



BEAUTY IN BRAIN DIFFERENCE

# DISCUSSION GUIDE



## INTRODUCTION

Pauktuutit Inuit Women of Canada has created this discussion guide after a community research and consultation phase which identified an opportunity to provide consistent messaging about Inuit and Fetal Alcohol Spectrum Disorder (FASD).

Our Inuit-led research report provided the foundations for this discussion guide, which was developed in consultation with our Inuit-specific FASD Community of Practice.

## HOW TO USE THIS DISCUSSION GUIDE

The Beauty in Brain Difference FASD discussion guide is an accessible, introductory resource for people in positions of power that interact with Inuit with FASD, their families and caregivers. The intent is to provide needed background, context, and usable tips for fostering FASD and trauma-informed and dignity-informed conversations that help end stigma and ensure all Inuit receive needed care, support and community.

## WHAT IS FETAL ALCOHOL SPECTRUM DISORDER?

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disability that affects the brain and body of a person exposed to alcohol in the womb. The diagnostic term was changed from 'syndrome' to 'spectrum disorder' because people with FASD have strengths and challenges unique to them; no two people with FASD are the same.

FASD affects an estimated 4% of Canadians, more than any other neurodevelopmental disability, yet there is no national strategy in place to diagnose and support people with FASD

## BRAIN DIFFERENCE AND FASD IN INUIT NUNANGAT

“Alcohol use stems from something else. Like no [parent], in my mind would ever drink with the intention of harming [their] child” (*Service provider, May 25, 2020*).

FASD in Inuit Nunangat has a specific history tied to the arrival of settlers and introduction of alcohol, policies of assimilation that sought to destroy Inuit ways of life, and ongoing intergenerational trauma.

**FASD is not more common in**

**Inuit or Indigenous communities,**

**it exists wherever there is alcohol.**

FASD educational campaigns often focus on a preventative message, the Beauty in Brain Difference campaign is focussed on ending FASD stigma. The distinct lack of FASD knowledge, research, as well as wrap-around services mean that people with FASD still face significant stigma. This stigma creates social and physical barriers that can prevent families from accessing the appropriate services or level of care required to meet their unique needs.

FASD is a brain difference. Inuit with FASD see and move through the world with a unique perspective. This is an opportunity to see things from a new point of view.

Let's support and build the needed services and structures that will increase the positive life outcomes of Inuit with FASD and their communities.

Together we must work to end FASD stigma, speak openly about FASD and celebrate all of us.

There's beauty in brain differences.

# DO'S DON'TS

Use these tips when talking to, or about someone with FASD

## AVOID

FASD Person / Kid

Suffering from FASD /  
Victim of FASD

FASD is caused by maternal  
alcohol use

FASD is 100% preventable

FASD is an Inuit/  
Indigenous problem

Talking only about  
negative parts of FASD

## RECOMMENDED

Person/individual  
with FASD

Affected by FASD

FASD is caused by prenatal  
alcohol exposure

Prenatal alcohol use  
is complex

FASD exists wherever  
there is alcohol

People with FASD have  
many strengths, talents,  
and abilities. Millions of  
people around the world  
live successfully with FASD

Sources:

Piruatigijt Resource Centre, [Language Matters: Fetal Alcohol Spectrum Disorder \(FASD\)](#).

Piruatigijt Resource Centre, [Reporting on Fetal Alcohol Spectrum Disorder in Nunavut](#).

# HELP END FASD STIGMA

The Inuit community members and key services providers who participated in our research report 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

The language used when talking about FASD affects our attitudes, judgements, and understanding about FASD and how to respond to it. Shifting towards a trauma-informed and dignity-informed practice recognizes that there are underpinning social factors behind prenatal alcohol exposure. It also encourages families, caregivers, service providers, and members of the public to root their approach to FASD in compassion and cultural safety.

## OPPORTUNITY 2: IMPROVE INUIT-BASED CULTURAL SUPPORTS FOR PEOPLE AND FAMILIES WITH FASD

Overwhelmingly, community members and service providers called for improved FASD supports and services that are community-based and grounded in Inuit values. This includes offering services and programs in Inuktitut, training and hiring more Inuit employees 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 FASD services for communities across Inuit Nunangat.

## OPPORTUNITY 3: IMPROVE FINANCIAL SUPPORTS FOR INUIT FAMILIES IN URBAN AND REMOTE COMMUNITIES

Given the expensive costs that many Inuit families pay to access FASD services, participants have called for improved financial supports from territorial, provincial, and federal governments for necessary 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.

## 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 access to diagnostic services. Our research revealed that these

services are limited in smaller communities, and difficult to access due to a range of barriers (i.e. geography, awareness, stigmatization, etc.).

## OPPORTUNITY 5: PROVIDE INUIT-SPECIFIC CULTURAL SAFETY AND SENSITIVITY TRAINING FOR ALL FASD SERVICE PROVIDERS, EDUCATORS, AND HEALTHCARE WORKERS

Cultural competency training helps improve understanding and address issues related to stigma, cultural and institutional biases, systemic racism, residential schools, the Sixties 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

This helps foster stronger and healthier relationships with Inuit women and families. In turn, this may help to improve service delivery, reduce stigma within Inuit communities, and improve access and services being offered to women and individuals with FASD.

## OPPORTUNITY 6: PROVIDE CONSISTENT MESSAGING ABOUT FASD

Consistent messaging that is developed and informed by Inuit may contribute to providing clearer communication around FASD, and its causes. This is the goal of the Beauty in Brain Difference educational campaign.

## 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.

## INUIT, FASD AND THE EDUCATION SECTOR

School teams and school boards need to be FASD informed. A more comprehensive understanding of the unique skills and strengths of children with FASD will help reduce barriers as well as implement policies and actions designed for true accessibility and inclusion. This includes considerations such as:

- Children with FASD learn and absorb knowledge in different ways because of their brain differences.
- Brain differences will vary from child to child and no one way is best for teaching those who live with neurodiversity.
- Specialized learning resources and different techniques can help children with FASD learn in ways that they need.
- We need a more comprehensive understanding of the unique skills and strengths of children with FASD.
- When systems are FASD informed and responsive to the needs and strengths of children with FASD, children can thrive.
- Every child has the right to have their needs met.

## INUIT, FASD AND THE CRIMINAL JUSTICE SYSTEM

Inuit with FASD are at increased risk of coming into contact with the criminal justice system as victims, witnesses and/or offenders.

Individuals in the justice sector who come into contact with Inuit with FASD should understand that a brain difference may influence interactions. An informed approach is essential to avoid escalation and protect Inuit with FASD. This includes:

- Inuit with FASD have brain differences and are often non-judgmental and forgiving, putting them at greater risk of victimization. They may not recognize this increased risk and extra care must be taken to protect them
- Inuit with FASD are not inherently predisposed to criminal activity and should not be treated as such. Their brain differences requires that more factors are considered to ensure they comprehend the law
- Seeking additional FASD education and training for members of the criminal justice system
- Awareness of local FASD resources that can be shared with individuals

## INUIT, FASD AND THE HEALTH CARE SECTOR

Early diagnosis is a key protective factor to ensure that Inuit with FASD live full and meaningful lives. Early diagnosis is also essential in order to access disability supports and services.

### Stigma around alcohol use during pregnancy and FASD stigma are barriers for Inuit seeking a diagnosis.

Health care providers can adopt a harm-reduction approach to foster a safe environment for conversations about FASD. This includes considerations such as:

- Taking a non-judgmental approach when discussing healthy pregnancies with Inuit patients that does not perpetuate shame, stigma or harm
- FASD exists wherever alcohol is consumed. FASD is not associated specifically with Inuit or Indigenous people; this is a harmful stereotype and factually inaccurate
- Recognizing that the presence of alcohol in Northern Inuit communities is a legacy of colonization and that alcohol use is influenced by complex factors, including a history of trauma
- Fostering an environment where Inuit patients feel safe with their health care providers, allowing for open discussions about alcohol use during pregnancy
- Recognizing and acknowledging the strengths and unique skills of people with FASD
- Conducting more strengths-based research studies to help build a comprehensive understanding of the unique skills and strengths of people with FASD
- Sharing the Beauty In Brain Differences Toolkit to share with fellow health care providers to increase the quality of care of Inuit with FASD

# RESOURCES

## LEARN MORE ABOUT FASD

[Pauktuutit](#) is a national non-profit organization representing Inuit women in Canada. Its mandate is to foster a greater awareness of the needs of Inuit women, and to encourage their participation in community, regional and national concerns in relation to social, cultural and economic development.

Pauktuutit 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, Pauktuutit produced a comprehensive [Environmental Scan and Research Report](#).

## Piruatigiit Resource Centre

A nonprofit organization located in Iqaluit, Nunavut, providing evidence-based, culturally guided education, support and programming for Nunavummiut with suspected and confirmed Fetal Alcohol Spectrum Disorder (FASD) and their families.

## Community Resources

Piruatigiit Resource Centre provides a useful list of organizations, funding, resources and emergency services available in Nunavut.

## Glossary of Terms

Piruatigiit Resource Centre, offers a useful overview of keywords related to FASD.

## Canada FASD Research Network

Canada FASD Research Network is a collaborative, interdisciplinary research network, with collaborators, researchers and partners across the nation.

## Health Canada

Resources about Fetal Alcohol Spectrum Disorder.

## CanFASD

FASD and the Criminal Justice System, CanFASD, offers specific recommendations for enhanced understanding of the concerns of people with FASD in all areas of the Canadian justice system.