Indigenous Approaches to FASD Prevention

Revitalizing Culture and Healing
My grandmother lived to be around 100 years old, passing into the spirit world at the end of the 20th century. She lived a traditional life; eating traditional foods, harvesting medicines, and passing on Tutchone ways of being. My grandmother understood the rhythm of seasons and how to live off the land and water. She knew the medicines from the plants, animals, and the importance of caring for each other and sharing the bounty of the land.

My mother also lived a long life well into the digital era. She was a hunter, a gatherer, a knowledge keeper, and a caregiver. She became a health worker liaising between the health nurses and community. My mother practiced the age-old laws of taking care of our Elders in the community through home visits to check on how they were doing and visit with them; she took them out snaring rabbits, berry picking, and brought traditional foods to the oldest Elders. She helped to bridge the communication gap between community members and with the health care system.

I became a nurse. The first “identified” Indigenous Registered Nurse in the Yukon. Soon, I became a founding member of the Canadian Indigenous Nurses Association and my career focused on Indigenous health. I worked as a nurse, a public health nurse, trained as a midwife, and focused on the determinants of health and Indigenous rights through land claim negotiations and finally as a community-based researcher. I researched and wrote a manual on Fetal Alcohol Spectrum Disorder (FASD), entitled *It Takes a Community*, on behalf of the Canadian Indigenous Nurses Association. In my 40+ years in Indigenous health, I have seen that a constant theme has been the importance of healthy mothers, healthy babies, healthy children, and healthy families as a basis of self-determination.

It has become increasingly urgent that the legacy of colonization demands a wholistic socio-economic cultural and political response based on Indigenous Rights and Title. Equally important is addressing the complexity of health issues through a cultural health framework that is community-based and Indigenous-led, and includes Indigenous research, traditional knowledge and healing, bidirectional capacity building, and wraparound programming. Surrounding a mother and child with care and compassion during the beginning of new life is a powerful path toward addressing, in tangible ways, unfulfilled justice for our people.
Across Canada, this goal of ensuring healthy births is being realized through culture and healing. There are numerous Indigenous communities where women, children, and their families are being supported in finding healthier ways of being through drawing upon cultural wisdom, community strengths, and the teaching of “it takes a community to raise a child.” These teachings uphold the traditional roles and responsibilities of fathers, partners, sisters, mothers, aunts, uncles, friends, and Elders in the well-being of each child born to that community. While traditional roles and responsibilities have changed, the concept of surrounding a community member in need with love and support is once again becoming a reality.

The role of traditional values and cultural ways of being are being drawn upon to address historic and present-day trauma and substance use issues. These strategies are in line with advancing the Truth and Reconciliation Commission’s (2015) Call to Action on collaborative and community-led FASD prevention and with *It Takes a Community* (1996).

*It Takes A Community* included a wholistic framework for understanding the complex root causes of substance use during pregnancy and the potential of community action. It embodied fundamental Indigenous values wherein the child is a gift of the creator, and as such, the whole family and community take responsibility in raising the child to their fullest potential. The manual recognized the importance of self-determination in developing community-led strategies unique to individual communities and linked traditional knowledge of Indigenous values and wholistic health frameworks with the latest medical knowledge about FASD.

In the 20 years since *It Takes a Community* was published, there has been a greater appreciation of the overall well-being of an Indigenous woman in the context of her family and community. Indigenous-led, women-centred, trauma-informed, and wholistic wellness are some of the current approaches to bring about the improved health of women with substance use issues. However, despite the emergence of modern-
day treaties and self-government initiatives, there continues to be far too many Indigenous communities across the land that are struggling with poverty, intergenerational trauma, and substance use. Eclipsing this reality is the urgency of climatic change, food insecurity, and an uncertain future for the children of today. The continuing theme is the role of community in helping one another. Regardless of a community’s size, location, or who is included - whether it is family, extended family, friends, peers or caregivers - the community remains paramount in supporting families in overcoming these often complex challenges of inequality.

Guiding principles of respect in community-based approaches reflect Indigenous teachings that: we are one with the land, water, animals, plants, each other, and all parts of the circle of life; that those around a pregnant or mothering woman take responsibility for ensuring their good health; that the gifts of each child must be nurtured to the fullest. This respect translates to non-judgemental care and is vital for women who have been previously judged and marginalized in society. Understanding the legacy of colonization and historic trauma on our communities, families, and ourselves is central to a respectful and non-judgemental approach. Approaching the overall well-being of women and families from an Indigenous wellness perspective where culture and language, coordinating basic needs, and addressing complex challenges become part of community-based strategies for women’s health, goes hand in hand with a non-judgmental supportive approach.

I am pleased to introduce the good work that is happening in Indigenous communities in Canada, with the hope that it can be an inspiration to all communities. While substance use in pregnancy is a global issue, these culturally-based approaches demonstrate the diverse and exemplary ways of supporting healthy beginnings for women and their families. Across Canada, there are dedicated caregivers and program workers who are demonstrating how language, ceremony, protocols, traditional knowledge and Elders are key to healing and repairing a sense of cultural identity for individuals and communities alike. This work continues to follow age-old traditional values that reflect the teaching, “it takes a community to raise a child,” and are guiding the way forward to healthy pregnancy and parenting.

The following programs are community successes of how these teachings and guidance from an Indigenous wellness perspective are making a difference for women, their families, and their communities. The work exemplified in this booklet is intended to help program planners and service providers learn from these successes, and expand and decolonize their thinking around what FASD prevention can look like, and how language, ceremony, protocols, traditional knowledge and Elders can be incorporated into wellness programming.

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“Central to Indigenous wellness is balance in all things. This balance is delicate, but its strength lies in its malleability and its capacity for modern medicine to be interwoven with traditional knowledge, healing practices, and teachings.”

Toni Winterhoff and Lindsay Wolfson
Id Gidgalang Daagwiiyah (Our Strong Children) works with families to provide prenatal and postpartum care and education to families, including children, parents, grandparents, aunts, and uncles to support the children, in whatever way the family may need. The program is grounded in Haida culture and works with families to build on their strengths, connect with community resources, and promote healthy families.

Id Gidgalang Daagwiiyah operates in Skidegate, Sandspit, Queen Charlotte, and Tlell, serving families in Haida Gwaii from conception to when their children are 19 years of age. Services in the program include system navigation, educational workshops, and hands-on support and information. Services can include self-regulation therapy, doula and postpartum doula, nutrition and cooking, advocacy, Growing Great Kids, celebrating milestones and rites of passage, and ongoing collaboration with the First Nations Health Authority and the school district. All services are FASD- and autism-informed, which requires service providers to think outside the box on where programs are held or how material is presented.

The program also provides system navigation whereby community champions work with families to identify their needs and foster relationships and trust that facilitate access to additional health and social service provision. As such, the most significant part of the program is relationship building and using Haida values and laws to guide how the work is presented to the communities. The needs of the communities vary, so how communities operationalize Id Gidgalang Daagwiiyah is and cannot operate as one-size-fits-all.

Community-Led approaches ensure that local concepts of health, wellness, and healing are central to service delivery, and that supports and services are built that respond to the local geography, infrastructure, language, culture, and resource capacity.
The Circle of Life program is a three-year mentorship program based on the Parent Child Assistance Program (PCAP) to support mothers with substance use concerns or who have child(ren) who were born with FASD, as well as their partners. The program is based out of Kermode Friendship Society, on Tsimshian Territory, and serves individuals in Terrace and the nearby First Nations.

The Circle of Life mentors work with mothers to identify their goals and support them in accomplishing their goals through advocacy, home visiting, budgeting, systems navigation and connecting them to community resources. Mentors are able to access services in Kermode Friendship Society, such as the outreach, housing, and employment workers, as well as outside services to provide wraparound support to women. Mentors are also able to connect women with cultural programming, such as naming feasts, smudging, cedar collecting and weaving, and collecting abalone shells. Parents are also invited to participate in sweats in the sweat lodge at Kermode Friendship Society or other healing practices – such as acupuncture, trauma-sensitive yoga, or reiki – that are available in the community.

Central to developing the program was identifying what was needed to better support and empower women in reducing their substance use. A male mentor was hired to support partners in reducing their own substance use and in achieving and responding to their own goals for themselves and their families. Many of the mentors also have lived experience with substance use and received training on FASD, trauma-informed practice, harm reduction, and de-escalation. Their lived experience, education, and dedication to relationship-building have facilitated the creation of safe spaces for mentors to work with women and their partners with compassion, empathy, and trust.
Wilp Dim Gaymaxghl Laaxws Ahl Majagaleeohl Gitxsan

Gitxsan Health Society, Hazelton, BC

Judy Wesley

Wilp Dim Gaymaxghl Laaxws Ahl Majagaleeohl Gitxsan serves pregnant women or new mothers with substance use concerns and families who have children with FASD. The program focuses on how culture can prevent FASD using the Gitxsanayookw (Gitxsan laws and Code of Conduct) to increase awareness of FASD, address individual, family, and community trauma, and work to honour individuals and families’ bodies, minds, and spirits.

The program follows the three-year PCAP mentorship and systems navigation model but has been updated and decolonized to reflect the community’s needs, recognizing that not all families will be ready to leave the program after three years and that the program has to be culture-driven. The decolonized program offers structured lessons that follow the four seasons. Using this structure, participants take part in activities and Yuuhlimox (teachings) each season and are able to track their Daxgyet Ant’imahlasxw (individual or familial stories) and evaluate their progress through quilting, scrapbooking, and song. Participants are also able to celebrate and share their successes with the whole community during an annual liliget (community-wide feast).

Additionally, a large component of the program is learning the Gitxsan language, which is used to demonstrate people’s Daxgyet and strengths, connects individuals with their culture, and has the Gitxsanayookw embedded within it including traditional ways of conducting oneself, governance structures, and lessons on pregnancy, parenting, hunting, and relationship to the land and spirit. The use of language and culture within the program has been integral to addressing stigma and helps support the whole family in preventing FASD, developing healthy support systems, and identifying the root of trauma.

Culture-Driven approaches re-centre service delivery around land, lineage, and language to support self-determination and give individuals Hope, a sense of Belonging, and a greater understanding of the Meaning of life, grounded in a sense of Purpose.

Learn More
First Nations Mental Wellness Continuum Framework thunderbirdpf.org
The Family Empowerment Team is a collaboration between PCAP, Growing Great Kids Parenting Program, traditional parenting, Indigenous doulas, and advocacy services. The program is primarily located in Chilliwack but serves each of the eleven Stó:lō communities. The collaborative nature of the program lends itself to supporting women and their families in mental, physical, emotional, and spiritual wellness in the absence of substance use and harm.

The Family Empowerment Team works in both rural and urban contexts, connecting women and families with substance use services, child welfare services and care committees, food banks, housing services, crisis support, income support, and other community-based programs and services. The Family Empowerment Team also holds acknowledgement ceremonies for the women where the community, friends, family, and service providers gather in the Longhouse to celebrate women’s accomplishments and honour their spirit and becoming who they are meant to be.

While the services available across the eleven communities vary, the Family Empowerment Team continues to provide wraparound support through mentorship and systems navigation. All of the mentors work in a trauma-informed, non-judgemental, and harm reduction-oriented manner. This approach allows mentors to build compassionate connections with women and help women understand their own histories, why they make the choices that they do, and how they can make healthier choices for themselves and their children. The results have been very positive as the mentors have seen that the healthier women get, the more empowered they are and the healthier they want to be.

Life Course approaches recognize the significant historical and ongoing roles of pregnancy, childbirth, and child rearing as sacred components of the life cycle. Adopting a life course approach promotes positive parenting and reinforces familial and community roles in raising children in ways informed by individual and community cultural identities.
“Ugicigebicen – Nagicishbabicen: Leading the Path to Nurtured Families,” Alexis Nakota Sioux Nation, AB
Sherry Letendre, Lia Ruttan, and Bev Latter

LIVE is a collaborative, community-led, and culturally-based program to support individuals with FASD and other developmental challenges, their families, and the community. Based in the Alexis Nakota Sioux Nation, the program is guided and directed by Ish?awimin (Elders) and Knowledge Keepers to ugicigebicen (help each other), nagicishbabicen (break the cycle), and lead the path to healing.

LIVE provides services and culturally-specific education and supports to individuals with FASD and the community using Nakota kinship relations. The program works the Ish?awimin (Elders) to identify program needs, approve program development and implementation, and demonstrate how wacigem (prayer), Wâkan (the sacred) and connections with children and ancestral teachings can inform community development, community education, and service delivery. The program further mobilizes cultural resources through culturally-specific protocols, methods, and relationships and by using Nakota language and values.

Through collaborating with local service providers, community support services, and government agencies, the program has delivered FASD- and culture-informed community education and staff training, community workshops, and an Indigenous Gathering on FASD. A kinship worker approach has been developed to provide mentorship, advice, information, systems navigation, and transportation to appointments outside of the community. A community facilitator works with representatives from collaborating agencies to better understand how history and culture can be used to promote healing.

A significant lesson from LIVE is that relationship building, planning, implementation, decision-making, and evaluation must be culturally-based. Prevention and education about the historical context of alcohol use has been pivotal and an important component of creating safe spaces that are non-stigmatizing, non-judgemental, and that allow individuals to discuss their own experiences with substance use and/or FASD.

Strengths-Based approaches recognize Indigenous culture as foundational, champion Indigenous women and their extended families’ rights to parent, the maternal-child dyad, and encourage families to see their own strengths and resources.
The New Brunswick FASD Dream Catcher Service Delivery Model was developed and designed with the knowledge and wisdom of Elders and community partners from all 15 First Nation communities in New Brunswick. The model is a self-determining healing-centred model created to help decolonize healthcare service delivery and build respectful relationships with the Mi’gmaq and Maliseet peoples. Guided by the Apigisigtoogen document, a peace-making process for deep-rooted conflict resolution through forgiveness, the model fosters collaboration and builds respectful working relationships between mothers, individuals with FASD, families, communities, and healthcare professionals by placing them at the centre of the healing journey and addressing deep-rooted conflicts.

The model uses a Two-Eyed Seeing Approach that merges Western Medicine and First Nation Science in service planning and delivery. Using a Two-Eyed Seeing Approach, service providers work together with the guidance of Elders to deliver services that meet the needs of women, children, and their families. This approach has enabled doctors in clinics to expand their scope of practice and work with Elders by prescribing language, culture, land-based practices, and sacred ceremonies as part of the healing process.

The ability to merge Western and First Nations Science allows for a more holistic approach and the creation of safe and compassionate spaces for non-judgmental dialogue to happen. Mothers, individuals with FASD, and their families each build their unique ‘Dream Catcher’ that includes people and service providers who can support them in addressing their unique needs and help and them to break free from the histories and associated effects of intergenerational and colonial trauma. This approach facilitates wraparound services through an existing network of community support that the clients’ trust. The Dream Catcher model ensures that the sacredness of the client’s spirit is always taken into consideration.

The ‘Dream Catcher’ is a living document that needs to be continually adapted to the changing needs of individuals and their families across the lifespan. The model reinforces the importance of supporting individuals on their healing journeys, fosters genuine and compassionate relationships, and ensures that mothers, individuals, and their families have the foundations for success, however that may look for them.
Etuaptmumk (Two-Eyed Seeing) is a concept developed by Mi’kmaq Elders Albert and Murdena Marshall. Etuaptmumk refers to the understanding of Indigenous and Western knowledges as distinct worldviews and encourages the ‘weaving’ between the two worldviews. This approach integrates the strengths of Indigenous knowledge about health and wellness with Western science to preserve and recognize traditional knowledge while concurrently utilizing the diverse healing and medical practices that are available.
The Lakeland Centre for FASD’s Mothers to be Mentorship Program is available in Treaty 6 Territory to Cold Lake First Nation and Beaver Lake Cree Nations, and to the Elizabeth, Fishing Lake, Kikino, and Buffalo Lake Métis Settlements. The program serves women who are pregnant or recently have given birth, used alcohol and/or drugs at any time during their pregnancy, and are interested in making changes in their lives and the lives of their children.

The goal of the Mothers to Be Mentorship Program is to provide one-on-one support to women; helping women connect with, and navigate through, health and social services. The program helps women to identify and achieve personal goals. Mothers to be Mentors support women through ongoing advocacy and goal setting, including through supporting them in addictions treatment and with family violence, housing, transportation, and financial needs. Mentors work with all supports in the woman’s circle of care, including spouses, family, and community supports, to ensure that wraparound care.

Relationship-building, harm reduction, and FASD- and trauma-informed services are central philosophies to the mentorship program. Through ongoing relationship-building, community participation, communication, and collaboration, mentors also work closely with the First Nations and Métis communities to offer culturally appropriate programming and meet the needs of the community.

Delivering consistent, non-judgemental, and evidence-based messaging is important for decreasing stigma associated with FASD in the communities. The Mentorship program has found that conversations about healthy families and FASD prevention with people of all ages can further reduce stigma.

Service delivery models must explore the **social and structural determinants of health** and their influence on substance use and service engagement. Offering services that address these determinants shifts service approaches away from individual stigma and blame to be about substance use and related health and social concerns in order to better support mothers, families, and communities.
Considerations for Expanding and Developing an FASD Prevention Program in Your Community

There are many important actions we can take to support healthy beginnings.

### Using Non-Stigmatizing Terminology

Our beliefs and the words that we use can help build compassion, help women feel safe to ask questions or share their stories, encourage women to seek help if they are having difficulties stopping or reducing their substance use, and challenge existing stereotypes about women, children, and communities. Therefore, as providers, we have the responsibility to use non-judgemental words and understandings that are supportive to self-determination. This may require us to consider our own personal beliefs in order to better support women and their families. It may also require us to reframe prevention programming towards terminology and approaches that are more supportive of Indigenous worldviews.

<table>
<thead>
<tr>
<th>Instead of using terms or holding beliefs such as:</th>
<th>Use the following terms and understandings:</th>
</tr>
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<tbody>
<tr>
<td>Female alcoholics, addicts, junkies</td>
<td>Women who use alcohol and drugs</td>
</tr>
<tr>
<td>Children who are injured by their mother's drinking</td>
<td>Infants born with FASD, children affected by FASD</td>
</tr>
<tr>
<td>She admitted to drinking alcohol during pregnancy</td>
<td>She reported drinking alcohol during pregnancy</td>
</tr>
<tr>
<td>Uncaring women who drink in pregnancy</td>
<td>Women who want to succeed but are facing many influences on their drinking</td>
</tr>
</tbody>
</table>
2 Identifying Existing Community Strengths and Programming

Beyond challenging our biases and assessing our language, it is also vitally important to acknowledge the strengths that already exist in the community, what the community’s needs are, and how linkages might be made. One way that programs have identified what resources are already available is through asset mapping, a process of identifying and mapping what community resources are available and facilitating how those resources work together to address community needs and improve health. The Circle of Life Program used this method to identify what services were available, which was helpful in creating a realistic goal for what could be developed in their community. Examples of related resources may include health centres, schools, Canadian Child Nutrition Programs, Growing Great Kids, parenting programs, youth programs, women’s nights, and land-based programming. Meeting with each community service to see how they are – and can be a part of – Indigenous wellness and FASD prevention is important. In some communities, the linkage of programs and services, rather than creating a dedicated FASD prevention program, will be key to supporting healthy families.

3 Connecting with those who have Walked the Path Before Us

Just as Marilyn Van Bibber described in the introduction, the programs highlighted in this booklet are community successes to learn from. These programs demonstrate how traditional teachings and guidance from an Indigenous wholistic perspective are making a difference for women, their families, and their communities. Their examples can help us expand and decolonize our thinking around what FASD prevention can look like and move us towards Indigenous wellness models. We can also connect to the work of others working on via websites such as www.fasd-evaluation.ca to learn about the design and evaluation of community-based programs across Canada.

4 Identifying Potential Funding Partners

Building relationships with potential funders is an important step. Identifying funding is a process of building relationships, as is the relational work you do with women, families, and the community. The included programs have been funded through:

- First Nations Health Authority (BC)
- Building Blocks Program, Ministry of Children and Family Development (BC)
- Social Assistance Program, Indigenous Services Canada (BC)
- Alberta FASD Network (AB)
- Ministry of Community and Social Services (AB)
- Métis Settlements General Council FASD Services (AB)
- Department of Health (NB)
- Intergovernmental FASD Partnership (NB)
Principles for Advancing Indigenous Wellness and FASD Prevention

The successes of the programs highlighted demonstrate the breadth of community-based and culture-driven Indigenous wellness and prevention programs. These programs are diverse, acknowledge the unique needs of individuals and families within their community, and are guided by local languages, cultures, and teachings. Often, these initiatives are not called “FASD Prevention” but meaningfully address the broad social and structural issues that are associated with mental, physical, spiritual, and emotional health and wellness. These principles (see diagram on previous page) can help guide the creation of community-based and culturally-informed programs, supports and services for women, families, and communities.

Descriptions of each of the principles can be found on:

- Community led, pg. 6
- Wraparound support, pg. 7
- Culture driven, pg. 9
- Life course, pg. 10
- Strengths-based, pg. 11
- Social and structural determinants of health, pg. 14

Reflection Questions

The following questions were developed by the highlighted program providers who contributed to this booklet as key considerations for you to ask yourself to support women, children, and their families. Use these questions to reflect on how you can support health beginnings in your community.

1. How does our program support women, children, and their families?
2. How does our program support women in addressing the issues that impact their substance use?
3. How are we reaching women who are most at risk for substance use in pregnancy?
4. How does our program integrate our Ancestors, Elders, Knowledge Keepers, culture and language?
5. Have we followed the proper community protocol(s) in all of our interactions with community members, community partners, and external partners?
6. Have we created a safe and welcoming space for women? Are our services trauma-informed, FASD-informed, and harm reduction-oriented?
7. Is our program welcoming, harm reduction oriented, trauma-informed and FASD-informed?
8. How can our program reduce stigma associated with FASD and substance use in pregnancy?
Conclusion

The seven programs highlighted in this booklet exemplify how Indigenous communities across Canada are working to integrate culture and healing into their efforts to improve the health of women, children, and their families. Each program has thoughtfully drawn upon traditional notions of wellness, whereby culture and language, coordinating basic needs, and addressing complex challenges become a part of community-based strategies. These go beyond how we have previously created FASD prevention programs to promote healing through language, ceremony, protocols, traditional knowledge, Elders, and (re)building cultural identity for individuals and communities.


Acknowledgements

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Women’s Conference at Cold Lake First Nation, April 2019