

# AGING MATTERS: INDIGENOUS PERSPECTIVES

*Bi pi maadzing zaagidwin  
teg jichaaming*

*Circle of Life in  
the Spirit of Love*



# PROJECT DESCRIPTION

Persons with intellectual and developmental disabilities (IDD) are living longer and more robust lives, but what are the challenges of aging with a disability?

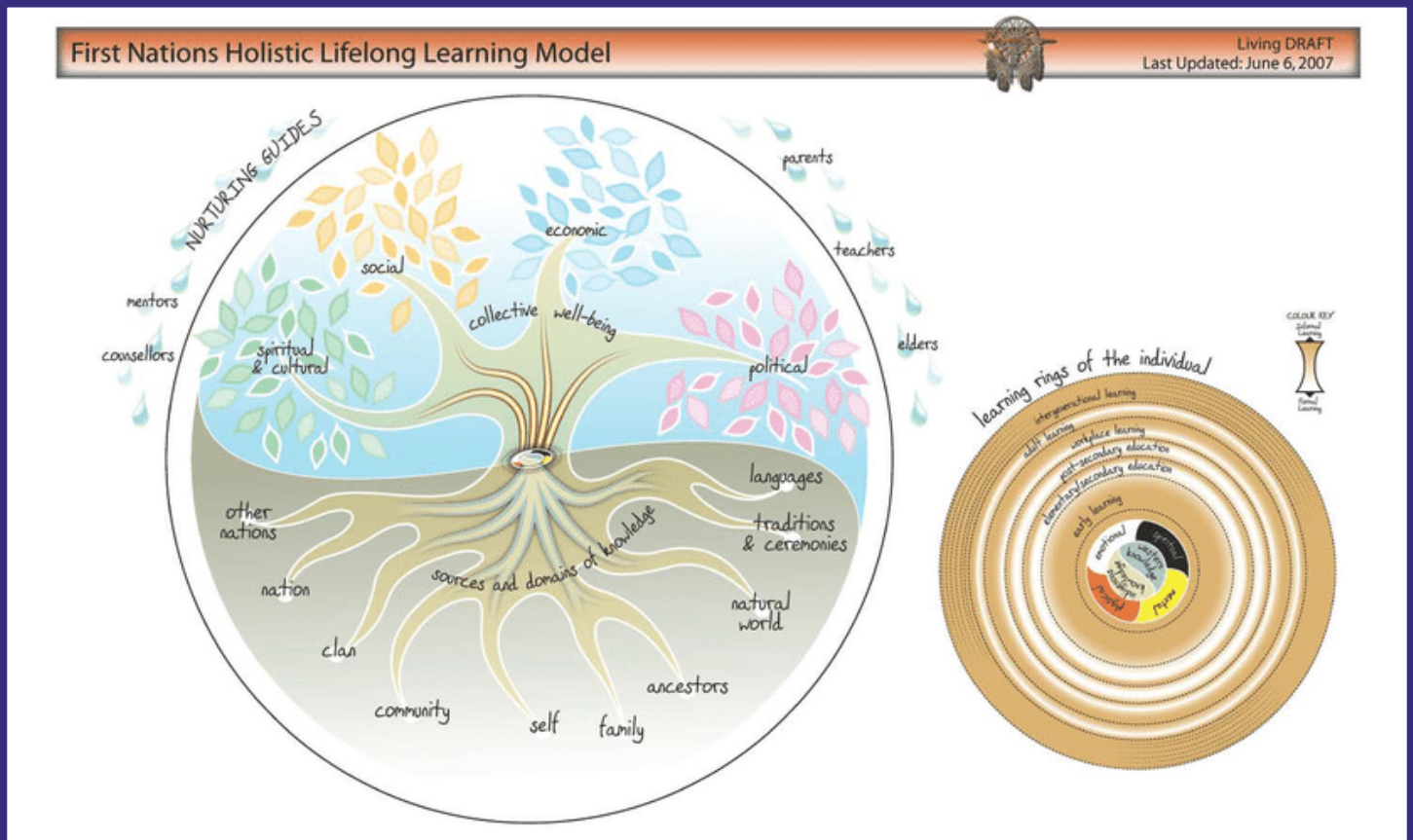
**The Bi pi maadzing zaagidwin teg jichaaming (Circle of Life in the Spirit of Love Project)** team hosted a free webinar series to highlight the challenges and strengths of Indigenous people who have IDD and those who support them. This webinar series brings Indigenous voices from Northern Ontario to the forefront. Featuring perspectives from professionals, caregivers and self-advocates, the project presents a view of supporting or being an Indigenous adult aging with IDD.

The research team developed three webinars to highlight the voices of those in the North, from the following groups:

- **Self-advocates and families** who can speak to their lived experiences of aging with IDD;
- **Community support workers and caregivers** who provide 1:1 support in Northern communities;
- **Professionals** who engage in knowledge sharing and work with those diagnosed with IDD.

To build these webinars, we did a call out for participants and spoke to a total of 40 people in Northern Ontario. We spoke with professionals, community supporters, frontline workers, self-advocates, and families. We hosted Gatherings, where we invited knowledge sharers to join us for a discussion on their lived experiences. These discussions were facilitated by an Elder, Dorothy Elie. When people were unable to join the group Gatherings, we offered one on one interviews.

# FIRST NATIONS HOLISTIC LIFELONG LEARNING MODEL



*The First Nations learner dwells in a world of continual re-formation, where interactive cycles, rather than disconnected events, occur. In this world, nothing is simply a cause or an effect, but the expression of the interconnectedness of life. These relationships are circular, rather than linear, holistic, and cumulative rather than compartmentalized. The mode of learning for First Nations people reflects and honours this understanding.*

# FIRST NATIONS HOLISTIC LIFELONG LEARNING MODEL

The project adapted the First Nations Holistic Lifelong Learning Model, which was developed by the Canadian Council of Learning, the Aboriginal Education Research Centre and the First Nations Adult Education Consortium.

The model is the representation of a tree. It represents growth and learning throughout an individual's lifespan, and highlights individual learning and overall collective wellbeing.

The project uses the tree to represent the three areas of the webinars

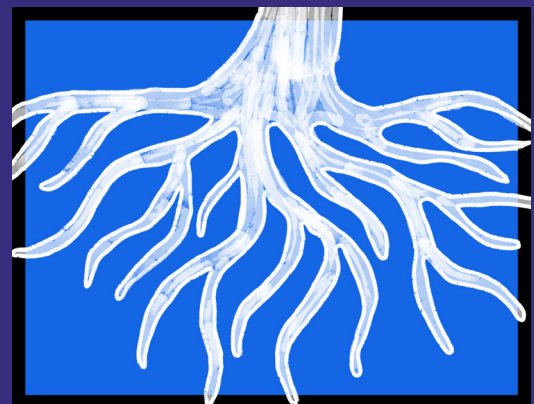
WATER DROPLETS:  
PROFESSIONAL PERSPECTIVES



TRUNK AND BRANCHES:  
PERSPECTIVES FROM  
CAREGIVERS AND COMMUNITY  
SUPPORTS



THE ROOTS:  
PERSPECTIVES FROM  
INDIGENOUS FAMILIES AND  
SELF-ADVOCATES





# WEBINAR 1 – WATER DROPLETS

## Perspectives from Professionals

[The Water Droplets webinar](#) explored professional perspectives on supporting people who are aging with an IDD in the North. The webinar looked to outline the systemic barriers that rural and remote communities face and address the strategies for better outcomes.

## Key Takeaways

*“[There’s that] whole issue about reimbursement of respite services that, I don’t even think people take that into account. [...] A lot of our communities are living in such poverty and don’t have employment opportunities or training opportunities. They’re disabled and they can’t work even if they wanted to work. And if they did want to work, there’s no jobs to work at.” – Indigenous Community Supporter*

Individuals with IDD can sometimes be ‘hidden’ or ultimately underserved because of limitations in capacity within the service system. Knowledge sharers mentioned that people can be missed, as families manage without knowing what supports are available, and providers struggle to do outreach as well as supporting their existing clients.

There is an unequal distribution of money and supports available for people with IDD/disabilities over the lifespan. Resources are much more readily available for children and youth than for adults, and there are very few resources available for aging people with IDD. The typical supports for people who are aging are not equipped to support people with IDD.

Diagnosis is often only valuable and worth seeking if it’s going to lead to services and/or funding opportunities. In some communities it does, and in others it does not.

The diagnostic and healthcare systems are colonial, and may conflict with Indigenous worldviews of health and wellbeing. As a result, individuals with or suspected of having an IDD diagnosis may not seek or receive appropriate support and preventative care. This is compounded by systemic racism within healthcare and social service systems, underfunding and ongoing colonial practices that work against traditional views of health.

Out of all of the strategies for better outcomes, relationship building is spoken of most frequently amongst service providers. Building respectful relationships with the communities, families and the individual’s service providers is the key way to build trust and understanding. Relationship building can be tricky, as some communities do not trust outside providers due to a long history of harm. Service providers recommend taking time to do outreach, build relationships, do not overwhelm or pile on supports and to spend more time listening than talking. Be consistent!



# WEBINAR 2 – TRUNK AND BRANCHES

## Perspectives from Community Supporters and Caregivers

[The Trunk and Branches webinar](#) highlighted caregivers and community support workers experiences in providing services to aging Indigenous adults with IDD. Conversations focused on participants perceived strengths and challenges of small and/or remote communities in Northern Ontario. As well, discussions included creative problem solving of the positive effects of relationship building and cultural competency when providing services.

### Key Takeaways

*“What that really means when we’re talking about remote and isolated [is] we’re talking about communities without any roads. Accessibility into the communities that rely mainly on flights in, and even relying on those flights in our weather, weather permitting. As well as internet services which are satellite based and those are prone to a lot of [...] power outages and again weather impacts.*

*When we’re talking about semi-isolated communities, some are within 90 kilometres to a Health Care Centre for example. Whereas [in another, more isolated community], it’s going to take you two or three different planes to get there. Now you’re talking about high transportation costs. You’re talking about impoverished communities as well” – Indigenous Community Supporter.*

Indigenous communities, and their belief systems and ways of being, vary widely across Northern Ontario. Colonization has been weaved into many areas of the Indigenous experience, as well as settlers’ views on Indigenous culture, which can result in stereotyping and discrimination. Issues of trauma, particularly intergenerational trauma, are important to note (although possibly not well understood) and may impact Indigenous families’ desire to reach out for support. Those we spoke with also noted that food security, housing and homelessness significantly impact Indigenous people in the North.

For organizations that wish to support people of the First Nation communities, it is important that they understand the history, and the protocols for doing so respectfully, such as engaging with the Chief and Council and asking for permission to visit the community, taking time to learn about the community, understanding it’s structure and existing programs.

Fly-in communities or remote communities in Northwestern Ontario have difficulties accessing medical services due to the distance, time and cost of flights. Typically, those in remote communities have to fly in or use ice roads to travel south for specialist appointments and hospital access.

More training – in cultural safety, Indigenous culture, and the Indigenous experience - is crucial to help supporters to provide the best care.

Service providers also stated that education on preventative care for aging adults is needed, including what to look out for in aging clients in terms of their behaviours, their physical and their mental health. and to spend more time listening than talking. Be consistent!



# WEBINAR 3 – THE ROOTS

## Perspectives from Indigenous Families and Self-Advocates

[The Roots webinar](#) captured the experiences of families, unpaid caregivers and aging Indigenous adults with IDD in Northern Ontario. Stories of resilience from self-advocates and their caregivers' were shared on the joys and challenges of supporting their unique needs. Conversations addressed a variety of subjects, including support navigation, systemic issues and planning for the future.

### Key Takeaways

*I have a counsellor [...] in Winnipeg. She helps me stay sober, she helps me stay strong and she helps me to play my drum and smudging – Indigenous Self Advocate*

Aging impacts family members and caregivers. It can bring changes in mobility, cognition, finances – all of which can impact a person's ability to provide support for their loved one and themselves. Families can reach a crisis point if those who provide primary support decline or pass away.

Providers report that families experience care fatigue (burnout) due to the many responsibilities placed on them, and that the families worry about caring for their loved ones with IDD. Parents also report that supporting their (adult) children – particularly through times of crisis - is very draining. The combination of parents' multiple responsibilities and the person with IDD's needs, which may be high medically or behaviorally, can result in challenges in accessing what care is available. At times, the person's needs can far outweigh the family's ability to provide support, and this fatigue can be so excessive, and community supports so limited that families are driven to dropping their loved ones at a hospital so that they can get support.

Families may be so busy dealing with the day-to-day that they do not have time or capacity to plan for the future of their loved one. When families do try to plan, they can be left on waitlists for extended amounts of time.

Limited services and support in isolated and semi-isolated communities result in people needing to move many hours away to a group home or Long-Term Care facility. This removes them from their fundamental support systems: family, friends and community. This isolation is extremely difficult and damaging for those affected. It dislocates them from their culture, and often exposes them to exclusion, racism and discrimination in city centers.

The joy of the everyday is noticeable in the self-advocates who participated in the project. Individuals face many hardships in their lives, but despite these issues, they were keen to share their successes in independent living and building relationships.





# STORYTELLING SERIES

The Storytelling Series reflects voices and perspectives from those with lived experiences. Participants include Indigenous caregivers and individuals with intellectual and developmental disabilities living in Northwestern Ontario. Three videos were produced with those with lived experience:

[Joyce and Chris' Story: An Indigenous Mother's Advocacy](#)

[Serena's Story: Isolation, Dedication & Holding Identity](#)

[Aaron's Story: Self-Advocacy and Support in Sioux Lookout](#)





# IMPORTANT TERMS

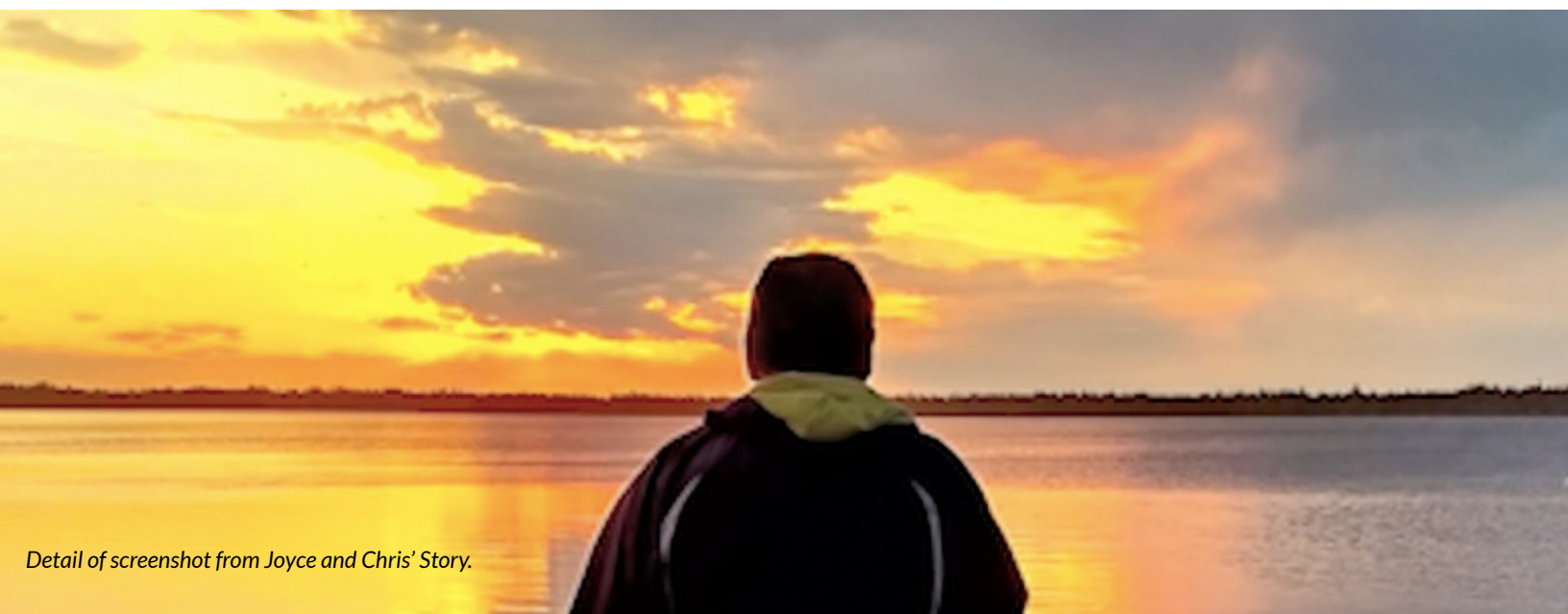
**Aging:** Signs of aging start earlier with people with Intellectual and Developmental Disabilities (IDD), often at 40.

**IDD:** An Intellectual and Developmental Disability (or IDD) can be defined as deficits in intellectual and adaptive functioning that appear before the age of 18. People with a developmental disability may learn, understand or remember things at a slower pace than others. This can affect their personal care, language skills and their ability to live without support.

Examples of intellectual and developmental disabilities include Developmental Delay, Down Syndrome, and Fetal Alcohol Spectrum Disorder (FASD).

**Lived Experience:** Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.

**Colonialism:** when one nation takes control over another, brings in settlers, and exploits the land for people and profit. Colonial practices include attacking and reducing population numbers of Indigenous populations, destruction of social and cultural structures, exerting external political control, establishing systems of low-quality services for colonized peoples, imparting racist ideologies and ideas around superiority over Indigenous populations to justify their exploitation and cultural genocide.



# IMPORTANT TERMS

**Intergenerational trauma** is the result of centuries of colonial policies and practices that were aimed at suppressing and undermining the cultural identity of Indigenous peoples. As an example, the residential school system was an effort to destroy Indigenous culture by “killing the Indian in the child”. This attempt at cultural cleansing has led to severe trauma that is being passed through the generations. Over time, the effects of this trauma can affect a whole population, resulting in a legacy of physical, psychological and economic disparities that impact generations. Intergenerational trauma is cumulative. Chronic exposure to trauma can manifest in individual symptoms such as normalization, anxiety, depression, grief, addictions, and self-destructive behaviors.

*“There’s still a fear. That if your child isn’t like the kid next door, isn’t running, isn’t doing whatever, that the system will come and take them. And you could be the best parent and they will just come and say, well, you don’t have the services in your community, you should give them up. So, I think that has instilled a fear to share. And we do have a lot of hidden kids” – Settler Professional.*

There has been a failure to understand the connection between historical and contemporary trauma and how it impacts individuals and communities, especially by Western educated physicians and mental health professionals.

**Rural and remote communities** are geographic areas that are located outside large towns and cities. Because of their distance from larger urban centers, these areas may have disparities in the availability of resources like medical care, reliable internet and other social services. In this project, we define rural areas as being outside of larger cities but can be accessed by roads or traditional forms of transportation, and remote communities are defined as areas accessible only by flights or ice roads in the winter.

**Settler** is a term that refers to a non-Indigenous person.

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