



WHAT WE HEARD

Based on Community Engagement
on the Yukon FASD Action Plan



1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a permanent condition caused by prenatal alcohol exposure. It affects the development of the whole body and brain. Its effects are felt in any community where alcohol is available.

The number of people living with FASD in Yukon is not clear. We do know that it is a significant issue that affects individuals, families and communities across the territory.

We also know that FASD imposes a high cost on our society. There are direct costs to our health care, social services, education, and justice systems. There are also indirect costs, including the premature deaths of people with FASD.

Here in Yukon, there are a number of services and initiatives available to support people with FASD. Despite this, there are some gaps in these services, and coordination between agencies could be improved.

To help us achieve this, we began community engagement on FASD beginning in May 2017. The process was led by the Interagency Advisory Committee on FASD, which includes people living with FASD, families, First Nation Governments, non-profit organizations, and Government of Yukon departments and agencies.

We are grateful for the strength of everyone who gave us their time during the community engagement. The wisdom they shared will inform the Yukon government as it works to better support everyone who is affected by FASD.

2. Engagement Process

2.1 Purpose

Throughout May 2017 – March 2018, the Government of Yukon and NGO partners met with people living with FASD, their families and service providers. The purpose of these meetings was to learn from their experience and better understand how FASD is impacting our communities.

How many people are living with FASD?

- FASD is a leading cause of preventable brain damage and birth defects in Canada
- The Public Health Agency of Canada estimates that between two and five per cent of Canadians have FASD (2016).
- This rate may actually be higher, because there are likely many people who are undiagnosed and untreated.
- Diagnosis can be difficult, because most people with FASD do not show any physical signs of the condition. This means that people who need support often don't get it.
- Some families may not seek support because of the stigma associated with FASD, or because they fear that their child may be removed by Children's Services.

By listening to Yukoners, we can find ways to work better together to support everyone who is affected by FASD. Our goal is to find solutions that will have lasting positive impacts on our communities.

The information we gathered will guide us as we develop the Yukon 10-Year FASD Action Plan, which we hope to launch in the summer of 2018.

2.2 Notification

The Minister of Health and Social Services and the Minister of Justice sent letters to the Chief and Council and the Mayor in each Yukon community to invite their involvement in engagement sessions. Follow up telephone calls and e-mails were also made.

A news release was issued when the engagement was launched in May 2017. Notice was posted on the Health and Social Services and EngageYukon.ca websites, and information was circulated via social media. Printed material with information on how to provide input was also distributed.

2.3 Engagement Participation

We held engagement sessions in the following communities:

- Watson Lake
- Burwash Landing
- Beaver Creek – White River First Nation
- Old Crow – Vuntut Gwitchin First Nation
- Dawson City – Tr'ondëk Hwëch'in
- Haines Junction – Champagne and Aishihik First Nations
- Carcross – Carcross/Tagish First Nation
- Teslin – Teslin Tlingit Council
- Whitehorse (public awareness event, parent-support group and foster parent sessions)

At these sessions we met with everyone who was interested in sharing their stories and ideas. This included people living with FASD and their families. It also included First Nations chiefs and councils, front-line providers of health and social services, RCMP members, teachers, social workers and religious leaders. As most of the sessions took place outside of Whitehorse, we heard a lot about the services and supports needed in rural communities.

About 120 people took part in the sessions. These ranged in size from groups of three to as many as twenty-five people. Following each session, a written report was shared with community contacts to verify content and get feedback.

In addition, a total of 110 people visited a website with information about the Yukon FASD Plan between May 1 and October 31. A discussion document was available on the site to give Yukoners a chance to provide us further input. Though the document was downloaded 16 times, none were returned to the department.

2.4 Engagement Topics/ Methods

Each session began with an introduction that provided context about the development of the FASD 10-Year Action Plan. This was followed by an open discussion about how FASD impacts communities. We talked about the barriers and challenges that people face. We asked for ideas about what needs to be done to provide better support for all affected by FASD.

In many sessions the Medicine Wheel Community Development Tool (next page) was used to guide the discussion. This tool was successful in engaging meaningful conversations about FASD in communities and for us to better understand the needs of families.

The sessions also provided time for personal reflection, as well as for discussions about the need for individual and community commitment. In all sessions, we used language that promotes respect and dignity, to help create safe spaces for participants.

Participants were asked to respond to five questions:

1. What supports are available for people with FASD and their caregivers?
2. What is working in your community to support people with FASD and their caregivers?
3. What can we do differently to support women and families to prevent FASD?
4. What are your concerns about reaching out for help?
5. What could be done differently?



The Medicine Wheel Community Development Tool

Developed by Dr. Lori Vitale Cox, this tool provides a culturally sensitive way to talk about FASD. Participants created maps that visually demonstrate how FASD affects their community. In our sessions, tears were used to represent lived experiences. Boulders were used to talk about the barriers people face. Fish, moose and bears represent people's physical, emotional and mental strengths. The people are indicators of personal commitment to work towards change. Above all these, eagles are the changes that need to happen to improve the lives of everyone who is impacted by FASD.

2.5 Engagement Limitations/Challenges

We recognize that there were limitations in the engagement process. Most notably, the communities of Carmacks, Pelly Crossing, Ross River, Mayo and Faro were not a part of the engagement sessions.

There were a number of reasons why these communities didn't participate: lack of time, limited capacity and resources, and community fatigue from other engagements. That said, we heard that all communities want to be engaged as we develop our action plan. We also recognize that some communities may want to take the lead and create their own FASD plans.

We also recognize that there was a lack of representation by people with FASD – and their families and caregivers – at many of the sessions. We acknowledge the important voice these people have in this work, and are looking for ways to increase their involvement as we develop the 10-Year FASD Action Plan.

3. Results: What We Heard

3.1 Summary of themes with analysis

The Government of Yukon is grateful for the honesty and openness of everyone who took part in the engagement sessions. We have compiled and analyzed their valuable ideas and suggestions. The following is an overview of the key themes identified by participants:

Awareness

Overall, we heard a that there is a lack of awareness and understanding about FASD among Yukoners. People need to know more about how to best support people living with FASD and their families. People feel fear about FASD. People are also frustrated by the lack of support in their communities. Health care providers and community members feel they have limited resources to provide support.

Stigma

Stigma was a major theme at all sessions. Lack of awareness and understanding about FASD can lead to prejudice and discrimination towards people living



with FASD. We heard that blaming and shaming is being felt in all communities.

Education, training and mentorship

To build awareness and a common understanding of FASD and impacts, communities recognized the need for better FASD education, training and mentorship – at all levels. This applies to students and teachers, RCMP, health care providers, social service workers and justice system staff. People also need to learn more about how to use the new information they learn about FASD.

Community and local supports

They need additional supports and services that are embedded in communities and offered by trusted and respected providers. These services can include diagnosis, interventions, supports for teachers, students, and families and prenatal and birthing supports.

We were told that communities need to be supported to lead in coordinating those supports and services. There is also a lack of knowledge at the local level about what resources are currently available.

Strength-based

Despite the many challenges, we heard about the amazing strengths, resilience and opportunities that exist in each community and throughout the territory.

The Medicine Wheel Community Development tool was key in helping participants identify the many strengths in their community. We need to acknowledge the positive things that people living with FASD bring to their communities.

Elders' wisdom, traditional knowledge and languages, cultural activities, and the strengths of families and community members can all contribute to better outcomes for people living with FASD and their families. Moving forward, we need to take advantage of strength-based approaches.

Holistic approaches

There was a lot of discussion about understanding the root causes of FASD. For many, this includes a connection to the intergenerational trauma caused by colonialism, racism and the residential school system. Further, this can include lack of basic needs being met such as safe and affordable housing, poverty, food insecurity, mental wellness, education and support. We need to recognize these societal causes in order to move forward in a positive way.

Current approaches are at times uncoordinated and inefficient. There is a need for collaboration that is both comprehensive and meaningful. Our government, First Nations governments, municipal governments, service providers, non-governmental organizations, and families and people with lived experience all need to work together.

If we are to really make a difference, we need to work to address the greater systematic issues related to the social determinants of health. These include culture and language, housing, food security, education, income distribution, mental wellness, and the environment.

APPENDIX I

Detailed Notes from FASD Community Engagement

3.2 What we asked and what we heard

The following pages are a summary of what we heard from Yukoners who took part in our community engagement sessions. It details the challenges families and communities are facing, the strengths that currently exist, and actions that could be taken to create a better future for everyone impacted by FASD.

Challenges and barriers

We asked participants about the challenges and barriers that individuals, families and communities face in the awareness of FASD and accessing services and supports. The following details are presented in no particular order of priority.

Lack of awareness about FASD

- Lack of – or perceived lack of – prevention, awareness and education programs and activities in communities.
- People with FASD report having feelings of shame, guilt, loneliness and isolation.
- People with FASD feel they are judged and stigmatized.
- FASD and its affects are often ignored.

Issues with the diagnosis and assessment process

- Many people have not been assessed and are undiagnosed.
- Lack of access to assessment services in communities – people don't want to travel to Whitehorse.
- Long waitlists and few options for diagnosis, school based assessments and adult assessment.
- Many families said they could not receive an Individualized Education Plan (IEP) in schools without a formal diagnosis.

- The system of assessment and diagnosis perpetuates the stigma around FASD, and is seen by some as a tool of colonialism.
- Admitting alcohol use during pregnancy in order to be diagnosed is a barrier.

Lack of access to services and supports

- Programs and services provided by governments are not well coordinated.
- Challenges with the Non-Insured Health Benefits (NIHB) process.
- Limited availability of services in communities – they are time-limited, focused on acute services and not long-term support, few or no services are available on weekends or after hours.
- Lack of specialized supports and services for children and youth with FASD – providers not always equipped to offer the right kind of support.
- Assumptions about cultural differences can lead to ineffective responses and service delivery.
- Many people are unaware of existing resources and services.
- High staff turn-over and lack of housing in communities causes issues with continuity of care.

Lack of supports for people with FASD

- Lack of opportunities for employment, especially for those who may have a harder time keeping jobs.
- Few resources or supports to build life skills.
- Lack of supported housing options.
- Lack of supports for aging people.
- Lack of mental wellness supports.
- Challenges with the income assistance program and understanding FASD

Lack of supports for parents, families and caregivers

- Many families fear or do not trust the system. Parents are afraid that children will be taken away if an assessment is done.
- Lack of support for parents who have FASD themselves.
- Lack of respite care support options.
- What happens to adult children with FASD when their parents die? This is a large concern for families of children who require constant care.

Lack of understanding of the root causes of FASD

- Lasting effects of colonialism, including racism, residential schools and inter-generational trauma.
- Lack of respect for First Nations peoples, culture and traditions.
- Need for First Nations self-determination in the process.
- Poverty and low income creates multiple stresses.

Education System

- There is not enough assessment and intervention in the school system from Kindergarten to Grade 12.
- Lack of training for teachers, educators staff. Not all are competent.
- High turn-over of teachers leads to inconsistency and challenges for students.

Justice System

- A lot of fear of the justice system.
- There was substantial discussion about crime and criminal records for those living with FASD. There was also a perception that victims do not get justice.
- Lack of support, understanding and awareness from the RCMP about how to best support people with FASD in order to de-escalate situations.

Funding

- Lack of funding FASD-specific funding. Most funding is pilot or short-term projects that are not sustainable and are eventually cut. Lack of funding and support for parents and families in rural communities.

Not enough community involvement

- All work around FASD is based in Whitehorse (committees, decision makers, programs, services, supports). It is hard to be involved in the process if you live in other communities.

Lack of information and data

- Lack of baseline information and data on FASD
- Issues around privacy and confidentiality. In order to provide the best client care, information needs to be shared.
- Feelings of disillusionment, mistrust and doubts that this process will be more successful than previous ones. After 25 years of talking, not much has changed for individuals and families living with FASD.

Strengths in communities

Participants in our engagement sessions were very open about the amazing strengths, resiliencies and opportunities that exist in communities across the territory, including:

- Elders, traditional knowledge, practices and teachings.
- Culture and language.
- Family, kinship and the social network of each community.
- Love, patience, acceptance, reconciliation and resilience.
- A commitment to helping each other.
- Traditional parenting and child rearing practices.

- The uniqueness of each community.
- On-the-land programming, culture and wellness camps, healing activities connected to the land.
- The strength of women and their leadership
- The school as a central hub of activities and supports.
- Ceremonies, gatherings, events, traditional food and feasts, celebrations
- The community radio
- Interagency committees in communities – a means of collaborating.
- Rural Yukon communities have a lot to offer.
- Pregnancy tests available in washrooms at restaurant and bars.

Realizing Our Vision: Future Actions

We asked all participants about their vision for the future, and about what actions could be taken to solve the challenges and barriers that were identified.

- Create greater awareness, improve prevention and de-stigmatize FASD.
- Understand that FASD is not a First Nations issue. It affects everyone.
- Reframe and shift the language used when talking about FASD. Use language that is respectful and does not blame, shame or perpetuate stigma.
- Celebrate the unique gifts, strengths and positivity of people with FASD.
- Invite FASD role models and champions to share information and messages.
- Recognize FASD as a lifelong condition caused by brain damage, instead of as a behavioral issue or something individuals have control over.
- Create healthier options, supports and activities for women who are pregnant or planning to be pregnant, especially those who are using or at risk of using substances. Provide more programs in communities like the Parent-Child Assistance Program (PCAP)

Ensure there is support for individuals with FASD.

- Recognize and respect the dignity of people with FASD.
- Ensure there are supports specifically in place for children and youth with FASD.
 - Ensure staff are trained and equipped to work with children with FASD.
 - Create more activities for children and youth with FASD. These can include: recreation activities after hours and on weekends; camps; day programs; casual outings; integrated programs.
 - Ensure that intervention and support approaches are diverse, because FASD is different for every person.
- Offer more supports for people in crisis.
- Ensure there is more support for people who are transitioning in the school system, from youth to adulthood, or out of foster care.
- Create more activities and opportunities for adults living with FASD.
 - More day programs, recreational activities and outings.
 - Ensure that support services like FASSY are well resourced financially and available in all communities.
 - Create stable, meaningful employment opportunities with regular hours.
 - Offer side-by-side job mentoring.
 - Provide transportation to work.
 - Ensure there is a range of supportive housing options for people with FASD (i.e. independent apartments, condos, group living, innovative models, supported housing for parents who have FASD and their children).
 - Improve support for homeless people with FASD.

- Change policies for income assistance programs so people with FASD do not need to check in once a month at social assistance, but do an annual check-in instead.

Ensure there is more support for parents, families and caregivers.

- Improve the public guardian office. Ensure guardians are well trained, supported and funded. Ensure there is a plan in place for individuals with FASD after their parent or caregiver is no longer able to care for them.
- Ensure there are respite care options. Develop a roster of qualified respite care providers. (Currently, respite care is only available for foster parents.)
- Create subsidy programs for parents and caregivers to attend training and workshops.
- Improve access to healthy, affordable food. Food banks should be available in all communities, with extended hours.
- Improve mental health supports.
- Create separate support groups for adoptive parents, foster parents, biological parents, family members and caregivers.
- Foster parents told us about some specific needs: more respite care options; more expertise and support from professionals; training or mentoring on how to best support children in their care; help with navigating the various support systems; grief and loss counselling and supports; reinvigorate the Foster Care Association.

Use a “whole system approach” to improve access to supports and services

- Ensure that all government departments and agencies, NGOs and other partners are working together as a team, without barriers, to best support people with FASD.
- Improve collaboration, communication and case-management practices between service providers.

Improve access to assessment and diagnosis

- Use culturally appropriate approaches in assessing and diagnosing FASD.
- Review the “proof of alcohol use” policy for a diagnosis.
- Create new assessment options to ensure that early intervention and support is available without having a formal diagnosis.
- Develop mobile assessment/diagnosis clinics in communities so that people don’t have to wait or travel to Whitehorse.
- The waitlist for in-school diagnosis is too long. Make this happen faster and as early as possible.
- Develop and implement a pre-screening tool for adults with FASD, especially when diagnosis is not possible.

Work towards reconciliation

- Create a space for First Nations communities and leadership to work together to create solutions for their communities.
- Self-determination in the implementation of programs and services is essential – “Nothing about us, without us.”
- Include cultural and traditional practices in programs and services.
- Work towards reconciliation – connect to the important work of the Truth and Reconciliation Commission calls to action numbers 33 and 34.
- Ensure that services and supports available are culturally informed, trauma-focused and informed.

Support community capacity and community leadership

- Invite people with lived experience to share their story to help build greater awareness and understanding of FASD.

- Create a safe space in all communities where people can talk about FASD, openly and respectfully.
- Provide FASD training to local leaders and decision makers.
- Ensure service providers are equipped with the tools necessary to provide the best care possible.

Develop and deliver education, mentoring and training

- Establish standards for FASD training in the territory. These should include core competencies.
- Ensuring there is consistent and quality FASD training in all communities
- Implement FASD training for all supervisors in all sectors (public and private).
- Create FASD training and cultural competency training for frontline staff in health, social services, justice and education.
- Create and share new strategies and resources about how to start the conversation about FASD.
- Offer more educational opportunities for people with FASD, including job coaching, social skills training, and money management.
- Create new educational opportunities for families (that are free of charge and subsidized) to ensure that parents can learn about new research findings, tools and techniques for support.

Education system

- Adapt the school system to be more responsive, and offer better in-school services and supports for children and youth living with FASD (and other disabilities).
- Provide ongoing FASD training for teachers and educators.
- Provide restorative and trauma informed practices supports in schools
- Create transition plans and mentorship programs

for people who are transitioning to new schools and from school to adulthood.

- Try innovative approaches and supports that accommodate children with FASD (i.e. more one-on-one supports, offer Individual Education Programs (IEP) regardless of whether there is a diagnosis).

Justice system

- Adapt the justice system to ensure a greater understanding of FASD as a life-long disability and create better supports in the correctional system.
- Implement Truth and Reconciliation Commission call to action #34.
- Provide training for RCMP, with a focus on respectfully approaching and supporting people with FASD.
- Provide education and training for court officials.
- Include restorative practices in the justice system that recognize reconciliation and community approaches to justice.
- Look for ways to decrease criminal charges to individuals who have FASD.

Family and Children's Services

- Many families have felt unsupported.
- Assessment of children's needs should be done upon entry into the Family and Children's Services system, to ensure that foster parents and workers are aware of how to best support children while in their care.
- Addressing issues with confidentiality and provide foster parents with all information about a child (history and suspected diagnosis). Provide training and support for these parents.
- Provide consistent FASD-informed support to families. A system of constantly changing social workers and lack of continuity is very challenging for individuals and families.
- Better-support the transition from Family and Children Services to Adult Services.