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Community Report

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.

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Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

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:

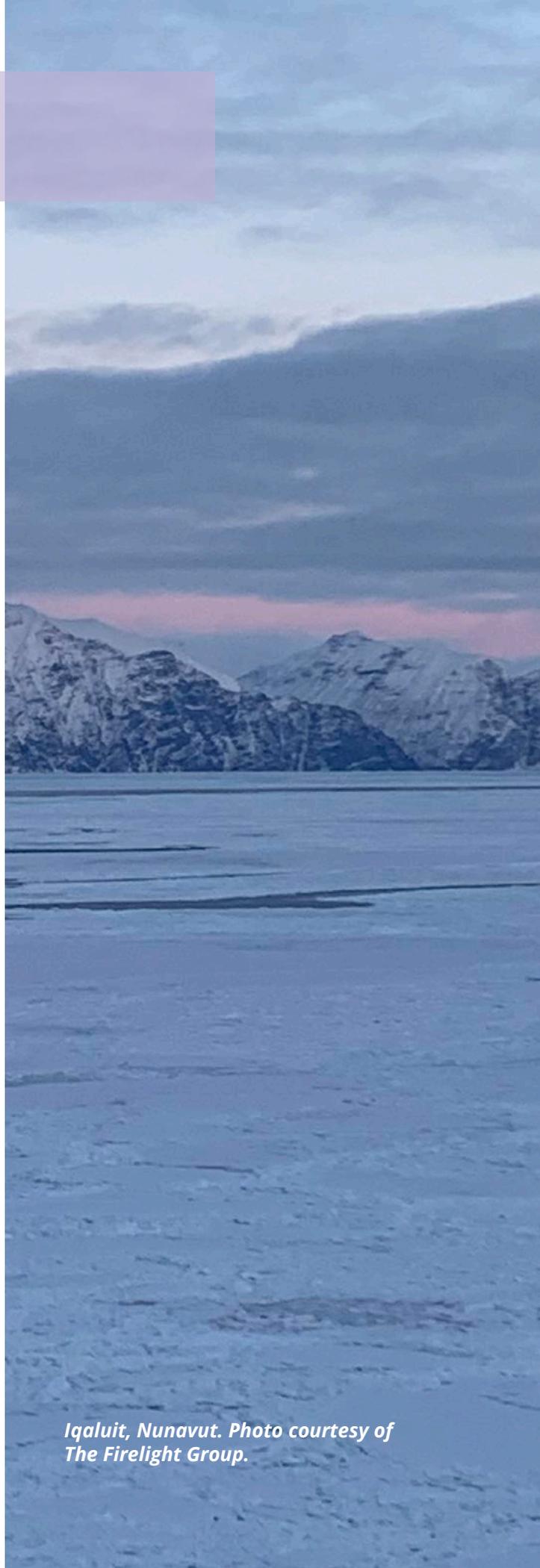
*Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, 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)*



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.

Today, FASD is increasingly understood as being inextricably linked to a 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 continue to exemplify strengths in many areas of their lives.



Iqaluit, Nunavut. Photo courtesy of The Firelight Group.



Iglulik, Nunavut. Photo courtesy of The Firelight Group.

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 pregnancies¹. 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.

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.

Sanirajak, Nunavut. Photo courtesy of The Firelight Group.





Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

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)



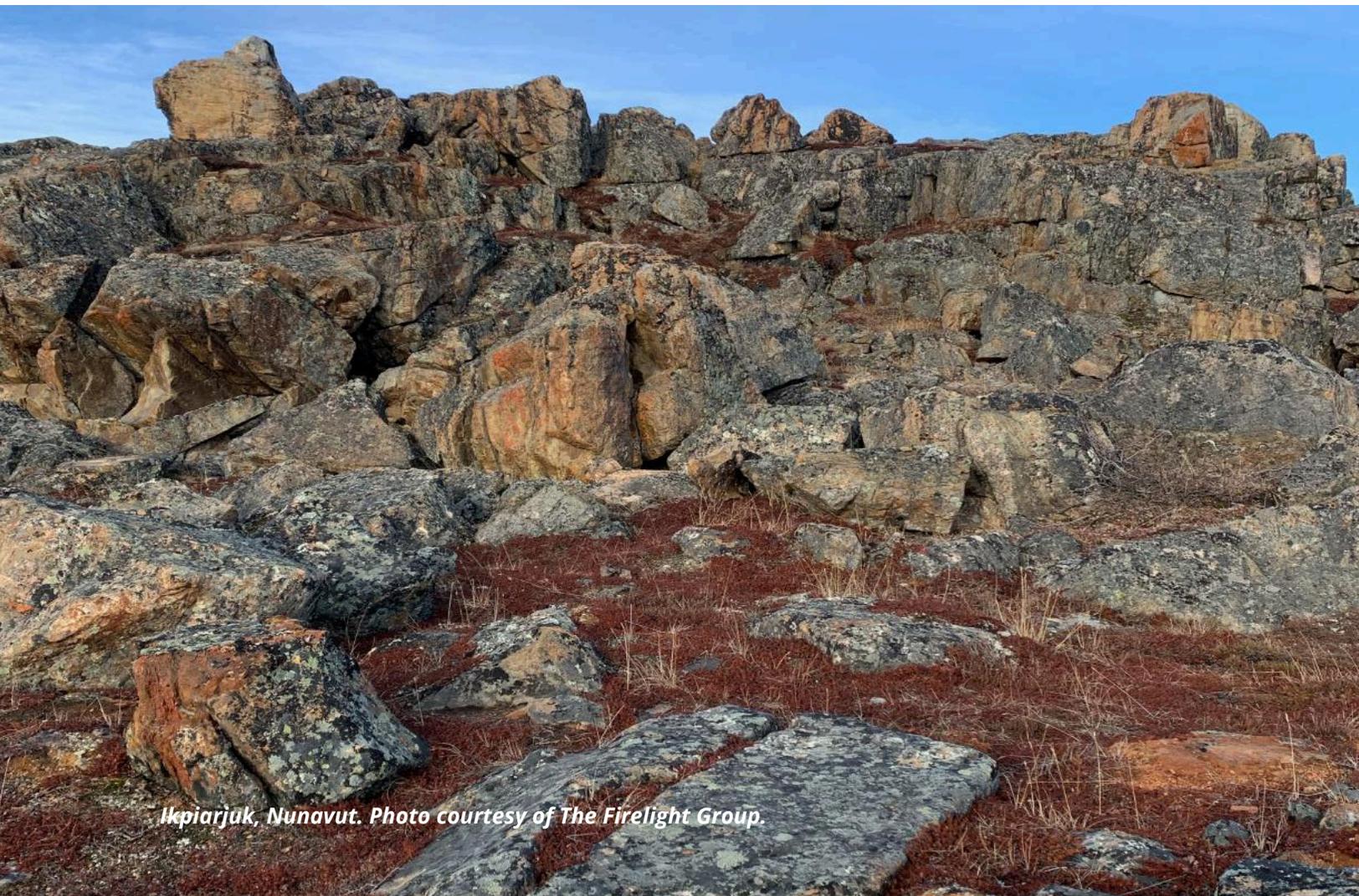
Kangiqtugaapik, Nunavut. Photo courtesy of The Firelight Group.

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)



Ikpiarjuk, Nunavut. Photo courtesy of The Firelight Group.



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)



Iqaluit, Nunavut. Photo courtesy of The Firelight Group.

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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