Learning Together: Let's Talk About FASD

(FETAL ALCOHOL SPECTRUM DISORDER)

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What Is FASD?

The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) describes FASD as:

"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"

> FASD IS A LIFELONG DISABILITY THAT CAN AFFECT THE BRAIN AND BODY.
> EACH PERSON WITH FASD HAS BOTH STRENGTHS AND CHALLENGES.
> PEOPLE WITH FASD MAY NEED SUPPORT WITH DIFFERENT PARTS OF THEIR LIVES.
>
> CanFASD Family Advisory Committee

The new 2015 Canadian diagnostic guidelines include:

- **FASD with sentinel facial features – facial differences including short palpebral fissures (the opening between the eye lids), smooth or flattened philtrum (the groove between the nose and lip) and a thin upper lip**
- **FASD without sentinel facial features**
- **At Risk for Neurodevelopmental disorder and FASD**

FASD is often described as an 'invisible disability' because you can't look at someone and tell that they have brain or body differences that require support and accommodations. The presence of facial features is rare. The presence of facial features is not an indicator of the level of support needed for the individual to be able to manage daily difficulties.

The 'invisibility' of FASD can create barriers for people who need understanding, resources, accommodations and support from the various people and places they are involved with on a daily basis.

How can FASD affect a person?

Some of the areas that people with FASD may have difficulty include:

- Learning differences
- Memory difficulties
- Emotional dysregulation and outbursts
- Attention and concentration difficulties
- Hyperactivity
- Social relationships
- Sensory processing difficulties
- Difficulty with higher order thinking processes including planning and organizing; prioritizing; making connections between cause and effect; time management; abstract processes; interpreting social cues; self regulating processes, etc.
- Informed decision making
- Managing impulses
- Processing information
- Following instruction and requests

New research tells us that FASD doesn't just impact the brain. It is is a 'whole body disorder', where prenatal alcohol exposure can affect other systems in the body leading to co-occurring medical conditions[1].

Often times, the only indicator that someone may have been prenatally exposed to alcohol are behavioural features due to brain differences. FASD informed caregivers and service providers, including educators, can build on a person's strengths and provide individualized support and accommodations to increase well-bing and personal success.

Who has FASD?

Anyone from anywhere in the world where alcohol is consumed can have FASD. This disability has existed for as long as alcohol has been used and has been described for hundreds of years prior to its identification in 1973.

- New research has identified up to 4% of the population in Canada as having FASD, with some North American studies indicating 5% or higher
- We do not have reliable and consistent data on how many Nunavummiut have FASD. If the national average of 4% is applied to the population, that could mean over 1,500 people may have FASD in Nunavut
- Over 1.4 million Canadians have confirmed FASD
- 7% of the global population are estimated to have FASD, with many countries having much higher incidents of FASD, including some European countries with close to 50% prevalence[2]

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[1] See CanFASD's report titled Learning Together available from: http://canfasd.ca/wp-content/uploads/sites/35/2016/10/FASD-Learning-Together-Final.pdf

[2] https://jamanetwork.com/journals/jamapediatrics/fullarticle/2649225

FASD AFFECTS ALL PEOPLE FROM ALL PLACES AND BACKGROUNDS.

FASD DOES NOT ONLY AFFECT INDIGENOUS COMMUNITIES.

FASD EXISTS WHEREVER THERE IS ALCOHOL CONSUMED.

CanFASD Executive Director Audrey MacFarlane has stated:

> “THREE TIMES THE NUMBER OF CANADIANS HAVE FASD AS AUTISM SPECTRUM DISORDER, YET THERE IS STILL REMARKABLY LITTLE PUBLIC DISCUSSION OR URGENCY ON THE TOPIC”

Opinion piece in response to the 2018 federal budget
which did not allocate funds toward FASD can be found at:
http://canfasdblog.wordpress.com/2018/04/18/canfasd-responds-to-federal-budget/

Researchers and the FASD community agree that the prevalence of FASD is much higher than what is reported for many reasons. Fear, stigma, lack of FASD knowledge within healthcare and other systems, and no standardized approach to asking about prenatal alcohol exposure among other barrier impact accurate identification.

In Canada, 50% of pregnancies are unplanned with approximately 11% of women respondents confirming drinking alcohol in pregnancy before they realized they were pregnant[3].

In 2011, 74% of Canadian women consumed alcohol in the past year[4]. 56% of teenaged female respondents in a separate study reported drinking-use categorized as ‘risky’ including ‘binge-use’ according to Canadian alcohol standardized guidelines[5].

While these studies do not examine the relationship between women and girls who may be experiencing addictions and other complicated factors leading to alcohol use in pregnancy, it tells a story of alcohol use trends that may also occur during pregnancy.

Emerging research also confirms a male's consumption of alcohol can affect fetal development from the point of conception by both increasing the risk of FASD if the mother also consumed alcohol, as well as leading to brain differences resembling FASD even if the mother did not consume any alcohol during the pregnancy[6]. In 2011, 82% of Canadian male respondents reported consuming alcohol in the last year[7].

With this in mind, the likelihood of alcohol exposed pregnancies is much higher than 4%. As a territory and nation, we need to work together toward promoting respectful, culturally responsive conversations and support for people with FASD as well as for pregnant women and girls. Additional statistical data can be found at: *https://canfasd.ca/wp-content/uploads/sites/35/2018/01/Alcohol-Consumption-and-FASD.pdf*

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[3] https://fasdprevention.wordpress.com/2014/04/09/alcohol-consumption-during-pregnancy-in-canada/

[4] http://www.addictionresearchchair.ca/wp-content/uploads/Alcohol-Use-and-Pregnancy-An-Important-Canadian-Health-and-Social-Issue.pdf

[5] https://www.canada.ca/en/health-canada/services/health-concerns/drug-prevention-treatment/drug-alcohol-usestatistics/canadian-alcohol-drug-use-monitoring-survey-summary-results-2011.html

[6] https://canfasd.ca/wp-content/uploads/sites/35/2019/03/Fathers-Role-1-Issue-Paper-Final.pdf

[7] https://www.canada.ca/en/health-canada/services/health-concerns/drug-prevention-treatment/drug-alcohol-usestatistics/canadian-alcohol-drug-use-monitoring-survey-summary-results-2011.html

Circles of Support – *Tamatta* – All of Us

Mother's do not choose to cause harm to their developing babies. Inuit Qaujimajatuqangit looks at preventing prenatal alcohol use and reducing harm through the concept and visual of a **Circle of Support – *Tamatta***. Everyone in the circle plays a role in supporting alcohol-free pregnancies and promoting the well-being of mother and baby. This includes partners, family, extended family, friends, co-workers, Elders, social and spiritual connections within the community, organizations and service providers. Each of us has a responsibility to look out for each other and promote harmony and well-being. Working together, being open, being warm and non-judgmental is helpful. When we blame and shame women for the existence of FASD, we create barriers for mothers, pregnant women and girls, as well as for families and individuals to ask for the information and help they might need.

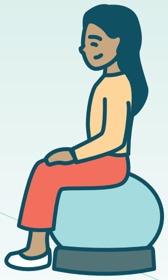
Assessment & Diagnosis

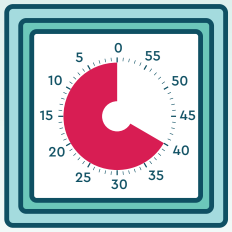
Why do some people choose to be assessed for the diagnosis of FASD?

- It may help to understand the challenges people with FASD experience and guide strategies or accommodations to better support their needs and strengths
- A diagnosis provides information that can support applications for financial supports or supportive services for the individual or their caregivers
- Having a diagnosis protects the rights of children and youth to access school-based accommodations and other needed supports and learning approaches
- It can help others see the person as having hidden difficulties that impact outward behaviour and learning, rather than seeing the person as 'being difficult' and accommodating accordingly

Some Helpful Strategies & Tips to Support People with FASD

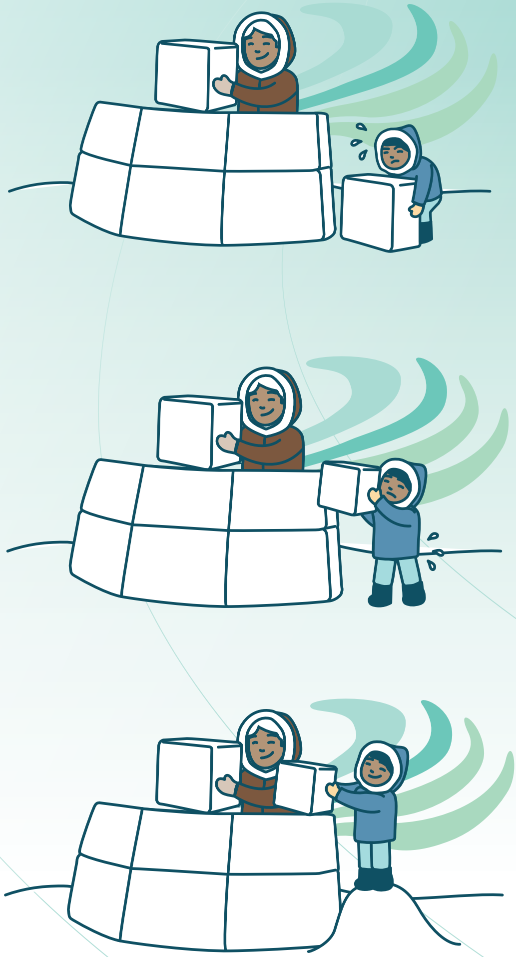
- Learn as much as you can about FASD from reliable sources (can be found under additional information and online resources).
- Consider brain-based approaches to thinking about outward behaviour. Assess for stressors and help your loved one with FASD reduce those stressors through consistency and routine; support with abstract concepts; additional support and supervision with many tasks; and extra support with many life skills.
- Reduce hidden stressors such as screen time, over-stimulating environments. erratic schedules, etc.
- Be aware of sensory stressors including sight, sound, touch, smell, taste and internal senses affecting balance and one's perception of their body and movement. The way people process sensory information can have a big impact on behaviour and learning. Assistive devices and accommodations can help.
- Support self-regulating and calming activities through movement and play; sensory tools and equipment including squish toys, 'heavy work', and opportunity for deep pressure and stretching.
- Allow for breaks as necessary. People with FASD may experience fatigue and hypersensitivity to stress and environments. Sometimes fatigue might look like hyperactivity and overstimulated behaviour.
- Provide consistency and routine. Visual schedules and clear communication can be helpful.
- Provide frequent reminders – help your loved with FASD remember what comes next, or an upcoming appointment or activity by giving frequent reminders.
- Support social skills by using social stories, practicing social skills, and role playing social skills and scenarios.
- Allow time for processing – provide time between instruction or questions for the individual to process and retrieve the information in order to respond/follow instruction.
- Repeat instructions/requests as necessary. Provide fewer instructions at a time.
- Repeat safety messages frequently and help make connections between settings where the same safety message applies, but might not be immediately clear to the person with FASD.





- Impulsivity places some children, youth and adults with FASD at an increased risk of experiencing harm without support. Keep medication (even over-the-counter medication) in a secure location or locked tackle box, as well as sharps and other household items that might become dangerous for a child or youth with FASD to use impulsively when experiencing high rates of stress.
- Try to envision the world the way your loved one with FASD might experience it, and anticipate stressors they might encounter. This way we can help to reduce those stressors and support self-regulation skills for improved well-being.
- Recognize stress behaviour and seek to reduce the stress. Consequences and punishment for behaviour will not be helpful.
- Remember that many people with FASD often experience differences between their chronological age and developmental maturity, or 'age' in many areas of their life. This is known as '*dysmaturity*'. When someone with FASD is struggling with a task or expectation, it's helpful to make sure our expectations of them match their development and skills.
- Think brain, not behaviour. Ask '*what is this behaviour telling me?*' to see if any stressors can be identified and reduced to help support calm and improved functioning for the individual.
- Provide opportunities for concrete learning, observation and practice. Remember that abstract concepts can be difficult for people with FASD. Provide hands-on, concrete examples and learning as much as possible.
- Avoid punishment/reward systems; time-outs and other behaviour shaping methods based on learning theory. Consider adapting the environment, including parenting, teaching and employment approaches to the needs and strengths of the individual, rather than trying to change a life-long disability that can't be changed. With the right supports and a good match between expectations and the abilities of an individual, everyone benefits. Tangible, concrete opportunities for observation and practice can be very helpful. Think 'show and do together' rather than punish.
- People with FASD benefit from early identification of FASD including individualized support and accommodations provided in the home, as well as in places of learning and working across the life span.

* For more information, resources and programming see "Piruqatigiit Resource Centre Programs".



People with suspected and confirmed FASD have a right to fully participate in their communities, places of learning, and places of work. Ensuring policies and approaches are FASD informed, including the provision of accommodations and assistive devices and other supports honour people's rights. When people with FASD are well supported, their many talents and strengths can shine. Sometimes people need different tools to help create equality: ***Equity*** makes ***Equality*** possible.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Being Open, Welcoming & Inclusive

By using respectful, person-first language and talking openly about FASD, we can create more awareness about the needs and strengths of people and families living with this disability. Public awareness helps us to create FASD-informed spaces, practices and policies. Providing appropriate, individualized accommodations and support for people with FASD is a human right. We all have the right to accessible, equitable and inclusive opportunities to participate in our communities, places of work, places of learning, and other settings throughout our life time.

Piruqatigiit Resource Centre's **Inuit Advisory Circle** strongly supports an open discussion of FASD that is respectful and strengths-based, so that Nunavummiut with suspected and confirmed FASD can receive the support and accommodations that they might need without shame or stigma.

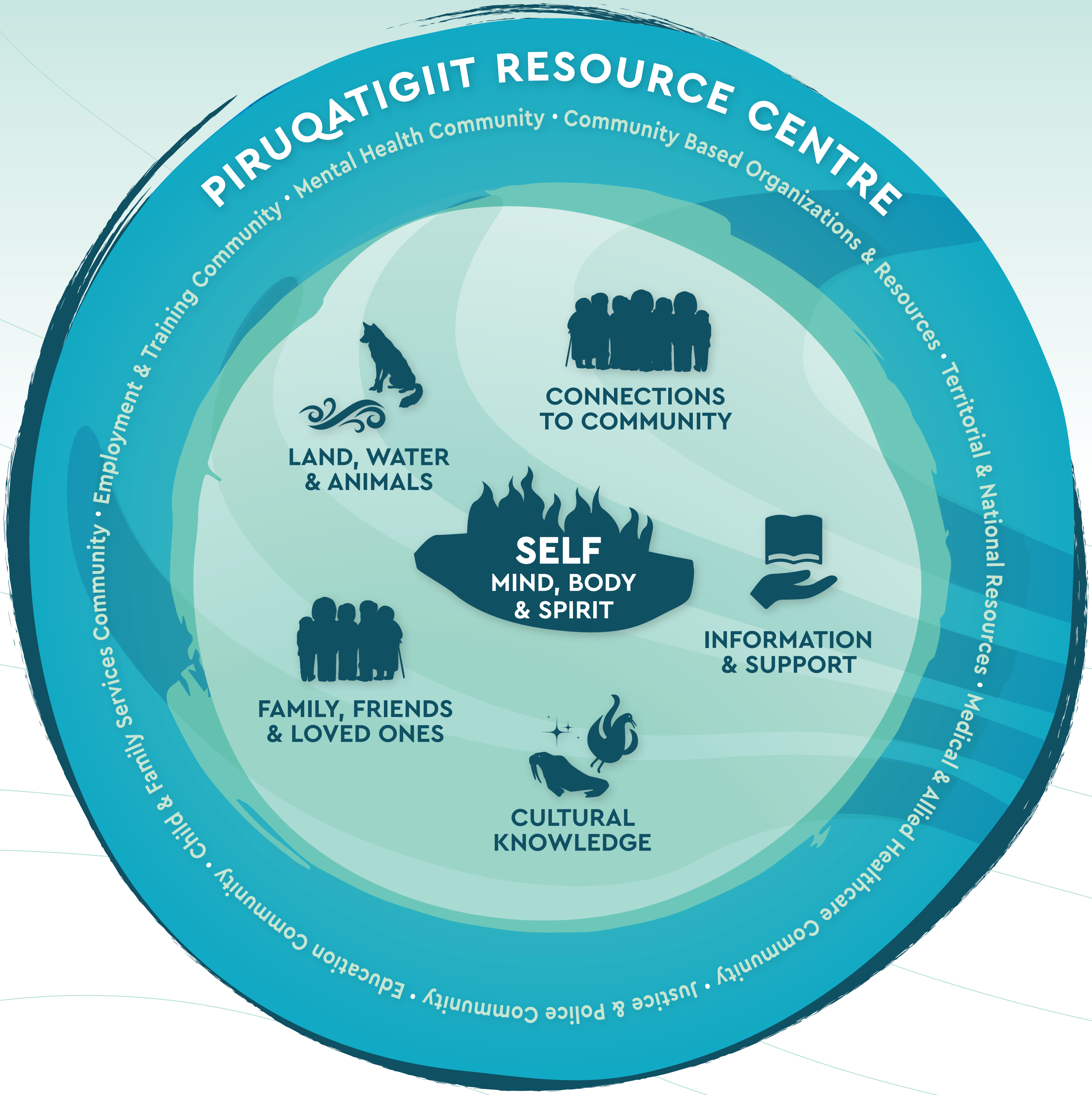
The importance of talking openly about FASD is guided by the Inuit Societal Values of *Tamatta* (interconnectedness; all of us together); *Tunnganarniq* (Fostering good spirit by being open, welcoming and inclusive); and *Inuuqatigiitsiarniq* (Respecting others, relationships and caring for people). These values support Nunavummiut with FASD, but also help to reduce shame, blame and stigma for women and girls who used alcohol and other substances during pregnancy.

By making it safe and welcoming to talk about FASD, more people and families can ask for the help and resources that they might need that promotes well-being, harmonious relationships, and to prevent adverse outcomes.

> “WE’VE KNOWN FOR A LONG TIME THAT CHILDREN, YOUTH AND ADULTS HAVE BEHAVIOUR PROBLEMS AND DIFFICULTIES BECAUSE OF PRENATAL ALCOHOL EXPOSURE. IT’S TIME WE TALK OPENLY ABOUT IT”
>
> *Annie Nattaq, Piruqatigiit Elder Advisor, Iqaluit*

About Piruqatigiit Resource Centre

We are a nonprofit organization located in Iqaluit, Nunavut providing evidence-based, culturally guided education, support and programming for Nunavummiut with suspected and confirmed FASD and their families across the lifespan. We work collaboratively with organizations and services to ensure a wraparound circle of support. Piruqatigiit also provides FASD training and education for organizations and service providers.



PIRUQATIGIIT RESOURCE CENTRE

Mental Health Community • Community Based Organizations & Resources • Territorial & National Resources • Medical & Allied Healthcare Community • Justice & Police Community • Education Community • Child & Family Services Community • Employment & Training Community •

LAND, WATER & ANIMALS

CONNECTIONS TO COMMUNITY

SELF
MIND, BODY & SPIRIT

INFORMATION & SUPPORT

FAMILY, FRIENDS & LOVED ONES

CULTURAL KNOWLEDGE

Vision Statement: Piruqatigiit Resource Centre holds a vision for Nunavummiut with suspected and confirmed FASD to experience improved quality of life and equitable opportunties to participate in places of learning, working, and gathering in community. We envision services, systems and the general public to become FASD aware and informed in a way that promotes dignity, equity, accessibility and inclusion for Nunavummiut with FASD and their loved ones.

Mission Statement: To provide evidence based, Inuit guided and informed programming, education, resources and support to Nunavummiut with suspected and confirmed FASD and their families across the lifespan. Piruqatigiit will also be a leader in developing and providing evidence based, community-responsive FASD training and education to community members, organizations and systems to promote FASD informed policy, practices and knowledge capacity within Nunavut.

Tamatta – All of us – we all have value, worth and contributions to make in our communities and within our families and networks. All of us can work together to create awareness about FASD. All of us can promote dignity and ensure equitable opportunities are provided to Nunavummiut with suspected and confirmed FASD that promote wellbeing and belonging. Tamatta is the foundation for Piruqatigiit's model of service provision and how we we will treat each other. Tamatta – we are we; all of us together.

Tamatta. Interconnectedness. Equity.

Piruqatigit Resource Centre honours the voices and choices of Nunavummiut with FASD regarding their personal goals and well-being. We embrace the lived experiences, insights and knowledge of people with FASD and their caregivers as equal members of the circle of support team.

Tamatta – all of us are working together to promote the dignity and quality of life for people with FASD by:

- Listening to people and families
- Valuing lived experience and knowledge
- Providing advocacy, awareness training and education to systems and organizations to reduce barriers
- Advocating for equitable, accessible and inclusive participation in community, education and employment opportunities
- Promoting healthcare equity and accessibility
- Ensuring Piruqatigiit programs are responsive, strengths based and grounded in Inuit Qaujimajatuqangit
- Providing information and support to individuals and loved ones that promote personal and family well-being
- Providing opportunities for meaningful connection to community and peers

Piruqatigiit Resource Centre Programs

For Parents/Guardians/Caregivers

- Qaumajuut Caregiver Program (Group FASD education, parenting skills and individualized accommodation planning for parenting children/youth/adults with FASD)
- Katimajuut Peer Support Program (Group drop-in style informal support led by other parents caring for children with FASD – last Thursday of the month in Iqaluit 1089F Mivvik St. 7:30 – 9:00 pm)
- Ilagiit Katujijut/Family Working Together (Individual family/caregiver support and education sessions)
- Family drop-in programs
- Remote family support via telephone and video conferencee

For Children & Youth

- Programming for children & youth with suspected and confirmed FASD
- Programming for siblings of children/youth with FASD

FASD Education & Training

- For Coaches & Program Providers
- For Educators and School Teams
- For Organizations and Departments
- For Employers
- For Justice Professionals
- For Healthcare Providers
- Public Gatherings & Knowledge-Sharing
- Future on-line certificate training

For program schedules and to book appointments visit www.piruqatigiit.ca or call 867-877-4155

Additional Information & Online Resources

Canada FASD Research Network

- **Online learning including free Foundations Certificate program:** *https://canfasd.ca/online-learners/*
- **Caregiver Guide:** *https://canfasd.ca/wp-content/uploads/sites/35/2018/03/Caregiver-Resource-Guide-FASD-March-2018.pdf*
- **Blog:** *https://canfasd.ca/2017/04/26/canada-fasd-research-network-blog/*
- **Research and relevant information:** *https://canfasd.ca/*

Health Canada

- *https://www.canada.ca/en/public-health/services/diseases/fetalalcohol-spectrum-disorder/about.htm*

Saskatchewan Prevention Institute

- **Excellent video series for parents and individuals impacted by FASD including lived voice**
  https://skprevention.ca/resourcecatalogue/ alcohol/fasd-lets-talk-about-it/

POPFASD

- **Videos and resources:** *https://www.fasdoutreach.ca/*

Lived Voice

- https://www.heretohelp.bc.ca/visions/alcohol-vol2/my-life-with-fasd
- https://www.fasdoutreach.ca/resources/all/f/fasd-through-variety-lenses-e02-himmelreich
- https://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf

Other helpful resources

- **Kids Brain Health Network:** http://kidsbrainhealth.ca/
- **Better Nights Better Days (Sleep support for children with neurodevelopment disorders)** http://betternightsbetterdays.ca/
- **Healthy Child Manitoba:** What Educators Need to Know: https://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf
- **Stuart Shanker Self Reg & The Mehrit Centre:** https://self-reg.ca/

Books

- **Trying Differently Rather Than Harder** – Diane Malbin
- **Self Reg: How to Help your Child Break the Stress Cycle** – Stuart Shanker
- **Children's Books & Photovoice Book** – Piruqatigiit Resouce Centre

Glossary of Terms

Accessibility: Everyone has access to opportunities for full participation in activities; accessing spaces; having information and requests provided in multiple modes and languages, etc. Accessibility often goes hand-in-hand with the concept of equity. Accessibility makes sure differences are considered and that all people's rights, needs and strengths are supported.

Accommodations: tools, assistive devices, adaptations, and flexible solutions to ensure all people learn, experience or participate in the best way that works for them. Some examples include: visual schedules and timers, reduced or flex hours of work or schooling, individualized education plans or accommodation plans, wearing noise reduction headphones, taking frequent breaks, etc.

Adverse outcomes: undesirable situations or health conditions such as homelessness, involvement with the law, mental illness, isolation, risk taking, vulnerability to victimization, family break down, suicide, etc. (commonly referred to as secondary and tertiary disabilities)

Confirmed FASD: Following a multidisciplinary team assessment (consisting of a speech language pathologist, psychologist, pediatrician, occupational therapist, etc) and confirmation of prenatal alcohol exposure based on the 2015 Canadian paediatric guidelines, an FASD diagnosis is given to a person.

Emotional Dysregulation: Having difficulty managing feelings, energy and impulses. It can look like agitated, frustrated, explosive behaviour.

Equity: differences are taken into consideration that fosters social justice, universal designs and approaches that create equality. Sometimes when everyone is treated the same (equally), it doesn't accommodate for differences. This can lead to an imbalance of power. Equity promotes inclusion for all people to participate and have their needs met, while acknowledging differences in the distribution of power and privilege. Equity reminds people that we all have value and our human rights should be honoured by others at all times.

Canada Northwest FASD Partnership Language Guide: http://www.fasdcoalition.ca/wp-content/uploads/2016/10/LAEO-Language-Guide.pdf

CanFASD's Common Messages Guidelines for talking & writing about FASD: https://canfasd.ca/wp-content/uploads/sites/35/2019/01/Common-Messages-FINAL-Dec-14–2018.pdf

FASD-informed: Understands the nature of the disability and supports the needs and strengths of people with suspected and confirmed FASD through accommodation and promising approaches.

Inclusion: Diversity is celebrated. Differences are welcomed. Everyone has an equal place and feels welcomed and included. Practices and policies need to consider ways they can be inclusive to all community members.

Marginalization: Being pushed to the 'margins' or outside. Feeling misunderstood. Feeling disconnected from the larger group or community. Feeling oppressed and rejected by the majority.

Neuro-diversity: brain differences

Neuro-typical: people who *do not* have a brain based disability

Strengths-based: Recognizes the talents, perseverance and resilience within the person; the family; the community or other systems that can be validated and better supported through programs, resources, and opportunities that further enhance the identified strengths.

Suspected FASD: a person is not diagnosed with FASD but their are flags that prenatal alcohol exposure may have affected the person's development

> "CELEBRATE NEURO-DIVERSITY BY ACKNOWLEDGING BRAIN DIFFERENCES & CREATING RESPONSIVE ENVIRONMENTS, THE UNIQUE STRENGTHS, INSIGHTS AND GIFTS OF INDIVIDUALS WITH FASD CAN SHINE THROUGH"

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Building Nunavut Together
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Bâtir le Nunavut ensemble

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United for Life

Inuusivut Anninaqtuq
Unis pour la vie

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