



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024





First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

TABLE OF CONTENTS

| | |
|--|----|
| 1. Executive Summary..... | 3 |
| 2. Introduction | 7 |
| 3. Guiding Principles..... | 8 |
| 4. Examination of the FNIHCC and AL Programs..... | 9 |
| 4.1 First Nations Population Profile..... | 9 |
| 4.2 FNIHCC and AL Programs | 10 |
| 4.3 Background of the Current LTCC Services..... | 10 |
| 5. First Nations Priorities & Policy Recommendations | 11 |
| 5.1. Comprehensive Review of the First Nations-led Engagements..... | 11 |
| 5.2 First Nation Priorities & Policy Recommendations..... | 12 |
| Policy Priority #1: Culture as the Foundation for LTCC Services to First Nations.... | 12 |
| Policy Priority #2: Wholistic Approach from Preconception to End of Life..... | 13 |
| Policy Priority #3: Restructuring and Advancing Infrastructure in First Nations.... | 15 |
| Policy Priority #4: Scalable and Sustainable Resources..... | 16 |
| Policy Priority #5: Building and Supporting First Nations Health and Social Human Resources | 17 |
| Policy Priority #6: Governance and First Nations-determination | 19 |
| Policy Priority #7: Equitable Access to Services Across Canada | 20 |
| 6. Additional Considerations | 21 |
| 6.1. Impacts of COVID-19..... | 21 |
| 6.2. The Safe Long-term Care Act..... | 21 |
| 6.3. The Accessible Canada Act..... | 22 |
| 6.4. Expanding Non-Insured Health Benefits | 22 |
| 6.5. Distinctions-based Indigenous Health Legislation..... | 22 |
| 6.6. Jordan’s Principle..... | 23 |
| 6.7. Challenges in First Nations Data in LTCC | 24 |
| 7. Definitions..... | 25 |



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

1. EXECUTIVE SUMMARY

The Assembly of First Nations (AFN) is a national advocacy organization that works to advance the collective aspirations of First Nations across Canada. First Nations-in-Assembly have mandated the AFN to develop policy options that strengthen health and social supports for priority populations—First Nations seniors, Elders, individuals living with chronic illnesses, and persons with different abilities (PWDA), as well as persons facing decreasing independence or diminished capacity. The aim is to create an environment where all First Nations can experience a lifelong home-centric continuum of care, ensuring the ability to live comfortably at home in their First Nations community and have access to comprehensive high-quality, equitable health and social supports and services.

The longstanding and persistent funding and service gaps in the First Nations and Inuit Home and Community Care (FNIHCC) and Assisted Living (AL) Programs contribute to access barriers and significant health inequities for First Nations priority populations. As such, First Nations have long called for a Wholistic Long-term and Continuing Care Framework.

AFN Resolution 44/2022¹ and 59/2023² mandate the AFN to develop policy recommendations for a Wholistic Long-term and Continuing Care (LTCC) Framework and the reform of the FNIHCC and AL Programs. Through region-specific engagement initiatives³ conducted between 2020 and 2022, as well as the AFN's regional virtual focus groups held between July and September 2023, First Nations identified seven priority areas for the development of a Wholistic LTCC Framework that is responsive to their unique needs, rights, and self-determined goals. These priority areas include:

- Culture as Foundation for Long-term and Continuing Care Services to First Nations: Leveraging the two-eyed seeing approach to bridge the Western and Traditional health modalities, with the inclusion of land-based activities, ceremonies, and traditional medicines.
- Wholistic Care from Preconception to End of Life: Encompassing First Nations' priorities of wellbeing to encapsulate an individual and community in all dimensions from preconception to end of life, addressing the social determinants of health, and shifting from a deficit-based model to a strength-based model.
- Restructuring and Advancing Infrastructure in First Nations: Securing adequate investments to develop multi-use facilities and wellness centers on-reserve, including related infrastructure, home adaptations, refitting existing buildings, technological updates, data management, and telecommunications.

¹ AFN Resolution 44/2022, *Co-Developing Policy Options with Indigenous Services Canada for a Memorandum to Cabinet on the Wholistic Long-term and Continuing Care Framework* – a mandate for AFN to co-develop policy recommendations with ISC on the Wholistic Long-term and Continuing Care Framework, concerning the Assisted Living and First Nations and Inuit Home and Community Care Programs.

² AFN Resolution 59/2022, *Call for Extending Indigenous Services Canada's Timeline for Developing the Long-term and Continuing Care Framework* – a mandate for AFN to advocate additional time to co-develop policy recommendations with ISC on the Wholistic Long-term and Continuing Care Framework.

³ Indigenous-led region-specific engagements occurred between 2020-2022. Budget 2019 included \$8.5 million for the development of a wholistic long-term care strategy in First Nations and Inuit communities.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- **Scalable and Sustainable Resources:** Transition to needs-based, predictable, and sustainable funding that accounts for emergency preparedness, prevention and transitional efforts, utilities and operations, capital, socio-economic realities (including remoteness and inflation) and rising needs across all sectors, and attaining wage parity.
- **Building and Supporting First Nations Health and Social Human Resources:** Encourage multidisciplinary teams to work in a circle of care model by including: nurturing kinship systems, recruitment and retainment efforts, safe work environments, system navigators, hybridization of Western and Traditional health modalities, increased specialized training, and the development of accredited certification programs.
- **Governance and First Nations-Determination:** Supporting First Nations-determination through partnerships and capacity building to build readiness, coordination of partnerships, and bridge the gap between services and jurisdictions.
- **Equitable Access to Services Across Canada:** Promote diversity, equity, empowerment, and inclusivity for persons with different abilities and diverse populations across the lifespan, ensuring individuals can live and thrive within their First Nations and have equitable access to services.

At the forefront of First Nation priorities for the development of a Wholistic LTCC Framework is upholding First Nations inherent, Treaty, and Constitutional rights, and supporting First Nations-determination and capacity. There must be a commitment to create a context where all First Nations can embrace the journey of living within their own cultural and community setting, accompanied with the assurances of readily available access to a comprehensive spectrum of high-quality, equitable, client- and family-centered health and social supports and services.

The policy recommendations for a Wholistic LTCC Framework aim to improve First Nation health and wellness and ensure equitable health outcomes for priority First Nations populations, while maintaining the fundamental principle of self-determination. The goal is to go beyond services that are complementary to provincial and territorial standards, and instead strive for excellence in First Nations health and social service provisions.

In pursuit of a comprehensive LTCC Framework that supports First Nations in achieving their health and wellness goals, the AFN has completed a cross analysis of the First Nations priority areas with current FNIHCC and AL Programs operations and policy. Doing this, the AFN was able to develop applicable policy recommendations to inform the development of a Wholistic LTCC Framework that is reflective of First Nations priorities for LTCC reform. The document outlines the seven priorities for reform, annotating specific recommendations tailored to each priority for effective implementation. This Executive Summary condenses the policy recommendations into four categories, serving as overarching policy domains, presented below:



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- 1. Funding and Resource Allocation for Wholistic and Comprehensive Services:** Central to the First Nations' vision is the provision of accessible, culturally founded, and comprehensive care services that are available 24/7. First Nations propose substantial funding and resource allocation measures that support the implementation of First Nations-designed care services and standards, including key components such as traditional healing practices and First Nations language accommodation. The framework should trigger full investment in the Assisted Living Program and the entire spectrum of FNIHCC services, encompassing both essential and supportive services. This approach ensures that all components, including palliative and end-of-life care, receive adequate funding enabling equitable access to these services within the broader context of health and social services. This approach requires resourcing to support health promotion and cultural wellness programs that address the diverse stages of life, offering preventative and early diagnostic care, wholistic supports, and improved wellness across the life span. Additionally, funding mechanisms must be updated to ensure flexibility and responsiveness to current First Nations populations, inflation, socio-economic realities, cost increases, and service needs. It is also recommended to increase in existing service capacity, increase in accessibility services capacity, and the remove the income means tests in the AL program to ensure equitable access and responsiveness to diverse needs.
- 2. Strengthen the First Nations Workforce and Quality of Care Delivery:** Recognizing the pivotal role of healthcare and social service professionals, along with the wide spectrum of support workers, from informal caregivers to professional personal support workers, the recommendations emphasize the importance of a strengthened and culturally competent First Nations workforce. The framework advocates for the formal recognition and support of traditional healers, Elders, and Knowledge Keepers within care settings. First Nations underscore the necessity of mandatory cultural competency and trauma-informed care training for healthcare and social staff to combat anti-Indigenous racism in healthcare, social services, and other settings. To build First Nations paraprofessionals, funding and resources will need to be allocated to ensure training and certification programs for respite care, escorts, personal support workers, and caregivers. Recommendations include eliminating pay discrepancies, providing competitive salaries, expanding the roles of healthcare practitioners (e.g. nurse practitioners), streamlining administrative processes, and collaborating on the reform of the Non-Insured Health Benefits (NIHB) Program.
- 3. Overcome Jurisdictional Barriers through Collaboration and Respecting First Nations-Determination:** To address jurisdictional challenges, First Nations emphasize the need for collaboration among all levels of government, ensuring affirmation of First Nations-designed care services and standards. The recommendations call for the recognition of inherent, Treaty, and Constitutional rights, including upholding the Treaty Right to Health to ensure First Nations can



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

exercise their jurisdictional rights. This encompasses First Nation rights to define their own health and social programming to enable alignment with First Nations-determined priorities, plans, and systems, including the principle of portability. Tri-partite communications are proposed to establish clear standards and roles, and accountability mechanisms to foster the collaborative approach recommended.

- 4. Advance Physical and Technological Infrastructure for Inclusive Care:** Recognizing the importance of robust infrastructure, First Nations propose sustainable investments in continuing care centres, accessible homes, and technological upgrades. The framework should advocate for collaborative initiatives and investments to build infrastructure and retain technology, covering associated capital, operational, and management costs. First Nations call for investments in First Nations for the Accessible Canada Act (ACA) implementation and assurance of immunity from ACA penalties incurred due to resource limitations and imposed infrastructure deficits. The importance of allocating resources for First Nations-led data systems and developing equitable access comparability measures regarding wellness and program effectiveness, respecting data sovereignty, and aligning with OCAP® Principles, is also highlighted.

It is the hope of the AFN that these recommendations will be incorporated into ISC's Memorandum to Cabinet to help ensure the proposed Wholistic LTCC Framework provides the foundation for a visionary First Nations-led strategy, centered around cultural relevance, equity, inclusive environments, and self-determination that enables the achievement of excellence in health and social service provision for First Nations across Canada. First Nations priorities and AFN Wholistic LTCC Framework policy recommendations for LTCC reform are discussed in further detail within this document.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

2. INTRODUCTION

The Assembly of First Nations (AFN) is a national advocacy organization that works to advance the collective aspirations of First Nations across Canada. First Nations-in-Assembly have mandated the AFN to co-develop policy recommendations aimed to strengthen the health and social supports for First Nations priority populations—First Nations seniors, Elders, individuals living with chronic illnesses, and persons with different abilities (PWDA), as well as persons facing decreasing independence or diminished capacity, who chose to reside at home.

This mandate is articulated by AFN Resolution 44/2022 – *Co-Developing Policy Options with Indigenous Services Canada for a Memorandum to Cabinet on the Wholistic Long-term and Continuing Care Framework* and AFN Resolution 59/2023 – *Call for Extending Indigenous Services Canada’s Timeline for Developing the Long-term and Continuing Care Framework*. These two resolutions direct the AFN to draft policy recommendations for the development of a Wholistic Long-term and Continuing Care (LTCC) Framework through the reform of the Assisted Living (AL) and the First Nations and Inuit Home and Community Care (FNIHCC) programs. The overarching aim of these mandates is to create an environment where all First Nations can experience a lifelong home-centric continuum of care, ensuring the ability to live comfortably within their own home and community with access to comprehensive high-quality, equitable, client- and family-centered health and social services.

The COVID-19 pandemic underscored systemic challenges within Canada’s Long-term Care (LTC) sector, including issues like understaffing, inadequate infrastructure, varying care quality, and lapses in infection prevention and control measures, severely impacting LTC residents. The pandemic created an urgency for comprehensive reform. Because First Nations experience higher health disparities and more significant health and social services gaps in comparison to the general Canadian population, the impacts of systemic LTC shortcomings highlighted by the pandemic burdened First Nations communities and families both significantly and disproportionately. Without appropriate cultural safety or emergency preparedness plans in place, many mainstream LTC facilities systemically implemented colonial practices of isolation and disconnections from their kinship networks. In this way, the pandemic reinforced First Nations desire to design and control services for their citizens, to enable them to remain at home while having equitable access to high-quality and culturally appropriate supports and services for all levels of care.

In anticipation of Indigenous Services Canada’s (ISC) Memorandum to Cabinet scheduled for submission in Winter 2024, this document is designed to inform and influence forthcoming ISC policy options in a manner that advances First Nation health and wellness goals. This document includes:

- 1) guiding principles that provide context and understanding of the overarching and foundational goals for redressing colonial imbalances, fostering transformative reconciliatory action, and a future where the rights of First Nations are respected and the unique needs of First Nations are met with dignity and equity;



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- 2) an examination of the FNIHCC and AL programs that helps to illuminate relevant program evolutions and historic shortcomings;
- 3) an articulation of First Nations priorities for LTCC and action-oriented policy recommendations reflective of each priority area; and, finally,
- 4) an outline of additional considerations, such as the potential of federal legislation concerning health and national pandemic responses, that have interplay with proposed LTCC reforms and to which First Nations priorities and policy recommendations have relevance.

Overall, First Nations' priority is to achieve excellence in health and social service provisions. This means moving beyond services that are merely complementary to provincial and territorial services, asserting self-determination, and ensuring equitable health outcomes for all First Nations individuals and communities, including the most vulnerable priority populations. The policy recommendations for a Wholistic LTCC Framework outlined within this document are essential components of achieving these goals.

3. GUIDING PRINCIPLES

The following guiding principles provide context and understanding of the overarching and foundational goals for redressing colonial imbalances, fostering transformative reconciliatory action, and creating a future where the rights of First Nations are respected, and the unique and varying needs of First Nations are met with dignity and equity.

It is critical that the Wholistic LTCC Framework upholds these guiding principles, rooted in First Nations Treaties and Inherent rights, mutual respect, and reconciliation. This will enable the achievement of our shared commitments to a healthier and more equitable future through FNIHCC and AL Programs reformation and beyond. Guiding principles include:

- Respecting First Nations' Inherent rights, sovereignty, and jurisdiction while adhering to meaningful consultation, consent, and collaboration efforts to address historical injustice and persistent disparities.
- The Treaty Right to Health, established by oral and written promises negotiated as part of the numbered Treaties in Canada, guarantees that the federal government will ensure medical care to First Nations without usurping determination or control over First Nation systems, practices, and medicines.
- First Nations concepts of health are wholistic, where all aspects of wellbeing including, physical, mental, emotional, and spiritual dimensions, are interconnected as part of a unified concept of health. It underscores the importance of recognizing how the environment and social determinants of health play a role in shaping overall wellness.
- Healthcare and social services should be equitable, available, culturally safe, accessible, and



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- barrier-free for all First Nations regardless of where they reside or their types of ability.
- The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) outlines minimum standards for the health and wellbeing of Indigenous Elders, women, youth, children, and PWDA, in Articles 17(2), 19, 21(1&2), 23, 24(1&2), 29(3).⁴
 - The federal government must adhere to their commitments to reconciliation, including the Nation-to-Nation relationship, the Truth and Reconciliation Commission (TRC) Calls to Action⁵ and the Missing and Murdered Indigenous Women, Girls, and 2SLGBTQQIA people's Calls to Justice, and the United Nations Declaration on Rights on the Rights of Indigenous Peoples Act (UNDA).
 - Respecting First Nations collective rights requires all government(s) to uphold international human rights conventions, agreements, and standards, including the United Nations Convention on the Rights of Persons with Disabilities⁶ (CRPD). This is key to preventing discrimination, removing accessibility barriers, and promoting the capabilities of PWDA.

4. EXAMINATION OF THE FNIHCC AND AL PROGRAMS

4.1 First Nations Population Profile

According to 2021 Canadian census data⁷, First Nations in Canada constitute a diverse population, comprising over one million Status Indian members with a rich variety of cultures, languages, and traditions. First Nations are undergoing a noticeable aging distribution shift, emphasizing the pressing demand for LTCC services and support. Although these two programs support persons of all ages, many First Nations requiring LTCC support and services are senior citizens who are also Residential School Survivors, Day School Survivors, and/or Indian Hospital Survivors. At the same time, First Nations face significant health disparities compared to the non-Indigenous Canadian population, including higher rates of chronic illnesses⁸, disabilities^{9,10}, and mental health challenges. Many First Nations communities are remote and/or isolated, which exacerbates the many challenges already faced. These health disparities impact First Nation populations across the lifespan further demonstrating the urgency of addressing the comprehensive LTCC needs of First Nations priority populations¹¹, not solely limited to seniors but, encompassing all who face decreasing independence or diminished capacity, ensuring access to specialised care and support. This expanded perspective of the priority populations, ensures that LTCC services cater to the specific needs of individuals across the lifespan, fostering wholistic wellness and improved quality of life for all.

4 UN General Assembly, United Nations Declaration on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 2 October 2007, A/RES/61/295.

5 Truth and Reconciliation Commission of Canada. (2015). What we have learned. Principles of truth and reconciliation.

6 UN General Assembly, United Nations Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/06.

7 https://www.statcan.gc.ca/en/subjects-start/indigenous_peoples

8 <https://www.nccih.ca/docs/emerging/FS-UnderstandingChronicDisease-Earle-EN.pdf>

9 First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Portrait of First Nations in Quebec living with disability or having special needs*. FNQLHSSC.

10 First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2022). *Framework policy: On continuing care for persons with decreasing independence in Quebec First Nations*. Author.

11 Priority population definition provided within definition section of this document.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

4.2 FNIHCC and AL Programs¹²

The FNIHCC Program provides nursing services currently available in 99% First Nations communities. In the 2019/2020 period, the program served over 30,000 clients, delivering 1.4 million hours of home care. FNIHCC Program has nine essential services that range from structured client assessments to in-home respite care to nursing services.

The AL Program provides financial support to eligible individuals, facilitating access to in-home care, adult foster care, and institutional care. Designed as a means-tested initiative, AL offers funding for non-medical social services for seniors, adults with chronic illnesses, and individuals with mental or physical disabilities, thereby assisting them in maintaining their independence. In the 2020/2021 period, the AL program had an approximate total of 8,133 clients.¹³ There is some variance in AL program operations, reporting, and management across the regions and important to note that the completion rate for 2020-2021 is currently sitting at 67%.

4.3 Background of the Current LTCC Services

The concept of the First Nations seven generations continuum of care represents a profound commitment to the health and wellbeing of First Nations individuals and communities, encompassing a spectrum of health and social services designed to support individuals in maintaining wellness and independence as their care needs evolve. This commitment not only pertains to immediate and short-term care but also extends to addressing the long-term care needs of First Nations.

A significant challenge has persisted on this journey: the absence of a government mandate to provide comprehensive services and supports within the continuum of care for First Nations. Policy gaps and missing accountability have given rise to a complex patchwork of programs and services provided by two LTCC-like programs through ISC. Among these programs are the AL and FNIHCC Programs.¹⁴ AL was established in 1983 to offer affordable minimal levels of non-medical home care support to those accessing ISC's Income Assistance Program. The FNIHCC Program was created in 1999 to provide home care elements for seniors, persons living with chronic illnesses, and PWDA, requiring higher levels of nursing care. The AL and FNIHCC Programs face significant underfunding, rendering them incapable of meeting the growing demand for services. Moreover, culturally appropriate long-term care facilities located on or near reserves have historically fallen short in adequately addressing the unique care needs of First Nations, often necessitating First Nations in distant care facilities, disconnected from their homes and communities.

Recognizing these pervasive gaps and barriers within the continuum of care, the Standing Committee on Indigenous and Northern Affairs took action. In February 2018, they initiated a comprehensive study of long-term care on reserve, encompassing a wide scope, including elder care, persons living with

¹² The present dataset was provided by ISC upon request from the AFN on November 21, 2023.

¹³ This amount reflects the variances in regional reporting, including Ontario's Home Care Program information, which was provided by ISC.

¹⁴ Canadian Mortgage and Housing Corporation and Non-Insured Health Benefits also play a part in ISC's patchwork LTC system.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

chronic illness, palliative and hospice care, as well as culturally relevant practices and programs.¹⁵ In December 2018, the Standing Committee on Indigenous and Northern Affairs released a pivotal report titled, *The Challenges of Delivering Continuing Care in First Nations Communities*¹⁶. The report not only acknowledged the complex, historical and intergenerational trauma contributing to the poorer health outcomes of First Nations, but also shed light on the multitude of barriers that obstructed long-term care services. Among these barriers was a profound lack of government accountability, resulting from complex, unclear, and overlapping responsibilities and policies across all levels of government. This convoluted landscape created a disheartening cycle of passing responsibility for care back and forth, without any government ensuring care needs were addressed.

In response to the 2018 Standing Committee Report, the federal government, through Budget 2019, provided \$8.5 million over two years 2020-2022 for First Nations and Inuit-led engagements on developing a wholistic LTCC framework that aligns with their distinctive needs and adequately serves them. By December 2021, this commitment was further solidified as the Minister of Indigenous Services Canada was directed to, “Co-develop a distinctions-based Indigenous LTCC Framework to ensure Indigenous Peoples can receive these services in or near their own communities.”¹⁷

5. FIRST NATIONS PRIORITIES & POLICY RECOMMENDATIONS

This section articulates First Nations priorities for LTCC reform and outlines policy recommendations reflective of First Nation priorities. Policy recommendations offer actionable solutions to First Nation identified gaps, needs, and priorities regarding LTCC.

5.1. Comprehensive Review of the First Nations-led Engagements

Budget 2019 allocated \$8.5 million towards First Nations and Inuit-led engagements to inform ISC on developing a wholistic LTCC framework. ISC distributed the funding to a diverse array of First Nations and Inuit partners and organizations to host Indigenous-led engagements which were conducted between 2020-2022. The First Nations-led engagement activities sought input from various First Nations stakeholders including clients, families, communities, health and social services directors, other pertinent system representatives, as well as First Nations leadership.

The culmination of these engagements materialized in the form of approximately 35 regional and distinctions-based reports received by ISC in the autumn of 2022. To consolidate the reports, ISC contracted the Ontario Native Welfare Administrator’s Association, with the support of the Northern Ontario Research, Development, Ideas and Knowledge Institute, to compile the submissions into a singular national engagement summary report (NESR). The NESR was subsequently made available to First Nations for a national validation session in February 2023.

¹⁵ Standing Committee on Indigenous and Northern Affairs. (2018). *The Challenges of Delivering Continuing Care in First Nations Communities*.

¹⁶ [Ibid.](#)

¹⁷ Office of the Prime Minister. (2021). Minister of Indigenous Services Canada Mandate Letter.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

The initial release of the NESR-generated concerns among First Nations, with many expressing reservations about solely relying on that report to inform the development of the LTCC framework. This response underscored the importance of continued First Nations-led discussions on priorities for reform. To address these legitimate concerns, the AFN organized a series of Virtual Regional Focus Groups on LTCC between the months of July to September 2023. The series gathered insights on LTCC from First Nations leadership, individuals with lived experience with LTCC services or service needs, healthcare practitioners, health and social service providers, technicians, and others. These focus groups provided a platform for each region to share stories, visions, and feedback to clarify and reaffirm priorities for reform, further enriching the development of policy recommendations.

5.2 First Nation Priorities & Policy Recommendations

The synthesis of information drawn from the NESR, other regional First Nations reports made available to the AFN, and the AFN's series of Virtual Focus Groups and engagements, culminated in the articulation of seven overarching First Nation priorities for LTCC reform. These seven priorities, presented below, outline collective First Nations-developed visions, objectives, and aspirations for transformative change in LTCC. Each priority is accompanied by policy recommendations that provide clear and actionable means for Canada to implement changes reflective of each respective priority. All seven priorities are of equal importance and are not numbered or ordered according to any comparative or value scale.

Policy Priority #1: Culture as the Foundation for LTCC Services to First Nations

Culture is integral to First Nations identities and is woven throughout the life and essence of a community. The inclusion of cultural ceremonies, land-based activities, Indigenous languages, supported traditional medicine practitioners, and traditional food and medicines within the development of a LTCC Framework is imperative to maintain First Nations' identities and wellbeing. Applying a two-eyed seeing approach that bridges the Western and Traditional health modalities will create parallel supports to healing. The intended result is systems and environments that amplify First Nations' strengths to support the wellbeing of individuals, families, and communities. Reform must set precedence to address anti-Indigenous racism, through ongoing training and demonstration of culturally safe and trauma-informed care, to ensure all services are safe and comfortable for all clients. Further, continuing care centres, such as adult foster care and LTC facilities, must incorporate culture to create safe spaces for Residential School Survivors, Day School Survivors, Indian Hospital Survivors, and others impacted by colonial legacies.

Recommendations for Action:

- ✓ Increase capacity for First Nations community-based health and social services to shift the foundations of care to culture-based models that bridge Western and First Nation approaches by



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

fostering access to spiritual and cultural care in LTCC settings:

- Recognize First Nation healers, Elders, spiritual care givers, and Knowledge Keepers as health and social staff and provide resources to offer them salaried positions in LTCC settings;
- Increase the presence and involvement of First Nation healers, Elders, spiritual care givers, and Knowledge Keepers in LTCC settings, planning, and programming;
- Prioritize investments into community-based health and social services programming that enable alignment with First Nation designed and delivered services and standards;
- ✓ Provide resources and capacity to support the development of a plan for First Nation designed and delivered care services, including First Nations-specific standards of care.
- ✓ Uphold First Nations-specific standards for the provision of LTCC:
 - Provide required investments and capacities to achieve standards;
 - Increase communication and collaboration between provincial/territorial (P/T), federal, and First Nations government(s) to develop shared understandings of standards of care across all levels of government;
 - Adjust requirements for accessing LTCC services to First Nation-designed wholistic wellness assessment model(s).
- ✓ Work with First Nations to ensure proper training is available for all health and social staff working in First Nations and support formal recognition/accreditation of culturally appropriate training.
- ✓ Make cultural competency and trauma-informed care training mandatory for all health and social care staff working in First Nations.
- ✓ Commit all levels of government(s) and service providers to work in partnership with First Nations to develop and implement a strategy to eliminate systemic anti-Indigenous racism in the healthcare and social service systems.
- ✓ Provide capacity for First Nation language accommodation and services.

Policy Priority #2: Wholistic Approach from Preconception to End of Life

A First Nations wholistic approach focuses on the physical, spiritual, emotional, and mental wellbeing of the individual and community at all stages of life. It utilizes a client centered approach that is aware of and responsive to the interconnectedness between environment and health outcomes. This approach requires attention to and address of social determinants of health. It requires a transition from a sickness-based to a wellness-based model of care that supports early intervention, diagnosis, and preventative care. It entails wrap-around care services for individuals' entire life journey from pre-conception to end of life, ensuring work arrangements and services at the primary, secondary, and



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

tertiary levels of care that guarantee proper transitions within the continuum of care. This includes, but is not limited to, provision of palliative, end-of-life, and comfort care for chronic disease and pain management.

Recommendations for Action:

- ✓ Fully invest and build First Nations capacity to provide both essential and supportive FNIHCC services for all First Nations and remove barriers to accessing the supportive elements of the program.
- ✓ Fully invest in palliative and end-of-life care to ensure pain management and comfort care is easily accessible and available for clients living at home or in facilities.
- ✓ Increase investments to support First Nations access to primary, secondary, and tertiary levels of care for all First Nations citizens in their communities.
- ✓ Increase investments to support flexible work arrangements to ensure 24/7 care.
- ✓ Strengthen communication and collaboration between First Nations, P/Ts, and federal governments and commit to working together to:
 - Determine culturally appropriate client-centered service models that accommodate thorough care plans and incorporate First Nation understandings of family and culture, and recognize First Nation care givers;
 - Address jurisdictional chasms that create gaps, delays, and disruptions in care for First Nations and reduce overall quality of care, especially for those with acute care needs;
 - Co-develop and clarify definitions, administrative logistics, program authorities, and roles and responsibilities pertaining to program services;
 - Co-develop clear policies, processes, and protocols for accessing and transitioning care services;
 - Co-develop reciprocal accountability mechanisms in service provision that better meet First Nations needs;
 - Increase harmonization of complementary programs and services and develop models for adapting to First Nations needs and reducing administrative burden;
 - Develop information sharing linkages between First Nations, federal and regional organizations, service providers, and individual care stakeholders to foster care coordination amongst all those involved in an individual's care;
 - Co-develop comprehensive transition plans and support mechanisms for individuals with complex care needs and for Jordan's Principle clients reaching the age of majority.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- ✓ Increase capacity for First Nations to provide community health and social promotion, cultural, and prevention programs that target each life stage and provide preventative and early diagnostic care, wholistic support, and improved wellness across the lifespan.

Policy Priority #3: Restructuring and Advancing Infrastructure in First Nations

Homes and care centres built upon comfort and familiarity are pivotal for long-term individual and community wellness, ensuring First Nations are provided safe, culturally appropriate, lifelong home-centric supports within their First Nations. Increased home adaptations, refitting existing buildings, and constructing new wellness centres that meet regional construction standards will be required to achieve this universally accepted objective of ensuring appropriate housing for clients and health care practitioners. Multi-room wellness centres that adequately serve the First Nation for various capacities are required, enabling dedicated spaces for social and cultural ceremonies, specialized therapy, Elder care, palliative care, and mental health services. The buildings must be immersed with cultural elements along with technological upgrades to ensure optimal care that underscore safe and secure data management and stable telecommunications. Investments in infrastructure and technology must be made to support the use of wellness centers, including elements such as medical transportation services, appropriate furnishings, and suitable storage.

Recommendations for Action:

- ✓ Work with First Nations to restructure existing infrastructure guidelines to include continuing care centres, fully accessible homes, home adaptations, retrofits, data management, technological upgrades, and telecommunications and connectivity.
- ✓ Provide substantial investments to support the development of First Nations-determined, needs-based, and sustainable infrastructure initiatives on-reserve:
 - Prioritize the development of First Nations-led facilities and multiuse continuing care centres;
 - Increase flexibility and adaptability of investments to meet fluctuating community-specific needs & exceptional circumstances;
 - Commit to First Nations infrastructure capital (major and minor), operations and management (O&M) costs such as utilities, janitorial, etc.;
 - Include investments for medical and non-medical transportation services, as well as furnishings and operational equipment;
 - Support First Nations adult residential initiatives and accommodations as well as First Nations accreditation for adult residential continuing care centres.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- ✓ Commit to collaborative tripartite work with First Nations and P/T governments that enables First Nations' leadership to guide and drive the discussions with support from the federal government to facilitate crucial conversations. This collaboration aims to strengthen First Nations infrastructure by:
 - Resourcing the co-development and implementation of a comprehensive data strategy that aligns with OCAP® Principles¹⁸ to inform needs-based funding;
 - Providing required technological and telecommunications upgrades to First Nations;
 - Leveraging provincial long-term care funding and mandates to increase LTCC facilities and other multi-use facilities in First Nations.
- ✓ Provide investments to First Nations to enable adherence to the *Accessible Canada Act* (ACA) or other First Nation designed accessibility standard and ensure that First Nations are immune to penalties for not meeting ACA requirements due to lack of resources or existing infrastructure deficits.

Policy Priority #4: Scalable and Sustainable Resources

A Wholistic LTCC Framework for First Nations requires multi-year funding that has the flexibility to accommodate First Nations-determined priorities and autonomous First Nation budget design. Needs-based, predictable, and sustainable funding is required to transition services and supports from a reactive to a proactive care model that is reflective of First Nation needs as well as broader changing socio-economic realities and cost increases. The switch to multi-year, flexible, and needs-based funding will help ensure autonomy in First Nation comprehensive budget design eliminating reaction-based and short-term funding models.

The development of clear, streamlined funding processes and the removal of access barriers for clients, care takers, and navigators is also important for enabling timely access to services and supports.

Recommendations for Action:

- ✓ Shift the provision of funding for the AL and FNIHCC Programs to sustainable funding that combines formula and client needs-assessment-based funding models developed in collaboration with First Nations:
 - Ensure funding is flexible and barrier-free so that First Nations can meet community-specific needs and First Nations-determined priorities;
 - Streamline reporting and administrative processes to reduce burden on First Nations to access funding;

18 First Nations Center. (2007). OCAP® Ownership, Control, Access and Possession. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- Incorporate inflation and growth escalators to reflect broad and changing socio-economic realities, demographics, inflation, and cost increases;
- Funding for individuals with complex-care needs would be portable and not necessarily tied to the community.
- ✓ Support First Nations autonomy in budget design by increasing access to their program data and access to broader relevant medical and social service data to increase their capacity for data tracking and governance in alignment with OCAP® Principles.
- ✓ Ensure all federal and P/T departments and agencies involved in LTCC services work together with First Nations to develop an inter-departmental communication strategy to improve program navigation and timely access to funding sources. The strategy should include:
 - Commitments to regular tri-lateral meetings and strengthened inter-governmental communications;
 - Methods to enhance First Nation access to information and data to support First Nations planning and self-determination.
- ✓ Establish a dedicated reserve emergency preparedness fund or adopt an approach that reaches beyond the exceptional circumstance clause within the AL program, and recognizes the possibility of the sudden emergence of health and social issues in communities. This fund should be readily accessible to address unforeseen challenges, allowing for a swift and targeted response to urgent community-specific needs.

Policy Priority #5: Building and Supporting First Nations Health and Social Human Resources

Kinship defines a First Nation, where each member of the family and community have a role and a responsibility. Service providers must be a support system willing and able to assist clients and families to strengthen those family and kinship bonds during their continuing care journey. System navigators can contribute to removing barriers and stresses associated with accessing LTCC programs and services, including Non-Insured Health Benefits (NIHB), and provide support for individuals and informal caregivers. Recruiting and retaining healthcare workers, social providers, support staff, and traditional medicine practitioners is imperative to ensuring programs and services run effectively. The Framework should support the capacity of Employers to provide management support for registered health care staff, including the ability to provide appropriate accommodations to assist in retention and recruitment. Strong health care leadership fosters a strong health care workforce, which is crucial for building a strong First Nation human resources force. Capacity for First Nations to provide accreditation, certification, and training for community members to care for their own is also key to



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

building this capacity, shifting the Western physician-centric modality to a multidisciplinary team-based approach. This will help remove strain on doctors and nurses, easing their caseloads. Investments will help empower First Nations to take care for their own while also creating sustainable employment opportunities within communities by allowing those with specialized training to better assist in their areas of care. This will result in improved access and the removal of barriers to quality and culturally safe care.

Recommendations for Action:

- ✓ Work in partnership with the P/Ts and First Nations to co-develop and implement a comprehensive recruitment and retainment strategy for social and health workers. The strategy should aim to:
 - Increase the numbers of health care practitioners and social service providers in First Nations (i.e. respite workers, escorts, Indigenous liaison officers, homemakers, personal support workers, nurses, traditional medicine practitioners, systems navigators, etc.);
 - Create long-term service agreements with external care providers to ensure access to trained human resources while First Nations capacity is built;
 - Increase investments to prioritize the provision of equitable pay for all health and social workers on-reserve, comparable to the salaries of the equivalent positions off-reserve;
 - Amplify the voices of First Nation social and health professionals to ensure better understanding and address of existing challenges and barriers;
 - Provide incentives for and reduce barriers to social and health education for First Nations (i.e. ensure access to high-speed internet, offer remote learning options, adjust admissions requirements).
- ✓ Work in partnership with First Nations to promote training and professional development opportunities for social and healthcare personnel in First Nations.
- ✓ Increase respite services and training opportunities for informal care givers.
- ✓ Support First Nations in leading partnerships with post-secondary institutions to provide students with practical relationship building and cultural training, ensuring increased access to training opportunities for specialized care provision such as disability-based services, senior care, palliative care and end-of-life care, rehabilitation services and more. Training opportunities must be accessible to First Nations in terms of location, language, cost, etc.
- ✓ Expand the roles and responsibilities of nurse practitioners within First Nations to provide a wider range of care services.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

Policy Priority #6: Governance and First Nations-determination

An adequate continuum of care must uphold First Nations' Treaty and inherent rights to health and leverage a human rights approach as outlined within the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). A First Nations-led continuum of care upholds First Nations autonomy to determine and deliver services to members wherever they should reside. This requires coordinated partnerships with internal and external parties to ensure that portability of First Nations rights is understood, the roles and responsibilities in this regard are defined, standards and transition of care are clear and uniform, and the designing and delivering of a cost-effective and equitable continuum of care is reliable, accessible, and barrier free for all First Nations.

First Nations have identified a high administrative burden due to Federal data collection approaches, funding agreement reporting, and lengthy program eligibility requirements. Increasing administrative support staff, equitable salaries, flexible work schedules, revising reporting and data collection requirements, and increasing robust technological investments are all strategies needed to address these issues. First Nations governance systems require capacity development support to enhance First Nations' ability to develop their own standards and guidelines, as well as the systems and processes to implement them. Increased communication, accountability mechanisms, and information linkages will also support First Nation governance capacity and improve synthesis with those of external governments. This will enable enhanced self-determination capabilities and improve the quality of social and health care services, and health outcomes for First Nations.

Recommendations for Action:

- ✓ Support First Nations in leading the facilitation of tri-partite communications, collaboration, and agreements to ensure First Nation LTCC service standards, accountability mechanisms, roles, authorities, and responsibilities are clearly defined, and First Nation goals are able to be met.
- ✓ Support First Nation governance and capacity development by providing support and resources for the development, strengthening, and implementation of:
 - First Nation governance systems and mechanisms development;
 - First Nation program design, coverage, and delivery, including the principle for portability;
 - First Nations-specific standards of care.
- ✓ Increase flexibility within funding eligibility criteria by shifting to broad parameters to ensure First Nations can utilize funding in accordance with their community priorities, plan, and systems.
- ✓ Provide resources and information to First Nations to support informed decision making, partnership development, and agreements.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- ✓ Recognize First Nations Treaty and Inherent rights by engaging in meaningful consultation and collaboration with First Nations to develop and implement policy, legislation, accountability mechanisms, standards, and practices that honour and are reflective of these rights.

Policy Priority #7: Equitable Access to Services Across Canada

The creation of a Wholistic LTCC Framework must reflect and respect the diversity of First Nations in Canada, with an ethic of inclusivity, equity, and barrier-free accessibility at the core. An inclusive design that enables and empowers persons with different abilities and diverse populations across the life span to have the same substantive opportunities to access services is critical. An inclusive design embraces and enables access to physical, spiritual, emotional, and mental wellness needs across the lifespan. A self-determined continuum of care will look different for each First Nation. Provincial and territorial standards must not limit what a First Nation is able to provide, nor to whom they can provide services. Recognizing the remote contexts, medical transportation services should be a sustainable mechanism for client care and improved access to services. A pathway that has both supportive services and an accessible environment that is inclusive and usable by everyone across all dimensions is always an underlying objective.

Recommendations for Action:

- ✓ Adopt First Nations-specific standards of care to inform the development of any future legislation or policy changes concerning LTCC.
- ✓ Work with First Nations and P/T governments to co-develop and implement equitable access strategies and assessment tools.
- ✓ Ensure resources to First Nations to assist in First Nations-led development of equitable access comparability measures.
- ✓ Ensure capacity to First Nations to increase provision of First Nation language services, as well as the two official Canadian languages, and hearing and vision-impaired services in LTCC settings.
- ✓ Shift the provision of services within the AL and FNIHCC Programs from a comprehensive eligibility list to a set of broad parameters.
- ✓ Remove the AL income means tests or empower First Nations to reassess and establish their own standards regarding income tests.
- ✓ Include an exceptional circumstances clause in AL and the FNIHCC Programs to ensure timely access to all care needs from other programs.
- ✓ Work with First Nations to reform the NIHB program to fill gaps First Nations face when accessing medications, assistive devices and programs, medical transportation, dental care, vision care, and mental health support.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

- ✓ Invest and support the development of First Nations-led data systems that advance First Nations data sovereignty and uphold First Nations-led data strategies in alignment with OCAP® Principles.

6. ADDITIONAL CONSIDERATIONS

In the context of a Wholistic LTCC Framework, it becomes evident that addressing the challenges posed by the FNIHCC and AL Programs necessitates a comprehensive and nuanced approach. This section explores various complexities that may impact and interplay with proposed LTCC reforms in terms of efficacy and longevity. Attention to these areas when contemplating the reform of pivotal LTCC programs is crucial to ensuring the wellbeing of our diverse populations and the sustainability of these indispensable social and healthcare programs.

6.1. Impacts of COVID-19

The pandemic exacerbated the systemic challenges within the First Nations LTC sector, highlighting the need for enhanced emergency preparedness and management, adequate building infrastructure for infection control and management, public health services, additional health and social human resourcing and the development of First Nations-led data collection strategies to strengthen First Nations data and funding advocacy. There was a significant gap in public health surveillance around LTC services. The absence of robust surveillance mechanisms highlighted a key vulnerability within the sector, hindering the timely identification and response to emerging health threats. COVID-19 forced First Nations to adopt innovative public health practices to ensure the safety of their community members despite limited resources. First Nations' resilience during the pandemic demonstrates not only the readiness for First Nations-determination in health and social systems, but the necessity of this. As the LTCC Framework is developed, it is important to consider how First Nations can be supported to prepare for future pandemics and public health emergencies and the negative impacts the existing health disparities, capacity deficits, and lack of self-determination in health and social services have on First Nations in this context.

6.2. The Safe Long-term Care Act

Recognizing the enduring challenges in LTC and the systemic issues illuminated by the COVID-19 pandemic, the government identified plans to develop a Safe Long-term Care Act. The government outlined a financial commitment in Budget 2021 to provide Health Canada \$3 billion over 5 years starting in 2022-2023 to support P/Ts with the application of and changes to the voluntary national standards of LTC. First Nations with LTC facilities on-reserve will be subject to these pan-Canadian standards, however it is imperative that the development of a Safe LTC Act uphold First Nations-identified priorities for the development of a Wholistic LTCC Framework. First Nations must be solely responsible for defining First Nations-specific standards of LTC.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

6.3. The Accessible Canada Act

Embedding disability inclusion from the onset in all environments, programs, and service decisions, in frameworks, budgets, and legislation, serves to support the human rights of First Nations persons with disabilities and seniors among others, without having to face the costly drawbacks of a systemic overhaul or human rights challenges if disability and accessibility are not considered in all policy developments from the onset. A significant amount of First Nations are not accessible for PWDA, primarily due to systemic discrimination and underfunding in the areas of health and social and infrastructure. First Nations have raised concerns about being subjected to the *Accessible Canada Act* (ACA) in 2026, as they could be liable for enforcement and penalties due to pre-existing infrastructure deficits caused by unaddressed chronic and ongoing underfunding. The Government of Canada introduced the ACA in 2019 in aims to create a barrier-free Canada by 2040. Yet, First Nations require additional financial investments to implement the mandates within the ACA and to meet their own goals of becoming fully accessible. Improving accessibility and removing barriers for First Nations PWDA residing within and outside of their respective Nations, including the crisis of misdiagnosis, must be a priority for the federal government in all legislative and policy work. This is a critical component to consider in the development of a Wholistic LTCC Framework.

6.4. Expanding Non-Insured Health Benefits

The development of a wholistic LTCC Framework is intrinsically linked with addressing the gaps and shortfalls of the Non-Insured Health Benefits (NIHB) Program. The NIHB Program aims to cover supplementary non-insured health benefits to eligible First Nations and Inuit across Canada, however First Nations have identified that it falls short of meeting the needs of First Nations across the lifespan. The development of a Wholistic LTCC Framework must acknowledge the profound impact that the NIHB Program has on the overall health and wellbeing for First Nations. Recognizing and addressing the shortcomings of the NIHB Program is integral to creating a comprehensive and inclusive care framework that adequately services the unique needs of First Nations across the lifespan.

6.5. Distinctions-based Indigenous Health Legislation

The Distinctions-based Indigenous Health Legislation is an opportunity to address the unique needs of First Nations health including those like Elders, PWDA, and persons living with chronic illnesses in a manner that respects the Treaties and Inherent rights of First Nations. It is important to consider alignment between this legislative effort and the LTCC Framework development in terms of incorporation of First Nation LTC priorities. Determining federal accountability mechanisms for improving the overall health status and outcomes for First Nations and integrating First Nation priorities throughout all levels of program and service delivery within the AL and FNIHCC Programs is a critical component to consider as these efforts advance.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

6.6. Jordan's Principle

Jordan's Principle is a child-first principle named in honour of Jordan River Anderson, a First Nations child from Norway House Cree Nation in Manitoba who passed at age 5 without the chance to live in his First Nation because of gaps in disability services on-reserve and jurisdictional barriers. Jordan's legacy gifted us Jordan's Principle, a child-centered principle that aims to ensure that First Nations children have access to the services and supports they need to thrive, eliminating gaps, delays, or denials in provision of care.

Long-term and continuing care needs are not limited to seniors, Elders, and those with disabilities; individuals at all stages of their life journey, including adolescents and young adults, require comprehensive, wholistic and sufficiently funded long-term and continuing care supports. As such, the scope of LTCC supports must encompass all individuals at all stages of life, from pre-conception to end-of-life care. The development of a Wholistic LTCC framework must embed Jordan's Principle to ensure youth with special gifts and needs remain in their communities to receive the supports and services they need to thrive, surrounded by their families, cultures, languages, and land. Action must be taken to design and implement systemic reforms to address the gaps in programs, services, and supports that created the need for Jordan's Principle and that continue to exacerbate gaps in supports across the life course, as determined by First Nations.

Due to significant gaps with disability, health, education, and social supports and services for First Nations children and youth, both on- and off-reserve and at all levels of government, Jordan's Principle plays a critical role in meeting the needs of First Nations children and youth with chronic care needs and disabilities. There are limited or non-existent supports, services and/or programs available to youth after they reach the age of majority and "age out" of Jordan's Principle eligibility, re-creating the very gap that Jordan's Principle was intended to fill. There is a dire need for adequate supports to sustain services for clients aging out of Jordan's Principle, which a long-term and continuing care framework must address. The framework should adopt a person-centred approach that eliminates jurisdictional gaps and barriers, ensuring that services are provided to the individual when and where they are needed. Funding for such services should not inhibit access to necessary services and supports, with governments resolving any disputes over payment after a service has been rendered. Service navigation will be an integral part of transitioning young adults from Jordan's Principle to adult services and programs.

6.7. Challenges in First Nations Data in LTCC

A shared challenge confronting both the AL and FNIHCC programs is the substantial lack of comprehensive data. Lack of data hinders effective evaluation and adaptation to evolving health and social service needs. While some data is available, it is collected and maintained by the federal government through eSDRT, and is not First Nations controlled or readily available. Critical information needed to properly inform formula- and needs-based funding, is absent. Presently, many



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

areas of FNIHCC program funding are based on 1999 population figures. This means that many funding determinations throughout FNIHCC are based on data that is nearly 25 years old. This results in funding formulations that do reflect and respond to on-the-ground needs, ultimately causing services—especially those of a rapidly growing, aging population with disproportionately low health indicators—to be drastically underfunded. Currently, palliative care funding, which was increased in 2017, represents the only area of funding increase for FNIHCC programs since 1999. In this way, lack of data continues to enable objectively unjustifiable funding stagnation which, considering general population health care funding, is nothing short of discriminatory.

Advocating for investments in First Nations-led data strategies is imperative to ensuring access to information needed for sustainable and adaptable funding that is reflective of First Nation needs. To further increase FNIHCC funding adaptability, a mechanism similar to that used in the AL program could be implemented. This mechanism incorporates an 'exception clause' to addresses unique circumstances that may not align with standard eligibility criteria, recognizing that specific situations may warrant special attention, and allowing for discretionary consideration.

The development of First Nations-led data strategies and modern data-sharing agreements between First Nations and ISC, respecting the autonomy of First Nations, would benefit both parties. Such agreements are a means to enable First Nations data to be shared in a manner that adheres to the principles of OCAP® so that comprehensive analysis required to understand the current LTCC landscape can be completed without causing harm or infringing upon First Nation rights. The development of such strategies is critical for enabling better insight into short- and long-term trends, helping to monitor shifting demographics, and improving the programs' accountability, transparency, adaptability, and responsiveness to evolving health needs.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

7. DEFINITIONS

Caregivers are essential contributors to the continuum of care, representing family members or friends who provide assistance without financial compensation. Their pivotal role extends across various healthcare and social settings, emphasising the interconnectedness of informal caregiving with formal health and social services.

Comfort Care involves integrating essential cultural elements that recognize the significance of values, identities, families, and communities in conjunction with palliative and end-of-life care. Prioritizing kindness, compassion, and quality of life, comfort care respects the spiritual beliefs, cultural protocols, and practices of individuals and families facing health changes and discomfort.

Continuing Care Centres refers to health care settings that offer a range of services within the context of multi-use long-term care residential facilities, home support, home care, and case management. The adoption of the term 'continuing care centres' over alternatives like "health care facilities" and "health care institutions" is aimed at better aligning with First Nations values and philosophies specifically reflective of a Seven Generations Continuum of Care.

Continuum of Care is an ongoing, dynamic, wholistic approach that provides care to a person's/group's needs throughout their lifetime. A continuum considers the entire environment of that person's care, including managing and promoting wellness where services are coordinated and delivered by various providers in a coherent, logical, and timely manner.

Disability is often understood in First Nations cultures as a natural aspect of human diversity as opposed to a problem to be fixed. First Nations teachings do not portray persons with disabilities as having a medical condition that requires intervention to restore normal functioning, but as a member of the community that has unique gifts. Disability is considered a functional difference or exceptionality—whether permanent, episodic, or temporary—that requires accommodation for a person's full and equal participation and inclusion in society. Disability encompasses not only physical aspects, but also the mental, intellectual, cognitive, communicative, sensory, functional, emotional, and spiritual components that impact an individual's balance (between mind, spirit, body, and emotion) that is, in wholistic frameworks of understanding, considered essential to attaining health and wellness¹⁹.

First Nations-led Care involves assistance and associated initiatives, interventions, practices, and services spearheaded by First Nations individuals, communities, and/or organizations. These initiatives are exclusively directed at resolving issues, fulfilling needs, or addressing conditions faced by First Nations individuals with accessibility needs and/or illnesses, as well as their families and communities.

¹⁹ Department of Community Engagement & Inter-Governmental Relations First Nations Health and Social Secretariat of Manitoba (2023) Supporting the Gifts of First Nations Adults Living with Exceptionalities: Research Report.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

Home encompasses more than a physical dwelling normalized in Western contexts. Indigenous accounts of home highlight networks of responsibilities and include ties to the land, water, Earth, and territories, as well as connections to human kinship networks, teachings, songs, names, stories, and ancestors. Home is a wholistic and layered concept that simultaneously relational, material, spiritual, and emotional interplaying with senses of rootedness, identity, and community bond.²⁰

Misdiagnosis refers to the incorrect conclusion about the cause of health conditions as a result of inadequate resources, knowledge, tools. First Nations People are particularly susceptible to misdiagnosis as a result of inequity in the health system created through racism and colonialism. It underscores the need for a cultural and trauma informed approach to assessment and treatment, recognizing that existing tools may lead to inaccurate diagnoses, particularly concerning mental health conditions such as post-traumatic stress disorder.

Partnerships represent collaborative relationships between equal entities sharing common interests, whether among First Nations or between First Nations and non-Indigenous organizations. Partnerships leverage capital, expertise, and connections to pursue shared goals and opportunities, fostering joint efforts to generate output.

Priority Populations denotes specific groups requiring heightened attention and specialized support to address their unique health and social needs. Within the LTCC context, this generally encompasses First Nations seniors, Elders, individuals living with chronic or acute illnesses, and persons with different abilities, as well as those facing decreasing independence or diminishing capacity on a continued or temporary basis due to aging, chronic, illness, injury, or other reasons.

Seven Generations Continuum of Care is deeply rooted in First Nations ways of knowing. It represents a wholistic process encompassing health, social and economic services that follow the health and wellbeing of First Nations from preconception to end of life—ensuring that every decision is committed to upholding a sustainable world, considering the impact on seven generations into the future.²¹

Standards of Care in the context of First Nations refer to culturally grounded and community-driven practices and protective measures that govern the provision of healthcare and social support services. These standards encompass a wide range of wellness considerations, actively working towards creating an inclusive and secure environment for all First Nations.

20 Canadian Observatory on Homelessness (2021) *Endaamnaa: Homes for all Nations—A First Nations Homelessness Literature Review*. Jessica Rumboldt.

21 Assembly of First Nations (2020). *Options for a First Nations 7 Generations Continuum of Care: Document for discussion*. Author.



First Nations Policy Recommendations for the Development of a Wholistic Long-term and Continuing Care Framework

*The Reform of the First Nations and Inuit Home and
Community Care and Assisted Living Programs*

2024

Trauma-informed Care is a wholistic approach addressing the root causes of trauma across the lifespan, and acknowledging its prevalence and impact, including intergenerational trauma. It recognizes the risk of re-traumatization in biomedical healthcare settings and emphasizes pathways to healing. This care is committed to providing welcoming, safe, and inclusive healthcare services tailored to the unique needs of individuals affected by trauma. Key principles include acknowledgement of trauma, safety, trust, choice and control, compassion, collaboration, empowerment, and peer support. It is particularly crucial in navigating impacts of intergenerational trauma, such as post-traumatic stress disorders, stemming from reminders of colonialism and historical tensions.

Wholistic refers to an approach that considers the entire system or whole entity, recognizing the interdependence of various elements and the importance of addressing all aspects of something to achieve a balance. The intentional spelling of 'wholistic' underscores this perspective, emphasizing the consideration of the whole person and the importance of interconnectedness among spiritual, emotional, mental, and physical aspects of oneself.



Assembly of First Nations
50 O'Connor Street, Suite 200
Ottawa, Ontario
K1P 6L2
Tel: 613-241-6789
Fax: 613-241-5808
www.afn.ca