



Canada FASD Research Network's Commitment to Indigenous Partnership, Reconciliatory Research, and Action

The Canada FASD Research Network (CanFASD) is a collaborative, multidisciplinary research network that works to address the complexities of Fetal Alcohol Spectrum Disorder (FASD) through research and knowledge exchange. Our mission is to conduct and engage in research to inform prevention, diagnostic, and intervention strategies, improved support, and policy action.

Brief Summary

Preventing and supporting individuals living with FASD has emerged as a health priority within Indigenous communities over the past few decades. Although several early studies showed high prevalence of FASD among Indigenous peoples¹, these studies are largely outdated and were limited by significant methodological concerns. Most notably, data on FASD prevalence in Canada is often pan-Indigenous, discounting the cultural, linguistic, and geographic diversity of Indigenous peoples and creating challenges for identifying Indigenous-specific FASD prevalence rates [1-3]. The published research has been largely conducted by non-Indigenous researchers who use Western epistemologies and methodologies. These studies have not integrated Indigenous worldviews or practices, and often are not contextualized within the diagnostic capacity in Canada. Moreover, they do not account for the complexities to accessing diagnostic services, including a referral bias that has historically resulted in increased referrals for Indigenous children and limited access to diagnostic services in many remote, Northern, and rural areas, making FASD prevalence in Indigenous communities quite challenging to ascertain. Despite these limitations, FASD has been noted as a “clear public health concern” amongst Indigenous peoples by the National Collaborating Centre for Indigenous health [1], which was also reflected in the inclusion of FASD in the Truth and Reconciliation Commission of Canada's (TRC) Final Report (2015) and through two Calls to Action on FASD [4]:

¹ 'Indigenous peoples' describe the peoples of North America who were present before colonization. In Canada, this term encompasses three distinct groups of people: First Nations, Métis, and Inuit. These three populations are distinct and diverse groups with unique histories, languages, cultural practices, and spiritual beliefs.

“33. We call upon the federal, provincial, and territorial governments to recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD), and to develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.

“34. We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:

- i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.
- ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
- iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.
- iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety” (p.221).

Supporting Indigenous peoples and communities in the journey of healing from colonization, intergenerational trauma, and the interrelated social determinants of health requires support at many levels, ranging from the individual to the national scale [5, 6]. Moving forward requires an understanding of the systemic causes and issues underlying FASD in Indigenous communities. This understanding includes consideration of the historical and intergenerational trauma that underlie the risk of alcohol use in pregnancy and addressing and responding to the 2015 Truth and Reconciliation Commission’s Calls to Action #33 and #34 [4, 7-10].

CanFASD is committed to aligning our research priorities and actions with those guided by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and TRC. Both outline the need for meaningful understanding of the impacts of colonization on Indigenous peoples, further engagement and reconciliatory relationship building, and integration of Indigenous values, knowledge, and worldviews into research, knowledge exchange, and policy action [7-9].

Calls to Action #33 and #34 have acted as a driver of new and renewed action on FASD prevention and supports in Indigenous communities and urban Indigenous populations. In partnership with Indigenous and non-Indigenous researchers, community organizers and collaborators, CanFASD has developed two frameworks for action including:

- [Consensus Statement: Eight Tenets for Enacting the Truth and Reconciliation Commission’s Call to Action #33](#) (herein referred to as “the Consensus Statement”) [11]; and,
- [Truth and Reconciliation Call to Action #34: A Framework for Action](#) (herein referred to as the “Framework for Action” [12].

Our Commitment to Partnership, Reconciliatory Research, and Action

CanFASD staff and researchers come from multidisciplinary backgrounds with expertise in FASD prevention, diagnosis, intervention, justice, and child welfare, each with diverse experience working with Indigenous peoples and in Indigenous communities. The following commitments to partnership, reconciliatory research, and action with Indigenous peoples and in Indigenous communities recognize the diverse positionality of CanFASD staff and researchers.

CanFASD staff and researchers are committed to:

1. Understanding the impact of colonization and subsequent assimilatory policies and practices on intergenerational trauma, substance use, addictions, and FASD.

Colonial and assimilatory policies and practices, including the Indian Act, Indian Residential Schools (IRS), historical and contemporary child welfare practices including the 60s and millennial scoops, and systemic violence against women, have disrupted families, communities, and traditional approaches to Indigenous peoples' health [7-9, 13]. These colonial policies, practices, and systemic responses have impacted Indigenous peoples and communities in different ways, including the disruption of families and communities; loss of land, culture, language, and identity; and the perpetuation of shame and loss. The effects of IRS were not experienced only by those forced to attend, but rather have been felt across generations through the intergenerational transmission of trauma. The losses associated have manifested within communities in many ways, including through the need to self-medicate as a means of coping with the historic and persistent trauma, contributing to high rates of substance use and addiction [14, 15].

It is recommended that CanFASD staff and researchers:

- Develop or enhance their understanding of the historical and contemporary colonial legacies and practices, and their collective impact on both Indigenous peoples and communities in Canada generally, as well as on FASD more specifically;
- Increase their knowledge of the key elements of UNDRIP, the TRC's Final Report, and relevant Calls to Action;
- Participate in courses or workshops about reconciliation (i.e., the [KAIROS Blanket Exercise](#)), or cultural safety (i.e., the [Indigenous Cultural Safety Training](#) program);
- Contribute to building an iterative repository of knowledge enhancing materials; and,
- Identify their role in responding to the TRC Calls to Action based on their own knowledge, expertise, skills, and supplemental learning.

2. Building meaningful partnerships with Indigenous peoples and communities that are based on the values of reconciliation.

Reconciliation is a collective transformative process that requires Indigenous and non-Indigenous peoples to build relationships based on mutual recognition, respect, sharing, and responsibility [4, 16]. Building new and upon existing relationships requires working in partnership and through a relational approach that is predicated on those values [16, 17].

It is recommended that CanFASD staff and researchers:

- Develop research and funding proposals in partnership with Indigenous organizations, communities, and research institutions (as applicable);
- Dedicate time to, and prioritize the process of relationship-building within current and future research initiatives in Indigenous communities/with Indigenous peoples;
- Advocate for Indigenous partners/communities and address misconceptions about FASD prevalence and alcohol use in Indigenous communities; and,
- Demonstrate interest in learning from community partners.

3. Developing research that is guided by community needs, values, and knowledge systems.

Research priorities must be determined by Indigenous communities and researchers, and recognize the diverse worldviews, knowledge systems, and epistemologies of Indigenous peoples [6, 11]. Research processes should incorporate communities' epistemologies, language(s), culture(s), and traditional knowledge, as relevant through Indigenous leadership in these processes [6]. Knowledge generated should be held by the community and used by researchers with permission.

It is recommended that CanFASD staff and researchers:

- Take a training on the [fundamentals of OCAP®](#) and use the four components of Ownership, Control, Access, and Possession as the basis for all work with First Nations peoples and with Métis and Inuit, as applicable;
- Identify and follow community's research ethics community protocols (if they exist);
- Following the lead of Indigenous co-researchers, adopt approaches that invite equal partnership, collaboration, and, as appropriate, a Two-Eyed Seeing approach, which 'weaves' Indigenous and Western epistemological systems back and forth without assimilation or superiority and,
- Refer to guiding principles and resources developed or co-developed by Indigenous researchers, communities, and civil society or health organizations related to FASD, such as:
 - [Consensus Statement: Eight Tenets for Enacting the Truth and Reconciliation Commission's Call to Action #33](#) related to FASD prevention;

- [Truth and Reconciliation Call to Action #34: A Framework for Action](#) related to supporting individuals with FASD in the justice system;
- [Imagining Child Welfare in the Spirit of Reconciliation](#);
- [New Brunswick FASD Centre of Excellence’s Dreamcatcher Model](#), a service delivery model for First Nations individuals in New Brunswick with FASD; and,
- [Medicine Wheel Student Index](#), a diagnostic tool for First Nations youth.

4. Advocating for Indigenous-led research through sustainable and long-term funding

Current funding models do not often provide equitable access to funding for Indigenous researchers and civil society organizations, and often favour Western research and epistemologies [11, 17]. Moreover, funding often follows short-term cycles that do not prioritize trust and relationship-building as a necessary component of reconciliatory research and action [6, 11, 16]. There is a need to decolonize research to support community-led research and respect Indigenous epistemologies; provide equitable access to funding; and follow Indigenous ethics and research protocols [11, 17].

It is recommended that CanFASD staff and researchers:

- Continue to advocate for dedicated funding streams for Indigenous-led research;
- Continue to advocate for funding for long-term and sustainable projects; and,
- Identify opportunities to decolonize FASD research.

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