FIRST NATIONS HEALTH AND SOCIAL
SECRETARIAT OF MANITOBA

MANITOBA FIRST NATIONS-LED LONG-TERM CARE ENGAGEMENT

FINAL REPORT

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EXECUTIVE SUMMARY

Long-term care can include a variety of services and supports which help meet both the medical and non-medical needs of elderly people or those with a chronic illness or disability who cannot care for themselves for long periods. First Nations Elders and persons with disabilities want to be able to receive culturally inclusive and safe care in their community, close to family and friends, as they age or their care needs change. In 2021, Indigenous Services Canada was mandated to engage First Nations on the "co-creation of options for a holistic long-term care continuum of health and social services for community members with continuing care needs at all stages of life, including seniors, people living with disabilities and others." (Trudeau, 2021)

Following this, the First Nations Health and Social Secretariat of Manitoba (FNHSSM) was directed via resolution passed at the 7th Annual General Meeting on March 16 & 17, 2022 by Manitoba Chiefs in Assembly to "facilitate regional engagement in partnership with Manitoba First Nations and Indigenous Services Canada to co-develop a comprehensive First Nation Holistic Continuum of Long-Term Care." The FNHSSM developed an approach to engagement that involved three phases: Phase I: Planning & Preparation; Phase II: Community Engagement; and Phase III: Final Report, Validation, Dissemination, & Knowledge Translation. The FNHSSM hosted a total of seven engagement sessions across all tribal areas on how First Nations in Manitoba envision a long-term and continuing care strategy that identifies community-defined challenges, needs, priorities, approaches, and recommendations. One additional session was facilitate by FNHSSM with representatives from various departments across the Government of Manitoba to provide preliminary results of engagement and to discuss how to best serve First Nations between both federal and provincial government-delivered services. Engagement discussions centered around current long-term care services & supports, First Nations' values and understandings around long-term care, and how First Nations envision a long-term care continuum.

Key themes of engagement that arose across all discussion concerned the following:

- A need for equitable services and supports between on-reserve and off-reserve as well as between First Nations and all other Manitobans;
- Reformation of funding approaches & funding formulas to better meet actual need in communities and to allow flexibility so communities can direct funds to meet evolving needs;
- Calls to involve First Nations/families/individuals in design & implementation and uphold community self-determination;
- Improved efforts to integrate Indigenous culture, language, & spirituality;
- Enhanced access to holistic wellness approaches;
- Enhanced continuity of care across the lifespan;
- Accessibility (namely accessibly infrastructure and accessibility to land-based activities, culture, recreation, health/social services);
- Investments infrastructure, capital funding including for operation & maintenance;
- Local capacity building;
- Tackling challenges around human resources;
- Home & Community Care Program transformation to improve the program's access and impact;
- A focus on support to remain in the home community;
- Improved supports for families and caregivers including respite and counselling;
- Concrete mechanisms to resolve jurisdictional disputes/quagmires;
- Personal care home licensing; and
- Provide in-community palliative care, dignity in dying, & connection to home when dying

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REVIEW OF THE LITERATURE

INTRODUCTION

Long-term care can include a variety of services and supports which help meet both the medical and non-medical needs of elderly people or those with a chronic illness or disability who cannot care for themselves for long periods. Long-term care is typically focused on individualized and coordinated services that promote independence, maximize patients' quality of life, and meet patients' needs over a period of time. Disability is commonly defined using the social model of disability, which takes into account not just a person's impairments or task difficulties, but also the added impact of environmental barriers to create disability. Examples of environmental barriers can include physical obstacles such as stairs; technological barriers such as inaccessible websites; or they can be social barriers, resulting in discrimination and exclusion. This perspective on disability focuses more on barriers to the participation of persons with disabilities in society and the economy and less on the perceived deficits of the individual (Government of Canada, 2019).

First Nations Elders and persons with disabilities want to be able to receive culturally inclusive care in their community, close to family and friends, as they age or their care needs change. This may involve, among other approaches, caring for their physical, spiritual, emotional, and mental well-being by providing holistic practices and connections to family, community, culture and land (Gionnas et al., 2021). 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 care services must leave their homes community to travel a significant distance to access provincial/territorial care. The absence of cultural inclusivity has been a longstanding issue. Healthcare systems in Canada were developed on a foundation of systemic racism, which continue to facilitate and force assimilation into "mainstream" healthcare treatment and disregard First Nations practices and perspectives (Gionnas et al., 2021). While in recent decades, more First Nations-run long-term care facilities have emerged which endeavour to incorporate culture, language, and traditional healing, the privileging of Western, colonial biomedical models of care by funders and regulators still creates significant barriers and impediments to First Nations' self-determination in long-term care.

This review of the literature seeks to define long-term care and identify the types of services and supports that typically fall under the umbrella of long-term care and then specifically outline and describe those available or not available to First Nations living in Manitoba including strengths, challenges, and gaps in care. Moreover, this review will seek to understand how these services and supports might relate or interact with each other under a continuum of care model. This review will also aim explore literature on Western and Indigenous understandings and values as they related to aging, disability, and care and how these can be incorporated into the provision of care. This literature review will inform a community engagement initiative with First Nations in

Manitoba to ultimately guide the development of a Manitoba First Nation-led Long-term care strategy.

DEFINING LONG-TERM CARE & LONG-TERM CARE CONTINUUM

Long-term care typically refers to ongoing, indefinite, care for individuals who can no longer fully care for themselves. Long-term care straddles both health care in the form of nursing/medical care and social services in the form of income supported housing, assistance with "activities of daily living," and the provision of recreational and social programs (Vladeck, 2003). Activities of daily living are commonly defined as basic functional tasks performed on a daily basis, such as general mobility, being able to clothe or feed oneself, to be continent and use the toilet, and to shower or bathe. Long-term care can be provided at home, in the community, in assisted living facilities or in nursing homes. It may be needed by people of any age, although it is especially important for many as they age.

Long-term care in Canada is commonly defined as representing: a range of services that addresses the health, social and personal care needs of individuals who, for one reason or another, have never developed or have lost some capacity for self-care. Services may be continuous or intermittent, but it is generally presumed that they will be delivered for the "long-term" that is, indefinitely to individuals who have demonstrated need, usually by some index of functional incapacity. (Havens, 2002).

Long-term care is commonly described in the context of a *continuum of care*, which aims to describe the need to provide "the right services, in the right place, at the right time" (Alexander, 2002). Through this conceptualization of a long-term care continuum, governments strive better meet individuals' and communities' needs, eradicate redundancies, and increase efficiencies through the integration and co-ordination of services. The concept of a continuum of care reminds us that long-term care does not just involve facility-based care alone, but a network of other institutions, services and supports such as home care, assisted living, supportive housing, chronic care, income assistance, complex continuing hospital-based care, and more. The continuum of care model thus has many implications for long-term care overall, where decisions made for one service/support can impact others and how individuals receive care across services. For example, the goal of shortening hospital stays, for instance, has resulted in the offloading of patients into long-term care facilities and the development, in some instances, of long-term sub-acute care beds. In the context of First Nations, this can mean pressure to send patients to their home communities that may not be suitable environments to adequately heal in (due to lack of resources for home care support and poor housing conditions that can add challenges for mobility and hygiene).

LONG-TERM CARE NEEDS OF FIRST NATIONS

Little comprehensive research has been done on continuing health care needs of 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. Moreover, although disability and aging have been studied widely for the general Canadian population (Arim, 2012; Burlock, 2017; Casey, 2015; Morris et al., 2018), there is a paucity of research among Indigenous peoples and First Nations people living on-reserve in particular. In the limited research that is available, Indigenous peoples have been shown to experience a disproportionate burden of disability when compared to the non-Indigenous population that amounts to as high as twice the rate of the national average (Burlock, 2017; Durst et al., 2006). According to the 2012 Canadian Survey on Disability, Indigenous women were more likely to have one or more disabilities than non-Indigenous women, with a similar pattern between Indigenous and non-Indigenous men albeit to a lesser degree (Burlock, 2017). Indigenous women were also more likely to experience greater severity in disability in comparison to the experiences of non-Indigenous women (Burlock, 2017).

There is also a limited research on disability types among Indigenous peoples. Much of the research conducted on these populations has approached the topic from the perspective of chronic health issues rather than disability. For instance, according to the 2008/2010 First Nations Regional Health Survey, based on First Nations adults living on reserve and in Northern communities, the most frequently reported chronic health conditions were 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%). Previous studies on pain among Indigenous peoples in Canada and the United States have found markedly higher rates of reported pain overall and in specific areas of the body. A greater proportion of First Nation people are also likely to suffer from chronic health conditions at a younger age compared to the general Canadian population (First Nations Information Governance Centre [FNIGC], 2012).

First Nation individuals frequently require continuing care at a younger age (Health Canada, 2007). Moreover, some evidence suggests an increase in the incidence of Alzheimer's and dementia among First Nations and an age of onset of about 10 years younger, which can increase and accelerate the transition from home and community care to facility-based long-term care (Warren et al., 2015). Projections based on only age as a risk factor suggest the number of First Nations people over the age of 60 with dementia of will increase 4-fold by 2031, compared to a 2.3-fold increase in the non-First Nations population (Walker & Jacklin, 2019). The First Nations population, in particular the seniors'/Elders' population on-reserve (55 years and older) is growing at a faster rate than the non-Indigenous senior population. First Nations population in Canada is expected to increase by 1.4 times between 2006 and 2030 with a disproportional amount of growth among those aged 60 and older (an increase of 3.4 times) (Caron & Morency, 2011).

Outcomes from a survey of health care workers in the First Nation and Inuit communities indicate that the demand for services across multiple activity types has increased, despite the decrease in the total number of service hours per client, including:

- Managing and coordinating care

- Home care nursing services
- In-home health care support services or in-home personal care
- Linking with other professionals and social services
- Access to specialized equipment, supplies and pharmaceuticals
- In-home services such as homemaking, house cleaning, meal preparation or
- companion/attendant support
- Client assessments
- Record keeping and data collection
- In-home respite care
- Need for admittance to long-term care facility
- Palliative care services

(Indigenous Services Canada [ISC], 2019)

Additional pressures that impact First Nation and Inuit communities are the limited availability of local facilities, cultural considerations in caregiving, and increases in youth with care needs stemming from Jordan's Principle (specifically, the clearer accountabilities and requirements to respond/act in a timely manner in these cases adds strain to an already strained system) (ISC, 2019). The increase in demand is more pronounced where communities are more geographically isolated (ISC, 2019).

Furthermore, seniors are the highest users of long-term care services, thus the growing population of seniors will create increasing pressures (ISC, 2019). The segment of the First Nations population aged 45 years and older is expected to more than double by 2026 from approximately 63,000 in 2001 (21% percent of the population) to 159,000 in 2026 (31% of the population) (ISC, 2019). The First Nations population, in particular the seniors'/Elders' population on-reserve (55 years and older) is growing at a faster rate than the non-Indigenous senior population. As a result, hospitals and long-term care services will continue to face increasing pressures to serve clients and patients with greater need, which may inadvertently result in lower prioritisation of those with less urgent needs, while also shortening hospital stays, and shifting the pressure to at-home care. While this shift may often be appropriate and even desired, it is important that services are able to accommodate increasing demands going forward.

With an expanding need to serve clients in their homes comes a growing need to ensure communities are able to deliver services and accommodate client needs in a culturally-consistent manner. Findings from the literature indicate that there is a continuing need for First Nations and Inuit communities to be able to define and receive health services. This goes beyond the need for cultural sensitivity and cultural competency. Rather, it speaks to directly addressing the power relations between service users and service providers (cultural safety), addressing some Calls to Action from the Truth and Reconciliation Commission Report. Specifically, it indicates a need for increased funding of Indigenous health centres, recognizing the value of Indigenous healing practices and their use in the treatment of Indigenous patients in collaboration with Indigenous healers and Elders, to increase the number of Indigenous professionals working in health care, and to provide cultural competency training for all health care professionals.

Anecdotal evidence from the grey literature highlights a number of notable barriers and gaps in disability services, programs, and supports offered on-reserve that negatively impact First Nations adults living with disabilities and their families. A commonly experienced challenge involves limited access to required medical and other resources (Assembly of First Nations [AFN], 2017). Some of the factors that may affect the delivery of resources to communities include: "demand for services; availability of local expertise based on demand for services and recruitment and retention challenges for care providers; year-round infrastructure for transportation; and weather and climate barriers impacting year-round service" (Canadian Home Care Association, 2016). As many of communities are remote and small, they lack many essential services such as medical care and homecare due to issues around transport and economies of scale. Moreover, many buildings on reserves are not accessible to persons with disabilities, and are not mandated to meet accessibility guidelines like many provincial/territorial and federal government buildings (AFN, 2006). Significantly, the issue of winter-roads affects many northern reserves and communities, making it difficult to have extensive and available access to the services requires (AFN, 2017). This means many must leave their home communities and move to urban centres in order to receive the necessary resources (AFN, 2017). Long wait lists, difficult diagnostic processes, and limited numbers of practitioners in some regions lead to poor access to intervention for many families (Underwood et al., 2018). First Nations with disabilities who must access care in urban settings are also prone to experiencing racism and disability-related discrimination while also being isolated from their communities and cultures (Durst, Bluechardt, Morin, & Rezansoff, 2001).

Research on long-term care needs among Indigenous peoples is especially relevant in light of colonization, experienced discrimination, historic oppression and trauma (Truth and Reconciliation Commission of Canada, 2018) that are tied to various social and health inequalities (Firestone, Tyndall, & Fischer, 2015). Some have highlighted how the overrepresentation of First Nations among those with disabilities is largely shaped by the impacts of colonization and on-going marginalization which have created elevated risk for injuries, substance use, chronic illness, and other conditions/determinants that are connected to disability (Ineese-Nash, 2020).

Moreover, in consideration of the social model of disability, First Nations—particularly those living on-reserve—are arguably further impacted by environmental conditions that work to shape limitations to activities for daily living and thus exacerbate experiences of disability. Such environmental conditions can include poor housing/living conditions and community infrastructure; inequitable, inaccessible, or inadequate access to disability support services; reduced support from informal social networks (family and community); lower Socio-economic Status (SES) which impacts an individual's ability to access the resources necessary for health and wellbeing (Adler & Newman, 2002; Reading & Wein, 2009). The literature on the disparities experienced by First Nations, relative to the general Canadian population, consistently shows direct and indirect links to a colonial-shaped socio-cultural, political, economic, and environmental context in which First Nations live today.

Not only do the environments shape First Nations peoples' experiences of disability and aging, so do the jurisdictional issues and disputes between governments and service providers for the provision of essential services, programs, and supports. First Nations living on-reserve are caught in a complex web of government-based jurisdictional and departmental wrangling, offloading, complexities, and ambiguities, directly impacting the types of services and supports they receive at the community-level (National Collaborating Centre for Indigenous Health, 2019).

The *Canada Health Act* (CHA) (1985) sets out criteria and conditions that a province's health care insurance plan must meet to receive the full cash contribution to which it is entitled under the Canada Health Transfer. However, there is no requirement that provincial health insurance plans cover extended health care services. "Extended health services" are defined in section 2 of the CHA and include the following: (a) nursing home intermediate care service; (b) adult residential care service; (c) home care service; and (d) ambulatory health care service. As continuing care is not an insured service under the CHA, "provinces deliver it in different ways … Even within provinces there are variations." (CHA, 1985) Registered/Status Indians living off-reserve, receive such services and medical care from provincial and territorial governments which deliver universal health services to all Canadians. The federal government is involved in providing disability services and supports on-reserve and in providing home care or funding through the following programs: the First Nations and Inuit Home and Community Care Program (Home Care Program), the Assisted Living Program, the First Nation Basic Foot Care Program (unique to Manitoba), Elders' Lodges, First Nations Personal Care Homes, Jordan's Principle-Child First Initiative, and On-reserve Income Assistance (Indigenous Services Canada [ISC], 2018). For a full catalogue of both federal/on-reserve and provincial, off-reserve services for persons with disabilities in Manitoba, please see **Appendix A**.

Since the 1960s, the federal government has adopted the position that health services are provided to First Nations in Canada "as a matter of policy only for humanitarian reasons and not due to any Aboriginal or Treaty rights" (Lavoie et al., 2016, p.8). The First Nations and Inuit Health Branch (FNIHB) of Indigenous Services Canada funds and delivers community-based health promotion and disease prevention programs, home and community care, and programs to control communicable diseases and address environmental health issues, as well as hires over 800 nurses and home care workers to work directly in First Nations and Inuit communities (ISC, 2018).

Decades of complex, ambiguous and fragmented jurisdictional issues, however, continue to result in frustration, confusion, unmet health care needs and, most concerning, higher mortality and morbidity of Indigenous peoples (Greenwood et al., 2018; Lavoie et al., 2015). As stated by Martin and colleagues (2018) "[a] dizzying array of services in the health-care system, including federal programmes, provincially provided services, and highly bureaucratized add-ons together continue to fail to meet the needs and constitutional rights of Indigenous people" (p. 1729). The case of Jordan River Anderson underscores the inequity of health service provision for Indigenous peoples and children living on reserve. A Cree child from the Norway Cree House Nation in northern Manitoba, Jordan was born in 1999 with complex health issues. He died in 2005 in a Winnipeg hospital at the age of five after waiting two years for federal and provincial governments to resolve the issue of who should pay for the necessary specialized care in his home community (Chambers & Burnett, 2017; Jordan's Principle Working Group, 2015). On February 26, 2016, a landmark ruling of the Canadian Human Rights Tribunal (HRT) called on the Government of Canada to end racially discriminating against First Nations children and to provide equitable funding and access to health, education and social services, with a fifth non-compliance order issued in February 2018 (First Nations Child & Family Caring Society of Canada, 2018). The Canadian government has been working to address these inequities under a program named after Jordan called the Jordan's Principle Child-First Initiative (ISC, 2018).

Overall, jurisdictional barriers have led to lengthy disputes between various levels of government over who has financial responsibility for particular health services for Indigenous peoples. Ultimately, ongoing jurisdictional disputes, funding inequities and structural discrimination raise "questions about where responsibilities [lie] for the 'implicit social contract' guiding Canada's vision of equitable health care," and how this affects the health and well-being of Indigenous peoples (Greenwood et al. 2018, p. 1647). Despite some research being invested into exploring the impacts of jurisdiction issues on the health status of First Nations peoples overall and the impacts on First Nations families and children living with disabilities on-reserve, we are not aware of studies that have explored how they impact, from the perspective of those navigating these systems, the lived-experiences of First Nations adults living with disabilities on-reserve.

BEST PRACTICES IN LONG-TERM CARE SERVICE PROVISION FOR FIRST NATIONS

The definition of adequate and appropriate disability services, programs, and supports is inextricably tied to cultural and social values and understandings of aging, disability, and caregiving. Accordingly, Indigenous and specifically First Nations' cultural values and understandings have important implications for the provision of care to First Nations individuals living with disabilities and their families. In fact, many aspects of how care is typically provided through Western, biomedical approaches can be culturally misaligned with Indigenous paradigms, contributing to feelings of loneliness and social and spiritual isolation, disconnection from family and community, alienation, communication breakdowns, associated impacts on health, and more (Government of Ontario, 2017).

First Nations' control over the design, delivery and administration of health and social services is recognized as central to ensuring cultural safety in health care provision in their communities (Cameron et al., 2014; Horrill et al., 2018; Ringer, 2017). Moreover, 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 well-being (Reading & Wien, 2009). This is especially true in contexts where dominant biomedical approaches have failed to reverse the course of the growing gap between the health of First Nations and non-First Nations persons in Canada (Angell, 2017; Katz et al., 2019). However, many First Nations leaders and scholars have critiqued current self-governance arrangements—purported to enact self-determination—are in fact mere "self-administration", where First Nations' control over programs and services is extremely limited and First Nations bands are still subject to federal government control via mechanisms like financial transfers, departmental administrative and accountability requirements, the use of third party management, and its ability to override all by-laws (Ladner, 2009; *Indian Act*, 1985; Elias, 1991). Ultimately these limitations on self-determination impact a community's ability to address the needs, priorities, aspirations and demands of the community, including the assurance of cultural inclusivity and safety in health and social service programming (Ladner, 2009).

Current long-term care services and supports available to First Nations on-reserve have been criticized to be culturally unsafe or inappropriate and unable to address the full scope of needs and priorities of First Nations individuals living with disabilities across the lifespan (Gionnas et al., 2021). The definition of adequate and appropriate supports and services is inextricably tied to cultural and social values and understandings of aging, disability, and caregiving (Gionnas et al., 2021). Accordingly, Indigenous and specifically First Nations' cultural values and understandings have important implications for the design and delivery of services, programs and supports. Western, biomedical approaches to health and social services can be culturally misaligned with Indigenous paradigms (Gionnas et al., 2021). The literature highlights the importance of two concepts are identified as key to long-term care service provision to Indigenous peoples: cultural competence and cultural safety. These concepts must be integrated into both the practitioner/worker and organizational levels.

Cultural competence is defined as the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, race, ethnic backgrounds, religions, and other diversity factors in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each. Providing culturally competent care means integrating and respecting Indigenous values into program policy and programming.

While First Nations are culturally and linguistically diverse, the literature has identified some shared cultural understandings and values that are pertinent to consider in developing and implementing long-term care services and supports. First, research has emphasized the holistic aspects of wellbeing in health service provision to First Nations. Good health and what it means to age well requires a balance between the mind, body, spirit, and emotions (Hillier & Al-Shammaa, 2020). A concept know as Mino Bimaadiziwin, or "The Good Path" or "The Good Life" is a cornerstone of many Indigenous teachings. This idea is based on the life-long pursuit of following the rightful path by respecting all life and understanding cultural teachings based on honouring oneself, one's relations and all of creation (Ineese-Nash, 2020). The Haudenosaunee have a similar concept known as "The Good Mind" (Antoine, 2013). In this way Indigenous teachings do not see disability as a medical condition that requires intervention to restore normal functioning, but a member of the community that maintains their place using their individual gifts as a resource (Bell, 2013). This contrasts Western, biomedical understandings that tend to focus primarily on the physical aspect of wellbeing, with services and supports that centre mainly around tending to physical needs. Spiritual, mental, and emotional wellbeing are often treated as outside of the scope of care or as recreational/optional instead of essential.

In an effort to decolonize policy pertaining to notions of disability support resources to First Nations, and to integrate Indigenous values systems, the addition of the medicine wheel to traditional models has been proposed The Medicine Wheel teachings are founded on a principle of holism, putting forth the importance of a balance between all four domains of humanity, namely the mental, physical, emotional, and spiritual (Lavallée, 2007). The Government of Ontario have developed a system of Aboriginal Health Access Centres (AHAC) that have integrated Indigenous healing practices that engages Elders, healers, medicine people, helpers and others from a traditional healing background. This model has been endorsed by all major Indigenous Provincial Treaty and Territorial Organizations. With this model they have found that cultural considerations have improved health outcomes (Government of Ontario, 2022).

Secondly, Indigenous understandings of health and wellness promotion typically aim tend to focus on strengths and resilience in opposition to the typical focus on deficits and problems. Indigenous notions of disability are distinct from the Western, colonial understandings that shape Canadian legislation and policy regarding disability support services. One colonial understanding of disability is exemplified in the Federal Disability Reference Guide (Canada, 2013). 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.

In contrast, the Disability Reference Guide also states the social approach views of disability "a natural part of society, where attitudes, stigma and prejudices present barriers to people with

disabilities, and prevent or hinder their participation in mainstream society" (Canada, 2013). This definition is more aligned to the Indigenous beliefs in its claim that disability is natural and normal; however, Indigenous teaching do not carry the same stigmas. Indigenous beliefs align with more recent advocacy and social justice approaches that speak of dis(ABILITY) and inclusion.
This distinction is embodied in the Indigenous languages spoken by the inhabitants of Turtle Island, which do not commonly have a word to describe the concept of disability. In Anishinaabe culture for example, children are named in ceremony and their names reflect the gifts and responsibilities that they hold within their community. Naming ceremonies reflect the understanding that all people are gifts to the community. In this sense, there is a focus on a child's abilities, strengths and talents, rather on their perceived limitations or weaknesses. The understanding that everyone within a community is kin comes from the cultural recognition that each individual is a descent of the original being Nanaboozhoo (or Nanabush). Consequently, Western, colonial notions of disability are viewed as in conflict with traditional teaching Indigenous worldviews. Thus, integrating an Indigenous approach to disability and long-term care supports may involve transforming programming to be more inclusive of building and maintaining client ability and strengths while still providing support for their challenges.

Thirdly, connectedness is a core aspect of Indigenous understandings of wellbeing. This often encompasses connection to family, community, the land, culture, and traditions (Balestrery, 2016; Coombes et al., 2018; Gabel & Pace, 2016; Habjan et al., 2012; Waugh & Mackenzie, 2011). Connectedness has also been highlighted as a key factor in what it means to age well among Indigenous Elders. Maintaining connections with one's community despite living away in a long-term care facility, a connection to the land despite mobility challenges, and being able to maintain intergenerational relationships are particularly important to Indigenous Elders (Balestrery, 2016; Baskin & Davey, 2015; Browne & Braun, 2017; Browne et al., 2014; Lewis & Allen, 2017; Owen-Williams, 2012; Wilson et al., 2010). Research outcomes emphasize how Indigenous culture, knowledge, and language are transferred from Elders to youth and Elders see this as a critical role and cultural obligation. Disability supports thus need to foster these relationships to support Elders' sense of meaning, belonging, and purpose, which are key components of Indigenous understandings of mental wellness (Health Canada, 2013; Gabel & Pace, 2016; Lanting et al., 2011; Lewis & Allen, 2017; Tobias & Richmond, 2016; Waugh & Mackenzie, 2011, Baskin & Davey, 2015; Brooks-Cleator & Giles, 2016; Waugh & Mackenzie, 2011).

Supporting connectedness is not commonly prioritized in the provision of disability services and supports that operate from a Western, biomedical model. Consequently, Indigenous Elders and persons with disabilities accessing disability supports and services often report a need for improved social support networks. Such improvements would ideally be achieved by being able to stay home or at least close to their homelands for as long as possible. Research has noted the critical role that family members, peers and social networks have in assisting with the management of care; however, many receiving care expressed concern with burdening their family and community (Government of Ontario, 2017). This is complicated by the noted change in the traditional extended family system, such that family and community networks were breaking down as a result of colonization (Muir & Bohr, 2019). Thus some studies noted how Indigenous individuals receiving disability supports viewed a need for shared responsibility of social support (caregiving) by the family/community and government system (Bonita & Weber-Beads, 2012). It is suggested that the opportunity for educational interventions be provided to the caregivers to assist with mitigating anxiety and cultivating supportive practices (Schulz et al., 2016). Creating social avenues to enable older adults to connect with both each other, and their culture, through health promoting activities was seen as important. Improved community-based resources to support such activities is key, especially increased funding to hire enough staff to meet need and flexibility in funding to support community-driven activities.

Related to supporting connectedness and holistic notions of health is the need for preservation and promotion of cultural approaches to living a good life and achieving holistic balance between the spiritual, mental, emotional, and physical aspects of wellness. Cultural activities on the land (berry picking, tanning hide, medicine picking, gardening, etc.), sharing circles, art-based activities, participation in ceremony, access to traditional foods, participation in community (via special events, volunteering, Elder-youth groups, Elder lodges, storytelling, language groups, drumming and singing groups, etc.).

Cultural safety incorporates the idea of a changed power structure that carries with it potentially difficult social and political ramifications (Ramsden, 2002; Cooney, 1994). It questions and challenges the concept of cultural competence and, by bringing in the notion of safety, it extends the debate by focusing less on the benefits of cross-cultural awareness and sensitivity, and more on the risks associated with their absence (Curtis et al., 2019). Culturally unsafe practices have been defined as “any actions that diminish, demean or disempower the cultural identity and well-being of an individual.” (Kirmayer, 2012) Power imbalances need to be addressed so that Indigenous and non-Indigenous ways of knowing can come together and be equally valued (Blanchet-Cohen & Richardson/Kinewesquao, 2017). The current power structure undermines the role of Indigenous people as partners with healthcare workers in their own care and treatment.

In contrast, culturally safe long-term care services can be supported through a number of actions. Firstly cultural safety training for all staff is paramount and should be designed and delivered by Indigenous organizations. Such training could include topics like:

- respect for Indigenous views of aging, disability, and of the understandings of care;
- knowledge of the complexity of the Indigenous determinants of health;
- understanding the role of the family in care;
- approaches for relationship development with primary care professionals to help minimize distrust in the health care system;
- culturally specific coping strategies;

- knowledge of historical policies that may affect care giving today and of contemporary policies that result in differential access to care;
- training on appropriate advocacy for Indigenous caregivers; and
- the development of health promotion and prevention tools that are sensitive to diverse Indigenous peoples' understandings of aging, disability, and care.

Activities and programming overall should be driven by clients and community, with policies and mechanisms in place to engage, consult, and evaluate all aspects of programming with community, clients, and families on a frequent basis to ensure that Indigenous clients' needs, priorities, values and ways of knowing are equally valued alongside Western, biomedical approaches. Such policies and mechanisms could involve establishing a committee that consists of clients, family members, community leaders and more to guide programming. Such a committee would also support on-going self-determination in disability supports. Programs could also adopt practices to integrate cultural information into the care plan; create constructive mechanisms for dealing with intercultural conflict and encouraging respect; innovative ways to attract and retain Indigenous staff, supervisors, board members; and more (Schill & Caxaj, 2019).

Despite these advancements in knowledge and understanding of the important of gaps in services, impacts of jurisdictional issues, role of self-determination, and importance and meanings of cultural inclusivity/safety in health and social services in general, no research has explored these factors in relation to disability supports specifically, especially from the perspectives of First Nations adult individuals and their families living on-reserved directly utilizing and relying on them. A comprehensive exploration of the lived-experiences of First Nations adults living with disabilities and accessing disability services and supports on- and off-reserve would give invaluable insight into avenues for system changes to better meet needs and priorities; reduce gaps and barriers; and foster improved quality of life for these individuals and their families. Consequently, the objective of this qualitative study was to explore the lived-experiences of First Nations adults living with disabilities in Manitoba, with a particular focus on their experiences and perspectives around disability services, programs, and supports.

LONG-TERM CARE IN MANITOBA: PROVINCIAL SERVICES, OFF-RESERVE

In Manitoba, the responsibility for long-term care for First Nations is shared between provincial and federal governments. Different services and supports that fall under the long-term care continuum are provided across several different provincial ministries and health service providers. Manitoba Health funds many long-term care services via the five regional health authorities including home care, supportive housing, personal care homes, and palliative/end-of-life care supports and services. There are five Regional Health Authority offices including the Interlake-Eastern Regional Health Authority, Prairie Mountain Health, Winnipeg Regional Health Authority, Northern Regional Health Authority, and Southern Health-Santé Sud offices. These provincial services are available to all eligible Manitobans in their respective regional health authorities, including First Nations. However, provincial programs operate off-reserve only, with the exception of some costs paid for adult care in long-term care facilities on-reserve. Manitoba Department of Families funds and delivers income supports for Elders/seniors and persons with disabilities as well as the Community Living disABILITY Services and Children's disABILITY Services programs.

https://www.ltcam.mb.ca/options_map.htm

MANITOBA HOME CARE PROGRAM

The Manitoba Home Care Program, established in September 1974 and provides a continuum of services including home–based care planning and provision, liaising with other care providers, and managing Personal Care Home placement. In 2004, Manitoba Health announced Aging in Place as an alternative to PCH care for some individuals. This in effect expands Manitoba's continuum of home and PCH care to include supportive housing.

Home Care is provided to Manitoba's of all ages based on assessed need and taking into account other resources available to the individual, including families, community resources and other programs. The Home Care program was established to help people live at home and remain independent for as long as possible, thereby avoiding or delaying the need for individuals to go into long term care facilities.

The mandate of the program is to provide effective, reliable and responsive community health care services to support independent living, develop appropriate care options with clients and/or family, and facilitate admission into long term care facilities when living in the community is no longer possible.

Typical home care services under the program may include:

- Personal Care Assistance (bathing, dressing, toileting)
- Home Support (meal preparation, light housing keeping and laundry)

- Health Professional Services (example nursing)
- Assistance with taking medications
- Respite Care
- Other specialty services and clinics

Individuals seeking home care services must access the program via their respective regional health authority. Individuals looking to access other provincial supports such as home care, supportive housing or a personal care home must start with their respective regional health authority home care access point as well.

Some regional health authorities are also looking to provide enhanced transitional care under their home care programs. These “Transitional Care Environments” will aim to benefit patients who have completed the acute care portion of a hospital stay but who need some transitional support before returning home. The goal of separating transitional care from an acute care environment is to improve the quality of care and reduce unnecessary hospital burden and costs. Clients using transitional care will be medically stable and ready to be discharged from hospital, but still need time to make long-term arrangements for their care. Following a short term (30-90 day) transitional care stay in an acute care setting, clients may be able to return home with home care supports, be eligible for a supportive housing environment or, or receive care in a personal care home. In a transitional care environment, the care team will assess and determine the level of care and support necessary for each client.

Transitional care will eventually be offered out of community hospitals once the WRHA’s Healing our Health System consolidation plan is fully implemented. In the interim, this transitional care environment will provide additional capacity to establish and implement an enhanced home care system – called Priority Home – which will help many clients return straight home with robust home care supports.

Another planned strategy called a “Priority Home” may be available as part of the home care program in the future. The new service is anticipated to provide intensive home care to clients for up to 90 days as an alternative to a transitional care stay in a hospital or acute care setting. Following the 90 days, it is anticipated that most clients will be able to remain in their homes with regular, ongoing home care, and not require immediate paneling for a personal care home.

Being able to recover at home, among familiar surroundings and comforts, can have a profound effect on recovery and also reduce the potential for injury. It is a much healthier option for those clients who don't need to be in hospital. This intensive service will also help reduce the length of time clients spend in hospital, and may help some avoid placement in a personal care home altogether.

SUPPORTIVE HOUSING

Supportive Housing is designed for individuals who require access to 24 hour supervision and some assistance managing with physical limitations, or ongoing health conditions such as dementia. . In Supportive Housing, people live in their own apartment within a group community setting. Meals are provided and people share a common kitchen and living area. Laundry and housekeeping services are available, as well as social and recreational activities. Residents receive some support and cueing with activities of daily living such as bathing, dressing, and medication reminders.

Individuals seeking to access Supportive Housing must do so via their respective regional health authority's home care contact. Rent and services are paid by the resident, while the support component is funded though the Regional Health Authorities of Manitoba. The cost of living in a supportive housing unit average between $1695-$3195 per month. Both the Disability Tax Credit and the Primary Caregiver Tax Credit can be used to offset some of the costs of Supportive Housing.

PERSONAL CARE HOMES

A Personal Care Home (PCH), also known as a "Nursing Home" or "long term care home," provides personal care services to individuals who can no longer manage independently at home with family support and community services.

The insured personal care services provided throughout Manitoba's 125 licensed personal care homes include the following:

- meals (including meals for special diets)
- assistance with daily living activities such as bathing, getting dressed and using the bathroom
- necessary nursing care
- routine medical and surgical supplies
- prescription drugs eligible under Manitoba's Personal Care Home Program
- physiotherapy and occupational therapy, if the facility is approved to provide these services
- routine laundry, linen and housekeeping services

Access to a personal care home is provided through regional health authority's Home Care program. The provincial government (Manitoba Health) and the client or resident who needs the services share the cost of personal care home services. Manitoba Health pays the majority of the cost through the regional health authorities. The personal care home resident pays the other portion of the cost, called a Residential Charge.

A classification system for PCH residents is used to define the extent of their dependence, to approximate the amount of daily nursing care they may require, and thus determine which facilities may be best suited to meet the resident's level of care need. All nursing home (PCH) residents are assessed at one of four levels of care based on the Dependency Assessment Supplement (DAS). This assesses the residents' abilities to complete activities of daily living tasks, on their need for professional interventions, and their degree of behavioral problems. This leads to a determination of the number of nursing hours they require per day.

Assessments occur as part of the panelling process for admission to a personal care home (PCH) and at regular intervals during the residents' stay in a PCH. All residents are assigned a level of care based on their assessed dependence in six areas:

1. bathing and dressing,
2. assistance with meals including feeding,
3. ambulation/mobility/transfers,
4. elimination,
5. professional intervention (such as oxygen therapy, skin care, recording of vital signs, and treatments/medications), and
6. behaviour management/support and supervision required.

In each of the six areas of care, people receive a score ranging from:

- Independent (score of X) - requires no supervision or assistance
- Minimum dependence (score of A) - requires some supervision/encouragement and/or intermittent assistance
- Partial dependence (score of B) - requires ongoing supervision and/or assistance
- Maximum dependence (score of C) - completely dependent and/or requires ongoing supervision
- Chronic care indicator (score of D) - as 'score C' but requires ongoing attention by medical staff and/or multiple people to provide assistance.

Individuals that are assigned a score of 'chronic care indicator' in any of the six areas of care may be considered for placement into a chronic care facility in Manitoba, such as Deer Lodge or Riverview located within the Winnipeg Regional Health Authority (WRHA).

The assessment is currently done using a standardized tool called the Dependency Assessment Supplement (DAS). Based on the scores in each of the six areas, an algorithm is used to assign people to one of four levels of care.

Based on the individual area scores, the level of care is defined using the following rules:

- Level of Care I : Score of 'independent' or 'minimal dependence' in all six items.
- Level of Care IV : Score of 'maximum dependence' in four or more items.

- Level of Care III :
    - a) Score of 'maximum dependence' in two or three areas of care plus a score of 'independent' or 'minimal dependence' in all other items OR
    - b) Score of 'maximum dependence' in the behavioral management item plus a score of 'partial dependence' in at least two other items.
- Level of Care II : All remaining combinations.

Hours of nursing care in a PCH have been estimated for residents assigned to different levels of care. Residents assigned to Level of Care I are estimated to require 0.5 hours of care in a 24-hour period. Residents assigned to Level of Care II are estimated to require 2.0 hours of care in a 24-hour period, while those assigned to Level of Care III or IV are estimated to require at least 3.5 hours of nursing care during a 24-hour period.

AGING IN PLACE COMMUNITY

An “Aging in Place Community” sometimes known as a “Campus of Care” model, can be described as a residence or group of residences, where more than one type of living and/or care option is offered on the same property. As more “Aging in Place Communities” are developed, individuals may choose to live in a community such as this in order to accommodate future service and care requirements should they arise. The options within an Aging in Place Community could include two or more of the following settings:

- Independent Living with Services (also known as Assisted Living)
- Supportive Housing Residence
- Personal Care Home

Aging in Place communities are designed to improve the continuum in care and reduce the potential detrimental impact of moving an individual from their established community (circle of friends, familiar staff, familiar setting, close to family, etc.) or away from their spouse should they require a higher level of care. In situations involving spouses, such communities would aim alleviate the caregiver burden, while providing an environment where the couple can still be together.

PALLIATIVE/END-OF-LIFE CARE

Palliative or end-of-life care is an approach to care that improves the quality of living and dying for the patient and their families. The palliative approach provides exceptional care to alleviate suffering and provides important physical, psychological, social, spiritual and practical supports. Palliative/end-of-life care is available in many care settings in Manitoba, including the home, in a palliative care unit (in a hospital or acute care setting) or in a hospice, a personal care home (PCH) or other health care facilities.

The Winnipeg Regional Health Authority (WRHA) Palliative Care program provides access to care 24 hours a day to people registered with the WRHA program. The program also provides consultative services to patients and health care professionals across Manitoba. Direct palliative care services in the community are provided through home care in some regional health authorities.

End-of-life care delivered at a hospice facility is intended for individuals who have symptoms that are relatively well-controlled and who do not require specialized treatments in an acute care facility. In general, hospice is considered if a patient has a prognosis of one to three months and cannot or do not wish to receive care at home.

The Palliative Care Drug Access Program (PCDAP) provides deductible-free drug coverage for individuals who choose to remain at home for the final days of their life. Manitoba Health already covers the costs of drugs for individuals who are in hospital or a personal care home, so the PCDAP ensures that the same cost-free coverage is available to those who reside at home in their final days. The PCDAP is administered through Manitoba Health, and includes the costs of all eligible drugs prescribed by an eligible health care provider. Individuals enrolled in the program will not be charged for their prescribed medication when filling their prescriptions at the pharmacy of their choice.

The program is open to residents of Manitoba with a current Manitoba Health registration number. When an eligible health care provider makes a palliative diagnosis, an application form must be completed and signed by the patient (or guardian) and their health care provider. The health care provider will then send the completed application form to the palliative care coordinator in the local regional health authority. If the patient is eligible for coverage, the form will be forwarded to Manitoba Health for registration.

CHILDREN’S disABILITY SERVICES PROGRAM

Children's disABILITY Services offers a variety of resources and supports to parents to assist them to care for their children at home in their own communities, where children grow and thrive. This program, provided through Manitoba Department of Families, supports families who are raising a child (or children) with developmental and physical disabilities, to meet some of the additional needs they may have. Children under the age of 18, who live in Manitoba with their birth, adoptive or extended families, are eligible. Eligible children must also have a medical diagnosis confirming one or more of the following conditions:

- intellectual disability
- developmental delay
- autism spectrum disorder
- lifelong physical disability
- high probability of developmental delay due to a pre-existing condition

Eligible families can be referred to Children's disABILITY Services by medical professionals, schools, and day cares. Families may also apply to the program directly by completing the Referral and Intake Application form (PDF) and submitting it, along with diagnostic assessment or medical report, to the regional Children's disABILITY Services office in their region. Services are not available on-reserve.

COMMUNITY LIVING disABILITY SERVICES PROGRAM

Community Living disABILITY Services aims to support eligible Manitoban adults (18 years of age or older) with significantly impaired intellectual functioning with impaired adaptive behaviour, existing prior to the age of 18. The program, provided through Manitoba Department of Families, aims to assist individuals with intellectual disabilities in Manitoba to live good and satisfying lives in their communities and empowers clients to make their own decisions regarding their life and care. Namely, the program aims to work with clients to provide client-driven supports and service via development of a “person-centred plan” that aims to empower clients to

- make decisions about their own life, including what services they may want
- have the right amount of support needed to be happy and healthy
- do things in the community that are important to them
- stay connected with family and friends, and other important relationships
- meet new people in their community

Potential services and supports provided through the program include:

- Supports to People Living at Home with Family: respite, in-home services vis support to family (person-centred and family focused planning, problem solving, before and after school/day service support, recreational activities, training or learning opportunities) or via outreach services (assistance with moving, help with developing skills that align with client goals, learning opportunities for the client or family)
- School In-Service and Summer Programming (for those 18-21 years of age)
- Day Services (employment, job training, or accessing a day service operated by an agency or recreational activity in community)
- Residential Services (supported independent living, rent top-up, home share, staffed home/group home)
- Clinical Services (assistance with clinical needs including specialized diets, therapy, etc.)
- Crisis Intervention (short-term crisis intervention services, establishing and accessing safe living arrangements)

You can apply to Community Living disABILITY Services by contacting their closest office. Referrals can also be made via the individual’s school, family, an agency, a doctor, or other person in their support network with consent of the prospective client. The program is available to First Nations, but they must have an established permanent residence off-reserve in Manitoba prior to referral or request for services.

DISABILITY AND HEALTH SUPPORTS UNIT

Disability and Health Supports Unit (DHSU) assists with obtaining health-related supplies, equipment, and nutritional or diet supplements required based on medical need. In order to qualify for DHSU the individual must be enrolled in the Employment and Income Assistance Program, the Children's disABILITY Services Program or the Community Living disABILITY Services Program. All requests for health related products must be made by an approved health care professional and can include: specialized medical equipment; medical supplies; and nutritional supplements and diets to support a diagnosed medical conditions.

Medical equipment can include assistive devices; mobility aids; support stockings; hearing aids and batteries; customized seating for wheelchairs, and wheelchair lifts, or ramps. Medical supplies can include diabetic supplies; feeding supplies; incontinence supplies for medical conditions; and oxygen. Eligible items may be delivered to an applicants home.

TRANSPORTATION

A number of services exist in Manitoba to support access to subsidized and specialized transportation for Seniors/Elders and those with disabilities; however these services are typically limited to the urban setting of Winnipeg alone. These services include the following:

- Canadian Cancer Society Volunteer Driver Program: Provides transportation to ambulatory cancer patients receiving active cancer treatments who have no other options. Fees are applied monthly.
- **Ring-a-Ride Program**: Assists older adults in the community get to appointments, social outings and more with the help of a volunteer driver. All volunteers are screened to ensure client safety. Clients accessing this program must be independently mobile (ambulatory). Program users must live independently and live within the postal codes R3L, R3M, R3N, R3P, and R3T. Donations are requested to help support this program.
- Winnipeg Transit Plus: Winnipeg Transit Plus is a service of Winnipeg's public transit system that provides door-to-door transportation for people who are unable to regularly use the City's fixed route transit system because they are legally blind or have a disability that significantly impairs their mobility.

FINANCIAL SUPPORTS

Financial assistance for those requiring care and/or services is available depending on the individual's need. There are a variety of provincial tax credits, benefits, subsidies, and supplements to assist persons requiring long-term care, depending on their specific situation. Financial assistance supports specifically for Seniors/Elders and those with disabilities include:

- 55 PLUS Program, a Manitoba Income Supplement which provides quarterly benefits to lower-income Manitobans who are 55 years of age and over, and whose incomes are within certain levels

- Employment and Income Assistance (EIA) through the "Persons with Disabilities" category that provides financial help to Manitobans in need, supports for clients to meet their health needs, supports and referrals to help clients gain employment and achieve financial independence, and is available to all Manitobans living off-reserve. EIA is a program that is not specifically geared to First Nations, despite First Nations being disproportionately represented among EIA clientele. There are many different categories of assistance with a sub category for those who have a mental or physical disability that prevents them from earning enough money to meet individual and/or families basic needs. The disability must be likely to last more than 90 days and a financial need must be demonstrated. Financial need is based on basic need and shelter costs. Financial resources are based on assets and income. Basic needs are calculated according to family size and cost of ongoing medical needs. Rent assistance may also be applied to offset the cost of shelter, utilities and fuel and is calculated at 80% of Median Market Rent according to household size. Unlike for those in other categories of the program, EIA for those with disabilities does not require individuals to look for work to qualify.
- A new income support program for Manitobans with severe and prolonged disabilities, separate from EIA, is currently in development (). Design of new program is being informed by community feedback that urged for a service navigation component that provides information and referrals, case management, employment and training supports, enhanced communication with clients, and transition support.
- Rent Assist is a financial benefit for people who receive Employment and Income Assistance (EIA) and have housing costs to cover. It is also available to other low-income private renters. The amount paid from Rent Assist depends on the number of people in the household especially dependent children, the total household income, age of applicant (55 years or older), and disability status of applicant. This program is available to First Nations, but they must not live on reserve or in Manitoba Housing, a personal care home, supportive living, student housing, or receive any other housing benefit or subsidy.

INDEPENDENT/ASSISTED LIVING (PRIVATE)

Independent/Assisted Living is an uninsured service that is not associated with the provincial government Private senior living buildings are rented by individuals and different support services are offered depending on different service packages offered at different residences. The residence may offer various services such as housekeeping, meals, recreation, and more. Individuals who require financial assistance may qualify for Rent Assist to supplement the cost of Independent/Assisted Living. Home Care services can be used by individuals living in an Independent/Assisted Living residence.

OTHER SERVICES/SUPPORTS

Allied Health Services

Within Manitoba, the Reginal Health Authorities (RHA's) also offer therapy services that include physiotherapy, occupational therapy, speech language pathology and audiology. Therapy are delivered by RHA and service providers in hospital and community settings. Hospital-based therapy services are funded by Manitoba Health as an insured health benefit. Many community-based therapy services are also fully funded. A referral from a physician or other health professional may be required for community-based services. Services that are offered by the provincial government are accessible to First Nations persons but not offered on-reserve.

Not-For-Profit/Charitable Services

Indigenous Friendship Centres in Manitoba typically offer a number of different programs to support Indigenous seniors in the local community. Such programs can include cultural/spiritual activities and supports, recreation, assistance with programs, and other lifestyle choices and needs

The Indigenous Senior Resource Centre is a non-profit, charitable organization that utilizes a holistic approach to ensure the respect and well-being of Indigenous Seniors in Winnipeg. Their goal is to help improve the health and well-being of Indigenous Seniors in Winnipeg by:

- Increasing access to information, resources, and supports for Indigenous Seniors.
- Creating opportunities for active involvement within the community as a means of achieving physical, emotional, mental, and spiritual balance.
- Providing opportunities for Indigenous Seniors to pass on their traditional values and historical knowledge to our younger generations.
- Create an environment where Indigenous Seniors can celebrate their uniqueness and build strong community friendships.

Manitoba Senior Centres are health promoting, capacity building, and community focal points on aging where older persons can come together for services and activities that enhance their dignity, support their independence and encourage their involvement in and with the community. Open to all individuals 55 years and older, or retired, senior communities provide programs that offer core health services, are governed by a community-based board of directors, respond to diverse needs of older persons, hire professionals, provide education, develop innovative programming approaches, and are a community resource for information on aging.

A & O: Support Services for Older Adults is a not-for-profit organization that provides specialized services for older Manitobans across the province. The goal of these programs is to empower and support older adults in the community. The Agency aims to improve the quality of life for older adults in Manitoba through advocacy, education and service delivery and involve older adults in decision-making.

Community Respite Service Inc. provides quality respite in parts of southern Manitoba, especially Winnipeg and the Westman regions, for the caregivers of and to individuals with physical and/or intellectual disabilities. Community Respite Service (CRS) provides parents and caregivers of people with intellectual and/or physical disabilities the opportunity to take a much deserved break. We also provide support, companionship and assistance to people with disabilities whether they are living independently in their communities or with their caregivers.

St. Amant is a not-for-profit organization for Manitobans with developmental disabilities, and autism that offers a wide range of programs and services to support individuals and their families. St.Amant programs include a large residence for complex-care with more than 100 community sites and homes. They are a member of the Catholic Health Network and offer programs for children with autism and also for families who care for an individual with a developmental disability at home.

LONG-TERM CARE IN MANITOBA: FEDERAL SERVICES, ON-RESERVE

The *Canada Health Act* (CHA) sets out criteria and conditions that a province's health care insurance plan must meet to receive the full cash contribution to which it is entitled under the Canada Health Transfer. However, there is no requirement that provincial health insurance plans cover extended health care services. "Extended health services" are defined in section 2 of the CHA and include the following: (a) nursing home intermediate care service; (b) adult residential care service; (c) home care service; and (d) ambulatory health care service. As continuing care is not an insured service under the CHA, "provinces deliver it in different ways … Even within provinces there are variations."28

The federal government is involved in continuing care on reserve and in providing home care or funding through the following programs: the First Nations and Inuit Home and Community Care Program (Home Care Program), the Assisted Living Program, the First Nation Basic Foot Care Program (unique to Manitoba), Elders' Lodges, First Nations Personal Care Homes, Jordan's Principle-Child First Initiative

FIRST NATIONS AND INUIT HOME AND COMMUNITY CARE PROGRAM

The First Nations and Inuit Home and Community Care program supports the delivery of a continuum of basic home care services. This suite of services is based on a case management approach that includes client assessment and reassessment, which can involve the client, family caregivers or service providers, and help determine a client's needs and the services required. Home care nursing includes direct service delivery, personal care services and support to family caregivers. The basic home care services also encompass home support (e.g., bathing and grooming, home management assistance, etc.), as well as in-home respite benefiting clients, families and caregivers. The program also entails access to medical equipment and supplies, management and supervision, data collection and record-keeping, as well as linkages and referral, as needed, to other health and social services. Depending on community needs, priorities, infrastructures and resources, the Program may also incorporate supportive services: rehabilitation and other therapies; adult day programs; meal programs; in home mental health; in home palliative care; and, specialized health promotion, wellness, and fitness services. On-reserve First Nations, of all ages, with disabilities, chronic or acute illnesses and the elderly, as well as those who require continuing care on-reserve, are eligible for the program.

While the Home Care Program has authority to provide supportive services such as palliative care, mental health home-based care and therapies, it does not directly fund them. According to the most recent internal audit of the Home Care Program, "These services can only be provided once essential service elements are provided and if there are remaining funds."34 In her appearance before the Committee, an ISC representative noted that the Home Care Program had gaps, such as limited hours of service and limited types of services (i.e., physiotherapy and occupational therapy).35

ASSISTED LIVING PROGRAM

The Assisted Living Program provides funding for non-medical, social support services to seniors, adults with chronic illness, and children and adults with disabilities (mental and physical) on-reserve to help them maintain their independence. It includes in-home care, adult foster care, and institutional care (for those needing personal non-medical 24-hour care). The services are available for people who live on reserve and do not maintain a primary residence off-reserve. Funding is approved though a band appointed assisted living coordinator or band managers.

Services included home care, institutional care, adult foster care and disability initiative. The program does not offer nursing or medical care. However, eligible individuals can receive light housekeeping services and supervision as part of an in-home care or adult foster care service. The in-home care incorporates funding for assistance for daily living including but not limited to housekeeping, meal preparation and laundry services. Adult foster care provides management for adults in family settings that are unable to live on their own but do not require 24-hour supervision. For institutional care, the program helps to subsidize the facility copayment fees related to room and board for those within an institutional environment, long-term care facility, or personal care home, either on or off reserve.

The scope of the Assisted Living Program is limited and functions like an income support program, available to those individuals who cannot pay for institutional care or in-home care supports themselves and who do not have any available family members who can provide the service for them. In addition, the financial support for institutional care (on or off reserve) is provided only for people requiring Types I and II care.39 The responsibility to provide funding for delivering care in institutions (on or off reserve) for Types III, IV and V care falls to the provinces and territories.

FIRST NATION BASIC FOOT CARE PROGRAM

First Nation Basic Foot Care Program aims to help Manitoba First Nations lower their risks of diabetes-related foot complications and will see services provided by certified foot care nurses through Tribal Councils or directly by community health services. The Foot Care Program was developed to ensure access to Basic Foot Care Service in all Manitoba First Nation communities with an overall goal of reducing diabetes related foot complications and the rate of lower limb amputations. Basic Foot Care services is provided by a nurse (LPN/RN) with basic foot care certification and services are often provided alongside the Home and Community Care Program. The Foot Care Program is jointly led by the FNHSSM/Diabetes Integration Project (DIP) and the Manitoba First Nations Diabetes Leadership Council (MFNDLC). The program also provides professional development and capacity development opportunities in communities.

FIRST NATIONS PERSONAL CARE HOMES

Manitoba currently has 8 First Nations Personal Care Homes. Those that are unlicensed by the province include: Ochekwi Sipi Personal Care Home (32 beds); George M. Guimond Care Centre (30 beds); Peguis Senior Centre (22 beds), Dakota Oyate Lodge (26 beds); Rod McGillivary Memorial Care Home (40 beds); and George Colon Memorial Home (34 beds). Those that are license by the province are: Nisichawayasihk Personal Care Home (24 beds) and Pinaow Wachi Personal Care Home (26 beds)

ELDER’S LODGES

Elders’ Lodges are community-based live-in residences that provide collective housing, social, dietary and cultural activities. The Elders’ Lodges operate either funded through the Home & Community Care Program or by our Assisted Living program funding. There are currently 7 Elders’ Lodges in Manitoba: Kasayak Centre (16 units), Ginew Elders Lodge (12 units); Poplar River Elders Lodge (12 units); Private Matthew Sinclair Elders Lodge; Pine Creek Elders Lodge; Gods Lake Elders Lodge; and Tataskweyak Elders Lodge.

JORDAN’S PRINCIPLE-CHILD FIRST INITIATIVE

Jordan’s Principle is a child-first principle to resolving jurisdictional disputes within and between federal and provincial/territorial governments within Canada. It was named in memory of Jordan River Anderson, a young boy from Norway House Cree Nation, who spent more than two years unnecessarily in hospital while Canada and Manitoba argued over payment for his at-home care.

Under the Jordan’s Principle – Child First Initiative, Niniijaanis Nide “My Child, My Heart” Program provides supports to families with children with complex needs and to help enhance the child’s life and facilitate health care interventions and developmental stimulation. The program engages families and the community in working together to improve services. The goal is to contribute to quality of life ensuring that children, young people and their families are enabled to experience a life that is as full and as normal as possible. Children living on- reserve with complex needs are eligible under the program.

Supports and Services may include Respite Care and Support Groups, Child Development Program (Preschool), American Sign Language (ASL), Therapy, Intervention Programs, Socialization Activities, and Land-Based Activities.

NON-INSURED HEALTH BENEFITS

The Non-Insured Health Benefits (NIHB) program provides eligible First Nations with coverage for a range of health benefits that are not covered through other social programs, private insurance plans, or provincial or territorial health insurance. NIHB covers a wide variety of "medically necessary" goods and services essential to people living on reserve with disabilities, chronic illness, or other challenges associated with aging including vision, dental, mental health counseling, medical supplies and equipment, prescription and over-the-counter medications, and medical transportation. Medical transportation includes transportation to enable access to health services that are not available on-reserve or in the community of residence. In order to qualify for NIHB you must be a First Nations person registered under the Indian Act (Status Indian) or a child less than 18 months old of a parent that is eligible.

FINANCIAL SUPPORTS

On-Reserve Income Assistance is delivered by Indigenous Services Canada and administered locally by community-based Social Assistance Administrators. The program intends to alleviate poverty in First Nations by providing families and individuals the means to meet their basic needs and typically matches payment amounts and policies delivered by comparable provincial/territorial programs.

- An additional monthly allowance called a disability allowance is payable to a recipient or adult dependent who has been medically assessed as having a disability (a physical or mental illness, incapacity or disorder that is likely to continue for more than 90 days) and who is residing in the community.
- A benefit payable on behalf of an eligible physically and/or mentally disabled adult who requires assistance in activities of daily living and who is residing with his or her family or in a private boarding home is available called a special care room and board allowance or a special care allowance.
- There are also two Social Categories that pertain to adults (age 18 or older) and who lack sufficient financial resources to provide for basic needs due to family responsibilities or circumstances. These responsibilities include:
    - parents of a child with special needs (severe disability) who requires extensive parental care;
    - persons who are providing full-time unpaid care for an elderly or disabled relative residing in their household

Other Federal Financial Supports:

OAS, CPP, Guaranteed Income Supplement

- Primary Caregiver Tax Benefit
- Disability Tax Credit
- Employment Insurance sickness & caregiving benefits

Canada Mortgage and Housing Corporation On-Reserve Program

- Residential Rehabilitation Assistance Program for Persons with Disabilities
- Home Adaptations for Seniors Independence (HASI) Program

METHODS

OBJECTIVES

This engagement project aims to conduct thorough and meaningful community engagement on how First Nations envision a long-term and continuing care strategy that identifies community-defined challenges, needs, priorities, approaches and recommendations. Namely, via this engagement, we seek to:

- Explore First Nation understandings/values of what it means to age well or live well with a disability and what good long-term care means
- Develop community-driven solutions and ideas for culturally-safe care in long-term care
- Assess current services to determine needed changes
- Determine what services, resources, supports are missing according to need and values
- Develop a Long-Term Care Continuum Framework steeped in First Nations values, culture, needs and priorities
- Advocate for processes to ensure self-determination and on-going community input into long-term care planning
- Information management (eHealth, managing data, defining evaluation measures), who should Own, Control, Access, and Possess data

RATIONALE

In 2021, Indigenous Services Canada was mandated to engage First Nations on the "co-creation of options for a holistic long-term care continuum of health and social services for community members with continuing care needs at all stages of life, including seniors, people living with disabilities and others." (Trudeau, 2021) The federal government has proposed the following to "close the gap between Indigenous and non-Indigenous communities for culturally appropriate programming and services in long-term care services":

1. Co-develop a distinctions-based, community-led, Indigenous Long-term and Continuing Care Framework that prioritizes ensuring Indigenous peoples can receive long-term and continuing care services in or near their own communities and culturally appropriate care and programming, whether they are in urban, rural, and northern areas
2. Bolster Indigenous health system navigators so they can provide dedicated support to Indigenous people and their families to specifically help them navigate services related to long-term and continuing care

FNHSSM's Mandate to Undertake Proposed Project

The First Nations Health and Social Secretariat of Manitoba (FNHSSM) was directed via resolution passed at the 7th Annual General Meeting on March 16 & 17, 2022 by Manitoba Chiefs in Assembly to "facilitate regional engagement in partnership with Manitoba First Nations and

Indigenous Services Canada to co-develop a comprehensive First Nation Holistic Continuum of Long-Term Care." This directive is also an key component of the FNHSSM's mandate to:

> "carry on business in the area of health and social development for First Nations in Manitoba that are founded in the Treaty and inherent right to health and that are culturally appropriate, holistic, and community-based, and that:
>
> a) Develops strategies and initiatives to promote and increase the participation of Manitoba First Nations in the control and delivery of health.
>
> c) Promotes understanding of health and social issues affecting First Nations through partnerships, research, and collaboration."

Moreover, FNHSSM recently conducted a qualitative study of the lived-experiences of Manitoba First Nations adults with disabilities, the outcomes of which were used to supplement and inform this project and final report.

APPROACH

FNHSSM developed an approach to engagement that involved three phases:

Phase I: Planning & Preparation

This stage involved putting in place the groundwork conducting background research, a thorough review of the literature (including Indigenous long-term care strategies from other provinces), and developing content for session presentations (see **Appendix B**) that was critical to ensuring engagement participants are familiar and knowledgeable on issues pertinent to First Nations long-term care strategy development. This information was also incorporated into the final report (under "Review of the Literature Section").

Phase II: Community Engagement

This stage involved community engagement that occurred via hubs. There was a total of 10 in-person sessions that occurred in hubs located close to communities, Tribal Council offices, or regular meeting places. These 2-day community engagement sessions involved the presentation of pertinent background research and information, followed by a facilitator-led strengths-based engagement session that will aim designed to elicit observations, concerns, and ideas on what needs to happen to make meaningful and impactful change to long-term care provision to First Nations in Manitoba (see **Appendix A** for Engagement Questions). **Table 1** below outlines community engagement hubs, including target participants, the tribal area they represent, and location of the session. The full Facilitator Guide for community engagement session is attached in **Appendix C**.

Phase III: Final Report, Validation, Dissemination, & Knowledge Translation

This stage involved the compiling of final report that will comprise the background research, review of literature, incorporation of MB First Nations with disabilities lived-experiences research study outcomes, community engagement session outcomes, and Manitoba First Nations-driven long-term care recommendations and next steps. A summary of this report can be found in **Appendix E**.

The final draft report will be presented in a virtual validation feedback session to ensure that participants have a final opportunity to comment on the report, recommend amendments, and add further perspective, so that ultimately, the final report accurately portrays the intended vision of participants. The outcomes of this validation session will be incorporated into the final report.

CHALLENGES

We encountered a number of challenges when planning and conducting this engagement process that we feel are important to note. First, these sessions occurred throughout the summer and into the fall of 2022. This is commonly a challenging time to coordinate in-person gatherings, as many key participants are away on vacation or busy planning community events such as treaty days and pow wows. This was an issue we also encountered, which likely contributed to a lower participation rate. Secondly, we found that many communities and tribal councils were already preoccupied with other in-person commitments. Many programs were attempting to catch up with needed in-person efforts following the COVID-19 pandemic that prohibited gatherings for a long period. Thus, we found that many we invited or who would have typically liked to participate had pre-existing commitments, also impacting the participation rate. As such, we had to combine some of our original hubs and change dates to accommodate the most participants possible.

Table 1: Summary of Community Engagement Hubs			
Target Group	**Tribal Area**	**Location of Engagement Session**	**Number of Community and Tribal Council Representatives**
Local health and social service providers designated by community (e.g. Jordan’s Principle, Home and Community Care, Health Directors, Elders, Knowledge Keepers, Tribal Council staff, Treaty Organization staff, On-reserve Elders’ Lodges)	Keewatin Tribal Council and Independents Hub	Thompson	14
	Cree Nation Tribal Health Centre and Independents Hub	Opaskwayak Cree Nation/ The Pas	13
	West Region Treaty 2 & 4 Health Services Hub	Dauphin	12
	Dakota Ojibway Health Services and Independents and Four Arrows Regional Health Authority Hub	Brandon	14
	Southeast Resource Development Council and Interlake Reserves Tribal Council Hub	Winnipeg	18
Manitoba First Nation Personal Care Home Network (consists of administrators for the 8 First Nation Personal Care Homes in MB) & Social Development Technical Advisors Group (consists of Tribal Council and Independents Social Development Advisors)	Manitoba Region	Winnipeg	20
Provincial Partners (with identified provincial service providers whom serve First Nations Elders and those living with disabilities)	Manitoba	Winnipeg	12
Total Number of Participants			**103**

RESULTS: WHAT WE HEARD

The First Nations Health and Social Secretariat of Manitoba (FNHSSM) hosted a total of seven (7) engagement sessions on how First Nations in Manitoba envision a long-term and continuing care strategy that identifies community-defined challenges, needs, priorities, approaches, and recommendations. One (1) additional session was facilitate by FNHSSM with representatives from various departments across the Government of Manitoba to provide preliminary results of engagement and to discuss how to best serve First Nations between both federal and provincial government-delivered services. Outcomes of this session with provincial partners were kept separate and are attached in **Appendix D**.

FNHSSM obtained input from community-designated experts in long-term care, Elders, seniors, and persons with disabilities from across First Nations in Manitoba about gaps, challenges, strengths within current long-term care services and supports and how they might envision a better system. These sessions included:

- July 26-27, 2022 – in Winnipeg with participants from the Southeast Resource Development Corporation and Interlake Region Tribal Council areas.
- August 9-10, 2022 – in The Pas with participants from the Swampy Cree Tribal Council area.
- August 16-17, 2022 – in Winnipeg with participants from Personal Care Homes, Elders' Lodges, and the Social Advisors Technical Group.
- August 22-23, 2022 – in Brandon with participants from the Dakota Ojibway Health Services area.
- August 25-26, 2022 – in Dauphin with participants from the West Region Tribal Council area.
- August 31-September 1, 2022 – in Thompson with participants from the Keewatin Tribal Council area.
- October 17-18, 2022 – in Winnipeg with participants from Independent First Nations, the Island Lakes Tribal Council area, and those unable to attend previous sessions.
- November 23, 2022—in Winnipeg with representatives from various departments across the Government of Manitoba

This section provides a detailed overview of participant input and feedback and is arranged according to the engagement format.

CURRENT LONG-TERM CARE SERVICES & SUPPORTS

Important Problems or Gaps

Several important problems or gaps in current services available to First Nations in Manitoba were identified. First, **there are no or limited long-term services available.** While patients require long-term care services, these services are not available in some communities and are limited in others. This situation results in individuals having to leave the community to access services that they need. There are a broad range of limitations of current services including:

- Assisted living programs have not changed over time despite need, e.g., home care services offered only 3 hours per day, funding levels have not increased since the 1990s, and level 3-4 levels of care need have remained status quo.
- Hours of operation limited to 8:30am-4:30pm with no availability of after hour services or lack of 24-hour care.
- Limited services for end-of-life care, with provincial services based more on family dependencies.
- Home care visits are only once per week while there is a high need amongst families.
- Lack of bed space.
- Lack of capacity for First Nations to handle level 3 and 4 care needs.
- Level 4 care needs – lack of appropriate funding, and lack of proper equipment, professional and support staffing, and facilities.
- Service gaps for individuals aging out of Jordan's Principle, i.e., ages 18-64 years old.
- Long wait lists for individuals trying to enter a care home outside of communities and for those seeking access to treatment centres because none are available within.
- Lack of the following services within the community:
    - Physiotherapy
    - Dental
    - Prenatal
    - Escorts for travel to locations outside of the community
    - Detox (bed shortage within Manitoba, resulting in having to send patients requiring supports out of province).

It was noted that some First Nations communities are risking their licensing to provide care within the gaps of the current system.

Worker shortages and staffing needs are a second area of problems or gaps in current services. There are lack of workers to be able to provide the care and supports needed. There is difficulty in finding and retaining workers for Personal Care Homes and all departments. Specific positions that are under-staffed are respite workers and home makers. There is no funding in the budget for these service staff. Supports for end-of-care in the home and senior home settings are also lacking. Activity Workers provide some support to patients with cognitive and mental wellness; however, speciality health care staff are needed to help provide wrap around support system these patients need.

Patients require a broad range of service staff and specialist care providers to meet their diagnoses and needs. An entirely new program to support those individuals aging out of Jordan's Principle and being transitioned to home care is urgently needed.

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. While in some First Nations communities this is working well, in other communities it is stressful and harmful for residents and does not fully address service shortages.

Solutions to address worker shortages and staffing issues are:

- Updating skills and providing refresher course for service staff to address gaps and professional development needs.
- 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.
- Provide training for rehabilitation assistance to Health Care Aides through partnerships with colleges such as Assiniboine Community College.
- Provide training for nurses to provide 24-hour care, seven days a week.
- Increased staffing in the areas of nursing, counselling, physical therapy (PT)/occupational therapy (OT), x-ray, and data entry.
- Ensure a specific individual is on staff that focuses on policies and procedures.
- Support safe work environments and safe working procedures by putting in place security service staff.
- Address wage disparity experienced by on-reserve staff.
- Offer self-care to all staff to help address burnout and to help cope with increased suicided deaths within First Nations.

Staff shortages, the lack of services required, and underfunding impact the health and wellness of patients. The wishes of community members to pass away at home should be supported and First Nations' own community members should be trained to assist with this. There are benefits to having own community members as service staff including having more of a connection between staff and patients.

Culture and language must be better incorporated and addressed within current programming and facility settings. 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. 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. The wrap around approach and living experience can have a positive effect on the trajectory of a patient's life.

Solutions are to:

- Prove opportunities for Elders to share and pass on traditional teachings.
- Promote positive family involvement.
- Prove traditional foods. This will require service staff to prepare and ensure proper service and safe consumption procedures and requisite policies are in place.
- Involve youth more through land-based activities such as hunting camps and harvesting of traditional foods.

- Integrate culture within care facilities' structure and operations – e.g., creating culturally safe and private spaces to conduct assessments, changing western approach to conducting assessments, and ensuring support services are culturally aware.
- Increased activities for Elders that keep them active and make them feel supported and connected, e.g., gatherings, regularly scheduling celebrations, etc.
- Involve elders and patients in discussions to plan, provide, and ensure cultural and holistic services needs.
- Utilizing a prevention and strengths-based approach to understanding and addressing patient needs. In home care needs are different in these settings.
- Make funds available within First Nations for traditional healers and that these funds are community-based or are ensuring they are retained within the community for these supports needed in the community.
- Increase awareness amongst non-Indigenous services providers working on-reserve for better understanding of patients' needs.
- Increased land-based counselling, particularly for individuals returning to the First Nation from outside the community to receive addiction support services.
- Ensure differences of languages are not a barrier.
- Ensure respect for diversity in beliefs – e.g., some First Nations patients are Christians.

Transportation is a significant gap and current services are not adequate for patients' needs. EMT services are overextended in some communities and are non-existent in others. There are long wait time for air ambulance services which results in having to prioritize higher levels of care and bumping other patients who may have to wait for over 12 hours. In turn, this causes strain on nurses at health centres and can result in longer wait times at those facilities. For those First Nations without EMT, these services coming from outside the First Nation are unfamiliar with finding patients' homes. This can be very taxing on the individual requiring urgent care. Medical transportation vans are often full for patients with appointments off-reserve. This results in individuals having to use private vehicles for this purpose, which means they are not provided with supports for gas and meals.

Lack of sufficient funding for supplies and the lack of infrastructure, including to support availability of dialysis equipment must be addressed. There have been recent cutbacks on would care and hospitals discharging patients when they have wound care needs mean patients do not have adequate dressing supplies. Local pharmacies often do not have incontinent supply products available. The lack of proper infrastructure, i.e., water and hydroelectric power, means limited accessibility to dialysis machines by patients whose treatment schedule may be up to 3 times per week. 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. Lack of capital funding for First Nations means that facilities (e.g., Elders' Lodge, accommodations for staffing, patient housing, etc.) and programming (e.g., PT/OT, meals on wheels, etc.), needed are not available. It is suggested that training and education in the trades be made available within First Nations to address infrastructure needs. 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.

Lack of housing can contribute to another gap – **transition supports for individuals and their families**. There are issues with coordination between programs, particularly for those individuals that are younger in age and have mobility issues. Some Personal Care Home transitions are not keeping First Nations elders close to home. Some members in the extended family have taken over suites of individuals in independent living facilities. Assisted living, prevention supports, transitional supports, and family advocacy supports, are needed.

Additionally, supports for individuals who are returning to the First Nation having accessed addictions services outside of the community are needed. It is a very difficult process and treatment may not have been enough for them to overcome issues that they may face in returning to the same environment. After addictions treatment, mental health needs are high requiring more staff and staff time to provide support. Possible solutions to this are taking a cultural approach to healing (i.e., spiritual, emotional, mental, and physical), increased staffing, establishing an assessment office, and revising policies and procedures.

Supports for individuals aging out of Jordan's Principle is another type of transitional support needed because people are sometimes falling through the cracks. New and designated facilities are recommended for this population because of the high number of individuals in need, they are too young for the PCH setting, and due to the high care needs, which can be overwhelming for families. Improvements in the referrals and discharge planning process are needed including providing more detailed information, particularly for patients returning to remote and isolated communities.

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.

Strengths

Strengths of current services available to First Nations are as follows:

- **Having facilities in the community.** Some First Nations have an assisted living complex or an elders'/seniors' lodge within the community. Networking amongst all departments and with the respective regional healthy authority is important for the patients' care and service needs including updates and follow-up. Palliative care honours the wishes of the patient to pass at home.
- **Having programming in the community or in proximity**. Traditional programming and mental health and wellness supports, including therapists and wraparound services, were highlighted. If services are not available within the community, the need to have these services as well as a hospital, emergency care, paramedics, and onsite doctors, in close or surrounding communities was identified.
- **Staffing from the community.** There is a greater sense of community that results in more supportive care when staff are from the community. Additionally, it is usually family or community members who step up to aide in the care level needs or to help address changing health needs of patients. This practice helps facilitate a holistic approach, thereby, improving the quality of life for patients and is comforting to them. Community staffing

also helps to ensure elders and individuals can remain close to their home and to the land. Workers are resilient when patients or colleagues to through difficult times or pass away.

- **Coordination amongst all programs in the community.** Some programs are currently combining services to provide extra supports to patients, including the health centre where registered nurses are available and to addiction programs. Summer students are placed within the PCH setting and patients get to enjoy the "meals on wheels" program, which it was shared that the elders look forward to. A coordinated approach allows for goal setting within the facility setting.
- **Positive work environment.** Creating and maintaining positive work environments helps to promote health and wellness of patients and of staff. Patients are more receptive in these environments and all programs work together and help each other. Information-sharing, including knowing what each other's program does and what services it offers, and teamwork were highlighted.
- **Inclusion and empowerment of residents and elders.** Impactful personal care homes are those that engage and honour residents by having many social events including birthday celebrations and recognition ceremonies. Engagement also includes involvement of elders in program development, implementation, and monitoring. Elders want and like to have a say in how they will live in lodge settings. In some personal care homes, there are monthly resident council meetings where discussion, planning, and decisions are made. In some First Nations, there are elders and knowledge keepers groups that advocate for all elders.
- **Leadership.** Strong leadership is demonstrated in various ways and are beneficial for moving things forward. Having a clear vision and dream for a healthier community, having a community health plan, a strategic plan, strong leadership within the health centre, and a good working relationship between leadership and other departments, committees, boards, and organizations, are all markers of strong leadership.
- **Holistic care approach.** This approach involves food security and food sovereignty, with the provision of wild, natural foods and feasting. It also involves land-based activities and respect for and accommodation of each other's choice of religion and spirituality. Band staff that are trained on the holistic care approach are more supportive and in turn, promote this approach.
- **Prevention approach.** This approach was highlighted to improve and/or prolong patients' health status and quality of life. This requires an increased prevention supports such as diabetic foot care. It also requires fundamental understanding that culture is prevention.
- **Community volunteerism.**

During discussions on strengths of current available services, the following gaps and challenges were raised:

- Lack of infrastructure and maintenance of existing infrastructure.
- Staffing shortages, particularly the need for more registered nurses, health care aides, and PT/OT, and the need for more training opportunities.
- When a person passes, the immediate family is expected to handle the removal of the body and this process sometimes requires overtime hours from workers in the community.
- Need for increased activities for patients, including those engaging the broader community and cultural programming including land based.

- Need to build more awareness about long term care, whether it is about what supports area available within the community or about building awareness of and addressing issues regarding off-reserve facilities, such as not utilizing a holistic approach and individuals' rights in accessing services.
- Unlicensed personal care home.
- Disconnected between leadership and community departments.
- Lack of access to PT/OT services available through schools.
- No set times for home visits under provincial system.

Redefining the Scope of Existing Services or How They Are Delivered

Discharge planning and communication is the most significant theme identified regarding how the scope of existing services or how they are delivered could be redefined in a way that would better meet the needs of community members. Increased supports to the discharge planning process are required including the following:

- Providing all information required.
- Increased discussions on discharge plans.
- Insufficient staffing at the community level to provide follow-up care.
- Follow-up on referrals or testing. This includes follow-ups for wound care or prescription needs.
- Addressing gaps on the provincial side when First Nations members are in hospital – who is registered where and does the patient require a new or additional level of care. Notice must be given, and information shared with First Nation service staff. This does not seem to happen unless the family provides notice.
- Information-sharing during Friday discharges.
- Ensuring files are kept up to date.
- Ensuring sharing of critical documents.
- Address that nurse-to-nurse reporting seems to be non-existent.
- Address communication from hospital to health care centre.
- Address inter-departmental communication.
- Redefine current job descriptions to address current lack of communication.

A second significant area requiring redefining scope of service or delivery is **home care**. Home care services are currently underfunded and understaffed and the job description for this job position is overextended. Much is expected of home maker service providers. While many are doing more than what is expected, some are not doing what they are supposed to, but are documenting that they are. Another challenge is that some home care referrals are not being given to proper care providers. More training is required. Weekly meetings amongst of home care staff and progress reports help to meet client needs.

A third significant area for redefining scope of service or delivery is **after-hour/on-call care**. The current hours of operation do not cover the full extent of needs that are required for long-term care in First Nations communities. Funding is only for 8:30am-4:30pm. In particular, mental health, medical transportation, and paramedic services are needed after-hours. Such services would help to keep the client home and can assist with palliative care. On-call staff policies and procedures would need to be developed to provide higher care levels including on-call staff lists to be prepared months in advance.

Examples of **specific professions requiring a redefining of scope of practice** is a fourth significant area identified by participants of these engagement sessions. This included the following:

- Nurses – LPN, RN, home care nurses, public health nurses, etc. Their scope of practice was impacted by the covid-19 pandemic when many were expected to do much more than their own scope of practice. Immunization training is required.
- Visiting health care providers are often not in the community long enough for proper diagnosis and treatment options.
- Home Care Aides and Home Makers
- Service staff. Their scope of practice was also impacted by the covid-19 pandemic when they had to do some procedures that had nothing to do with what they were required to do.
- Lacking continuity of care needs for patients from agency nurses' scope of practice. Clarity on expectations of agency staff is required, including proper documentation.
- Silos with the scope of practice within the regional health authority.
- Further discussions are required with issues to be explored: extended care and having to send elders out of the community versus bringing services into the First Nation (e.g., IV therapy and treatments), doing more within the scope of practice (e.g., nurses requiring doctor's consent to medivac authorities), and provincial accreditation (e.g., policies, standards, safety, transfer of function and delegation).

Specific policies were also identified, including:

- FNHIB policies, especially surrounding agency staffing, should be co-developed in a transparent manner. An example is the funding disparity for temporary nurses – FNIHB covers private agency nurses but when First Nations secure temporary nurses, they have to pay for in on their own and it quickly gets expensive. Other examples are disparities in payment for travel, training, and wages.
- Policies (and funding) regarding patient travel and escorts required for out of community medical appointments.
- Liabilities associated with palliative care. For example, the transfer of function from the RN to the Health Care Aide, for which forms are made available to support these processes.

Other key areas in which current services must be redefined or delivered include:

- **Individuals aging out of Jordan's Principle** still have service needs and these needs are not being met due to jurisdictional issues including provincial policies. Service expansion including home care must be undertaken to bridge the gap.
- **Individuals with diabetes in long-term care is not being properly managed.** There are many struggles in getting dialysis for these individuals and other supports they need. Further discussions are needed managing home dialysis and providing these services is out of scope of practice. An example provided is that the province and federal governments

will not train Home Care Aides to support the peritoneal dialysis process of clients and only train family members with the home hemodialysis process.

- **Confidentiality.** Confidentiality must be addressed when programs and all entities of care services are working together to support the patient. Solutions are to develop and institute confidentiality agreements when working together on admissions including PCH settings, release of information and having community members sign this form and addressing concerns with the approach of gathering information generated by use of provincial health cards and postal code.
- **Communication.** Communication must be done in simple terms and plain language. Nurses, health care aides, and home care workers, seem to have their distinct ways of communication, and this must be more accessible to patients and their families and even amongst these professions. Language should not be a barrier. Long-term care services providers should be able to explain to elders in simple, understandable terms what it within their scope of practice.
- **Occupational Therapists/Physical Therapists.** Full-time OT/PT specialists are needed in geriatric care in First Nations. This can be done by training more First Nations people to become these specialized service providers. Availability of these services is critical to the quality of life of patients and is a preventative and holistic approach to service delivery.
- **Staffing challenges.** FNIHB nurses run public health and nursing stations and health services is separate form this. There appears to be a segregation of band nurses from FNIHB nurses. These nurses lack a holistic understanding of care and cultural sensitivity. There is an overall lack of staffing and resources. An annual review of training needs with opportunities for training and educating out of the office setting was suggested.
- **Supports to families.** Existing services to families should include education and training sessions to help them on what services are available, to learn how to provide supports their family members need, such as escort services, and also to learn about preventative measures such as how to avoid and work with others to address possible prescription drug abuse, depression, and anxiety.
- **Involvement and coordination with all community programs.** New and more programs are needed to ensure quality of life. Some programs are doing a great job with broad coordination long-term care for community members, while others can improve. The benefits of this approach are patient quality of life, patient understanding and awareness of what is available to them, and less reliance on nurses to provide the range of services needed.
- **Integration of land-based and traditional healing practices.**

Under-utilized Community Strengths

The most under-utilized community strength is volunteerism. Community members are volunteering to clean elders' homes, to maintain elders' yards, and to facilitate activities and outings for elders. This spirit of volunteerism must be reignited and can be done through education and awareness on how we can help take care of one another.

Other under-utilized community strengths are:

- **Cultural connectedness.** Elders play a pivotal role in maintaining cultural connectedness, which benefits everyone. Knowledge transfer between elders and youth not only help to revitalize and keep culture and language alive, it makes the elders feel involved, which contribute to their health and wellness. This can be done through simple acts such as providing them a ride to events and inviting them to share stories.
- **Supports to families.** Ensuring families understand and are trained on the supports for the changing needs of their family members. This can include involving them in care planning. By family and staff working tougher, the likelihood of burnout is decreased.
- **Recognition of family-identified solutions.** Family lived experience and perspectives help to identify solutions to various challenges, for example, that therapists should get out into the community and be visible to increase trust.
- **Gifted community members.** Some community members are gifted in knowing how to draw people out of their shyness or inability to speak in a group setting or with service providers.

Challenges were also raised during this discussion and include the following:

- Colonial, institutional policies. A solution suggested is to look differently at end-of-life care so that individuals do not have to relocate to receive the supports they need including providing more land-based and intergenerational activities.
- Not focusing on residential school survivors' needs.
- Elder abuse including subtle acts and some elders may not understand how they are being abused.
- Abuse of the system.
- Some "volunteers" have an expectation of payment. It was suggested that creative solutions can be found by looking at existing programs such as income assistance.
- The covid-19 pandemic has increased isolation amongst community members who typically enjoy visiting with family and friends.
- Community gardens are no longer being planted or maintained.
- Feeling overwhelmed that there are too many problems and too little solutions.
- Being frustrated by someone telling you, "you can't do that."

How First Nations Can Get Adequate Resources to Fund Needed Long-term Care Services

There is an immediate **need to re-evaluate the funding approach** to long-term care services and increase accountability of government to First Nations utilizing a First Nations understanding of the continuum of care and drawing upon certain aspects of Jordan's Principle. This re-evaluation must include a needs-based approach rather than population-based. A related issue is that federal government data lags 3-5 years and do not reflect current population figures. This is particularly problematic for housing and contributes to the overcrowding situation on-reserve. It also creates significant barriers for individuals with limited or no mobility, particularly in isolated and remote areas where there are unique infrastructure challenges. There is a need to move away from block funding, which allocates only a certain amount to care, and though needs may change, funding does not.

The re-evaluation of the funding approach must also include inclusion not exclusion of all capital costs including operation 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. The costs of doing business in remote, isolated communities is higher than in other areas due to transportation costs and other factors. All First Nations are impacted by inflation.

The funding approach must be expanded not limited eligibility to access services. While Jordan's Principle is needs-based, it is limited to up to 18 years of age, creating an entire population – those aged 18 to 60 years-old and living with a disability - with need but are aging out of eligibility for services under that program. Furthermore, addictions must be recognized as a disability. All First Nations people, no matter what age or circumstance, have a right to long-term care, including in their home community. Policies and programming should be re-evaluated and revised to support the transition from Jordan's Principle to other long-term care services taking a prevention approach.

Funding levels must be re-evaluated to sufficient meet needs and systemic limitations, shortfalls, and inequities. First Nations are funded federally for levels 1 to 3 are federally funded; however, they are not funded for level 4 clients though the province is. Home care programs are currently underfunded. Matters of geography must be considered and accounted for. Percentage of beds should be based on surrounding First Nations communities. Catchment areas should be discussed. The delays caused by NIHB's request for annual prescription renewals must end. So too must the practice of putting a moratorium on Personal Care Homes on-reserve. Lack of funding for other infrastructure needs in the community such as water treatment, lack of wages, and funding for escorts and interpreters to be able to sufficiently access supports outside of the community, are issues of inequity. There is a need for more First Nations people to be involved in creating and changing policies for long-term care, and for government to be accountable to First Nations including on matters of inequity.

Training First Nations members to provide the range of services required for long-term care in the communities is critical. This includes RNs, LPNs, health care aides, case managers, and specialized services such OT/PT. These needs are ongoing and are difficult to support when there are no resources within the community. Building community capacity relates not only to direct service provision, but related services such as the trades to retro-fit and winterize homes. Families benefit when services are available in the community – they get to remain together in their home community. Patients benefit when community members are trained – these workers understand the culture, history, and community. The whole community and future generations can benefit from this approach – youth are assets of First Nations.

Funding must support **integration of culture and healing from intergenerational trauma** resulting from Indian residential schools. First Nations cultural ways are an important component of long-term care and can be integrated into the following ways:

- Orientating care to aging well and holistic care needs, which includes access to land-based healing, traditional foods, herbal teas and medicines, elder-youth connections, elder engagement in community, and elders being able to remain in their home community.
- Access to spiritual care in all settings – ability to smudge and have ceremonies, taking a critical look at prescriptions that cause more illness than healing and how this supports the pharmaceutical industry, looking to traditional medicines and/or healers,
- Spiritual care integrated into the beginning of the hiring process as a mandatory requirement to provide supports to First Nations patients.
- Understanding the intergenerational impacts of Indian residential schools including as a cause of intergenerational disconnection, addictions, mental health issues, and homelessness.

Home care funding is currently very inadequate and requires a significant increase. Individuals should have the opportunity to stay in their home or home community and receive the proper supports they require 24 hours, 7 days a week throughout the year. Home care is also confined by policies and procedures, lacks land-based programming, and requires increased respite services within the home setting.

Additional input regarding how First Nations can get adequate resources to fund long-term care includes:

- The Province of Manitoba provides palliative care and has a responsibility to provide higher levels of care to First Nations.
- Chief and Councils must discuss supports to on- and off-reserve members due to differences in experiences of Jordan's Principle and to advocate that First Nations be eligible for not-for-profit grants regardless of residency.
- Discuss strategies with families.
- Increased community involvement.
- Determine if current facilities are meeting patient needs including identifying services that are and are not being utilized in First Nations communities.
- Ensuring every First Nation has a personal care home on-reserve.
- This is a complex issues involving many barrier and there is no easy fix.

FIRST NATION LONG-TERM CARE UNDERSTANDINGS/VALUES

How "co-development" of a First Nations Long-Term Care Strategy with the Federal Government should happen

Co-development of a First Nations long-term care strategy with the federal should be **First Nations-led** because: a grassroots-lens ensures a strong perspective on patients' needs and cultural understanding of how to look after one another; spiritual, mental, physical, and emotional care is unique to First Nations and is different from the Western model of care which is institutional; and First Nations want to exercise governance. This will involve the following activities:

- Co-development governance must develop a terms of reference and mandates for the implementation of the strategy.
- Setting parameters on what full involvement is.
- Transparency in co-development process and discussions – First Nations have a right to know.
- Determine mitigation plan for possible delays.
- Community-led so that First Nations feel supported and identify what they need.
- Elders must be consulted because they understand the way of life for First Nations people. *Wahbung – Our Tomorrows* (Manitoba Indian Brotherhood, 1971) can help inform what is needed.
- A gender-based analysis and approach – i.e., consider gender-sensitive issues related to care needed and delivery of services. Turn to our cultures and traditions on how we looked after one another.
- A social determinants of heath approach – i.e., consider relation of housing and other issues.
- A human rights approach identifying areas of inequity.
- Obtaining input from those requiring services.
- Sharing lessons learned and best practices models.
- Identifying the needs of individual First Nations, recognizing that what works for one First Nation may not work for another.
- Discussion of infrastructure needs.
- Development of policies that benefit First Nations.
- Determine ways to ensure what is developed and decided is implemented for positive impact on the ground.
- First Nations come together to develop a strategy on long-term care.
- First Nations leadership to sit with health directors and staff for fulsome understanding of long-term care issues. This can then go to the regional level through a Chiefs Assembly or similar forum and then to the national level.

The co-development process can examine the following **regarding the federal government**:

- How can it play a more active role – what are their responsibilities and obligations and assessing their actions in this areas, not only mandating policies and procedures.
- How is it handing over more decision-making responsibility to First Nations.
- What are its information and data holdings and is this the same that First Nations have access to.

A goal of the co-development process should be to strategize how First Nations can gain control over long-term care.

The provincial government should be involved in the co-development process because it is responsible for long-term care needs. It decides where how and where services are provided. The co-development process can examine the following regarding the provincial government:

- First Nations sharing information on what services are needed.

- First Nations educating on cultural understanding of long-term care and integration into the system.
- Information sharing by the province on service utilization by First Nations.
- Discussions on how to improve current agreements and build new ones.
- Discussions on improving service delivery for First Nations people.

Topics for discussion with federal and provincial governments in the co-development process to include jurisdiction, mandates, services and service delivery, liability. This can involve discussing roles and responsibilities of federal and provincial governments including assessing if they have fulfilled their mandates, obligations, and commitments for service provision and to provide transparency in funding.

First Nations, federal, and provincial governments must be viewed as equals at the table, and work together to elevate and implement this work.

Other important topics for discussion in the co-development process include:

- **Community needs assessments** to determine what services, programs, and resources are needed and to prioritize them. Identifying holistic needs are critical to developing meaningful strategies including goals. For example, First Nations would like to develop their own licensing process to develop standards including cultural components. This is also a proactive approach that can enable patients to remain in their community no matter their individual and geographical circumstances.
- **Accessibility**, including the availability and duration of doctors in the community, the frequency within which patients must visit clinics outside the community, challenges, and barriers to accessing services outside the community and the impacts it has on individuals and their families, catchment areas, and division of funds based on respective jurisdictions of services.
- **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.
- **Establishing meaningful standards** that reflect the need, reality, and aspirations of First Nations people and culture.
- **Capital funding** – exploring creating solutions to funding capital required for long-term care and developing strategies to take necessary actions.
- Gaining **clear understanding on how funding formulas are determined**.
- **Addressing human resources shortages** including through training and educational opportunities and other investments in recruiting and maintaining capacity.
- **Pathways for on- and off-reserve patients** must be clearly identified for greater understanding by clients and to clarify funding confusion. 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.

- **Addressing addictions and mental health** – types of services needed, where to go to become healthier, the impacts of not being able to access these supports in a timely manner not only on the individual but their families and communities too.
- **Culture and language** – the provision of culturally appropriate care by current staff is limited to the English language. First Nations languages are an asset, particularly with elder patients, because they can enable individuals to express how they feel, and to communicate their needs as well as effectiveness and quality of care. Connections with the land can help to establish closer relationships between staff and clients and contributes to healing and wellness.
- **Holistic understanding long-term care**, including activities for daily living.

What it means to "age well across the lifespan" from a First Nations perspective

Several key themes emerged from discussions on what it means to "age well across the lifespan" from a First Nations perspective. **Culture** involves maintaining connection to the land and having knowledge of traditional medicines including their uses. It involves being in balance emotionally, spiritually, mentally, and physically. Finding ways to engage all four quadrants of the Medicine Wheel are critical, even if there are limitations such as mobility. Sharing teachings as life skills helps elders exercise their role as teachers to the younger generations and makes them feel valued and joyful. Treating everyone with kindness, love, and support.

Remaining in the home community is a second theme. This is connected to the first theme of culture in that long-term care supports and specialized services in this setting can help to ensure balance and to be amongst family and community from birth to death and to the land that they love. It can be traumatic for elders when they must leave their community because supports are not available or they require a high level of services than what they have access to.

Accessibility relates to being able to remain in the home community and is an issue at many levels – policies and jurisdiction. It also relates to culture and the social determinants of health in that individuals in long-term care must have access including food security and the land.

Activities are crucial to individuals in long-term care not feeling isolated but empowered by being supported to participate, staying active as possible, and maintaining connections with people and the land. Activities are also to engage the emotional, spiritual, mental, and physical for balance and wellness. Elders look forward to a variety of activities. Cognitive regeneration can result from such activities. Regression due to the covid-19 pandemic was observed in some individuals.

Self-care and independence of individuals in long-term care are important for an individual to have their basic needs met and feel like they are living a fulfilling life. It was stated that living like tomorrow is not promised, to have a sense of balance and the good life, helps in accepting the journey beyond the physical world for individuals and their families.

Positive feelings of being honoured, respected, having dignity and a strong sense of identity, are critical for individuals in long-term care. It is important to have a sense of home and of belonging, and being in a loving environment. Feelings of stress must be avoided.

Family support in taking care of our own is an important value. It is recognized that patients do not always have the support of family because of trauma and the disruption of values and connectedness in upbringing due to IRS and/or hydro developments; however, taking care of our own is something everyone can learn and practice in all settings, whether at home, in the school setting, or in long-term care settings and care.

Disability can be understood as disruptions to First Nations' way of life and traditional teachings especially roles and responsibilities, resulting in prevention of "aging well across the lifespan". While this was discussed more fully in the subsequent discussion topic at these engagements, it was raised here to highlight that disruptions to those items above prevent "aging well across the lifespan". Additional matters that prevent First Nations individuals from aging well are:

- Intergenerational trauma including values lost when young mothers and fathers are not taught how to prepare to become parents and when rites of passage are not conducted. This also frustrates parents of children born with delays or disorders from learning the skills needed to take care of their children.
- The trauma of the covid-19 pandemic with individuals abusing substances due to the loneliness and grief that resulted from the many deaths of First Nations people during this time.
- Addictions, even before the pandemic, resulted in increased responsibility amongst elders and grandparents to take up the role of caregivers again, which is hard on their health and wellness.
- Disconnection due to technology. This is not limited to young people but the entire First Nation population. There is a need for a spiritual foundation to support our way of life including learning and practicing roles and responsibilities.
- Individuals' changing health needs may bring limitations to what they previously were able to do, impacting them spiritually, physically, emotionally, and mentally. This situation can bring about depression.
- Understanding and reality that when an individual holds sadness internally too long, it affects health and wellness. It can cause conflict and sickness.

What "disability" means from a First Nations perspective

First Nations have multiple understandings of disability:

- **Disability as having purpose or gifts.** Individuals living with a disability are teachers. They demonstrate to others not to give up by not allowing their disability to hold them back in life. They teach others to focus on not what is wrong with someone but what is right and to focus on gifts and abilities. These individuals still have roles and responsibilities as valued members of families, communities, and nations.
- **Disability a result of disruption to First Nations way of life.** Physical and cognitive impairments result from lack of access to health services in communities, individuals not being properly prepared to be parents, and poverty. 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. It was noted

that not all impairments are recognizable or are visible. Furthermore, all individuals, including those with “disabilities” require their own type of balance for wellness - spiritual, emotional, physical, and mental. Individuals with disabilities help to bring out resiliency in themselves and others to deal with and overcome these disruptions.

- **Disability as requiring extra care.** Elders have shared that there is no word for “handicap”, and that individuals with “disabilities” require extra care in a culture where we take care of each other. Requiring extra care is also a factor of lack of infrastructure in communities. For example, in some remote, isolated communities that do have roads and sidewalks, wheelchair bound individuals will require extra care than if they were in settings with walkways and roadways that are well-maintained.

Discussions on disability also included identifying **ways First Nations people can help** and that education and training is needed in doing so. It is imperative that individuals understand the disability to know what can be done about it. It can be genetic or environmental. Patient navigators and social workers were identified as resources to help patients and their families navigate the health system. However, a barrier is that the latter are not authorized by NIHB to provide supports including obtaining information to help in the systems navigation. Training and education of community youth were identified as solutions to the shortage in required supports.

A few **concerns** were also identified during this discussion on understanding of “disability” – supports needed by young families, trauma experienced in having to engage a Western/institutionalized system which may have caused the disability, and language barriers.

What “activities to daily living” should be supported from a First Nations perspective

Four types of key activities emerged from discussions:

- **Cultural and land based.** These include medicine picking, culture camps, self-care through returning to the land and water, fishing and trapping, socializing including through the language, and sharing traditional teachings. These activities facilitate socialization, connectedness, spirituality, and improve quality of life. Culture is not always integrated in mainstream approaches to long-term care. These activities can be made available to individuals by choice.
- **Socializing.** 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.
- **Family supports.** 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.
- **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.

Other activities identified include:

- The need to understand the unique needs of individuals in providing activities or supports, e.g. hearing impaired and the use or availability of sign language.
- In community supports for individuals experiencing mental illness, including land-based activities.
- Transitional supports direct to individuals and their families as well education and training for families and workers.
- Supports and care plans for individuals aging out of Jordan's Principle.

What long-term care is from a First Nations perspective

Cultures and traditions significantly define what long-term care is from a First Nations perspective:

- Holistic understanding.
- Seeing life as a cycle.
- Seven sacred teachings.
- Respectful relationships between relatives.
- Intergenerational transmission of knowledge.
- Observing cultural protocols such as smudging.
- Use of traditional medicines.
- Conversing in own language.
- Group interactions on the land.
- Supports from extended family.
- Cultural treatment programs.
- Food security – community gardens, traditional food preparation, picking, harvesting, etc.

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. Long-term care is balance including what access to and relationships with land and waters.

As long-term care is understood as caring for one another, it is then about **having sufficient human resources**. Home care workers, home makers, and respite workers are needed but are often underfunded. Chiefs and Councils must advocate for these services. EMT and rehabilitation services (i.e., OT/PT and SLP) are desperately needed in communities. There are limited nurses and Health Care Aides. Health Care Aides need opportunities to upgrade and/or further their education. Pre-requisites for post-secondary education is a barrier as is the lack of training and education programs offered in community. A possible solution is for Tribal Council to establish these training and education programs within First Nations communities. Increased supports for youth, young parents, and families regarding parenthood are needed.

Addictions and mental health supports are needed as there these issues are at an all-time high and there are many accessibility challenges such as wait times and FNIHB cutbacks for therapist and a fee for service. Additionally, these services not covered under Manitoba Health and municipal and provincial crisis response services are not supportive, inadequate, not culturally appropriate, and are bound by the Mental Health Act. Furthermore, when individuals access services from off-reserve facilities, they are sometimes dropped off on highways because there are no supports in this situation and no where to go. This can be a crisis situation and neglect can occur. The RCMP can get involved in self-harm situations, but they provided limited supports or often deny assistance. It is difficult to get through on the Southern Chiefs' Organization crisis line and it is difficult to obtain supports from them when First Nations reach out. Solutions are funding for mental health crisis teams should go directly to First Nations communities, training community members to aide in these crisis situations as mental health therapists and rehabilitation assistance, and training current supports such as doctors, nurses, and health care aides to provide supports during these situations.

Long-term care from the First Nations perspective is the **ability to stay in home or community**. Palliative care services in First Nations enable individuals to age in place. Individuals have broad and strong ties to the community. Elders want their journey to end at home. Services must work with the family to provide the supports needed, and the planning and preparation of these supports should cause as minimal disruption to individuals as possible, e.g., modifications to homes.

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.

Long-term care from the First Nations perspective also includes:

- Healing from traumas and breaking cycles.
- Availability of services after hours and beyond the 8:30am-4:30pm work week with no or minimal wait times, particularly in the PCH panelling process.
- Adequate funding to meet patients' needs regardless if accessing services means travelling to another province, though these should be made available in the community so individuals do not have to leave in the first place.
- The role of tribal councils to ensure specialized services (e.g., OT/PT) reach all First Nations and not just one and exploring how they can set up personal care home and treatment centres in partnership with First Nations to support many communities.
- Maternal Child Health services should be funded within each First Nation and the current proposal process for grants must be re-examined to ensure access and fairness.

There was additional discussions by some groups in the engagement sessions on who is in need of long-term care. They identified the following:

- Elders and individuals who cannot care for themselves.
- Special needs patients born with disabilities.

- Elders and individuals with mobility issues.
- Individuals experiencing addictions, mental health issues, or homelessness (and a disability).

These groups also discussed that there are different age groups that would require age-appropriate settings whether supports are provided within a home or a facility.

Family relationships are important to consider. Caregivers should also receive supports as they provide supports to family members across the life space including during times when needs change.

What First Nations value with respect to long-term care

First Nations value **cultural and holistic end-of-life supports** with love and other cultural values and roles and responsibilities in taking care of each other as the foundation. Readapting old ways and integrating values ignites connections that elders need. These connections can be made through the following ways:

- Take a holistic approach to long-term care.
- Create a setting within personal care homes that elders will enjoy and feel loved as this may be where they pass on.
- Integrate storytelling and visiting in activities to uplift elders' spirits.
- Elders are medicine people who understand the medicinal properties and how to use plans and roots within their regions. They can pass on this knowledge to the youth as part of training the next generation.
- Go back to the land by establishing community gardens and move away from processed foods results in declining health.
- Educate on meal planning with nutritionally rich foods including traditional foods found on the land and in the community.
- Develop a guide on food sovereignty, the land, and climate.
- Educate families on balance and traditional values to improve quality of life.
- Conduct these engagements within First Nations communities.
- Establish supports that enable decision-making about the care of unwell individuals to be made based on what is best for that person.
- Palliative care to honour the wishes of individuals to die at home.
- Make end-of-life doulas available.
- First Nations must take control over their own health and wellness to have a better quality of life.

Numerous **staffing issues** were raised during this discussion regarding what First Nations value with respect to long-term care including:

- Staff must meet elders' needs.
- Staff are not properly trained on the needs of patients with dementia.
- Staff need language training.

- Support teams for families are not funded, they work much overtime, and they assist with aftercare when a patient dies, which is a program and service gap.
- Patients with brain injuries do not have proper services providers.
- Staff shortages and lack of trained service providers results in staff having to wear too many hats.
- Currently there are uncertified workers within First Nations who are often those who provide the most support to patients and have knowledge of the culture and community members' needs. They are also often those who are good staff needed to contribute to improved quality of life of patients.
- Community members work better with First Nations patients because they are known to each other.
- Workers are impacted by the passing of a client/patient but are expected to be at work the next day despite experiencing grief.
- Personal care homes manage levels of care based on staff levels in place. Level 4's are hard to place as hospitals want individuals requiring this level of care to go to personal care homes sooner because it appears they do not want this workload. This may present risks for the personal care home as its staffing will need to adjust to level 4 patient care.

First Nations also value **being able to remain at home in the community, connectedness, and ability to modify housing**. Elders want to remain at home in the community. They are often required to leave the First Nation to access supports and services they require. This creates a sense of loss during the transition contributing to depression which in turn affects their quality of life. Care that is trauma-informed and provides wrap around supports, while maintaining connections to family members and communities, are important.

Connectedness also refers to individuals maintaining a sense of purpose, focusing on wellness, and community and cultural connections through the language and being out on the land and waters.

Housing modifications refer to how long-term care from the First Nations perspective is not just the patient but their environment. This involves looking at patient needs in constructing and customizing homes or facilities within the community with the intention that individuals will age in the community. CMHC should consider modifications before construction as a more proactive approach and to minimize impact on Elders and individuals. It is recognized that building personal care homes on-reserve may take time; therefore, in the meantime, housing modifications should be made so support Elders' needs.

Other things that are valued are education on what services are available, companionship for elders such as home makers and youth visits, and basic care for active daily living such as bathing.

A few **challenges** were highlighted during this discussion on what First Nations value in long-term care:

- **Issues with federal and provincial governments** – differences in facilities and operations; hospital panelling process is unfair and racist; levels of care are not being met; escorts must be recognized as caregivers and receive proper training, supports, and compensation; long wait for funding and need to re-evaluate funding process and a move

away from proposal-driven and towards a focus on community needs; need to spend time in the community to increase knowledge and understanding of community needs; and long wait times with result in some individuals not waiting to go for further assessments or hospital visits.
- **Discharge and follow-up issues** – unsafe discharges from hospitals have been observed; lack of adequate supports; 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; and the need for increased escorts and increased supports to those in this support role.
- **Service gaps** – there are no OT/PT, SLP, mental health workers, social workers, and patient advocates in personal care homes; need to bridge the gap between individuals aging out of Jordan's Principle and needing to access long-term care; there has been a rise in addictions since the covid-19 pandemic; support team for families when a patient dies and who conduct aftercare; and non-Indigenous service providers are often culturally unaware raising the need for mandatory cultural training.
- **Community challenges** – community divisions, staff are not supported to look after each other, need for increased collaboration and teamwork, and need for stronger advocacy by leadership.

Ensuring First Nations voices are included in long-term care planning moving forward

First Nations must be engaged to ensure their voices are included in long-term care planning moving forward. These engagements must include grassroots individuals including elders to elevate lived experience. Ensure involvement of frontline staff.

Specific activities include:

- Taking a holistic view of long-term care – from birth to death. Having further discussions on challenges in this process to increase understanding of how to more effectively move forward on decision-making.
- Documentation of all concerns and these concerns are forwarded to the appropriate staff.
- First Nations to elevate these discussions at higher levels.
- Political leaders, Directors of Health, portfolio holders, and service providers, must be educated on First Nation community's health needs.
- In order to advocate effectively, First Nations people in leadership positions must be educated on how to access health care programs.
- Advisory groups to support leadership in addressing what is needed.
- A planning process that includes a governance model for First Nations, by First Nations. This must be adequately funded and include an evaluation mechanism for each community to measure success.
- Development of a communication strategy with clear and transparent processes to ensure proper flow of information in all directions.
- Development of First Nations based on a long-term care strategy.
- Ensure service and operational planning involves the right people and takes a more proactive approach to policy changes.

- Ensure accountability including through the establishment of a provincial ombudsperson to whom concerns with the health system and navigating it can be taken. The individual in this role must understand human rights legislation and health policies and procedures.
- Ensuring proper resources including staffing, infrastructure, and funding.
- Ensure First Nation are able to monitor the situation of elders who have to leave the community to access personal care homes.
- Adjustments to scope of practice.
- Address services gaps for individuals aged 18 to 60 years.
- Ensure impact – proper facilities, services, and supports are available in the community.

Holistic care plans must be discussed including addressing the impact of processed foods, the high costs of nutritional foods in the north, and the need for education on meal planning with proper nutritional values and access to traditional foods from the land. Families must be educated on balance through a return to traditional ways to improve quality of life. Plans must be based on geographic location, isolation, and needs of individual First Nations.

Family liaison positions must be established. They would help families navigate the health care system, 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. The role of current liaisons is not known and there is a concern that they may presently have too many tasks.

The **Province of Manitoba** utilizes First Nations population and health data to receive funding transfers from the federal government. It assumes that First Nations cannot do the work of health care including long-term care. First Nations can and they must take a lead.

Co-development between First Nations and the province must occur at the beginning of the process and not after things have already been developed. Engagement sessions must occur with each First Nation rather than one group with limited representation. More discussions with the province on First Nations needs and values must occur.

First Nations are invested in carrying out this work and must be at all relevant tables including representation on provincial boards and committees, at regional health authorities (RHAs) and Shared Health. First Nations must be part of communication from, and developments undertaken by, the province. RHAs must understand First Nations needs and have a responsibility to integrate culture within provincial personal care home settings. RHAs and the province must provide more services.

First Nations must be unified in strategic development and implementation of long-term care. First Nations in the north and south must come together and focus on service needs, develop a strategy, and implement that strategy. More gatherings are needed to support this.

Storage & management of long-term care information and data

Some First Nations are currently using a paper filing system due to connectivity issues and lack of access to service personnel in the community setting. The standard for retaining files is 7 years.

Types of information being collected are age group and meals hours of services, as examples. A challenge with this approach are duplication, lack of information sharing between the north and south.

Other First Nations have moved to e-chart. These First Nations govern and protect their information through putting in place processes and protocols, such as confidentiality agreements and resolutions on data storage. Some First Nations have information technologists who are responsible for who has access or data specialists who support data storage and data servers. A challenge is data-sharing amongst different programs within the community such as Jordan's Principle and Child and Family Services. A concern is that in some communities, medical staff who conduct their own charting do not share information and take it out of the communities.

First Nations own their data and information. Individual First Nations should retain their own data and develop their own governance structures and ethics.

First Nations may want to explore a regional database of one common system for First Nations in Manitoba by working together to determine what this database may look like. This data system must be user-friendly and meet the needs of First Nations.

Further discussions is needed on the following topics:

- Need to **increase education and awareness amongst First Nations** people of data, health data, confidentiality, and the circle of care needed.
- **Confidentiality** – PHIA and 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.
- **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 AMC, MKO, and 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.

- **Connectivity** – Connectivity remains a concern for many First Nations. Further discussion and sharing of the pros and cons of current service providers and whether they meet the needs and situations of First Nations is needed including transitioning from paper charting to e-charting.
- **Resourcing** – human resources, hardware and software, system maintenance, and training and updating skills.

Measuring success of long-term care services/supports from a First Nations perspective

The following table provides key themes of indicators to measure success of long-term care services/supports with related measurements:

Table 2: Indicators to measure success of long-term care services/supports

Key Themes – Indicators	**Measurements**
Remaining within First Nation	• # of elders requiring long-term care supports that are able to stay within the community • How long elders can stay within the community. • Increase of members who can pass at home. • Considering measurements related to the home care panelling process.
Family Supports	• Duration of family supports across the life span of the patient. • Family awareness and knowledge of patient's needs and current medical status. • Family awareness and understanding of expectations of them in providing supports. • Family presence at medical appointments and at patient-family activities. • Family sharing and learning from other families providing supports. • Participation in family engagement sessions. • Specific family individuals who are trusted by patients being involved in patient planning and other forums where information about the patient must be provided.
Human Resources	• Opportunities for community members to further their education in the area of long-term care. • # of people providing care and the types of care they are providing. • # of these members who return to their home community to work in this area. • # of PT/OT and dietician service staff who are Indigenous. • # of PT/OT and SLP speciality staff coming into the First Nations to provide services, e.g., # of visits. • Staff retention.

Table 2: Indicators to measure success of long-term care services/supports	
Key Themes – Indicators	**Measurements**
	• Wage parity – including between agency and First Nations staff.
Circle of Care	• Communication between providers, staff, and patients and their family. • Discussions of cycle of life with young parents. • Clients receiving long-term care and where they are receiving care. • Ensuring everyone is taken care of including those aging out of Jordan's Principle. • Coordination and collaboration amongst programs. • Government accountability to First Nations, including funding levels for quality care and service delivery.
Culture	• Cultural connectedness. • Holistic approach. • Sense of being balanced – mentally, emotionally, spiritually, and physically. • Land-based activities. • People are treated as they would want to be treated. • Social activities. • Coming together for feasts and celebrations. • Youth-elder connections. • Increase in youth speaking the language.
Nutritional foods and food security	• Measures for food sovereignty, e.g., community freezers, traditional foods, land-based activities to procure traditional foods, implementation of food sovereignty program. • Access to dietician. • Ensuring diary, wheat, and other food allergies are accommodated. • Limited or no use of process foods.
Services responses	• Response standard for client planning and requests, including retrofitting client homes. • Response standard minimum for urgent cases. • Increased EMT services. • Ambulance response time. • Effectiveness of EMT services. • Meeting medical transportation needs – ensuring safety and accessibility. • Meeting medical equipment needs. • Meeting medical supply needs.
Patient concerns	• Patients feel free to speak up about inadequate care. • Patients feel heard.

Table 2: Indicators to measure success of long-term care services/supports	
Key Themes – Indicators	**Measurements**
	• Actions are taken to address concerns. • Lack of reprisals for voicing concerns.
Funding	• Appropriate levels of funding. • Connection to effective care for patients.
Patient Happiness	• Needs are being met resulting in happiness. • Good quality of life.
Mental Health	• Availability of supports. • Less people requiring mental health supports because they are not needed. • Individuals are utilizing effective coping mechanisms. • Decrease in suicides.
Chronic diseases	• Prevention • Management • Treatment • Follow-up care

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.
- A lunch gathering to discuss needs. Communication is key.
- Develop a communication mechanism. Educate the members on these mechanisms and processes.
- Program evaluation.

It was also suggested that an evaluation tool or toolkit to collect data from all First Nations and which First Nations can adapt for their community specific use. Findings from this evaluation can be added to a database that also needs to be developed by First Nations. As each First Nation community is different, there may be some differences. The community-perspective is important. Once the First Nations data base is developed, the province will have to communicate with our tools.

FIRST NATIONS LONG-TERM CARE CONTINUUM

How First Nations envision a long-term care continuum

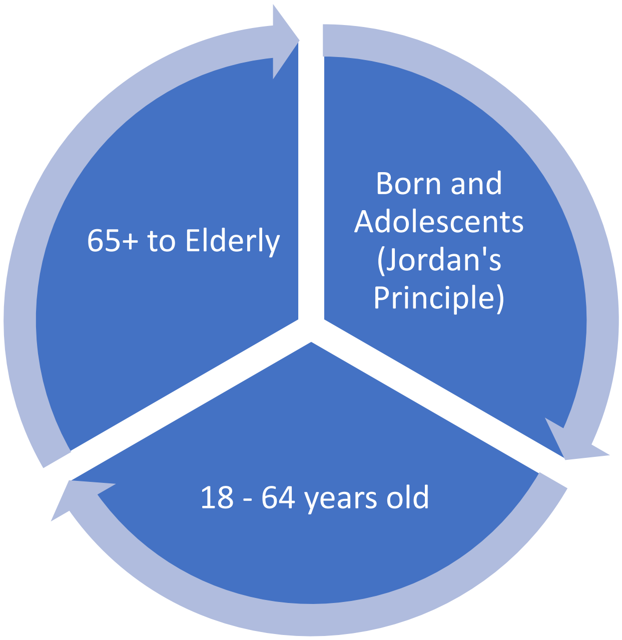
A **Circle of Care model** is envisioned for a First Nation long-term continuum. This is a holistic wellness approach based on the belief that First Nations take care of each other, and services are provided based on an individual's path for health and wellness. This takes into consideration an individual's family and housing circumstances, their needs, health status (which can change from time to time), and the different pathways to service care needs. This model requires that a decolonized and First Nations-led approach to the long-term continuum must be taken. It also suggests that individuals aging out Jordan's Principle be included within this service model.

The following are additional aspects and considerations of how First Nations envision a long-term care continuum:

- **Seamless, comprehensive, and adaptable** (to the changing needs of demographics).
- **Equitable** – no one must fall through the cracks in any system and the RHAs must provide care services to off-reserve members.
- **Training** – is needed to enable First Nations people to take care of each other in their own homes and communities. Trained and qualified staff are required to effectively provide programming and service delivery.
- **Data** – First Nations own their own information and data. Ongoing connectivity issues must be resolved, and First Nations must conduct meaningful and useful data collection, ensure proper, safe, and secure storage within the community, and ensure access to data by relevant individuals and groups.

It was also stressed that standards be put place, including regarding workplace safety and a plan for risk management. It is important to allow residents to have a voice and to educate First Nations members. Elders and individuals seeking and utilizing long-term care supports must be treated with love and know that they are special to everyone.

One group in these engagement sessions developed the following graphic and description of the life journey within the long-term care continuum:



FOUNDATION: structures, culture, language, values, looking after each other, food, medicines, family, respect, roles and responsibilities, caregivers, way of life, supports

It is explained that within this circular graphic is how we can age well – limited health issues, love, family, values, way of life, purpose, identity, forgiveness, being in balance with yourself, healthy foods and food security, spirituality, good diet, independence, self-care, taking charge of our health, acceptance that we are aging, and having supports.
Further to this graphic, the Life Journey was described in the following way:

- When we are born into this world, there are supports for babies, e.g., birth doulas, midwifes, etc.
- There is a gap in services for individuals 18-64 years; however, those aged 65+ are not necessarily in a care facility or have a care plan for their needs. There is a concern that ageism is not a priority. This is a reflection on how the current system values people based on their age.
- We need to support and provide resources for everyone in their life journey if they require long term care for disability, mental health, additions, etc.
- 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.
- 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.

GENERAL THOUGHTS ON FIRST NATIONS LONG-TERM CARE IN MANITOBA

The ultimate goal is to take care of our loved ones and our people.

Many next steps were suggested and fall into two categories: 1) who to consult and how to consult them; and 2) matters identified for further discussion or for action:

1) Further engagements:

   - Engagement sessions with those living with disabilities to hear directly from them. Discussions can include supports required, looking at their capabilities, and how they would like to be understood or viewed.
   - Consulting individuals requiring long-term care whose diagnosis is not supported and left unknown and untreated.
   - Conducting sharing circles.

2) Matters for further discussion or for action:

   - Discussions on “old ways” of end-of-life care and looking at supports from pre-natal care to the end of life including access to land and being able to remain in the home community in a continuum of care.
   - Addressing the gaps in services and supports for the population aged 18-50 years who require a continuum of care and long-term care. This includes looking at the entry point into long-term programs they require and how to best stabilize their situation when assessments are not being completed.
   - How to improve Jordan’s Principle, particularly looking at eligibility criteria, using a First Nations led and First Nations-led approach.
   - Personal care home complex living.
   - Extension of home care hours.
   - Available resources not being accessed by community members.
   - The need for members to be educated at a younger age to help take greater responsibility and accountability for their own health and wellbeing.
   - Provide plain language educational materials to community members on nutritional and unhealthy foods.
   - Provide more healing and wellness training to community members. Addressing the spiritual component is critical as traumas can be held in certain places within the body which eventually causes sickness.
   - Take action on food security including through instituting a community freezer.
   - Encourage and create/seek opportunities for community members to pursue education in medical professions such as nursing.
   - First Nations members are being re-traumatized by having to leave the First Nation to access services and by having to live within facility settings that are not culturally appropriate.
   - Programs not being funded appropriately.
   - Further discussion on data and detail regarding data collection, data input, and analysis regarding what services are being utilized and work hours. Data supports First Nation community needs and this is a challenge for funders.

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APPENDICES

APPENDIX A: ENGAGEMENT QUESTIONS

1. What are some important problems or gaps you are aware of in the current services available to First Nations in Manitoba?
    a) Differences between on and off-reserve?
    b) Missing services for needs not currently addressed?
    c) How could these gaps be addressed?
    d) How do existing services and providers at the community level currently collaborate? How can this be improved?

2. What are some strengths you are aware of in the current services available to First Nations?
    a) How can current services and their delivery be improved? (optimized, realigned, with/without new funding)

3. Could the scope of existing services or how they are delivered be redefined in a way that would better meet the needs of community members?

    For example, foot care, home & community care nurses could have expanded scope to do more for more time (expanded hours), community LPNs could do more, Jordan's Principle could be available for adults?

4. What are some under-utilized community strengths that can be better directed/supported toward caring for individuals?

5. How can First Nations get adequate resources to fund needed long-term care services? (funding formulas, pay structures for cultural & spiritual care providers, etc.)

6. How do you think "co-development" of a First Nations long-term care strategy with the federal government should happen?

7. What does it mean to age well across the lifespan from a First Nations' perspective?

8. What does "disability" mean from a First Nations perspective?

9. What are the "activities to daily living" that should be supported via long-term care supports/services from a First Nations perspective?

10. What is long-term care from a First Nations perspective?
    a) Who is in need of long-term care? (Elders, seniors, persons with disabilities, are we missing anyone?)

    b) What are important relationships to consider (not just between services or client/carer, but with family, community, between communities, with the Creator/ancestors)?
    c) Who are caregivers that need to be brought in and supported?
    d) What are the needed services/supports (Western and Traditional)?
    e) What does holistic long-term care mean from a First Nations' perspective?

11. What are some things that First Nations value with respect to long-term care?
    a) How could First Nation culture and values be better integrated into services/supports?
    b) What considerations are excluded from long-term care services/supports currently?

    For example, some Elders talk about how teaching and mentoring young people is a sacred responsibility, but this isn't always considered in long-term care

12. How can we ensure First Nations voices be included in long-term care planning moving forward?
    a) What processes would you like to see to uphold self-determination at the individual/family level (person-centered care) and at the community level?

13. How should long-term care information and data be stored and managed and by whom?
    a) How should data be reported back to community and accessed by community if it is housed elsewhere?
    b) How should funders be able or not able to access information?
    c) How do we protect our community and community members information?
    d) How should decisions be made moving forward on data management?

14. How do we measure success of long-term care services/supports from a First Nations' perspective? (i.e. think program evaluation)?
    a) What types of outcomes would show program success and wellness indicators (i.e. think program evaluation)?

15. How do you envision a long-term care continuum?
    a) What is a good "framework" design, what considerations would it include?
    b) How would you represent the "continuum of care" across time/life course (a metaphor or shape/image)?
    c) Long-term care from a First Nations' perspective on the life course? (Anishinaabe 8 stages of life and 7 phases of life; Medicine Wheel and 4 stages of life)
    d) How can services/supports be better coordinated and linked to provide better care?

APPENDIX B: ENGAGEMENT SESSION PRESENTATION SLIDES

Engagement for a First Nations-Led Long-Term Care Continuum

First Nations Health & Social Secretariat of Manitoba (FNHSSM)

OVERVIEW

Day 1

Time	Activity
9:00am	Opening Prayer
9:15am	Defining Long Term Care
9:30am	Long-Term Care in Manitoba: Off-Reserve/Provincial
9:45am	Long-Term Care in Manitoba: On-Reserve/Federal
11:00am	Breakout Session: Examining Current Long-Term Care Services & Supports
11:15am	Health Break
11:45am	Review Federal Mandate: Distinctions-Based Long-Term Care Continuum
12:00pm	Review of FNHSSM's Engagement Process
1:00pm	Lunch
2:00pm	Health Break
2:15pm	Breakout Session: First Nation Long-Term Care Understandings/Values
3:30pm	Day 1 Finish

OVERVIEW

Day 2

Time	Activity
9:00am	Welcome Remarks for Day 2
9:15am	Defining Long-Term Care Continuum
10:00am	Health Break
10:15am	Breakout Session: First Nation Long-Term Care Continuum & General Discussion
12:00pm	Lunch
1:00pm	Wrap-Up Remarks & Closing Prayers

What is long-term care?

- Ongoing, indefinite, care for individuals who can no longer fully care for themselves
- Straddles both health care in the form of nursing/medical care and social services in the form of income supported housing, assistance with “activities of daily living,” and the provision of recreational and social programs
- Activities of daily living are commonly defined as basic functional tasks performed on a daily basis, such as general mobility, being able to clothe or feed oneself, to be continent and use the toilet, and to shower or bathe.

What is long-term care?

- Long-term care is provided in different places (at home, in the community, in assisted living facilities or in nursing homes).
- It may be needed by people of any age, although it is especially important for many as they age.
- It can be provided by many different types of caregivers (formal and informal)

What is long-term care?

Western, biomedical perspective/approach

- Institutionalized, away from or excluding family/community
- Focus on meeting physical needs almost exclusively
- Medicalizes, problematizes, and others aging and disability as opposed to a normal and common aspect of the life journey or of the human experience (diversity)
- Treats those who are aging or with disability as a burden to society as opposed to a valuing their knowledge, wisdom, differing perspective
- Tendency to label and identify persons based on their disability
- Focus on individual's choices, effort, and behaviors as contributing to challenges
- Focus on deficits & impairments

Indigenous perspectives/approaches:

- Aging 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
- Identity not necessarily defined by disability
- Focus on social determinants of health and environment as a contributing to challenges
- 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

Other Literature Review Highlights

- Cultural values and understandings shape services and care
- First Nations’ holistic understanding of wellness (mind, body, spirit, emotion)
- Preference to focus on strengths and resilience in addition to providing intervention and support for challenges
- Importance of connectedness (to family, community, land, spirit)
- Integrating cultural activities into programming to promote living a good life
- Cultural safety of programming and staff (training, accountability, problem-solving mechanisms, client/family involvement)
- Mechanisms and policies for self-determination in care (both client and community-level self-determination)
- Continuum of care (coordination, case management within and across service providers)

Person-Centered Care

- Self-determination at individual
- Puts patients at the forefront of their care, ensures they retain control over own choices, helps them make informed decisions and supports a partnerships between individuals/families & services providers

Key components:
- self-management;
- shared and informed decision-making;
- an enhanced experience of care;
- improved information and understanding; and,
- the advancement of prevention and health promotion activities.

Individuals/families & caregivers are partners, supported and encouraged to participate in:
- their own care;
- decision-making about that care;
- choosing their level of participation in decision-making;
- quality improvement; and,
- care redesign.

Culturally Competent and Culturally Safe Care

Culturally competent care in long-term care contexts means integrating and respecting Indigenous values into program policy and programming.

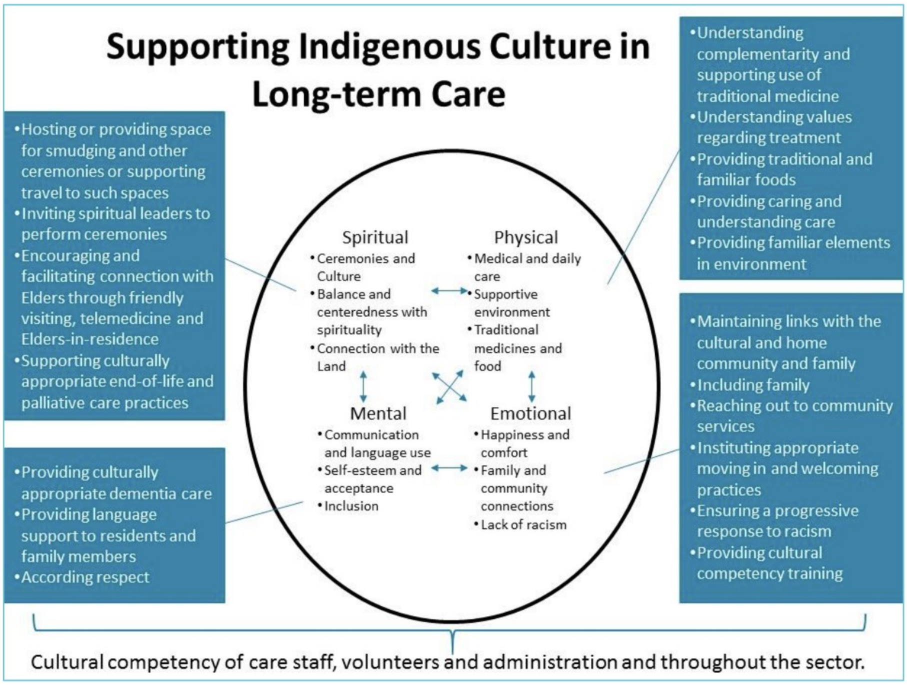
Cultural safe care incorporates the idea of a changed power structure, it focuses on ensuring Indigenous voices are decision makers in care programs and policies.

Culturally unsafe practices are "any actions that diminish, demean or disempower the cultural identity and well-being of an individual." Power imbalances need to be addressed so that Indigenous and non-Indigenous ways of knowing can come together and be equally valued.

Incorporation of Culture into Long-Term Care

Dimension of Wellness	Activity	Program/Policy Approach
Spiritual Wellness	Facilitate/organize/fund spiritual activities or access to them including smudging and other ceremonies, sacred medicines, bible study, church services, spiritual teaching sessions, visits with family/community, etc.	• Implement practice to identify spiritual needs, daily and end-of-life/palliative practices of client and their family • Establish committee to guide recognition and exercise of Indigenous practices in services • Communicate times of in-house and local community services along with indicating the faith and denomination • Facilitate transport to support participation in community spiritual events/services • Provide or facilitate access to sacred space for smudging, sacred fire, tobacco burning

Supporting Indigenous Culture in Ontario's Long-Term Care Homes (2018)



Supporting Indigenous Culture in Long-term Care

- Hosting or providing space for smudging and other ceremonies or supporting travel to such spaces
- Inviting spiritual leaders to perform ceremonies
- Encouraging and facilitating connection with Elders through friendly visiting, telemedicine and Elders-in-residence
- Supporting culturally appropriate end-of-life and palliative care practices

- Providing culturally appropriate dementia care
- Providing language support to residents and family members
- According respect

Spiritual
- Ceremonies and Culture
- Balance and centeredness with spirituality
- Connection with the Land

Physical
- Medical and daily care
- Supportive environment
- Traditional medicines and food

Mental
- Communication and language use
- Self-esteem and acceptance
- Inclusion

Emotional
- Happiness and comfort
- Family and community connections
- Lack of racism

- Understanding complementary and supporting use of traditional medicine
- Understanding values regarding treatment
- Providing traditional and familiar foods
- Providing caring and understanding care
- Providing familiar elements in environment

- Maintaining links with the cultural and home community and family
- Including family
- Reaching out to community services
- Instituting appropriate moving in and welcoming practices
- Ensuring a progressive response to racism
- Providing cultural competency training

Cultural competency of care staff, volunteers and administration and throughout the sector.

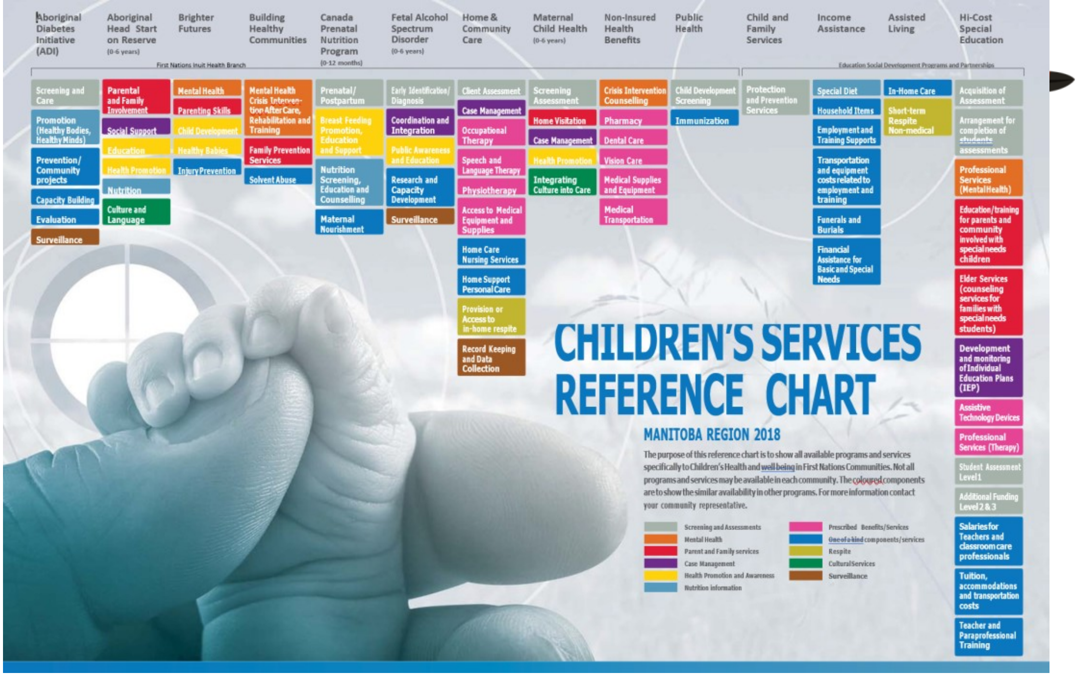
Long-Term Care in Manitoba: Off-Reserve/Provincial

- Provincial Home Care & Respite
- Supportive Housing
- Personal Care Homes
- Aging in Place Communities
- Independent/Assisted Living (Private)
- Palliative/End-of-Life Care
- Children's disABILITY Services
- Community Living disABILITY Services
- Disability and Health Supports Unit
- Transportation
- Financial Supports
  - 55 PLUS Program
  - Employment and Income Assistance (EIA) “Persons with Disabilities” category
  - New Disability Income Support Program (in development)
  - Rent Assist

❖ Not available on-reserve, but serve many First Nations in MB citizens who live off-reserve

Long-Term Care in Manitoba: On-Reserve/Federal

- Home & Community Care
- Foot Care
- Assisted Living Program
- Elder’s Lodges
- First Nations Personal Care Homes
- Jordan’s Principle-Child First Initiative
- Non-Insured Health Benefits (hidden policies: what is available isn’t always advertised)
- Financial Supports
  - Disability Income Assistance
  - OAS, CPP, Guaranteed Income Supplement
  - Primary Caregiver Tax Benefit
  - Disability Tax Credit
  - Employment Insurance sickness & caregiving benefits
- Canada Mortgage and Housing Corporation On-Reserve Program
  - Residential Rehabilitation Assistance Program for Persons with Disabilities
  - Home Adaptations for Seniors Independence (HASI) Program
- Other, Unadvertised Services?



First Nations Inuit Health Branch

Aboriginal Diabetes Initiative (ADI)
- Screening and Care
- Promotion (Healthy Bodies, Healthy Minds)
- Prevention/ Community projects
- Capacity Building
- Evaluation
- Surveillance

Aboriginal Head Start on Reserve (0-6 years)
- Parental and Family Involvement
- Social Support
- Education
- Health Promotion
- Nutrition
- Culture and Language

Brighter Futures
- Mental Health
- Parenting Skills
- Child Development
- Healthy Babies
- Injury Prevention

Building Healthy Communities
- Mental Health Crisis Intervention After Care, Rehabilitation and Training
- Family Prevention Services
- Solvent Abuse

Canada Prenatal Nutrition Program (0-12 months)
- Prenatal/ Postpartum
- Breast Feeding Promotion, Education and Support
- Nutrition Screening, Education and Counselling
- Maternal Nourishment

Fetal Alcohol Spectrum Disorder (0-6 years)
- Early Identification/ Diagnosis
- Coordination and Integration
- Public Awareness and Education
- Research and Capacity Development
- Surveillance

Home & Community Care
- Client Assessment
- Case Management
- Occupational Therapy
- Speech and Language Therapy
- Physiotherapy
- Access to Medical Equipment and Supplies
- Home Care Nursing Services
- Home Support Personal Care
- Provision or Access to in-home respite
- Record Keeping and Data Collection

Maternal Child Health (0-6 years)
- Screening Assessment
- Home Visitation
- Case Management
- Health Promotion
- Integrating Culture into Care

Non-Insured Health Benefits
- Crisis Intervention Counselling
- Pharmacy
- Dental Care
- Vision Care
- Medical Supplies and Equipment
- Medical Transportation

Public Health
- Child Development Screening
- Immunization

Education Social Development Programs and Partnerships

Child and Family Services
- Protection and Prevention Services

Income Assistance
- Special Diet
- Household Items
- Employment and Training Supports
- Transportation and equipment costs related to employment and training
- Funerals and Burials
- Financial Assistance for Basic and Special Needs

Assisted Living
- In-Home Care
- Short-term Respite Non-medical

Hi-Cost Special Education
- Acquisition of Assessment
- Arrangement for completion of students assessments
- Professional Services (Mental Health)
- Education/training for parents and community involved with special needs children
- Elder Services (counseling services for families with special needs students)
- Development and monitoring of Individual Education Plans (IEP)
- Assistive Technology Devices
- Professional Services (Therapy)
- Student Assessment Level 1
- Additional Funding Level 2 & 3
- Salaries for Teachers and classroom care professionals
- Tuition, accommodations and transportation costs
- Teacher and Paraprofessional Training

CHILDREN'S SERVICES REFERENCE CHART

MANITOBA REGION 2018

The purpose of this reference chart is to show all available programs and services specifically to Children's Health and well being in First Nations Communities. Not all programs and services may be available in each community. The coloured components are to show the similar availability in other programs. For more information contact your community representative.

- Screening and Assessments
- Mental Health
- Parent and Family services
- Case Management
- Health Promotion and Awareness
- Nutrition information
- Prescribed Benefits/Services
- One of a kind components/services
- Respite
- Cultural Services
- Surveillance

Other Considerations

- Support for family as caregivers (training, income, what else?)
- Respite care, Dementia care
- Support for traditional human resources (healers, knowledge keepers, medicine people, who else?)
- Mechanism to build cultural sensitivity/competence among those serving First Nations
- Support for those healing outside of hospital, i.e. acute care in home, rehabilitation (post surgery/injury)
- Chronic disease management assistance
- “Recreation”, wellness promotion supports, connection building activities (community groups, land-based activities, etc.)?
- Dedicated health advocacy
- Community-based end of life/palliative care
- Integration of Indigenous approaches and healing to all elements of long-term care continuum
- What else?

Breakout Session: Examining Current Long-Term Care Services & Supports

1. What are some important problems or gaps you are aware of in the current services available to First Nations in Manitoba?

Breakout Session: Examining Current Long-Term Care Services & Supports

2. What are some strengths you are aware of in the current services available to First Nations?

Breakout Session: Examining Current Long-Term Care Services & Supports

3. Could the scope of existing services or how they are delivered be redefined in a way that would better meet the needs of community members?

Breakout Session: Examining Current Long-Term Care Services & Supports

4. What are some under-utilized community strengths that can be better directed/supported toward caring for individuals?

Breakout Session: Examining Current Long-Term Care Services & Supports

5. How can First Nations get adequate resources to fund needed long-term care services? (funding formulas, pay structures for cultural & spiritual care providers, etc.)

Health Break

Developing a Long-Term Care Strategy

- ISC mandated to engage First Nations on the
    - “co-creation of options for a holistic long-term care continuum of health and social services for community members with continuing care needs at all stages of life, including seniors, people living with disabilities and others.”
- First Nations Elders and persons with disabilities want to be able to receive culturally inclusive care in their community, close to family and friends, as they age or their care needs change
- Recognition of longstanding issue of lack of cultural inclusivity and self-determination in long-term care

Federal Framework for Long Term Care:

1. Co-develop a distinctions-based, community-led, Indigenous Long-term and Continuing Care Framework that prioritizes ensuring Indigenous peoples can receive long-term and continuing care services in or near their own communities and culturally appropriate care and programming, whether they are in urban, rural, and northern areas
2. Bolster Indigenous health system navigators so they can provide dedicated support to Indigenous people and their families to specifically help them navigate services related to long-term and continuing care

Critique of Federal Approach

- Approach of **“co-development”** not defined
  - It is not yet defined how community engagement will feed back into the resulting strategy, policy, programming, funding
  - This can be good as we can have input into what “co-development” *should* mean
- Unclear how provinces will be part of implementing the strategy, policy, programming, funding

Engagement Coordinated Through FNHSSM

Approached by ISC and Chief Henderson to undertake this work

FNHSSM mandated via resolution at 7th Annual General Meeting on March 16 & 17, 2022 by Manitoba Chiefs in Assembly to

> “facilitate regional engagement in partnership with Manitoba First Nations and Indigenous Services Canada to co-develop a comprehensive First Nation Holistic Continuum of Long-Term Care.”

- ❖ Extensive Literature Review and Environmental Scan
- ❖ Engagement Hubs with experts in supporting Elders/Seniors/those with disabilities
  - Tribal councils & independent communities
  - Leadership
  - Council of Elders
  - Special Considerations Group: urban First Nations, youth, and 2SLGBTQQIA+
  - Manitoba First Nation Personal Care Home Network Group
  - Provincial partners
  - Social Development Technical Advisors Group
- ❖ Informed by lived-experiences of First Nations with disabilities on-reserve from **Supporting the Gifts of First Nation Adults with a Disability Study**
- ❖ Final Report drafting and validation session/input process

Engagement Process

MB First Nations Long-Term Care Engagement Timeline 2022

Planning & Preparation — May-June

Community Engagement — July-September

Outcomes Analysis & Report Composition — July-September

Completion of Report & Dissemination — October

Knowledge Translation — October-Ongoing

Goals of Engagement

- Explore First Nation understandings/values of what it means to age well or live well with a disability and what good long-term care means
- Develop community-driven solutions and ideas for culturally safe care in long-term care
- Assess current services to determine needed changes
- Determine what services, resources, supports are missing according to need and values
- Develop a Long-Term Care Continuum Framework steeped in First Nations values, culture, needs and priorities
- Advocate for processes to ensure self-determination and on-going community input into long-term care planning
- Information management (eHealth, managing data, defining evaluation measures), who should Own, Control, Access, and Possess data

****Values and understandings shape what we see as appropriate care, so we organized structure of engagement in a way where community voices are heard****

LUNCH

Breakout Session: First Nation Long-term Care Understandings/Values

6. How do you think “co-development” of a First Nations long-term care strategy with the federal government should happen?

Breakout Session: First Nation Long-term Care Understandings/Values

7. What does it mean to age well across the lifespan from a First Nations’ perspective?

Breakout Session: First Nation Long-term Care Understandings/Values

8. What does “disability” mean from a First Nations perspective?

Breakout Session: First Nation Long-term Care Understandings/Values

9. What are the “activities to daily living” that should be supported via long-term care supports/services from a First Nations perspective?

Breakout Session: First Nation Long-term Care Understandings/Values

10. What is long-term care from a First Nations perspective?

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13. How should long-term care information and data be stored and managed and by whom?

Breakout Session: First Nation Long-term Care Understandings/Values

14. How do we measure success of long-term care services/supports from a First Nations' perspective? (i.e. think program evaluation)?

END of DAY 1

WELCOME to DAY 2

OVERVIEW

Day 2

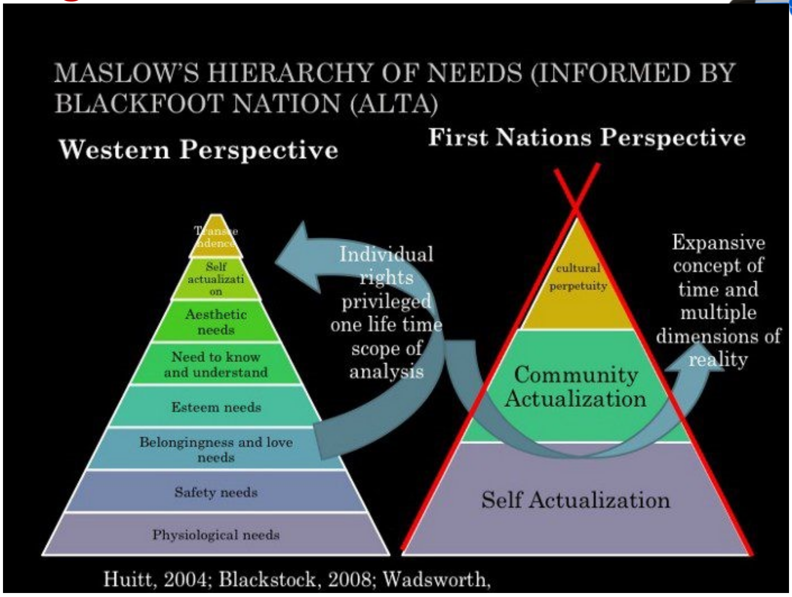
Time	Activity
9:00am	Welcome Remarks for Day 2
9:15am	Defining Long-Term Care Continuum
10:00am	Health Break
10:15am	Breakout Session: First Nation Long-Term Care Continuum & General Discussion
12:00pm	Lunch
1:00pm	Wrap-Up Remarks & Closing Prayers

What is a long-term care continuum?

- **Continuum of care** aims to describe the need to provide “the right services, in the right place, at the right time” (Alexander, 2002)
- Means striving to better meet individuals’ and communities’ needs, eradicate redundancies, and increase efficiencies through the integration and co-ordination of services
- Refers to bundled care options that follow an individual through time, adapting to their changing needs.
- Aims for a coordinated effort, with few “cracks”, gaps, delays, or lost information when transitioning between services/supports means better outcomes for the client
- Often represented visually in a “framework” or “conceptual model”

What is a long-term care continuum?

Some examples



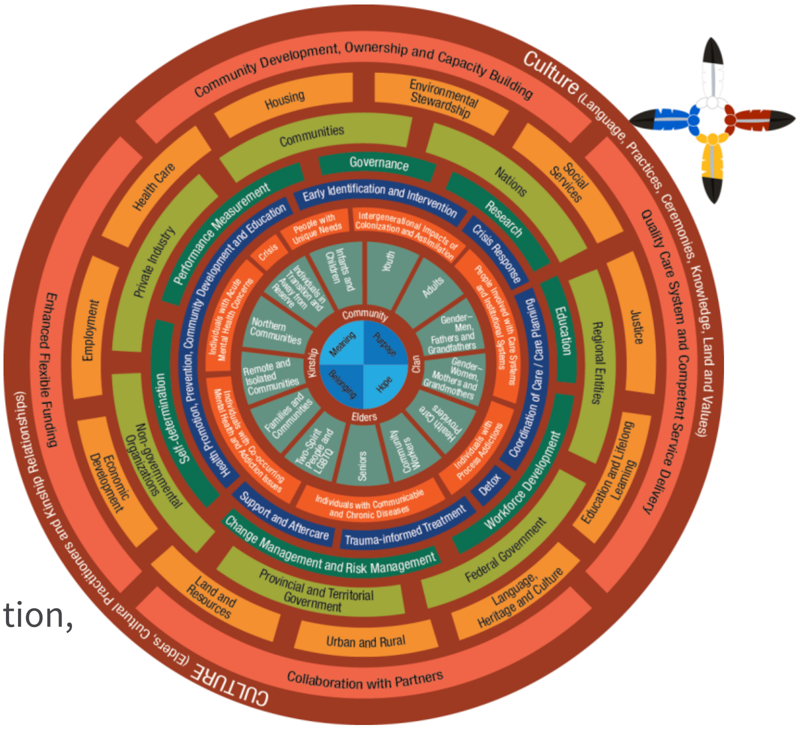
MASLOW'S HIERARCHY OF NEEDS (INFORMED BY BLACKFOOT NATION (ALTA)

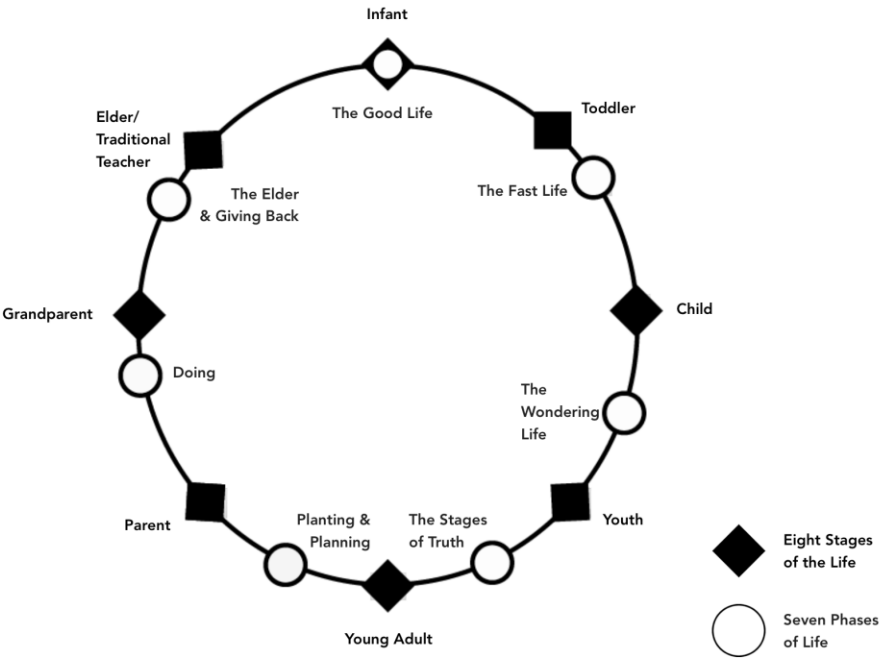
Huitt, 2004; Blackstock, 2008; Wadsworth,

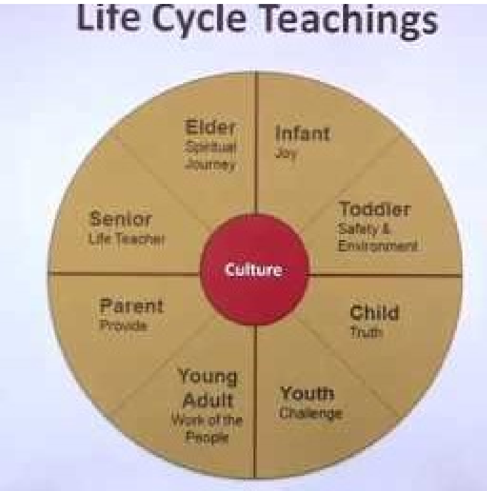
Characteristic Populations	Innovations	Community Living Environments
Older Adults with Complex Care Issues and Needs Living in Designated Buildings	• Innovative Models of Care *Eden Alternative/The Green House Project/The Butterfly Model of Care/Dementia Villages/Wellspring/ INTERACT Program* • Innovative Behavioural Support Approaches *The Gentle Persuasive Approach/Montessori Methods for Dementia*	Building-Based Intensive Services
Older Adults with Complex Care Issues and Needs Living in the Community with Intensive Supports	• Innovative Canadian Models of Support for Unpaid Caregivers *Tax Relief/ Caregiver Support Programs* • Supportive Care Program • Interprofessional and Home-Based Primary Care (HBPC) • Enhanced Home and Community Care Models and Care Practices in Canada *Neighbourhood Care Teams (NCTs)/DIVERT-CARE Model/eSHIFT/Home First and Home is Best* • Enhanced Adult Day Program (ADP) Models *CHOICE/PRIME* • Supportive Housing Models *Ewart Angus House/SageCare/Campuses of Care, Continuing Care Hubs and Continuing Care Retirement Communities (CCRC)* • Nursing Home Alternative Care Models *Adult Foster Care Models/Program for All-Inclusive Care of the Elderly (PACE)*	Home and Community-Based Intensive Services
Older Adults with Moderately Complex Care Issues Living at Home in the Community	· Naturally Occurring Retirement Communities (NORCs) · Dementia Friendly Communities · Independent Transportation Network (ITN) · Community-Based Home Visiting Nursing Programs · Community Paramedicine Programs · Reablement Programs	Home and Community - Based Moderate Intensive Services
Healthy Older Adults with Minimal Care Issues and Needs	• Age-Friendly Communities • Property Tax Deferral Programs • Home Accessibility and Modification Programs • Home Sharing/Co-Housing Models • Life Lease Housing Models • Enhanced Home Support Programs	Independent Community Living

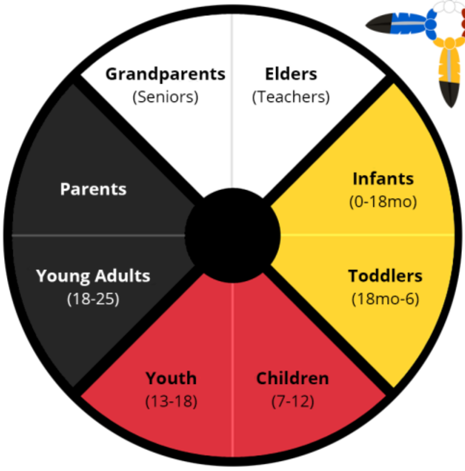
Example of Indigenous Continuum Framework

"Mental Wellness Continuum Framework" (Thunderbird Partnership Foundation, 2015)









Breakout Session: First Nation Long-term Care Continuum

15. How do you envision a long-term care continuum?

Breakout Session: General Discussion

16. General thoughts on First Nations Long-Term Care in Manitoba?

Wrap-Up Remarks & Closing Prayer

Ekosani – Wopida - Miigwech – Ekosi - Mahsi –Merci - Thank You!!

APPENDIX C: FACILITATOR GUIDE

FIRST NATIONS HEALTH AND SOCIAL
SECRETARIAT OF MANITOBA

FACILITATOR GUIDE

First Nations-Led Long-Term Care Strategy for Manitoba

Engagement Process

Prepared by:
Community Engagement & Inter-governmental Relations Department
First Nation Health and Social Secretariat of Manitoba

July 5, 2022

Table of Contents

Introduction

Long-term care can include a variety of services and supports which help meet both the medical and non-medical needs of elderly people or those with a chronic illness or disability who cannot care for themselves for long periods. Long-term care is typically focused on individualized and coordinated services that promote independence, maximize patients' quality of life, and meet patients' needs over a period of time. First Nations Elders and persons with disabilities want to be able to receive culturally inclusive care in their community, close to family and friends, as they age or their care needs change. This may involve caring for their physical, spiritual, emotional, and mental well-being by providing holistic practices and connections to family, community and land (Gionnas et al., 2021).

Care available within communities is not often suited to meet some of the more specialized or acute care needs of individuals. For the most part, those needing long-term care services must leave their homes community to travel a significant distance to access provincial/territorial care. The absence of cultural inclusivity has also been a longstanding issue. Healthcare systems in Canada were developed on a foundation of systemic racism, which continue to facilitate and force assimilation into “mainstream” healthcare treatment and disregard First Nations practices and perspectives (Gionnas et al., 2021). While in recent decades, more First Nations-run long-term care facilities have emerged—which endeavour to incorporate culture, language, and traditional healing—privileging of Western, colonial biomedical models of care by funders and regulators still creates significant barriers and impediments to First Nations’-led approaches and self-determination in long-term care.

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 well-being (Reading & Wien, 2013). This is especially true in contexts where dominant biomedical approaches have failed to reverse the course of the growing gap between the health of First Nations and non-First Nations persons in Canada (Angell, 2017; Katz et al., 2019). Current long-term care services and supports available to First Nations from both federal and provincial governments have been criticized to be culturally unsafe or inappropriate and unable to address the full scope of long-term care needs and priorities of First Nations across the lifespan.

Consequently, this engagement project aims to conduct thorough and meaningful community engagement on how First Nations envision a long-term and continuing care strategy that identifies community-defined challenges, needs, priorities, approaches and recommendations.

Approach

A. Planning & Preparation

This stage will involve putting in place the groundwork conducting background research, a thorough review of the literature (including Indigenous long-term care strategies from other provinces), and developing content for session presentations that will be critical to ensuring engagement participants are familiar and knowledgeable on issues pertinent to First Nations long-term care strategy development. This information will also be incorporated into the final report. Topics will include but are not limited to:

- Research outcomes on the lived-experiences of First Nations Elders and people with disabilities including challenges around access to care, social isolation, discrimination, and more
- Integration of health and social systems, including jurisdictional challenges
- Human resources including support for informal caregivers
- Cultural inclusivity of care
- Information systems
- Care facility design
- Home adaptations for Elders and people with disabilities
- Different types of care: Long-Term Care, Group Homes, Family Care Homes, Respite care, Dementia care, Palliative and end-of-life care
- On- and off-reserve programs: Home and Community Care, Foot Care, Jordan's Principle
- Disability-specific income support

B. Community Engagement

This stage will involve community engagement that will occur via hubs. There will be a total of 10 in-person sessions to occur in hubs located close to communities, Tribal Council offices, or regular meeting places. These 2-day community engagement sessions will involve the presentation of pertinent background research and information, followed by a facilitator-led strengths-based engagement session that will aim designed to elicit observations, concerns, and ideas on what needs to happen to make meaningful and impactful change to long-term care provision to First Nations in Manitoba. **Table 1** below outlines proposed community engagement hub, including target participants, the tribal area they represent, and location of the session.

C. Final Report Development, Validation, Dissemination, & Knowledge Translation

This stage will involve the compiling of final report that will comprise the background research, review of literature, incorporation of MB First Nations with disabilities lived-experiences research study outcomes, community engagement session outcomes, and Manitoba First Nations-driven long-term care recommendations and next steps.

The final draft report will be presented in a virtual validation feedback session to ensure that participants have a final opportunity to comment on the report, recommend amendments, and add further perspective, so that ultimately, the final report accurately portrays the intended vision of participants. The outcomes of this validation session will be incorporated into the final report.

The text of the final report will first be sent to a graphic designer to include pictures, infographics, and a mix of other aesthetic elements keep readers actively engaged with the pertinent content and then be printed and mailed out to Nations and participating organizations, as well as disseminated digitally.

The FNHSSM Intergovernmental Committee on Manitoba First Nations Health team will develop a presentation on the report to deliver at relevant forums such as the Tribal Nursing Quarterly, Health Directors Advisory Committee, Manitoba First Nation Child Development Advisory Committee, Manitoba First Nation Mental Wellness Advisory Committee, FNHSSM Annual General Meeting, and more. The team will also create a video version of the presentation that can then be disseminated on relevant digital platforms.

Target Engagement Groups

Table 1: Summary of Proposed Community Engagement Hubs		
Target Group (Hub)	**Tribal Area**	**Location of Engagement Session**
Local health and social service providers designated by community (e.g. Jordan's Principle, Home and Community Care, Health Directors, Elders, Knowledge Keepers, Tribal Council staff, Treaty Organization staff, On-reserve Elders' Lodges)	Keewatin Tribal Council & Independents	Thompson
	Cree Nation Tribal Health Centre & Independents	Opaskwayak Cree Nation
	West Region Treaty 2 & 4 Health Services	Dauphin
	Dakota Ojibway Health Services & Independents	Brandon
	Southeast Resource Development Council & Independents	Winnipeg
	Four Arrows Regional Health Authority	Winnipeg
	Interlake Reserves Tribal Council	Winnipeg
Manitoba First Nation Personal Care Home Network Group (group consists of administrators for the 8 First Nation Personal Care Homes in MB)	Manitoba Region	Winnipeg
Social Development Technical Advisors Group (consists of Tribal Council and Independents Social Development Advisors)	Manitoba Region	Winnipeg
Special Considerations Group: urban First Nations, youth, and 2SLGBTQQIA+	Manitoba Region	Winnipeg
Council of Elders	Manitoba Region	Winnipeg
Leadership (Chiefs)-Contribution to Chiefs Meeting	Manitoba Region (all 63 Nations)	Winnipeg
Provincial Partners (with identified provincial service providers whom serve First Nations Elders and those living with disabilities)	Manitoba	Winnipeg
Validation Feedback Session-All participants invited to attend & provide comment on the final draft report	Manitoba Region	Virtual

Breakout Format Options

Maximum Number of People Per Group

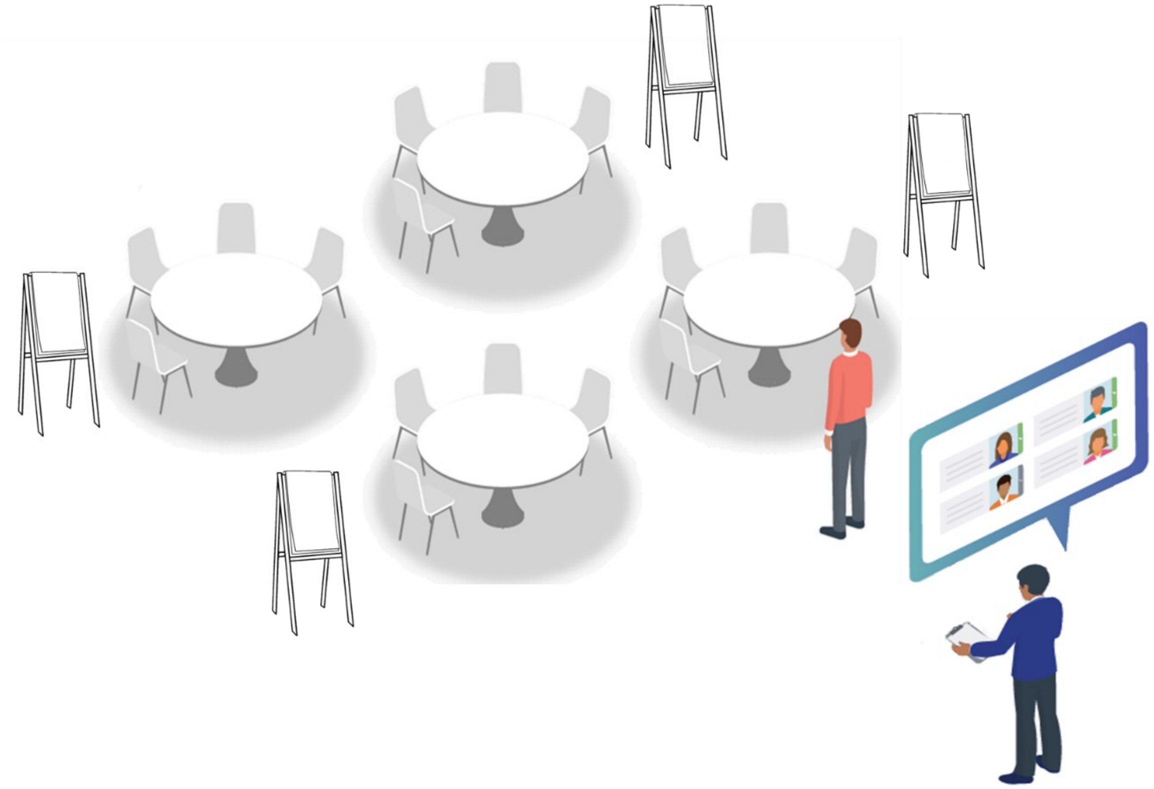
Each breakout group should have a maximum of 8-10 people seated at one table, and additional groups should be created for each increment of 10. For example:

- 17 total participants= 2 groups total, 8 in one group and 9 in the other
- 35 total participants= 4 groups total, 3 groups of nine, 1 group of 9

Maximum of 40 people per engagement session hub due to time and staffing constraints.

Breakout Session Seating Arrangement

Breakout groups should be seated banquet style with their group at one table (see diagram below). This way, all can view the larger presentation and engagement questions presented on the main screen but have discussions about the topics within their smaller groups. Answers will be documented by a note taker with a flipchart and one the group can choose one person who will present their answer back to the whole group.



Engagement Administration

Process

1. Main facilitator will spend the morning of the first day presenting the content of the PowerPoint presentation (project information & process, literature review, defining long-term care, review of long-term care supports & services for First Nations)
2. Breakout sessions will occur on the afternoon of the first day and morning of the second day (afternoon of first day for single day engagement sessions)
3. Breakout sessions will be lead by the main facilitator using the main screen to present each question via the PowerPoint.
4. Each group will be asked to discuss the question amongst themselves with a FNHSSM staff (co-facilitator) assisting by taking notes on the flip chart.
5. Groups will be given about 15 minutes to discuss the question at hand.
6. FNHSSM staff will ask for a volunteer from each group to summarize their discussion to the whole group.
7. Once each group has summarized their discussion for the question, there will be about 5 minutes given for the opportunity for the larger group to comment on the overall discussion for the question.
8. This process will be repeated for each question.
9. A broader concluding comment session (about 30 minutes) will occur on Day 2 as part of the engagement session wrap-up process.

Notes About Facilitating

1. The main facilitator and co-facilitators should try to encourage all to participate and comment during group breakout sessions, perhaps inviting comments in a circle or encouraging those who haven't spoken yet.
2. Encourage participation by asking prompt questions, giving examples, or highlighting what the research might say about a topic when the group is silent.
3. Don't be afraid to admit what you don't know. There may be a lot of questions for which the main facilitator and co-facilitators don't immediately know the answer. Ask the other facilitators; see if anyone in the group has an idea; or suggest that you'll do some research offline and get back to the group with the answer.
4. At the end of each day, ask the participants what they remember. Let them summarize the major points and discussion findings, if time permits.
5. Keep the atmosphere informal so that the participants are comfortable asking questions, participating in activities and sharing their knowledge or concerns.

Staffing Requirements

	Role	Number Required	Possible FNHSSM Staff
Master of Ceremonies	• Greet & welcome participants • Review "housekeeping" notes • Review schedule for day, keep day on schedule • Introduce team • Introduce breaks/lunch, call back participants after breaks	1	Vanessa Tait
Main Facilitator	• Present PowerPoint • Introduce engagement sessions, discuss process, and ask engagement questions • Facilitate breakout groups' summaries in response to questions • Answer participant questions pertaining to project	1	Marsha Simmons
Co-Facilitators	• Record breakout group responses to engagement questions on flip chart • Encourage participation from all breakout group members • Help breakout groups summarize their discussion • Answer any questions from breakout	Dependent on how many participants in total 10-20 participants=2 Co-Facilitators 20-30 participants= 3 Co-Facilitators 30-40= 4 Co-Facilitators	Avery Laforte Alyson Ross Amanda to share calendar and seek support via SMT
Main Note Taker	• Take detailed notes (verbatim where possible) of discussions, questions asked, and engagement question responses for breakout groups • Link engagement question responses for breakout groups to flipchart notes taken by co-facilitators • Draft an engagement outcomes	1	Caleigh Hocaluk
Registration / Sign-In	• Register participants as they arrive, give out session packages, name badges, and seating arrangement	2	Alyson Ross
Total Staff Required per Session		Minimum=7 Maximum=9	

Process Checklist

One Week in Advance, Minimally:
☐ Create a participant registration list
☐ Confirm extra FNHSSM staff who will be assisting
☐ Communicate with participants via e-mail, to introduce yourself and provide the agenda and session location information
☐ Conduct IT walk through/test run with venue and/or FNHSSM IT support
☐ Confirm catering
☐ Create session evaluation form
☐ Create registration list and sign-in sheet
☐ Final edit of PowerPoint slides

Materials Checklist

☐ Registration/ Sign-In Sheet
☐ Name tags
☐ Projector, speakers, microphone, laptop, and other AV equipment
☐ PowerPoint file
☐ Agenda printouts
☐ PowerPoint notes printouts
☐ Evaluation forms printouts
☐ Flipcharts (x 5)
☐ Flipchart markers (minimum 5)
☐ Participant notebooks
☐ Participant pens
☐ COVID-safe materials for tables (hand sanitizer, masks, etc.)

Engagement Questions

Goals of Engagement Questions

- Explore First Nation understandings/values of what it means to age well or live well with a disability and what good long-term care means
- Assess current services to determine needed changes
- Determine what services, resources, supports are missing according to need and values
- Information management (eHealth, managing data, defining evaluation measures), who should Own, Control, Access, and Possess data?

APPENDIX D: OUTCOMES OF SESSION WITH PROVINCIAL PARTNERS

Report on Engagements for a First Nations-Led Long-Term Care Continuum

Provincial Engagement

November 23, 2022

Prepared by:
First Nations Health and Social Secretariat of Manitoba

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INTRODUCTION

The First Nations Health and Social Secretariat of Manitoba (FNHSSM) hosted a series of seven engagement sessions with Tribal Councils, personal care home and Elders lodge staff, social development advisors, and other health and wellness staff from First Nation communities. The engagement sessions were held from July to October 2022, the purpose of the engagement sessions was to determine how First Nations envision a long-term care strategy that identifies community-defined challenges, needs, priorities, approaches, and recommendations.

On November 23, 2022, FNHSSM hosted a provincial engagement forum, which included provincial partners and staff within the provincial system. The engagement session provided a presentation of key findings from the initial seven engagement sessions, discussed the objectives, purpose and process of the engagement sessions, and provided an opportunity for those in attendance to provide input through a series of breakout session questions and to provide feedback on partner commitments within the long-term care strategy. Appendix A provides the PowerPoint utilized in the engagement session to further provide details to what was discussed during the provincial engagement.

This report provides a detailed overview of the provincial engagement and the feedback provided from the breakout sessions; there was both plenary discussions and smaller group discussions and is documented in the report as it was discussed.

WHAT WE HEARD

Plenary Discussion of Key Findings from the Engagement Sessions with First Nations

Opening prayer was provided to start the engagement session in a good way.

A total of thirteen participants attended the engagement session and a roundtable introduction to understand the demographics and backgrounds of those that attended the session was conducted. Those that were in attendance were:

- Project Lead for Personal Care Home Standard Modernization Project for Province of Manitoba.
- Manager with the Seniors in Long Term Care Department for the Government of Manitoba.
- Policy Analyst with the Department of Seniors and Long-Term Care.
- Senior Policy Analyst with the Department of Families – Community Living with Disabilities Services.
- Policy and Program Analyst with the Department of Families – Community Living with Disabilities Services.

- Indigenous Liaison Coordinator for the Manitoba Renal Program – Winnipeg Regional Health Authority
- Nurse Transitional Coordinator for the Manitoba Renal Program – Winnipeg Regional Health Authority
- Regional Indigenous Patient Advocate – Indigenous Health with Winnipeg Regional Health Authority
- Palliative Care Physician – Southern Health Authority
- Resident Doctor – Family Medicine with Southern Health Authority
- Director of Community Oncology Program at Cancer Care Manitoba
- Education and Liaison Nurse Health Equity with the Underserved Population for Cancer Care Manitoba
- Senior Policy Analyst for Province of Manitoba – Intergovernmental and Indigenous Relations

The co-chair presented the PowerPoint slides from the engagement session (Appendix A) and provided an opportunity for the participants to ask questions or provide insight as needed. The key areas that were discussed were:

- Objective and Purpose of Provincial Engagement Forum.
- Review of Federal Mandate, the Federal Framework for Distinction-Based Long-Term Care Continuum.
- Review of FNHSSM engagement process and coordination through FNHSSM
- Goals of the Engagement Sessions.
- An overview of what we heard from the previous seven engagement sessions with Tribal Councils, personal care home and Elders lodge staff, social development advisors, and other health and wellness staff from First Nation communities in Manitoba.
- A brief background and overview of the findings from the "Supporting the Gifts of First Nations Adults with a Disability Study".

As mentioned by co-chair, no one from Indigenous Service Canada (ISC) was present. The feedback from ISC was that they did not want to interfere with engagements and wanted to allow participants to speak and provide feedback freely.

There was mention in the plenary discussion of Dr. Marcia Anderson's work that she is leading around race, ethnicity, and indigeneity. There is a provincial group and cancer care is a part of it, so to answer your question, cancer care does not identify anyone by race and ethnicity and neither does a lot of the health care systems. The first pilot project will be starting soon, and cancer care will be one of the pilot sites to begin to do this work on identifiers, but it will only start in their screening program, more specifically the breast screening program. The health sciences centre it is going to start as a pilot as well. Within all that there is a lot of work on the government of what that data and how that data will be used. And then it will evolve the whole health care system that used the admission, discharge, and transfer (ADT) system to register patients into their facilities. It is not only for Indigenous people, but it will also identify all ethnic groups and races.

Co-chair presented the PowerPoint slides and mentioned to the participants that the information presented would be provided in the First Nations Long-Term Strategy Final Report.

Breakout Sessions: What We Heard

The larger group was broken up into two smaller groups for the breakout sessions where there was discussion around the following important topics, which are:

- Navigating between First Nations and Provincial Service Delivery
- How to co-develop a seamless, culturally safe continuum of care

Navigating between First Nations and Provincial Service Delivery

What are the following gaps you are aware of in the current delivery of services to First Nations in Manitoba?

Several gaps were identified in the current delivery of services to First Nations in Manitoba for long term care. Firstly, **the transition of patients from provincial health care systems to First Nations systems and vice versa.** There is a breakdown in education and awareness between health care providers from the provincial side and the First Nations side to understand each other's systems. The jurisdictional barriers that are in place for First Nations that must navigate between federal, provincial and First Nation level health care services needs to be addressed on all levels of care. The following were examples and areas discussed:

- End stage renal disease patients that are discharged from the hospital setting to a First Nations Personal Care Home (PCH) setting (specific Nelson House), and now there is no medical van to transport the patient from the PCH in Nelson House to the dialysis unit in Thompson, Manitoba.
- The inability of the communities to provide medical care for the multiple comorbidities of end stage renal patients. For example, a patient could go to Berens River First Nation, there is a four-station dialysis unit, but no PCH there to support that patient, so therefore the patient stays in hospital until an out of region panel could be approved, with a preference of Southeast Personal Care home, but they are full capacity. So, the patients are then sent to a PCH that may not be culturally competent and have access to their culture.
- The provincial system provides more services, resources, and supports versus on-reserve. It is more difficult to get a hospital bed to a First Nation then a provincial town, there is a jurisdictional barrier that is happening.
- When you transfer patients to home hemodialysis or peritoneal dialysis, the training that is required to administer these types of treatments is a gap and barrier.
- Cancer Care: one of our big gaps, the episodic care that happens in community. It is not necessarily the same physician that sees the patient. Even though we are not an inpatient facility, all our care is ambulatory and the follow up care is important, and they need to be supportive.
- It is that care that is provided in community how do we communicate. Physicians that give that care in communities, state that they do not have access to the discharge that was sent home with the

patients. It is finding a way to make sure that when they come to see the patient that they have access to their information.

- Years ago, we were giving all cancer treatments in the hospital and now we are doing them in an ambulatory setting, which is good. But this means that the discharge planning is that much more important and complicated, because you are sending people back to the community that are on drugs that have a lot of side effects.
- Transferring someone from a level 3 or 4 care, First Nations does not have adequate space or service in the First Nation community. Is it a transfer issue or a liability issue. Coming from a provincial system and federal system (their First Nations community). There are two worldviews in play here. The individual or First Nation needs to have adequate equipment, human resources and supports in place to transfer them from a fully equipped facility (i.e., hospital) to their homes or community-based facility. For example, a Hoyer lift, they need this for safe transfers.
- There are often jurisdictional battles with governments when it comes to level 1 to 3 care for patients. Level 4 care is different, the province is currently working on the licensing.
- Examples were provided of not having assisted living supports, a PCH or if they have one it is not licensed. There are eight personal care homes in our First Nations; three of them are licensed, these PCH are in Norway House, Nelson House, and Sagkeeng First Nation. The others five are not licensed.
- Policies within the provincial system, such as safety issues needs to be addressed at all levels, to understand risk and reason for certain decisions that are made.
- If you want to do home hemodialysis, the provincial renal program will need to assess your home to ensure that the machine has the capabilities to run in your home. If it does not then we would look at another community building, such as the health centre/nursing station to provide a room to administer the home hemodialysis machine.
- The acceptance of the self-determination piece of it and the acceptance of risk. We all have a personal choice and sometimes we fight as a system because we want to make sure people are safe and you feel a need to protect in a way. However, understanding that no I am ok at my house if I fall. The person is ok with it, but we are not as a system ok with it, as we see vulnerabilities.
- There are existing issues in accessing systems, such as service delivery when they need equipment such as wheelchairs, which is harder on reserve where there is no OT/PT.
- Relocating back and forth, funds are an issue, as the waiting period is longer than most.
- Service delivery for outpatient and inpatient, is different, inpatient have access to more services.
- Moving back home after treatment, who covers that service, access to supplies versus needs.
- Cancer Care has services that most other providers do not.
- What is the delivery time for equipment and medication. It is hard to access medication without going against discrimination. The inpatient and outpatient shipment of medication to communities is a challenge depending on the vendor of the supplies and this needs to be addressed.
- Give us people involved in health care, a bit of anxiety and we see this as potentially being a poor outcome. And the work of medicine that I do (palliative), I deal with patients that are at points where they say I do not want to do X, Y or Z. I talk with different people, First Nations or not who are accepting

different risks of going home, main risk I deal with is end of life. They all realize they will risk passing away.
- There are a lot of staffing challenges in the province, especially in rural areas and communities.
- There are training challenges, and due to covid restrictions there is no consistency.
- There are some communities that have more services then others.
- There is a lack of access of services and support in community for long term care, such as physiotherapy, dental, prenatal, detox shortages in Manitoba, and many other services.
- The personal care homes from provincial standards are very institutionalized.

Furthermore, the communication between all health care providers for patients is a huge barrier and the interoperability of systems talking with one another causes breakages in the transfer of information for all patients. Case management and planning needs to happen when physicians, health care providers, patients and their families need to make important health care decisions. There are people that are displaced geographically and isolated from families and do not have their cultural supports.

The systems need to talk to each other, the PCH, the hospital, the patient records, and all that are a part of the circle of care should be able to see the information needed for the patient no matter where you are transferred to.

As a new physician or health care provider that is meeting patients for the first time, it is difficult to have a conversation with them and at times is not a productive visit because the person cannot make the decisions because they need their wrap around supports there to assist in the decisions needing to be made. We often, because of the system, separate people from the decision, whereas as health care providers we meet to talk to occupational therapist, and other specialized care about this equipment and then talk the nursing station about this equipment; but we do not all come to the table and say can we make this work for this patient.

An adult with disabilities should have the same case management as a child with disabilities, there needs to be family conferencing, so that everyone knows the needs, resources, and supports that are required to care for a loved one safely and properly. Families and communities need to be aware of the risks and understanding of what they are going to be dealing with based on the people they need to provide care to. If you assess the needs of the community members that require extra care, all aspects of their daily living, then the adequate supports and resources should be provided. Reason people are unable to go home to their communities, is due to the lack of adequate resources, supports and services to provide the care needed in a safe and healthy manner and environment.

The coordination of services, specifically in rural and northern communities is a gap. The medical transport for First Nations, there should be a better way, a mechanism in place to schedule a specialist one day and another one another day; to avoid having to make two separate visits; the system should be able to coordinate these services better. However, there is no centralized intakes for specialists. Many patients must travel great distance to get health care.

There is a gap in self-determined care and decision-making regarding treatments, for such diagnosis as cancer. Often patients are diagnosed, see a specialist and they must decide right then and there on treatment. For First Nations, they may need to consult with their family, the patient may want to go back to community, they may want to go to ceremony and connect with the spirit world before making such a decision about treatment and First Nations are not given that option. If it were another non-Indigenous person, who was sitting in a specialist office and was diagnosed with cancer, they would ask to go speak to their prayer chain and pray on it, and I am sure the specialist would allow that. But I think again that is where racism and our assumptions are in the health care system. It comes to cultural training, but it is way beyond that, really understanding what people's needs are to make decisions about their health care. The system is so flawed for all of us, but specifically for people who cannot make a life changing decision like treatment on their own, that is a part of their life that you make all your decisions with your community, by connecting to the land and by connecting to the people.

The **wait list for some health care treatments**, such as dialysis is long in some regions. For example, the wait list is long for dialysis patients for some areas, they are disease burdened. On the other hand, in Dauphin, they have five open spots, but they have no staff, therefore they close their doors to transfers. The lack of human resources is impacting patient care. There are five or six beds open in Boundary Trails, but do not have any patients waiting to go home right now that we are aware of, so that is a positive. There are other regions, such as Portage la Prairie where the wait list is longer, so this affects the First Nations in that region that are awaiting a transfer to be closer to home.

The billing and fee for service model in Manitoba is not adequate for a family physician to participant in a family conferencing that would take more than 15 minutes, as the fee for service is billed in 15-minute intervals as physicians. In Manitoba, a nephrologist can end up doing primary care work on a fee for service model. At times they are doing things from a gynecologist exam to MPI forms because there are no primary care doctors, and if they do not deal with it, it will turn into an acute infection causing hospitalization. For a palliative physician, this is contract with the health region and can be billed hourly and that way the physician can spend as much time with families. There is only a limited amount of these types of contracts that are available, so the palliative care nurses in the Southern Health Region do a lot of that role for the family doctors.

Ageism and racism are barriers for Indigenous people, and this has been discovered as the province is developing its seniors and long-term care strategy, and this gap needs to be addressed. The delivery of health care services is very ageist, which means because of your age or your appearance of being elderly, that a physician or a care provider might make a judgement on services or recommendation on health care services you may receive. For example, if your 75 years old, there may be a judgement call that due to your age there is no chance of recovery, so why would I provide this service for you. If there is a need for resuscitation for a patient, the judgement call if it was not discussed with the patient and family is on the physician or care providers in that facility. For cancer treatment who makes that judgement call for the patient to receive treatment as mentioned earlier about palliative patients not being able to receive cancer treatment. Racism is affecting First Nations patients in seeking care, which causes further problems in their health needs due to not being diagnosed or not detecting the illness before it gets worse.

The **terminology of long-term care needs to be the same across all the systems**. The understanding of long-term care and what is the age group, and what levels of services are provided, the criteria and the eligibility. Often when we talk about long term care, we are discussing the elderly. It is not so much about the elderly, but about the continuity of care for all age groups that is so important. Often, we get caught up in the language used, what long term care and models of care have made navigation difficult. For example, assisted living, supportive housing and age range for long term care is different from community to community. There are patients that are paneled for long term care, but they are too high functioning, therefore they need assisted living, but there is no assisted living. For patients who are only 30, has a lot of disabilities and cannot live at home, at times that is the only place they are provided is a PCH facility, and that facility is not giving that person the care they need because they are not elderly, and the care they are getting is elderly care.

On the other hand, the ineligibility for long term care, younger folks who are on dialysis care and diabetics, that need assistance on glucose monitoring four times a day, so they do not qualify for PCH. These patients are often sent to Riverview or Deer Lodge. Also, many of our younger generation patients that have mobility issues, and disabilities that are not eligible for PCH or long-term care end up on the street of Winnipeg, homeless because no one wants to take them in.

Another gap is the **funding of long-term care facilities and for First Nation health care providers,** these are funded so differently and there is no flexibility. For example, where do you access infrastructure dollars for both facilities and housing, the criteria are very rigid; you either can only have one or the other. There is no flexibility, the vision is to develop those facilities with more flexibility that could accommodate young and old for different needs. We should not be stuck in a model but being responsive to the care level needs of the person at that time.

It is often policy around funding that dictates that model of care. For example, for supportive housing, there is eligibility criteria and there are certain building codes, there is specific per diem paid to those types of housing. Whereas, you have assisted living program, that is considered private care. It is not person centered or the needs or level of care of the people, but rather the funding model that has been attached to it. There is no flexibility around the staffing models as well, so this would include adapting policy and funding structure around models. And, who pays, for supportive housing and assisted living, these are client paid services, but in PCH it is subsidized. Often what a person can pay dictates where they go.

We have lost approximately 10 doctors in the Southern Health Region that have left to practice in British Columbia (BC) or other areas of Manitoba. This is due to burnout and in BC the new payment model for family doctors has increased. The funding is not adequate in First Nation communities, we lose nurses and other health care providers to hospitals and other health authorities, as the pay scales and wage parity is not equal. The agency nurses and provincial nurses have a higher pay scale compared to the funding that is provided by the federal government to First Nations.

Palliative and end of life care there are many gaps for First Nations in Manitoba. End of life treatment, it is a different transition, but still requires primary care, but if that is not done in a continuity of care by one provider, it really causes a lot of gaps in that system. The follow up palliative care needed for patients needs to be adequate to meet the comfort needs of the patients.

We have patients that get lost in the system and the health care providers on reserve inform physician that the patient is involved in their health care program, but are unsure if they are on palliative, which in most cases they are. There are times the physician will meet with the patient and sometimes it is a matter of phoning cancer care for example to let them know that the patient had declined what they had offered for treatment, and it is still sitting on the table. There is just break downs in communications.

Some patients may not be ready to say they do not want resuscitation yet, therefore this is not palliative case for those patients. The patients that have already accepted that part because it is just a system requirement to choose palliative care, rather than to continue interventions.

Palliative care is no equal in the province at all for all people, it is not equal for First Nations. There is a lot of work going on in that area as well through Southern Health and some of the work that they are doing, being led through the Dakota Ojibway Tribal Council (DOTC). For example, it is Southern Health where you can be on cancer treatment while on palliative care. Whereas, in the Winnipeg Regional Health Authority, it is very seldom that a patient is allowed to stay on treatment while on palliative care. These are some of the inequities that are out there

Many health care providers have reverted to virtual care, which saves money on medical transportation, but also may not be the right care, the right way at the right time. For example, the renal program is doing virtual telemedicine and telehealth and clinic solvers for chronic kidney disease stage 4 or 5, unless the patient must be assessed on volume and immediate start for dialysis. However, there are patients showing up to the community cancer care program; that primary care, medical oncology, and radiation oncology did not see in person, and they did not need surgery. The patient gets to the cancer care program and the nurses say this person cannot get treatment because no one has assessed the patient in person. Also, it goes back to equity, a lot of First Nation communities do not have adequate Wi-Fi access and experience connectivity issues.

Non-Insured health benefits for First Nations status patients are a barrier and gap for equipment, services, and resources needed to access proper care in First Nation communities and where they require it. The covering of food equipment for preparation of foods, coverage form accountability, advocate for escort services, and it is difficult for the elders to understand the barriers that are in place that is needed for them to have a good life. At times patients that require escorts or language translators, especially the Elders, do not have access to escort services or are not approved to have one. Also, mental disabilities patients do not have access to escorts, and this poses a safety risk. The transition from provincial system to First Nation system, there is an inequity of services and resources from one system to the next. The federal government needs to provide First Nations with adequate resources and supports, it needs to be equal for everyone and not a case-by-case management. All First Nations deserve what all Manitobans receive for safe transfer from a facility to home community.

If the federal government and provincial government officials were to navigate that system from a First Nation lens and patient journey, they could experience the realities of what First Nations must endure.

For example, get on a bus from Thompson to Winnipeg and wait on a payphone for 3 to 4 hours, to know where your accommodations will be before being able to get medical transportation. Drive on our roads, only allocate 21 cents a kilometer, and they get the treasury board rates, why is it different for First Nations.

How can these gaps be addressed?

The transferring of patients from provincial services to First Nations, the solution is the co-design where all the stakeholders need to sit down together, the federal and provincial governments, and the First Nation community to develop the circle of care model. A continuum of care is not a straight path for a lot of people, they might go back and forth within the system, and developing something that works for everyone. The power of working together and sharing best practices to maximize the outcome of service delivery in the health care system.

The Grand Chief of the Southern Chiefs Organization (SCO) signed a tripartite agreement with the federal and provincial government in June 2022, that all three parties would commit to a working relationship. This is a strategic and action step that will result in the formation of a “holistic, trauma-informed Anishinaabe and Dakota health-care system”, which is to include culturally competent primary care, improved mental health services, enhanced access to traditional healing methods, and local community access to health care are among the priorities. First Nation leadership within our governments need to be equal partners in this process.

The Assembly of Manitoba Chiefs (AMC) Secretariat should be able to provide the medical transportation, but this is not a service it is providing; they do have patient advocates.

The gap is that many times the physician does not have the adequate time to review, and case manage with the patient based on the fee for service model in Manitoba. Therefore, preparing the case plan with others within the system could be beneficial to ensure that the physician understands what the patient, their family, and the possible solutions moving forward, so that the physician has all the information to assist in helping the patient with their care plan or to make an informed decision. Also, the patient wants to hear from the physician and not a nurse or other health care provider and once they speak with the physician the nurses or other health care providers can continue to do the care plan as instructed by the physician.

We need to understand both systems (federal and provincial), need health care providers and professionals that are really invested in understanding what the gaps are. It takes resources, if a person is going to get care in a First Nation that is federally funded, what is it that will be covered for that person and what is covered under the provincial system.

In a perfect world, the federal and provincial systems would get together and fix this and not independently. The navigation is a huge gap in the health care system for all people. Often people say they are in crisis when they need something and as much as we want to educate people on what is available, they are not looking for it, they are not listening until they need it. It must be accessible and for some people that is different models, such as resources online or someone they can call in person. For

First Nation communities, it may be someone that they can call in their communities that knows the system that can help them navigate it. Within the Provincial system, there are seniors support services, senior resource finders, that can be leveraged.

A circle of care model and pathway to be developed for First Nations patients to assist in navigating the system. For example, if you have cancer and needs treatment, this is the pathway and decisions you will come across, these are the resources and supports that are available to you based on where you are geographically located. Having the federal and provincial government come together to support First Nations to develop these pathways for and by First Nations would be beneficial. Treatment and follow up needs to be scaled up. The screening for many diseases should have the capabilities in First Nations communities for patients to have these completed in a clinic by a professional in their community.

There is a Cancer care navigator at Bounty Trails Hospital – Southern Health Region, and any patient who is referred to an oncologist in Cancer Care Manitoba gets referred to the navigator and the patient can call the navigator to find out what is happening with tests, and any other questions they may have. Any patient can use the navigator, whether your First Nation or not. In palliative care, the nurses act as a coordinator between the family doctor, the palliative care doctor, and the home care team, and the families can just call them if they have any questions. We need to ensure that the families and communities are aware of these navigation services, informing the health director or the public health programs in the community.

There is a disconnect between public health and primary health care in First Nation communities, this gap needs to be addressed. The physicians and provincial systems also need a communication link to First Nations in community. There needs to be a communication strategy implemented, as the physician does not know who to contact in the community, and often sending emails to the higher ups in the regional health authority to advise them they have a consult from a First Nation community and the health care provider that was previously linked to this patient is nowhere around, and unsure who to call in First Nations community.

Updating a list of health care provider contacts for First Nations community, provincial system patient navigators, federal government health contacts especially for non-insured health benefits, need to ensure that these lists are updated often. Currently, we have different systems and different ways of doing this, need to find a way to get it to the right people and a system in place to do this. Continuity of doing it repeatedly, updating the contact lists for health care systems, community level, provincial level, and federal level.

Education and awareness of the governance structures of First Nation communities for provincial systems to understand the structure and communication pathways they would need to inform, for reasons such as transfer of care, assistance of a community members that may have to stay in city for specialized care, and so on. Some have Chief and Councils with a health portfolio, others have health committees, and most have health directors. A provincial template that existed in our emergency rooms to be able to contact the community health director or someone to inform them that this is the aftercare that the patient will need, or the patient may need to stay in the city. Upper management needs to also get the same education and awareness about First Nations governance structures to ensure they understand the structures and scenarios that First Nations patients must go through. Also, anti-racism training should be taken by all front-line workers, upper management and all health care providers.

Education and awareness about First Nation governance and where they fit within the health care system in Manitoba, and when the federal government is responsible. As a provincial policy analyst, we get asked to analyze policies and we do not know what applies, and it’s so complex. Some of our policies are so old and have not been reviewed.

There needs to be more education and awareness about different diseases, where the patients, their families and the community are provided more training and education on prevention and caring for themselves, their family or community members. For example, utilizing a 12-foot giant colon for teaching and information as a visual tool for education and awareness in this area.

Cancer Care Manitoba has a navigator, and they hear time and time again that the First Nation does not know anything about the navigator. There is a community engagement liaison in every region and the role of that person is to promote navigation and other tools from Cancer Care Manitoba about cancer care services, what is available and where, and Cancer care is always looking for resources closer to home.

Cancer Care is developing community profiles, they are trying to work with all 63 First Nations with a larger entity that has certain First Nation communities underneath their umbrella. It is a tool for the health care system, a way of talking to the physicians about what is available in their home community. This should be available to all physicians and not just Cancer Care, the tool is a map of the patients First Nation, it tells you if they have a pharmacy, a health care centre (how is run), provides an overview of basic things that is available for safer transfer, to ensure that the physician is not making a decision with the patient about a treatment that cannot be supported in the home or in their home community. It is allowing the physician and the health care system to make a better decision about how to transfer the patient home or near the community and the discharge can be planned.

There is no formalized system for palliative care and long-term care, how do we educate our service providers and our systems. When a new physician gets hired by the region, we are now part of their orientation, trying to catch that turnover piece. Similarly in the nursing orientation, there is a piece where our palliative program is explained when you are hired by our region, but that does not necessarily cover agency nurses or our federal nurses on reserve.

Need to understand the support services to patients, not only health care, but also need to know the social programming that is available as well.

There is a need for advocacy for the patient, often when you build in advocacy structures they are usually within the system, so that advocate works for the system and not the individual. Also, if we create a formalized advocacy structure, the question always will always come back and who is going to fund it. And when we get to who is funding it, then we get back to it belonging to the system that funded it. How do we have an arm’s length person who can bring all these advocates together to develop something or have a system where we do not need advocacy. Everyone should play a role in advocating, doctors, other health care providers, and community service providers and families.

There is a need and want to contribute towards changes that goes beyond just advocacy because you can advocate until your blue in the face, but if the resources are not there or the rules are stacked against you, you are not going to get too far. The health care systems need to provide the adequate resources and supports to have a system where advocates are not needed.

The Department of Families – Community Living with Disabilities Services funds services that assist or support adults with intellectual disabilities. For example, within our communities there are day services or day programs, where the clients can go to the facility for the day. If the client is First Nation, the federal government pays for this service, however when COVID hit these services closed. Those patients that are supported by provincial service providers, were able to stay home because they were provided staff. However, the clients that are from a First Nation community they do not have respite services funded, so they do not have assistance with staff. There are clients who have previously received federal funding, but they need assistance, supports and resources that are not provided in their First Nation. These clients must move to the city, so that they can be supported by the province. However, the provincial system is saying these clients should be funded by the federal government, so there are talks on who funds what.

Advocacy groups with people with intellectual disabilities have a strong voice and advocated for higher wages for disability support workers, who were previously being paid minimum. Disability support workers function like health care workers, they administer medicine, do Hoyer lifts, but were paid minimal.

And example, the Podcast – The Waiting Room Revolution, a health researcher and palliative care physician, who have this podcast on how people can navigate our healthcare system and the fact that there lens is in a death denying culture, a culture where we do not see our lives as terminal and somewhat empowering to patients. That patients have the right to ask their doctor, "I want to have these conversations and I want these people involved."

It could be less of a formalized system, on how we can educate on all our levels, both on reserve and off reserve to educate people on what their basic rights to health care are, no matter whose funding it, talk to your family on what is important to you, and let us see where the system can uphold that or where it might fail you if that is your goal.

Discharge planning is important, it need to be detailed with all required equipment, health care needs at home, and who needs to be in the circle of care for the patient. If not done properly, at times need to go back to the physician to request these, so that the proper funding bodies, such as the federal government will assist in funding these resources and services.

As a physician, I did not understand or learn about these structures for First Nations, the federal funding for equipment, resources, supports and services if you are a status First Nation. Also, the difference between on and off reserve when it comes to funding formulas. The transfer from provincial to federal jurisdiction and vice versa and who is responsible to provide support and service for First Nation patients.

How the structures of governance for health care in the First Nation communities' work. Solution is to have all medical students and health care providers learn this in the institutional education and make it a requirement. It should go through all the professions within the health care system.

What communication mechanisms are in place to promote collaboration between service providers and with First Nations?

Engagements such as this are needed, having open conversations, dialogue, and collaboration. There are still challenges to get the right people to the table. Communication mechanisms to be put in place to promote collaboration between service providers and First Nations.

Need to interlace all the parties that are involved in patient journey, such as Southeast Resource Development Corporation, Interlake Tribal Council and other tribal councils, the western system, Cancer Care, the community-based programs and services, and all others that are involved.

The province has had meetings with First Nations communities, it is more specific topics though like PCH licensing. Last year, there was meetings about palliative care, where they met with each community within the Southern Health region. Our medical director and nurse manager did a sit down with those meetings to review them. There is an end to these meeting, they are hiring a research manager and one of them will be First Nations and one non-First Nation member. It is essentially trying to lay out this model of palliative care, where physicians go to the First Nation reserve, and work with the reserve and federally based nurses. The physician would be available as a provincially and regionally funded physician as a link for that model. The frustrating part about this process, is that we have done these meetings, we have engaged with First Nations communities, and we still do not we know who we need to contact in the First Nation community, we should have access to some sort of communication mechanism on who is who on the First Nations community-based health system.

Need better representation of First Nations at the Regional Health Authority (RHA) level and decision-making tables.

Finding the funding to research these communication mechanisms required to provide collaborations between service providers and First Nations or government levels is a huge barrier.

There is a need for evidence performed practice, informed, and amplifying lived experience. The ethics of service providers. There needs to be a mechanism in place for quality assurance and improvements, possibly a survey. Need lived experience, visions going forward, what did and did not work, and best practices do change annually.

The medical officer (health care provider) needs to collaborate more with person on medical appointments because if these appointments are missed it takes months to get another one scheduled.

The physicians, such as our nephrologists push these issues for research on innovation or innovative ways, it is very research driven. Usually does not include program leadership due to it being research. Front line workers and program leadership do see the day-to-day gaps, barriers, and issues of the health care system, they need to be engaged, to provide solutions to the systemic changes that are needed.

There is no continuity of human resources, the turn around with staff and even in provincial health system changes, for example, changing to shared health from what we had before.

Things in government moves very slowly. Then we also have things that move too quickly, we are developing strategies and we have a tight timeline. And you can't have some meaningful engagements when you have some timeline restrictions, but at the same time can't go on forever. You need to have action, there needs to be a balance.

The provincial system, services and programs needs to work with First Nation communities to align priorities, it was stated that oftentimes we do not get anywhere because we have different priorities. Cancer Care is one of those organizations that only looks at one lens, everything is about cancer. We can think about our priorities for better health outcomes, however when we connect with community, they say we have other priorities right now, such as suicide prevention, basic health care needs that our community has, so we do not have any space or time to talk about a cancer care priority at this time. Ensuring that the provincial systems meet with the First Nation, rather than just shutting the door on communities if the priorities do not align, maybe asking what within this priority could fit into your priorities, maybe they want to talk about prevention, but we are talking about treatments. It is about listening and making sure we are connecting with the priority of community and not with our (provincial system) priorities because it is not going to resonate.

Need to start drafting policies for many of the areas that we are discussing, and not just continue to talk about them. We need to put these into action, and it needs to be measurable.

How to co-develop a seamless, culturally safe continuum of care

Who are the partners that need to be included to achieve this?

The co-development strategy should start with a needs assessment for long-term care for and by the First Nations, that is the foundation; to the individual, the family, and the community. This process needs to include the patient and their patient journey, everyone has a right to determine their own care plan, and you need to include the family and community health services. First Nations leadership, the federal and provincial government needs to be involved in this process.

The engagements that you have completed with the First Nations for the long-term care strategy, this could be aligned with the consultations the province is completing with their senior and long-term care strategy. Building on what we have started here and integrating it into the provincial system, and as you develop the initiatives it goes back to the circular model; this is what we need, these are the initiatives that we need to make it happen, and how do we implement and who is needed at the table to implement this strategy, and then getting down to the funding for developing this strategy.

There are many silos, and, in these engagements, there is such an opportunity to really connect and network; and find ways to address the barriers together rather than in silos, which unfortunately you know is not as sustainable or beneficial to the people we serve.

There is a need for a research portion, the health care team that has the data and the statistics that is needed to capture the information to determine the needs of each region. Also, you need physicians, nurses, program staff, First Nations health staff, and front-line workers engaged in this process.

If we are developing initiatives based on community needs, what are the outcomes, and how do we measure success. Who do these measurements come from and what lens, these are questions that need to be addressed in developing a strategy.

There was an example provided that the ISC staff in Quebec region, plan with the First Nations every year and discuss how the funds should be spent and where they will be invested; this is to ensure that First Nations are involved in the planning process and the decision making.

How can we ensure First Nations voices are included in long-term care planning moving forward?

As mentioned, co-developing and planning, each community is going to have a needs assessment. Is there a mechanism from the First Nations leadership tables that can present what their needs are and identify the similarities. Is it easier to present those similarities, to build more of a stepwise strategy where you can knock off the things that are similar first and then tailor it a little bit and joining in with the provincial system. The next step after the community needs assessment, First Nations are going to need to build a level of trust before sitting at the table with the federal or provincial governments.

There is a need to include physicians, the resident physician would have never known this engagement sessions were happening if I did not inform them. I think that we need to learn this in medical school again on how you become involved in engagement like this to help with systemic changes, because as physicians we do have a heart for things, but we do not necessarily know how to access and how to be a part of decision making.

From a physician perspective, it would be amazing to have long term care facilities in each First Nations reserve and community, but we do not even have any primary care doctors there right now. Is there a mechanism for physicians (family medicine) to do contract work with First Nations communities for primary care services in a similar way that we do with palliative care; but how do we get that person funded.

For some of the road accessible First Nations, they struggle to keep doctors locally, or they get doctors that are international doctors that are not culturally sensitively trained, and patients do not connect with them, and they are there for only 2 years at a time and they leave, or they are at the neighbouring community and First Nation community members must travel to access their care. A part of that comes to funding and how can doctors find funding to work with First Nations care if it is not under the branch of Ongomiizwin Health Services or travelling north. If you are going to put in a long-term care strategy in place, you are going to want your nurses, your health care aides, and your patients to have a primary care provider.

The senior and long-term care provincial care strategy is a whole provincial government strategy, this one is different than the other strategies previously. It is not just focused on the continuum of care, its focused on everything, from economic security, health, housing, and finance. Previous strategies were solely focused on health, so it makes things complex. So, for example, the housing side of things, well health does not provide infrastructure dollars to anything other than facilities, and housing will not build anything that is not just housing because they do not build facilities. We are just in the engagement process for the senior and long-term care strategy for the province. The Ministry Advisory Committee for the Senior and Long-Term Care strategy has Indigenous representation; however, we will need First Nations specific representation.

Long term care facilities and personal care homes should have traditional food served, the restrictions when it comes to this needs to be addressed.

How could First Nations culture and values be better integrated into services and supports?

If you look at the long-term care standards, it is usually aligned with provincial standards, and they are very westernized. We are focusing on water and room temperatures when we need to be focusing more on the quality-of-life indicators and incorporating those values and having person-centered care. Long term care facilities and PCH should have a strategic plan that incorporates First Nations values and culture should be a part of their inclusion and vison when they are onboarding.

The circle of care model may look different from a First Nations perspective then from a provincial systems approach. In some of the provincial programs there is an opportunity to tailor specific programs to First Nations as needed. For example, provincial support services to senior supports service programs, we do senior centers and friendship centres that are tailored to Indigenous First Nations. There is opportunity in those programs to do more.

An example, that a provincial personal care home is funded as faith based. There should be opportunity for First Nations to be funded for a personal care home that incorporates their culture and values. The health science centre does have a smudging room now, not sure if the other hospitals have integrated this in.

There are different structures of personal care homes in the province, there is for profit, non-for-profit, devolved and non-devolved, and some have regional affiliations, and some do not.

Faith-based when we talk about access. For example, the accessibility of a personal care home for 2SLGBTQQIA+ couple, as they age, they need assisted living or a personal care home, a lot of what we have is faith based and the acceptance is a gap. With First Nations, if it is faith based, lets us say catholic affiliation, I can see why the options are not culturally appropriate or even trauma informed.

Barriers of having to tell your story repeatedly, and the patient having to explain themselves in a long-term care facility that they are paying to be there, and to have to feel comfortable being in that environment is hard on the individual.

Home care workers and services that are provided, when patients must retell their story repeatedly, and they have a little more complex story, homecare making comments or asking questions or making suggestions that are not particularly helpful for that scenario. The homecare worker needs to be following there care plan that has been developed with the client, and not trying to make changes as they see fit.

To have to tell your story repeatedly, might be retraumatizing to the clients, so the health care provider staff do not need to put the patient through this.

PARTNER COMMITMENTS

The next section of plenary discussion to end the day was to do a roundtable and ask each participant what there provincial partner commitments are for the First Nation Long Term Care strategy. These were the comments provided:

- Cancer Care Manitoba has undertaken work and has partnered with the Southern Chiefs Organization, and this is important work to move things forward. Cancer Care Manitoba is working to find these opportunities with First Nations, Metis, and Inuit partners to help support identifying actions for cancer care strategic plan. The road map for cancer control in Manitoba, which includes supporting and planning for health services that provide care for people with cancer. Not Cancer Care alone, but any health partner providing care. This work is very valuable to make sure that these ideas are identified by First Nations people at the grassroots and leadership level, and that we can move forward in implementing that into actions identified in the roadmap of cancer control around the priorities and objectives around Cancer Care Manitoba. Priority 6 in our roadmap is improving and enhancing the care for First Nations, Metis and Inuit peoples for their experience, control, and cancer health outcomes.
- The link to the road map to Cancer Control in Manitoba is: https://www.cancercare.mb.ca/export/sites/default/.galleries/files/Roadmap-to-Cancer-Control-MB.pdf
- The priorities identified in the road map were developed with the connections with many partners, which included First Nations, Metis and Inuit people and communities. As mentioned in the group discussions, we can have all the priorities we want, but they also must be the priorities that the community and organizations want to support, not what we want. For example, prevention of cancer or transition of care that is what we would put the focus on. We need to work with the community. Looking at the objectives with self-determination with cancer care patients, this is a very important principle and priority. Cancer Care Manitoba, is open to dialogue and discussions, just get in contact with them.
- Resident physician thanked everyone for being involved and was honored to be involved in the engagements. She is very new to the medical practice she is working with. She mentioned it was important to be a part of these engagement sessions and to recognize the many issues of the medical system, and it was good to hear others' opinions and solutions. One of the areas that she touched on is the discussions on educating medical service staff and health care providers earlier on in their career. For example, in the medical school setting, taking that opportunity to educate people before entering the medical health care system about First Nations communities, the

accessibility and resources that are available in First Nations communities. So, hopefully, in the future as a First Nations physician, I can use my voice to educate people in these areas. This is to educate the service providers attending First Nation settings.

- From a program and partner perspective for palliative care, it is continuing to be present, to be present in long term care, and with the lens of how we incorporate First Nation values and missions. As a physician, to be present in communities, doing visits, supporting the staff and the families and the patient where they are at.
- The Manitoba renal program, thankful for the invite to engagement session. For our program we remain committed to being at the table to progress First Nation patients and long-term care. Looking at the importance of getting passed the barriers and having First Nation patients return to the community setting.
- Policy Analyst was grateful to attend and was able to contribute to the discussion from a policy and technician perspective. Learned a lot with the attendance of this engagement session. Information shared very informative, and this is encouraged to be done more. Aided with more understanding with what the government-to-government approach is. The language needed to be widened and safer for First Nations. More mainstream and more supported. Discussions on the Truth and Reconciliation Calls to Action, the province needs to do more to these calls, specifically, to the calls to action in health section. Discussions on province only having reporting mechanisms and legislation of the TRC, but it is just a roll over for Indigenous indicators and some programs and services that they illustrate, but I do not think it is substantive real call to action outcomes.
- The invite to this engagement went to our Manager for the Department of Families, who was not able to attend, so it was extended to us to attend, and we are grateful that we were sent. There was a lot that we learned here at this engagement. As a policy writer, I am more aware now to have a policy landscape, that includes First Nation perspectives. The Department of Families – Community Living with Disabilities Services is currently doing an engagement plan, where we will meet with stakeholders to look at programs and discuss how to better support adults with intellectual disabilities. All that I have learned here, I will bring it back to the manager, so that we can engage with First Nation communities to listen to them and integrating what we hear into our new policies.
- Our program is person-centered (referring to the community living with disabilities services with the Province of Manitoba), however it is a great opportunity to include more traditional First Nations views on how to better serve Indigenous people with disabilities, this is something we can bring into policy going forward.
- Two of our main team members that are in our working group are a part of the First Nations personal care home working group. We will continue to visit sites and Indigenous personal care homes. I have promised that group that once we start trailing our new provincial standards for personal care homes, that one of those trails will be occurring in an Indigenous personal care home.

- The Seniors and long-term care department, we are committed to continuing to work with First Nations, Metis and Inuit stakeholders and communities as we continue to develop our senior and long-term care strategy and I will be sharing what I have learned here and your work forward as we continue to develop our strategy.

The engagement session ended with a closing prayer.

APPENDIX A

Engagement for a First Nations-Led Long-Term Care Continuum

First Nations Health & Social Secretariat of Manitoba (FNHSSM)

OVERVIEW

Time	Activity
8:30am	Registration
9:00am	Opening Prayer
9:15am	Introductions
9:30am	Objective of Provincial Engagement Forum: Federal Government
9:45am	Review Federal Mandate: Distinctions-Based Long-Term Care Continuum
10:00am	Review of FNHSSM's Engagement Process
10:15am	Health Break
10:30am	What We've Heard
12:00pm	Lunch
1:00pm	Breakout: Navigating Between First Nations and Provincial Service Delivery
1:45pm	Health Break
2:00pm	Breakout: How to co-develop a seamless, culturally-safe continuum of care
2:45pm	Roundtable: Partner Commitments
3:15pm	Next Steps
3:30pm	Closing Prayer

Introductions

Why we are here today

- ISC directive to engage provincial partners
- Share what FNHSSM has heard so far during community engagement
- Discussions to inform policy direction within the Assisted Living Program and the Home and Community Care Programs
- Aim to move away from the siloed approaches that exist to better support a continuum of holistic long term care for First Nations
- Outcomes of the discussions will provide advice and guidance on how services will be delivered and lay the foundation for potential future investments

Reviewing Federal Mandate

- ISC mandated to engage First Nations on the
  - “co-creation of options for a holistic long-term care continuum of health and social services for community members with continuing care needs at all stages of life, including seniors, people living with disabilities and others.”
- First Nations Elders and persons with disabilities want to be able to receive culturally inclusive care in their community, close to family and friends, as they age or their care needs change
- Recognition of longstanding issue of lack of cultural inclusivity and self-determination in long-term care

Federal Framework for Long Term Care:

1. Co-develop a distinctions-based, community-led, Indigenous Long-term and Continuing Care Framework that prioritizes ensuring Indigenous peoples can receive long-term and continuing care services in or near their own communities and culturally appropriate care and programming, whether they are in urban, rural, and northern areas
2. Bolster Indigenous health system navigators so they can provide dedicated support to Indigenous people and their families to specifically help them navigate services related to long-term and continuing care

Engagement Coordinated through FNHSSM

- Approached by ISC and Chief Henderson to undertake this work
- Extensive Literature Review and Environmental Scan
- Engagement Hubs with experts in supporting Elders/Seniors/those with disabilities
    - Tribal councils & independent communities
    - Leadership
    - Council of Elders
    - Special Considerations Group: urban First Nations, youth, and 2SLGBTQQIA+
    - Manitoba First Nation Personal Care Home Network Group
    - Provincial partners
    - Social Development Technical Advisors Group
- Informed by lived-experiences of First Nations with disabilities on-reserve from **Supporting the Gifts of First Nation Adults with a Disability Study**
- Final Report drafting and validation session/input process

Goals of Engagement

- Explore First Nation understandings/values of what it means to age well or live well with a disability and what good long-term care means
- Develop community-driven solutions and ideas for culturally safe care in long-term care
- Assess current services to determine needed changes
- Determine what services, resources, supports are missing according to need and values
- Develop a Long-Term Care Continuum Framework steeped in First Nations values, culture, needs and priorities
- Advocate for processes to ensure self-determination and on-going community input into long-term care planning
- Information management (eHealth, managing data, defining evaluation measures), who should Own, Control, Access, and Possess data

Health Break

Engagement Questions: Part I

1. What are some important problems or gaps you are aware of in the current services available to First Nations in Manitoba?
2. What are some strengths you are aware of in the current services available to First Nations?
3. Could the scope of existing services or how they are delivered be redefined in a way that would better meet the needs of community members?
4. What are some under-utilized community strengths that can be better directed/supported toward caring for individuals?
5. How can First Nations get adequate resources to fund needed long-term care services? (funding formulas, pay structures for cultural & spiritual care providers, etc.)
6. How do you think "co-development" of a First Nations long-term care strategy with the federal government should happen?

Engagement Outcomes: Problems/Gaps

Broad range of limitations in current services

- Assisted living has not evolved to meet need
- Lack of infrastructure and maintenance of existing infrastructure
- Hours of operation
- Palliative/end-of-life care
- Inadequate home care support
- Lack of bed space
- Lack of capacity for First Nations to handle level 3 and 4 care needs
  - Level 4 – lack of appropriate funding, proper equipment, professional and support staffing, and facilities
- Aging out (Jordan's Principle)
- Long waitlists for care homes and treatment centres
- Lack of access in community (namely to Physiotherapy, Dental, Prenatal, Detox (bed shortage within Manitoba, resulting in having to send patients requiring supports out of province)

Engagement Outcomes: Problems/Gaps

Worker shortages & staffing needs

- Poor recruitment and retention
- Worker absenteeism
- Burnout
- Use of agency nurses (high cost, contributes to lack of continuity)
- Low wages for on-reserve workers, disparate to off-reserve wages
- High need for on-reserve respite workers and home makers
- Professional development needs to enhance capacity to provide comprehensive care to individuals with complex needs
- Need for staff from the community or at least culturally-matched staff

Engagement Outcomes: Problems/Gaps

Culture and language

- must be better incorporated and addressed within current programming and facility settings
- 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
- 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
- Institutionalized care lacks “feeling of home”
- Lack of access to cultural, spiritual, and recreational activities

Engagement Outcomes: Problems/Gaps

Other gaps

- Transportation
- Lack of sufficient funding for supplies and the lack of infrastructure, including to support availability of dialysis equipment
- Lack of infrastructure and maintenance of existing infrastructure in general
- Housing conditions
- Transitioning/navigating between programs, particularly between on-reserve and urban programs
- Person-centered patient/client advocacy
- Support for families to handle body when a loved-one passes
- Poor awareness of long-term care
- Unlicensed personal care homes
- Lack of access to PT/OT services available through schools
- No set times for home visits under provincial system

Engagement Outcomes: Strengths

- Having facilities in the community
- Having programming in the community or in proximity
- Staffing from the community
- Coordination amongst all programs in the community
- Positive work environment
- Inclusion and empowerment of residents and elders
- Leadership
- Holistic care approach
- Prevention approach
- Community volunteerism

Engagement Outcomes:

Redefining the Scope/Delivery of Existing Services

- Discharge planning and communication
- Home care: delivery, job scope & training for workers, case management, referral processes
- After-hour/on-call care
- Specific professions requiring a redefining of scope of practice
- Policies:
  - Need for co-development with community
  - FNIHB agency staffing policies
  - Patient travel & escort policies
  - Liabilities associated with palliative care

Engagement Outcomes:

Redefining the Scope/Delivery of Existing Services

- Individuals aging out of Jordan’s Principle
- Individuals with diabetes in long-term care is not being properly managed
- Confidentiality
- Communication
- Occupational Therapists/Physical Therapists
- Staffing challenges
- Supports to families
- Involvement and coordination with all community programs
- Integration of land-based and traditional healing practices

Engagement Outcomes:

Under-Utilized Community Strengths

- Cultural connectedness
- Supports to families
- Recognition of family-identified solutions
- Gifted community members

- Noted challenges:
  - Colonial, institutional policies
  - Not focusing on residential school survivors’ needs.
  - Elder abuse and lack of awareness of what constitutes Elder abuse
  - Abuse of the system.
  - Some “volunteers” have an expectation of payment
  - COVID-19 pandemic has increased isolation
  - Community gardens are no longer being planted or maintained
  - Feeling overwhelmed that there are too many problems and too little solutions
  - Being frustrated by someone telling you, “you can’t do that.”

Engagement Outcomes:

Getting Adequate Resources for Long-Term Care Needs

- Needs-based approach rather than population-based
- Lagging data (especially for housing & infrastructure)
- Unchanging block funding
- Need for inclusion of all capital costs (incl. operation & maintenance)
- Increased costs with inflation and remoteness
- Funding to support expanded eligibility for those in need (those with disability age out of Jordan’s Principle, recognition of addiction as a disability)
- Revising policies/programs to support transition from Jordan’s Principle to other long-term care services taking a prevention approach

Engagement Outcomes:

Getting Adequate Resources for Long-Term Care Needs

- Address limitations, shortfalls, and inequities on-reserve
  - Beyond level 1-3 care
  - Equitable funding per capita to all other Manitobans?
  - Geography & catchment areas (decisions on LTC resources like percentage of beds should consider FN communities)
  - Delays to annual prescription renewals with NIHB
  - Moratorium on Personal Care Homes on-reserve
  - Other community inequities (waters, housing, wages, etc.)

- Training for FN workers
- Building community capacity in LTC and related services (e.g. retro-fitting homes, building accessible infrastructure)
- Integration of culture and healing from intergenerational trauma
- Home care funding inadequate

Engagement Outcomes: Meaning of Co-Development

- Primary goal of co-development: To strategize how First Nations can gain more control over long-term care
- First Nations-led:
  - grassroots-lens, strong perspective on patients'/communities' needs
  - cultural understanding of how to look after one another
  - Holistic: spiritual, mental, physical, and emotional care, different from Western/institutional
  - First Nations want to exercise governance
  - Involve Elders
- Transparent process
- Considers gender, social determinants of health, human rights
- Obtaining input from those requiring services: "Nothing about us without us"
- Evidence-based best practices
- On-going (perpetually evaluates, utilizes lessons learned)
- Recognizes different communities have distinct needs
- Aims to have positive impacts on the ground (real world impacts)

Engagement Outcomes:
Meaning of Co-Development

- Federal Government should:
  - Play more active role in long-term care
  - Hand over more decision-making to FNs
  - Disclose information and data holdings

- Provincial government should be involved:
  - First Nations can share information on what services are needed
  - First Nations can educate on cultural understanding of long-term care and integration into the system
  - Information can be shared by the province on service utilization by First Nations
  - Discussions on how to improve current agreements and build new ones
  - Discussions on improving service delivery for First Nations people

- Both governments can conduct community needs assessments better define jurisdiction/responsibility, setting standards with FN as partners

Engagement Questions: Part II

7. What does it mean to age well across the lifespan from a First Nations' perspective?
8. What does "disability" mean from a First Nations perspective?
9. What are the "activities to daily living" that should be supported via long-term care supports/services from a First Nations perspective?
10. What is long-term care from a First Nations perspective?
11. What are some things that First Nations value with respect to long-term care?
12. How can we ensure First Nations voices be included in long-term care planning moving forward?
13. How should long-term care information and data be stored and managed and by whom?
14. How do we measure success of long-term care services/supports from a First Nations' perspective? (i.e. think program evaluation)?
15. How do you envision a long-term care continuum?

Engagement Outcomes:

Aging Well Across the Lifespan

- Connection to culture
- Remaining in community
- Accessibility to social determinants of health, essential needs, services, culture, the land
- Activities
- Self-care and independence
- Positive feelings (honour, respect, dignity, belonging, sense of home)
- Family support

- Disability can be understood as disruptions to First Nations' way of life and traditional teachings especially roles and responsibilities, resulting in prevention of "aging well across the lifespan"

Engagement Outcomes:

Meaning of Disability

- Disability as having purpose or gifts
- Disability a result of disruption to First Nations’ way of life
- Disability as requiring extra care

Activities to Daily Living

- Cultural and land based
- Socializing, participation in community
- Family supports
- Self-care activities

Engagement Outcomes:

First Nation Perspectives & Values on Long-Term Care

- Culture and traditions
- First Nations people care for each other
- Having sufficient human resources
- Inclusive of addictions and mental health supports
- Ability to stay in home, connected to community & land
- Involves understanding of the Life Journey as a circle of life process
- Strengths-based
- Healing from traumas and breaking cycles
- Holistic

Engagement Outcomes:

Ensuring Inclusion of First Nations Voices

- Regular, on-going engagement and co-development
- Proactive approach to policy changes
- Advisory groups
- Planning process with governance model and evaluation mechanism
- Education for leadership, community-based staff and other service providers
- Communication strategy
- Develop accountability mechanism
- Adequate resources
- Supporting a unified approach by First Nations

Engagement Outcomes:

Data

- Explore a regional database of one common system or a way for data to be readily shared/accessed across different services/programs
- Education & awareness
- Confidentiality
- Access
- Storage
- Data Use
- Data collection
- Identifiers
- Connectivity
- Resourcing

Engagement Outcomes:

Measuring Success

Participants identified a number of indicators/measures for evaluating outcomes:

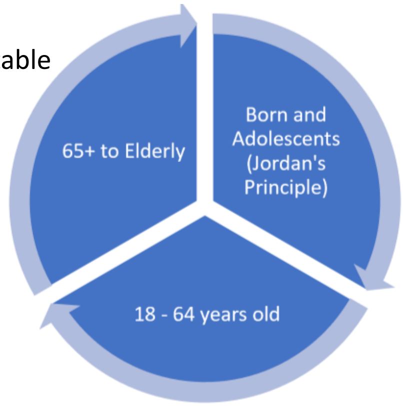
- Remaining in the community
- Family supports
- Human resources
- Circle of Care
- Culture
- Nutritional foods and food security
- Service responses
- Patient/client concerns & happiness
- Funding
- Mental wellness
- Chronic disease-related outcomes

Appropriate methods for collecting information included quantitative & qualitative: storytelling, surveys, meetings, community celebrations/feasts/lunch gatherings to discuss supports needed (much like a townhall meeting), population health data

Engagement Outcomes:

How First Nations envision a long-term care continuum

- Circle of Care model
- Seamless, comprehensive, and adaptable
- Equitable
- Training
- Data



FOUNDATION: structures, culture, language, values, looking after each other, food, medicines, family, respect, roles and responsibilities, caregivers, way of life, supports

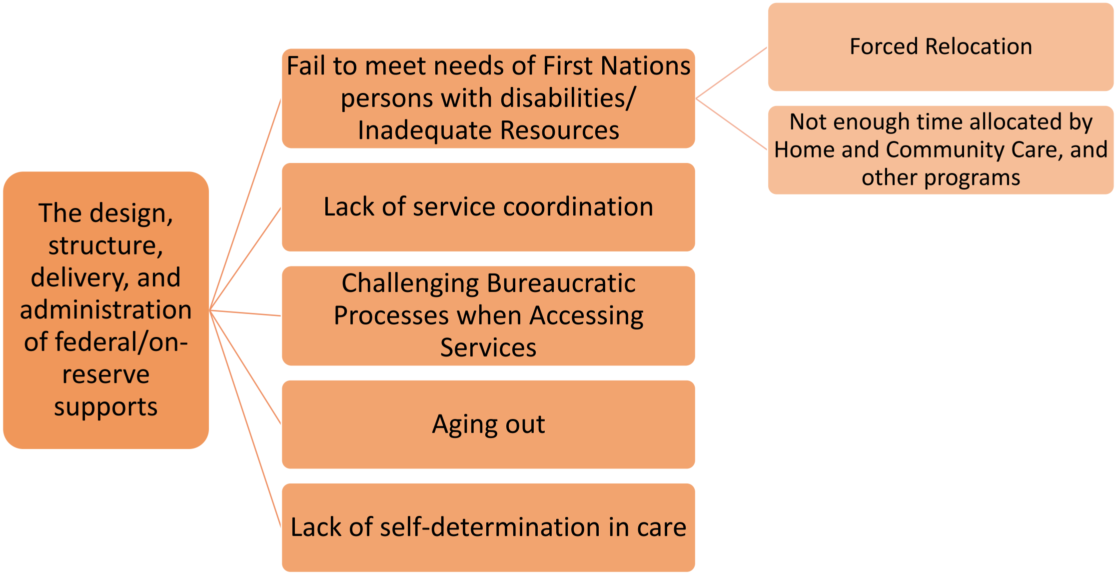
Engagement Outcomes: Key Takeaways

- Need for equity (on- vs. off-reserve)
- Funding formulas
- Involve First Nations/families/individuals in design & implementation
- Integration of culture, language, & spirituality
- Access to holistic wellness approaches
- Enhanced continuity of care across lifespan
- Accessibility (infrastructure, to land-based activities, culture, recreation, health & social services)
- Infrastructure, capital funding including for operation & maintenance
- Local capacity building
- Human Resources
- Home care
- Supporting remaining in the home community
- Jurisdictional disputes/quagmires
- Personal care home licensing
- Palliative care, dignity in dying, & connection to home when dying

Supporting the Gifts of First Nation Adults with a Disability

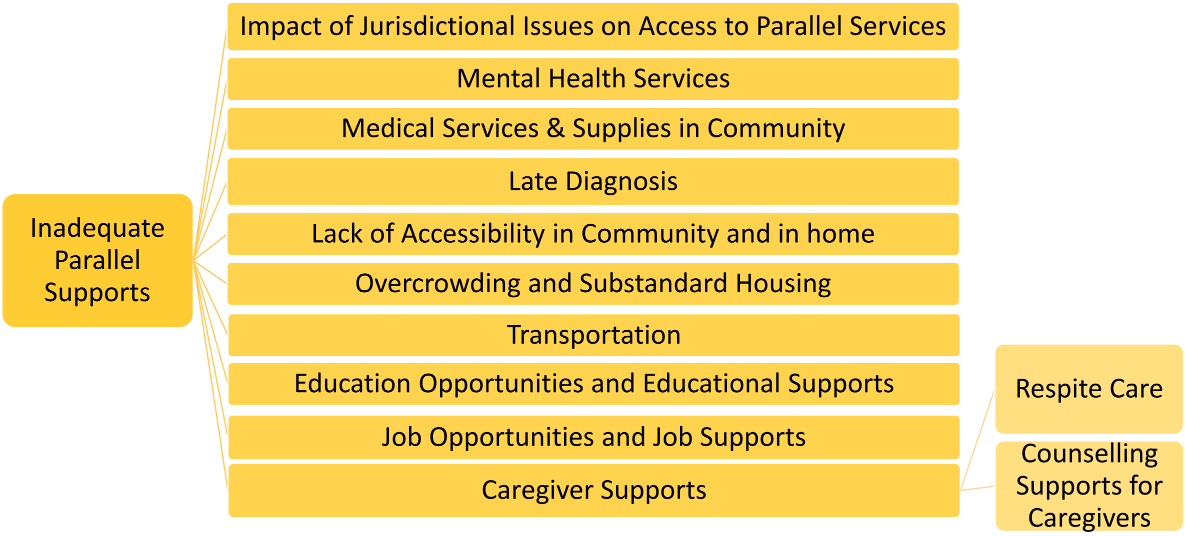
- **Goal**: to explore the lived-experiences of First Nations adults living with disabilities in Manitoba, with a particular focus on their experiences and perspectives around disability services, programs, and supports.
- **Method**: qualitative, conversational interviews
- **21 interviews with 32 participants** (persons with disabilities with their families and/or caregivers)
- Types of disabilities are diverse: developmental/learning disability, psychiatric, physical, neurological, other

Results



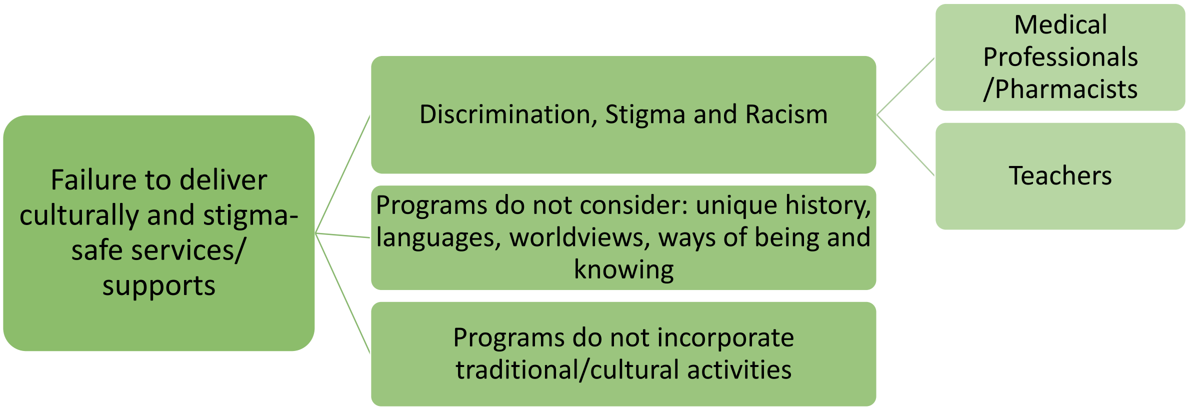
- The design, structure, delivery, and administration of federal/on-reserve supports
  - Fail to meet needs of First Nations persons with disabilities/ Inadequate Resources
    - Forced Relocation
    - Not enough time allocated by Home and Community Care, and other programs
  - Lack of service coordination
  - Challenging Bureaucratic Processes when Accessing Services
  - Aging out
  - Lack of self-determination in care

Results



- Inadequate Parallel Supports
  - Impact of Jurisdictional Issues on Access to Parallel Services
  - Mental Health Services
  - Medical Services & Supplies in Community
  - Late Diagnosis
  - Lack of Accessibility in Community and in home
  - Overcrowding and Substandard Housing
  - Transportation
  - Education Opportunities and Educational Supports
  - Job Opportunities and Job Supports
  - Caregiver Supports
    - Respite Care
    - Counselling Supports for Caregivers

Results



Failure to deliver culturally and stigma-safe services/ supports

- Discrimination, Stigma and Racism
  - Medical Professionals /Pharmacists
  - Teachers
- Programs do not consider: unique history, languages, worldviews, ways of being and knowing
- Programs do not incorporate traditional/cultural activities

LUNCH

Breakout Session

Navigating Between First Nations and Provincial Service Delivery

- What are important gaps you are aware of in the current delivery of services to First Nations in Manitoba?
- How can these gaps be addressed?
- What communication mechanisms are in place to promote collaboration between service providers and with First Nations?
- How can this be improved?

Breakout Session

How to co-develop a seamless, culturally-safe continuum of care

- Who are the partners that need to be included to achieve this?
- How can we ensure First Nations voices are included in long-term care planning moving forward?
- How could First Nation culture and values be better integrated into services/supports?
- What support can your organization provide towards implementation?

Health Break

Roundtable: Partner Commitments

Next Steps

Wrap-Up Remarks & Closing Prayer

Ekosani – Wopida - Miigwech – Ekosi - Mahsi –Merci - Thank You!!