g., Baskin et al., 2015; Lyall et al., 2023).

3.3.4 Access to care for rural and remote communities

The Indigenous populations in Canada live in both urban and rural/remote parts of the country, with the proportion varying by Indigenous group. Due to the location of many Indigenous communities across Canada, these populations tend to be in remote settings making access more challenging (College of Family Physicians of Canada, 2016).

The demographic characteristics and ethnocultural fabric of rural and remote communities are quite diverse. In the Northwest Territories for example, Yellowknife, which is home to nearly half the territory's residents, has a predominantly (76%) non-Indigenous population, while the majority (74%) of residents in the other 32 communities self-identify as First Nations, Inuit, or Métis (Government of the Northwest Territories Bureau of Statistics, 2024).

Access to healthcare, an issue in most rural and remote communities, is compounded for Indigenous Peoples and communities, because of the need for culturally safe, appropriate services.

Personnel availability and continuity

A key issue for access to healthcare in Northern communities is the availability of personnel. Physician availability is uneven and inequitable (Young & Chatwood, 2017), and access to allied health professionals other than nursing staff very limited. Gupta et al. (2023) found that the density of allied health professionals studied (providers of prevention, diagnostic evaluation, therapy, and rehabilitation services) is 15 times lower in rural and remote regions of Canada than in urban areas, a pattern that had been stable over the previous decade (Gupta et al., 2023). Access to sexual and reproductive health services by substance-using pregnant women is limited in suburban, rural and Northern regions in Canada, and is greater in major metropolitan areas in Western Canada (Mathias et al., 2024).

High rates of staff turnover in remote communities are a main challenge in ensuring accessibility (Young & Chatwood, 2017). The provider retention issue was also addressed by the Truth and Reconciliation Commission, whose call to Action 23ii is: "We call upon all levels of government to: ii. Ensure the retention of Aboriginal health-care providers in Aboriginal communities" (Truth and Reconciliation Commission of Canada, 2015).

Complementing this evidence is an overarching concern for FASD prevention, intervention and support expressed by engagement participants: the importance of ensuring adequate local mental health and primary care in Indigenous communities. Participants emphasized that many people in Indigenous communities have inadequate access to primary care. This impedes FASD screening, education, and supports, undermining prevention. As a participant stated:

> *Healthcare needs to be in place first for everything else to fall into place.*

Long waitlists for prenatal care and services such as speech therapy after FASD assessment coupled with lack of access to family physicians were cited as factors affecting FASD risk and outcomes in some parts of the country. A need for free addictions counselling and psychological therapy was also identified. For families, the momentum toward engaging with services that was gained through the assessment process may then be lost due to personnel shortages. Lack of intervention services post diagnosis may also impede trust in FASD assessment.

According to some engagement participants, service delivery by local practitioners is desirable:

> *I work in Indigenous communities and I believe that initiatives have to be offered right at the community level utilising local community workers.*

A concern was expressed by some engagement participants about biases held by non-Indigenous practitioners in Indigenous community work. This echoed research findings about some non-Indigenous practitioners' judgmental attitudes toward Indigenous pregnant women (Badry & Felske, 2013a, Mitchell-Forster et al., 2021). At the same time, Pei et al. (2017) found that community preferences for local workers varied, with acceptability of FASD support workers being higher in particular communities due to their own internal histories and politics. This was echoed in the engagement sessions, where it was suggested that in small communities there is sometimes a preference for culturally informed healthcare providers from outside the community as this helps to maintain privacy.

Flannigan, Wrath, McFarlane et al. (2021) have detailed some of the challenges faced by FASD practitioners working in rural and remote communities, including meeting high demand for services; balancing heavy caseloads with administrative and data collection responsibilities; engaging with medical professionals, and finding appropriate and specialized supports to meet the complex needs of their clients. To be able to create the necessary trusting relationships, northern practitioners are sometimes required to take on tasks well outside their job description, that allow them to be integrated into the communities where they are working (Pei et al., 2017).

Staff continuity is important in the FASD context because of the need to develop relationships of confidence and trust with those affected or potentially affected by FASD. An evaluation of the PCAP program in northern Alberta found that program implementation at the community's pace with a commitment to long-term presence of the mentorship program and of mentors was necessary to establish the relationships within the community that could lead to referrals, partly because of discontinuities experienced with previous programs (Pei et al., 2017).

The issue of discontinuity in healthcare was highlighted in a coroner's report on a recent inquest into the death of a Kingfisher Lake First Nation person. The report recommended that the Ontario Ministry of Health "facilitate a transition to a single electronic medical record for patients residing in remote First Nation communities (Office of the Chief Coroner, 2024). FASD is a whole body condition yet the diagnosis may not follow an individual despite the fact that it has important implications for medication and physical and mental health treatment. Engagement participants also noted the importance of ensuring continuity in FASD care, so that trusting relationships can be built over time and that information circulates appropriately among multiple providers and across federal and provincial or territorial systems.

A recent assessment on Canada's Health Workforce examined health and human resources for Indigenous Peoples and communities and that expert panel identified the following leading policies and practices (Canadian Academy of Health Sciences, 2023, p.31):

- Creating space and providing support for Indigenous leadership to design, develop, direct, deliver, and evaluate Indigenous health programs and services.
- Increasing the population of Indigenous learners and practitioners within healthcare education and clinical settings and supporting successful and fulfilling transitions to healthcare practice.
- Disrupting racism within the health workforce and health systems through Indigenous-led development of anti-racism policies, safe reporting and investigation processes, and mandatory education and training.
- Implementing Indigenous data sovereignty and research principles in relation to workforce data collection, outcome-based research, and evaluation including the development and support of the Indigenous health research workforce.

Transportation, accommodation, and communication

The need to travel long distances to access health and allied services is a major challenge all across the North, not specific to FASD. Weather and seasonal conditions, lack of transportation options and high travel costs have been found to act as barriers to appropriate care (Huot et al., 2019). Feedback from Indigenous-specific engagement sessions indicated that in more remote communities, transportation is a real barrier to accessing assessment and support services in FASD. People with FASD benefit from specialized assessments and supports, for example in occupational therapy, speech and language therapy and physiotherapy; travelling to urban centres for these is a major burden, as is the accommodation necessary while away. Engagement participants recommended that these services be made more easily available in the community, and that they be culturally appropriate:

> *Making things more accessible - these smaller communities are impossible for some people to get their needs met because of their isolation.*

Mobile clinics that travel into communities were noted as possible solutions:

> *We need a mobile diagnostic clinic for … First Nation Communities, so that they do not have to leave their community and can have the cultural connections during diagnostics. This will help to reduce the stigma. Then there need to be mobile supports, as SLP, OT, PT [speech language pathologists, occupational therapists and physiotherapists] are not available in the communities or that are culturally based.*

The problem of accessing local services is particularly acute for children. Engagement participants noted that some parents are reluctant to send their children far away from their family and support network to receive services. The urban environment may be seen as unsafe for children, and given the historical experiences with residential schools, the Sixties Scoop and more recently, with apprehension by child welfare authorities, this may re-awaken trauma within the families and communities.

Also affecting accessibility are telephone and internet services that would be required to follow up on referrals and contact specialists: in a national infrastructure assessment, less than 3% of 748 rural and remote First Nations communities had the necessary components to ensure adequate broadband service (Assembly of First Nations and Indigenous Services Canada, 2023).

3.3.5 Funding

Long-term, sustainable funding is one of the eight consensus-based tenets for enacting Call to Action 33 identified by Wolfson, Poole, et al. (2019). The effects of impactful programs such as PCAP have been shown to dissipate if funding is not maintained (Tait, 2008). Short-term funding is viewed by Indigenous communities as harmful to the individuals most in need of services, and detrimental to progress toward reconciliation (Pei et al., 2017).

Engagement participants also highlighted a need for adequate and stable operational funding, not just project funding, for holistic community-based programs of supports and services for pregnant and postpartum women as well as their families. In their view, it is only through long-term, reliable and predictable funding that the necessary service infrastructure can be built. As one participant noted.

> *There have been phenomenal programs like CAP-C/CPNP [Community Action Program for Children-Canada Prenatal Nutrition Program] and their ongoing funding is critical in providing FASD prevention efforts. However, many FASD prevention programs that exist in Canada are community-based programs that operate with project or piecemeal funding rather than operational funding. We need secure funding for these programs so that we can increase the availability and reach of prevention programs.*

Moreover, engagement participants recounted challenges related to the coordination among jurisdictions in funding of services, as well as gaps in the monitoring of outcomes and accountability for funding received.

Implementation of Jordan's Principle (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative (Indigenous Services Canada, 2024d) must ensure that First Nations children in Canada, including those with disabilities such as FASD, have equitable access to needed products, services and supports that are culturally appropriate. Funding is available for a wide range of health, social and educational needs, up to the age of 19 (Indigenous Services Canada, 2021). A recent review of the Health Child Development group of programs funded by Indigenous Services Canada noted that community-based service providers had identified Jordan's principle as an avenue to support children requiring assessments for FASD and other neurodevelopmental conditions, but that long wait times impeded access to appropriate resources (Indigenous Services Canada, 2024e).

Also raised by engagement participants was the problem of irregular or unpredictable cash flow into Indigenous communities. Participants recounted that sometimes when funding is allocated it takes months to be disbursed; when it is finally available, it must be spent too quickly, before expiry of that allocation. Timely disbursement would help stabilize FASD prevention and intervention efforts.

Key Findings:

Because Indigenous communities vary in myriad historical, cultural, geographic, and resource dimensions, their mixtures of assets, strengths, and needs will differ. Indigenous communities are best placed to determine the relevance and applicability of prevention strategies that respond to their own needs, culture, context, and objectives.

Holistic, trauma-informed, culturally-appropriate, integrated service delivery are promising approaches to reducing harms associated with alcohol and substance use for Indigenous Peoples.

Attention to the broader context and improvement of social determinants of health at the population level is important for reducing the prevalence of harmful alcohol use and FASD. This involves addressing the health and well-being of Indigenous communities and families more broadly, and not focusing solely on pregnant women.

Key Findings:

Evaluation of prevention strategies is in general limited, making it challenging to identify those that are most effective. There is some evidence to support the implementation of prevention models that are Indigenous community-led and incorporate Indigenous community knowledge of healing and well-being. Program funding that includes resources to evaluate efficacy of new strategies can build the knowledge base.

Continuity of care helps to build the relationships of trust that are crucial to addressing problems with alcohol and substance use, and to diagnosing and supporting families affected by FASD. Yet, access to culturally informed FASD healthcare services in Indigenous communities continues to be limited. This is compounded by limited access to basic healthcare services and continuity of healthcare in these communities.

The development and training of Indigenous community-based health professionals and para-professionals would build local capacity, reduce turnover and provide culturally informed FASD health services. In small communities where members are well known to each other, privacy concerns and stigma related to substance use and FASD are barriers to accessing supports, and there may therefore be a preference for building stable relationships with Indigenous healthcare providers from outside the community or with non-Indigenous healthcare providers who are culturally informed.

Stable, long-term and sustainable funding is preferable to project-based funding. This enables Indigenous communities to develop long-term strategies and to build enduring and effective infrastructure for FASD diagnosis, prevention, intervention and supports.

3.4 Child welfare system

The child welfare system continues to affect FASD prevention efforts, and is particularly important for Indigenous communities because of the impact of the colonial legacy of child removal on FASD. More recently, the movement towards Indigenous-led child welfare systems has the potential to affect the manner in which child welfare policy interacts with efforts to prevent PAE and to support those with FASD and their families. Calls one through five of the TRC Calls to Action identify the desired future directions for child welfare policy affecting Indigenous children (see figure 4). Child welfare is discussed in greater depths in Chapter 7, but this section addresses aspects specific to Indigenous Peoples.

The Supreme Court of Canada recently affirmed the constitutionality of Bill C-92 *An Act Respecting First Nations, Métis and Inuit Children Youth and Families,* which affirms Indigenous jurisdiction in relation to child and family services as part of the right to self-government, and sets up a framework for the assumption of legislative authority over child and family services by Indigenous governing bodies (Act Respecting First Nations, Inuit and Métis Children, Youth and Families, 2024). Cowessness First Nation was the first Nation to assert legislative authority over its child welfare services pursuant to Bill C-92 (Cowessess First Nation, 2024).

Figure 4: **TRC Calls to Action specific to the child welfare system**

1. We call upon the federal, provincial, territorial, and Aboriginal governments to commit to reducing the number of Aboriginal children in care by:
   i. Monitoring and assessing neglect investigations.
   ii. Providing adequate resources to enable Aboriginal communities and child-welfare organizations to keep Aboriginal families together where it is safe to do so, and to keep children in culturally appropriate environments, regardless of where they reside.
   iii. Ensuring that social workers and others who conduct child-welfare investigations are properly educated and trained about the history and impacts of residential schools.
   iv. Ensuring that social workers and others who conduct child-welfare investigations are properly educated and trained about the potential for Aboriginal communities and families to provide more appropriate solutions to family healing.
   v. Requiring that all child-welfare decision makers consider the impact of the residential school experience on children and their caregivers.

2. We call upon the federal government, in collaboration with the provinces and territories, to prepare and publish annual reports on the number of Aboriginal children (First Nations, Inuit, and Métis) who are in care, compared with non-Aboriginal children, as well as the reasons for apprehension, the total spending on preventive and care services by child-welfare agencies, and the effectiveness of various interventions.

3. We call upon all levels of government to fully implement Jordan's Principle.

4. We call upon the federal government to enact Aboriginal child-welfare legislation that establishes national standards for Aboriginal child apprehension and custody cases and includes principles that:

i. Affirm the right of Aboriginal governments to establish and maintain their own child-welfare agencies.
ii. Require all child-welfare agencies and courts to take the residential school legacy into account in their decision making.
iii. Establish, as an important priority, a requirement that placements of Aboriginal children into temporary and permanent care be culturally appropriate.

5. We call upon the federal, provincial, territorial, and Aboriginal governments to develop culturally appropriate parenting programs for Aboriginal families.

3.4.1 Impacts of the colonial legacy of child removal on FASD

In Canada, the well-documented and ongoing overrepresentation of Indigenous children in the child welfare system is a direct result of the country's colonial history and the intergenerational legacy of residential schools (Choate & Badry, 2019; Tait, 2003; Wolfson, Poole, et al., 2019) and the Sixties Scoop (Tait, 2003). This legacy's racialized and patriarchal constructions of Indigenous motherhood as abusive, neglectful and dangerous, coupled with increased surveillance due to perceived dangerousness, contribute to high rates of Indigenous child placement in the child welfare system (Salmon, 2011; Baskin et al., 2015; Allen et al., 2023).

The issue of Indigenous children in care is underscored in a 2019 retrospective cohort study by Brownell et al. (2019) which examined health, social, education, and justice outcomes for First Nations young people with FASD from Manitoba in a linked dataset containing FASD cases since 1999. The study found that although First Nations and non-First-Nations youth were equally likely to receive child welfare services, First Nations youth with FASD were significantly more likely to have been taken into the care of child welfare than their non-First Nations FASD counterparts (90% versus 75%). The 2019 First Nations/Canadian Incidence Study of Reported Child Abuse and Neglect report found that First Nations children aged 0-15 years in Canada were 3.6 times as likely to be the subject of a child maltreatment-related investigation compared to non-Indigenous children; this over-representation was driven by investigations of child neglect (Fallon et al., 2021). Disparities in the treatment of First Nations and non-Indigenous children increased at every decision point in the service continuum, with the result that 13% of Indigenous versus 4% of non-Indigenous children investigated ended up in an out-of-home placement.

Overrepresentation of Indigenous youth with FASD in child welfare is also documented in Australia (O'Leary et al., 2020), and the United States (Richards et al., 2023; Rebbe et al., 2019). A study in Alaska by Austin et al. (2020) found that contact with child protective services for children five and younger was significantly higher among Indigenous children as compared with non-Indigenous children, although maternal alcohol use was a significant determinant for both groups.

Anti-Indigenous racism, negative stereotypes of Indigenous parenthood (Salmon, 2011), and stigmatization of FASD have a direct, compounding impact on the abilities of communities to address FASD prevention, diagnosis and supportive intervention. Although practitioners may perceive themselves to be providing compassionate care without bias, Indigenous patients may experience hurt, loss, and judgement when they interact with healthcare providers during pregnancy (Mitchell-Foster et al., 2021). The threat of child apprehension, "always present to some degree for Indigenous women in colonial institutions, can prevent a mother from seeking care for herself, and can enlarge barriers to care" (p. 176). Baskin et al. (2015) showed that among pregnant Indigenous women dealing with substance use, fear of child apprehension and judgmental attitudes led to inadequate prenatal care, creating additional health risks and missed opportunities for FASD prevention. In the United States, some states legally define PAE as child maltreatment and the disclosure of alcohol use during pregnancy can be used to terminate a mother's parental rights (Richards et al., 2023). Child welfare involvement is even more stigmatizing in Northern communities because it is less well hidden (Badry & Felske 2013a, 2013b, 2013c).

3.4.2 Improvement of Indigenous child welfare intervention

Holistic and restorative child welfare interventions are recognized as crucial for more effective FASD prevention and supports (Badry & Felske 2013b). Such improvements could attempt to mitigate the impact of fear of the child welfare system, and to heal and support families affected by FASD. In Canada's northern context, Choate and Badry (2019) recommend an approach to intervention where FASD is not a "diagnosis of exclusion in parenting but one of considered management and support of the relationship between the parent and the child" (p. 45). Child welfare systems based on extended family strengths (Badry 2013b), and taking an individualized, multisectoral, lifespan approach (Badry, et al., 2018) are suggested to be most effective. In such models, maintaining and supporting the child's involvement with their family would be vital (Richards et al, 2023).

Several authors call for actions to reduce FASD practitioners' unconscious or overt racism and bias, including trauma-informed training (Richards et al., 2023; Mitchell-Foster et al., 2021) and increased cultural humility (Mitchell-Foster et al., 2021).

Grounding child welfare practices in traditional ways is also considered important by researchers in this field. Key here would be Knowledge Keepers' and Elders' teachings about treating communities holistically, supporting families as a whole, and centering the family as a unit rather than one viewing the needs of the child and mother as separate and competing (Allen et al., 2023; Baskin et al., 2015; Shahram, Bottorff, Oelke, Dahlgren et al., 2017).

3.4.3 Indigenous-led child welfare systems

Movement toward Indigenous-controlled child welfare, health, and social services in line with Indigenous People's right to self-governance is a necessary step to ensure adequate FASD prevention and supports. The Truth and Reconciliation Commission's Call to Action 4, was:

> *We call upon the federal government to enact Aboriginal child-welfare legislation that establishes national standards for Aboriginal child apprehension and custody cases and includes principles that affirm the right of Aboriginal governments to establish and maintain their own child-welfare agencies (Truth and Reconciliation Commission of Canada, 2015).*

An Act respecting First Nations, Inuit and Métis Children, Youth and Families (Justice Canada, 2019) came into force on January 1, 2020. The Act recognizes the authority of First Nations, Inuit and Métis peoples to exercise jurisdiction over child and family services, setting various principles relevant to prevention, prenatal care, decisions about apprehension and placement. It contemplates delivery of child and family services by Indigenous governing bodies over time. It is distinctions-based, stating that there is no one-size-fits-all approach, and Indigenous communities, groups and peoples can exercise jurisdiction to develop their own child and family services models, systems and laws based on Indigenous values, worldviews, languages and cultures (Government of Canada, 2022a) although some national standards will still apply (Franks, 2024). Challenged by Québec, the law was ruled constitutional by the Supreme Court of Canada (Supreme Court of Canada, 2024).

Franks (2024) discusses the implications of this law. For FASD, it means that funding of child welfare and other social services will be negotiated among governments. This has the advantage of enabling culturally appropriate and locally managed child welfare systems, which could help by providing holistic family supports rather than child removal. There is, however, a risk that funding arrangements may not be adequate to ensure that such services can actually be designed, implemented and sustained (Franks, 2024).

Key Findings:

Colonial policies, including residential schools and the forced adoption system now known as the Sixties Scoop, as well as more recent and continuing practices of apprehension of Indigenous children under child welfare legislation cast a long shadow that undermine efforts to address FASD today.

Recent changes made pursuant to the TRC calls to action, in particular the legislative recognition of the jurisdiction of Indigenous communities over child and family services and a path for them to assume legislative authority, offers an opportunity to develop approaches that better support effective responses to PAE and FASD.

3.5 Criminal justice system

Indigenous people are overrepresented in Canada’s criminal justice system, as are Indigenous people with FASD (Brownell et al., 2019; McLachlan et al., 2019.; Hughes et al., 2016). While contributing factors and interventions to address the intersection of FASD and the justice system will be more fully discussed in Chapter 7, some unique elements for Indigenous Peoples with FASD are addressed here.

3.5.1 Impacts of the colonial legacy on criminalization of people with FASD

This over-representation is also true in other countries (Flannigan, Pei et al., 2018; Sessa et al, 2022; O’Leary et al., 2020). This intersection of Indigenous populations, FASD, and the criminal justice system is recognized to flow from the colonial legacy (Blagg et al., 2017; Bush, 2017; Dickson & Stewart, 2022; Mullally et al., 2023; Stewart et al., 2017). These authors argue that in this context, an adequate response would not only address the needs of people and families affected by FASD who are at risk for involvement in the criminal justice system or are already involved, but also address reconciliation and decolonization more broadly.

All four components of the Truth and Reconciliation Commission’s Call for Action 34 (2015) are key for this assessment:

> We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:
>
> i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.

ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.
iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.

Call to Action 30 addresses the issue of overrepresentation of Indigenous Peoples - with or without FASD - in Canadian jails and prisons:

> We call upon federal, provincial, and territorial governments to commit to eliminating the overrepresentation of Aboriginal people in custody over the next decade, and to issue detailed annual reports that monitor and evaluate progress in doing so.

However, this overrepresentation continues and in 2020, the Office of the Correctional Investigator called the Indigenization of Canada's prison population a national travesty, noting that Indigenous overrepresentation had continued to increase since the Truth and Reconciliation report (Office of the Correctional Investigator, 2020).

3.5.2 Preventing involvement of youth with FASD in the criminal justice system

Community supports to protect against criminal justice involvement

In Canada as elsewhere, a disproportionately large group of youth offenders were under child protection as children. These "crossover children" face significant challenges and risks, and calls have been made for initiatives to prevent or divert them from justice system involvement (Bala et al., 2013; Baidawi & Sheehan, 2019). Engagement participants viewed the criminal justice involvement of youth with FASD as a failure of social systems, at the end of a long series of missed opportunities to intervene and support people with FASD and their families.

There appears to be little literature specific to preventing Indigenous youth with FASD from becoming caught up in the justice system (Flannigan, Pei et al., 2018). Chapter 7 explores protective factors that are relevant for all youth.

3.5.3 Access to diagnosis for Indigenous people in the criminal justice system

In an effort to address the overrepresentation of Indigenous Peoples in the criminal justice system, the federal government modified the Criminal Code's sentencing provisions to direct courts to consider whether non-carceral sentences are appropriate for all offenders, paying particular attention to the circumstances of Aboriginal offenders (Government of Canada, 2024e). As a result of the Supreme Court rulings interpreting this provision in *R. v. Gladue*

[1999] and *R. v. Ipeelee* [2012], the use of specialized pre-sentence reports - known as Gladue reports - have arisen to ensure sentencing judges consider the unique background and circumstances of the people before them (Dickson & Stewart, 2022). However, there appears to be inconsistency across Canada in the extent to which full reports are used, as opposed to attempting to convey the information in other ways, such as oral submissions (Dickson & Stewart, 2022).

FASD poses a challenge at sentencing because courts interpret it as a disability that can reduce moral blameworthiness, but it is also seen as an exacerbating factor because it is viewed as an untreatable problem leading to lack of self-control and therefore ongoing risk to the public (Dickson & Stewart, 2022). For this reason, defense lawyers may avoid raising FASD to avoid this “double-edged sword” in some types of cases (Johansen-Hill, 2019).

In some jurisdictions, Gladue practice involves an FASD assessment and diagnosis being carried out and submitted to the court at the time of sentencing Indigenous offenders. In other jurisdictions, FASD diagnosis is not available as there may be limited capacity to gather background information. Diagnosis for Indigenous accused early in the court process would allow for accommodations to be made for their FASD disability, increasing understanding of the court process, their rights, and the terms or conditions of their release.

Criticisms of the enactment of the Gladue principles are found in the literature. Dickson and Stewart (2022) argue that the intentions of the Gladue ruling are being “fundamentally undermined” in the courts through carceral risk models built around non-Indigenous views of risk, rights and deservedness, to the detriment of Indigenous Peoples (p. 15). Milward (2014) reiterates that the principles in Gladue “demand a more ameliorative approach with a search for non-carceral options” (p. 1035). Engagement participants expressed concern that facilitating assessment and diagnosis only for Indigenous people may fuel the impression that FASD is an Indigenous issue and further skew prevalence data. Moreover, given the continuing overrepresentation of Indigenous people in prisons, it is not clear to them whether application of the Gladue principle has in fact mitigated incarceration.

3.5.4 Alternatives to carceral sentencing

The Truth and Reconciliation Commission’s Call to Action 31 (2015) is:

> We call upon the federal, provincial, and territorial governments to provide sufficient and stable funding to implement and evaluate community sanctions that will provide realistic alternatives to imprisonment for Aboriginal offenders and respond to the underlying causes of offending.

Diversion of offenders with FASD into community owned and managed structures and processes has been examined in the research literature. Milward (2014) underscores the need to de-emphasize deterrence and retribution as sentencing objectives, which may not be as operative for people with FASD, and move towards needs-based sentencing. This author provides arguments and evidence that non-custodial sentences that provide improved guidance and structure in an FASD accused's living situation, and include elements of Indigenous culture and spirituality, are effective in reducing risk of re-offending. In Australia, Blagg & Tulich (2018) and Blagg et al. (2015) proposed reform of police diversionary mechanisms and the creation of mobile "needs focused" courts, offering comprehensive screening and rapid entry into land-based programs with strong Indigenous community involvement. As alternatives to carceral sentencing, engagement participants favoured providing and supporting Elder informed, on-the-land healing for youth with FASD.

Engagement participants noted that community diversion may be especially important for Indigenous people with FASD, because while in prison they may be at risk for exploitation, abuse, and gang recruitment. Engagement participants also noted that some Indigenous people with FASD may be doing relatively well in prison, and noted that it would thus be important to ensure that such alternative programs provide at least the same level of stability and support as offered by imprisonment.

As is called for by the Truth and Reconciliation Commission, appropriate strategies are needed to ensure that alternative sentencing programs are indeed effective. Bell et al. (2019) outline strategies and resources for such evaluation.

3.5.5 Supports for rehabilitation and reintegration

A second important period of transition is that between incarceration and community living. Ensuring rehabilitation of offenders with FASD and their reintegration into the community requires knowledgeable service providers and established pathways of referral to FASD-specific and culturally appropriate services (Pedruzzi et al., 2021). Indigenous justice-involved adults have diverse needs sometimes driven by neurodevelopmental difficulties, many physical and mental health challenges, complex experiences of psychosocial trauma, and varied criminogenic needs (Flannigan, Tremblay et al., 2022). Successful transition can be aided by programming such as that provided by Central Alberta's In-Reach Support, which provides individuals with FASD education, assessment and diagnosis, along with necessary support services, in order to ensure a successful transition back into the community upon release (Central Alberta FASD Network, n.d.-a)

In a study of an FASD-informed Indigenous restorative justice program, Flannigan, Rollans et al. (2023) indicated that blending FASD diagnostic and clinical services with a restorative justice program helped participants meet basic needs and facilitated their access to essential supports, including medical, mental health and substance use services. Better access to community supports increased self-insight, knowledge of FASD and helped participants develop new skills and strategies and future orientation (Flannigan, Rollans et al., 2023).

Engagement participants also emphasized the need for supports for rehabilitation and community reintegration of people with FASD exiting correctional systems, who will be at risk of stigmatization, marginalization and isolation, ensuring that they can be set up for success. They noted that failure to provide supports results in people with FASD having to face continued struggles, with a risk of re-incarceration often present, and that supports for transitions from the correctional system are lacking in some provinces. There was also a suggestion from some engagement participants that prison can in fact provide the types of supports enumerated above - assured meals, stable shelter, routine and structure, social connection and sobriety — and thus that some people with FASD will do relatively well there. As one participant stated:

> *We hear of some people with FASD seeing jail as the only way they are assured of a place to live and food. We need better ways of ensuring they have the necessities of life.*

Key Findings:

Indigenous people, including Indigenous people with FASD, are overrepresented in Canada's criminal justice system. In addition to continuing to increase the general awareness in all parts of the criminal justice system of the impacts of the colonial legacy on Indigenous Peoples and the impact of FASD, a deeper understanding of how FASD may affect over-represented groups and persons with unrecognized neurodevelopmental disabilities and adverse social determinants of health would further improve the judicial process and correctional responses.

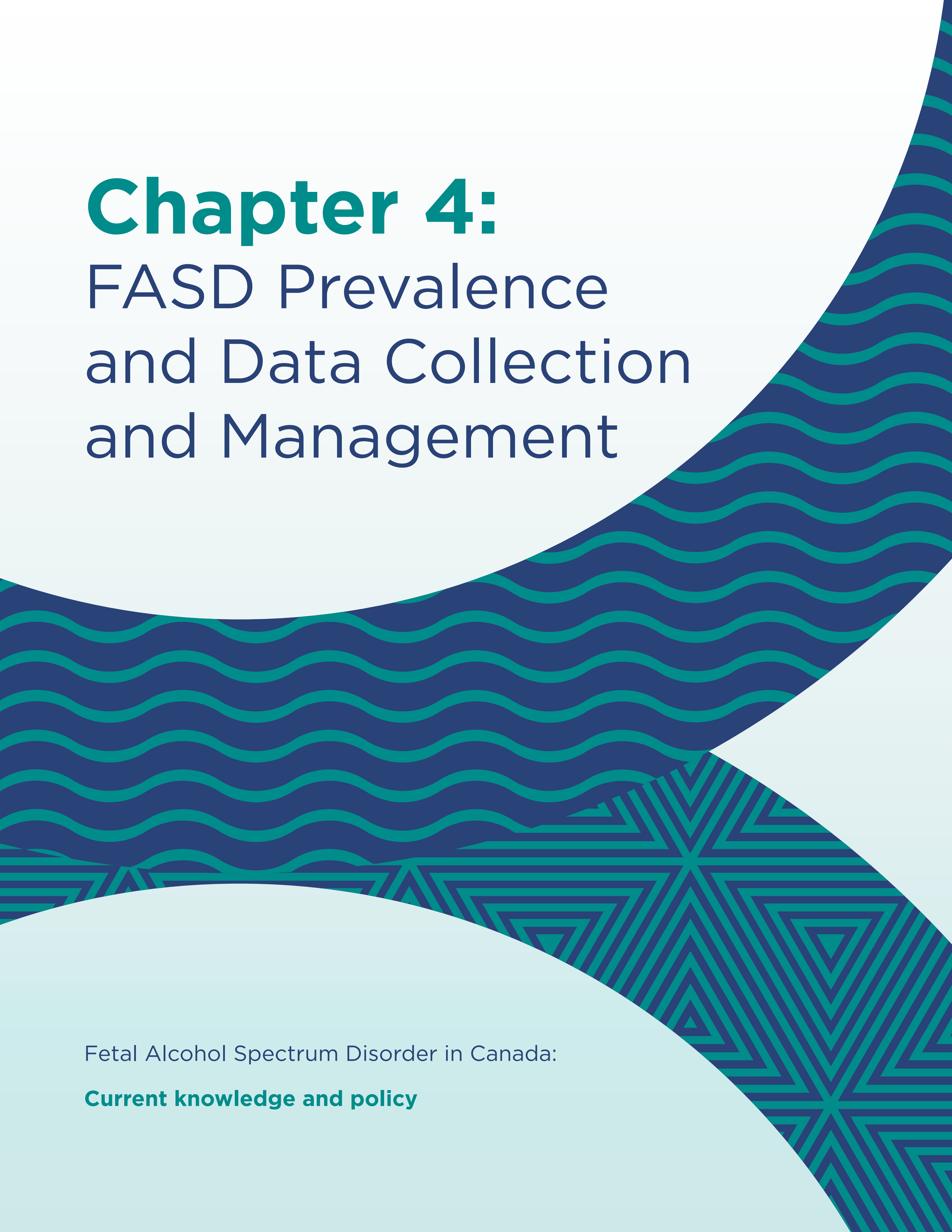
Supporting people with FASD can help to avoid involvement with the criminal justice system and reduce recidivism. Supports include early interventions, which depend upon access to FASD health services in the community for early screening and diagnosis, and family based services. Other supports are substance use disorder treatment, positive and engaging activities, social connections and mentorship, pathways to success through school and employment, and connections to culture, traditional values and land-based healing.

Key Findings:

It is important to develop and properly fund structures for non-carceral support and supervision that work for the diverse populations who are overrepresented in the justice system, including Indigenous Peoples.

3.6 Conclusion

The harms of past and present colonial patterns are significant ongoing contributors to the challenges of FASD and its consequences for Indigenous individuals, communities and Peoples. Access to accurate information, collected in a culturally safe way and controlled by Indigenous communities will enable them to make informed decisions on FASD policy and service delivery in their communities, and to advance Indigenous-led, sustainable, long-term structures to respond to FASD. It is also important that culturally appropriate and distinctions-based prevention, interventions and supports founded in holistic, trauma-informed practice are designed and implemented taking into consideration social and Indigenous determinants of the outcomes they address. Policies at all levels of government can contribute to redressing the harms of colonialism and racism, building positive interactions with health, education, social services and justice systems. A distinctions based approach that acknowledges the diversity among Indigenous Peoples and communities, and which is founded on relationships of trust and implements the Indigenous ways of knowing, doing, and being is a pathway forward.



Chapter 4:

FASD Prevalence and Data Collection and Management

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

4.1 Introduction

One of the questions that the Canadian Academy of Health Sciences (CAHS) was asked to examine in this assessment is: *What are the clinical/community and federal/provincial/territorial challenges associated with case identification and data collection in Canada?*

Because of the complexity, intersectionality and sensitivity of FASD and the multi-sectoral and multi-jurisdictional nature of the support and services involved, as mentioned in Chapter 1, the nature and governance of the systems that collect, store, analyze, share and report on all these types of data are also important considerations. This was evident in Chapter 3, which captured some of the unique considerations of relevance to Indigenous communities.

This chapter focuses on prevalence data. Collecting data that addresses the impact of FASD and of interventions is also important, and other forms of data and gaps in knowledge are discussed in subsequent chapters. Chapter 6 further examines challenges associated with case identification as they relate to the assessment and diagnosis of FASD, and Chapter 7, the need for robust data on the effectiveness of supportive and preventive interventions.

After discussing the importance of prevalence data, the chapter provides recent prevalence estimates for FASD (see Chapter 1, Section 1.3 and Chapter 6, Section 6.2 for definitions) and PAE, worldwide, in Canada, and in some subpopulations. It then details the various challenges and limitations of existing FASD prevalence data. Existing data collection and management systems in Canada are critically reviewed. The chapter closes with potential improvements for strengthening FASD prevalence data and systems.

4.2 Importance of prevalence data

Comprehensive, accurate and unbiased data on FASD prevalence are necessary to identify risk factors and enable effective prevention, early detection, diagnosis, and intervention to mitigate short- and long-term effects (Lange, Probst, Gmel, et al., 2017, Popova, Lange, Poznyak et al., 2019). Prevalence data are also crucial for understanding the scope and impacts of FASD within populations, and informing policy-makers about its economic and social consequences and necessary investments (Popova, Lange, Shield et al., 2019; Popova, Lange, Probst, Gmel et al., 2017). In other words, the failure to adequately document prevalence, and in particular underestimation due to non-diagnosis and misdiagnosis, likely reduces the focus of policymakers and the public that might otherwise be directed to this public health issue and the needs of people with FASD.

Key Findings:

Accurate and comprehensive prevalence data on FASD informs decision-making and evaluation of the effectiveness of public health policy, resource allocation and interventions to prevent PAE and to support people with FASD and their families.

4.3 Prevalence estimates

Prevalence estimates vary across studies due to different data sources, collection methods, case identification criteria, and populations (Roozen et al., 2016; Popova, Lange, Poznyak et al., 2019; Lange, Probst, Gmel, et al., 2017; Cook et at., 2021). Challenges associated with case identification and data collection systems are described in the subsequent sections of this chapter.

Many researchers conclude that the prevalence of FASD worldwide (May et al., 2021) and in Canada is substantially underestimated (Marquis et al., 2018; McLachlan et al., 2019; Palmeter et al., 2021; Popova, Lange, Poznyak et al., 2019). Popova et al. (2024) estimated that in Canada, the vast majority of individuals with FASD are undiagnosed or misdiagnosed.

4.3.1 FASD prevalence

General population

Estimates of FASD prevalence vary widely across and within countries and subpopulations. Table 3 below summarizes recent estimates of FASD in the general population.

Table 3: Selected prevalence estimates of FASD in the general population

Method	Setting	Estimate
Pooled prevalence estimates from meta-analysis of 24 studies that used ACA[8] or clinic-based methods. For countries with 1 or no empirical study, the prevalence of FASD was estimated by using country-specific data on the prevalence of alcohol use during pregnancy (obtained from Popova Lange, Probst, Gmel et al., 2017).	Global: children and youth	7.7 per 1,000 (95% CI, 4.9-11.7 per 1,000 population; Lange, Probst, Gmel, et al., 2017)

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[8] Active case ascertainment (ACA) is a robust epidemiological method that actively seeks cases for assessment and diagnosis within a population, rather than, for example, relying upon passive surveillance (PS) methods which use data that is already available such as birth registries. This is further discussed later in this chapter.

Method	Setting	Estimate
Meta-regression of 13 studies that used ACA, clinical diagnosis, or passive surveillance (PS)	Global	22.8 per 1,000 (95% CI, 0-176.8 per 1,000 population; Roozen et al., 2016)
Meta-regression of studies that used ACA, clinical diagnosis or PS: 2 studies	Canada	30.5 per 1,000 (95% CI, 23.1 - 38.0 per 1,000 population; Roozen et al., 2016)
Provincial health database for FAS ICD codes, with attributable fractions of FASD-related conditions based on systematic review	Alberta	11.7 per 1,000 population (95% CI, 8.2-15.1 per 1,000 population; Thanh et al., 2014)
National survey, completed by person most knowledgeable	Canadian Health Survey of Children and Youth	1 per 1,000 (95% CI, 1-2 per 1,000 population[9]; Palmeter et al., 2021)
Teacher completed survey, Canadian Children's Health in Context Study	Kindergarten aged children in Canada	1 to 3.1 per 1,000 (Pei, Reid-Westoby et al., 2021)
ACA with PAE recall	Population-based study of elementary school students in Greater Toronto Area	18.1 per 1,000 to 29.3 per 1,000 (Popova, Lange, Poznyak et al., 2019)

In large meta-analytic studies, the global prevalence of FASD was estimated to be 7.7 per 1,000 population (95% CI, 4.9-11.7 per 1,000 population) (Lange, Probst, Gmel, et al., 2017) and the global prevalence of Fetal Alcohol Syndrome (FAS[10]) was estimated to be 14.6 per 10,000 people (95% CI 9.4–23.3; Popova, Lange, Probst, Gmel et al., 2017). The pooled prevalence of FASD was estimated via random-effects meta-analyses for each country with 2 or more existing studies on the prevalence of FASD. For countries with one or no empirical study, the prevalence of FASD was estimated by using country-specific data on the prevalence of alcohol use during pregnancy (for the detailed description of the methodology see Supplementary Appendix in Popova, Lange, Probst, Gmel et al., 2017).

The estimated prevalence of FASD varies significantly among regions and countries. The above-mentioned meta-analysis by Lange, Probst, Gmel et al. (2017) found the WHO European

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[9] The authors note that there was high sampling variability (coefficient of variation between 15.0% and 25.0%)

[10] Fetal Alcohol Syndrome (FAS), which is considered at the more severe end of the spectrum, is no longer a diagnostic term in Canada (see Chapter 1); however, this term continues to be used in other countries and in the literature, so we have used it where appropriate.

Region to have the highest prevalence (19.8 per 1,000 population; 95% CI, 14.1-28.0 per 1000 population) and the WHO Eastern Mediterranean Region the lowest (0.1 per 1,000 population; 95% CI, 0.1-0.5 per 1000 population). The authors note that the low rate in the Eastern Mediterranean is not surprising given cultural and religious factors leading to high rates of abstention from alcohol. Given Canada's multicultural make-up, these factors may also lead to significant variation within the Canadian population.

Another meta-analytic study reported global FASD prevalence to be 22.8 per 1,000 population (95% CI, 0-176.8 per 1,000; Roozen et al., 2016).

In Canada, the prevalence of FASD varies depending on the population studied and the methods used. One outdated study estimated FASD prevalence in the general population at 5.26 per 1,000 (Asante and Nelms-Matzke, 1985). Another pooled FASD prevalence for the general population was estimated at 30.5 per 1,000 based on two studies using passive surveillance (Roozen et al., 2016).

Prevalence rates of FASD reported among studies of Canadian children in the general population are also available. Using data from the Canadian Health Survey of Children and Youth, the prevalence of FASD was estimated to be 1 per 1,000 (Palmeter et al., 2021). A Canadian study, supported by PHAC, using an active case ascertainment method that was developed under the auspices of the WHO and National Institute on Alcohol Abuse and Alcoholism (NIAAA) and considered more reliable, estimated the population-based FASD prevalence among elementary school students (aged 7 to 9 years) to range between 18.1 per 1,000 (1.8%) to 29.3 per 1,000 (2.9%), although this estimate is applicable mostly to the general population of large urban areas of Canada (Popova, Lange, Poznyak et al., 2019; Popova et al., 2018).

Within Canada, in the meta-analysis (Popova, Lange, Probst, Parunashvili et al., 2017) the FAS prevalence was estimated to be 1.1 per 1,000 (based on two outdated studies Asante and Nelms-Matzke, 1985 and Habbick et al., 1996). A study using 10 years of birth registry data in British Columbia found an FAS prevalence of 1 to 1.8 per 1,000 (Marquis et al., 2018).

Subpopulations

Population-based prevalence studies in the general population have found that FASD occurs throughout society, regardless of socioeconomic status, educational attainment, or ethnicity (Popova, Lange, Poznyak et al., 2019). However, there are higher prevalence rates in several subpopulations, reflecting concentrations of risk factors and unfavorable conditions in these population subgroups. Engagement participants expressed concern that the characteristic labels taken to define these subgroups can obscure variation within the subgroup and the characteristics themselves can be mistakenly seen as causal factors. For example, as discussed in Chapter 3, the epidemiological label “Indigenous” is a general term that obscures significant differences between and among First Nations, Inuit and Métis communities. Generalized conclusions about the prevalence of FASD for all Indigenous Peoples that are drawn from small and skewed samples contribute to harmful stereotyping.

Keeping these issues in mind, Table 4 below presents some recent FASD prevalence data for Canadian subpopulations, all of which have been found to have a higher prevalence compared to the general population.

Table 4: Selected prevalence estimates of FASD in subpopulations

FASD Prevalence: International and Canadian subpopulations		
Subpopulation	**Setting and Method**	**Estimate**
Corrections -involved populations	Youth justice systems in Canada: synthesis, 4 studies	109 - 210 per 1,000 (Hughes et al., 2016)
	Correctional population in Canada - adult (meta-analysis of 2 studies)	146.7 per 1,000 population (95% CI, 98.2-204.9 per 1,000 population; Popova, Lange, Shield et al., 2019)
	Northern Canadian correctional population (British Columbia, active ascertainment)	175 per 1,000 (95% CI, 92-258; McLachlan et al., 2019) Note: These authors estimate that this rate would have been 312 per 1,000 if PAE could have been confirmed
	Forensic Mental Health Hospital Patients (Saskatchewan, assessed at discharge)	460 per 1,000 (12 out of 26 patients assessed; Mela et al., 2022)
Children in care of child welfare authorities (orphanage, foster care, child welfare system)	Meta-analysis of active case ascertainment studies (n = 33; several countries)	169 per 1,000 (95% CI, 109 - 238 per 1000 population; Lange et al., 2013)
Children in child welfare system or permanent wards	Canada (four studies)	Range 32.6 to 241.4 per 1,000 (Popova, Lange, Shield, et al., 2019)
Indigenous population	Canada (meta-analysis, three studies)	86.8 per 1,000 (95% CI, 0 - 198.7 per 1,000 population; Popova, Lange, Probst, Parunashvii, et al., 2017)

FASD Prevalence: International and Canadian subpopulations		
Subpopulation	**Setting and Method**	**Estimate**
Indigenous population	Canada (meta-analysis, three studies)	43.6 per 1,000 (95% CI, 37.9 - 49.3 per 1,000 population; Popova, Lange, Shield et al., 2019)
Indigenous children and youth living off reserve	Canadian Health Survey of Children and Youth (completed by the person most knowledgeable)	12 per 1,000 (95% CI, 4-19 per 1,000 population ; Palmeter et al., 2021)
First Nations Children	First Nations Regional Health Survey (cross-sectional surveys, respondent reports of clinical diagnoses)	18 per 1,000 in 2002-2003 (95% CI not available) and 5 per 1000 in 2015-2016 (95% CI 3-8 per 1000 ; First Nations Information Governance Centre, 2018)

Based on a meta-analysis of studies from multiple countries, the estimated prevalence of FASD in these specific subpopulations is between 10 and 40 times higher compared to the general population prevalence (Popova, Lange, Shield, et al., 2019). These higher prevalences can be associated with historical and ongoing social determinants of health, including poverty, limited access to healthcare, and the intergenerational trauma of colonialism (Di Pietro & Illes, 2014) and over-surveillance and stigmatization of specific groups, notably Indigenous women (Aspler et al., 2019; Di Pietro & Illes, 2014). There are also multiple intersections among the subpopulations: overrepresentation of Indigenous children in care of child welfare authorities (Choate & Badry, 2019); higher rates of justice-involved individuals who were both Indigenous and involved in the child welfare system (Brownell et al., 2019). It is also important to note that the biases that result in over and under-diagnosis in specific subpopulations, discussed below, will affect the accuracy of the rates.

4.3.2 Prenatal alcohol exposure

Clinical evidence has failed to establish a threshold of safe alcohol consumption in pregnancy (Mugglie et al., 2024; Bandoli et al. 2023; Long and Lebel, 2022), and so it is recommended that all women be counselled that the safest option is to abstain completely from alcohol throughout their pregnancy (Graves et al., 2020). The harm from PAE is affected by the dose, pattern, timing, and duration of exposure, fetal and maternal genetics, maternal nutrition, concurrent substance use, and epigenetic responses (Popova, 2023). A pattern of heavy episodic consumption (4 or 5 drinks consumed on a single occasion) is the most harmful to the development of the fetal brain and other systems (Maier & West, 2001). However, low levels of consumption may also harm the developing fetus (Long & Lebel, 2022).

Although much about the complex interplay of causal factors in FASD remains to be elucidated, it is clear that "FASD is a relatively prevalent alcohol-related disorder that greatly increases the risk of long-term adversity" (Popova, Lange, Shield, et al., 2019). Prevalence data on PAE are, therefore, a valuable supplementary way to estimate the rate of FASD in a population (see Table 5).

Table 5: Selected prevalence estimates of prenatal alcohol exposure

Issue	Setting and Method	Estimate
Alcohol use (any amount) during pregnancy	Global (meta-analysis, 62 studies)	9.8% (95% CI 8.9-11.1) of pregnant women (Popova, Lange, Probst, Gmel et al., 2017)
Alcohol use (any amount) during pregnancy	Canada (meta- analysis, Canada, 14 studies)	10% (95% CI 5.2-16.2) of pregnant women (Popova, Lange, Probst, Parunashvili, et al., 2017)
Heavy episodic consumption (4 or more standard drinks on a single occasion)	Canada (meta- analysis, Canada, 14 studies)	3.3% (95% CI 2.6-4.2) of pregnant women (out of 10%; Popova, Lange, Probst, Parunashvili et al., 2017)
Alcohol use (any amount) during pregnancy	Canadian Community Health Survey (self reported)	2.2% (95% CI 1.3-3.0) of pregnant women (Public Health Agency of Canada, 2024a)
Second & third trimester alcohol exposure registered in meconium samples	10 Canadian obstetric units	1.16% to 2.40% of births (Delano et al., 2019)

The 9.8% global prevalence of PAE varies considerably across different regions and countries (Popova, Lange, Probst, Gmel et al., 2017), reflecting cultural differences, socioeconomic factors, and public health policies related to alcohol use and maternal health. High-income countries tend to report higher rates of alcohol consumption during pregnancy, likely due to differing social norms and alcohol accessibility (Lange, Probst, Rehm, et al., 2017). Variation in PAE underscores the importance of understanding regional and cultural contexts in interpreting prevalence data.

Globally, it is estimated that one in every 67 pregnancies during which alcohol is consumed will produce a child born with FAS (Popova, Lange, Probst, Gmel et al., 2017), and one in 13 with FASD (Popova, Charness et al., 2023).

In Canada, estimates of the prevalence of prenatal alcohol consumption at any level varies from 2.2%, based on self reported Community Health Survey data from 2022 (Public Health Agency of Canada, 2024a) to 10%, based on a meta-analysis of 14 studies, with the oldest dating back to 1982 (Popova, Lange, Probst, Parunashvili et al., 2017). This meta-analysis further estimated that during pregnancy 3.3% of women (out of 10%) consumed four or more standard drinks on a single occasion (heavy episodic consumption or "binge drinking"; Popova, Lange, Probst, Parunashvili et al., 2017). A study using meconium samples, which capture alcohol use in the last two trimesters of pregnancy, found PAE (defined as more than two standard drinks per week) in 1.16 to 2.40% of births (Delano et al., 2019).

As noted above, a pattern of heavy episodic consumption is known to be associated with an elevated risk of FASD, and this pattern is more common in populations who have experienced trauma, including some Indigenous populations, which may in part explain the elevated levels of FASD in these populations as compared to the general population (First Nations Information Governance Centre, 2018). The intergenerational effects were apparent in the First Nations Information Governance Centre survey (2018) which found that First Nations youth with a parent or grandparent that attended residential schools were at greater risk for heavy episodic drinking compared to those not affected. The pooled prevalence of heavy episodic drinking during pregnancy in some Indigenous populations, based on two studies from Northern Canada in the 1980s and 1990s, was 22.1% (95% CI: 0.0-52.9; Popova, Lange, Probst, Parunashvili, et al., 2017).

Key Findings:

The estimated prevalence of FASD in the Canadian general population is affected by the method used, which may include surveys, passive surveillance and active case ascertainment. It is believed that Canadian estimates generally underestimate prevalence. Active case ascertainment is the most robust and accurate way to estimate prevalence, but it is resource-intensive and so is applied to studies of small sub-populations, which are not necessarily representative of the general population. A Canadian study using active case ascertainment estimated FASD prevalence in an urban population of children to be between about 1.8 and 2.9%.

Estimated prevalence of FASD in specific subpopulations in Canada is up to 16 times higher than the general population. These higher rates are associated with historical and ongoing social determinants of health, including poverty, nutrition, limited access to healthcare, current and intergenerational trauma, colonialism. It is possible that a bias toward FASD referral and diagnosis may contribute to the higher apparent prevalence rates for certain groups.

Key Findings:

Prevalence data on PAE are important for understanding the scope and pattern of alcohol consumption in pregnancy, a direct cause of FASD, as well as for developing policies to prevent PAE and to mitigate its harms. And yet, there is limited rigorous data with estimates of the prevalence of prenatal alcohol consumption at any level in the general population varying from 2.2%, based on recent self-reported Community Health Survey data to 10%, based on a meta-analysis that examined data from a number of earlier prevalence research studies. This meta-analysis further estimated that 3.3% of pregnant women (out of 10%) in the general population had a heavy episodic consumption of alcohol (four or more standard drinks on a single occasion), with higher rates in some groups.

4.4 Challenges associated with case identification

This section briefly examines the multiple challenges and limitations of case identification as they affect prevalence data, including the ways in which these intersect.

4.4.1 Impediments to accessing assessment and diagnosis

Challenges and impediments to diagnosing FASD contribute to an underestimation in prevalence data. Assessment and diagnosis issues are treated in depth in Chapter 6; but one of the impediments to accessing assessment and diagnosis is a lack of available services. Even if FASD diagnostic services are accessible, families may not pursue diagnosis due to potential social harm, stigma, and lack of perceived benefits. Lack of access to primary care in many regions reduces opportunities for prenatal alcohol screening, identification of potential cases and referrals for assessment.

Limited and uneven access to assessment and diagnosis across the country means that data on diagnosed cases of FASD under-represents actual prevalence, especially in some provinces (Popova et al., 2024) and rural and remote areas. In the survey of clinical diagnostic capacity reported by Popova and colleagues (2024; see also Dugas et al., 2022), the waiting time for assessments ranged from one month to 4.5 years. Further issues related to diagnostic capacity are examined in Chapter 6.

4.4.2 Lack of FASD understanding or confidence in diagnosing FASD

Healthcare providers may fail to correctly identify possible FASD cases due to the complexity of its presentation and the overlap of its symptoms with other neurodevelopmental disorders (Weyrauch et al., 2017). This challenge is compounded by the requirement for confirmation of PAE. This evidence is more easily obtained within established relationships of trust that providers may not have the time nor the skills to develop. As a result, some healthcare providers may hesitate to pursue a diagnosis, may point families toward other diagnoses, or may incorrectly diagnose FASD as another condition that offers more readily accessible supports (Popova et al., 2024). These impediments contribute to an underestimation of prevalence of FASD.

4.4.3 Inaccessibility, unreliability of information about prenatal alcohol exposure

Contributing to the impediments to diagnosis is that evidence of PAE can be difficult to obtain. There are two main modes of screening for PAE: by clinical interview and through analysis of biomarkers of the newborn or the mother.

Screening for PAE by clinical interview refers to service providers routinely querying pregnant women about their consumption of alcohol. If these data are systematically recorded in the child or pregnant woman's health record, they can contribute to prevalence estimates. However, there are questions about how effective screening is given patients' reluctance to disclose alcohol consumption during pregnancy. Delano et al. (2019) found that the rate of self-reported heavy drinking in their study (0.24%) was ten times less than revealed by the meconium analysis (2.4%).

In addition to this, healthcare providers' screening for PAE may be ineffective due to a lack of healthcare provider comfort, training and time to ask questions in a non-threatening and non-stigmatizing way (Graves et al., 2020). During the engagement we heard that blame and stigma associated with alcohol consumption during pregnancy, as well as fear of child apprehension in some cases, reduce patients' willingness to disclose prenatal alcohol use. Proposals suggesting mandatory inclusion of PAE in a child's birth record as a way to ensure access to this important information may run up against reluctance to disclose this information.

Engagement participants underscored that tracking down PAE evidence can be time-consuming, taking away time from service provision. Engagement participants noted that access to PAE data may be particularly challenging for adults whose relatives cannot attest to observing PAE, or adopted children whose adoption records may not contain this information.

4.4.4 Limitations of biomarker screening

Use of biomarkers such as hair, blood or meconium samples to screen for PAE and hence FASD risk is emerging. In this mode, biological samples or measurements are taken from the newborn, the mother, or both, to detect the consumption of alcohol during pregnancy. Biomarkers of alcohol consumption can be found in the blood and tissues of mothers and newborns (Franceschetto et al., 2022); in the meconium of newborns (Delano et al., 2019);

and in baby teeth (Montag et al., 2022: proof of concept). Biomarker screening can be done for two purposes: a) for case-finding of infants to be referred for assessment or of mothers to be referred for intervention (to be discussed as part of assessment and diagnosis in Chapter 6); or b) anonymously, to measure population prevalence of FASD, as discussed in the current chapter.

Currently, however, no biomarker with acceptable sensitivity, specificity, and overall accuracy exists (Popova, Charness et al., 2023; Kable & Jones, 2023). Meconium tests, for example, detect PAE only during the second and third trimester of pregnancy because meconium is not yet formed during the first trimester, therefore, it does not reflect first trimester maternal alcohol use.

Biomarkers also present ethical concerns. Arkell and Lee (2022) argue that such screening is not ethically justified. The complex ethical issues engendered by screening though biomarkers will require patient-centred reflection, including the possible targeting of populations for PAE screening, consent, participation rates, stigma, consequences of false-positive and false-negative results, appropriate follow-up of positive results, confidentiality and the divulgation of results for legal purposes (Zizzo et al., 2013).

4.4.5 Inconsistent application of the Diagnostic Guideline

As discussed in Chapter 6 (Assessment and Diagnosis), the Canadian diagnostic guidelines have existed since 2005 (Chudley et al., 2005), and were most recently updated in 2016 (Cook et al., 2016). A survey of diagnostic clinics serving children and adolescents found that although the majority appeared to follow the Guideline, there was some variability in the requirement of PAE evidence for being accepted for FASD assessment (Dugas et al., 2022). This was echoed in the engagement process findings where participants also referred to what was viewed as sufficient evidence of PAE. Other studies have also documented the use of FASD brain function measures not included in the Guideline (Flannigan, Wrath, McFarlane et al., 2020; Coons-Harding, Flannigan et al., 2019). The use of a multidisciplinary team is also variable, due to resource constraints (Dugas et al., 2022). Moreover, existing research has focused on specialized FASD clinics and interdisciplinary groups, and data is lacking on practices of clinicians outside these groups (Popova et al., 2024; Dugas et al., 2022).

The variation in diagnostic approach and possible interpretation of criteria further impact prevalence estimates in Canada. Documenting the variability in such practices is one of the objectives of the Canadian Paediatric Surveillance Program study described later in this chapter.

4.4.6 Referral and diagnostic bias

During the engagement process, we heard that there are potential biases in referral to and uptake of diagnostic services based on ethnicity and socio-economic status, with the suggestion that non-Indigenous and children of higher socio-economic status may be more likely to be referred for and diagnosed with other neurodevelopmental disorders including Attention Deficit and Hyperactivity Disorder (ADHD), learning disorders, and Autism Spectrum Disorder rather than FASD. These potential biases are discussed further in Chapters 3 (Indigenous Communities) and 6 (Assessment and Diagnosis). These reported biases further underscore the challenges associated with accurate FASD prevalence estimation.

4.4.7 Stigmatization of PAE and of FASD

Stigmatization of PAE and of FASD by healthcare providers, communities and the public is widespread, as attested by engagement participants and some research literature (see, for example, Aspler et al., 2021). It is experienced by the expectant or new mother as judgment and blame, and can also spark fears of child apprehension (Oni et al., 2022). As one person with FASD stated in the engagement process:

> *You won't get the truth out of someone who feels attacked or judged.*

Stigmatization results in underreporting and underdiagnosis, further complicating the ability to obtain complete, accurate prevalence data (Aspler et al., 2019; Burd et al., 2021).

Evidence of the extent of underreporting comes from the study of meconium samples, mentioned above: prevalence estimates based on pregnant women's self-reports of heavy alcohol consumption were 10 times lower than prevalence obtained through meconium testing in that study (Delano et al., 2019). Engagement participants also indicated that, due to stigmatization, caregivers of those with FASD may prefer to pursue other neurodevelopmental disorder diagnoses such as Autism Spectrum Disorder rather than FASD, further compounding the referral bias as noted above.

Indigenous Peoples face the intersecting and compounding effects of FASD stigmatization, stereotyping and systemic racism. The traumatizing history of child removal and the continuing over-representation of Indigenous children in care of child welfare authorities may lead expectant mothers with alcohol use challenges to avoid treatment and may also contribute to FASD under-diagnosis due to avoidance of a stigmatizing diagnosis. At the same time, the referral biases based on stereotypes and socio-economic status may operate in the opposite direction to increase diagnosis rates for Indigenous Peoples. Aspler et al (2019), in a study of major Canadian news outlets, reported exaggeration of FASD rates in Indigenous communities. Over-surveillance of Indigenous mothers due to stigmatization can skew prevalence data and perpetuate harmful stereotypes (Aspler et al., 2019; Di Pietro & Illes, 2014).

Stigmatization is further discussed in Chapter 7, and other aspects of FASD and Indigenous communities are explored in Chapter 3.

Key Findings:

Accurate and comprehensive FASD prevalence data remains challenging to obtain due to diagnostic complexity, methodological limitations and variations, and under-diagnosis.

The challenges with FASD case identification in Canada lead to underestimation of the true prevalence. These challenges include:

- lack of access to diagnostic assessments,
- avoidance due to stigma,
- failure to refer potential cases for diagnostic assessment,
- difficulty in gathering evidence of PAE, and
- preference for alternative diagnoses that lead to better supports.

Despite these challenges, some epidemiological studies do exist, but there is a need for improved data collection and more robust epidemiological studies in both general and specific subpopulations of Canada.

4.5 Challenges related to data collection systems in Canada

Because of the impact of FASD across multiple social policy sectors (e.g. health, education, child welfare, justice) and the multiple levels of government with responsibilities for those sectors (i.e., federal, provincial/territorial, Indigenous), establishing data collection systems that capture this complexity and are robust, comprehensive, and useful to multiple parties is challenging. Below are some of the challenges identified through this assessment.

4.5.1 National FASD data collection

There is currently no comprehensive, centralized or coordinated national monitoring system for FASD prevalence in Canada. This gap is nonetheless partially filled by some key national or multi-jurisdictional resources.

National FASD Database

A National FASD Database is operated by the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD), a collaborative, interdisciplinary research network. It collects case data using a uniform instrument from many, but not all, FASD clinics in Canada (Cook et al., 2021; CanFASD, 2016). The data include: patient demographics, challenges, results of neurodevelopmental assessments, physical and mental health comorbidities, adverse outcomes being experienced, specific FASD diagnosis, and recommendations made following the assessment (CanFASD, 2016). As of February 2024, it contained data for close to 5,000 cases, from eight provinces and territories (CanFASD, 2024a). As a voluntary clinical case registry, its primary mission is to facilitate research pursued by its member researchers and jurisdictions (CanFASD, 2024a).

Health surveys

Data from national or provincial and territorial surveys of people who are or have been pregnant about alcohol consumption may be used for passive surveillance prevalence estimates.

Canadian Community Health Survey. This nationally representative Canadian Community Health Survey collects data regarding health behaviours including alcohol consumption (Government of Canada, 2023f). Self-reported alcohol consumption during pregnancy is measured on a two-years on, two-years off cycle. Along with data from the Canadian Institute for Health Information (CIHI), its data are summarized in a *Perinatal Health Indicators Report* (Public Health Agency of Canada, 2024a). Its data have been used to estimate prevalence and patterns of alcohol use during pregnancy and while breastfeeding (Popova et al., 2021). For the 2024 survey cycle, the drinking behaviors of persons aged 18 and older who consumed at least one alcoholic beverage during a specified period are reported (Government of Canada, 2023f). However, the survey does not capture data specific to FASD and while its overall response rate is about 80%, response rates to sensitive questions may be lower (Sequeira, 2024).

Maternity Experiences Survey. This 2006-2007 survey was the first national survey devoted to collecting data from recent mothers on important perinatal health indicators, including PAE (Statistics Canada, 2007).

Parental Experiences Survey. This survey will also collect data on PAE and is currently underway. Canadian parents are being asked about their experiences, knowledge and behaviours regarding pregnancy, childbirth, and access to and use of healthcare services (Statistics Canada, 2024a). This contains several questions about alcohol use during pregnancy, including the frequency of alcohol use and frequency of heavy episodic consumption (4 or more drinks on one occasion).

Canadian Health Survey on Children and Youth. Since 2016, this national survey has collected data on issues that have an impact on the physical and mental health of children and youth, including FASD. More recently, the survey has been designed to include longitudinal sampling (Statistics Canada, 2024b).

First Nations Regional Health Survey. This is a national health survey of First Nations people living on reserve and in Northern communities, carried out by the First Nations Information Governance Centre, a non-profit organization with a mandate from the First Nations Chiefs-in-Assembly. It reports alcohol use during pregnancy and the number of individuals told by a health professional that they have FASD (First Nations Information Governance Centre, 2018).

4.5.2 Screening and data collection through health systems

Systematic screening though provincial/territorial health delivery systems could contribute to prevalence estimation of PAE and risk for FASD. There are several different forms of screening, using different types of tools and processes. Some of them are designed only to contribute to prevalence estimation, whereas others aim to support efforts to reduce alcohol-exposed pregnancies while also contributing information to prevalence estimation (Popova, Lange, Probst, Parunashvili, et al., 2017; Chu et al., 2023). Provincial differences in data collection complicate efforts to obtain a clear picture of prevalence across Canada.

As part of an initiative to develop a multi-source national surveillance system, supported by PHAC, Popova et al. (2021) examined mechanisms across six jurisdictions: four provinces (BC, Alberta, Manitoba, Ontario) and two territories (Northwest Territories and Yukon). They found that although these jurisdictions capture data about PAE and FASD through a number of data collection mechanisms, the data produced by the different sources are often too fragmented or inconsistent, making integration difficult to achieve. They also sometimes produce quite different prevalence portraits.

Screening for PAE

The Canadian Society of Obstetricians and Gynecologists has issued PAE screening guidelines (Graves et al., 2020), which are as yet partially implemented (Sword et al., 2020).

According to the report by Popova et al. (2021), systematic PAE screening and recording is carried out in some but not all parts of the country:

- In the Northwest Territories, the prenatal record includes screening for PAE at a minimum every trimester and automatic referral for patients who have a positive alcohol screen;
- Prenatal PAE information obtained through systematic screening is captured in Manitoba through two programs: Families First, a universal screening and home visiting program for the non-First Nations populations, and Strengthening Families, for First Nations;
- Ontario’s Better Outcomes Registry & Network (BORN) Information System captures substance use during pregnancy through maternal self-report to antenatal care providers;
- In Alberta, PAE is mandatorily recorded on the birth record, where known;
- PAE information in British Columbia is systematically captured in the Perinatal Data Registry, containing clinical maternal and neonatal information on all births. Through Perinatal Services BC, the province maintains a quality-controlled database containing clinical maternal and neonatal information on all births in the province, from all service providers and obstetric facilities, including ICD-10 codes.

Screening for the risk of FASD and estimating FASD prevalence

Active case ascertainment (ACA) studies screen a defined population to identify cases of FASD within that population. Active case ascertainment is expensive and time-consuming and so not realistic for large population studies; however, it may produce the most robust prevalence assessment for the studied population. This form of screening collects anonymized data for epidemiological purposes, adjacent to assessment and diagnosis. Key Canadian prevalence studies using active case ascertainment are Popova, Lange, Poznyak et al.'s (2019) study among elementary students in the GTA, and McLachlan et al.'s (2019) study in a Northern corrections population. The active case ascertainment method is considered the 'gold standard' epidemiologically in estimating population prevalence.

Passive surveillance methods are better suited for estimating prevalence in large populations, given the resource-intensiveness of the more comprehensive ACA method. It uses data already recorded in health registries. Data sources that are used to estimate prevalence rates are described by Popova et al. (2021):

- In Ontario, the BORN Registry includes data on birth and neonatal encounters and outcomes including service utilization. This system also collects data on confirmed and suspected congenital anomalies at birth, including FAS and other alcohol-related birth defects.
- Manitoba's Families First system collects confirmed and suspected congenital anomalies at birth, including FAS and other alcohol-related birth defects. Public health nurses administer a screening questionnaire to families of newborns within one week of discharge from hospital.
- Additionally, as mentioned in Chapter 2, all three territories require reporting of FAS as part of their public health surveillance regulations.

There are other types of data collection systems that could contribute to prevalence estimation, although there are important limitations in their use for that purpose. For example, information on diagnosed cases will substantially underestimate actual cases given limited access to diagnosis, avoidance of FASD diagnosis, and other reasons documented above. Some of the data collection systems documented in the Popova et al. study (2021) are:

- **Data from clinic programs for people with FASD or for disorders that include FASD**: For example, in BC, the Complex Developmental Behavioral Conditions program assesses children who have been exposed to substances in utero, including alcohol, who have been referred through physicians, nurse practitioners, community service providers through the Infant Development Program, preschools, and schools. Data for this program are input into a provincial database that allows both referrals and outcomes to be tracked. In Alberta, the FASD Online Reporting System (ORS), an initiative of the Alberta FASD Cross-Ministry Committee managed by the Ministry of Community and Social Services, collects mandatory assessment and diagnostic clinic data from the 19 FASD clinics that receive provincial cross-ministry funding.

- **Chart-based studies**: One-off chart-based studies sometimes contribute to prevalence portraits. For example, a study at the Ron Joyce Children's Health Care Centre, part of Hamilton Health Sciences, abstracted patient information on demographics and suspected and confirmed comorbidities.
- **Clinic diagnostic capacity survey data**: There are surveys administered to all clinics with capacity for neurodevelopmental assessments for FASD, reporting on assessment availability and diagnosed cases over defined periods.
- **Epidemiological studies**: Jurisdiction-specific studies have been carried out in certain provinces and the Northwest Territories.
- **Data captured through referral networks and systems.** For example, surveillance in Manitoba is informed by the FASD Diagnostic Network, in which regional diagnostic coordinators facilitate referrals and support development of diagnostic capacities in rural and remote communities.

These sources provide a foundation for improved estimation of prevalence, although consistency in data reporting and analysis would be required to integrate across these disparate data sources. One continuing challenge in using health system data is the use of ICD diagnostic codes that do not adequately capture the full range of FASD, and instead capture the smaller subset of FAS (see the next section). In Ontario, integration of multiple data sources is performed by a McMaster-based research team. Its MOM-BABY dataset, a derived cohort, allows examination of FAS and PAE through diagnostic codes recorded as part of hospital-based encounters (data used in Popova et al., 2021). In Manitoba, a linked administrative database that includes FASD cases, managed by the Manitoba Population Research Data Repository also permits integration of multiple data sources (data used in Brownell et al., 2019).

4.5.3 FASD codes in administrative databases: health and education

Administrative databases used for health system management can be used to identify services provided to patients within diagnostic categories. To the extent that these systems have adopted common identification codes specific to FASD and use them systematically and uniformly within and across locations, they can contribute to prevalence estimates (Astley Hemingway et al., 2019). Unfortunately, these codes are currently of limited utility for prevalence estimation.

The main general diagnostic classification systems are the International Statistical Classification of Diseases and Related Health Problems, 11th edition (ICD-11), and the Diagnostic and Statistical Manual (DSM-5-TR). Neither of these two systems contain specific codes for FASD, instead capturing it within residual categories that include other neurodevelopmental conditions that also do not have specific codes. To the extent that administrative databases use these dominant diagnostic systems, therefore, the databases are not very helpful for assessing prevalence of diagnosed cases of FASD.

As outlined in Table 6 below, the ICD-11 contains a code for FAS, but no specific code for FASD. Under the ICD-11, FASD falls within a residual code for "other specified neurodevelopmental disorders." The DSM-5-TR contains a residual code for "other specified neurodevelopmental disorder" that includes, among other things, "neurodevelopmental disorder, associated with prenatal alcohol exposure." The DSM-5-TR proposes "neurobehavioral disorder associated with PAE" or ND-PAE as a condition for further study, and this proposed condition would capture FASD.

Table 6: Summary of codes related to FASD in the ICD-11 and DSM-5-TR

Codes in the ICD-11 (2019)	
LD2F.00	Fetal alcohol syndrome (FAS) (Q86.0 in ICD-10)
JA85.Y	Maternal care for known or suspected damage to the fetus from alcohol (O35.4 in ICD-10) Maternal care for (suspected) damage to fetus from alcohol
KA06.2	Fetus or newborn affected by maternal use of alcohol (P04.3 in ICD-10)
6A0Y	Other specified neurodevelopmental disorders Residual category that can include neurodevelopmental syndrome due to PAE.
Codes in the DSM-5-TR (2022)	
F88	Other specified neurodevelopmental disorders Residual category that includes "neurodevelopmental disorder associated with prenatal alcohol exposure" (315.8 in DSM-5)
Condition proposed for further study	Neurobehavioral disorder associated with PAE (ND-PAE)

The issue of codes arises in relation to provincial health services billing systems that tie physician billing codes to the ICD; which, through the Canadian Institute for Health Information's Patient Level Physician Billing (PLPB) metadata, provides morbidity and health service delivery data at various jurisdictional levels (Canadian Institute for Health Information, 2023a). Engagement participants noted that some health systems have FASD-specific billing codes, for example Alberta and New Brunswick, but they may not be extensively used. In general, within the FASD context, billing data is not very useful for epidemiological information because generic procedural codes may be used, often a limited number of diagnoses may be included when billing, and it is usually the most responsible diagnosis that is listed (which may be something other than FASD).

In the study by Popova et al. (2012), ICD-10 codes for FAS-related diagnosis were used to gain an understanding of the utilization of healthcare services by individuals diagnosed with FAS and estimating the associated healthcare cost. However, a limitation is that FAS is the only FASD-related diagnosis coded in the ICD-10. FAS represents only 10–20% of cases of FASD (Roberts & Nanson, 2000) therefore, the burden and cost figures in this study would increase if all FASD-related diagnoses were included.

In addition, there is a lack of concordance between diagnostic systems used internationally (Myers et al., 2024). Astley Hemingway et al. (2019) applied four main diagnostic systems to charts of 1,392 patients assessed for FASD (the 4-Digit-Code from Astley, 2004; Hoyme et al., 2016; Cook et al., 2016; Bower, 2016). Eighty-two percent were diagnosed with FASD by at least one system; only 11% by all four systems. These differences limit the comparability of prevalence estimates across countries.

Education systems also use diagnostic categories to identify children referred for services for special needs. Here as well, categories specific to FASD may not exist: rather, FASD cases may be included in broader categories. For example, the Special Education Manual of the BC Ministry of Education classifies children diagnosed with FASD or other complex developmental behavioural condition within "Chronic Health Impairment" (British Columbia Ministry of Education, 2016). During the engagement process, participants recounted that this meant that the educational databases were not helpful for tracking prevalence given that this category includes multiple conditions other than FASD.

Further, even when appropriate diagnostic codes are in place, they may not be used consistently across social sectors, due to lack of understanding and capacity or because they are not mandatory (BC Representative for Children and Youth, 2021).

As will be discussed later in the Chapter 6 on Assessment and Diagnosis, there can be a tension between the objective of improving data collection for the purposes of improved prevalence estimates and the objective of ensuring that social supports are accessible to those who need them. Social supports that are predicated on a specific diagnosis can distort diagnosis-based prevalence estimates. Engagement participants repeatedly recounted how diagnoses that offer access to better supports are preferred, and this skewing is compounded where those other diagnoses are less socially stigmatized than FASD. Another problem with using diagnosis-based supports in the case of FASD is that many people who do in fact have FASD may struggle to obtain the diagnosis due to lack of sufficient evidence of PAE. A proposed solution, already used in some places, is to provide supports based on functional impairments rather than diagnosis. This approach may be helpful when FASD diagnosis is unavailable but using an FASD-sensitive lens can still allow the implementation of interventions that are appropriate and specific to FASD. We also heard concern that a functional approach without diagnosis may reduce interest in pursuing the diagnosis and this would, in turn, reinforce the substantial underestimation of FASD prevalence. Engagement participants also underscored the value of the diagnosis, since it provides understanding and information of value to people with FASD and their families. In summary, there is a complex tension between the objectives of prevalence estimation, which pushes toward more use of diagnosis, and supporting people with FASD, which may prioritize support independent of diagnosis with the possible side effect of reducing interest in diagnosis. Reduced use of the diagnosis may also affect support for the parent and efforts to address PAE in subsequent pregnancies.

4.5.4 Privacy, ethics, data sharing and governance

Establishing effective and efficient data collection systems for FASD requires consideration of: protecting the confidentiality, privacy and dignity of the people whose data are being recorded; the role and responsibilities of the practitioners recording it; the importance of complying with applicable ethical standards and legal rules for personal health information collection, use and disclosure, and ensuring interoperability across multiple organizations, jurisdictions and levels of government.

Privacy and ethics

The collection and sharing of health information related to FASD involve significant privacy and ethical considerations. Ensuring the confidentiality of personal health information is paramount to maintaining trust between patients and healthcare providers, which in turn encourages individuals to participate in data collection efforts (Di Pietro et al., 2016). Engagement participants raised concerns over privacy, data collection and potential liability for improperly reporting patient information about FASD contrary to privacy legislation.

A distinction should be drawn between policies that encourage the recording of information about PAE and FASD in a personal medical record, and suggestions for mandatory reporting of de-identified information about cases of PAE and FASD to registries for epidemiological surveillance. Personal health information typically attracts privacy concern when it is about an identifiable person; de-identified information is of less concern, although attention must be paid to the possibilities of re-identification in some circumstances.

Information about PAE is important for diagnosing FASD and intervening early to mitigate its impacts, and this has given rise to suggestions that information about PAE should be recorded in infants' medical records. There are ethical tensions around the PAE information given that this information also relates to the biological mother. *The 2020 Guideline of the Canadian Society of Obstetricians and Gynecologists* states that the diagnosis of maternal alcohol use disorder should be documented on an infant's medical record with the knowledge of the mother, but does not comment on the questions of consent or objection by the mother (Graves et al., 2020).

The possibility of screening for biomarkers of prenatal alcohol consumption - e.g. meconium testing - has raised ethico-legal concern about whether parental consent is required, and about the possible use of that evidence of PAE in subsequent legal proceedings (Zizzo et al., 2013; Arkell & Lee, 2022). Healthcare workers in the U.S.A have raised concerns about the mandatory reporting of prenatal substance use to child welfare authorities which exists in some states, suggesting there be modifications to this requirement that better support the mother and the child (Jarlenski et al., 2019). Wilkinson et al. (2016) argue that "even if the fetus is regarded as having no legal or moral status, there is an ethical and legal case for intervening to prevent serious harm to a future child". Although the former practice of "birth alerts" (notification of hospitals prior to birth that the newborn was believed to be in need of protection, leading to removal of the child immediately after birth) has ended, child welfare laws require healthcare personnel to report concerns about a child's safety or well-being (Ontario Association of Children's Aid Societies, 2020). Engagement participants frequently mentioned that concern about the possibility of this notification and subsequent removal of children would lead mothers to avoid disclosing alcohol use. Screening without consent would likely raise the same fears, and could also have negative consequences for the therapeutic relationship. Hackler (2011) noted that "[u]nderlying most of these concerns is a particularly agonizing conflict of obligations: to protect vulnerable, nascent human life on the one hand, and to preserve the privacy, dignity, and trust of one's patient on the other."

Data sharing and data governance

In Canada, the privacy of personal health information is legally protected by various federal and provincial laws. However, feedback gathered during the engagement process revealed concerns about the sharing of client information with data repositories. This appears to be a particular concern for smaller communities where it may be harder to reliably de-identify information and ensure anonymity. The protections necessary to share information among organizations and across jurisdictions may limit the information shared, reducing completeness of prevalence information (Cook et al, 2021; Popova et al., 2024). Clarification of the rules on health information privacy might be helpful, given feedback during the engagement that there are concerns in some locations about whether client information can legally be shared with data repositories.

Indigenous data sovereignty

The *Truth and Reconciliation Commission's Calls to Action* (2015) address the need for improved monitoring of health-related indicators in order to close the gap in health outcomes between Indigenous and non-Indigenous communities. As noted in Chapter 3, respectful processes and adequate protections of Indigenous data sovereignty, as well as Indigenous researcher, practitioner and community participation in data system design are key. Indigenous data sovereignty is supported through application of the ethical guidelines cited in Chapter 3, with specific reference to First Nation Ownership, Control, Access, and Possession (OCAP) principles (First Nations Information Governance Centre, 2020; n.d.), Inuit Access, Ownership and Control (OCA) over data and information (Inuit Tapiriit Kanatami, 2018), and Manitoba Métis principles of Ownership, Control, Access, and Stewardship (OCAS; Martens et al., 2010; University of Manitoba, 2021). The collaboration of non-Indigenous researchers, where welcomed by Indigenous communities, can help to generate FASD-related data that can support policy-making and advocacy by those communities.

Key Findings:

At present Canada lacks a comprehensive, coordinated surveillance system to collect data on FASD and PAE. Provinces and territories vary in relation to their collection of information on diagnosed cases of FASD, and this information is not always comprehensive, reliable and suitable for use in a range of clinical, research and other contexts.

As for data collection within administrative databases (e.g. education and healthcare), there is a lack of FASD-specific codes or categories. Where general codes that include FASD along with other conditions are used, it is difficult to use these systems to accurately determine FASD prevalence. Establishing FASD-specific codes could enhance the utility of these systems, if they are reliably used. However, this would exclude many individuals who are unable to obtain a formal diagnosis.

4.6 Possible improvements to case identification, data collection and management

Various pathways to improving the collection and management of prevalence data were identified in the course of this assessment, from the literature as well as by engagement participants. They can be grouped into three main categories: improving screening systems for PAE and FASD; improving diagnostic practices and information on cases of FASD; and improving case reporting and data collection.

4.6.1 Improvements to screening for PAE and FASD

Increased national systemization of screening for data collection purposes as well as for case identification would ensure more comprehensive, nationally representative and up-to-date prevalence information.

Screening for PAE

Participants in the engagement process for this assessment endorsed comprehensive, routine screening that could contribute to prevalence estimation. There was a recurring theme in the engagement findings that stigmatization, mistrust of the healthcare system and fear of child welfare intervention work against screening for PAE and FASD. Reducing stigmatization through the development and implementation of culturally sensitive screening approaches and tools may help foster the trust necessary for pregnant women and new mothers to participate in screening programs (McLachlan et al., 2022).

A proposed social biobank will, in one community-research partnership, collect biological samples, social-contextual health survey data, and clinical/administrative data on community and clinical cohorts of children and families. Although not a prevalence assessment resource, these data could provide important information about cases missed by screening, as well as longitudinal information about FASD presentation and evolution (Elias et al., 2018).

Enhancing effectiveness in FASD screening and referrals

Many healthcare, education and justice system personnel lack the awareness, training and confidence to screen for FASD effectively, being inadequately informed of the full spectrum of FASD symptoms and the nuances of its diagnosis (McCormack et al., 2022).

Health and allied workers who are not FASD specialists would benefit from widely accessible free and high quality training and professional development that is context-adapted and delivered remotely (Bagley, et al., 2023) to assist in screening efforts. Deployment of networked support such as Manitoba's FASD diagnostic coordinators in all health regions, which supported a 60% increase in referrals between 2009 and 2014 (Manitoba Government, n.d., cited in Popova et al., 2021), would also contribute to improved prevalence capture.

Engagement participants emphasized the importance of integrating the clinical, social and ethical dimensions of FASD detection into the core curricula of medical, nursing, and allied health programs to ensure that new graduates enter the workforce with a foundational understanding of FASD. There was also strong support for the development of continuing professional education programs focused on FASD to keep current practitioners informed of the latest diagnostic criteria. Fostering non-judgmental approaches to screening and ensuring that screening tools are culturally appropriate are critical steps toward enhancing case identification, thus improving completeness of prevalence data (McLachlan et al., 2022; Burd et al., 2021).

Popova et al. (2024) concluded that annual FASD diagnostic capacity in Canadian provinces and territories would have to be increased 67-fold in order to detect all cases each year. Broad screening of young children for neurodevelopmental delays is important, with referral and follow up for further assessments and diagnosis.

Prioritizing populations where there is an elevated risk of PAE for screening for neurodevelopmental delays would help to increase identification of challenges and support earlier interventions for children. It could also better identify needs in adult populations where there is an elevated rate of FASD, such as in the criminal justice system. However, prioritizing specific groups for screening will at the same time necessarily mean that more cases are detected in those groups, potentially reinforcing stigma and the perception that FASD is a problem specific to them.

Another issue raised during the engagement is whether it is appropriate, given the stigma and social consequences of the diagnosis, to identify cases when supports and follow-up are not available; however, the diagnosis still furnishes important health-related information and it is also ethically questionable to ignore a health condition.

Regular national and standardized surveys of service-providing organizations such as the survey of diagnostic clinics conducted by Popova et al. (2024) could also contribute to the improvement of FASD prevalence data by providing a clearer picture of factors that influence diagnosis rates and by supporting a more consistent and informed approach to FASD diagnosis across Canada.

4.6.2 Improving diagnostic practices and information on cases of FASD

Prevalence data would be improved if the barriers to FASD diagnosis related to accessibility of assessment and stigma were reduced. In addition to these considerations, the accuracy of prevalence data can be increased by improving the diagnostic and data collection processes.

Improving feasibility of and adherence to diagnostic criteria

Despite the availability of the *2016 Canadian Diagnostic Guidelines* (Cook et al., 2016), there is some evidence that they are not always fully applied, nor is it always feasible to do so, especially in under-resourced clinical contexts (Dugas et al., 2022). Some engagement participants suggested that less rigid or demanding diagnostic guidelines would make them more feasible to apply in a broader range of settings, although this may reduce diagnostic precision. This issue is addressed more fully in Chapter 6.

Collection and reporting of data about diagnosed cases

Participants proposed additional training and support, streamlined reporting processes, and adequate resources to support time-consuming data collection and reporting. As engagement participants saw it, there is a trade-off between data quality and resource-intensiveness: data collection is either time-consuming and detailed (e.g. the CanFASD case database) or efficient but simple and limited (e.g. hospital system data).

FASD-specific codes in administrative databases

Universal implementation of a consistent set of FASD-specific diagnostic codes in administrative databases in healthcare and education systems could help improve prevalence estimates. Implementation of such codes is likely most effective when accompanied by appropriate resources for training, programming, and analysis, and when it includes regular audit of coding practices (BC Advocate for Children and Youth, 2021).

Data disaggregation

Disaggregated prevalence data - broken down by factors such as sex, gender, racial or ethnic group, and geographic location - can provide insights into how different populations are affected by FASD, revealing disparities and trends that may be masked in aggregate data (Popova, Lange, Shield, et al., 2019). However, the risk of reinforcing stigmatization by oversimplified interpretation and presentation of epidemiological categories such as Indigenous status must be balanced against the benefits of more nuanced prevalence information.

Context-specific data

As noted by Cook et al. (2021), “individuals with FASD are an exceptionally complex and heterogeneous group.” In order to allow a more nuanced understanding of FASD prevalence, engagement participants offered many suggestions about data elements that could be tracked to understand FASD patterns, risk factors, and issues requiring policy attention. These included social determinants of health such as socioeconomic status, adverse childhood experiences and past trauma, as well as involvement with the justice system and children welfare services.

Longitudinal outcome data on impacts

While prevalence data provides essential insights into the scope of FASD within populations, outcome data is equally critical for understanding the long-term impacts of FASD and evaluating the effectiveness of interventions. Longitudinal data collection, which tracks individuals with FASD over extended periods, offers valuable information not only on the strengths and challenges associated with FASD over the life span, but also on which factors and characteristics identified during the assessment process are the most important predictors of favorable and unfavorable outcomes. Currently, there is a significant lack of comprehensive outcome data on FASD in Canada (Popova, Charness et al., 2023; Cook et al., 2016; Pei et al., 2011). As described in section 4.5.1, the 2023 Canadian Health Survey on Children and Youth Health was designed to include longitudinal sampling.

Inclusion of strengths in surveillance measures

Engagement participants and researchers alike have noted that the strengths, capacities and assets of people with FASD are rarely documented, as a focus on impairments and challenges permeates all levels of professional and public discourse (Choate & Badry, 2019). Prevalence data could be made more complete and more useful if strengths were part of the data routinely collected (McLachlan et al., 2022). Engagement participants also suggested collecting success stories and documenting positive outcomes as a means to reduce stigma and support the social inclusion of people with FASD.

Case finding in early childhood and adulthood

While diagnosis of FASD is possible throughout the lifespan, assessment in infancy and early childhood can be more difficult as some of the neurocognitive domains assessed as part of the process are difficult to accurately evaluate at this early age. The existing diagnostic guidelines offer a possible designation of “at risk for neurodevelopmental disorder and FASD”; however, this is not a diagnosis and these cases would not be captured in prevalence data.

Additionally, as will be discussed in section 6.3, some diagnostic clinics do not accept referrals for children under six years or for adults, further limiting case finding in these age categories.

Popova et al., (2020) suggested consideration of promising approaches using web-based technology such as computer-based facial recognition software and camera and computer vision to track eye movement in young children. Diagnostic approaches that better capture FASD cases for all intervals of the life span, would improve access to diagnosis and hence prevalence estimation for the entire population (Popova et al., 2024).

4.6.3 Improving case reporting and data collection

There are currently disparities across and within jurisdictions in availability of good quality prevalence data. In addition to the measures mentioned above, steps could be taken to support increased case reporting and comprehensive data collection systems.

National data repository

Efforts to create a national data repository for information about FASD cases have been ongoing, with the goal of centralizing data from all provinces and territories to facilitate consistent, country-wide data collection. A recent and substantial step forward to improve data collection is represented by the CanFASD National FASD Database, which collects data from participating diagnostic clinics across Canada. This registry is intended as a research and clinical tool and currently includes about 5,000 patients (Cook et al., 2021; CanFASD, 2024b). While the Database can detect trends in prevalence, it is not a comprehensive surveillance tool for estimating national prevalence.

The Canadian Paediatric Surveillance Program is a joint project of the Public Health Agency of Canada and the Canadian Paediatric Society, and is engaged in national surveillance and research into childhood disorders that are high in disability, morbidity and economic costs to society. Despite their low frequency There is a focused FASD initiative currently in this program which will help determine incidence of FASD in school-aged children (Probert et al., 2024), but it alone cannot meet the need for long-term FASD surveillance because it is limited to surveying pediatricians or teams with pediatricians.

A national data repository that receives consistent contributions from all provinces and territories would help address the current fragmentation in data collection. Some engagement participants suggested that the way forward was to build upon the CanFASD National FASD Database, while others preferred a national effort managed by a federal agency such as the Public Health Agency of Canada or national clinical organization, in partnership with the Public Health Agency of Canada. The adoption of FASD-specific diagnostic codes in provincial health-related administrative databases would enable the addition of FASD to existing national data repositories. The Canadian Chronic Disease Surveillance System can serve as an example of such an approach (Public Health Agency of Canada, 2024b).

Engagement participants indicated that to be effective, a national repository would ideally ensure that funding is available to increase the capacity of clinics to contribute to the database, and that all data collected be useful and used to benefit people with FASD, their families and communities - not just ‘data for data’s sake.’ Similar recommendations about addressing privacy concerns and ensuring adequate resources to support detailed and accurate reporting were made in relation to the CanFASD National FASD Database (Cook et al., 2021). Additionally, mandatory reporting to the national repository (see below) could improve the consistency and reliability of FASD data, enabling more coordinated and efficient policy-making at the national level.

Evidently, the functionality and reliability of any database is critical. Engagement participants commented that an existing provincial FASD-specific database was outdated and unreliable, making it difficult to maintain records when clients relocate, and further that redesign to improve the format of output reports was required.

Mandatory reporting of FASD cases

Some discussion in the engagement process supported improving prevalence data by making FASD a mandatorily reportable condition, as long as sufficient resources were allocated to reporting clinics.

There are already provincial and territorial public health statutes that mandate the reporting of certain health conditions, particularly infectious diseases. And federal, provincial and territorial collaborations have enabled national data collection within the Canadian Notifiable Disease Surveillance System (Totten et al., 2019).

Data on congenital anomalies from all jurisdictions in Canada are collected through the Canadian Congenital Anomalies Surveillance Network, but FASD is not included–as it makes use of hospitalization data, which is not a reliable source for FASD diagnosed cases. In several jurisdictions, the reporting of congenital anomalies is legally mandated (Bedard et al., 2024). FAS (as opposed to FASD) diagnosis must be reported by law to the jurisdiction's Chief Public Health Officer in the three Canadian territories; this requirement is set out in the public health surveillance legislation in those jurisdictions (Yukon, 2000; Government of the Northwest Territories, 2009; Government of Nunavut, 2024).

Mandatory reporting may improve prevalence data, but raises important questions of ethics and privacy (see section 4.5.4). Given the stigma associated with FASD and concerns about child welfare involvement, mandatory reporting - particularly if it is not de-identified - might further dissuade families from seeking diagnosis.

Case study: Australian approaches

FAS is a notifiable birth defect in South Australia through their Birth Defects Register (Women's and Children's Health Network, 2024) and FAS/FASD are notifiable in Western Australia, through the WA Register of Developmental Anomalies (WARDA; FASD Hub Australia, 2024; Government of Western Australia, n.d.).

Other Australian approaches include the FASD Australian Registry (FASDAR; FASD Australian Registry, n.d.), which aims to collect detailed information about Australian children under 15 years of age living with FASD to improve diagnosis, treatment, and prevention. However, inclusion in FASDAR is voluntary and driven by patients and their families, resulting in a relatively low number of registrants. Despite this, FASDAR remains a valuable tool for maintaining a central database of FASD cases across the nation and informing better diagnosis, treatment, and prevention strategies.

The Australian Paediatric Surveillance Unit (APSU; n.d.-a) monitors rare childhood conditions that include congenital/genetic disorders, infectious/vaccine preventable conditions, mental health and other injuries. FASD is the focus of one of their studies, which collects information to estimate the incidence of FASD in children under 15, and also includes describing diagnostic practices, health service utilization and feedback on their guidelines (Australian Paediatric Surveillance Unit, 2019). They collect information through a printable or online case report form (Australian Paediatric Surveillance Unit, n.d.-b).

Key Findings:

Increased training and education on FASD could help to ensure that more potential cases are identified and referred for assessment as many personnel in the health, education, justice, and child welfare systems have limited awareness and knowledge about FASD.

Disaggregated data regarding PAE and FASD (e.g. by age, sex, gender, racial or ethnic group, geographic location) is helpful for understanding risk factors as well as ensuring supports are best directed where they are most needed. It is important to carefully design and interpret studies of prevalence in sub-populations, and to contextualize them, for example, by including data on the corresponding social determinants of health when communicating the results to avoid stigmatization of affected groups.

Data on the strengths and challenges associated with FASD are currently limited. Longitudinal outcome data provides a more comprehensive view of the most important predictors of favorable and unfavorable outcomes, including the possible impact of policies in the Canadian context.

The implementation of universal and comprehensive screening programs for PAE would help to identify more cases and improve the accuracy of prevalence data. Increased awareness of the importance of conducting this screening can occur through training of clinicians to build confidence and skills to screen effectively and address the fear of disclosure due to stigmatization of PAE and the fear of possible consequences, such as child apprehension.

Key Findings:

A national data repository, to which all provinces and territories contribute consistent data, and which is suitable for the needs of the whole community, would be helpful to gather consistent pan-Canadian data and to facilitate coordinated and efficient policy. Mandatory 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. Given recent suggestions that it would be helpful to use the diagnosis of complex neurodevelopmental disorder (NDD), along with specific diagnoses like FASD where applicable, consideration of a broader national data repository that captures NDD, along with FASD and other applicable diagnoses, and information on pre- and post-natal adverse exposures, would improve understanding, bolster prevention efforts, and include a broader range of affected people.

4.7 Conclusion

The accurate estimation of FASD prevalence is complex and challenging, but crucial for effective public health planning, resource allocation, and the development of targeted interventions. Throughout this chapter, we have highlighted the various factors that contribute to the variability and underestimation of FASD prevalence data within Canada.

Key challenges include the lack of diagnostic capacity across provinces and territories, which is thought to lead to a substantial underestimation of prevalence. The stigmatization of PAE and FASD by healthcare providers, communities and the public further complicate the diagnostic process, with many cases going undiagnosed or misdiagnosed due to fear of judgment and social repercussions.

Despite these challenges, several possible pathways to improvement have emerged from this review, in three main areas: improving screening for PAE and FASD; improving diagnostic practices and information collection; and improving case reporting and data collection systems. The establishment of a national data repository, with adequate financial resources and the collaboration of all territorial and provincial governments, would facilitate the collection of more comprehensive data across the country. Provinces and territories could consider mandated reporting to improve comprehensiveness.

At the same time, important ethical challenges surround data collection in a context of blame and stigma associated with the consumption of alcohol in pregnancy. Stigma is a critical problem that impedes both efforts to support healthy pregnancies and reduce alcohol use through screening as well as to improve diagnosis of FASD through documentation of PAE and encouraging affected families to pursue diagnosis, thus directly undermining prevalence data collection. Stereotyping and bias compound the problem of stigma for particular sub-groups, including members of Indigenous communities who continue to be affected by the structural causes of FASD stemming from colonial and intergenerational trauma and systemic inequities.

Chapter 5:

Prevention

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

5.1 Introduction

This assessment was charged with the question "*How can FASD prevention activities be strengthened to support the overall objective of reducing the prevalence of FASD in Canada?*" FASD prevention is both a priority and a challenge, in Canada and worldwide. It is a priority because of FASD's high prevalence (Palmeter et al., 2021; Popova, Lange, Probst, Gmel, & Rehm, 2017; Popova, Lange, Poznyak et al., 2019), its many lifelong effects on people with FASD and their families and caregivers (McLachlan, Flannigan et al., 2020), and its high system and lost productivity costs due to morbidity and premature mortality (Greenmyer et al., 2020; Popova, Lange, Burd et al. 2016).

PAE is recognized as causing FASD, and reducing alcohol exposure to the fetus is a public health priority. At the same time, there are multiple influences that intersect with PAE to result in FASD and its adverse effects (McQuire et al., 2020). PAE is itself associated with many factors (Popova et al., 2022). There is a need for sensitivity and respect toward pregnant women and those of childbearing age, people with FASD and their families, and birth parents, ensuring that prevention attitudes and initiatives are centered on optimizing health and wellbeing (Canada Northwest FASD Partnership Initiative, 2017).

Prevention efforts include efforts to directly reduce PAE. Early detection and mitigation of the effects of PAE through the provision of interventions and supports to people with FASD is also an important form of prevention and is described in Chapter 7.

Given the multiple, intersecting causes of PAE and FASD, the approach to prevention must be similarly complex, addressing the various populations and levels of intervention appropriate to a public health issue that cannot be isolated to one group or reduced to one simple set of causes. This chapter is informed by three prevention-relevant frameworks. The Four-Level FASD Prevention Framework (Poole et al., 2016; Public Health Agency of Canada, 2008; CanFASD, 2013; Wolfson et al., 2022) was developed through a scoping review of prevention efforts and gaps:

- Level 1: Broad awareness building and health promotion efforts
- Level 2: Discussion of alcohol use and related risks with all women who could become pregnant and their support networks
- Level 3: Specialized, holistic support of pregnant women with alcohol and other health/social problems
- Level 4: Postpartum support for new mothers assisting them to maintain/initiate changes in their health and social networks and to support the development of their children

These prevention levels are complemented by the dimensions of the Ottawa Charter for Health Promotion (Government of Canada, 2017), which calls for building healthy public policy, creating supportive environments, strengthening community action, developing personal skills and reorienting health services. The Ottawa Charter is helpful in the FASD context for its emphasis on the role of alcohol policy in FASD prevention efforts (supportive alcohol policy is at the center of the Four-Level Framework, see Poole et al. 2016; see also Section 5.6 of this report) and creating supportive environments, strengthening community action, and reorienting systems to provide holistic, wrap-around services though FASD informed providers (these are consistent with Levels 3 and 4 of the Four-Level Framework, see Poole et al. 2016; see also Section 5.4 of this report).

FASD prevention is also relevant to the Quintuple Aim for healthcare improvement, which focuses on improved population health, health equity, patient experience, care team well-being and reduced costs (Nundy et al., 2022; Mulligan et al., 2024). The Quintuple AIM model is pertinent to FASD prevention because both primary prevention (preventing alcohol consumption during pregnancy, see Section 5.2) and secondary prevention (early detection and preventive intervention to reduce the effects of PAE that has already occurred, see Section 5.5), necessarily involve health providers and the consideration of patient experience.

In addition, our assessment on prevention of FASD is informed by what has been called a women's determinants of health perspective (with "women" referring here to all people who can become pregnant; CanFASD, 2022). Enacting this perspective requires prevention efforts that are: 1) respectful; 2) relational; 3) support self-determination; 4) centered on women who could become pregnant; 5) harm reduction oriented; 6) trauma and violence informed; 7) health promoting; 8) culturally safe; 9) supportive of parenting; and 10) use an FASD-informed and disability lens (CanFASD, 2022). The approach to understanding FASD prevention is further enriched by Indigenous determinants of health and wellness (CanFASD, 2022), which: 1) center prevention around Indigenous knowledge and wellness; 2) use a social and structural determinants of health lens; 3) highlight extended family and community relationships; 4) are community based and community driven; 5) provide wraparound support and holistic services; 6) adopt a life course approach; 7) make use of strengths-based models that support resiliency of women who could become pregnant and families; and 8) ensure long-term sustainable funding and research (CanFASD, 2022).

5.2 Raising awareness about FASD

5.2.1 Level of public awareness about FASD

Awareness of FASD in the Canadian population is quite high and has increased over the years. In 2005, 86% of Canadians were aware of FASD or FAS (Environics Research Group, 2007). In 2000, 56% of the Canadian population had heard of Fetal Alcohol Effects (Government of Canada, 2000). However, understanding of FASD was not as high: when asked what FASD was, 42% mentioned brain disorders or learning or cognitive disabilities/lower IQ/memory problems; 29% mentioned PAE; 19%, physical deformities/birth defects/organ formation and 17%, developmental or growth problems (Environics Research Group, 2007). In a survey conducted in Alberta in 2017, 85% of males and 96% of females had heard of FASD, up from 82% of males and 90% of females in 2011 (Choate et al., 2019). A 2017 study comparing public and expert understanding of FASD showed that public perceptions were founded on a view that FASD is caused by pregnant women's individual choices (Frameworks Institute, 2017). A review by Choate & Badry (2019) of FASD discourse in professional documents showed a dominant focus on mothers' use of alcohol and on negative outcomes for people with FASD (Choate & Badry, 2019).

5.2.2 Universal public education campaigns

Public education campaigns are one component of a multi-level strategy in FASD prevention (Public Health Agency of Canada, 2005a; Jacobsen et al., 2022; Thomas, Gonneau, et al., 2014). They are considered universal prevention, reaching entire populations (Jacobsen et al., 2022). Most public education related to FASD has been about alcohol consumption.

The Public Health Agency of Canada (2005a) sponsored a study of roughly 70 FASD awareness campaigns carried out in Canada between 2000 and 2004, of which only four had been evaluated. This review resulted in guidelines based on lessons learned from the wide variety of campaign types carried out, including that the programs be evaluated (Public Health Agency of Canada, 2005a). A review of five educational and multi-media FASD prevention campaigns showed some positive effects on knowledge, but no impacts on alcohol consumption behaviours (Crawford-Williams et al., 2015). Mewton et al. (2018), in a systematic review of drug education mass media campaigns in Australia, found them to be ineffective in changing behaviour (Mewton et al., 2018). Jacobsen et al. (2022) concluded that universal approaches such as public education campaigns may reduce likelihood of PAE, but it was difficult to determine the actual effects on FASD incidence rates and it may be necessary for campaigns to be ongoing.

An advantage of universal alcohol education campaigns is that they also reach men (Jacobsen et al., 2022). Some research has emphasized that partners, and more broadly the social norms in pregnant women's environments, can be influential in supporting FASD-preventive behaviors

(Kautz-Turnbull et al., 2021; Bridge, 2011; Lyall et al. 2021; McBride & Johnson, 2016; Brahic et al., 2015; Popova et al., 2022; Astrom et al., 2022). There is also evidence that males make epigenetic contributions to their children's risk of FASD (Liyanage et al., 2017; McBride & Johnson, 2016).

Health warnings and labels

Health warnings on alcohol products and other types of alcohol education campaigns are another form of public education. Many of these efforts have focussed on alcohol's role in cancer or heart disease, or on promotion of safe drinking levels generally for the entire population (e.g, through information on standard drinks and healthy drinking limits; Winstock et al., 2020; World Health Organization, 2022; Hobin et al., 2020; Stockwell et al., 2020). Studies of the effectiveness of these campaigns find that well-designed labels focussed on drinking limits increase knowledge and recall of guidelines but have mixed results in terms of changing drinking intentions or behaviour (Hassan & Shui, 2018; Hobin et al., 2022; Giesbrecht et al., 2022). In general population campaigns increased initial awareness decays over time (Budenz et al., 2022; Jacobsen et al., 2022).

Studies of alcohol education campaigns through container warning labels specifically for FASD prevention have found results similar to those for other health domains: although they may play a role in shifting social norms, they tend not to influence the behaviour of those most at risk for PAE contributing to FASD (Public Health Agency of Canada, 2005a; Thomas, Gonneau, et al., 2014). These campaigns also lose effectiveness over time due to message habituation (Thomas, Gonneau, et al., 2014). Label novelty and quality affect their noticeability and impact on buying intentions (Lacoste-Badie et al., 2022). Thomas, Gonneau, et al. (2014) indicate that alcohol warning labels alone may have limited impact as an FASD prevention strategy (Thomas, Gonneau, et al., 2014). They may, however, play a role in a universal alcohol education campaign.

Public education about FASD and other health issues through alcohol-related messaging have found that such campaigns can meet resistance from alcohol industry lobby groups and political pressures (Heenan et al., 2023; Stockwell et al., 2020). In Yukon, a cancer warning label study received significant industry pressure through criticism of its design, resulting in the study stoppage and then modification (Government of Yukon, 2018; Stockwell et al., 2020). An Australian initiative in 2011-2018 to allow industry self-regulation with respect to messaging about alcohol and pregnancy was found to result in ineffective messaging (Tinawi et al., 2018). O'Brien (2019) notes that this was replaced in 2018 by government-mandated labeling standards, and argues that the industry-led scheme failed to include necessary self-regulatory arrangements, resulting in major lost opportunity for FASD prevention.

Social media platforms and advertising

Use of social media platforms for prevention in other health domains, including smoking cessation, have been found to enhance reach, especially to young people (Latha et al., 2020). Targeted programs, tailored to risk profiles, may be especially effective (Wouldes et al., 2021).

Information campaigns of any media type that attempt to prevent alcohol-related harms occur in the context of significant alcohol advertising. In 2017, global alcohol sales surpassed USD $1.5 trillion (approximately 1.9 trillion CAD; Jernigan & Ross, 2020). In Canada, a 2021 media report revealed that alcohol brands allocated approximately USD $97 million (approximately 121.8 million CAD) to digital media and USD $27 million (approximately 33.8 million CAD) to television advertising as part of their annual expenditure budgets (Connell, 2021). This is highly influential on youth drinking behaviour, including starting to consume and increasing consumption once started (Anderson, de Bruijn, et al., 2009). Jernigan et al. (2017) found that youth were more likely than adults to be reached by internet-based alcohol advertising.

Messaging a shared responsibility and no-blame culture

In efforts to raise awareness and prevent FASD, there is a risk that universal public education campaigns may inadvertently reinforce stigmatization (Bell et al., 2016; Public Health Agency of Canada, 2005a). Given the multiple causal contributors to FASD, many playing out over multiple generations, awareness-raising initiatives can contextualize individuals' needs and challenges within their larger family, social and community systems (Flannigan, Pei et al., 2022), avoiding messaging that criticizes or blames (Okulicz-Kozaryn, 2022).

A non-stigmatizing, no blame approach is inherent in Australia's National FASD Strategic Action Plan 2018-2028 (Commonwealth of Australia & Department of Health, 2018), which provides the key narrative that the responsibility for the prevention of FASD ought not solely to be placed on women who could become pregnant and that interventions could also focus on partners and their families, as well as changing the wider social norms that promote drinking (Commonwealth of Australia & Department of Health, 2018).

While Canada's National FASD Month and FASD Day (see Chapter 2; Government of Canada, 2024f) are seen as helpful, interest was expressed in raising FASD and PAE prominence as a year-round public health concern. Engagement participants supported the use of non-stigmatizing and trauma-informed prevention campaigns to improve public awareness about PAE and FASD. Given the expense of public information campaigns, it would be important to verify that they are beneficial in terms of raising awareness without stigmatizing, and are linked with supports for women who are and could become pregnant and people with FASD, so the campaigns can ultimately contribute to reducing PAE and FASD.

5.2.3 Approaches for youth

Targeted FASD prevention initiatives are directed to specific groups, some of whom may have specific risk factors such as existing problematic alcohol consumption, or may be more general, for example, all youth of a certain age (Jacobsen et al., 2022). Interventions targeting youth often engage them through school-based education programs, individualized school-based interventions, or social media programming.

Though not specifically about FASD prevention, much research has examined the effectiveness of school-based alcohol prevention programs, with varying results. A broad range of these school-based programs exist, with some focusing on increasing knowledge and awareness about alcohol, and others using cognitive and behavioural approaches such as the development of resistance or refusal skills. They may be teacher delivered lessons, small group sessions by professional counselors, psychological interventions targeted to help people with personality risk factors linked to heavier alcohol consumption, motivational interviewing aiming to help students explore their own behaviour, on-line based interventions or a combination of these.

A systematic review of school-based alcohol prevention programs identified 40 programs that had been evaluated; of these, most (29) were inconclusive while three programs had good evidence in favor of reduced or less risky alcohol use (Lee et al., 2016). Another systematic review of school-based alcohol and drug prevention programs found that 58% of the programs demonstrated some positive effects, with some showing stronger results than others (Agabio et al., 2015). Similar results were found in a Cochrane review, with six of the 11 trials evaluating alcohol-specific interventions showing some evidence of effectiveness within certain subgroups, compared to a standard curriculum, and 14 of the 39 more generic behaviour risk prevention programs resulted in significant reductions in some drinking related outcomes for some subgroups of pupils (Foxcroft & Tsertsvadze, 2012). Another review of school-based alcohol prevention interventions found small, but significant effects of the interventions, with positive effects on only some outcome measures (Strøm et al., 2014). A more recent meta-analysis of 66 studies found moderate to low quality evidence of little to no benefit from multi-substance use (alcohol, tobacco and drug) prevention program which offer individual-, family- and school-based interventions to prevent multiple risk behaviours (Tinner et al., 2022). Tinner et al. (2022) concluded that more trials to produce better evidence are needed as even a “small benefit of universal interventions can have high public health benefit” (p. 2). Effectiveness of school-based alcohol education programs could be improved by involving students in program design (Dietrich et al., 2016).

A systematic review of 70 alcohol education programs targeting young people 15-24 across a variety of mainstream and novel contexts (school and community such as aquatics) found that recent programs (2010 to 2020) were more likely to report benefits on behaviour and amongst these, most (71%) were either entirely online, or involved an online component. Though promising, the authors expressed some caution with implementation of interactive online components to ensure the nature of interaction is suitable and effective (Calverley, 2021). De la Rosa et al. (2023) found similar results in a scoping review of eight programs with online and mobile psychosocial preventive interventions, with six of eight programs showing positive results. It was less clear how much of the success of these programs could be attributed to the use of social interaction features.

Identification of the most effective elements of interventions aimed at preventing alcohol use and abuse may be most helpful for designing FASD prevention strategies. Hennessy & Tanner-Smith (2015) examined 17 school-based brief alcohol interventions and found that individually delivered, but not group, programs were consistently effective and associated with significant reductions in alcohol use, although it is possible that the type of intervention and not the individual/group format difference explained this result (e.g. if the most effective interventions were generally delivered individually and not in group formats). An analysis by Stigler et al. (2011) identified elements that appear to be more effective, including cultural appropriateness and training and support for facilitators. Programs that are theory-driven, delivered over several sessions and maintained over several years, are interactive and incorporate more than one strategy such as, addressing social norms, building social resistance skills, and using peer leaders are most effective (Stigler et al., 2011; Botvin & Griffin, 2007). Especially when co-designed with community involvement, programs can improve alcohol knowledge, attitudes and behaviors among Indigenous youth (Snijder et al., 2020; Comeau et al., 2005).

Promising results have been identified in reviews of preventive interventions specifically for youth with specific personality risk factors that make them more vulnerable to problematic alcohol consumption and alcohol-related harms (Conrod, 2016; Edalati & Conrod, 2019). These personality-targeted interventions are designed to develop cognitive and behavioral coping skills to resist social pressures and develop safer choices. While personality-targeted brief psychological interventions have been shown to be effective in reducing alcohol consumption in girls and women of all ages, and to have sustained effects up to 7 years post intervention (Newton et al., 2022), research has yet to demonstrate direct impact on FASD related outcomes. Linking large prevention trials to administrative health databases in the future might provide opportunities to evaluate the effects of targeted prevention on multi-generational FASD outcomes.

Combining school and home-based intervention may also increase longer-term maintenance of prevention effects of alcohol consumption in youth (Cairns et al., 2014) but few programs of this nature have been evaluated (Tinner et al., 2022).

Although different from the programs discussed above, which were aimed at reducing risky alcohol consumption in general, engagement participants often raised the possibility of including education about FASD and the harms of PAE during classes on biology or reproductive health. At the same time, engagement participants also warned of the risk that these awareness-raising efforts might inadvertently stigmatize students with FASD who may be in the classroom. For example, one participant urged:

> *Please, please be aware that children with FASD in the classroom will be affected by who [addresses it] and how awareness in school is done.*

Another stated:

> *There are people with FASD in the classroom and this can be very value laden and stigma producing - you need to consider the biases, beliefs and actions of other students including outside that class discussion.*

Reaching at-risk populations through targeted prevention campaigns is pertinent because of their heightened vulnerabilities. Younger people, those with cognitive disabilities, and those with a history of alcohol dependence have been shown to be particularly vulnerable to alcohol-related problems, experiencing disproportionate harm and being more susceptible to alcohol marketing (Babor et al., 2017). A review of studies of sexual health education for those with neurodevelopmental (autism) and intellectual disabilities found the majority of the studies demonstrated improvement in sexual health knowledge and all of the studies that included behavioral outcomes reported improvements, but there is a need for further evaluation (Schmidt et al., 2020).

Key Findings:

Ongoing general public information campaigns about FASD may increase awareness, but more research is needed regarding its effect on PAE.

Multi-dimensional interventions targeting specific at-risk populations have demonstrated some success in reducing PAE.

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. While such interventions have been shown to reduce alcohol use and alcohol-related harms, research is needed to evaluate their effectiveness in preventing drinking during pregnancy or FASD.

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.

5.3 Approaches for women of child-bearing age

5.3.1 Preconception interventions

Systematic literature reviews of studies of women who consume alcohol during pregnancy found that the main themes in their reasons for drinking were lack of knowledge about the effects of alcohol on the fetus and lack of skills to resist social pressure (Hammer & Rapp, 2022; Popova et al., 2022). Some programs addressing FASD have focused on young women prior to conception, aiming to address these reasons. Chang (2023) reviewed trials of five preconception interventions that used motivational interviewing and cognitive behavioral strategies targeting effective contraception and reduction of alcohol use. Most were based on Project CHOICES (see below). The trials showed improved effective contraception in women of childbearing age who were sexually active, with inconsistent effects on alcohol use. Reid et al. (2021) reviewed preconception interventions to reduce the risk of alcohol exposed pregnancies, finding that many interventions, including multi-session, single session and telephone and web-based interventions reduced PAE risk during the preconception period, mainly through preventing unplanned pregnancy, driven by changes in contraceptive behavior. Changes in alcohol consumption were limited (Reid et al., 2021). Access to reproductive care is further discussed in section 5.5.

Project CHOICES was initially developed in Indigenous contexts in the US, Australia and New Zealand (Espiner et al., 2022). It has been widely adapted and adopted, including in Manitoba, where it is part of the provincial FASD strategy. Sexually active youth and young adults who use alcohol may receive up to four motivational interviewing sessions with counselors; topics covered include FASD prevention (Government of Manitoba, 2010).

5.3.2 Screening for alcohol use in pregnancy

Screening for alcohol use in pregnancy is a primary prevention strategy that involves identifying pregnant women who are consuming alcohol in order that appropriate interventions can be used to reduce PAE (Doherty et al., 2019; Floyd et al., 2009; Graves et al, 2020; Dozet et al., 2023). Here, we document how screening during contacts with health practitioners can aid prevention, as well as some of the challenges screening poses.

Being asked about alcohol consumption is considered acceptable by most pregnant women (Howlett et al., 2017; Toquinto et al., 2020). Although practice recommendations indicate routine screening by physicians, obstetricians, midwives, and/or nurses for all pregnant women, in practice it may not always occur (Dozet et al., 2023; Hanlon-Dearman et al., 2015, Leruste et al., 2024).

The Canadian Society of Obstetricians and Gynecologists has issued PAE screening guidelines based on strong evidence, stating that:

> All pregnant women should be questioned about alcohol use by asking a single question (in a nonjudgmental way) to determine use. If women consume alcohol, one of the following screening tools should be used: AUDIT-C or T-ACE, or another evidence-based screening tool available in the provincial/territorial prenatal record. If women consume alcohol, the pattern of use should be established to screen for binge drinking. (Graves et al., 2020, p.1159).

To be effective, these screening guidelines must be fully implemented. A 2005 survey of health professionals (family physicians, pediatricians, psychiatrists, gynecologist/ obstetricians, midwives) conducted by PHAC prior to the release of the screening guidelines showed that while 94% indicated they routinely asked about alcohol consumption during pregnancy; standardized screening tools were used by 62% (Public Health Agency of Canada, 2005b). A more recent online pan-Canadian survey of 588 respondents who provided care to pregnant women or to women of childbearing age (midwives, obstetricians, family physicians, and nurses) found that although 95% of practitioners were questioning pregnant women about PAE, 38% were using a screening questionnaire for all pregnant women and 45% were using one when alcohol consumption was reported (Sword et al., 2020). These studies focused on healthcare practitioners and not patients' reports. Although not Canadian data, an Australian study of pregnant women's reported receipt of guideline-recommended questions about PAE during pregnancy found that less than two thirds were questioned about alcohol consumption at their first antenatal visit, and less than 10% after that (Doherty et al., 2019).

Even when providers are aware of the role of PAE in FASD and that many pregnant women consume alcohol, they may not consider it likely among their own patients (Burd & Popova, 2022). The profile of women who consume alcohol during pregnancy may not be evident to practitioners, especially if they are either unaware of FASD or influenced by their own personal experiences or prevalent demographic stereotypes (Doherty et al., 2019; Bagley & Badry, 2019). In the 2005 PHAC survey mentioned above, patients most likely not to be questioned were over 35, highly educated and high SES, social drinkers, and those with a history of sexual or emotional abuse (Public Health Agency of Canada, 2005b). The Australian study of pregnant women's reported receipt of guideline-recommended questions about PAE during pregnancy found that queries were more often addressed to disadvantaged and Indigenous women (Doherty et al., 2019).

Other barriers to screening for alcohol use in pregnancy include practitioner constraints, unplanned pregnancies, delayed access to prenatal care, and stigma associated with substance use in pregnancy (Dozet et al., 2023). Prenatal screening may be limited by time constraints, especially among physicians (Dozet et al., 2023). To maximize efficiency, a two-step process has been suggested, as noted above in the SOGC Guidelines, with a positive response to a single question screen followed by more detailed questions on exposure (Chu et al., 2023).

A systematic review of electronic screening and brief interventions for problematic alcohol consumption in the general population found strong evidence that they reduce excessive alcohol consumption (Tansil et al., 2016). The authors observe that this is an alternative way to conduct screening and brief intervention that might help to support universal screening by addressing time constraints in clinic.

The Canadian Society of Obstetricians and Gynecologists Guidelines recommend periodic alcohol screening of all women who could become pregnant, with every clinical encounter seen as an opportunity to discuss alcohol use (Graves et al., 2020).

Once PAE has been detected through screening, the SOGC guidelines recommend that the practitioner either conduct a brief intervention (e.g., of the type assessed by Popova, Dozet et al., 2023) or refer the pregnant woman for substance use disorder treatment (Graves et al., 2020). Similar recommendations for routine screening followed by appropriate intervention have also emerged in psychiatry and psychology (Thibaut et al., 2019). The Canadian survey of midwives, obstetricians, family physicians, and nurses found that about two-thirds of respondents had provided brief intervention and referral to harm reduction or treatment services (Sword et al., 2020).

An underlying issue is that current challenges with access to primary care for many Canadians impedes efforts to ensure systematic screening for PAE.

5.3.3 Preventive interventions during pregnancy

Erng et al. (2020) reviewed and compared the results of 34 intervention studies using different strategies to prevent FASD by influencing alcohol use among pregnant women. Fifteen studies employed brief intervention methods, six used long-term/intensive strategies, five were educational interventions, three used counseling approaches, two evaluated multicomponent interventions, and three assessed nutritional supplementation interventions. (The use of medications and supplements are further discussed in Section 7.4). Intervention effectiveness varied according to participants' characteristics: brief interventions were effective among pregnant women with higher initial alcohol consumption, polysubstance use, and partner involvement. Longer term case management intervention with pregnant women with polysubstance use was effective in part because it addressed the interplay of factors involved in the health and social well-being of women and their families (Erng et al., 2020). This is consistent with findings of a systematic review of factors associated with FASD risk: prior mental illness, anxiety, depression, exposure to abuse and/or domestic violence and alcohol consumption behaviours of partners and family members were strong predictors of risky alcohol consumption during pregnancy and therefore associated risk of FASD (Ward et al., 2021). Popova, Dozet et al. (2023) conducted a systematic review of brief interventions in FASD, finding that they had modest effects in increasing the odds of abstinence during pregnancy, but no significant influence in decreasing the mean number of drinks per week among those that used alcohol. Brief interventions also showed some effect in reducing preterm births.

Oh et al. (2022), in a meta-analysis of alcohol abstinence interventions involving digital messages delivered on various platforms (computer, tablet, email, text) between pregnant patients and healthcare providers or professionally developed services, found effects on self-reported abstinence for computer/internet-based platforms. Too few studies of texting were available to draw a conclusion. A systematic review of screening and brief pre-recorded interventions delivered through a computer or tablet to women with problematic alcohol or drug consumption during a prenatal visit or postpartum hospital stay found some reductions in substance use that were sometimes maintained at follow-up. One intervention in this review included pre-set text messages customized to screening results as an intervention arm, but the study focused on intervention feasibility and on cannabis use as an outcome, so no PAE-relevant outcomes were reported (Wouldes et al., 2021). These authors emphasize that this type of intervention has the potential to reduce health inequities in access to substance use services, but cautioned that more study is warranted of their effectiveness in populations facing multiple life and health challenges (Wouldes et al., 2021).

Another prevention strategy targeting pregnant women is staff intervention training in alcohol-selling premises. Management and server staff are trained to discourage alcohol consumption by visibly pregnant customers. Some positive effects on drink refusal behavior have been found (Dresser et al., 2011).

Jacobsen et al. (2022) reviewed studies using a mix of approaches to PAE prevention including product warning labels, awareness and educational posters in women's restrooms, multilevel FASD awareness programs, educational interventions for healthcare professionals, web-based and/or mail-based interventions, video, brochure, or motivational interviewing and telephone or in-person interventions. The authors found that warning labels decreased the odds of prenatal alcohol consumption, particularly prenatal binge drinking, but it was difficult to determine the actual effect on the incidence of FASD. Even very brief interventions, especially motivational interviewing techniques, seemed to be effective in reducing PAE risk. Increasing effective contraceptive behaviour was easier and more effective than decreasing alcohol use (For further discussion on this see section 5.5). Overall, the more individualized and tailored intervention programs were (and therefore the more resource-intensive), the higher the reduction in PAE (Jacobsen et al., 2018).

Key Findings:

Systematic and universal screening for alcohol use by healthcare providers before conception and during pregnancy, and providing brief interventions and referrals for treatment as needed, offer an opportunity to increase awareness of FASD and prevent PAE.

5.4 Consistent prevention messages from healthcare providers

Healthcare providers have important roles to play in FASD prevention. Key professional bodies including the Society of Obstetricians and Gynecologists of Canada (Graves et al., 2020), and the Canadian Medical Association (Canadian Medical Association, 2024) have published clinical practice guidelines for counseling and screening for Substance Use Disorder or alcohol use when pregnant. The Canadian Centre on Substance Use and Addiction's document, entitled *Canada's Guidance on Alcohol and Health*, buttresses these positions by also recommending abstinence from alcohol during pregnancy and breastfeeding (Paradis et al., 2023).

Medical practitioners have a role to play pre-conception and for all patients in conveying clear and consistent messages about alcohol consumption to anyone who may become pregnant or a partner of a pregnant woman (Graves et al., 2020). However, only fifteen percent of Canadians report that, in the last 12 months, a doctor or any health professional spoke with them about alcohol use, a lower proportion than in other Commonwealth countries (Canadian Institute for Health Information, 2024).

Despite the clear recommendations advising abstinence from alcohol during pregnancy, it seems that some medical practitioners continue to suggest that there is a safe threshold for alcohol consumption during pregnancy. A main theme in Popova et al.'s (2022) systematic literature review of reasons for consuming alcohol while pregnant was having received insufficient or mixed advice from medical practitioners (Popova et al., 2022). During the engagement process, several participants reported that healthcare providers were advising that light drinking was acceptable:

> *Healthcare professionals are still telling people it's ok to drink just not get drunk.*

A study of expectant couples screened for alcohol use found that receipt of confusing messages about alcohol consumption during pregnancy was a key theme in their reactions to the screening (Howlett et al., 2017).

A 2005 survey of health professionals (family physicians, pediatricians, psychiatrists, gynecologist/ obstetricians, midwives) conducted by PHAC showed that while 92% indicated they asked about alcohol consumption during pregnancy, 88% provided advice consistent with no-consumption guidelines. Regional variations were found, with 75% of healthcare professionals in some regions providing guideline-consistent advice, compared to over 90% in others (Public Health Agency of Canada, 2005b).

5.4.1 Training of healthcare providers

Studies of healthcare providers' messaging confirm the need for professional development support around FASD. Although health professionals are a preferred source of information about alcohol use in pregnancy (Tsang et al., 2020), they have been shown to lack confidence in their abilities to ask women about alcohol use during pregnancy, leading to reluctance to intervene. Further professional development for various types of professionals has been recommended (Okurame et al., 2022; Tsang et al., 2020; Poole et al., 2016; Payne et al., 2014).

In ensuring consistent messaging, it is important that health providers recognize that women's alcohol consumption behaviours during pregnancy are embedded in their broader cultural contexts and the relationships women have with others in their social environment, including their healthcare providers (Gibson et al., 2020; Meurk et al., 2014).

In a quasi-experimental evaluation of a multi-level FASD prevention campaign of which one component was provider education, physicians and midwives were trained in one city, while those in a comparison city received no education. The trained health providers had a higher post-campaign probability of having advised pregnant women to abstain from alcohol than those in the comparison city. Pregnant women in the intervention city had a higher probability of having received only correct advice about alcohol and pregnancy (Bazzo et al., 2015). This study was conducted in Europe, where guidelines about alcohol consumption during pregnancy may be inconsistent (Mamluk et al., 2017).

Training can improve providers' capacity to screen. Evaluation of an FASD training for health and education professionals from Australia and New Zealand found self-reported practice changes in asking about alcohol use during pregnancy (Reid, White et al., 2019). Similarly, training on FASD improved nurses' and nursing students' knowledge of FASD and intervention confidence (Zoorob et al., 2014).

Resources have been developed to help make practitioners more skilled and comfortable in addressing substance use issues in pregnancy (Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale; 2022, Nathoo et al., 2018; Government of Alberta, 2017c). In Alberta, the Prevention Conversation targeted healthcare professionals and social service providers to develop capacity for engaging women in supportive and non-judgmental conversations about alcohol use and pregnancy. The evaluation documented that over 7,800 professionals and 1,500 post-secondary students in health, education, addictions and mental health, child intervention services and justice received this training, and that it had been helpful in increasing awareness and understanding of FASD. However, challenges were reported with reach to medical professionals, especially doctors (Government of Alberta, 2017a). The reluctance of health professionals to ask and advise women could be overcome through undergraduate and postgraduate education of health professionals (Poole et al., 2016) and embedded systems at the workplace to improve information seeking and recording (Tsang et al., 2020).

Key Findings:

There is regional variability in the uptake of the Society of Obstetricians and Gynecologists of Canada Guidelines regarding screening for alcohol use during pregnancy. Many physicians in Canada do not ask about alcohol use and some continue to give mixed messages regarding alcohol use during pregnancy.

A comprehensive approach to physician education on screening for alcohol use and counseling patients to abstain from alcohol during pregnancy in a non-judgmental, and supportive manner would be beneficial, as would the recognition of screening for alcohol use as a standard aspect of professional practice.

5.5 Access to reproductive and mental health care and substance use treatment

Many of the effective interventions mentioned above for pregnant women depend upon connection to healthcare and community services. Access to primary health care, however, is a challenge across Canada. Canadians with a lower income, First Nations people living off-reserve, and people living in Nunavut and the Northwest Territories are less likely to have access to a regular healthcare provider compared to the rest of Canada (Statistics Canada, 2023). A case-controlled study in Manitoba found that women who had given birth to a child with FASD had lower socio-economic status, higher rates of inadequate prenatal care, and were more likely to have mental health disorders and involvement with the child welfare system than the women in in the matched control group (Singal et al., 2019).

5.5.1 Access to reproductive care

Unplanned pregnancy is fairly common, meaning that PAE may occur while a person is unaware of being pregnant. In North America from 2010-14 among women 15-44 years old, 36% of pregnancies were unintended, and a third of those, 36%, ended in abortion (Bearak et al., 2018). Therefore, 23% of North American pregnancies that resulted in births 2010-2014 will have been unplanned. In Canada, 58% of unplanned pregnancies occur in women aged 20–29 years (Black et al., 2015). During the period that a pregnancy is unknown, people are likely to continue their usual alcohol consumption behavior.

Thirty-one percent of Canadian women of reproductive age consume alcohol weekly, and 18% report drinking levels exceeding the (then current) *Canada's Low-Risk Alcohol Drinking Guidelines* (Varin et al., 2021). Most (87%) report that they stop drinking when their pregnancy is confirmed (Government of Manitoba, n.d.-a, Popova et al., 2022).

One-quarter (25%) of non-pregnant women who did not wish to become pregnant reported not using any form of contraception the last time they engaged in sexual intercourse (Statistics Canada, 2019). Hulme et al. (2015) interviewed a group of healthcare providers and representatives of organizations in reproductive health from various regions in Canada, finding that the main barriers to accessing contraception are costs and access to regular primary care providers, especially among vulnerable populations including new immigrants, and people in small rural, Northern and Indigenous communities (Hulme et al., 2015). Sexual health education is reported as inconsistent, even within provinces (Hulme et al., 2015). Healthcare provider competence and attitudes affect the quality of contraception access: physician bias and outdated practices were cited as significant barriers to quality (Hulme et al., 2015). Barriers to accessing contraception among adolescents include lack of transportation, difficulty navigating large healthcare systems, appointment availability, confidentiality concerns, and cost (Reilly et al., 2024).

According to the interviewees in Hulme et al.'s study (2015), access to family planning services in Canada would be enhanced by multiplying entry points, including expanded scope of practice of nurses, nurse practitioners and pharmacists, alongside telephone and virtual healthcare consultations (Hulme et al., 2015).

Among unintended pregnancies, 69% are attributed to imperfect use or failure of contraceptive methods (Black et., 2015). Hormonal contraception is the most effective mechanism for preventing pregnancy, with long term hormonal methods not requiring daily administration, being the most effective (Teal & Edelman, 2021).

As of 2023, eight provinces allow pharmacists to prescribe hormonal contraception; Ontario, Manitoba and the three territories do not (Canadian Pharmacists Association, 2023). In Alberta, Saskatchewan, Quebec and Nova Scotia, pharmacists are also able to prescribe hormonal contraceptives that do not require daily administration (e.g., vaginal rings, transdermal patches; Soon et al., 2021).

The national, universal pharmacare plan will include contraception coverage, reducing the cost barrier. Current typical costs of contraception are: oral birth control pills: up to $300 per year; hormonal intrauterine device (IUD): up to $500 per unit; copper intrauterine device (IUD): up to $100 per unit; hormonal implant: up to $300 per unit; hormonal vaginal ring: up to $300 per year; contraceptive injection: up to $150 per year; emergency contraceptives: about $30 per dose (Department of Finance Canada, 2024b).

All Canadian provinces subsidize emergency contraception, that is contraception used post-intercourse, although with different over-the-counter versus behind-the-counter status, and with differing eligibility criteria for coverage (e.g., being in receipt of income assistance, having overspent the pharmacare deductible, age under 25; the Territories were not included in this study; Lee & Norman, 2022). In a study of barriers to prescribing a prescription-only emergency contraceptive in BC, interviews with patients, community pharmacists, and prescribers found that patients felt shame and stigma in accessing the prescription (Chan et al., 2021). A study of family physicians in New York found significant negative attitudes towards pre-prescribing emergency contraception, reflecting moral judgment of sexually active women (Karasz et al., 2004).

Access to contraception and pregnancy tests alongside sexual and reproductive health education and care are important from a health-promoting and self-determining women's determinants of health perspective as well as in preventing PAE (Poole et al., 2016; Public Health Agency of Canada; 2008; CanFASD, 2013; Wolfson et al., 2022).

5.5.2 Access to mental health care and substance use treatment

Access to adequate mental health care and substance use treatment is also key to FASD prevention among people who are experiencing these challenges. One of the main reasons for alcohol consumption during pregnancy are psychological and mental health circumstances: alcohol as a coping mechanism for adverse events during the pregnancy, unplanned or unwanted pregnancy, or alcohol dependence or addiction (Popova et al., 2022). Access to adequate services is hampered by the intertwined health and social stability issues faced by people with substance use and mental health problems (Flannigan, Murphy et al., 2023; Lyall et al., 2021; Rutman et al., 2020).

Mental health and substance use disorder treatment are key components of FASD prevention and are recommended as a priority for women affected, not only during pregnancy but also following birth and throughout their parenting journey (Burd & Popova, 2022). In a systematic review of gateways and barriers to substance use disorder treatment for pregnant women and mothers, Choi et al. (2022) found that the main access barriers included fear, stigma, potential for charges of child abuse, siloed services and cost. Additionally, data from a recent national survey shows that access to mental health care in Canada is uneven, with more barriers experienced by visible minorities and Indigenous Peoples, younger adults and those with lower incomes. Most commonly encountered barriers are long waitlists (62%), financial barriers (58%), lack of local resources or professionals (47%), and difficulty finding specialists (41%; Faber et al., 2023). McPherson & Boyen (2017) report that access to substance use disorder treatment is similarly limited, with estimates showing that two-thirds of Canadians with substance use disorder are not able to access treatment. Barriers, including wait lists, costs, admission requirements and stigma, are more frequently experienced by Indigenous Peoples, people who are LGBTQ, women, women with children, people in poverty, people who are incarcerated, and members of minority racial or ethnic groups, those in rural communities and those who are unhoused (McPherson & Boyne, 2017). Barriers to access for mental health and substance treatment are compounded by rapidly increasing population demand (Faber et al., 2023; McPherson & Boyne, 2017).

In an American study, states that adopted multi-pronged prenatal substance use policies, including treatment and supportive services, experienced an increase in substance use treatment admissions, whereas states that had criminalized prenatal substance use showed declines (Kozhimannil, 2019).

Longer-term substance use disorder treatment programs pose particular difficulties for people with children, who may find separation from their families for the treatment duration to be a barrier. In Québec, the Mère-enfant residential treatment program addresses this issue for children (but not partners). It is available in limited capacity for substance-dependent mothers and their children 0 to 6. Children in this three-to six-month program receive assessment and stimulation (Gouvernement du Québec, 2024).

People with FASD often face challenges with mental health and substance use disorders and many experience additional barriers in accessing services (Anderson et al., 2019; Choate et al., 2024). Among clients in a residential, wraparound program for women and girls with complex challenges, those with possible or diagnosed FASD were less likely to access recovery meetings and more likely to engage in substance use after discharge than clients without FASD. This may be related to FASD-linked challenges such as weaker social networks, difficulty navigating siloed services, and lack of professionals' understanding of FASD (Flannigan, Murphy et al., 2023).

Key Findings:

Providing easy access to effective contraception is an important part of an overall strategy to prevent PAE. This approach is applicable to the general population and may be a particularly valuable option to make available to people who could become pregnant and who have a substance use disorder, along with other supports and treatment for their alcohol use. Longer-term options (e.g. patch or IUD) and emergency contraception are part of reproductive health, and help to reduce the risk of PAE occurring in the case of unknown and unintended pregnancies.

Timely access to mental health care and substance use treatment during pregnancy is an integral component of FASD prevention. People who are most at-risk, including those with FASD themselves, may also have the most difficulty accessing mental health care and treatment for substance use disorders. Longer-term treatment programs can be a particular challenge for parents as separation from their children for the duration of treatment is a barrier.

5.6 Holistic, wraparound supports to address risk factors

The development of wrap-around programs as a component of FASD prevention is part of moving away from a mode of individual blame and responsibility, toward a compassionate, trauma-informed, and integrative approach that addresses health inequities (Morton Ninomiya et al., 2023; Lyall et al., 2021; Pei, Carlson et al., 2019; Stoner et al., 2023). Wraparound programs are consistent with the dimensions of the Ottawa Charter for Health Promotion (Government of Canada, 2017), and the Quintuple Aim for healthcare improvement (Nundy et al., 2022; Mulligan et al., 2024), a women's determinants of health perspective (CanFASD, 2022) and, when implemented in Indigenous communities, with Indigenous women's determinants of health, particularly wraparound support and holistic services (Pei, Carlson et al., 2019; CanFASD, 2022).

As mentioned in Chapter 3, wraparound programs have been shown to contribute effectively to prevention and intervention efforts in FASD (Pei, Carlson et al., 2019; Rutman, 2013; Rutman et al., 2020; Rutman et al., 2021).

5.6.1 Effectiveness of holistic, wraparound supports

Wraparound programs implement linkages and partnerships among multiple service providers for pregnant women facing a diversity of challenges, helping address siloed service delivery, which is also addressed in Chapter 7 (Rutman et al., 2021; Centre of Excellence for Women's

Health, 2022). Such programs ensure inclusion of family, caregiver and community support for affected individuals to reinforce the sense of connectedness necessary for growth (Umlah & Grant, 2003) and attention to the needs of each individual (Kanda et al., 2022). Evidence suggests that it is the integrated service delivery approach that attracts and retains women in these programs, perhaps allowing them to reach women who would not otherwise be reached (Hubberstey et al., 2019; Rutman & Hubberstey, 2019).

Wrap-around programs offer multiple services in one location, including health, child welfare, addiction services, as well as support for basic needs such as housing and food security (Rutman et al., 2020; Hubberstey et al., 2021). They often operate on a hub or partnership model, with programming that integrates with prenatal healthcare, midwifery programs, public health, addictions supports and mental health supports in local communities (Hubberstey et al., 2021). Their integrated service delivery design is adapted for people at risk; not having to access services at multiple entry points means these people are less likely to fall through the cracks between systems. In addition, wrap-around programs can support prevention by aiming intensive supports toward women with an affected child, or women who themselves have FASD, perhaps helping to prevent more cases (Flannigan, Wrath, McFarlane et al., 2021). Engagement sessions also noted this advantage of wraparound services, observing that they can help to improve general access to mental health and substance use supports (e.g. counseling, substance use treatment, social supports). This can benefit the broader community, but also help to reduce FASD risk by acting upstream.

The importance of ensuring strong partnerships among linked services providers in wrap-around programs has been identified in the literature (Hubberstey et al., 2021. For example, although an advantage of wraparound services is their capacity to engage with people who are struggling with addictions, there can still be problems in accessing appropriate treatment at the opportune time. An engagement participant stated:

> *Access to treatment and detox, in the moment when the person is ready. Hard to find beds when a person is ready to make this type of commitment—often waiting, and the "moment" passes. These barriers to access treatment often mean losing kids to care.*

Hubberstey et al. (2021) identified steady, open communication with partner organizations as key to ensuring seamless access.

An evaluation of wraparound programs delivered in eight communities in six jurisdictions (Rutman et al., 2021), serving women at high risk of having an infant prenatally exposed to alcohol or other substances, found that the participating programs benefited women and their families through: reduced or stopped problematic substance use, improved physical and mental health and access to health services, retained child custody, and/or stronger connection with their children, improved housing, and healthier pregnancies and birth outcomes. The authors report the fact "that clients identified reduced substance use or recovery as their most significant change is all the more noteworthy given that these are not programs with substance use treatment as the focal service" (Rutman et al., 2021, p. IV). Based on analyses of birth outcomes of 408 clients whose infant's birth outcome was known, 73% of infants had a healthy birthweight, and 76% had healthy gestation. Approximately half of clients' infants (49%) required Neonatal Intensive Care Unit care. In terms of PAE, 33% of infants were not substance-exposed, 51% of infants were substance-exposed, and 17% of infants' prenatal substance exposure was unknown. The authors state that these birth outcomes are similar to those reported in previous evaluation studies of wraparound programs for pregnant women with substance use and complex concerns (Rutman et al., 2021).

An assessment of a residential, wrap-around program for pregnant or potentially pregnant women experiencing complex challenges, including substance use, found reduced rates of substance use and justice contact and higher levels of caregiving involvement post-program and at follow-up (Flannigan, Murphy et al., 2023). However, none of these evaluations used a controlled or comparative design, a common quality problem with FASD prevention studies (Symons et al., 2018).

The Parent-Child Assistance Program (PCAP) is a wraparound program aimed at preventing future alcohol- and drug-exposed births. A sub-study of Alberta's 10-Year FASD Evaluation found that after 6 months, 52% of PCAP participants were abstinent from alcohol for at least one month and, after 30 months, 35% were abstinent for at least one month. At 6 months, 39% of non-pregnant women were using an effective method of contraception. In addition, many clients reported improved wellbeing, better participation in educational programs, stronger connection to services, increased employment, stabilized housing, decreased welfare utilization, improved parenting and advocacy skills, and many women resumed care of their children (Abells et al., 2017). Early results of a pilot PCAP program in New Brunswick suggest similar post-program levels of substance-exposed pregnancies and abstinence (Gander et al., 2023).

Engagement participants were highly supportive of wraparound approaches and of PCAP in particular. Its appropriateness for Indigenous contexts, given its alignment with Indigenous women's determinants of health, was also noted. Chapter 3 provides further examples of holistic and culturally adapted wraparound programming in Indigenous communities, including The Eastern Door in New Brunswick's Elsipogtog First Nation and the Wilp Dim Gaymaxghl Laaxws Ahl Majagaleehl Gitxsan in British Columbia. The Eastern Door has implemented an effective holistic FASD healing model that centers prevention around an Indigenous perspective of health and wellbeing (Cox, 2023). Results of a 20-year active case ascertainment prevalence study indicate that this approach has been effective in lowering rates of FASD in the community (Cox, 2023). Wilp Dim Gaymaxghl Laaxws Ahl Majagaleehl Gitxsan adapts the Parent-Child Assistance Program model to include a longer follow-up and culture-driven programming (documented in Wolfson, Van Bibber et al., 2019).

An economic modeling study estimated that, compared to the incremental lifetime cost of FASD, the Alberta PCAP is cost–effective and its net monetary benefit, significant (Thanh et al., 2015). A social return on investment (SROI) analysis of a subset of staff-reported outcomes of participants in the HerWay Home program also found a net benefit, of a social value of approximately $4.45 for every dollar invested in the program (Hubberstey & Rutman, 2020).

5.6.2 Steps to strengthen community capacity to offer holistic, wraparound support

Although wraparound programs supporting people at risk have been shown to be acceptable (including in Indigenous communities: Pei, Carlson et al., 2019) implementable, and possibly effective in reducing FASD rates, they are also resource intensive and require significant inter-agency collaboration (Prouty et al., 2019; Wolfson, Poole, et al., 2019; Hubberstey et al., 2021).

In a study of the implementation of wraparound programs in six jurisdictions, partnerships were found to have been most often with child welfare, health services (e.g. primary care, public health and perinatal care) and specialized health services such as mental health services and addictions. Partnerships were more easily created with services within the same organizational entity, such as a regional health authority. The wraparound FASD programs had created fewer partnerships with housing, income assistance, Indigenous cultural programming, infant development and legal services. Partnerships sometimes involved community organizations active in serving the same clientele. Written partnership agreements among entities not part of the same organization were established to help define roles, facilitate referral pathways, and define limits of client confidentiality. Informal collaborative arrangements between the programs and partnered services were developed through senior staff, relying on mutual goals, shared clientele, common values and approaches, and a sense of trust and common purpose. Ongoing dialogue among partners helped overcome barriers encountered. These were most frequent between the programs and child welfare systems, in part because of high turnover rates in the latter and differing levels of risk tolerance for children (Hubberstey et al., 2021).

At a broader level, Flannigan, Wrath, McFarlane et al. (2021) examined the network structure of Alberta's FASD programming, which supports wraparound programs including program sites in Indigenous communities. The network was developed to enact the 10-Year Strategic Plan, which includes five pillars: awareness, prevention, assessment and diagnosis, support for individuals and caregivers, and organizational learning (Government of Alberta, 2017c). The regional networks contributed cross-disciplinary and cross-sectoral programming to all four service delivery pillars. Evaluations at several midpoints and at 10 years showed the networks to have been effective in creating and implementing locally-adapted programming, while maintaining a high level of fidelity to the wraparound PCAP model (Abells et al., 2017).

Funding of holistic, wraparound programming is important for the support workers who connect clients to the various agencies involved in the partnerships, as well as to offset the cost of partnerships themselves (Abells et al., 2017). In Alberta's 10-Year FASD Strategic Plan, a total of $20.5M ($2.05M/year) was allocated to operate the regional FASD networks, whose activities include PCAP programming among others (Government of Alberta, 2008).

Key Findings:

Prevention of FASD includes effective supports to address the individual, social, cultural and environmental risk factors for risky alcohol use. Substance use disorders frequently reflect a complex mix of risk factors such as trauma, abuse, unmet mental health problems, and poverty. Effective prevention of FASD in these cases requires holistic, trauma informed, culturally safe wrap-around support that addresses risk factors. Wraparound or integrated service delivery, in which multiple services are delivered together in one site as opposed to being offered by multiple agencies in different locations, is more effective.

There are fewer programs to help women postpartum maintain or initiate healthy changes and to support the development of their children. Research on these programs is limited, but an encouraging model identified is the Parent-Child Assistance Program (PCAP).

Steps that would strengthen community capacity for prevention are adequate, predictable, and sustained funding of community organizations that deliver holistic wraparound support, strong partnerships between community organizations and government funding agencies, and good systems for quality assessment and accountability.

5.7 Alcohol policy

Public health approaches to reduce the many documented harms associated with alcohol consumption call for governmental policies that shape the accessibility of alcohol and the normalization of its use (World Health Organization, 2018; Anderson, 2009; Caswell & Thamarangsi, 2009; Laranjo et al., 2024). Earlier in this chapter, we reviewed evidence on the effectiveness of educational interventions about alcohol's health effects, notably product labeling, as FASD prevention strategies; in this section, we turn to macro-level policies on alcohol accessibility and marketing. While education and public awareness have limited effects on alcohol-related behaviours, policies limiting alcohol accessibility and marketing consistently reduce alcohol related harms.

The WHO's Global Alcohol Action Plan 2022-2030 (WHO, 2022) proposes six areas for action: high-impact strategies and interventions, advocacy and awareness, partnership and coordination, technical support and capacity-building, knowledge production and information systems, and resource mobilization. With a focus on integrating alcohol policy within broader public health agendas, it sets specific targets for reducing alcohol consumption and improving health outcomes. This plan recognizes FASD as among the population health harms due to alcohol (World Health Organization, 2024).

The WHO notes that, among decision-makers and the general public alike, awareness and acceptance of the overall negative impact of alcohol consumption on population health is low. Alcohol marketing combined with limited, weak and unenforced government policy contribute to deprioritizing public health efforts to reduce harms (World Health Organization, 2024). While cost-effective interventions to reduce harm exist, most countries lack adequate policies due to insufficient political will, limited capacity to support implementation, and economic challenges in responding within free-trade environments and the alcohol industry's influence on policy making (Casswell & Maxwell, 2005; Casswell & Thamarangsi, 2009; Jankhotkaew et al., 2022; Muhlack et al., 2016); Anderson, Chisholm, et al., 2009).

Research evidence indicates that national alcohol policies involving government-controlled marketing (Manthey et al., 2024; Esser & Jernigan, 2014), pricing/taxation (Kilian et al., 2023), availability restrictions (e.g. number of days per week alcohol can be sold; Kilian et al., 2023), and alcohol content restrictions (Jones-Webb et al., 2014) form an effective, multipronged approach to reducing health harms of alcohol consumption in the general population and some subpopulations (World Health Organization, 2024; Berdzuli et al., 2020; Neufeld et al., 2021; Giesbrecht et al., 2024). In an umbrella review of reviews, the following were identified as effective control measures: 1) community mobilization; 2) multi-component interventions in the drinking environment; 3) restricting alcohol advertising; 4) restricting on- and off-premise outlet density; 5) police patrols and ignition locks to reduce drink driving; and 6) increased price and taxation including minimum unit pricing (Siegfried & Parry, 2019). As some of these components are intertwined, care must be taken to balance them appropriately; in Scotland for example, insufficient attention to controlling alcohol availability has worked against pricing and marketing control initiatives (Dimova et al., 2023). Policy enforcement has been shown to be key in ensuring population health benefits (Thomas et al., 2012; Jones-Webb et al., 2014). Countervailing influences from the alcohol industry appear to also be influential in shaping government alcohol policy (Giesbrecht et al., 2024).

Nordic countries have imposed especially stringent alcohol controls on accessibility and marketing along with raised taxation, with a resulting effect on population consumption: alcohol drinking levels in the Nordic countries, including Denmark, Finland, Iceland, Norway and Sweden, are among the lowest in the European Union (World Health Organization, 2023).

The Canadian Alcohol Policy Evaluation (CAPE) is an ongoing research project that assesses provincial, territorial, and federal alcohol policies. Policy domains assessed include pricing and taxation, physical availability, alcohol control system, impaired driving countermeasures, marketing and advertising controls, minimum legal age, health and safety messaging, liquor law enforcement, screening and treatment interventions, alcohol strategy, and monitoring and reporting (University of Victoria, 2024). The CAPE provides report cards at federal, provincial, territorial and regional levels and by domain, grading the presence and quality of existing evidence-based policies and the extent to which they are implemented or enforced. The domain of health and safety messaging includes indicators for alcohol use and pregnancy-related risks (Farkouh et al., 2024; Naimi et al., 2023).

Supportive alcohol policy is considered a key element of FASD prevention, at the hub of the Four Level Model (Wolfson & Poole, 2023) as well as with the Ottawa Charter's call to strengthen healthy public policy. Within the CAPE system, policies pertaining to health and safety messaging, pricing and taxation, marketing and advertising controls and screening and treatment interventions could be especially pertinent to FASD. At the federal level, all of these except the last received a failing grade in 2023 (University of Victoria, 2024).

With respect to health and safety messaging, Canada, like most countries, currently has no legal requirements for alcohol warning or ingredient labeling (Stockwell et al., 2020). However, cannabis product labels are required by federal law to contain the message: "WARNING: Do not use if pregnant or breastfeeding. Substances in cannabis are transferred from the mother to child and can harm your baby" (Government of Canada, 2019a; 2019b). CAPE awarded Canada a score of 1 out of 10 on its assessment of Canada's health and safety messaging policy, based on indicators such as the quality and rotation of warning labels, as well as the presence of ongoing alcohol-specific public health media campaigns. Another indicator of note was the absence of public health input on alcohol policy (University of Victoria, 2024).

According to the 2023 CAPE report card, pricing and taxation policies favorable to health that were in place in Canada were concentrated in excise taxes and their indexation according to alcohol content. There are no policies on minimum pricing, including an absence of incentives for provinces and territories to introduce minimum pricing. In the marketing of alcohol in Canada, restrictions are limited and evidence of enforcement is lacking. Federal alcohol policy related to screening and treatment was graded at C+, largely due to the development of national alcohol guidance and federal support for provincial and territorial screening, brief intervention, and referral (SBIR) initiatives through transfer payments, and availability of these services in military and federal corrections populations (University of Victoria, 2024).

As described in Chapter 2, jurisdictions across Canada have implemented different alcohol control policies, some of which are related to FASD:

- Newfoundland and Labrador's Provincial Alcohol Action Plan integrates FASD prevention (Government of Newfoundland and Labrador, 2022). One of the 13 items in the action plan is to "support provincial FASD networks to improve capacity for prevention, screening and assessment, and increase understanding of the services required by individuals affected by FASD." The plan also declares the intention to work with the federal and other provincial/territorial governments on the requirement for health and safety labelling on alcohol products, as has been done for tobacco and cannabis.
- Ontario's *Liquor Licence and Control Act, 2019* requires point-of-sales warnings of the danger of fetal alcohol spectrum disorder (Government of Ontario, 2019). This is a continuation of the mandatory FASD warning required since 2005 under Sandy's Law (Government of Ontario, 2004).
- As part of its 10-Year Strategic FASD Plan, Alberta's Gaming and Liquor Commission introduced changes to regulations requiring Class A licensees (restaurants, bars, nightclubs, etc.) and Class D licensees (liquor stores) to post FASD prevention signage (Government of Alberta, 2017a).
- Municipal and local governments can play an important role through their bylaws regarding alcohol use and FASD risk (Thomas & Poole, 2014).

The CAPE project identifies provincial and territorial policy leaders in all the alcohol policy domains it covers. In 2023, on the indicator "Adequacy of off-premise health and safety messaging - alcohol use and pregnancy-related risks," Alberta, Ontario and Northwest Territories received recognition as policy leaders, and on the indicator "Adequacy of on-premise health and safety messaging - alcohol use and pregnancy-related risks," Alberta and Ontario were recognized (Naimi et al., 2023).

The report from the Canadian Centre on Substance Use and Addiction - Canada's Guidance on Alcohol and Health: Final Report (Paradis et al., 2023) - aims to provide Canadians with information and context that supports their healthy decision making about alcohol consumption. The report identifies a need for "governments to design a healthier environment to make it easier for people to make difficult decisions about alcohol." Among other suggestions, it suggests mandatory labelling of all alcoholic beverages with both information about alcohol content levels as well as health warnings. Canada's Guidance on Alcohol and Health as well as the National

Alcohol Strategy Advisory Committee have also supported measures to strengthen alcohol advertising and marketing regulations, restrict the physical availability of alcohol, and adopt minimum prices for alcohol (Paradis et al., 2023). The extent to which these measures would be effective in contributing to reduced FASD incidence is unknown.

Key Findings:

Supportive alcohol policy is recognized as a key part of FASD prevention. A recent general evaluation of current policies across Canada found significant room for improvement.

As demonstrated by Nordic countries, national alcohol policies using a multi-pronged approach can reduce alcohol consumption, and the health harms of alcohol. Policy approaches include controls on marketing and advertising, pricing and taxation, alcohol content, and restrictions on availability.

5.8 International best practices in FASD prevention

FASD prevention is a key component of national FASD strategies in several countries, including Canada (Public Health Agency of Canada, 2003); Australia (Commonwealth of Australia & Department of Health, 2018); New Zealand (Health New Zealand; 2023); and Ireland (Health Service Executive, 2022), and a prevention guideline exists in South Africa (Adebiyi, Mukumbang, & Beytell, 2019). Several elements of their approaches may provide positive examples for the Canadian context.

5.8.1 Australia

Prevention is one of four national priorities in Australia's National FASD Strategic Action Plan 2018-2028 (Commonwealth of Australia & Department of Health, 2018), supported by five enablers: appropriate recognition of FASD as a disability; elimination of stigma; education and training; policy coordination and research and evaluation. The FASD Action Plan is aligned with and informs the implementation of other national health strategies and frameworks, including the National Drug Strategy 2017-2026 and the National Alcohol Strategy 2018-2026. Prevention priority objectives for the Plan are to: *1) Reduce access and consumption of alcohol in the Australian community;* and *2) Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy.* Prevention programming includes multi-level campaigns with universal and targeted elements: changes to maternal health record policies and practices; supports to health professionals; and models of care to incorporate a continuum inclusive of preventing FASD while addressing behavioural, structural and environmental contributors to FASD.

In Australia, states and territories deliver a range of services in relation to PAE and FASD. In several regions, large-scale FASD prevention activities are underway, including some exemplary Indigenous community-led, holistic approaches. One of these is the comprehensive Marulu FASD Prevention Strategy (Fitzpatrick et al., 2017). Over five years of implementation, the proportion of pregnant women reporting alcohol use in the region decreased from 61% in 2010 to 32% in 2015 (Symons et al., 2020). Subsequent community-driven FASD prevention initiatives in the Marulu region have included comprehensive parental skills training as a form of secondary prevention (McIlduff et al., 2023), development of preventive and supportive interventions for youth 17-19 struggling with PAE, FASD and adverse experiences (Rice et al., 2022), and integration of technology-based preventive interventions (the Marrura-U project: Elliott, 2020).

5.8.2 New Zealand

New Zealand's FASD Action Plan (New Zealand Ministry of Health, 2016) recognizes prevention as offering the greatest return on investment and focuses on population-based, universal prevention approaches, with attention to vulnerable groups and communities. New Zealand reports annually on progress on FASD prevention (more specifically, on the implementation of planned activities) in two specific prevention action areas: *1) Increase collaboration and coordination to better support activities aimed at shifting New Zealand's drinking culture and targeting harmful alcohol consumption; and 2) Develop and disseminate clear, unambiguous and consistent messages to increase the whole community's awareness of the risks of drinking during pregnancy, including FASD.* A number of initiatives were planned under each of these action areas, including universal, school-based, family-based and target community-based harm reduction programs, the production of guidance on alcohol and pregnancy for professionals and for the public, and review of existing alcohol labeling control strategies (Government of New Zealand, 2022).

5.8.3 Other Countries

Other notable prevention initiatives found in our review of international FASD prevention efforts are:

- **Awareness:** As in Australia and New Zealand, in Ireland, FASD prevention actions include enhancing public awareness through nationwide campaigns about the risk of alcohol during pregnancy (Health Service Executive, 2022; Department of Health, 2012).

- **Multidisciplinary collaboration on person-centered policies:** In South Africa, FASD prevention policies, legislation, and support services must reflect multidisciplinary and multi-sectoral cooperation (departments of education, health, social development, justice, labour, among others), in provision of user-, family-, and caregiver-focused resources, policies, and support services (Adebiyi, Mukumbang, & Beytell, 2019).

- **Training of healthcare and other professionals:** Ireland's Health Service Position on FASD includes the aim to implement training in alcohol screening and brief intervention (SBI) nationally to health and social care professionals via the MECC (Making Every Contact Count) and SAOR (Support, Ask and Assess, Offer Assistance, Refer) initiatives (Health Service Executive, 2022).
- **Research:** In the US, the National Institute on Alcohol Abuse and Alcoholism has an FASD Research Grant Portfolio, which provides funding for FASD-related projects that address FASD prevention, diagnosis, treatment, and etiology. In 2023, NIAAA allocated approximately 7% of its extramural research and training budget, or roughly $30 million, for its portfolio of FASD-related grants (National Institute on Alcohol Abuse and Alcoholism, 2023).

5.9 Research gaps

The evidence basis for addressing FASD prevention covers many domains and disciplines, and although there has been significant development in the last decade, gaps remain. One such gap is the need to better understand, prevent and mitigate the stigmatization associated with FASD, which continues to limit the effectiveness of preventive intervention (Wolfson et al., 2022).

Research on the effectiveness of prevention interventions is challenging, and controlled and multi-site studies on multicomponent prevention initiatives in vulnerable populations are complex and expensive. However, such evaluations have been identified as a significant gap, and the needed next step in advancing prevention knowledge (Rutman & Hubberstey, 2019). Authors of systematic reviews of prevention programs call for greater rigor in research design (Symons et al., 2018), including development and use of standard outcome measures to allow better synthesis and meta-analysis (Poole et al., 2019; Roozen et al., 2018).

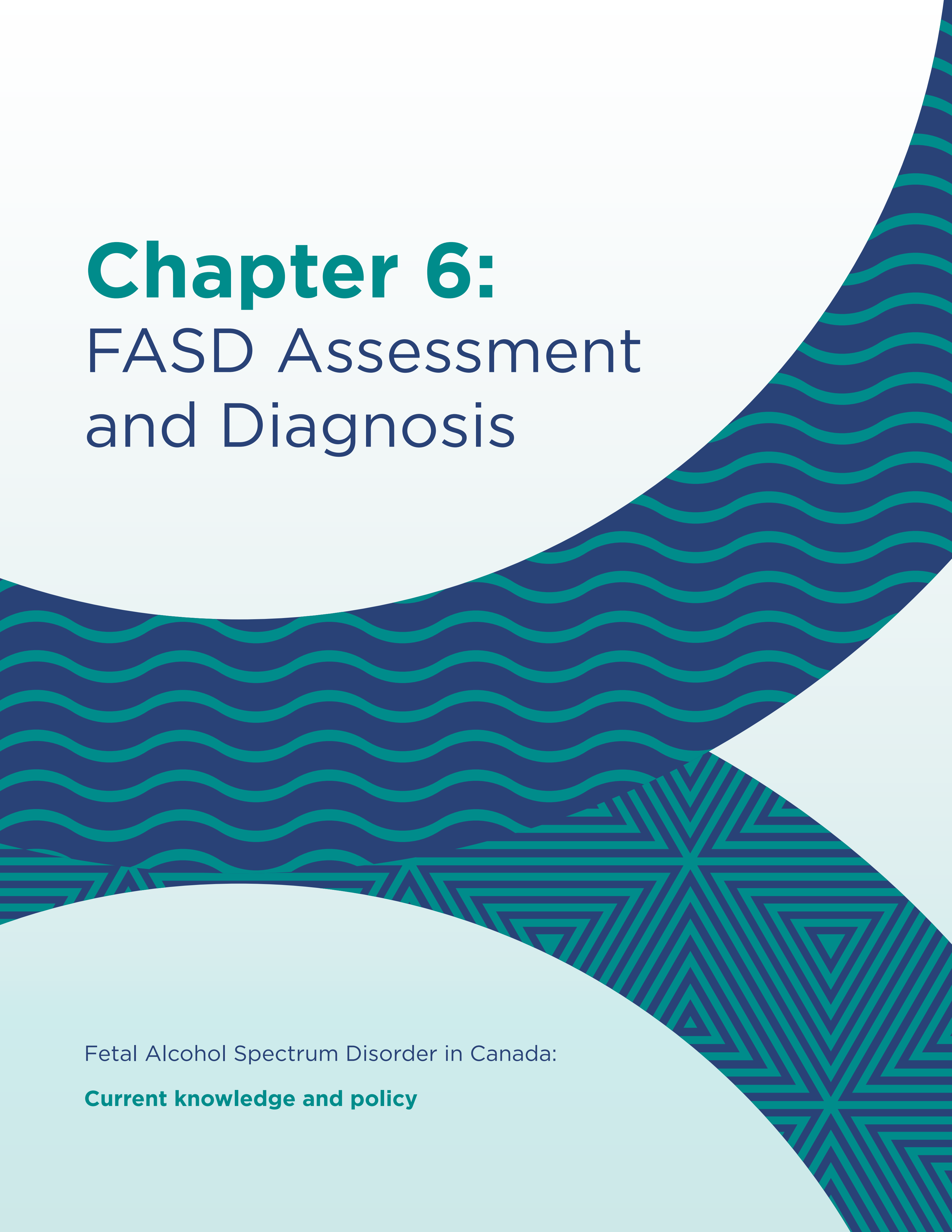
Engagement participants stressed that pursuing new developments in FASD prevention is key. Interest was expressed, for example, in continued investigation of the potential for nutritional supplements such as choline to play a role in FASD prevention (Serwatka et al., 2023). This is further discussed in Chapter 7.

Because of the multidisciplinary nature of research on FASD, collaborative and cross-disciplinary efforts, with a focus on policy-directed knowledge mobilization across intervention domains such as health, child welfare and education (Badry et al., 2019) and, according to engagement participants, across all Canadian jurisdictions, are most helpful. Adebiyi, Mukumbang, & Erasmus (2019) examined the distribution of FASD prevention interventions worldwide, finding relatively greater access in countries, like Canada, with relatively low FASD prevalence. These authors called for greater international collaboration in FASD prevention (Adebiyi, Mukumbang, & Erasmus, 2019).

5.10 Conclusion

This chapter has documented a wide range of approaches to FASD prevention, covering the spectrum of micro-level, individualized interventions to macro-level environmental modifications. It has been informed by useful models of prevention, health promotion, and health system improvement, which provide organizing frameworks for coordinated, multi-level prevention programming. More research on the effectiveness and cost-effectiveness of prevention programs is needed to support decision-making about some of the promising interventions outlined here. Effective prevention of FASD can be strengthened through the implementation of supportive alcohol policy, more consistent alcohol screening and messaging by physicians, implementation of a life span approach to prevention, and more consistent and widespread application of evidence-based programming at all four levels of prevention.

Chapter 6:
FASD Assessment and Diagnosis



Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

6.1 Introduction

Diagnosing FASD is challenging because of the complexity of its etiology (McQuire et al., 2020) and because it shares symptoms with other neurodevelopmental disorders (Cook et al., 2016). Until the Canadian Guidelines were published in 2005, diagnosis for FASD was primarily undertaken by geneticists, pediatric neurologists and pediatricians (Cook et al., 2016; Chudley et al., 2005).

FASD has such a heterogeneous presentation that the diagnostic label alone is not sufficiently informative about the functional needs of the individual. An FASD assessment and diagnosis provides critical information for a treatment plan and is essential in securing supports to address the functional challenges and strengths identified in the assessment.

Through this assessment, the Canadian Academy of Health Sciences was asked to examine: *What is needed to support broader uptake of the Canadian FASD Diagnostic Guidelines in Canada?* This is also related to the question addressed in Chapter 4: *What are the clinical/community and federal/provincial/territorial challenges associated with case identification and data collection in Canada?*

This chapter focuses on FASD assessment and diagnosis, examining the current uptake of the Canadian Guidelines, mapping the diagnostic process and capacity in Canada and identifying challenges and barriers.

6.2 Discussion of the Canadian Diagnostic Guidelines

6.2.1 History

The current Canadian Diagnostic Guidelines for FASD (*Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan*: Cook et al., 2016) were developed by a multidisciplinary team (Brown et al., 2019; Cook et al., 2016) through evidence review and national and international consultations. The development process was based on the Appraisal of Guidelines, Research and Evaluation (AGREE II) framework (Brouwers et al., 2010), to ensure a rigorous, evidence-based approach.

The 2016 Guidelines updated those published in 2005 (*Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis*: Chudley et al., 2005). The 2005 Guidelines aimed to reach a first consensus on a Canadian standard, harmonizing the 2005 IOM and 4-Digit Code diagnostic systems (Brown et al., 2019; Cook et al., 2016). These two systems had been developed in the US to operationalize or define diagnostic criteria for the full spectrum of FASD including fetal alcohol effects (FAE). The 2005 Canadian guidelines were the first to propose harmonization across different diagnostic systems (Farag, 2014). There is often an unusual pattern of inconsistencies in the functional profile of each individual who experiences PAE. This is not reflected in the usual scoring of central nervous system functional domains and can result in a misunderstanding of the level of dysfunction that a person with FASD experiences. In light of this the 2005 Guidelines introduced criteria for discrepancy scoring for the central nervous system functional domains.

The 2016 Canadian guidelines included important updates to reflect the evolving understanding of FASD and included:

- Use of fetal alcohol spectrum disorder (FASD) as a diagnostic term when it had previously been an umbrella term subsuming the diagnoses of Fetal Alcohol Syndrome (FAS), partial FAS (pFAS) and alcohol-related neurodevelopmental disorder (ARND). The latter diagnoses were removed because in clinical practice as well as in research, it was clear that individuals without the characteristic facial features or growth restrictions had a similar neuropsychological profile and brain dysfunction (Cox & Loock, n.d.);
- Inclusion of special considerations for diagnosing FASD in infants, young children and adults;
- Deletion of "growth" as a diagnostic criterion;
- Addition of an "at-risk" non-diagnostic designation for individuals who do not meet the diagnostic criteria but are still at risk of FASD;
- Elimination of a sensory assessment;
- Revision and refinement of brain domains evaluated in the neurodevelopmental assessment (Cook et al., 2016);
- Inclusion of "affect regulation" as a brain domain recognizing that mental health is a primary FASD disability rather than a secondary condition.

The 2016 Guidelines propose a differential diagnostic algorithm that includes consideration of PAE, facial features, central nervous system impairment, and microcephaly.

The Guidelines identify special consideration for diagnosis of infants and young children, reflecting the challenge of identifying the required pervasive brain dysfunction in at least three of the specified brain function domains for children below school age. The designation of "At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure" is seen as an opportunity to signal that a child's condition warrants further neurodevelopmental investigation with maturity, while allowing access to possibly beneficial services and supports, which a deferred diagnosis does not (Flannigan, Gill et al., 2019; Hanlon-Dearman et al., 2020). Differential diagnoses are also urged for children under six, to exclude any underlying structural brain malformation or a genetic/metabolic disorder that may have similar symptoms to FASD (Cook et al., 2016).

In summary, for a diagnosis of FASD, the current Guidelines offer three possibilities: FASD without sentinel facial features (SFF), FASD with SFF, and the At Risk designation. FASD without SFF requires the presence of: significant brain dysfunction in at least three domains, along with evidence of significant PAE. The Guideline suggests a definition of significant PAE as 7 or more standard drinks per week, or at least 2 occasions of drinking 4 or more drinks within two hours (Cook et al. 2016, Appendix 1). Confirmation of PAE requires:

> …documentation that the biological mother consumed alcohol during the index pregnancy based on: reliable clinical observation; self-report; reports by a reliable source; medical records documenting positive blood alcohol concentrations; alcohol treatment; or other social, legal or medical problems related to drinking during the pregnancy (Cook et al., 2016, p. 193).

Diagnosis without confirmed PAE is only possible if all three sentinel facial features are present.

6.2.2 Health and other allied professionals' use of the diagnostic guidelines

Under the current Canadian Guidelines, reaching a diagnosis of FASD and other PAE-related conditions involves a physical and neurodevelopmental assessment, typically by a multidisciplinary team (Cook et al., 2016). The Guidelines were intended to be used with flexibility*:*

> These guidelines were drafted with the aim to be sufficiently specific to guide the complex diagnostic process, but with enough flexibility for diagnostic centres to implement the principles and approaches in their own settings (p.5).

A multi-disciplinary approach

The Guidelines recommend a multidisciplinary, team-based assessment and diagnostic process, including a pediatrician or physician with expertise in FASD and differential diagnosis and specialists able to conduct physical and functional assessments (e.g., speech-language pathologist, physiotherapist, occupational therapist, clinical psychologist; Cook et al., 2016). Each team member is responsible for conducting appropriate tests in their respective domains. The clinician's choice of measures may vary depending on characteristics of the client and the testing circumstances as well as the clinician's preference and experience (Coons-Harding, Flannigan et al., 2019).

Individual physicians are not restrained from diagnosing FASD, alone or with colleagues (Clarren, 2018), provided they have the required information and expertise in FASD. This is currently the practice in many areas of Canada when the diagnosis is clear and where there is no access to a multi-disciplinary diagnostic clinic. A pediatrician or physician may assemble existing documentation (e.g. confirmation of PAE through pre-natal or birth records, testing from a speech language therapist in the school system, and a neuropsychological assessment from a psychologist), have sufficient expertise to interpret this information, and make an FASD diagnosis. A trained Nurse Practitioner would also have the necessary expertise in FASD, and in parts of Canada may be the clinician best positioned to gather the needed information and make the diagnosis. Nurse practitioners have roles that are similar to or shared with primary care physicians in the areas of diagnosis, referral, and case management (Masotti et al., 2015). For more complex cases, direct collaboration amongst colleagues is essential.

Although some authors have argued that diagnosis solely based on multidisciplinary team assessment may be too costly and impractical (Burd & Popova, 2019), it remains the recommended approach because specialists can identify specific areas of dysfunction that can be treated or supported after diagnosis. *A*n engagement participant cautioned:

> *We should collectively be seeking routes to greater quality of assessment, not just greater number of assessments, and especially not at the expense of accuracy.*

Overall, by 2011, the 2005 Diagnostic Guidelines "were well known to all programs and actively referred to by most." However, while 90% of respondents were using the team approach, only 46% had a full staff of professionals on site for diagnosis (Clarren et al:, 2018). In a 2021 study of Canadian FASD clinical capacity in which 41 pediatric FASD clinics participated, Dugas et al. (2022) found that 60% of clinics that diagnosed FASD in infants and preschool children followed the interdisciplinary guidelines compared with 80% of clinics that diagnosed school-aged children/adolescents. These authors report that "most clinics that did not have a complete interdisciplinary diagnostic team because of limited human and/or financial resources—they were simply doing the 'best they could.' (Dugas et al., 2022).

Assessment tools and measures

A 2019 survey of FASD diagnostic team members (physicians, psychologists, speech-language pathologists and occupational therapists) in 23 Alberta FASD clinics, found considerable adherence to the Guidelines in terms of Guideline recommended assessment tools (Coons-Harding, Flannigan et al., 2019). However, some assessment tools suggested in the 2016 Guidelines were not being used by any clinics and there were additional assessment tools being used that were not listed in the guidelines (Coons-Harding, Flannigan et al., 2019). Flannigan, Coons-Harding et al. (2022) reported similar results in a national survey of clinicians, finding that although only 32% of measures aligned fully with those recommended in the Canadian Guidelines, almost all of the most frequently reported measures aligned with them. They also identified some commonly used measures not included in the Guidelines that they reported would be useful to consider as the Guidelines evolve.

In an international study of FASD diagnostic clinics, Reid et al. (2022) identified a preference among some for measures developed within their own clinical, geographic, or cultural settings. Clinicians may prefer particular tests that are not included in the Guidelines that, in their view, effectively assess the particular brain domains (Coons-Harding, Flannigan et al., 2019).

An engagement participant captured this view of a need for flexibility, also expressed by others:

> *Guidelines are not rules. By the time the Guidelines are published the literature has moved on and so they are soon out of date. So we need to rely on the Guidelines as well as literature informed diagnostic processes.*

There was nonetheless some concern about differences among clinics in their interpretations:

> *I believe the guidelines are interpreted differently in different clinics giving different processes and outcomes for clients and families.*

Although evidence suggests the uptake of the Guidelines among FASD diagnostic teams is high (Dugas et al., 2022), engagement responses indicate a need for greater awareness of FASD and its diagnostic process in the broader healthcare community. Participants called for more engagement with professional medical organizations and health professional educational institutions to raise the profile of FASD.

6.2.3 Concerns regarding the diagnostic guidelines

Several critiques of the Guidelines and its underlying approach to FASD have been published (Klein, 2016; McLennan, 2015; McLennan & Braunberger, 2017; Eliason et al., 2024; Price & Miskelly, 2014; Miller, 2013). Additional points were raised during the engagement sessions. As one engagement participant stated:

> *In a clinic setting, I'm not sure we have "huge knowledge gaps" as much as we have lots of clinicians with very strong and different opinions about FASD.*

Drawing on Heimdahl Vepsa's (2020) analysis of FASD discourse in Sweden, we have grouped the critiques into three main (and necessarily interconnected) types: ethical, technical and implementation-related. Table 7 presents the main arguments on each side.

Table 7: Critiques of the Diagnostic Guidelines and their approach, and rejoinders

Critiques	Rejoinders
Ethical critiques/ethical discourse	
Focusing on the causes or etiology of the observed neurodevelopmental problems is stigmatizing as well as unsound given uncertainty about whether a child's challenges are explained by alcohol exposure rather than a number of other things that could have caused those challenges; a focus on functional impairment regardless of the causes would be more helpful (Klein, 2016; McLennan, 2015; McLennan & Braunberger, 2017; Eliason et al., 2024; Price & Miskelly, 2014; Miller, 2013).	The Guidelines recognize that the effects of PAE are well-established and cannot be ignored (Cook et al., 2018)
Diagnosis is not warranted because it will not help and will possibly harm people with FASD (McLennan & Braunberger, 2017).	Diagnosis in some cases leads to improved self- and caregiver understanding, functioning and quality of life, and draws attention to the need for more and better interventions (Skorka et al., 2020, Temple et al., 2020).
Medicalizing FASD as a condition caused primarily by PAE affects how it is seen in health and society (McLennan & Braunberger, 2018), shifting emphasis away from systemic root causes in social determinants of health (Abadir &, Ickowicz, 2016; Eliason et al., 2024).	Evidence-based medicine acknowledges complex causal pathways and contributes to the push for breakthroughs that will both prevent FASD and improve the lives of those affected (Cook et al., 2018).
Technical critiques/scientific discourse	
The Guidelines are not based on sufficient evidence, or evidence for some elements is overstated (McLennan & Braunberger, 2017), perhaps in biased ways (McLennan & Braunberger 2019).	The Guidelines were based on best available research evidence at the time and systematic, reasoned consensus development, which is judged to be adequate for the purpose (Poitras & Argáez, 2017), and they are open to improvement (Cook et al., 2018).
The Guidelines, being too inclusive of comorbidities and not sufficiently distinguishing between FASD and other problems with other causes, result in lack of proper attention to the other conditions (McLennan, 2015; McLennan & Braunberger, 2017).	The Guidelines recognize the full complexity of FASD causes and presentation, proposing that "diagnosis is merely an identification process and not a replacement for the scientific process of understanding pathogenesis of disease" (Cook et al., 2018, p.84). Moreover, the Guidelines state that there will be some cases where an FASD diagnosis is not made, despite confirmed PAE, when another diagnosis provides a better explanation for the observed effects (Cook et al., 2016).

Critiques	Rejoinders
The present Canadian Guidelines do not include diagnostic criteria for the conditions that are on the milder end of the FASD spectrum (Astley Hemingway, et al., 2019). This means that some individuals with moderate or significant dysfunction, but not in multiple areas, may not receive the support they need.	“A diagnosis of FASD implies that alcohol is a causative factor, not just “associated with” the deficits and there is no empirical data that would support relaxing the clinical cut-off to 1.5 SD. Statistical models of changes to a cut-off score on a battery of neuropsychological tests suggest that small changes in the threshold for diagnosis may have a very large effect on prevalence rates” (Cook et.al., 2016, p 24, Appendix 1).
The “at-risk” category is harmful (McLennan & Braunberger, 2017) because it may prime attribution of emerging developmental concerns to PAE, potentially downplaying the role of other causal factors increasing the risk of missing other potentially modifiable variables.	The “at-risk” category is helpful to ensure that individuals who do not yet meet the criteria for an FASD diagnosis, are not lost in the system, but are flagged for management and intervention (Cook et al., 2018).
The Guidelines fail to adequately consider lived experience (Poitras & Argáez, 2017; Lim et al., 2022).	The steering committee which created the Guidelines included a parent and clinicians working closely with individuals living with FASD (Cook et al., 2016).
Implementation critiques/pragmatic discourse	
The Guidelines are too demanding in terms of expertise (Goulden, 2005), resources and processes to be fully implemented in all parts of the country and particularly outside of urban areas, which reduces their accessibility and equity (Poitras & Argáez, 2017).	The Guidelines model evidence-based medicine that set the desired standard across the country, and allow for clinical discernment that is in fact being applied (Cook et al., 2016).
The confirmation required of PAE is unrealistic and unreasonable, especially for adult diagnosis (Petryk et al., 2019).	Alcohol in utero is a teratogen and its effects are preventable through behavior and policy modification; it is therefore essential to confirm (Cook et al., 2016).

Cultural appropriateness of the Guidelines

Issues have also been raised about the Guidelines’ cultural sensitivity and safety, with a view to developing more culturally informed diagnostic practice (Loock et al., 2020). These issues were examined in the revision of Australia’s FASD diagnostic guidelines (Hayes et al., 2022).

Accurately identifying FASD in many ethnic populations is challenging because clinicians lack normative data on characteristics like sentinel facial features or neurodevelopmental impairment (Tsang & Elliott, 2017). Cultural sensitivity could be heightened by developing culturally adjusted norms for accurate measurement of sentinel facial features (Clarren et al., 2010; Tsang, Lang-Aiken et al., 2017). The study by Tsang, Lang-Aiken et al. (2017) further stressed the need for race-appropriate norms in facial phenotype assessment to ensure a more accurate and culturally sensitive assessment. In Indigenous populations, as in other linguistically and culturally distinct communities, linguistic and cultural differences can affect the results of standardized intelligence assessments, necessitating that clinicians take these cultural factors into account (Mushquash & Bova, 2007). Cultural sensitivity in FASD diagnosis would thus also be served by developing and using culturally and linguistically appropriate tools to assess the functional brain domains.

Cultural safety would be improved by developing a process that includes individuals and family in the diagnostic process, values their perspectives and uses diagnostic terminology they feel comfortable with (Coons & Makela, 2017; Representative for Children and Youth, 2024). In a 2021 report, Pauktuutit Inuit Women of Canada link the lack of Inuit-led and culturally sensitive FASD diagnostic and support services to stigma and misinformation about FASD within Inuit communities (Pauktuutit Inuit Women of Canada, 2021). Ongoing, culturally safe research initiatives can support First Nations communities through culturally and linguistically appropriate FASD training and materials, as well as equipping First Nations communities and organizations to offer a comprehensive range of FASD services that contribute to overall community well-being (Coons & Makela, 2017).

In BC, the Representatives for Children and Youth (2024) recommended a comprehensive review of current FASD awareness training for frontline staff working with children and youth with FASD, in order to develop evidence-based and culturally sensitive training. Chudley et al. (2005) emphasize the importance of educating patients and family members on the features of FASD in a culturally sensitive manner, using appropriate language.

Recent debate over using FASD as a primary diagnostic category

There is currently a debate over the use of FASD as the primary or sole diagnostic category (see Eliason et al., 2024; CANFASD, 2024c).

Eliason et al. (2024), suggest FASD is a “misleading and outdated” practice of diagnosing disabilities as medical illnesses, and suggest that this practice attributes individuals’ functioning and participation to their health conditions without recognizing the complex interactions and experiences of the families and societies in which they live. They encourage a 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 access to a diagnosis in cases where evidence of PAE is unavailable. It would 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. They suggest that identification of the broader range of risk factors opens up avenues for both primary and secondary prevention. It has also been argued that the focus on only PAE perpetuates stigma towards the mother, reduces the opportunities for diagnosis and management and diverts attention away from other preventable causes (Eliason et al. 2024).

At the same time, there is concern that shifting away from FASD as the primary diagnosis would have harmful effects.

> Disconnecting the effects of PAE from our clinical understanding of neurodevelopment will cloud the unique aspects and expression of the teratogenic effects of alcohol. Without this nuanced information and understanding of etiology, individuals with FASD will get lost in systems… (CanFASD, 2024c, p.2).

Such a shift might disincentivize identifying PAE and diagnosing FASD. 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 living with FASD this proposed approach might impede access to supports dependent on an FASD specific diagnosis. The impact of shifting away from FASD could also disrupt the sense of community and shared identity that some people with FASD have built around their common experiences. Finally, if PAE is not clearly identified as an important causal factor, this might reduce attention to the unique aspects of its effects on the brain as well as other parts of the body, leading to less precise diagnosis and decision-making about interventions and supports. Where diagnosis-specific treatments, supports and accommodations do exist, having access to the diagnosis is essential to accessing them.

In response to the concerns that the term FASD is stigmatizing, it has been noted that removing the label FASD may not remove the stigma (CanFASD, 2024c). The impact of stigma is further explored later in this chapter.

Another approach reflected in the ongoing debate over this proposal is to treat this not as an “either/or” proposition, but instead to use the complex neurodevelopmental disorder diagnosis in conjunction with specific applicable diagnoses such as FASD. This would enable a diagnosis in cases where PAE is lacking, while also acknowledging the presence of multiple causal factors where appropriate.

The literature reviewed for this assessment, as well as the opinions expressed during the engagement process reflected this full range of views on the question of the optimal diagnostic approach, and it remains an area of debate at the time of writing this report.

6.2.4 Intervening prior to diagnosis

FASD is most commonly diagnosed when children reach school age and fail to attain behavioural and developmental milestones (Dugas et al., 2022). However, interventions may be helpful when signs of neurodevelopmental problems are first emerging, particularly during the period of neuroplasticity (Olson et al., 2007). Guidelines-based assessment of preschool children do provide reliable information about neurodevelopment (Hanlon-Dearman et al., 2020). If FASD is possible but not diagnosable, as noted in the earlier section, the 2016 Guidelines' designation "At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure" is meant to identify situations when pre-diagnosis intervention may be helpful. In such cases, interventions can be based on assessment of a child's functioning in domains that are associated with or predictive of FASD diagnosis, such as standardized assessment of motor and sensory processing skills and comprehensive language assessment (Hanlon-Dearman et al., 2020). This type of assessment can inform various types of early intervention for preschool children as well as caregivers (Olson et al., 2007; Aldharman et al., 2023; see Chapter 7, Section 7.3.).

Provision of services based on functional assessments

Given the importance of early intervention, calls have been made to provide services and supports based on needs identified through functional assessments, rather than waiting for an FASD diagnosis. This could provide necessary interventions and supports before a diagnosis can be made, as noted above, in children under six years old, or when no FASD diagnostic services exist, or when PAE information is not available or reliable.

The diagnostic guidelines for FASD do include functional assessment, which refers to an evaluation of how well an individual performs in everyday activities in areas such as language, motor skills, cognitive abilities, attention, and memory. However, the guidelines in addition rely upon PAE confirmation as well as setting a threshold of severity for impairment of central nervous system functioning. This means that in many cases FASD diagnosis may not yet be available due to the difficulty of conclusive evaluation of certain brain domains in very young children, or may be out of reach because of the absence of evidence of PAE. However, if the diagnostic criteria are met during the functional assessment, a diagnosis can be made to further direct management.

A primary benefit of functional assessments is increased access to FASD services and supports which may otherwise require a diagnosis. It provides a practical approach that can serve as a first step to put resources in place and monitor for possible developmental delays, with diagnosis occurring later when it is possible and appropriate. Notably, such supports and services would have to be effective, readily and equitably available; as we will see in Chapter 7, this is not always the case. As an engagement participant said:

> *Functional assessments make sense. Hard to do primarily psych assessments on preschool kids as they are too young. Would love to see more sensory assessments. We do not require dx for services and supports. How these kids function and strategies for success are more important.*

A current pilot program in BC of "Family Connection Centres" is providing support based on functional assessment for children and youth aged 0-19 (Government of British Columbia, 2023b). The intent is that these centres will ease access to resources by making services not dependent on a diagnosis. Access to many other disability supports (federal and provincial) may still require a diagnosis, however.

Key Findings:

There appears to be broad uptake of the Guidelines by specialized FASD clinics, but less information about use outside those clinics. Clinics vary in the assessments used to evaluate the diagnostic criteria. Regularly updating guidelines through a consultative process to reflect current research findings would support uptake and consistent application. Culturally sensitive and safe diagnostic practices would also support efficacy, trust and acceptance. A dissemination plan might help to address implementation issues and increase uptake of the Guidelines.

FASD diagnosis may sometimes be appropriate in young children, but it 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.

Early intervention prior to school age is important to reduce the harm of PAE when the developing brain is the most responsive to external stimulation and environmental experience. Provision of services based on functional assessments can improve timely access to services until FASD diagnosis is available or in circumstances when a diagnosis is not obtainable. Supporting parents and children with early concerns (e.g. confirmed PAE) allows professionals to start interventions sooner, and to refer for diagnostic assessment early to mitigate long waitlists.

Key Findings:

The Canadian FASD Guidelines furnish a basis for consistent diagnosis, where assessment and diagnostic capacity exists; however, there are concerns and critiques that limit uptake. A debate has emerged over the use of FASD as the primary diagnostic category and the suggestion to shift toward using a broader diagnostic term of complex neurodevelopmental disorder, in conjunction with other diagnoses including FASD where those diagnostic criteria are met. Reasons in favour include capturing cases where evidence of PAE is unavailable, as well as addressing uncertainty about the relative contributions of the many potential causal factors present in a given case. Concerns with this proposed approach include the possibility that reduced prioritization of FASD as a sole or primary diagnosis might reduce the emphasis on PAE and undermine efforts to understand and prevent the condition.

6.3 Diagnostic process in Canada

The diagnostic process varies depending on the individual and where in Canada they live, but usually begins with concerns raised by family, healthcare providers or teachers, which may lead to referral for an FASD assessment, with eligibility for that assessment sometimes depending upon the availability of evidence of PAE.

6.3.1 Screening for PAE and screening for risk of FASD

Before outlining the process of referral and diagnostic assessment, we first discuss screening, which is distinct from diagnosis and instead identifies individuals with heightened risk, for subsequent follow-up with further diagnostic assessment and possible intervention.

Screening for alcohol use in pregnancy is intended to offer opportunities to intervene to prevent PAE, but can also be used to identify infants at risk of developing FASD. Various factors signal the risk of FASD, including learning and behaviour indicators. Screening for these potential indicators offers an opportunity to identify individuals in a population who would benefit from diagnostic services. It can also inform prevalence estimates.

Screening is justifiable when a) high quality screening tools exist; b) high quality diagnostic tools and services are accessible and acceptable to those screened in; and c) effective and efficacious treatments and services exist that are accessible and acceptable to those diagnosed (WHO Europe, 2020; Association of Faculties of Medicine of Canada, 2024).

For screening tools to be judged as high quality, they must demonstrate acceptable measurement properties (reliability and validity); performance characteristics, including high:

sensitivity (detecting all cases: few false negatives); specificity (detecting only cases: few false positives); positive predictive value and negative predictive value (correctly classifying people screened in and screened out relative to a reference standard), and scalability or implementability (Grubb et al., 2021; Lim et al., 2022; Kable & Jones, 2023).

Population screening for prevalence estimation can use active case ascertainment on an entire but limited population, as described in Chapter 4. In population screening intended to find cases for the purpose of intervention, all members of a defined population are routinely (i.e., without any risk assessment) invited for testing so that positive screens can be referred for assessment, diagnosis and intervention. This second type of screening is relevant for this chapter's discussion of assessment and diagnosis and could be conducted in a smaller sub-population understood to be at high risk.

In FASD, there is a tension between the risk of stigmatization by targeted screening in populations believed to be at high risk versus universal screening of the whole population of pregnant women or newborns (McCormack et al., 2022; Lim et al., 2022). At the same time, there is consensus in the literature that the earliest possible identification of cases at risk, during and immediately following pregnancy, could increase opportunities for harm reduction and interventions to optimize early brain development, minimizing the effects of PAE and concurrent causes of FASD (Kable & Jones, 2023; Lim et al., 2022).

Several Canadian jurisdictions have implemented policies on universal PAE screening. These were documented in the report by Popova et al. (2021) and are summarized here.

In the Northwest Territories, the prenatal record includes screening for PAE at a minimum every trimester and automatic referral for patients who have a positive alcohol screen (Government of Northwest Territories, 2021). Antenatally, two jurisdictions capture prenatal PAE information obtained through systematic screening: Manitoba's Families First, a universal screening and home visiting program (Government of Manitoba, n.d.-b; University of Manitoba, 2023), with a parallel program in Indigenous communities called Family Support Program (Métis Child, Family and Community Services, n.d.); and Ontario's Better Outcomes Registry & Network (BORN) Information System (BORN Ontario, n.d.). In Alberta, PAE is a check box on the standardized form completed at the time of birth for all newborns.

Screening for PAE

As discussed in Chapter 4, there are two modes of screening for PAE: by clinical interview and through analysis of biomarkers of the newborn or the mother. Chapter 4 explored both types of screening for prevalence estimation, while Chapter 5 addressed screening as a prevention measure.

To recap, evidence-based guidelines exist for clinical interview screening, but these guidelines are not fully implemented, resulting in healthcare practitioners not always asking pregnant women about alcohol use, and not always using standardized tools when they do. This is further challenged by patients' reluctance to disclose alcohol use. Biomarker screening can also identify alcohol use, but this type of screening has significant limitations as well.

In a systematic review and quality assessment of 31 PAE screening tools, Kable and Jones (2023) found greater specificity than sensitivity, resulting in underdiagnosis. They concluded that biomarkers and screening tools for PAE do not yet have adequate predictive validity, but that recent developments using microRNAs related to growth and vascular development, proteomic changes associated with PAE, and combinations of markers, showed potential (Kable & Jones 2023). Berrigan et al. (2019) found case finding through meconium testing to be cost-effective, although with a risk of false negatives for some of those screened due to inability to detect first trimester exposures before meconium is produced in the fetal gut, missing or delaying diagnosis and consequently interventions until later in their lives.

Screening for risk of FASD

Case-finding of FASD with sentinel facial features (FASD-SFF, previously known as FAS) is relatively straightforward, as long as the screening tools are culturally appropriate, as noted above. Several FASD-SFF tools have very high sensitivity and specificity (Lim et al., 2022). However, FASD-SFF likely represents less than 10% of the entire FASD spectrum (Popova et al., 2021).

Neurobehavioral screening of children (Berrigan et al., 2019; Grubb et al., 2021); teacher ratings of executive function (Cheung et al., 2021); and life history screening of adults (Grubb et al., 2021) are being used as FASD screening tools. Berrigan et al. (2019) found case-finding by neurobehavioral screening to be cost-effective in terms of health systems costs saved, although with a risk of delaying FASD diagnosis due to false negatives for some people.

The Medicine Wheel Screening Tools developed in a Mi'kmaq First Nation offer a culturally rooted Two-Eyed Seeing approach to screening for risk of FASD annually in a school population and they serve as tools in a two staged screening process to provide referrals to a community clinic that diagnoses neurodevelopmental disorders, including FASD (Cox, 2023; Goh et al., 2008).

Facial imaging (Roomaney et al., 2022) and eye tracking (Maurage et al., 2020) have been developed as biomarker screening tools for FASD. Lim et al. (2022) identified and assessed seven tools for screening FASD developed in relation to four sets of diagnostic criteria, including (most frequently) the Canadian Guidelines. These FASD screening tools showed limited accuracy identifying people at risk, although performance was better for assessing FASD with SFF (Lim et al., 2022). This situation is rendered more complex due to the presence of competing diagnostic systems, discussed above (Grubb et al., 2021; Lim et al., 2022; Kable & Jones, 2023).

Analysis of biomarkers that do not involve facial assessment would be helpful for identifying the many individuals with FASD but without sentinel facial features. For example, the eye tracking tools mentioned above can be used in children and adolescents to assess some characteristic abnormalities, which differ somewhat by gender, in the cognitive processes underlying eye movements (Maurage et al., 2020). Also, EEG recordings have shown some promise: in a study of 50 children with FASD and 50 controls, all aged 7–13, some EEG differences were found in response to activation tests (Dyląg et al., 2021).

Zhang et al. (2019) have developed a Machine Learning model to detect FASD in children using multiple data sources: eye movement behaviors, psychometric test scores, and neuroimaging. The model was tested in 46 (24 controls vs. 22 FASD) youth aged 5-18. Although it involves a set of costly tests, the authors modelled a staggered, high throughput approach, estimating it to be cost-effective in population screening for FASD. A recent review of Machine Learning tools for FASD assessment argued that because FASD is a multifaceted diagnosis, combining accessible modalities such as neurodevelopmental assessment and facial imaging will improve sensitivity and specificity. These authors emphasize however, that these tools have been developed on clinical samples, so may perform less well in the general population, and balancing accuracy and cost in wide deployment remains to be demonstrated (Suttie et al., 2024).

Indeed, screening tools are usually developed in clinical populations, which may be unrepresentative of the entire FASD population due to lack of awareness of FASD among referring clinicians and the stigma associated with FASD, which discourages participation in screening (Lim et al., 2022).

Other research has concentrated on developing biomarkers and other methods to screen for FASD that could potentially be adapted for use in remote populations. An Alaskan study demonstrated the feasibility of including some telehealth components in a hybrid diagnostic system. This can include triaging potential FASD through use of a computerized analysis of digital facial photographs that are then reviewed and analyzed by FASD diagnostic experts (Western Interstate Commission for Higher Education Behavioral Health Program, 2019). Other telehealth applications have also shown some promise (King et al., 2023; Whittingham & Coons-Harding, 2021). A smartphone application, FASD-Tree, is being used to help clinicians in screening for FASD; this tool shows good accuracy, with small rates of misclassification (Mattson et al., 2023).

Screening approaches are most successful when supported by effective and efficacious treatments and services that are accessible and acceptable to those diagnosed (WHO Europe, 2020; Association of Faculties of Medicine of Canada, 2024).

6.3.2 Referral for assessment

A key step in the diagnostic process is referral of people who may have FASD for assessment. Referrals can be made by a wide variety of practitioners and professionals who, in their contacts with individuals, believe that assessment may be appropriate.

The Guidelines encourage referrals from families and caregivers; physicians including pediatricians and emergency room doctors; nurses and other health professionals; social services providers; addictions workers; teachers and other education system practitioners, and workers in the justice system such as probation offers (Cook et al., 2016).

Referral policies for FASD diagnosis and assessment across Canada vary. In some provinces and territories, FASD referrals are made to a centralized entity such as a provincial organization, health authority, or Centre of Excellence. In other jurisdictions, referral is organized around regionally-sited FASD clinics. Across both centralized and regional locations, there are differences in who can make referrals, such as healthcare practitioners, school staff, caregivers, and adults self-referring. There is sometimes variation in referral policies within a single province, with some clinics requiring a referral from a physician (Prairie Central FASD, n.d.), and others accepting referrals from anyone, provided they meet the eligibility criteria (Central Alberta FASD Network, n.d.-b).

The referral source can be indicative of the type of challenges the individual is currently experiencing or can be a reflection of their life stage (Cook et al., 2016). When ascertained, reasons for referral are most likely to be: learning and cognitive problems; behavioural problems, mental health problems, or social problems (study of 161 diagnosed Asante Centre FASD cases, reported in Popova et al., 2021). Engagement participants' reports concurred with this information, indicating that referrals are spurred by observations of developmental delays, behavioural issues, or known or likely PAE. Family members of people with FASD indicated that most children were diagnosed when they reached school age and challenges started to appear.

Several studies in Hayes et al.'s (2023) systematic review of qualitative evidence about the lived experience of the diagnostic process reported that FASD was not considered even when the caregiver raised it as a possibility. Concerns were similarly expressed in the engagement sessions that referrals depend on the extent to which professionals (e.g. medical, educational, social work, psychology) are FASD-informed and trained to recognize relevant signs. As stated in Chapter 4, service provider sensitization to and knowledge of FASD could be improved (McCormack et al., 2022).

In a study of the use of primary care by pregnant women who had given birth to a child with FASD compared to matched controls, people in the study group had higher rates of inadequate or no prenatal care (Singal et al., 2019), resulting in lack of contact with potentially referring healthcare providers. As described by engagement participants:

> *Poor access to primary/secondary healthcare leads to poor referral quality and increased vulnerability for misdirected referrals.*

Engagement participants noted that hesitation to refer can also occur, even when professionals are FASD-informed. Teachers reported FASD as a very sensitive topic to broach with families, saying they will generally avoid mentioning FASD, and instead they focus on developmental delays and behavioural issues as a basis for referral for further assessment. Physicians may also hesitate or find reason not to broach the topic with their patients (Burd & Popova, 2022).

Referral may be made specifically for assessment of FASD, or for a broader spectrum of neurodevelopmental conditions, or for an FASD stream within a broader spectrum of assessed disorders; this seems to depend on the organization of FASD services within provincial/territorial and regional jurisdictions (Popova et al., 2021). Referrals may also be shaped by perceptions of the FASD diagnosis and its relative disadvantages compared to that of other neurodevelopmental disorders whose expressions overlap somewhat with FASD, such as Autism Spectrum Disorder (ASD) and Attention Deficit Disorder (ADHD). As a participant in the engagement put it:

> *There is a bias in referral patterns. We are referred children to our ASD [autism] clinic who we have identified PAE in and suggested further assessment in FASD clinic -- families DECLINE FASD assessment for preference of an ASD assessment due to stigma and lack of perceived value of this diagnosis. This is not uncommon!! The conversation of FASD needs to shift.*

Because more than half of the individuals assessed for FASD receive no diagnosis or are designated not at risk (Popova et al., 2021), and because about 12 out of 13 pregnancies with PAE may not result in FASD (Popova, Charness et al., 2023), many more individuals undergo assessment than are detected as cases. A suggestion was made in the engagement sessions to streamline referrals so that only those who have major functional impairments are referred, even with confirmed PAE; one clinic reported receiving referrals of children with confirmed PAE but minimal functional impairments, otherwise thriving at that time. Engagement participants also expressed interest in developing triage systems to identify which children need full assessment and diagnosis and those that do not need it despite having PAE. As the disabling impact of PAE may emerge with age and developmental expectations, it is important to include an opportunity to re-refer when and if significant functional impairments are more evident.

6.3.3 Eligibility for diagnostic assessment

Referrals are usually accompanied by documentation about the referred case, with the required information determined by the organization receiving the referral. These can include results of previous assessments, other diagnoses, other required pre-testing, and PAE information. Once a referral is made, the receiving organization will review it according to its eligibility criteria for assessment intake. The intake process can vary, depending on individual clinic practice.

Our review found that the main eligibility criteria for FASD assessment across all jurisdictions are age and PAE confirmation. Regarding eligibility based on PAE, at least 10 of the clinics or network websites reviewed included confirmation of PAE as a requirement for assessment. The majority of these clinics are located in Alberta, Northwest Territories, and Ontario. This regional variation was also documented in a published survey of 41 pediatric FASD clinics. The confirmation of PAE or the presence of three sentinel facial features was required prior to referral by 67% of clinics in Western/Northern Canada, 77% of clinics in Central Canada, and 43% in Atlantic Canada (Dugas et al., 2022). As an engagement participant noted,

> *...confirming PAE is a major barrier/limitation to helping children and families access our assessments especially if the parent is deceased [or] unavailable.*

While some people with FASD may be diagnosed earlier, significant and more measurable differences become more apparent and the tests are more validated after age six years. Among clinics offering FASD assessments, age eligibility varies. In a survey of 41 child FASD clinics across Canada, one study noted seven providing diagnosis for infants (<18 months), 25 providing assessments for children 18 months to five years, and nearly all (40) providing services for children 6-18 years (Dugas et al., 2022). Because of the age eligibility criteria, engagement participants reported that assessments may not be sought for younger children with possible FASD:

> *Open up assessments for under age 6. At this point families and legal guardians are under the impression it's mostly "off the table", therefore a higher number of youth being referred.*

For adults, in addition to PAE confirmation, potential eligibility criteria for FASD assessment may include severity of client symptomatology, reason for referral, level of need, current level of support received through community services, or usefulness of diagnosis (Badry, 2010; Public Health Agency of Canada, 2011).

The proportion of people assessed who were adults also varies according to location. In Alberta, 44% of those assessed for FASD between 2015 and 2019 were 18 years or older; whereas in Manitoba, only 5% were 18 or older. In Yukon, few of those assessed, 6%, were adults, likely because the only clinic in the territory contributing data was pediatric (Popova et al., 2021).

Our website review found that in many jurisdictions in Canada, limited or no adult FASD diagnosis is available. For example, in British Columbia we found only two centres providing assessment and diagnosis of adults (Asante Centre, n.d.; Independent Living Vernon, n.d.). In Manitoba, FASD diagnostic services cover adults up to the age of 25 only if they are involved in the criminal justice system (Manitoba FASD Network, n.d.-b). In a list of Ontario clinics, only six out of 25 provided services to adults (CanFASD, n.d.-c). In Alberta, however, the majority of clinics provide assessment services for both children and adults, while in the Atlantic provinces, it appears that no adult FASD diagnostic services are available in publicly funded clinics, although individual physicians are able to diagnose FASD. As one engagement participant stated,

> *…there are no options for adult diagnosis and this is fundamentally discriminatory, we cannot be promoting the need for FASD education and diagnosis and then not offer diagnostics for adults.*

This regional variation in eligibility criteria impacts the passive surveillance data efforts described in Chapter 4 and would also impact data of a national repository as they are dependent on clinics' submissions.

6.3.4 Assessment experiences and reactions to the results

A systematic review of caregivers' experiences of the assessment and diagnosis process found strong evidence of both improved insight and mixed emotions -- a sense of relief, hope and confidence, as well as grief, hopelessness, guilt and shame (Hayes et al., 2023). In a follow-up study of 20 patients from a clinic some years after their FASD diagnosis,75% reported having a diagnosis was beneficial, providing better adaptation and self-understanding (Temple et al., 2020).

In a review of studies of the assessment experience, Hayes et al. (2023) found that a safe and supportive assessment environment without judgment was validating and empowering. Caregivers reported positive experiences with high levels of satisfaction and feelings of empowerment, attributed to welcoming, supportive interactions with clinic staff who were helpful, reassuring, and respectful without being judgmental or stigmatizing (Hayes et al., 2023).

In their study of pediatric FASD clinics, Dugas et al. (2022) found wide variability in how children's diagnoses are communicated to caregivers. Strengths-based assessments were found by caregivers to be helpful in orienting them to services that can develop strengths while taking vulnerabilities into account (Hayes et al., 2023).

Many benefits of a diagnosis were identified in the engagement process. FASD diagnosis is seen as valuable in better understanding a person's needs and accessing appropriate interventions. For adults, there was a clear message from people with FASD in our engagement that diagnosis was highly beneficial. It helped their self-understanding, validated their experiences, and reduced internalized shame, stigma, and self-blame. Key to this was understanding that their differences were not their fault. As one person with FASD stated:

> *Knowing gives an explanation for all the health issues, life issues and educational and work challenges that will arise. THEY WILL ARISE. There may not be sympathy, but a lot of inner turmoil may be calmed by knowing what differences you may expect. A label gives clarity. It is not detrimental. Essentially, you have the opportunity to "own" who you are, and to research more about it, and even to educate others.*

Materially, engagement participants indicated that diagnosis led to better access to supports, accommodations and possibly financial assistance. Likewise, in the follow-up study conducted by Temple et al. (2020), patients were more likely to receive disability income and intellectual disability services than before diagnosis. A diagnosis also helped people with FASD plan and manage their own lives, including health, employment and educational issues, and seek out appropriate resources and coping skills. In a systematic review of qualitative studies on the lived experience of the diagnosis process, a common post-diagnosis theme was that strengths-based diagnoses were helpful in orienting future decision-making (Hayes et al., 2023).

At an emotional level, the diagnosis helped foster understanding and empathy in others, leading to better support from them. It allowed people with FASD to help connect with others with similar issues, sometimes creating a sense of community or shared identity. Some felt that assessment was useful even without a diagnosis, to help them to access support groups and learn about what supports might be available.

Caregivers also emphasized the importance of early diagnosis to avoid misdiagnosis or blame on parents and children. Participants stressed the importance of helping others understand and not blame a child for what may otherwise be seen as "bad behaviour":

> *When a child/youth gets diagnosed with FASD then their caregivers/teams can come to understand that it's not an issue of what they won't do but what they can do. This new framework can assist in managing expectations, providing support and increased understanding. Strength based diagnosis and education for children/youth/caregivers/families/school teams etc. are super important.*

Engagement participants stressed the importance of diagnosis for struggling youth, particularly those involved in criminal justice, where diagnosis provides an:

> *...important context for unwise and impulsive behaviour. These youth also rarely have advocates, which can mean that no one is supporting them to navigate systems to acquire the FASD assessment.*

For some people with FASD a diagnosis causes mixed feelings. Some may be angry that their mother wasn't supported to be able to care for them, to address maternal early life trauma, or to escape a violent relationship. Some may be resentful at having to deal with life-long problems they did not choose. In the engagement sessions, the main anticipated unintended consequence of diagnosis identified was that it would lead to stigmatization and blame of the mother, and negative labelling of children. It was noted that because of these concerns, sometimes parents and guardians refuse consent to assessment, even when referred.

Key Findings:

At present, efficient screening methods to identify cases at risk of PAE exist but are not used consistently or effectively. A number of screening tools for risk of FASD exist and have proven useful in specific subpopulations, but no one tool has emerged that is both efficient and effective. The development of screening tools for risk of FASD that are valid, reliable with high sensitivity and specificity, and suitable for widespread application is a key area for continuing research.

Greater sensitization and training of front-line professionals about FASD, especially those who may encounter individuals with heightened risk, could improve the identification of possible cases and referral for assessment.

Eligibility criteria for diagnosis varies by age, with few or no clinics accepting very young children or adults for assessment in some locations.

People with FASD report that diagnosis has been helpful for self-understanding, and reducing shame and self-blame. They also report that the diagnosis aids in seeking appropriate supports, interventions and accommodations, and in planning and managing their lives.

6.4 Diagnostic capacity

There are FASD diagnostic capacity issues across Canada, with uneven access due to resources, age of the person referred for diagnosis, or location/geography.

6.4.1 Overall capacity

In 2011, Clarren et al. observed that the need for FASD diagnostic services across Canada ”is still many times greater than what is currently available” (Clarren et al., 2018 p. e494). Several studies converge to indicate that FASD diagnostic capacity in Canada is still insufficient and that the vast majority of individuals with FASD in Canada are undiagnosed or misdiagnosed (Dugas et al., 2022; Popova et al., 2024).

Based on the survey data from 33 Canadian FASD diagnostic clinics, and assuming a population-based FASD prevalence between 2.5% and 4%, it was recently estimated that very few of the probable cases of FASD are actually captured. The estimated percentage of FASD cases diagnosed from birth to 18 years per year in Alberta is from 2% to 1.2%; British Columbia: 3.5% - 2.2%; Manitoba: 1.8%-1.1%; Ontario: 0.8% - 0.5%; and Northwest Territories: 3.2%-2.0% (Popova et al., 2024).

In a national study, the diagnostic capacity of participating FASD clinics was assessed by dividing the annual number of completed assessments by the number of referrals received. Overall diagnostic capacity was 71%, meaning that 71% of eligible cases were assessed within one year. Western/Northern clinics received the highest number of FASD referrals per year and had the highest diagnostic capacity, at 83%. Diagnostic capacity in Central clinics was 55% and in Atlantic clinics, 43% (Dugas et al., 2022). This study is informative in showing that clinics vary in their ability to cope with incoming referrals and none of them seem to have the capacity to keep up with the demand. However, as noted above, it is believed that most cases are not being referred for assessment.

Waiting times for FASD assessment documented in Popova et al.’s study (2024) ranged from 1 month to 4.5 years across participating clinics. The number of individuals on a waitlist ranged from 53 to 103 per clinic. Results of a 2016 Alberta waitlist study also found variability: eight clinics had no waitlist and 15 clinics had waitlists which ranged in number from 7 individuals to 216 individuals waiting for an FASD assessment (Burns, 2016, cited in Coons-Harding, Flannigan et al., 2019).

In their systematic review of lived experience studies, caregivers’ frustrations with accessing assessment services was a key theme in their accounts (Hayes et al., 2023).

Data on the ages of people actually assessed for FASD reflect the challenges of assessing pre-school aged children. Popova et al. (2021) found that the largest proportions of FASD assessments done across the six jurisdictions studied were of children between 6 and 11 years (39%) and adolescents between 12 and 17 years (29%). In terms of the age distribution of pediatric assessments, Dugas et al. (2022) found in their national study that few clinics assessed and diagnosed FASD in infants and preschool-aged children. This echoes engagement findings about limited referral of children prior to school age. As noted in Section 6.2, the current Canadian Guidelines identify special considerations for diagnosis of infants and young children, given that reliability of the tests used is lower among younger children (Cook et al., 2016).

6.4.2 Assessment and diagnosis services across jurisdictions

Our scan found information about diagnostic and assessment services in almost every province and territory. Alberta, Manitoba, and Yukon include diagnosis as part of their provincial FASD strategies, discussed in Chapter 2.

The governments of British Columbia, Northwest Territories, Saskatchewan, and Yukon provide information on assessment services on their governmental websites (Government of British Columbia, 2023c; Government of Northwest Territories, n.d.; Government of Saskatchewan, n.d.; Government of Yukon, n.d.). In other provinces and territories, FASD networks share information about diagnosis and assessment. In Newfoundland and Labrador, child assessment is available to all residents, and adult assessment is available to residents of the Labrador-Grenfell region (FASD Newfoundland and Labrador, n.d.). The FASD Ontario Network of Expertise (FASD ONE) shares information about several diagnostic clinics in regions across the province (FASD ONE, n.d.-a). In Québec, the Cree Board of Health and Social Services implemented an FASD Diagnostic and Intervention Clinic, which has now evolved into a Neurodevelopmental Clinic and Specialized Services Team (Cree Board of Health and Social Services, 2018). FASD Diagnostic Services for children aged 0-7 are available upon referral through the Montreal Children's Hospital (Montreal Children's Hospital, n.d.). In Nunaviut, the Piruqatigiit Resource Centre in Iqaluit conducts FASD assessment for children and youth (Piruqatigiit Resource Centre, 2024).

Between 2011 and 2015, Yukon received funding from PHAC for a project focused on improving outcomes for adults with FASD involved in the criminal justice system. A key component of the project was diagnosis and case management and a Yukon-based team was established and trained to assess and diagnose adults with FASD. This complemented assessment and diagnostic services already available for children in the territory. In 2004, a local diagnostic team was developed to assess preschool children and in 2006, this was expanded to include school-aged children (Government of Yukon, 2015).

While Nova Scotia's Department of Health and Wellness has noted that the Halifax based IWK Developmental Pediatrics Clinic does FASD assessments (Simon & Smith, 2020), the clinic's official webpage does not mention FASD, while highlighting Autism Spectrum Disorder and attention deficit hyperactivity disorder (IWK Health, n.d.). The New Brunswick FASD Centre of Excellence offers diagnosis province-wide in New Brunswick (Vitalité Health Network, n.d.). We found no information about FASD diagnostic services in PEI.

One method of comparing diagnostic capacity across regions is to calculate the number of funded assessment slots per population. In 2011, Clarren et al. (2018) found a diagnostic capacity of 0.64 slots per 10,000 population. For the years 2014-2019, Popova et al. (2021) found capacities of 0.76 to 0.87 per 10,000 across the six jurisdictions examined.

Popova, Lange, Burd, Chudley et al. (2013) estimated that the entire diagnostic process from referral through assessment and diagnosis required between 32 and 47 hours of specialist time, with costs of several thousands of dollars. Limitations on funded spots mean that families and adults unable to access timely publicly funded assessments may need to pay for assessments privately, using funds from private insurance or paying out of pocket. Some federal and provincial support programs may also cover, in part or in full, the costs of private assessments for those eligible for those supports. For example, Indigenous Services Canada's mental health assessment benefit coverage allows for two hours of reimbursed services for assessments (Indigenous Services Canada, 2024f.) Badry noted that adult FASD assessment is not covered by provincial/territorial health plans (Badry, 2010).

For children and youth up to the age of 19 (Indigenous Services Canada, 2021), implementation of Jordan's Principle (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative (Indigenous Services Canada, 2024d) have made funding available for a range of health, social and educational needs, including FASD assessment and diagnosis. Jordan's Principle is not limited to children with disabilities and can provide services to First Nation children even when the support service is not available to other children provincially (Assembly of First Nations, 2018b). The Inuit Child First Initiative specifically serves Inuit children under the age of majority in their province or territory (Indigenous Services Canada, 2024d).

Key Findings:

Access to diagnostic clinics is uneven across Canada – sparse in rural and remote Canada, non-existent in many regions, and with lengthy wait times in some locations.

FASD diagnosis in Canada at present is primarily performed by a relatively small number of specialized clinicians, teams, or clinics that cannot accommodate the many people with FASD.

Limited capacity contributes to FASD frequently not being considered or diagnosed. Evidence suggests the vast majority of individuals with FASD are undiagnosed or misdiagnosed.

6.5 Challenges and barriers to FASD assessment and diagnosis

In a qualitative study of 10 FASD diagnostic clinics across Canada, Harding et al. (2024) identified precarious or insufficient funding, inadequate human resources and lack of access for rural and remote residents as common barriers to access and uptake. Here we discuss these and other possible challenges or barriers that came to light during the literature and policy reviews and engagement process, and that also affect efforts to improve prevalence data through reporting to a national registry as described in Chapter 4.

6.5.1 Stigma as a barrier to FASD assessment and diagnosis

Stigma is a significant barrier to FASD assessment and diagnosis. Parents, families and communities avoid the diagnosis because of stigma. Stigma also suppresses the availability of evidence of PAE because of reluctance to disclose alcohol consumption during pregnancy. Lack of adequate evidence of PAE makes diagnosis impossible under current diagnostic guidelines in the absence of sentinel facial features.

As described in an earlier sub-section that summarized concerns related to the Guidelines, there is debate about how the term FASD contributes to stigma, especially the explicit inclusion of the word “alcohol” in the diagnostic label, and whether changing this name could remove barriers and lead to greater inclusion for people affected by the condition. Eliason et al. (2024) express concern about stigma faced by parents due to the diagnostic label of FASD that reduces the causal complexity to PAE.

> Collective reflection is needed to reconsider the social and ethical implications of a lifelong disability diagnosis that hinges on birthing parents disclosing an otherwise confidential, sensitive, and sometimes traumatic portion of their own history.
> (Eliason et al., 2024 p.840)

At the same time, Eliason et al (2024) recognize that an abrupt removal of diagnoses, like FASD, that “identify and validate the lived experiences of people with neurodevelopmental differences” and around which supports and resources may be available, would cause harm (p. 839).

Views were mixed during the engagement sessions on the advantages of changing the term FASD. While removing the reference to alcohol could potentially contribute to de-stigmatization, there was little certainty that this would be effective and the stigma associated with FASD might simply transfer over time to a replacement term. Some participants suggested that stigma and inclusion be addressed directly rather than indirectly by a name change.

Several suggestions were made in engagement sessions to address the impact of stigma and to increase the acceptability of assessment and diagnosis by creating clinics that address a range of neurodevelopmental disorders rather than dedicated FASD clinics. These clinics would offer diagnosis of a range of conditions such as autism, attention deficit and hyperactivity disorder and FASD.

Engagement participants also noted that the development of trust and strong local relationships could attenuate stigma as a barrier to diagnosis:

> *Having FASD become more familiar, common, and included in professional practice will reduce the stigma. In rural clinics that have been operating for more than 20 years, the stigma is greatly reduced, and people know they can come forward without judgement and get the help that they need. These are best addressed through community based dx [diagnosis] clinics vs hospital based traditional health clinics.*

Work is being done to reframe FASD through a strengths-based lens, while "shining a much-needed light of visibility on the role of PAE" (Kachor, 2024). Significant effort has been expended to mobilize effectively around FASD to secure much-needed attention and support, and it has also helped to forge a community for people with FASD and their families. "We must also respect the perspectives of the many families and self-advocates who have embraced the term FASD and consider it part of their identity" (Kachor, 2024).

During the engagement process, some participants suggested that clinicians may overestimate the impact of stigma:

> *More likely the medical community sees the stigma more profoundly than the impacted families. They need any supports available and without the diagnosis that is difficult.*

6.5.2. The perceived futility of a diagnosis

Engagement participants also raised the perceived futility of an FASD diagnosis, driven by lack of beneficial services and supports flowing from that diagnosis. An example of this perspective was the statement:

> *Helping children should be the main reason for assessments and diagnoses, otherwise it tells them that there is "something wrong with them" but that there are no supports for them, unless their parents can pay for private therapy and tutor.*

This view was the basis for the ethical objection laid out in section 6.2.3 by McLennan and Braunberger (2017) and noted by engagement participants:

> *Diagnosis, without support, is unethical and a set up for failure, poorer outcomes.*

The perceived lack of supports may also be a professional challenge for clinicians:

> *When our clinicians say "Why bother," it comes from a place of being burnt out with a complicated assessment process that doesn't work well to connect families with supports they are looking for. Clinicians are human too, and as helpers, it is really hard for them to put so much effort into assessments that seem to yield so little for families.*

It is not clear how often this happens, but the lack of supports and services may reduce motivation to recommend diagnosis:

> *Most [of our] team discussions openly recognize that an FASD diagnosis will likely [result] in no additional supports or services - so it's often bypassed as there is nothing that the label currently adds (no doors get opened, so it's seen as nothing added.)*

The engagement sessions identified increases in health inequities as an unintended consequence of how supports are funded for families with children who have neurodevelopmental disorders. Wealthier families may be able to access post-diagnosis services such as private tutoring, psychological and other professional services; children seen in FASD clinics are more often those who need diagnosis to access publicly available supports.

Another point raised frequently during the engagement sessions was that in those locations where supports are diagnosis-based, and where greater resources are made available to certain diagnoses like autism, the FASD diagnosis may be avoided or not pursued because of this.

> *Diagnosis based funding such as ASD [autism] is a huge disadvantage to FASD and other diagnoses. Families will be encouraged to get a private funded assessment (as there is a payout at the end) while FASD does not have the same benefits.*

Here, engagement participants suggested that a way forward would be to offer supports based on assessment of functional needs. A representative comment was that:

> *Qualifying for funding for supports needs to be adjusted away from diagnosis based, to needs based.*

It was, however, noted that this may disincentivize diagnosing FASD which would undermine efforts to understand the condition, evaluate the efficacy of interventions, and draw attention to its high but underestimated prevalence. It also might disqualify individuals with FASD whose complex pattern of functional needs might not meet eligibility criteria for services if criteria such as IQ score are used. In addition, as described in Section 6.3, adults with FASD in the engagement process attested to the value of the diagnosis to them once received:

> *…making diagnosis more difficult will leave many people without meeting criteria for any diagnosis and falling through the cracks of services and supports.*

Meanwhile, practitioners identified increased and ongoing sensitization to FASD as a benefit:

> *I hear that sort of response far too often that there is no purpose for making the FASD diagnosis. But then I have been hearing it for over 30 years and only by diagnosing did we eventually educate our community. I now believe that FASD 101 is constantly needed even in an FASD informed community.*

6.5.3 Confirming PAE

Confirmation of PAE is required for an FASD diagnosis if sentinel facial features are not present (Cook et al., 2016). This was repeatedly identified in the engagement sessions as a significant barrier to diagnosis of FASD, and hence to the services and supports requiring the diagnosis.

Under the 2016 Guidelines, the threshold to confirm PAE is a "an estimated dose at a level known to be associated with neurodevelopmental effects" (Cook, et al., 2016, p. 193), operationalized as 7 or more standard drinks per week, or at least 2 occasions of drinking 4 or more drinks within two hours (Cook et al., 2016, Appendix 1). As the effect sizes seen with a single binge episode are relatively small, a threshold of 2 binge episodes is recommended as a minimum for diagnosis (Wincott, n.d., p.1).

This threshold for confirmation of PAE has been termed in one study as an insurmountable problem. Petryk et al. (2019), found service providers (in this case, social workers) involved in diagnosis were unaware of the threshold criteria in the 2016 Guidelines. If PAE information from the birth mother was absent, they used a variety of sources, including extended family members, admitting credibility was difficult to assess; and third party sources such as police record of arrests, emergency hospital visits, visits to detox centers during pregnancy, and birth records accessed especially for a biological mother with a known history of substance use. Interviewees acknowledged that PAE accuracy was unverifiable, due to underreporting because of stigmatization, recall bias, second hand information, reliance on distant memory, and changes in drink sizes with situation and location. Anecdotally, providers reported parents inflating their partner's alcohol use during child custody issues, or other misreporting in legal situations (Petryk et al., 2019). In engagement sessions, the diagnostic cut-offs were recognized as necessary and appropriate, but somewhat arbitrary, representing a policy choice about what needs to be medicalized as a "disorder."

The engagement sessions indicated that there is some variability across FASD clinics in what counts as sufficient evidence of PAE: what is appropriate alcohol exposure history, and what are appropriate sources. For example, a participant said:

> *If a parent does not confirm, are we able to take into account their normal behaviour - e.g., they regularly use alcohol and report doing so before and after pregnancy? The ability to use observations/comments from other family members involved - some FASD assessments will accept this, some do not.*

Training may be required to develop the interviewing skills to enable and also motivate mothers to disclose PAE. Questions were raised in the engagement about how the effort to determine PAE through various information sources fit within the scope of practice of the clinical disciplines involved.

Difficulty in accessing adequate evidence of PAE may be a particular challenge for certain groups. In the case of children in care, adoption records may recommend future FASD assessment but fail to include evidence of PAE:

> *Many kids in care do not have confirmation of prenatal alcohol exposure, and that may limit their access to good assessment and coordinated care. (i.e. ...that impacts how people may reframe behaviour).*

In addition, participants also noted that it is extremely difficult to confirm PAE for adults, with challenges of acquiring that evidence increasing as time passes.

To help overcome the consequences of requiring PAE confirmation for diagnosis of FASD without sentinel facial features, suggestions were made in the engagement sessions about ways to improve PAE documentation during and after pregnancy. Consistent with the routine documentation of PAE on the infant's medical record, as recommended by the SOGC, as discussed above (Graves et al., 2020) "with the full knowledge of the mother," there were calls to focus on improving knowledge, skills and confidence of healthcare providers to inquire about prenatal alcohol consumption, normalizing it as part of routine prenatal and postnatal care.

Over and above destigmatizing healthcare providers' attitudes, addressing the reluctance to disclose alcohol consumption during pregnancy and the related concern of child apprehension is fundamental. In the engagement sessions, it was noted that fear of child apprehension can impede disclosure and subsequent participation in treatment of alcohol use problems. It was stressed that child welfare policies could be better aligned so support and treatment can be encouraged by providers and accessed by women without fear, while still giving appropriate attention to child safety. Presently, child protection legislation requires healthcare professionals and other service providers to notify child welfare authorities if they encounter a child whom they have reasonable grounds to believe is in need of protection (Public Health Agency of Canada, 2019a). This may be the case if a baby is noted to have been exposed to alcohol prenatally and possibly at risk if the mother is perceived to have substance use or mental health concerns, or lack of access to key social determinants of health.

The foregoing has emphasized how the need to present adequate evidence of PAE may operate as a barrier to diagnosis. At the same time, another issue is that evidence of PAE may incorrectly encourage a kind of “tunnel vision” and narrow the focus to FASD and away from other potential explanations of a child’s difficulties. The risk of over-focus on alcohol identified in the literature (Eliason et al., 2024), as well as the engagement sessions would also come into play here: the labelling of children as having an alcohol-caused disorder could increase the likelihood that FASD would become the default presumed explanation for later, unrelated problems:

> *[This] could also lead to assumptions about the child before it is even born. Future “behaviours” might be chalked up to potential FASD and not investigated further.*

In addition to informing a diagnosis, identifying PAE is an opportunity to provide supports and services for the mother, at any point along the journey (Graves et al., 2020). Supporting disclosure of alcohol use during pregnancy is an important skill for health professionals.

6.5.4 Professional capacity, knowledge, training, and tools

Information on the numbers and availability of practitioners in the specific health professions involved in assessing and diagnosing FASD is limited. However, in one study of challenges faced by clinics, some study participants noted a shortage of providers sufficiently trained and experienced in FASD, and several clinics reported relying on traveling physicians, causing scheduling constraints (Harding et al., 2024).

Training for health providers who could provide referrals for diagnosis is also important. The websites of accrediting organizations’ (College of Family Physicians of Canada, Royal College of Physicians and Surgeons of Canada, Canadian Association of Occupational Therapists, Council for Accreditation of Canadian University Programs in Audiology and Speech-Language Pathology) were searched for information on educational competencies related to FASD. There is very little publicly available information regarding the FASD training provided in the core curricula of relevant medical specialties and health professions (training gaps are discussed in detail in Chapter 8). As described in Chapter 2, FASD networks and some professional organizations offer training. Nevertheless, many engagement participants called for increased specific and specialized FASD training opportunities across the health education continuum for professions involved in FASD referral, assessment and diagnosis. In the engagement sessions, support was strong for including education about FASD as part of core curricula in universities and colleges. Post-licensure, suggestions included increased physician and allied health provider access to high-quality professional body accredited FASD education, including free online courses, easily accessible diagnostic resources, and regular training and review of existing FASD diagnostic teams.

A variety of online training courses are currently available (Alberta Council of Disability Services, n.d.; CanFASD, n.d.-d; FASD/TSAF Ontario, n.d-b.; Lakeland Centre for FASD, n.d.-a), but engagement participants highlighted that funding is often needed to maintain and update these, and uptake requires providers to be sufficiently aware of these courses' existence and utility.

Beyond raising the general level of awareness and proficiency among healthcare professionals, some respondents suggested creating and funding educational pathways for specialization in FASD. These programs would include multidisciplinary training as well as extensive experience in FASD-specific clinical environments.

Improvements in screening tools, with particular attention to their scalability for widespread use in primary care and other natural frontline encounters with children and their families, may be a potential way forward. Development of screening tools for specific types of providers in their contexts, for example the Screening and Referral Tool for Youth Probation Officers (Conry & Asante, 2010) could systematically engage more types of practitioners in screening for FASD in both children and adults. Machine Learning tools may also be developed to facilitate referral.

6.5.5 Rural and remote access

Another commonly cited challenge to diagnosis is the lack of patient access to FASD assessment and diagnostic services in rural and remote areas and Indigenous communities (King et al., 2023; Whittingham & Coons-Harding, 2021). Contributing factors include the large distances often needed to travel to a clinic as well as lower recruitment and retention rates of healthcare providers in these areas, in addition to the concerns about stigmatization and child apprehension. An engagement participant noted:

> *Geographic location is a huge barrier … We do not have the services available in the communities. Not only is it difficult to travel for the diagnosis, but also the wait times and stigma associated with FASD and First Nations. Many families will not go for a diagnosis for fear of losing their children. The supports are not available in the community after a diagnosis, so there is the belief that it would be a waste of time to get the diagnosis.*

Indeed, most FASD clinics appear to be located in urban centres; in an Ontario list of clinics, most of the 25 are located in southern Ontario, with four based in Kenora, Sudbury and Thunder Bay (CanFASD, n.d.-c). Providing services from a distance can be challenging:

> *We receive referrals from up to 12 hours away and are unable to maintain contact with families in sufficient quality to build a chart for assessment.*

One of the major barriers to diagnosis in Inuit Nunangat identified in research carried out by Pauktuutit was the lack of access to diagnostic services in most of the region. Funding for travel is limited and traveling many hundreds of miles with complex connections are required (Pauktuutit Inuit Women of Canada, 2021).

Over and above the time between referral and assessment, the assessment process itself can be lengthy as scheduling the various component tests of the assessment with a multidisciplinary team may require multiple visits over the course of several days. Some individuals and their families from outside the community require travel and accommodation, and all families would incur lost productivity.

Engagement suggestions to mitigate these disparities included funding for virtual and mobile clinics, travel funds for patients, and increased funding for recruitment and retention of providers to practice in the North.

The Diagnostic Guidelines have been used to develop a virtual FASD model (King et al., 2023) and a telehealth method of diagnosis (Whittingham & Coons-Harding, 2021).

These studies support the use of virtual FASD diagnostic clinics to enhance patient and provider convenience, quality of care, and cost effectiveness (King et al., 2023; Whittingham & Coons-Harding, 2021). However, some engagement participants felt that currently available tools were inadequate to get sufficiently valid assessment results. These methods may be better suited for adult assessment and diagnosis, and may work less well in assessing children because of the need to have someone with the child to help administer the assessment tasks.

Mobile clinics to serve rural/remote locations were suggested to assist with access in those locations. In addition, it was suggested that these mobile clinics focus more generally on diagnosing neurodevelopmental disorders and not just FASD in order to reduce stigmatization of those attending the clinics. It was suggested that such clinics use the “social pediatrics” approach of horizontal leadership, bridged trust, interprofessional training and community empowerment (Tyler et al., 2019). As an engagement participant stated,

> *This can’t be a “fly-in, fly-out” approach. It takes a village approach.*

Engagement participants suggested that clinical teams be funded for travel to communities with high levels of prenatal alcohol use and other FASD risk factors and spend the time working with community members to build trust, as:

> *this increases the awareness of judgment-free effective services available to them.*

Rather than FASD diagnostic teams these could be clinical pediatric teams working within a social pediatric model. The strength of a social pediatric approach is its focus on overcoming families’ distrust and accepting care (Tyler et al., 2019). This model for identifying PAE and diagnosing FASD and other neurodevelopmental disorders is used in Vancouver's RICHER Social Pediatrics model, as described in Tyler et al. (2019).

Improving knowledge and confidence of potential neurodevelopmental assessors could help increase the pool of those able to assess and diagnose. It was also suggested to build on available resources in each community, developing capacities where potential already resides, for example, by involving nurse practitioners more closely in the assessment process.

Providing cultural training to practitioners serving northern Indigenous communities and providing culturally safe and sensitive services might work to build trust. Involving Elders in a community in the diagnostic process and post diagnostic interventions has been shown to be effective in Australia (Symons et al., 2020) and Canada (Cox, 2023). Indigenous land-based education from Elders can also promote well-being among Indigenous Peoples in Canada (Hansen, 2018), and Elders are seen as valuable cultural resources for health in rural Indigenous communities (Varcoe et al., 2010).

A potential strategy for increasing knowledge and confidence within communities could be the development of communities of practice as suggested by an engagement participant:

> *Cultivating interagency communities of practice in our area has been extremely beneficial, especially for those of us in rural/remote areas. It helps to maximize resources such as the PsychEd, OT and SLP assessments where the need vastly outweighs the supply.*

6.5.6 Administrative barriers

Administrative barriers include the lack of FASD-specific diagnostic codes, limited funding for FASD clinics, and clinician remuneration models that do not recognize case complexity.

Diagnostic codes

Chapter 4 addressed the issue of diagnostic codes in administrative databases that could be used for prevalence estimation. The lack of FASD-specific diagnostic codes in the most common classification systems does not directly impede clinical assessment and diagnosis. However, engagement participants stated that the lack of specific FASD codes reduces its perceived importance, especially in relation to other disorders that do have their own codes:

> *FASD does not even have its own category of diagnosis in the DSM 5. It falls under Other Neurodevelopmental Disorders, while autism, ADHD and others are recognized as significant enough to the point of having their own code of diagnosis. FASD is buried within a sub category (315.8). As long as this is the case, the recognition of the reality and magnitude of the existence of FASD will or is likely to also stay in the shadows.*

Funding adequacy

In a study conducted in 2005 and replicated in 2011, the number of publicly-funded Canadian FASD clinics had declined from 55 to 41 (Clarren et al., 2018). In Popova et al.'s study across 2015-2019, two clinics closed during the study period (Popova et al. 2021). Both these authors attributed lower clinic numbers to funding decreases, but the effects of lower numbers on overall capacity and accessibility are not stated. In addition to publicly funded services, some private clinics conduct FASD diagnosis (CanFASD, n.d.-c)

The most frequent challenge related to limited diagnostic capacity raised by engagement participants was the lack of sufficient resources. As noted by Harding et al (2024), FASD clinics identified inconsistent and inadequate funding as a barrier to clinician availability.

Lack of funding for full-time FASD clinic hours was also flagged as a barrier to patient access and health professional staffing. It was observed that some clinics are only operating part time because they are unable to offer full time employment to allied health practitioners, who leave for more stable employment. As one survey respondent explained regarding their province*,*

> *...many clinics operate only a few days a week/month. Agencies don't have funding to offer allied health full time employment to complement these roles (for SW, OT, SLP, psychologists).*

This may contribute to the clinics' inability to fulfill the Guidelines' requirements for multidisciplinary assessments in a timely way.

It was also reported in the engagement sessions that there may be regional inequities within provinces due to their funding allocation models. A participant stated that in one province:

> *...regions receive funding to provide assessment to families in their community. Unfortunately, not all regions requested funding so there are families who have zero options for diagnosis because no clinic available and cannot access out of region.*

Remuneration

The engagement discussions surfaced some concerns about how clinicians are compensated for FASD assessment and diagnosis. The lack of appropriate billing options for adequate compensation may dissuade clinicians, especially coordinating physicians in fee-for-service primary care. Some provinces have updated their remuneration structures to recognize the time required for these types of complex cases. Innovative approaches exist across Canada to address the constraints of current remuneration models.

6.5.7 Additional challenges for adults

Adolescents and adults face additional challenges related to FASD diagnosis, such as clinics that restrict their assessments to younger children. A key challenge is the difficulty of confirming PAE in the absence of reliable biological parental information or incomplete medical histories in adoption records (Kable & Jones, 2023; Chasnoff et al., 2015). As such, the requirement to confirm PAE disproportionately affects adoptees whose adoption records do not contain this information, including Indigenous Peoples who were part of the Sixties Scoop.

In addition, evidence suggests that the sentinel facial features become less distinctive in adulthood, lessening their utility in adult diagnosis (Badry, 2010; Lemoine, 2003; Burd et al., 2003; Mutsvangwa et al., 2010). The Guidelines include considerations for adolescent and adult diagnosis, recognizing the challenges that are often present, including limited family support, poverty, homelessness, mental health, addiction, legal problems, and parenting challenges. As young adults transition to independent living, it may be necessary to reassess their adaptive function (Cook et al., 2016).

As outlined in 6.3.4, people with FASD value having a diagnosis to understand their challenges and to access both informal and formal supports. While access to government-funded assessment for adults is uneven across the country, in some regions, these may be becoming more available for youth and adults involved in the criminal justice system (see Sections 6.3 and 6.4).

Key Findings:

Stigma operates as a barrier to assessment and diagnosis. It reduces access to information about PAE by reducing the likelihood that pregnant women disclose alcohol consumption. The absence of this information makes FASD diagnosis in their child more difficult. In addition, stigma reduces the uptake of diagnosis by parents, families and communities.

Lack of access to post-diagnostic supports and services also leads people to reject FASD diagnosis, and may result in them pursuing diagnoses that lead to better supports. Improving access to FASD-informed health services, especially post diagnostic supports, would help improve FASD diagnostic up-take.

The requirement for evidence of PAE for diagnosis in the absence of sentinel facial features operates as a significant barrier to FASD diagnosis. Universal screening for alcohol use in pregnancy, along with documentation of significant exposure in infant medical records would be helpful. Challenges to this include reluctance to disclose alcohol use due to fear of child welfare interventions as well as stigma.

Key Findings:

Diagnostic capacity is inadequate to meet the needs of the population, and access is particularly difficult in rural and remote locations when long distances must be travelled to access diagnostic services. Capacity could be improved through recruitment and retention strategies that specifically include approaches to develop a workforce for FASD diagnostic services. For example, alternative models of service delivery, such as virtual and mobile clinics, and an increased role for nurse practitioners could improve access.

There are many adults in Canada with undiagnosed FASD. Diagnosis can offer a range of important benefits to adults, including reduced blame and self-blame, improved access to supports and accommodations, and valuable information about potential physical and mental health issues associated with FASD throughout the lifespan.

Improving access to adult diagnosis across all regions of Canada could help to ameliorate adverse outcomes associated with lack of diagnosis and support, and allow appropriate accommodations to be made in the community and the criminal justice system. Diagnosis and support also help to prevent future cases of FASD.

Adults face challenges in accessing diagnosis in many locations, and it may be harder to obtain necessary evidence of PAE due to the passage of time. Adults can be encouraged and supported to seek assessment by raising awareness about FASD, improving funding for adult assessment/diagnosis, supporting mechanisms for peer support, and developing platforms for adults with FASD to speak more broadly about their experiences.

6.6 International context

The international case studies carried out for this assessment offer insights into approaches to FASD assessment and diagnosis that have relevance to Canada. First, as detailed in Chapter 8, the Canadian Diagnostic Guidelines have been influential in several countries' approaches to assessment and diagnosis. There is no international consensus on diagnostic criteria for FASD (Lim et al., 2022; Brown et al., 2019). Other approaches to FASD diagnosis have been developed and implemented across the world, using a range and combination of tools and domains. Aside from the Canadian Guidelines, the most widely used are (Reid et al., 2022):

- the 4-digit Code (Astley, 2004)
- Hoyme 2016 FASD system (Hoyme et al., 2016), operationalizing the US Institute of Medicine (IOM) Criteria for FASD Diagnosis (Hoyme et al., 2005)
- Australian guidelines, based on the Canadian Guidelines (Bower & Elliot, 2016; 2020; Hayes et al., 2022).

6.6.1 Australia

To facilitate assessment and diagnosis of FASD, Australia has implemented universal screening for PAE among all pregnant women using the AUDIT-C tool (Commonwealth of Australia & Department of Health, 2018). Similar to Canada's SOGC guideline, their national guidelines recommend that healthcare practitioners ask about alcohol use during pregnancy, advise that abstaining is the safest option, provide brief interventions for those who do consume alcohol, and refer individuals to specialist services when necessary (Australian Government & National Health and Medical Research Council, n.d.).

The Australian Guide to the Diagnosis of FASD (Bower et al., 2017) is an adaptation of the Canadian Guidelines and aims to standardize diagnostic criteria, while also emphasizing the consideration of functional impacts, cultural contexts, and environmental demands in FASD assessment (Bower & Elliott, 2020; Hayes, et al., 2022). Similar to Canada, FASD assessment and diagnosis is conducted in multidisciplinary diagnostic clinics. A need has been acknowledged to expand these services to meet demand across various settings, including rural and remote areas (McLean & Australian Institute of Family Studies, 2022).

6.6.2 USA

The USA has provided leadership in many aspects of FASD assessment and diagnosis. FASD was first recognized in a pediatric clinic in Seattle, Washington in 1968-1969 (Ulleland, 1972) and soon after the diagnostic criteria for FAS were defined (Jones & Smith, 1973). For many years there were no diagnostic categories for the rest of the spectrum. Systematization of terms defining the full effects on children with PAE began with the US Institute of Medicine's (IOM) 1996 *Fetal Alcohol Syndrome Diagnosis, Epidemiology, Prevention, and Treatment* (Stratton et al., 1996). The Institute of Medicine did not clearly define criteria for Alcohol Related Neurodevelopmental Disorder (ARND, now FASD without SFF). In 1997, the 4-Digit Diagnostic System developed at the University of Washington fully operationalized diagnostic criteria for the whole FASD spectrum. This diagnostic system is available in a guide for clinicians that continues to be regularly refined and updated (Astley Hemingway, S., 2024). In 2004, *FASD Guidelines for Referral and Diagnosis* were developed by the National Center on Birth Defects and Developmental Disabilities at the CDC, in collaboration with the National Task Force on FAS and Fetal Alcohol Effects (Department of Health and Human Services et al., 2004). This represented a national effort toward identification of individuals with FASD using uniform criteria. While they reached consensus on the diagnostic criteria for FAS they failed to come up with diagnostic criteria for Alcohol Related Neurodevelopmental Disorder. Hoyme et al. updated the Institute of Medicine guidelines operationalizing the full spectrum of FASD in 2005 with an update in 2016 (Hoyme et al., 2005, 2016).

To improve the use of diagnostic criteria and reduce underdiagnosis, various organizations and entities have developed supportive resources.These include the *CDC's Alcohol Screening and Brief Intervention* (SBI) and a guide for its implementation for primary care practices (Centers for Disease Control and Prevention, 2024; National Center on Birth Defects and Developmental Disabilities & Centers for Disease Control and Prevention, 2014). Other implementation guidance materials for the SBI include the *BRFSS Statistical Brief: Alcohol Screening & Brief Intervention* optional module (Centers for Disease Control and Prevention, & Behavioral Risk Factor Surveillance System, 2023).

States have implemented a number of strategies to improve FASD identification efforts (US Department of Health & Human Services, 2022a) including screening and assessment. Due to the number of individuals affected by FASD in the criminal and juvenile justice systems, some states have supported targeted identification efforts within these systems as well.

More recently, the *FASD Respect Act* addressed FASD on a national level and was re-introduced during the 2023-2024 118th Congressional Session (FASD United Policy and Training Center, n.d.). Although it did not pass with the change in government, the bill's key provisions would have reauthorized and strengthened existing federal FASD programs, including establishing FASD Centers of Excellence as central entities for State, Tribal, and local governments and non-governmental organizations seeking to develop new or improved best practices for FASD prevention, screening and identification, diagnosis, and FASD-informed intervention programs and services (FASD United Policy and Training Center, 2021.; Murkowski Senate, 2023).

6.6.3 New Zealand

As part of New Zealand's FASD Action Plan the early identification of FASD through timely and effective assessments from healthcare practitioners is noted as a key priority area, with the recommendation of ensuring cross-sector collaboration and capacity to provide effective assessments for people showing signs of FASD (FASD Working Group, 2016). The Action Plan outlines recommended activity in relation to assessment and diagnosis of FASD in New Zealand, as well as key performance indicators.

FASD is diagnosed in New Zealand using the Canadian diagnostic guidelines (FASD-CAN, n.d.), requiring a multi-disciplinary team, including a paediatrician, psychologist, and ideally a speech and occupational therapist (FASD-CAN, n.d.). However, not all District Health Boards across New Zealand have assessment teams able to provide FASD assessments (FASD-CAN, n.d.). According to the Overview of Services Available for People with FASD and their Families report, the use of the best practice multidisciplinary diagnostic approach for FASD has been limited (Ministry of Health, 2017).

6.7 Conclusion

Effective systems for assessment and diagnosis of FASD are key for many reasons. They furnish the data for prevalence estimates (Chapter 4) as well as for developing and evaluating prevention approaches (Chapter 5). They are key for the recognition of challenges and strengths of people with FASD and access to supports (Chapter 7). Yet a key message of this chapter is the limited and uneven capacity for assessment and diagnosis of FASD in Canada compared to the estimated prevalence.

Numerous challenges were identified affecting access to and uptake of diagnosis and assessment opportunities. One of these challenges, stigmatization of PAE and FASD, contributes to the current debate over the use of FASD as the primary or sole diagnostic category. Within the debate, however, there is broad consensus on the value of having assessments and diagnoses. There may be an emerging proposition 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. This would enable a diagnosis in cases where PAE is lacking, while also acknowledging the presence of multiple causal factors where appropriate.

Notwithstanding this discussion, the Canadian Guidelines for FASD diagnosis are well integrated into practice where diagnostic capacity exists. Diagnostic capacity can be expanded by helping a wider range of health professionals build confidence in referral and assessment and adopting new delivery models. Broader uptake of the Guidelines can also be supported by increasing FASD awareness.

Engagement participants as well as the evidence and policy reviews contributed suggestions about ways forward to improve assessment and diagnostic services and systems for FASD in Canada.

Chapter 7:
Interventions and Supports

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

7.1 Introduction

In this chapter, we examine the tools, resources and supports needed to improve outcomes for those with FASD through their lifespan. The heterogeneity of FASD means that different individuals will need support in varying areas of life, and the supports needed will evolve according to the life stage of the individual.

Evidence-based FASD interventions typically address specific cognitive and behavioural effects associated with FASD (Paley & O'Connor, 2009; Petrenko & Alto, 2017). Calls have been made to shift from a focus on intervening to address impairments to include interventions that could develop FASD-specific strengths (Olsen & Sparrow, 2021). FASD interventions can aim to help people with FASD as well as their caregivers. For the person with FASD, these interventions can address a range of domains, including attention and self-regulation, executive, psychological, behavioral, social, and adaptive functioning, nutrition and medication. For the parent, caregiver, and service provider, these interventions are largely focused on education and training (Petrenko & Alto, 2017).

FASD supports are broader, going beyond the interventions mentioned above to provide individuals with FASD and their caregivers with needed resources to support them in multiple life domains, including health, social functioning, education, adaptive life skills, employment, income, and housing—along with help accessing these services and support networks (Pei, Kapasi et al., 2019; Petrenko & Alto, 2017:, B.C. Representative for Children and Youth, 2021). Caregiver needs include advocacy, respite and the opportunity to participate in support groups (Wilson et al., 2023; Domeij et al., 2018; Ilchena et al., 2023; Schwartz et al., 2017; Skorka et al., 2020).

Because FASD is a lifelong, whole body condition (Himmelreich et al., 2020), the needs of a person with FASD evolve as they move through life stages. In Chapter 5 on prevention, the focus was limited to preventive interventions and supports prior to assessment and diagnosis: primary prevention of PAE and early secondary prevention aimed at mitigating the effects of PAE. In this chapter, we focus on interventions and supports provided to children early (prior to diagnosis) as well as following diagnosis, some of which may also be preventive for adverse outcomes later, through capitalizing on early neuroplasticity in young children, as well as through reducing risk factors, fostering resilience, and strengthening protective factors.

Throughout this chapter, we recognize two aspects of FASD that shape the need for interventions and support and the challenges in providing them. The first is that FASD, being primarily about brain difference, is a hidden disability: a chronic condition that interferes with a person's activities of daily living, often without outward physical signs to indicate limitations (Ysasi et al., 2018; Hyseni et al., 2022; Santuzzi et al., 2014). The invisibility of FASD contributes to numerous social and systemic challenges in daily life (Olson, 2002). Second, the heterogeneity of FASD manifestations (Flannigan, Pei et al, 2022; Cook et al. 2021) means that others may underestimate or overestimate the abilities of a person with FASD, especially those who have demonstrated functional strengths in some domains (Anderson et al., 2019; Flannigan, Pei et al, 2022).

In Indigenous communities, identity, culture, and relationships are central elements of action on FASD (Wolfson, Poole et al., 2019). This chapter will build on Chapter 3 to explore Indigenous as well as non-Indigenous experiences with interventions and supports.

7.2 Cross-cutting issues

Several issues cut across or intersect with all or many domains of intervention and support. We address these before considering specific interventions and supports.

7.2.1 Eligibility criteria for intervention and supports

One cross-cutting issue relates to the use of IQ or adaptive behavior scores as cut-offs or thresholds to establish service eligibility.

IQ scores

Some support programs require clients to have an IQ at or below 70 to be eligible for the program. This is two standard deviations below the mean where the population mean is 100 with a standard deviation of 15. IQ tests are widely accepted and usable across a broad age range, and they are efficient measures to use in existing health and support systems. However, given that IQ scores of people with FASD can range from 20 to 120 with an average of 72, close to half will score higher than 70 (Mattson et al. 2019), and thus be excluded from needed services that use an IQ cut-off of 70. Moreover, adults with FASD may have lower daily living skills than other individuals with similar IQ scores. This suggests that IQ is not a good predictor of need in adults with FASD (Temple et al., 2018).

In addition, Petrenko et al. (2014) found that ineligibility for services, often due to IQ thresholds, was a common systemic barrier faced by parents of children with FASD. This is a major source of stress for parents (Pepper, Watson, & Coons-Harding, 2019). These findings echo a national US study, where in testimony from 500 parents and professionals in 15 states, difficulty qualifying for services was one of the most frequently reported challenges (Ryan et al., 2006).

Chipeur and Zwicker (2023) report on a Human Rights Tribunal case in BC where eligibility for community living services required an IQ below 70. The Tribunal found that relying on IQ to determine access to services was discriminatory, especially when children with different diagnoses or with higher IQs still needed support.

Levels of adaptive functioning

Levels of adaptive functioning are sometimes used as an alternative or in addition to IQ thresholds. These are the conceptual, social, and practical skills needed to participate in everyday life that emerge during the developmental period (Mattie et al, 2023.). Children with FASD show deficits in adaptive functioning compared to children with ADHD or children who were not exposed to alcohol prenatally even when controlling for IQ, executive functioning, and age (Kautz-Turnbull & Petrenko, 2021).

Adults with FASD may be unable to access the standardized assessments of intelligence or adaptive behavior needed to prove eligibility for services as it can be challenging navigating support systems and programs generally. The Adaptive Behavior assessment requires an informant to fill out a questionnaire regarding functioning. This can be particularly difficult for socially isolated adults with FASD, as noted by an engagement session participant.

> *The only way to demonstrate low adaptive function is to have someone that knows you fill out a questionnaire like ABAS or Vineland... this means the most vulnerable patients —the ones who have severed their ties with supporters cannot qualify.*

Federally, eligibility for the Disability Tax Credit is determined on the basis of functional limitations, as determined by a medical practitioner (Canada Revenue Agency, 2024).

Provinces and territories differ in their approaches to service eligibility, meaning that where an individual lives can determine whether or not they qualify. In Alberta, the Persons with Developmental Disorders program has an IQ eligibility threshold of 70 or lower (Government of Alberta, n.d.-b). Some provinces use adaptive functioning or daily living skills as part of their eligibility requirements. In BC, supports from Community Living BC are offered in two forms. People with a developmental disability will be eligible if they have: 1) an IQ of 70 or below, or an IQ above 70 but with limitations in adaptive functioning so severe that they are equivalent to an IQ below 70; 2) impaired adaptive functioning that contributes to a DSM-5 diagnosis of intellectual disability; and 3) onset of these before age 18 (Community Living BC, 2018). Autistic people or people with FASD who do not have a developmental disability are also eligible for the Personalized Supports Initiative if they have significant limitations in adaptive functioning along with the diagnosis of Autism Spectrum Disorder (ASD) or FASD (Community Living BC, 2018). The Ontario Developmental Services application process states an IQ test is required along with evidence of adaptive functioning and age of onset before 18, but does not give an IQ cut-off (Ontario Developmental Services, n.d.). The Daily Living Support Assessment used in Saskatchewan's Cognitive Disability Strategy is based on adaptive function, with no mention of IQ (Government of Saskatchewan, 2014).

Finlay, Wittevrongel et al. (2023) found that the requirement to regularly reconfirm eligibility, despite FASD being a lifelong disability, was a frequently mentioned problem with accessing supports. Although Canada's Disability Tax Credit, which confers eligibility for the Registered Disability Savings Fund (RDSP), does not require annual renewal, applicants may be required to submit a new application (Canada Revenue Agency, 2024). This can be a barrier for young adults with FASD who lose funding, unless they have access to an advocate to help them re-apply. Engagement participants indicated that it can be challenging finding a medical professional that understands FASD in adulthood and this creates a risk of being turned down upon re-application, meaning benefits are lost and:

> *[The] RDSP set up by family for their future is compromised.*

Intervention and supports are sometimes available to people who may have FASD without an official diagnosis (e.g., Regina Community Clinic, n.d.), but a diagnosis, confirmed PAE, or being on a waitlist for assessment is often required to access programs (e.g., Government of Manitoba, 2024b). This can be an eligibility barrier for those who, for example, do not have evidence of PAE, which is required for diagnosis in most cases.

As Chapter 6 outlines, there are many barriers to accessing diagnoses, and FASD is often not diagnosed until school age. This delays access to interventions and supports. As noted previously, offering interventions based on functional deficits until full FASD diagnostic services are available would provide earlier access to the supports and services that could improve outcomes.

7.2.2 Siloed delivery of services and supports

The complexity of FASD means that people with FASD and their families often require interventions and support from multiple service areas (Flannigan et al., 2024; Flannigan, Wrath, McFarlane et al., 2021). Care fragmentation, lack of coordination services like central access hubs, and ensuing service gaps (Pei, Poth et al., 2021) can lead to worsened outcomes for people with cognitive disabilities and complex support needs (Dowse et al., 2020).

Engagement participants frequently mentioned the importance of coordination at both service and policy level. They noted that people with FASD and their families are often struggling with many challenges, and having to navigate a complex, fragmented system, repeating their stories multiple times, can be overwhelming. A participant stated that the ideal situation would be

> *Integrated designated systems that include health, First Nations, immigrant systems representation, paediatric and adult systems with transitioning models, long term family practice models, community training for follow-up care including education, mental health, and interdepartmental governance at provincial and national levels.*

In the research literature, effective strategies to address fragmentation and reduce siloing include actions at the level of delivery systems, service delivery (Masotti et al., 2015; Dowse et al., 2020; Pei, Poth et al., 2021), and professional practice, including interprofessional training (DiCemente et al., 2021; Reid, Kent et al., 2023). The Lakeland Centre for FASD is an example, providing commonly needed services under one umbrella and connecting the person with FASD with a personal outreach coordinator to help determine needs and services over time (Lakeland Centre for FASD, n.d.-b).

7.2.3 System navigators

To mitigate the fragmentation and siloed service delivery encountered by people with FASD, their caregivers and their service providers, the concept of "system navigators" has been explored. Several navigation models exist, including layperson-led (e.g. service coordinators) and professional-led (e.g. nurses, social workers, occupational therapists) models (Carter et al, 2018). By addressing social determinants of health (e.g., housing, food insecurity, employment), these models focus on facilitating access to care, promoting continuity, and addressing barriers, while reducing health disparities (Natale-Pereira et al., 2011). In other health domains, system navigators have been shown to facilitate patient-provider communication, address issues of distrust, provide emotional and informational support, improve compliance with treatment, and reduce stress in navigating complex health systems, making it easier for individuals to access a continuum of care from primary services to specialized treatments. Although sometimes criticized as band-aid solutions diverting attention from the need for broader system-level reform and as challenging to implement, they can improve access to care, health outcomes, and patient satisfaction, especially for complex patients (Carter et al, 2018). A study of caregivers of children and youth with neurodevelopmental diagnoses including FASD found that support from social networks, professionals acting as unofficial gatekeepers, and service navigators facilitated access to underused disability supports (Finlay, Wittevrongel et al., 2023).

"System navigators" or "key workers" have been successfully implemented in some locations across Canada. In BC, the Centre for Child Development of the Lower Mainland and the British Columbia Centre for Ability Key Worker Support Services develop and help implement multi-component service plans. Services are available up to age 19; FASD diagnosis is not required (British Columbia Centre for Ability, n.d., Centre for Child Development, 2023). In Alberta, the North West Region FASD Society - Mackenzie Network provides coaching supports to agencies, families and individuals with FASD (Mackenzie Network, n.d. -a), similar to the previously mentioned Lakeland Centre for FASD. Ontario's FASD community-based workers "provide information and develop service plans. They also help families access services and connect individuals to available support networks and diagnostic services" (Government of Ontario, n.d.-b) Continuity can be challenging for programs that lack sustainable operational funding. Ottawa's Fetal Alcohol Resource Program (FARP) was established in 2015 in collaboration with Ottawa ABLE2 and initially provided a navigator role, connecting individuals with FASD and their families to existing supports and services in their community. This program has now taken on clinical service delivery through partnership with the Children's Hospital of Eastern Ontario, as well as a leadership role with Ontario's Key Workers. As its research-based funding ends, it is moving to a fee-for service model (Kids Brain Health Network, 2024b), potentially impacting access for some individuals with FASD and their families.

Engagement participants noted that access to such system navigators is important to ensuring access to interventions and supports across multiple needs domains. They urged that such navigators be trained and available through the lifespan to help navigate education, health, mental health, employment, housing, justice, and child welfare systems:

> *Enhanced training for healthcare providers, educators, and social workers is crucial. This training should not only focus on the clinical aspects of FASD but also on the practical challenges that families face.*

This view is supported by broader investigations of navigation systems (Hébert et al., 2023).

7.2.4 FASD-informed and adapted resources

To adequately support people with FASD and their caregivers, the providers and organizations offering interventions and support are encouraged to be aware of the unique characteristics and needs associated with FASD (Flannigan et al., 2024; Lesinskienė et al., 2023; Rutman, 2016). This can apply to providers in multiple sectors, including health, education, justice and mental health (McCormack et al, 2022; Burd et al., 2021; McLachlan, Mullally et al., 2020).

In a scoping review of experiences of professionals working with people with FASD, Wilson et al. (2023) found that they reported difficulty supporting individuals with FASD because of a lack of professional training, institutional support, and unclear professional boundaries, leaving them feeling unprepared and overwhelmed. Some research evidence suggests that interprofessional training to equip providers with science-based knowledge on addiction, stigma reduction, and trauma-informed care, can increase provider knowledge, self-efficacy, and plans for greater collaboration (DiClemente et al, 2021.)

For individuals with FASD, stability, structure and consistency are crucial. Strategies which promote placement stability may contribute to more positive outcomes especially for children with FASD (Pelech et al., 2013).

7.2.5 Neurodevelopmental disorders or diagnosis-specific supports

There is sometimes a question of whether interventions and supports need to be specific to the diagnosis of FASD or more general interventions and supports suitable to a broad range of neurodevelopmental disorders would be effective and also offer resource-savings.

Advantages of FASD-specific services:

- They focus on the unique and multiple challenges of the issues stemming from PAE and connected causes. A key example is the need for trauma-informed approaches in FASD (Kautz-Turnbull et al., 2023). More general approaches may group people with dissimilar needs together in unhelpful ways, especially if resources and approaches are then skewed toward the needs of the part of the group that are less characteristic of those with FASD. Furthermore, interventions and supports designed for other neurodevelopmental disorders may not be effective with FASD. An engagement participant wrote:

  > *Relying on functional skills and not dealing with the PAE leads to professionals/educators not having all the information and developing strategies that are not necessarily going to be effective. Strategies for people with FASD/PAE are different, and having the full neurological/psych picture is important to developing these strategies otherwise everyone gets frustrated and the child ends up being blamed…*

- They can address and adapt to the stigmatization that accompanies FASD.

Advantages of services offered under a neurodevelopmental disorders umbrella, tailored to functional challenges rather than FASD diagnosis:

- They may provide greater accessibility to intervention and support for those who cannot obtain an FASD diagnosis due to the difficulty confirming PAE, discussed in Chapter 6;
- Because of the variation within FASD diagnosis, interventions and supports are generally highly customized to individual cases; a more general approach would retain customization, but tailored to the individual rather than the diagnosis;
- They may be more acceptable if people are avoiding services that are labeled as FASD-related due to stigma;
- Diagnosis-specific funding creates competition between disability groups for scarce resources, affects affordability of private sector supports for unfunded disability groups (because private sector fees increase as more funded families compete for access to existing private sector supports), and also skews diagnosis as people may pursue diagnoses that lead to better supports;
- More general systems may be more efficient, allowing sharing of resources and expertise, rather than spreading these more thinly among parallel diagnosis-specific services.

In BC, a pilot program for “Family Connection Centres” is being trialed in four locations, and provides supports based on functional assessment for children and youth aged 0-19 who have developmental delay, confirmed developmental need or disability (Government of BC, 2023).

It is intended that these centres will make supports more readily available by not depending upon an FASD diagnosis. Concerns were raised about whether the system would be able to provide adequate services, given the expected increased demand as eligibility was expanded, as well as around the loss of specialized services tailored to specific diagnoses (Matassa-Fung & McArthur, 2022).

In our engagement sessions, a concern was expressed that FASD stigma may undermine the development of specialized expertise in FASD and the provision of valuable FASD-specific supports. They explained that more families may come forward for services with less stigmatizing labels - autism spectrum disorder was often cited as an example - leading to an apparent lack of need or desire for FASD-specific interventions:

> *A lot of areas are saying they have no families with FASD in order to justify lack of services.*

Key Findings:

Interventions and supports that promote stability, structure and consistency are important for individuals with FASD.

IQ assessments can be useful in providing information about areas of strength as well as challenges. IQ cut-off scores used to determine eligibility for disability services and supports are used in some locations, and these can exclude individuals with FASD whose IQ exceeds the cut-off, but who still have significant functional challenges and problems with daily living.

Adaptive behavior assessments measure daily living skills in order to understand a person's specific needs for support. While helpful in many circumstances, formal tools or questionnaires can be difficult to access for the adult population. A trained support worker doing a careful assessment with an adult who has FASD may be the most effective approach.

Adults with FASD may struggle to navigate the systems for financial support and services, meaning they may be excluded, even if eligible, if they lack a supportive family member or other advocate to assist them.

The siloed operation of the various services and systems that a person with FASD and their family may encounter (e.g. healthcare, housing and income support, education and occupational training, child protection, justice) along with expectations to re-prove eligibility increases complexity from both the service provider and client perspectives.

Key Findings:

A system "navigator" (e.g. key worker, mentor, coach) assigned to a child or youth with FASD and his or her family, or to an adult with FASD, is very helpful in offering practical and emotional support as well as help in accessing community resources, health and other social services.

Training regarding the unique complexities of FASD and its associated challenges would be helpful for professionals working with people with neurodevelopmental disabilities.

7.3 Early, continuing and multi-faceted interventions

As the evidence base on FASD has expanded, awareness has increased of its complex consequences across the lifespan and the multiple needs and opportunities for intervention and support throughout the lifespan (Popova et al., 2020; Flannigan et al., 2020; Pei, Kapasi et al., 2019).

7.3.1 Early intervention

As noted in Chapter 6, FASD is most commonly diagnosed when children reach school age and fail to attain behavioural and developmental milestones (Dugas et al., 2022). However, interventions are potentially beneficial well before that during periods of maximum neuroplasticity (Olsen et al., 2007; Andreu-Fernández et al., 2024; Hanlon-Derman et al., 2020).

Interventions for preschool children might aim to mitigate the effects of PAE and environmental risk, while at the same time enhancing protective factors. This could include comprehensive intervention programs adjusted to each child's unique needs and family situation, for example home visits to help caregivers understand their children's cognitive capacities, modify expectations and attitudes, develop specialized parenting skills, and learn effective advocacy to access existing community supports that may be required later (Olsen et al., 2007). As one engagement participant stated:

> *I have seen first-hand with early diagnosis and supports put in place, good things happen.*

Early interventions before diagnosis have the potential to ameliorate the effect of PAE. If early FASD diagnosis is not available, family support and specific interventions for young children at risk of neurodevelopmental disorders can be offered. A recent systematic review has identified a number of promising early intervention strategies for neurodevelopmental diagnoses more generally, including: telehealth interventions for case management, comprehensive interventions targeting behavioral, educational, and social development, and parent-children relationship supports; machine learning may also contribute (Aldharman et al., 2023). For example, a caregiver-implemented communication development intervention for toddlers at risk of communications delays produced positive results (Roberts & Kaizer, 2015).

There are few reviews, however, assessing early interventions for the primary cognitive features specific to FASD. In a review of 11 psychological interventions to improve executive function in children aged 3 to 16 with PAE or FASD, Betts et al (2022) found evidence for small to medium sized improvements in executive function based on direct measures (cognitive flexibility, verbal working memory and visual working memory) and indirect measures (behavioural regulation, shifting, inhibition and meta-cognition). These findings all derived from pre-post single-group studies, and the authors therefore qualify the results as limited and uncertain (Ordenewitz et al., 2021). The dearth of evidence on this topic exists, at least in part, because clinical studies need well-documented study populations with clear measures of outcome, and children with PAE are not systematically identified at an early age. As a result, it is difficult to identify a clear target population to investigate interventions, creating a vicious cycle in which it is difficult to identify the relevant target population for an early intervention until the window to intervene early has passed.

Most available studies have implemented FASD interventions for school-aged children (six-12): these are summarized in the next section.

7.3.2 Childhood and adolescence

As children mature into school age and beyond, the primary neurodevelopmental manifestations of FASD's diagnostic domains may persist, and issues in social, behavioral and academic functioning may emerge (Streissguth et al., 2004; Petrenko et al., 2014). These associated difficulties are sometimes called 'secondary disabilities or difficulties', meaning that they are consequences of the initial PAE and the failure to intervene effectively to mitigate those consequences. These are in no way less important, and instead are critical to the lives of people with FASD. Streissguth et al. (2004) showed that risk of adverse life outcomes including disrupted school experiences, legal problems, institutionalization, confinement (i.e. prison, rehabilitation), inappropriate sexual behaviors and alcohol/drug problems, was two to four times lower for those diagnosed at a younger age and who had benefited from supportive, stable environments.

Several systematic reviews have examined the effectiveness of interventions to mitigate the impact of FASD and to avoid development of associated difficulties in children and adolescents. Ordenewitz et al. (2021) reviewed 25 randomized control trials of a wide range of interventions for FASD, including language and literacy training, the Alert Program® for self-regulation skills, parental training, the Math Interactive Learning Experience (MILE) Program, the GoFAR program, and Children's Friendship Training (CFT) for social skills training. There was evidence that some therapeutic interventions, particularly those involving a combination of parent and child sessions, were effective in children and adolescents with FASD. Positive treatment effects of interventions seemed to be domain specific: stress reduction, information and adaptive skills, but more general effects were found for self-regulation and social interaction. The authors note these interventions can mitigate some consequences of FASD although they rarely led to improvements of performance into a "normal range."

In a meta-analysis of 25 studies on allied health and educational interventions for children aged 5 to 18 with FASD, Hilly et al. (2023) found child-focused interventions to be effective in improving attention, executive functioning, academic skills, social skills, fire safety skills, task completion, learning to use metacognitive strategies, and a reduction in problem or disruptive behavior. Interventions supporting caregiver/teacher awareness and capacity to support children and adolescent activity outcomes were also effective. There was no evidence that interventions designed to improve social participation were effective.

In a scoping review, Champagne et al. (2023) reviewed four intervention studies addressing the frequency and severity of aggressive behavior, which is sometimes exhibited by children aged 5 to 12 with FASD toward family members. The four interventions studied did not specifically target aggression, instead reporting on broader aggression-related behavioural constructs (such as disruptive behaviors, externalized behaviors, emotion regulation, temper tantrums, frustration tolerance, impulsivity, and destructiveness). However, the interventions resulted in positive changes in behavior, cognition, and self-regulation and pointed to psychosocial interventions targeting aggression as worthwhile. The authors conclude that given the importance of this issue for individuals with FASD and their families, research on how to support families and people with FASD who may demonstrate aggressive behavior would be extremely helpful.

Flannigan et al. (2020) reviewed 33 studies of interventions to improve mental health and substance use outcomes for individuals with PAE or FASD, mostly aged 6 to 12 years. The interventions varied by target age: in early childhood, they focussed on supporting attachment and family wellness, with caregiver participation; in middle childhood and early adolescence, they primarily involved building skills and strategies a to support behavioral, social, or emotional functioning (self-regulation, social skills, and behavioral skills); whereas in later adolescence, emerging adulthood, and adulthood, they centred on responding to risk and reducing harm related to substance use. This review found favorable and emerging evidence for interventions at all these life stages but noted limited research on adults and adolescents and lack of research regarding interventions that directly targeted mental health and substance use outcomes.

Despite empirical evidence of the positive effects of interventions in the domains of parenting and education, attention and self-regulation, adaptive functioning, and nutrition and medication, these interventions are often deployed and tested in limited contexts (Petrenko & Alto, 2017). Broader dissemination and implementation may be constrained by cultural and policy contexts; an implementation science perspective may aid wider implementation of FASD interventions.

In a retrospective analysis of the level and types of needs found in a group of 1440 children and adolescents aged 6-17 with confirmed PAE and assessed for FASD at Canadian diagnostic clinics, McLachlan et al. (2023) identified four subgroups:

- Global needs: significantly impaired in all domains. Highest cumulative number of significantly impaired neurodevelopmental domains; highest cognitive impairment; high probability of significant impairment in language, academic achievement, memory, attention, executive functioning, and adaptive/social functioning.
- Cognitive needs: moderate number of significantly impaired neurodevelopmental domains including cognition, academic achievement, language; moderate probability of significant impairment in memory, attention, executive functioning, and adaptive/social functioning.
- Regulation needs: moderate number of significantly impaired neurodevelopmental domains but with notable differences in the overall pattern.
- Attention needs: relatively low probabilities of significant neurodevelopmental impairment.

The authors suggest that the subgroups can point to distinct service pathways, adapted for their needs, potentially increasing access to more personalized treatment and improved outcomes.

In summary, there are several successful intervention strategies and they often include using a strengths-based approach, using repetition, building relationships, providing structure and consistency, and ensuring an individualized approach based on a person’s actual skill or developmental level rather than chronological age.

A challenge identified in the evidence review was how to scale up promising programs, often developed with significant research funding, that involve one-on-one intervention and appear to be too resource-intensive for wide-scale implementation. For example, Rasmussen & Pei (Kids’ Brain Health Network, n.d.) are adapting the Math Interactive Learning Experience (MILE), developed by the Emory University School of Medicine (Coles et al., 2009), to address the specific mathematics processing issues of children with FASD for broad group-based implementability in classroom settings. The program will also be broadened to include capacity to address needs in other neurodevelopmental disorders (Kids Brain Health Network, 2023a).

7.3.3 Adulthood and aging

Although FASD is a lifelong condition, research on the whole-body aspects of aging with FASD is underdeveloped (Wozniak et al., 2019; Reid et al., 2015). Individuals with FASD have higher frequencies of a wide range of health conditions and develop these earlier than in the general population (Himmelreich et al. 2020). Without ongoing attention, mental and physical health concerns may remain undetected or become exacerbated, putting adult and aging people with FASD at further risk of developing preventable co-occurring conditions (Olsen & Sparrow, 2021).

Challenges in daily living can also become more prevalent as people with FASD age and face new contexts. In a study of adolescents, transition-aged youth, and adults assessed for FASD (including those determined as at risk for FASD and those not diagnosed, about 25% of the sample), difficulty rates were highest for independent living support needs (63% of those assessed), substance misuse (46%) alcohol misuse (38%), employment problems (37%) and legal problems (30%). Rates for six of the nine categories of difficulty were greater for adults, suggesting that problems continue to accumulate with age, and for those with lower intellectual functioning (IQ < 70). In addition, higher cumulative difficulty was associated with male gender, living placement (itself highly associated with IQ) and greater neurodevelopmental impairment (McLachlan, Flannigan et al., 2020). In a study of 16-year outcomes, in South Africa, adults with FASD were less likely to be in a relationship, and more likely to have poorer educational outcomes and to have been more exposed to violence as victim or perpetrator than a control group (Broodryk et al., 2024). Streissguth et al. (2004) found that protective factors for these impacts were early diagnosis and provision of support and interventions at home and in the community.

In discussing the challenges of adult diagnosis, Badry (2010) indicated that over and above the multidisciplinary teams involved in the assessment, those diagnosing adults can interact with community partners and resources to maximize the intervention potential for each affected individual: social service agencies, employers and vocational training professionals, parole officers, guardians and members of support networks, and advocacy workers among others.

Reviews of adult FASD assessment and diagnosis in Canada highlighted serious gaps in services as people with FASD get older and identified diverse service needs for adults: comprehensive assessment; substance-abuse screening and treatment; psychotherapy; suicide prevention; employment assistance; housing assistance; and family/parenting support. Similar gaps exist in the US and other countries (Flannigan et al., 2020). A follow up study of people with FASD diagnosed as adults found that most experienced significant challenges (Temple et al., 2020).

Despite the prevalence of these challenges, there are few systematic pathways to addressing them. Researchers have noted that there is a paucity of evidence-based interventions for adolescents and adults (Flannigan et al., 2020). From a scoping review, Quan et al. (2018) identified the following elements for developing community-based interventions for adults with FASD:

- Inclusion of a functional context, especially training in life skills and vocational skills to increase capacity of people with FASD to find and maintain employment and housing, manage finances, access healthcare, and build social networks;
- Individualized support from consistent care providers such as one-to-one mentorship and outreach-based supports that connect adults to community agencies and provide assistance in daily living skills such as banking, budgeting, problem-solving, grocery shopping, and crisis intervention;
- Education for service providers so they have the knowledge to correctly identify problems in FASD;
- Ensuring structure, supervision, and routine for optimal functioning by both participants and key support individuals;
- Using a strengths-based approach, honoring the unique strengths and abilities of people with FASD while recognizing individual differences; and
- Environmental adaptations (such as avoiding fluorescent lights and bright colors, decluttering noise/auditory stimuli and visual distractions, using visual aids such as photographs of program staff on the office door, having calm, quiet spaces for interviews or meetings, and ensuring that the physical space is non-confining).

Role of regional and local support networks

Some supports are available for adults with FASD as well as families and caregivers in different regions of Canada.

- Plexus FASD, a regional partnership in Waterloo Region, provides services and supports for people with FASD and their caregivers, from diagnosis through special education classrooms, as well as resources and supports for service providers. With the Ontario Senior Caregiver Action Network (OSCAN), it produced an FASD resource guide for senior caregivers of adults with FASD in order to reduce caregiver stress, build peer support; and assist with lifetime planning (Ontario Senior Caregiver Action Network, 2022).
- In Manitoba, the Touchstone FASD Program provides everyday support and advocacy for youth and adults with FASD (Touchstone, n.d.). To be eligible, participants must meet the eligibility criteria of the provincial disabilities program.

- In Saskatchewan, the Regina Community Clinic operates an FASD Centre, offering targeted life skills and specialized addictions programming and supports for individuals over the age of 16 years who may be diagnosed with or suspected of having FASD (Regina Community Clinic, n.d.).

Interdependence

The idea of interdependence rather than independence as a goal has arisen because of the recognition that most people rely upon one another and networks of support throughout their lives, and also because for many adults with FASD the goal of independent living is an unreasonable expectation (Gault et al., 2023). The objective of interdependence describes the manner in which people with FASD transitioning to adulthood can draw on their families and support systems when needed (Michaud, 2019). Engagement participants were supportive of this idea, pointing out that the goal of "independence" may also be unfair and ableist. As one caregiver stated:

> *Let's not focus on independence, but switch words to interdependence and really have a sliding scale based on abilities. My goal for my teens moving to 20s are not to live independently, but to live interdependently. If I expected independence they would probably end up on the streets.*

Recognizing and fostering interdependence will help to reduce the sense of blame and shame associated with difficulty achieving "independence."

Peer support and networking for people with FASD

Connecting with others who have FASD can be very valuable for people with FASD. People with FASD participating in the engagement sessions noted that peer connections and networks help to: combat loneliness; get and receive support from other people with FASD; offer hope to others who are struggling.

Engagement participants identified that a key stressor for parents and caregivers is how to ensure a support network for their children when they are no longer able to provide it. Indeed, the odds of premature mortality for parents of children with FASD are significantly higher than that of the general population (Schwartz et al., 2017). In this context, the need for "natural", in addition to professional, supports has been emphasized. This notion refers to the informal assistance and resources provided by individuals within an affected person's immediate environment (including family, friends, peers, neighbours, community members) who offer emotional support, guidance, and practical help (Calgary Fetal Alcohol Network, 2016).

Parenting

Relatively little information is available about supporting parents who have FASD. Reid et al. (2015) identified two studies of interventions for parents with FASD, both of which resulted in improved health and social outcomes. However, parents with FASD face significant challenges in being permitted to parent, often encountering stigma and stereotypes in the child welfare and legal systems (Rutman & Van Bibber, 2010; Choate et al, 2024). As described later in this chapter when discussing child welfare, recognizing the parent's abilities while accepting their limitations and providing supports in these areas, can help realize the goal of family preservation and reunification.

7.3.4 Importance of a lifespan approach - transitions and community supports

Interventions and supports for people with FASD are often organized around particular life stages. Transition periods between those stages can result in gaps and reductions in services, with challenges to navigate new health and social service systems (McLachlan, Flannigan et al., 2020; Pepper et al., 2019; Gault et al., 2023). Engagement participants indicated that because transition supports are usually delivered through provinces and territories, there is variation within the country, and the need to maintain access to supports limits mobility within Canada for people with FASD.

Adolescence to adulthood

The transition from adolescence to adulthood with its pressure for increasing independence (see "interdependence", above) is a time of vulnerability for young adults (Gault et al., 2023; Rice et al., 2022; Kippin et al., 2021; McLachlan, Flannigan et al. 2020), and not enough is known about the effectiveness of and barriers to uptake of transition planning tools or resources (Coons-Harding, Azulai et al., 2019). In a qualitative case study of the school experiences of a 21-year-old individual with FASD, the participant noted that while there had been supports within school that appropriately met his needs, the supports no longer existed for him when he graduated despite these needs continuing into adulthood (Brenna et al., 2016). In a scoping review of promising transition practices, Gault et al. (2023) identified the following factors in successful transitions:

- Understanding FASD: lack of knowledge of FASD by professional service providers was identified across studies as a key barrier to preventing adverse psychological and social outcomes of FASD over transition periods;
- Ensuring availability of support beyond school age, especially for adolescents who are ageing out of the care of child welfare authorities and others whose natural support networks may be less developed;

- Stable advocacy: Studies identified caregiver advocacy as a specific element that supported successful experiences of youth with FASD during the transition to adulthood. For youth without a family support system, for example those leaving the child welfare system, a consistent, caring case manager or support worker can fill this role;
- Reducing the discrepancy between needs experienced by individuals with FASD and their eligibility for supportive services was a key theme found in studies focused on preventing adverse psychosocial outcomes.

Gault et al. (2023) also synthesized studies of lived experience of people with FASD making this transition, finding that they attributed successful transitions in employment and education to employers and school staff who demonstrated understanding regarding the ways in which FASD can impact individuals, and their role in providing support. Overall, relationships, over and above specific resources, tools and policies, were the most important factor in successful transition of youth with FASD to adult roles.

Specifically for people with FASD, Manitoba's Rural Connections provides services for youth and adults with FASD in two rural regions with transition planning for youth entering adulthood, clinical case management, and family support (Rural Connections, n.d.). Spectrum Connections is a similar program in Winnipeg (Spectrum Connections, n.d.). Similar programs exist in other provinces and territories as well.

Transition of youth out of child welfare systems

The risks of the transition from youth to adulthood are especially great for youth transitioning out of the child welfare system who lose access to services and supports such as caseworkers and educators (Bala et al., 2013; Burnside & Fuchs, 2013). Because, as mentioned above, they may lack a consistent advocate and stable support network to help them avoid negative choices, they may engage in risky behavior and encounter legal problems (see Section 7.4).

Engagement participants suggested that providing a longer and slower transition to interdependence may be helpful for youth with FASD transitioning out of the child welfare system. While extending child- and youth-focused care can provide an interim solution, expansions of supportive services for adults with FASD are still needed (Gault et al., 2023). These young adults may benefit from supports throughout early adulthood, such as skills training, mental health support, tutoring and help with high school completion, and housing stability, especially if offered as a reliable, wraparound network of supports. These observations are consistent with those of Gault et al. (2023) and Flannigan, Poole et al., (2023) on successful transitions more generally.

Some jurisdictions have implemented programs to facilitate the transition out of child welfare systems for people with FASD. For example, Alberta's "Transitions to Adulthood (TAP) - Advancing Futures Program" provides youth aged 18-24 who have been in the care of the child welfare system with access to social and emotional supports: mentoring opportunities, life skills development, mental health and addiction supports and employment help. Some educational supports are available until age 31 (Government of Alberta, 2023). In BC, the Strengthening Abilities and Journeys of Empowerment (SAJE) program offers supports and services to youth and young adults ages 14 to 27 with experience in the child welfare system. These include financial help, housing supports, health and wellness coverage, as well as funding for training, life skills, or cultural learning programs not covered elsewhere. In addition, navigators and guides are available to help with transition planning (Government of BC, 2024).

Engagement participants noted however, that even once those extended transition services end, people with FASD will still be facing the challenges associated with their condition:

> *FASD does not magically end at a certain age.*

Transition supports for Indigenous youth with FASD may be accessible using Jordan's Principle (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative although this ends when a youth turns 18 or 19 depending upon the province or territory.

Adulthood to seniorship

Understanding FASD throughout the lifespan is crucial for educators, employers, and caregivers to prevent adverse outcomes and support individuals into and throughout adulthood (Petrenko & Kautz-Turnbull, 2021; Pei, Flannigan et al., 2016; McLachlan, Flannigan et al., 2020; Moore & Riley, 2015; Gault et al., 2024). Engagement participants stressed that people with FASD have permanent disabilities and associated service needs that continue across their lifespans:

> *...many and often multiple issues can affect individual health across the life course. Focusing on the needs of children with FASD helps reduce secondary effects on education and employment, but this does not capture all of the health needs of a person with FASD through adolescence, adulthood, and into old age.*

Aging adults with FASD may be losing natural supports as the people in their support networks age. Some adults with FASD may become caretakers of their aging parents.

And yet, other than the Plexus FASD initiative for senior FASD caregivers, which may address the needs of the ageing adults with FASD, our assessment found very little information about intervention and supports for people with FASD moving from adulthood into old age - even though there have been several calls for such programs (Pei, Flannigan et al., 2016; Petrenko & Kautz-Turnbull, 2021).

Engagement participants underscored this blind-spot in the discussion of supports for people with FASD, commenting for example that the transition from social assistance to Old Age Security as income support could present challenges for older people with FASD, in terms of the application process and the subsequent reduced income, when their support needs continue and may increase.

7.3.5 Gaps in interventions and supports for FASD

Accessibility of interventions and supports

In addition to the accessibility challenges posed by service fragmentation, siloed systems, and eligibility barriers discussed in Section 7.2, additional accessibility issues were identified by engagement participants. These include access to services for those living in rural/remote areas, linguistic barriers, cultural barriers when services do not take into account alternative cultural worldviews and healing practices, and cost barriers when services are not available within the publicly funded systems or involve significant travel.

Increased access to diagnosis in some areas, while welcome, means, according to engagement participants, that post-diagnosis support services will have to be increased as they are already inadequate for families struggling with FASD:

> *Since a large investment was made in [province's] diagnostic services in the last two years, we expect pressure will continue to grow for supports, now that more individuals with suspected FASD are being identified.*

Also suggested was expanded access to interventions such as adaptive skills training, group therapies specific to social skills and healthy coping practices, risk assessments, and caregiver supports for psychoeducation and systems navigation.

Engagement participants also identified more stable funding of intervention programs, notably core operational funding rather than project-based funds as an enabler for expanding access.

The enactment of Jordan's Principle (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative (Indigenous Services Canada, 2024g) has aimed to ensure access to services and supports for First Nations children with disabilities, including FASD. A 2021 review of Jordan's Principle found that although implementation and coordination and hence accessibility challenges were observed in funded initiatives (which include but are not limited to FASD services), some funded projects appeared to have positive outcomes for children with complex needs and their families. Cited were: reduction of negative incidents among youth, improved school attendance, the ability for families to remain living on-reserve, and improved supports for parents. Parents identified significant benefit with the "introduction of an active champion who helped assess and meet the needs of their children" (Indigenous Services Canada, 2021, p. iv), a finding that echoes the call for system navigators discussed in Section 7.2. An evaluation of the FASD component of Indigenous Services Canada's Healthy Child Development Program found that long wait times have become a barrier to connecting children and families with the appropriate resources through Jordan's Principle (Indigenous Services Canada, 2024e). Little data is available for the Inuit Child First Initiative.

Access to a range of healthcare practitioners

Given the range of cognitive, sensory and physical health conditions people with FASD may experience, they can benefit from services provided by a range of allied health professionals, including social workers, speech and language therapists, occupational therapists, physiotherapists, psychologists and other types of counselors (Government of Canada, n.d.-c). However, given the diversity of FASD presentations and intervention and support needs, many of those diagnosed find it challenging to process the lengthy lists of recommendations they may receive following a diagnosis (Kids Brain Health Network, 2023b). The COMPASS tool is being developed to assist individuals and families with navigating among the recommendations about services, supports and interventions. It is based on a synthesis of the data in the National FASD database identifying patterns in recommendations provided to people with FASD and their caregivers at the time of diagnosis. The data synthesis is being used to develop algorithms to help orient newly diagnosed people to the combination of supports, services, and interventions that best fits their profile (Kids Brain Health Network, 2023b; CanFASD, 2023c).

7.3.6 Strengthening the evidence base for FASD interventions

Many researchers and practitioners in the area of FASD have concluded that there is a paucity of robust research on the effectiveness of FASD-related interventions in various areas of investigation (Flannigan, Pei et al., 2018; Gault et al., 2023; Mullally et al., 2023; Roozen et al., 2022). Some dimensions of FASD have received little research attention, for example interventions that target mental health and substance use challenges (Flannigan et al., 2020) and aggressivity (Champagne et al., 2023). There is a major gap in research on effective interventions for adolescents and adults (Flannigan et al., 2020). Research on effective intervention designs (Ordenewitz, 2021), and the rigour of intervention evaluations can also be improved (Betts et al., 2022).

At the same time, Flannigan et al. (2020) have noted that at least some evidence has accrued about effective interventions at most life stages and that if combined, it may contain the components necessary for integrated care planning for individuals with FASD across the life course.

Key Findings:

Interventions and supports for individuals with FASD and their families can contribute to better outcomes and protect against adverse consequences associated with FASD.

Early interventions have the potential to mitigate the effect of PAE and reduce environmental risk. Family support and specific interventions for young children at risk of neurodevelopmental disorders can be offered prior to diagnosis and during this period of high neuroplasticity. Without interventions and support there is a risk of more severe difficulties emerging as children mature into school age and beyond, for example in social, behavioral and academic functioning.

People with FASD have elevated rates of challenges in multiple realms including activities of daily living, social relationships, employment, substance use, and the law. A reasonable goal for many people with FASD is interdependence, where they can draw on their families and support systems when needed. Without interventions and supports, these challenges can accumulate.

The transition from adolescence to adulthood can be a particularly difficult and risky period. People with FASD can be very vulnerable at this time, particularly youth lacking supportive networks. 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 with FASD transitioning out of the child welfare system may have less developed natural support networks and would especially benefit from longer term, targeted supports during the transition to adulthood that recognizes the slower pace with which this occurs.

There is very little attention to the challenges faced by aging adults with FASD, and support services are limited. The aging of caregivers who support adults with FASD is a source of anxiety and concern for people with FASD and their families.

Peer support and networking with others who have FASD can provide a valuable community and source of information for people with FASD.

Key Findings:

Parents who themselves have FASD encounter significant challenges due to stigma and stereotypes in the child welfare and legal systems. More FASD-informed supports may enable them to succeed and to preserve their families.

Further work on how to adapt, scale and evaluate promising interventions for broader implementation would be beneficial.

7.4 Interventions and supports by outcome domain

In this section, we review the evidence base for interventions and supports aimed at improving outcomes in key domains affected by FASD.

7.4.1 Family and caregiver intervention and support

Families and caregivers report that caring for someone with FASD is both rewarding and challenging (Kautz-Turnbull et al., 2022; Coons et al., 2016; Ritland et al., 2020). People with FASD may continue to rely on some form of lifelong support from others in their household throughout their lives. The survey of adults with FASD conducted by Hargoves et al. (2024) found that 43% were in a partner relationship, and 14% percent were married. Twenty-nine percent had children, and about 14% had children living with them.

Family and caregiver experiences

Many of the families interviewed for a qualitative study of the experiences of parenting children with FASD reported that raising their children with FASD was enriching and that their children brought positive, transformative contributions to their lives (Coons et al., 2016). Kautz-Turnbull et al. (2022) found that many caregivers experienced positive influences on their families from having a child with FASD, along with personal and parental growth and skills, which were considered adaptive strengths. In the Indigenous context, a scoping review found several factors contributed to positive outcomes for caregivers, including: self-determination of parents, families, and communities; connection to culture and traditional values; healing from intergenerational, historical, and lifetime trauma and building trust through cultural safety (Ritland et al., 2020).

There is also evidence that FASD can be associated with negative outcomes for families and caregivers (Wilson et al., 2023; Domeij et al., 2018; Ilchena et al., 2023; Schwartz et al., 2017; Skorka et al., 2020). Significant parenting stress is found for birth parents, adoptive parents, foster parents, and other legal guardians (Ilchena et al., 2023). During the engagement process, participants reported negative impacts on caregivers for children with FASD including: emotional strain, social isolation, impact on work or school commitments; financial repercussions; setting aside personal interests and leisure activities, and exhaustion. One participant recounted:

> *Parents of children and adults with FASD are struggling as they are living with exhaustion, depression, grief and loss, and fear what will happen to their adult child when they are too old to care for them. There are limited accessible and knowledgeable mental health services for parents who often develop serious health issues related to stress and loss.*

Interventions and supports for families and caregivers

In the engagement sessions, the need for adequate support for parents and caregivers was underscored. Participants mentioned the need for respite support, as well as information and support from social networks. Support for parents and caregivers is important not only for their sake, but because of the potential to improve outcomes. As one engagement participants put it:

> *Effective support for parents and caregivers is vital. While we can establish various supports for individuals with FASD, the real impact is felt when caregivers themselves are supported. This involves helping them build the emotional capacity and resilience needed not just to manage daily challenges, but also to effectively access services and implement necessary accommodations. It's this foundational support that enables caregivers to provide the best care and advocacy for their loved ones with FASD.*

Ilchena et al.'s (2023) systematic review found elevated levels of stress reported by parents caring for children with FASD, although sample sizes were small. The review found mixed results reported in the small number of studies involving interventions to reduce parent stress.

Behavioral problems observed among children with FASD can include physical aggression (Tsang, Carmichael Olson et al., 2017). Engagement session participants noted there were few effective options and resources for families and communities when a child with FASD is demonstrating challenging behavior.

The value of supporting and including parents in interventions for children and adolescents was revealed in a systematic review that found that the most positive treatment effects of those interventions were found for family interventions that included information on FASD for parents, and both child and parent training. This positive effect was attributed to personal demonstration to children of instructions to improve behavior regulation; parent training alone was not as effective (Ordenewitz et al., 2021).

Parents and caregivers benefit from formal and informal networks and support groups (Coons et al., 2016). Needs for support are especially acute for caregivers who live in contexts where FASD symptoms and characteristics are poorly understood, as the weight of both advocacy and education of others on the individual with FASD's behalf falls to them (Coons et al., 2018).

Several parent education and training interventions implemented during pregnancy and soon after have been shown to be effective in improving caregiver as well as child outcomes. Outcomes found included decreased maternal substance use, improved maternal mental health and FASD knowledge, increased relationship capacity, strengthened behavior management strategies and advocacy and resources skills, parenting stress, caregiver self-efficacy and self-care, increased utilization of medical and mental health care services, greater use of contraception, and acquisition of stable housing and finances (Petrenko & Alto, 2017).

Developed from CIHR-funded research at the Strongest Families Institute based in Nova Scotia (SFI, 2024), the Strongest Families program is an evidence-based, distance intervention designed to support caregivers of children aged 4 to 12 diagnosed with behavioral and mental health disorders. The program is free of charge and helps parents with strategies to manage challenging behaviours that are commonly associated with FASD. Parents work online through a progressive curriculum that includes exercises, instructional videos, and they participate in weekly telephone sessions with a trained coach. Although the coaches are not clinicians, they have undergone extensive training at the SFI and are skilled in providing support, responding to questions and concerns, and discussing the program content (IWK Health Centre and Queen's University, 2015).

Parents of children with neurodevelopmental disorders, including FASD, face barriers to accessing evidence-based training for parent-implemented behaviour and communication interventions (Tan-MacNeill et al., 2021). The most significant barriers were financial cost, living in a remote area, long waits for access, parental stress and lack of professionals with adequate training. The authors' systematic review found that on-line parental education has the potential to overcome some of these barriers, but concluded that more and higher quality research was required.

Some research has also addressed the needs of caregivers of children in the child welfare system, including birth parents and foster parents. In their synthesis of scoping reviews, Marcellus & Badry (2023) noted the existence of supports and services to maximize family preservation, including child care, respite, housing support, and mental health and substance use counseling, access to case management services, education on best practices and if foster care was required, and supports to sustain relationships and address timely permanency planning.

The remaining sections focus primarily on interventions and supports for people with FASD; however, as noted by engagement participants:

> *Services are most effective when they are relationship-based and holistic, considering the whole person and their surroundings. For example, interventions are more effective when they involve and support the family, not just the individual.*

Key Findings:

Family members and caregivers benefit from education and training to help them understand the impacts of FASD and how to support the development of life skills.

Supports for families and caregivers, such as opportunities for respite, peer networking opportunities, and broader social acceptance, understanding and inclusion, are key to family well-being. Respite supports assist with the demands and stress of caring for children with FASD. There is limited knowledge about other types of effective interventions to reduce family stress.

7.4.2 Education

School system opportunities

As children with diagnosed or possible FASD enter the school system, there are opportunities to prevent disrupted school experiences that arise from the neurodevelopmental, physical, psychological and behavioural challenges associated with FASD (Akison et al., 2019; McLachlan, Flannigan et al., 2020) by adapting educational strategies, tools and resources (Job et al., 2013; Lees et al. 2022).

Many children are diagnosed with FASD after they reach school age (Dugas et al., 2023), which highlights the crucial role educators play in recognizing potential FASD-related impacts. Educators play an important role in supporting FASD screening and assessment by sharing relevant information about a student's academic and social functioning at school. Educators can provide detailed observations of the student's learning, behaviour, implemented interventions, and progress at school. This information can be shared with families and, with parental consent, medical professionals, who can then determine if further diagnostic assessment is needed (Pei et al., 2013). Positive relationships between caregivers and educators, administrators and allied health professionals can facilitate the implementation of targeted support strategies and proactive response to learning and behavioural challenges (Job et al., 2013; Millar et al., 2017). In a scoping review, Gault et al. (2023) found that a consistent recommendation was for strategies and supports that demonstrate an understanding of the unique strengths and needs of students with FASD. Engagement participants also identified this opportunity, noting that it is often missed:

> *...students without a diagnosis lack access to early interventions and opportunities for educators and caregivers to understand earlier where challenges and strengths are.*

As described in Chapter 6, young children may not yet have a diagnosis for multiple reasons. Even if an FASD diagnosis is not possible or has not yet been completed, the most commonly occurring comorbid condition, ADHD, can be treated with a stimulant medication, where necessary (Wrath et al., 2022), in combination with environmental and behavioural strategies. Medication usage is further discussed in Section 7.4. Similarly, diagnosis of learning disorders can support appropriate implementation of educational strategies.

The Diagnostic Guidelines allow for the ‘at risk’ designation for children with known PAE where diagnosis cannot yet be conclusively performed. With parental consent, this could be shared with educators so that children who are at risk could be monitored and supported with FASD appropriate interventions before diagnosis.

In the engagement sessions, participants underscored that understanding FASD-related learning impairments and behavioural difficulties is key to recognizing students’ need for services and supports. It was pointed out that undiagnosed children with emotional lability and impulsivity are sometimes identified as having “behavioural challenges,” and are blamed for their behaviour, as are their parents.

School-based interventions and supports

In a systematic review of evidence-based interventions for individuals with FASD, Petrenko & Alto (2017) identified several interventions that improved attention and self-regulation in school-aged children, including some that were delivered in the school context. Other studies have found evidence of the effectiveness of programs focused on remediation of specific skills in math, language and literacy (Reid et al., 2015, Adnams et al., 2007); language skills (Hilly et al., 2023) and math skills (Ordenewitz et al., 2021). The latter authors recommended providing supportive tutoring programs at school or in the community (Ordenewitz et al., 2021). However, these programs were generally targeted interventions delivered in one-on-one interactions between a child and a trained therapist or specialist. Calls have been made to improve the reach of such interventions by enabling classroom teachers and school-based teams to effectively intervene for students with FASD (Job et al., 2013; Millar et al., 2017; Kids Brain Health Network, 2023a).

School systems that are FASD-informed are better situated to meet the unique strengths and needs of students with FASD. Engagement participants emphasized that understanding the root causes of behavior, particularly FASD-related learning impairments and behavioral difficulties, is essential for accurately identifying students' needs for services and supports, thereby shifting the blame away from students and families.

Expanding school-based support through multiple levels of intervention can best meet the diverse needs of students with FASD. This tiered approach allows for proactive differentiated levels of support, which may include FASD-specific individualized interventions.

A distinction has been made between three policy levels for FASD supports: generic education policy, special education policy, and explicit FASD policy (Jonsson et al., 2009). Some jurisdictions have explicit FASD policies to offer direct intervention for primary and/or secondary students with FASD. For example:

- In British Columbia, the Ministry of Education created a specialized organization, POPFASD (Provincial Outreach Program for Fetal Alcohol Spectrum Disorder), to enhance educators' capacity to support students with FASD (POPFASD, n.d.-a). Since the program's inception in 2006, a small multi-disciplinary team of educators have worked to understand, collaborate, and create FASD-informed resources and inclusive educational approaches. POPFASD's structure utilizes representatives in each school district, known as District Partners, who may provide general or direct FASD-specific information, training and interventions.

- In Alberta, in order to maximize school engagement, increase academic success and enhance students' social, emotional, and physical well-being, the Wellness Resiliency and Partnership (WRaP) project provided school-based individualized mentorship and coaching supports for children and youth with FASD in schools (Tremblay, Matsangelo & Pei, 2021). In place from 2009 to 2017, it has been succeeded by the WRaP 2.0: FASD Coaching Partnership Project (2021-2026), a collaboration between the Ministry of Education, Ministry of Community and Social Services and Alberta's 12 FASD Service Networks. This initiative aims to maintain the same goals as the WRaP Project while extending supports across the province.

- The Winnipeg School Division offers the Bridges program at the elementary level and the Passages teams in high school (Winnipeg School Division, n.d.).

- Federally, Indigenous Services Canada has implemented a High-Cost Special Education Program to provide programs and supports to First Nations children on reserve who are affected with moderate, or severe to profound behavioural and/or physical challenges, such as FASD. Funding is provided on a project basis for programming, remedial instruction, clinical services and resource teacher staffing (Indigenous Services Canada, n.d.).

- In New Brunswick, the Elsipogtog First Nation Education Authority in collaboration with the Eastern Door Centre offers a comprehensive approach to school based screening, diagnosis and school accommodations (Eastern Door Centre, n.d.-b; Elsipogtog Education Authority, n.d.).

Resources and supports for educators

A first challenge in establishing effective school-based intervention and support is ensuring knowledge and awareness among school staff about FASD and the various ways it may present in children (Clark et al., 2014; Lees et al, 2022; Millar et al., 2017). Some research has focused on developing evidence-based tools and resources to support educators. For example, Clark et al. (2014) evaluated the effects of a professional development program for teachers on the academic achievement and classroom behavior of students with FASD in B.C. Following the training, teachers reported changes in teaching and more positive views of student behavior. There were no statistically significant differences in the observed behaviours or the academic achievement of students with FASD, however the authors noted that these findings were not generalizable due to survey limitations, especially the small sample size.

Preliminary findings from a 4-year external evaluation, through the Early Childhood Education Lab at Queen's University, have corroborated the findings from Clark et al. (2014). The study used mixed methods of survey, short and long form interviews with past participants of POPFASD's various educational training options (Early Childhood Education Lab, n.d.).

Our scan found tools and resources on FASD for educators and allied professionals to use in school settings in some education and provincial/territorial jurisdictions. For example:

- The guide "What Educators Need to Know about FASD: Working Together to Educate Children in Manitoba with Fetal Alcohol Spectrum Disorder" is a comprehensive example (Healthy Child Manitoba Office and Manitoba Education and Training, 2018). A Manitoba-developed guide is also available for early childhood educators (Healthy Child Manitoba, 2010).

- The Special Programs Unit of the Yukon Department of Education released the manual "Making a Difference: Working with Students who have Fetal Alcohol Spectrum Disorders" (Government of Yukon, 2006), aiming to help school staff understand challenges facing students with FASD.

- Saskatchewan Learning's Planning for Students with Fetal Alcohol Spectrum Disorder: A Guide for Educator' was adapted from Manitoba Education, Training and Youth's 2001 resource "Towards Inclusion: Tapping Hidden Strengths: Planning for Students Who Are Alcohol-Affected" (Saskatchewan Learning, 2004).

- Alberta has produced a comprehensive strategy guide for educators specifically about FASD called *Re: defining success: A team approach to supporting students with FASD* (Alberta Education, 2009), and a report for educators on relational-based supports informed by the province's FASD strategy (Government of Alberta, 2021).
- In BC, POPFASD's Provincial Outreach Program for Fetal Alcohol Spectrum Disorders shares many free resources created for educators, but accessible to everyone. These include the FASD 101 On-Demand course, Livestreams, Podcast series, Films, E-learning video series, newsletters, and graphic short format resources (POPFASD, n.d.-b).
- CanFASD has many tools and resources to support educators, including their on-demand courses which provide a foundational understanding of FASD and specific school-based strategies and supports (CanFASD, n.d.-e).
- SafEra/SOS TSAF, based in Trois-Rivières, Québec, offers online training courses for teachers and psychosocial workers, as well as resource kits in prevention and support (Safera, n.d.).

In their scoping review of English-language FASD educational resources for primary school educators, Lees et al. (2022) found that most resources were average to good quality, but very few had been evaluated. These authors concluded that there is a critical need for referral guides, evidence-based short format resources and centralized access to high-quality resources. These resources can also be used in conjunction with educational presentations by people with FASD, providing a better understanding of the condition.

Educational adaptations and accommodations, both universal and targeted

One approach to reaching children with FASD in the classroom is to use universal supports and strategies to accommodate FASD and other forms of neurodiversity while being available to all students (e.g., School District 46 Accessibility Committee, 2023; New Zealand Ministry of Education, n.d.). Universal interventions can include: variation in content, process and product in lesson planning, adaptations of assessment tools; use of flexible grouping, respectful learning activities; cultural responsiveness; a school-wide approach, and collaboration among specialists and peers, among others (Medicine Hat Catholic Board of Education, n.d.; British Columbia School District 57, 2023). In Ontario, the Equity and Inclusive Education in Ontario Schools: Guidelines for Policy Development speaks to a broader approach for inclusive education (Ontario Public Service, 2014). Equity and inclusive education are prominent in the Ontario government's renewed vision for education, as set out in Achieving Excellence: A Renewed Vision for Education in Ontario (Government of Ontario, 2014).

At the same time, there is support for improving tools and resources to enable flagging and following up on all students with functional limitations, including those with undiagnosed FASD. As mentioned in Chapter 2, several attempts have been made to pass legislation in Ontario to require boards of education to develop policies and guidelines with respect to FASD and teachers' colleges and early childhood education programs to provide training with respect to FASD (most recently, Bill 108, Ontario, 2023). For engagement participants, if enacted this bill would have increased sensitization of educators to the needs of diagnosed and undiagnosed students with FASD allowing them:

> *to support students with undiagnosed FASD by using FASD-informed teaching strategies and behavioural strategies that are appropriate for these student's functional abilities.*

It was noted in engagement sessions that raising the profile of FASD within more school boards across the country to make understanding comparable to that of other neurodevelopmental disorders (e.g., ADHD, intellectual disability, or autism) would help ensure that more appropriate, school-based resources are widely available to support students with FASD.

In many school systems, there is a requirement to produce and enact an Individualized education plan (IEP) for students identified as having special needs (e.g., British Columbia Ministry of Education, n.d.; Government of Ontario, n.d.-c). Students with FASD may require individualized, intensive interventions that go beyond classroom support. This could include small group instruction, access to educational assistants who facilitate the use of supports and strategies, specialized needs-based support, or IEPs developed with the assistance of an enhanced school team. Maintaining a focus on responsive support within their professional scope, schools can meet students' needs, regardless of whether a formal FASD diagnosis is in place. However, if the "special needs" criteria are not attuned to FASD, students with FASD may be placed in programs which do not best address their needs. Ontario's exceptionality categories explicitly name autism, but currently not FASD (FASD ONE, n.d.-b). Engagement participants noted that, although inclusion in a special-needs category confers access to interventions and supports:

> *it can be difficult for students with FASD to get help and supports for learning because of rules about who can get what…*

In the past, education has deferred to a deficit-based model when supporting neurodiversity, including FASD. Recent research investigating the strengths of individuals with FASD has identified five categories of strengths: strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges, and hope for the future, as well as the need to "both acknowledge the challenges and realities of living with a complex

NDD and seek to identify positive characteristics and recognize the potential for fulfillment and well-being" (Flannigan, Wrath, Ritter et al., 2021).

Participants in the engagement sessions underscored that the decentralized provision of school services can create interjurisdictional (among provinces/territories, and among school boards within provinces/territories) disparities in available interventions and supports, and that communities with smaller numbers of students may not be able to offer the necessary supports. As one participant from a northern community stated:

> *...lack of specialized classrooms, lack of training, extreme shortage of staff. We do not have any supply coverage for support staff. On any day, at least half the support staff are absent and students go without required support. Smaller communities are not as inclusive.*

Given the sex and gender related differences in comorbidities that exist in FASD, for example higher rates of ADHD (which is generally recognized as an educational disability category enabling access to supportive services) among males with FASD and higher rates of anxiety and depressive/mood disorders in females (which are not as recognized), it will also be important to ensure gender equity in access to services (Flannigan, Poole et al., 2023).

Diagnosis specific classrooms and alternative high school streams for students with FASD have been implemented in some locations. For example:

- The Fort (primary school) and Temenos (high school) day treatment programs offered in partnerships between a mental health agency and the Waterloo District School Board provide academic instruction, life skills training, social skills development, work readiness and family support through specialist teams (Camino Mental health, n.d.).
- In five of its schools, the Winnipeg School Division, in partnership with Healthy Child Manitoba offers small-class, specialized classrooms for students diagnosed with FASD. In these classrooms, students access effective learning strategies, individualized plans, and environmental adaptations. As students demonstrate readiness they can be integrated into regular programs (Winnipeg School Division, 2023).

Engagement participants noted the limited availability of specialized classrooms:

> *FASD classroom models like Manitoba would be amazing nationally.*

To date, there is limited research into the efficacy of streaming students with FASD. FASD specific alternative high school streams' outcomes may vary drastically and some engagement participants expressed concern about special streams for students with FASD who could succeed in the regular classrooms with adequate supports.

While this section focuses on primary and secondary education, adaptations can also support people with FASD pursuing post-secondary education.

Collaboration

School-based interventions for children with FASD are most effective when there is a parent/caregiver component (Petrenko & Alto, 2017), and caregiver involvement in education planning and goal-setting is recognized as a best practice for successful school experiences for children with FASD (Millar et al., 2014).

There is also a role for workers outside the formal school system to collaborate within it. For example, in its guide outlining a team-based approach to supporting students with FASD, Alberta Learning defines roles and strategies for mentors, community workers and coaches to work effectively along with parents and the school team to support not only the students with FASD, but also each other. Suggested strategies are: help school staff build an understanding of FASD; identify student strengths and interests; align strategies with student needs; build rapport with school staff; keep informed about current research and best educational practices; support positive behaviour; work with staff to make school a safe place; help build a circle of peer support; help build a circle of adult support; plan for transitions; support learning at home; and advocate for increased understanding and support for students with FASD (Alberta Education. 2009). Implementation of this approach would address interest expressed by engagement participants in greater collaboration between community organizations and schools so that proactive, wrap-around supports can accommodate students' individual needs and build on their strengths and interests. Engagement participants also support the role of System Navigators or Key Workers described in Section 7.2, in collaboration with the education system:

> *Key Workers and other relationship-based support people to advocate in school settings is extremely valuable! Having an FASD educator who can help to explain a student's diagnosis and their unique neurodevelopmental profile (and also empowering students and their families to be able to explain their disability themselves) is so valuable.*

Key Findings:

Many children are diagnosed only after they reach school age, however, identifying and intervening to support children as early as possible is most beneficial. Children identified ‘at risk for FASD’ because of known PAE, as described in the Guidelines, benefit from being followed, supported, and referred for diagnosis as soon as possible. Educators, including those involved in preschool programs, can play a critical role in supporting these children and in identifying others who may be similarly affected but not flagged at risk.

FASD-informed school-based supports, including a tiered approach that offers increasingly intensive interventions to students depending upon their strengths and needs, can best meet the diverse needs of students with a diagnosis, as well as those who do not yet have or cannot access a diagnosis of FASD.

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

Although universal supports and strategies that work across a range of neurodiversity can efficiently support students with FASD and other students simultaneously, students with FASD may have unique needs and challenges that do not necessarily fit well with strategies designed for other neurodevelopmental disorders.

Students with FASD may require FASD-informed targeted and individualized interventions within an FASD-aware school setting. This may include access to educational assistants who facilitate the use of supports and strategies, evidence-based FASD programming, and individual education plans (IEPs) designed by FASD-informed teams. In some places, FASD-focused classrooms are available, and this may be helpful for some students.

Close collaboration and wrap-around support between school teams, family and caregivers, service providers, and community organizations is helpful and contributes to the effective design of educational programs that build on a student’s unique strengths while effectively meeting their challenges.

7.4.3 Child welfare system

As mentioned in Chapters 1, 2, and 3, there is a strong intersection between FASD and the child welfare/protection systems across the country. Infants, children and youth with FASD and PAE are over-represented in foster care and the child welfare system (Popova, Lange, Shield et al., 2019; Marcellus & Badry, 2023), especially if they are also Indigenous (Brownell et al., 2019). Chapter 3 detailed the overrepresentation of Indigenous children in Canada's child welfare systems (Badry & Felske, 2013; Brownell et al., 2019; Salmon, 2011) and the measures undertaken in response to the Truth and Reconciliation Commission Calls to Action, including the enactment of the Jordan's Principle ruling (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative (Indigenous Services Canada, 2024g).

There is evidence that people who have been involved with child welfare systems struggle with education, employment, income, housing, health, substance use and involvement in the criminal justice system whether or not they have FASD or other neurodevelopmental disorders (Gypen et al., 2017). As mentioned above in section 7.3, youth with FASD who are transitioning out of child welfare care benefit from stable supportive relationships and often need longer term, targeted supports to transition to adulthood that recognizes the slower pace with which this occurs. In this section, we review interventions and supports that have been or could be developed to address FASD and child welfare.

Supports to help families stay together or close

A first form of intervention and support for children with FASD facing involvement with the child welfare system is to prevent or mitigate their involvement (Bezeczky et al., 2020). Child welfare research has supported the prioritization of family preservation for families affected by FASD and identified strategies to maintain access to FASD care while preserving their families. The strategies identified include:

- partnerships between child welfare and other community providers to focus on PAE as an indicator of needs and to facilitate assessment and diagnosis;
    - With respect to this point, engagement participants emphasized that timely FASD diagnosis, for the child as well as parents who may also have FASD, facilitates access to supports for child and family, including increased financial support and respite support. It can also help to maintain the parent-child relationship and reduce child apprehension.
- implementation of interventions that address FASD and are adapted for PAE's neurocognitive impacts;
- ongoing monitoring of racial and ethnic disparities to help maintain attention to equitable access to child and family outcomes;
- developing effective services that build on the community's cultural strengths;

- improving staff knowledge and addressing staff bias to promote engagement of and support for families (Richards et al., 2023).

A reduction in the number of permanent child placements can occur if children are reunited with their birth families; this is especially challenging to achieve if parents themselves have FASD (Choate et al., 2024). Parents with FASD can benefit from a long-term supportive relationship that recognizes the parent's abilities while accepting their limitations, which is unfortunately not the common approach. Nonetheless, family preservation is generally a priority within Canadian child protection systems (e.g., Surrey Family Preservation Program [Children's Foundation, n.d.]; Ontario Association of Children's Aid Societies, n.d.). In Québec, a recent change to the *Youth Protection Act* requires "that interventions in respect of an Indigenous child must be carried out taking into account the circumstances and characteristics of his community or of another environment in which he lives so as to respect his right to equality and foster cultural continuity" (Legis Québec, 2024).

Engagement responses suggested that compared to child apprehension, increasing community resources and providing more proactive support to families is less stigmatizing, more economically effective, and likely to improve outcomes for children. In this type of approach, the system's primary response could focus on family preservation according to parents' strengths and areas of challenge, with apprehension occurring only when this is not safe or possible. An example of this approach is being implemented in Yukon, where the Indigenous led Family Preservation Services of the Council of Yukon First Nations provides housing and supports to families at risk of child apprehension in a culturally grounded environment (Council of Yukon First Nations, 2024).

Ensuring that children in care have access to assessment and diagnosis

In their scoping review of literature regarding interventions for infants, children and youth affected by PAE and who were in foster care, Marcellus and Badry (2023) found that although early diagnosis is considered best practice and conducive to better outcomes, only a small percentage of children and youth with FASD in foster care were able to access diagnostic services, no matter their age.

Engagement participants noted that it is sometimes unclear whose responsibility it is to pay for the assessment and diagnosis service. Child welfare services are administered at the provincial and territorial levels with some provinces having specific programs and funding in place while others do not (Rutman, 2016). As already discussed in Chapter 6, Section 6.3, accessing PAE information may be difficult for children in care, whose placement records may not contain this information. This may result in diagnostic delays and later consequences for the child's future. As one engagement participant stated:

> *In a preschool placement, there is a wait and see what diagnosis may evolve unless there is known maternal PAE for this particular child. That is fraught in an adversarial*

system & that probably changes the calculus for 'adoptability' once that is the identified path in care.

Interventions and supports in FASD-informed child welfare systems

Within child welfare systems, preserving and supporting families and providing developmental and FASD-informed intersectoral interventions are both critical for optimizing outcomes of children with FASD (Rutman et al, 2016; Marcellus & Badry, 2023).

In their synthesis of two scoping reviews, Marcellus & Badry (2023) identified several evidence-based and effective interventions and programs developed specifically for children in care of child intervention authorities, although not necessarily FASD-targeted. For infants and young children, interventions were primarily focused on supporting the development of attachment within the context of dysregulation, caregiving challenges, and disruptions in relationships. With older preschoolers, emphasis shifted to diagnosis and comorbidities. Interventions and programs for school-aged children were centered on improving self-regulation and emotional control, remediating problem behavior in classroom settings, supporting cognitive development, and developing skills of daily living: these were essentially a subset of those referred to in section 7.4.3.

Marcellus & Badry's (2023) review also highlighted the value of offering specific training on PAE and FASD that is trauma-informed and inclusive of the specific needs of individuals with FASD from infancy to adulthood. This reinforces findings from an earlier review that reported specialized FASD training for foster care workers and caregivers was associated with a significant decline in the number of placement changes compared to standard care (Reid et al., 2015).

Key Findings:

People with FASD are over-represented in the child welfare system, and involvement in this system is an additional risk factor affecting long-term outcomes. Strategies to preserve families could include providing access to diagnoses for the child and possibly the parent, encouraging long-term supportive relationships, and increasing proactive community supports.

For children and adolescents in the child welfare system, beneficial approaches include access to diagnosis and interventions as early as possible and support and training for foster care placements to enable continuity, stability and well-being.

Youth with FASD in the child welfare system have a particular need for longer term, targeted supports as they navigate the transition to adulthood as well out of the child welfare system.

7.4.4 Health and healthcare

Many of the previously described interventions and supports are meant to treat or diminish the specific cognitive and behavioral consequences of FASD. In this section, we focus on the interventions and supports necessary to effectively address the "whole-body" aspect of FASD: in particular, physical comorbidities as they emerge throughout the lifespan, as well as an elevated risk of mental health conditions.

Comorbidities

A diverse range of comorbidities are common in people with FASD. In a synthesis of 127 studies, Popova, Lange, Shield et al. (2016) identified 428 comorbid conditions that co-occur with FASD, found in 18 of the 22 chapters of the ICD-10.

Comorbidities complicate the provision of appropriate interventions, supports and resources for people with FASD because they increase the complexity of care and decrease the likelihood that evidence-based interventions will be available for each specific comorbidity combination (Burd et al. 2021).

Table 8 summarizes prevalent neurodevelopmental and mental health comorbidities found in FASD. The most common is ADHD, found in up to 70% of people with FASD, with likelihood varying by age (Lange et al., 2018; Weyrauch et al., 2017; Popova, Dozet et al., 2021). Clinical presentation of ADHD in people with FASD is more likely to be an earlier-onset, inattention subtype (O'Malley & Hansen, 2002). ADHD may also occur in some individuals who have PAE but don't meet the criteria for FASD.

Conduct and oppositional disorders are found in a sizable minority of people with FASD, (Lange et al., 2018; Weyrauch et al., 2017), as are depression and anxiety disorders (Wrath et al., 2022; Weyrauch et al., 2017). Well over the majority of children with FASD experience sleep problems (McDougall et al., 2020; Hayes et al., 2020) and atypical sensory (tactile, auditory, vestibular) processing (Jirikowic et al. 2020). There is little overlap between FASD and autism (Lange et al., 2018; Wrath et al., 2022) but both are significantly underdiagnosed (Carpita et al., 2022).

The portrait of FASD comorbidities is rendered more complex by gender-related differences. In a study of 2,574 clinical records from 29 FASD diagnostic centers in Canada, Flannigan, Poole et al., (2023) found several sex (as indicated on birth record) -related differences in comorbidities. Males were recorded as having higher rates of ADHD, conduct disorder, and oppositional defiant disorder, while females experienced higher rates of anxiety, and depressive/mood disorders (Flannigan, Poole et al., 2023). The life-long persistence of the sex-specific effects of PAE was demonstrated in a study of the brains of middle-aged people with FASD, which found that the significant reductions in brain volume (including the corpus callosum, cerebellum, and subcortical structures) are maintained from birth. Greater reductions in females suggest a potential for accelerated cognitive decline in ageing (Bischoff-Grethe, 2024).

Research literature on physical comorbidities and FASD-associated conditions across the lifespan is emerging, confirming a need for a holistic perspective in intervention and support given the many physical health challenges for people with FASD (Reid, Kent et al., 2023; Hanlon-Dearman et al., 2015; Moritz et al., 2023; Himmelreich et al., 2020). Preclinical (Akison et al., 2019) and clinical studies (Akison et al., 2019; Fuglestad et al., 2014; Amos-Kroohs et al., 2016) point to the risk of metabolic issues in childhood (Fuglestad et al., 2014) and later adulthood (Kable et al., 2021); these issues differ by gender (Fuglestad et al., 2014; Amos-Kroohs et al., 2016; Hayes et al., 2021). A clinically-oriented review found associations between FASD and physical conditions including impaired growth, vision, hearing, heart defects and seizures (Hanlon-Dearman et al., 2015); many of these were corroborated in a large survey of people with FASD (Himmelreich et al., 2020). People with FASD or PAE may have weakened immune systems (Reid, Kent et al. 2019; Himmelreich et al., 2020); higher rates of asthma (Himmelreich et al., 2020) and kidney problems (Himmelreich et al., 2020); reproductive health challenges (Akinson et al., 2019; Himmelreich et al., 2020), elimination concerns (Reid, Kent et al., 2023) and reduced bone density (Young et al., 2022).

Preclinical studies suggest there are linkages between PAE and pain susceptibility and chronicity (Sanchez et al., 2017; Oberlander et al., 2010); this corresponds to reports of people with FASD of increased, decreased or otherwise disrupted processing of pain, especially after a secondary injury (Domeij et al., 2018; Himmelreich et al., 2020). Pain may be associated with other health issues that are more commonly reported in people with FASD than in the general population, such as frequent or chronic joint, gastrointestinal and dental problems (Moritz et al., 2023; Himmelreich et al., 2020).

Table 8: Prevalence of comorbidity in sample of people with FASD (unless otherwise indicated)

Type	Comorbid condition	Findings: % of FASD (unless otherwise indicated) sample
Other neurodevelopmental disorders		
	ADHD	52% (Lange et al., 2018) 50% (Weyrauch et al., 2017) 39% (Wrath et al., 2022) 78% males, 56% females (Flannigan, Poole et al., 2023)
	ADHD/ADD	70% in children and adolescents, 48% in adults (Popova, Dozet et al., 2021)
	Autism Spectrum Disorder	3% (Lange et al., 2018) 4% (Wrath et al., 2022) 3% (Carpita et al., 2022)
	Language disorder/ impairment	41% in children and adolescents (Popova, Dozet et al., 2021)
	Learning disorders	20% (Weyrauch et al., 2017)
Behavioural Disorders		
	Oppositional Defiant Disorder	12% (Lange et al., 2018) 16% (Weyrauch et al., 2017)
	Conduct Disorder	7% (Lange et al., 2018) 15% (Wrath et al., 2022)
Mental health disorders		
	Anxiety disorders	26% (Wrath et al., 2022) 14% (Weyrauch et al., 2017) 38% males, 50% females (Flannigan, Poole et al., 2023)
	Depressive disorders	32% (Wrath et al., 2022) 14% (Weyrauch et al., 2017)
	Depressive/mood disorders	42% males, 53% females (Flannigan, Poole et al., 2023)

Type	Comorbid condition	Findings: % of FASD (unless otherwise indicated) sample
	Psychotic disorders	12% (Weyrauch et al., 2017)
	Suicidality	16% (Wrath et al., 2022)
	Personality disorders	6% (Wrath et al., 2022)
Other common issues		
	Sleep problems	65% according to caregivers (Hayes et al., 2020; also qualitatively common, McDougall et al., 2020)
	Atypical sensory (tactile, auditory, vestibular) processing	73% of children with PAE (Jirikowic et al. 2020)

Mortality

While life expectancy for FASD is not known, some data exist for FAS. Based on data from all patients recorded in Alberta provincial databases of inpatients, outpatients, or practitioner claims from 2003 to 2012, life expectancy of those with FAS was an average of 34 years, far lower than that in the general population. Forty-four percent of causes of death were said to be “external,” including suicide, accidents, and poisoning by illegal drugs or alcohol (Thanh & Jonsson, 2016). The results of this study have been misinterpreted, with the presumption that there is the same life expectancy for FAS as FASD (Australian Medical Association, 2016). A further challenge is that this data may be skewed to higher spectrum cases with less access to social determinants of health.

Health services

Masotti et al. (2015), reporting on a national multidisciplinary consensus conference, pointed out that given the complexity of FASD, adequate management requires the involvement of a number of medical and non-medical specialties. As these care systems are currently not well-aligned, there are challenges to envision planned, coordinated care for people with FASD (Masotti et al., 2015; Hanlon-Dearmon et al., 2015). This was echoed in the engagement sessions, where calls for better integrated care systems were made.

Several authors have suggested that primary care practitioners could play a coordinating role among the necessary components of integrated care plans for people with FASD (Masotti et al., 2015; Hanlon-Dearmon et al., 2015, Leruste et al., 2024). Because many of the health issues affecting people with FASD are chronic and require continuous care, they could be suited to multidisciplinary primary care group practice models that include patient navigator roles, similar to those played by FASD Key Workers. Primary care physicians are in the position to coordinate sub-specialty referrals as needed (Hanlon-Dearman et al., 2015). This view was reflected in the engagement sessions:

> *But FASD care requires teamwork…and additional team members need to be accessible in the community after the diagnosis…. we need to engage primary health care better.*

Electronic medical records that are accessible to multiple medical and non-medical providers would also be an important feature of such care systems, as would alignment of eligibility criteria for services, cited as the major barrier to coordinated case management (Masotti et al., 2015).

In a scoping review of the literature on roles played by primary care physicians in FASD, Leruste et al. (2024) identified multiple roles, in: prevention, assessment, diagnosis, follow-up, education, and service coordination. However, by far the most attention in the literature was on prevention and particularly PAE detection and counselling, with relatively little guidance for primary care physicians on lifelong management of people with FASD. Some literature has examined the role of nurse practitioners in FASD, of interest given their expanding role noted by engagement participants, especially in northern Canada. In this discipline as well, the focus has been mainly on prevention (Mitchell et al, 2019; Hughes et al., 2019). However, a multidisciplinary symposium identified roles for nurse practitioners in providing supportive intervention, liaising with primary care (Masotti et al., 2015).

Preventing and treating FASD with nutritional supplements

As noted in Chapter 5, there is accumulating interest in the potential for nutritional supplements such as choline, to play a role in FASD prevention (Serwatka et al., 2023). Because of its effects on brain development and cognition in both typical and atypical development, prenatal and postnatal choline supplementation following PAE is now receiving significant research attention in both animal and human studies (Ernst et al., 2023). Ernst et al.'s review of the available evidence found that choline improves neurocognitive function including aspects of non-verbal and visual-spatial processing, working memory, and behavioral symptoms, prior to the detectable age of deficits. Choline supplementation is more effective prenatally than postnatally, and earlier postnatal supplementation is most effective. Beneficial effects of choline supplementation are additive and may compound with age. Genetic factors may partially mediate choline's neuroprotective effects (Ernst et al., 2023). Ritfield et al., reviewing 60 studies involving choline treatment, reported that choline may improve memory in preschoolers but not global cognitive ability (Ritfield et al., 2022). A systematic review of pharmacological approaches to FASD concluded that choline had beneficial effects on nonverbal intelligence, visuospatial abilities, verbal memory, and working memory, but that conclusions about how and when it should be used were disparate (Andreu-Fernández et al., 2024).

In a systematic review of emerging pharmacological interventions for FASD, Andreu-Fernández et al. (2024) found that epigallocatechin gallate (EGCG), a nutritional supplement, may be a protective agent against the effects of PAE, ameliorating fetal growth restriction and preventing PAE related cognitive impairment. Use of these treatments can be effectively combined with psychosocial interventions such as social skills development programs. Also promising were natural antioxidants that can stabilize neural membranes (Andreu-Fernández et al., 2024).

Pharmacological treatment of comorbidities

Other research has focussed on pharmacological treatment of comorbidities of FASD. Although there is currently no approved pharmacological treatment for FASD itself (Ritfield et al. 2022; Mela et al., 2020), evidence is emerging that some medications may be effective in treating some aspects of FASD and some of its prevalent comorbidities (Ritfield et al., 2022; Mela et al., 2020). As the most prevalent comorbidities are ADHD and psychiatric disorders, we briefly summarise evidence in these areas.

Children affected by both FASD and ADHD show greater verbal, perceptual reasoning, working memory, processing speed, and adaptive skills deficits than in those with ADHD alone (Boseck et al., 2015). Similarly, the combined effects of PAE and ADHD on conduct disorder are greater than in either condition alone (Ware et al., 2013). To help improve these conditions, medications for ADHD are commonly used to treat children with comorbid FASD. In their systematic review of clinical studies in this area, Ritfield et al. (2022) found that most studies reported a mix of outcomes across a range of medications: for example, that stimulants improved hyperactivity but not attention or impulsivity (n=11 studies), and that more children responded to amphetamine (79%) than to methylphenidate (22%; n=30 studies). Mela et al. (2018) in a narrative review, found that second-generation antipsychotics may improve social skills, agitation and ADHD, but caution that the effectiveness of pharmacological interventions for treating FASD can depend on many factors such as the severity of the disease spectrum and on gender and age. A study aiming to develop a prescribing algorithm for FASD found it challenging to accommodate the range of presentations in children with FASD, with several FASD symptoms being unclassified (Durr et al., 2021).

A 2016 British-based consensus statement on the treatment of ADHD with associated FASD recommends an individualized approach that takes into account other comorbidities such as early onset post-traumatic stress disorder due to violence exposure or attachment disorders due to multiple family disruptions and placements. The recommended treatment plan begins with non-pharmacological approaches, but if these are ineffective may be supplemented by medications recommended in the clinical guide for treating ADHD symptoms, especially those aiming to improve attention and reduce hyperactivity and impulsivity. The aim of such treatment would be to allow people with FASD and ADHD to more effectively manage their co-occurring challenges and engage with other types of intervention and support (Young et al., 2016).

With respect to psychiatric disorders, people with FASD are prescribed antidepressants, anxiolytics and antipsychotics at higher rates than people without FASD (Wrath et al., 2022). In a systematic review of clinical studies (Ritfield et al. 2022) concluded that overall, evidence for the effectiveness of pharmacological treatments in children with comorbid psychiatric conditions and FASD is limited and conflicting. Stimulants appear to improve inattention and inhibitory control, but not to clinical levels. There are insufficient data on pharmaceutical treatment of comorbid emotional dysregulation, impaired mood or anxiety disorders, and psychoses. According to Ritfield et al. (2022), while some medications may be effective in some cases, they will rarely resolve all symptoms and effects will be less robust than those observed in people with these psychiatric conditions but without FASD. These authors recommend that medication be offered in conjunction with other forms of intervention including behavioural, cognitive, and educational interventions (Ritfield et al. 2022).

Access to healthcare for physical and mental health conditions

Over and above the existence of healthcare to address the needs of those with FASD, there are challenges in ensuring that they can and will access it. First, as described in 7.5, the stigmatization of people with FASD including pregnant women with FASD at risk for PAE, along with their intersectional stigmatizations and discrimination, creates reluctance to use health services such as prenatal care of substance use treatment, even when they are available (Singal et al., 2019; Flannigan, Murphy et al., 2023; Nathoo et al., 2023). A scoping review of studies on lived experience with FASD found that providers feel unprepared and unsupported to help individuals with FASD (Wilson et al., 2023.)

Second, accessible healthcare services are currently limited in many areas pertinent to the care of people with FASD. In many jurisdictions, access to primary care practitioners is limited (Canadian Institute for Health Information, 2023b). Lack of accessibility is especially problematic for mental health and substance use treatments (Canada Institute for Health Information, 2023c). Engagement participants expressed concern that people with FASD have additional barriers accessing mental health supports:

> *Those with FASD are often told they are not a good candidate for mental health supports due to having "too complex" of a profile.*

The overall population access issues will affect people with FASD as well, and possibly disproportionately in the absence of advocates or care navigators (Carter et al, 2018).

A final challenge is posed by the characteristics associated with FASD itself. In a scoping review of lived experiences, Wilson et al. (2023) identify the following as common issues: difficulty maintaining attention, difficulty with memory, difficulty comprehending or understanding information, difficulty learning from mistakes and indecisiveness. Some people with FASD also confabulate, while others have difficulty being believed. These can affect capacity to remember to schedule and attend appointments; and challenges with transportation, navigating safely in the community, and compliance to care recommendations (Community Living British Columbia, 2011). As a result, even those who are able to initially access medical or mental health care may be dismissed from care.

Key Findings:

PAE can affect all organs and systems and therefore, people with FASD have multiple health and mental health conditions that can affect them through the course of their lives.

The complexity of health issues experienced by people with FASD may require management by a primary care team that understands the disabilities associated with FASD and the supports that may be beneficial. This can be difficult for people with FASD and their families as access to primary care is not always readily available in parts of Canada.

The cognitive challenges of some adults with FASD make it difficult for them to navigate the healthcare system without support, which may result in non-adherence or poorer compliance with care recommendations and even dismissal from care when the necessary support is lacking.

7.4.5 Finances, employment, and housing

Adults with FASD face many challenges managing the tasks of daily life, and benefit from intervention and supports adapted to their needs (McLachlan, Flannigan et al., 2020; Hargrove et al., 2024).

Quan et al. (2019) reviewed existing programs and provided six themes for developing successful community-based interventions for adults: training for life skills to support managing finances, housing and employment; individualized supports including one-to-one and outreach services; education for service providers; using a strengths-based approach; incorporating structure, consistency, and routine; and environmental adaptations that reduce stress.

Life skills coaching, mentorship and support

As discussed in Section 7.3, adults with FASD will best thrive in situations of interdependence, when they are supported by a network of care and support with various aspects of life (Michaud, 2019). When asked what interventions or supports could help them, respondents in a survey of 485 adults with FASD indicated several needs in terms of life skills coaching, mentorship and support:

- Access to a mental health clinician who specializes in FASD.
- Availability of a doctor or nurse practitioner who knows about FASD.
- A person who can help when something goes wrong.
- A person who can be trusted to give advice when needed.
- Enough money to meet monthly needs.
- Help with tasks of daily living such as cleaning and laundry.
- A trusted person who, with permission, can speak and act for the person with FASD.
- A trusted person to manage or help with money so that the person with FASD is less likely to be taken advantage of. This may also include being able to attend appointments so that there is someone present to support the person's understanding of what has been said and recommended.
- Help to obtain and sustain employment (this would be a person who understands what is and is not possible).
- The ability to engage in activities that are important to the person (Hargrove et al., 2024).

Almost two-thirds (63%) of the people assessed for FASD in McLachlan, Flannigan, et al.'s study (2020) were found to have a need for support with life activities. Engagement participants suggested that comprehensive life skills training programs tailored to people with FASD can help to improve employment outcomes and can support interdependence. They stressed that beginning programs in high school would help individuals learn strengths and skills, supporting their transition to adulthood. Furthermore, continuing these programs throughout adulthood, is valuable because the core disabilities of impulsivity and difficulty planning will remain problematic and are not amenable to "training:"

> *It has been my experience, both as a parent and as someone who provides support to quite a few other adults with FASD, that they ALL have the skills....but they have a problem remembering to do them or becoming overwhelmed and UNABLE in the moment to do them. It is NOT the skill itself that is lacking...it is a time/event specific issue.*

Respondents in Hargrove et al.'s (2024) survey reported being unable to remember to do things without help, such as paying the rent (51%) or bills (73%), taking medications (60%) and refilling prescriptions (60%), doing laundry (59%), and cleaning house (74%). Needs for help were also expressed for showering (30%), cleaning teeth (55%), washing hair (36%) or grooming hair daily (37%).

Some life skills supports for people with FASD are available. BC's Guide to Creating Environments that Support Success addresses many aspects of life skills, including daily living activities, sleep, self-care, money and budgeting, shopping and meal preparation, house maintenance, time and schedules, and work life (Community Living British Columbia, 2011). However, this guide is intended to orient staff, service providers, community members and others working with adults with FASD to supports that could be provided; it does not direct implementation. The guide notes that:

> A good life in community for a person living with FASD must include informal safeguards, working together as informed networks of care. The key to successful formal and informal networks is understanding behaviours from a brain-based perspective (p.21).

Further advice on how to create and maintain informed networks of care, and to evaluate their effectiveness would be helpful.

In a review of the literature on interventions to improve mental health for individuals with FASD, Flannigan et al. (2020) found that most interventions focused on improving underlying skill sets that indirectly affect mental health.

Financial stability and management of finances

Financial skills are a key need of many people with FASD, as they may have difficulty comprehending the basic value of money. Strategies and support could include financial literacy training, including how to budget and shop, and seeking ways to support individuals while respecting their rights to manage their own money. An engagement participant explained this need:

> *I have spent years working with my son on budgeting, money management, showing him how to grocery shop and meal plan. He still struggles due to impulsivity and difficulty with long term planning.*

It was suggested that it may be preferable to help some people with FASD to determine who to trust, and to accept help from trusted people with various aspects of life including money management. This would also help address concern about people with FASD being vulnerable to fraud:

> *Protection from fraud and scams is hard for anyone and especially people with disabilities and with FASD.*

Other strategies mentioned in the engagement sessions were: automated or direct payments of essential expenses and having regular small amounts of money made available, to protect against unwise spending.

The issue of income inadequacy of people with FASD was also raised. In the survey of adults with FASD, of the 142 employed at the time of the survey, 71% reported earning less than $1,500 per month (Hargrove et al., 2024). Engagement participants indicated that financial supports for people with FASD are often insufficient and unstable, and many live in poverty:

> *You have to jump through a lot of "hoops" to get any additional financial supports and it's limited in how you use it… it's not enough with how expensive rent, food, and gas are.*

Those not accessing financial supports may be unaware of what is available or find it difficult to navigate the financial support systems. Finlay, Wittevrongel et al.'s (2023) study of caregivers of children and youth with neurodevelopmental diagnoses including FASD found that only 32% were accessing available supports, with barriers to access including not being aware of the programs, difficulty applying, and rejections and re-application requirements. Engagement participants also pointed out that gaining employment can mean no longer qualifying for essential disability financial supports in some provinces and territories.

Employment

People with FASD often require support in finding and maintaining employment (McLachlan, Flannigan et al., 2020; Young et al., 2016). In McLachlan, Flannigan, et al.'s (2020) study, 37% of the people assessed for FASD were found to have employment problems. In a recent survey of adults with FASD, 49% were employed full or part time at the time of the survey, and 80% reported that they enjoyed working. Seventy-one percent indicated that working made them feel valuable and productive, like others in society. However, the overall stress of being employed meant that 63% could only work part time (Hargrove et al., 2024).

In the survey data reported by Hargrove et al. (2024), 67% of respondents with FASD had experienced being fired or laid off, and 46% had experienced it more than three times. Challenges that affected employment sustainability reported by survey respondents included being overwhelmed; things going wrong in other parts of their life; worrying about performing the job properly; being too tired to do other things; physical and/or mental health growing worse; and struggling to get along with co-workers. The behavioural characteristics of some people with FASD may affect their stable employability (Wilson et al., 2023).

Employers' understanding of the nature of FASD and how to support the needs of employees with FASD could be improved (Hargrove et al., 2024). Seventy-two percent of the employed people with FASD surveyed said they would keep the diagnosis secret from an employer, and

77% believed they would not or probably would not have been hired if the employer knew their diagnosis (Hargrove et al., 2024). Following a review of the literature, Gault et al. (2023) stated that employment success may increase if employers are aware that their employee has FASD and understand the accommodations that can be made.

Nankoo et al. (2023) conducted a scoping review of the literature on resources that support employment particularly for people with FASD who had been involved with the justice system. They found that most of the resources described FASD, addressed typical employment challenges, and provided specific supports and accommodations to maximize employment; however, they also found that none of the resources had been adequately evaluated.

In the engagement sessions, workplace accommodations for people with FASD were identified as a valuable support. Stigma can be a large barrier in employment. Because of stigmatization, it would be preferable if, rather than disclosing an FASD diagnosis, employees could provide a function-based description to employers in order to determine needed accommodations. Because of the heterogeneity of FASD, individualised accommodations would be best -- although participants recognized the resource challenges of this solution. Other suggested accommodations and supports included: having a third party explain FASD and accommodation needs to employers; mentoring; employer training; buddy systems and "walk alongside" approaches and other supported employment programs. However, engagement participants were aware that, especially in the current economy and in minimum or lower wage environments where many people with FASD might seek employment, the cost of such initiatives would be a significant barrier. It was also suggested that government subsidy programs to support hiring of people with disabilities be evaluated to ensure they are working to encourage the creation of jobs that optimize the needs, skills and abilities of people with FASD.

Resources do exist to support the employment of people with FASD. Some examples include:

- WorkBC's guide to inclusive hiring (Work Bc, n.d.);
- CanFASD's guide for employment professionals (CanFASD, n.d.-f)
- NWT guide for employers (Inclusion NWT, n.d.);
- Saskatchewan FASD Network's tips for employment (for employees; Saskatchewan FASD Network, n.d.)

Some post-secondary institutions have programs for diverse learners, offering employment and community engagement opportunities through hands-on and work-integrated learning opportunities (Kwantlen Polytechnic, 2024). One program specifically focuses on enhancing economic participation and fostering independence for BIPOC persons with disabilities (Douglas College, 2024).

Opportunities in addition to paid employment such as internships and volunteer positions may also be welcome opportunities for inclusion and learning in some cases.

Housing

Access to affordable, suitable housing for adults with FASD is key to their stability and well-being (Pei et al., 2018). Respondents to Hargrove et al.'s (2024) survey had experienced housing instability: at the time of the survey, 5% were homeless and 26% had experienced eviction.

A study by Gault et al., (2024) examined the perspectives of Canadian caregivers supporting adults with FASD on current support strategies and future living arrangements. The authors also examined housing from the perspective of four people with FASD, finding both positive and negative perspectives and illustrating the tensions between needs for autonomy and social support.

Although there is little literature assessing the effectiveness of housing interventions in FASD or comparing alternative forms of housing support (Pei et al., 2018, Appendix 3; Chilvers et al., 2006), a recent study of the effects of providing stable housing to people with complex disabilities including neurodevelopmental disorders found positive effects on wellbeing and community and home integration with a trend toward improved health and reduced support needs (Douglas et al., 2023). Research in both autism (Kinnaer et al., 2016) and FASD housing design suggests that it can be challenging to align overarching design guidelines with individual customization and adaptation needs (Pei et al., 2022). A study of residents in assisted housing for FASD in Germany found their needs for support ranged from 5 to 30 hours per week (Becker, 2018).

A comprehensive review of FASD housing needs and programs resulted in a person-centred framework to support housing for people with FASD. This framework aims to facilitate assessment and access to housing supports that meet the physical, psychological, and sell-fulfillment needs of people with FASD, including housing tenure. It includes a set of tables to help practitioners working with FASD clients understand housing needs from the client's point of view, given the specific cognitive and behavioral characteristics of FASD (Pei et al., 2018). These considerations are aligned with the principles of housing design for young adults with FASD proposed by Proof Alliance in the US (Proof Alliance and LHB, 2021). A recent review of housing in FASD complements the Pei et al. framework (Pei et al., 2018) by stressing that successful housing for people with FASD requires a networked, collaborative approach that leverages relational supports (Fazari et al., 2024). This report makes the following recommendations for housing policy in FASD:

- Increase available housing options for people with FASD along the entire continuum of housing (emergency shelter programs, second-stage housing, transitional housing, and/or interdependent or independent living);

- Leverage and integrate existing social and community programs into housing interventions;
- Adopt person-centred and integrative systems approaches to housing;
- Nurture and incorporate meaningful relational connections to increase housing tenure;
- Provide ongoing education for service providers, both for those who work directly with people with FASD and for those who work in the housing sector more broadly (Fazari et al., 2024).

These recommendations echo observations made in the engagement sessions, where participants identified that there are few supported housing options that provide programming to achieve successful interdependence for people with FASD. Supports could include addressing parenting with FASD, healing trauma, managing addictions, and promoting mental health. Youth with FASD aging out of child welfare care are at higher risk of homelessness than those who have never been in care (Burnside & Fuchs, 2013). Transitional housing support for youth moving into their own spaces was suggested, as were housing options that support access to natural support networks. A number of housing programs for people with FASD were mentioned in the engagement sessions:

- In Alberta, Edmonton's Bissell Centre provides supportive housing for people with FASD, with 24-hour support services (Bissell Centre, n.d.) In High Level, Alberta, the Northwest FASD Society-Mackenzie Network manages the Sheltering Arms Housing Facility that provides *safe, secure, stable, structured, supervised and subsidized* housing for individuals diagnosed with FASD (Mackenzie Network, n.d.-b).

- Yukon's Options for Independence supports adults with semi-independent FASD supportive housing. Support to live semi-independently is provided in areas such as money management, public transportation, household maintenance, food preparation, and healthy lifestyle and relationship planning (Options for Independence, n.d.).

- In BC, Westcoast Genesis Society provides services to men on conditional release and men who are unhoused, including individualized care for individuals with FASD and a detox program to address addiction (West Coast Genesis Society, n.d.).

- Other housing programs are also presented in Pei, Kapasi et al. (2019).

A study conducted in Regina in 2005 highlighted the complexity of FASD and the limited stable housing options with consistent supports (Brownstone, 2005). A 2009 report looked at supportive housing opportunities for adults with FASD in the Lakeland-Cold Lake, Alberta service area and recognized the strength in a collaborative approach, identifying a will from all levels of government, agencies, and community to look at positive housing solutions for people with FASD (Burns, 2009). The National Homelessness Strategy, Reaching Home (Government of Canada, 2019c), has led to some provincial and territorial exploration of housing programs that may be appropriate and helpful for people with FASD. Reaching Home includes four regional streams that could address the needs of unhoused or poorly housed people with FASD: designated urban communities outside the territories, Indigenous homelessness; rural and remote communities, and territorial homelessness.

Engagement participants pointed out that other housing options for people with FASD could include technology-assisted environments such as ‘smart homes’ that are not currently considered disability supports.

Key Findings:

Many people with FASD struggle with managing their finances, and are vulnerable to scams. Financial literacy training, including training on budgeting and shopping, can be helpful but insufficient, as ongoing supports are often important. Where acceptable to the person with FASD, mechanisms such as a trusted person to help manage funds as well as automated payments of essential expenses like rent can be of assistance. Disability benefits programs that are flexible, needs-based, and accessible are important to achieving financial security and stability for people with FASD. However, eligibility criteria for some disability benefits programs can make access challenging for many individuals with FASD.

Many people with FASD are and want to be employed. However, they may struggle to find and maintain employment without support, and may be reluctant to ask for accommodations or disclose their diagnosis to employers due to stigma. Employers would benefit from having a better awareness of FASD and understanding of how jobs could be structured for successful employment of people with FASD. Work experience opportunities, on-the-job training, mentorship and buddy systems can further support the economic inclusion of people with FASD.

Maintaining access to disability income supports during early work experiences, when self-employed, and when in short-term employment positions can support financial stability and labour market participation of people with FASD.

Stable housing with consistent support is conducive to successful interdependence of people with FASD. Many individuals with FASD require ongoing assistance and skill-building to plan for, choose, access, maintain, and manage housing. Youth with FASD aging out of child welfare are particularly vulnerable. Affordability is often a barrier for people with FASD, but without co-occurring intellectual disability or physical impairments they are often not considered as a disability priority group for affordable housing.

7.4.6 FASD and the criminal justice system

People with FASD are over-represented in the criminal justice system and this has a high cost (Flannigan, Pei et al., 2018; Hughes et al., 2016; Mullally et al., 2023). People with FASD are 19 times more likely to be involved with the criminal justice system than their non-FASD counterparts (Popova, Charness et al., 2023; Gilbert et al., 2022). For the year 2011-2012, Thanh and Jonsson (2015) estimated the costs of FASD to the Canadian justice system to be approximately $2.1 billion (range $1.0 billion to $3.7 billion). In this section, we review access to diagnosis, interventions and supports for people with FASD who are involved with the law. Although people with FASD can engage with the legal system in various ways, including as victims of and witnesses to criminal acts and litigation surrounding child apprehension and custody (Institute of Health Economics, 2013), our focus will primarily be on people with FASD accused of criminal offences.

Need for interventions and supports due to multiple vulnerabilities

Over and above the social determinants of health that are associated with both FASD and justice system involvement -- such as educational and employment under-attainment, economic disadvantage, substance use (Walt & Jason, 2017) -- some of the specific features of FASD render affected individuals more vulnerable (Khalifa et al., 2022). In a systematic review of the literature, Khalifa et al. (2022) found nine articles that compared justice involved individuals with FASD to various comparison groups. The authors reported evidence that justice involved individuals with FASD had greater deficits in executive function, language, academic achievements, motor skills and adaptive living skills. Pei, Leung et al. (2016) identified factors that had primed offenders with FASD to enter the criminal justice system and hindered them once within the system, such as challenges in verbal ability and decision-making, lack of self-awareness including limited understanding of the link between their actions and consequences, lack of foresight, inability to self-advocate, and limited understanding of court processes and expectations. Poor communication skills characteristic of FASD cognitive processing may compromise performance in interviews in criminal justice, forensic mental health, and other legal contexts (Brown et al., 2020; Kippin et al., 2021). As well, people with FASD who have high IQs and forms of related verbal fluency may be less likely to be supported through their legal procedures as their needs are less likely to be recognized (Gilbert et al., 2022).

There is also evidence that individuals with FASD are vulnerable to suggestibility and manipulation during investigative interviews, due to their greater vulnerability to peer pressure and being easily manipulated, acquiescence or higher levels of suggestibility, and difficulty understanding consequences (Brown et al., 2022). These characteristics may lead to higher levels of self-incrimination (Gilbert et al., 2022), false confessions and false accusations (Brown et al., 2020). People with intellectual and developmental disabilities are also more likely to be victims of violent and sexual crimes than the general population, more likely to be victimized repeatedly, and less likely to report being victimized to police (Stancliffe and Frantz, 2024); similar findings have been noted for FASD specifically (Stewart, 2015). In the survey of 485 adults with FASD, 83% of respondents reported that they had been manipulated into doing something that someone else wanted, 31% talked into doing something that was wrong, 41% into criminal activity and 51% into sexual activity (Hargrove et al., 2024).

Difficulties with meeting deadlines, keeping appointments, and generally complying with administrative obligations in the criminal justice system can lead to the accumulation of charges for people with FASD (Institute of Health Economics, 2013). The engagement sessions also suggested that individuals entering the criminal justice system can face escalating problems when FASD makes it difficult to follow the system's structures and rules. One participant stated:

> *Personally, I would avoid calling the police for help because I've heard too many stories of situations snowballing once a person enters the system (e.g. getting more charges because of not showing up for court, or not having capacity to follow probation rules).*

Reducing risk of involvement in the criminal justice system

There is little literature on interventions to reduce justice system involvement of youth with FASD. In their systematic review, Flannigan, Pei et al. (2018) report on studies showing that young offenders with FASD were more likely to have been first charged at younger ages and to show more difficulties understanding their legal situation. Protective factors identified included staying in school, absence of substance use problems, and cultural and spiritual factors contributing to stronger enculturation and resilience. Currie et al. (2016) identified early diagnosis, help with addictions, consistent structure and supervision, and vocational opportunities as protective.

Justice involvement was more likely for adults diagnosed with FASD later in life, especially over age 20, suggesting that early diagnosis and intervention helps to prevent later trouble with the law (Currie et al. 2016). Flannigan, Pei et al. (2018) recommended that additional research be conducted in the areas of prevention of criminal behaviour among those with FASD and identifying risks of re-offending.

Engagement participants identified many upstream supports for people with FASD that could help prevent involvement with the justice system. Generally speaking, these can be seen as addressing the social and Indigenous determinants of health that raise the risk of entering the criminal justice system.

Mentioned frequently by engagement participants was that supportive communities can be protective against criminal justice involvement. Positive social networks including mentors, friends, family and support workers/navigators are important. As one participant attested:

> *Preventing criminal justice system involvement; everyone needs a network.*

Supportive networks and communities can create or maintain a sense of belonging, raised by engagement participants as important to prevention of gang involvement. It was noted that gangs are able to provide supports and structures for struggling youth in the absence of better support systems. An engagement participant underscored the risk of failing to provide appropriate community support:

> *Because we don't identify, diagnose, & then accommodate individuals' needs and insist on consequencing and disciplining, we are forcing individuals to find "community" in gangs, etc. We are creating the issue of overrepresentation in the justice system.*

Engagement participants stressed that mentorship programs provide stable supportive relationships that model social skills for making positive choices:

> *Consistent routines, trustworthy people to help support & guide their activities & model more positive community activities. Social skill programs for ongoing education of those with FASD to keep learning & practicing skills especially in the community so they can make better choices & learn ways to not engage with those who don't have their best interests in mind.*

Such programs could also be protective against manipulation and exploitation that could lead to criminal activity, which engagement participants reported are not uncommon in some places, for example, using youth with FASD as drug mules.

Engagement participants noted FASD-informed activities such as camps, sports, arts, music, employment, and volunteering can help people with FASD to be busy and productive. However, resourcing such programs was seen as challenging, especially since locally accessible programming is important. One caregiver reported:

> *Preventing involvement with criminal justice would include those programs you list but we do not have appropriate programs & need them to be in driving distance because our child does not travel well for programming. Everything we add, even positive, adds stress. Limiting the stressors is key to co-regulation being effective at home.*

FASD-informed health and social services, in particular for mental health challenges, were also mentioned as underpinning youth capacity to engage in preventive community activities. Disability supports providing stable income, adequate and stable housing, and employment were also identified as key.

While preventing criminal justice involvement is important, there is need for caution for fueling a stigmatizing stereotype that links FASD and criminality (Aspler et al., 2022, Flannigan, Pei et al., 2018). In particular, embedding FASD into legislation and having it serve as an explicitly named mitigating factor in sentencing, risks conveying a message that FASD results in criminality rather than the more accurate view that FASD may increase a cluster of risk factors that can be reduced with supportive intervention (Flannigan, Pei et al., 2018).

An evaluation of a Southern Ontario pilot program to reduce justice system involvement by providing wrap-around supports and resources to youth with FASD, their caregivers, and the broader community, found positive outcomes, including reduced youth contact with police. Intervention with younger youth, at ages 12-13, was more successful in preventing engagement with the justice system (Costa et al., n.d.).

Reducing risk of system involvement though supports during transition periods

The transition between adolescence and adulthood is especially important for preventing justice system involvement because of the risk of destabilization and having people fall through the cracks between support systems (Gault et al., 2023; Rice et al., 2022; McLachlan, Flannigan et al. 2020). This risk is more pronounced for youth transitioning out of the child welfare system (Bala, De Filippis & Hunter, 2013).

Coons-Harding, Azulai et al. (2019) identify the characteristics of effective supports for the careful planning needed for this transition, and in particular finding the appropriate balance to maximize adult independence while still offering the specialized supports and safety nets that FASD-affected young adults may need. Burnside and Fuchs (2013), in a qualitative study of youth at the time of transition out of youth protection services, noted their determination to achieve the same positive life outcomes as their peers who did not grow up in care, but underscored the importance of providing FASD-affected youth with the services and supports required to meet those goals as they transition into adulthood. Key protective elements identified were the maintenance of significant relationships with caring adults, and planned development of skills for independent living.

Engagement participants agreed that the transition between adolescence and adulthood is a risky time. People with FASD experience tension between needing support and the desire for independence; they can feel and express resentment of overprotective parents. Homelessness in this period is a particular risk, and engagement participants identified the need for community-based emergency shelters and support programs for youth with FASD aged 16 to 25 who are out of care and homeless.

Screening interventions for justice-involved people with FASD

Screening of people for FASD who become involved with the justice system is recommended to ensure there is a more complete understanding of their challenges and that they can receive appropriate, FASD-informed supports (Mullally et al., 2023; Sessa et al.; 2022). At the same time, it has been noted that information about FASD is itself likely insufficient without the availability of appropriate evidence-based supports, services and sentencing options that would allow judges the ability to craft optimal responses (Mullally et al. 2023).

A 2015 environmental scan found a lack of early identification and diagnosis of offenders with FASD. Few screening and diagnostic resources were available, especially for adults (Stewart, 2015). Young et al. (2016) also recommended screening for ADHD and FASD in all juvenile and adult criminal justice systems, and additionally that individuals be given an identification card indicating the presence of a disability for use when interacting with law enforcement services. McLachlan et al. (2021), in a study of forensic mental health clinicians, reported their need for additional specialized training about FASD as well as evidence-based screening approaches and tools and practice guidelines to support their work.

As discussed in Chapter 3, in order to comply with the Supreme Court's rulings in *R. v. Gladue* [1999] and *R. v. Ipeelee* [2012], Canadian courts are required when sentencing Indigenous offenders to consider the "unique background and circumstances" of the person and reasonable alternatives to incarceration (Dickson & Stewart, 2022).

FASD is recognized as a "Gladue factor" associated with intergenerational or community-level alcohol misuse (Ralson, 2021, at p. 187). In practice, this means FASD assessment and diagnosis can be carried out and submitted to the court at the time of sentencing. The legal team is supposed to provide evidence about the background and circumstances, which may include an FASD diagnosis, of an Indigenous offender that could impact their access to justice in the sense of the *Gladue* ruling, and judges must attempt to inquire into these circumstances where counsel do not provide the information (O'Bonsawin, 2020).

A 2017 report of the federal Department of Justice noted that Gladue reports were not at that time available in all jurisdictions, and that inadequate resources for preparing reports were a major impediment to their availability for use in sentencing. In some locations, Gladue Reports are only prepared for cases involving longer potential sentences (Justice Canada, 2017). In a pan-Canadian review, Ralston noted that constraints on the availability of FASD assessments may qualify as a systemic factor that could contribute to Indigenous over-incarceration (Ralston, 2021). The same report notes that the effective implementation of Gladue principles is limited by the lack of community resources for supporting Gladue-sentenced offenders with FASD (Justice Canada, 2017).

The FASD Youth Justice Pilot Project, carried out in Winnipeg in two phases between 2004 and 2006, was developed to ensure that youth with FASD who have come in contact with the law received a formal diagnosis, appropriate sentences and improved access to services. The program evaluation showed increased access to diagnostic services. However, the program did not have sustainable sources of funding (Justice Canada, 2021b).

Community services who work with youth offenders have developed screening tools to help identify when diagnostic assessment should be pursued. One example is the Manitoba Youth Justice FASD Program's presentencing FASD screening tool for youth 12 to 18 (described in Singal et al., 2018). Another is the Asante Centre's Youth Probation Officer Screening Tool (Conry & Asante, 2010), now being updated (Schuurman and Gushue, 2023).

Mullally et al. (2023) examined Canadian trial and appellate decisions for evidence of FASD in criminal cases. They found that FASD was generally accepted as a mitigating circumstance in both youth and adult case decisions, but that insufficient diagnostic resources resulted in evidence regarding FASD to be haphazardly introduced and applied. However, they also found that FASD was also associated with concerns about public safety and pessimism about prospects for rehabilitation and risk management. Where there is a lack of options for non-carceral settings that offer suitable community-based supports and supervision, a carceral sentence may be selected for risk management reasons – termed "incarceration by default" in one case (Mullally et al, 2023; Dickson & Stewart, 2022). A 2013 consensus statement on legal issues related to FASD noted the high costs associated with incarceration and recommended that more resources should instead be devoted to much less expensive forms of community-based support and supervision (Institute of Health Economics, 2013).

Improving understanding of FASD in the criminal justice system

Several studies have identified the importance of improving understanding of FASD among professionals working in various components of the justice and correctional systems, including police, corrections officers, lawyers, judges, and probation and parole officers (Burd et al., 2021; Flannigan, Pei et al., 2018; McCormack et al, 2022; McLachlan et al., 2021; Mullally et al., 2023; Passmore et al., 2021; Sessa et al., 2022). Lack of knowledge can lead to unrealistic expectations and inadequate referrals for additional support (Russell et al., 2023).

A 2015 environmental scan found that there is a lack of FASD training and education among frontline justice personnel (police, judges, lawyers, corrections and court staff; Stewart, 2015). In their systematic review, Flannigan, Pei et al. (2018) found that while there is an overall awareness among professionals in corrections, legal, and judicial settings that many in the populations they encounter are affected by FASD, more training and practice guidelines are desired. McLachlan et al. (2021), in an international study of forensic mental health clinicians, found that some had not received any formal education or training about FASD, and generally reported feeling inadequately prepared for forensic practice with this population. In addition, a majority of the clinicians surveyed reported experiencing barriers in their forensic assessment and intervention practices in working with clients with FASD. These included: difficulty obtaining records; making culturally-informed assessments; lack of cooperation from clients with FASD; a lack of treatment options and/or methods for managing risk; and a lack of research linking best forensic practices for clients with FASD. Additional training, resources, and support were identified as important enabling factors for clinicians; these could include evidence-based screening approaches and tools, clinical guidelines for best practice in diagnosis, in-depth workshops and/or accredited training opportunities; and access to a registry of specialists available for consultation (McLachlan et al., 2021).

The engagement sessions likewise highlighted the value of improving FASD knowledge among police, corrections officers, lawyers and judges. A participant stated:

> *I have so many examples of people diagnosed with FASD who have charges that are caused by system failure… or the lack of FASD knowledge or education… professionals or workers deciding to change the rule on their shifts and youth are paying the price by escalating…*

Engagement participants concurred that additional culturally and trauma-informed FASD training and support would be beneficial.

Professional development interventions and supports have been developed for professionals working in justice contexts. These range in scope and delivery method. Some examples are:

- FASD Justice is a bilingual information site developed by the FASD Justice Committee, an independent group of justice system professionals and FASD experts, with the support of the Law Foundation of Ontario. Designed for justice system professionals and others who want to understand more about FASD, it provides background information, case law, legal resources and strategies for effective intervention with persons with FASD who are involved with the justice system as accused, victims or witnesses, or through the child welfare system. It covers criminal law, policing, corrections, civil law, Indigenous law, and youth legal systems (FASD Justice, n.d.).
- CanFASD offers two online training courses: one for professionals in the Solicitor General systems (CanFASD, n.d.-g), and the other for Judicial and Legal Professionals (CanFASD, n.d.-h);

- The Asante Centre produced a series of resources for legal and justice professionals, including animated videos and discussion guides for police officers introducing FASD, explaining communication breakdowns, and describing a day in the life of someone with an invisible disability like FASD (Asante Centre, 2021);
- The Asante Centre's Youth Probation Officer Screening Tool is now being updated through a project funded by the Law Foundation of BC, with the overall aim of improving the services and supports received by individuals with FASD and other neurodevelopmental conditions in the legal system and ultimately, their trajectory and outcomes. An updated screening toolkit will be implemented with accompanying resources, including training of professionals in the criminal legal sector across BC and creation of an FASD-focused community of practice (Schuurman and Gushue, 2023);
- As part of the three-year project *Toward Prevention* launched in 2021 in the Atlantic provinces, an FASD 101 and the Justice System training curriculum was developed, tailored to justice professionals, including police, corrections and parole officers, lawyers, and judges (Public Health Agency of Canada, 2021).

Engagement participants also expressed concerns about lack of awareness and knowledge of FASD among justice system professionals, but also noted improvements:

> *Some Defense lawyers on duty counsel and some judges have been educated. Rapport with those with FASD has been handled well. Judges give realistic sentences that are modified for FASD to be able to succeed in completing.*

FASD courts or other diversion programs

Recent years have seen increased calls for implementation of specialized courts or court dockets for people with FASD (Stewart, 2019; FASD Justice Canada, 2024). These allow for the development of knowledge and expertise in assessing, considering, and reflecting FASD-related challenges in court decisions as appropriate. Aiming to help ensure that relevant conditions that influence capacity and behaviour are considered in assessing responsibility for criminal behaviour, they also help orient offenders with FASD towards appropriate rehabilitation and recidivism prevention, in addition to determining the appropriate sentence. These supportive interventions may also reduce risk of escalation of legal problems due to offenders' lack of understanding of rules, regulations, and the importance of compliance with justice system obligations like terms of probation and court orders. Common to these initiatives are provision of FASD-informed supports, so that courts better understand people with FASD; and ensuring that access to informed professionals is not limited to those with financial means.

- In 2019, Manitoba introduced an FASD Court to support justice-involved youth and adults with FASD. While all ages are eligible to appear in the Court, only those under 25 receive comprehensive program supports. Coordinators from the FASD Justice Program attend court to support youth, young adults and family (CanFASD, 2021a). In the FASD Court, if a link is identified between the offending behaviour and FASD, the Court can consider how that impacts the offender's responsibility, while linking the offender to existing supports for improved outcomes (Manitoba Indigenous Reconciliation and Northern Relations, 2022). When the Court was introduced, the FASD Justice Program, in partnership with the Province of Manitoba and the Manitoba FASD centre, launched a pilot to provide FASD assessments to young adults aged 18 to 25 who have come into contact with the law, with the goal of preventing future justice system involvement. This program is being evaluated (Government of Manitoba, 2020; CanFASD, 2021a).
- The Alberta provincial FASD strategy includes a Justice Support Project for Youth that organizes case conferences ordered by youth court judges. An evaluation found that reductions in criminal charges were strongly associated with reductions in criminogenic risk factors that followed from the case conference, resulting in a significant decline in the overall risk of offending for 32% of youth (Government of Alberta, 2021).

Many programs are youth-focused. Interventions and supports for justice-involved people with FASD older than 25 appear to be less available. One example identified is in Alberta, where the Central Alberta FASD Network supports a court diversion program, beginning with a screening process to ensure that the individual is or may be impacted by FASD and that the charges are deemed eligible for diversion by the Crown. Individuals accepted into this program are provided support through the Restorative Justice Program (Central Alberta FASD Network, n.d.-c).

Specialized assistance is sometimes provided through FASD caseworkers or through community connections to support people with FASD in navigating the judicial process. This is important to mitigate some of the challenges they might face with understanding the process, communicating effectively and complying with court conditions due to the characteristics of FASD (Khalifa et al., 2022; Central FASD, n.d.).

A recent Justice Canada publication reported on navigator programs throughout Canada (Justice Canada, 2022). These programs provide legal information and support throughout justice system processes to individuals. Although this scan of general and population-specific Canadian navigator programs did not identify FASD-specific programs, it addresses the types of supports offered as well as their potential role in improving access to justice, particularly for vulnerable groups. These programs can be seen as part of Canada's broader Access to Justice agenda, promoting Sustainable Development Goal 16, which commits to "promote peaceful and inclusive societies for sustainable development, provide access to justice for all, and build effective, accountable, and inclusive institutions at all levels." Justice Canada is the lead department within the Government of Canada for achieving these goals (Justice Canada, n.d.).

Engagement participants supported the use of alternative justice processes for people with FASD. It was, however, noted that they are usually only available in larger centres, when what is needed is broad expertise throughout the criminal justice court system. The conditions of diversionary programs may be challenging for some youth with FASD; without supports they may lack understanding of the importance of following the requirements of the program:

> *The Diversion Program is helpful, however without supports to those individuals they often lack understanding of the importance of attending, which can impact them negatively.*

Also noted by an engagement participant was the importance of ensuring an adequate support for families:

> *When a youth finds themselves in court and has a diversion plan there needs to be more support from outside of the family to enable the youth to complete the plan. Conflict can arise in the family when they are the ones holding the youth accountable.*

Several other types of specialized courts exist in Canada, for example drug treatment or mental health courts, which could handle cases in which there is intersection of FASD with these issues, in the absence of FASD-specific courts or dockets. Positive outcomes were reported by engagement participants:

> *We have drug court and FASD court here in Lethbridge, AB. We have seen great success. It gives the crown and judges more knowledge about how an FASD brain works and that typical court systems are not effective.*

Given the heterogeneity and diversity of individuals with FASD, it is important to tailor these alternative justice structures to their specificities, as well as to recognize that people with other types of disabilities may face similar issues with the legal system. Flannigan, Pei et al. (2018) recommended that additional research be conducted in development of tailored programs for individuals with "cognitive diversity" to divert youth away from pathways into the justice system.

Alternative non-carceral sentences for people with FASD

Concerns about the vulnerability and needs of people with FASD in the justice system has led to the repeated introduction of private members bills (Bill C-583, March 2014; Bill C-656, March 2015; Bill C-235 February, 2016) aiming for amendments to the *Criminal Code of Canada* and the *Corrections and Conditional Release Act*. The proposed amendments would have: added a definition of FASD in the *Criminal Code*, allowed judges to order an FASD assessment, required courts to consider FASD a mitigating factor in sentencing, and provided for external support plans to be put in place within probation orders for individuals with FASD (Justice Canada, 2023b). These attempts were largely supported by the Canadian Bar Association (Basque, 2016).

The possibility of restorative justice approaches to address criminal offending by people with FASD has been discussed. Restorative justice is an approach to sentencing based on the understanding that crime causes harm to people and communities. Those who have caused the harm have a responsibility to repair it; those who have been harmed are entitled to decide what is needed to repair it; and communities have a role to play for both victims and offenders (Justice Canada, 2023b). The restorative justice process may lead to different forms of reparations for the harms, such as community service. A recent review of 5 programs found a high level of completion of the restorative justice agreements and that victims were satisfied with the process and outcomes, as assessed during the three to six-month follow ups. Victims also reported better understanding of the circumstances that led to the harm (Justice Canada, 2023). One challenge identified was that restorative justice programs are usually well-connected to community resources that can help support reintegration, but that the intensive and long-term supports needed by offenders with FASD to avoid re-offending are often unavailable in many communities (Justice Canada, 2023).

For people with FASD, due to their risk of exploitation and manipulation by others (Hargrove et al, 2024; Institute of Health Economics, 2013), incarceration may be criminogenic or exacerbate negative outcomes such as gang involvement and risky behaviour. The Criminal Code allows for various forms of non-carceral sentences. However, there is continuing concern about the limited availability of options to support community-based sentences for people with FASD despite recognition that these could be less expensive and simultaneously more effective for rehabilitation and longer-term risk management (Mullally 2023; Stewart, 2015; Milward 2014; Institute of Health Economics 2013). Conditions associated with community-based sentences need to be carefully implemented given evidence that people with FASD may fail to satisfy court conditions in a reliable and timely way, leading to the accumulation of charges for administrative breaches, and conditions run the risk of amounting to a situation that is “designed to fail” (Institute of Health Economics, 2013; Milward 2014; Justice Canada, 2023)

Other forms of alternative sentences proposed by engagement participants included: providing community-based alternatives where individuals with FASD can access tailored rehabilitation, such as transition housing and employment programs, enhanced mentorship, accompaniment, and supervision, and supervised living arrangements or healing and wellness approaches. An overarching consideration is what interventions from the system could help interrupt cycles of justice system involvement and provide the greatest overall benefits.

FASD programs recognize the benefits of supporting offenders with FASD once they are released, in order to help them rebuild social networks, re-establish material supports, and prevent re-offending. For example, the Central Alberta FASD Network's programs include interventions and supports for those released as well as in-reach support to set people up for a successful transition back to the community upon release, including FASD education, FASD assessment and diagnosis, and necessary support services (Central Alberta FASD Network, n.d.-c).

In the Indigenous context, as mentioned in Chapter 3, alternatives to incarceration may involve land-based engagement and cultural healing practices, in a community setting (Milward, 2014; Blagg & Tulich, 2018; Blagg et al., 2015). As mentioned in Chapter 3 and earlier within Section 7.4, courts are also required to consider Gladue factors when sentencing Indigenous offenders.

Key Findings:

People with FASD often experience unfavourable social determinants of health that raise the risk of involvement in the justice system. They may also have other risk factors such as heightened vulnerability to manipulation by others, and may seek community within troubled peer groups (e.g. gangs). Consequently, people with FASD are over-represented in the criminal justice system, both as victims and offenders.

The provision of upstream interventions and supports can prevent problems with the justice system. These might include support to achieve financial and housing stability, positive mentorship relationships, and a sense of belonging within supportive networks and communities. These supports are especially valuable during the transition between adolescence and adulthood, and a supportive network is key for youth transitioning out of the child welfare system.

Improving access to assessment and diagnosis for people who may have FASD in the criminal justice system will help to ensure that necessary accommodations are provided and their behaviour is better understood. While FASD awareness exists in some parts of the justice and correctional system, it is inconsistent. The use of specialized FASD courts or dockets can help to ensure that the processes and decisions are more informed about FASD, although these are likely to exist only in urban centres.

There is a strong need for alternatives to incarceration, particularly given the criminogenic and harmful effects of incarceration, the diminished capacity of people with FASD, and the possibility that adequate systems of non-carceral support and supervision could better protect public safety at lower cost than incarceration.

7.5 Stigmatization and inclusion

Stigmatization is a pervasive factor in FASD experience and policy response. As defined by Bell et al. (2016), it is a "process that involves the endorsement by others of negative stereotypes (i.e., socially informed notions and impressions of particular groups), accompanied by prejudice, including emotion-based reactions (e.g., anger or fear), and potential discrimination (e.g., systemic/structural or direct forms of discrimination). FASD stigma tends to ignore the structural and environmental determinants that are also causal factors of PAE and FASD (Eliason et al., 2024). We have already reviewed the consequences of the stigma surrounding FASD in previous chapters:

- Chapter 3 discusses the impact of stigma on Indigenous Peoples and communities;
- Chapter 4 examines the impact of stigmatization on prevalence estimation and the accuracy of prevalence estimates;
- Chapter 5 presents findings on how stigmatization affects prevention initiatives; and
- Chapter 6 notes how assessment and diagnosis are affected by desire to avoid stigmatization and how this has stimulated debate on the term FASD as a diagnostic label.

To summarize what has been presented in previous chapters: FASD is surrounded by stigmatization and stereotyping, affecting people with FASD, and their birth and adoptive parents. It is reflected in the attitudes of the general public, and the attitudes and behaviours of workers in health and social services, policing and justice, education, and child welfare. The effects of stigmatization are compounded by racism, including anti-Indigenous racism (Aspler et al., 2022; Choate & Badry, 2019: Dunbar Winsor, 2021; Hargrove et al., 2024; Roozen et al., 2022).

In this section, we therefore focus on social inclusion and exclusion, the effect of stigma on supports for people with FASD and their families, and suggested ways to prevent and reduce stigmatization.

7.5.1 Dimensions of stigmatization

Bell et al. (2016) propose a model of FASD stigmatization, derived from a literature review, with three components: personal responsibility and blame towards biological mothers; felt and enacted stigma experienced by children and families; and anticipated life trajectories for individuals with FASD. Roozen et al. (2022) documented four types of stigma affecting people with FASD: public stigma affecting individuals; self-stigma or internalization of stigma leading to low self-esteem and an underestimation of one's potential; stigma by association extending beyond the individual with FASD to their associates, and biological and non-biological parents; and structural stigma, the stigma perpetuated by society's institutions and ideological systems.

7.5.2 The experience of being stigmatized and the harms caused

In the engagement sessions, people with FASD reported reluctance to self-disclose because of judgment and stigma, as well as experiencing other people's anger and frustration at work and school. They also reported often hearing things like:

> *'I know mothers who drank and their kids are fine.'*

In the engagement process, caregivers of people with FASD and support workers identified many ways that stigmatization affects children they are caring for:

- From other children: shaming, bullying, insults and blame for their behaviour
- From adults and professionals
  - denying the diagnosis because the child does not have the sentinel facial feature;
  - stating that the child is just oppositional or showing bad behaviour and making excuses for it;
  - saying that the child is just unmotivated, and can just try harder;
  - arguing that their problem is because of bad parenting or lack of proper care; and
  - having low hopes/expectations of children with FASD.

Caregivers also shared that they had experienced being personally stigmatized in many ways, including:

- being made to feel like a bad parent:

> *to school boards they... are just the "kids with bad behaviours and terrible parents";*

- being told they are using FASD as an excuse for bad behaviour and need to be stricter and punitive;
- being told they are "over-controlling";
- feeling a need to explain they are adoptive parents because of the stigma attached to FASD;
- feeling that teachers and social services do not believe or dismiss their observations or reports;
- dealing with reluctance of healthcare providers to diagnose FASD, or invalidating concerns and observations of people with FASD or families; and
- blaming and judging mothers.

Aspler et al. (2019) documented media stereotypes contributing to stigmatization; these included people with FASD as having negative life trajectories and being incapable of success. In the engagement sessions, participants with FASD recounted the misperceptions they have encountered:

- that you have to look or act in a certain way to have FASD (e.g. sentinel facial features);
- that they have low IQs;
- that they cannot live normal lives;
- that they will outgrow effects of FASD with age; and
- that their children will be affected with FASD.

These stereotypes and misperceptions often become internalized, resulting in self-stigmatization (Hargrove et al., 2024; Roozen et al., 2022). Hargrove et al. identify a key step in self-stigmatization as listening to the message that FASD is “100% preventable”, which leads to an understanding of oneself as a product of prevention failure (Hargrove et al., 2024).

Peer-reviewed research on FASD stigmatization is emerging and confirming that it is harmful to health and well-being. Wilson et al. (2023) performed a scoping review that included 47 published and grey literature papers on life with FASD from the perspective of those with FASD, their caregivers, and professionals working closely with them. This review found that caregivers experience significant stigmatization and that individuals with FASD were left socially isolated and excluded by their peers. Hargrove et al. (2024), reported on the results of an anonymous survey of 485 people with FASD, developed by people with FASD. Survey respondents reported an overall sense of being poorly understood and excluded, along with an internal sense of inferiority: 91% felt mentally or intellectually inferior to other people; and 82% felt their FASD had been used against them. Sixty-two percent reported they would keep the diagnosis secret from an employer, and more than half (54%) reported not letting anyone at work know. Seventy-seven percent believed they would not or probably would not have been hired if the employer knew of the FASD. Social exclusion and a sense of low self-worth takes a toll on social relationships: 77% of respondents described that being with people is exhausting, and 72% that being with other people makes them anxious and nervous. Two-thirds, 66%, reported that making friends is difficult, and 61% reported being happier alone, with half having most of their social interactions online.

In the engagement sessions, participants with FASD reported that the impacts of FASD included:

- barriers to accessing supports and diagnostic services, as there can be reluctance to seek a diagnosis that is already difficult for the family and is also socially stigmatized;
- effects on social interaction, leading to exclusion and reduced social participation; and
- reduced desire to self-disclose and self-advocate for accommodations and supports, and lowered self-esteem, self-image, mental health and well-being.

7.5.3 Sources of stigmatization in professional activity

Stigmatization operates directly, through overt and covert criticism and judgement of behaviour, and indirectly, through systemic factors embedded in social systems (Hargrove et al., 2024). It may be so deeply embedded as to be invisible to well-intentioned professionals, who can cause inadvertent harm (Bell et al. 2016). Sources of stigmatization emanating from professional activity have been identified:

- Bell et al. (2016) note that prevention campaigns that focus narrowly on PAE stigmatize pregnant women who consume alcohol, fuel blame of mothers and are reductionist and ineffective. Masella (2020) likewise discusses the ethical dimensions of FASD awareness campaigns, noting their potential to contribute to stigmatization.
- Choate and Badry (2019), in a review of FASD content in professional journals across a wide range of disciplines, concluded that the discourse is predominantly negative with an overarching emphasis on negative outcomes and more severe cases. Attention to the entire range of outcomes is infrequent and to positive outcomes especially so. They argue that this bias results in catastrophizing professional perceptions of FASD, contributing to stigmatization.
- In a review of the content of free online training modules on FASD aimed at health and social work professionals, Bagley et al. (2022) found that the discussions rarely addressed social factors, socio-economic status, cultural differences and the stigmatization of people with FASD, and most lacked consideration of lived experience, thus failing to dispel common community misconceptions.
- Oni et al. (2022) found a disjuncture between professional policies of compassion and non-judgement, and pregnant women's lived experience of being judged, blamed and stigmatized. Health professionals report having conflicting views about their own socially-accepted alcohol consumption, the expectations placed on pregnant women, and about exercising control over pregnant women's bodies and their reproductive rights (Bagley & Badry, 2019).
- Olsen and Sparrow (2021) argue that the use of terminology such as secondary disabilities in the research literature has contributed to stigmatization of people with FASD.

7.5.4 Language used to discuss FASD – reducing stigmatization

As described in Chapter 6, one of the factors mentioned in the current debate on the term FASD as a diagnostic label is a desire to reduce stigmatization through a shift in terminology. There are additional elements in the language used to discuss FASD that can change how people with FASD and their families and caregivers are viewed.

In an argument for a standard definition and nomenclature for FASD, Harding et al. (2021) point out that historically individuals with disabilities have experienced discrimination through the use of stereotypic or demeaning language, and that those with FASD may be particularly affected. They encourage strength-based, person-centred language that avoids blame and guilt.

Similarly, various advocacy organizations have emphasized that “language matters”: how FASD is talked about contributes to stigmatization. They have proposed alternative non-stigmatizing language and media guides (Piruqatigiit Resource Center, n.d.; CanFASD, n.d.-i; Willow Winds Support Network, n.d.; Manitoba FASD Coalition, 2025).

7.5.5 Increasing public understanding and awareness of FASD

A lack of public awareness and understanding of FASD is regarded as one of the drivers of stigmatization as it allows the perpetuation of stereotypes and false information (Aspler et al., 2019). Stigmatization is considered a public health issue and a determinant of health (Paradies et al., 2015).

Some research has shown that mass media campaigns targeting mental health stigma produce small to moderate short-term positive impacts (Thornicroft et al., 2016; Rao et al., 2019). Stigma is also impacted by media representations, which can spread fear and prejudicial attitudes. The most promising interventions to produce more balanced reporting about stigmatized groups are contact-based educational approaches and the provision of guidelines by authoritative institutions (Maiorano, et al., 2017).

The 2019 Chief Public Health Officer’s Report on Public Health called for reducing stigma to develop a more inclusive health system (Public Health Agency of Canada, 2019b). Stigmatization related to substance use disorder and PAE are described. The report describes three main causal routes by which stigma affects public health: reduced access to and quality of protective resources and health services; production of chronic stress and poor coping responses and behaviours; and exposure to violence and assault, all of which lead to adverse mental and physical health outcomes. Based on a literature review and consultations, core principles for the development of anti-stigma interventions were identified:

- Driven by collaboration between health system leaders and people with lived experience of stigma;
- Designed based on research evidence, diverse ways of knowing, and experiential knowledge;
- Multi-level, with particular attention to multi-level initiatives that prioritize institutional- and/or population-level interventions to address systemic stigma and discrimination in health systems;
- Guided by approaches such as cultural safety and trauma- and violence-informed practice;
- Attending to intersectionality, including the strengths, resources, and solidarity within communities who experience stigma; and

- Grounded in principles of intervention research and implementation science, to advance knowledge in the field (Public Health Agency of Canada, 2019b, p.54).

Specific to FASD, participants in our engagement process suggested messaging emphasizing:

- prevalence of unintended pregnancy and therefore of alcohol consumption while unaware of pregnancy;
- the role of Social Determinants of Health (SDH), trauma and vulnerability leading to alcohol use to cope;
- risks of dependency and the challenges of accessing treatment/supports for alcohol use problems;
- the manner in which SDH, trauma, vulnerability compounds the effects of PAE on children.

7.5.6 Focusing on successes and strengths of people with FASD

As we have noted in Chapter 1, professional (Choate & Badry, 2019) and public (Aspler, 2019) discourse about FASD is skewed to the negative. However, there is also evidence capturing the 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 (Flannigan, Wrath, Ritter et al., 2021), independence, resilience, kindness and adaptability (Petrenko & Kautz-Turnbull, 2021).

In the engagement sessions, people with FASD also saw similar strengths to those captured in the literature: 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.

To counter the negative discourse, engagement participants discussed the opportunity for portrayal of successes and strengths of individuals with FASD, their families and their communities. However, mixed views were expressed about portrayals of successes and strengths in FASD. On one hand, this form of public education could be effective in alleviating negative stereotypes about limited trajectories and broadening understanding of effective supports and interventions:

> *It would be great to feature and highlight examples of what is working - and amplify voices of adults with FASD to change some of the erroneous narrative and assumptions about people with FASD. Encourage building on strengths and successes - that preserves dignity of people with FASD, hope for people who support people with FASD, and ideas of how to implement policy, programs, training, and other initiatives.*

At the same time, concerns were expressed by people with FASD that painting a misleadingly rosy picture would create false hope, stress, pressure and a sense of failure for some. Our examination of the research evidence did not find studies on the advantages and disadvantages of FASD success stories, but some criticisms of attempts to shift opinions through positive portrayal in other domains reveal concerns about "tokenism, stereotyping, focusing upon 'exceptional' people, and fueling sanitized accounts which deny, or at least obscure, the harsh lived realities of many" (Thomas, 2021). Recognizing FASD's heterogeneity across a full spectrum of abilities and needs can present a more accurate picture.

7.5.7 Hearing the voices of those with FASD

Dunbar Winsor (2021) points out that the dominance of negative stereotypes about FASD renders invisible the actual experience of what it is like to live with it - another form of invalidation and exclusion. To reduce stigma and support inclusion, there are increasing calls to centre discussion about FASD on the lived experiences of those most affected: people with FASD and their caregivers (Hargrove et al., 2024; Bagley et al., 2022). There is a particular knowledge gap about the lived experiences, through their own voices, of children under 14 (Skorka et al., 2020). Engagement participants stated that personal narratives can humanize issues and increase learning and understanding.

Engagement participants concurred that it is important to include the voices of people with FASD, but raised concerns about ensuring representativeness among those who are able to share their voices. Those most able or likely to participate in discussion may have a level of functioning that is not realistic for others, meaning that these other voices are not captured. Participants suggested that if mothers with lived experience were supported to overcome guilt and shame, and felt able to speak out about their experiences, this could help others to reach out for support.

7.5.8 Improving community participation and social inclusion

Social isolation and exclusion are experienced by many people with FASD and their families (Hargrove et al. 2024). Community participation is seen as an important avenue to improve social inclusion.

In order to provide children and adolescents with socialization opportunities, there were calls in the engagement sessions for FASD programs, camps and groups. Because school-age children have trouble making and keeping friends, more structured recreational programs that foster positive peer relationships were seen as desirable:

> *Increased support for community programs to have trained staff. Having a low participant - trained staffing ratio to support individuals with FASD where they feel included and supported to share their strengths and feel like they belong. Many times we hear from families "this is the first time their child has ever had a 'friend' and felt like they belonged."*

Engagement participants noted the positive impact of strengths-based recreation activities for children and youth with FASD. At the same time, some parents preferred opportunities for their children with FASD to be integrated into FASD-informed but non-segregated activities.

According to engagement participants, FASD-informed community supports are seen by parents and caregivers as a safe respite, where they know children are safe and accepted. However, it was pointed out that making these activities broadly accessible may rely upon subsidizing or making them free:

> *We need funding for recreational activities for families who cannot afford it.*

Some jurisdictions offer community participation activities for children with FASD, sometimes with their caregivers, and sometimes as family respite. For example, Stepping Out on Saturdays Manitoba* (S.O.S. MB), a respite day camp for children ages 5-12 years who have FASD, is offered once per month in 5 locations (Government of Manitoba, 2024b). In High Level, Alberta, the FASD Society has an after-school program three times per week that offers a variety of activities for children with FASD or at risk for FASD. Youth with FASD are provided opportunities to be team leaders helping to run the program.

Whitecrow Village in BC offers a summer camping program for children with FASD run primarily by adults with FASD (CanFASD, 2021b). They also offer programs for educators and parents of children with FASD taught by adults with FASD, with organizational assistance provided by a community helper (Whitecrow Village, n.d.). In the engagement process, adults with FASD recommended that adult-oriented community participation programs and supports be run by people with FASD but with support from system navigators and community groups behind the scenes to help launch programs and to keep them running smoothly. It was also suggested that delivery of such community programming could benefit from tools such as British Columbia's *Supporting Success* Guidebook. This Guidebook, developed with people with FASD, covers the topics of: relationships and community involvement; social relationships, transportation and safety in community, including examples of challenging social situations and how to help people with FASD navigate them (Community Living British Columbia, 2011).

Key Findings:

Stigma related to FASD deeply harms the health and quality of life of people with FASD and their families and caregivers. It creates barriers to accessing supports, and to self-disclosure in order to access accommodations. Stigmatization is considered a public health issue and a determinant of health.

Stigma-free and blame-free language is helpful in communicating about FASD, in public education, and in providing interventions and supports. This includes recognizing that FASD is a broad spectrum with variable impacts on functioning and avoiding stereotypes about deficits. Educational resources and training to embed stigma-free and blame-free language in all professional activities in health and social services, education, policing and justice, and child welfare is important for addressing systemic stigma.

People with FASD and their families and caregivers emphasize the importance of being connected and included within their communities, but there can be limited opportunities for inclusion and participation, and as a result, they often feel isolated and excluded. People with FASD can benefit from help and guidance with social skill development to protect against isolation. Together with education of others about FASD, this can help to reduce instances in which their neurodevelopmental differences and associated social behaviours are misunderstood. Programs, groups and camps, led by adults or youth with FASD with support from community facilitators, are promising approaches for socialization opportunities.

Hearing the voices of people with FASD offers a powerful learning experience for others by challenging stereotypes and increasing awareness and understanding, and for peers with FASD, provides a pathway to stories of strength, resiliency and success. This can be achieved by including people with FASD who have variable demonstrated functional strengths in a diversity of domains. Examples of mechanisms for sharing the voices of people with FASD are educational presentations by people with FASD, the involvement of people with FASD as program facilitators, and in participatory research and continuing professional education programs.

7.6 International best practices in interventions and supports

7.6.1 Australia

To support people with FASD across Australia, the country has implemented several initiatives. The overarching National Disability Insurance Scheme (National Disability Insurance Scheme, n.d.), is a nationwide program that provides funding for reasonable and necessary support, goods, services, or equipment to people with disabilities, including people with FASD. Specifically, this centralized system enables consistent support services across the country, tailored to the person's specific need.

Australia also prioritizes educational resources and training to improve the outcomes for young people with FASD (Commonwealth of Australia & Department of Health, 2018). Resources, such as guides and podcasts, provide targeted and specific programs that recognize and address the particular needs of children with FASD in schools.

Across Australia, another support system in place is the FASD Justice Employment Program which offers tips, tools, and strategies to improve the employment outcomes of people with FASD who are transitioning out of the justice system (Patches Australia, n.d.). By targeting the intersection of the justice and employment sectors, Australia aims to streamline support services and provide specialized support for vulnerable populations. Australia addresses the high prevalence of FASD in youth justice settings by emphasizing therapeutic justice interventions and providing FASD education and training to staff in the juvenile justice systems and community policing (Commonwealth of Australia & Department of Health, 2018; FASD Hub Australia, 2021). This systemic approach works to reduce recidivism and support rehabilitation for individuals with FASD.

7.6.2 USA

In the USA, children with FASD can be automatically referred for special education services and can receive an Individualized Education Program (IEP) or services under Section 504 of the Rehabilitation Act of 1973, depending upon the level of assessed need (US Department of Health & Human Services, 2022a). States have also implemented a number of strategies to support people with FASD and their families and caregivers. For example, Alaska has integrated support for FASD into its education system (National Organization on Fetal Alcohol Syndrome, n.d.). The USA also offers vocational rehabilitation services that provide counselling, training, education, transportation, job placement, and other support systems to individuals with a disability, including FASD (Center for Substance Abuse Prevention US, 2014). This comprehensive support extends beyond education into employment, facilitating smoother transitions into the workforce.

Across the justice system, the USA provides training for legal professionals on FASD. Training resources include the FASD technical assistance bulletin and FASD bench guide for judges, and continuing legal education on FASD for judges and legal professionals (US Department of Health & Human Services, 2022a). Additionally, state-level initiatives, such as in Alaska, include policies that consider FASD in sentencing and provide training on FASD for parole officers, judges, attorneys, and public defenders (US Department of Health & Human Services, 2022a).

7.7 Conclusion

People with FASD and their families face significant challenges across many domains of life. In addition to being a life-long neurodevelopmental condition affecting functioning in activities of daily living, education, social and family relationships, mental and behavioural health, and employment, it is a full body condition associated with many physical health risks. Early intervention offers significant benefits at a time of greater neuroplasticity, school-age interventions can help reduce the effect of the downstream consequences of PAE and FASD on the lives of people with FASD. Continuing supports in all systems adapted to all the life stages of people with FASD are needed, and there are important transitional periods and gaps that create vulnerabilities, such as the transition between systems for support of children and adolescents and support programs for adults, as well as supports for aging adults with FASD who may be losing natural supports as the people in their support networks age. Barriers to support for people with FASD exist, such as programs requiring formal diagnosis which may not be possible for those without evidence of PAE or access to diagnosis. The use of IQ cut-offs for disability support programs also are poorly adapted to the reality of people with FASD, where many will have IQs above the cut-off but still face significant struggles with adaptive functioning. The lack of upstream investment in appropriate supports increases the risk of later problems, including poor outcomes in education, employment, relationships, addictions and involvement with the criminal justice system, all of which are associated with substantial societal and human costs that could be avoided or reduced.

Chapter 8:

Implementation of the 2003 Canadian FASD Framework for Action

Fetal Alcohol Spectrum Disorder in Canada:

Current knowledge and policy

8.1 Introduction

This chapter addresses the implementation of the *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action* (Public Health Agency of Canada, 2003). It first briefly recalls the Framework's development and implementation context as outlined in Chapter 2. Then, in order to aid interpretation of implementation progress, we identify the many changes in the FASD and broader population health landscape that have occurred since the Framework's publication. Based on evidence review and the engagement process, in particular a survey completed by close to 100 individuals and organizational representatives, the chapter then discusses barriers and challenges to the Framework's implementation, followed by considerations for moving forward. The chapter also includes an assessment of current training, education, and guidance needs and opportunities, as well as measures to promote research and intergovernmental/federal, provincial, and territorial information-sharing.

8.1.1 Framework development and features

As Chapter 2 noted, the *FASD Framework for Action* was developed following national consultations as a statement of shared commitment among the federal government, and provinces and territories to address what was then becoming recognised as a significant public health concern (Bacon, 2012). Awareness of alcohol-related pregnancy outcomes had been growing over the previous decade, since the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women's 1992 report *Foetal Alcohol Syndrome: A Preventable Tragedy* (Green & Wilbee, 1992) and the 1996 *Joint Statement on the Prevention of Fetal Alcohol Syndrome/Fetal Alcohol Effects in Canada*, issued by Health Canada and 18 national professional associations (cited in Bacon, 2012).

The Framework's intention was to be "far from ... restrictive or directive." Its five overarching goals were to be seen as "guideposts for the development of more specific and measurable objectives and action plans by all jurisdictions and sectors." The initial goals were:

- increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy;
- develop and increase capacity;
- create effective pan-Canadian screening, diagnostic and data collection and reporting tools and approaches;
- expand the knowledge base and facilitate information exchange; and,
- increase commitment and support for action on FASD.

The Framework provided orienting directions at the federal and provincial and territorial levels, summarized in Table 9. At the federal level, the Framework was a guide for interdepartmental work to address gaps and issues not currently undertaken in other sectors. Additionally, the Framework captured the suggestions made during the 2003 consultations for directions to be taken at the provincial/territorial level.

Table 9: Orienting directions in the 2003 *FASD: Framework for Action*

Federal	Provincial/territorial
Development of national guidelines for screening, and diagnosis of FASD, and the collection, analysis and reporting of incidence, prevalence and economic impact data through evidence-based research and consultations across sectors; Expanding scientific and social science knowledge relevant to prevention of FASD and effective support for those affected across sectors, and providing tools and expertise for evaluating interventions and developing best practices; Building the evidence base and establishing mechanisms for knowledge exchange across sectors and communities - ensuring that research and evaluation results are available and accessible to inform future planning and action; and Increasing awareness of FASD among professionals across the array of sectors that work with people with FASD and their families and communities.	Establishing and strengthening coalitions and networks that span sectors and communities, and that bring together experience and resources; Reinforcing province-/territory-wide plans that work toward the vision and goals of the Framework - while taking into account the stage of readiness for action unique to each jurisdiction; and Enabling provincial and territorial organizations to contribute to, and draw on, the growing body of knowledge, expertise and tools to prevent FASD and support those affected by the disability.

8.1.2 Implementation of major initiatives consistent with the 2003 Framework

While previous chapters have primarily focused on current issues and future opportunities, it is important to recognize the progress that has been made since 2003. Some of this progress can be directly attributable to federally-supported initiatives conducted because of the Framework, others are initiatives led by other jurisdictions that aligned with the Framework and may have been oriented by it, whereas others represent partnerships and consortia that have evolved with the shared aims of information sharing and initiative co-development. As these have all been referred to in previous chapters, they are only briefly listed again here:

Framework-linked initiatives

PHAC’s National Strategic Projects Fund supported a total of 37 projects between 1999 and 2023 (Public Health Agency of Canada, 2023c). These include:

- Development and updating of the FASD diagnostic guidelines (Chudley et al., 2005; Cook et al., 2016). The 2005 Guidelines proposed a first consensus on a Canadian standard (Brown et al., 2019; Cook et al., 2016). As Chapter 6 noted, the 2016 Guidelines are now widely disseminated and awareness and uptake of them are relatively high, with some barriers and challenges (Flannigan et al., 2020; Coons-Harding, Flannigan et al., 2019; Dugas et al., 2022). The Guidelines intended to increase understanding of FASD among the many disciplines involved in assessment and diagnosis, through increasing attention to the large proportion of those diagnosed with FASD without SFF and at risk for FASD, and the great heterogeneity of FASD presentations (Cook et al., 2016).

- Development and updating of Alcohol Use and Pregnancy Consensus Clinical Guidelines (Carson et al., 2010, 2017; Graves et al., 2020). These Guidelines represented a consensus among healthcare professionals about recommending abstinence during pregnancy and screening and counselling pregnant women.

- Development of a National FASD Screening Toolbox (Goh et al., 2008). While this toolkit is no longer available, three of the five screening tools it included were often mentioned throughout this assessment: screening for PAE in neonatal meconium (Delano et al., 2019), the Medicine Wheel tool (Cox, 2023) and the Asante Centre Screening and Referral Tool for Youth Probation Officers (Conry & Asante, 2010).

- Estimation of population-based FASD prevalence among elementary school students using an active case ascertainment approach (Popova, Lange, Poznyak et al., 2019). The methodology of this study, developed under auspices of the WHO and National Institute on Alcohol Abuse and Alcoholism (NIAAA), can be used in other Canadian jurisdictions (Popova, Lange, Poznyak et al., 2019; Popova et al., 2018).

- The Four-Level Prevention Model (Poole et al., 2016; Poole & Public Health Agency of Canada, 2008; CanFASD, 2013; Wolfson et al., 2022).

- Development of the National FASD Database (CanFASD, 2024b; Public Health Agency of Canada, 2023a).

- Development of a Multi-source Surveillance System for Fetal Alcohol Spectrum Disorder and Prenatal Alcohol Exposure (Popova et al., 2021).

- Projects delivered through the First Nations and Inuit Health Branch, now Indigenous Services Canada, for example, the Atlantic First Nations Health Partnership which led to the implementation of FASD services and positions in nine Atlantic First Nations (Atlantic First Nations Health Partnership, 2018).

- Estimation of burden and economic cost associated with FASD in Canada. This cost-of-illness study examined the impact of FASD on the material welfare of Canadian society by analyzing the direct costs of resources expended on healthcare, law enforcement, children and youth in care, special education, supportive housing, long-term care, prevention and research, as well as the indirect costs of productivity losses of individuals with FASD due to their increased morbidity and premature mortality (Popova et al, 2014; Popova, Lange, Burd, & Rehm, 2016).

Framework-aligned provincial/territorial FASD Strategies

As discussed in Chapter 2, provinces and territories have, prior to and since publication of the 2003 Framework, implemented FASD strategies and action plans. These include:

- British Columbia's 2003-08 and 2008-2018 provincial action plans (Government of British Columbia, 2008).
- Alberta's FASD 10-Year Strategic Plan 2007-18 (Government of Alberta, 2008, 2017). including support for the development of the Parent Child Assistance Program (PCAP) model (Pei et al., 2017).
- Saskatchewan's 2014 FASD Prevention Framework (Saskatchewan Ministry of Health, 2014).
- Manitoba's provincial FASD strategies beginning in 2007, currently the 2024-29 Provincial FASD Strategy (Government of Manitoba, 2024a).
- Yukon's 2019 Yukon FASD Action Plan (Government of Yukon, 2019a).

Investments to address FASD in other policy areas or in the broader context of their health systems in other jurisdictions are also detailed in Chapter 2.

Framework-aligned partnerships, consortia and regional networks

Also, since 2003, partnerships and consortia have evolved with shared aims of information sharing and initiative co-development. These include:

- The Canada Northwest FASD Partnership (Government of the Northwest Territories, 2015).
- The Canada FASD Research Network (CanFASD, n.d.-j)
- The PHAC-funded Atlantic Intergovernmental FASD Partnership (Atlantic FASD Network, 2022; Canadian Intergovernmental Conference Secretariat, 2016).
- Regional FASD networks, some of which are described in Chapter 2.

8.1.3 International alignment and influence

The 2003 Canadian *FASD: Framework for Action* is aligned with major international FASD efforts, and has been influential in shaping aspects of some of these.

Diagnostic Guidelines:

- In a nine-country study of FASD diagnostic services, the Canadian guidelines were one of the three most often used, either alone or in combination with others (Reid et al., 2022).
- The Diagnostic Guidelines informed the development of guidelines in South Africa (Adebiyi, Mukumbang, & Beytell, 2019) Scotland (Healthcare Improvement Scotland, 2022) and Australia (Hayes et al., 2022).

National FASD Initiatives:

- Australia's FASD Action Plan echoes the community-based, prevention-focused approach seen in Canada's Framework, especially in its aim to support at-risk communities and provide comprehensive diagnostic and support resources (Commonwealth of Australia & Department of Health; 2018).
- The UK's guidelines emphasize community-centered FASD diagnosis and support, drawing from Canada's model of multi-disciplinary engagement across health, social services, and education sectors (Department of Health & Social Care UK, 2021).
- In the U.S., the CDC's FASD guidelines support initiatives that incorporate cross-sectoral collaboration and community involvement, principles underscored in Canada's Framework (Centers for Disease Control and Prevention, n.d.).

8.2 Considerations in the FASD and broader population health landscape

Since 2003, the Canadian landscape has evolved in ways that are relevant to FASD policy within and across jurisdictions. While presenting the full impact of each of these systemic changes is beyond the scope of this assessment, considering the implementation of the FASD Framework without this context would be incomplete.

8.2.1 Advances in medical and social science knowledge

Since the 2003 Framework was published, there have been major advances in medical and social science knowledge, especially about the multiple causal influence on FASD (McQuire, et al., 2020) and the range of its effects (Flannigan, Pei, et al., 2022; Cook et al., 2021). As one survey respondent stated:

> *The medical world knows much more than we knew in 2003. Advances have been made in what we know about genetics, attachment, trauma, nutrition, impacts of paternal health, maternal health, medications, poverty, adversity, other substance use -- it is, more often than not, more than just PAE that impacts neurodevelopment.*

8.2.2 Reconciliation

FASD affects all Canadians, but, as described in Chapter 3, health inequities and the historical and current effects of colonialism lead to FASD's significant effect on Indigenous Peoples. The Truth and Reconciliation Commission (TRC) of Canada (2015) greatly increased public awareness of the colonial harms caused to Indigenous Peoples. Its Calls to Action specifically address FASD, raising the profile of the intersectionality of social and Indigenous determinants of health and FASD as well as injustices in the child welfare and legal systems linked to FASD. There have been important legal changes, some leading to additional resources: the Jordan's Principle ruling (Indigenous Services Canada, 2024c) and the Inuit Child First Initiative (Indigenous Services Canada, 2024d); the sentencing principles developed following the decisions of the Supreme Court of Canada in *Gladue* and *Ipeelee* (*R. v. Gladue,* 1999; *R. v. Ipeelee,* 2012; Dickson & Stewart, 2022) and the First Nations social service delivery agreement (Government of Canada, 2019d). These developments have occurred in the broader international context of Canada's commitment to the *United Nations Declaration on the Rights of Indigenous Peoples* (Justice Canada, 2021a).

8.2.3 Increased attention to racism and violence experienced by women

Increased attention to violence experienced by women has underpinned new ways of designing FASD interventions, shifting toward holistic, trauma and violence informed and strengths-based supports and services (Petrenko & Kautz-Turnbull, 2021) that include harm reduction approaches and shift away from blame-driven interventions (see Chapter 7).

The Missing and Murdered Indigenous Women and Girls Report (Government of Canada, 2019e) raised awareness of structural racism intersecting with patriarchy and misogyny, lending strength to FASD approaches grounded in Women's Determinants of Health (Network Action Team, 2022) and Indigenous Women's Determinants of Health (CanFASD, 2022). These women-centred approaches are of special importance, as evidence of on-going violence experienced by women continues to emerge (Canadian Women's Foundation, 2023).

8.2.4 Strengthened disability policies

National disability policy (Canada Disability Inclusion Action Plan; Government of Canada, 2022b) aligned with the UN Convention of the Rights of Person with Disabilities (Government of Canada, 2010) has been strengthened, and disability communities with shared policy interests have organized and increased their advocacy efforts. FASD is beginning to be recognized along with other neurodevelopmental disorders as a form of neurodiversity. There are tensions, however, over the space afforded to FASD in public policy and resource allocation related to the pervasive stigmatisation of FASD. Throughout this assessment, numerous ways FASD fits poorly within current more general disability policy and services have been identified, along with suggestions from engagement participants to change models to accommodate

FASD (for example, the issue of using IQ scores as eligibility thresholds for disability supports and services: see Chapter 7). This growing trend toward a neurodiversity focus has also been accompanied by increased understanding of shared comorbidities of FASD and other neurodevelopmental disorders (Cook et al., 2016; Weyrauch et al., 2017; Popova, Lange, Shield, et al., 2016; Reid, Kent et al., 2023).

8.2.5 Expectations for more inclusive approaches

Increased attention to the importance of including the voices of those with lived experience in the development and deployment of interventions in all areas of healthcare, is now integrated into accreditation systems (Health Standards Organization and Accreditation Canada, 2024) and mainstreamed into research funding (Canadian Institutes of Health Research, 2016; Bird et al., 2020). The centering of lived experience fits naturally with the *Nothing About Us Without Us* call from the disability justice movement (Khedr & Etmanski, 2021). In FASD, research and needs assessment activities led by people with FASD about people with FASD have started to appear (for example, Himmelreich et al., 2020; Hargrove et al., 2024).

8.3 Barriers and challenges to the implementation of the 2003 Framework

As required by the federal Policy on Results and the *Financial Administration Act* (Government of Canada, 2016), PHAC's FASD program has undergone routine evaluation three times. In addition, an evaluation of knowledge mobilisation outcomes was conducted in 2011 (Government of Canada, Evaluation Directorate, 2014). These successive evaluations, while focused on PHAC's role and not the Framework implementation as whole, provide valuable insights.

The survey conducted as part of the engagement process for this assessment specifically asked about barriers and challenges to the implementation of the Framework and respondents (94 organisations) articulated an overarching view that there have been positive developments in addressing FASD, but progress has been patchy and inconsistent. Moreover, the problem of the lack of sufficient prevalence information identified in the Framework remains, so it is not possible to gauge success of efforts to reduce the prevalence and impact of FASD. Findings from the additional engagement processes support this observation, indicating that there is currently a generalized sense of inertia regarding progress on FASD across the country.

The main barriers and challenges to implementation of the Framework and achievement of its five goals are summarised below.

8.3.1 Lack of implementation strategy

The 2003 Framework was not accompanied by a formal implementation strategy, as it intended to offer “a focus for collaborative action into the future”, without being “restrictive or directive.“ It is thus important to recognize that it was not intended either as a Strategy nor Action Plan, but rather as an orienting tool for action plans that would follow.

This was recognized in the Framework as one of its future objectives: Developing action plans for prevention, support and services at the community, provincial/territorial and national/federal levels. Several provinces and territories have developed FASD strategies or action plans, outlining their priorities and commitments in the many areas of FASD programming that fall within their jurisdiction, including prevention, assessment and diagnosis, interventions and supports.

The evaluation of the 2008/09-2012/13 period found that while the Framework suggested action measures at all levels, these measures were “broad, loose, non-directive and full of ideas” (online document cited in Government of Canada, Evaluation Directorate, 2014).

Engagement participants stressed the uneven and uncoordinated evolution of action taken to address FASD, the lack of articulated connection to health and social services delivery by most provinces and territories, and the gaps in Indigenous health and social services.

8.3.2 Public awareness

Most respondents who completed the engagement survey for this assessment were aware of the 2003 Framework. While the engagement findings suggested that public and policy attention to FASD has remained relatively flat since 2003, the evidence review found that public awareness of FASD has increased in the last 20 years (Environics Research Group, 2007; Choate et al., 2019). However, awareness campaigns may have contributed to stigmatization (Bell et al., 2016), and understanding of the complexity and diversity of FASD presentations and causal factors is still suboptimal (Frameworks Institute, 2017; Choate & Badry, 2019).

Financial interests in alcohol and Canada’s pervasive drinking culture counter efforts to increase FASD awareness. Chapter 5 detailed Canada’s low level of integration of evidence-based, health promoting alcohol policies, and the challenges of implementing effective alcohol-related FASD prevention programming in the context of a prevalent drinking culture, industry pressures, and governments’ taxation interests (University of Victoria, 2024). This is of special concern given the exacerbation of risk that alcohol marketing can create for youth and for those with neurocognitive developmental disabilities (Babor et al., 2017).

8.3.3 Limited capacity

A challenge identified in the 2003 Framework was: Identifying, securing and integrating funding from a variety of sources to achieve the predictable and sustained resources needed for effective programs to prevent FASD and improve quality of life for those with the disorder.

PHAC's FASD National Strategic Projects 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. This amount has not changed since program inception in 1999. The program evaluation for 2017- 2022 showed that FASD program funds were underspent by about 20% across those years (Government of Canada, 2023b).

As documented in Chapter 6, the insufficient and perhaps declining diagnostic capacity in Canada (Dugas et al., 2022; Popova et al., 2024; Clarren et al., 2018; Popova et al. 2021) is contributing to the ongoing situation in which the vast majority of cases are undiagnosed (Popova et al., 2024). There have been some calls to reconsider the current approach to FASD diagnosis (Burd & Popova, 2019). According to engagement findings, this continuing lack of access is leading to discussions of alternative approaches. For instance, one option mentioned is the development of complex neurodevelopmental disorder teams with a broader focus instead of multi-disciplinary teams focused exclusively on FASD assessment. Specially trained nurse practitioners might play a central role in these teams. These approaches are put forward to maintain diagnostic integrity while improving access to FASD services especially in remote and rural areas.

While there are effective champions in some domains (for example, CanFASD in policy-relevant research) and regions (e.g., regional networks such as FASD ONE in Ontario), much of the onus for advocacy remains with volunteers among people with FASD and their parents and caregivers, who are already faced with many challenges.

Pockets of excellent and potentially useful advances have been developed, but without reliable operational resources or strategies to ensure they are made fully available and their uptake supported, these efforts cannot be spread or sustained. This issue is not unique to FASD: "…Canada is a country of perpetual pilot projects. We seldom move proven projects into stable, funded programs, and we rarely transfer the outcomes of pilot projects across jurisdictions" (Bégin et al., 2009).

Part of this challenge lies in the jurisdictional complexities: PHAC's National Strategic Projects Fund may develop and pilot initiatives, but scaled-up implementation and sustained funding are generally under provincial and territorial jurisdiction, suggesting a need for a more integrated planning cycle. The 2023 FASD Program evaluation documented interest in a dynamic and collaborative strategic planning approach (Public Health Agency of Canada, 2023a).

8.3.4 Lack of concrete measures, evaluation and accountability

As noted earlier in this chapter, the intention of the Framework was to inspire and encourage all jurisdictions and sectors to develop action plans with measurable objectives that could be aligned with the broad overarching goals. Engagement participants, however, still indicated there would have been value in:

> *Greater structure in accountability and oversight to ensure the framework is being implemented.*

They were supportive of the role of provincial and territorial strategies or action plans to complement and dovetail with a federal approach — but concerned by the variability among jurisdictions in their response and their capacities. Alberta's 10-year FASD program included regular, published evaluations (Government of Alberta, 2017b).

8.3.5 Intersectoral and jurisdictional complexities

The complexity of FASD as a public health and social issue, with intersecting challenges across prevention, intervention and supports, and posing challenges throughout the lifespan of people with FASD, requires engagement of many partners, across and within jurisdictions, social sectors, and policy levers. The Framework calls for "widening the circle of interest in and commitment to preventing FASD and supporting those affected by it" and identifies a very broad range of intended audiences and hence groups whose work could be coordinated. These are frontline workers and program or policy developers working at the local, provincial/territorial, national or federal level in the following fields: Indigenous issues; child and family welfare, community development, corrections, disability issues, education, employment, ethno-cultural issues, health education, homelessness, justice, medicine, policing, and poverty (Public Health Agency of Canada, 2003, p. 2).

This requirement for collaboration contributes to the complexities of developing and sustaining momentum. The Framework recognized that while necessary, a challenge is forging and strengthening partnerships within communities and across the country to share resources, expertise, experience and ideas across all sectors. This challenge is amplified by the tension between provincial and territorial autonomy and the interest in pan-Canadian approaches or standards supported by all. A pertinent example here is the CanFASD network, which is very active, but has incomplete coverage with eight of 13 provinces and territories enrolled (CanFASD, n.d.-a).

The need for more effective coordination within PHAC and among key partners across sectors and jurisdictions was identified in the 2023 evaluation report, which noted the absence of a national approach that: defines the roles and responsibilities of all FASD key partners to help coordinate efforts; ensures consistency across jurisdictions for on and off-reserve Indigenous services delivery; and connects directly to the broader substance use harm reduction and social determinants of health approaches (Government of Canada, 2023b).

Engagement participants suggested that implementation of the 2003 Framework could have been more effective with stronger leadership at both federal and provincial/territorial levels: to raise concern/awareness, to serve as conveners and coordinators across the multiple involved governments, service providers and community sectors, and to promote and fund necessary activity.

8.4 Considerations for moving forward on FASD

Looking back also stimulates looking forward: examination of the implementation of the 2003 Framework naturally engendered discussion of ways forward for addressing FASD across Canada.

8.4.1 Perspectives on a national FASD role

The engagement process consistently found support for the concept of pan-Canadian and ideally federal government leadership and coordination on FASD policy. The main advantages of such a role are seen to be:

- Enhanced prominence given to FASD by formal federal government action, driving momentum for collaborative action on a complex intersectoral, interjurisdictional issue;
- A solid unifying structure around which the many key parties and sectors that need to be involved can rally;
- Greater consistency in FASD efforts across country, leading toward more equitable outcomes/supports for all of those with FASD and those who support them, across their lifespans;
- Clear channels to ensure fluidity and efficiency of information-sharing, collaboration and expectations across the country; this would be especially beneficial for jurisdictions with fewer resources;
- The potential to support further development and implementation of Canadian practice guidelines that can influence policy across the country via standards of care;
- Strategic direction and funding to address gaps in the evidence base for policy recognizing the importance of collaborating with provinces and territories as much of FASD policy implementation responsibility lies within their jurisdiction.

Support for a national role notwithstanding, there was concern expressed by some that diagnosis-specific frameworks and policies create an environment of competition between disability communities for resources. Some suggested that an overarching framework on neurodiversity and disabilities, including FASD, could increase attention, effort and investment overall. Others suggested an FASD-specific framework would complement the recently released *Framework for Autism in Canada* (Government of Canada, 2024g). FASD-specific frameworks and policies would be able to most directly address some of the aspects unique to FASD among neurodevelopmental disorders, such as intersections with the TRC, the legacy of colonial harms and persistent, pervasive stigmatization.

With respect to Indigenous considerations in relation to a national leadership or coordinating role for FASD, advantages are seen in ensuring connection with the federal responsibility for on-reserve delivery of healthcare and healthy environments, but also to provide interfaces with Canada-wide policy as Indigenous communities begin to provide social service delivery for their communities along with provincial and territorial services. A coordinated approach nationally could also facilitate the necessary intersectoral collaborations between Indigenous services in health and education and justice, helping to improve access to diagnosis and to address gaps and disparities in provincial health systems.

8.4.2 Perspectives on provincial/territorial FASD strategies

Provincial and territorial FASD strategies can facilitate collaboration across government systems, including health, education, justice, and social development, as well as with service providers, community groups, and local governments. FASD strategies at the provincial and territorial level are thus critical to address the siloed service delivery addressed in Chapter 7, and to develop and implement holistic, wraparound FASD programming integrating client-centred provincially and territorially delivered services in a single point of interface.

8.4.3 Shared accountability and ongoing improvement

The aspirational, flexible and inclusive nature of the 2003 *FASD: Framework for Action* is seen as having been appropriate for its time and context — an expression of emerging consensus on addressing a complex and important challenge. Engagement for this assessment found current support for a more structured approach that, guided by a collective intent for broad, measurable and significant impact, clearly assigns roles and responsibilities for specific areas and types of action and is accompanied by robust systems to assess performance for shared accountability and ongoing improvement.

A more structured approach to shared accountability in addressing FASD could include milestones and targets in a transparent reporting system. Australia's FASD Action Plan (Government of Australia, 2018a), with its concrete assignment of roles and responsibilities, governance structure, and monitoring and evaluation framework, also provides a model. Canadian federal examples of accountability processes include mechanisms for publicly reporting on progress through Parliament, such as the commitment made in the recently announced *Framework for Autism in Canada* (Government of Canada, 2024g) and the annual reports published since the release of the dementia strategy (Public Health Agency of Canada, 2019c). Moreover, Canada's commitments to the TRC Calls to Action (Truth and Reconciliation Commission, 2015), the UN Convention on the Rights of Persons with Disabilities (United Nations, n.d.) and the UN Declaration on the Rights of Indigenous Peoples (Justice Canada, 2021a), all of which intersect deeply with FASD, include public accountability.

8.4.4 Ensuring adequate resources for success

A broad range of engagement participants identified the importance of adequate resources to move forward on FASD. Long-term sustainable funding and research is one of the eight tenets for enacting TRC Call to Action 33 (Wolfson, Poole et al., 2019). Inadequate resourcing is seen as having deleterious effects over and above the lack of support to those affected by FASD, including creating harmful trade-offs and ethical tensions between the various needs for diagnosis, interventions and supports. There is also a risk of creating and exacerbating tension and conflict among disability communities in the context of limited resources for all.

This question of resource adequacy was raised in the evaluation of PHAC's 2008-09 - 2013-14 FASD program: the "financial resources that were allocated to the Initiative ($3.3 million) were modest for the breadth of activities to be addressed as outlined in the program authorities" (Government of Canada, Evaluation Directorate, 2014). It is worth noting existing estimates of the annual costs of FASD across various systems of $1.8 billion (range $1.3 - $2.3 billion; Popova, Lange, Burd, & Rehm, 2015b; Popova, Lange, Burd, et al., 2016). As engagement participants noted, it is important to recognize the cost-effectiveness of FASD prevention, supports and services, as these earlier interventions can avoid the need for more costly investments that may be required in their absence, for example, in health and mental health care, justice system expenses and social services.

8.4.5 Applying implementation science and collective impact approaches

The field of implementation science has developed rapidly since the 2003 *FASD: Framework for Action* was published. Its main aims are to ensure that evidence-based interventions are taken up, integrated and maintained. While initially focused on implementation of specific clinical practices, it has now expanded to address implementation challenges of larger scale health services (Damschroder et al., 2009) and population health initiatives (Lobb & Golditz, 2013). In the FASD sphere, an implementation science perspective has been applied to the issue of FASD screening (McLachlan et al., 2024; McLachlan et al., 2022) and lifespan intervention (Petrenko & Alto, 2017; Petrenko & Kautz-Turnbull, 2021).

The various available implementation science frameworks share a focus on three dimensions of implementation (Damschroder et al., 2009):

- The nature of the evidence-based intervention, including the strength of the evidence, its core components and adaptable periphery, and its complexity, trialability and adaptability. The intervention in this case is a framework, which can be defined as "a professional consensus within a particular scientific community. It stands for the entire constellation of beliefs, values, and techniques shared by members of that community" (Damschroder et al., 2009). In the FASD context, McLachlan et al. (2024; 2022) underscored the importance of defined and operationalized intended outcomes and goals of the initiative to be implemented, an aspect of the PHAC FASD program that was identified as needing development (Government of Canada, Evaluation Directorate, 2014). Furthermore, participation by individuals with FASD, their families and care providers to ensure identified goals and outcomes are shared was also identified as key to successful implementation (McLachlan et al., 2022).
- Successful implementation depends upon the implementation environment. This includes organisational readiness, intervention champions, the internal structural, political, and cultural contexts of the organisation through which the implementation process will proceed and the external economic, political, and social contexts within which the implementing organization resides. In the case of the *FASD: Framework for Action*, the implementation context of federal/provincial/territorial distribution of roles and responsibilities in public health and health services, as detailed in Chapter 2, created a highly complex and evolving implementation environment.
- Active change processes aimed to achieve individual and organizational level uptake, such as training and professional development can also facilitate implementation. In the FASD context, as noted in Chapters 5, 6 and 7, various resources, guides and training programs have been initiated, but not in a coordinated fashion across the country and there is a question about motivation for uptake. McLachlan et et al. (2022) mention the need for increasing broader FASD awareness and response capacity at the system level; and advocating for continued policy reform and resources to enhance effective community-based support (2021).

Also, of interest given the Framework's intentions is the extent to which it embodied the conditions necessary to achieve "collective impact," lasting solutions to social problems on a large scale (Kania & Kramer, 2011; Tamarack Institute, 2017). These necessary conditions are:

- A common agenda, including shared issue definition and ultimate goals. As an expression of national consensus, the Framework met this condition in 2003;
- Shared measurement to ensure mutual accountability. The element is absent from the Framework and is also generally in need of strengthening for PHAC's FASD role, according to the evaluations (Government of Canada, Evaluation Directorate, 2014; Government of Canada, 2023b). This was also noted as a challenge by engagement participants;
- Mutually reinforcing actions, with clear division and assignment of responsibility. The 2023 evaluation report noted: "There is no national approach or strategy that defines the roles and responsibilities of all FASD key partners and stakeholders to help coordinate efforts (Government of Canada, 2023b, p.16);
- Continuous communication among stakeholders, to foster trust-based coordination;
- A backbone organization. The authors note that the expectation that collaboration can occur without a supporting infrastructure is one of the most frequent reasons why it fails (Kania & Kramer, 2011; Tamarack Institute, 2017).

8.5 Key enablers

8.5.1 Filling research gaps

Across all the domains addressed in this assessment, considerable depth was found in existing research, with great expansion in some areas in the last decade. At the same time, many research needs were identified, along with opportunities to ensure information sharing to gain maximum benefit from research. Some overarching observations can be made about these needs and opportunities.

First, the patchiness and inconsistency observed across jurisdictions - provinces, territories, regions, communities - in prevention and intervention programming reflects both lack of awareness of existing evidence-based strategies, and lack of systems and resources for adapting and scaling pilot projects for widespread adoption. Chapter 5 identifies several forms of effective preventive intervention at multiple levels, from professional encounters to classrooms to wraparound service integration to broad alcohol-labelling policy and Chapter 7 identifies effective interventions and supports in multiple sectors, systems and age ranges. However, most jurisdictions have been unable to call upon and implement the broad range evidence-based interventions, and those that have come closer lack effective mechanisms in which to share their successes.

Concerns were raised in the research literature about the limitations of existing research on some key questions for FASD policy, and in particular of studies assessing the efficacy of prevention and early intervention strategies, prevalence data, and lifespan perspectives on FASD. Evidence in many areas is still inadequate to enable systematic reviews and meta-analyses. Despite the existence of strong research and evaluation guidelines relevant to FASD (British Columbia Centre of Excellence for Women's Health, n.d.; Bell et al., 2019; Hubberstey et al., 2015; Interagency Advisory Panel on Research Ethics, 2022; First Nations Information Governance Centre, 2020; Assembly of First Nations, 2018c; Inuit Tapiriit Kanatami; 2018), most community-developed resources found and cited throughout the assessment had undergone no or only superficial evaluation: with some noteworthy exceptions (e.g., Pei et al., 2017), our scan found few publicly available formal evaluation reports. Opportunities to generate and accelerate evidence-based policy change could come from enhanced financial and capacity development support for FASD research and evaluation, along with stronger central signaling of the importance of rigorous evidence-making.

The lack of robust national and jurisdiction-level prevalence estimates of PAE and FASD in the general and subpopulations is of general concern. The lack of data means that assessment of progress in reducing FASD prevalence is still limited, if not impossible. This is a critical issue now because, as more modern provincial and territorial FASD strategies are adopted, their evidence-base about what has worked and what hasn't could be substantially strengthened.

Changes in perspective on FASD as a societal issue highlight the importance of building on the current understanding of strengths and resilience of people with FASD and their caregivers (Flannigan, Wrath et al., 2021, Petrenko & Kautz-Turnbull, 2021). As people with FASD age, there is a concomitant opportunity to better understand FASD from a lifespan perspective. With this focus on the life course, as in all areas of FASD research and evaluation, it is essential that people with lived experience play meaningful roles in research: question development and prioritization, design and methodology, analysis and interpretation, and knowledge mobilisation.

Federal research funding agencies, in particular, the Canadian Institute of Health Research (CIHR) and the Social Sciences and Humanities Research Council (SSHR) support research and training in their respective disciplines and sometimes support targeted calls for research in particular areas. Federal funding through the Network of Centres of Excellence program supported FASD-related research through substantial support over the years to the Kids Brain Health Network (formerly known as NeuroDevNet), as noted in Chapter 2.

Research consortia like the CanFASD Research Network (CanFASD, n.d.-a) have been especially active and influential contributors to both policy advocacy and FASD research in Canada, and university-based centres also have an important role to support research. For example, integration of disparate health system data sources to follow people with FASD through their encounters with the health system has been demonstrated by the McMaster-based MOM-

BABY cohort and a linked administrative database that includes FASD cases, managed by the Manitoba Population Research Data Repository.

8.5.2 Interjurisdictional information-sharing

Building on the issues raised above, enhanced promotion of interjurisdictional information-sharing would be welcomed by the FASD community, as expressed in our engagement sessions. Part of the sense of inertia and loss of momentum is due to lack of awareness of what is being worked on and accomplished elsewhere. As a survey respondent stated:

> *It can often feel like we are starting from scratch after a decade. Some amazing work has been done in pockets of the country.*

The lack of infrastructure and supports for information-sharing has been addressed indirectly above, in the discussion of interest in greater opportunities for collaboration and coordination across the country. This issue was raised specifically in the 2014 evaluation of PHAC's FASD program, which found that although PHAC funding as well as regional activities had produced many knowledge products, there was limited and anecdotal evidence of their uptake and use (Government of Canada, Evaluation Directorate, 2014). The 2023 evaluation came to a similar conclusion, stating that it would be desirable to have more evidence that knowledge and information were being translated into uptake and use (Government of Canada, 2023b).

A facilitative mechanism for information-sharing mentioned in the 2014 evaluation of PHAC's FASD program is the PHAC-chaired Federal Interdepartmental Working Group on FASD, established to provide coordinated federal leadership on FASD. This group includes representatives from Health Canada, Employment and Social Development Canada, Status of Women Canada, Department of Justice, Public Safety Canada, and the former Aboriginal Affairs and Northern Development Canada. The 2014 Evaluation Report stated that this Group had ties to both CanFASD and the Kid's Brain Health Network, as well as some provincial FASD groups and key NGOs (Government of Canada, Evaluation Directorate, 2014). This Group continues to meet, and hosted an information sharing webinar for the funded recipients to share outcomes from their projects in September 2024.

Information-sharing is also a resource utilization issue. Engagement participants cautioned against the inefficiencies of the proliferation of local and community-based initiatives working on public education, prevention and supports, in the absence of pathways for wider sharing and resources and processes for scaling up. It was suggested that cooperation, collaboration and networking of all these initiatives is needed: echoing the lack of effective intersectoral and cross-jurisdictional coordination identified among the implementation barriers in the previous section.

8.6 Analysis of current training, education, and guidance needs and opportunities

Training and professional development for health, allied health, social service workers, educators, justice professionals and employers has been a core component of several provincial and territorial FASD strategies (e.g., Government of British Columbia, 2008; Government of Yukon, 2006) as well as of non-governmental organizations such as FASD Justice and FASD/TSAF Ontario, which are two examples among many others cited in the previous chapters. These organizations have often developed training in various formats as well as toolkits and guidance; however, information about the extent to which they have been implemented and shown to be effective in improving practice is generally not available.

Evidence review and scans throughout this assessment as well as engagement sessions identified several types of training, education and guidance needs. These needs are summarized below. Throughout the assessment, engagement participants emphasized the value of having people with FASD involved in the design and delivery of training and support resources.

8.6.1 Professional core training

As mentioned in Chapter 2, this assessment searched for FASD training provided in the core curricula of relevant medical specialties and health professions' accrediting organizations, finding very little publicly available information. Engagement participants identified a need for the core curricula of medical, nursing, and allied health programs to include a foundational understanding of PAE and the multi-faceted nature FASD, along with training to translate this knowledge into practice. Engagement sessions also identified interest in the creation of educational pathways for specialization in FASD, including training profiles for community-based, FASD-trained Nurse Practitioners. These programs would include multidisciplinary training as well as extensive experience in FASD-specific clinical environments.

In the literature, needs were identified to update core curricula to include FASD within professional medical and allied health education, including general FASD knowledge and the full spectrum of FASD symptoms, characteristics strengths and challenges (Wilson et al., 2024; Lesinskienė et al., 2023). Specific opportunities were mentioned in FASD training of nurses (Zoorob et al, 2014) and the range of professionals involved during pregnancy, delivery, and postpartum: community primary care, acute care, and post-partum public health (Mitchell-Foster et al., 2021). Calls were made for more widespread training in FASD assessment and diagnosis as part of core professional training of those professions involved (Wilson et al., 2024; Reid et al., 2015), including in specialized diagnostic strategies adapted for forensic settings (Burd et al., 2021).

8.6.2 Ongoing professional development

Target groups and their needs

FASD-related ongoing professional development and support were also often identified in the literature and by engagement participants. Targeted for this type of support would be health, mental health and allied health (McCormack et al., 2022), and social services (Richards et al., 2023) professionals who are not FASD specialists but who may be working with people with FASD, as well as rehabilitation professionals (Quan et al. 2019; Bagley et al., 2022). Social services workers would include those in the child welfare system (Richards et al., 2023; Marcellus & Badry, 2021).

Ongoing professional development needs, in terms of training, guidance, resources or tools for those working with people with FASD or their families and caregivers, were identified in two overarching areas:

- Culturally and trauma-informed intervention and care, which could include education about the Indigenous determinants of health and the history and impacts of colonialism, as well as anti-racism and anti-stigmatization training, trauma-informed care and training in cultural humility (Richards et al., 2023; Lyall et al. 2023). Such training and guidance should also address the relationship between colonial harms and substance use (Mitchell-Foster et al., 2021).
- FASD characteristics and the strengths and needs of children, youth and adults with FASD, to inform service delivery and reduce bias (Rutman, 2016; Richards et al., 2023). For practitioners working with people with FASD in therapeutic or support roles, needs for training and guidance, as well as resource materials, were noted in the areas of attention and self-regulation, executive, psychological, behavioral social and adaptive functioning; nutrition and medication (Petrenko & Alto, 2017; Tan-MacNeill et al., 2021); strengths-based, FASD-informed approaches (Rutman, 2016; Lyall et al., 2023), and for adults, support for life skills to support managing finances, housing and employment (McLachlan, Flannigan, et al., 2020; Quan et al., 2019). Such training could also be adapted for parents and caregivers (Marcellus & Badry, 2021; Tan-MacNeill et al., 2021; McLachlan, Flannigan, et al., 2020; Ordenewitz et al., 2021).

Additional training, guidance and support needs were noted for professionals in the legal system, including police, corrections officers, court staff, lawyers, public defenders, judges, probation and parole officers. In a systematic review, Flannigan, Pei et al. (2018) noted that while there was some level of awareness of FASD among these professionals, more evidence-based training and practice guidelines are needed to assist their work. McCormack et al. (2022), in a survey which included legal system professionals, reached similar conclusions. Developing realistic expectations for individuals with FASD in the justice system has been named as a need (Passmore et al., 2021; Stewart, 2015), as have bench guides (US Department of Health & Human Services, 2022a). Burd et al. (2021) and Russell et (2023) indicated legal professionals should have guidance on how FASD and ADHD differ and intersect, and on implications for the forensic context. Forensic mental health professionals additionally have needs for evidence-based screening tools and clinical guidelines for best practices including in risk management (McLachlan, Mullally, et al., 2020).

Providers of healthcare during and after pregnancy, including nurses, nurse practitioners, family physicians, obstetricians, midwives, and public health service providers could be targeted for professional development related to the SOGC Guidelines (Graves et al., 2020; Sword et al., 2020). Supports for implementing standardised PAE screening tools and non-threatening and non-stigmatizing PAE questioning guides (Reid, Kent et al., 2023; Richards et al., 2023; Mitchell-Foster et al., 2021) and brief intervention (Bazzo et al., 2015; Graves et al., 2020) could benefit these groups.

Education system personnel, such as teachers and special education support workers, could receive information and training on detection and timely referral for FASD assessment and on how to understand FASD diagnosis and its educational implications (Clark et al., 2014; Pei et al., 2013; Reid, White et al., 2019; Millar et al., 2017; Bill 108 Ontario, 2023). Early childhood educators and daycare staff could also be included (Bill 108 Ontario, 2023).

Training and guidance about FASD throughout the lifespan and about expectations for adults with FASD is needed for employers (Gault et al., 2023) and rehabilitation professionals working with adults with FASD (Quan et al., 2019) as is supportive workforce policy guidance (Mclachlan, Flannigan, et al., 2020).

Because of the multidisciplinary nature of FASD interventions such as wraparound services, another important training need for practitioners is for interprofessional training (Tyler et al., 2019; DiClemente et al., 2021) as well as training or guidance on professional boundaries (Tyler et al., 2019; Wilson et al., 2024).

Professional development modalities

For all of these areas and target audiences, current, accurate and comprehensive training, guidance, and resource material that includes the perspectives and strengths of people with FASD were identified as important (Bagley et al., 2022).

Two main types of preferred modalities emerged from the literature on professional development needs:

- In-depth workshops and webinars/seminars, either in-person or online (Green et al., 2021; Bagley et al. 2022; Rutman, 2016), are recommended to increase awareness, knowledge and understanding. When appropriate, these sessions should be accredited through professional bodies (McLachlan, Mullally, et al., 2020). Given the dispersion of the FASD workforce across Canada and challenges that accessing professional development might pose for professionals in rural, northern or remote contexts, Bagley et al. (2022) recommend that FASD professional development could be provided through no-cost, widely accessible, high quality, context-adapted online channels. Petrenko & Kautz-Turnbull (2021) similarly note the potential of digital services providers in strengths-focused FASD training.

- Practice development opportunities to further understanding of FASD and FASD-informed practice could be implemented through face-to-face and/or web-based professional fora, including communities of practice and reflective practice discussions with colleagues, supervisors and community partners (Rutman 2016; Quan et al., 2019).

Social media were only mentioned as delivery methods for material on the SOGC Guidelines (Green et al., 2021).

8.6.3 Supporting training uptake

Engagement participants highlighted that while a variety of training, education and guidance resources exist, funding is often needed to maintain and update these resources, and the target audiences could benefit from increased awareness of their existence and utility to encourage uptake — consistent with an implementation science approach. There could be opportunities to consolidate, update and share these resources across jurisdictions for greater reach and efficiency.

8.7 Conclusion

Since the publication of the 2003 *FASD: Framework for Action,* the Canadian landscape has evolved on multiple fronts. There is greater understanding of the contribution of the broader social determinants of health to the risk of PAE and FASD. The process of reconciliation has highlighted the continuing impacts of colonialism and racism in health outcomes for Indigenous Peoples and communities, and the Truth and Reconciliation Commission specifically identified the importance of addressing FASD. Disability policies have been strengthened, and approaches to research, services, and supports are expected to be more inclusive, holistic, trauma-informed, and strengths-based.

In addition, there have been many important steps forward since the 2003 Framework. Advances have been made with the development of Canadian diagnostic guidelines, recommendations for systematic PAE screening, epidemiological research and the development of models of prevention. Several provinces have developed FASD-specific strategies of their own.

However, many of the problems identified in 2003 remain today. Comprehensive prevalence data is lacking, diagnostic capacity is inadequate and most people with FASD remain undiagnosed. Despite promising pilot programs for FASD-specific interventions and supports, many programs struggle to find sustainable long-term funding that would encourage the long-term community investment required for maximal impact. This brings high and ongoing costs to people with FASD, to their caregivers and families, and to Canada's health, education, social welfare, justice, and economic systems. Despite significant commitment and mobilization by dedicated experts and advocates, substantial unmet needs persist.

This assessment identified many challenges, but also many opportunities to strengthen Canada's approach to addressing FASD. For example, mechanisms to promote interjurisdictional information-sharing, and research to fill key information gaps could be pursued. Implementation science approaches that look at how to translate existing knowledge to practice would also be helpful. In addition, renewed effort could be made to ensure that high quality and up to date training, education and guidance materials are both available and their use encouraged across all sectors involved in FASD prevention and response. A variety of resources exist across multiple professions, but their uptake is uneven or unknown. Consolidating, updating, and sharing these 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.

National leadership is helpful in several key ways such as 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. Jurisdictional divisions of power mean that progress will require all levels of government to collaborate and be committed to action. Clear objectives, roles and accountability mechanisms are key to maintaining momentum.

Appendix A: Assessment Key Findings

Prevalence and Data Collection and Management

Key Findings: Importance of prevalence data

Accurate and comprehensive prevalence data on FASD informs decision-making and evaluation of the effectiveness of public health policy, resource allocation and interventions to prevent PAE and to support people with FASD and their families.

Key Findings: Challenges associated with case identification

Accurate and comprehensive FASD prevalence data remains challenging to obtain due to diagnostic complexity, methodological limitations and variations, and under-diagnosis.

The challenges with FASD case identification in Canada lead to underestimation of the true prevalence. These challenges include:

- lack of access to diagnostic assessments,
- avoidance due to stigma,
- failure to refer potential cases for diagnostic assessment,
- difficulty in gathering evidence of PAE, and
- preference for alternative diagnoses that lead to better supports.

Despite these challenges, some epidemiological studies do exist, but there is a need for improved data collection and more robust epidemiological studies in both general and specific subpopulations of Canada..

Key Findings: Challenges related to data collection systems in Canada

At present Canada lacks a comprehensive, coordinated surveillance system to collect data on FASD and PAE. Provinces and territories vary in relation to their collection of information on diagnosed cases of FASD, and this information is not always comprehensive, reliable and suitable for use in a range of clinical, research and other contexts.

As for data collection within administrative databases (e.g. education and healthcare), there is a lack of FASD-specific codes or categories. Where general codes that include FASD along with other conditions are used, it is difficult to use these systems to accurately determine FASD prevalence. Establishing FASD-specific codes could enhance the utility of these systems, if they are reliably used. However, this would exclude many individuals who are unable to obtain a formal diagnosis.

Key Findings: Prevalence estimates

The estimated prevalence of FASD in the Canadian general population is affected by the method used, which may include surveys, passive surveillance and active case ascertainment. It is believed that Canadian estimates generally underestimate prevalence. Active case ascertainment is the most robust and accurate way to estimate prevalence, but it is resource-intensive and so is applied to studies of small sub-populations, which are not necessarily representative of the general population. A Canadian study using active case ascertainment estimated FASD prevalence in an urban population of children to be between about 1.8 and 2.9%.

Estimated prevalence of FASD in specific subpopulations in Canada is up to 16 times higher than the general population. These higher rates are associated with historical and ongoing social determinants of health, including poverty, nutrition, limited access to healthcare, current and intergenerational trauma, colonialism. It is possible that a bias toward FASD referral and diagnosis may contribute to the higher apparent prevalence rates for certain groups.

Prevalence data on PAE are important for understanding the scope and pattern of alcohol consumption in pregnancy, a direct cause of FASD, as well as for developing policies to prevent PAE and to mitigate its harms. And yet, there is limited rigorous data with estimates of the prevalence of prenatal alcohol consumption at any level in the general population varying from 2.2%, based on recent self-reported Community Health Survey data to 10%, based on a meta-analysis that examined data from a number of earlier prevalence research studies. This meta-analysis further estimated that 3.3% of pregnant women (out of 10%) in the general population had a heavy episodic consumption of alcohol (four or more standard drinks on a single occasion), with higher rates in some groups.

Key Findings: Possible improvements to case identification, data collection and management

Increased training and education on FASD could help to ensure that more potential cases are identified and referred for assessment as many personnel in the health, education, justice, and child welfare systems have limited awareness and knowledge about FASD.

Disaggregated data regarding PAE and FASD (e.g. by age, sex, gender, racial or ethnic group, geographic location) is helpful for understanding risk factors as well as ensuring supports are best directed where they are most needed. It is important to carefully design and interpret studies of prevalence in sub-populations, and to contextualize them, for example, by including data on the corresponding social determinants of health when communicating the results to avoid stigmatization of affected groups.

Data on the strengths and challenges associated with FASD are currently limited. Longitudinal outcome data provides a more comprehensive view of the most important predictors of favorable and unfavorable outcomes, including the possible impact of policies in the Canadian context.

The implementation of universal and comprehensive screening programs for PAE would help to identify more cases and improve the accuracy of prevalence data. Increased awareness of the importance of conducting this screening can occur through training of clinicians to build confidence and skills to screen effectively and address the fear of disclosure due to stigmatization of PAE and the fear of possible consequences, such as child apprehension.

A national data repository, to which all provinces and territories contribute consistent data, and which is suitable for the needs of the whole community, would be helpful to gather consistent pan-Canadian data and to facilitate coordinated and efficient policy. Mandatory 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. Given recent suggestions that it would be helpful to use the diagnosis of complex neurodevelopmental disorder (NDD), along with specific diagnoses like FASD where applicable, consideration of a broader national data repository that captures NDD, along with FASD and other applicable diagnoses, and information on pre- and post-natal adverse exposures, would improve understanding, bolster prevention efforts, and include a broader range of affected people.

Prevention

Key Findings: Raising awareness about FASD

Ongoing general public information campaigns about FASD may increase awareness, but more research is needed regarding its effect on PAE.

Multi-dimensional interventions targeting specific at-risk populations have demonstrated some success in reducing PAE.

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. While such interventions have been shown to reduce alcohol use and alcohol-related harms, research is needed to evaluate their effectiveness in preventing drinking during pregnancy or FASD.

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.

Key Findings: Approaches for women of child-bearing age

Systematic and universal screening for alcohol use by healthcare providers before conception and during pregnancy, and providing brief interventions and referrals for treatment as needed, offer an opportunity to increase awareness of FASD and prevent PAE.

Key Findings: Consistent prevention messages from healthcare providers

There is regional variability in the uptake of the Society of Obstetricians and Gynecologists of Canada Guidelines regarding screening for alcohol use during pregnancy. Many physicians in Canada do not ask about alcohol use and some continue to give mixed messages regarding alcohol use during pregnancy.

A comprehensive approach to physician education on screening for alcohol use and counseling patients to abstain from alcohol during pregnancy in a non-judgmental, and supportive manner would be beneficial, as would the recognition of screening for alcohol use as a standard aspect of professional practice.

Key Findings: Access to reproductive and mental health care and substance use treatment

Providing easy access to effective contraception is an important part of an overall strategy to prevent PAE. This approach is applicable to the general population and may be a particularly valuable option to make available to people who could become pregnant and who have a substance use disorder, along with other supports and treatment for their alcohol use. Longer-term options (e.g. patch or IUD) and emergency contraception are part of reproductive health, and help to reduce the risk of PAE occurring in the case of unknown and unintended pregnancies.

Timely access to mental health care and substance use treatment during pregnancy is an integral component of FASD prevention. People who are most at-risk, including those with FASD themselves, may also have the most difficulty accessing mental health care and treatment for substance use disorders. Longer-term treatment programs can be a particular challenge for parents as separation from their children for the duration of treatment is a barrier.

Key Findings: Holistic, wraparound supports to address prevention factors

Prevention of FASD includes effective supports to address the individual, social, cultural and environmental risk factors for risky alcohol use. Substance use disorders frequently reflect a complex mix of risk factors such as trauma, abuse, unmet mental health problems, and poverty. Effective prevention of FASD in these cases requires holistic, trauma informed, culturally safe wrap-around support that addresses risk factors. Wraparound or integrated service delivery, in which multiple services are delivered together in one site as opposed to being offered by multiple agencies in different locations, is more effective.

There are fewer programs to help women postpartum maintain or initiate healthy changes and to support the development of their children. Research on these programs is limited, but an encouraging model identified is the Parent-Child Assistance Program (PCAP).

Steps that would strengthen community capacity for prevention are adequate, predictable, and sustained funding of community organizations that deliver holistic wraparound support, strong partnerships between community organizations and government funding agencies, and good systems for quality assessment and accountability.

Key Findings: Alcohol policy

Supportive alcohol policy is recognized as a key part of FASD prevention. A recent general evaluation of current policies across Canada found significant room for improvement.

As demonstrated by Nordic countries, national alcohol policies using a multi-pronged approach can reduce alcohol consumption, and the health harms of alcohol. Policy approaches include controls on marketing and advertising, pricing and taxation, alcohol content, and restrictions on availability.

Assessment & Diagnosis

Key Findings: Diagnostic process in Canada

At present, efficient screening methods to identify cases at risk of PAE exist but are not used consistently or effectively. A number of screening tools for risk of FASD exist and have proven useful in specific subpopulations, but no one tool has emerged that is both efficient and effective. The development of screening tools for risk of FASD that are valid, reliable with high sensitivity and specificity, and suitable for widespread application is a key area for continuing research.

Greater sensitization and training of front-line professionals about FASD, especially those who may encounter individuals with heightened risk, could improve the identification of possible cases and referral for assessment.

Eligibility criteria for diagnosis varies by age, with few or no clinics accepting very young children or adults for assessment in some locations.

People with FASD report that diagnosis has been helpful for self-understanding, and reducing shame and self-blame. They also report that the diagnosis aids in seeking appropriate supports, interventions and accommodations, and in planning and managing their lives.

Key Findings: Diagnostic capacity

Access to diagnostic clinics is uneven across Canada – sparse in rural and remote Canada, non-existent in many regions, and with lengthy wait times in some locations.

FASD diagnosis in Canada at present is primarily performed by a relatively small number of specialized clinicians, teams, or clinics that cannot accommodate the many people with FASD.

Limited capacity contributes to FASD frequently not being considered or diagnosed. Evidence suggests the vast majority of individuals with FASD are undiagnosed or misdiagnosed.

Key Findings: Challenges and barriers to FASD assessment and diagnosis

Stigma operates as a barrier to assessment and diagnosis. It reduces access to information about PAE by reducing the likelihood that pregnant women disclose alcohol consumption. The absence of this information makes FASD diagnosis in their child more difficult. In addition, stigma reduces the uptake of diagnosis by parents, families and communities.

Lack of access to post-diagnostic supports and services also leads people to reject FASD diagnosis, and may result in them pursuing diagnoses that lead to better supports. Improving access to FASD-informed health services, especially post diagnostic supports, would help improve FASD diagnostic up-take.

The requirement for evidence of PAE for diagnosis in the absence of sentinel facial features operates as a significant barrier to FASD diagnosis. Universal screening for alcohol use in pregnancy, along with documentation of significant exposure in infant medical records would be helpful. Challenges to this include reluctance to disclose alcohol use due to fear of child welfare interventions as well as stigma.

Diagnostic capacity is inadequate to meet the needs of the population, and access is particularly difficult in rural and remote locations when long distances must be travelled to access diagnostic services. Capacity could be improved through recruitment and retention strategies that specifically include approaches to develop a workforce for FASD diagnostic services. For example, alternative models of service delivery, such as virtual and mobile clinics, and an increased role for nurse practitioners could improve access.

There are many adults in Canada with undiagnosed FASD. Diagnosis can offer a range of important benefits to adults, including reduced blame and self-blame, improved access to supports and accommodations, and valuable information about potential physical and mental health issues associated with FASD throughout the lifespan.

Improving access to adult diagnosis across all regions of Canada could help to ameliorate adverse outcomes associated with lack of diagnosis and support, and allow appropriate accommodations to be made in the community and the criminal justice system. Diagnosis and support also help to prevent future cases of FASD.

Adults face challenges in accessing diagnosis in many locations, and it may be harder to obtain necessary evidence of PAE due to the passage of time. Adults can be encouraged and supported to seek assessment by raising awareness about FASD, improving funding for adult assessment/diagnosis, supporting mechanisms for peer support, and developing platforms for adults with FASD to speak more broadly about their experiences.

Key Findings: Discussion of the Canadian Diagnostic Guidelines

There appears to be broad uptake of the Guidelines by specialized FASD clinics, but less information about use outside those clinics. Clinics vary in the assessments used to evaluate the diagnostic criteria. Regularly updating guidelines through a consultative process to reflect current research findings would support uptake and consistent application. Culturally sensitive and safe diagnostic practices would also support efficacy, trust and acceptance. A dissemination plan might help to address implementation issues and increase uptake of the Guidelines.

FASD diagnosis may sometimes be appropriate in young children, but it 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.

Early intervention prior to school age is important to reduce the harm of PAE when the developing brain is the most responsive to external stimulation and environmental experience. Provision of services based on functional assessments can improve timely access to services until FASD diagnosis is available or in circumstances when a diagnosis is not obtainable. Supporting parents and children with early concerns (e.g. confirmed PAE) allows professionals to start interventions sooner, and to refer for diagnostic assessment early to mitigate long waitlists.

The Canadian FASD Guidelines furnish a basis for consistent diagnosis, where assessment and diagnostic capacity exists; however, there are concerns and critiques that limit uptake. A debate has emerged over the use of FASD as the primary diagnostic category and the suggestion to shift toward using a broader diagnostic term of complex neurodevelopmental disorder, in conjunction with other diagnoses including FASD where those diagnostic criteria are met. Reasons in favour include capturing cases where evidence of PAE is unavailable, as well as addressing uncertainty about the relative contributions of the many potential causal factors present in a given case. Concerns with this proposed approach include the possibility that reduced prioritization of FASD as a sole or primary diagnosis might reduce the emphasis on PAE and undermine efforts to understand and prevent the condition.

Interventions and Supports

Key Findings: Cross-cutting issues

Interventions and supports that promote stability, structure and consistency are important for individuals with FASD.

IQ assessments can be useful in providing information about areas of strength as well as challenges. IQ cut-off scores used to determine eligibility for disability services and supports are used in some locations, and these can exclude individuals with FASD whose IQ exceeds the cut-off, but who still have significant functional challenges and problems with daily living.

Adaptive behavior assessments measure daily living skills in order to understand a person's specific needs for support. While helpful in many circumstances, formal tools or questionnaires can be difficult to access for the adult population. A trained support worker doing a careful assessment with an adult who has FASD may be the most effective approach.

Adults with FASD may struggle to navigate the systems for financial support and services, meaning they may be excluded, even if eligible, if they lack a supportive family member or other advocate to assist them.

The siloed operation of the various services and systems that a person with FASD and their family may encounter (e.g. healthcare, housing and income support, education and occupational training, child protection, justice) along with expectations to re-prove eligibility increases complexity from both the service provider and client perspectives.

A system "navigator" (e.g. key worker, mentor, coach) assigned to a child or youth with FASD and his or her family, or to an adult with FASD, is very helpful in offering practical and emotional support as well as help in accessing community resources, health and other social services.

Training regarding the unique complexities of FASD and its associated challenges would be helpful for professionals working with people with neurodevelopmental disabilities.

Key Findings: Early, continuing, and multifaceted interventions

Interventions and supports for individuals with FASD and their families can contribute to better outcomes and protect against adverse consequences associated with FASD.

Early interventions have the potential to mitigate the effect of PAE and reduce environmental risk. Family support and specific interventions for young children at risk of neurodevelopmental disorders can be offered prior to diagnosis and during this period of high neuroplasticity. Without interventions and support there is a risk of more severe difficulties emerging as children mature into school age and beyond, for example in social, behavioral and academic functioning.

People with FASD have elevated rates of challenges in multiple realms including activities of daily living, social relationships, employment, substance use, and the law. A reasonable goal for many people with FASD is interdependence, where they can draw on their families and support systems when needed. Without interventions and supports, these challenges can accumulate.

The transition from adolescence to adulthood can be a particularly difficult and risky period. People with FASD can be very vulnerable at this time, particularly youth lacking supportive networks. 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 with FASD transitioning out of the child welfare system may have less developed natural support networks and would especially benefit from longer term, targeted supports during the transition to adulthood that recognizes the slower pace with which this occurs.

There is very little attention to the challenges faced by aging adults with FASD, and support services are limited. The aging of caregivers who support adults with FASD is a source of anxiety and concern for people with FASD and their families.

Peer support and networking with others who have FASD can provide a valuable community and source of information for people with FASD.

Parents who themselves have FASD encounter significant challenges due to stigma and stereotypes in the child welfare and legal systems. More FASD-informed supports may enable them to succeed and to preserve their families.

Further work on how to adapt, scale and evaluate promising interventions for broader implementation would be beneficial.

Key Findings: Family and caregiver intervention and support

Family members and caregivers benefit from education and training to help them understand the impacts of FASD and how to support the development of life skills.

Supports for families and caregivers, such as opportunities for respite, peer networking opportunities, and broader social acceptance, understanding and inclusion, are key to family well-being. Respite supports assist with the demands and stress of caring for children with FASD. There is limited knowledge about other types of effective interventions to reduce family stress.

Key Findings: Education

Many children are diagnosed only after they reach school age, however, identifying and intervening to support children as early as possible is most beneficial. Children identified ‘at risk for FASD' because of known PAE, as described in the Guidelines, benefit from being followed, supported, and referred for diagnosis as soon as possible. Educators, including those involved in preschool programs, can play a critical role in supporting these children and in identifying others who may be similarly affected but not flagged at risk.

FASD-informed school-based supports, including a tiered approach that offers increasingly intensive interventions to students depending upon their strengths and needs, can best meet the diverse needs of students with a diagnosis, as well as those who do not yet have or cannot access a diagnosis of FASD.

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

Although universal supports and strategies that work across a range of neurodiversity can efficiently support students with FASD and other students simultaneously, students with FASD may have unique needs and challenges that do not necessarily fit well with strategies designed for other neurodevelopmental disorders.

Students with FASD may require FASD-informed targeted and individualized interventions within an FASD-aware school setting. This may include access to educational assistants who facilitate the use of supports and strategies, evidence-based FASD programming, and individual education plans (IEPs) designed by FASD-informed teams. In some places, FASD-focused classrooms are available, and this may be helpful for some students.

Close collaboration and wrap-around support between school teams, family and caregivers, service providers, and community organizations is helpful and contributes to the effective design of educational programs that build on a student's unique strengths while effectively meeting their challenges.

Key Findings: Child welfare system

People with FASD are over-represented in the child welfare system, and involvement in this system is an additional risk factor affecting long-term outcomes. Strategies to preserve families could include providing access to diagnoses for the child and possibly the parent, encouraging long-term supportive relationships, and increasing proactive community supports.

For children and adolescents in the child welfare system, beneficial approaches include access to diagnosis and interventions as early as possible and support and training for foster care placements to enable continuity, stability and well-being.

Youth with FASD in the child welfare system have a particular need for longer term, targeted supports as they navigate the transition to adulthood as well out of the child welfare system.

Key Findings: Health and healthcare

PAE can affect all organs and systems and therefore, people with FASD have multiple health and mental health conditions that can affect them through the course of their lives.

The complexity of health issues experienced by people with FASD may require management by a primary care team that understands the disabilities associated with FASD and the supports that may be beneficial. This can be difficult for people with FASD and their families as access to primary care is not always readily available in parts of Canada.

The cognitive challenges of some adults with FASD make it difficult for them to navigate the healthcare system without support, which may result in non-adherence or poorer compliance with care recommendations and even dismissal from care when the necessary support is lacking.

Key Findings: Finances, employment, and housing

Many people with FASD struggle with managing their finances, and are vulnerable to scams. Financial literacy training, including training on budgeting and shopping, can be helpful but insufficient, as ongoing supports are often important. Where acceptable to the person with FASD, mechanisms such as a trusted person to help manage funds as well as automated payments of essential expenses like rent can be of assistance. Disability benefits programs that are flexible, needs-based, and accessible are important to achieving financial security and stability for people with FASD. However, eligibility criteria for some disability benefits programs can make access challenging for many individuals with FASD.

Many people with FASD are and want to be employed. However, they may struggle to find and maintain employment without support, and may be reluctant to ask for accommodations or disclose their diagnosis to employers due to stigma. Employers would benefit from having a better awareness of FASD and understanding of how jobs could be structured for successful employment of people with FASD. Work experience opportunities, on-the-job training, mentorship and buddy systems can further support the economic inclusion of people with FASD.

Maintaining access to disability income supports during early work experiences, when self-employed, and when in short-term employment positions can support financial stability and labour market participation of people with FASD.

Stable housing with consistent support is conducive to successful interdependence of people with FASD. Many individuals with FASD require ongoing assistance and skill-building to plan for, choose, access, maintain, and manage housing. Youth with FASD aging out of child welfare are particularly vulnerable. Affordability is often a barrier for people with FASD, but without co-occurring intellectual disability or physical impairments they are often not considered as a disability priority group for affordable housing.

Key Findings: FASD and the criminal justice system

People with FASD often experience unfavourable social determinants of health that raise the risk of involvement in the justice system. They may also have other risk factors such as heightened vulnerability to manipulation by others, and may seek community within troubled peer groups (e.g. gangs). Consequently, people with FASD are over-represented in the criminal justice system, both as victims and offenders.

The provision of upstream interventions and supports can prevent problems with the justice system. These might include support to achieve financial and housing stability, positive mentorship relationships, and a sense of belonging within supportive networks and communities. These supports are especially valuable during the transition between adolescence and adulthood, and a supportive network is key for youth transitioning out of the child welfare system.

Improving access to assessment and diagnosis for people who may have FASD in the criminal justice system will help to ensure that necessary accommodations are provided and their behaviour is better understood. While FASD awareness exists in some parts of the justice and correctional system, it is inconsistent. The use of specialized FASD courts or dockets can help to ensure that the processes and decisions are more informed about FASD, although these are likely to exist only in urban centres.

There is a strong need for alternatives to incarceration, particularly given the criminogenic and harmful effects of incarceration, the diminished capacity of people with FASD, and the possibility that adequate systems of non-carceral support and supervision could better protect public safety at lower cost than incarceration.

Key Findings: Stigmatization and inclusion

Stigma related to FASD deeply harms the health and quality of life of people with FASD and their families and caregivers. It creates barriers to accessing supports, and to self-disclosure in order to access accommodations. Stigmatization is considered a public health issue and a determinant of health.

Stigma-free and blame-free language is helpful in communicating about FASD, in public education, and in providing interventions and supports. This includes recognizing that FASD is a broad spectrum with variable impacts on functioning and avoiding stereotypes about deficits. Educational resources and training to embed stigma-free and blame-free language in all professional activities in health and social services, education, policing and justice, and child welfare is important for addressing systemic stigma.

People with FASD and their families and caregivers emphasize the importance of being connected and included within their communities, but there can be limited opportunities for inclusion and participation, and as a result, they often feel isolated and excluded. People with FASD can benefit from help and guidance with social skill development to protect against isolation. Together with education of others about FASD, this can help to reduce instances in which their neurodevelopmental differences and associated social behaviours are misunderstood. Programs, groups and camps, led by adults or youth with FASD with support from community facilitators, are promising approaches for socialization opportunities.

Hearing the voices of people with FASD offers a powerful learning experience for others by challenging stereotypes and increasing awareness and understanding, and for peers with FASD, provides a pathway to stories of strength, resiliency and success. This can be achieved by including people with FASD who have variable demonstrated functional strengths in a diversity of domains. Examples of mechanisms for sharing the voices of people with FASD are educational presentations by people with FASD, the involvement of people with FASD as program facilitators, and in participatory research and continuing professional education programs.

Indigenous Peoples and FASD

Key Findings: Prevalence

Patterns of alcohol consumption among Indigenous communities vary widely and drawing general conclusions from limited samples can reinforce historical stereotypes, while neglecting broader sociocultural and historical influences. Correcting these stereotypes can help foster conversations at community and individual levels that are key to progress on responding to FASD.

Many Indigenous Peoples and communities face inequities in social determinants of health and have experienced historic and contemporary trauma and resulting intergenerational effects (e.g. adverse childhood experiences) due to the effects of colonialism and racism. These factors increase risk for PAE and FASD.

Some data suggests that prevalence rates of FASD and PAE are significantly elevated for some Indigenous communities. Accurate, up-to-date data on FASD and PAE prevalence and risk factors among Indigenous communities would help to inform policy responses and resource allocation for prevention and support. This includes robust Indigenous-led community level data collection methods, consistent with data sovereignty principles.

Key Findings: Prevention, interventions and supports

Because Indigenous communities vary in myriad historical, cultural, geographic, and resource dimensions, their mixtures of assets, strengths, and needs will differ. Indigenous communities are best placed to determine the relevance and applicability of prevention strategies that respond to their own needs, culture, context, and objectives.

Holistic, trauma-informed, culturally-appropriate, integrated service delivery are promising approaches to reducing harms associated with alcohol and substance use for Indigenous Peoples.

Attention to the broader context and improvement of social determinants of health at the population level is important for reducing the prevalence of harmful alcohol use and FASD. This involves addressing the health and well-being of Indigenous communities and families more broadly, and not focusing solely on pregnant women.

Evaluation of prevention strategies is in general limited, making it challenging to identify those that are most effective. There is some evidence to support the implementation of prevention models that are Indigenous community-led and incorporate Indigenous community knowledge of healing and well-being. Program funding that includes resources to evaluate efficacy of new strategies can build the knowledge base.

Continuity of care helps to build the relationships of trust that are crucial to addressing problems with alcohol and substance use, and to diagnosing and supporting families affected by FASD. Yet, access to culturally informed FASD healthcare services in Indigenous communities continues to be limited. This is compounded by limited access to basic healthcare services and continuity of healthcare in these communities.

The development and training of Indigenous community-based health professionals and para-professionals would build local capacity, reduce turnover and provide culturally informed FASD health services. In small communities where members are well known to each other, privacy concerns and stigma related to substance use and FASD are barriers to accessing supports, and there may therefore be a preference for building stable relationships with Indigenous healthcare providers from outside the community or with non-Indigenous healthcare providers who are culturally informed.

Stable, long-term and sustainable funding is preferable to project-based funding. This enables Indigenous communities to develop long-term strategies and to build enduring and effective infrastructure for FASD diagnosis, prevention, intervention and supports.

Key Findings: Child welfare systems

Colonial policies, including residential schools and the forced adoption system now known as the Sixties Scoop, as well as more recent and continuing practices of apprehension of Indigenous children under child welfare legislation cast a long shadow that undermine efforts to address FASD today.

Recent changes made pursuant to the TRC calls to action, in particular the legislative recognition of the jurisdiction of Indigenous communities over child and family services and a path for them to assume legislative authority, offers an opportunity to develop approaches that better support effective responses to PAE and FASD.

Key Findings: Criminal justice system

Indigenous people, including Indigenous people with FASD, are overrepresented in Canada's criminal justice system. In addition to continuing to increase the general awareness in all parts of the criminal justice system of the impacts of the colonial legacy on Indigenous Peoples and the impact of FASD, a deeper understanding of how FASD may affect over-represented groups and persons with unrecognized neurodevelopmental disabilities and adverse social determinants of health would further improve the judicial process and correctional responses.

Supporting people with FASD can help to avoid involvement with the criminal justice system and reduce recidivism. Supports include early interventions, which depend upon access to FASD health services in the community for early screening and diagnosis, and family based services. Other supports are substance use disorder treatment, positive and engaging activities, social connections and mentorship, pathways to success through school and employment, and connections to culture, traditional values and land-based healing.

It is important to develop and properly fund structures for non-carceral support and supervision that work for the diverse populations who are overrepresented in the justice system, including Indigenous Peoples.

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