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PAUKTUUTIT
INUIT WOMEN OF CANADA 2021

Pauktuutit Inuit Women of Canada

Fetal Alcohol Spectrum Disorder: Supporting Inuit Families and Communities

Environmental Scan and Research Report

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Fetal Alcohol Spectrum Disorder:
Supporting Inuit Families and Communities
Environmental Scan and Research Report

Prepared by Firelight Research Inc.

ACKNOWLEDGEMENTS

We would like to extend our sincere thanks and appreciation to the many people who contributed to this report.

Primarily, we would like to thank the community members, service providers, and key informants who took the time to share their knowledge and stories with us. This work could not have been completed without their participation.

This report was a collaborative effort of a research team that worked to design, implement and complete the work. This includes core team members from Pauktuutit and Firelight Research Inc. who worked together to design the research methods, traveled to Nunavik and the Inuvialuit Settlement Region to facilitate and carry out focus groups and interviews, conducted virtual interviews, and provided analysis and writing support. Crystal Martin-Lapenskie from Okpik Consulting aided in the virtual interviews and engagement and provided critical report support at a time when the pandemic caused the report to shift from an in-person to virtual setting.

Lastly, we would like to especially acknowledge all of the Inuit families across Inuit Nunangat and Canada who are impacted by FASD, those with suspected or confirmed FASD, those who are caregivers, and those providing essential services to others affected by FASD.

Prepared by Firelight Research Inc.

EXECUTIVE SUMMARY

This report set out to explore how FASD is understood, and how those affected by it are supported within Inuit communities. Through a series of focus groups and interviews with Inuit community members and service providers in urban and remote communities, the findings from this research suggest that there are improvements being made regarding education and awareness about FASD, in addition to improved early intervention efforts. At the same time, stigma and misinformation about FASD continues to persist within Inuit communities, which is linked to the limited number of Inuit-led and culturally sensitive FASD diagnostic and support services.

The definition of FASD has changed and evolved over time. For the purposes of this work, the definition provided by CanFASD was relied on:

> *Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges. (CanFASD et. al 2019)*

A total of 52 community members and service providers participated in a series of focus groups and interviews for this report. Participants were from eight different communities, including Kuujjuaq, Montreal, Edmonton, Inuvik, Iqaluit, Yellowknife, Ottawa, and St. John’s, and were asked about their unique perspectives regarding attitudes and behaviours towards FASD. The findings and conclusions in this report are reflective of what the participants were able and willing to share, and are not intended to represent the perspectives of all Inuit. This report is also intended to highlight what was heard from participants to identify the knowledge and service-based gaps and solutions to improving FASD supports.

Results from the environmental scan show a growing number of Inuit-led and culturally safe FASD services that are available to Inuit communities. And while access to services have improved over time, many Inuit identified a series of social and physical barriers that can prevent families from obtaining the appropriate services or level of care required to meet their unique needs. Community based services such as the ᐱᕈᖅᑲᑎᒌᑦ ᑲᑎᕝᕕᖏᑦ Piruqatigiit Resource Centre in Iqaluit, as well as SIPPE in Nunavik, are examples of emerging promising practices that are contributing to the growing level of education and awareness about FASD in Inuit communities, which have contributed to an increase in instances of early intervention.

Understanding FASD in the Context of Inuit Communities

A number of participants spoke about common assumptions surrounding the cause of FASD. For many years, FASD was understood to be the direct result of expectant parents drinking alcohol while pregnant. For community members and service providers who participated in the study, many understand FASD is linked to prenatal alcohol consumption, and also deeply rooted in community-specific social determinants of health and wellbeing. Participants shared knowledge that children and adults who are living with FASD experience a range of behavioural and cognitive challenges; however, many individuals with FASD continue to exemplify strengths in many areas of their lives.

Since this is not well understood by the general public or most service providers, some participants suggested that people with FASD can be misdiagnosed as other disorders (i.e. attention deficit disorder) and referred to services that are not necessarily appropriate for them.

At the heart of the attitudes and behaviours of Inuit community members was the desire to protect and support their family members with FASD. Several participants stressed the importance of recognizing that knowledge and awareness about prenatal alcohol consumption are not enough to 'prevent' FASD, or promote healthy pregnancies[1]. Some service providers suggested that more comprehensive prenatal care needs to be provided to Inuit parents and families, both for FASD and other medical and social services. This includes looking at the protective factors from a more holistic perspective when exploring supports for FASD, such as parents' and families mental health, cultural well-being, sexual health, food security, and access to safe housing.

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[1] According to Piruqatigiit, language that supports healthy pregnancies, as well as supporting individuals or families living with FASD, is preferred over of language that speaks of FASD "prevention" (2020). This is in effort to reduce the stigmatization of those living with FASD.

Community Understandings about the Effects of FASD

Some of the participants who have children living with FASD (diagnosed and undiagnosed) spoke about its lifelong impacts and effects at different developmental stages. Behavioural challenges were often described as being a key indicator for children's prenatal exposure to alcohol. This might include parents observing their child's inability to self-regulate, demonstrating more frequent and extreme outbursts, and their difficulty in building and maintaining social relationships.

Adults living with FASD may experience similar effects as when they are children, however, as their circumstances change, so might the supports. For example, when an individual with a FASD diagnosis or exposure turns 18, support services can become complicated – particularly for those who were not officially diagnosed. Some adults may be required to undergo an assessment to access services, which can be beneficial for adults who were never diagnosed as children.

The effects of FASD were also discussed at a family level. Family dynamics and parent-child relationships, for example, can be strained due to the complications of FASD. These relationships can be further strained if some family members also struggle with alcohol use. Several parents of children with FASD spoke about the importance of exercising patience and understanding with their children. Practicing patience, several parents explained, can allow for familial relationships to strengthen and remain healthy.

> *It's [FASD] been a benefit for my family because it's been kind of a reality check because we all have to learn to be a lot more sensitive. I'm the parent of the family so with all my siblings I'm always messaging and telling them just before anything happens to let them know like hey, they might lash out they might go in your face...they're going to disagree with like half the [stuff] you say so you have to be careful with that. But at the end of anything, just know it's not their fault. Just because, you know, like it's always just that you guys need to understand that, you know if they lash out but they don't realize that it's so negative. They don't understand that and you know, that's something that has changed everybody's relationship between each other – it's been so much healthier. Because now we're all like hey, wait, if I do that, you know growing up for me, it wasn't like that. (Community member, September 3, 2020)*

The growing number of Inuit-guided support services, such as the Piruqatigiit Resource Centre, is a positive shift towards a dignity-and trauma-informed approach that recognizes and honours a person's individuality and agency, as well as takes extra care to build relationships of respect, trust, kindness and safety.

Community Understandings about the Prevalence of FASD

The prevalence of FASD in and among Inuit communities is difficult to discern as many children and adults with FASD are undiagnosed. Many individuals are undiagnosed due to a range of barriers in accessing diagnostic services, including stigmatization, systemic racism, geographical distances to services, cultural and social barriers, lack of interpretation and translation, limited awareness and understanding about FASD, poor funding, criminalizing Inuit women, outdated medical record keeping, and the lack of continuity in care (i.e. fly-in medical teams). The lack of public knowledge and awareness about FASD was cited as a core element of community-felt effects.

> *I think introducing it [FASD] to children at a young age might actually help them to, to understand why their classmate is going through this or understand why in the future they are going to have to be patient, you know, with the circumstances. I also think that at birth might actually help a lot. So, like I said before a lot of people are ashamed or become ashamed by other people or that their child has looks with FASD but if it was, if it was careful or respectful or more like right at the beginning of birth, or even in pregnancy then the, the parent might actually be able to talk about it more and that will be able to be giving the resources that they need or the support. (Community member, August 19, 2020)*

Several service providers suggested that there is insufficient data regarding the prevalence of FASD in Inuit communities. Some providers believe that FASD rates may be higher than what the available data indicates, due in part because of the lack of studies and information about past and current rates of FASD. Understanding the levels of FASD in Inuit communities is closely linked to having safe and equitable access to diagnostic services, which many participants suggested is not the reality in most communities. Some community members and service providers in the Inuvialuit Settlement Region, Nunavut, and Nunavik disclosed that FASD is likely more common than any data shows, and that there are likely more people with FASD than there are diagnosed. In regions such as Labrador and Nunatsiavut, however, Inuit and Innu families may be diagnosed with FASD more than non-Indigenous people due to the location of diagnosis services, which contributes in part to the stigmatization of FASD and Indigenous families.

Needs and Opportunities

The availability of Inuit-guided services was identified as an opportunity and key barrier and for FASD services being offered to Inuit families. A number of service providers spoke about the need for improved awareness and understanding about FASD within healthcare, education, and at a community level. With improved levels of awareness and learning, service providers are optimistic that this may reduce some of the stigma around FASD, and potentially reduce some of the social barriers Inuit families face when seeking diagnoses or accessing supports. Service providers from all regions spoke about the need for improved awareness and understanding about FASD within healthcare, education, and at a community level.

> ***I think there kind of needs to be a shift, like, one people need to start like for Nunavut it's really important that all service providers have, like, a comprehensive education on any new history, colonization and culturally competent care right and that there's at least the willingness that if they can't speak Inuktitut that they learn yeah. Because I think until that shift happens there's always going to be barriers. (Service provider, April 24, 2020)***

Baffin Island, Nunavut. Photo courtesy of RyersonClark from Getty Images Signature.

The community members and key services providers who participated in this study identified seven key opportunities for continuing to improve upon FASD supports and services for Inuit families and communities.

- **Opportunity 1:** Move towards a “trauma-informed” and “dignity-informed” practice in FASD service delivery
- **Opportunity 2:** Improve Inuit-based cultural supports for people and families with FASD
- **Opportunity 3:** Improve financial supports for Inuit families in urban and remote communities
- **Opportunity 4:** Improve access to diagnostic services for children and adults across Inuit Nunangat
- **Opportunity 5:** Provide Inuit-specific cultural safety and sensitivity training for all FASD service providers, educators, and healthcare workers
- **Opportunity 6:** Provide consistent messaging about FASD
- **Opportunity 7:** Talk about FASD more openly within families, communities, and from a holistic systems perspective within the education and healthcare systems

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GLOSSARY

At-Risk for Neurodevelopmental Disorder and FASD	Those who do not meet criteria for FASD but have confirmed prenatal alcohol exposure.[2]
Fetal Alcohol Syndrome (FAS)	The original and former term used to describe specific birth defects caused by prenatal alcohol exposure. Due to the growing body of knowledge on the subject, as well as the stigma associated with the term FAS, the term Fetal Alcohol Spectrum Disorder is now used.[3]
Fetal Alcohol Spectrum Disorder (FASD)	"Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges."[4]
FASD with Sentinel Facial Features	The presence of sentinel facial features associated with FASD and evidence of microcephaly.[5]
FASD without Sentinel Facial Features	The presence of three or more identified neurodevelopmental domains associated with FASD with a lack of sentinel facial features.[6]
Pervasive Brain Dysfunction	Severe impairment in three or more neurodevelopmental domains.[7]
Sentinel Facial Features	Identifiable facial features that are associated with FASD.[8]

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[2] Cook et. al (2016).

[3] CanFASD (n.d.).

[4] CanFASD et. al (2019)

[5] Cook et. al (2016).

[6] *Ibid*

[7] *Ibid*

[8] *Ibid*

1. INTRODUCTION

1.1 Background

This report provides an overview of how Fetal Alcohol Spectrum Disorder (FASD) is understood and supported within Inuit communities. FASD is a diagnostic term that is used to describe impact on the brain and body of individuals exposed to alcohol in the womb (CanFASD et. al 2019). FASD affects approximately 4% of people in Canada (CanFASD 2018). Evidence shows that there is insufficient research to understand how many Inuit have FASD, as it has historically been stigmatized and unequally diagnosed among Indigenous populations. This study offers a glimpse into how FASD is understood from an Inuit perspective.

This report broadly conceptualizes the current understandings/prevalence of FASD, the effects of FASD, some of the available resources for those living with FASD, and some of the opportunities for support services and initiatives within Inuit communities. While not all communities across Inuit Nunangat were able to participate, the community members and service providers who did provided a glimpse into the current social and cultural context for FASD and Inuit families.

To undertake this work, Pauktuutit Inuit Women of Canada (PIWC) partnered with Firelight Research Inc. (Firelight) to develop and deliver focus groups and key informant interviews with over 50 community members and service providers. All participating community members are of Inuit heritage, whereas service providers are a mixture of Inuit and non-Inuit heritage. Participants from both remote and urban centres participated in the research, within and outside of Inuit Nunangat. In speaking with a diverse range of Inuit who have experiences with FASD (directly and indirectly), a rich understanding about the varying and complex attitudes, behaviours, and effects of FASD were revealed. Furthermore, an environmental scan was completed to better understand what FASD supports are available to Inuit families.

Findings from this research suggest that supports, education, and awareness about FASD is improving within Inuit communities (urban and remote), however the disorder is still stigmatized and, in many cases, misunderstood. More services that are Inuit-led are emerging in northern communities, however a number of Inuit families still experience a range of physical and social barriers in accessing diagnostic and support services. While there is opportunity for a variety of improvements and changes, one of the key recommendations to come from the research is the need for more Inuit-led education, training, and support services for Inuit and non-Inuit who are working with, caring for, and living with individuals who are impacted by FASD.

The findings of this study are reflective of what community members and service providers were able and willing to share with the research team, and are not intended to generalize all Inuit, communities, or FASD.

1.2 Approach to Research

This research set out to explore the current landscape of FASD for Inuit Communities. In having conversations about FASD and eliciting feedback from communities, and recognizing that it is a sensitive and complicated subject for many Inuit families and communities, it was important that this research took care and sensitivity in its approach. To ensure that the topic of FASD was discussed appropriately, the report was guided by the following four standards:

1. The research process should be collaborative, inclusive, and community-based;
2. The research methods should be culturally appropriate;
3. The research process should be strengths-based and dignity promoting; and
4. The research process should be systematic, objective, and methodologically rigorous.

These four standards guided the research team in their design, implementation, and analysis of the study. These standards helped to ensure that participants felt safe in their interviews, that participants felt respected in the research process, and to ensure that the study would contribute to the topic of FASD in a culturally-respectful way.

1.3 Report Organization

This report was prepared to support Inuit women and families, Inuit and non-Inuit service providers, and any other partner who is working in the context of FASD with Inuit families. The bulk of the report is detailed in the environmental scan (Section 3) and summary of key findings from the focus groups and interviews (Section 4).

The report is organized as follows:

- **Section 1:** Introduction, summarizes the purpose of study, its approach, and the contents of the report.
- **Section 2:** Methodology, summarizes the methodological approach taken for this study, including the breakdown of participants for interviews and focus groups.
- **Section 3:** Environmental Scan, presents an environmental scan detailing current FASD-related supports, programs, and resources in Inuit Nunangat and beyond.
- **Section 4:** What We Heard, details the findings of the interviews and focus groups held with community members and service providers in the communities of Inuvik, Iqaluit, Kuujjuaq, Yellowknife, Edmonton, Montreal, Ottawa, and St. John's.
- **Section 5:** Conclusion summarizes the key findings of this report.

2. METHODS

The goal of this research was to explore community members perspectives, understandings, awareness, and core needs as they relate to FASD. This involved completing an environmental scan of FASD services across the four regions of Inuit Nunangat, and conducting focus groups and interviews with community members and services providers.

A mixed-methods approach was taken, utilizing both open and closed-ended questions to allow for a range of responses. Questions were related to the topics of:

- Understanding the prevalence of FASD in communities;
- Understanding the effects of FASD in communities;
- Available FASD resources and supports; and
- Key areas of need/opportunities.

These topics, in addition to the focus group and interview guides, were developed in close collaboration with Pauktuutit staff. Research questions were informed primarily by Inuit who have training in community-care approaches to ensure accuracy and dignity in supporting people with FASD.

2.1 Data Sources

2.1.1 Environmental Scan

An environmental scan was undertaken to identify current programs, services and resources across Canada with a mandated focus on FASD-related support. The environmental scan relied on publicly available academic and grey literature, and publicly available listings of programs, services, and resources across Canada. Initial documents that formed the basis of the environmental scan were identified by Pauktuutit staff, and were supplemented by a web search in public search engine (i.e., Google) and academic databases.

2.1.2 Focus Groups and Key Informant Interviews

Focus groups and interviews for this report were completed in eight different communities. This included the communities of Kuujjuaq (Nunavik), Inuvik (Inuvialuit Settlement Region), Iqaluit (Nunavut), Yellowknife (Northwest Territories), Montreal (Quebec), Edmonton (Alberta), and St. John's (Newfoundland). The table below details the number of interview and focus group participants by location.

Table 1: Focus Groups and Interview Participants

	# of Focus Group Participants	# of In-Community Interview Participants		# of Individual Telephone Interview Participants		***Total***
Location	Community Members	Community Members	Key Service Providers	Key Service Providers	Community Members	
Kuujjuaq, Nunavik	0	5	4*	0	0	***9***
Inuvik, Inuvialuit Settlement Region	4	0	1	3	0	***8***
Iqaluit, Nunavut	0	0	0	4	4	***8***
Yellowknife, Northwest Territories	0	0	0	2	0	***2***
Montreal, Quebec	17	0	0	0	0	***17***
Ottawa, Ontario	0	0	0	1	3	***4***
Edmonton, Alberta	0	0	0	2	0	***2***
St. John's, Newfoundland-Labrador	0	0	0	2	0	***2***
Total	***21***	***5***	***5***	***14***	***7***	**52**
****One Key Service provider who participated in a Kuujjuaq interview is also a community member. They are counted as a Community Member in the table.***						

Focus groups and interviews were requested by email, phone, or in-person communication, and were conducted between February 5, 2020 and October 22, 2020. A list of potential focus group and interview participants was compiled based on recommendations from community members' and Pauktuutit staff.

Two in-community focus group sessions were conducted between February 5, 2020 in Montreal and February 27, 2020 in Inuvik. A total of 21 community members participated in these focus groups. A total of 31 key informants were interviewed for this report. Of these, 10 key informants were interviewed in-community, and 21 were interviewed via telephone.

Key informants included community members, service providers, and community professionals who have experience with and/or knowledge of FASD in Inuit Nunangat. Key informant interviews were guided by open-ended interview questions (see Appendix A), and followed a semi-structured interview format. These interviews included discussions regarding community attitudes and behaviours surrounding alcohol consumption during pregnancy, and current programs, services, and resources in their respective communities, including key gaps, challenges, and opportunities. All key informants signed a written consent form or provided oral consent to allow their words and responses be recorded on audio recording devices. Some identifiers have been removed throughout the report to protect anonymity.

2.2 Limitations

The aim of this report is to highlight key findings from a small number of Inuit community members, and key service providers who support and work with Inuit families who are impacted by FASD. The findings of this report are limited to the literature reviewed for the environmental scan, as well as what participants from the eight communities were able and willing to share. The majority of participants and key informants live outside of Inuit Nunangat, and therefore a number of the responses below are reflective of experiences in southern and urban centres.

Given the conservative number of participants from each community, the findings in this report are best understood as a conservative range of perspectives on FASD. This report can be understood as a small snapshot of how FASD is understood by some Inuit communities within Inuit Nunangat as well as in some urban centres.

The aim of this study is not to generalize the perspectives of all Inuit, or the regions of Inuit Nunangat. The study provides a high-level understanding of community member and key service provide perspectives from particular communities, both within Inuit Nunangat and within urban centres.

COVID-19 Limitations

The original intent of the research was to conduct interviews and focus groups in-person in each region of Inuit Nunangat. When the COVID-19 pandemic occurred in March 2020, research plans were adjusted to accommodate travel restrictions while prioritizing the health and safety of community members. COVID-19 made connecting with community members difficult as regional capacity was understandably limited during this time.

Given these unprecedented circumstances, it was not possible to conduct in-person interviews or focus groups in Iqaluit, Ottawa, Yellowknife, St. John's, or anywhere in Nunatsiavut. Remote interviews were conducted with a select number of community members and service-providers. This report is therefore limited to the findings of the 51 individuals who were able to participate in this study. This report is therefore limited to the results, analysis, and findings of the 51 individuals who were able to participate, and who reside in Nunavut, Nunavik, and Inuvialuit, in addition to the urban centres.

3. ENVIRONMENTAL SCAN OF FASD-RELATED RESOURCES IN INUIT NUNANGAT

The environmental scan for this report provides an overview of current FASD resources, literature, information and support, and promising practices that relate to Inuit Families living within and outside of Inuit Nunangat. The environmental scan is organized by the following categories:

- **Section 3.1** Data Sources;
- **Section 3.2** Overview of FASD;
- **Section 3.3** Supports and Services in Inuit Nunangat; and
- **Section 3.4** Promising Practices.

As mentioned in Section 2.3, the results of the environmental scan are not intended to generalize the reality of FASD across all Inuit communities, or across Canada. The information provided below highlights key pieces of research, resources, and supports that are relevant to the communities, community members, and service providers that participated in the study.

3.1 Data Sources

This environmental scan is informed by existing resources produced by Pauktuutit on the topic of Fetal Alcohol Spectrum Disorder (FASD). These include the following key resources:

- Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD hand book (Pauktuutit Inuit Women of Canada 2006);

- Five-Year Strategic Plan for Alcohol Spectrum Disorder 2010-2015 report (Pauktuutit Inuit Women of Canada 2013);

- The Choices we Make During Pregnancy poster (Pauktuutit Inuit Women of Canada 2011); and
- Before I was Born, Preventing FAS/FAE in Inuit Communities' video (Pauktuutit Inuit Women of Canada 2001).

This environmental scan was also informed by some of the responses shared during the study's focus groups and interviews, as well as a review of relevant programs and resources across Inuit Nunangat, which includes the four regions of Nunavut, Nunatsiavut, Inuvialuit, and Nunavik. The environmental scan of programs and services relied on publicly available academic and grey literature, and was retrieved through web searches in public search engines. The environmental scan identified programs and services largely through government websites and news articles.

It is important to note that this environmental scan is not comprehensive, and is intended to provide an overview of existing programs and materials, promising practices, and accessibility of FASD-related supports in Inuit Nunangat.

3.2 Overview of FASD

The language surrounding FASD is important for contextualizing the term within this research. Terms that are used to describe FASD can affect how people think and make decisions about FASD, and those who are affected by it. CanFASD defines FASD as the following:

> *Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges. (CanFASD et. al 2019)*

There is limited data related to the prevalence of FASD in different regions of Canada, and particularly in regions of Inuit Nunangat. This lack of prevalence data may be attributed to various limitations in FASD services, including a lack of official diagnostic services and a lack of epidemiological surveillance related to FASD.

The potential for FASD in a community can be indirectly predicted based on the levels of binge-drinking and substance use among the population (Pauktuutit FASD 2019). Although there is inadequate diagnostic data regarding FASD in Inuit Nunangat, statistics regarding the prevalence of binge drinking and the self-reported consumption of alcohol while pregnant indirectly informs prevalence of FASD in Inuit communities. For instance, the 2012 Aboriginal Peoples Survey disclosed that 26% of Inuit aged 15 and up reported heavy drinking, which is linked to FASD (Statistics Canada 2014).

Multiple links exist between the prevalence of FASD and interlinking factors, such as substance use and substance use disorders, trauma, mental health, intimate partner violence, forced alcohol consumption, intergenerational impact of colonialism, and others. Pregnant people who are undiagnosed themselves may also not have the information they need, or have access to necessary health and social supports. Given these complex links, there are a number of programs and services that generally support the early intervention of FASD exposure, which are available to varying degrees across Inuit Nunangat, and Canada more broadly. The provision of these services is highly dependent on the availability of personnel, infrastructure, and accessibility of community social and health programs.

These general programs range across a wide array of program areas and fields of intervention. A review of the literature concluded in a (non-comprehensive) list of general programs that may support the prevention of FASD, as well as the treatment and ongoing support of those affected by FASD:

- Medical personnel (i.e., doctors, nurses) who may provide general interventions, such as medical advice and monitoring during pregnancy and child development;

- Substance use and substance use disorder counselling for pregnant people or people at a reproductive age;

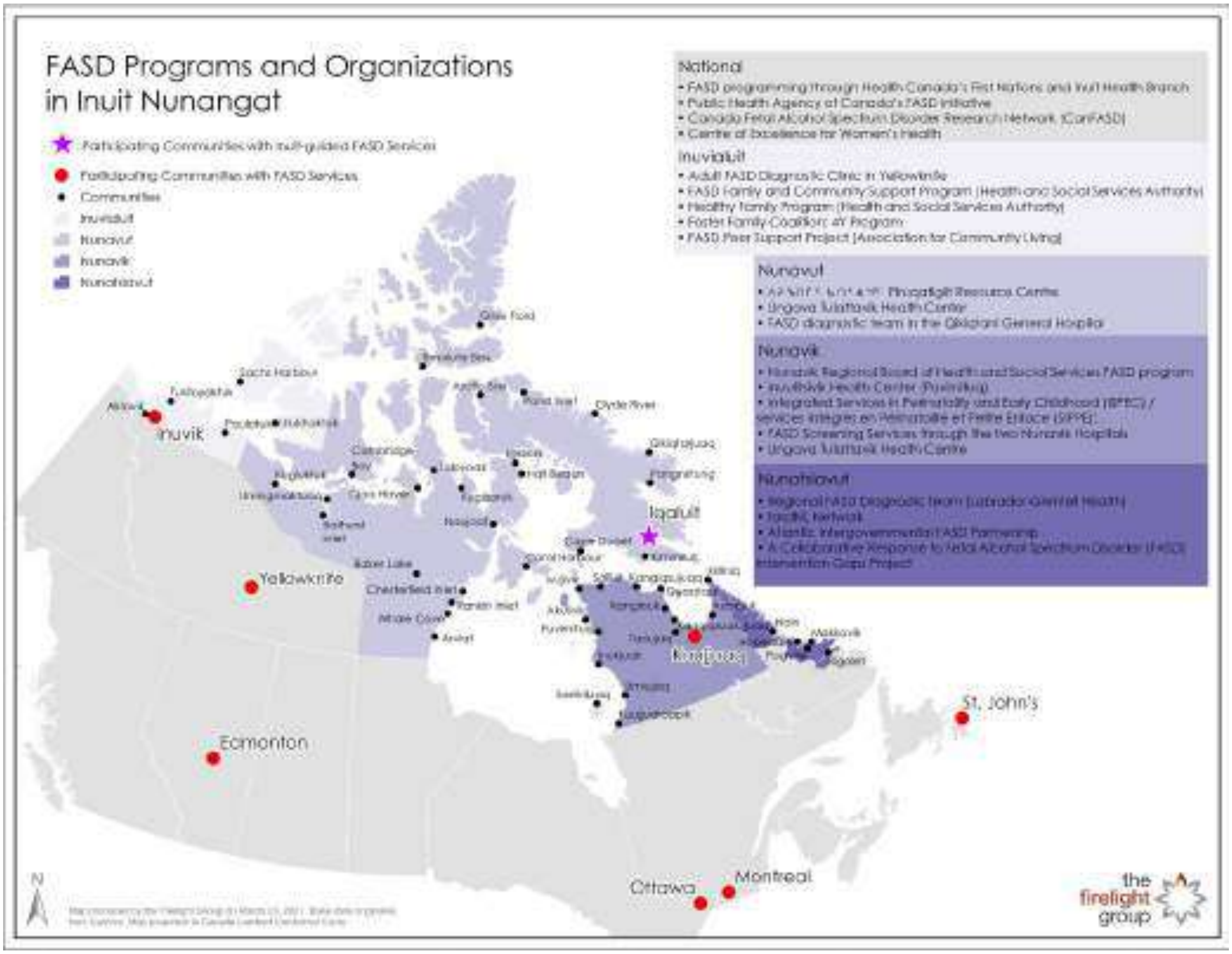
- General wellness programs and supports (i.e., cultural programming, land-based programs) that may contribute to substance use support, parenting and family cohesion, interventions for people with FASD, etc;

- Parenting programs and resources that may contribute to prevention of alcohol consumption during pregnancy and postpartum, as well as guidance in parenting a child with FASD;

- Early education supports that may identify children with FASD and provide educational support; and

- Skills development and employment coaching for individuals with FASD.

Despite the growing collection of resources and services targeted towards FASD-related prevention and support, an insufficient availability of diagnostic and screening services in Inuit Nunangat remains (Nunatsiaq News 2019a). Diagnostic and screening services requires a specific set of clinical team members to offer these services. These clinical team members may include: physician (with training specific to FASD diagnosis); psychologist (with expertise in clinical testing); speech language pathologist; occupational therapist; and clinic coordinator (CanFASD, n.d.). Nunavut and Nunatsiavut are the only regions in Inuit Nunangat with access to these specialized services for people under the age of 18.



National
- FASD programming through Health Canada's First Nations and Inuit Health Branch
- Public Health Agency of Canada's FASD initiative
- Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD)
- Centre of Excellence for Women's Health

Inuvialuit
- Adult FASD Diagnostic Clinic in Yellowknife
- FASD Family and Community Support Program (Health and Social Services Authority)
- Healthy Family Program (Health and Social Services Authority)
- Foster Family Coalition: 4Y Program
- FASD Peer Support Project (Association for Community Living)

Nunavut
- [illegible] Pinagtigit Resource Centre
- Ungava Tulattavik Health Center
- FASD diagnostic team in the Qikiqtani General Hospital

Nunavik
- Nunavik Regional Board of Health and Social Services FASD program
- Inuulitsivik Health Center (Puvirnituq)
- Integrated Services in Perinatality and Early Childhood (ISPEC) / Services intégrés en Périnatalité et Petite Enfance (SIPPE)
- FASD Screening Services through the two Nunavik Hospitals
- Ungava Tulattavik Health Centre

Nunatsiavut
- Regional FASD Diagnostic team (Labrador-Grenfell Health)
- [illegible] Network
- Atlantic Intergovernmental FASD Partnership
- A Collaborative Response to Fetal Alcohol Spectrum Disorder (FASD) Intervention Gaps Project

Figure 1: FASD Programs and Organizations in Inuit Nunangat

3.3 Supports and Services in Inuit Nanangat

Pauktuutit has provided valued research, activities, and resources prepared for FASD-related prevention activities and services in Inuit Nunangat from 1995 to present day. This includes multiple publications, gatherings, and focus groups that have contributed to growing knowledge and awareness of FASD. Pauktuutit's Five-Year Strategic Plan (2013) provides a comprehensive description of the organization's initiatives between 1995 and 2013. These initiatives included workshops and associated guides or handbooks, educational and awareness resources, and strategic approaches to addressing FASD.

- Fetal Alcohol Syndrome: A Resource for Inuit Communities to Understand What FAS is and What They Can Do to Help (1996);
- Ikajuqtigiinniq resource guide (1998);
- Train the Trainer workshop (2004-2005);
- Before I Was Born (2001);
- Children Come First: A Resource About FASD (2003);
- Survey of FASD training opportunities within Inuit Communities (2005);
- Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD (2006);
- Piaranut For Our Children: Quality Practices in Inuit ECD (2008); and
- Born on the Land with Helping Hands (2008).

Among these key resources is the Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD handbook, which details best practices in supporting women and families in the prevention and treatment of FASD. The topics covered in these resources vary, and include education approaches for pregnant people; overviews of substance use disorders and trauma; challenges associated with FASD for individuals, families, and community; Inuit-specific approaches to treatment and support; and prevention strategies and solutions, among others.

The Inuit Five-Year Strategic Plan for Fetal Alcohol Spectrum Disorder (Pauktuutit Inuit Women of Canada 2013), from which this list of resources is sourced, provides a valuable strategic plan in addressing FASD across Inuit Nunangat. Of particular significance in this document is its focus on opportunities, gaps to fill, and important factors to consider in moving forward with FASD-related supports and services that are in alignment with Inuit Qaujimajatuqangit. Over time, research in substance use, neuroscience, and FASD has grown, and the Strategic Plan may be updated in the future, building off of the strategies previously identified.

3.3.1 Nunavut

Puvirnituq, Nunavik. Photo courtesy of MartB from Getty Images.

Nunavut has 25 communities and approximately 85% of the population are Inuit. The territory of Nunavut has seen an increase in supports and services dedicated to FASD-related support in the recent years. The Government of Nunavut, at Qikiqtani General Hospital in Iqaluit, for instance, has established a pediatric FASD diagnostic team, comprised of a neuropsychologist and a paediatrician, and may include a speech-language pathologist (Nunatsiaq News 2019b). Nunavut and Nunatsiavut (Labrador Grenfell Health) are the sole two locations in Inuit Nunangat that provide these diagnostic services.

In addition to diagnostic services, Nunavut has seen an increase in educational supports in the region. The ᐱᕈᖅᑲᑎᒌᑦ ᑲᑎᕝᕕᖏᑦ Piruqatigiit Resource Centre (Piruqatigiit), a non-profit organization based in Iqaluit, opened its doors to the community in 2018. Piruqatigiit was created by “Nunavummuit with lived FASD experience and professional knowledge” to provide holistic and Inuit Qaujimajatuqangit informed approaches to FASD-related services and supports. Working closely with the FASD clinic in Iqaluit, Piruqatigiit provides an array of supports, including: educational resources; programming for children, youth, and adults living with the effects of FASD; supports for caregivers and loved ones of those with FASD; and education and consultation for organizations to support FASD and trauma-informed practice (Piruqatigiit Resource Centre 2018).

At Piruqatigiit, they are guided and led by an Inuit Advisory Circle to ensure resources and programming reflect Inuit values and worldviews. They also partner and work with government services and NGOs to provide training and capacity building to work toward FASD-informed service providers, communities and families. Piruqatigiit runs a pre-employment training, Taqaiqtitisijiit Community Respite Caregiver training, to build the FASD-informed workforce in Nunavut. They also facilitate a Qaggiq caregiver support group and programs for children and youth. Piruqatigiit will soon offer a free Nunavut-wide online training and specialized training.

The Government of Nunavut has produced a number of resources in recent years, including FASD awareness posters, handouts for expectant parents and families, and handouts for medical providers on approaches to speaking with clients (Nunatsiaq News 2019b). Additional supports provided by the Government of Nunavut include: community events during Substance Use Awarenss Month; supports by Community Health Workers; and the FASD Mentoring Project to provide training to community workers about FASD (Nunatsiaq News 2019b). A small portion of the Health Promotion Division focuses FASD resources.

3.3.2 Nunavik

The Inuit region of Nunavik is located in the northern portion of the province of Quebec, and is comprised of fourteen Inuit communities (INAC 2016). As of 2018, Nunavik did not have services that directly provide diagnosis and support designed specifically for those effected by FASD (Gordon and Nunavik Regional Board of Health and Social Services 2018).

Kitty Gordon, the Assistant Director of Public Health at the Nunavik Regional Board of Health and Social Services (NRBHSS) provided an overview of current FASD-related services as of 2018 in the region of Nunavik. Among these services is the FASD program coordinated by the NRBHSS. The FASD program is intended to promote healthy pregnancy, build partnerships and collaboration between services and stakeholders, and raise public awareness and education surrounding the facts and risks of alcohol consumption during pregnancy.

It is offered in conjunction with various family-directed programs, including the Canada Prenatal Nutrition Program (CPNP); Integrated Services in Perinatality and Early Childhood (ISPEC), otherwise referred to as services intégrés en périnatalité et petite enface (SIPPE); substance use services, the Nunavik midwifery program; and a nurse located at Ullivik lodging facility for pregnant people in Montreal. Two facilities in Nunavik house staff working in the realm of FASD support: the Inuulitsivik Health Center (Puvirnituq) has two FASD staff who work with the

ISPEC team and other partners on the Hudson Coast, and the Ungava Tulattavik Health Center (Kuujjuaq) houses one FASD coordinator who is a member of the ISPEC team and works closely with the substance use intervener.

SIPPE offers various support from social assistance, food coupons ($80/month for babies' first year), systems navigation to access housing, work or education, informative workshops, as well as social support through parental support groups, hosting baby showers, and parent-child activities. There is also an FASD coordinator position that provides workshops for families from time to time.

SIPPE is provincially funded, offered through the Ungava Health centre and predominately run by social workers. A substance use counsellor also joins occasionally to provide further outreach and support to pregnant people that might be struggling. SIPPE staff also connect regularly with the local midwives to discuss at-risk clients and how further support or care might be offered. These staff work closely with the doctor and vaccination nurse when diagnostic screenings are being provided to children.

Health services teams often travel to communities across Nunavik. The SIPPE team in Kuujjuaq also travels from the south with an eight week-on, two-to-four week-off schedule. Community members who participated in this report suggested that there is a lack of infrastructure and staff available to support programming or further supports in Nunavik communities.

Other supports provided in Nunavik through the FASD program include the funding and support of community activities, awareness campaigns, sober networks, and school resources, all with a focus on healthy pregnancies and healthy consumption of alcohol (Gordon and Nunavik Regional Board of Health and Social Services 2018).

Although there is a reduced availability of diagnostic services in Nunavik (and furthermore within the province of Quebec), Nunavik communities receive screening services from a newly funded health intervention team in the region. The screening team is to be comprised of a prosthetist-orthopist[9], a speech therapist, a psycho-educator, a special educator, and a nutritionist. The team is available to the two Nunavik hospitals and is accessible via web-based consultation wherein parents complete questionnaires related to their child's development. The goal of this screening team is to facilitate access to needed services for children experiencing effects of FASD. The Government of Quebec has committed $48 million to deploy the initiative across the province of Quebec in 2019-2020 (Nunatsiaq News 2019a).

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[9] An orthotist-prosthetist designs and creates medical supportive devices for patients.

Nunavik, Quebec. Photo courtesy of Celine Bisson from Getty Images.

3.3.3 Nunatsiavut

The Nunatsiavut region is located within Newfoundland and Labrador, and is comprised of Inuit Settlement lands in northern Labrador. There are five Inuit communities in the Nunatsiavut region: Nain; Hopedale; Postville; Makkovik; and Rigolet (INAC 2016).

The majority of the FASD services available to Inuit residing in Nunatsiavut are located in Happy-Valley Goose Bay and St. John's, which are communities outside of the Inuit Land Claims settlement region. Few of these services are Inuit-focused, as they are accessed by Inuit and non-Inuit families.

Inuit communities in the Nunatsiavut region have access to FASD screening and diagnostic services through a multidisciplinary Regional FASD Diagnostic team, coordinated through Labrador Grenfell Health (Inuit Tapiriit Kanatami 2014, 2). The diagnostic team travels from Labrador into Nunatsiavut to provide services. This team consists of a paediatrician, family physician, psychologist, two speech language pathologists, an occupational therapist, and clinic coordinator (Labrador Grenfell Health 2018).

The Clinic provides a pamphlet on their website that provides information on FASD, early diagnosis, and the interdisciplinary diagnostic team. Their website also hosts a referral sheet that can be used by any individual wishing to refer someone who they believe may be affected by FASD ("Fetal Alcohol Spectrum Disorder (FASD)" 2018).

Nunatsiavut is involved with the fasdNL Network, which contributes to FASD awareness, education and training in Newfoundland and Labrador. Services provided by the fasdNL network include: FASD 101 training (customized to target audience); virtual support groups for parents and caregivers; private chat group for parents and caregivers; FASD day events; resources libraries; and networking events (i.e., conferences) (FasdNL n.d.).

Additionally, the Nunatsiavut region is involved with the Atlantic Intergovernmental FASD Partnership (AIFASDP) – a partnership comprised of provincial, federal (FNIHB; PHAC), and regional representations, including the Nunatsiavut government. This partnership hosts multidisciplinary representatives across health (physical and mental health), education, substance use, and community services. AIFASDP works towards developing partnerships and collaboration, pooling resources, and prioritizing services and supports towards FASD-related prevention and treatment in the Atlantic region (Canadian Intergovernmental Conference Secretariat 2016).

The Labrador Correction Centre also has an FASD case manager that provides support to incarcerated individuals with FASD, as well as training to parole officers and other individuals incarcerated. There is also an FASD working group in Happy-Valley Goose Bay.

Finally, the Nunatsiavut Government received funding from The Aboriginal Health Transition Fund (Integration envelope) in 2007 for A Collaborative Response to Fetal Alcohol Spectrum Disorder (FASD) Intervention Gaps Project: Integrated Competency Development in Support of Multi-jurisdictional Teams. The funding was received by the Nunatsiavut Government's Department of Health and Social Development, and partnered with two Innu communities, a regional health authority, provincial school board officials, and Health Canada, with the end deliverable being an action plan intended to increase Innu and Inuit participation in health care service delivery (Health Canada 2005b). While the funding term for this report has ended, this environmental scan could not locate the end deliverable or any public documentation of report outcomes.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

3.3.4 Inuvialuit Settlement Region and Yellowknife

The Inuvialuit Settlement Region is located in the northern portion of the Northwest Territories, and is comprised of six Inuit communities: Aklavik; Inuvik; Paulatuk; Sachs Harbour; Tuktoyaktuk; and Ulukhaktok (INAC 2016).

As of 2018, the Northwest Territories Department of Health and Social Services provides early intervention screening as a component of the "NWT Well Child Clinics, rehabilitation services, the Stanton Territorial Hospital Child Development Team, and the territorial FASD Family and Community Support Program" (Government of Northwest Territories 2018). The FASD Family and Community support program supports youth up to the age of 16 years by producing and implementing strategies for FASD affected youth. However, this program only covers 10 assessments per year, and referrals must come from a healthcare provider or social worker (Government of Northwest Territories 2018).

Another territorial government program offered is the Healthy Family Program, that provides information to healthy families, development, and prenatal life. Some FASD-related programming is offered through this service. Additionally, there is an NWT child development coordinator that travels to remote communities to provide training for those with FASD and their families, which is still growing and developing.

The Northwest Territories has an Adult FASD Diagnostic Clinic, located in the city of Yellowknife. The goal of the clinic is to produce and implement treatment strategies for adults diagnosed with FASD. The clinic hosts a multidisciplinary diagnostic and assessment team, accessed by referral by one of the following: Health and Social Services Worker; government and non-government organizations; family members; and self-referral (Northwest Territories Health and Social Services Authority n.d., 1). In addition to diagnostic services, this clinic provides referrals, service coordination (including income support, housing, adult services, counselling services, rehabilitation services, and social workers), as well as follow-up in the home community within the first year to ensure needed supports are provided (Northwest Territories Health and Social Services Authority n.d., 1).

The Foster Family Coalition of the Northwest Territories have created the 4Y Program in Yellowknife. The Program works with youth ages 12 and up who have suspected or confirmed FASD. The 4Y program offers youth individual counselling, life skills programming, and other basic supports, such as transportation services to and from appointments.

The Yellowknife Association for Community Living provides a number of FASD-related programs and services, including the FASD Peer Support Project (personal support, service referrals, education and awareness, and workshops) and the Living and Learning with FASD Project (family support, outreach, support groups, home visits, family advocacy, life strategies, workshops, and presentations). These services are all based out of Yellowknife, Northwest Territories, and do not have an Inuit-specific mandate or focus (Yellowknife Association for Community Living 2016).

Although there are a number of FASD supports in the Northwest Territories aimed at supporting diagnosis, assessment and rehabilitation, there are few Inuit-specific FASD supports in the region of Inuvialuit and across the NWT. This includes a reduced availability of specialized medical services (i.e., diagnostic teams) in Inuit communities, and a lack of Inuit-focused strategies or resources in the territory.

3.3.5 Select Urban Centres

The following is a compilation of the supports described by study participants in each of the urban centres that this study focused on. Both community members and service providers spoke about the challenges that urban Inuit face with accessing FASD-related supports and services, including Inuit-focused programming. The systems are frequently unclear and there is often less of a support network for Inuit in urban areas.

Montreal, Quebec

For those struggling with substance use disorders in Nunavik, community members are likely to be referred to a treatment centre in Montreal. Participants indicated that treatment centres are more accessible in Labrador, however, it is often challenging to receive health care coverage or acceptance of referral due to the jurisdictional differences between Quebec and Labrador. The Charles J. Andrew Youth and Family Treatment Centre in Sheshatshiu, NL, is one centre that participants were aware of. The treatment centre requires a minimum month stay. Children are allowed to join families after ten days, however, there is a two-child maximum.

Participants suggested that Montreal is limited in its parenting and youth programs, with most accessible through the Indigenous Friendship Centres. FASD supports are also often offered through the hospitals or social services, which community members emphasized were not accessible.

Community members reported on the frustrations of not having Inuit supports in hospitals or social services because services are often in English or French, not Inuktut, not based on Inuit worldviews, and frontline workers can be judgemental and racist towards Inuit.

Ottawa, Ontario

Ottawa FASD-related services mostly consist of general prenatal and early childhood programs/services. Within the last five years, the City of Ottawa received an anonymous donation for FASD supports that triggered the implementation and growth of additional supports.

The Citizen Advocacy organization provides community-based training workshops to frontline workers across public sectors, including education, justice, health, mental health, child welfare, housing, employment, as well as caregiving. They also provide system navigation support to those diagnosed with FASD, or in the process of diagnosis, and those suspected of being prenatally exposed to alcohol. The Wabano Centre in Ottawa also offers some FASD programming for First Nations, Métis, and Inuit community members.

There are also community events through social media and annual walks to raise community awareness of the effects of FASD. Ottawa also has the Kids Brain Health Network, a centre of excellence for neurodiversity and the Children's Aid Society of Ottawa that have been partnering with Citizen Advocacy to invest funds into a pilot project for individuals and families with FASD. The goal of the pilot project is to continue spreading community awareness, individual and family support, as well as lifetime planning and networking, so that the individual will always be consistently supported by volunteers, even if their primary caregivers are unavailable.

St. John's, Newfoundland-Labrador

fasdNL is a pan-provincial organization that fosters FASD education, prevention, promotion, and awareness. It is one of the primary FASD resources and supports available across Newfoundland and Labrador. fasdNL includes representation from Nunatsiavut as well as the Innu Roundtable Secretariat. They provide support to families and individuals with FASD, seeking to maintain family units and residential stability as a protective factor for those living with FASD. They also provide a variety of trainings to caregivers, frontline workers, and other professionals interested in, or in need of, more education and awareness around the effects of FASD and how to support individuals.

Within St. John's, the Key Assets organization provides residential and foster care support, with an FASD lead. Daybreak, also located in St. John's, provides several different community and family-based programming, with some focus on FASD and maternal health. Daybreak has been a parent-child centre since 1972, with increasing family resource programming provided since 2002. They provide prenatal programs and healthy baby clubs to support women and families in having healthy babies. Since 2012, Daybreak has had a FASD working group to provide FASD prevention and intervention support.

Daybreak works closely with First Light, an Indigenous Friendship Centre, to provide cultural supports for families who may be dealing with FASD. The family and children programming at First Light seeks to support families in navigating conflict or complex needs to prevent family crisis such as violence or poverty. There is also a family support group that provides a free meal to families and childcare during the program.

Edmonton, Alberta

FASD supports are available in the City of Edmonton and are often targeted towards more vulnerable populations and those at risk of homelessness. The Boyle McCauley Health Centre, a non-profit community-operated health centre, offers the Pregnancy Pathways program that supports homeless and pregnant women with housing, health care, mental health, and substance use support.

The Healthy, Empowered and Resilient (H.E.R.) Pregnancy Program, which is offered through Boyle Street Community Services, supports street-involved pregnant and parenting people to address issues such as substance use, poverty, and family violence. This program is not Inuit nor Indigenous specific, however, 50% of their staff is Indigenous and they have Knowledge Keepers available to support community members in accessing cultural supports.

Additional programs in Edmonton and surrounding areas include the Edmonton Fetal Alcohol Network, The Lakeland Centre for FASD, and the Government of Alberta FASD Service Networks. Each of Edmonton's available FASD-related supports have a particular focus on harm reduction, meaning their goal is to provide the necessary supports to reduce pregnant people's alcohol consumption, and in other incidences, to replace drugs or hard alcohol or less harmful substances.

3.3.6 National

FASD resources identified by interview and focus group participants and research, indicated that there are a number of organizations and governmental bodies that provide FASD-related strategic guidance across Canada. Among these is Health Canada's First Nations and Inuit Health Branch (FNIHB) who provide funding for FASD programming in communities (Canadian Intergovernmental Conference Secretariat 2016). These programs include: "training for community health workers and early childhood educators to increase community awareness; helping communities develop local plans to reduce FASD; and supporting mentoring projects that pair pregnant at-risk women with community members who have had similar experiences" (Health Canada 2017).

CanFASD is one of the largest research networks in Canada that addresses the complexities of FASD. The organization focuses on producing research about FASD – awareness, evidence, and knowledge of FASD – that translates to a community level. Through their various partnerships with communities and organizations across the country, CanFASD promotes prevention strategies and improved support services for people affected by FASD. In 2010, CanFASD released a consensus statement on the “10 Fundamental components of FASD prevention from a women’s health determinants perspective.” In this statement, CanFASD states that messaging surrounding FASD must be: 1) Respectful; 2) Relational; 3) Self-determining; 4) Women-centered; 5) Harm reduction oriented; 6) Trauma-informed; 7) Health promoting; 8) Culturally safe; 9) Supportive of mothering; and 10) Uses a disability lens.

The Centre of Excellence for Women’s Health is a centre that produces research and community knowledge translation on a range of topics related to sex and gender. This includes womens’ and girls’ health as it relates to alcohol and FASD.

Additionally, The Public Health Agency of Canada’s FASD Initiative operates at a national level through the provision of strategic leadership and coordination related to FASD prevention and treatment. Lastly, the FASD Interdepartmental Working Group provides leadership on behalf on the federal government in regards to strategies for the prevention and improvement of FASD in Canada (Canadian Intergovernmental Conference Secretariat 2016). The working group is comprised of representatives from various federal organizations, including representatives from the Public Health Agency of Canada, Health Canada, Canadian Institutes of Health Research, Canada Mortgage and Housing Corporation, Employment and Social Development Canada, Indigenous and Northern Affairs Canada, Justice Canada, National Defence and the Canadian Armed Forces, Public Safety Canada, and Status of Women Canada (Canadian Intergovernmental Conference Secretariat 2016).

Sanirajak, Nunavut. Photo courtesy of The Firelight Group.

The Assembly of First Nations (AFN) released an environmental scan in 2015, titled: Best Practices and Community-Based Supports and Diagnostics for Fetal Alcohol Spectrum Disorder (FASD). This resource lists existing FASD-related strategies in Canada, at both the national and provincial/territorial level (Assembly of First Nations 2015, 11). In terms of national strategies, AFN lists the following resources:

- Health Canada's It Takes a Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative, A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects (1997), which details historical background and cultural contexts necessary to addresses FASD prevalence;

- Public Health Agency of Canada's Fetal Alcohol Spectrum Disorder (FASD): A Framework into Action (2005), meant as a guiding document for frontline workers providing FASD-related services; and

- Native Women's Association of Canada's NWAC-FASD Action Plan (2010-2015), which details key objectives in FASD-related services, such as capacity building among workers, policy makers, and researchers, and increasing FASD awareness and education within communities.

3.4 Promising Practices

There are two streams of promising practices relating to FASD-related prevention, supports, and programs: 1) promising practices for FASD prevention; and 2) promising supports for those living or affected by FASD. Additionally, there are overall promising practices in ensuring the implementation of culturally appropriate, meaningful, and accessible FASD-related care for Inuit communities. These will be discussed below.

Promising Practices for FASD Prevention

In terms of promising practices for general FASD prevention, the Government of Canada website on FASD stresses that early intervention is a key priority in addressing the effects of FASD. Early intervention can lessen the effects of FASD symptoms and build individual and community adaptability (Public Health Agency of Canada 2017).

The Alberta Clinical Community-Based Evaluation and Research Team (2018) developed several aspirational practice principles when working with individuals affected by FASD. These four overarching principles include: consistency, collaboration, responsiveness, and proactivity. A selection of the organizational best practices include: consistency, collaboration, responsiveness, and proactivity. A selection of the organizational best practices identified in the report include: the importance of attending to the delivery of supports, support worker education, implementing appropriate hiring practices, early diagnosis, bolstering individual supports, improved education on FASD, improved support for accessing medical care, preventative mental health supports, managing sexually exploitive situations, secure housing, family supports, financial aids, legal support, and others.

Promising practices regarding FASD prevention include the involvement of multiple actors. This includes awareness and education through various outlets that can reach a wide audience. For example, there is a need for targeted awareness campaigns for pregnant people – particularly those with a higher risk of alcohol consumption during pregnancy (i.e., those experiencing substance use, trauma), as well as more general awareness campaigns that target community understanding and awareness of FASD (Nunatsiaq News 2019b; Pauktuutit Inuit Women of Canada 2013).

Furthermore, awareness and education campaigns need to communicate consistent messages and recommendations regarding the risks of alcohol consumption during pregnancy, as ambiguity surrounding acceptable levels of alcohol consumption during pregnancy creates confusion and substantial risk for women navigating a healthy pregnancy. This is of particular importance for medical personnel giving advice and guidance to women and families (i.e., nurses, doctors, counsellors) (Pauktuutit Inuit Women of Canada 2013). In Nunavik, midwives have been praised as a valuable resource for FASD counselling and support for women (Pauktuutit Inuit Women of Canada 2013).

Pond Inlet, Nunavut. Photo courtesy of The Firelight Group.

Promising Practices and Ongoing Support for Those Affected by FASD

In terms of promising practices regarding ongoing support for those living with FASD, there is a need for comprehensive and multilevel approaches to addressing FASD in Inuit communities. FASD has been identified in the literature as a community issue and priority, rather than solely an individual matter. A multilevel focus on FASD means addressing FASD at the individual level, family level, and community level (Health Canada 2005a). For example, Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD handbook described the "Wrap Around Model" of care, an approach that involves support and collaboration among a number of actors, including "families, schools, elders, and other helpers, "where services and care plans are designed and implemented in a way that best suits the individual (including their "strengths, values and wants and ways of doing things..." (Pauktuutit Inuit Women of Canada 2006, 28). Key promising practices or "criteria for success" of the Wrap Around Model include the following:

- Services are community-based;
- Services and supports are tailored to the needs of the individual or family, and support family involvement; and
- The model includes a balance of formal (medical) services and informal (community, familial or cultural) resources and supports (Pauktuutit Inuit Women of Canada 2006, 28).

The wrap around approach provides a meaningful example of culturally appropriate and accessible services for Inuit communities. As stated in Katujjiqatigiitsuni Sanngin (2016), the Wrap Around model is a natural occurrence in Inuit communities.

The priority of early intervention is echoed by Nunavut MLA for Iqaluit-Manirajak Adam Lightstone: "Early intervention is crucial for those living with FASD, as we must assist them to learn to live with their disability before it is too late" (Nunatsiaq News 2019b).

Finally, effective and accessible services and programs should adhere to the cultural protocols of the communities in which they are provided. As stated in the Regional Action Plan for Public Health in Nunavik (2016-2020), effective programming should “reflect traditional Inuit values and approaches,” and should be offered through a strength-based lens that honours the resilience of local community members (Nunavik Regional Board of Health and Social Services 2017, 18). Piruqatigiit echoes the messaging of promising practices by championing for a localized service model to address FASD needs. This includes grounding evidence-based research FASD practice, as well as Inuit Qaujimajatuqangit and local language.

To ensure accessibility and relevance, the translation of resources into local dialects is a key promising practice in ensuring culturally safe and accessible support for Inuit communities. As demonstrated throughout this environmental scan, there are a number of national and regional programs and resources that may not provide the intended level of support to Inuit communities given the language barriers present when not translated into the local language.

4. WHAT WE HEARD

This section provides a summary of the responses from the community members and key service providers that we spoke to in the communities of Kuujjuaq, Montreal, Edmonton, Inuvik, Iqaluit, Ottawa, and St. John's, as it pertains to the community attitudes and perceptions of FASD. The findings from participants are organized around these four sections:

- **Section 4.1** Understanding FASD in the context of Inuit Communities.
- **Section 4.2** Community Understandings about the Effects of FASD.
- **Section 4.3** Community Understandings about the Prevalence of FASD.
- **Section 4.4** Needs and Opportunities.

As mentioned in Section 2.3, the results are not intended to generalize FASD across Inuit Nunangat, but provide a high-level snapshot of how FASD is experienced, understood, and responded by the individuals who participated in this research.

4.1 Understanding FASD In the Context of Inuit Communities

4.1.1 What People Know about FASD

In order to conceptualize how FASD is understood within the context of Inuit communities, community members and service providers were asked to share their understandings about what FASD is. Overall, participants understand FASD is a brain-disorder that can affect an individual's ability to process information, self-regulate, form social relationships, and connect behaviours with consequences. Some community members understand that FASD can also affect a person's facial features. Some community members and service providers, however, clarified that many people living with FASD do not have sentinel facial features, and this is largely an outdated and unreliable assumption.

Service providers in Yellowknife and Iqaluit emphasized that FASD presents itself differently and on a spectrum of functioning for every individual. Some individuals with FASD may experience learning challenges and continue to exemplify strengths in other areas, such as having high intelligence quotients (IQs).

Since this is not well understood, the FASD service worker in Yellowknife suggested that people with FASD can be misdiagnosed and referred to services that aren't necessarily appropriate for them.

Assumptions surrounding the cause of FASD were discussed in interviews. For many years, FASD was assumed to be the direct result of people drinking while pregnant. While FASD is linked to prenatal alcohol exposure, a service provider from Inuvik explained that FASD is more complex than an alcohol-related disorder; it is also inextricably linked to multitude of social conditions and behaviours. Specific strategies for individuals with FASD may be required to meet their needs.

> *I think a lot of people still think of FASD as problems only related to you know, women who are alcoholics or heavy – substance – users of substance and also that it's an Indigenous problem … I think that there's just a lack of understanding of FASD as a brain-based disorder. A lot of people think that there's a recipe solution to FASD that people can come in and get them strategies, a list of strategies and they're going to work, without kind of understanding some of the underlying conditions that lead to behaviours that lead to learning difficulties whatnot. (Service provider, June 3, 2020)*

Another service provider and community member from Inuvik explained how FASD and its causes are linked to factors beyond alcohol consumption, such as stress, limited supports, and environmental conditions.

> *It's not only for me when I think of fetal alcohol syndrome, but fetal – It's in general that environmental stressors, the lack of medical assistance, the lack of knowing even like. So you think of the really, really early stages children have rights to be born healthy. … So when we look at fetal alcohol syndrome, we're going to identify stressors … Because if they [parents] don't have enough food on the table, they're worried about rent those are stressors, environmental stressors that number one effects the response of the partner, or even the mom and the happy development of their baby. So it's just really like, it starts right here. (Service Provider, April 7, 2020)*

The extent to which an individual might be affected by FASD was described by one parent in Iqaluit as being attributed in part to the biological parent's maternal health, metabolism, stress, nutrition, the type and amount of alcohol they might have consumed, and when within their pregnancy they consumed it.

> *No two people are going to be exactly the same, you know, depending on pattern of exposure, maternal health, you know, mom's stress, food, and all of the ways that they process alcohol and how that impacts and timing and all of that stuff but and the type of alcohol used. But yes, it affects the family. (Service provider, May 5, 2020)*

A number of community members spoke about learning about FASD by proximity to family members who had it. One parent from Iqaluit disclosed a range of behaviours that can arise in children with FASD, such as being distracted easily, dealing with anger management issues, as well as being hyperactive and loud. These behaviours, they explained, can often appear in adults who have FASD, especially if there are limited supports available for them.

> *From my observation in family members that do have FASD, they grew up not being able to pay attention as well as they want to. They may get distracted easily and their anger thing. They have anger management issues. They also have a tendency to be very hyper, but unknowingly be hyper and also very loud. So that's my observations with the child but it's also because that child doesn't have the proper support. And as adults, grown adults with FASD, I think it is very similar to poor attention and unable to be consistent with the things that they are doing and moving to be told to calm down a lot or to take a minute or two to calm down a little bit. Also not being able to like say the right things or keep a pace like a run-on sentence where they just keep talking and talking about and not being able to stop or unable to control yourself in anyway. (Community member, August 19, 2020)*

FASD was described by participants as a brain disorder that may be linked to alcohol consumption, but also inextricably linked to a range of environmental and social conditions that may affect an expectant parent's well-being. Today, FASD is increasingly understood as being inextricably linked to multitude of social conditions and behaviours. Participants shared knowledge that children and adults who are living with FASD experience a range of behavioural and cognitive challenges; however, many individuals with FASD exemplify strengths in multiple areas of their lives.

4.1.2 Risks and Protective Factors

Community members and service providers alike spoke about how they understand and make sense of the risks and protective factors of FASD. For many, risks of FASD are not limited to alcohol consumption during pregnancy. Risks also extend to social and cultural conditions that may contribute to FASD, such as intergenerational trauma and stigmatization, lack of information on FASD, lack of access to appropriate medical and social services, as well as housing and food security.

Alcohol consumption during pregnancy is largely understood as being a primary risk factor for FASD, especially among community members. While a number of service providers recognize that this is not the only risk factor, public perceptions about FASD often attribute it to the parent's behaviour. A service provider in Inuvik spoke about how alcohol consumption does not mean ill-intent, and that there may be other risk factors that the parent needs support with.

> *Alcohol use stems from something else. Like no mother, in my mind would ever drink with the intention of harming her child, like I said. So what is the reason for the drinking, until you get to that root how are you supposed to combat the, the syndrome right? (Service provider, May 25, 2020)*

Some community members suggested it was common for young women and girls not know that they are pregnant for several months, which has sometimes been attributed to limited sexual health education in northern communities, as well as reduced access to appropriate medical services. In some cases, this was attributed to women's experiences of sexual assault. During the period of not knowing about a pregnancy, young women may be vulnerable to prenatal alcohol exposure (PAE) as they may be partaking in behaviours that they otherwise would not be if they knew they were pregnant. And when a parent does become aware of a pregnancy, those residing in Inuit Nunangat have limited access to appropriate maternal health care and diagnostic clinics (once the child is born / is a few years old). Most access health care and diagnostic clinics in Yellowknife, Iqaluit, or Labrador-Grenfell Health.

Inconsistent messaging around alcohol consumption has contributed to confusion and misunderstandings about FASD within Inuit communities. Service providers from urban and Inuit communities spoke about the unclear messaging that many Inuit women and families receive, particularly around alcohol consumption. For instance, service providers in Iqaluit and Ottawa spoke about how they're often asked by parents about the "minimum amount" of alcohol that is safe to consume during pregnancy. This question, they report, is not answerable as there is no known safe amount of alcohol, FASD is not caused solely by alcohol consumption, and individual women will experience consumption differently.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

> *We, we need to get really consistent messaging out there. Because they're even in the media. You'll see some people saying well, you know, a couple of drinks isn't harmful or in moderation alcoholism isn't harmful. And the thing is, we can't – research can't tell us what is the minimum amount that doesn't cause harm. Plus, it's really individualized, like the studies have shown two women at the same point in pregnancy who have had the same amount of alcohol can have very different outcomes … It also depends on things like stress while they're pregnant and nutrition and their own metabolism and whether they've taken other substances or things like that. So, so we can't tell what a safe amount is. So, the only thing we can do is say no alcohol. That's, that's the safest choice. So, we need that out there consistently we need physicians to receive training about FASD in medical school … I can't tell you how many times we do workshops and then people will come up to us privately after and say "but my doctor said it was okay to drink in moderation in pregnancy." (Service provider, May 13, 2020)*

Alcohol consumption within Inuit communities is frequently closely linked to the stigma associated with FASD that many community members and service providers spoke about in all communities. Some community members in Montreal spoke about how alcohol has become a social norm, which has become ingrained into everyday life. These social pressures can add to challenges in stopping drinking, particularly when it's closely connected to friend and family gatherings, and becomes a part of everyday life.

Alcohol consumption was described by participants in Montreal, Ottawa, Inuvik, St. John's, and Iqaluit as a social condition that is rooted in intergenerational and colonial trauma. Service providers in Edmonton and Ottawa shared their experiences in observing the links between alcohol consumption and intergenerational trauma, recognizing that prenatal alcohol consumption is more complicated than being a cognitive choice on the parent's part.

> *Alcoholism is hereditary, and then FASD can cause more addictive personalities, major risk factor there. We see a lot of cases where parents had FASD, then had children with FASD, cycle continues, more addictions, etc. (Service provider, May 13, 2020)*

> *I think that [risk factors] is about, you know, like their own intergenerational trauma and their own history and that alcohol might not be a choice. It might be their coping mechanism. It might be a lot of things to them where it wasn't. And it could be also not fully understanding the impacts of what that means… (Service provider, May 14, 2020)*

Numerous participants spoke about their awareness of alcohol use and its complicated relationship with many Inuit families living in northern and urban communities. A community member from Ottawa suggested that a harm reduction approach is more constructive for pregnant people – particularly parents with substance use issues – rather than preaching abstinence.

> *Well it is obviously frowned upon because we know better now – it's not very acceptable. But there is, with woman, it's not just alcohol but also with drugs and severe addictions, where it could be detrimental for the woman to stop drinking. So there is harm reduction and organizations that have been providing programs to help women as far as I know. (Community member, August 31, 2020)*

Community members and service providers from Edmonton, Inuvik, St. John's, Yellowknife, and Iqaluit observed that FASD rates tend to be lower in middle class families when compared to low-income families. An Inuvik service provider suggested that social stressors, such as lack of housing or involvement with the legal system, can exacerbate the risks of PAE and parent's ability to provide their families with the necessary supports.

> *[Parents] have suffered all the secondary effects, like losing their housing and not being able to keep a job, and living in poverty, and not getting kicked out of school, and going through the legal system … Children and their children may have the effects of alcohol use and then they're now they're trying to cope with. Not only their own limitations, but the people who are least equipped are trying to support this child who [has] very high needs that any one of us would be really challenged to care for … it's really a difficult painful thing and it's something that women bear the brunt of, right? It was never your father who was drinking, [it] was your mother … and those mothers are in pain. (Service provider, February 28, 2020)*

Participants stressed the importance of recognizing that knowledge and awareness about prenatal alcohol consumption is not enough to 'prevent' FASD. Other service providers in Iqaluit, Kuujjuaq, Inuvik, Yellowknife, Ottawa, Montreal, and Edmonton suggested that more comprehensive prenatal care needs to be provided to Inuit parents' and families, both to prevent FASD and support women with other health and social service needs. This includes looking at the protective factors from a more holistic perspective when exploring supports for FASD, such as a parents' and families' mental health, cultural well-being, sexual health, food security, and access to safe housing.

> *...if we were to provide like comprehensive prenatal care, and if we had in communities and if we had comprehensive sexual health care, if we had food security and safe housing and all the social determinants of health were like on par with average Canadians, that's actually FASD prevention. (Service provider, April 24, 2020)*

4.1.3 Attitudes and Behaviours towards FASD

Community attitudes towards FASD are varied, complex, and rooted in social and cultural environments. This is due largely to the variations in community members' knowledge and awareness about the risks and protective factors described above.

A community member and service provider in Iqaluit explained how community attitudes and behaviours towards FASD have changed over time. Knowledge and awareness around FASD have improved, as well as communication and messaging in communities about FASD.

Sanirajak, Nunavut. Photo courtesy of The Firelight Group.

> *So, I think that like historically Inuit knew that FASD was something that they wanted to prevent. And then, you know like with colonization and contact and the introduction of alcohol into communities … from the 90s on, people are really aware of what FASD is and I think that there is a certain amount of like wanting to intervene. There's definitely different cohorts that, like, know the difference. And I'm kind of hopeful like I've I feel like maybe my parents' generation and like my generation. I'm 35. I feel like our generations were probably more impacted by FASD because people didn't know as much and continued to consume alcohol while pregnant, and there wasn't really support for it back then and there was more shame stigma, right? I think things are changing. I think that like the Department of Health is putting out more messaging around like supporting healthy pregnancies and supporting pregnant people and starting to have more consistent language around FASD. Sometimes they don't always communicate that effectively or in a culturally sensitive way and, I think that there's starting to be a shift right. (Service provider, April 24, 2020)*

Some community members in urban centres, however, expressed continued challenges when seeking support for FASD. One of the focus group participants from Montreal recognised how difficult it can be for pregnant people who may be drinking and the lack of support available to them – sometimes within the community.

> *…there's not a lot [of people] in the communities that are willing to listen to somebody who's under distress. You know, pregnant and drinking. You know it's hard. It's a very tight knit community but yet when it comes to something very important like this, not very many people are open to listening to somebody who's six months pregnant and drinking. (Community member, February 2, 2020)*

There are varying attitudes and behaviours towards alcohol consumption. One community member from Iqaluit explained how they were aware of the risks; however, they also knew that if a parent was unable to avoid alcohol consumption, then they at least know to take additional care in their pregnancy. This may include, but is not limited to, speaking with their families about their pregnancy, and nurturing their support system.

In Inuvik, a community member and service provider noticed how people's attitudes have shifted towards one of support for one another. The community is working hard to reduce blame and anger towards birth parents who drink alcohol during pregnancy, and instead understand how they can support and care for parents who are experiencing challenging situations.

The need for improved Inuit-focused education and training on FASD was identified as a critical need for communities. Service providers and community members recognize that when FASD is misunderstood, this can lead to the stigmatization of children and families who are living with FASD. Improving education and awareness about FASD has, in part, been attributed to the positive change in attitudes about FASD, as people can start to feel more open and supported.

> *I think introducing it to children at a young age might actually help them to, to understand why their classmate is going through this or understand why in the future they are going to have to be patient, you know, with the circumstances. I also think that at birth might actually help a lot. So, like I said before a lot of people are ashamed or become ashamed by other people or that their child has looks with FASD but if it was if it was careful or respectful or more like right at the beginning of birth or even in pregnancy then the, the parent might actually be able to talk about it more and that will be able to be giving the resources that they need or the support. (Community member, August 19, 2020)*

At the heart of the attitudes and behaviours of Inuit community members was the desire to protect and support their family members with FASD. A community member from Iqaluit described how community attitudes and behaviours towards children with FASD are shifting for the better, at least among Inuit families. While the education and public system may still be catching up, the community member described how Inuit families are gaining positive attitudes towards caring for children who may have FASD;

> *I know that for sure a lot of people are more aware now, whether they're pregnant or not. I think they are just more aware and trying to care for it [the child] rather than preventing it [FASD] from happening … But in the schools and public workers, I think don't understand it as much as a parent would, like the attitude toward a child with FASD. But with pregnant woman, in my community, yes I think they have a different attitude, and more positive with everything they have a different attitude. (Community member, August 19, 2020)*

4.2 Community Understandings About the Effects of FASD

What is known about FASD at a clinical (or practitioner) level can vary from what is known about FASD at a community level. For example, while FASD is generally known to be linked to alcohol exposure in the womb across populations, the knowledge of how FASD may impact an individual over the course of their life varies. Moreover, FASD can affect people differently depending on their stage in life, in addition to affecting familial relationships and community cohesion.

While FASD may begin in the womb through prenatal alcohol exposure, children are rarely diagnosed with FASD before they are toddlers. Many individuals are never diagnosed at all.

Furthermore, a number of practitioners emphasize the importance of early interventions (both prenatal and pre-conception) to minimize the prevalence of FASD. The reality for many Inuit families, however, is that a number of expectant parents have limited awareness of, or access to, necessary and appropriate social and economic supports.

Some developmental challenges and behaviours linked to FASD may be recognized in infancy, which can grow and evolve throughout childhood and into adulthood. Each stage of life for individuals affected by FASD can lead to different psychological, social, physical, and developmental effects – all of which may be responded to differently by the individual's family and community. While FASD-related behaviours are largely attributed to behavioural challenges and may be understood by a person's family or caregiver, FASD continues to be misunderstood and stigmatized at a broader level. Efforts are underway to champion community-driven and Inuit-led approaches for promoting FASD-related education and awareness, and to bridge the gap between what is known about FASD at a clinical level versus community level.

The findings presented below provide a snapshot of how some families understand FASD through various life stages, and how this resonates within Inuit families and communities more broadly.

4.2.1 Children with FASD

Some of the participants who have children with FASD spoke about its lifelong effects at different developmental stages. Some parents and service providers spoke about prenatal interventions that can provide supports, other parents were not aware of their child was prenatally exposed to alcohol, and were therefore surprised to see FASD symptoms in their child. Such was the case for one parent from Kuujjuaq.

> *I started seeing as soon as my last child was born. I noticed that there was some differences in my child. I, my three first children were very normal. And they were not developing cold, or runny nose. They were having fever which was very natural when they were teething. But I noticed that my fourth child was always, wow. What I could say was her health was poorly, and the first three ones. And I didn't realize until much later that I could be the cause of alcohol because I was drinking. And I was smoking cigarette, which I didn't do to my first three children. I was very, very depressed back then after my third child. That I, I regretted to this day. (Community member, February 6, 2020)*

Behavioural changes were often described as being a key indicator for children's prenatal exposure to alcohol. Behavioural challenges such as a child's ability to self-regulate, or demonstrating more frequent and extreme and outbursts, were explained as common symptoms of FASD. As explained by a parent in Iqaluit, their child has complex behavioural needs that require specific attention so that her strengths can be seen and acknowledged.

> *In our family, for example, our child's FASD profoundly affects their ability to self-regulate. They're so bright and that really gets in the way of them being seen and understood, especially in a school setting or socially, as having exceptional needs or differences. So our goal is not to other them ever, at the same time you have to advocate for them to have equitable access to what they needs to be safe healthy, you know learning and thriving. Their needs are so, so complex and so high and they're so at risk of harming you know themself and us. We have to be 24/7 supervision. (Community member, May 5, 2020)*

The table below highlights key findings from literature and participant observations about children with FASD.

Table 2: Children with FASD Summary

	Literature Highlights	**Participant Observations**
Children with FASD	• Preconception and pregnancy are critical stages for FASD awareness, education, and intervention (Pauktuutit 2015) • Children with FASD may have difficulty with learning, memory, emotional regulation, attention and concentration, hyperactivity, social relationships, sensory processing, difficulty with process and abstract thinking (Piruqatigiit 2020) • FASD is often invisible. Many children are not diagnosed until school-age (CanFASD n.d.)	• Observed impacts from consuming alcohol while pregnant, often once their child was older • Behaviour changes at a young age include difficulty self-regulating behaviour, as well as more frequent and extreme and outbursts • Behaviour needs for children with FASD are complex • Children with FASD are entitled to a safe and healthy environment

4.2.2 Adults with FASD

A central challenge for adults living with FASD is being misunderstood. For example, service providers in Yellowknife, Iqaluit, and Inuvik observed how adults with FASD might still struggle with an attention span, which then might present itself as unable to maintain consistency within a job or relationship.

The inability to self-regulate may be interpreted as an individual having poor impulse control and decision-making skills, when in fact these are often a result of FASD. The inability to self-regulate and difficulty with impulse control and decision-making can lead to frustrations among adults with FASD, whose disability is often invisible and therefore not accommodated.

Adults living with FASD may experience similar effects as when they were children, however, as their circumstances change, so might the supports. A service provider in Yellowknife explained that once an individual with FASD diagnosis or exposure turns 18, support services can become complicated – particularly for those who were not officially diagnosed. Some adults may be required to undergo an assessment to access services, which can be beneficial for adults who were never diagnosed as children. They explained that with the adult diagnostic clinic in Yellowknife there is hope that more adults can get a proper assessment so that they can receive the appropriate supports for their needs.

Adults with FASD were also understood as being more vulnerable to being targeted by coercive and predatorial behaviours. Where some adults may not have the cognitive ability to connect action with consequence and may have difficulty with abstract reasoning and social cues, their likelihood of being coerced or assaulted can increase.

Some community members spoke about how people with FASD may be at risk of being targeted by individuals involved in sex trafficking or being victims of sexual assault.

Service providers, particularly from Yellowknife and Ottawa, recognized that adults living with FASD require more support. In many cases, adults with FASD can feel isolated from a lot of the FASD initiatives, which are targeted towards infants and children. Providing more funding and improving adult programming was identified as a key need and opportunity for FASD programming. Programming should include life skills and working on educating the general public on being compassionate and understanding towards adults in their community with FASD.

Iglulik, Nunavut. Photo courtesy of The Firelight Group.

The table below highlights key findings from literature and participant observations about adults with FASD.

Table 3: Adults with FASD Summary

	Literature Highlights	Participant Observations
Adults with FASD	• Obtaining a diagnosis for adults with FASD is very limited (AFN 2015) • More adult-specific and lifetime supports for individuals with FASD are required (AFN 2015) • Some adults with FASD (diagnosed or not) may deal with depression, difficulty with post-secondary school, legal trouble, substance use issues, and homelessness (Health Canada 2017) • Support recommendations for adults include income support, housing, adult services, counselling, rehabilitation, social work support, and more (Northwest Territories Health and Social Services Authority n.d.)	• Many adults with FASD are not diagnosed • Adults with FASD can be misunderstood • Difficulty with self-regulating may be interpreted as having difficulty with impulse control and decision making • Adults with FASD may experience difficulties to hold a job or with relationships • Supports for adults with FASD are limited • Adults with FASD may be more vulnerable to predatorial behaviours

4.2.3 Experiences of Families Affected by FASD

The effects of FASD were also discussed at a family level. Family dynamics and parent-child relationships, for example, can be strained, particularly when various family members may struggle with alcohol use. One parent in Kuujjuaq explained how their struggles with substance use has extended down to their children, which has led to a difficult situation for them and their child.

> *I guess they're [my child] now suffering also, they wants to stop drinking but they have difficulties. I blame myself for that. Although I sat down with them and explained to them my situation. I, I know that if I had not drank, it could have been different … I can't say it's because I drank from my pregnancy that they're like that because, I see a lot of people do that. Drink heavily even though their parents went drinking before. But it, it kind of haunts me. I explained to them in the past, why, what, what might have cause. I told them that I am to blame and I didn't want to hide anything from them, I told them that I drank when I shouldn't have drank and smoked. They seemed pretty normal [neurotypical] and they don't show any symptoms of behavioural [issues]. (Community member, February 6, 2020)*

Raising a child with FASD can place stress on Inuit families. When adequate supports are not available for families living with FASD, various family members are often relied on to provide care, such as siblings and grandparents. One grandparent from Inuvik explained how they were frequently providing care for their granddaughter with FASD, as their adult children live in overcrowded housing. A community member from Iqaluit who has siblings with FASD explained they end up providing care for their family members in order to alleviate the pressures on their parent.

> *My mom was told by the doctors that my, our first adopted sibling was [a person with] FASD so they gave her all the information and then my mom would talk to me as best as she could just to understand because she would tell me that I would get frustrated with them. You know she would be like baby just to let you know they are going to be a little bratty you know. Like just to get me to understand that they are going to be in your face you know, like things like that. They weren't bad like that thankfully but you know that's the kind of things that she was told about from the doctor that you might experience these things so my mom would always try to tell me like right away because I was the big sibling you know? I was a single child my whole life until they came in so it was like right off the bat, all my siblings came in and it was like wow, all my siblings were [people with] FASD except my older sibling. (Community member, September 3, 2020)*

Other tensions that have arisen within families include the level of care and attention that many children with FASD require. This was explained as being stressful on other familial relationships, as it can impact a caregiver's capacity to be present and attentive to other family members. Without appropriate familial supports, the energy required of parents can be taxing on the family unit, which was described by a parent in Iqaluit.

> *... within a family or a household the support to family members with FASD would be needed, much more needed than any other family in that often takes off to a jealously thing or just – not ungrateful but like on an understanding like "oh you're always thinking this person, or doing things for that person." ... if everyone has something to do and one of them has to take care of the family members with FASD, and then it becomes like "oh no, I did that last time, it is your turn." And that also could create time tension. I find a lot of the impacts of having to take care of someone with FASD with in the family just generally has to do with like the relationship with yourself, or all not agreeing on the same thing for how to take care of the child, just different perspective of the FASD. (Community member, August 19, 2020)*

Another parent from Iqaluit explained how FASD affects their child's behaviour, which can include lashing out or expressing anger towards family members. This parent explained the importance of exercising patience and understanding with their child, knowing that they are not always aware of how their behaviour may affect others. Practicing patience with their child, the parent explained, has allowed her familial relationships to strengthen and remain healthy.

> *It's [FASD] been a benefit for my family because it's been kind of a reality check because we all have to learn to be a lot more sensitive. I'm the parent of the family so with all my siblings I'm always messaging and telling them just before anything happens to let them know like hey, they might lash out they might go in your face ... they're going to disagree with like half the [stuff] you say so you have to be careful with that. But at the end of anything, just know it's not their fault. Just because, you know, like it's always just that you guys need to understand that, you know if they lash out but they don't realize that it's so negative. They don't understand that and you know, that's something that has changed everybody's relationship between each other – it's been so much healthier. Because now we're all like hey, wait, if I do that, you know growing up for me, it wasn't like that. (Community member, September 3, 2020)*

The table below highlights key findings from literature and participant observations about experiences of families affected by FASD.

Table 4: Experiences of Families Affected by FASD Summary

	Literature Highlights	**Participant Observations**
Experiences of Families Affected by FASD	• Parents of children with FASD also require supports to raise their family and cope with the challenges they face (Pauktuutit 2015) • Caring for a family member with FASD is challenging, and can exacerbate other social issues, such as housing, learning and education, food security, and others (AFN 2015) • More social workers are starting to work with families, not just individuals with FASD (Public Health Agency of Canada 2017)	• Family dynamics have the potential to be strained • Struggles with substance use can be cyclical, and be passed on to children • Family networks are frequently relied on for care due in part to lack of services • The energy required by the caregiver can be taxing on the family unit • Practicing patience with children with FASD can strengthen familial relationships

4.2.4 Community-level Effects of FASD

Community members and service providers alike described how FASD effects are also experienced at a community level. Given the tight-knit nature of many Inuit communities, there is often a feeling of familial responsibility to raise and care for Inuit who are living with FASD. A community member and service provider in Inuvik explained how the sense of responsibility to care for those with FASD is felt at a community level, which can be challenging given the lack of supports and services.

> *They bring the community and a lot of communities in general feel bad because there were times when it was kind of the whole community, you know, who feels sort of like they were all in on it and responsible. And it so when you have a community also you have people in the community who really want to do something. That's their brother. That's their grandson. That's their whoever right their daughter whoever and there are no services there available. (Service provider, February 28, 2020)*

FASD is an invisible disability. Because of this invisible nature, community interactions with individuals with FASD were described as being sometimes harmful. In some urban settings, for example, Montreal focus group participants explained how they are frequently stigmatized and mistreated, particularly when it comes to alcohol consumption. Challenges for individuals with FASD may actually be mistaken as exhibiting behaviour related to substance abuse. This misunderstanding can exacerbate the stigmatization and mislabelling of FASD as an "Indigenous issue" and direct cause of alcohol consumption.

The lack of public knowledge and awareness about FASD was cited as a core element of community-felt effects. Be it in an educational setting, workplace, or when dealing with the judicial system, community members and service providers all shared the difficulties that many children and adults with FASD face within these situations. The challenges many children and adults face in these situations were explained by a service provider from Iqaluit.

> *Kids with FASD don't learn the same as other kids, they can't be disciplined the same way as other kids so and it goes all around justice system, they're the ones that revolve in and out in and out. Because it's like putting a kid in a room and count to ten and come back. You know, or sending and adult to jail and come out … it doesn't actually change behaviour … So a lot of these kids cycle through, get into trouble in school and getting into trouble with the law and it you know, under-employed – unemployed, they're very impulsive and are risk takers sometimes and a lot of them, they end up with substance abuse. And I find, there's like a cycling, you can see it happening, right? If you don't have the right resources right at the beginning … you can see them kind of spiral down. It's heart-breaking. 'Cause I've seen it over and over because we in the system don't have the resources to support them. And it starts with diagnosis I think. (Service provider, April 22, 2020)*

Importantly, there are resources and centres that are operating within Inuit Nunangat that offer community-based support for FASD. The Piruqatigiit Resource Centre in Iqaluit, for example, focuses on Inuit-guided approaches to support parents, families, and individuals who are living with FASD. As one service provider explained, their approach is intended to replace blame and stigma with education and awareness. Their trauma-informed services attempt to reduce the individual burden of navigating FASD services alone, and instead take a community-driven approach to support, healing, and understanding for Inuit and non-Inuit families.

The table below highlights key findings from literature and participant observations about community-level effects of FASD.

Table 5: Community-level Effects of FASD Summary

	Literature Highlights	**Participant Observations**
Community-level Effects of FASD	• Greater education and awareness about FASD is required amongst health care professionals, early childhood workers, educators, social workers, family therapists, law enforcement officials, and anyone in the judicial system about FASD (Pauktuutit 2015) • More screening support is required within Inuit communities (Pauktuutit 2015) • FASD services ought to be provided that are community-driven, culturally informed, focused in harm reduction, self-determining, and respectful, among others (Can-FASD 2010)	• Communities may take a supporting role for people with FASD, due in part to lack of services • The invisibility of FASD can lead to stigmatization of FASD and Inuit people, particularly in urban settings • Greater awareness is needed in more community settings, such as schools, the workplace, and judicial system • Inuit-guided approaches are helping to improve the narrative around FASD in communities

4.3 Community Understandings About the Prevalence of FASD

To understand the prevalence of FASD, community members and service providers were asked questions related to the following topics, which are broken down into subsections below:

- Prevalence of FASD in Communities; and
- Barriers to Diagnosis.

In sum, the prevalence of FASD in and among Inuit communities is difficult to discern as many children and adults with FASD are undiagnosed.

Many individuals are undiagnosed due to a range of barriers in accessing diagnostic services, including stigmatization, geographical distances to services, cultural and social barriers, limited awareness and understanding about FASD, poor funding, criminalizing Inuit women, outdated medical record keeping, inconsistent access to healthcare providers (ex. fly-in services), and systemic racism.

Inuit parents and families understand the risks of FASD, which can be exacerbated by existing social and intergenerational trauma. Protective factors that have been identified by Inuit families to support the prevention, intervention, and continued care of children and adults with FASD include having access to stable housing, food security, cultural well-being, and appropriate educational and medical services.

4.3.1 Prevalance Of FASD in Communities

> *It's really hard for me to answer how common FASD might be. I, I suspect that it's much higher than what anyone would think. And not just because we're here [in Nunavut], but because FASD is everywhere. (Service provider, May 5, 2020)*

Understanding the prevalence of FASD in Inuit communities is complex. CanFASD estimates the prevalence of FASD as 4% of the Canadian population[10]. Community-specific data on FASD is limited, however, there is evidence that points to higher rates of FASD among children in care (i.e., welfare system, foster care, etc.), and among those in the justice system. Importantly, CanFASD has been working to dispel the misconception that rates of FASD are higher in Indigenous communities (2018), a conclusion that has been made based off of outdated research from specific communities that has been generalized to all Indigenous peoples in Canada.

When community members and key service providers were asked “what is the prevalence of FASD in your community?”, people from each of the eight communities suggested there was not enough data or knowledge around FASD to wholly understand its prevalence. While some data exists on the rates and diagnosis of FASD, it is difficult to gain an accurate understanding of the prevalence of FASD in Inuit communities without safe and equitable access to diagnostic services and consistent medical reporting.

In Kuujjuaq, one community member suggested that it is difficult to understand the rates of FASD as it is not something that is always diagnosed at birth. A service provider in Inuvik suggested that there are children, teens, and adults in every community who have FASD, many of which may be undiagnosed.

> *I don’t know a percentage, but several young children in every community. Many teens and a great many adults ... There are many, many people who are not diagnosed. (Service provider, February 28, 2020)*

SIPPE is one example of a community-driven program that offers comprehensive maternal care support to expectant parents in Kuujjuaq. The SIPPE team meets with community midwives weekly, offers free pregnancy tests, and offers family programs related to substance use, maternal care, and healthy relationships. Their goal of working with every pregnant person in the community is one means of intervening early to support parents who may be at risk of having alcohol-exposed pregnancies.

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[10] In a study completed by Poplova et. al (2019), the prevalence of FASD was conservatively estimated to be 1.8% of students ages 7 to 9 in the Greater Toronto Area population.

Several community members in Inuvik and Iqaluit indicated that children are often not diagnosed, or recognized as having signs of FASD, until they are school-aged. An Edmonton service provider suggested that FASD is often seen in marginalized communities, such as racialized and low-income communities, children living in foster care, and parents struggling with substance use. They also observed, however, that there is also a growing population of middle-aged, university-educated, middle-income families that have children with undiagnosed FASD.

Many community members and service providers shared that FASD is generally not a visible disability, and when combined with low diagnosis rates, this exacerbates the difficulties in understanding its prevalence. The limited visibility – or invisibility – of FASD can lead to public misunderstandings about developmental delays or learning disabilities exhibited by affected individuals.

This points towards the importance of messaging and education about FASD. A number of service providers in remote and urban communities suggested that FASD is likely more common across Canada than the current available data suggests. One service provider in Nunavut emphasized that FASD rates are more common that the data tells us, but reduced funding for diagnosis services have created challenges for obtaining an accurate representation of its prevalence.

> *If you ask the administration and the government, they say "we don't have very much diagnosis of FASD". One, because they cut off all, they cut off all the funding to access services and that's the biggest issue … I suspect that our FASD prevalence is substantial but, because of the barriers to getting diagnoses we don't have the numbers to say this is how many diagnosed children we have. It's, it's honestly been an uphill battle … the numbers that are diagnosed are just are hugely underrepresented. So much so that you can't put any value in them. (Service provider, April 22, 2020)*

Understanding the levels of FASD in Inuit communities is closely linked to having safe and equitable access to diagnostic services, which many participants suggested is not the reality in most communities. While many community members and service providers in the Inuvialuit Settlement Region, Nunavik, and Nunavut stated that many Inuit families have difficulty accessing diagnostic services in their regions, a service provider in St. John's suggested that Innu and Inuit families living within the Labrador-Grenfell Health Authority (which includes Nunatsiavut) have greater access to diagnostic services and multi-disciplinary health assessments than people living in different health authorities in Newfoundland.

Improved access to diagnosis services in Labrador, however, was met with some caution. As the St. John's service provider explained, because there are more diagnostic services available in the Labrador-Grenfell Health Authority than in Newfoundland, more Indigenous people are diagnosed with FASD than non-Indigenous people in the province. This can make FASD appear like an "Indigenous issue", when in reality, there are more Indigenous and Inuit families living within the regional health authority that provides diagnostic services. This stigma contributes to the difficulty of understand the prevalence of FASD when diagnostic access remains unequal across the region.

In sum, it is difficult to quantify the prevalence of FASD in Inuit communities, or even across Inuit Nunangat, as a result of unequal access to diagnostic services. Community members and service providers from Inuvik, Iqaluit, and Kuujjuaq disclosed that FASD is likely more common than any data shows, and that there are likely more people living with FASD than there are diagnosed. Compared to the findings from Labrador and Nunatsiavut, Inuit and Innu families may be diagnosed with FASD more than non-Indigenous people due to the location of diagnostic services, which contributes in part to the stigmatization of FASD and Indigenous families.

4.3.2 Barriers to Diagnosis

As mentioned above, one of the key barriers to diagnosing and understanding the prevalence of FASD is access to diagnostic services. Challenges that were raised by interview and focus group participants include stigmatization of FASD, the physical location of services, cultural and social elements, misunderstandings about FASD, and institutional barriers. The section below reflects what community members and service providers we spoke to reported and are intended to highlight some of the obstacles that Inuit families face within certain urban and remote communities.

Stigmatization

The stigmatization of FASD within remote and urban Inuit communities is central to discussions about diagnoses and prevalence. Simply put, the stigmatization of FASD as an “Indigenous problem” contributes to a number of Inuit women and families not receiving the appropriate level of care when seeking a diagnosis or support, Inuit women and families experiencing feelings of guilt and shame for addressing FASD (which may exacerbate other social conditions), and individuals with FASD not receiving the appropriate level of care required due to lack of social understanding and awareness about FASD.

A FASD coordinator in Inuvik spoke about how the stigmatization of FASD can lead to ignorance and misunderstanding about the level of care women and families may require:

> *So, I think there’s a lot of, there’s a lot of there’s a lot of ignorance. But I, I get the sense that a lot of people want to learn more… I think a lot of people still think of FASD as problems only related to you know, women who are alcoholics or heavy substance – users of substance and also that it’s an Indigenous problem … I think that there’s just a lack of understanding of FASD as a brain-based disorder. A lot of people think that there’s a recipe solution to FASD that people can come in and get them strategies, a list of strategies and they’re going to work, without kind of understanding some of the underlying conditions that lead to behaviours, that lead to learning difficulties. (Service provider, June 3, 2020)*

A service provider in Edmonton described the stigma and stereotypes that can exist within the healthcare profession. For people who come into the hospital, the worker has observed how non-Indigenous people who earn higher incomes are often not asked questions about alcohol consumption during pregnancy, whereas pregnant Inuit frequently are.

> *Women who earn higher incomes are the most at risk and they’re usually the ones not addressed. So, you’ll have like, you know, doctors, for example, who will ask the young Indigenous mom if she’s drinking and then you’ll take in the – and I’ve actually experienced this like my sister, who is a middle-class white girl, wasn’t asked about her use, but my client who is a young Indigenous mom was asked about her use. So, there’s a stereotyping and stigma just in the healthcare profession. (Service provider, May 14, 2020)*

The issue of stigmatization is a central thread in understanding the range of barriers for FASD prevention, diagnosis, interventions, and understanding prevalence in Inuit communities.

Geographical and Transportation Barriers

Unsurprisingly, a number of FASD supports for diagnosis, assistance, and intervention are located in southern urban centres. Community members in Inuvik, Iqaluit, and Kuujjuaq spoke to the limited availability of FASD supports in Inuit Nunangat communities. In order for parents, to access post-natal care, mental health supports, rehabilitation, and FASD diagnosis, it requires travelling down to cities such as Ottawa, Montreal, Winnipeg, Yellowknife, and Edmonton.

For instance, a flight from Iqaluit to Ottawa is three hours; families may need to take two additional flights before some Nunavummiut even reach Iqaluit. With limited funding available for travel, as well as the time commitments required to travel, this option is not always feasible for families.

In Inuvialuit, accessing support services for FASD is challenging for many families. Children cannot attend the diagnostic clinic in Yellowknife until they are seven years old, and there is a limited amount of time that therapists and specialists can travel to the communities in the region. As a service provider explained, the territorial supports are in place to help offset these challenges.

> *Our rehab team's therapist and the doctors will go into all of the communities. Because we service 13 communities total, we also have Gwich'in and Sahtu communities. They cannot – like, our therapists specifically can only go about twice a year so that gives you an idea of how often professionals are able to go into the communities and do the work. Just because their scope is so large and their geographic area's so large. But, like that's another indirect way that services are provided because a doctor will flag a kiddo, and they're flagging them a lot younger now as query FAS. And then, even though they can't go through the diagnostic clinic until they're seven, we follow them and implement supports right away from the get-go. Just to give that family a head start and diagnosis or not like the diagnosis up here really doesn't do much other than provide access to some funding because we don't have the resources, like I said. But we can at least follow along and support the families as much as we can from there. (Service provider, May 25, 2020)*

In some instances, the geographical distance between Inuit communities and FASD support services can displace families. For one participant in Iqaluit, their sibling with FASD was placed in state care in Ottawa.

> *I don't really see my family member that has it [FASD] because they had to be sent down to Ottawa [from Iqaluit] … They didn't know of any support or there was some kind of doctors that were able to give us some information and they would also provide words to prescribe what is a medicine they give you to help with it but that is all that they would give, you know, they would just say oh have another pill but nothing that, no book or show them stuff that might help in the long run with FASD. (Community member, August 19, 2020)*

In larger urban centres, being able to access and afford transportation was one additional barrier to being able to connect with and access FASD supports. For one parent who lives in Ottawa, transportation to access services was a key challenge for her.

In urban centres such as Edmonton, Montreal, Ottawa, and St. John's, community members have to navigate a complicated health care system to figure out where and how to access diagnostic services and support. Service providers in these cities recognize that many urban centres simply do not have diagnostic facilities available to families.

> *One of the other things I would say beyond prenatal support – one of the biggest barriers that we keep seeing in our work is that there just aren't a lot of places to go to get a diagnosis, and we know that the best outcome is early diagnosis and early interventions. So, you can't cure FASD, it's life long, but the best predictor of more positive outcomes is early diagnosis, early intervention, but it's a lot of cities and communities in Canada don't have diagnostic facilities. (Service provider, May 13, 2020)*

In Nunavut, children between the ages of 3 and 17 can access FASD assessment services in Iqaluit, however there are no assessment services for adults within the territory. Adults would have to travel outside of Nunavut territory to access FASD services. Depending on the health region that an individual lives within Nunavut territory, persons from Iqaluit and Qikiqtani region would likely have to travel to Ottawa; for Kivalliq region it is often Winnipeg; and for Kitikmeot region it is often Yellowknife and Edmonton.

In Nunavik, participants said they have to travel to Gatineau or Montreal to access diagnosis, and it can take up to a year of visits to receive a full assessment. Both Nunavut and Nunavik participants suggested that the trip is often long, labour intensive, and expensive, with limited funding to support travel.

Yellowknife has two diagnostic clinics, a child-specific (under age 18) and an adult specific one (over the age of 18). These clinics support families throughout the Northwest Territories, including Inuvialuit. While there are new and improved forms of virtual clinics being implemented, community members still have to wait until their child is at least seven to be placed onto a wait list and then travel to Yellowknife to access diagnosis. There is also limited funding to support travel from Inuvik to Yellowknife for FASD diagnostic services.

Diagnostic services are more readily available for those residing in Nunatsiavut, as the Labrador-Grenfell Health Authority is currently the only health authority in the province offering diagnostic services. Still, there are Inuit and non-Inuit families who live outside of this health authority who do not have access to any diagnostic services. Travel costs and weather delays within Nunatsiavut are also a key consideration for families accessing services.

In addition to the geographical barrier, the jurisdictional barrier between provincial and territorial health regions can also pose a challenge. For example, for those in Newfoundland and Labrador, there is a strict limitation to who can access which supports based on which of the four health regions an individual resides in. It is challenging for those residing in Newfoundland-Labrador's capital, St. John's, to access FASD diagnostic services that are only available in the Labrador-Grenfell region. One participant from Nunavik spoke about the limited capacity that some urban centres, such as Montreal, have for rehab treatment and interventions. They attempted to connect families to the second closest treatment centre in Labrador, however, they were initially rejected and not covered as a result of the different jurisdictions.

Since the pandemic, more supports and services have transitioned to virtual delivery, improving their reach to communities across Inuit Nunangat. Participants noted this was a positive change and expressed reserved optimism about this potentially mitigating the past and current challenges for accessing diagnostic services.

Cultural and Social Barriers

Having access to culturally-relevant and culturally-supportive diagnostic services was highlighted as a key requirement by community members and service providers. Receiving culturally-relevant diagnostic services was described as a challenge by one service provider in Nunavut. Diagnostics, they disclosed, still largely exist within a colonial medical system, which is not always safe for Inuit. This is where Inuit-driven support services, such as the Piruqatigiit Resource Centre, play a central role in providing culturally-based support services for Inuit families in Iqaluit. However, Piruqatigiit does not provide assessment or medical services, and there remains a need for Inuit-guided medical care across Inuit Nunangat.

In Kuujjuaq, community midwives spoke about the importance of working with Inuit parents in a compassionate way, particularly during prenatal screening. When non-Inuit health care professionals screen Inuit parents and ask pointed questions about alcohol consumption during pregnancy, these questions can be interpreted as racist and stereotyped. The midwives emphasized that these cultural and social stereotypes are commonplace for Inuit parents during screenings.

> *Sometimes they are like "okay why do you ask if I drink? Because I am Inuit?" – No, because you are pregnant. That's the difference. But they feel that we think they are Inuit ... and we're stereotyping. And that's because often times they are. And that's their experience with other services.*
> *(Service provider, February 8, 2020)*

Receiving a diagnosis of FASD without Sentinel Features requires parental confirmation of prenatal alcohol exposure. This was discussed as another critical barrier in diagnosing FASD, as the stigma attached to alcohol consumption during pregnancy is so high. This becomes further complicated where children have been removed from their biological parent's care. A FASD service provider in Edmonton discussed how requiring a parent to disclose this information can have negative effects on the parent's mental health, as there is shame and guilt attached to these behaviours. Consequently, this may affect the parents' willingness to access the services they may need.

> *I think it affects the parent because then they don't want to admit. So, a lot of times FASD is getting misdiagnosed because there's, there's a shame in being honest. Instead of the – and, and not and people not recognizing the social determinants of health that are connected to that and, and that people don't go out to harm their child and, and just being, you know, understanding and compassionate to somebody's worldview. And I so I think that impacts just a lot of, you know, personal shame and, and feeling and like guilt and, and just some you know mental health impacts. And then I think on the children it impacts their ability to get this the services they need because of the potential constant misdiagnoses. (Service provider, May 14, 2020)*

One community health nurse in Inuvik explained how there is little incentive for people to self-report drinking during pregnancy to obtain a diagnosis when there are so few support services available. This, the nurse explained, can place substantial mental and emotional strain on the parent, for which they may not receive any supports for. Without the incentive of support for the child's or parent's health, there is little incentive for a parent to self-disclose behaviours that they could be penalized and judged for.

Another social consideration – and sometimes barrier – for Inuit families accessing FASD diagnostic services is the anonymity. In a Nunatsiavut community, one of the FASD referral clinics was located in a separate trailer, making it difficult to maintain privacy and anonymity for those accessing the service. When community members walk to the trailer, the public can see them entering, which limits a person's ability to seek these services in confidence. This is particularly stigmatizing for pregnant people or parents of young children. A service provider who worked in this community has been working on this issue with the community and they are in discussions about relocating the centre to somewhere less visible.

At the core of many diagnostic barriers for Inuit families is the need to improve culturally-rooted and culturally-specific services. Despite FASD frequently being thought of as an "Indigenous issue", the supports are rarely rooted in an Indigenous worldview. While a number of national services are offered in English and French, community members from Montreal, Inuvik, and Iqaluit spoke to the need for resources and supports to be grounded in Inuit values and language.

> *… for somebody that needs like the proper help … it's not Inuk person who's treating this person. But why is it not Inuk? There should be an Inuk or at least somebody and not, not healed by, by another culture … They should be able to heal in their cultural, in their general culture. Not treated by the white or French people. (Community member, February 2, 2020)*

Awareness and Understanding of FASD

Providing Inuit-focused services was identified as a key barrier and opportunity for FASD services being offered to Inuit families. One service provider in Nunavut suggested that historical and cultural education is needed amongst all service providers, and that services should be offered in Inuktitut for Inuit families.

> *I think there kind of needs to be a shift, like, one people need to start like for Nunavut it's really important that all service providers have like a comprehensive education on any new history, colonization and culturally competent care right and that there's at least the willingness that if they can't speak Inuktitut that they learn yeah. Because I think until that shift happens there's always going to be barriers. (Service provider, April 24, 2020)*

Service providers from all regions spoke about the need for improved awareness and understanding about FASD in healthcare, education, and at a community level.

With improved levels of awareness and learning, service providers are optimistic that this may reduce some of the stigma around FASD, and potentially reduce some of the social barriers Inuit families face when seeking diagnoses or accessing supports.

Service providers in St. John's and Ottawa suggested that there are limited diagnostic facilities across their provinces, and throughout Canada, due in part to a lack of awareness or understanding about FASD in healthcare and in communities. Service providers and community members form Inuvik, Iqaluit, and Kuujjuaq suggested that due to the lack of knowledge about what FASD actually is, means that health care workers and social services are likely unable to properly diagnose people, or understand what supports are needed for the individual.

A community member from Iqaluit sees parallels between FASD and how autism used to be understood within communities. They hope that more awareness and understanding can be brought forward on FASD, so it, too, is met with more compassion.

> *I was a long time ago advocating that we just changed the name entirely. Why do we need to call it FASD? Why don't we call it the neurodevelopmental disability that it is? And, and warn about you know, the use of alcohol can contribute to a neurodevelopmental disability and then kids like mine would have access to all the same autism resources and we have access to the same compassion. We wouldn't have to say alcohol in the disability name, you know? (Community member, May 5, 2020)*

The lack of awareness and cultural understandings about FASD within Inuit communities, combined with limited resources and travel required to access diagnostics for some people, is a compound of barriers for families. These challenges were described by a community member form Iqaluit.

> *Oh for sure [people might not prioritize diagnostics] because like the diagnostic process you have to like first have the inkling and then try to ask your nurse or doctor and then they make you travel out and go get it done. And it doesn't happen one day, like it's multiple things, multiple assessments. It's a brutal process, so I think for a lot of people they probably feel like it's not really worth it. Even though in in the long term, like, having that diagnosis is helpful because then that comes – like the accommodations that you need, the access to health care that you need. (Community member, April 24, 2020)*

The presence, awareness, and understanding of FASD is also linked to colonial contact. For example, colonialism in Nunavut and Nunatsiavut occurred in more recent generations, which means that alcohol exposure is a more recent occurrence. This means that some Elders may not have the same knowledge of FASD or understand the risks of prenatal alcohol use the same as younger generations. This colonial barrier points towards the importance of elder involvement in awareness and education-related activities about FASD.

Institutional Barriers

The diagnostic process required can be an onerous process for individuals and families. As explained by several FASD service providers, an FASD diagnosis requires a multi-disciplinary assessment, and can require community members to seek out their own assessments, and to carry their own records along the way.

The requirement to obtain and track personal medical records was another diagnostic barrier identified by community members and service providers, particularly for adults who are seeking a diagnosis, people who are homeless, and those who do not have ties to their biological family.

Tracking medical records can be challenging for individuals who may be struggling with adaptive functioning. If those who are undiagnosed are not able to track medical records, this can exacerbate challenges in receiving social assistance.

> *One of the criteria [for diagnosing FASD] is that you must have evidence of maternal alcohol use during pregnancy. So, we're talking about health records that are 50 years old that are not on a computer system that are stored somewhere in a maybe if they still exist. And so there are you know there needs to be other ways to solidify the diagnosis. People who could be witnesses or give evidence are gone. I mean there's you know, the all kinds of difficulties with that and then lack of services. So, the one of the reasons that I have tried to get people diagnosed is hoping that it will open doors for them to get disability pension to have some kind of recognition if they go before the courts to maybe get into housing services. (Service provider, February 28, 2020)*

Even after diagnosis, service providers and community members recognize that receiving social supports, particularly financial support, can be challenging. A community health nurse in Inuvik described how important it is for them to follow up on funding opportunities for families once they receive a diagnosis, as resources are limited.

> *The diagnosis up here really doesn't do much other than provide access to some funding because we don't have the resources, like I said. But we can at least follow along and support the families as much as we can from there. (Service provider, June 2, 2020)*

Having limited funding decreases Inuit families' ability to access financial resources for FASD diagnosis and interventions. Service providers from several communities have observed an unequal allocation of public and private funds for supporting FASD support services, particularly when compared to other disabilities such as autism or ADHD. Some of these service providers suggested that this is because of stigmatization and misperception that FASD is a "preventable" issue.

Other institutional barriers that families deal with speak to the criminality and risk of losing their children. Some community members described their reluctance to seek out diagnosis for fear of losing their child to the child welfare system or being criminally convicted for drinking while pregnant. One parent from Kuujjuaq explained how a social services agency monitored them for a year after they asked for their child to be screened for FASD. They explained how they were stigmatized throughout the process by healthcare professionals.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

4.4 Needs and Opportunities

As highlighted above, the community members and service providers offered a range of perspectives on FASD, as well as suggestions for improvement. This section summarizes the key areas of opportunities for improving attitudes, awareness, and services on FASD in Inuit communities and beyond.

Opportunity 1: Move towards a "trauma-informed" and "dignity-informed" practice in FASD service delivery

The environmental scan, as well as the interviews and focus groups, revealed that there is work to be done with regards to the language used around FASD. In particular, a number of service providers – specifically, Inuit service providers – are wanting to move away from a "prevention" framework, and towards a "trauma-informed" and "dignity-informed" practice. The language used when talking about FASD affects our attitudes, judgements, and understanding about FASD and how to respond to it.

For instance, discussing FASD in the context of prevention suggests that individuals with FASD may be less valued or unwanted. Furthermore, "prevention" can shift blame towards birth parents. Shifting towards a trauma-informed and dignity-informed practice suggests that there are underpinning social factors behind prenatal alcohol exposure, in addition to encouraging community members, service providers, and members of the public to examine FASD through a compassionate and cultural lens. This is echoed in the work demonstrated by Piruqatigiit, whose programming is centred in Inuit Qaujimajatuqangit and guided by the principles of Tamatta (interconnectedness), Tunnganarniq (fostering good spirit), and Inuuqatigiitsiarniq (respecting and caring for others).

Opportunity 2: Improve Inuit-based cultural supports for people and families with FASD

Overwhelmingly, community members and services providers called for improved FASD supports and services that are community-based and grounded in Inuit values. This includes offering services and programs in Inuktut, training and hiring more Inuit workers in a range of medical and program support positions (i.e., doctors, nurses, social workers, FASD coordinators, midwives, policy positions, elders, etc.), offer land-based programs and services for parents and individuals with FASD, and critically, improve the number of in-community services for communities across Inuit Nunangat. An important opportunity is to increase the number and quality of programs for adults with FASD, and across the lifespan.

Most participants spoke about the cultural barriers that exist between Inuit parents, individuals, and families within a westernized healthcare system. This can lead to a range of challenges for people living with FASD or birth parents, such as not wanting to disclose prenatal behaviours, which can exacerbate stigma associated with FASD within Inuit communities. Programs, services, and supports that are rooted in Inuit values, and delivered by Inuit, can contribute to individual and family feelings of cultural safety.

Kangiqsujuaq, Nunavut. Photo courtesy of The Firelight Group.

Opportunity 3: Improve financial supports for Inuit families in urban and remote communities

Given the expensive costs that many Inuit families incur to access FASD services, participants have called for improved financial supports from territorial, provincial, and federal governments for necessary FASD travel. This extends to transportation costs, such as flights for Inuit families in remote communities, as well as public transportation costs for Inuit families living in urban centres.

While there is desire to see improved in-community and Inuit-led service delivery, many Inuit communities have and will continue to travel to access critical FASD support services for their family members. In some cases, multiple trips may be required to receive the appropriate care. In Inuvik, for example, residents must travel to Yellowknife to access diagnostic services. If families cannot access financial supports, they may not be able to access the necessary services as flights are very expensive in the North.

On a smaller scale, participants within urban centres are required to arrange for transportation to access supports within cities. This is not always feasible for Inuit families, as they may not have a vehicle, or cannot afford the costs of a taxi or bus fare. These are serious financial limitations that may prohibit families from accessing services.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

Opportunity 4: Improve access to diagnostic services for children and adults across Inuit Nunangat

Community members and service providers spoke about the central need to address community member access to diagnostic services. As revealed in the study, diagnostic services are limited in smaller communities, and difficult to access due to a range of barriers (i.e., geography, awareness, stigmatization, etc.).

In recent years, there have been some improvements related to accessing diagnostic services, albeit slowly. Yellowknife for example, has an outreach team that travels to all of the Inuvialuit Settlement Region communities for diagnosis. A similar program is run out of the Qikiqtani General Hospital in Iqaluit, screening expectant parents for prenatal alcohol use and providing assessment services for children with FASD. The SIPPE provides similar services in Kuujjuaq for pregnant people. In short, these community-driven programs have improved access to diagnostic services for Inuit families, which comes from improving funding, examining transportation barriers, and offering in-community services.

Some community members would like to see improved virtual service delivery to alleviate existing transportation barriers. A paediatrician in Yellowknife spoke about how their diagnostic clinic is shifting towards virtual appointments, which was necessary when the pandemic began. While this may not be a solution for every type of program and support, it may serve as a means for connecting remote Inuit communities with healthcare professionals and access to a greater range of diagnostic supports.

Ikpiarjuk, Baffin Island, Nunavut. Photo courtesy of The Firelight Group.

Opportunity 5: Provide Inuit-specific cultural safety and sensitivity training for all FASD service providers, educators, and healthcare workers

A number of community members and service providers would like to see Inuit-specific cultural competency and sensitivity training implemented for anyone working in healthcare or who may work with individuals who have FASD. Service providers and community members would like to see vast improvements with respect to cultural competency within healthcare, education, and social services, particularly for non-Inuit workers.

Cultural competency training was flagged as a critical need for programs related to maternal care and sexual health. In the past, it was not common to discuss sexual health within communities, and maternal health supports were very limited in more remote communities. Community members in Iqaluit and Kuujjuaq all spoke about how the availability of these programs are improving, due in part to some programs being Inuit-led.

Cultural competency training is understood to address issues related to stigma, cultural and institutional biases, systemic racism, residential schools, the ‘60’s scoop, examining personal biases, and more. The intent of cultural competency training is to inform service providers about Inuit culture and history in a positive way, so as to foster stronger and healthier relationships with Inuit women and families. In turn, this may help to improve service delivery, reduce stigmatization within Inuit communities, and improve the access and services being offered to women and individuals with FASD.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

Opportunity 6: Provide consistent messaging about FASD

Messaging and communication on FASD was described by community members as being an important component to understanding FASD. Several community members spoke about how messaging surrounding FASD is often inconsistent, and at times, confusing. In particular, messaging around alcohol consumption during pregnancy is not consistently discussed, and in some cases, Inuit parents are given different advice than non-Inuit parents.

Consistent messaging that is developed and informed by Inuit may contribute to providing clearer communication around FASD, and its causes. For instance, some community members understood that FASD is often linked to a variety of social stressors, but others were unaware of this. Taking holistic and comprehensive approaches can help to improve community awareness, attitudes, and behaviours, as seen in the Piruqatigiit Resource Centre in Iqaluit.

Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

Opportunity 7: Talk about FASD more openly within families, communities, and from a holistic systems perspective within the education and healthcare systems

Participants spoke about the need to talk about FASD more within households, communities, education, healthcare, and the justice system in an effort to improve awareness and understanding. With FASD being highly stigmatized, many people do not always feel comfortable or safe talking about it.

Participants and service providers alike both discussed how the stigma surrounding FASD is slowly eroding, due in part to the push to speak about it more openly. This includes speaking about it in schools with teachers and students, speaking about it with siblings and family members, and improving the range of public supports available to families. While the conversations around FASD within these public and private spheres are slow to pick up, the gradual shift towards openness has made some small improvements for families and individuals living with FASD.

Kangiqtugaapik, Nunavut. Photo courtesy of The Firelight Group.

5. CONCLUSION

This report summarizes the attitudes, awareness, and understanding of FASD within urban and remote Inuit communities, as informed by the participating community members and service providers. On the whole, the community members and service providers recognize that FASD is a complex health issue that is closely linked to a range of social, behavioural, and environmental factors. It is not something that can simply be "prevented" but is inextricably linked to the historical and contemporary landscape of many Inuit communities.

A number of the participants observed how FASD can present itself uniquely within children and adults, many of whom live full lives without a diagnosis. A number of parents of children with FASD (diagnosed and undiagnosed) spoke about the importance of patience and compassion for maintaining healthy family relationships amidst a difficult environment with limited supports. The importance of community and familial-level supports is pivotal to many Inuit families, both in urban and remote settings.

The prevalence of FASD within Inuit communities is difficult to pinpoint due in part to the difficulty many families experience accessing diagnostic services. Some families and individuals never receive a diagnosis due to a range of factors, such as stigmatization, geographical distance and financial constraints, cultural and social risks, institutional barriers, inconsistent access to healthcare services, and systemic racism. In some regions, Inuit and Indigenous people are overrepresented in diagnostic centres, which partially contributes to the stigmatization of FASD as "Indigenous issue."

Despite ongoing systemic challenges, Inuit community members and service providers identified a number of opportunities that are helping to improve overall attitudes, awareness, education, and services about FASD within Inuit communities. Central to these opportunities is the improvement of Inuit-led supports that are grounded within Inuit language, culture, and perspectives. Initiatives such as these are already being championed by a few agencies in the North, which point towards an optimistic change for many Inuit families and communities living with FASD.

REFERENCES

Alberta Clinical and Community-Based Evaluation and Research Team, Jacqueline Pei, Melissa Tremblay, Cheryl Poth, Btissam El Hassar, and Sabine Ricioppo. 2018. “Best Practices for Serving Individuals with Complex Needs: Guide and Evaluation Toolkit.” PolicyWise for Children & Families in collaboration with the University of Alberta.

Assembly of First Nations. 2015. “Environmental Scan: Best Practices and Community-Based Supports and Diagnostics for Fetal Alcohol Spectrum Disorder (FASD).”

Canadian Intergovernmental Conference Secretariat. 2016. “ANNEX – Fetal Alcohol Spectrum Disorder (FASD) Partnerships Inventory.” Available online at https://scics.ca/en/product-produit/annex-fetal-alcohol-spectrum-disorder-fasd-partnerships-inventory/.

CanFASD. “Fetal Alcohol Spectrum Disorder (FASD),” n.d. Available online at https://canfasd.ca/

———. 2010. “10 Fundamental Components of FASD Prevention from a Women’s Health Determinants Perspective.” 2010. Available online at https://canfasd.ca/wp-content/uploads/2016/09/ConsensusStatement.pdf.

———. 2020. “Supporting the FASD Community during COVID-19.” Supporting the FASD community during COVID-19, 2020. Available online at https://canfasd.ca.

CanFASD, Kelly Harding, Katherine Flannigan, and Audrey McFarlane. 2019. “Policy Action Paper: Toward a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada.” CanFASD: Canada FASD Research Network. Available online at https://canfasd.ca/wp-content/uploads/2019/08/Toward-a-Standard-Definition-of-FASD-Final.pdf.

Cardinal, Amélie, and Michelle McConkey. n.d. “Fetal Alcohol Spectrum Disorder (FASD): Assessment of FASD Services and Programs for Inuit across Ontario”, 48.

CBC News. 2017. “N.W.T. MLAs Call for Formal Fetal Alcohol Spectrum Disorder Strategy, Health Minister Says No Need | CBC News.” CBC, November 17, 2017. Available online at https://www.cbc.ca/news/canada/north/nwt-fasd-strategy-1.4406531

Cook, Jocelyn L., Courtney R. Green, Christine M. Lilley, Sally M. Anderson, Mary Ellen Baldwin, Albert E. Chudley, Julianne L. Conry, et al. 2016. “Fetal Alcohol Spectrum Disorder: A Guideline for Diagnosis Across the Lifespan.” CMAJ : Canadian Medical Association Journal 188, no. 3: 191–97.

FAS Diagnostic and Prevention Network. 2019. “What Is FASD?” Available online at https://depts.washington.edu/fasdpn/htmls/fasd-fas.htm.

fasdNL. 2017. “Fetal Alcohol Spectrum Disorder (FASD) in Newfoundland and Labrador.” 2017 Landscape Paper on FASD in Newfoundland and Labrador. Available online at http://www.fasdnl.ca/

———. 2019. “What We Do.” fasdNL. Accessed December 16. Available online at http://www.fasdnl.ca/what-we-do.html.

Labrador-Grenfell Health. 2018. “Fetal Alcohol Spectrum Disorder (FASD).” Available online at https://www.lghealth.ca/your-health/programs-and-services/mha/fetal-alcohol-spectrum-disorder-fasd/.

First Nations Child and Family Caring Society of Canada. 2006. “FASD Training Study: Final Report.” Ottawa, ON.

Gordon, Kitty, and Nunavik Regional Board of Health and Social Services. 2018. “FASD in Nunavik.”

Government of Alberta. 2008. “FASD 10 Year Strategic Plan.” Ministry of Child and Youth Services.”

Government of Northwest Territories. 2018. “Glen Abernethy: Improving Supports for Fetal Alcohol Spectrum Disorder and Autism.” Available online at https://www.gov.nt.ca/en/newsroom/news/glen-abernethy-improving-supports-fetal-alcohol-spectrum-disorder-and-autism.

Halseth, Regine, and Margo Greenwood. Indigenous Early Childhood Development in Canada: Current State of Knowledge and Future Directions. 2019. Available online at https://apps.uqo.ca/LoginSigparb/LoginPourRessources.aspx?url=http://www.deslibris.ca/ID/10099666.

Harding, Kelly, Katherine Flannigan, and Audrey MacFarlane. 2019. “Policy Action Paper: Toward a Standard Definition of Fetal Alcohol Spectrum Disorder in Canada.” CanFASD: Canada FASD Research Network.

Health Canada. 2005. “Fetal Alcohol Syndrome/Fetal Alcohol Effects.” Education and awareness aboriginal treaties. Available online at https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/family-health/healthy-pregnancy-babies/fetal-alcohol-syndrome-fetal-alcohol-effects-first-nations-inuit-health-main-page.html.

———. 2005. “Integration Envelope - Funded Projects.” Available online at https://www.canada.ca/en/indigenous-services-canada/services/first-nations-inuit-health/health-care-services/improving-access-health-services/integration-envelope-funded-projects.html#lab2.

Health Canada, Health. 2017. “Fetal Alcohol Spectrum Disorder.” Available online at https://www.canada.ca/en/health-canada/services/healthy-living/your-health/diseases/fetal-alcohol-spectrum-disorder.html.

Ilinniapaa Skills Development Centre. 2019. “Ilinniapaa Skills Development Centre: Training Courses.” Ilinniapaa Skills Development Centre. Available online at http://ilinniapaa-training.ca/training-courses.html.

INAC. 2016. “Inuit Nunangat Map.” Available online at https://www.aadnc-aandc.gc.ca/Map/irs/mp/index-en.html.

Inuit Tapiriit Kanatami. 2014. “Social Determinants of Inuit Health in Canada: Fact Sheet 02.” Available online athttps://www.itk.ca/wp-content/uploads/2016/07/EarlyChildhood_FactSheet.pdf.

Northwest Territories Health and Social Services Authority. n.d. “Adult FASD Diagnostic Clinic,” Available online at https://www.nthssa.ca/sites/nthssa/files/resources/fasd_diagnostic_clinic_info_sheet_0.pdf.

Nunatsiaq News. 2019a. “FASD in Nunavut a Health-Care Rights Issue, Stakeholders Say.” Nunatsiaq News (blog). Available online at https://nunatsiaq.com/stories/article/fasd-in-nunavut-a-health-care-rights-issue-stakeholders-say/.

———. 2019b. “Quebec to Launch New Developmental Screening Program for Young Children.” Nunatsiaq News (blog). Available online at https://nunatsiaq.com/stories/article/quebec-to-launch-new-developmental-screening-program-for-young-children/.

———. 2019c. “We Can’t Determine FASD Prevalence, Nunavut Government Says.” Nunatsiaq News. Available online at https://nunatsiaq.com/stories/article/we-cant-determine-fasd-prevalence-nunavut-government-says/.

Nunavik Regional Board of Health and Social Services. 2017. “Regional Action Plan for Public Health 2016-2020.”

Pauktuutit Inuit Women of Canada. 2001. Before I Was Born, Preventing FAS/FAE in Inuit Communities. Ottawa, ON.

———. 2006 “Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD.” Ottawa, ON.

———. 2011. “The Choices We Make During Pregnancy Bilingual Poster.” Ottawa, ON.———

——— 2015. “Inuit Five-Year Strategic Plan for Fetal Alcohol Syndrome Disorder: 2010-2015.” Ottawa, ON.

———. 2020. “Fetal Alcohol Spectrum Disorder.” Ottawa, ON.

Piruqatigiit Resource Centre, ᐱᕈᖅᑲᑎᒌᑦ ᐱᓕᕆᕝᕕᒃ/Piruqatigiit Resource. 2018. “Piruqatigiit: About Us.” Available online at https://piruqatigiit.ca/about-us.

Popova, Svetlana, Shannon Lange, Vladimir Poznyak, Albert E. Chudley, Kevin D. Shield, James N. Reynolds, Margaret Murray, and Jürgen Rehm. 2019. "Population-Based Prevalence of Fetal Alcohol Spectrum Disorder in Canada." BMC Public Health 19 (1): 845–845.

Public Health Agency of Canada. 2017. "Support for Fetal Alcohol Spectrum Disorder (FASD)." Available online at https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/support.html.

Statistics Canada. 2014. Inuit Health: Selected findings from the 2012 Aboriginal Peoples Survey. Available online at https://www150.statcan.gc.ca/n1/en/pub/89-653-x/89-653-x2014003-eng.pdf?st=Y6pzlB1H

Yellowknife Association for Community Living. 2016. "Services | Yellowknife Association for Community Living." Available online at https://ykacl.ca/services/.

APPENDIX A: INTERVIEW GUIDE

Interview Guide for Pauktuutit FASD: Supporting Inuit Families and Communities Environmental Scan and Research Report

Pre-Interview

Before formally beginning the interview, ensure the following steps have been completed:

1. **Introductions**
   - Introduce yourself and the research team, who you work for, who you were hired by and who you report to.

2. **Give the participant an overview of the report**

3. **Explain the interview process and goals of the research.** Read the following:
   - The purpose of this research is to support Pauktuutit in their ongoing work and research towards the following goals:
     - Current information, services, and supports available to Inuit communities across Inuit Nunangat;
     - Foster FASD awareness and prevention in Inuit communities to improve maternal and infant outcomes; and
     - Reduce stigma associated with FASD.
   - From this, we will be preparing a report for Pauktuutit that provides an environmental scan and status assessment with respect to the above listed eight focus areas.

4. **Provide an opportunity for the participant to ask questions**
   - Providing accurate answers to participants' questions is an important aspect of free, prior and informed consent.

5. Review the consent form

- Read the consent form aloud to the participant if requested.
- Ask the participant if they have any questions.
- Once the participant's questions have been answered, we will need to review the consent form before beginning the interview. For obtaining verbal consent, ensure that the audio recorders are on, read through the consent form, and have the participant provide their verbal consent for the recording.
- If the participant does not provide recorded written consent, do not continue with the interview.

Introduction

[Read the text below with AUDIO RECORDERS ON at the start of each interview.]

Today is [date]. We are interviewing [participant name] for the Pauktuutit FASD Report. Thank you for your time today.

My name is [name]. [Participant name] has provided verbal consent, and I have explained the purpose of the study and interview plan.

Background and Experience

1. What is your current position (including position title, affiliations, etc.)?
2. What Inuit Nunangat region(s) do you work in?
    a. Where within the region are you located?
3. Can you describe your level of involvement with FASD-related supports and services?

Prevalence of FASD in Your Region

1. Is FASD/alcohol consumption during pregnancy common in your community? In your region?
    a. Has this changed over time?

Attitudes and Behaviours Towards FASD

1. Can you explain the attitude and behaviour towards alcohol consumption during pregnancy in your community/region?
    a. What influences these attitudes?
    b. Has this changed over time?
2. Are there known risk factors for alcohol consumption during pregnancy in your region (e.g., addiction, lack of appropriate housing, lack of supports, etc.)?
3. Is there a stigma associated with FASD in your region?
4. Is there a stigma associated with alcohol consumption during pregnancy in your region?
5. Is there a stigma in accessing FASD prevention or addictions supports?
6. What would make it easier to talk about FASD?
7. Is there a way that stigma could be reduced?

Understanding the Effects of FASD

1. What are the effects of FASD at the individual level?
    a. For children living with FASD?
    b. For adults living with FASD?
2. What are the effects of FASD at the family level? (e.g., effects on relationships, responsibilities, etc.)
3. At the community level?

Current Services and Resources, and Key Challenges

1. What FASD-related supports or resources are currently available in your region? Can you describe them?
    a. Are current resources aimed at awareness/prevention, diagnosis, or ongoing supports?
    b. Which communities in your region have access to these supports or resources?
2. Are there barriers to implementing/sustaining effective FASD-related services and resources?
3. Are there supports to accessing FASD resources (e.g., referrals, outreach, etc.)?
4. Are there challenges or barriers in accessing these services or resources (e.g., cultural, linguistic, transportation, geographical)?

Opportunities

1. Are there opportunities to improve FASD-related prevention activities and services in your region?
    a. How do you think these opportunities could be acted upon?
2. Are there any individuals, groups, or stakeholders who are well positioned to advance these opportunities?
3. Are there opportunities for partnerships?
4. Ideally, what would an FASD education or awareness campaign or resource look like in your community?
5. Are there particular settings where FASD awareness/education could be implemented (e.g. prenatal classes, healthy babies programs, schools, radio, addictions programs)?
6. What is the best way to ensure that these programs and services are culturally-grounded and accessible? Who should be involved in program development and implementation?

Conclusion

Read with audio recorders on after every session

Today is [date]. We have just finished interviewing [participant name] for the Pauktuutit FASD: Supporting Inuit Families and Communities Environmental Scan and Research Report.

My name is [name]. Notes are recorded in/on [notebook/computer]. This interview has taken approximately [#] hours [#] minutes.

APPENDIX B: FOCUS GROUP GUIDE

Pauktuutit FASD: Supporting Inuit Families and Communities Environmental Scan and Research Report

Draft Focus Group Facilitation Guide

Time	Activity	Notes
1:30-1:45	Opening prayer (as appropriate) Opening remarks and facilitator introductions Report Overview Questions	• Pauktuutit introductions • Firelight Introductions • Group Introductions • Pauktuutit and Firelight to explain the focus group process and goals of the research • Opportunity for participants to ask questions
1:45-2:15	**Discussion #1:** Understanding prevalence, attitudes, and behaviours	A series of discussion points to understand the prevalence of FASD in your region or community. • Is FASD/alcohol consumption during pregnancy common in your community? • Has this changed over time? • Can you explain the attitude towards alcohol consumption during pregnancy in your community?

Time	Activity	Notes
1:45-2:15	**Discussion #1:** Understanding prevalence, attitudes, and behaviours continued	• Is there a stigma associated with FASD/ alcohol consumption during pregnancy? Has this changed over time? • What would make it easier to talk about FASD? • Is there a way that the stigma could be reduced?
2:15-2:45	**Discussion #2:** Understanding the effects of FASD	A series of discussion points to understand the effects that FASD has on the individual, family, and community. Discussion on the effects of FASD: • What are the effects of FASD at the individual level? For children living with FASD? For adults living with FASD? • What are the effects of FASD at the family level (i.e., the effects on family structure, relationships, etc.)? • What are the effects of FASD at the community level?
2:45-3:00	**Break**	
3:00-3:45	**Discussion #3:** Current services and resources	A discussion on what is currently available in your region, including a discussion on challenges and barriers to accessing services • Where did you first learn about FASD? From who? At what age? • What did this information involve? (e.g., was it prevention/awareness related?) • Did you find this information helpful? Was it accessible? • What other FASD programs and resources are you aware of in your community? For prevention/awareness? For ongoing support?

Time	Activity	Notes
3:00-3:45	**Discussion #3:** Current services and resources continued	• Are there supports to accessing FASD prevention/ interventions supports? • Are there challenges or barriers in accessing these services or resources? • What would make it easier to access services for FASD? • Are these resources culturally appropriate?
3:45-4:15	**Discussion #4:** Key areas of need, and opportunities	A series of discussion points regarding key areas of need in regards to FASD support in your region or community, including: • Ideally, what would an FASD education or awareness campaign or resource look like in your community? • In what setting should FASD awareness/ education be implemented (e.g. prenatal classes, healthy babies programs, schools, radio, addictions programs)? • What is the best way to ensure that programs are culturally relevant and accessible? Who should be involved in developing programs?
4:15-4:30	Conclusion and wrap-up	• Pauktuutit and Firelight to provide closing remarks • Next steps • Opportunity for questions

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