Final Report: 2023 Looking After Each Other Gathering

May 24, 2023



Prepared by: The Looking After Each Other Project Planning Committee

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On May 24th, the 2023 Looking After Each Other (LAEO) Gathering took place at Camp Manitou in Headingley, Manitoba. Once again, the Gathering brought together FASD coalition members, FASD service providers, program participants, and Elders and Indigenous leaders from across Manitoba. This was the first gathering since the COVID-19 pandemic; the last LAEO gathering was held in 2019. The focus for this year was reconnecting with one another after three years without in-person gatherings, celebrating the successes of the LAEO project over the past several years, and discovering ways that we can work together to continue to reduce stigma towards people impacted by FASD and promote dignity.

Special Thanks

The planning committee would like to thank all the Elders and Knowledge Keepers, those who led prayers, the various event speakers, the event facilitators and the note takers. We would also like to give special thanks to Ron from Life's Journey Inc. for being the LAEO Gathering fire keeper, the Life's Journey Inc. drumming group who drummed at the gathering, Russ and Dallas from Visions and Voices for their impact on the gathering, and Sam for his wonderful display of traditional dancing.



Pipe and Water Ceremony



Ron, the fire keeper, began the day by lighting the sacred fire, which burned throughout the entire event. This was followed with a Pipe Ceremony in which several Elders from around Manitoba participated. Tobacco ties were provided to everyone who wanted to participate and connect with the Creator, by placing tobacco into the sacred fire. This was followed water blessing by Elder by Marv Maytwayashing, where everyone was invited to drink a small cup of water. A feast dish was

offered in the sacred fire before gathering participants headed over the dining hall.

Welcome and Opening Remarks

After the Pipe Ceremony and water blessing, everyone gathered in the dining hall to enjoy breakfast and begin making connections with other Gathering participants. The Emcees for the Gathering, Twyla Gilroy (Chair of Manitoba FASD Coalition) and Chris Fillion (Visions and Voices Program Coordinator), welcomed everyone and acknowledged Treaty 1 territory, the land on which we gathered. They acknowledged that the Manitoba FASD Coalition Inc. and Looking After Each Other project gathers and works on the



Treaty lands of Manitoba: traditional territories of the Anishinaabeg, Cree, Oji-Cree, Assiniboine, Dakota and Dene peoples, and the homeland of the Red River Métis Nation. Twyla and Chris started off the day by drawing a ticket for the first of many prize giveaways throughout the day. Ken Lamoureux and Melanie Muehling from the Government of Manitoba talked about the background of LAEO and the LAEO Gathering.

Celebrating the Successes of the Looking After Each Other Project: Stations



Gathering participants were able to explore different stations discussing successes in relation to FASD and understanding FASD. At each station, there was a presentation and/or the opportunity for conversation about the various projects and their impact. Stations discussed how their project aimed to reduce stigma surrounding FASD, and what they were currently working on to further reduce this stigma. Gathering participants were given the opportunity to

ask questions to the representatives at each stations.

At each of the five stations, LAEO Gathering participants were given the chance to answer the following two questions, using post-it notes.

- 1. What impact has this initiative had on reducing stigma and promoting dignity?
- 2. How could this initiative be used or continued in the future?

For the full list of responses, please refer to Appendix A.

FASD Language Guide



The Common Language sub-committee created the FASD Language Guide, which addresses key phrases and words used to discuss FASD and substance use in pregnancy, and explains more dignity-promoting words, phrases, and visuals that do not perpetuate stigma. The Common Language Guide has gained world-wide attention, has gone on to be endorsed by the Canada Northwest FASD Partnership, and has been translated for use in several languages in different parts of the world.

The FASD Language Guide can be found on the Manitoba FASD Coalition website: https://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/

FrameWorks Report

The Common Language sub-committee also oversaw a study that the FrameWorks

Institute conducted in Manitoba. In 2017, FrameWorks produced a report called "Seeing the Spectrum: Mapping the Gaps between Expert and Public Understanding of FASD in Manitoba". This report explained common ways that Manitobans understand issues related to FASD and substance use provided initial in pregnancy. and recommendations of ways to bridge the gaps between these public values and beliefs, and 'expert' understanding of FASD and substance use in pregnancy. The report can be found on the Manitoba FASD Coalition website:



https://www.fasdcoalition.ca/wp-

content/uploads/2017/09/Seeing-the-Spectrum-May-2017-1.pdf

Documentaries/Popular Education

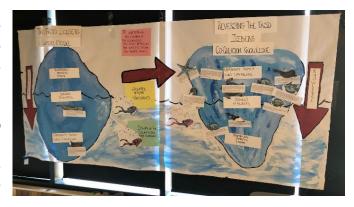


The Popular Education sub-committee created three documentary videos that all tell stories of how community can come together to support people with FASD and people who use substances during pregnancy. The first video tells the story of an adult with FASD, the second showcases the Mothering Project program, and the third follows two middle-school students with FASD and how their schools support them. The videos are also on the Manitoba FASD Coalition website:

https://www.fasdcoalition.ca/looking-after-each-other-project/mini-documentaries/

Research

A team of researchers from the University of Manitoba received a \$2.5 Million grant from the Social Sciences and Humanities Research Council (SSHRC), and conducted research in a variety of focus areas related to promoting dignity for people impacted by FASD. A couple of the researchers and their team were present to share more about their work.



Looking After Each Other Gatherings



Another activity of the LAEO Project is the annual LAEO gatherings that have occurred every year since 2016. Early on in the project, members provided very important feedback regarding the lack of representation and engagement from Indigenous communities in the project. FASD service providers also found that many program participants were asking for more cultural programming and service providers did not know where to start.

As a result, the first annual LAEO annual gathering brought together service providers, Elders and Indigenous community members together from across the province to begin building relationships and sharing information. The Manitoba FASD Coalition is a key partner in carrying out

these gatherings. Feedback from the first gathering led to a more land-based gathering in 2017.

Gatherings continued in 2018 and 2019 and both events took place outside of the Winnipeg area. Over the past three years we have not been able to host in-person, land-based LAEO gatherings due to the COVID-19 pandemic. Instead, we met virtually to continue learning from one another, to build stronger relationships and promote dignity.

Teachings from Elders

After the stations, everyone gathered by the fire and had the chance to hear teachings from the Elders. The teachings surrounded themes such as:

- Our connection with the earth and water
- The importance of caring for the environment
- Unfolding prophecies from the Creator
- The importance of maintaining culture and language
- How to cope with difficult events in our lives
- Supporting children and youth at all stages of development

This time of teachings closed with a feast dish offered in the sacred fire, and Elder Carolyn Moar offered a prayer before lunch.



Self-Directed Learning

After a wonderful lunch cooked for us by the Camp Manitou staff, participants were able to take part in self-directed learning by participating in various activities.

Tobacco Teachings

Gathering participants had the option to gather by the fire to hear tobacco teachings from Elder Robert Maytwayashing. Elder Robert shared about the significance of tobacco as a sacred medicine. The teaching time was a rich time of interaction and discussion amongst all of those in attendance, with plenty of opportunities to ask questions to Elder Robert. Fire keeper Ron also shared reflections with the group.



Women's Teachings

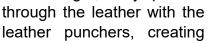


A small group of about 12 people sat down in the sunny foyer of the building to hear Elder Carolyn Moar share women's Teachings. Elder Carolyn taught participants about the significance of all of the seasons of life for women: the power women carry as life-givers, the special gift and responsibility of pregnancy, the significance of a woman's moon time, how the community can support a young woman who has just begun her moon time through a berry ceremony, and the importance

of having women lead and make decisions in Indigenous communities today, as was traditionally done. To conclude this time together, Elder Carolyn shared a bowl of beautiful, juicy strawberries for the group to enjoy!

Crafts

Inside the dining hall, gathering participants were able to make medicine bags and story sticks. At the medicine bag station, participants were given the chance to choose the leather that they wanted to use to make their medicine bag, along with an assortment of buttons. Using all their strength, they pierced







holes so that they could lace the sides of the bag shut. After creating their medicine bags, participants were offered some medicine to put into them. At the story stick station, gathering participants were given an assortment of materials to use in the

making of their story stick. Using creativity, beads, leather, ribbon, feathers and more, they were able to create their own unique story stick.

Nature Walk

Gathering participants who wanted to connect with nature were given the chance to explore the trails at camp Manitou and spend some time outside. The day at Camp Manitou was warm and sunny, but it was quite pleasant to walk along the shaded trails. The paths took walkers along the banks of the Assiniboine River and through rich forests. There may have even been some bird and squirrel sightings! Walkers appreciated the opportunity for quiet reflection in the middle of a full day of learning.



Visions and Voices Presentation

After the self-directed learning activity, everyone gathered in the dining hall to listen to a presentation from two members of the Voices and Voices Program, Russ Hilsher and Dallas Parisien. The Visions and Voices Program offers presentations led by people with FASD. Presenters share their stories of hope, struggle and accomplishment in order to increase FASD awareness, understanding and promote dignity for those impacted by





Russ and Dallas shared their stories and their experience with FASD. Russ talked about how he recently learned the origins of his FASD and was able to meet with his biological mom. He was able to see that she had gone through a lot and helped him understand who he was. Russ talked about the amount and type of support that he personally requires but makes note that it will differ from person to person, and that there is nothing wrong with needing support. Finally, he talked about the impact that the COVID pandemic had on him as someone with FASD. Russ mentions that during the pandemic, supports were taken away, and that he is more thankful than ever to have the support now.

Dallas shared with us that everyone has problems and may need support in some form or another. He shared his experience of raising children and the impact that his FASD has had on this. Dallas revealed that sometimes it is a struggle for him and that he can

get overstimulated. For him, it was important to find an efficient way to cope so that he can continue raising his children.

Russ and Dallas took some time to answer questions from the audience before ending the presentation. Many of the questions were related to how to support a person with FASD. They shared that it is all accommodation since everyone's specific needs are different. They also mentioned that there is a certain importance in caregivers building a connection and developing trust with the person that they are caring for. When asked about how to reduce stigma, Russ stated that "people who matter will know that FASD is part of my life and will respect me" and that those are the people you should focus on surrounding yourself with.



The Future of Looking After Each Other: Interactive Discussion

The next part of the day consisted of group discussions regarding the future of LAEO. The discussion was guided by four questions and gathering participants changed groups for each round of the activity. This gave them a chance to meet new people and to discover different points of view, deepening their understanding of FASD and its complexity. The four guiding questions were:

- 1. Define: What is our desired outcome how would we like people to view FASD and people who use alcohol during pregnancy?
- 2. Discover: What are our strengths, and what is currently working to reduce stigma around FASD?
- 3. Dream: What does a positive future look like for people who use/used alcohol during pregnancy and individuals, families, and communities impacted by FASD?
- 4. Design: What role do we and the rest of the community have in furthering this positive future and how do we put these ideas into action?

The goal of this interactive discussion (appreciative inquiry) was to discover what is working, and what else can be done to help reduce stigma and promote the dignity of individuals, families, and communities affected by FASD. It was identified that Gathering

participants would be invited to a follow-up meeting to continue these discussions about what is next for LAEO.

Please see Appendix B for a summary of the interactive discussion.

Sharing Thoughts about the Day

Before the closing ceremony, LAEO Gathering participants were given the opportunity to discuss and share their thoughts about the day. Participants pointed out that they really enjoyed beginning the day with the pipe and water ceremony. They also enjoyed having the various teachings throughout the day. LAEO Gathering participants enjoyed the first hand accounts from the Visions and Voices presentation and felt that it was beneficial in



educating others about the realities of FASD. Participants really enjoyed the flexibility of the self-directed learning activities in the afternoon and the fact that they were able to choose the activity that they connected with the most.

One suggestion was that the Celebrating the Successes of the Looking After Each Other Project stations activity in the morning could have been more structured and more time could have been allotted to this part of the day so that everyone had

the chance to visit all the stations. Participants communicated that the gathering started quite early for those who live further away.

Closing

The Life's Journey drumming group brought participants back together around the Sacred Fire one more time before Elder Don Robinson led the closing prayer and wished everyone safe travels home.

Sam, a young adult with FASD, ended the day with a traditional dance demonstration. Dressed in his regalia, Sam shared about how he was introduced to powwows and traditional



dancing when he was young, which helped him to connect with his Indigenous culture. Sam shared about the meaning of the dances, and then invited everyone to join him in an intertribal dance, ending the Gathering together on a joyful note!







Appendix A: Celebrating the Success of LAEO- Responses

Common Language/FASD Language Guide

What impact has this project had on reducing stigma and promoting dignity?

"Send with New Student With FASD to Supports, Teachers,"

"assisted in language shift over various services"

"Breaks it down, provides concrete examples and language for people to use"

How could this project be used or continued in the future?

"Call on signatories to present their action plan for implementation (endorsing is not sufficient w/o action)."

"Infiltrate standards of practice."

"provide to various services to use that may not be aware: schools, counsellors, Dr., anyone writing reports, etc"

"Make additions w/ colonization as context; Seek input from Ka Ni / those working on new FASD training"

"It should be a part of the health unit for students"

"Holding service delivery accountable. Utilize oversight legislation such as MACY + Ombudsman office, for example."

Looking After Each Other Gatherings

What impact have these events had on reducing the stigma and promoting dignity?

"Education"

"mindfulness, being present, connecting with emotions"

"Able to give folks common language - handout"

"Life Journey Participant - Pretty welcoming, accepted, respectful"

"Compassion, Respect, Kindness, Understanding"

"Diverse teaching across Canada"

"As a parent taught me how to understand + help children"

"Express self in a cultural way"

"Success Stories, different perspective"

"Connection, Inclusive"

"North & South. Cultural"

"Connecting with MB Elders, Knowledge Keepers, Grandmothers"

"Consistent Messaging"

How could these events be used or continued in the future?

"Teaching students 'ALL STUDENTS"

"Northern event, The Pas"

"Collaborate w/ STAR Program"

"Different funding coursed, partnerships with agencies, virtual webinar series"

"Have events in Indigenous Communities"

"Information to gather + share to assist in various teachings"

"Extend invites beyond FASD community"

"Put into curriculum"

"Making more culture camps for all"

FrameWorks Report

What impact has this project had on reducing stigma and promoting dignity?

"Using the FASD report to shape FASD awareness messaging"

How could this project be used or continued in the future?

"Discuss what impact the term/name FASD impacts people's reactions/beliefs"

"How do we increase health care providers' understanding of FASD?"

Documentaries/Popular Education

What impact has this project had on reducing stigma and promoting dignity?

"Gives schools visions about new ways to be inclusive"

"It encourages others to be ok with talking about FASD"

"the strength-based story telling shows how families +individ have the skills when provided a responsive/supportive environment"

"Understanding & Respect"

"Dignity promotion within social services; staff training"

"Modeling in school 'how to' without \$ i.e. Anyone can do it"

"Helps care givers feel heard"

"Feeling accepted, believed in"

"Creating a safe and welcoming place for mothers to come anytime. When people are safe, they are able to ask for help and let others in."

"modeling what dignity-promoting can look like"

"Helps others understand impact on school + families + community"

How could this project be used or continued in the future?

"New families with more great stories."

"we have used the videos to explain to staff why we fund this work"

"Normalizing/reducing the stigma of using substances during pregnancy"

"Feature on CBC/APTN playing Learning the Dances for awareness"

"Algorithms in search engines – make sure positive stuff comes up"

"playing films in classrooms (All grades, if age appropriate)"

"Researching impacts on young woman (more education)"

"Would love to see more videos..... Another series"

"Need marketing to forward the videos out to all: community, RHA's, School,

Regular TV"

Research

What impact has this project had on reducing stigma and promoting dignity?

"Promote self-awareness"

"Help build self-esteem"

"By sharing Looking After Each Other in the community"

How could this project be used or continued in the future?

"Promotion of Research"

THE ISSUE: The Looking After Each Other Dignity Promotion Project recognizes stigma and discrimination as significant barriers experienced by people who are impacted by FASD and alcohol use during pregnancy.

Attendees at the 2023 Looking After Each Other gathering were asked questions, through a process of appreciative inquiry, generating discussions about what is working, and what else can be done now to reduce stigma and promote the dignity of individuals, families, and communities impacted by FASD.



"Progress has in fact been made, and we should keep working on this progress; FASD has come a long way"

Discussion highlights: Define

What is our desired outcome - how would we like people to view FASD and people who use alcohol during pregnancy?

Shared responsibility, not shouldered by pregnant people.

Nothing for us, without us. We need peers and lived experience people at the table.

Information provided in a matter of fact, non-judgmental, and non-punitive way

Look beyond alcohol use during pregnancy to why it happened

Seen similarly as other disabilities (e.g., Autism, Down Syndrome, etc.), especially since prevalence of FASD is higher

Honouring the person's story... their story is sacred

Through the teachings of blood and bone in trauma (epigenetics)



Change society's cookie cutter view of alcohol

We are all human, we are all different

Discussion highlights: Discover

What are our strengths, and what is currently working to reduce stigma around FASD?

Education: about FASD, effects, trauma, reasons behind alcohol use during pregnancy, and social context

"Stuff like this" (gathering)... an opportunity for networking and increased individual knowledge

Lived experience people (experts) speaking at events

Research that is led by lived experience people

Advocacy alongside and for pregnant people

Storytelling evokes response; "my story has meaning"

Self-advocacy: people with FASD speaking for themselves and showing their strengths and abilities

Focusing in on the good; one person at a time

Promoting pride for lived experience people

Cultural ceremony and practices that meet needs where people are at

Trauma-informed service providers

Plain language, using simple terms

Discussion highlights: Dream

What does a positive future look like for people who use/used alcohol during pregnancy and individuals, families, and communities impacted by FASD?

"I grew up being bullied. I felt stupid, felt like less of a person"

No judgement, no bullying

Prenatal support, care, and conversations without judgement for all; support versus punishment

People are supported, included, and have pride & self-worth

Increased funding, education, supports, and programs across the lifespan without barriers or exclusion criteria

"Community standing with me", people working together

Stronger families, more connection

Social interactions that do not leave people vulnerable

More access to engage in individual passions

Positive and inclusive media (television, movies, social media) representation

People feeling free to ask for the accommodations they need

Discussion highlights: Design

What role do we and the rest of the community have in furthering this positive future and how do we put these ideas into action?

Utilize legislative resources to ensure systemic accountability to research and recommendations; we are not short on information, it exists and is available

Ensure action aligns with what has been said

Come together as a coalition, learn the existing legislation, and create a framework for <u>advocacy</u>

Increase education provided by lived experience groups

Creating safe spaces for people with FASD to go and talk about it

Speak up and advocate in a positive way, with stories

Grassroots work coming together; coordinated radical action



Seeing ourselves as part of the solution

Supporting pregnant partners

Self promotion- show what we've done

Harm reduction and awareness



"Acknowledge your role within and as part of a system"

Keep an open mind

NO JUDGEMENT

Be vocal about FASD

Speak up and advocate

Share personal stories

HAVE MORE OPENNESS

People who aren't "in the FASD world" should take up the cause



Visibility **Grassroots work**

Community **Approaches**



Break Down **Barriers**

WHAT CAN **COMMUNITIES DO TO** REDUCE STIGMA AND

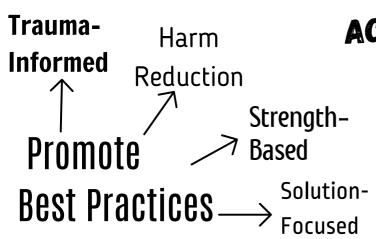
Understanding of the second in PROMOTE DIGNITY?

Increase Individual knowledge

Networking

Share stories of success and strength in media

Promote involvement and belonging



ACCESSIBILITY

Safe spaces to talk about FASD

Advocate for parents and pregnant people

20

Grandmother's Council

All FASD Acknowledge risk factors systemic issues that lead to...

workers'

compensation

Research that is lived experience led

Allocate resources to the community

Substance Use Increase

Prenatal care across jurisdictions

Mandatory FASD training in helping

professions



Fund all social determinants of health

SYSTEMS DO TO REDUCE STIGMA AND PROMOTE DIGNITY?

Individual Deficit

Eliminate Barriers

Medical

Model

Discourses

People who use alcohol during pregnancy

Real harm reduction conversations everywhere

Child care, transport

Lived experience people at government tables

Community Recommendations

More



FASD Justice Pilot

Research ← Findings

ACCOUNTABI

WHAT ELSE IS NEEDED?



MEDIA & PUBLIC CAMPAIGNS

The media and public information can play an important role in promoting dignity and reducing stigma for people and communities impacted by FASD.

The media can be used by creating pamplets, publications, Facebook, etc. advertisements that are 'in your face', promoting awareness events, and highlighting the strengths of those with lived experience. Increased attention should be paid to the targeting of women in alcohol advertising.

CULTURALLY RELEVANT SUPPORTS

Increasing cultural support and urban areas for cultural ceremony and practices is needed to promote dignity and reduce stigma of people and communities impacted by FASD. Cultural teachings "feed the spirit" and connect children, youth, and adults back to their culture and identity.





Training and education can promote dignity and reduce stigma of individuals and communities impacted by FASD. Education about FASD can be embedded into regular and/or sex education curriculum, including the "culture of alcohol", social context, reasons behind addiction and substance use, and the effects of alcohol use during pregnancy. Training and education can be provided by lived experience people through video interviews or attending schools to speak to educators, staff, and students.

Training opportunities should be widely offered to foster parents and medical service providers, and the inclusion of life skills with more resources and supports placed in schools for those students who need it.