National Community Engagement in First Nation Long-Term and Continuing Care (LTCC)

FINAL SUMMARY REPORT

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EXECUTIVE SUMMARY
FIRST NATIONS VISIONS OF LONG-TERM CONTINUUM OF CARE

In response to the Government of Canada's 2019 budget, Indigenous Services Canada (ISC) approached First Nations and Indigenous communities across the country to undertake community engagements with stakeholders of the Assisted Living and Home and Community Care Programs (See Appendix D). This included individuals with increasing dependence, their families and caregivers, homemaking and nursing staff and program coordinators, and included other First Nation members, involved in the administration and delivery of care to children and adults, including elders. This summary report is the result of community engagements with First Nations conducted primarily throughout the 2021-22 fiscal period.

33 regional community engagement reports, together with four organizational and/or governmental reports, were provided and reviewed by the writing team of this final summary report. The community engagement reports documented the insights, experience, and knowledge of over 700 First Nation participants engaged in the delivery of in-community long-term and continuing care in over 300 First Nations in culturally and geographically diverse regions of the country.

The COVID-19 pandemic resulted in a dependence on technology for engagement sessions which impacted participation, as did numerous other factors including shorter than desirable time frames, and a generalized frustration and lack of trust that voiced concerns might not result in change.

Participation of those individuals most affected, i.e., those with increasing dependence, was particularly highlighted as concerns by those who did participate.

A draft report was circulated to community engagement participants for their review, and in February, 2023 a 'validation' gathering was held with 107 participants.

Of those participants, 74 were representing First Nation communities and organizations across Canada (both in-person and on-line). They provided feedback including gaps, clarifications, errors and omissions, in breakout groups. 33 ISC personnel were also present at this validation gathering. Representatives from ISC shared and gathered information at the workshop but they did not participate or provide feedback in the breakout groups.

This final summary report has incorporated the feedback from the 74 First Nation participants and 33 community engagement reports to shed light on the numerous challenges and strengths, as well as provide recommendations for transforming long-term and continuing care in First Nations.

Key proposals for change as well as an overall vision emerged from the engagement sessions, and were validated in February 2023 at the validation exercise. The authors have summarized these below for convenience.

This engagement process is not reflective of all of the voices involved in the LTCC process and the Path Forward suggestions and options identified in this report must be reviewed with First Nation communities and individuals most affected by change before implementation. Discussions with other departments and service programs outside of Assisted Living, and First Nation and Inuit Home and Community Care also needs to occur in order to break down some of the silos of effective service provision.

The reality of First Nations must be well-understood by change-makers. The community engagement reports emphasized again and again that the community's culture, history and context must serve as a foundational understanding for developing appropriate processes for program planning, development and implementation. The first section of this report titled "Context" attempts to reflect the common elements of those realities facing the delivery of care in First Nation communities, and respecting the diversity of history, culture and context of individual communities and Nations.

RECOMMENDATIONS & OPTIONS FOR CHANGE

I. GOVERNANCE & POLICY

Long-term care services to be either led by First Nations or by a First Nation agency selected by the First Nation, respecting and acknowledging the uniqueness of each Nation, their strengths, people and innovation.

- Policy and programs need to acknowledge equal access to health care as a human right.
    - Discrepancies must be addressed and coverage of needed services be provided to all First Nations members, regardless of age, income level and/or residency.
    - Remove ’90 day rule’ of determination of residency.
- First Nations must be involved prior to revising or introducing new policies and programs:
    - Review and adapt all program and related policy, rules, procedures, and materials to ensure cultural safety and to reflect First Nations’ realities.
    - Recognize the uniqueness of each Nation, their strengths, people and innovation.
        - Change policies [to provide] for flexible services and training strategy specific to needs of each region, and each sub-region.
- Expand Indigenous community and organizational capacity for policy analysis, program development and partnership.

Co-Development of Framework – Recommendations for Process

- Co-develop a distinctions-based Indigenous long-term and continuing care framework to ensure Indigenous Peoples can receive these services in or near their own communities and bolster Indigenous health system navigators to provide dedicated support for Indigenous people and their families to navigate services related to long-term and continuing care.
- All First Nation communities must be engaged in the co-development processes, including those not affiliated with Assembly of First Nations (AFN), such processes to respect and accommodate the autonomy and diversity of each.
- The co-development process must respect and accommodate negotiated structures and agreements that are already in place (e.g. treaties, bi- and tri-partite agreements, First Nations Health Authority (BC-specific) etc.).

Improving Engagement Processes

- Reciprocal accountability – participants to be informed of intent, planned outcomes, as well as notice of uptake of reports.
- Pre-engagement communications to political & community leaders, elders, service providers and individuals.
- Trusted intermediaries to facilitate engagements.
- Options for participation: examples – face to face, telephone, on-line, community events.
- In-community opportunities.
- Reporting back to community on outcomes, next steps.

Removing Jurisdictional Boundaries

- Remove jurisdictional (federal, provincial/territorial) silos and guarantee accessibility to all health and allied LTCC services.
- Remove silos within the various government departments involved in meeting the needs for LTCC in First Nations – inter-departmental communication.

Accountability

- Establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends.
- Accountability needs to be reciprocal between all programs with additional standards built into LTCC programs and policies.
    - Accountability means both accessibility and quality of care, as well as financial accountability.
- FNs need to be engaged in establishing accountability criteria and standards of care for LTCC delivery, and such criteria and standards need to be rooted in First Nations (FNs) realities and worldviews.
- Formalize accountability for anti-Indigenous racism and cultural safety in provincial health and social services.
- Training for federal, provincial and health authority managers and staff to ensure implementation of changes.

Communication and Collaboration in Policy-Making

- Strengthen communication, collaboration and partnerships between local First Nations governments, [and] between the provincial government, and the federal government. Partner collaboration is critical to ensuring the long-term use of communication mechanisms and service agreements.

Facilitate Information Sharing and New Partnerships

- Develop an official guide for First Nations that clearly lays out what LTCC-related programs and funding options are provided by all levels of government, in all regions [A regional guide was requested from ISC during the engagement process prior to the National Validation February 2023, but none is available].
- Training for LTCC staff to learn what programs are available is crucial, including training in the specific program requirements and uses.

II. FUNDING

- Autonomy: Ensure First Nations have autonomy in managing continuing care and associated funding.
- Adequacy: Expand funding to adequate levels to provide FN partners a means to effectively create a more wholistic continuum of care.
- In-community LTCC: Address urgent needs in infrastructure.
- Address realities of FNs: Funding must reflect the realities of First Nations histories and contexts, cultures, locations and access to service.
- Culturally safe: Adequately fund culture, language (including translation services) and Indigenous worldview of health and wellbeing.
- Address jurisdictional disparities: Funding should address realities specific to the provinces and territories and adapt their funding distribution practices to the pre-established provincial and territorial practices.
- Equity: Increase First Nations funding levels to at least those provided for non-First Nations residents of Canada.
- End wage disparities between in-community service providers and service providers in non-First Nations.
- Ensure the allocation of funds is stable, fair and sustainable, while taking into account the context and needs of each community.

Funding to Improve Current Programs

- End complexities and confusion. Provide guides and training modules to funding programs.
- Increase funding for the Assisted Living Program and First Nations and Inuit Home and Community Care Program (FNIHCCP) to provide communities with the resources they need to offer support services to in-home, community-based care (See Appendix D for more information on programs delivered).
- Program funding must be sufficient to include necessary medical equipment and supplies, and services.
- Improve coordination between funding partners so there is only one overall budget envelope and reduce/eliminate confusing and complexity of funding.
- Allow communities to have joint funding agreements for both programs if they so choose and standardize program eligibility criteria. Program funding must be sufficient to include necessary medical equipment and supplies, and services.
- Funding is required to address serious gaps in long-term and continuing care.
- Recognize and support adequate funding to meet the transportation costs of health care program needs.
- Re-evaluate the funding approach to include all capital costs including [long-term care facility] and maintenance.
- Improve access to Non-Insured Health Benefits.

III. INFRASTRUCTURE

Housing and LTCC Facilities

- Provision of appropriate, culturally safe long-term care housing and treatment facilities is crucial and urgent.
    - Urgent need to address the lack of facilities, including facilities to accommodate Levels 3 & 4 nursing care, health and wellness centres, palliative, respite & convalescent, gathering space for elders. Expressed support for recognizing such facilities in northern communities as top priorities.
- Make housing (whether at home or in an adult residential care facility) adaptable, appropriate, affordable and safe.
    - Existing federal housing programs (including the Canada Mortgage and Housing Corporation's [CMHC]) and Indigenous Services Canada's Capital funding should be reviewed and improved for better clarity and coordination between providers and clients.
- Link health facility infrastructure processes with health service delivery planning.
    - Well-planned facilities could locate convalescent and respite beds inside long-term care facilities; health centres could provide much-needed gathering spaces.

- Support collaborative First Nation efforts in developing innovative responses to community need for health facilities.
- Encourage and support cultural safety in all facility development through policy and regulation modification.
- Share wise practices with First Nations in community facility development.
- **NB:** Such collaborations must be identified by First Nations themselves (see Governance, above).

- Address *Accessibility Act* requirements (by 2024).
- Increase spaces and staffing for cultural activities, ceremonies and gatherings in long-term care facilities.
- Ensure culturally safe alternative housing when in-community care is not yet available.

Transportation

- Recognize realities of transportation needs and costs in FNs, and develop programs and policies to support.
- Provide transportation for people to visit their loved ones in the hospital or long-term care homes and establish minimum standards for visitations.

Information Technology (IT)

- Improve connectivity to facilitate health care service delivery.
- Increase bandwidth to support LTCC.
- Support implementation of telehealth tools in First Nations communities.
- Software infrastructure is needed to save lives. Health records need to follow patients.
- Develop a data governance framework to control and ensure that you have access to information. It needs to include data ownership, with ownership, control, access and possession (OCAP®) principles. Data sharing agreements are fundamental.
- Data infrastructure-asset mapping of all of data collection tools - to capture the numbers to best suit the needs of the community.
- Support access to financial, technical and human resources.
- Prioritize the needs of community members living with disabilities and increase coordination.

Infrastructure Human Resource Development

- Support initiatives to increase First Nation capacity in IT support and technology development.
- Training and education in the trades be made available within First Nations to address infrastructure needs.

IV. SERVICE PROVISION

NB: There is wide variation in availability of services which requires a community-by-community identification of most urgent needs.

First Nations-Led, In-Community Vision of Care

- First Nations-led programs and services, reflecting Indigenous worldview of differently abled, re-enablement.
- Communities and families need choices and options to fit their needs.
- Policies and regulations must be consistent with the provision of incorporating traditional health care, in addition to western care.
- Combine regional resources to provide elders with culturally safe institutions to make sure elders are still active, as opposed to passive recipients in western institutions.

Wholistic & Two-Eyed

- Wholistic services include treating physical, mental, emotional and spiritual health, over entire life cycle from pre-birth to post-death, from health promotion and illness prevention to acute care.
- Include traditional practices and cultural activities in the system of care such as Indigenous art and other cultural activities, traditional healing and medicine, traditional foods, Indigenous helpers, and ceremony.

- Involve elders and patients in discussions to plan, provide, and ensure culturally safe and wholistic services.
- Appropriately resource and acknowledge benefits of Traditional Knowledges related to health and fully integrate them into service delivery options.
    - Enhance services to include land-based activities.
- Community-led gatherings and ceremonies that promote wellness (such as sharing circles, sweats, and teachings) were of the utmost importance for non-discriminatory healthcare.
- Address major gaps and inadequacies in services: [**NB**: This is not an exhaustive list and availability of services differ from community-to-community. See Section 7 for more details]
    - Levels 3 and 4 nursing care,
    - Palliative care,
    - Convalescent and respite care,
    - Traditional care including medicines, healers and ceremony such as smudging,
    - Programs for preventative care such as dietary instruction for parents of children, or family members of diabetics,
    - Social, cultural and land-based programs for elders to reduce isolation and promote mental health,
    - In-community dialysis, and
    - Address addictions and mental health.

Culturally Safe

- Improve cultural safety by in-community care delivered by First Nations staff.
- Integrate culture within care facilities' structure and operations – e.g., create culturally safe and private spaces to conduct assessments, changing western approach to conducting assessments, and ensuring support services are culturally aware.
- Ensure cultural safety is included in all health care planning and program development.
- Kindness and empathy help create cultural safety.

Trauma-Informed Care

- Education and training on the impacts of historical, intergenerational and complex traumas for all family/kin and caregivers.
- Trauma-informed education for all non-FN health care providers.
- Care and care settings that reflect a trauma-informed approach.
- Teaching the history and roots of intergenerational trauma and residential school.
- Training for staff and family caregivers in positive coping methods, harm reduction, recognizing triggers and the tools to deal with trauma.

Human Resources Staffing

- Acknowledge and respect knowledge of FNs homemakers and nursing staff members.
    - Homemakers' ability to recognize deterioration of patient health and elder abuse needs to be acknowledged.
- Establish parity in wages of Staff with non-First Nations agency staff.
- Increase the number of FNs professionals working in the health-care field.
- Ensure the retention of FNs health-care providers in FN communities.
- Provide cultural competency training for all healthcare professionals.
- Resource and implement immediate, specific, and targeted cultural humility and cultural safety training for all professional staff (long-term facility workers, physicians, nurses, homemakers, etc.) associated with long term care provision.
- Provide training in cognitive disabilities and dementia caring methods such as 'Gentle Persuasion' for all caregivers.
- Build capacity through education and training.
    - Educate healthcare providers caring for members on Non-Insured Health Care Benefits program.
    - Build on partnership strengths with educational and training providers.
- Create/increase family liaison and systems navigators/coordinators positions to support family caregivers, advocate, and support transitions.

- Address worker shortages and staffing issues by providing training and skills updating.
- Increase training and awareness of handling of data, health data, confidentiality, and the circle of care needed.
- Involve communities and build partnerships to encourage wellness.
- In collaboration with First Nations, develop a long-term strategy to support the development and training of LTCC staff and professionals.

Family/Kin Caregivers

- Proactively support and care for these providers - financially, educationally and emotionally.
    - Build a care system that honors this and supports them. This needs to be a huge part of moving forward.
    - Supporting family connections and systems, through helping to learn about healthy meal planning, exercise, and other skills.
    - Expand and enhance respite care.
    - Provide support for self-care activities.

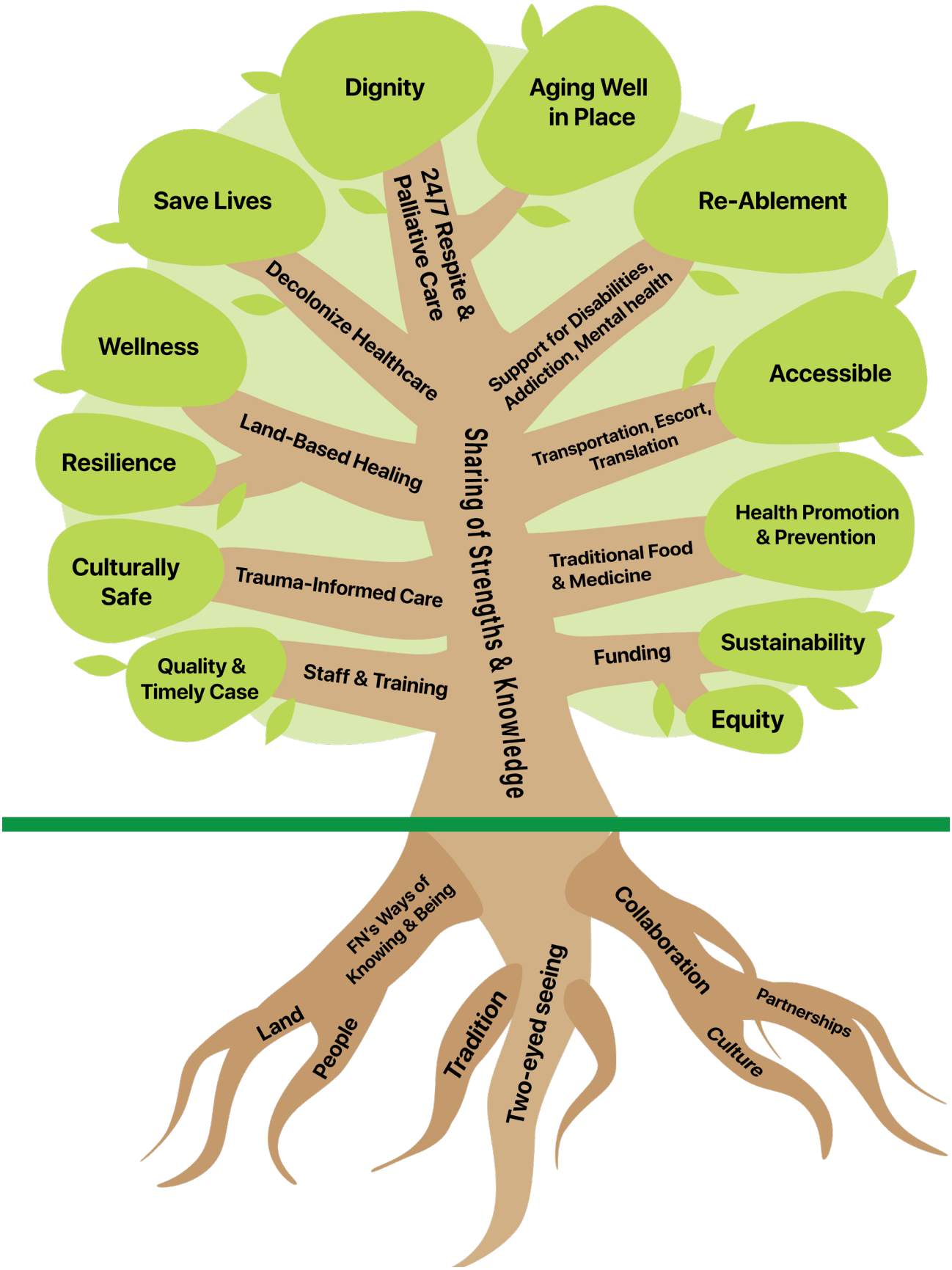
Increasing Medical and Allied Professional Service In-Community

- Improve access to specialized services and ensure they work to complement services in the community in the long term.
- Collaborate with First Nations in the development of Indigenous care teams:
    - To address priority needs, add providers to care teams,
    - Explore opportunities to develop mobile First Nation care teams, and
    - Explore potential for multi-partner operational teams.

Strong Planning, Advocacy and Collaboration

- More dialogue with communities to capture actual need and plan for next 20 years including financial resources required.
- Establish base reporting on First Nations-identified indicators that are useful and measurable for First Nations that simplify the [reporting] process and meet their planning needs.
- Standardize reporting tools.
    - Analyse the Jordan's Principle requests to gaps in service provision at provincial/territorial levels, and identify where federal funding is needed to enhance access to or quality of care.
    - A plan needs to be created for those young people who will age out of care.
- Explore opportunities to enhance and evaluate cross-sectoral collaboration and coordination for meaningful partnerships.
- Establish a network/association of First Nation home support programs to share knowledge and experience, identify solutions to gaps/challenges, and provide advocacy and awareness.
    - Co-ordination to be led by the First Nations, or the agency selected by the First Nation.
    - Collaboration and co-ordination should include not only long-term care providers, but family/kin caregivers and program administrators.

Figure 1: *Sharing of Strengths & Knowledge Tree*



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Preface

The community engagement activities in First Nations described in this report were a joint initiative between Indigenous Services Canada's Assisted Living and First Nations and Inuit Home and Community Care programs. Staff of the program described the motivation in communication with the authors of this report in November 2022:

- *Existing federal government program funding models create challenges within First Nations and Inuit communities to comprehensively address care needs across the lifespan. Often, the care available within communities is not suited to meet some of the more specialized or acute care needs of individuals. For the most part, those needing long-term and continuing care services must leave their home community to travel a significant distance to access provincial/territorial care.*
- *In an effort to better address the long-term and continuing care needs in First Nations and Inuit communities, Budget 2019 provided $8.5M for ISC to work with First Nations and Inuit communities on developing a new and more wholistic long-term and continuing care strategy that could cover the full spectrum of services from supports for people living with disabilities, to aging in place approaches, to improvements to facility-based care, and could include services for those previously served under Jordan's Principle.*
- *This is a joint initiative between Indigenous Services Canada's Assisted Living and First Nations and Inuit Home and Community Care programs.*
- *ISC is supporting ongoing regional Indigenous-led engagement activities that concluded in the fall of 2022 that aimed to gain input from a wide range of First Nations and Inuit partners, organizations, and individuals on the elements of a wholistic long-term care continuum that responds to their needs. As per the 2021 Minister's mandate letter that commits to expanding this engagement to all distinctions groups, ISC is looking to broaden the engagement to also include Métis partners.*

N.B.: This final summary report reflects engagements which occurred in First Nations only.

First Nation communities from all regions across Canada participated in community engagement sessions related to long-term and continuing care.

Impacts of COVID-19, including grief and loss in communities, time limitations, transportation and/or IT connectivity, and other factors limited, and sometimes prevented, participation. Despite these limitations, however, over 700 individuals, drawn from more than 500 First Nations, were able to give voice to challenges, strengths, and community needs related to LTCC.

In 2022, First Nation communities submitted 33 community engagement reports, summarizing the results of those engagement discussions, with input from First Nation communities from every province and two territories. An additional four (4) reports from First Nations organizations and government services were received related to engagements on LTCC and were reviewed by the authors summarizing the engagement reports. The first draft summary report was reviewed at a validation gathering in February 2023, and feedback from the 74 community participants was included in this final summary report.

Ontario Native Welfare Administrator's Association (ONWAA) and Northern Ontario Research Development Ideas and Knowledge Institute (NORDIK) collaborated on hosting the validation gathering noted above, and on writing this final report. The goal of this report and validation process is to present the data gathered from grassroots First Nation communities and present their perspectives as conveyed in their reports, in order that readers may better understand the needs of First Nation communities and individuals who access the service. This information is vital to understanding how to meet the actual needs of individuals and communities.

Some key points for reviewers of this report to consider:

- Community engagement reports documented the use of a variety of tools to engage participants including on-line surveys, interviews, townhalls and group interviews/focus groups. They were not intended to meet academic research standards for rigour and validity (although some may have) and thus, this report should not be considered a 'research report' although it provides valuable insight into many aspects of long-term and continuing care. The facilitators of the engagements also demonstrated determined efforts to be as inclusive as possible in terms of the roles of participants (ranging from service providers, administrative, family and recipients), and in using multiple engagement methods.
- The views and insights quoted in this report are from individual participants. These have been used by the authors to illustrate some of the most frequently mentioned challenges, strengths or suggestions for improving LTCC in First Nations.
- Community engagement reports reflected some of the tremendous diversity of First Nations' experience, knowledge, cultures, geographic regions, as well as the diversity of programs and funding offered by differing jurisdictions, or supported by negotiated treaties and agreements. This report has attempted to demonstrate some of this diversity but it is impossible to reflect the full breadth of this in a summary report. Readers are encouraged to read the community engagement reports attached in Appendix A of this report to better appreciate these.
- *Path Forward* recommendations represent some of those most frequently mentioned. Participants were quick to point out that possible solutions must not be assumed to suggest that one policy will work in every community. Again and again, participants stated that close collaboration with First Nations was needed in all policy and program development, that 'one size does NOT fit all', and that flexibility was key to resolving issues.

Finally, **the writing team wishes to acknowledge the quality of the community engagement reports, and the in-depth knowledge and understanding of LTCC demonstrated by participants.** We have been privileged to work with these materials, and at the validation gathering, to hear directly from participants. We have attempted to reflect their voices, and hope this report accurately reflects what we have read and heard.

Section 1: Context

The 33 community engagement reports identify a substantial divide between the history, culture and context of First Nation communities and that of settler communities in Canada, yet the same legislation, policies, rules and regulations related to long-term care remain virtually the same for both. The community engagement reports identify multiple areas where such a divide results in serious challenges for providing culturally safe and competent care to individuals experiencing decreasing independence in First Nation communities including:

- Differing understandings and approaches to medicine, health and disability
- Differing understandings of long-term care and its delivery
- Differing history and governance issues
- Colonial oppression and systemic racism
- Community impacts and social determinants of health
- Community needs for long-term care
- Diversity and uniqueness of First Nations communities

Understanding the realities that communities face was identified by engagement participants as foundational to considering improvements to long-term care in First Nations. This section attempts to provide the context and a 'reality check' for the issues, concerns and suggestions for change that engagement participants identify throughout the remainder of the report.

It should be noted that the issues raised in this section of this report, like those raised in other sections, have been drawn directly from the community engagement reports.

1.1 Western vs Indigenous Views of Medicine, Disability, and Health Care

1.1.1 Competing Views of Medicine

> *Indeed, if for a majority of Canadians, the concept of medicine is a result of socio-historical factors related to western science, it is generally not the case for Indigenous Peoples who have their own vision of this concept, linked with their own cultures. Hence "western medicine" can sometimes come into conflict with the Indigenous visions, their cultures, spirituality, and other factors. (BC- Northern BC First Nations, CSFS, 2022).*

The differences between Western and Indigenous views of medicine are well documented and shape the current divide between what an ideal continuum of care looks like in on-reserve and off-reserve delivery of LTCC. Traditional medicine and healing are integral to the cultural values and long-standing practices of Indigenous communities. Western medicine typically fails to embrace Indigenous medicinal practices and therefore feels culturally inappropriate to many First Nation peoples. The delivery of western medicine is institutional in nature with a strong emphasis on treatment of physical illnesses, overlooking the wholistic view that encompasses mental, emotional, and spiritual health and well-being.

> *"These disruptions also include an English-centric health system where individuals are expected to understand Western medical jargon in a language that may not be their original and first language." (MB- FNHSSM, 2022).*

In sum, Western paradigms on health and healing label traditional healing and Indigenous healing practices as "folk medicine" or "alternative healing" implying inferiority of our ways of knowing.

1.1.2 Competing Views of Disability

> *There is no single definition for disability across federal health programs but the bio-medical approach cited in the Federal Disability Reference Guide states "disability is viewed as a medical or health problem that prevents or reduces a person's ability to participate fully in society." Disability is thus defined as a limitation or deficit, and disability programs attempt to provide services that aim to adjust a person's ability to function in society. (MB-FNHSSM, 2022).*

Western medicine portrays disability as a burden with a focus on deficits and impairments. The Western view problematizes aging and disability where the Indigenous view sees it as part of the normal human experience and life journey.

An Indigenous worldview of disability is described as having a special purpose or gifts. Individuals living with disability can be teachers and are valued members of the community. This worldview emphasizes the well-being of the collective whole of the community and views everyone as equally contributing members, sharing their gifts with one another. The focus is on strengths and resilience versus deficits and impairments.

> *"Indigenous notions of disability are distinct from the Western, colonial understandings that shape Canadian legislation and policy regarding disability support services." (MB-FNHSSM, 2022).*

1.1.3 Competing View of Healthcare

> *Healthcare, according to participants, is a wholistic concept which includes general overall "wellness," traditional conceptions of wellness (body, mind, emotions, and spirit), access to needed medical services, and community/family care. Healthcare is also considered, by many participants, to be an Indigenous right. (ON- GCT #3 Report, 2022).*

The Western Health Care system that currently exists addresses only the physical needs of Indigenous people (Nokiiwin Tribal Council LTCC Engagement Report, 2022). Wholistic healthcare, from an Indigenous perspective, would require more resources to address other needs, i.e., mental, emotional, spiritual. The mind-body connection is well-known and respected in Indigenous cultures while Western cultures remain skeptical of the impacts of mental health and emotions on the physical body. Meaningful engagement is required to acknowledge Indigenous peoples' contributions to modern medicine.

1.2 Long-Term Continuum of Care From a First Nations Perspective

Mino-Bimaadzaawin in Anishnaabemowin, loosely translated in English means "The Good Life". The state of wellness of all four domains i.e., spiritual, emotional, mental and physical, is the underlying philosophy informing First Nations across Turtle Island. This philosophy is not easily translatable, as it encompasses notions of health and well-being, living in accordance with traditional values and with respect for 'all our relations'.

1.2.1 Life Journey

> *First Nations perspective of long-term care also involves understanding of the Life Journey as a circle of life process that is strength-based with individuals finding out what works for them within an enabling environment. It is life plans from childhood through to adulthood. It is fulfilling the wishes of the patient for their care. It is a healing journey involving spiritual supports including through ceremony. (MB-FNHSSM, 2022).*

Indigenous culture holds the circle of life as a sacred value that should be reflected in culturally grounded LTCC. Within the circle of life, there are life stages that require different levels of care. From an Indigenous perspective, everyone is entitled to long-term care and support throughout their entire life journey regardless of age, status, or location.

1.2.2 Kinship

> *Long-term care is also understood as how First Nations people care for each other. It is kinship, it is roles and responsibilities, and it is values – sharing, caring, and loving. (MB-FNHSSM, 2022).*

The connection to each other and the ability to care for one's own is important in Indigenous cultures. Engagement reports expressed a deep longing within communities to be able to care for their own people. Since kinship is so important to Indigenous culture, LTC outside the community is viewed as a last resort.

1.2.3 Rooted in Culture and Traditions

The First Nations and Inuit Home and Community Care Program (FNIHCCP) and Assisted Living Program (ALP) are best suited to Indigenous needs when they are deeply rooted in the culture, reflect an Indigenous worldview, and are provided in their first language. Cultures and traditional knowledges, protocols and processes differ from nation to nation and from community to community, but some of the commonalities which emerged from engagements included:

- Wholistic worldview
- Seeing life as a cycle from pre-birth to post-death
- Respectful relationships between all peoples and the world we live in
- Intergenerational relationships, sharing and support, and transmission of knowledge
- Use of traditional medicines and foods
- Conversing in own language
- Land-based activities and programming

1.3 History and Governance

The history of colonization and colonialism has been well documented and governance with its accompanying jurisdictional issues between federal and provincial governments have long had challenging and even tragic impacts on First Nations members. The silo effects of dividing the responsibility for health programs between differing levels of government and differing departments within those levels, has resulted in a myriad of confusing and complex intersection of programs, funders, policies, rules, and regulations which First Nations are required to navigate.

1.3.1 Governance

> *It is so well known and respected within our communities that – if we look backwards – the Elders and people that were dying were looked after. Our lands and resources have provided our people with food, shelter, clothing, sustenance, wealth, and health. Everybody got an equal share of all the resources that supported them, and even though Elders sometimes couldn't participate in the gathering, they got a share because of their knowledge. That was our pension fund. That's how we looked after everybody and recognized the value that they held in our communities. They had a role and a responsibility that was assigned to everybody, and it was only since the Indian Act was imposed on us that all the structure underneath that traditional economy was destroyed, that we became dependent on Indian Affairs for the funding that we get in our communities. (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).*

Historically, First Nations have been consistent in their assertion of self-determination, and their rights to govern themselves but treaties and other agreements with the Government of Canada have not always been respectful of these rights. After numerous legal battles, the Royal Commission on Aboriginal Peoples in the mid-1990s, and more recently the Truth and Reconciliation Commission's report in 2015, First Nations and the federal government find themselves in a transitional period. While the federal government has a fiduciary responsibility towards First Nations members and other Indigenous peoples, responsibility for the delivery and funding of many programs, including, for example, health and education, has been delegated to provincial governments. For example:

> *The [Ontario]1965 Indian Welfare Agreement, commonly referred to as the 1965 Agreement, survives to date as the only federal-provincial cost-sharing agreement related to social assistance in Canada. The Agreement identifies the cost-sharing to cover "General Welfare Assistance, Child Welfare, Homemaking and Nursing Services, and Day Nurseries". (ON-ONWAA & NORDIK, 2022).*

As the above quote illustrates, First Nations whose territory has been identified as within the Ontario provincial boundaries, are subject to an agreement that is now almost 60 years of age, while some First Nations have established treaties covering health care within the last 25 years. A tri-partite agreement in Quebec between First Nations and provincial and federal governments have attempted to address the complexities involved in such a legislative and policy environment, while First Nations in other jurisdictions are subjected to two or more provincial/territorial pieces of legislation (in addition to the federal government's) due to their proximity to provincial/territorial boundaries. Additionally, many provinces have established regional bodies for program and funding delivery, resulting in further intersections and jurisdictional issues. Differing standards of care, licensing of LTCC and allied professionals, housing standards and more, result in further challenges for LTCC delivery.

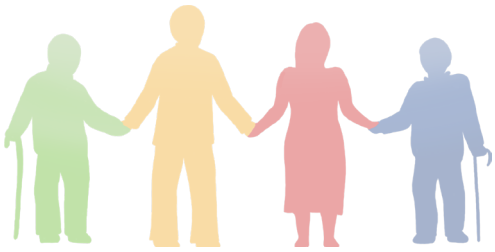
Engagement participants reported that funding and reporting requirements arising from these intersecting, confusing and complex governance arrangements, place a heavy workload and stretch the capacity of usually quite small First Nations communities. Jurisdictional issues often require community or family advocates to educate medical professionals and sometimes program managers regarding entitlement benefits and to obtain access to care, while finding funding pots to address the range of community needs is a never-ending process.

1.3.2 Modern Treaties and Self-Governing Agreements

Some First Nations (in BC and Yukon particularly) have more recently negotiated modern treaties or land claim agreements and self-government agreements, adding complexity to policy and program revision. The modern treaties and agreements illustrate the theme that "there is no one size fits all approach" to the development of LTCC programs. Inconsistencies in negotiated treaties and agreements have resulted in disparities in eligible health services between First Nations. Treaty rights need to be explored in the context of each First Nation when evaluating LTCC throughout Canada.

> *It is critical to understand that in the Yukon there are already 11 of the Yukon's 14 First Nations with Modern Treaties (Land Claims Agreements) in place along with companion Self-government Agreements. What this means in practice is that negotiated arrangements are already in place with these First Nations regarding the delivery of social services, including long-term care. Therefore, unlike many other parts of Canada, there will be no need to develop new delivery instruments as these agreements along with companion program implementation and funding agreements already provide the foundation to put in place new or restructured programs to address long-term care needs. (YK, Yukon First Nations, NGI, 2022).*

The delegating of funds and programs between levels of government and organizations needs to consider the unique relationships that Nations with such treaties and agreements have with the government of Canada. Furthermore, consideration should be given to Nations that do not have modern treaties to understand the resulting limitations.



1.4 Oppression and Systemic Racism

> *While race is socially constructed, the racial discrimination that arises from it must, very importantly, be understood as lived: as experienced and manifested materially, corporeally, and physically within the confines of homes, communities, and various structures of the real and everyday world. (BC- Northern BC First Nations, CSFS, 2022).*

Many reports voiced stories of lived racism in both social and medical contexts. Stories were shared of people being denied or unable to access care, and sometimes refusing to accept Western health care all together, due to both systemic and individual racism. It must be acknowledged that racism continues to oppress Indigenous peoples throughout Canada. One region stated that its people feel "like second class citizen" while numerous participants indicated that experiences of racism influenced members of their communities to refuse to go to non-First Nation facilities including hospitals, resulting in earlier deaths.

1.4.1 Colonialist Attitudes and Policies

The history of colonialism and harmful government policy must be acknowledged as it continues to directly shape the realities of Assisted Living and First Nations and Inuit Home and Community Care Program in First Nations, Inuit, and Métis communities today.

Many reports shared the sentiment that First Nations' voices are not heard, and their values and needs are not reflected in colonialist policies.

> *The consistent application of colonialist attitudes and policies towards First Nations has had serious and disproportionate consequences for FN members in accessing equitable health care, as reflected for example, in the establishment of 'Jordan's Principle'…that medical care must be provided to Indigenous persons, regardless of any provincial/federal*

disputes over who is responsible for the payments. (ON- ONWAA & NORDIK, 2022).

Jordan's Principle was adopted after Jordan River Anderson died in hospital at age 5. The Human Rights Tribunal decision held the federal government accountable for lengthy disputes regarding covering costs which prevented Jordan from ever living with his family. Jordan's story is just one of many who have suffered because of colonialist attitudes.

Despite the implementation of Jordan's Principle, existing provincial legislation is still used today to deny necessary services for Indigenous peoples on reserves. Discrepancies in policy leave gaps and create discriminatory barriers to equal access to care. The frustration over policies that support care for some but not for all is widely felt throughout the regions in Canada.

Policy language and terminology was also reported to be offensive. The terms "Adult Foster Care" and "Institutional Care" were described as both demeaning, i.e., suggesting adults are children, as well as triggering trauma impacts due to the linkage of 'foster' with discriminatory child welfare practices.

1.4.2 Breakdown of Family Units

The critical role that family plays with the management of care has been well researched and documented. The traditional extended family and kinship systems of First Nations have changed with breakdowns in family and community networks as a result of colonization. The ongoing disruptions of families and communities by policies such as residential schools, Sixties Scoop, PASS system, and Day Schools significantly increase the need for continued support and LTCC. It cannot be assumed that First Nation members have extended family members who are available and able to assist in their care without substantial support.

1.4.3 Historical, Intergenerational and Complex Trauma

Problem with substance abuse and increase in mental health issues through multi generational impact of residential schools. (YK, Yukon First Nations, NGI, 2022).

Research has documented the complex trauma faced by First Nation communities. The legacy of colonial policies such as residential schools includes loss of language, culture, and traditional family systems and includes historical and intergenerational trauma. The ripple effects include significant health impacts which continue to be exacerbated by ongoing trauma as a result of natural disasters and community displacement, as well as suicide, substance abuse and family violence arising from colonization.

Education, mental health, addictions, living conditions, access to clean water, diet and nutrition, and health co-morbidities are only a few of the ways in which the impacts of colonization and intergenerational trauma can be seen today within the community.

1.4.4 Mistrust: Internal and External

Lateral violence has a deep impact on Citizens in need, causing them to go into isolation; health services, therefore, are not received. (YK, Yukon First Nations, NGI, 2022).

Deep external mistrust of the health and social service system, due to experiences of racism, was reported by many engagement participants. Hospital intake, diagnostic, and discharge processes and procedures were reported as unfair and racist, with individuals being discharged prematurely due to bias or negligence. The premature demise due to racism and discrimination have made headlines in the cases of Joyce Echaquan and Brian Sinclair for very treatable conditions, further validating fears of maltreatment and professional misconduct.

There is a reluctance of some Indigenous people to seek treatment or services for fear of systemic

racism, discrimination, and re-traumatization. This creates higher risk for earlier onset of disability and increased mortality risk with delayed diagnoses and treatment. Rebuilding trust with culturally appropriate LTCC programs is critical to overcoming this issue.

> *The community is in need of a lot of support, but many community members will not ask for help from the health and social department. That department will pick and choose who to help and who not to. Sad but it's true. (YK, Yukon First Nations, NGI, 2022).*

1.5 Social Determinants of Health (SDOH)

> *It is important to recognize the strong correlation between social determinants of health and wellbeing when assessing the wholistic lifelong continuum of care. (ON- Six Nations Health Services, 2022).*

The social determinants of health (SDOH) are the non-medical factors that influence health outcomes. They are the systems and conditions in which people are born, grow, work, live, and age including economic policies and political systems (WHO, 2022). Social determinants of health have been widely studied in many cultures, yet little research has been done on the social determinants of Indigenous health. One study in 2014 looked at the Inuit Tapiriit Kanatami social determinates of Inuit health in Canada. It highlighted the ongoing challenges with lack of long-term/continuing care options, particularly for individuals requiring a high level of care (BC-Interior, Naut'sa mawt Resources Group, 2022).

Examples of social determinants of health that influence health equity include:

- Income and social status,
- Social support networks,
- Education and literacy,
- Employment and working conditions,
- Social environment,
- Physical environment,
- Personal practices and coping skills,
- Race/racism,
- Health child development,
- Access to health services,
- Gender, and
- Culture.

Engagement reports voiced concern that social determinants of health (housing, employment, poverty, access to health care) are largely influenced by trauma, oppression, and the systemic racism that still exists. According to the World Health Organization, "In countries at all levels of income, health and illness follow a social gradient: the lower the socioeconomic position, the worse the health." (2022). Poverty and higher rates of illness are disproportionately higher in Indigenous populations compared to the general Canadian population.

> *Funding, infrastructure, housing and poverty remain as lingering effects of colonialization with negative health impacts to AIAI members. (ON- AIAI, 2021).*

First Nations struggle to overcome the social ramifications of colonization. Children born in First Nations today are at greater risk for illness based on social factors beyond their control. Elders are left especially vulnerable when basic amenities and health care are not available. Youth and adults have limited opportunities to pursue higher education and find careers upon graduation.

> *Many caregivers identified that they are unemployed because of the help that they were providing to their loved ones. Others who are still working often reduce their work hours to be able to care of their loved one. (ON- Nokiiwin Tribal Council, 2022).*

Caregiving for family members can require enormous time, commitment, and support. For First Nations members, where opportunities for employment are often quite limited, such caregivers' health and financial security suffer because of the stress and sacrifice associated with caring for loved ones.

Caregiving affects staff shortages as workers are not available to work due to the demands of caring for family members. Social determinants of health affect the community as whole.

1.6 Community Need for Long-Term Care

Little comprehensive research has been done on continuing health care needs for First Nation; however, there is evidence to demonstrate the growing and disproportionate need for long-term care supports among First Nations when compared to the general Canadian population. (MB- FNHSSM, 2022).

1.6.1 Higher Rates of Disability and Chronic Illness

Disability and aging have been studied extensively in the general population but there is limited research on First Nations members living with disability, especially on-reserve. Research that is available shows that First Nations members experience disproportionate rates of disability, as high as twice the rate of the national average, with individuals suffering chronic health conditions and requiring care at younger ages (Manitoba, 2022). Indigenous people have higher rates of Alzheimer's and dementia with an age of onset approximately ten years younger than the general population, accelerating the transition from home and community care to facility-based long-term care (Manitoba 2002). Further, Indigenous women are more likely to experience greater severity in disability compared to non-Indigenous women, a factor that also impacts family caregiving capacity.

There is also limited research on disability types as relevant research focused on chronic health issues rather than disability. For example, the 2008-2010 First Nations Regional Health Survey identified that First Nations adults living on reserve in northern communities located within Manitoba's boundaries reported the following chronic health conditions; chronic back pain (16.2%), hearing impairment (8.8%), blindness or vision problems (3.6%), learning disability (3.6%), and cognitive or mental health issues (1.2%). (MB- FNHSSM, 2022).

1.6.2 Increasing Elder Population

Elders are at increased risk for health issues and abuse. The First Nations population over 60 years of age is growing 3.4 x faster than the non-Indigenous senior population. This growth is expected to increase the demand for medical and social supports over time. (ON- Nokiiwin Tribal Council, 2022).

1.6.3 COVID-19

Grief and loss, together with staff and caregiver 'burnout' were the most frequently mentioned items [impacts of the pandemic]. The loss of community Elders together with their knowledge including cultural and language-based knowledge, loss of children, long-term isolation, and incredible stress on families and caregivers as they struggled to work, care for two or more generations, tried to isolate family members in overcrowded housing, etc., will no doubt have serious and long-term impacts. (ON- ONWAA & NORDIK, 2022).

The pandemic imposed further hardship on First Nations populations and exposed vulnerabilities in an already fragile health system. According to engagement participants, COVID-19 increased issues related to mental health, addictions, chronic diseases, information systems, LTCC outside the home, food security, infrastructure, and human resources. It created fear and further mistrust of what is widely perceived as a broken system.

Many critical services were halted completely during the pandemic. The delivery of Assisted Living Program was not delivered in some communities for some lockdown periods, while delivery was limited in most FNs due to preventative measures and staff illness and death (ON- NAN, n.d.). The loss of this home support program added stress and suffering to patients and families.

One major flaw in tracking the impact of the pandemic on the health and morbidity of First Nations peoples was that First Nations communities were not able to determine how many of their citizens were in LTCC Homes, as most of these are located outside of their communities (ON- GCT #3 Report, 2022) causing difficulty in accessing information.

> *Research into the impacts of the pandemic and mitigation strategies for the future needs to be conducted as soon as possible. (ON- ONWAA & NORDIK, 2022).*

The full impacts of COVID-19 cannot be ignored as they may provide valuable opportunities for change and lessons learned.

1.6.4 Mental Health & Addictions

> *Mental health and addictions concerns span the continuum from children to elders, and many conditions become chronic. The continued trauma from residential schools, only compounded by the recent revealing of children buried on school grounds requires consideration for treatment modalities moving forward as individuals age. (ON- AIAI, 2021).*

Mental health issues are positively correlated to substance abuse with many people suffering from co-morbidities, such as depression and alcoholism, although funding for health promotion and prevention, treatment centers and medical services for these illnesses fall outside the purview of First Nations and Inuit Home and Community Care Program and Assisted Living Programs. Additionally, these illnesses have impacts on both the individual experiencing increasing dependence as well as their families and caregivers, as the impacts may go both ways, i.e., the person requiring LTCC may be experiencing mental health and addictions, and/or caregivers may have one or both illnesses. As people requiring long-term care services frequently share housing, and thus home supports, with family caregivers, these issues are particularly challenging to resolve.

1.6.5 Social Isolation

> *There is a negative correlation observed between further isolation away from family and community and the impacts on mental health and well-being and substance use.(ON- Six Nations Health Services, 2022).*

Social isolation is a risk factor for mental health, addictions, and abuse issues. Engagement reports unanimously agreed that families only consider long term care placement when it is not possible for elders to remain at home and in the community. It was expressed that families prefer to care for their elders at home so that they can maintain their social connections and not be alone for the end of their life journey.

> *Often elders refuse treatment and sign waivers to be able to live at home and as a result they live at risk. It is a big problem. Elders refuse to comply with treatment outside the community because they do not want to leave their homes. (SK- FSIN, Katenies Research & Management Services, 2022).*

> *Safety checks are done on a regular basis for elders but not for everyone in the community. Funding is needed for all people to be visited. One person froze to death last year. (YK, Yukon First Nations, NGI, 2022).*

1.6.6 Multi-generational Households

> *As well, care needs are unique and complex within households. For example, a household can be comprised of aging older adults with chronic care needs living with an adult child with mental health or disability needs. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Multi-generational households are common in First Nation communities for cultural and socioeconomic reasons, as well as the well-documented lack of housing on-reserve. This situation can be beneficial for caregiving when there are healthy individuals within a household but there is serious need for additional supports and assistance when there are

multiple people with illness or disability within a household. There can be three or four generations, each with their own unique needs, living in close quarters under one roof.

1.7 Diversity of First Nations

1.7.1 Diversity of Nations, Community Structures, and Cultures

> *The Atlantic region is comprised of Indigenous communities in NS, NB, PE and NL. Each provincial context differs with respect to health and social services. There are three Nations (Mi'kmaq, Wolastoqiyik, Innu), a landless band (Qalipu First Nation) and a fly-in community (the Innu community of Natuashish). (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

The Atlantic 'region', as illustrated above, is one of several regions where First Nation communities access LTCC services that straddle more than one provincial/territorial border. Treaties and agreements which define First Nations lands and traditional territories were not acknowledged in the establishment of provincial/territorial borders, thus First Nations may be required to deal with two or more provincial/territorial sets of legislation, programs, etc.. Further, transportation routes, particularly in more remote areas, may not provide direct access to what may appear to be the closest service provider. These unique features of Nations, bands and remote communities and the various access points for service are not well accommodated by inter-jurisdictional policies and programs. The diversity of community cultures adds to the complexity of creating a comprehensive system.

> *"There are also significant cultural and language differences that must be considered given Canada's interest in finding options that are "culturally grounded". (YK- TRTFN, DDC, & DRFN, NGI, 2022).*

Communities can more frequently find cultural alignment when they are within the same Nation (cultural and language group) but significant differences are not usually acknowledged by policy and/or service provision. For example, the community engagement process in northern BC engaged with participants drawn from two communities within the Kaska Nation, as well as one Tlingit community. This adds to the complexity of creating a culturally appropriate system of care and highlights the need for improved communication in respective languages.

1.7.2 Diversity of Geographies, Size, and Proximity

> *Communities are all of different sizes with different health and social service systems and differing access to adjacent health service centres. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

> *There is tremendous diversity in the geographical locations and sizes of First Nation communities across Canada. Communities like Old Crow are over 800 km from the closest medical center in White Horse. It is accessible only by air, with flights in and out once daily. The most remote locations experience significant hardship in accessing health care professionals in urban centers especially in emergency situations. Communities whose geographical location is only accessible by air or boat experience much less service delivery and care than those located closer to cities and the cost of providing such services is much higher. (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).*

> *We have a high cost of living and accessibility challenges. We need to make this point, that remoteness, lack of transportation, food insecurity make care more challenging, especially with the limitations of care in our areas. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

> *Communities with small populations also have less access to healthcare than larger communities and are the most underfunded and understaffed. Some communities only have 1 rotating fly in doctor or locum for an entire*

community. The size of First Nations sometimes limits their capacity to hire community members so external service providers are sought through purchase of service agreements. This affects the level of quality and culturally appropriate delivery of services as it creates a revolving door of service providers in clients' lives. (ON- ONWAA & NORDIK, 2022).

In sum, as First Nations attempt to provide a continuum of long-term, in-community care to a growing cohort of individuals facing increasing dependence, they are faced with a complex array of extremely challenging issues. Sharing a wholistic worldview of health and well-being First Nations are confronted with programs and policies that separate one illness from another, that require separate justifications for funding and reporting requirements, and where service providers are frequently unaware of the histories, cultures and contexts of Indigenous peoples.

Given the above, it is not surprising that the engagement participants identified many ways to improve the delivery of LTCC. Nor is it surprising that they found much consensus in identifying a vision for long-term care that includes a wholistic, culturally safe, trauma-informed LTCC system.

Section 2:

Community Engagement Processes and Methodology

2.0 Background

This summary report is a compilation of 33 summary reports of community engagement sessions conducted with First Nation communities across Canada, some in-person, others facilitated through technology, and some using a hybrid model of both methods. Several additional documents were made available to the authors, including a summary report compiled by staff from the ISC regional office in BC, and Assembly of First Nations (AFN) document prepared by AFN staff and drawn from their previous research regarding health, including long-term care. These latter documents were reviewed by this report's writing team to assist in their orientation to the project but did not form part of this final document as the mandate for this report was to compile and reflect the voices of participants in the engagement sessions undertaken in this initiative.

2.0.1 Summary Report Development

To compile the community engagement reports, the writing team used grounded theory analysis to identify major and minor themes in the various reports. NVivo, a data analysis program, was then used to sort the topics raised in the reports using coding based on the themes identified.

A draft summary report was then written in the period December 2022 – January 2023, and circulated to the authors of the regional reports, facilitators of engagement sessions and community participants for their review. These individuals were invited to attend a validation gathering in Sault Ste. Marie February 22-23, 2023, to provide feedback on the draft.

To facilitate participation in the validation exercise, participants were invited to participate either face-to-face or through technology mediated sessions. 74 First Nation participants from all regions attended the event, hosted by ONWAA and NORDIK, and were welcomed with traditional protocols by Garden River First Nation and the Healing Lodge Singers, as well as representatives from the hosting organizations. Indigenous Services Canada and NORDIK provided presentations on the next steps, and some of the key points in contained in the draft summary respectively. The remainder of the agenda over the two days was taken up with facilitated sessions where participants provided feedback on the draft. 51 pages of direct feedback was provided by participants for incorporation. At the conclusion, participants were given an additional two weeks until March 10 to make any further comments.

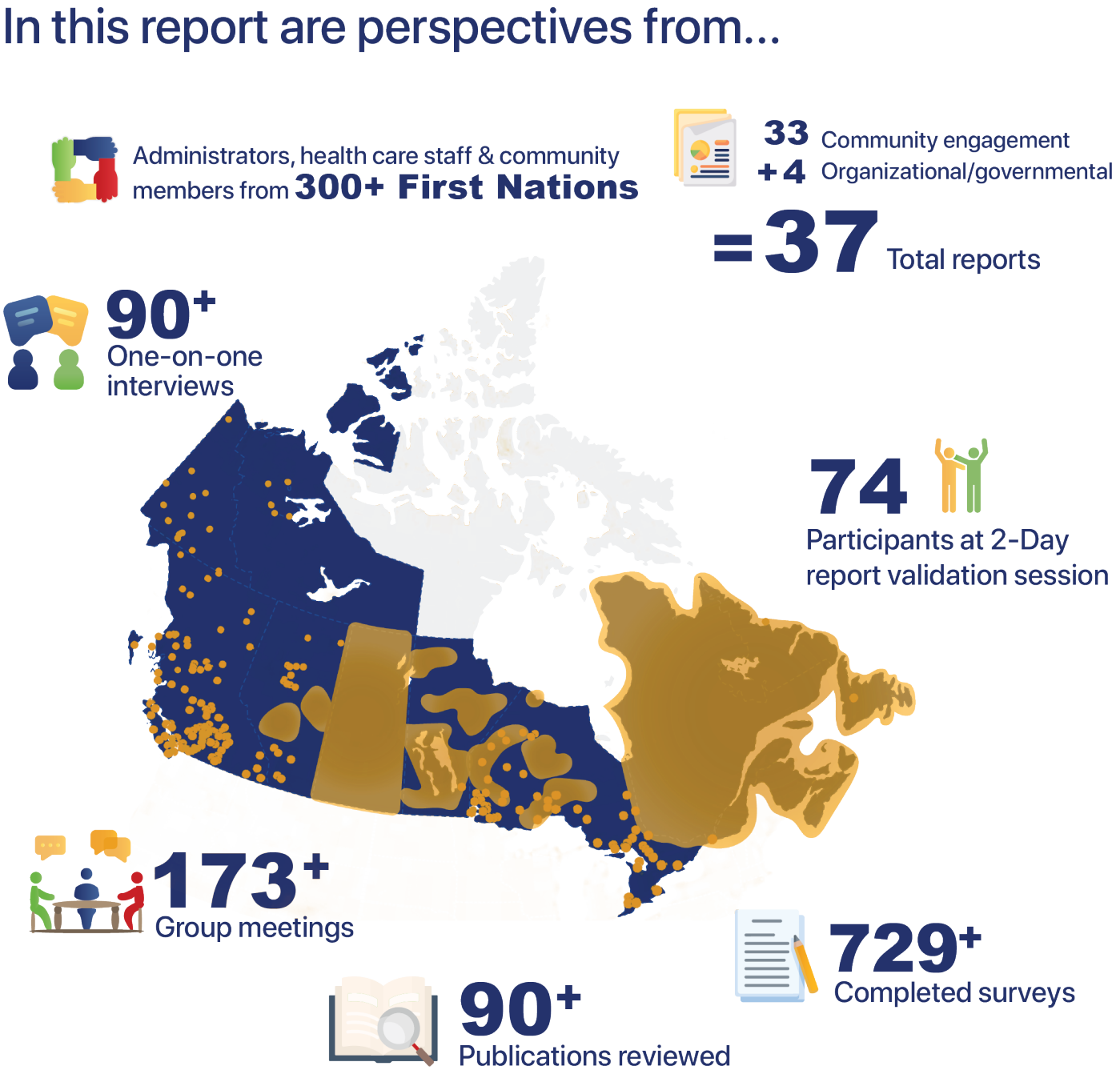
This feedback was incorporated into this final summary report.

The authors of this summary report have attempted, to the best of their ability, to remain true to the voices of engagement participants and as much as possible have used the language of the reports themselves to describe and illustrate various points. This report is intended to:

- Ensure that those themes which were identified most frequently and/or as having most impact on long-term care in First Nations, receive significant focus,
- The diversity of viewpoints expressed is respected and reflected in the report, and
- The complexities of LTCC delivery in First Nation communities, given the history, diversity of Nations and cultures, and context are extremely difficult to capture in words alone. Thus, visual representations have been used in several instances to better convey these complexities.

The remainder of this section outlines the methods/processes used to engage First Nation communities in sharing their views, perceptions and experience with LTCC.

Figure 2. *Report Representation Map*



Please note:

1. Where names of individual nations have been omitted within the reports, we have attempted to show the generalized area that was represented.
2. Inuit engagement is not included in this report.

2.1 Challenges to Community Engagement

Engagement participants, as well as engagement facilitators and reporters, identified a number of challenges in the community engagement processes including the following:

2.1.1 Lack of Trust, Accountability and Communication

> *Accountability and follow up is important. There is often inadequate communication back to informants on these and other engagements. This, too, contributes to a lack of trust and lack of hope that concerns will be addressed. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Reports identified that in some cases the same or similar questions had been asked in previous engagements, some in response to more general health care studies, while others were in engagements specifically related to long-term care itself. They pointed out that local, regional and sometimes even larger engagements (e.g. provincial or federal) had resulted in a broad variety of reports and recommendations, but changes had not yet been implemented. Lack of implementation and/or communication about the status of such reports has resulted in a lack of confidence that the views of participants will result in change and discourages further participation.

2.1.2 Asking About LTCC When Only Part of the Continuum Is Being Addressed

Every regional report, without exception, discussed the wholistic viewpoint of health and wellbeing and the impacts of the social determinants of health (SDOH). To discuss LTCC, when it deals with only one piece of this complex intersectional puzzle, is a challenge for participants and limits their capacity to identify priorities and recommendations for change.

2.1.3 Short Time Frame, Capacity to Reach Individuals and Communities

The short time frame and limited the capacity of facilitating organizations to engage with potential participants, particularly those in remote communities, as well as service recipients. Technology was often relied upon to conduct surveys, often with less than optimal results. Reports identified that in some cases, particularly in rural and more remote communities, the lack and/or unreliability of internet services limited/interrupted/prevented access in some cases. The short turnaround time – in most cases 3-4 months – meant that establishing communication and building relationships with communities was difficult, particularly in those instances where prior relationships were not well- or fully established.

2.1.4 COVID-19 Pandemic

The COVID-19 pandemic also contributed to limiting the number of community engagement sessions. Some communities were deeply feeling the loss of community members, indeed one community which participated in the discussions advised that their single community homemaker had died as well as several community elders as a result of the disease. Additional impacts identified as limiting participation included the impacts of social isolation restrictions, impacts on family and community caregivers who were unable to participate, as well as fears of contracting the illness.

2.1.5 Validity Questions

> *Even among the 8 participating Nations, the number of returned Community Surveys and program Staff Questionnaires are very small. Therefore all the conclusions drawn by the researcher, and summarized in this report, should be viewed as extremely tentative, and should be verified independently through additional research before they can be considered as trustworthy. (AB- Treaty Six, JTK Research and Consulting Inc., 2021).*

When consolidated, the number of engagement participants – individuals, communities and Nations – appears substantial, yet community engagement participants noted concerns relating to the validity of findings due to a lack of participation by some First Nations, and/or by the absence in some engagements by those receiving care, or in other roles. At least one report noted that recipients of service were assisted in completing engagement questionnaires by administrative personnel who may have minimized the challenges faced at the direct delivery level. A case given to exemplify this concern centred around assessment of individuals for eligibility for services, i.e., community caregivers and service recipients noted that there were substantial wait-times between assessment determination of eligibility for service and actual service delivery (sometimes as long as several months during which time the applicant for care's health may have seriously declined), whereas administrative staff did not identify this as a serious challenge for service provision.

2.2 Strengths of Engagements

> *Relationships and previous connections with Elders was imperative prior to asking questions for the LTCC engagement project. (BC- Stó:lō Service Agency & Three Sisters Consulting, 2022).*

Facilitators made exemplary efforts at engaging a broad range of participants despite the many challenges to engagement (see above), and as Figure 1 above illustrates, their efforts resulted in participation of First Nation members drawn from over 300 communities and from all regions. Some of the inclusionary practices used to engage and encourage a diversity of participants' views included:

- Forming an advisory committee to guide the project's engagement process and make recommendations about contacting and supporting potential participants, as well as providing insights about prior engagements and related reports.
- Relationships and previous connections with elders was 'imperative' prior to asking questions for the LTCC engagement project.
- Facilitation and report writing by Indigenous-led and/or community-known organizations and /or individuals. Their established credibility helped to mitigate the impact of short time frames with community members.
- Use of a broad variety of participation methods. Surveys, interviews, focus groups, discussions at community events were all used to give as much opportunity for participation as possible.
- Most engagements employed both on-line and in-person opportunities for participation, recognizing the challenges inherent in the use of technology in rural/remote areas, and particularly with elders and persons living with disabilities.
- Creative use of visuals, photo-voice, and recording of discussions and interviews added insights and validity where these were able to be employed.
- Flexibility in alternative scheduling or re-scheduling to better accommodate participation.
- Sessions designed to confirm reports and findings through reviews by participants and/or Advisory committees (and in one case, a motion by band council) provided additional level of validation and credibility within the community.

The use of these practices resulted in mitigating some of the factors inhibiting participation as outlined in an earlier section of this report but engagement facilitators cautioned that service recipients and caregivers were particularly noted in a number of reports as being underrepresented.

2.2.1 Diversity of Participating Nations, Communities and Individuals

Research evidence has illustrated that engaging a broad diversity of participants is a key contributor to the validity of research findings. This evidence would apply to community engagement exercises as well. The 33 community engagement reports generated by this initiative illustrates a broad range of First Nation communities and Nations, in terms of sizes, locations, cultures, and other variables.

Participants in the LTCC engagement drew on their diverse experience(s) as community members, service providers, and community and political leaders. Participating individuals included:

- Political and community leaders,
- Traditional knowledge holders,
- Allied health professionals such as occupational and physiotherapists,
- Community health workers, nurses, homemakers and program administrators involved in LTCC delivery,
- Family and/or community caregivers,
- Service recipients,
- Elders and persons with disabilities, and
- Funders and/or ISC employers.

2.3 Engagement Reports

The 33 engagement reports summarized rich data reflecting the history and context of First Nations wholistic view of health, and the challenges, strengths, opportunities for change (or recommendations), and vision for LTCC rooted in health promotion and overall wellbeing. The reports included evidence of extensive related research and community engagement in earlier attempts to address the pressing health needs of First Nation communities.

2.4 Opportunities/ Recommendations for Improving Engagement Processes

> *Commit to clear, regular, and ongoing consultations with First Nations in unceded northern British Columbia about evolving needs and visions for long-term continuing care. (BC- Northern BC First Nations, CSFS, 2022).*

Numerous community engagement reports referenced previous engagements related to health, well-being and long-term care and frustration that once the engagement concluded, no further communication was provided to the participants. Recommendations related to respect for and accountability to individual participants, communities and Nations include:

- *Adherence to the OCAP® principles (ownership, control, access and possession). (SK- FSIN, Katenies Research & Management Services, 2022).*

Prior to any engagement commencing, the following actions should be taken:

- *Introductory discussions, led by a senior team member and in person is the required respect that must occur before projects can proceed with the confidence of the First Nation. (YK- TRTFN, DDC, & DRFN, NGI, 2022).*
- *Best practice would be to develop relationships with community support workers or community healthcare workers and meet Elders in person. (BC- Stó:lō Service Agency & Three Sisters Consulting, 2022).*
- *In-person discussions with political leadership. (YK- TRTFN, DDC, & DRFN, NGI, 2022).*

2.4.1 Communicating About Engagement

> *Communication from community administration to Elders takes time and personal connection. Virtual communication is also not recommended for engagement with this population. Elders and people with disabilities require technology assistance. (BC- Stó:lō Service Agency & Three Sisters Consulting, 2022).*

As noted above, engaging First Nation communities in discussions related to LTCC face numerous challenges, but the strengths identified in the community engagement reports also identify wise practices and recommendations of both participants and facilitators to promote greater inclusivity, relevance and insights in future discussions of LTCC.

Communication is key. Develop a communication mechanism. Educate the members on these mechanisms and processes. (MB-FNHSSM, 2022).

In person or telephone interviews with family and community caregivers, and with persons who receive care –Engagement participant

Participants suggested that ongoing communication and engagement to provide feedback could take various forms.

Participants of these engagement sessions identified a broad range of methods to collect data for measuring success of long-term care including:

- *Elder storytelling*
- *Surveys including a satisfaction survey*
- *Comment box for suggestions and needs*
- *Monthly and annual meetings for discussions on what supports are needed and being used or not available.*
- *Celebrations and/or feasts for coming together to discuss good things happening and what can be changed. This gives First Nation members a chance to voice issues and concerns supporting current issues. -Engagement Participant*
- *A lunch gathering to discuss needs. (MB-FNHSSM, 2022).*

Some participants indicated a willingness and even eagerness to continue this discussion:

A few participants also expressed pleasure in having the sessions they were engaging in: people were very encouraged and eager to participate. Indeed, participants noted they would like to see more sessions like this in the future: moreover and ideally, community members articulated that it would be great to see a mid-term evaluation conducted in five-years, with subsequent follow in another five years. (BC- Northern BC First Nations, CSFS, 2022).

Undertake more, and ongoing, consultations including and imperatively with those people who are receiving long-term continuing care services. (BC- Northern BC First Nations, CSFS, 2022).

2.5 Stages or Phases in Engagement Processes

LTCC was a complex topic for individuals and communities to discuss in this engagement exercise. One report suggested that to adequately address such complexities requires a re-work of engagement. To identify issues related to implementation of a complex phased or staged engagement process is preferred.

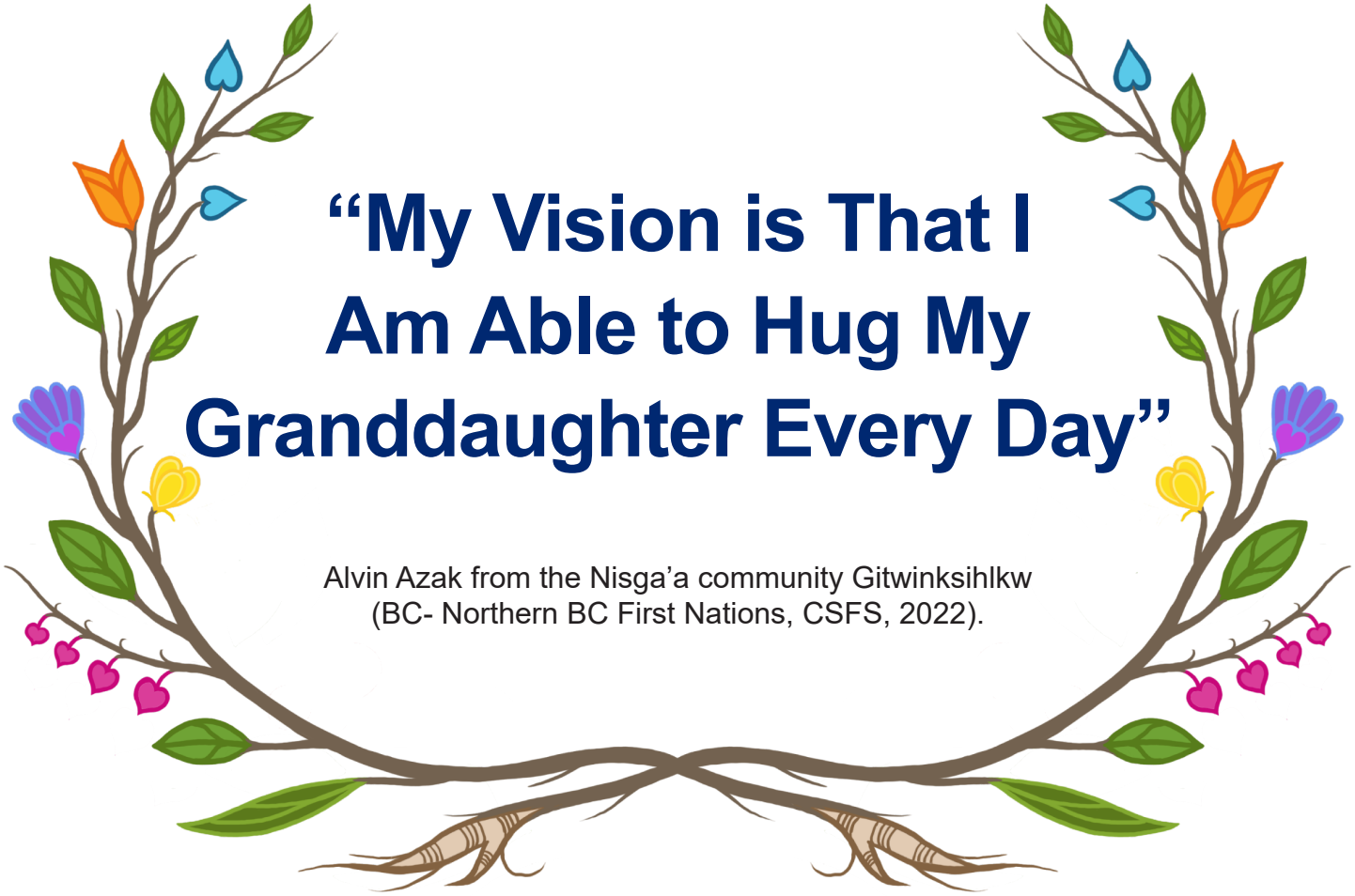
For example, a wholistic continuum of care and steps required to implement it are included in the Assembly of First Nations discussion document Options for a First Nations 7 Generations Continuum of Care (2020). Engagement advice: Instead of summarizing these, engage internally and with communities on a staged change approach to address these. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Although the recommendation was only provided in one report, it may be worthy of a discussion with communities prior to future engagements.

2.6 Conclusion

Despite the serious and sometimes severe impacts of COVID-19 and a number of other limiting factors, the community engagement processes employed in this initiative resulted in remarkable numbers and diversities of First Nations participating and sharing their views and experiences of long-term and continuing care programs. Facilitators demonstrated substantial creativity in reaching out to communities, and report authors provided data rich in the knowledge and insights of participants. The validation exercise brought together over a hundred participants who addressed gaps, corrected errors and provided clarifications on the draft summary, and provided guidance to improve this summary report. Participants were quick to point out, however, that more collaboration and engagement is necessary in the next step of co-developing a framework for LTCC in First Nations communities, and that more needs to be done to benefit from the knowledge of those who are themselves experiencing increasing dependence, to ensure that their needs are met.

Section 3: Vision



“My Vision is That I Am Able to Hug My Granddaughter Every Day”

Alvin Azak from the Nisga’a community Gitwinksihlkw
(BC- Northern BC First Nations, CSFS, 2022).

3.0 Foundational Vision of Care

Five key principles for the delivery of long-term care emerged from community engagements.

1. **First Nations led and administered** – The community engagement reports overwhelmingly supported a system of care that was First Nations-led and administered to ensure a culturally safe, trauma-informed and equitable service; accessibility first, jurisdictional issues resolved after delivery (Jordan's Principle).

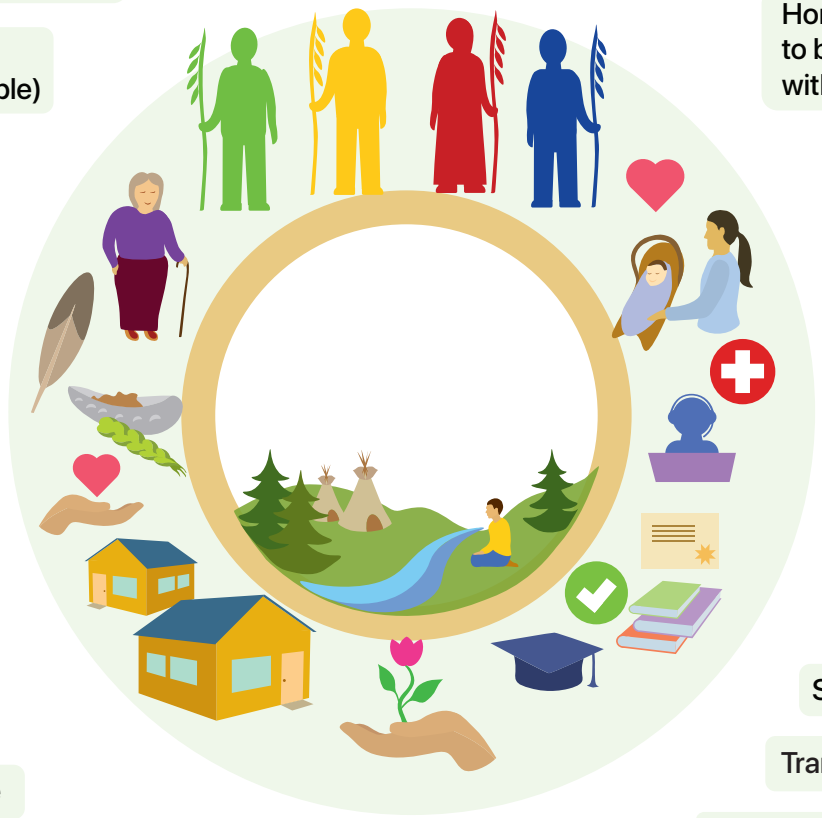
2. **Wholistic** – A LTCC model based on a wholistic understanding of the indivisible health of body, mind, spirit & emotion of the individual; that the health of an individual is a part of and reflected in the health of the family, community and Nation; a wholistic continuum of care throughout the life cycle from children and youth to adults and elders , from pre-birth to post-death; using a two-eyed approach (including language, land-based and traditional healing and medicines and western science) in recognition of the knowledges and wisdom available.

3. **Accessible** – In-home and in-community barrier-free facilities; culturally safe, respectful of diversities of cultures and individual needs; supported wherever possible by family caregivers provided with training and adequate respite and resources; home supports and professional services to be provided in respectful collaboration with First Nations providers first, who have opportunities to access high-quality training and education, and other culturally competent and trusted providers; in first language (or with translation) of service user; transportation when required; use of telehealth services, barrier-free design; in a timely manner.

4. **Universal** – eligibility for everyone requiring service; irrespective of jurisdictional boundaries/disputes.

5. **Portable** – services provided to FN members, no matter where they live, both on and off reserve.

Figure 3: *Vision for Long-Term and Continuing Care in First Nations*



Culturally safe trauma-informed and equitable service

First Nations Led and Administered

Respecting treaties & agreements

Gatherings to share knowledge, collaborate & strengthen services

Flexibility to address FN's unique needs

Accessibility first, jurisdictional issues resolved after delivery (Jordan's Principle)

Home supports and professional services to be provided in respectful collaboration with First Nations providers first

Respectful of diversities of cultures and individual needs

Culturally safe & competent

Trauma-informed

Health of body, mind, spirit & emotion

Qualified FN staff

Wholistic

Accessible

Wholistic continuum of care throughout the life cycle

Barrier-free design

In-home and in-community in barrier-free facilities

Decent, affordable housing

24/7 Services - Level 3 - 4

Two-eyed seeing - respect for traditional practices

Services provided in users' first language

First Nation members on and off reserve

Transportation - mobile health teams

Services available across jurisdictions

Family caregivers provided with training, respite & resources

Seamless wrap around services

Portable & Universal

Eligibility for everyone

3.1 Introduction to Sections 4, 5, 6 and 7

> *Much of what the future held, according to participants, involved a concurrent (and somewhat paradoxically opposing) undertaking of getting rid of problematic things while simultaneously supporting what participants felt could work in their communities. There was a consistent and steady reiterating of the need to change things that were not working — policies that did not work, gaps in transformation and infrastructure, lack of culturally safe, humble, trauma-informed service provision — with a concurrent voice about lifting up the things that WERE working in communities…. land-based teachings and practices, working with Elders, celebrating Indigenous languages and local knowledges, amplifying relationships across multiple scales from the familial to the multi-community and multi-sectoral, and strengthening and supporting resident skills. While these visions for continuing care may feel somewhat ephemeral, they are important to understand, appreciate, and pay attention to with regard to future service provision. (BC-Northern BC First Nations, CSFS, 2022).*

Throughout the compiling of this report, the challenges facing First Nations individuals and communities in the delivery of a culturally safe, trauma-informed, preventative and re-ablement suite of services to individuals requiring support to remain in their homes and communities seems, at first glance, to be overwhelming. As the quote above indicates, the numerous opportunities for change identified within the reports covers a broad spectrum from 'getting rid of problematic things' – such as systemic racism – through to identifying and 'supporting what participants felt could work in their communities', recognizing that there is significant cultural, social, and geographic diversity within and among First Nation communities themselves.

Part of the challenge in compiling the recommendations arises from the inter-connectedness of the concerns: for example, a recommendation for improved access to respite and palliative care in communities is inextricably linked to funding issues which in turn, are connected to governance of the program.

Ultimately, the authors have attempted to write this section of the report on some guiding principles outlined by engagement participants themselves:

- Reflect the strength of the combined voices of First Nations communities across all the regions. Given the multiple diversities of these communities, there was remarkable agreement on many crucial opportunities for change and recommendations regarding the improvement of the delivery of a wholistic continuum of long-term care in First Nations.
- Build on the foundation of First Nations strengths, avoiding a deficit-based approach to change and/or transformation.
- Recognize and acknowledge that this report must be tentative in nature – every opportunity for change must be questioned, reviewed, and carefully considered by the First Nations affected before any decision-making.

The authors of this report offer these 'opportunities for change' with much humility, attempting to gather the voices of community engagement participants into a strong and vibrant chorus.

Each of these major areas are explored by summarizing engagement participants' input. Participants' insight into their lived experience in facing the numerous challenges, as well as their communities' strengths that have assisted them in sometimes finding solutions, provide a foundation for pathways forward in creating options for the elimination or substantial reduction of these challenges.

The need for change is urgent. Again and again, participants urged immediate action to resolve crucial issues that are reducing life expectancy in FN communities. At the same time, engagement participants expressed very serious concern that communities – including those most in need of LTCC services, as well as their families and caregivers – must be engaged throughout the change process. There was a general consensus that without such engagement, the relationships necessary to support those most in need would not develop, and the community need would continue to grow.

Section 4:
Governance & Policy

Currently, two programs at Indigenous Services Canada mainly deliver long-term care services and supports: the Assisted Living Program managed by the Education and Social Development Programs and Partnerships (ESDPP) sector and the First Nations and Inuit Home and Community Care Program of the First Nations and Inuit Health Branch (FNIHB). (SK- FSIN, Katenies Research & Management Services, 2022).

The above-noted quote from the guidelines for the community engagements which inform this report, suggests that a thorough understanding of these two programs might be sufficient for First Nations communities to address the needs of those individuals and families experiencing increasing dependence and/or chronic illness and disability. Instead, engagement participants reported substantial challenges in navigating and coordinating complex and confusing eligibility criteria, jurisdictional issues, and policies reflecting community contexts and resources not relevant nor available in many First Nations communities, and with no roadmap or guidance.

Participants described a complex regulatory web, intersecting at various points dependent on treaty stipulations and negotiated settlements, bi- and tri-partite agreements developed with provincial/territorial governments and various First Nations representative bodies, and the overarching

Indian Act itself. Regional health authorities, hospitals and emergency services, health and allied professional bodies, as well as licensing and accreditation bodies all contributed to layers of rules and regulations for the delivery of care, reflective of the lack of an overall governance and policy framework. Engagement participants identified that rarely, if ever, did these various governing components come together cohesively; rather, participants found that regulatory bodies and program funders tended to operate within 'silos', with sometimes insurmountable walls to climb to obtain crucial services for an individual or family.

> *We have to connect the programs ourselves. Most of the programs are patchwork. (National Validation Participant, 2023).*

Community engagement participants identified four major areas related to the governance and policies of Long Term and Continuing Care (LTCC) in First Nations communities that must be addressed in the development of services responsive to community needs:

- Decolonizing governance & policy of LTCC,
- Jurisdictional clarity and collaboration,
- Standards of care and accountability, and
- Flexibility to address First Nation diversities.

4.1 Challenge: Decolonizing Governance & Policy

> *We have been shamed. We have been taught that we don't have any authority to shape policy. The areas that we work in are disregarded. And some of the policies that we work in are meant to displace us. They are not meant to support us in our communities. They are not meant to make us comfortable in our own communities. (BC- Northern BC First Nations, CSFS, 2022).*

Engagement participants from across the regions expressed ongoing colonial attitudes remain a substantial barrier to providing First Nations-responsive LTCC in their communities and engagement reports describe policies which uphold colonial attitudes and agendas. Every community engagement report identified the need for decolonization and greater autonomy over the governance and decision-making of programs related to providing LTCC in a culturally safe and competent manner:

> *Participants at these engagements identified the need for decolonization, Indigenous control, adequate and sustainable funding to create Indigenous controlled, culturally safe, trauma informed and comprehensive wellness and care systems in Indigenous communities. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Some community engagement reports identified that colonialist attitudes are rooted throughout the decision-making and administration of LTCC with the resulting need for decolonizing attitudes and policies to extend to all the decision-making bodies, including provincial/territorial and regional health authorities.

> *Not all provincial/RHA partners include Indigenous perspectives in policy and program development, nor are they always willing, or able, to be accountable for the changes needed to enhance care. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Participants expressed that governments are reluctant to make policy changes that are in line with decolonization and reconciliation. As noted in Section 1 of this report (entitled 'Context'), there is a large body of research that demonstrates the trauma First Nations members have experienced, and continue to experience in their lives: the historical trauma resulting from the loss of lands and territories, their economies and social impacts together with the intergenerational trauma of residential schools, and the current traumas experienced by many members due to environmental crises such as flooding, forest fires, community displacements, suicides and addictions – have resulted in complex traumas with multiple layers. Policies which ignore these realities re-traumatize and fail to meet the needs of First Nations communities across Canada.

With respect to the Adult Foster Care component of Assisted Living, insights from engagements include the following: - Due to colonization and ongoing and intergenerational trauma, Indigenous families continue to be over-represented in the child welfare system. The program needs to be renamed as the program title is triggering and degrading. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Program titles, such as 'Adult Foster Care', are one of many examples of how language within current policies perpetuates feelings of shame and distrust towards the current system and deters individuals from seeking much needed services.

Engagement reports illustrated the contradictions inherent in guiding documents for LTCC service delivery on reserve. Proscriptive social development does not foster the development of a wholistic continuum of care.

The proscriptive, inflexible, and colonial nature of The Social Development Policy and Procedures Handbook BC Region (Volume 2), which is the "on the ground" document that currently governs administration of LTCC services on reserve, stands somewhat in contrast to the document A Holistic Continuum of Care: Guide for Engagement Discussions on Long Term Care. That guide, prepared in 2021/2022, makes clear its intent to "not be proscriptive" . (BC- Northern BC First Nations, CSFS, 2022).

Throughout the engagement reports, participants again and again stressed the importance of applying an Indigenous lens to all aspects of LTCC planning, development, and delivery, and consistently expressed the imperative of providing culturally safe, trauma-informed care based on an Indigenous worldview. Participants also stressed that successful program development resulted from greater community control.

In sum, the current governance and policy structure reflect colonialist attitudes that are not easily addressed through minor modifications to the current system. The engagement participants indicated significant change is required in the governance and policies of LTCC to address the disparities arising from the lack of autonomy, discrimination and 'shaming' that has arisen from colonization, and ground LTCC service and delivery in a culturally safe, trauma-informed environment with culturally competent service providers.

4.2 Path Forward: First Nations-Led Governance & Policy

TRC Call to Action #18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the healthcare rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties. (2015).

The above-noted Call to Action of the Truth and Reconciliation Commission reflects the voices of the participants of this engagement, i.e., to recognize and implement the legal healthcare rights of First Nations, in part, by establishing a First Nations-led LTCC.

Treaty Right to Health is a basket of protected services. (National Validation Participant, 2023).

Participants identified policy handbooks along with numerous other documents for program delivery that almost completely ignored the small, rural and remote nature of many First Nations, and used language that reflected biases and discrimination of Indigenous peoples.

The recommendation that a First Nations organization provide overall leadership to LTCC was perceived to be fundamental to achieving cultural safety in the planning, development and delivery of care. As phrased in one community engagement report, the current system needs a major overhaul:

Review and adapt all program and related policy, rules and procedures materials to ensure cultural safety and to reflect First Nations' realities.

> *The revision of such materials, according to the engagement participants, must go hand in hand with training for federal, provincial and health authority managers and staff to ensure implementation. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

As participants pointed out, the benefits of self-determination are supported by abundant research:

> *Research has consistently demonstrated that self-determination in health policy and program development, along with incorporation of Indigenous culture, language, knowledge, and traditional healing have positive impacts on health and wellness among First Nations. In fact, self-determination is one of the most important determinants of Indigenous health and wellbeing. (Reading & Wien, 2009, as quoted in a MB- FNHSSM, 2022).*

Further, such leadership is required to ensure the development of programs and policies that respect Indigenous knowledges and perspectives, and to ensure that services are provided in a culturally safe manner:

Long-term care services to be either led by First Nations or by a First Nation agency selected by the First Nation, respecting and acknowledging the uniqueness of each Nation, their strengths, people and innovation. This is required to build trust and to ensure that culturally safe and culturally appropriate services are provided (ON- Nokiiwin Tribal Council, 2022).

> *The First Nation is most informed about needs, challenges and gaps in their community. (ON- Nokiiwin Tribal Council, 2022).*

Participants identified cultural safety and the cultural competence of service providers as foundational to all aspects of LTCC in First Nations.

> *Culture and language are foundations. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Participants described an Indigenous wholistic approach which encompasses a broad range of factors contributing to their assertion that First Nations-led LTCC governance, planning, development, and delivery was crucial. One community engagement report described the elements of a wholistic approach:

- A*ging well: achieving holistic health and wellbeing (spiritual, mental, physical, emotional)*
- *Maintaining connections (to family, community, culture, spirit, identity, the land, intergenerational connections)*
- *Revealing resilience, humor, and a positive attitude*
- *Facing challenges*
- *Care is collective approach, responsibility of family and community*
- *Care is multidimensional, with a greater focus on adaptation, meaningfulness, and connection*
- *Focus on social determinants of health and environment as contributing to challenges*
- *Identity not necessarily defined by disability*
- *Focus on strengths & positive attributes, uniqueness; "disability" is a natural part of being*
- *Embraces and values differences and diversity: persons with differences recognized for their contributions, rather than for their impairments. (MB- FNHSSM, 2022).*

4.2.1 LTCC Framework Co-Development (ISC and Assembly of First Nations) Process

> *Co-develop a distinctions-based Indigenous Long-term and Continuing Care Framework to ensure Indigenous Peoples can receive these services in or near their own communities and bolster Indigenous health system navigators to provide dedicated support for Indigenous people and their families to navigate services related to long-term and continuing care. Minister of Indigenous Services and Minister responsible for the Federal Economic Development Agency for Northern Ontario Mandate Letter, December 16, 2021.*

At the concluding event of this series of community engagements, held in Bawaating (Sault Ste. Marie, Ontario) February 22-23, 2023, to review a draft of this summary report and validate its findings, ISC representatives advised that a process between ISC and the AFN was underway to co-develop a new framework for long-term and continuing care in First Nations, with an anticipated conclusion of August, 2023 (barring unforeseen events such as an election). The introduction of this new information at the final step in the community engagement process necessarily limited the discussion of its implications for LTCC. Participant comments, however, together with earlier observations regarding self-governance which occurred at the community engagements, provide some guidance for the process of co-development, particularly as it pertains to respecting the multiple diversities of First Nation communities.

Engagement participants throughout the regions asserted that First Nations-led initiatives were most capable of creating culturally safe care, an essential component for communities where historical, intergenerational and other forms of trauma are continuously present. Although community engagement participants were quick to point out the diversity of cultures, all of the community engagement reports identified that Indigenous ways of 'knowing and being' were key strengths in the delivery of LTCC.

During the engagement process, including at the validation gathering, two key factors were identified by engagement participants as crucial to a successful co-development process aimed at establishing a FN-led LTCC program:

- All First Nation communities must be engaged in the co-development processes, including those not affiliated with AFN, such process will respect and accommodate the autonomy and diversity of each.
- The co-development process must respect and accommodate negotiated structures and agreements that are already in place (e.g. treaties, bi- and tri-partite agreements, First Nations Health Authority (BC-specific) etc.).

4.2.2 Engaging All First Nations in LTCC Decision-Making and Planning

> *Not all First Nations belong to the AFN – this must be taken into account, and those non-AFN communities must be engaged in the co-development process. (National Validation Participant, 2023).*

Engagement reports indicated that self-determination in planning, developing, and delivering LTCC is already in process, with individual First Nation community efforts appearing at various points along the broad spectrum of autonomy. The engagement reports also identify that First Nations have undertaken the self-determination process in the way in which their leadership have determined best suits their culture, history, and context. This is reflected in a diversity of approaches to working with federal and provincial/territorial governments in the work towards greater control and autonomy over planning, decision-making and implementation of LTCC service models.

> *It is essential to also recognize the uniqueness of each Nation, their strengths, people and innovation. While it is possible to learn from other communities and try to implement similar programming, care must be taken to ensure there is not a one size fits all approach. (ON- AIAI, 2021).*

The 'not a one size fits all' approach, and greater autonomy in responding to individual First Nation community needs was identified again and again as

crucial by engagement participants. This included a strongly stated need for individual First Nations to be able to **self-identify with 'clusters' of communities**, and pointed out the success of such partnerships. For example, by partnering with other First Nation communities to build facilities for increased levels of nursing care, or to provide more in-community services:

> *The 11 self-governing First Nations have far greater capacity to attend to in-community needs than the non-self-governing three… although there are differences in First Nation community and Citizenship size among the self-governing First Nations as well. (YK, Yukon First Nations, NGI, 2022).*

Engagement participants asserted that First Nation members are in the best position to make decisions and provide care as they are the most knowledgeable about the complex care needs in their communities. They provided several successful examples of how communities are already dealing with complex health issues in ways that address community needs and that can serve to inform developing and improving LTCC programs:

> *Nimoyo et al, (2020) present a plan for community mental wellbeing which has been implemented in five First Nations communities in Ontario with success. This program is rooted in self-determination and is developed for the Nation by the Nation. Additionally, the program is rooted in culture, in relationships to one another and the land. This program provides an exemplar of rethinking mental health and addictions. (ON- AIAI, 2021).*

Participants identified that the recent COVID-19 pandemic provided evidence of the success of community-led initiatives when greater control of resources was allocated to First Nations in Ontario to address the emergency situation:

> *The Ontario Auditor General's response to the pandemic notes' success in response for Indigenous communities came from the collaboration and work within communities. Further, the report notes the ability to respond quickly without being required to deal with the same levels of red tape as government agencies, provided for quick, community specific responses. This serves as a perfect exemplar of self-determination in action, along with positive outcomes. (ON- AIAI, 2021).*

Further, engagement participants stressed the **benefits of bringing communities together** on a regular basis to share knowledge and experience, identify solutions to gaps/challenges and provide advocacy and awareness.

> *Bringing together the Home and Community Care workers every year to allow them the space to share their success and failures in the community allows the program to grow within the First Nations by learning from each other. (ON- Matawa, n.d.).*

Participants also stressed that such gatherings should not be limited to LTCC staff alone however, and encouraged gatherings that could include other long-term care providers, primary care teams that provide services in FNs, and representatives of various departments and levels of government.

> *Strengthen communication, collaboration and partnerships between local First Nations governments, [and] between the provincial government, and the federal government. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

4.2.3 Path Forward: Data Collection, Ownership & Confidentiality

> *Partner collaboration is critical to ensuring the long-term use of communication mechanisms and service agreements. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

One of the areas of particular concern for participants in the community engagement, was the protocols and sharing of information, particularly in new government – First Nations agreements regarding health care and LTCC. Recommendations regarding these matters include:

> *Facilitate new partnerships and information*

sharing. Information from user files is not always transferred efficiently between the various service providers serving people with decreasing independence, which can cause delays in service delivery. People with decreasing independence may have complex care pathways including in-home care, hospital stays, episodes requiring caregiver support, etc. The challenges associated with sharing information on the needs of people with decreasing independence create gaps in the continuum of long-term care and services offered and mean that functional autonomy assessments must be repeated by professionals in both the community and the Quebec health and social services network (RSSS). (QC- CSSSPNQL, FNQLHSSC, n.d.).

Increase training and awareness of handling of data, health data, confidentiality, and the circle of care needed. Confidentiality – Personal Health Information Act (PHIA) and Freedom of Information and Protection of Privacy Act (FIPPA) and current policies within First Nations that align with these legislations such as confidentiality forms; information and data sharing within and outside the community for program use and service delivery; and community concerns. (MB- FNHSSM, 2022).

Engagement reports identified a number of issues to be addressed in developing protocols and agreements:

Access – who is setting up data systems and who has access, release of information including to family members for advocacy and concerns about family dynamics, third party access with particular concern for use by intervention entities, information and data should always be returned to the community, and individual/patient rights to their own information.

Storage – where data will be stored and best practices for First Nations, including the processes, procedures, and protocols, for doing this, including systems backup; First Nations capacity to store data (hardware, software, and human resources); and the role of Assembly of Manitoba Chiefs (AMC), Manitoba Keewatinowi Okimakanak (MKO), Southern Chief's Organization (SCO) in data storage.

Data use – how to ensure care is being provided to loved ones and needs are being met; advocacy including evidence base to identify and address barriers; evidence base for decision-making; planning including discharge planning; conducting research and surveillance, for example, testing protocols during the covid-19 pandemic; and regular reporting.

Data collection – patient data including that collected by facilities outside of the community and lack of data sharing and communication.

Identifiers – status numbers, date of birth, client numbers, and the different challenges and benefits presented by these and other identifiers including disaggregation of data by First Nations, Métis, and Inuit. (MB- FNHSSM, 2022).

4.2.4 Respecting Structures, Agreements & Planning

At the February validation gathering, participants expressed concern that the co-development process currently being undertaken needed to acknowledge and respect the numerous negotiations, planning and agreements that have already been established to address LTCC.

Regionally, and sometimes individually, FNs have made strong efforts to achieve greater self-determination through a variety of negotiations, including embedding health governance in a number of structures. Reflecting the diversity of histories, cultures and contexts of FNs, such negotiations have, for example, resulted in a number of 'new' treaties (BC), tri-partite agreements (Quebec), substantial long-term care planning (e.g., Atlantic region, Akwesasne, Nishnawbe Aski Nation, Association of Iroquois and Allied Indians (AIAI)) that have impacts for the co-development process. BC also has a First Nations Health Authority that provides specific services, particularly to northern and FNs reliant on boat and/or fly-in access that participants identified

as a key support to under-resourced communities. These efforts, in which many communities have already been engaged, must be respected and utilized in the co-development process.

The broader community engagement reflected in this summary report identified that FNs were not all in the same place on the spectrum of LTCC development for their members, and there is substantial diversity of communities as well – geography, access to transportation, varying cultures and languages, etc. – I.e., 'one size does not fit all', and substantial flexibility needs to be built into the overall structure to ensure that communities can respond to their individual needs.

4.3 Challenge: Jurisdictional Clarity & Collaboration

Community engagement reports identified significant areas of jurisdictional overlap, gaps and complexity that require greater clarity for the delivery of LTCC in First Nation communities, including:

- Federal-provincial/territorial divisions of responsibility,
- Children & youth – Jordan's Principle,
- 'Aged out' persons with disabilities, and
- On-reserve, off-reserve members & time limits.

> *Multiple entities are involved in the provision of funds, programs and services for home care, long term care, and Non-Insured Health Benefits (NIHB). This creates complexity for individuals, their families/caregivers and health care providers to understand what is available, what individuals may be eligible for and how to access care. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

The community engagement reports refer to numerous governing bodies involved in various aspects of LTCC resulting in a sometimes confusing array of policy and decision-makers, funding sources or 'pots', and reporting requirements that stretch the capacity of already over-worked staff. Engagement participants and reports identified that both federal and provincial/territorial governments deliver programs related to LTCC in First Nations, with substantial variance between regions depending on agreements between the two levels of government (e.g. Ontario's ALP).

A further lack of clarity was identified in the BC region arising from recent treaty negotiations. In a number of the community reports participants from **First Nations who have recently established treaties with the federal government were uncertain of their jurisdictional boundaries with regard to health programs and LTCC** jurisdictional authority, and even questioned their own participation in this engagement process.

Participants also noted that provincial governments have sometimes further devolved these responsibilities to regional health authorities (RHAs), including in BC, where a First Nations Health Authority (FNHA) has been established. This frequently results in difficulties in identifying which level of government is responsible for funding the service, and since the complex health needs of community members often require services from several providers, program administrators are often left with frustrating dilemmas.

> *We are caught between the two government systems--what is covered and not covered? (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Regional participants explained that service providers do not always know what is covered and what is not, a matter further complicated for communities which must deal with more than one provincial/territorial service provider. FNs struggle to navigate pathways for eligibility and funding between the differing levels of government, as well as a number of different programs.

Ambiguity regarding roles and responsibilities creates serious gaps and delays in care, especially for those at risk of "aging out" or other determinations of ineligibility. Transitional supports and mental health acts were specifically highlighted as challenges that stem from undefined roles and responsibilities.

Many of the measures implemented in the RSSS are not accessible to First Nations without an agreement, either because they do not meet the eligibility criteria (due to their place of residence) or for reasons of jurisdictional authority. This widens the service gap between First Nations and non-Indigenous people in Quebec. (QC- CSSSPNQL, FNQL-HSSC, n.d.).

Eligibility criteria is a unique challenge to Indigenous communities. Participants explained that jurisdictions have different levels of authority and restrictions for eligibility. This adds further complexity to service navigation, delivery, and funding and widens gaps between Indigenous and non-Indigenous populations.

With the complicated system of health care in Ontario, and the often arguments around whether the provincial or federal government will be covering costs of care, participants detailed the difficulties they face in accessing home care support when not in their First Nation. (ON- Nokiiwin Tribal Council, 2022).

Reports voiced concerns that this type of case management, which relies heavily on patient advocacy, leaves room for discretion and bias. Client advocacy takes a toll on staff who report that they feel burnout from the constant struggle to work around restrictive policies. It leaves people vulnerable who are unable to advocate for themselves or do not have someone advocating on their behalf.

Further, untangling jurisdictional issues in one instance does not often resolve future such cases:

Working around challenges with provincial legislation currently requires case-by-case solutions that rely on relationships with governments and partners rather than policies and accountability. (AB- Blackfoot Confederacy, IPHCPR, 2022).

The intergovernmental complexity creates challenges for smooth delivery of services and supports to all three communities [represented at one engagement session]. A thorough review of the jurisdictional impediments is needed with the goal of finding legal, policy and program alternatives that mean members from all three are given equal treatment and services. (YK- TRTFN, DDC, & DRFN, NGI, 2022).

Adding additional complexity to the overall LTCC 'system', is that provincial/territorial boundaries do not reflect First Nations territorial boundaries, nor do they necessarily reflect the closest service providers. Jurisdictional disconnects are particularly problematic in geographically remote areas. FNs in northern BC, for example, frequently find easier access to services governed by Yukon or NWT legislation due to their proximity, than travelling much longer distances within BC.

LTCC services provided to children and youth experiencing disabilities formed part of the engagement discussions, and jurisdictional challenges were identified by engagement participants:

There are interprovincial challenges where youth are involved. Again, very dependent on Whitehorse to address. MOU needed to work with some areas. Yukon and BC mental health Acts are different creating an inter-jurisdictional disconnect. Terrace is closest in BC when the Yukon can't be used due to capacity or jurisdictional disconnects. Logistical challenge is that Terrace is 16 hours travel time. Need to look about alignment through an MOU to enable Yukon to be more aligned with the requirements of the BC system. (YK- TRTFN, DDC, & DRFN, NGI, 2022).

First Nations in the 'Atlantic region' reported similar complex challenges in administering LTCC in four provincial jurisdictions which all have unique legislation, while being treated as a single 'region' by the federal government.

Other community reports indicated some engagement participants were uncertain which level of government and/or which program funded which

service. This confusion not only illustrates the complexities faced at the community level, they also resulted in some communities not accessing funding pots that could have addressed some of the unmet needs.

4.3.1 Path Forward: Establishing Jurisdictional Clarity

> *There are differences between federally funded home and community care program and provincial continuing care programs and services. While these programs may have some similarities (e.g. philosophy-to support people to remain home longer), they are not comparable in terms of capacity and range of services. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

There appears to be no **official guide for First Nations that clearly lays out what LTCC-related programs and funding options provided by all levels of government are available in any given region.** It would appear that this is something that must be learned 'on the job'. Engagement participants from all regions stated that **training in program availability and use was crucially needed, including training in the specific program requirements** of those most commonly used at both federal and provincial/territorial levels of government. Participants also suggested that jurisdictional conflicts and disconnects could be reduced and/or eliminated by **involving First Nations prior to revising or introducing new policies and programs:**

> *Reduce Jurisdictional Conflicts through First Nations engagement in program and policy development. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

Production of regionally specific guides, together with training on the various programs criteria and usage, and the active engagement of First Nations in program and policy development will require collaboration between different levels of government, as well as within departments and ministries to address current disconnects.

4.3.2 Services First, Jurisdictional Disputes Later

> *TRC Call to Action #3. We call upon all levels of government to fully implement Jordan's Principle. (2015).*

Throughout the community engagement reports, a common theme was how 'Jordan's Principle' has addressed jurisdictional issues as they relate to children. In February 2007 a complaint was filed under the Canadian Human Rights Act that Canada discriminated in the provision of services to First Nations children, and the implementation of Jordan's Principle was identified as a solution to jurisdictional disputes as part of this complaint. Following this, in December 2007, a Private Member's Motion on Jordan's Principle was passed in the House of Commons with unanimous support. The motion stated, "The government should immediately adopt a child first principle, based on Jordan's Principle, to resolve jurisdictional disputes involving the care of First Nations children." Despite the implementation of Jordan's Principle at the federal level, however, existing provincial legislation is still used today to deny necessary services for Indigenous peoples on reserves as the Canadian Human Rights Tribunal orders have no jurisdiction over provincial/territorial governments, thus the above-noted TRC Call to Action.

Several community engagement reports identified that the basic principle of "child first, jurisdictional issues later" should be extended beyond children to include people of all ages, thereby ensuring that access to all needed health services be addressed. In Quebec particularly, participants referred to the need to implement a proposed 'Joyce's Principle' to address systemic racism and ensure universality of care.

The establishment of Jordan's Principle and its importance to accessing services was identified by almost all engagement sessions as a key strength. Participants in community engagements repeatedly identified its value in ensuring access to a variety of services and equipment, though they also indicated that advocacy was frequently required to obtain benefits that Jordan's Principle guarantees.

Many of the current challenges with Jordan's Principle are long standing, involving multiple levels of government. An area at risk of getting lost is planning for youth aging out of care and planning for youth with disabilities. (ON- AIAI, 2021).

Jordan's Principle is a child-first substantive equality principle that Canada is legally obliged to uphold but 'aged out' adults between 19 and 64 remain unprotected, leaving service providers without options. Participants suggested that immediate collaborations were necessary to address the needs of youth and adults with disabilities, and that these could build on the benefits provided under Jordan's Principle:

Adaptation and bridging with Jordan's Principle - how certain aspects can be adapted for long-term care such as the funding approach but also to address individuals in that program who are aging out and require transition supports. Strategies to effectively bridge the programs and provide services like OT/PT to address needs that do not go away with age. (MB-FNHSSM, 2022).

Despite the many challenges, the engagements demonstrated determination and perseverance in finding ways to address these. One community described how it overcame the challenge of meeting the needs of adults who had 'aged out' of care:

One community was able to build a residential and long-term care centre (CHSLD) in their territory to offer services in the community for people with severe loss of autonomy. The construction of the CHSLD followed a long series of negotiations with the [provincial] Ministère de la Santé et des Services sociaux (MSSS). However, the ministry is now in talks with the federal government to have this funding refunded. (QC- CSSSPNQL, FNQLHSSC, n.d.).

4.3.3 Resolving On- and Off-Reserve Jurisdictional & Policy Issues

TRC Call to Action #20. In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples. (2015).

While participants unanimously stated that LTCC programs needed to be delivered on-reserve, they also identified that due to a lack of the full spectrum of health care and other services available to on-reserve FNs members, some members would require treatment, and sometimes residency, off-reserve. In many cases, if a FN member is **off-reserve for a period exceeding 90 days (e.g., convalescent care, or Levels 4-6 nursing care), then they are deemed to be living off-reserve and subject to provincial/territorial program requirements.** This policy often results in additional assessments being required, along with determination of eligibility, and can result in loss of access to on-reserve housing and services.

The Atlantic Region shared that the province of New Brunswick has an excellent Disability Support Program for personalized and flexible disability supports (ATL - Union of Nova Scotia Mi'kmaq, 2022) but this program is not available on-reserve.

Adults and children with disabilities living on reserve are denied access to these programs.

Although the denial of service is not explicitly stated in these two programs, they fall under the NB Family Income Security Act. This Act defines 'persons in need' and explicitly denies assistance to individuals who are residents of a reserve. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

One of the most significant themes that was voiced throughout engagement reports was the need for governments to focus on **equal access to health care as a human right.** Each region expressed in their own way the extent to which they do not receive equal access to services and care.

Existing provincial legislation in NS and NB is used to deny necessary services to individuals with advanced care needs living on reserve. This is discriminatory. Continuing Care nursing and home care policy provides client assessment and is available for acute conditions, but services for chronic conditions are denied for status First Nations people living on-reserve." (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Many other regions shared that there are large discrepancies between what is offered between nations within regions. Regional comparisons may be required to determine and better understand the diversity of inequalities expressed in these regional engagement reports. Of prime concern to participants is that **discrepancies be addressed and coverage of needed services be provided to all First Nations members, regardless of age, income level and/or residency,** and that provision of service be culturally safe and trauma-informed.

4.4 Breaking Down Silos

Remove silos by collaborating within federal departments and with provincial partners to enable seamless access to and use of the program by Indigenous partners. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Participants repeatedly called for a **removal of silos not only between jurisdictions, but also between departments of the various government departments involved in meeting the needs for LTCC in First Nations.**

This complexity requires First Nations to be extremely well informed and highly skilled to bring together the resources required to deliver LTCC in their communities. Once again, participants called for training and educational opportunities to share knowledge and experience, to engage with funders and program delivery agents at all levels of governments, and to interact with people employed and engaged in all aspects of LTCC governance, funding and care delivery.

Figure 4 *Vision for First Nation's LTCC Governance*

4.5 Clarify Accountability and Responsibilities

> *TRC Call to Action #19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services. (2015).*

The history and legacy of colonizing policies of assimilation and denigration of Indigenous peoples requires that First Nation communities have the right to self-identify with other First Nations of their choosing for the purposes of planning, developing, and delivering services and programs on the long-term care continuum. Federal, provincial/territorial governments need to acknowledge the right of First Nations to form collaborations in the provision of service and respect First Nations' right to exercise autonomy in establishing such 'clusters' for program planning, development and delivery.

Participants in the community engagements stressed that **FNs need to be engaged in establishing accountability criteria and standards of care for LTCC delivery, and such criteria and standards need to be rooted in FNs realities and worldviews.**

> *It is important to add the context of who's deciding on what the results should be. A worry on the technical side of funding is that there are often parameters established by funders (Federal government in this case). It is important for results and benchmarks to be established by the community and not the government". (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).*

Participants also stressed that **accountability back to communities needs to be built into LTCC programs and policies.** Engagement reports indicated that participants were concerned that reporting requirements stressed financial accountability but that benefits of care to service recipients were not sufficiently weighted. They stressed that accountability is not a one-way street, **and it means both accessibility and quality of care, as well as financial accountability**. Issues such as cultural safety in service provision needed to be evaluated as well, as this example points out:

> *The review of the ALP must address the challenges of having ISC be the group setting standards. The communities know what needs to be addressed and having outcomes decided by outsiders isn't right. It should be up to the communities themselves to decide what outcomes look like and how to collectively move towards successfully achieving those outcomes. If they're continuing to mandate expectations from the outside the community, there will continue to be challenges. (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).*

Engagement participants expressed frustration with the current system of accountability which, in their experience, seemed to privilege financial accountability over meeting community needs, and which omit such key components as ensuring cultural safety, and stressed that accountability needed to include ensuring cultural safety:

> *Formalize Accountability for anti-Indigenous racism and cultural safety in provincial health and social services. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

4.6 Conclusion

> *In addition to involving the partners in a process of governance of First Nations in Quebec, this [2019 tri-partite] Agreement aims to give them more control over the design, management and delivery of their health services and to advance cultural safety and self-determination for Indigenous peoples in health care. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

The community engagement reports showed unanimous support amongst participants for a First Nations led organization to coordinate the delivery of long-term care. Participants at the validation gathering of this summary report (February 2023) suggested that an ISC - AFN co-development of a framework for LTCC would require accommodation of non-AFN First Nations, recognition of treaties and other bi- and tri-partite agreements already in place, as well as planning and development efforts underway led by First Nations and/or FN organizations. Such a framework would also need to have the flexibility to accommodate substantial diversity across regions as well as individual FN communities.

Participants throughout the engagement process identified foundational principles (See Vision, p. 34) that could inform such a framework that would lead to a culturally safe, trauma-informed, wholistic LTCC in First Nation communities.

Engagement participants also identified a number of challenges that the implementation of such a Framework would need to address/overcome: jurisdictional issues and program silos in particular, and the need for a mechanism that provides two-way accountability from communities to funders/programs, and from funders/programs back to communities.

First Nations' participation in all aspects of planning, development and implementation of programs and policies were identified by participants as crucial to moving forward. Spaces for collaboration, training and education at all levels were seen as key to making a new model of LTCC be responsive to FNs individuals, families, and communities.

Section 5:
Funding

The most obvious priority that many community members identified is the need for increased operating and capital funding. Numerous examples were provided where insufficient operating funding was provided, not allowing for appropriate level of care services; capital funding was provided but then operating funding was not; operating dollars were provided for a period of time, but then not continued; and lastly, operating dollars have simply not been provided for key initiatives that the First Nation would like to offer, but has no access to funding to deliver the same. (ON- Nokiiwin Tribal Council, 2022).

At the validation gathering (February 2023) many participants expressed concern that a 'Vision for LTCC in FNs' could not be achieved without adequate funding. Throughout the community engagement exercises, participants consistently expressed deep frustration with funding inadequacies, inequities, and gaps, ranging from inability to attract and retain qualified staff to provide care, through to overcrowded and unsafe living conditions, and inability to access culturally safe, two-eyed seeing medical care.

The inadequacies, disparities and gaps in funding were further complicated by highly complex funding arrangements involving various levels of government and resultant jurisdictional disputes, as well as onerous administrative requirements. Lack of information and clarity about potential 'pots' of funding that might be available to communities acted as further barriers to obtaining funding for much needed services.

In brief, funding programs demonstrated a systemic bias against a decolonizing framework for LTCC delivery in First Nation communities. Participants consistently shed light on the multiple ways that funding did NOT reflect FNs' realities; instead, they called for a model of funding that would support a 'wholistic, culturally safe, trauma-informed, two-eyed seeing' approach which could promote health and address the underlying social determinants.

5.1 Challenge: Funding Inadequacies, Inequities, Gaps & Complexities

Funding inadequacies, inequities and gaps were identified by all regions as a crucial challenge to creating a wholistic continuum of care. Engagement reports describe funding arrangements that cause challenges across all levels of Assisted Living and First Nations and Inuit Home and Community Care programs.

> *We have lived under an envelope for many years that has not had enough money for First Nations to continually care for individuals from birth to death and that's the services our communities should be providing. (National Validation Participant, 2023).*

Additionally, concern was expressed that some programs were not fully funded for FN members:

> *Some provincial programs require a co-pay which is more than many families can afford. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Finally, there was general agreement amongst participants that the need for more adequate funding was particularly urgent in remote regions where all costs are higher, and where transportation costs to attend medical services and obtain treatment, are extraordinary.

5.1.1 Inadequacies of Funding

> *Funding levels of Assisted Living Programs have not increased since the 1990's despite increased demand. (MB- FNHSSM, 2022).*

The community engagement reports consistently documented the realities of First Nations including the historical, intergenerational, and ongoing traumas and their impacts. Stories shared by participants illustrate the widespread presence of poverty, below-standard housing, and numerous other social determinants of health. Yet the per capita funding formula for long-term care does not recognize these, nor does it recognize other indicators of health crises in First Nations communities: rates of chronic illness, earlier onset of illnesses; suicide, addictions and mental health impacts on families and their capacity to support other family members with increasing dependence; and the need for respite care for grandparents and grandchildren who are caring for each other.

> *Funding needs to address social inequities and health inequities. Can't assume that only elders are in LTC facilities as demographics have changed. You may see people in 20's in cancer ward or on dialysis. (National Validation Participant, 2023).*

> *It is hard to retain staff with lack of funding for equitable salaries and who will pay for the training? Once they are trained, we lose them to other facilities due to wage parity. (National Validation Participant, 2023).*

Further, the funding formula neglects to account for the lack of community infrastructure, the remote locations and therefore increased travel costs of many communities, and the need for 'two-eyed' seeing approaches to health care delivery.

> *The National Table for Jordan's Principle (child welfare) has not changed over 35 years. We are always fighting for children's rights. Urgency is needed in this program. Funding structure and community are still in poor conditions. (National Validation Participant, 2023).*

Participants shared that funding continues to be inadequate for children in need of LTC, highlighting the critical urgency of increasing funding.

Participants in engagements highlighted the principle of inclusivity of needs. Funding allocations currently do not cover the diversity of needs in Indigenous communities as illustrated by challenges in service delivery. Members of nations understand the needs of their communities and should be part of the process in determining funding allocations.

> *There is some funding via Non-Insured Health Benefits (NIHB) but it is insufficient. For example, a resident needed a wheelchair and the one they had was too small. NIHB would not pay the $5,000 required for a properly fit wheelchair. (SK- FSIN, Katenies Research & Management Services, 2022).*

Furthermore, challenges arise when families are required to copay for services that can add up to thousands of dollars as described by a participant at the national validation workshop (2022);

> *Usually, people with dementia get pushed into the LTC arena which pushes it to the provincial basket. The patient is removed from reserve because we don't have special care for level 4, 24/7 care. Keeping that in mind and cost associated with it. I know from going through it myself with a family member in the north, it costs me about $25000 out of pocket that year, and I was a good navigator. But what about that person that doesn't have a job or that family-based support. Our family dynamics have changed and sometimes you can't provide a safe place within the community, so they are pushed out. It's the same in Nunavut dealing with the same issues we dealt with 10 years ago as they are just starting the process. You need to look at the funding of your health system themselves. Health transfer agreements with federal government need to be updated to the demographics of today. Economies of scale type funding. Capacity issue is why you need appropriate funding. (National Validation Participant, 2023).*

> *A related issue is that federal government data lags 3-5 years and do not reflect current population figures. (MB- FNHSSM, 2022).*

Provinces use population and health data to obtain funding transfers from the federal government which affects accuracy of funding assessments. The current reality of First Nations and Inuit Home and Community Care and Assisted Living Programs in 2023 is vastly different than it was in 2019 as the pandemic stressed an already weak system. Many elders are now more reluctant to go to LTC facilities so funding priorities need to shift quickly to reflect their increasing preference for at home care.

> *Data management is a big issue. Health information systems are needed along with data sharing agreements. This is a big challenge. It is difficult to forecast need without accurate data. We need to know the health data trends in First Nations in order to estimate the care needs of the future. (SK- FSIN, Katenies Research & Management Services, 2022).*

A lack of Indigenous specific data compared to general population data has been a longstanding funding challenge, particularly given the strong reliance on per capita funding models. Funding remains an ongoing barrier to Indigenous focused research. Furthermore, under-reporting affects accuracy of data that is used to determine funding. It is difficult to reflect needs when so many conditions go undiagnosed yet still require services.

Many participants emphasize the need to plan for growth within LTC. One participant summarizes below their concerns for repeating this engagement process to address the same issues in the future as LTC capacity continues to lag behind demographics and population growth.

> *This needs to go further and address growth because if this is successful as it is, all of us are going to be back here in 10 years unless this starts to address the actual growth in communities and start saying there needs to be a roadmap with direct route to expansion. Like the program HCC, which is this 10 years ago, but it was reviewed and it still has the same problems. Unless this will be the norm that we*

come here every 10 years to address a dying population. (National Validation Participant, 2023).

It was shared that FN communities desperately need funding that goes beyond 1 year. Not only does it cause delays and create more work for already overworked staff, but it creates more complexity and frustration.

Why dangle the carrot at them for a year of funding and now pulling back programs and ripping patients out of communities. Very backwards and frustrating. (National Validation Participant, 2023).

5.1.2 Inequities in Funding

Regions pointed out large discrepancies in funding between the amounts provided by the federal government to First Nations to care for individuals in their communities, vis a vis amounts provided by the respective provincial government for similar services provided in non-First Nations communities. For example, Saskatchewan reported that the funding is $1600 per client in First Nations communities compared to $3000 for individual residents elsewhere in the province (2022). This rate has not increased in 20 years despite increasing costs of living and service delivery. Indigenous communities are left having to do more with very significantly less. Other regions noted similar discrepancies:

According to some participants, these monies are not enough to support their living costs. Some participants stated that there should be increased financial or other supports to help them better manage daily costs and increased care costs including transportation services to health care appointments, home maintenance and nutrition costs. (ON- Nokiiwin Tribal Council, 2022).

Participants also noted significant disparities in funding. Disparities were noted between per capita funding provided to First Nations ($1500-1600) versus rates provided to non-First Nations (ranging from $3000 in Manitoba to $4500 in Ontario/BC). Wage disparities between 'agency nurses', i.e, nursing staff who were provided by external agencies were paid at significantly higher rates in many regions (particularly in more remote communities) than nurses resident within the FN community itself. Such disparities discourage FN health care professionals from remaining in their communities, and is a constant source of frustration to administrators.

Funding levels must be re-evaluated to sufficiently meet needs and [address] systemic limitations, shortfalls, and inequities. First Nations are funded federally for levels 1 to 3 [nursing care]… however, they are not funded for levels 4 and 5 clients though the province is. Home care programs are currently underfunded. Matters of geography must be considered and accounted for. (MB- FNHSSM, 2022).

Furthermore, participants at the national validation workshop expressed concerns regarding the real costs of delivering long-term care.

Need to see the real costs based on quality long-term care. We get funded less than the province but need to be funded at the real costs especially for northern and remote where costs are even higher than southern communities. (National Validation Participant, 2023).

Inequities in funding lead to scarcity of resources, including human resources. Participants described how provinces get grants to gain more nurses with conditions that they work in the health care system, so then they can't come back to the community. FN communities need incentives to attract nurses. It was also highlighted that a total lack of funding for infrastructure contributes to challenges with attracting and retaining nurses as suitable housing is limited. (National Validation Workshop, 2023).

5.1.3 Gaps in Funding

> *As the largest reserve in Manitoba, there are gaps in funding processes that need to hurry up and happen. Processes take too long, and people are suffering. We want standard of living like anyone else. People are still suffering. Especially adults with disabilities. Our people are worth it so let's hurry up with these processes. We have suffered enough. (National Validation Participant, 2023).*

Significant gaps in funding forces individuals to leave their communities which is a deterrent to FN members in need of care. Many elders or individuals living with disability would rather stay in their communities with loved ones than receive necessary care, resulting in delayed treatments and exacerbating health conditions. Gaps in many communities included little or no respite care, lack of levels 3 and 4 nursing care including no convalescent beds, no palliative care. Many communities had no access to in-community dialysis which some participants reported as leading to shorter life expectancies.

> *We do not institutionalize our elders. But there does come a time when people can no longer live in their homes. (National Validation Participant, 2023).*

> *There is a big concern for elders who have Level 3-4 needs who chose to live at home [instead of relocating outside of community]. Costs for their care are often refused. They usually have to a sign waiver form if they want to stay at home. There are many risk factors for these clients. They are hard to track because they are often not reported. (SK- FSIN, Katenies Research & Management Services, 2022).*

> *We don't have LTC in our province. We don't have any increases in our funding to prevent people from going to nursing home and leaving communities, especially for those that do not have AL or LTC nearby. (National Validation Participant, 2023).*

While many communities work to gather funds to build LTC facilities, other communities struggle to fund already built facilities as there is no funding for ongoing operations and maintenance.

> *They had a LTC facility built but had to convert it into family units because they didn't have sustainable funding. You can build infrastructure but if you don't have sustainable funding, can't stay open. (National Validation Participant, 2023).*

This community now grapples with the visible building as a reminder of the short lived LTC facility that they were once so proud to open and operate while simultaneously grieving the loss of their community members and elders who now must move away from their communities because of the closure.

A participant at the National Validation Workshop (February 2023) shared the roadblocks and frustration they currently face with funding their 18-bed facility that opened in 2018 in Fort McKay, Alberta.

> *Our Chief and Council partnered with other folks and built an 18-bed facility. Since opening, it has received ZERO funding from provincial or federal government. The reasons are absurd. The McKay reserve is unusual- within the reserve proper, there were little pockets of land that are under municipal jurisdiction, but it has taken time. It is not eligible for funding because it is now on reserve.*
>
> *There is no category at ISC in its Capital Asset listing for which the long-term care facility qualifies. We know the building exists but can't give it the classification to make it qualify so you get nothing. That is absurd. There is a further condition with ISC funding where any building where people stay overnight, they become ineligible for funding, but they require 24/7 care. It is crazy making, and it shouldn't be. (National Validation Participant, 2023).*

Many participants in the funding sessions at the national validation workshop echoed similar challenges they face with a lack of sustainable funding for LTC facilities.

Another community finally got the money to build and how will that be sustained to have the support to continue for years to come. You shouldn't have to apply every year for funding to operate the facility. There should be sustainable funding to the community needs. (National Validation Participant, 2023).

Funding challenges were echoed throughout engagement reports. According to ONWAA & NORDIK (2022), inadequate and/or lack of funding has resulted in serious risks to service delivery including:

- Lack of consistency across the province in meeting clients' needs for range/type of services.
- Lack of office space & equipment to ensure confidentiality.
- Lack of training in such things as Health & Safety, Gentle Persuasion Approach.
- Inability to provide needed services such as client education on self-care.
- High turnover of staff, resulting in unfilled positions and lack of consistent care.
- Increasingly high costs of transportation limits services.
- Inability to provide education to clients and caregivers on essential self care such as dietary requirements.

Engagement reports listed many additional under or non-funded service areas including foot care, detox and additional treatment, traditional medical practitioners and medicines, mental health/social work, land-based healers, interpreters, youth coordinators, elders' coordinators, food preparation and delivery, safety checks, home renovations, and wood chopping.

Funding, as mentioned around the table, needs to include service agreements for professional services. For communities that are forced to go off reserve, there are long distances to get professional services so there needs to be funding for that transportation. (National Validation Participant, 2023).

Participants unanimously agreed that funding need to address all issues not just some. For example, one community received a $10000 dialysis machine to keep people at home, yet it remained unused as they did not have trained staff to operate. (National Validation Workshop Participant, 2023). This further illustrates the need for sustainable funding that goes beyond capital costs and factors operating costs.

5.1.4 Complexity of Funding Arrangements

Community approaches to address complex needs are constrained by existing federal program silos and program requirements. This work is supposed to be about creating a more wholistic system, not taking a program-by-program approach. But the federal programs are what informants know best and work from. It's challenging for participants to 'redesign' this complex system. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Community engagement reports identified funding inadequacies, disparities and gaps combined with cumbersome and numerous reporting requirements as posing significant challenges to service delivery. Successfully applying to numerous funding 'pots' in order to meet the identified community need for service resulted in loading program coordinators/ administrators with almost overwhelming workloads.

Many engagement reports explained challenges that arise from the governments program-by program approach to funding. Participants described the current system as operating in "silos" and felt limited in their abilities to collaborate between programs.

A comprehensive care continuum cannot be created because program funding is added over time, not directly provided based on assessed needs and a proposed systems model. Often, too, funding is designed to meet an immediate front line service need. However, as funding grows, communities have identified big gaps in the supports, processes and infrastructure needed to implement front line service systems effectively. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Funding allocation has been focusing on front line and crisis management particularly since the start of the pandemic. More funding has been provided over the last few years, but additional challenges arise when infrastructure and systems have not expanded enough to support growth.

> *A key aspect of funding inadequacy, as detailed by engagement participants, is the lack of funding for the administrative costs, a gap which has placed service delivery at serious risk due to the staffing implications. This lack of funding jeopardizes adequate compensation to recruit and retain staff; the capacity to provide training in emerging issues such as increased dementia amongst clients; and the ability to ensure confidential services to clients. (ON- ONWAA & NORDIK, 2022).*

Human resources challenges are difficult to resolve in the short term as solutions require long-term investments in educational and operational infrastructure. With funding maxed out and demand for services on the rise, funding solutions that meet the diversity of needs within communities and the system are urgently needed.

> *Staff face a challenge in that people think the Band pays for everything, yet they apply to ISC or sometimes FNHA on behalf of Band members for payment. I'm the middleman and have to fill out all these forms and do all this work to secure the amount of funds that do not come with service delivery dollars." (BC- Interior, Naut'sa mawt Resources Group, 2022).*

> *Participants reported challenges accessing various funding pots for home support services. The provinces wait for funds from the federal government before they can pay the Nations. (BC- Interior, Naut'sa mawt Resources Group, 2022).*

Participants also reported challenges with receiving and processing payments. There are numerous funding arrangements that are very complex. Nations end up covering costs and repayments are delayed. It creates administrative issues and further delays.

In some regions, automatic payments for clients' increases are no longer available and applications have to be redone annually. Payment processes are further complicated by invoicing processes of service providers. For example, some hospitals will direct bill ISC only requiring the First Nation member's status card number, while others require that the First Nation pays the hospital invoice and then obtain reimbursement through ISC thereby increasing administrative workloads for the First Nation. One First Nation from Saskatchewan shared that they were getting billed for on-reserve home visits that were never done, which highlights ongoing challenges with accountability (SK- FSIN, Katenies Research & Management Services, 2022). Nations end up covering costs and incurring deficits in budgets due to delayed payments.

> *It is frustrating because we have First Nations Health Authority who deal with LTC but not Assisted Living. We have total disconnect. People on the front line say very clearly funding is insufficient and processes are 14 pages of a form that haven't been revised since the 80's. Frustration is through the roof. Operational funding is dysfunctional. From strategic declaration of rights, here in BC, all are completely out of alignment. (National Validation Participant, 2023).*

The complexity of funding arrangements is further exacerbated by policies that frequently restrict funding to specific priority areas set by the funder, but that do not necessarily respond to perceived community priorities. Mental health and addictions funding was given as one example of funding that is restricted for programming use.

Eligibility criteria, sometimes requiring that individuals demonstrate financial eligibility, others that require medical documentation from professionals not located on reserve, can also cause challenges to access appropriate care. Participants noted that not all individuals requiring care were able to obtain all the necessary documentation, nor go through onerous and sometimes lengthy processes to 'prove' their eligibility.

Participants talked about the difficulty in receiving funds where eligibility criteria was cumbersome or limited. Participants shared that funding can be restrictive and dependent on whether or not you live on reserve (Ontario Nokiiwin Tribal Council, 2022) .

In sum, current funding levels, inequities, gaps and complexities are failing to address critical community needs in LTCC. Further, this funding failure is forcing FN members to relocate off-reserve, sometimes hundreds of kilometers from family, community and cultural support in order to access necessary levels of care. As many participants pointed out, this is not the health care guaranteed to them under treaties, United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and other agreements.

> *There needs to be clear funding guidelines from provincial to federal government. (National Validation Participant, 2023).*

5.2 Path Forward: Decolonizing Funding Policy

> *Demolish the financial board. AFN is in a position to open that door. Institutional racism is in plain site. (National Validation Participant, 2023).*

> *The residential schools took people out of their homes as a child and then at the need stages they are taken out of community for the end stage of their life. So, I say we keep them home. You took them once; you are not taking them again. Advocacy goes hand in hand with funding. (National Validation Participant, 2023).*

> *Like colonialist attitudes, funding is not directed towards our people. (National Validation Participant, 2023).*

5.2.1 Path Forward: First Nations Led Funding Policy

> *The cost of support for one client using in-home services was estimated to be $4658.00 annually (2016) compared to the estimated cost of $80,819.00 annually for an individual living in a long-term care facility. (ON- ONWAA & NORDIK, 2022).*

Research evidence quoted in an earlier section of this report points out that there are substantial health benefits of supporting 'clients' to live in their homes for as long as possible. Several of the community engagement reports point out that the provision of in-home services also results in enormous financial savings.

> *All needs are urgent, and all needs are not getting enough funding, thus the impetus is on how to decide where to focus. Self-determination would support Nation to Nation conversations regarding funding and distribution of funding based on need. (ON- AIAI, 2021).*

Engagement participants identified the need for a transformative health strategy and planning to address the inequities resulting from the history of colonization and colonialist policies. Adequate funding and addressing significant gaps in funding is a foundational component of such a transformation.

> *I think it is really important that we find a place to root and serve FNs. The ultimate question is what is it going to take to build full self governance. It's going to take data and funding asks. (National Validation Participant, 2023).*

5.2.2 Path Forward: Adequate Funding to Support a Wholistic, Culturally Safe Continuum of Care

> *...strengthen and improve health governance structures to remove barriers, set direction through community-based needs, and allow for flexibility of resource allocation to enable transformative change towards wholistic life-long care for all. (ON- Six Nations Health Services, 2022).*

Participants pointed out that a First Nations-led governance structure for long-term care required adequate and equitable funding under the control of FNs, and that a wholistic, culturally safe continuum of care could not be achieved without many of the same foundational principles.

> *Ensure First Nations have autonomy in managing continuing care and associated funding. Independent management and funding mean that stakeholders in the continuum of long-term care have the necessary resources and freedom to act to offer services adapted to the actual needs of the people served. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

> *Expand funding to allow Indigenous partners to effectively create a more wholistic continuum of care. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

The wholistic continuum of care (encompassing spiritual, emotional, mental and physical health, from birth to death, and with access to both traditional and western medicine knowledges and practice) was identified in every community report as a prerequisite for cultural safety in the provision of care.

Funding must reflect the reality of First Nations culture, locations and access to service by providing culturally safe, trauma-informed, wholistic services. Further, First Nations comprise the majority of communities located in Northern and remote regions, often requiring travel to larger, non-First Nation centres to obtain care. Public transportation is not available in many locations, road access is sometimes limited to winter months or not at all, and many individuals do not own or have access to vehicles, placing the onus on First Nations to locate drivers and vehicles. Language speakers may need translators at medical appointments to ensure understanding of treatment and care. All this and more must be reflected in determining adequacy of funding.

> *Adequately fund culture, language (including translation services) and Indigenous wellness approaches. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Again and again, participants identified funding that supports cultural safety as a crucial component for promotion of re-ablement and illness prevention, and pointed out that land-based programs, access to traditional foods, gathering spaces to increase and improve social supports, were necessary parts of a LTCC program.

As outlined in the Governance Section of this report, participants were anxious to point out that FNs have already been active in their attempts to address funding, and negotiated agreements related to funding need to be respected in the planning and development of any new funding policy:

> *ISC funding should take into account the realities specific to the provinces and territories and adapt their funding distribution practices to the pre-established provincial and territorial practices. In Quebec, this means taking into account the decision-making process adopted by the First Nations. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

5.2.3 Path Forward: Equitable Funding

> *Long-term care is so different from non-First Nations and First Nations are always receiving less than others. (National Validation Participant, 2023).*

The current inequities in funding are discriminatory and need to be addressed immediately. As outlined in the 'Context' section of this report, First Nations members are at much higher risk for ill-health than

non-First Nations residents of Canada due to their experience of colonization and subjection of colonialist policies. Health promotion and prevention education and supports, together with trauma-informed and culturally safe care are key to mitigating some of these health impacts. Without equitable funding, such supports are not possible.

Participants identified serious difficulties in recruiting and retaining staff due to wage disparities between service providers. Communities valued the increased funding for wages made available during the COVID-19 pandemic to increase staff wages, as well as the benefits inherent in such an increase, i.e, greater wage equity between First Nations' staff and staff employed in similar positions in other regions:

> *During the pandemic, the MSSS increased the wages of health professionals who work with users. To offer a comparable increase, the ISC provided additional funding for the Assisted Living Program and FNIHCCP. This allowed these programs to increase staff wages. Parity - it also allowed health care workers to receive the same recognition as their peers in other provinces. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

Community engagement reports echoed the call to address disparities:

> *Address wage disparity experienced by on-reserve staff. (MB- FNHSSM, 2022).*

Funding for project-specific time frames, without possibilities of establishing permanent and ongoing funding, even when the projects demonstrated their value, was an area of particular concern for a number of participants. Once again, collaboration with FNs in resolving these concerns was identified as key to addressing the need for fairness and equity in funding programs and policies:

> *Ensure the allocation of funds is stable, fair and sustainable, while taking into account the context and needs of each community. Funds should not be allocated on an ad hoc basis or as a result of calls for proposals and should meet the needs of the communities. Resource distribution formulas should account for the factors identified by and for the First Nations, such as each community's situation (geography, demography, specific structural characteristics, etc.), inflation, the aging of the population, the needs of people with decreasing independence and the general health condition of the First Nations. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

5.2.4 Path Forward: Funding Wrap-Around Continuum of Care

Engagement participants, as noted earlier, consistently identified that FNs' members experiencing increasing dependency need a range of programs and options in order to remain in their homes and communities. Participants acknowledged that not all medical care can be delivered in-community due to community size, but they also identified that funding to support in-community LTCC required much more than is currently available.

F**unding for health promotion and prevention as well as re-ablement approaches** were mentioned by many, approaches which would reduce higher health costs. For example, dietary control of diabetes extends life expectancy and reduces overall health care costs. Community reports identified numerous ways that funding could better support in-community care by filling gaps.

- **Palliative care, respite care for family caregivers and Level 3 and 4 nursing care** were frequently unavailable to persons living at home.
- **Payment for traditional care including medicines, healers and ceremony such as smudging.**
- **Programs for preventative care such as dietary instruction for parents of children, or family members of diabetics.**
- **Social, cultural and land-based programs for elders to reduce isolation and promote mental health.**
- **In-community dialysis.**

Funding to support family caregivers, including providing respite care, would also contribute to keeping FN members in-community longer.

> *Increase funding for the Assisted Living Program and FNIHCCP to provide communities with the resources they need to offer support services to caregivers (e.g., the Government Action Plan for Caregivers (2021-2026) – Recognize to Better Support). (QC- CSSSPNQL, FNQLHSSC, n.d.).*

Several engagement participants indicated that more funding is needed for caregiving services, as families struggle to maintain employment while caring for ill family members.

Although the Non-Insured Health Benefits (NIHB) as well as some provincial programs are intended to address medical equipment and supply needs, numerous participants indicated that either they had been unable to obtain funding or alternatively the funding was insufficient. **Program funding must be sufficient to include necessary medical equipment and supplies, and services.**

5.2.5 Funding Gaps and Inadequacies for Infrastructure

Detailed needs identified by participants elsewhere in this report outline tremendous gaps and inadequacies and a need for substantial investment across all regions. Priorities include:

- Health and wellness centres, especially in northern and remote regions,
- Housing, both new builds and renovations and repairs, and to accommodate visiting medical staff,
- Facilities to meet diverse community needs including Levels 3 & 4 nursing care, beds for respite, convalescent and palliative care,
- Accessibility funding,
- Transportation,
- IT – improve connectivity and increase bandwidth, and
- Electricity and water.

(See the following section on Infrastructure for more details and *Path Forward*.)

5.2.6 Ending Funding Complexities

> *There should be better awareness of funding that is available. It is there but must dig to find it and their response is, "Oh you didn't know about that?". We need to work together as advocates. (National Validation Participant, 2023).*

> *Improve coordination between funding partners so there is only one overall budget envelope. The flexibility associated with having a single overall budget envelope means that service delivery is the priority and user needs come first. The costs will be covered by the appropriate program after the user has received the service. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

Funding complexities resulting from the multiple funding programs as well as a number of levels of government and/or separate departments/ministries are widespread. While overworked staff do their best to coordinate between the multiple funding partners, FNs members frequently experience delays in treatment and/or are forced to leave their communities. Action must be taken to end these.

Envelope funding would also grant First Nations greater autonomy and flexibility in allocating funding which could improve community-wide health, for example by providing more health promotion and prevention education, thereby improving health and reducing some service demand.

Another improvement suggested was one that is in place in some communities already:

> *Allow communities to have joint funding agreements for both programs if they so choose and standardize program eligibility criteria. (QC-CSSSPNQL, FNQLHSSC, n.d.).*

5.3 Conclusion

In conclusion sustainable service and program delivery relies on stable and adequate funding that reflects current needs. Inadequacies, inequities, gaps and complexities of funding arrangements add substantially to the workload of LTCC staff as they work to provide adequate care to First Nations' members experiencing increasing dependency. To adopt a decolonizing approach to LTCC requires a complete overhaul of the funding processes to better reflect the community needs arising from colonization and colonial policies.

The inadequacies, inequities and gaps in funding need immediate and urgent redress: these are a significant contributor to the immigration from First Nations to urban centres, as well as to shorter life expectancies for those who live on-reserve. Envelope funding for LTCC services, together with one intake/assessment process, and funding of a wholistic, trauma-informed, culturally safe, two-eyed seeing approach to health, with the crucial infrastructure to support its delivery, is necessary to reflect First Nation realities and decolonize LTCC in First Nations.

Section 6:
Infrastructure

Deficiencies in infrastructure create challenges for the delivery of LTCC in First Nation communities. The lack of residential and commercial buildings together with their maintenance, schools, roadways, water and sewage, and satellite and broadband systems has been described in numerous reports as 'third-world' conditions.

Engagement participants frequently expressed that they are often unable to fulfill elders' wishes to age well in their communities with such limited infrastructure in place.

> *One of the key objectives in this [LTCC] project was to help First Nation members stay in place, as long as possible. (ON- Nokiiwin Tribal Council, 2022).*

> *LTCC covers all infrastructure - water, electricity, transportation, communications, etc. (National Validation Participant, 2023).*

Engagement participants identified five major areas for infrastructure improvements:

- Housing for individuals, families and professional staff,
- Facilities to accommodate Levels 3 & 4 nursing care, convalescent care, respite and palliative care, and/or other health care needs,
- Transportation,
- IT broadband width, availability and services, data management systems, and
- Equipment.

Figure 5: *Vision for Infrastructure*

Establish processes & protocols for data sharing

Gathering spaces for health, teaching & to reduce isolation

Build capacity of FN's to deliver and service IT needs

Urgently address lack of spaces - health and wellness centers

Telehealth for consultation with specialists

Funding for housing adaptations

Reliable internet and increased bandwidth

Smaller facilities with respite and convalescent care beds

Transportation to services not available in-community & to assist family

Reevaluate funding to include capital & maintenance costs

Improve federal housing programs (CMHC)

Prioritize needs for people living with disabilities

Adequate funding for transportation to hospitals & health centres in-community & road maintenance

More facilities including longterm care homes

Link facility infrastructure processes with service delivery planning

Participants also noted that improvements to accessibility of all built infrastructure will be legally required of First Nations commencing in 2024:

> *Bill C81 is the Accessibility Act of Canada which is the law with regard to ensuring compliance in all of Canada to accessibility especially for persons with disabilities which is part of LTCC. (National Validation Participant, 2023).*

To implement this legislation will require an allocation of special funding to provide ramps and/or other infrastructure to make housing and all public spaces accessible. An increase in construction costs is expected as well that puts additional pressures on communities (see Funding section).

Finally, the need for more qualified tradespeople to work on building, repairing and maintaining Infrastructure was identified.

> *Trades people few and far between in communities—needed for community human capacity. (National Validation Participant, 2023).*

6.1 Challenges: Housing Inadequacies & Gaps

> *One of the most significant barriers to safely supporting seniors to remain at home is housing and a lack of affordable and accessible housing. (ON- AIAI, 2021).*

Participants described numerous accounts of elders in their communities living in inaccessible and unsafe housing as the alternative would involve moving far away from their communities.

> *An Elder lived in a non-accessible home because he didn't want to live away from his community or move to a city 400 km away. (National Validation Participant, 2023).*

Engagement reports illustrated accessibility challenges for those with disabilities and mobility challenges. A lot of homes are not wheelchair accessible or friendly. Homes without ramps or walk-in showers are dangerous but modifications are out of reach for many families.

> *Lack of safe, accessible, and affordable housing was listed as a significant issue by many regions. There are many challenges with lower income housing, trailers, and single dwelling homes that are in very poor condition. Homelessness, unsafe homes, homes with mold, and overcrowded homes were identified as four significant challenges that were identified by Alberta Six Nations. (AB- Treaty Six, JTK Research and Consulting Inc., 2021).*

Across all regions, housing was identified as a serious challenge to providing LTCC in-community. As the above quote illustrates, it is not only the lack housing available, but also the conditions and the overcrowding:

> *While home adaptations may be considered a relatively simple fix, when homes are in complete disrepair or have a large number of family members, it could be extremely difficult to complete home renovations to ensure that they are accessible for elders and adults with disabilities. (ON- Nokiiwin Tribal Council, 2022).*

Renovating and updating homes is a complex and challenging process in communities. There is limited support for individuals in need of home repairs.

According to FNHA, 40% of participants reported that home renovations are not possible (2022).

Some communities have funds available from the band or government programs, but there are many hurdles to making homes suitable for people with disabilities including obtaining the services of skilled tradespeople and finding professionals to install medical equipment.

New construction has its own challenges especially in the wake of the pandemic. Higher building costs, labour shortages, supply shortages, and lack of funding are challenges that currently limit improvement of infrastructure. Many communities

have high rates of poverty so families cannot afford to upgrade their homes.

> *We need to address homelessness. We have a lot of clients who are trying to come through our door and have nowhere else to go. They will stay in detox until they are able to get a bed. They are going into treatment because they have no place to go. Homelessness is really difficult. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Homelessness is a reality in First Nations. Homeless shelters are uncommon on reserves so many utilize treatment programs or extended hospital stays for shelter. This adds further strain to those facilities that already struggle with bed capacity and waitlists.

The lack of housing also contributes to poorer health:

> *Housing plays a part in mental health. We have four generations living in a three- bedroom bungalow. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

The housing reality in FNs is not always well understood by program funders. As the quote below illustrates, this lack of understanding can result in a serious mismatch between community needs and proposed solutions:

> *We had a child with severe mental health issues, sleeping in a closet. We had letters from professionals saying he needed his own bedroom. Health Canada wouldn't renovate but offered him a sleep machine. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Multi-generational households are traditional in Indigenous cultures, but many homes can not accommodate large extended and blended Indigenous families. Families outgrow houses but have no ability to build additions or move to larger homes.

> *Sharing of rooms, sometimes inter-generationally due to overcrowded conditions and long housing waiting lists, placed stress on clients and family care givers, and compromised clients' health and safety, due to exposure to other illnesses and slip and falls. (ON- ONWAA & NORDIK, 2022).*

Overcrowding is a challenge that also limits the ability of homemakers, nurses, and PSWs to work within homes and causes hygiene, health, and safety issues. It places vulnerable members of the community, such as elders and children, in stressful living conditions that are detrimental to their wellbeing.

6.1.1 Challenge: Gaps and Maintenance of Care Facility and Built Infrastructure

> *10+ years of nursing and not one person has been able to die at home. (National Validation Participant, 2023).*

Participants that worked in LTCC described the difficulty they face administering quality and safe care when they simply do not have the facilities and building space to do so. LTCC facilities and hospitals are frequently too small, with insufficient beds to meet the needs of the population, and long wait lists. Service providers from all areas, including addictions, mental health, and health care all stated that they are at capacity and urgently need to expand.

> *Nursing station model is not working for communities, don't have the capacity. Last summer, an elder died in the hallway of the hospital in Sioux Lookout Health Authority. [Greater] capacity is required for dignity. (National Validation Participant, 2023).*

Participants shared their lived experiences - the lack of Levels 4 & 5 nursing care and poor and overcrowded housing have resulted in people having to leave their communities and travel to areas where the infrastructure and capacity are in place. These stories illustrate the reality that elders, many of whom are residential school survivors, are being forced to re-locate against their wishes. Participants shared how this contradicts FN's traditions and beliefs and causes incredible stress and re-traumatization to individuals and families. Furthermore,

participants unanimously expressed deep seated fear and grief over the racism that their community members still experience in non-First Nations' health and LTCC facilities.

Community engagements asked participants to describe what facilities are available in their communities for elders and clients with high nursing needs. According to a citizen from Selkirk First Nation,

> *There is none. We don't have an elders' care home or assisted living facility. (YK, Yukon First Nations, NGI, 2022).*

Community participants reported a lack of community facilities such as nursing homes and hospice facilities. As a result, there is a complete lack of palliative and end-of-life care.

Many engagement reports expressed **urgency in addressing the lack of facilities, including health and wellness centres, and activity space for elders and some communities expressed support for recognizing such facilities in northern communities as top priorities.**

Participants expressed the emotional impact of dealing with facilities' inability to meet the needs of an aging and growing population. Providing a wholistic continuum of care with end-of-life support is currently not possible in many communities due to infrastructure limitations. National validation participants echoed concerns that extending such capacity is completely contingent on securing adequate and sustainable funding.

> *Cannot foresee long-term care homes being built and properly funded and run for the next 5-10 years with the current models of ISC funding for infrastructure. (National Validation Participant, 2023).*

> *Lack of capital funding for First Nations means that facilities (e.g., Elders' Lodge, accommodations for staffing, patient housing, etc.) needed are not available. (MB- FNHSSM, 2022).*

6.1.2 Maintenance and Repairs

Not only is it difficult to secure the capital funding to build new facilities, participants shared that the approval process has its own challenges;

> *FN need to get approval from ISC to build projects—creating challenges in our communities – not really Indigenous led if you have to go to ISC for yes or no approval processes. (National Validation Participant, 2023).*

Poor maintenance and lack of repairs to facilities were listed as challenges that affect the health and safety of staff and clients.

6.1.3 Gathering Spaces, Treatment Rooms & Professional Accommodation

As participants in every engagement process identified, wholistic approaches to health require assessing all of the health needs of the individual, family and primary caregiver, and cannot be separated into 'silos'.

> *No central space for elders to age together. No place to meet for socializing. (YK, Yukon First Nations, NGI, 2022).*

As the quote above illustrates there is also a need for gathering places to address social and mental health needs, as well as for education around health issues, and particularly for traditional health services such as smudging and other ceremony. Although most of the larger FNs have health centres, many communities do not have recreation centers or community housing facilities that could serve a dual purpose to provide space for social gatherings.

Participants raised concerns about community gathering places to accommodate health education, cultural activities such as beading, ribbon shirt and skirt making, and social gatherings to improve mental health and reduce social isolation.

Office and treatment space in some communities were also identified as key to care delivery and housing for visiting medical professionals such as nurses,

physiotherapists and occupational therapists. Traditional healing spaces such as 'lodges', 'roundhouses' and others were identified as essential to providing care from a 'two-eyed seeing' approach; and accommodations to meet Level 3 and 4 nursing standards were most frequently not available in First Nation communities.

Thus, the engagement process revealed community need for a variety of built health facilities to address the various aspects of individual, family and community health:

- Long-term care facilities that meet requirements for Level 3 & 4 nursing care,
- Rehabilitation beds/facilities,
- Palliative care beds,
- Respite beds and 'day-away' spaces,
- Convalescent beds,
- Health centres,
- Community gathering places for health teaching, luncheons,
- Addiction treatment centres,
- Office space that can ensure confidentiality for visiting professionals, and
- Traditional healing spaces.

Participants also stressed community diversity and that community autonomy must be respected in determining the type of long-term care facilities. Engagement reports noted that 'institutions' were trauma-triggering for many FN members, and that small facilities which could support higher-needs individuals were required to meet the healthcare needs of their residents.

> *The biggest thing with infrastructure is that the elders do not want western style long-term care homes. (National Validation Participant, 2023).*

Research evidence demonstrates serious impacts of systemic racism on health, and for First Nations communities, the imperative of culturally safe health care cannot be over emphasized. Thus the provision of appropriate, culturally safe long-term care housing and treatment facilities is crucial and urgent.

6.1.4 Challenges: Water and Electricity

> *During a boil water advisory, do not use tap water to bathe those who need help... (https://www.sac-isc.gc.ca/eng/1538160229321/1538160276874, accessed March 21, 2023).*

According to the above-noted website, 28 FN communities are still experiencing 'long-term drinking water advisories' (1 year plus) despite substantial improvement efforts since 2015. Additionally, although three long-term advisories had been resolved since November 2022, in that same time period, three additional long-term advisories had been issued, thus suggesting that the problem could be a 'revolving door'.

Although 'long-term' advisories are extremely problematic, even short-term advisories impose substantial workload increases for family caregivers and home-making staff. It also imposes a similar challenge for individuals with increasing dependence who are attempting to care for themselves and remain in their own homes, or to assist in care for children.

Power outages, especially during storms and natural disasters, are also a frequent challenge in remote FNs, particularly for LTCC, as many pieces of medical equipment require electricity to operate. Such outages can continue for days or even weeks, and delays in funding portable generators have sometimes taken years:

> *A new generator is also needed, and it took five years to get one which was required due to frequent power outages. (SK- FSIN, Katenies Research & Management Services, 2022).*

It was pointed out that a lot of medical equipment can't operate without electricity.

Many homes are completely off the grid as costs to install hydro lines and poles are astronomical.

6.1.5 Challenges: Transportation & Emergency Services

> *For many First Nations in Ontario, distances and lack of accessible road transportation essentially prohibits the use of other health-care professionals and facilities beyond those available within their own community, unless the medical condition is acute, or unable to be treated within the community. As a result, health conditions of clients frequently deteriorate for some time before treatment can be obtained. (ON- ONWAA & NORDIK, 2022).*

Transportation was highlighted as a top challenge in every region, both externally in accessing services, as well as internally within communities. Many communities do not have year-round road access and are only accessible by air or water. Some have seasonal roads that are closed throughout winter. There are limited airports, planes, and pilots so fly-in communities are extremely isolated.

The most remote communities experience the greatest difficulty arranging transportation. For example, it takes 16 hours to travel from Old Crow to reach Terrace to receive specialized care and high-level services.

> *Medical specialists, rehabilitation services and hospital/acute care are primarily located outside of the community and for some individuals, such specialized care is only available through air ambulance or private transportation. (ON-ONWAA & NORDIK, 2022).*

Furthermore, public transport is unavailable in most communities. The Band itself provides medical transportation in some communities but this is limited. Some communities reported that they do have a vehicle available, yet they continue to struggle to meet the 24/7 transportation needs of the patients in their community.

> *Several engagement participants reported that transportation both within the community for workers, and in a number of cases, to medical professionals located far from the community itself, restricts and/or limits the ability of the community to address these needs. (ON-ONWAA & NORDIK, 2022).*

Additionally, lack of transportation substantially limits the ability to recruit and retain trained staff, such as homemakers, nurses, and other LTCC staff, who are required to provide their own transportation.

6.1.6 Emergency Services

Emergency services was also identified as a key component of infrastructure frequently lacking in First Nation:

> *911 service is not available. (National Validation Participant, 2023).*

> *Ambulance services and lack of ambulance services---some places take up to 4 hours to reach hospital services. (National Validation Participant, 2023).*

The lack of signage as well as distances makes it challenging for outside Emergency Medical Services to access patients in need, often delaying services.

> *Reserve land is allocated by lots and not addresses so it takes longer to access residences. Road infrastructure is required for EMS. Finding houses in communities to access patients can become a challenge. (National Validation Participant, 2023).*

The lack of public transportation hinders patients' return to community upon discharge as well:

> *EMS takes them to the hospital and no one to take them back home. Becoming displaced when being discharged (sometimes being discharged in the middle of the night). (National Validation Participant, 2023).*

These transportation challenges and limitations have placed individuals with decreasing independence at risk due to delayed appointments which sometimes result in escalating acuity of need and lack of information/education on prevention or alleviating treatment and care.

6.1.7 Challenge: Technology

> *Communities have identified big gaps in the supports, processes and infrastructure needed to implement front line service systems effectively. This includes but is not limited to the need for administrative supports, human resource (HR) services, intake, assessment and reporting systems, databases and IT systems, supervision, training and teaming options and so on. There is also a need for equipment, supplies, infrastructure like electronic medical records (EMRs). (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

Several engagement reports noted they currently do not have the technological infrastructure to operate effectively. Electronic Medical Records are not available. The process of data system entry for front line staff was described as "archaic." In one case, a staff member mentioned that data information about patients must be re-entered, which is time consuming and unnecessarily onerous. The forms are lengthy and require significant time to complete.

Participants observed that their patients and families are frustrated when they must relay information between health care providers or start from scratch when reassigned to new service providers. Reports pointed out that in some contexts, this was re-traumatizing. Lack of regional databases makes information sharing between professionals challenging and leaves gaps in communication that negatively affect quality of care.

> *With the* [COVID] *pandemic raging across the country and LTCC homes getting negative media attention, one of the issues which was problematic and foreseen as a major issue was the lack of information regarding how many of our citizens were in LTCC Homes within the GCT territory and in other LTCC homes across the province and country. (ON- GCT #3 Report, 2022).*

> *Specific to our area, only one LTCC home had a contract with Indigenous Services Canada and it was not easy to collect the aggregate information that there were eight (8) First Nation residents in the Rainy Crest Home in Fort Frances. (ON- GCT #3 Report, 2022).*

It was very challenging to determine where residents of Nations were located at the beginning of the pandemic. This exposed gaps in records and information storing. Participants questioned the accountability and accessibility of the information.

Internet connectivity and bandwidth were also serious challenges for many communities:

> *Connectivity challenges can prevent or affect the use of MRI and x-ray machines and results in some First Nations continuing to use paper charting. (MB- FNHSSM, 2022).*

In remote areas, there is limited or no broadband or satellite internet service. This was flagged as a serious challenge that causes delays and interruptions in important medical procedures. It limits access to virtual services and online resources. Without reliable internet services, professionals cannot improve record keeping and data storage systems. Many issues with confidentiality arise without secure connections and protected regional data systems.

> *Up to date data management systems and software systems are required. We can use them in proposals to justify funding. You need data to support infrastructure funding—key to expanding services. (National Validation Participant, 2023).*

6.1.8 Challenges: Equipment

Participants described hardships in delivering quality and safe LTC due to a lack of medical supplies and equipment. The remote, fly-in communities experience the greatest challenges with obtaining necessary resources. Participants that work in LTC described the difficulty they face when a child outgrows a wheelchair, an elder requires a medical bed, or a patient requires oxygen (National Validation Participant, 2023). Even basic hygiene supplies, such as gauze for wound care, are in limited supply in many communities with higher costs on items that are available.

> *Something as simple as a ramp or palliative bed can prevent someone from receiving proper care. (National Validation Participant, 2023).*

> *They need to increase the funding for these costs. (National Validation Participant, 2023).*

6.2 Path Forward: Accessible, Physically & Culturally Safe Infrastructure to Meet Growing Community Needs

> *We need to have an adaptive growth model, or we will be here again in 10 years. Growth that adapts to governance models, policies and structures. (National Validation Participant, 2023).*

> *The growth of communities leaves us in a position where healthy communities are thriving, and unhealthy communities are dying. (National Validation Participant, 2023).*

Community participants identified that the enormous gaps and inadequacies of infrastructure are placing 'differently' abled persons at risk of reduced life expectancy, and reducing the ability of elders to age well in their communities.

Participants indicated that First Nations require substantial planning and development, as well as major investment to address these gaps and inadequacies. Prioritizing development requires a human resource and capital investment strategy that is planned in collaboration with First Nations and accommodates the diversities of culture, history and context. The engagement participants were not asked to identify priority areas, but they did identify a number of suggestions and recommendations that can provide guidance to the development of a plan to address these deficiencies.

6.2.1 Path Forward: Safe, Affordable Housing for First Nations Members

> *All community programs that deal with infrastructure (running water, ramps, hydro, food security etc.) must prioritize the needs of community members living with disabilities and increase coordination. (MB- FNHSSM, 2022).*

> *Care needs to be grounded in-community: The ability to remain in-community - either in one's own home with appropriate family and community support systems, or in Elders' accommodations/housing within the community – is a priority. (ON- NAN, n.d.).*

All regions identified housing as a priority. As the quote above indicates, the ability to provide safe, affordable housing, tailored to community need is an absolute necessity to retain and restore family structures and relationships after the trauma of residential schools and the Sixties Scoop. Such accommodation meets the cultural imperative to provide homes for every community member, as well as ensuring the best health outcomes.

Participants described innovative community responses to this desperate community need:

> *…creative ways that communities have been addressing housing challenges, including paying for home renovations to keep people in their homes for longer, installing a shower, washer and dryer in the health center, using RVs to provide homes to under-housed*

members, and using hotels for convalescent or detox spaces. One community is embedding accessibility into future housing development by requiring all new houses in community be built without stairs. (BC- FNHA, 2022).

Participants identified that the diverse needs of people with differing abilities, together with their caregivers, were crucial elements to consider in the development of appropriate accommodation and that, once again, the individual needs and caregiver supports must be of central consideration in the provision of appropriate housing. One engagement report addressed the need to fully integrate housing – whether at home or in facilities, repairs and maintenance, modifications, or new builds – with LTCC programs:

Existing federal housing programs (including the Canada Mortgage and Housing Corporation's [CMHC]) should be reviewed and improved for better complementarity and coordination so they better meet the needs of First Nations communities and organizations. This review must help to: Make housing (whether at home or in an adult residential care facility) adaptable, appropriate, affordable and safe. And offer more housing and support options to First Nations communities (including adapting the home). (QC- CSSSPNQL, FNQLHSSC, n.d.).

Increasing opportunities for communities to access resources to increase or modify housing available for members who want to remain in community. This may include home remediation (e.g. mold or structural issues), modification (e.g. safe installation of medical equipment), or development of flexible housing solutions to meet community needs and support members to safely stay in community for as long as they desire. *(BC- FNHA, 2022).*

Although not identified by all participants, many First Nations, particularly those with smaller populations and/or without road accessibility, have no short-term rental space available and require housing for health professionals. Thus, health professionals such as nurses and nurse practitioners, locum doctors and traditional healers, find only 'makeshift' accommodations, such as staying with another family, using a bed in the Band office or healing centre, etc. This compromises recruitment of professionals to attend the community to provide regular care. For individuals experiencing trauma, where developing trust is quite often a lengthy process, retaining ongoing care from trusted professionals is essential for health outcomes.

6.2.2 Path Forward: Elders/Seniors Housing, Long-term Care Facilities, Palliative & Respite Beds

Jesken Aerie includes 60 units of Elders/seniors housing along with common/communal space for recreation, meals and personal care services. The site is just minutes by foot from all major amenities (doctors, groceries, restaurants, post office, etc.).The residents are seniors and Elders, as well as adults with disabilities who are able to direct their own care and whose health will be better managed by support and care within the community rather than within a residential care setting. These services and accommodations will be made affordable to lower income Residents through financial assistance from BC Housing and the Vancouver Island Health Authority. (BC- Northern BC First Nations, CSFS, 2022).

Although most communities identified a woeful lack of safe, culturally appropriate, affordable housing, some communities found success and the community engagement process provided a space to share their experience with others. The experience above, as well as the one outlined in the quote below, illustrate two drawn from BC where the provincial housing Ministry and regional health authorities were pivotal to funding.

The Ts'i'ts'uwatul' Lelum (pronounced Ts-ee-tsu-wa-tul Laylum in Hul'qumi'num) means "Home for Helping Each Other" and celebrates independence throughout the life journey. There is a recognition that support likely will require additional support as we age, and these supports will extend our independence in a

healthy and safe way. Ts'i'ts'uwatul' Lelum is designed with these life changes and corresponding supports in mind. We provide culturally responsible support to Elders with on-site professionals and Indigenous culturally trained and qualified staff who provide many services and personal care support. Our property features 50 self-contained apartment styled units. (BC- Northern BC First Nations, CSFS, 2022).

While the above examples are both for supportive housing, some reports featured long-term care facilities (with higher levels of nursing available) either completed or in process:

In March of 2021 Batchewana First Nation was granted a licence for a 96-bed long-term care facility.

Similarly, Oneida Nation of the Thames and the Mohawks of the Bay of Quinte also have long-term care facilities within their Nations. (ON- AIAI, 2021).

Most participants reported that their communities had not yet been able to construct such facilities (or did not intend to as larger facilities were not suited to their communities). Others indicated that they were in process, and some reported that they had been 'approved', but were not as yet funded. Many expressed concerns about the lengthy waits and delays for infrastructure building/funding.

One report summarized action that was required to address the urgent need for LTCC facilities that could meet community needs:

Re-evaluate the funding approach to include all capital costs including [long-term care facility] and maintenance.

This is a major source of First Nations individuals having to leave the community to remain with their families or in their home community. First Nations may have an elders' lodge, but it may be unlicensed as a personal care home. Nurses are allowed to go into only licensed facilities. All First Nations are impacted by inflation. (MB- FNHSSM, 2022).

Participants in the engagements and at the concluding validation gathering identified the value of sharing experience and knowledge so that communities can better understand how to negotiate the complex arrangements and garner the support necessary to undertake larger infrastructure projects.

Share wise practices with First Nations in community facility development.

There are many best practices in the Netherlands and even British Columbia, where homes focused on dementia care have been developed and operated successfully for years. (ON- Nokiiwin Tribal Council, 2022).

6.2.3 Path Forward: Respite, Convalescent and Palliative Facilities

Since 2017, funding for the FNIHCCP has been aimed at bolstering the ability of communities to offer palliative and end-of-life care services. As a result, some adult residential care facilities have set up dedicated palliative care rooms.... When palliative care services are offered at adult residential care facilities, users receive scalable services and are able to remain in their living environment and community at the end of their lives. (QC- CSSSPNQL, FNQL-HSSC, n.d.)

Several community reports identified significant value in taking a wholistic approach to infrastructure planning. By planning for the whole life cycle including aging, increasing dependency and death, infrastructure could be designed to address three serious gaps in meeting community need:

Link health facility infrastructure processes with health service delivery planning. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

The reports suggested that **well-planned facilities could locate convalescent and respite beds inside long-term care facilities; health centres could provide much-needed gathering spaces**, etc.. Communities which had already completed comprehensive health planning were particularly vocal about this opportunity.

Support collaborative First Nation efforts in developing innovative responses to community need for health facilities.

Some participants shared their experiences of collaboration with other First Nations to achieve long-term care facilities in 'closer to home' locations. Such collaborations can make best use of community capacity to negotiate funding applications, reporting requirements, etc..

NB: Such collaborations must be identified by First Nations themselves (see Governance, above). Some communities are, of course at prohibitive distances to allow such collaboration, while others may have other diversities (language, culture, history, context) which prevent such collaborations and these must be respected.

6.2.4 Path Forward: Cultural Safety

Encourage and support cultural safety in all facility development through policy and regulation modification.

> *Policies and regulations must be modified to consider the infrastructure required to enable First Nations and other agencies to meet the needs of First Nations. For example, increased spaces and staffing for cultural activities, ceremonies and gatherings must be considered in long-term care facilities. (ON- Nokiiwin Tribal Council, 2022).*

Peguis First Nation's EMS service appeared to be unique amongst participants but demonstrates the diversity of strengths to be found in individual communities who have brought together the funding and human resources to provide emergency and critical care. Engagement participants from some communities indicated that having their own health centres located on-site were strengths. These on-site facilities provided easier access to services and health care professionals and often provided a 'gathering space' where cultural activities, meals and/or food services, as well as health teaching was provided. Traditional healers were also available at these locations in some communities.

Many community participants reported that no health centres were located in their communities; others reported that health centers did not have sufficient space to house traditional health practices or gatherings. Some communities reported lack of funding to support such activities. Some communities were able to identify culturally appropriate spaces:

> *A few community members from Grassy Narrows described the building of the Roundhouse as a strength. (ON- GCT #3 Report, 2022).*

> *A dedicated cultural space which can be used for smudging. (ON- GCT #3 Report, 2022).*

As the quotes above indicate social and/or ceremonial spaces were identified as a strength contributing to a two-eyed and wholistic view of health which identifies social and spiritual, as well as physical and mental health.

Again and again, participants identified the need for cultural safety and respect for diversities. A community engagement report acknowledged that this must extend beyond communities and into urban or municipal centres, as many FN members are unable to remain in–community or prefer to live elsewhere:

Ensure culturally safe alternative housing when in-community care is not yet available.

> *Some communities have set up convalescent homes in urban areas. These offer accommodation, a place to prepare meals and cultural activities. These convalescent homes do not receive funding through federal or provincial programs (the Non-Insured Health Benefits Program will partly reimburse users and their attendants for accommodation and meals). In addition, a pilot project involving two resource persons (a social worker and a nurse) has*

been established for users receiving services and care in Québec City. Access to the two resource persons allowed users to benefit from culturally appropriate activities and experience less social isolation. The resource persons also provided support in navigating the RSSS and in implementing medical recommendations. (QC- CSSSPNQL, FNQLHSSC, n.d.).

6.2.5 Path Forward: Transportation

Peguis First Nation has a good EMS for 2 years, fully equipped paramedics, seen improvement in response time--- service Peguis First Nation and Fisher River First Nation. 15-minutes from on-reserve hospital. Human resources capacity—paramedics—without this service reserve residents would wait 1-hour. (National Validation Participant, 2023).

Creative solutions are needed to address transportation needs within communities and flexibility and adaptability of funding, policy and rules and regulations are needed to respond. Engagement participants indicated that they have addressed transportation challenges to accessing health care in a number of ways:

- Some First Nations, particularly those with access restricted to water or air, have been able to obtain visiting health professionals who can provide services over a period of days or even weeks.
- Some communities have been able to purchase a health-specific van or bus that travels to a (relatively) nearby community transporting all those requiring scheduled appointments.
- Some communities have identified community members with vehicles who are able to transport those in need of medical treatment on a regular basis.
- Some family members provide transport when able to do so.

Health care delayed is often health care denied due to inability to attend appointments, with long wait-lists for a wide variety of needed health services. Participants recommended necessary supports to community-based solutions:

Recognize and support adequate funding to meet the transportation costs of health care program needs.

Provide transportation for people to visit their loved ones in the hospital or long-term care homes.

6.2.6 Path Forward: Technological Innovations & Tools

Software infrastructure is needed to save lives. Health records need to follow patients. (National Validation Participant, 2023).

Increasingly, communities have been using technology to provide telehealth and specialty services (geriatric psychiatry, addiction and other counselling services, pain specialists, etc.) to their communities but internet bandwidth and unreliable technology services have proven challenging.

Support the implementation of telehealth tools in First Nations communities. (QC-CSSSPNQL, FNQLHSSC, n.d.).

Participants noted that agreements with provincial or regional networks can increase access to bandwidth and improve service.

Improving connectivity to facilitate health care service delivery can also support community members to connect with each other and facilitate knowledge sharing more broadly (e.g. virtual feasts and ceremonies). (BC- FNHA, 2022).

Community engagement reports identified that FN communities have been developing apps and other technological innovations to address some of program complexities, improve services, and decrease onerous administrative demands.

Develop a data governance framework to control and ensure that you have access to information. It needs to include data ownership, with OCAP principles. Data sharing agreements are fundamental. (National Validation Participant, 2023).

Data infrastructure-asset mapping of all of data collection tools---to capture the numbers to best suit the needs of the community. *(National Validation Participant, 2023).*

Participants described the critical role data collection plays in determining actual infrastructure and capacity needs.

Future policy development and increases to capital funding should utilize data management systems to obtain data necessary for ISC funding applications and proposals.

Some examples of innovation:

Some communities have acquired tools to determine the services to which health centre users (community residents, non-residents, etc.) are entitled based on the two [funding] programs' eligibility criteria. These tools direct users to the services to which they are entitled based on their status or place of residence. (QC- CSSSPNQL, FNQLHSSC, n.d.).

This approach breaks down program silos right from the time the individual is accepted.

These tools were created by the communities in response to inconsistencies between the two programs' eligibility criteria. Although the tools give the user a better sense of the services they are entitled to, they have little impact on community self-governance, particularly in terms of managing program eligibility criteria.

Another innovation by one community has improved after-hours distribution of medications to ensure that they are taken in a timely fashion, and thereby reducing demands on caregivers.

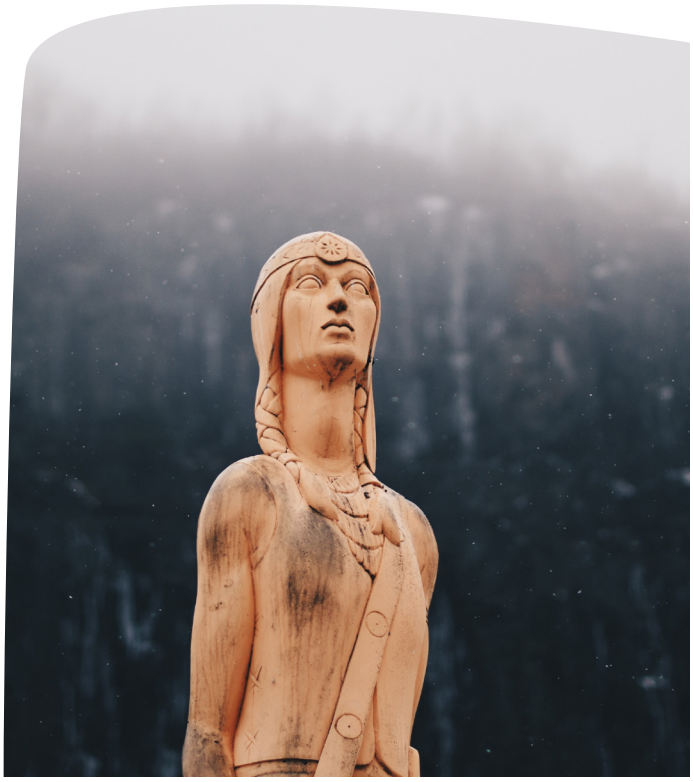
We have a machine that distributes medicines to clients and ensures its being taken on time, and that's one barrier that has helped after hours. (BC- Interior, Naut'sa mawt Resources Group, 2022).

Several communities identified technological innovation as assisting in reducing reporting complexity and time and at least one community's solution is highly replicable once issues related to confidentiality of client records are resolved:

This participant reported that through a separate 'funding pot' they were able to develop an application and obtain iPad devices that have vastly reduced reporting time, and improved client confidentiality. (ON- ONWAA & NORDIK, 2022).

Support access to financial, technical and human resources.

Participants also identified that **supporting initiatives to increase First Nation capacity in IT support and technology development** could assist in ensuring more secure internet access. **Funding for training in IT** was also highly valued and considered a strength by some participants.



6.3 Conclusion

Infrastructure in First Nations needs significant expansion, repair and enhancement. Housing needs are particularly acute and housing itself is of particular acuity as a social determinant of health. Concerns related to housing include the absolute lack of housing, poorly maintained and even unsafe living conditions, overcrowding, and lack of barrier-free housing. In sum, housing, including long-term care and nursing care, respite, palliative and convalescent care, are all urgent needs. Culturally safe, appropriate housing is, for most communities, a distant dream. Participants throughout identified that the lack of built infrastructure also extended to communities with no health care centres, or centres with insufficient space to meet needs; need for housing to accommodate visiting health professionals; water and electricity maintenance; transportation costs that exceed the norm and prevent residents from accessing needed care; and poor internet connectivity and bandwidth. Clearly a major investment in infrastructure to address urgent LTCC needs is required.

First Nations' determination to address these needs is remarkable, and engagement participants have pointed out that training in at least two fields could support their aspirations to better provide LTCC in-community:

> *It is further suggested that all community programs that deal with infrastructure (e.g., running water, ramps, hydro, food security, etc.) prioritize the needs of community members living with disabilities and increase coordination.(MB- FNHSSM, 2022).*

Communities would like to train their own members to help address labour shortages and unemployment. Unfortunately, colleges and apprenticeship opportunities are too far outside the community in many cases. Growing educational infrastructure provides equal access to education and prepares Indigenous youth and young adults for the workforce.

It was suggested that training and education in the trades be made available within First Nations to address infrastructure needs.

Section 7:
Service Provision

Some people accept death journey. Some families do not talk about death. There is a need to talk with people who are going through this because grief is communal and social. (MB- FNHSSM, 2022).

Even when their health struggles were at their worst, community members preferred to receive HCC services at home over going to a continuing care facility by a 5-to-1 ratio – even if the facility were in their own community. (ON- Six Nations Health Services, 2022).

Voices from FNs across Canada repeatedly expressed the strong preference of their community members to remain at home or as close to home as possible. Unfortunately, several gaps and challenges with on the ground service delivery continue to impede First Nations and Inuit Home and Community Care Program and Assisted Living Program.

Due to residential schools, there is an issue of fear with elders who do not want to go to institutions due to Residential School trauma. There is especially a desire to stay in community as a result, needs to be facilities that are culturally relevant in terms of design, food, programs. (National Validation Participant, 2023).

If care can't be provided after a certain level, residents may have preferences to LTC facilities elsewhere but have long waiting lists and must go to other facilities even further away due to availability and limited facilities, for those with higher level of care needs, elders having to go to LTC out of communities who have never

been out of community. (National Validation Participant, 2023).

As this section of the summary report outlines, there are many challenges in the delivery of LTCC in First Nation communities, but the overall value of delivering long-term care was affirmed again and again by community engagement participants. As the quote below illustrates ALP (and the Home and Community Care program funded by FNIHB) were viewed as crucial supports although serious gaps and revisions to the program needed to be addressed.

The Assisted Living Program works and collaborates with other programs to provide (as much as possible) wrap-around support and eliminate duplication. Some examples of the Assisted Living Program information and referral services include but are not limited to training and instruction in household management and the care of the children (particularly in preparation of special diets for infants and children), music and memory programs for dementia patients, and social meals with elders. (ON- ONWAA & NORDIK, 2022).

Why are we supported after someone dies, and not when they're alive and fighting for a better life and better system? (National Validation Participant, 2023).

Engagement participants from all regions identified fundamental principles for the delivery of long-term and continuing care to First Nations' members (See Vision, Section 3):

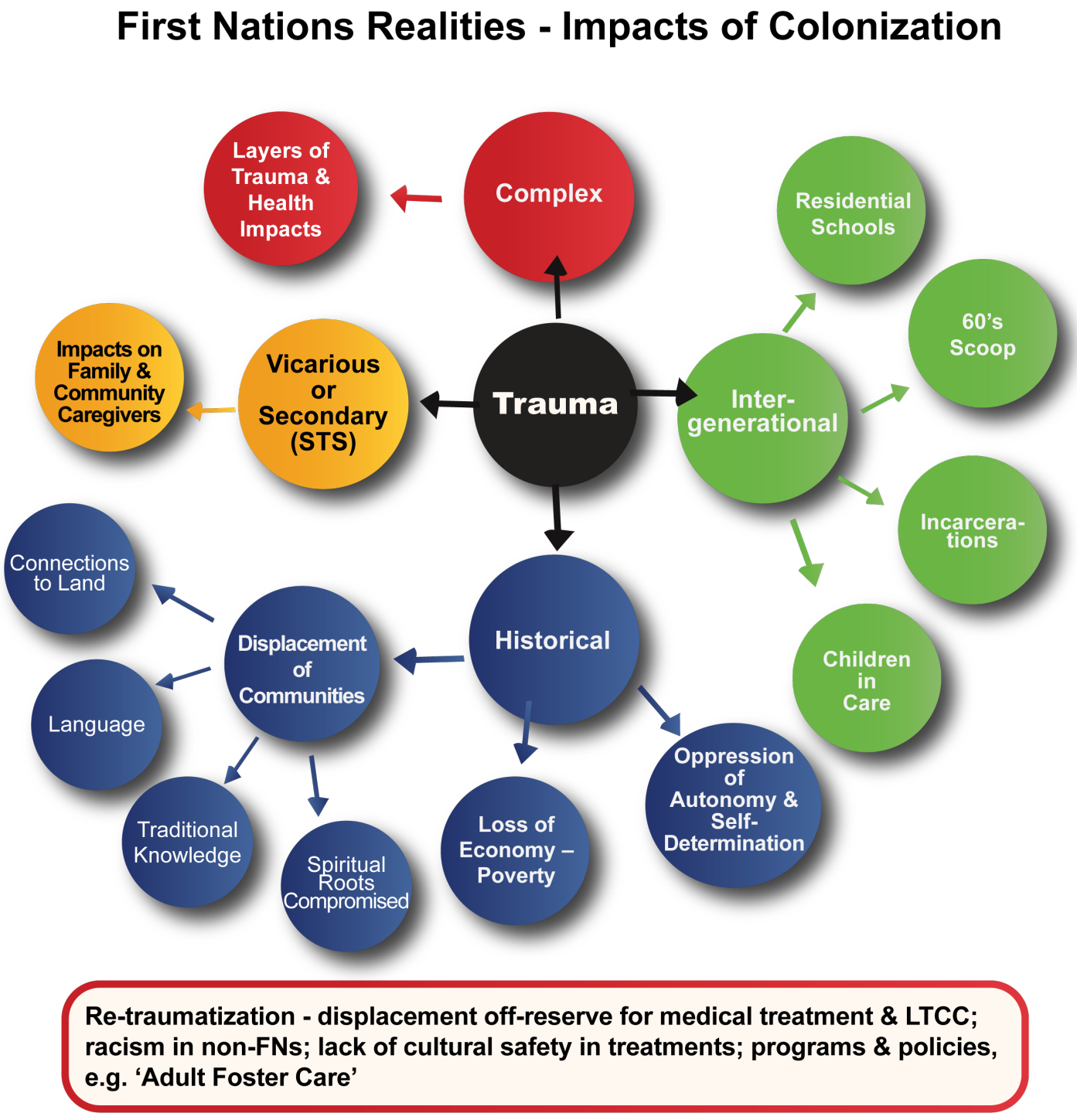
- Wholistic (comprehensive) – addressing the physical, emotional, mental & spiritual well-being, and a continuum of care from pre-birth to post-death that reflects a two-eyed understanding of health science.
- Culturally safe & trauma-informed (accessible) – FN-led, In-community delivery of services, and respect and support for an Indigenous worldview of differently abled, re-ablement, and family/kinship care and trauma-informed - addressing the realities and impacts of colonial policies and racism.
- Universal and portable - Available to all FN members, on and off-reserve, without means testing, and across jurisdictions.
- Adequately and equitably funded.

Challenges identified by participants include multiple issues in each of these areas. Participants reported that numerous essential services simply are not available on-reserve. First Nations are seldom able to offer a full suite of services ranging from in-home supports through to nursing care, palliative care and respite for family caregivers. People residing in their First Nation community must navigate the complexity from initially finding out about the various programs available to having their needs assessed and eligibility confirmed, then frequently maintaining themselves while on a waitlist, before finally obtaining services that may be limited by available resources. Further, few participants reported availability of case managers/coordinators, or systems navigators who could assist program applicants in negotiating these processes.

Multiple issues were reported in recruiting qualified homemaking and health care staff, exacerbated by gaps in funding for training, and a lack of cultural competency particularly amongst non-FN staff. Participants reported re-traumatization, family obligations, and transportation costs, along with a lack of translators and systems navigators or coordinators often prevented individuals from obtaining the care required.

Despite, or perhaps because of, these many challenges, however, engagement participants provided key insights and opportunities to improve current program delivery and plan, develop and implement a continuum of long-term care in First Nations communities which is **wholistic, culturally safe, trauma-informed, and employs a two-eyed seeing approach.**

Figure 6: *Complex Trauma & Re-Traumatization*



7.1 Challenges to Decolonizing LTCC Service Provision

As noted earlier in this report, in-community care was identified by all participants as the underlying principle for LTCC service provision yet there are numerous challenges. Participants again and again expressed frustration at the 'silos' which separate physical health from other health needs. A wholistic approach does not separate one type of illness from another. Addictions and mental health issues demonstrate the need for a wholistic approach:

> *Participants described numerous scenarios whereby increasing rates of addictions and mental health issues contribute to the issue of end-of-life care and support. (National Validation Participant, 2023).*

Rarely considered a part of LTCC programs, addictions were identified repeatedly as having serious repercussions throughout the community with numerous implications for LTCC. Cognitive impairments, the impact of addictions and mental on capacity to provide care, and safety of caregivers going into homes where addictions are present were all raised as significant challenges.

> *… The opioid crisis is affecting caregivers – adults are not able to take care of the elderly because they are struggling with addictions and symptoms of unresolved trauma. (National Validation Participant, 2023).*

Participants identified three major areas of challenges to providing quality LTCC:

- Gaps and inadequacies in service access,
- Lack of cultural safety and competency, and
- Lack of training and support to FN staff and family caregivers.

7.1.1 Gaps and Inadequacies in Service Access

> *According to participants, their ability to access healthcare in their communities has been negatively impacted by insufficient funding, the lack of healthcare services on reserve, intergenerational trauma, racism, insufficient staffing and worker turnover, and language gaps. These are important areas which, according to participants, require attention. (ON- GCT #3 Report, 2022).*

Access to adequate and appropriate services is a major challenge for First Nations and obliges many individuals to obtain care in larger urban centres which are infrequently culturally safe nor reflective of an Indigenous worldview:

> *Cultural and holistic needs of First Nations individuals who must leave the reserve to access services are not being met. Non-Indigenous Personal Care Homes and hospitals are not appropriate. More of a "home feeling" and not institutional is needed. (MB- FNHSSM, 2022).*

LTCC in this context is viewed negatively by many First Nation people who explain that LTCC outside of the community does not typically align with Indigenous worldviews. It feels institutional in nature.

> *Within AIAI communities there is a need for palliative, hospice and end of life care that is provided from an Indigenous worldview. (ON-AIAI, 2021).*

The inadequacies, inequities and gaps in funding and infrastructure has been addressed in earlier Sections of this report so is not further elaborated here, but some of the priority areas for services are outlined below. **NB**: There is wide variation in availability of services and resolution of this requires a community-by-community identification of most urgent needs, and this is not an exhaustive list:

- Respite care and support.
- Detox and addictions.
- Mental health supports, social workers, counsellors.

- Occupational therapy, physiotherapy, massage therapy.
- Diabetic foot care.
- Dialysis.
- Transportation.
- Wellness worker.
- Financial assistance.
- Cognitive care: Alzheimer's/dementia, brain injury supports, impacts of substance abuse.
- Geriatrics & psychogeriatrics.
- Gerontology.
- Intensive functional rehabilitation.
- Chiropractic.
- Traditional healer & medicines.
- Palliative care and Indigenous end of life guide.
- System navigation and coordination.
- Human resources – Homemakers, PSWs, nurses, and other FN medical professionals.
- Land-based programs.

Homemaking supports and services that were most needed in homes include:

- Cleaning,
- Food delivery and/or preparation,
- Support person/care aid,
- Yard work, firewood, and
- Nursing care, wound care.

The lack of available services and supports makes it challenging to deliver wrap around services. Individuals receive substandard healthcare without further treatment and care options to aid healing and recovery. Post-operative infections and other complications arise when families are left to care for loved ones after surgery without necessary supports. Wound care was highlighted as a significant gap in service delivery as was the lack of convalescent beds.

> *When residents came home from hospitals, care items stopped being covered by the province, but it's not fair because they don't have money for the care items, getting caught between lack of funding from federal, provincial won't cover a lot of things. (National Validation Participant, 2023).*

> *Each community experiences unique challenges that they require support to overcome. Small health issues that an individual could have immediately treated and overcome in a large city center grow into serious health concerns when left untreated. (ON- Matawa, n.d.).*

Accessing simple nursing procedures is not simple on-reserve, resulting in additional costs in transportation and sometimes burnout of family members seeking support and assistance:

> *Simple things like nurses in the community being able to provide simple procedures e.g. flushing pick lines because patients aren't in their specific program. Our systems don't allow us to access these simple and vital services. Federal Nursing Station policy barriers. If someone requires a simple flush, they have to transport to other places because they don't qualify for community care. We can't coerce families into providing services; caregiver burnout. (National Validation Participant, 2023).*

Another area of care that was seriously lacking was in the provision of care for persons experiencing cognitive impairments, a field that is of particular significance for First Nations due to increased risk arising from addictions, dementia related to aging, and brain injuries due, in part, to the higher rates of accidents and injuries in FNs.

> *Cognitive care is not available on-reserve. Persons with cognitive disabilities have a right to care just like everyone else. (SK- FSIN, Katenies Research & Management Services, 2022).*

Palliative care was also identified as a gap across many communities, once again, forcing individuals out of their homes and communities to receive end of life services elsewhere.

Many communities want palliative care within the community. They said they do not want anyone to leave the community and go to die somewhere else. They want the ability to build long-term care homes on reserve that are created and run by the community. Currently, placement in a local long-term care place has a very long waitlist. (BC- Interior, Naut'sa mawt Resources Group, 2022).

There is a need to have a death doula that can assist in this process because we need to care for our elderly the same way we would care for our babies. (MB- FNHSSM, 2022).

Communities that do have palliative care and LTCC services available reported that there are major challenges regarding capacity. Local placements have long waitlists and there is specific lack of capacity to meet the higher Levels 3 and 4 nursing care.

Waitlists are commonplace for in-home care as well, due to demands on service and lack of human resources to meet community needs:

It has been so frustrating for me as the home care nurse, knowing that I have about 20 people I need to add to the homemaker list, but I can't offer that. My elders in the homecare program get put on a waitlist. (BC- Interior, Naut'sa mawt Resources Group, 2022).

The challenge of providing adequate in home LTCC was outlined in detail in several reports. With limited hours and services available, higher needs clients are often unable to remain at home safely. Despite the risks associated with remaining at home with inadequate supports, it was still voiced as the preferred option for most Indigenous communities. Reasons for this include stress and isolation associated with LTC facilities.

Many Indigenous care aides expressed distress that they cannot see their clients on weekends and holidays when there is no family visiting. The first day back to work would often find people/clients in a bad way. (National Validation Participant, 2023).

There are little or no supports, such as transportation and translators/escorts, to help overcome accessibility barriers. The farthest communities from municipalities have the most challenges accessing care.

According to AIAI member Nations, wait times for community-based, long-term care placements is 105-135 days, which is pre-COVID data. By the end of the first year of the pandemic there were 35,000 people waiting for long-term care beds in the province of Ontario alone. (ON- AIAI, 2021).

People are constantly getting bumped from their medical travel flights last minute. (NWT- Sahtú, SRRB, n.d.).

Funding constraints that include travel time within the hours of care provide severe limitations on time available for service provision, and lack of in-home services on weekends and overnight, is also challenging:

Clients in some regions receive services once a week, for up to 3 hours, within the hours of 8:30-4:30. This leaves service gaps for high-needs clients that require services more frequently and outside of business hours.

Delayed treatment leads to poor health outcomes and need for more acute care, exposing individuals to greater health risks:

There are individual challenges that prevent access to health care such as those who can not find caregivers for their children or afford to travel. It was shared that some individuals will only seek medical treatment for emergencies. (ON- Matawa, n.d.).

Participants shared that there was a lack of awareness regarding available service and eligibility.

I have lived out here for 45 years and still struggle to find what will work for me. I don't know if there is help. Is it free? (BC- Stó:lō Service Agency & Three Sisters Consulting, 2022).

Participants explained that many communities do not have resource lists to provide contact and pathways for service navigation. Knowing where to start in the process is a challenge for families. Forms are complicated and outdated with accessibility barriers for those with disability, language, or technology barriers.

Climate change and other natural disasters pose significant challenges for communities that are already under-resourced and highly stressed. Participants throughout engagements noted LTCC disruption by natural disasters, including re-traumatization occurring from community dislocations.

> *[In BC] Absolute devastation in emergencies [wildfires, flooding]… the programming is affected by these because people are displaced to locations that are hours away from primary residences and [we] found in engagement [sessions] that there is a disconnect between the ability to provide services and the level of service being increased due to emergency placements, although they are not regular events… (National Validation Participant, 2023).*

7.1.2 Challenge: Ensuring Cultural Safety and Competency

> *Client wants to go to their trap line, but it's against policy and procedures to step off property with the client. Care is to be provided in the home, not in the bush. How are you culturally sensitive to FN needs? (National Validation Participant, 2023).*

Ensuring that LTCC is provided in a culturally safe and competent manner is challenging for First Nations. Participants again and again identified the need for programs, policies and staffing that understood and embraced the language and culture, the significance of land-based activities, food and medicines, and the need for access to trauma-informed care as essential to a culturally safe continuum of care.

> *Previously our children were taken away and put into Residential Schools, now our Elders are being taken away from our communities. In other words, residential school survivors being moved to a long-term care facility may fear being re-traumatized. In some cases, the fact that health services and support cannot be delivered in a language that Indigenous elders can understand is especially problematic and can negatively affect their healing process. (BC- Northern BC First Nations, CSFS, 2022).*

> *Note the importance of language, culture and nutrition. Many who go off reserve note that food is a big deal for them and that they hate the food being served [because it is not traditional]. (National Validation Participant, 2023).*

Participants voiced concern that professionals are not well educated or trained on issues such as intergenerational trauma (ON- ONWAA & NORDIK, 2022).

> *There are many cultural competency and cultural sensitivity issues, particularly amongst agency nursing staff who do not know or understand the impacts of Indian Residential Schools and associated traumas. (MB-FNHSSM, 2022).*

Participants shared that communication between professionals and patients is a challenge. Professionals often use complicated medical terminology unfamiliar to community members. English is a second language for many community members, and for elders particularly, may lack English skills completely. This language barrier affects their ability to describe symptoms and understand directions without a translator present.

> *Our healthcare system has a goal to get people in and out quickly and people are going home sooner after major surgeries or hospitalizations, but there are not community resources both financial and social to meet those needs. (National Validation Participant, 2023).*

There are significant challenges related to patient discharge and follow-up that pose serious health and safety risks to patients.

When individuals access services from off-reserve facilities, they are sometimes dropped off on highways because there are no supports in this situation and nowhere to go. This can be a crisis situation and neglect can occur. The RCMP can get involved in self-harm situations, but they provide limited supports or often deny assistance. (MB- FNHSSM, 2022).

Discharge issues are especially dangerous for individuals who are homeless and have no where to go, or whose reserve is far from a medical facility. Several engagement reports outline challenges with discharges and transitions in their communities:

- *Unsafe discharges from hospitals due to lack of adequate supports. (MB- FNHSSM, 2022).*
- *Many communities do not have a social worker to support arriving patients in their transition and to support doctors in challenging conversations around death. (YK, Yukon First Nations, NGI, 2022).*
- *Lack of notice and information sharing on follow-up from hospitals to community care e.g., wound care, resulting in patient neglect, no follow up for screenings for cancer and other diseases. (MB- FNHSSM, 2022).*
- *Need for increased escorts and increased supports to those in a support role. (MB- FNHSSM, 2022).*

7.1.3 Human Resources Challenges

53.2% of respondents mentioned not having enough staff. (AB- Treaty Six, JTK Research and Consulting Inc., 2021).

Human resource challenges have been an issue in LTCC across Canada for decades due to its aging population and increasing demand for care. Yukon FNs report that they are facing a critical shortage of nurses at 40% of an adequate community level (YK, Yukon First Nations, NGI, 2022). Many regions reported difficulties with staff shortages and difficulty hiring for multiple professions including administrative staff, occupational therapists, rehabilitation therapists, speech therapists, physicians, homemakers, and respite workers.

We could easily hire 3 more full time and that might cover our elders, but that's not including clients with disabilities. (BC- Interior, Naut'sa mawt Resources Group, 2022).

Inequities in wages between workers employed directly by Bands and those employed by agencies contracted to work on-reserve is just one of many issues facing the recruitment and retention of home-making and nursing, as well as other professional staff:

Capacity building for the whole team is needed. We need to be included and get the same treatment for our staff as non-Indigenous facilities. Staff being paid wages our facility can't accommodate, need reimbursement. Massive turnover from being overworked and underpaid. We're not paid for level of care. Our employees aren't fully trained for level 4 care facility. We want residents cared for well. They're crying out for better care, better providers to come in. It's difficult to accommodate everyone living in the facility. There was trouble with heating and ventilating, so our patients suffer. Communication and support of the Senior Centre team and Band Council will make things easier and flow much better. (National Validation Participant, 2023).

Some communities reported they have no nurses at times due to a 5-week fly-in rotation.

Often nurses will not return after one trip or fail to arrive for their scheduled start dates leaving five-week gaps in staffing. There is high turnover and many shifts left uncovered. It is challenging for managers to maintain service delivery when staff absenteeism is beyond their control (YK, Yukon First Nations, NGI, 2022).

The COVID pandemic was particularly challenging for LTCC staff:

Many community programs remained closed, and those that were operational – including the HCC program – were functioning with a

skeletal crew of staff who were consumed with non-stop community crises. (AB- Treaty Six, JTK Research and Consulting Inc., 2021).

COVID has affected service delivery greatly. Trauma and grief related to pandemic needs to be addressed, but the LTCC facilities are still having to screen visitors and wear masks, so need to look at the impact on FN LTCC in terms of the cost of COVID and increase of costs, infection control and training still necessary. (National Validation Participant, 2023).

The critical need to plan and prepare for emergencies was highlighted by recent wildfires and floods, including planning to address the tremendous demands placed on caregivers:

Frequent community crises – flooding, forest fires, winter ice road closures – result in tremendous demands on homemaking and health care workers, some of whom are caring for their own extended families in their 'off hours'. (National Validation Participant, 2023).

With understaffed and underfunded programs as the norm, the alarming rate of burnout needs to be addressed as a major challenge in sustainable service delivery.

While on-reserve staff go "above and beyond" to provide supports, current wages are too low and are disparate with those offered off-reserve. This is reported to contribute to staffing issues such as sick leave and burnout. Staff absenteeism amongst those who are certified to work within Personal Care Homes is a concern. These shortages result in First Nations communities having to utilize agency nurses, which has become common practice, particularly after the pandemic. (MB- FNHSSM, 2022).

How do we even have the capacity in human resources to make the funding happen? [i.e., administrative capacity to apply for funding. (National Validation Participant, 2023).

It is common for communities to have only one nurse who is always on call. Communities struggle to contract external services to bridge the gap, but this often results in higher costs and more complications.

Recruitment for some communities is challenging because the wages offered are below that of a living wage. The current budget allocation is insufficient and does not consider pay increases for long-term employees. No one at ISC could answer questions regarding fair wages and labour standards requirements such as increased vacation time. (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).

Despite temporary wage increases since the start of the pandemic, managers reported that the pay is still not equitable especially when factoring in higher costs of living on- reserve.

What can we do to improve home-makers role in communities? Their duties exceed the hours they're being paid for. We should pay for their mileage, and the transition from house to house [transition between clients]. (National Validation Participant, 2023).

Disparity between different types of nurses working the same station. Agency nurses paid twice as much to do the same job (different models coming together don't match). Even with funding, we don't have the human capital. A lot of nursing agencies in MB, and having to compete with them due to shortages. Not having the funding to hire provincial agency nurses. (National Validation Participant, 2023).

Training was described as inadequate, infrequent and rushed. There is a lack of ongoing professional development and staff are often left to read through training binders outside of work time to keep up with best practices.

It was highlighted that Indigenous Services Canada needs to provide proper training on Assisted Living Policy for both staff and management as this was identified as a gap in training. (BC- Interior, Naut'sa mawt Resources Group, 2022).

Providing adequate training is difficult in regions where staff wear too many hats and are required to have a broad skillset. There is need for cross-training to cover multiple roles within departments, a gap which was highlighted during the pandemic. Also, nursing staff in some communities are always on call making it difficult or impossible to schedule professional development.

> *Home assessments and advocating for clients go by wayside because of lack of human capacity. (National Validation Participant, 2023).*

Clearly a strategy for addressing human resource gaps, including training, education and inadequacies and disparities in wages is urgently needed.

7.1.4 Family and Kin Caregivers

Family/kin caregivers are also stretched to provide care, sometimes because the nursing care level is beyond their capacity, but other times because their own health and/or family obligations interfere.

A number of community engagement participants noted that family caregivers were sometimes obligated to quit their jobs to return home to provide care.

Respite care is also required as intergenerational caregivers and overcrowded housing provides little opportunity for self-care, and sometimes the primary caregiver requires treatment:

> *Grandchildren need respite care as well, when patients are also primary caregivers. When we move 1 person out of the community it leaves 7 or 8 people who require care. (National Validation Participant, 2023).*

Transportation costs, and lack of transportation to provide the crucial family support to people with chronic illness/disability is not recognized in program funding and is particularly difficult for people from more remote communities.

As noted above, people requiring Levels 3 & 4 nursing care are often obligated to reside in nursing homes/facilities off-reserve. This is particularly difficult for families of children requiring such care:

> *Dene representation NWT [have] 31 [LTCC] placements in Edmonton. One individual visited [his home community] only once a year when mother's signature was needed because there is no paid visitation. Nobody's checking up on him, and when she does visit she's devastated with the care he's receiving. Who's checking on these people in long-term care? Pilot project: caregiver support where families look after loved ones 4hrs a week, 5 communities. Push for paid kinship care. Options are to put a loved one in a home or quit your job and lose income to care for them. Policy and procedure prevents our people from getting the services they need. (National Validation Participant, 2023).*

Not all families are willing to send their children experiencing serious chronic illnesses/disabilities off-reserve, but finding the resources to provide in-community care is extremely challenging. Sometimes the severity of the illness itself is an impediment:

> *Ontario Direct Funding pays to hire people to care for loved ones in your home. "Because of the extent of her disability, she doesn't qualify for funding." Severe disabilities not receiving supports. (National Validation Participant, 2023).*

Training for family members for use of specialized equipment is another gap in service delivery. For example:

> *Caretakers often need help in learning how to use in-home dialysis equipment and administer First Aid themselves. Families want to be involved with the in-home care of loved ones but there is a lack of resources to offer training to safely do so. (ON- NAN, n.d.).*

In sum, participants provided evidence of family caregivers' need for respite care, financial and emotional support, and training in areas of care specific to their family members' needs.

7.1.5 Lack of Communication, Systems Navigation and Advocacy

> *Manitoba Renal Program: barriers to getting patients home not specific to long-term care. Provincial programs in the past 15 years opened dialysis units at home attached to professional care. Regional health authority doesn't get paid to operate there. FN weren't at the table in creating this program. All parties need to be involved at inception. (National Validation Participant, 2023).*

There are challenges to delivering wrap around services when individuals work with multiple service providers and professionals. Participants stated that clients are frustrated when they must repeat their stories and receive disjointed services.

> *…many community members have sought out medical services, received initial treatment, and have been prescribed services or further treatment/follow up but have refused further supports by additional medical professionals due to the need to explain their medical issues to additional service providers. (ON- Matawa, n.d.).*

The issue is compounded by lack of collaboration and communication between service providers. A lack of regional databases together with service navigators/coordinators who could provide information, advocacy, and support results in poor health outcomes for many:

> *Patient/Client advocacy is a gap that is not currently available to patients in most First Nations communities. These supports are needed to help disabled young adults, to seek equitable services for those residing on-reserve, to help First Nations members residing off-reserve, and to support those in situations of transitioning. (MB- FNHSSM, 2022).*

Engagement participants identified several challenges that needed to be addressed through better system coordination and collaboration:

- Did not have access/knowledge how to access Indigenous end of life guide or traditional healers.
- Difficult to access mobility equipment, such as wheelchairs and beds, quickly when a client returns home from the hospital.
- Uncertainty in knowing who to contact when medical equipment and supplies are needed.
- System navigation.
- Pain management support to ensure proper use of medication and avoid opioid addictions.
- Collaboration and case management.

Engagement reports unanimously agreed that lack of patient/client advocacy and transitional supports was a major challenge to smooth service delivery. Efforts to bridge the gap are made by nurses and other allied professionals but no one is assigned as responsible for fulfilling this role specifically. **NB:** FNHA, a BC-specific organization, has addressed this need, especially in remote and Northern BC, however, such advocacy and case coordination was not evident in other regions.

> *Assisted living, prevention supports, transitional supports, and family advocacy supports, are needed. (MB- FNHSSM, 2022).*

Staff who were able to advocate on behalf of clients found the processes often time-consuming and frustrating:

> *We spend all our time arranging individual services. It would be better if we had full time OT, PT and SLP care staff in our community. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

In sum, the range of challenges facing in-community care for First Nations' members in a wholistic, culturally competent, two-eyed seeing, and trauma-informed way, is immense. Gaps, inadequacies and disparities in funding and infrastructure as well as colonialist policies, result in enormous pressures on family and community caregivers, as well as on the health and wellness of persons living with chronic illness and disabilities, as well as those experiencing increasing dependence. Despite these numerous and extensive challenges, however, FN individuals and families assert their determination to provide care and support people living and aging well in their homes and on First Nation lands and territories.

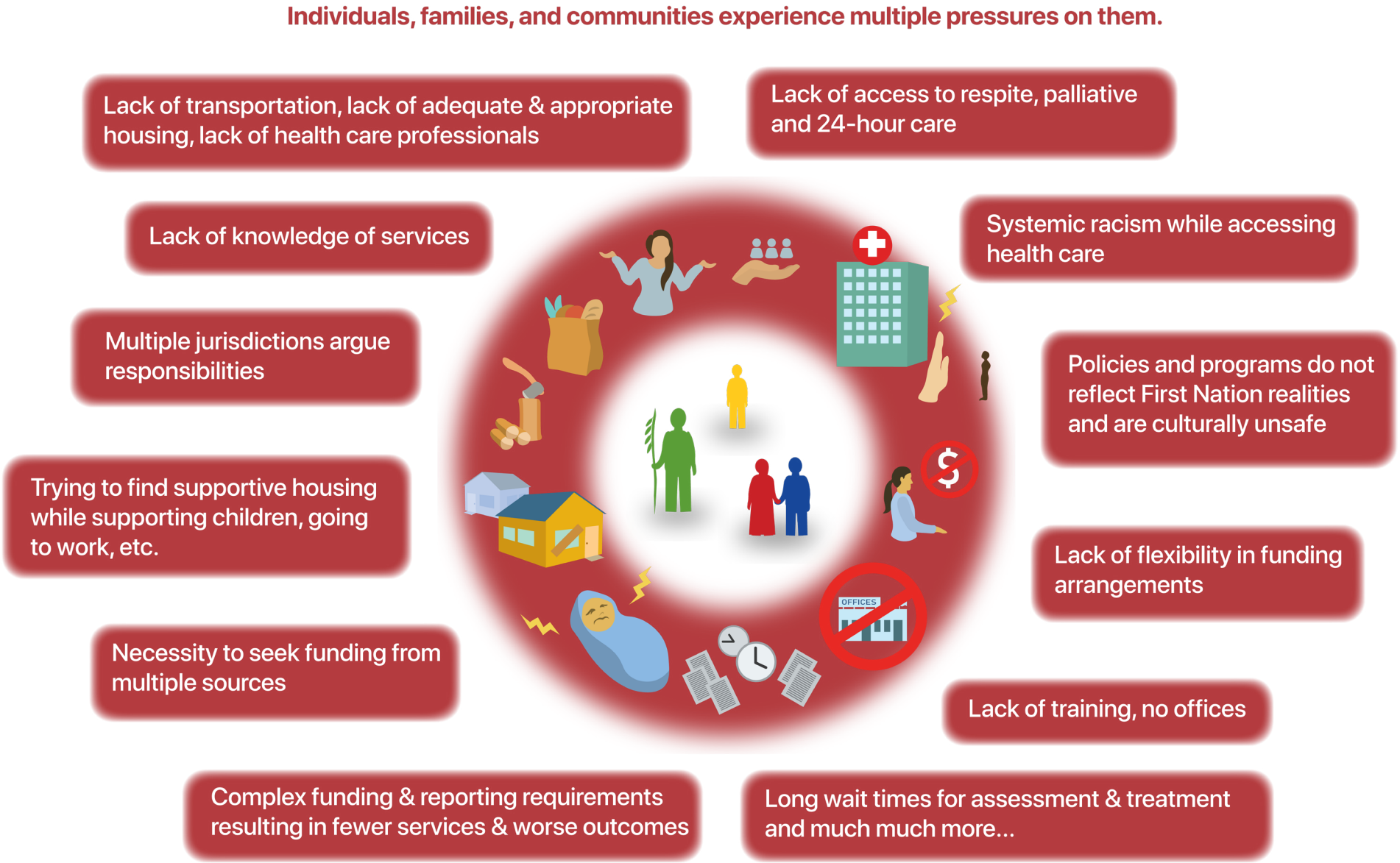
7.2 Path Forward: Decolonizing LTCC Services

> *SNHS achieves the delivery of wholistic care across the lifespan through weaving Haudenosaunee culture as a foundation into programs and services. This is a framework and practice model that is both trauma-informed and centres culture as a foundation for care delivery. SNHS strives to harmonize traditional Indigenous practices and beliefs with western "mainstream" practices and beliefs and how the two can complement one another to allow for better health outcomes. (ON- Six Nations Health Services, 2022).*

Throughout the community engagement reports there is overwhelming evidence that the provision of culturally safe community-based long-term and continuing care that supports First Nation members in their homes and/or communities is contributing to increased health outcomes and quality of life for their residents.

> *Care needs to be grounded in-community: The ability to remain in-community - either in one's own home with appropriate family and community support systems, or in Elders' accommodations/housing within the community – is a priority. (ON- NAN, n.d.).*

Figure 7: *Service Delivery Challenges*

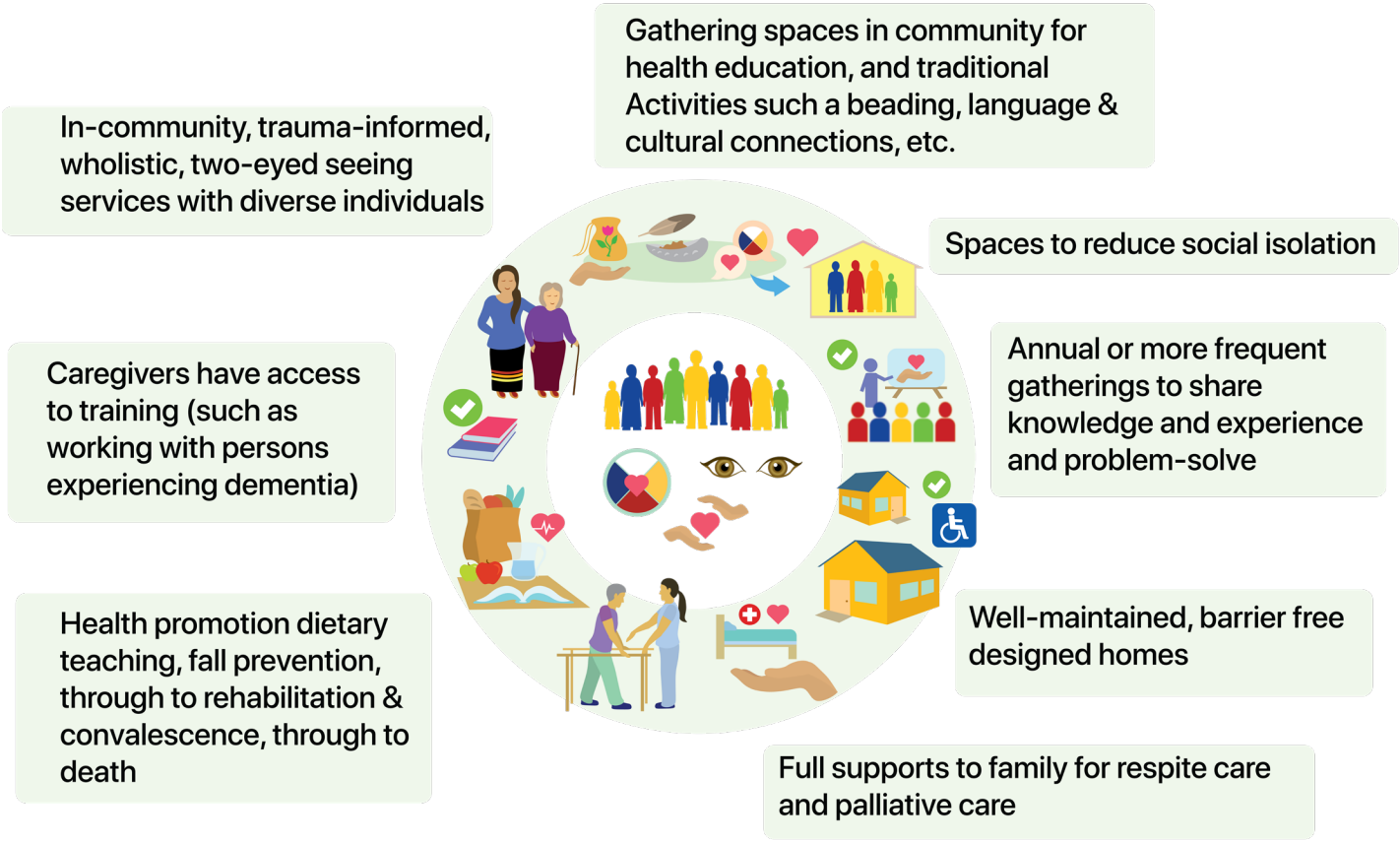


And such care must respect the diversity between and among FN communities and families:

> [We need to ensure] *communities and families have different choices and can choose the one that fits their needs;* [we need] *sustainability of services and supports. (BC- Northern BC First Nations, CSFS, 2022).*

Throughout the community engagement processes the provision of a continuum of long-term care in First Nations communities needed to be based on culturally informed foundation: wholistic, culturally safe, trauma-informed and employs a two-eyed seeing approach. Given the diversity of First Nation communities, with their varying sizes, locations and cultures, there was surprising consensus that these were the fundamental requirements of LTCC.

Figure 8: *Service Delivery Path Forward*



7.2.1 Path Forward: Wholistic

> *TRC Call to Action #22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients. (2015).*

Community engagement reports again and again repeated a need for wholistic services in delivering care, defining 'wholistic' as including all aspects of health [physical, emotional, mental and spiritual], a full continuum of service inclusive of all and ranging from health promotion to full dependence, all delivered within a 'wrap-around' or seamless services model, rooted in inclusive, two-eyed seeing respectful of both 'western' medicinal knowledge and traditional knowledges and healing practices.

Many reports summarized the strong connection between social, mental and physical health, and ways of addressing these wholistically:

> *Addressing Social Needs. These include visiting and storytelling, music and dancing, traditional games, bingo, Bannock-making, and interacting with grandchildren, as a few examples. These activities bring patients enjoyment, feelings of connectedness to families and others, and keeps elders engaged including in family modelling. This requires transportation, equipment (for mobility), accessible facilities, and policies that support these type of activities. (MB- FNHSSM, 2022).*

7.2.2 Cultural Safety and Accessibility

> *A holistic long-term care continuum should be culturally appropriate and include traditional practices and cultural activities in the system of care such as Indigenous art and other cultural activities, traditional healing and medicine, traditional foods, Indigenous helpers, and ceremony. Participants noted that ensuring respect, kindness and empathy help create cultural safety. (ON- Nokiiwin Tribal Council, 2022).*

> *SNHS strives to harmonize traditional Indigenous practices and beliefs with western "mainstream" practices and beliefs and how the two can complement one another to allow for better health outcomes. (ON- Six Nations Health Services, 2022).*

As the quote above illustrates, the blending of Indigenous approaches with western science - a two-eyed seeing of science - has had positive impacts on service delivery.

Engagement participants noted that not all FN members embrace traditional healing methods, and both types of treatment and care must be available to support cultural safety and continuity.

> *Policies and regulations must be consistent with the provision of incorporating traditional health care, in addition to western care. (ON- Nokiiwin Tribal Council, 2022).*

The blending of Indigenous approaches with western science have had positive impacts on service delivery, and the requirement of a two-eyed seeing approach to health care emerged as a key foundational strength to the delivery of culturally safe long-term care in FNs.

Participants again and again spoke of a worldview that embraced community support and caring for each individual member and the crucial need to engage youth with all community members to ensure intergenerational continuity of values related to this concept:

> *Culture and ceremony ties into another significant healthcare strength in communities, which is the communities themselves. Many people asserted that community involvement and partnerships were foundational to wellness in their communities. Many had a sense of community and mutual care in spaces such as addictions support circles and youth groups. Quite a few responses expressed consideration for future generations in terms of further services for youth and ensuring that young professionals come back with their expertise. (ON- GCT #3 Report, 2022).*

First Nations-led LTCC programs and services was seen as crucial to establishing a culturally safe environment that reflected an Indigenous worldview of health and well-being, differently abled and re-enablement:

> *Indigenous-led programs and services was the most significant response by a wide margin. This included the implementation of ceremony and traditional medicine into community healthcare. Many participants expressed that they would like to see Indigenous health practitioners represented in healthcare settings (both traditional healers and healthcare workers). Further, community-led gatherings and ceremonies that promote wellness (such as sharing circles, sweats, and teachings) were of the utmost importance to participants. Underlying these responses was the need for non-discriminatory healthcare. (ON- GCT #3 Report, 2022).*

First Nations leadership was identified throughout the community engagement reports as crucial to program development as well as to service delivery:

Improve cultural safety of in-community care delivered by First Nations staff.

Participants asserted that cultural knowledge – including the healing knowledge inherent in traditional healers – must be appropriately recognized and resourced:

> *Make funds available within First Nations for traditional healers. (MB- FNHSSM, 2022).*

Appropriately resource and acknowledge benefits of traditional knowledges related to health and fully integrate them into service delivery options.

As noted above those communities with access to traditional healers and medicines, land-based activities and programs, and traditional ceremony such as sweat lodges, roundhouses, smudges and many others (i.e., Nation-specific), found these culturally based practices to be a crucial strength in the delivery of long-term care.

Enhance services to include land-based activities.

The importance of the land to health and well-being is known and this should be an important aspect of planning for the care needs of the elderly and those living with chronic conditions and disabilities. Cultural safety as outlined above, requires knowledges and understandings of language, history and culture, together with medicines and land-based and traditional activities that can best be provided in-community with FN staff.

> *Ensure cultural safety is included in all health care planning and program development. Cultural safety, cultural competence, ethical space, relational and reflective practices form the AIAI Health Transformation Framework and should be central to all planning efforts (AIAI Health Systems Transformation Framework). (ON- AIAI, 2021).*

Others provided examples of ways some LTCC services/providers have integrated some FN cultural practices within facilities to improve cultural safety:

> *Whitehorse Hospital has a FN treatment program – allows families to stay and cook traditional food and bring in traditional treatments. (YK, Yukon First Nations, NGI, 2022).*

> *In some communities, initiatives were launched to adapt the menus in adult residential care facilities so that they respect both First Nations food traditions and users' dietary requirements based on their health conditions. (QC-CSSSPNQL, FNQLHSSC, n.d.).*

This combination of treatment options was identified as strengths to build upon in creating a culturally safe environment for FN members.

> *Integrate culture within care facilities' structure and operations – e.g., create culturally safe and private spaces to conduct assessments, changing western approach to conducting assessments, and ensuring support services are culturally aware. (MB- FNHSSM, 2022).*

Another participant suggested more culturally safe facilities could be achieved by a 'cluster' of communities combining resources to better realize the goal of health promotion and re-enablement:

> *Many long-term care recipients don't want to be institutionalized but have complex needs[that] families are stressed to take care of in day-to-day activities. Combine district resources to provide elders with cultural institutions to make sure elders are still active, as opposed to passive recipients in western institutions. (National Validation Participant, 2023).*

Again and again, participants stressed the need to engage First Nations, LTCC staff and those most affected by LTCC in the planning and provision of services:

> *Involve elders and patients in discussions to plan, provide, and ensure cultural and wholistic services needs. Utilizing a prevention and strengths-based approach to understanding and addressing patient needs. In home care needs are different in these settings. (MB-FNHSSM, 2022).*

7.2.3 Path Forward: Trauma-Informed

The context of today's First Nation communities with their history of colonization and colonial policies such as residential schools and the Sixties Scoop require **that all services provided to them [i.e. FN members accessing care] take into account the impacts of historical, intergenerational and complex traumas, and require that services be provided in a culturally safe environment with culturally competent staff and service providers.**

Mental health and addictions are impacted and exacerbated by the complex trauma experienced by FN communities. Participants stated vehemently that these impacts must not be ignored in LTCC planning and delivery:

Address addictions and mental health. Not being able to access these supports in a timely manner not only has impacts on the individual but their families and communities too.

The adverse conditions resulting from colonialist policies have further compromised -and continue to compromise - the health of First Nation communities as a whole with the social determinants of health - poverty levels, overcrowded and poorly maintained housing, few employment opportunities and more – placing heavy burdens on service providers. Engagement reports identified some of the work that is required:

- *Trauma-informed education for all caregivers. (National Validation Participant, 2023).*
- *Care and care settings that reflect a trauma informed approach to support residential school survivors are essential as are accountability mechanisms to address when those requirements are not being met. (ON- AIAI, 2021).*
- *Teaching the history and roots of intergenerational trauma and residential school.*
- *Presentations on positive coping methods, harm reduction, recognizing triggers and the tools to deal with trauma. (ON- GCT #3 Report, 2022)*

7.2.4 Path Forward: First Nations Staffing & Administration

Throughout the community engagement reports the importance of culturally rooted LTCC Staff was a key component in the delivery of culturally safe and quality care, with strong preference for Indigenous staff drawn from their own or nearby First Nations:

> *Many participants felt that they liked the First Nations' community home care programs because they were being helped by First Nation members. (ON- Nokiiwin Tribal Council, 2022).*

First Nations caregivers can provide culturally safe care – language, worldview, understanding of community and its culture.

Staff demonstrated creativity and determination in adapting programs to meet client needs, and an understanding that knowledge of the community and its culture is crucial for good health outcomes:

> *We went above and beyond to extend our home care and assisted living to work with him. And then we got him a home that accommodated his disability. He deserved to have a place of his own. He always has someone to look after him. (ATL - Union of Nova Scotia Mi'kmaq, 2022).*

In addition to ensuring cultural safety, First Nations caregivers' respect and understanding of an Indigenous worldview had some direct health benefits as the following quote shows:

> *Users feel that their values and traditions are being respected. Users tend to follow the instructions of staff when they feel that they are being respected. (QC- CSSSPNQL, FNQL-HSSC, n.d.).*

Participants noted that although homemakers are not considered health professionals, they play an important role in identifying the needs of the individuals for whom they provide support:

> *In BC FN Health Authority provides a health component. Homemakers are supposed to look after home, not person, but their ability to recognize deterioration of patient health and elder abuse needs to be acknowledged. (National Validation Participant, 2023).*

Further, participants stressed the need to build relationships of mutual trust and respect at all levels of care, in order to encourage people to access the care they need at the appropriate time:

> *A participant described a community member who refused health services. The participant would bring a daily meal to the client in order to establish a trusting relationship. Once the trust between the provider and the client was established, nursing services were accepted. (BC- FNHA, 2022).*

Trust is essential for cultural safety. There are often initial barriers working with clients who are mistrusting of the system and service providers. There is a strong need to build relationships and have compassion to address this challenge.

> *TRC Call to Action #23. We call upon all levels of government to:*
>
> *i. Increase the number of Aboriginal professionals working in the health-care field.*
>
> *ii. Ensure the retention of Aboriginal health-care providers in Aboriginal communities.*
>
> *iii. Provide cultural competency training for all healthcare professionals. (2015).*

Participants reported that there was a need to place greater emphasis on increasing the number of FN professionals in the health care field, and to improve the training of non-FN health care professionals.

> *Resource and implement immediate, specific, and targeted cultural humility and cultural safety training for all professional staff (long-term facility workers, physicians, nurses, homemakers, etc.) associated with long-term care provision. (BC- Northern BC First Nations, CSFS, 2022).*
>
> *Anti-racism training needs to be incorporated directly into the training of all healthcare professionals. (ON- ONWAA & NORDIK, 2022).*

Participants in the engagement identified many opportunities to change and improve service delivery, building on their knowledge, experience, creativity and cultural competence. Participants frequently identified that the diversity of cultures, geography, histories and context of communities may require unique solutions, which will also require flexibility of funding agreements and other regulatory mechanisms. Communication and collaboration in developing programs and processes that work on the ground, in-community will be crucial.

7.2.5 Path Forward: Expand & Enhance Support for Family & Community Caregivers

> *Family systems and community systems were also described as a strength under the "systems" category. (ON- NAN, n.d.).*
>
> *Respondents shared that families often understand their role in caring for one another. (BC- FNHA, 2022).*
>
> *The COVID-19 pandemic has shown that NAN communities know best how to protect their people. (ON- NAN, n.d.).*

Significant challenges were identified for family caregivers, including their own health and self-care, a lack of suitable housing and (often) inadequate respite services. Despite these challenges however, extended family and kinship ties within communities were frequently identified as a primary requirement and strength for communities to deliver long-term care.

How can healthcare workers be supported? We heard that often the bulk of care is provided by family caregivers, with the shortages in Health Care Workers and this only becoming more and more each year we need to be proactive in how we support and care for these providers - financially, educationally and emotionally. We need to build a care system that honors this and supports it. This needs to be a huge part of moving forward. (National Validation Participant, 2023).

Support for caregivers, that acknowledges and supports the family and friends of older people who provide unpaid care for their loved ones. (ON- AIAI, 2021).

These include supporting family connections and systems, through helping to learn about healthy meal planning, exercise, and other skills. Families are not always biological but can be chosen or made through ceremony. (MB- FNHSSM, 2022).

Expand and Enhance Respite Care. *Many elders in First Nation communities are the primary caregiver for children at varying ages and need levels. These elders will often manage aches and pains on their own as they are unable to always find an appropriate caregiver to care for the children while they seek out medical care. This combined by the time-limited access windows for care make seeking care for what are seen by people as small or manageable health concerns are often left unseen by a health professional. Without a manageable plan that allows accessible childcare many seniors will continue to manage smaller issues that will often grow more severe. Seniors will also put the needs of the children ahead of their own by missing set appointments or care routines to ensure the well being of children in the home. (ON- Matawa, n.d.).*

[Provide Support for] Self-care activities. These include taking care of self in various ways, decision-making, exercise, going to the land and waters, and self-care of body, mind, and spirit. These activities empower individuals and honours their abilities to do what they can do/still do independently or with assistance. It also helps them to strive for balance. Self-care activities are not all or nothing, and other community members and programs can contribute, such as meals on wheels. (ON- Matawa, n.d.).

To support individuals and family caregivers, it is essential that staffing be provided to assist with supporting, advocating and providing community education regarding how systems of care work, be present when the patient is transitioning from the hospital to the community, provide language translation, and assist in communication between the hospital and community nurse.

People in-care could be at home with extended support for assisted living. It's cost-saving to have a person in their community. More home-based support would prevent having to leave the community and lose benefits. (National Validation Participant, 2023).

7.2.6 Program Enhancements & Building Capacity

Participants in the community engagements provided numerous suggestions to address the gaps in service through enhancements to the various LTCC-related programs:

- Addressing advanced care needs of children and youth. *The key to many advanced care needs for children and youth is embedded in Jordan's Principle requests. Analysing the requests and needs can define what services provinces are supposed to be providing to Indigenous clients, gaps or barriers to accessing these services and can help identify where federal funding is needed*

to enhance access to or quality of care for those with advanced care needs. Addressing these needs by supporting long term staffing for the most requested services (such as mental health counselling, PT, OT and SLPs) will cost less in the long run and provide better quality care for advanced care clients. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

- *A plan needs to be created for those young people who will age out of care. Further, some of these individuals will need care in facilities as their parents age. This needs to be articulated in long-term planning. (ON- AIAI, 2021).*

- *Night care. Facilities in larger city centers have mechanisms in place such as camera monitoring, connected wireless wristbands that alert night staff that an individual of concern has awoken, providing community members of concern a panic button to alert staff, daytime exercise programs to exert healthy levels of energy to assist in a more restful sleep, a sitting service for community members experiencing higher needs during waking episodes. By extending the hours and scope of home and community care workers to maintain 24-hour support staff community members can remain in their community for a larger portion of their life as smaller health concerns can be monitored, assessed, and treated by trained community members. (ON- Matawa, n.d.).*

7.2.7 Improving Reporting Processes

Base reporting on First Nations-identified indicators that are useful and measurable for First Nations that simplify the [reporting] process and meet their planning needs. The reporting content required for the different federal and provincial/territorial programs should be simplified and aligned so that one report can be shared amongst programs and funders. The indicators can help the communities make decisions, develop their action plans, and make changes to improve the continuum of long-term care and services.

Standardize reporting tools. (QC- CSSSPNQL, FNQLHSSC, n.d.).

One First Nation indicated they had developed a unique solution to this problem. Through funding obtained through a non-health related program, the FN had developed an app, obtained tablets and cell phones (to access Wi-Fi 'hotspots' to support internet access) which were then provided to staff to enter and upload files immediately upon performance of client care. This substantially increased confidence of accuracy and reliability of service provision, and significantly reduced time spent on both payroll and reports to funders. Unfortunately, to date, this potential support has not been shared beyond the one community, as the app is not yet adequately secured for broader usage – and ironically, funding is not available to do so. (ON- ONWAA & NORDIK, 2022).

Sometimes funding reports talk louder than service delivery reports. If government can take time to read our input on quality of care, that would be important. (National Validation Participant, 2023).

7.3 Building Capacity

Improve access to specialized services and ensure they work to complement services in the community in the long term. For example:

- *Geriatrics.*
- *Psycho-geriatrics.*
- *Gerontology .*
- *Intensive functional rehabilitation. (QC- CSSSPNQL, FNQLHSSC, n.d.).*
- *Collaborate with First Nations in exploring the development of Indigenous care teams (for example palliative care teams, early intervention teams, assessment and case management teams). (ATL - Union of Nova Scotia Mi'kmaq, 2022).*
- *Addressing priority needs requires adding providers to care teams. This will not look the same*

in each community and can be via community staff, shared staff or contracts with external service providers. Providers identified included mental health specialists, home visitors, addiction specialists, social workers, assessment-case management leads, allied health professionals (Physiotherapy (PT), Speech and Language Pathology (SLP) and Occupational Therapy (OT)), disability support specialists, respite care staff, podiatrists, dieticians, physicians, nurses, Nurse Practitioners (NPs), Continuing Care Assistants (CCAs) and Licensed Practical Nurses (LPNs). (ATL - Union of Nova Scotia Mi'kmaq, 2022).

- *Explore opportunities to develop mobile First Nation care teams (e.g. palliative care teams, assessment teams, etc.) to decrease need for travel. (ON- Nokiiwin Tribal Council, 2022).*
- **Explore potential for multi-partner operational teams.** Set up multi-partner operational teams (as was done for the pandemic).

  During the pandemic, some socio-demographic regions set up crisis units that brought together the communities of the region, Indigenous liaison representatives from CISSSs and CIUSSSs in the [Quebec] provincial RSSS network and managers of the First Nations and Inuit Health Branch (FNIHB) programs in question. This type of committee should be formed again once the pandemic is over, as it has helped facilitate access to services, broaden the understanding of First Nations realities and clarify roles and responsibilities. (QC- CSSSPNQL, FNQLHSSC, n.d.).

- *Improve access to Non-Insured Health Benefits. (National Validation Participant, 2023). This is a longstanding issue with many attempts to resolve. One way to address knowledge and understanding related to NIHB is to educate healthcare providers caring for members on NIHB and accessing. (ON- AIAI, 2021).*

7.3.1 Training and Education

Training and education was seen by participants as a key component in building the capacity of communities to provide a full suite of LTCC services to their communities.

Some communities were able to obtain support for their staff through the funding programs available:

> *Continuing training funding is provided through the ISC-FNIHB. Until a few years ago, this funding was reserved for nurses. However, now these funds can be used toward training for all health care workers. This funding makes it possible to offer multidisciplinary continuing training that meets the needs of various health care workers in communities and First Nations organizations. (QC- CSSSPNQL, FNQLHSSC, n.d.).*

Unfortunately, many participants were unaware or unable to access such funding for staff, and in most engagements, recommendations came forward to address this gap:

- *Build capacity through education and training. There is strong interest in seeing enhanced promotion of/access to training and education opportunities in health for young people in NAN First Nations communities, to encourage the pursuit of careers in health care at the local level. (ON- NAN, n.d.).*
- **Build on partnership strengths with educational and training providers** to ensure culturally appropriate services.
- **Family Liaison, Case Managers & Systems Navigators and Advocacy.**
- *Create a navigation package to help FN's succeed! We need easy access that is customized to community and respects diversity. (National Validation Participant, 2023).*

Lack of funding for staff training and skills updating has placed First Nation members experiencing decreasing independence at risk as well as their service providers and caregivers. Training needs identified by participants ranged from basic health and safety through to dealing with dementia, understanding trauma, identifying self-care needs and solutions, and much more. Increased understanding by service staff of mental health diagnosis, brain injury patients, and the connection of mental health

issues to addictions, homelessness, and an individual's behaviour were another area of concern.

Address worker shortages and staffing issues by providing training and skills updating. *This may mean moving away from traditional ways of educating PSW's, RPNS and RNs in member communities. An example would be the Onkwehon:we Midwifery Care in Six Nations of the Grand River. This program supports developing Indigenous midwives from within community to care for community members and is held up as an exemplar for other providers. Additionally, programming such as this supports mentoring of youth to consider careers as health care providers. As noted in the TRC recommendations, true sustainable change to healthcare systems will only come from those who can challenge those systems. (ON- AIAI, 2021).*

Moving forward, immediate changes to policy [to provide] for flexible services and training strategy specific to needs of each region, and each sub-region (districts). (National Validation Participant, 2023).

Expand Indigenous community and organizational capacity for policy analysis, program development and partnership. This is needed to develop and implement unique, high quality, comprehensive and culturally-based models of care. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Engagement reports reflected a strong sense of urgency amongst participants that action be taken to improve LTCC in First Nations without delay. At the same time, participants expressed a strong wish to be involved in coordinating, collaborating and communicating with all levels of government throughout the change and transitioning processes.

7.4 Path Forward: Co-ordination, Collaboration and Communication

While it is not expected that ISC will enable a complete care system overhaul in the short term, as a result of this engagement process, the implementation of any strong plan will need steps, and funding, to be put in place to allow for increased care co-ordination and collaboration among partners. (ON- Nokiiwin Tribal Council, 2022).

[Conduct] An analysis of how much spending is being spent on these private contracts for health care services. I know in the territories we contract out locum doctors and dentist a lot. I'm sure the territories would go that route and offer resident physicians instead of contracting service providers which is disruptive in these communities. Different doctors coming in and out causes misdiagnosis, especially for elderly people. (National Validation Participant, 2023).

7.4.1 Planning, Advocacy and Collaboration

Suggestions for the planning and development processes included the following:

- **Strong planning, advocacy and collaboration** *within an interdepartmental and greater community scope are pivotal to establishing and maintaining of wholistic care across the lifespan. Data collected from past engagement has demonstrated the need for stronger collaboration between cross-sector organizations. In the context of viewing the individual as a whole in order to provide wholistic care across the lifespan, it is absolutely necessary that cross-sector collaboration be prioritized. (ON- Six Nations Health Services, 2022).*

- **Improve and share data for improved planning.** *Population data must be improved because it directly impacts funding. Data also helps in tracking members requiring services. First Nations members are fearful to disclosing information because of possible repercussions due to systemic limitations and shortfalls, such as overcrowded housing. (MB- FNHSSM, 2022).*

- Explore opportunities to *enhance and evaluate cross-sectoral collaboration and coordination for meaningful partnerships. (ON- Six Nations Health Services, 2022).* Some communities have found methods to fund a more wholistic system of care through partnerships with various funders (including government funders but not exclusively) and by forming collaborations with other Band departments such as economic development, as well as through cooperative services with other First Nations and even municipalities. 'breaking down silos' was a common theme in engagement sessions.

- *Support collaboration and agreements with First Nations to ensure services are available and are more culturally safe. (ATL - Union of Nova Scotia Mi'kmaq, 2022).* Participants provided a number of supports for the development of culturally safe collaborations including: possible role for an Ombudsman and/or an Indigenous secretariat in provincial departments of health and social services and the creation of transitions in care protocols for provincial health and social services system partners.

- *More dialogue with communities to capture actual need and plan for next 20yrs including financial resources required. Program has been dangling for years, this is the first time they've been engaged in policy issues re: home and community care. (National Validation Participant, 2023).*

7.4.2 Extend and Enhance Partnerships

Where partners had strong relationships and communication processes were in place, these were considered strengths. (ON- Nokiiwin Tribal Council, 2022).

Community engagement participants identified many strengths in collaborations, both through informal and formalized relationships and partnerships. First Nations strengthened their capacity to deliver services, improve cultural safety and responsiveness, and access health care providers on behalf of community members. While partnerships within and amongst First Nation communities and organizations demonstrated the strongest ties and closest collaborations, communities indicated a willingness to join with regional health authorities, provincial and federal government ministries, and departments, as well as researchers and consultants – in sum, anyplace they could find allies in providing quality services in planning, developing and delivering long-term care in their communities.

Participants stressed the need to collaborate with others engaged in the health care services relevant for LTCC. As noted above, building relationships of trust is a long-term process, and participants identified that where those relationships already exist, providing a forum to expand and enhance those relationships, and share their confidence in the relationships with others seeking similar collaborations, could build greater capacity in the LTCC system.

- *A network/association of First Nation home support programs is needed to share knowledge and experience, identify solutions to gaps/challenges, and provide advocacy and awareness. (ON- ONWAA & NORDIK, 2022). Collaboration and co-ordination should include not only long-term care providers but also primary care teams that visit First Nation communities. (ON- Nokiiwin Tribal Council, 2022).*

- *Co-ordination to be led by the First Nations, or the agency selected by the First Nation. This will allow for First Nations who have developed their own care models to implement that model to improve care in their community. For example, it is understood that Fort William First Nation has its own source study and is part of the Lakehead University Palliative Care study, developing a palliative care model that will work for their community. (ON- Nokiiwin Tribal Council, 2022).*

- *Collaboration and co-ordination should include not only long-term care providers. Participants suggested that other health providers that visit First Nation communities, nearby communities or self-identified 'clusters' of communities, and all levels and departments of government will be required to manage this significant challenge. (ON- Nokiiwin Tribal Council, 2022).*

7.4.3 Partnerships Within and Between First Nations

> *Participants feel that their communities possess important strengths when it comes to healthcare, including: Traditional knowledge, medicine, and ceremony, self-sustaining cultural practices like growing food and harvesting traditional medicine, and partnerships within and between communities. (ON- GCT #3, Narratives Inc., Survey, 2022).*

> *Participants reported that their strongest partnerships were with other service providers within their own communities, particularly with those departments engaged in health services, as well as programs designed to meet the needs of Elders. (ON- ONWAA & NORDIK, 2022).*

One report identified that collaborating with other First Nations resulted in a broad range of benefits, including:

- *…sharing of knowledge with a special emphasis on increasing funding options to enhance service delivery and address program inadequacies*
- *promotion of consistency in quality and range of services provided*
- *cost-sharing of staff training*
- *improving strategies for better recruitment and retention*
- *addressing institutional/systemic issues*
- *supporting staff in problem-solving, and in loss and grief. (ON- ONWAA & NORDIK, 2022).*

> *Gatherings Bringing together the Home and Community Care workers every year to allow them the space to share their success and failures in the community allows the program to grow within the First Nations by learning from each other. These gatherings would also be used as a point of contact with appropriate agencies within government to share program and educational opportunities for both program and individual development. These gatherings will also ensure that moving forward Home and Community Care programs are managed by the communities but are given the opportunity to share teachings and setbacks. (ON- Matawa, n.d.).*

> *To help First Nations, they would like to see the creation of a Social Development/Assisted Living Forum. A place to share experiences or contact information. (BC- Vancouver Island, Naut'sa mawt Resources Group 2022).*

7.4.4 Enhanced Partnerships with Funders and Other LTCC Deliverers, Researchers and Consultants

A partnership with a respite care organization has benefited families with children with developmental and physical needs, adults who have 'aged out', as well as families living with dementia and other chronic illnesses.

> *Many participants who experienced services provided by Wesway [Indigenous-owned service provider in Thunder Bay area], such as respite care, were impressed by service levels. Communication, attentiveness and quality of service were the key reasons for this program being considered a success. (ON- Nokiiwin Tribal Council, 2022).*

Community engagement reports also identified partnerships with local service providers who provided services in the community (usually at a community-based health centre) as a strength, and a few indicated that institutional partnerships also existed, for example:

> *…many participants stated that a strength in their communities is accessible healthcare. This included a solid emergency unit, some 24/7 services, an emergency van, and a nursing home. They described how healthcare providers visit their communities; however, there were some recommendations for improvement: (ON- GCT #3 Report, 2022).*

In Niisachewan there's nurse practitioners and doctors that come to the community every week. Would be nice to have them get their own office with appropriate equipment and privacy. (ON- GCT #3 Report, 2022).

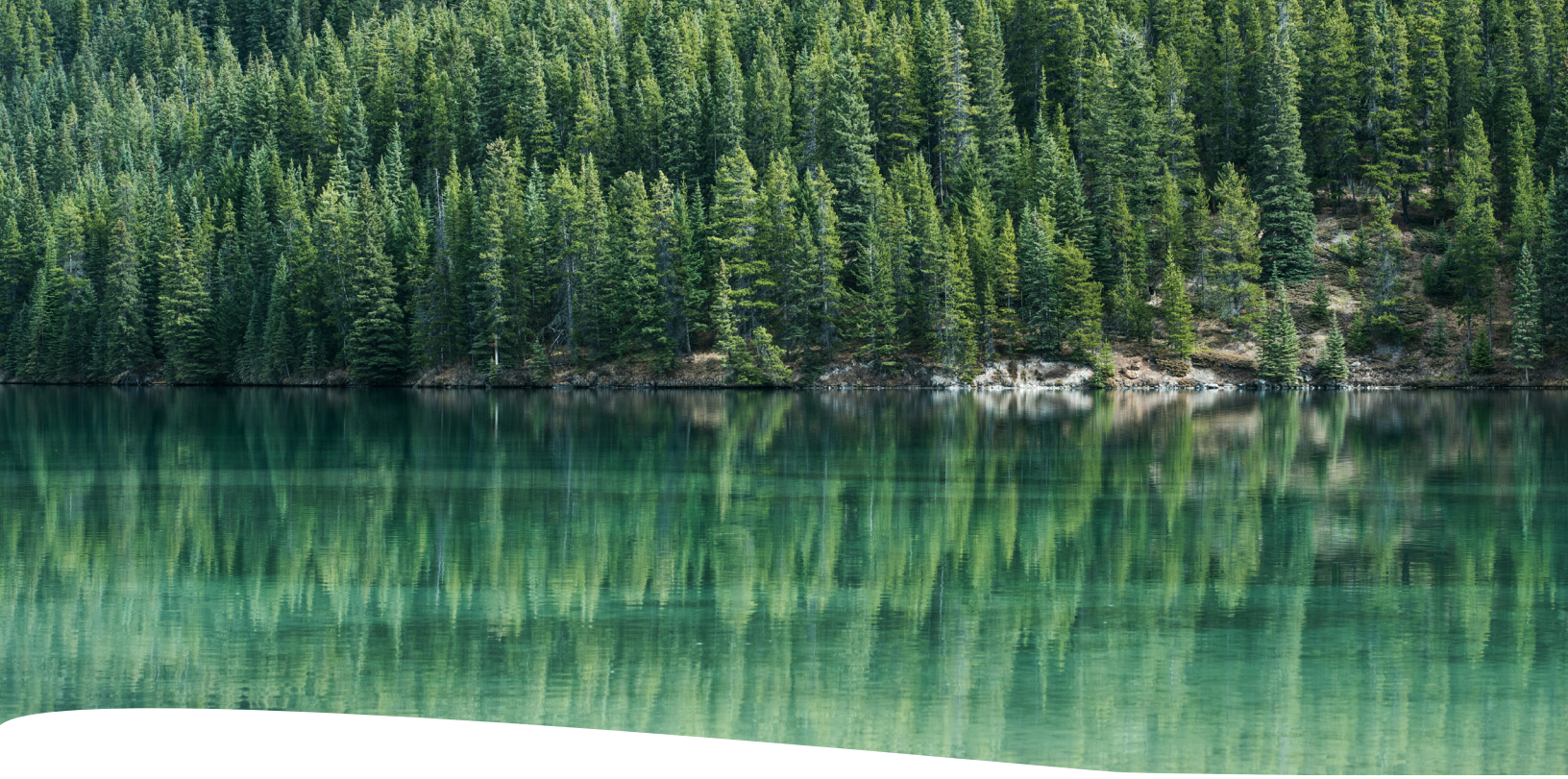
The First Nations and Inuit Home and Community Care Program (FNIHCCP) is one of the most important care resources for Indigenous communities. Staff in these programs go above and beyond to meet complex care needs. (ATL - Union of Nova Scotia Mi'kmaq, 2022).

Several community engagement reports identified that assistance and support from personnel employed by the various funders and government agencies were key to accessing funding and/or support for a variety of services essential to the provision of services. Such staff also assisted in identifying other possible funding sources, and provided support in completion of reports and forms.

The Together Design Lab (TDL) Project TDL is a long-term partner of NAN with technical expertise in planning, architecture and creating solutions to housing issues. The information shared with NAN Health Transformation at the Long-Term Care Engagement gathering has been invaluable in shaping the development of our next phase of work in partnership with TDL. (ON- NAN, n.d.).

In sum, engagement participants identified partnerships and collaborations as strengths in supporting First Nations' capacity to provide a wholistic continuum of care, but also recognized that building trusting relationships take time and commitment and often require patience and negotiation:

The original request was to secure a position on the board of directors with the intention of providing an Anishinaabe (Indigenous) voice when the opportunity to better the lives of residents within the LTC homes. Upon discussion and the formation of a positive relationship, it was learned there were no board positions available; however, there was a position within the Residents Experience Committee which GCT gladly accepted as a first step. (ON- GCT #3 Report, 2022).



Section 8:
Report Conclusion

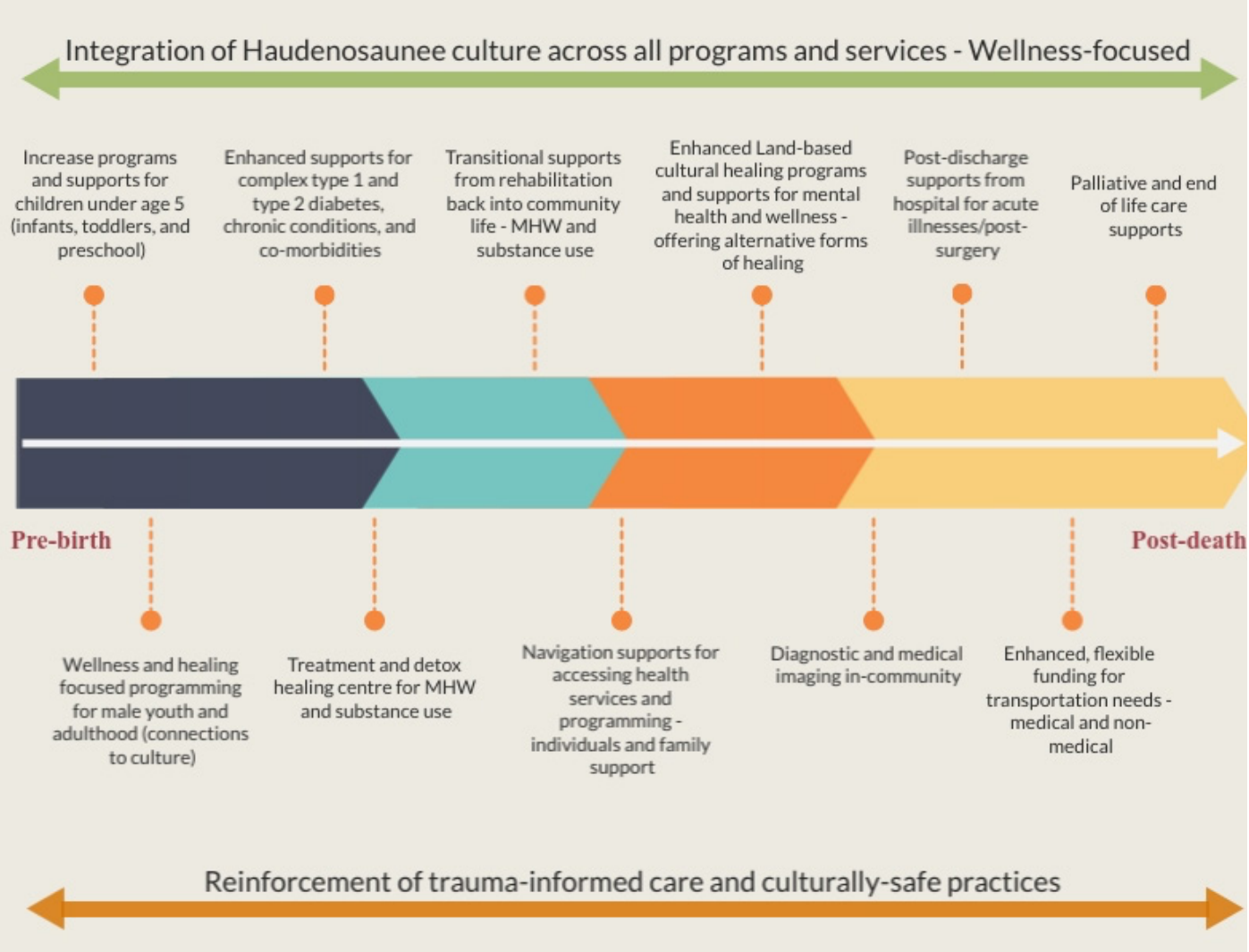
In summary, community engagement participants and reports endorsed a principles-based delivery of LTCC:

- Wholistic services, based on an Indigenous worldview encompassing physical, mental, emotional and spiritual health, and a life cycle from pre-birth to post-death.
- Primarily in-community delivery, with necessary transportation for specialized care only, delivered by culturally competent staff.
- Trauma-informed and culturally safe, reflecting the needs of diverse communities, and respecting the knowledges of traditional healers and traditional practices.
- Universally available to FN members, portable across jurisdictions.

Participants and reports also identified some of the methods necessary to achieve such goals for LTCC:

- Expansion and enhancement of funding to address serious and urgent gaps in infrastructure, disparities of staff wages, and to address the social determinants of health arising from colonization and colonialist policies.
- Supporting family/kin caregivers to provide in-home and community support through financial supports, training and professional support, and respite and recognition of their own health and self-care needs.
- Supporting LTCC safety through recognition of their skills and knowledge and addressing disparities in wages, providing training and educational opportunities, and opportunities to share knowledge and learn in peer-networks and gatherings.

Note: *Visual from Six Nations Health Services (2022).*



LTCC Staff and FN communities have already been engaged in planning and developing collaborations, networks and practical solutions to the numerous gaps and deficiencies in the LTCC 'system'. As the graphic above illustrates, some communities have even set priorities for change. These can serve as strengths to build, expand, and enhance a continuum of long-term care that meets the needs of FN communities.

It is crucial to recognize the autonomy of each First Nation in establishing its own priorities to reflect its own history, culture and context. Although this engagement process demonstrated that First Nations share what is termed by scholars and others as an 'Indigenous worldview' that informs the general approach to caring for community members throughout the life cycle, there are also significant differences in cultural knowledges and traditional healing practices, diversity arising from vastly differing geographies and jurisdictional boundaries, and histories and contexts.

The participants indicated strong interest in continuing the engagement with government and allied professionals, as well as with trusted partners and collaborations, and indeed, strongly recommended that the engagement be extended to involve as many people as possible, including the individuals and family/kin caregivers, so many of whom were unable to be engaged in these discussions. Participants requested that regular gatherings where LTCC professionals and others could share their knowledge, learn from each other and provide support to one another be an integral part of any changes and improvements to LTCC in First Nations.

Appendix A: LTCC Engagment Reports

NB: ONWAA/NORDIK have reviewed 33 community engagement reports and 4 organizational/governmental reports for this summary report.

The following reports have been approved by the authors of those reports for distribution.

(AB)	Blackfoot Confederacy *Continuing Care & Community Engagement*	2022
(AB)	G4 First Nations *Indigenous Based Healing Lodge A Continuing Care Model*	2021
(AB)	Treaty 8 First Nations of Alberta *Continuing Care Engagement Sessions*	2022
(BC)	Carrier Sekani Family Services (CSFS) *Long-Term Continuum Care Community Engagement Final Report: Results From Northern BC First Nations*	2022
(BC)	First Nations Health Authority (FNHA) *Engagement Report 2022 Long-Term And Continuing Care Continuum*	2022
(BC)	Naut'sa mawt Resources Group *Assisted Living Engagement Sessions: Interior Region*	n.d.
(BC)	Naut'sa mawt Resources Group *Assisted Living Engagement Sessions: South Coastal Region*	n.d.
(BC)	Naut'sa mawt Resources Group *Assisted Living Engagement Sessions: Vancouver Island Region*	n.d.
(BC)	Stó:lō Service Agency Health *Long Term Care Continuing Engagement*	n.d.

(NWT) Sahtú Renewable Resources Board (SRRB) n.d.
Holistic Continuum of Care Engagement

(ON) Matawa First Nations n.d.
Indigenous Long Term Care

(ON) Nokiiwin Tribal Council 2022
Holistic Long-term Care Engagement Sessions Summary Report

(ON) Ontario Native Welfare Administrator's Association (ONWAA) 2022
Assisted Living And Homemaking Needs To Support Elders And Persons Living With Disabilities

(QC) First Nations of Quebec and Labrador Health and Social Services Commision (CSSSNPQL) n.d.
Vision, recommendations and best practices: For a continuum of long-term care and services for First Nations in Quebec

(SK) Saskatchewan First Nations Family and Community Institute Inc. (SFNFCI) 2022
Long Term and Continuing Care: Engagement Report Saskatchewan Region Final Report

Appendix B: Acknowledgements

Baawaating is the traditional territory of the Anishinaabe of Batchewana First Nation and Garden River First Nation, signatories of the 1850 Robinson Huron Treaty. It is the homelands of the Métis and shared home of the Missanabie Cree First Nation who were historically displaced from their traditional territory.

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Chi-Miigwetch.

FINAL SUMMARY REPORT - National Community Engagement in First Nations Long-Term Continuing Care (LTCC)

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We also want to thank all of the Long-Term and Continuing Care Engagement team at Indigenous Services Canada and their effort to better address the long-term and continuing care needs in First Nations, Métis, and Inuit communities.

Appendix C: Glossary

AFN	Assembly of First Nations
AIAI	Association of Iroquois & Allied Indians
ALP or AL	Assisted Living Program
AMC	Assembly of Manitoba Chiefs
CHSLD	Residential and Long-Term Care Centres
CSFS	Carrier Sekani Family Service
CSSSPNQ	Commission de la Santé et des Services Sociaux
DDC	Daylu Dena Council
DRFN	Doig River First Nation
FIPPA	*Freedom of Information and Protection of Privacy Act*
FN	First Nation
FNHA	First Nations Health Authority
FNIHCC	First Nations and Inuit Home and Community Care Program
FNHSSM	First Nations Health and Social Secretariat of Manitoba
FNQLHSSC	First Nations of Quebec and Labrador Health and Social Services Commission

FSIN	Federation of Sovereign Indigenous Nations
GCT	Grand Council Treaty #3
ISC	Indigenous Services Canada
MKO	Manitoba Keewatinowi Okimakanak
NAN	Nishnawbe Aski Nation
NORDIK	Northern Ontario Research, Development, Ideas, & Knowledge
N.B.	Short for “nota bene”, a latin phrase meaning to take note or “note well”.
OCAP®	Ownership, Access, Control, Possession (Principles of First Nations’ data and information will be collected, protected, used, or shared.)
ONWAA	Ontario Native Welfare Administrator’s Association
PHIA	*Personal Health Information Act*
RHA	Regional Health Authority
SCO	Southern Chiefs’ Organization
SNHS	Six Nations Health Services
SLFHNA	Sioux Lookout First Nations Health Authority
SFNFCI	Saskatchewan First Nations Family and Community Institute
TRTFN	Taku River Tlingit First Nation
UNDRIP	United Nations Declaration Rights of Indigenous People

Appendix D: Existing ISC Long-Term and Continuing Care Programs Reviewed

ASSISTED LIVING PROGRAM

- Provides **income-tested, residency-based funding** for the delivery of **non-medical social support services** in three settings to **seniors, adults with chronic illness, and children and adults with disabilities** (mental and physical) on reserve and in the Yukon to help them maintain their independence.
    1. **In Home Care**: services which enable clients to remain in their homes while ill or disabled (e.g. house cleaning, laundry, meal preparation, respite care);
    2. **Adult Foster Care**: for those who require various levels of supports to live on their own, in a group home or other setting offering supervision or access to services 24 hour per day; and
    3. **Institutional Care**: for individuals in long-term care homes needing a low-level of health care.
- The current program budget is $160M and approximately 10,000 to 12,000 clients are supported each year.

FIRST NATIONS AND INUIT HOME AND COMMUNITY CARE PROGRAM

- The First Nations and Inuit Home and Community Care (FNIHCC) Program is almost **completely transferred** with a wide coverage area (98% of First Nation communities and 100% of Inuit communities, in 686 First Nations and Inuit communities).
- The FNIHCC program funds a suite of **primary care services provided to over 30,000 First Nations and Inuit clients**, most of whom are seniors.
- The program is a co-developed and community-based and aims to support individuals with **complex care requirements inclusive of palliative and end-of-life care and their caregivers**, allowing them to remain in their homes and communities for as long as possible.
- The program is **comprised of 9 essential service elements** that are provided to **First Nations and Inuit people of all ages**, including vulnerable seniors and those living with disabilities and acute or chronic illness. These 9 essential services include: client assessment, case management, data collection, home care nursing services, home support and personal care, in-home respite, access to medical supplies and equipment, and linkages with other professional and social services.[1]
- In 2019-2020 with an annual budget of 180M, the FNIHCC program funded services for **30,164 individuals**.

Provided by Indigenous Services Canada on November 30, 2023.