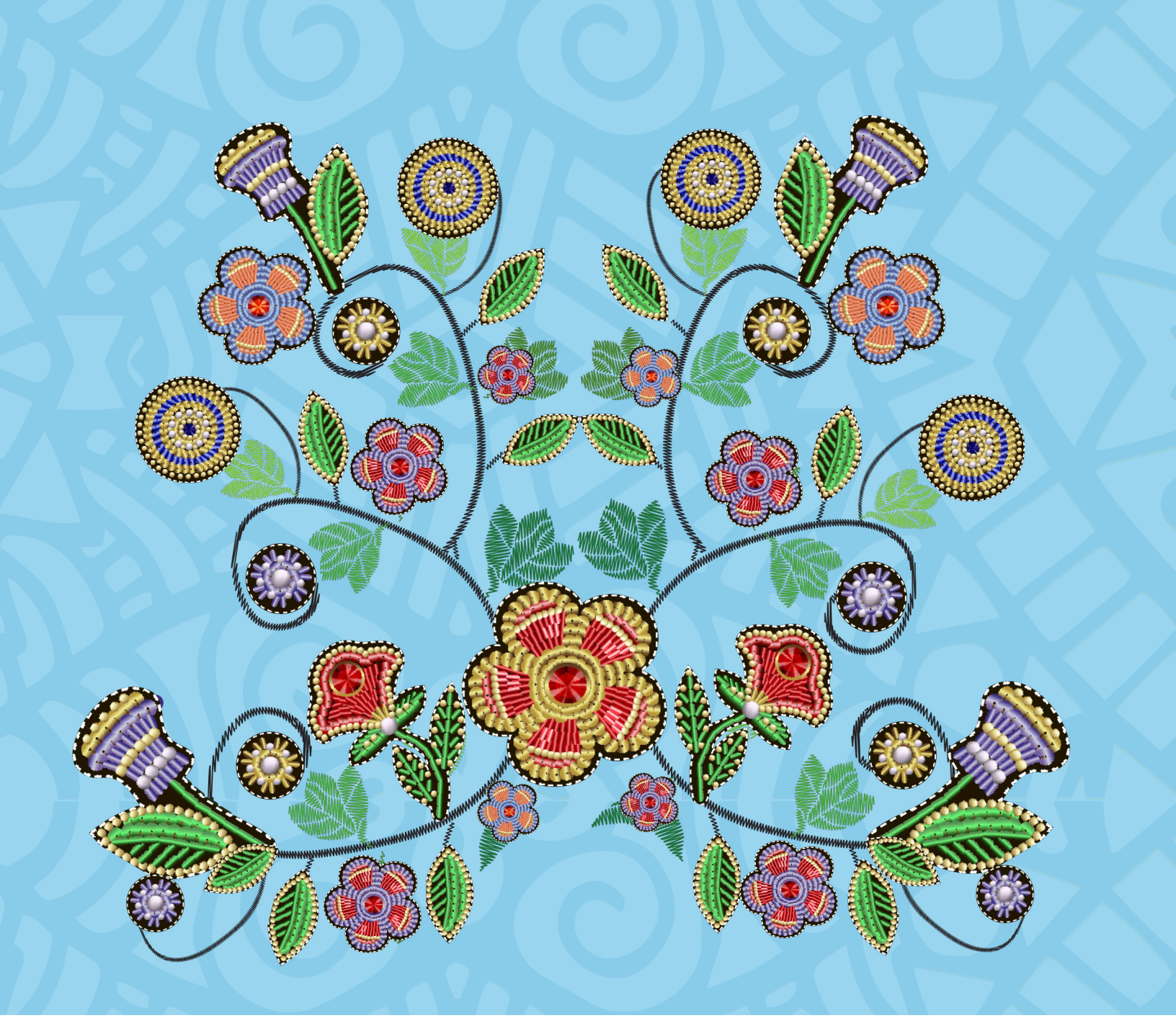

Our Right to Health:

First Nations' Perspectives Across the Generations

Assembly of First Nations' recommendations for a wholistic Seven Generations Continuum of Care approach to home, community care and long-term care across Canada

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2. Executive summary

Our Right to Health: First Nations' Perspectives Across the Generations is the Assembly of First Nations' (AFN) recommendations for a wholistic Seven Generations Continuum of Care approach to home, community and long-term care.

Our vision for the state of First Nations health includes First Nations Peoples, our families and communities designing and delivering equitable health care pathways and systems and coordinating access to health care regardless of a person's geographical location (on-reserve, off-reserve, remote, rural, urban, northern or governed under a provincial/territorial, federal or First Nations program/service) across Canada.

In response to the passing of Resolution 19/2019,[1] the Minister of Indigenous Services Office is committed to work with First Nations and other federal departments to identify needs and gaps in supports and services, capacity and infrastructure as well as develop options for moving forward a Seven Generations Continuum of Care for First Nations, by First Nations, through the reform of the Home and Community Care Program to support a wholistic approach to Long-term and Continuing Care. In readiness for Budget 2024, Indigenous Service Canada's (ISC) goal is to introduce policy recommendations in a Memorandum to Cabinet in Fall 2023. To this end, summary reports from regional First Nations-led engagements that were hosted between September 2020 and September 2022 that emphasized the importance of ensuring improved services and supports within the Home and Community Care Program are administered in a wholistic wraparound support method within First Nations, were submitted to ISC. ISC will use the regional reports feedback to produce a final national report of policy recommendations and options to improve First Nations' continuum of care—with a particular emphasis on home, community and long-term care.

The AFN advocates on behalf of First Nations across Canada as directed by First Nations-in-Assembly. The work includes facilitation and coordination of national and regional discussions and dialogue; advocacy efforts and campaigns; legal and policy analysis; communications with governments; and relationship building between First Nations and the Crown, public and private sectors and the general public.

[1] *AFN Chiefs-in-Assembly Resolution 19/2019: Developing a Seven Generations Continuum of Care for First Nations, by First Nations of Health, Economic and Social Services*. This resolution called for a wholistic approach to develop a continuum of health and health-related supports and services, which will provide a vision and a way forward to improved health and wellness for First Nations across the country.

The purpose of *Our Right to Health: First Nations' Perspectives Across the Generations* is to

- focus on First Nations' perspectives and experiences on home, community, and long-term care
- identify priorities and needs of First Nations in the continuum of care that can occur at any age across the lifespan and the generations; and
- share recommendations to support and fund self-determined continuum of care needs and priorities of First Nations Peoples.

In this report, the AFN provides readers with an up-to-date overview of First Nations living history and our complex relationship with the Canadian health care system. The social determinants of health are referred to throughout this report. They are factors that contribute toward health and well-being: income and socio-economic status; labour force participation; education and literacy; history of colonization; spirituality; connection to community and social support networks; culture and language; and connection to land, geography and physical environments.

Based on the spirit and intent of the Seven Generations Continuum of Care approach, the AFN briefly addresses 12 priorities in *Our Right to Health: First Nations' Perspectives Across the Generations* that relate to First Nations' continuum of care, identifying singular overarching objectives and providing corresponding sets of recommendations summarizing each priority:

1. Culture as foundation: A wholistic perspective to health and wellness
2. Home and community care services
3. Human resources
4. Case managers/navigators
5. Coordinated partnerships
6. Equitable health care access—jurisdiction
7. Health data/funding calculations
8. Health care infrastructure development and maintenance
9. Emergency preparedness
10. Chronic and life-limiting illnesses
11. Aging well and long-term care
12. Palliative and end-of-life care

With a focus on improving First Nations' continuum of care, the AFN's contribution to the ISC final report of policy recommendations and options involves:

(i) summarizing factors contributing to First Nations' continuum of care experiences across what is now called Canada; and

(ii) sharing a suite of priorities and recommendations focused on accessing a continuum of care that is timely, high quality and culturally relevant for First Nations.

The AFN acknowledges that there is much diversity among First Nations in terms of languages, lifestyles, histories, geography, values, practices and teachings. We further recognize that there is a need for home, community and long-term care strategies, programs, services and resources that acknowledge the unique cultural, jurisdictional topics and issues for First Nations.

Our Right to Health: First Nations' Perspectives Across the Generations is for

- First Nations communities, First Nations Regional Health Authorities, First Nations National and Regional Wellness-related Organizations, Tribal Councils; and

- Provincial/territorial and federal levels of government that engage in setting health care policy decision-making, regulating health care and funding priorities in the continuum of care in their given jurisdiction.

With a focus on home, community and long-term care, this report is intended to supplement regional engagements related to ensuring improved services and supports within the Home and Community Care Program and also, for those who are:

- interested in developing health care policies, programs, resources and strategies that meet the specific priorities and needs of First Nations

- engaged in or would like to collaboratively implement the Seven Generations Continuum of Care based on specific needs and priorities of First Nations.

In closing, the AFN seeks to contribute toward building and sustaining trust between orders of government (e.g., provincial/territorial and federal governments) and First Nations in supporting self-determined continuum of care priorities and improving the quality of health care. Our work focuses on home, community and long-term care that harmonizes First Nations' values and cultures.

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3. Introduction

The Assembly of First Nations (AFN) is a national advocacy organization that works to advance the collective aspirations of First Nations individuals and communities across Canada on matters of national or international nature and concern. The AFN hosts two assemblies annually where mandates and directives for the organization are established through resolutions directed and supported by the First Nations in Assembly (elected Chiefs or proxies from member First Nations).

In addition to the direction provided by Chiefs of each member First Nation, the AFN is guided by an Executive Committee consisting of an elected National Chief and Regional Chiefs from each province and territory. Representatives from five national councils (Knowledge Keepers, Youth, Veterans, 2SLGBTQQIA+ and Women) support and guide the decisions of the Executive Committee.

Elders and seniors are highly revered, maintaining prominent, vital and respected roles in First Nations societies. They are held in deepest regard as they are the knowledge carriers and keepers, leaders, teachers, role models and mentors in First Nations. Many of them are Residential Institution Survivors, Indian Hospital Survivors and Sixties Scoop Survivors. Historically, the average age of the First Nations population in Canada has been younger compared to the non-Indigenous Canadian population. However, there is a rapid aging trend and the number of adults aged 50 years and older is steadily growing. While it used to be rare to see First Nations live past their 50s, healthcare professionals are reporting that they are seeing more and more community members age well into their 70s and 80s.

The population explosion of First Nations seniors, coupled with other First Nations priority groups, such as those living with disabilities, chronic or life-limiting illnesses, and/or experiencing mental illnesses increase the growing program and service delivery costs, the demand for palliative and end-of-life care, respite care, home, community and long-term care. Yet, even with these growth anticipations, the funding for home, community and long-term care programs remained stagnant for almost twenty years until finally receiving an increase in the 2017 federal budget. For more than three decades (see resolutions below), the AFN has been raising concerns about the significant gaps in the continuum of care for First Nations Peoples requiring increased levels of care. There is a crisis in the making in First Nations communities. This crisis has many contributing factors: outdated funding formulas; fluctuating inflation rate strains; persistent pressures on human resource capacity in health care; demands for proper infrastructure needs; and outsourcing services to culturally unsafe environments for First Nations.

AFN resolutions related to wholistic long-term care

Resolution 25/2021 – Strengthen First Nations Distinctions-Based Approaches on Accessibility/Disability
Resolution 19/2019 – Developing a Seven Generations Continuum of Care for First Nations, by First Nations of Health, Economic and Social Services
Resolution 110/2019 – Funding for First Nations-Specific Programs, Services and Supports for Adults with Disabilities in First Nations
Resolution 24/2018 – Increased Focus on Disabilities Centered on Human Rights
Resolution 27/2018 – Support for the Long-Term Implementation of Jordan's Principle
Resolution 55/2018 – First Nations Disabilities Program On-Reserve
Resolution 74/2018 – Non-Insured Health Benefits: Ongoing Commitment to a Joint Process
Resolution 88/2018 – Support the Development of Wholistic First Nations Wellness Facilities
Resolution 63/2017 – Federal Engagement on Health Transformation
Resolution 55/2016 – First Nation Federal Accessibility Legislation
Resolution 125/2016 – Support for the Establishment of Culturally-based Indigenous Health Centres Across Canada
Resolution 10/2015 – Call for a Program Review of the Home and Community Care Program to Address Impacts of Insufficient Funding Increases
Resolution 75/2015 – Support the Economic, Social and Cultural, Spiritual, Civil and Political Rights of Indigenous Persons with Disabilities
Resolution 48/2014 – Support for Persons with Disabilities
Resolution 07/2013 – Increase in Funding for Palliative Care in First Nations Communities
Resolution 56/2009 – Establishment of Independent Health and Wellness Services and Programs
Resolution 60/2008 – Renewal of First Nations Health Programs
Resolution 54/2007 – First Nations Seniors
Resolution 30/2005 – Health Care Facilities in Remote First Nations Communities
Resolution 16/2005 – Equality of Health Funding for All Regions in Canada
Resolution 65/2005 – Continuing Care Needs of Elderly and Disabled
Resolution 37/2003 – Support for Long-Term Care Initiatives
Resolution 41/2001 – Funding for First Nation Operated Elders/Nursing Homes
Resolution 77/1998 – State of Emergency in First Nations Health Care
Resolution 17/1993 – National Initiatives on Healing and Wellness
Resolution 59/1988 – First Nations' Health Care

A pressing concern heard across many First Nations is to bring services back to the community so First Nations seniors, Residential Institution Survivors, Indian Hospital Survivors and Sixties Scoop Survivors can stay within the comfort of their homes and communities. Many First Nations do not want to leave their communities for medical, long-term or palliative/end-of-life care, nor should they be forced against their will to do so. It has been expressed for years that First Nations Home Care nurses are only paid for their 9-5 jobs, which is not always convenient for someone passing on. Most desire a culturally safe environment surrounded by the land and the familiarity of their family and friends with aging-in-place supports and maintenance care. For those reasons, there is urgent work to be done in accommodating the current population and appropriately planning for the generations to come.

In response to the passing of Resolution 19/2019,[2] and in anticipation of the Minister of Indigenous Services' Office call for First Nations policy recommendations to revise policies and programs to reform the Home and Community Care Programs to reflect a more wholistic continuum of care approach to long-term and continuing care in readiness for Budget 2024, the AFN reviewed all their past and current unmet recommendations on home and community care and long-term care and combined them into a single report.

Our Right to Health: First Nations' Perspectives Across the Generations' scope is home and community and long-term care. The report identifies and outlines 12 priorities to address the current landscape of health services and provides recommendations for a culturally relevant First Nations Health Transformation focus. Common themes include:

- bringing services back to the community
- having wholistic health care and social service systems where culture is the foundation to healing and helping
- recognizing self-determination and sovereignty over the health care system
- having First Nations-informed and led approaches to address the social determinants of health
- ensuring sustainability and scalability of policies, programs and services in First Nations communities and/or in close proximity to home

[2] *AFN Chiefs-in-Assembly Resolution 19/2019: Developing a Seven Generations Continuum of Care for First Nations, by First Nations of Health, Economic and Social Services.* This resolution called for a wholistic approach to develop a continuum of health and health-related supports and services, which will provide a vision and a way forward to improved health and wellness for First Nations across the country.

- coordinating continuum of care across the lifespan, the generations and jurisdictions
- recruiting and retaining First Nations health care providers; and
- ensuring equity in both access to health care services and outcomes of health interventions.[3]

With a focus on improving First Nations' continuum of care, the AFN's contribution to the ISC final report of policy recommendations and options involves:

- summarizing factors contributing to First Nations' continuum of care experiences across Canada; and
- sharing a suite of priorities and recommendations focused on accessing a continuum of care that is timely, high quality and culturally relevant for First Nations families and communities.

With the report's exclusive focus on First Nations' perspectives and experiences on home, community and long-term care, the AFN acknowledges that there is much diversity among First Nations in terms of languages, lifestyles, histories, geography, values, practices and teachings. We further recognize that there is a need for strategies, programs, services and resources that acknowledge the unique cultural, jurisdictional topics and issues for First Nations.

The AFN anticipates that this report will contribute toward building and sustaining trust between orders of government (e.g., provincial/territorial and federal governments) and First Nations in supporting self-determined continuum of care priorities and improving the quality of health care that harmonizes with First Nations' values and cultures.

Please refer to Appendix A for an overview of shared understandings about First Nations and our relationship with home, community and long-term care and our guiding principles on the continuum of care.

[3] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

3.1 Disclaimers

- The views, opinions, conclusions and recommendations expressed in *Our Right to Health: First Nations' Perspectives Across the Generations* are based on a review, synthesis and consolidation of past and current unmet recommendations pertaining to the continuum of care for First Nations.

- This report is intended to balance the depth and breadth of recommendations and related reflections that span 30-plus years of consultation and engagement sessions that the AFN has facilitated and/or participated in regarding First Nations' continuum of care. Therefore, *Our Right to Health: First Nations' Perspectives Across the Generations* is intended to share priorities that are representative of a variety of First Nations' voices across Canada and the generations about the needs, priorities, barriers and opportunities related to the continuum of care for First Nations Peoples—with a focus on home, community and long-term care.

- Funding formulas referenced throughout this report were increased by 20 percent to account for 2022 funding estimations: cost of living adjustments, inflation, COVID-19 implications, supply and labour shortages (human and technical) and related complexities.

- The AFN is not a Rights holder. This report will not supersede any discussions and decisions about First Nations title and rights that are made by First Nations at Treaty and self-government negotiating tables.

3.2 How is this report organized?

The *Our Right to Health: First Nations' Perspectives Across the Generations* report captures the current landscape of home and community care and long-term care by primarily referencing the AFN's past resources (e.g., resolutions, briefing notes, presentations, circulated literature) and presenting the information and recommendations in a single document. Members of the CCOH and the National First Nations Health Technicians Network (NFNHTN) provided additional documents and contributed to reviewing this document. As a result, *Our Right to Health: First Nations' Perspective Across the Generations* report provides readers with an up-to-date overview of First Nations Peoples' living history and complex relationship with the Canadian health care system.

When we use the term "living history", it means that we are collectively rewriting history by speaking truth to colonization.

Based on the spirit and intent of the Seven Generations Continuum of Care approach, there were 12 priorities identified that relate to the First Nations' continuum of care with each priority encompassing a brief definition, an objective(s) and description and a set of corresponding recommendations.

3.3 How do I use this report?

Our Right to Health: First Nations' Perspectives Across the Generations is intended to inform policy, planning and budget discussions for Indigenous Services Canada (ISC) about First Nations' continuum of care, with a focus on home, community and long-term care.

This report is also intended to serve as an accessible self-advocacy document for First Nations when engaging in dialogue and/or negotiating agreements with orders of government and related organizations that impact and influence health care needs and priorities for their communities.

With a focus on home, community and long-term care, this report is intended for readers who are:

- interested in developing health care policies, programs, resources and strategies specific to the priorities and needs of First Nations
- engaged in or would like to collaboratively implement the Seven Generations Continuum of Care based on specific needs and priorities of First Nations.

4. Context and considerations

The First Nations population is projected to continue increasing and the First Nations seniors population to increase as well. These increases point to a need for a greater emphasis on improving and increasing supports, funding and access to a continuum of care that accounts for the lifespan and the generations.

Currently in Canada, there are increased demands for accountability and assurance for continuing care and other health services (e.g., home, community and long-term care) due to population growth, higher proportions of First Nations living with disabilities, chronic and life-limiting diseases and mental illnesses, the need for culturally safe spaces, impacts and influences of government policy priorities and the continuation of the COVID-19 pandemic. Unfortunately, it took the pandemic to expose the already flawed and fragile health care system that services First Nations. There are and continue to be many lessons learned from the pandemic. A significant example is when First Nations are properly supported and recognized as active partners with federal and provincial/territorial governments, effective long-term strategic solutions emerge that appropriately address First Nations health and wellness needs and will ultimately elevate the health status and quality of life of First Nations Peoples.[5]

First Nations want equitable health and wellness outcomes. This will require full access to a high quality, responsive health service for First Nations within federal, provincial/territorial and First Nations systems. Our vision for the state of First Nations health includes First Nations families and communities designing and delivering equitable health care pathways and systems and coordinating culturally safe access to health care regardless of a person's geographical location (on-reserve, off-reserve, remote, rural, urban, northern or governed under a provincial/territorial, federal or First Nations program/service) across Canada.

[4] Assembly of First Nations (2021). A new path forward: *Supporting First Nations throughout and beyond the COVID-19 pandemic*. Author.
[5] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

4.1 First Nations Peoples and the Canadian health care system

First Nations are the original inhabitants of the land known as Canada. We continue to exercise our sovereignty and self-determination and maintain our connections to cultures and traditions. We continue to maintain our connections with the land and place which, since time immemorial, have supported livelihoods and spiritual and cultural well-being.[6]

First Nations health systems followed a natural continuum of care, which continues today. This continuum of care is based on the cycle of life, from pre-pregnancy education and birth protocols which are woven into ceremony; to walking out ceremonies for children as they make their first encounter with nature; to rites of passage embracing hunting; to providing sexual health and family planning, the use of the medicine lodge for formal training on medicines and energy work, and the practice of ceremony during dying and death. Our languages, stories and ceremonies are used for healing, helping, addressing incidents and sharing cultural practices and teachings.

According to 2021 Canadian census data,[7]

- Indigenous Peoples currently make up about 5 percent of the total population in Canada.
- there are more than one million (1,048,405) First Nations individuals in Canada and population growth is expected to be significant over the next several decades.
- the First Nations population in Canada grew by 54.3 percent, from 2006 to 2021.
- forty percent of the total First Nations population in Canada lives in a large urban centre.
- the low-income rate for First Nations is the highest amongst the three Indigenous groups in Canada at 22.7 percent, with a particularly high rate among status First Nations living on-reserve. Approximately one in three (31.4% percent) First Nations on-reserve lived in a low-income household.

[6] Nelson, M., Natcher, D.C., & Hickey, C.G. (2008). Subsistence harvesting and the cultural sustainability of the Little Red River Cree Nation. In D. David (Ed.). *Seeing beyond the trees. The social dimensions of Aboriginal forest management.* Captus Press. 29–40.

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

We cannot fully recognize the health inequities for First Nations without understanding specific colonized laws, policies and practices over time that have shaped and continue to frame the inadequate health care system. This includes access to timely, affordable and culturally relevant home, community care and long-term care programs, services and resources.[8,9,10]

Health inequities, the historical effects of colonization and the Residential Institution System in Canada are interrelated. The consequences of Canada's colonized history significantly link to the health of First Nations Peoples as evidenced by the high rates of poor spiritual, emotional, mental and physical health (e.g., intergenerational trauma, depression, substance misuse, suicide, diabetes, dementia, domestic violence, cancer, kidney failure, liver failure, heart disease, heart failure) compared to non-Indigenous populations in Canada.[11, 12, 13]

Moreover, the health of First Nations is closely related to many other effects of colonization, including the historical dispossession of lands in Canada that occurred through colonial wars and/or formal Treaties;[14] the creation and implementation of Indian Act legislation and the reserve system;[15] depopulation by epidemics of foreign diseases (e.g., smallpox, diphtheria, influenza, measles, polio, tuberculosis);[16] and unilateral appropriation of First Nations lands, territories and resources.[17,18,19,20,21]

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8 de Leeuw, S., Lindsay, N.M., & Greenwood, M. (2018). Rethinking (once again) determinants of Indigenous Peoples' health. In M. Greenwood, S. de Leeuw, & N.M. Lindsay (Eds.). *Determinants of Indigenous Peoples' health: Beyond the social* (2nd ed.). Canadian Scholars' Press.

9 Jacklin, K., & Warry, W. (2012). Decolonizing First Nations health. In J.C., Kulig, & A.M. Williams (Eds.). *Health in rural Canada.* UBC Press. 374–375.

10 Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

11 Browne, A.J., Varcoe, C., Lavoie, J., et al. (2016). Enhancing health care equity with Indigenous populations: Evidence-based strategies from an ethnographic study. *BMC Health Serv Res*, 16(544). https://doi.org/10.1186/s12913-016-1707-9.

12 Kim, P.J. (2019). Social determinants of health inequities in Indigenous Canadians through a life course approach to colonialism and the residential school system. *Health Equity, 3*(1). 378–381.

13 Assembly of First Nations (2016). *Submission to Senate Committees Directorate Social Affairs, Science and Technology. On the increasing incidence of dementia in First Nations communities: Causes, consequences moving forward.* Author

14 Weaver, J.C. (2003). *The great land rush and the making of the modern world,* 1650–1900. McGill-Queen's University Press.

15 First passed in 1876, the *Indian Act* gave the Government of Canada exclusive authority over those First Nations communities who were recognized as "Indians" living on unilaterally created reserves: https://www.rcaanc-cirnac.gc.ca/eng/1536350959665/1539959903708.

16 Tennant, P. (1999). *Aboriginal peoples and politics: The Indian land question in British Columbi*a, 1849–1989. UBC Press.

17 Bhandar, B. (2016). Status as property: Identity, land and the dispossessions of First Nations women in Canada. *Dark Matter*, 14. 1–20.

18 https://www2.unbc.ca/sites/default/files/sections/neil-hanlon/2009_hanlon_dialoguesfinalreport.pdf

19 DeCourtney, C.A., Branch, P.K., & Morgan, K.M. (2010). Gathering information to develop palliative care programs for Alaska's Aboriginal Peoples. *Journal of Palliative Care*, 26(1). 22–31.

20 Harris, C. (2002). Making native space: Colonialism, resistance, and reserves in British Columbia. UBC Press.

21 Macaulay, A.C. (2009). Improving Aboriginal health: How can health care professionals contribute? *Canadian Family Physician*, 55. 334–336.

4.2 The social determinants of health

The most important factors influencing the health of populations are life circumstances. Often called "social determinants of health," they are "the conditions in which people are born, grow, live, work, age—conditions that together provide the freedom people need to live lives they value."[22] The social determinants of health are shaped and deeply rooted by the distribution of money, power and resources in society and are responsible for the differences and inequities in health status within and between communities. They impact and influence an individuals' and communities' collective physical, mental, emotional and spiritual well-being.

The following are examples of the social determinants of health:[23]

- **Income and socio-economic status.** This determinant includes people having access to the basic needs in life (e.g., food security/diet, water quality, safety, housing/shelter) and access to high-quality health services, resources and supports (e.g., access to health information and technology services; transportation to hospitals and related continuing care centres from rural, remote and northern locations).

- **Labour force participation.** This determinant includes people and groups accessing economic diversification and employment opportunities in communities, regions, industries and sectors. Of note, there continues to be an increase in First Nations (in particular, younger people) leaving home communities for economic and other opportunities (e.g., formal employment). This increase has caused a significant shortage in health human resources (e.g., health care professionals and caregivers).

- **Education and literacy.** This determinant includes access to educational opportunities to support career/life development. Education and literacy barriers can prevent First Nations from having clear communications with health care providers and may prevent informed decision-making regarding access to home, community care and long-term care services, resources and supports.

- **History of colonization.** This determinant includes the history of colonization, racism, discrimination, oppression, marginalization, intergenerational trauma and health inequities.

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[22] Commission on Social Determinants of Health (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health final report of the Commission on Social Determinants of Health*. World Health Organization. p. 26.

[23] https://www.ccnsa-nccah.ca/docs/determinants/RPT-HealthInequalities-Reading-Wien-EN.pdf

- **Spirituality.** This determinant includes First Nations spirituality and connections (or reconnection) with our ancestors and the spirit world. Elders and Knowledge Keepers and Carriers can provide vital information to help guide care.

- **Connection to community and social support networks.** This determinant includes the role of community as a social determinant of health.

- **Culture and language**. This determinant includes First Nations cultures and languages. There are more than 70 Indigenous languages spoken across Canada.[24] Depending on where one has access to health care, the care may not be provided in an Indigenous language or by providers that have knowledge of First Nations' culture.

- **Connection to land, geography and physical environments.** This determinant focuses on First Nations relationship to land, people and place, including how geography influences where and how First Nations and our families access timely and culturally relevant health care. Geography disproportionately impacts wholistic care of First Nations residing in rural, northern and remote communities across Canada compared to those living in urban centres. Geographic locations often prevent First Nations (particularly, First Nations Elders, seniors, people with disabilities and people living with chronic and life-limiting illnesses) from having the necessary infrastructure (e.g., technology, water, heating, sewage treatment, medications, diagnostic testing, medical transportation) to remain in their home communities. This lack of infrastructure creates scenarios where people must move far away from their communities and their families for health care—resulting in relocation, high travel costs, social isolation, separation and the progression to advanced illness(es).

4.3 Special considerations

The following are special considerations when reading and subsequently implementing the suite of recommendations in *Our Right to Health: First Nations' Perspectives Across the Generations.*

[24] https://www.statcan.gc.ca/en/subjects-start/indigenous_peoples

4.3.1 Accessibility and disability lens

First Nations cultures have never considered persons with limited abilities as deficient. Rather, First Nations cultures have understood these individuals to have unique gifts that strengthen the community due to their unique perspectives.

In the natural continuum of care, every member of the community has strengths and challenges, and there is a continuous exchange of support systems to ensure individuals, families and the collective are taken care of and supported. In comparison, a colonized worldview perceives individuals with disabilities as lesser than. Unfortunately, the effects of colonization (both past and ongoing), have exacerbated the ability to support our disability priority population. Stigma plays a significant role in deepening the shame and hiding the "not so visible" disabilities (e.g., learning disabilities, post-traumatic stress disorder, mental illnesses, brain injuries), creating a situation where diagnoses are delayed or never occur, resulting in data that rarely reflect the actual landscape.

Subsequently, it is necessary to apply an accessibility and disability lens in the overall approach for the continuum of care. The inclusion of principles of universal design[25] are vital at the onset of healthcare initiatives to ensure the rights, dignity and inclusion of First Nations people with disabilities are considered and engaged over the lifespan and the generations.

4.3.2 Gender and 2SLGBTQQIA+[26] informed care

In taking a gender- and 2SLGBTQQIA+-informed approach, the AFN commits to assessing the potential impacts and implications of health care policies, programs, services and other initiatives on people with diverse gender identities. This commitment includes strengthening resources and ensuring equity in healthcare services for people with diverse gender identities—ensuring that their unique lived experiences are valued and supported.

People in the **2SLGBTQQIA+ community** often face hostility and discrimination in continuing care centres. They are more likely to face ignorance or outright prejudice leading to miscommunication, misdiagnosis, and mistreatments. Furthermore, the fear of poor treatment in biomedical continuing care centres can drive many people in the 2SLGBTQQIA+ community away from accessing timely and effective health care, particularly as it relates to home, community care and long-term care.

[25] Universal design refers to services or the environment that are accessible for as many people as possible.

The terms "men" and "women" are intended to include individuals identifying in this way, recognizing that not all people who identify as men/women were born with or have male/female anatomy. These terms may not be inclusive of all individuals that are nonbinary, agender, gender fluid or two-spirited.

Women can suffer from discrimination in the form of misogyny, stereotypes and expected gender roles. Individuals born with female anatomy can experience stigma and ostracism surrounding chronic and life-limiting illnesses such as cervical and breast cancers that can make them reluctant to seek health care services and related supports. Also, certain cultural contexts (e.g., being a First Nations female) may further limit access to timely health care (e.g., home, community care and long-term care).

Men can also face the negative effects of gender discrimination and societal and cultural taboos. Social norms surrounding masculinity may make some men less willing to discuss health concerns and cause delayed consideration in accessing a higher level of care. Certain life-saving procedures such as surgery for early-stage prostate cancer and testicular cancer may also cause hesitation due to the fear of side effects such as incontinence or impotence.

4.3.3 First Nations-informed healing and helping

First Nations-informed healing and helping bridges culture, land, identity and place as part of the healing medicines that can aid First Nations (particularly, First Nations seniors, people with disabilities and people with chronic and life-limiting illnesses). First Nations-informed healing and helping can provide wholistic approaches that acknowledge the interdependent relationship between mind, body, spirit and emotions. Furthermore, First Nations-informed healing and helping can aid in connecting (or reconnecting) First Nations to First Nations ways of knowing, for example, First Nations cultural teachings, languages, practices and healing ceremonies.

[26] This acronym stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and additional sexual orientations and gender identities.

4.3.4 Trauma-informed care

Colonization and intergenerational trauma have had and continue to have detrimental effects on First Nations. Therefore, First Nations benefit from trauma-informed care. Trauma-informed care is wholistic and addresses the root causes of trauma across the lifespan, rather than just focusing on the symptoms. This care recognizes the prevalence of trauma (e.g., intergenerational trauma); how trauma affects individuals, families and communities; how individuals who experienced trauma can be re-traumatized in biomedical health care settings; and ways to understand and share pathways toward healing.[27] Also, trauma-informed care involves a commitment to providing health care services that are welcoming, safe and inclusive to the unique needs of individuals affected by trauma or traumatic event(s).[28] Overall, trauma-informed principles include acknowledgement (of trauma), safety, trust, choice and control, compassion, collaboration, empowerment (strengths-based) and peer support.[29]

Trauma-informed care is particularly important in navigating intergenerational trauma manifesting in post-traumatic stress disorder (PTSD) often stemming from constant reminders of colonialism (e.g., institutional settings) which includes the effects of the Residential Institution experience, civil crises (e.g., Oka Crisis), and past and ongoing tension with law enforcement.

4.3.5 Resilience-informed care

A resilience-informed approach is guided by ethical values of respect, inclusion, truth telling, wisdom and belonging.

To reflect a resilience-informed care approach, it is beneficial for policies, funding, programs and practices to be based on shared values, foundations and processes in support of First Nations self-determination. These values, foundations and processes include practicing culturally safe, trauma-informed, resilience-informed care that are inclusive of Indigenous identity (e.g., Indigenous languages, cultures, values, beliefs, protocols, practices, worldviews and knowledge).[30]

Key terms are described in Appendix C of *Our Right to Health: First Nations' Perspectives Across the Generations.* They provide a common understanding of notable terms used throughout this report. Wording related to First Nations approaches to home, community care and long-term care were consistent and congruent as of the date of this report.

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[27] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/what-is-trauma-informed/
[28] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/becoming-trauma-informed/
[28] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/principles/
[30] https://www.fnha.ca/Documents/framework-accord-cadre.pdf

5. First Nations' perspectives and recommendations

5.1 Overview

In this section of Our Right to Health: First Nations' Perspectives Across the Generations, 12 priorities on home, community and long-term care are described. Refer to Appendix D for a summary of recommendations described in this report.

5.2 Culture as foundation: A wholistic perspective to health and wellness

Culture involves aspects of living and being in the world. While there is no single definition of wholistic health and wellness across diverse First Nations cultures, First Nations worldviews share an understanding of the (i) interconnectedness, interdependence, and balance between the physical, mental, emotional, and spiritual dimensions to wellness; (ii) attention to the social determinants of health; and (iii) recognition and respect for culture as foundation as it pertains to healing, helping and wellness for First Nations Peoples. When culture is a central dimension to health and wellness, there is an opportunity for strategies, policies, funding, and programs to honour local First Nations, for example, health, social, economic, and environmental values and contexts.[31]

A wholistic perspective to health and wellness means understanding that the social determinants of health are factors and life circumstances that influence the health of populations. With a social determinants of health perspective, numerous determinants are interwoven and layered into the social fabric of the community. The social determinants of health are shaped and deeply rooted by the distribution of money, power and resources in society and are responsible for the differences and inequities in health status within and between communities. They impact and influence an individuals' and communities' collective physical, mental, emotional and spiritual well-being.

Etuaptmumk/Two-Eyed Seeing is a guiding principle that bridges cultures and is crucial to

[31] http://www.thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf.

a wholistic perspective to Indigenous health and wellness. Introduced by Mi'kmaw Elder Albert Marshall circa 2004, *Etuaptmumk*/Two-Eyed Seeing refers to "learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing … and learning to use both these eyes together, for the benefit of all."[32] Elder Marshall indicates that *Etuaptmumk*/Two-Eyed Seeing is the gift of multiple perspectives treasured by many Indigenous Peoples. It is a foundational principle of collaboration between Indigenous and non-Indigenous Peoples and worldviews.[33,34]

Objective #1: To address the social determinants of health and practice the Etuaptmumk/ Two-Eye Seeing approach to achieve wholistic improvements in First Nations' physical, mental, emotional and spiritual well-being.

Description: When First Nations-informed and led healing and helping practices and ways of knowing are not fully recognized and harmonized with biomedical health care services, this often results in communication and decision-making challenges such as cross-cultural misunderstandings and value conflicts. These challenges and conflicts may alienate First Nations from accessing healthcare services such as home, community and long-term care. This alienation can manifest in cultural and social isolation. Racism, active stereotyping and other colonial health care values also contribute to cultural isolation.[35]

Recommendations:

Recommendation #1.1: Change to an All My Relations[36] standard when it comes to wellness. An All My Relations standard considers the social determinants of health for First Nations Peoples.

- 1.1a: Recognize First Nations health and wellness needs by incorporating care for spiritual, emotional, mental and physical well-being into home, community and long-term care.

- 1.1b: Ensure First Nations communities are provided predictable funding to engage with

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[32] http://www.integrativescience.ca/Principles/TwoEyedSeeing/

[33] Ibid.

[34] Rowett, J. (2018). Two-eyed seeing: A research approach and a way of living. Antistasis, 8(1). https://journals.lib.unb.ca/index.php/antistasis/article/view/25740

[35] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction…* FNQLHSSC.

[36] "All my relations" refers to interconnectedness—"this mindset reflects people who are aware that everything in the universe is connected. It also reinforces that everyone and everything has a purpose, is worthy of respect and caring, and has a place in the grand scheme of life." https://firstnationspedagogy.ca/interconnect.html.

and lead First Nations health care services. With First Nations communities leading healthcare services, there will be an increase in the use and availability of First Nations languages and cultural supports in health care programming.

- 1.1c: Move from a sickness-based model to a wellness promotion and health literacy model. This shift to a wellness and health literacy model should happen across a diverse range of First Nations health services and a continuum of care, with a focus on home, community care and long-term care. This model includes screening services; healthy lifestyle services; needle exchange services; gender- and 2SLGBTQQIA+-informed health services; improved inclusivity for those with accessibility needs; healthy eating, exercise and smoking cessation services; oral health; injury prevention; abuse and neglect prevention; and supporting First Nations Peoples and our families to manage our own health.

- 1.1d: Take a gender- and 2SLGBTQQIA+-informed approach to assess the potential impacts and implications of healthcare policies, programs, services and other initiatives on people with diverse gender identities. This approach includes strengthening resources and ensuring equity in health care services for people with diverse gender identities. This approach will ensure that their unique lived experiences are valued and supported.

Recommendation #1.2: Support First Nations in their respective jurisdictions in (re) building cultural knowledge systems around healing, helping and wellness.

- 1.2a: Support First Nations-led initiatives to determine effective ways that cultural knowledge systems can be revitalized, continued, expanded or promoted in and/or alongside provincial/territorial health systems.

- 1.2b: Support, through policy and funding, the formal inclusion of First Nations-informed and led healing and helping in programming such as mental wellness programs (e.g., Non-Insured Health Benefits[37]), the Assisted Living Program[38] and the First Nations and Inuit Home and Community Care program.[39] As a first step, the AFN recommends an annual investment of $33.5 million.

[37] https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517
[38] https://www.sac-isc.gc.ca/eng/1100100035250/1533317440443
[39] https://www.sac-isc.gc.ca/eng/1582550638699/1582550666787

Recommendation #1.3: Harmonize First Nations healing ceremonies, cultural teachings and practices into the continuum of care, particularly as it relates to home, community care and long-term care.

- 1.3a: Harmonize local First Nations cultural values, customs and beliefs, healing ceremonies and teachings into the continuum of care. For example, storytelling is a way of uniting everyone by sharing time, stories and understanding of one another. Another example is incorporating gift giving protocols and opening/closing prayers at healthcare and related gatherings.

- 1.3b: Work with First Nations communities to ensure funding support for traditional healers and family supports in home, community and long-term care.

Recommendation #1.4: Use a trauma-informed approach[40] for home, community care and long-term care that addresses the root causes of trauma across all stages of life, rather than the symptoms, so that the continuum of care cultivates healing, helping and wellness.

- 1.4a: Recognize the prevalence of trauma (e.g., intergenerational trauma) and how trauma affects individuals, our families and communities.

- 1.4b: Fully implement the *First Nations Mental Wellness Continuum Framework*.[41] The Framework recognizes that culture plays a central role in improving the mental wellness of First Nations Peoples.

- 1.4c: Educate health care professionals and groups providing care on the historical legacy of colonization and residential institutions. Institutional settings may be triggering for Indigenous Peoples, so it is advisable for individuals and groups creating care models and delivering care use a wholistic health lens with these considerations in mind.

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[40] Trauma-informed care is wholistic and addresses the root causes of trauma across the lifespan, rather than just focusing on the symptoms. This care recognizes the prevalence of trauma (e.g., intergenerational trauma); how trauma affects individuals, families and communities; how individuals who experienced trauma can be re-traumatized in biomedical health care settings; and ways to understand and share pathways toward healing. Also, trauma-informed care involves a commitment to providing health care services that are welcoming, safe and inclusive to the unique needs of individuals affected by trauma or traumatic event(s). Overall, trauma-informed principles include acknowledgement (of trauma), safety, trust, choice and control, compassion, collaboration, empowerment (strengths-based) and peer support.

[41] https://thunderbirdpf.org/first-nations-mental-wellness-continuum-framework/

5.3 Home and community care services

In the natural continuum of care, from prenatal to end-of-life care, culturally grounded, wholistic, *Etuaptmumk*/Two-Eyed Seeing approaches in health care are essential for our priority populations, especially those who are 18 years and older that do not have, or have lost, some capacity for self-care. Therefore, a "program that enables First Nations… People[s] of all ages with disabilities, chronic or acute illnesses [life-limiting illnesses] and the elderly to receive the care they need in their homes and communities"[42] needs to be adaptable to support individuals and families as their needs are varied, unique and evolving.

Home and community care are essential in providing wraparound services: (i) home-based care involving home assistance to complete activities of daily living, personal care,[44] homemaking,[45] home visit specialist appointments, limited supervised care and home adaption services; and (ii) community (supportive) care is to help individuals remain independent at home as long as possible. Community care provides increased services in the home when needed and if/when one can no longer stay at home, it provides an alternative higher level of care. This includes adult day services, recreational programs, transportation services, meal services and respite care.[46] *Note: Community (supportive) care may be called something different based on jurisdiction and regions across Canada.*

Objective #2: To improve home and community care by expanding the age limit based on Jordan's Principle or incorporating a resembling framework that serves those who have reached the age of majority. This objective includes adapting home and community care across the lifespan (from First Nations children, Youth, people with disabilities, people with chronic and life-limiting illnesses to Seniors) and respite care/ day programming.

Description: First Nations home and community care programs have limited resources (technical, financial, human) to meet the needs and priorities of First Nations and/or their caregivers after hours or during crises when immediate support or respite is required.

Caregivers play an important role in maintaining the independence, well-being and quality of life for First Nations (e.g., First Nations Elders, seniors, people with disabilities and

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[42] https://www.sac-isc.gc.ca/eng/1524852370986/1615723657104

[43] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

[44] For example, bathing and foot care.

[45] For example, meal preparation.

[46] Respite care provides temporary relief from the physical, mental, emotional and physical demands of caring for a family member or friend. Respite care includes home support services, in community adult day services or access (on a short-term basis) to long-term care, palliative care or other community care settings.

people with chronic and life-limiting illnesses). Caregivers do a great deal of unpaid work for their First Nations family members and/or friends with chronic and life-limiting illnesses, and they are at high risk for burnout and fatigue. More care, including respite, is needed for caregivers. Training for caregivers is limited and perhaps even out-of-date, and there are few support programs for family caregivers. Support is required for urgent respite and structured day programs funded as a preventative measure to meet the spiritual, mental, emotional and physical needs of First Nations Peoples, our families and communities.[47,48]

Without adequate home and community care services, many First Nations must leave their homes, families and communities to be placed in non-Indigenous provincial/territorial continuing care centres. For First Nations communities in rural, remote and northern regions across Canada, this means that First Nations are transferred to urban settings often hundreds of kilometers from home, resulting in feelings of social and cultural isolation furthering depression and loneliness. The stress of displacement often has negative effects on the person's identity, health and quality of life[49,50]and with the family members who cannot visit their loved ones in care.

First Nation living on-reserve have higher rates of disability compared to those living off-reserve.[51,52] First Nations with disabilities living in their home communities are more likely to have low incomes because they may not be able to maintain employment. Their low-income status results in First Nations with disabilities having to rely on income support programs to help meet the costs of daily living. In every province/territory across Canada, people with disabilities living on-reserve have access to disability-specific income supports. This can be either a specific program or through their income assistance program. In provinces/territories that have a disability-specific rate in the provincial/territory income assistance program, ISC matches the rates and the eligibility criteria. In provinces/territories where disability-specific income support is administered as a separate program from the provincial/territory income assistance program, ISC does not have policy authority to deliver the same supports for First Nations living in their home communities.[53,54]

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[47] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). The essential role of caregivers: A cultural and human-centered approach for quality care and services. Bill 56 An Act to recognize and support caregivers and to amend various legislative provisions. FNQLHSSC.

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

[49] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2006). *Assessing continuing care requirements in First Nations and Inuit communities: Quebec regional report.* Author.

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

[51] Ibid.

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

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

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

Recommendations:

Recommendation #2.1: Strengthen care in the community by improving home care, respite care and supporting cultural caregiving values.[55,56,57,58]

- 2.1a: Evaluate current needs and priorities regarding in-home care under the Assisted Living Program and the First Nations and Inuit Home and Community Care Program and recognize that First Nations have always had the ability to merge these two programs should they see fit.

- 2.1b: Review funding allocated for the First Nations and Inuit Home and Community Care Program to ensure that home care and/or in-home respite care in First Nations communities is accessible and adequate.

- 2.1c: Provide health care programs and services (e.g., home and community care) based on the Seven Generations Continuum of Care that reaches First Nations across the lifespan.[59]

- 2.1d: Increase sustainable funding in the Assisted Living Program and the First Nations and Inuit Home and Community Care Program that accounts for geography, levels of community infrastructure and demonstrated needs and priorities.[60]

- 2.1e: Support residential care settings[61] in First Nations communities and/or near First Nations communities that better reflect First Nations cultures, languages and values. This includes funding support.

- 2.1f: Fund urgent respite care and a structured day program as a preventative measure to provide First Nations families with enough support to be able to keep First Nations seniors, people with disabilities and people with chronic and life-limiting illnesses home as long as possible.[62]

- 2.1g: Support improved funding and access to home adaptations[63] for First Nations families and caregivers. Accessibility to proper health care services should not be affected by jurisdictional boundaries, inequitable funding or disputes.

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[55] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.*Author.

[56] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56: An Act to recognize and support caregivers and to amend various legislative provisions. FNQLHSSC.* Author.

[57] First Nations of Quebec and Labrador Economic Development Commission—FNQLEDC (2020). *Social economy innovation: Optimized home care service offer for First Nations Seniors.* FNQLEDC.

[58] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2006). *Assessing continuing care requirements in First Nations and Inuit communities: Quebec regional report.* Author.

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

[60] Demonstrated needs and priorities account for caseload, population base and complexity of (health care) needs and priorities.

[61] Residential care settings include a range of living options for people (e.g., First Nations Elders, Seniors, people with disabilities and people with chronic and life-limiting illnesses) with different support needs. Residential care settings can include lodges, assisted living, group homes, family care homes, supportive housing and long-term care settings.

[62] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.

- 2.1h: Provide resources and support to keep First Nations children and youth in their communities.[64] Some younger First Nations adults, children and youth may need care over the long term (due to disabilities or chronic and life-limiting illnesses), including children aging out of the supports provided through Jordan's Principle. It is important to recognize that home and community care is not limited to First Nations seniors. Regardless of residence or age, there is a general desire by First Nations to receive care and remain in their own home and/or community as long as possible.

Recommendation #2.2: Implement Jordan's Principle meaningfully and in full.

- 2.2a: Implement Jordan's Principle, as identified in the Truth and Reconciliation Commission of Canada Call to Action #3.[65,66] This step includes collaborating with First Nations communities related to Jordan's Principle implementation.
- 2.2b: Commit to a client-first principle that aligns with Jordan's Principle for all First Nations, regardless of age or residency.[68]

Recommendation #2.3: Decolonize the way caregiving is viewed.[69,70]

- 2.3a: Enhance collaboration and coordinated partnerships among caregivers and integration of home, community care and long-term care to ensure management of chronic and life-limiting illnesses, early diagnosis and treatment.
- 2.3b: Identify wise practices across First Nations communities in bringing back care to the community so First Nations ways of knowing and quality of care can be harmonized with treatments.
- 2.3c: Increase support for caregivers through additional respite care, training on how to provide quality care, information on specific disabilities, chronic and life-limiting illnesses and related conditions. This recommendation includes increased nursing and personal care hours to support caregivers.

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[63] Home adaptations include major and minor modifications to the home environment that help people live at home independently. Examples include handrails, grab bars, walk-in showers, ramps, chair lifts and bath lifts. These types of home modifications are effective in decreasing the incidence of accidents and injury. They can also strengthen home-based social relationships and reduce strain on caregivers.

[64] Using a Seven Generations Continuum of Care approach and Jordan's Principle, access to home, community care and/or long-term care now or in the future needs to be inclusive, equitable and First Nations-led across the lifespan.

[65] TRC Call to Action #3. We call upon all levels of government to fully implement Jordan's Principle. https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf

[66] https://www.sac-isc.gc.ca/eng/1583700168284/1583700212289

[67] https://www.rcaanc-cirnac.gc.ca/eng/1524494379788/1557513026413

[68] It is important to recognize that although Jordan's Principle is a child-first principle, the same jurisdictional gaps exist for First Nations adults with chronic and life-limiting illnesses and people with disabilities regarding jurisdictional disputes in care between provincial/territorial ministries and the First Nations and Inuit Health Branch.

[69] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

[70] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56 An Act to recognize and support caregivers and to amend various legislative provisions.* FNQLHSSC.

5.4 Human resources

A key component to advancing First Nations self-determination and local economic diversification is supporting First Nations communities and organizations to build and maintain capacity[71] in carrying out important work in First Nations health care. First Nations communities greatly benefit from having skilled health care professionals[72] to deliver high quality, safe, effective and culturally relevant health and social services.

In developing mechanisms to support First Nations health human resources, there is also a need to expand the roles that are considered part of First Nations-led health and wellness systems. From a wholistic perspective, wellness is not generated by specific health care professionals (e.g., physicians, nurses); rather, the community environment itself is a powerful facilitator of wellness. In this community environment, there is recognition of Elders, Healers, Helpers and Cultural Teachers. Therefore, efforts to strengthen First Nations health human resources need to be flexible enough to support staff that may fall outside of the biomedical definition of "healthcare professionals."

Culture as foundation guides all dimensions to First Nations healthcare. The subject of healthcare needs to incorporate the realities of racism, discrimination, colonization and the normalization of mistreating Indigenous Peoples, people of colour, immigrants and individuals of lower socio-economic status. Healthcare professionals working in First Nations communities and/or in non-Indigenous continuing care centres may be at different stages of cultural awareness (knowing), cultural competencies (applying), cultural safety (acting) and cultural agility (adapting) in their experiences working with and alongside First Nations.

Objective #3: To review options for recruitment and retention of health-related staff. This objective includes expanding policies and resources for caregivers and community helpers—rooted in cultural safety, humility and responsiveness.

Description: In response to Truth and Reconciliation Commission of Canada Call to Action #23,[73] there is significant need for First Nations health-related staff who can deliver culturally competent, safe and informed care. While the number of First Nations staff have increased in the health care and social services fields in recent years, they continue to make

[71] Capacity building ranges from employment and training of individuals, preferably First Nations (which can strengthen our health system and the community as a whole), to a focus on developing First Nations leaders in the workforce who can naturally progress to more senior positions and be role models with the capacity and vision to transform the health system to be responsive to First Nations community's needs and priorities.

[72] Health care professionals include nurses, doctors, allied health professionals (e.g., dietitians, physical therapists) and community-based health workers.

[73] TRC Call to Action #23. *We call upon all levels of government to: i. Increase the number of Aboriginal professionals working in the health-care field. ii. Ensure the retention of Aboriginal health-care providers in Aboriginal communities. iii. Provide cultural competency training for all healthcare professionals.* https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf

up a disproportionately smaller portion of the broader workforce. This will be a significant objective given the increasing population of First Nations in Canada, as well as the health burdens and gaps they continue to experience.

Recommendations:

Recommendation #3.1: Increase support for First Nations health care providers at all levels as they serve as a bridge between biomedical care and First Nations health, healing and helping practices, particularly for health care services close to home.

- 3.1a: Invest in the Aboriginal Health Human Resources Initiative (AHHRI) totalling $24 million annually and work with First Nations communities to ensure the administration of AHHRI reflects First Nations' priorities.

- 3.1b: Increase access to timely primary care in First Nations communities. For First Nations communities that do not have regular access to a physician, allow nurse practitioners to perform an expanded scope of practice (e.g., referrals to specialists), rather than delay care if there is no access to a doctor in the community or for First Nations communities who are on a limited rotational schedule (i.e., once a month or less).

- 3.1c: Increase the number of skilled health-related staff (i.e., health managers, nurses, home health aides and medical assistants) who are First Nations and/or trained to work in First Nations communities.

- 3.1d: Expand the definition of what constitutes a "health care/wellness worker" and/or "health care professionals" beyond current biomedical terms. The separation and specialization of work based on biomedical designations (e.g., nurse, medical doctor, social worker, psychologist) creates unnecessary barriers in access to care as many First Nations are often unaware of the health care role differences and are looking for support from whomever is involved.

- 3.1e: Take immediate steps to ensure wage parity with provincial/territorial standards in wages, pension and employee and family assistance programs for all health-related staff working in First Nations communities.

- 3.1f: Develop a mentorship program that includes peer support networks for nurses working in First Nations communities and access to an Advanced Practice Nurse[74] 24 hours per day.

[74] Advanced Practice Registered Nurses (e.g., nurse practitioners) are nurses who have met advanced educational and clinical practice requirements (minimum of a master's degree) and often provide services in community-based settings. Their services range from primary and preventive care and mental health to birthing and anesthesia.

Recommendation #3.2: Design First Nations-led programs and services that improve the coordination of health services between jurisdictions.

- 3.2a: Implement a multidisciplinary team-based approach, where all staff in each healthcare setting feel physically safe, and are appreciated, treated as equally important and included in the efforts to handle daily activities to crisis-level emergencies. The purpose of this approach is to improve the continuum of care and the quality of life of First Nations.

- 3.2b: Enhance health human resources that are flexible and First Nations-led to meet the goals of improving First Nations' health status, outcomes and wellness.

- 3.2c: Have First Nations health care professionals working in First Nations communities (where and when possible). Health care services should be delivered by and for First Nations—*nothing about us, without us.*

Recommendation #3.3: Support training and skills development that lead to employment for future First Nations health care professionals.

- 3.3a: Train 12,000 First Nations over the next 10 years for careers in health and social services, including the full range of health-related professional and managerial roles.

- 3.3b: Increase funding for First Nations to pursue careers in health care in First Nations communities. This step includes developing and/or expanding scholarship and bursary funds for First Nations post-secondary students in healthcare, with an emphasis on funding for areas of healthcare where there are shortages.

- 3.3c: Develop or expand targeted funds for post-secondary health care programs to increase First Nations participation and success. This development may include equity seats, preparatory and transition programs, and bridging programs from licensed practical nurse to registered nurse and licensed nurse practitioner, mentoring and peer support programs and Elders-in-residence.

- 3.3d: Provide loan forgiveness on Canada Student Loans for health care professionals (including midwives and life spectrum doulas) working in First Nations communities, like what already exists for family doctors, residents in family medicine, nurse practitioners and nurses who work in underserved rural, remote or northern communities.

- 3.3e: Partner with First Nations on recruitment campaigns which includes designing career development opportunities.

- 3.3f: Partner with educational institutions to offer co-op or internship positions, or full-time positions in First Nations for recent graduates.

- 3.3g: Offer First Nations Youth development programs with an emphasis at the secondary school level to promote and prepare students for post-secondary education.

Recommendation #3.4: Design and deliver cultural safety, humility and responsiveness training and related professional development.

- 3.4a: Establish health service standards of care for cultural safety, humility and responsiveness. This step involves health care accreditation and regulatory bodies working with First Nations communities and health authorities on these standards of care.

- 3.4b: Provide support to health and social services professional associations across Canada to design and deliver cultural safety, humility and responsiveness training to their members.

- 3.4c: Implement a mechanism for accountability and assurance in the healthcare system, supported by professional regulatory colleges (e.g., College of Physicians and Surgeons, College of Nurses) whose professionals are not being held accountable for their treatment of First Nations Peoples needing healthcare services. This mechanism will hold healthcare professionals accountable for culturally relevant care provided to First Nations Peoples, our families and communities.

- 3.4d: Direct health-related staff to attend First Nations-approved cultural safety and humility courses that outline, orient and improve participants' awareness of First Nations' complex relationship with colonialism and the Canadian health care system. This training includes learning about local First Nations protocols and values.

- 3.4e: Create financial incentives for post-secondary institutions to build, with and alongside First Nations, mandatory courses on cultural safety, humility and responsiveness for all faculties with a role in healthcare, including direct service and public policy and administration programs.

- 3.4f: Develop and administer work plans related to ensuring cultural safety, humility and responsiveness in the healthcare field.

- 3.4g: Develop and administer cultural safety, humility and responsiveness training for Health Canada headquarters staff.

- 3.4h: Ensure all health care staff that Health Canada employs (to work with First Nations communities) receive mandatory training in cultural safety, humility and responsiveness, particularly nurses.

5.5 Case managers/navigators

Communication is essential in the continuum of care. Specific considerations should be given to communication (e.g., oral, written, virtual) as a method of establishing healthy relationships between health-related staff and First Nations participating in informed decision-making. Effective communication includes managing caseloads; navigating the health care system; advocating for and actively listening when working with and alongside First Nations; providing cultural translation and interpreter services, particularly in biomedical care settings; and outlining the best available options for the individual and family to receive care that supports their unique needs. There is also an additional need for general translation of medical jargon to plain language in the same language. For example, even though a First Nations patient is able to speak English and the healthcare services are provided in English, difficulties may arise when health care professionals are unable to clearly communicate the diagnosis or treatment in plain language terms, causing further miscommunication and anxiety to the First Nations patient.

Objective #4: To develop culturally safer support services that can guide First Nations and their families through cultural healing programs, and through provincial/territorial and federal health and social care systems.

Description: In the spirit of cultural revitalization, access to, use and interpretation of First Nations languages in the continuum of care can improve communications, information and case management. Use and interpretation of First Nations languages as well as use of First Nations health navigation programming can improve the healthcare system for families and caregivers. Managing cases, navigating supports and advocating for First Nations in rural, remote and northern communities is critical throughout the continuum of care. First Nations living in urban settings require navigators as they may feel secluded from their community's safety supports. These individuals may be families, people who are experiencing homelessness, etc. The type of case management, navigation and advocacy supports available throughout the
continuum of care vary by jurisdiction.

Recommendations:

Recommendation #4.1: Encourage health care service providers to build healthy and sustainable connections with First Nations to foster trust and increase confidence.

- 4.1a: Recruit and retain case managers and/or medical navigators to assist and advocate for First Nations to receive proper equitable health care (e.g., home, community care and long-term care).

- 4.1b: Ensure health care service providers clearly inform First Nations on the range of services and programs available to them and that those providers develop a wraparound service plan.

5.6 Coordinated partnerships

Coordinated partnerships involve organizations and orders of government (e.g., First Nations governments/communities, provincial/territorial governments, federal government). To advance a Seven Generations Continuum of Care approach in healthcare (particularly home, community care and long-term care), it will be imperative that First Nations governments and organizations work with and alongside orders of government.[75] As is often the case, the galvanizing of local and regional efforts and actions can create catalysts for provincial/territorial and federal levels of government to hear from citizens about First Nations approaches to healthcare. This process can commence a transformative shift in changing perspectives, attitudes and behaviours.[76] Collaboration with partners includes bringing together and expanding multidisciplinary services across sectors (e.g., health, skills development and employment, social services). Coordinated partnerships will encourage First Nations communities and organizations to work cooperatively to ensure a wholistic continuum of care is timely, accessible and culturally relevant for First Nations.[77]

Objective #5: To determine how to improve the siloed and often fragmented health services between federal and provincial/territorial service delivery partners.

Description: Effective cross-jurisdictional and cross-sectoral relationships can assist in addressing the complex interplay of the social determinants of health which contribute to and exacerbate chronic and life-limiting illnesses. Importantly, investing in adequate and coordinated resources (co-facilitated by First Nations and orders of government) to build the capacity and drive system changes will aid in significantly improving chronic and life-limiting illnesses[78] related to morbidity and mortality rates among First Nations.

Coordinated partnerships may be needed among individual organizations and governments to achieve sustainability and scalability. This coordination can involve community-based services, or in the case of larger affiliations, secondary and tertiary services such as dental health, medical officer of health, nursing supervision and

[75] Assembly of First Nations (2020). *Options for a First Nations 7 Generations Continuum of Care: Document for discussion.:* Author.
[76] Assembly of First Nations (2017). *The First Nations health transformation agenda.* Author.
[77] http://www.thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf.
[78] First Nations have high rates of poor spiritual, emotional, mental and physical health (e.g., intergenerational trauma, depression, substance misuse, suicide, diabetes, dementia, domestic violence, cancer, kidney failure, liver failure, heart disease, heart failure) compared to non-Indigenous populations in Canada.

environmental health services[79] delivered directly by First Nations communities and/or organizations. A balance is needed between the need for community capacity development/local service delivery and the economic scope and centralization of services found with larger affiliations.

Recommendations:

Recommendation #5.1: Develop coordinated partnerships with external health care service organizations to ensure First Nations' needs and priorities are met and First Nations communities' health care operations have the ability to expand and maximize their reach.

- 5.1a: Support First Nations seniors, people with disabilities and people with chronic and life-limiting illnesses, our families, caregivers and communities to manage their disabilities and/or illnesses with follow-up community-based supports (e.g., equipment, services). This approach can improve many aspects of the health care experience for First Nations: access to timely healthcare; health outcomes; efficient and effective health care delivery; satisfaction among healthcare providers; and the ability of First Nations to manage one or more disabilities and/or chronic and life-limiting illnesses.

Recommendation #5.2: Draft policies and/or legislation options that outline medical care required for and entitled to First Nations Peoples living on-reserve and living off-reserve.

5.7 Equitable health care access—jurisdiction

Access to care is based on healthcare jurisdiction and funding. The Government of Canada (federal order of government) has responsibility for First Nations, while the delivery of health care services in Canada is primarily a provincial/territorial responsibility. Furthermore, healthcare is generally divided between primary (community), secondary (hospital), and tertiary (specialized treatment centres) services that often overlap orders of government and agencies (including federal, provincial/territorial, regional, community and First Nations-led organizations).[80,81]

[79] Environmental health services focus on aspects of the environment that can present a risk to health, for example, housing, a safe supply of food and water, the control of pests that can spread infection, air quality and noise.

[80] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

[81] Canadian Partnership Against Cancer (2013). *First Nations cancer control in Canada baseline report.* Author.

Objective #6: To improve access to equitable health care.

Description: Jurisdiction (law making authority) creates added complexities for First Nations attempting to access care. Jurisdiction in healthcare and the broader continuum of care has resulted in undefined roles and responsibilities; lack of coordination among services across orders of government (e.g., First Nations, federal and provincial/territorial orders of government);[82,83] and gaps in jurisdictional responsibility for funding between orders of government.[84]

With growing recognition of First Nations title and rights in Canada, there is a need to promote First Nations models of self-determination with a focus on the negotiation of practical and workable arrangements to implement self-government with jurisdiction and funding associated with healthcare (includes home, community care and long-term care).

Recommendations:

Recommendation #6.1: Engage in a trilateral process with the federal government, provincial/territorial governments and First Nations in our respective jurisdictions, to come to a clear and actionable shared position on jurisdictional responsibilities.

- 6.1a: Challenge the concept of remoteness for First Nations communities as it relates to us receiving inadequate healthcare. Remoteness is a colonial construct.
- 6.1b: Resolve identified health care jurisdictional barriers between First Nations, federal and provincial/territorial governments.[85]
- 6.1c: Support First Nations, both in policy and through stable adequate resourcing, in developing health centres for urban First Nations populations.
- 6.1d: Expand funding to First Nations representative organizations and allow flexibility to ensure that investments in First Nations communities and First Nations organizations for engagement and collaboration in meeting the demands on their valuable time and resources.
- 6.1e: Make meaningful investments, in line with those provided in the Province of British

[82] Habjan, S., Prince, H., & Kelley, M.L. (2012). Caregiving for Elders in First Nations communities: Social system perspective on barriers and challenges. Canadian Journal of Aging, 31(2). 209–222.
[83] https://spcare.bmj.com/content/bmjspcare/3/1/61.full.pdf
[84] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.
[85] For example, reduce the costs and barriers associated with First Nations Peoples (particularly, First Nations Elders, Seniors, people with disabilities and people with chronic and life-limiting illnesses) who must coordinate and navigate health care issues such as hospital-to-hospital transfers, transportation, prescription drug costs for individuals with chronic and life-limiting illnesses and/or disabilities, home and community care and long-term care costs.

Columbia, to build First Nations health governance capacity.

- 6.1f: Work with First Nations and First Nations organizations in transitioning funding currently being provided to non-Indigenous organizations that carry out work on behalf of First Nations, toward First Nations organizations that are mandated by First Nations themselves and that demonstrate the potential for and interest in taking on that work.

- 6.1g: Explore the development of an ombudsperson in each AFN Region, for First Nations Health.

- 6.1h: Determine funding levels based, in part, on community membership and citizenship, rather than based on "Indian Status" alone.

- 6.1i: Extend any new investments in First Nations health to First Nations communities in their territories and areas of interest, whether they have signed self-government agreements.

5.8 Health data/funding calculations

Data is imperative to have in order to make calculated and real-time informed decisions for the betterment of the community. The Truth and Reconciliation Commission of Canada Calls to Action outlined the importance of data and indicators of success as referenced in TRC Calls to Action #19[86] and #55.[87] TRC Call to Action #19 has a targeted focus on measuring the current landscape and "to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal communities and non-Aboriginal communities and to publish annual progress reports to assess long-term trends."[88] TRC Call to Action #55 re-emphasized the need to have data available and annually published to gauge the progress toward reconciliation. Health indicators include "infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services."[89]

Health data also inform funding calculations that can support an adaptable and scalable continuum of care for First Nations. The infusion of additional funding and flexible (funding)

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[86] TRC Call to Action #19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services. https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf

[87] TRC Call to Action #55. *We call upon all levels of government to provide annual reports or any current data requested by the National Council for Reconciliation so that it can report on the progress towards reconciliation. The reports or data would include, but not be limited to: iv. Progress on closing the gaps between Aboriginal and non-Aboriginal communities in a number of health indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.* https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf

[88] https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf, pp. 2-3.

[89] https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf, p. 6.

calculations aid in developing, implementing and most importantly, sustaining timely, accessible and culturally relevant health and wellness interventions for First Nations Peoples, our families and communities.[90]

Objective #7: To address the need for culturally centred and strengths-based First Nations wellness indicators to guide the revision of funding calculations, include assessing current population statistics and future First Nations health needs.

Description: There is a growing priority to allocate funding that guarantees predictable and sustainable monies to ensure long-term health projections can be delivered for First Nations. Health data (e.g., population statistics) and corresponding funding calculations are often outdated and siloed in different government departments (federal/provincial/territorial), making it challenging to fully address the social determinants of health and develop wholistic strategies for First Nations health and wellness. This priority includes the urgent need to fully implement the Seven Generations Continuum of Care approach.[91]

Recommendations:

Recommendation #7.1: Recognize the importance of collecting real-time, relevant data to advocate for necessary changes to the health care system.

- 7.1a: Use a decolonizing approach that includes strengths-based health methodologies and data.[92] This approach includes recognizing Indigenous data sovereignty as a cornerstone for cultural resurgence and nation (re)building.

- 7.1b: Coordinate First Nations regions, data governance champions and national partners to establish a national First Nations data governance strategy. This coordination includes working with First Nations communities in our respective jurisdictions, the Assembly of First Nations and First Nations Information Governance Centre at the national level to develop a set of key indicators on First Nations health outcomes to measure progress over time.

- 7.1c: Increase research that is respectful of First Nations governance, processes and OCAP Principles[93] to fully understand disabilities, chronic and life-limiting illnesses and their effects on First Nations. This step includes increasing funding for the First Nations Information Governance Centre related to data on disabilities, chronic and life-limiting illnesses.

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[90] http://www.thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf.

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

[92] Strengths-based data honour problems and strengths together, within the social determinants of health, and then ask how that data are used to inform the steps moving forward and support future generations. Strengths-based data generate whole-person information and knowledge that can be used to improve health outcomes.

[93] https://fnigc.ca/ocap-training/

- 7.1d: Update population statistics used when allocating funding for the Assisted Living Program and the First Nations and Inuit Home and Community Care Program, estimated at $74.5 million.

Recommendation #7.2: Develop an appropriate funding formula aimed at community wellness across program areas and departments, with support for data analysis and planning and capacity building.

- 7.2a: Determine a First Nations health care funding formula for comprehensive community planning that accounts for geography, levels of community infrastructure and demonstrated need, particularly as this planning relates to home, community and long-term care.[94]

- 7.2b: Implement and financially support First Nations communities in developing OCAP compliant community-based tools such as Community-based Electronic Medical Records (cEMRs), First Nation-led Client Registries and Health Surveillance systems that provide an electronic source of truth to track health status, trends and outcomes. These systems will be developed at a standard that supports interoperability with federal/provincial eHealth/Health applications. These systems will not infringe upon current First Nations community wellness initiatives and planning.

5.9 Health care infrastructure development and maintenance

Healthy communities require infrastructure that supports and facilitates wellness. For First Nations, this means infrastructure (e.g., continuing care centres, transportation, housing, telecommunications, water and waste management systems) that reflects a wholistic vision of health for individuals, families and communities. Each First Nations community across Canada will have unique needs and priorities in developing and maintaining health care infrastructure. Infrastructure tends to be costly and capital intensive. However, infrastructure is vital for a First Nation's ability to thrive—physically, mentally, emotionally and spiritually. There is a necessity to build and maintain health care infrastructure at the community level ensuring that First Nations seniors, people with disabilities and people with chronic and life-limiting illnesses have the ability to age-in-place.

Terms such as "healthcare facilities" and "healthcare institutions" are referred to as

[94] As it pertains to demonstrated need, this accounts for caseload, client base and complexity of needs. In addition, funding for demonstrated need is extended to cultural supports (e.g., support for traditional healers and family supports).

"continuing care centres" to better align with First Nations values and philosophies reflective of the Seven Generations Continuum of Care.

Objective #8: To survey infrastructure needs in First Nations communities for construction and maintenance of First Nations-led health centres, healing lodges and related continuing care centres (e.g., long-term care) in the community and/or in close proximity to First Nations communities (e.g., urban areas). This survey includes exploring how to improve housing for the aging population in First Nations communities.

Description: First Nations-led, community-based health centres, healing lodges and related continuing care centres involve developing and delivering wholistic health and social services. These wholistic services bring together, under one roof, a suite of multidisciplinary resources focusing on various health matters ranging from childcare to mental health care. Community-based health centres, healing lodges and related continuing care centres can also deliver medical care, make referrals to specialists, and develop and deliver health promotion programs. Overall, they serve as a hub of health and social services in First Nations communities. Among many First Nations, there remains hesitation and resistance to accessing continuing care centres (e.g., long-term care) outside of their home communities.

Intergenerational trauma is often associated with continuing care centres by First Nations seniors, people with disabilities and people with chronic and life-limiting illnesses as some continuing care centres may mimic triggering experiences from the Residential Institution System, Indian Hospitals and the Sixties Scoop (e.g., being forcibly moved away and socially isolated from their cultural identities, families and home communities).[95,96]

Recommendations:

Recommendation #8.1: Establish and/or expand access to higher-level health and healing centres and related continuing care centres (e.g., long-term care) in and/or in close proximity to First Nations communities.

- 8.1a: Negotiate coordinated partnerships between First Nations communities and orders of government (provincial/territorial and federal) to provide higher levels of care. These negotiations include expanding the federal government's role and authority in higher levels of care; securing new investments in planning, developing, infrastructure, operations and maintenance and human resource management; ensuring provincial/

[95] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada.* Author.
[96] First Nations of Quebec and Labrador Health and Social Services
[97] Commission—FNQLHSSC (2010). *Living conditions of the Elders of the First Nations of Quebec: Final report.* FNQLHSSC.
[97] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

territorial-designated and funded beds in continuing care centres are constructed in First Nations communities and/or ensuring preferred access to continuing care centres in close proximity to First Nations.

- 8.1b: Identify available economic diversification and infrastructure funding opportunities that can be used by First Nations communities to subsidize construction projects such as health and healing centres and related continuing care centres.

- 8.1c: Expand infrastructure to include more options for care in First Nations communities and better access to healthcare providers for First Nations.

- 8.1d: Create culturally safer places (e.g., multi-purpose buildings) that support First Nations community wellness. These places include meeting spaces, family friendly and welcoming spaces that feature local First Nations artwork and signage; clinical rooms to meet the needs of interdisciplinary healthcare teams; in-house laundry, locker rooms and showers; and dedicated spaces for First Nations cultural practices, healing ceremonies and spiritual activities.

Recommendation #8.2: Bring community to the city.

- 8.2a: Establish urban continuing care centres (culturally safe and supportive spaces and environments) for First Nations who, due to their level and type of care, need to leave their communities for healthcare services. These centres should provide optimal care while being responsive to the rights and cultural values of First Nations families and communities. Urban continuing care centres will also be accessible for First Nations who choose not to live on-reserve.

Recommendation #8.3: Increase investments in ISC Health Facilities Program[98] to reflect demonstrated needs. This process includes beginning with the existing waitlist but also ensuring sufficient resources for maintaining health care infrastructure.

- 8.3a: Affirm that the focus of the Health Facilities Program is to build spaces directed toward wholistic individual, family and community wellness. The Program must include built-in flexibility for First Nations to determine their own infrastructure needs, which may go beyond simple clinical applications.

- 8.3b: Require an initial investment of ~$420 million to clear the existing waitlist and a minimum of ~$25.1 million for ongoing infrastructure support needs and priorities—to avoid future waitlists.

[98] https://www.sac-isc.gc.ca/eng/1613078660618/1613078697574

5.10 Emergency preparedness

Emergency preparedness focuses on actions taken prior to an emergency or disaster to ensure an effective response. A recent example is pandemic care. Unfortunately, Canadian centres housing seniors were unprepared to adequately respond to and protect those most at risk of COVID-19. There were lessons learned from this event, one being the benefits of practicing virtual care.

Throughout the COVID-19 pandemic, virtual care has been used to facilitate outreach to and support for First Nations Elders, seniors, people with disabilities and people living with chronic and life-limiting illnesses, our families and communities. Furthermore, virtual engagement is also creating a safer place for dialogue and collaboration among caregivers, orders of government, healthcare organizations and providers, community leaders and educators to identify gaps and co-develop strategies and programs for enhancing the continuum of care (e.g., home, community care and long-term care).

However, emergency preparedness goes further than communicable disease prevention. First Nations communities and continuing care centres must account for the following factors:

- environmental—such as wildfires, floods
- meteorological—such as hailstorms, tornadoes, hurricanes
- pollutant—such as toxins, carcinogens
- non-communicable diseases—such as Lyme disease, blastomycosis, food-borne diseases, Legionnaires' disease
- infrastructure disruptions—such as supply chain delays, electrical grid blackouts, waste management failures, water shortages
- biomedical production shortages—such as oxygen, industrial grade chemicals, biochemical agents, pharmaceutical medicines
- civil tensions and unrest; and
- workplace violence—for example, if a patient or visitor becomes violent toward others in a healthcare setting.

Objective #9: To keep vulnerable First Nations individuals safe by providing options for responding to public health emergencies (e.g., communicable and non-communicable diseases; exposure to environmental pollutants, toxins and carcinogens; wildfires, flooding, heat waves, tornadoes, hailstorms; civil crises; workplace violence, water shortages, electrical grid blackouts). Vulnerable individuals are those who reside in various types of on-reserve and off-reserve continuing care centres.

Description: In response to the COVID-19 pandemic, most hospitals and continuing care centres across Canada restricted visitation. These restrictions limited the capacity of families and community members to support each other. Cancellations of healthcare appointments and fear of COVID-19 exposure further delayed diagnoses and treatments of disabilities, chronic and life-limiting illnesses. These disruptions in service only add to longstanding health inequities, particularly for First Nations Peoples, people with lower incomes and socio-economic status, 2SLGBTQQIA+ Peoples and people living in rural, remote and northern communities.

Many of the factors listed earlier in this section seem to be unimaginable; however, with climate change and future national or international crises, many of these factors will be unavoidable. Therefore, investments and resources are needed to prepare emergency preparedness and climate action plans and related strategies to continue services but to ultimately protect First Nations Peoples enrolled in home, community and long-term care programs.

Recommendations:

Recommendation #9.1: Provide resources (funding) for First Nations communities to develop their own emergency and evacuation action plans.

- 9.1a: Support the coordination of developing and subsequently implementing First Nations emergency and evacuation action plans with each order of government (provincial/territorial, federal).

Recommendation #9.2: Develop an emergency relief fund that First Nations communities can tap into in the event of unforeseen circumstances, to ensure continuity of health care services.

- 9.2a: Increase the availability of emergency response services (including mental health services) for First Nations, in particular, Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses.

Recommendation #9.3: Increase the use of telemedicine and videoconferencing to bring care closer to First Nations, reduce medical travel and increase cultural relevance.

- 9.3a: Set aside dedicated funding to advance eHealth initiatives in all First Nations across Canada based on community needs and priorities. At a minimum, this requires additional investments of $78 million ongoing.

- 9.3b: Work with First Nations in our jurisdictions to develop solutions related to eHealth needs and priorities. This work may include developing a joint strategy that complements provincial/territorial eHealth strategies.

5.11 Chronic and life-limiting illnesses

Life-limiting illnesses are most likely complex, progressive chronic diseases. Death is expected to be a direct consequence of the specified chronic and life-limiting illness. However, people actively live with such illnesses, often for long periods of time, and are not imminently dying. Therefore, chronic and life-limiting illnesses affect health and quality of life and can lead to death. Examples include:

Cancer. Cancer remains the leading cause of death in Canada. Compared to non-Indigenous populations in Canada, First Nations adults have higher incidences of colon, kidney, cervical and liver cancers.[99] First Nations Peoples are usually diagnosed in later stages of cancer which can reduce their life expectancy.

Chronic obstructive pulmonary disease (COPD). This lung disease causes breathing difficulties such as emphysema and chronic bronchitis. Complications from lung disease can include infection and increased respiratory demand requiring oxygen.

Diabetes. Diabetes is a chronic, metabolic disease that occurs when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin[100] it produces. Over time, diabetes can damage the heart, blood vessels, eyes, kidneys and nerves.

[99] Mazereeuw, M.V., Withrow, D.R., Nishri, E.D., Tjepkema. M,, & Marrett, L.D. (2018). Cancer incidence among First Nations adults in Canada: Follow-up of the 1991 census mortality cohort (1992–2009). *Canadian Journal of Public Health,* 109(5-6). 700–709.
[100] Insulin is a hormone that regulates blood sugar.

Dementia. This disease causes a deterioration of the brain. The disease progresses gradually and slowly. It gets worse over time and can result in aspiration (pneumonia) and decreased food intake.[101]

Heart disease and heart failure. This disease involves damage to the heart, whereby the heart cannot properly pump blood throughout the body. Complications from heart disease include weakness and breathing difficulties. Heart failure involves the buildup of fluid in the heart causing problems for the heart muscle's ability to pump properly.

HIV/AIDS. HIV (human immunodeficiency virus) is carried from person to person through body fluids such as blood, breast milk, semen or vaginal secretions. It damages the immune system, and this damage can increase risk of illness and infection. AIDS (acquired immune deficiency syndrome) is an advanced stage of the HIV infection. The virus attacks white blood cells resulting in some individuals with AIDS developing other life-threatening illnesses such as cancer.

Kidney failure. This condition involves damage to the kidneys which decreases one's ability to stay healthy. Complications with kidney failure include high blood pressure, anemia (low blood count), buildup of toxic breakdown products from the body, weak bones and nerve damage.

Liver failure. This condition involves damage to the liver (cirrhosis) which puts one at higher risk of confusion, bleeding, blood clots and fluid accumulation, including to the legs and abdomen (ascites). Liver failure can also increase toxic substances in the blood.

Multiple sclerosis. This illness of the central nervous system affects the brain, spinal cord and optic nerves.

Parkinson's disease. This progressive illness of the central nervous system affects muscles and movement.[102]

Objective #10: To examine current access to services for First Nations with chronic and life-limiting illnesses. This examination includes reviewing and implementing equitable health care services options for First Nations.

[101] Assembly of First Nations (2016). *Submission to Senate Committees Directorate Social Affairs, Science and Technology. On the increasing incidence of dementia in First Nations communities: Causes, consequences moving forward.* Author.
[102] https://getpalliativecare.org/whatis/disease-types/

Description: As the First Nations population in Canada grows and ages, chronic and life-limiting illnesses are increasingly affecting First Nations. Canadian health data show that First Nations Peoples have higher rates of chronic and life-limiting illnesses than non-Indigenous populations in Canada.[103,104,105,106] There is an urgent need to account and prepare for increased and ongoing use of the healthcare system for First Nations.

Recommendations:

Recommendation #10.1: Support First Nations-led wise practices and related initiatives on chronic and life-limiting illnesses.

- 10.1a: Develop and use culturally relevant and validated screening, diagnosis, assessment and treatment methods for First Nations with chronic and life-limiting illnesses, preferably in their home communities.

- 10.1b: Encourage and support continued engagement and collaborative efforts to address various chronic and life-limiting illnesses; their root causes; the consequences of inaction and apathy; and ways forward in a manner where First Nations can adapt, scale and transform wellness programs and services according to First Nations' needs and priorities.

Recommendation #10.2: Increase investments in First Nations to develop and administer multi-year sustainable and community-driven programs ranging from promotion and prevention to screening, diagnosis, assessment and treatment of chronic and life-limiting illnesses.

- 10.2a: Ensure the Government of Canada (e.g., Health Canada) accounts for chronic and life-limiting illnesses in policy and program work with food security as one example.

- 10.2b: Build upon existing capacity in First Nations communities with a focus on culturally relevant promotion, prevention, screening, diagnosis, assessment and treatment of chronic and life-limiting illnesses—meeting specific needs and priorities of First Nations families and communities.

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[103] Mazereeuw, M.V., Withrow, D.R., Nishri, E.D., Tjepkema. M,, & Marrett, L.D. (2018). Cancer incidence among First Nations adults in Canada: Follow-up of the 1991 census mortality cohort (1992–2009). *Canadian Journal of Public Health*, 109(5-6). 700–709.

[104] Browne, A.J., Varcoe, C., Lavoie, J., et al. (2016). Enhancing health care equity with Indigenous populations: Evidence-based strategies from an ethnographic study. *BMC Health Serv Res,* 16(544). https://doi.org/10.1186/s12913-016-1707-9.

[105] Kim, P.J. (2019). Social determinants of health inequities in Indigenous Canadians through a life course approach to colonialism and the residential school system. *Health Equity,* 3(1). 378–381.

[106] Assembly of First Nations (2016). *Submission to Senate Committees Directorate Social Affairs, Science and Technology. On the increasing incidence of dementia in First Nations communities: Causes, consequences moving forward*. Author.

Recommendation #10.3: Strengthen home and community-based supports (e.g., equipment, services) to meet complex challenges in caring for First Nations diagnosed with chronic and life-limiting illnesses.[107]

- 10.3a: Increase awareness and education for First Nations with chronic and life-limiting illnesses, our families, caregivers and communities.

- 10.3b: Access specialized equipment (e.g., onsite dialysis equipment) in First Nations communities and/or near home communities. This access includes, where necessary, use of portable equipment and travelling teams to increase home, community care and long-term care; and increase prevention, screening and treatment for a range of health conditions (e.g., diabetes, cancer screening) in areas where there are gaps in service delivery to First Nations communities.

- 10.3c: Access should not be denied, and systems should be in place to expedite without delay or disruption—if there is a jurisdictional dispute in coverage for needed equipment.

5.12 Aging well and long-term care

Aging well, experiencing life to the fullest, exercising personal self-determination, accessing support systems in the comfort of an individual's community: these are high priorities for all First Nations Peoples. In an accessible, culturally safe, equitable continuum of care, First Nations who require services beyond home and community-based care and who request 24-hour care services should have the opportunity to confidently enroll in local continuing care centres that are adaptable to meet their unique healthcare needs. These care settings include adult care, assisted living centres, nursing homes, continuing care retirement centres and 24-hour supervision and care.

Objective #11: To outline recommendations to keep our First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses in their First Nations communities by providing quality care in those communities. This process includes recognition that many First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses are Residential Instiution Survivors, Indian Hospital Survivors or Sixties Scoop Survivors do not want to leave their communities.

[107] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

Description: The population of First Nations aged 55 years of age and older is growing. As such, First Nations are accessing a wide range of health and social supports at an earlier age and over a longer period across the lifespan. Therefore, the needs and priorities for healthcare services (in particular, aging well and long-term care) will increase over time and across the generations.[108]

Currently, ISC funds the Home, Community, and Preventative Care Program[109] and the Assisted Living Program,[110] which together provide a continuum of basic home and community care services for First Nations and Inuit, including vulnerable First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses. Care can be provided in-home or in continuing care centres, depending on the person's needs and priorities. However, there are limitations to what can be provided through these programs. The level of care required can also fluctuate, making it difficult to anticipate future needs for aging well and accessing long-term care. While provinces/territories are responsible for the operational costs of providing higher levels of care in First Nations, there is often limited or no healthcare infrastructure (e.g., continuing care centres) available to support long-term care and aging well in a First Nations community setting.[111, 112, 113]

First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses prefer care in their own homes, their own communities and usually from family members (as their caregivers). Currently, First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses may be transferred to long-term care settings far from their home communities for highly specialized health care, where they are often isolated from their support networks (e.g., family and friends) and cultural practices (e.g., ceremonies and protocols). As a result of this transition to an unknown environment far from home and community, First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses face the prospect of being socially isolated in an environment where their cultural practices, beliefs and wishes are not known, respected or met and where they face language and cultural communication barriers. This experience can be traumatizing for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses and may

[108] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille.* FNQLHSSC.

[109] https://www.sac-isc.gc.ca/eng/1582550638699/1582550666787

[110] https://www.sac-isc.gc.ca/eng/1100100035250/1533317440443

[111] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille*. FNQLHSSC.

[112] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2014). *Brief on residential and long-term care resources for Quebec First Nations.* Author.

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

result in re-victimizing Residential Institution Survivors, Indian Hospital Survivors or Sixties Scoop Survivors.[114, 115]

Recommendations:

Recommendation #11.1: Expand the definition of First Nations seniors to 55 years of age.

- 11.1a: Support aging well and long-term care for First Nations by aligning government-funded healthcare policies and programs with specific needs and priorities expressed by diverse voices of First Nations (particularly First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses), our families and communities.[116]

Recommendation #11.2: Have access to both in-home care and community-based long-term care services—with the capacity to safely care for aging First Nations and/or First Nations people with disabilities and people with chronic and life-limiting illnesses.[117, 118, 119]

- 11.2a: Provide necessary supports to First Nations communities to establish and operate long-term care services, where demonstrated needs and priorities are established.

- 11.2b: Provide aging well and long-term care services closer to home. This includes the use of virtual care (as needed and as appropriate) for the level of care needed for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses, our families and communities.[120]

Recommendation #11.3: Harmonize protective factors for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses into planning and care for aging well.[121, 122, 123]

- This recommendation includes the following protective factors:

[114] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[115] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2010). *Living conditions of the Elders of the First Nations of Quebec: Final report.* FNQLHSSC.
[116] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[117] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille*. FNQLHSSC.
[118] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction…* FNQLHSSC.
[119] First Nations of Quebec and Labrador Economic Development Commission—FNQLEDC (2020). *Social economy innovation: Optimized home care service offer for First Nations Seniors.* FNQLEDC.
[120] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[121] This harmonization includes health promotion and wellness programs and long-term care services and related supports.
[122] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille.*: FNQLHSSC.
[123] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2014). *Brief on residential and long-term care resources for Quebec First Nations*. Author.

-participating in cultural practices and healing ceremonies;

-having social support (individual, family and community support) that provides practical help, positive interactions, emotional support and friendship;

-having access to health care supports (e.g., equipment);

-belonging to a community that promotes respect for First Nations' ways of life and cultural values;

-belonging to a community that promotes respect for First Nations Elders for their wisdom;

-belonging to a community that appreciates First Nations' resilience and diverse narratives of First Nations' lived experiences

-having access to social events that respect First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses and incorporate health promotion—making them feel safe, welcome and included

-having interpreters and translators when needed

-having social contact in the form of virtual calls (phone and video), friendly visits, excursions, physical activity programs and/or other interactions (e.g., cultural events, food-related gatherings, crafting, games); and

-having access to culturally relevant healthcare services in the community.[124]

Recommendation #11.4: Ensure First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses have access to all health benefits.[125, 126 127]

- 11.4a: Ensure care for the elderly and related funding for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses are also accessible to their caregivers.[128, 129]

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[124] Assembly of First Nations (2017). Report: First Nations Seniors health and wellness in Canada. Author.
[125] Ibid.
[126] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQL-HSSC (2013). Joint brief: Access for all? Fact or fiction... FNQLHSSC.
[127] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). Portrait of First Nations in Quebec living with disability or having special needs. FNQLHSSC.
[128] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[129] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

Recommendation #11.5: Develop and implement strategies that improve standards of care in long-term care.[130, 131, 132]

- 11.5a: Have funding in place to plan for improvements in standards of care for First Nations families and communities.

- 11.5b: Consider systemic discrimination and the legacy of the Residential Institution System, Indian Hospitals and Sixties Scoop in Canada when addressing abuse and neglect of First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses.

- 11.5c: Improve First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses' access to information, advocacy and education programs on preventing abuse and neglect.

5.13 Palliative and end-of-life care

Palliative care is a process from diagnosis to end-of-life in relieving symptoms (e.g., pain and discomfort) and improving the quality of life for people with chronic and life-limiting illnesses (e.g., diabetes, cancer, COPD, dementia, HIV/AIDS, kidney failure, liver failure, heart disease, heart failure, multiple sclerosis, Parkinson's disease). Palliative care includes physical, emotional, mental and spiritual support and focuses on the whole person and their family.[133, 134] For some First Nations Peoples, the term *palliative care* also means *comfort care*.[135]

Comfort care provides cultural contexts that acknowledge the role of values, identities, families and communities. With a focus on kindness, compassion and quality of life, comfort care honours the spiritual beliefs, cultural protocols and practices of First Nations living with chronic and life-limiting illnesses. In addition to care focusing on the whole person, comfort care supports the whole family and community of people with chronic and life-limiting illnesses.[136]

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[130] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada.* Author.
[131] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2010). *Living conditions of the Elders of the First Nations of Quebec: Final report.* FNQLHSSC.
[132] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Portrait of First Nations in Quebec living with disability or having special needs.* FNQLHSSC.
[133] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec*. FNQLHSSC.
[134] World Health Organization (2020). *The determinants of health.* Health impact assessment.
[135] https://www.partnershipagainstcancer.ca/wp-content/uploads/2022/09/Beginning-the-journey-into-the-spirit-world-FINAL-SM.pdf
[136] https://www.cancercareontario.ca/sites/ccocancercare/files/assets/ACCUPalliativeCare.pdf (p. 1).

A part of palliative care is *end-of-life care* that focuses on increasing care and meeting the goals of people in their last hours, days, weeks or months of life in addition to supporting family members through this process.[137]

Objective #12: To increase the accessibility of palliative and end-of-life care services for First Nations at the community level.

Description: For many First Nations, dying and death are not just about biomedical and physical processes. They are about an individual's transition to the spirit world—social and spiritual events to be honoured and celebrated as a collective.[138]

The majority of First Nations prefer to receive palliative and end-of-life care at home where our families, friends, community and cultural practices surround them. However, First Nations with chronic and life-limiting illnesses (especially from rural, remote and northern communities across Canada) often do not have access to timely, affordable and culturally relevant palliative and end-of-life care services, support and resources.[139]

First Nations may find it difficult to reflect on and discuss palliative and end-of-life care due to fear of hospitals, lack of trust, linguistic barriers and systemic racism[140] in the Canadian health care system. Stigma is often associated with chronic and life-limiting illnesses, dying and death.[141]

While ISC is responsible for funding arrangements and program implementation via the First Nations and Inuit Home and Community Care Program,[142] some First Nations communities deliver palliative and end-of-life care services themselves. Palliative and end-of-life care service coverage to First Nations communities varies widely across provinces/territories in Canada. Due to inconsistent home care services, First Nations lack the choice to journey to the spirit world at home if that is their wish. Rather, First Nations with chronic life-limiting illnesses are typically transferred for palliative and end-of-life care to urban hospitals and related continuing care centres for highly specialized medical care, where they are often isolated from their support networks (e.g., family and friends) and cultural practices (e.g., ceremonies and protocols regarding dying and death).[143] As a result of this

[137] https://www.partnershipagainstcancer.ca/wp-content/uploads/2022/09/Beginning-the-journey-into-the-spirit-world-FINAL-SM.pdf
[138] Ibid.
[139] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec.* FNQLHSSC.
[140] Barriers in the health care system include lack of recognition of cultural beliefs and practices associated with dying and death.
[141] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec*. FNQLHSSC.
[142] https://www.sac-isc.gc.ca/eng/1582550638699/1582550666787
[143] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec*. FNQLHSSC.

transition to an unknown environment far from home and community, First Nations Peoples with chronic and life-limiting illnesses face the prospect of being socially isolated in an environment where their cultural practices, beliefs and wishes are not known, respected or met and facing language and cultural communication barriers during the most vulnerable time in their lives.[144, 145]

There is also a strong economic rationale for providing palliative and end-of-life care in First Nations communities. Today, many First Nations are dying in the hospital which is the most expensive care setting and not an efficient use of health care services.[146]

Recommendations:

Recommendation #12.1: Prioritize palliative and end-of-life care to recognize changing demographics of First Nations Peoples.[147]

- 12.1a: Develop a policy framework to provide equitable palliative and end-of-life care in First Nations communities that is complementary yet distinct from a biomedical approach.

- 12.1b: Encourage the sharing of wise practices, national standards of care and common approaches to palliative and end-of-life care planning across First Nations, various continuing care centres and jurisdictions.

- 12.1c: Designate palliative and end-of-life care as an essential service in First Nations communities, with sustainable funding included in the health care funding formula.

- 12.1d: Fund palliative and end-of-life care in the First Nations and Inuit Home and Community Care Program, estimated at $60 million annually of new investments.

Recommendation #12.2: Explore collaborations between the AFN, Government of Canada and not-for-profit organizations specializing in palliative and end-of-life care and diseased-based organizations[148] to raise awareness of First Nations palliative and end-of-life care needs at the national level.

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144 https://www.canada.ca/content/dam/canada/health-canada/migration/healthy-canadians/publications/health-system-systeme-sante/strategy-palliative-strategie-palliatifs/alt/strategy-palliative-strategie-palliatifs-eng.pdf

145 https://www.lco-cdo.org/wp-content/uploads/2019/03/Dying-alone_An-Indigenous-mans-journey-at-EOL_C-Bablitz.pdf

146 First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec.* FNQLHSSC.

147 Ibid.

148 For example, Canadian Cancer Society, Canadian Hospice Palliative Care Association, Canadian Virtual Hospice, Canadian Partnership Against Cancer and The Way Forward Initiative.

- 12.2a: Involve First Nations and broader Indigenous healthcare professionals in palliative and end-of-life care systems planning.

- 12.2b: Collaborate, cooperate and partner with others (e.g., Indigenous and non-Indigenous health care professionals, service providers, orders of government and educators) to better support families who experience loss. This support is needed as decisions are complex, demands can be significant and grief can be intense.[149]

Recommendation #12.3: Ensure First Nations communities have palliative and end-of-life care along with other health care services and supports, so community members can receive equitable and wholistic health care support without leaving their homes.[150]

- 12.3a: Increase the availability of home care and palliative and end-of-life care among First Nations communities.

Recommendation #12.4: Take early palliative care approaches to increase quality of life for First Nations Peoples, especially with chronic and life-limiting illnesses.[151]

- 12.4a: Increase palliative care education and focus on capacity building in First Nations.

- 12.4b: Improve post-secondary training for emerging health care professionals to build capacity for providing culturally safer palliative and end-of-life care, including grief and bereavement support.

- 12.4c: Address any lack of access to affordable and equitable palliative and end-of-life care services for First Nations with chronic and life-limiting illnesses. For example, expand the acceptable diagnoses to qualify for palliative and end-of-life care that goes beyond a cancer diagnosis.

[149] Hordyk, S.R., MacDonald, M.E., & Brassard, P. (2016). *End-of-life care for Inuit living in Nunavik, Quebec: A report written for the Nunavik Regional Board of Health.* p. 25.
[150] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec*. FNQLHSSC.
[151] Ibid.

6. Conclusion

In closing, Our Right to Health: First Nations' Perspectives Across the Generations has sought to identify the priorities and needs of First Nations in the continuum of care and share recommendations to support and fund self-determined continuum of care approaches that adequately serve First Nations.

Aging is inevitable. Many individuals do not often think about it or may even avoid contemplating that part of their life, because envisioning the future can be daunting. Real and honest thoughts may arise evoking apprehension, 'will I live in my house or downsize to a living centre?' 'Do I have enough money to retire?' etc. All important questions. However, in First Nations, it does not matter where an individual falls in the age spectrum of life. There are friends, families and communities that step in and ensure everyone is taken care of. That was clearly seen during the pandemic. Communities placed quick public health measures to protect the most vulnerable to COVID-19 and that was our senior and those living with co-morbidity populations. We prioritized our seniors' needs before anyone. That sense of protection of seniors, has always been in our ways. Many of the recommendations listed in this report have been points of advocacy for many years.

It is evident with the listed recommendations, from each of the 12 outlined priorities that the current home and community care and long-term care structure and approach has not and does not, align well with our cultures, our practices and our communities' needs and capacities. With additional pressures from the growing First Nations senior population and a high proportion of First Nations living with disabilities, chronic and life-limiting illnesses and/or mental illnesses, there is a need for a well-coordinated continuum of care that supports First Nations individuals and families within the comfort of their own community. Brining services, supports, continuing care centres back to the community is a clear collective statement that we hear from all regions of Canada.

We are reaching a moment in time, where our demands are being heard at a national level. Resolution 19/2019,[152] set an ambitious and descriptive agenda in which the federal government in response provided funding to engage with First Nations regions and organizations to listen to feedback regarding an improved wholistic continuum a care approach that serves our priority populations. There are many anticipations and expectations for the outcomes of these engagements but this has been a great opportunity to ensure viable transformative changes are put into action that will address the long-standing outcomes from health inequities, that will focus on our knowledge, strengths, and protect wellness throughout the lifespan and for the next generations.

[151] *AFN Chiefs-in-Assembly Resolution 19/2019: Developing a Seven Generations Continuum of Care for First Nations, by First Nations of Health, Economic and Social Services*. This resolution called for a wholistic approach to develop a continuum of health and health-related supports and services which will provide a vision and a way forward to improved health and wellness for First Nations across the country.

Appendix A: Shared understandings

Our Right to Health: First Nations' Perspectives Across the Generations is informed by the following shared understandings about First Nations and our relationships with home, community care and long-term care:

- **Culture as foundation.** Culture as foundation recognizes the value of relationships in our cultures, identities and ways of knowing. First Nations approaches to healing and wellness are often linked to land and place through songs, teachings, ceremonies, language and writing. Land and place are often important dimensions of cultural identity, healing and wellness alongside the truth and reconciliation process. Our individual First Nations communities are diverse, particularly in terms of use of First Nations and non-Indigenous healing and wellness practices.

- **Distinctions-based approach.** This approach recognizes the unique rights, interests and contexts for First Nations, Inuit and Métis Peoples across Canada. With an exclusive focus on First Nations' perspectives and experiences in Our Right to Health: First Nations' Perspectives Across the Generations, it is important to listen to and honour the many diverse voices among First Nations Peoples and our communities—in terms of languages, lifestyles, histories, geography, values and wisdom. The AFN recognizes that there is a need for healthcare strategies, programs, services and resources that acknowledge the unique cultural, jurisdictional topics and issues for First Nations Peoples across Canada.

- ***Etuaptmumk*/Two-Eyed Seeing.** Albert Marshall (Mi'kmaw Nation Elder) specifies that *Etuaptmumk*/Two-Eyed Seeing is the gift of multiple perspectives treasured by many Indigenous Peoples. As Elder Marshall further explains, *Etuaptmumk*/Two-Eyed Seeing refers to learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing…and learning to use both these eyes together, for the benefit of all.[153, 154] *Etuaptmumk*/Two-Eyed Seeing supports an important shift in dialogue and reconciliation about integrative, cross-cultural and collaborative work between Indigenous and non-Indigenous peoples in Canada. Therefore, we acknowledge that Indigenous and non-Indigenous systems of healthcare can work together in home, community care and long-term care.

[153] http://www.integrativescience.ca/Principles/TwoEyedSeeing/
[154] Rowett, J. (2018). Two-eyed seeing: A research approach and a way of living. Antistasis, 8(1). https://journals.lib.unb.ca/index.php/antistasis/article/view/25740

- **Health as wholistic wellness.** While there is not a single definition of wellness in diverse First Nations cultures, First Nations worldviews share an understanding of the (i) interconnectedness, interdependence and balance between the physical, mental, emotional and spiritual dimensions to wellness; (ii) attention to the social determinants of health; and (iii) recognition and respect for culture as foundation as it pertains to healing and wellness for First Nations Peoples.

- **Health equity, diversity and inclusion.** To improve the health and wellness of our First Nations Peoples, our families and communities, equity, diversity and inclusion must be reflected in all approaches used throughout the continuum of care. With regard to home, community care and long-term care, this means co-creating culturally safer environments that welcome, embrace and respect all First Nations, our families and communities from diverse backgrounds with unique wellness needs and lived experiences. This co-creation of safer environments involves respectful consideration of gender and 2SLGBTQQIA+-informed,[155] trauma-informed, resilience-informed and First Nations-informed healing and helping approaches in health care for First Nations Peoples.

- **Nothing about us, without us.** Recognizing diverse voices of First Nations by respecting First Nations jurisdiction and wisdom in the continuum of care is needed to support self-determination, local authority and a sense of agency. Often, provincial/territorial and federal government legislation and policies that inform the development of programs and services for healthcare lack First Nations direct and meaningful involvement from beginning to end. However, many orders of government are increasingly recognizing that First Nations and communities are the most qualified to articulate and plan for First Nations health needs and priorities. In addition, it is our inherent rights and responsibilities as First Nations to develop and lead our First Nations health systems. Legal decisions on First Nations title and rights are facilitating ways for some First Nations communities in Canada to advance self-determination through the creation of their own community-based and community-led laws, programs and services (e.g., health care, infrastructure).

- **Partnerships and relationship building.** We need to identify ways for First Nations and non-Indigenous groups and communities to work in a mutually respectful and reciprocal manner across the continuum of care for First Nations.

[155] 2SLGBTQQIA+ refers to Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and additional sexual orientations and gender identities.

- **Person-centred approach.** This approach recognizes that our First Nations are placed at the centre of health care and treated as people first. The focus is on our First Nations and what they can do, not their geographic location, age, ability and/or chronic and life-limiting illness. Support focuses on achieving the home, community care and long-term care goals of First Nations Peoples, our families and communities across Canada and is customized to their needs and unique circumstances.

- **Seven Generations Continuum of Care approach.** A continuum of care means that people's care is continuous even though they may switch between caregivers and/or continuing care centres. A continuum looks at the entire environment of person-centred care, such as managing disabilities and/or life-limiting illnesses where services are delivered by different health care providers. A Seven Generations Continuum of Care approach involves health, social and economic services that follow the health and well-being of First Nations from conception to death. These continuous services reflect a wellness approach that follows individuals as they grow and their needs for care change throughout their lifespan.[156]

- **Strengths-based practice.** Strengths-based practice respects people's rights to self-determination and empowers people through a focus on their inherent rights to be resilient in the face of adversity. Some strengths-based approaches to care include honouring community voices through meaningful engagement; community and person-centred approaches; community capacity building and support; human health resources training and skills development; and recognition of First Nations culture, languages, values, ways of knowing and approaches to health care as strengths (gifts, assets). Strengths-based practice is an empowering and validating way for First Nations Peoples to develop, access and strengthen health care programs, services and supports. First Nations communities have unique ways to support their Peoples in health care and related wraparound support services.

- **Supporting First Nations' capacity first.** Ensuring the long-term sustainability of First Nations-led health systems requires ensuring capacity is supported at the First Nations-level. Any new investments across the continuum of care need to start by ensuring we (as First Nations Peoples and communities) have adequate capacity, rather than building up infrastructure and capacity in existing federal and provincial/territorial health systems first.

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

- **Terminology.** The terms "Aboriginal" and "Indigenous" may be used interchangeably in Canadian legislation and policies. "Indigenous Peoples" (an international term) and "Aboriginal Peoples" (1982 Canadian Constitution term) include all First Nations, Inuit and Métis Peoples in Canada. Gender-inclusive language (e.g., they/them) is used throughout this report to promote gender equality and remove any forms of gender bias and related stereotypes from the discussion and recommendations on home, community care and long-term care. Terms such as "health care facilities" and "health care institutions" are referred to as "continuing care centres" to better align with First Nations values and philosophies reflective of the Seven Generations Continuum of Care. The use of the term "community care" refers to "supportive care." Key terms are described in Appendix C. Wording related to First Nations approaches to home, community care and long-term care were consistent and congruent as of the date of this report.

Appendix B: Key terms

Aboriginal People. Defined in the *1982 Constitution Act of Canada*, Aboriginal refers to all Peoples of Indian (Status and Non-Status Indians), Inuit and Métis heritage. Aboriginal Peoples are Indigenous Peoples who have lived in Canada since time immemorial.

Aging well. Essential elements of healthy aging include physical, mental, emotional, social and spiritual well-being; empowerment (ability to make decisions about one's life); awareness of and access to information about existing programs and services; easy access to medical, social and other support services; aging in place with respect and dignity, for as long as possible (independent and interdependent living); a supportive social environment; continued community involvement and participation; financial security; adequate and affordable housing; and accessible and affordable transportation.[157, 158]

Bereavement. Bereavement is a time of loneliness and sadness that a person, family and/or community experiences due to a loss (e.g., death of a loved one).

Biomedical. Biomedical refers to science and study of life from a clinical medicine perspective.

Capacity building factors. Capacity building factors include development of competencies (knowledge, skills and abilities) to participate in any or all aspects of decision-making in communities, regions, provinces/territories and the country as a whole; and program planning, development, implementation and evaluation intended to enhance wholistic health care.

Caregivers. Caregivers are family members or friends who provide assistance without pay. Caregivers play an important role in the continuum of care, particularly in regard to home, community care and long-term care.[159, 160]

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[157] https://www.nia.nih.gov/health/what-do-we-know-about-healthy-aging

[158] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille.* FNQLHSSC.

[159] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

[160] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56 An Act to recognize and support caregivers and to amend various legislative provisions.* FNQLHSSC.

Colonization. Colonization is the deliberate attempt by Canadian governments to destroy Indigenous family systems, spiritual belief systems, customs and traditional ways of life through enacted and enforced legal sanctions. Examples of colonization include the Residential Institution System, the *Indian Act,* removal of Indigenous communities from their traditional territories, the Indian Hospital System and the Sixties Scoop.

Comfort care. Comfort care provides necessary cultural contexts that acknowledge the role of values, identities, families and communities when harmonized with palliative and end-of-life care. With a focus on kindness, compassion and quality of life, comfort care honours the spiritual beliefs, cultural protocols and practices of people living with life-limiting illnesses. In addition to care focusing on the whole person, support for the whole family and community of people living with chronic and life-limiting illnesses is included in comfort care.[161]

Community (supportive) care. A community-based model for delivery of healthcare. The goal of community (supportive) care is to help individuals remain independent at home as long as possible. Community care provides increased services in the home when needed, and if/when one can no longer stay at home, it provides an alternative higher level of care. This type of care recognizes the important contributions of families, caregivers and one's community who are supported through the care process. *Note: Community (supportive) care may be called something different—based on jurisdiction and regions across Canada.*[162]

Continuing care centres. Continuing care centres are healthcare settings that include a range of services provided in the context of long-term care residential facilities, home support, home care and case management. This term also reflects continuum of care that is short-term or long-term.[163]

Continuum of care. A continuous, dynamic, wholistic approach that provides care to an individual/group's needs over a lifetime. A continuum looks at the entire environment of that individual's care, such as managing chronic and life-limiting illnesses where services are delivered by different providers in a coherent, logical and timely fashion.

Competencies. Competencies are specific and observable knowledge, skills, attitudes and behaviours associated with effective functioning in a job. They can be measured against well-accepted standards, and they can be improved through education and skills development.

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[161] https://www.cancercareontario.ca/sites/ccocancercare/files/assets/ACCUPalliativeCare.pdf (p. 1).

[162] https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html

[163] https://www.canada.ca/en/health-canada/services/home-continuing-care.html

Crown. The Crown comprises all provincial and federal government departments, ministries and agencies, including all government employees who carry out work on behalf of government.

Cultural agility. Cultural agility means behaving in ways that put our skills in cultural awareness and safety into action—acting in ways that are curious, open-minded, flexible and appreciative of cultures that are different from our own.

Cultural awareness. When you are culturally aware, you know your own preferences and biases and acknowledge the commonalities and distinctions between cultures. Cultural awareness involves knowledge of the principles, values and cultural considerations important to Indigenous Peoples and understanding how values are uniquely expressed between and within First Nations, Inuit and Métis Peoples, families and communities.

Cultural competencies. These competencies are the attitudes, behaviours and skills that enable you to work ethically and effectively in cross-cultural settings; working to gain these competencies is a journey, not a final destination.

Cultural humility. Cultural humility is the recognition and valuing of Indigenous epistemologies (the study of knowledge) and the role of healers and Elders.

Cultural safety. Cultural safety is a way of being that is created by a trusting and respectful environment and involves the transformation of relationships by exploring and challenging power dynamics (in organizational structures, policies and practices). Culturally safer practices are actions in colonized spaces (e.g., biomedical continuing care centres) where First Nations, their families and communities feel respected, included, welcomed and comfortable being themselves and expressing all aspects of who they are as First Nations Peoples. *Of note, Indigenous health leaders advise us that care based on the biomedical approach can never be safe; it can only be "safer." Honouring this perspective, the term "safer" is used in* "Our Right to Health: First Nations' Perspectives Across the Generations" *with no comparative.*

Cultural teachings. Cultural teachings are the application of Indigenous healing approaches and practices passed on by traditional Indigenous teachers, healers and/or Elders who are recognized by their Indigenous community; teachings about theories and practices in Indigenizing and decolonizing approaches to health and wellness that address disparities among Indigenous Peoples in culturally relevant ways (storytelling and role modelling); approaches in Indigenous wellness, language revitalization in the context of understanding Indigenous approaches to health and wellness, and/or Indigenous community-based health program and organizational development; integration

of Indigenous wellness in relation to social justice, environmental/ecological justice, and/or reconciliation among diverse Indigenous communities; and self-care for healers and helpers with Indigenous communities.

Decolonization. Decolonization is the process of undoing colonizing practices. In a healthcare context, this means confronting and challenging colonizing practices that have influenced healthcare in the past and which are still present today. This process often involves reflecting on the structure of healthcare centres and their role in the broader society.

Elders. Elders are First Nations, Inuit or Métis individuals who make a life commitment to the health and wholistic healing of their community and Peoples. Elders are recognized in their community as possessing great wisdom and who are called upon as an authority to advise or act on important family and community matters.

End-of-life care. End-of-life care focuses on increasing care and meeting the goals of people in their last hours, days, weeks or months of life. End-of-life care includes supporting people's families through their chronic and life-limiting illness and after death. End-of-life care is part of palliative care.[164]

Family. Family refers to peoples' birth family, family through marriage and/or their family of choice. Family also includes legal guardians, friends and caregivers. First Nations Elders, seniors, people with disabilities and people living with chronic and life-limiting illnesses may identify family (or families) they would like included in any encounters with the healthcare system.[165, 166]

First Nations Peoples. First Nations are the First Peoples of Canada, both Status and Non-Status. Status (or registered) Indians are individuals who are registered according to the Indian Act and members of a band (First Nations community). Status Indians receive supports and related services (e.g., housing assistance and financial assistance for post-secondary education) from Indigenous Services Canada (ISC). Non-Status Indians are individuals that are not recognized as Indians under the *Indian Act*. At present, there are over 600 First Nations communities in Canada representing more than 50 Nations and language groups.

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[164] https://www.partnershipagainstcancer.ca/wp-content/uploads/2022/09/Beginning-the-journey-into-the-spirit-world-FINAL-SM.pdf

[165] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging*. Author.

[166] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56 An Act to recognize and support caregivers and to amend various legislative provisions*. FNQLHSSC.

Governance. Governance is the act of governing or controlling something, for example an organization, a society, or a country. Governance includes how decisions are made and who is accountable for those decisions. Principles of governance can be applied to any group—from communities and not-for-profit organizations to the United Nations. So, the scope of governance can vary widely from local to global collectives. Governance involves making and acting upon decisions on behalf of a group, community or organization.

Grief. Grief is a natural response to loss in the form of strong emotions and suffering. In relation to palliative and end-of-life care, grief is associated with the dying and death of loved ones. Grief has physical, socio-cultural, spiritual, emotional, physical and behavioural dimensions which can make this response complex. Anticipatory grief provides time and space for the family and community of the person with a disability and/or life-limiting illness to prepare for the eventual loss (death). Disenfranchised grief refers to a grieving process that does not align with the community or broader society's attitudes and beliefs about death and loss.

Healers. Healers are people, for example medicine persons, who have Traditional Knowledge about ways of healing and often hold positions of high respect in First Nations communities.

Healing ceremonies. Healing ceremonies focus on traditional healing specialties that address mental, emotional, spiritual and physical aspects of health and wellness. Engagement in ceremonies and healing approaches are facilitated by traditional healers and Elders who are recognized by their Indigenous communities. These ceremonies provide healing, helping and cultural support and may include the Medicine Wheel, Sweat Lodge and Ancestor Feasts.

Health care professionals. Healthcare professionals are members regulated by their health disciplines, for example, physicians, massage therapists, nurses and psychologists.

Health care providers. These are providers of health-related goods or services to people with chronic and life-limiting illnesses, for example, health care professionals, students, volunteers and other individuals acting on behalf of healthcare organizations.

Indigenous Peoples. Indigenous Peoples are recognized through a process of self-identification, historical continuity, strong linkage to ancestral territories and surrounding natural resources, and distinct cultural, social, economic and political systems.[167]

[167] United Nations (n.d.). *Who are indigenous peoples?* United Nations.

Indigenous Peoples have diverse histories, languages, beliefs and traditional practices.

First Nations-informed helping. This approach to helping is based on Indigenous ways of knowing and worldviews, aimed at ensuring environments, services, practices and programs are welcoming, culturally safer and engaging for First Nations and non-Indigenous people, families and communities. Biomedical and non-Indigenous ways of knowing may be integrated and used alongside Indigenous ways of knowing in First Nations-informed helping as a way of thinking about the role of culture across the continuum of care.

First Nations-led helping. This approach includes helping and related programs, interventions, practices and services led and driven by Indigenous Peoples, communities and/or organizations exclusively aimed at addressing issues, needs and/or conditions presented by Indigenous Peoples with disabilities and/or chronic and life-limiting illnesses, families and/or communities.

Informed consent. Informed consent is the voluntary agreement of individuals or their authorized representative who have the legal capacity to give consent and who exercise free power of choice, without undue inducement or any other form of constraint or coercion to participate in the given healing and helping relationship.

Knowledge Carriers. Knowledge Carriers (or Knowledge Keepers) are First Nations individuals who are recognized by their respective communities for the sharing of their culturally significant knowledge and Indigenous worldviews.

Laws. English common law focuses on rules of behaviour established by courts and legislation for defining the minimum standards of individual and community conduct and behaviour. They define the minimum standards that society will tolerate and are enforced by government. Other defining characteristics of the law are as follows: created by legislature and courts; governs citizens (local, provincial, federal); represents minimum standards; and enacts penalties in the form of fines and jail. In contrast, First Nations laws are often comprised of sacred law (e.g., origin stories); natural law (relationships to place, land and broader natural world); deliberative law (e.g., talking circles, council meetings, gatherings); positivistic law (e.g., teachings, protocols); and customary laws (e.g., family relationships, land claim agreements).[168]

[168] https://implementingtrc.pressbooks.tru.ca/chapter/natural-law/#footnote-304-7

Life-limiting illness (chronic illnesses). Life-limiting illness means that death is expected to be a direct consequence of the specified illness. People actively live with such illnesses, often for long periods of time, and are not imminently dying. Therefore, chronic and life-limiting illness affects health and quality of life and can lead to death.

Life spectrum doulas. In general, Indigenous life spectrum doulas are non-medical healers, helpers and companions to First Nations. They typically provide a wide range of culturally safer holistic services, including physical, emotional, spiritual and practical support across the lifespan. This support may include facilitating and coordinating access to health care services including traditional healing practices and spiritual and cultural supports.

Living history. Living history means that we are collectively rewriting history by speaking truth to colonization.

Marginalization. Marginalization is the act of putting or keeping someone or a group of people in society in a powerless or unimportant position. This act results in individuals or groups of people being disadvantaged and excluded in society.

Meaningful engagement. Meaningful engagement means a willingness and ability to provide opportunities for Indigenous Peoples or communities to actively take part in policy and decision-making processes that are balanced in terms of sharing power and influence.[169] At times, definitions of terms such as "meaningfulness" and "meaningful engagement" and putting these terms into practice have been confused with similar forms of participation in policy development and decision-making such as "information sharing" and "consultation."[170]

Objectives. They are concise statements that outline core components of what the project, program or service is to achieve to be seen as successful.

Ownership, control, access, possession (OCAP™) principles OCAP™ principles are First Nations standards in the collection, protection, utilization and sharing of data when conducting research with First Nations.[171]

Palliative care. Palliative care is a process from diagnosis to end-of-life in relieving symptoms (pain and discomfort) and improving the quality of life for people with chronic and life-limiting illnesses (e.g., diabetes, cancer, COPD, dementia, HIV/AIDS, kidney failure,

[169] https://www.ictinc.ca/blog/aboriginal-engagement-vs-aboriginal-consultation-whats-the-difference
[170] Organization for Economic Co-operations and Development (2016). *Open government: the global context and the way forward.*
[171] For more information about OCAP principles, visit https://fnigc.ca/ocap-training/.

liver failure, heart disease, heart failure, multiple sclerosis, Parkinson's disease). Palliative care focuses on the whole person and their family and includes physical, emotional, mental and spiritual support.[172]

Partnerships. A partnership is the relationship between First Nations and non-Indigenous organizations. Partnerships can be used to leverage capital as well as connections and expertise that lead to shared goals and opportunities.[173]

Person-centred approach. This approach recognizes that the person is placed at the centre of care and treated as a person first. The focus is on the person and what they can do, not their disability, chronic and life-limiting illness. Support focuses on achieving the person's care goals and is customized to their needs and unique circumstances.

Residential care settings. Residential care settings are a range of living options for people (e.g., First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses) who have different support needs. They include lodges, assisted living, supportive housing, long-term care homes and continuing care centres.[174]

Resilience. Resilience is the ability of a natural and/or human system to flourish and adapt to situations or environments with minimal negative effects during and after the change, hardship or crisis. Resilience emphasizes the individual or group's ability to effectively draw on positive attributes and capabilities rather than focus on weaknesses or pathologies.

Respite care. Respite care provides temporary relief from the physical, mental, emotional and physical demands of caring for a family member or friend. Respite care includes home support services, in community adult day services or access (on a short-term basis) to long-term care, palliative care or other community care settings.[175]

Seven Generations Continuum of Care approach. This approach involves health, social and economic services that follow the health and well-being of First Nations Peoples through pregnancy, childhood, adulthood and senior years. These continuous services reflect a wellness approach that follows the individual as they grow and their needs for

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[172] https://www.partnershipagainstcancer.ca/wp-content/uploads/2022/09/Beginning-the-journey-into-the-spirit-world-FINAL-SM.pdf

[173] Blackman, J. (2017). *Research Indigenous partnerships: An assessment of corporate-Indigenous relations*. Indigenous Works.

[174] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2014). *Brief on residential and long-term care resources for Quebec First Nations.* Author.

[175] https://www.healthcarecan.ca/wp-content/themes/camyno/assets/document/PolicyDocs/2012/External/EN/RespiteCare_EN.pdf

care change throughout their lifespan. A Seven Generations Continuum of Care approach is grounded in First Nations ways of knowing and is intended to ensure every decision maintains a sustainable world seven generations in the future.[176]

Social determinants of health. Social determinants of health are "the conditions in which people are born, grow, live, work, age—conditions that together provide the freedom people need to live lives they value."[177] These determinants are shaped by the distribution of money, power and resources in society and are responsible for the differences and inequities in health status within and between communities. Social determinants of health also impact and influence a person's physical, mental, emotional and spiritual well-being.

Social isolation. Social isolation occurs when an individual has little and poor quality contact with others, has few rewarding relationships, and few social contacts or social roles. In particular, it can be a serious concern for the health and well-being of First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses.[178]

Standards of care (standards of practice). These standards are guidelines used to determine what health care providers should or should not do. Standards may be defined as a benchmark of achievement which is based on a desired level of excellence. Standards of practice describe a competent level of effective and ethical care.

Strengths-based practice. Strengths-based practice respects people's rights to self-determination and empowers people through a focus on their inherent rights to be resilient in the face of adversity. Knowledge and recognition of First Nations approaches to health care as strengths (gifts, assets) is an empowering and validating way for our First Nations to develop, access and strengthen health care programs, services and supports. Our communities have unique ways to support our First Nations in long-term care and related wraparound healthcare services.

Trauma-informed care. Trauma-informed care is wholistic and addresses the root causes of trauma across the lifespan, rather than just focusing on the symptoms. This care recognizes the prevalence of trauma (e.g., intergenerational trauma); how trauma affects individuals, families and communities; how individuals who experienced trauma can be re-traumatized in biomedical health care settings; and ways to understand and share pathways toward healing.[179] Also, trauma-informed care involves a commitment

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

[177] Commission on Social Determinants of Health (2008). *Closing the gap in a generation: Health equity through action on the social determinants of health final report of the Commission on Social Determinants of Hea*lth. World Health Organization. p. 26.

[178] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.

[179] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/what-is-trauma-informed/

to providing health care services that are welcoming, safe and inclusive to the unique needs of individuals affected by trauma or traumatic event(s).[180]Overall, trauma-informed principles include acknowledgement (of trauma), safety, trust, choice and control, compassion, collaboration, empowerment (strengths-based) and peer support.[181]Trauma-informed care is particularly important in navigating intergenerational trauma manifesting in post-traumatic stress disorder (PTSD) often stemming from constant reminders of colonialism (e.g., institutional settings) which includes the effects of the Residential Institution System experience, civil crises (e.g., Oka Crisis), and past and ongoing tension with law enforcement.

2SLGBTQQIA+. This acronym stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and additional sexual orientations and gender identities.

Wise practices. These practices are based on group or community strengths and are grounded in ways of knowing and experiences in First Nations-informed and -led healthcare. They may vary from one group, community or jurisdiction to the next.

Worldview. A worldview is a set of principles, values and beliefs that organize a way of knowing, being and interacting in the world. Every person and society has a worldview. Worldviews influence how we locate or see ourselves in our environment.

[180] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/becoming-trauma-informed/

[181] https://trauma-informed.ca/about-us/mtiec-trainings-and-webinars/trauma-informed-organizations-and-systems/principles/

Appendix C: Summary of recommendations

The following is a summary of recommendations for each of the 12 priorities described in *Our right to health: First Nations' perspectives across the generations*.

Culture as foundation: A wholistic perspective to health and wellness

Objective #1: To address the social determinants of health and practice the Etuaptmumk/ Two-Eye Seeing approach to achieve wholistic improvements in First Nations' physical, mental, emotional and spiritual well-being.

Recommendations:

Recommendation #1.1: Change to an All My Relations[182] standard when it comes to wellness. An All My Relations standard considers the social determinants of health for First Nations Peoples.

- 1.1a: Recognize First Nations health and wellness needs by incorporating care for spiritual, emotional, mental and physical well-being into home, community and long-term care.

- 1.1b: Ensure First Nations communities are provided predictable funding to engage with and lead First Nations healthcare services. With First Nations communities leading healthcare services, there will be an increase in the use and availability of First Nations languages and cultural supports in health care programming.

- 1.1c: Move from a sickness-based model to a wellness promotion and health literacy model. This shift to a wellness and health literacy model should happen across a diverse range of First Nations health services and a continuum of care, with a focus on home, community care and long-term care. This model includes screening services; healthy lifestyle services; needle exchange services; gender- and 2SLGBTQQIA+-informed health services; improved inclusivity for those with accessibility needs; healthy eating, exercise and smoking cessation services; oral health; injury prevention; abuse and neglect prevention; and supporting First Nations Peoples and our families to manage our own health.

[182] "All my relations" refers to interconnectedness—"this mindset reflects people who are aware that everything in the universe is connected. It also reinforces that everyone and everything has a purpose, is worthy of respect and caring, and has a place in the grand scheme of life." https://firstnationspedagogy.ca/interconnect.html.

- 1.1d: Take a gender- and 2SLGBTQQIA+-informed approach to assess the potential impacts and implications of healthcare policies, programs, services and other initiatives on people with diverse gender identities. This approach includes strengthening resources and ensuring equity in healthcare services for people with diverse gender identities. This approach will ensure that their unique lived experiences are valued and supported.

Recommendation #1.2: Support First Nations in their respective jurisdictions in (re)building cultural knowledge systems around healing, helping and wellness.

- 1.2a: Support First Nations-led initiatives to determine effective ways that cultural knowledge systems can be revitalized, continued, expanded or promoted in and/or alongside provincial/territorial health systems.

- 1.2b: Support, through policy and funding, the formal inclusion of First Nations-informed and led healing and helping in programming such as mental wellness programs (e.g., Non-Insured Health Benefits[183]), the Assisted Living Program[184] and the First Nations and Inuit Home and Community Care program.[185] As a first step, the AFN recommends an annual investment of $33.5 million.

Recommendation #1.3: Harmonize First Nations healing ceremonies, cultural teachings and practices into the continuum of care, particularly as it relates to home, community care and long-term care.

- 1.3a: Harmonize local First Nations cultural values, customs and beliefs, healing ceremonies and teachings into the continuum of care. For example, storytelling is a way of uniting everyone by sharing time, stories and understanding of one another. Another example is incorporating gift giving protocols and opening/closing prayers at healthcare and related gatherings.

- 1.3b: Work with First Nations communities to ensure funding support for traditional healers and family supports in home, community care and long-term care.

[183] https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517
[184] https://www.sac-isc.gc.ca/eng/1100100035250/1533317440443
[185] https://www.sac-isc.gc.ca/eng/1582550638699/1582550666787

Recommendation #1.4: Use a trauma-informed approach[186] for home, community care and long-term care that addresses the root causes of trauma across all stages of life, rather than the symptoms, so that the continuum of care cultivates healing, helping and wellness.

- 1.4a: Recognize the prevalence of trauma (e.g., intergenerational trauma) and how trauma affects individuals, our families and communities.

- 1.4b: Fully implement the *First Nations Mental Wellness Continuum Framework*.[187] The Framework recognizes that culture plays a central role in improving the mental wellness of First Nations Peoples.

- 1.4c: Educate health care professionals and groups providing care on the historical legacy of colonization and residential institutions. Institutional settings may be triggering for Indigenous Peoples, so it is advisable for individuals and groups creating care models and delivering care use a wholistic health lens with these considerations in mind.

Home and community care services

Objective #2: To improve home and community care by expanding the age limit based on Jordan's Principle or incorporating a resembling framework that serves those who have reached the age of majority. This objective includes adapting home and community care across the lifespan (from First Nations children, Youth, people with disabilities, people with chronic and life-limiting illnesses to seniors) and respite care/day programming.

Recommendations:

Recommendation #2.1: Strengthen care in the community by improving home care, respite care and supporting cultural caregiving values. [188, 189, 190, 191]

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[186] Trauma-informed care is wholistic and addresses the root causes of trauma across the lifespan, rather than just focusing on the symptoms. This care recognizes the prevalence of trauma (e.g., intergenerational trauma); how trauma affects individuals, families and communities; how individuals who experienced trauma can be re-traumatized in biomedical health care settings; and ways to understand and share pathways toward healing. Also, trauma-informed care involves a commitment to providing health care services that are welcoming, safe and inclusive to the unique needs of individuals affected by trauma or traumatic event(s). Overall, trauma-informed principles include acknowledgement (of trauma), safety, trust, choice and control, compassion, collaboration, empowerment (strengths-based) and peer support.

[187] https://thunderbirdpf.org/first-nations-mental-wellness-continuum-framework/

[188] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

[189] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56: An Act to recognize and support caregivers and to amend various legislative provisions.* FNQLHSSC.

[190] First Nations of Quebec and Labrador Economic Development Commission—FNQLEDC (2020). *Social economy innovation: Optimized home care service offer for First Nations Seniors.* FNQLEDC.

[191] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2006). *Assessing continuing care requirements in First Nations and Inuit communities: Quebec regional report*. Author.

- 2.1a: Evaluate current needs and priorities regarding in-home care under the Assisted Living Program and the First Nations and Inuit Home and Community Care Program.

- 2.1b: Review funding allocated for the First Nations and Inuit Home and Community Care Program to ensure that home care and/or in-home respite care in First Nations communities is accessible and adequate.

- 2.1c: Provide health care programs and services (e.g., home and community care) based on the Seven Generations Continuum of Care that reaches First Nations across the lifespan. [192]

- 2.1d: Increase sustainable funding in the Assisted Living Program and the First Nations and Inuit Home and Community Care Program that accounts for geography, levels of community infrastructure and demonstrated needs and priorities. [193]

- 2.1e: Support residential care settings[194] in First Nations communities and/or near First Nations communities that better reflect First Nations cultures, languages and values. This includes funding support.

- 2.1f: Fund urgent respite care and a structured day program as a preventative measure to provide First Nations families with enough support to be able to keep First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses home as long as possible.[195]

- 2.1g: Support improved funding and access to home adaptations[196] for First Nations, our families and caregivers. Accessibility to proper health care services should not be affected by jurisdictional boundaries, inequitable funding or disputes.

- 2.1h: Provide resources and support to keep First Nations children and youth in their communities.[197] Some younger First Nations adults, children and Youth may need care over the long term (due to disabilities or chronic and life-limiting illnesses), including

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[192] Assembly of First Nations (2020). *Options for a First Nations 7 Generations Continuum of Care: Document for discussion*. Author.
[193] Demonstrated needs and priorities account for caseload, population base and complexity of (health care) needs and priorities.
[194] Residential care settings include a range of living options for people (e.g., First Nations Elders, Seniors, people with disabilities and people with chronic and life-limiting illnesses) with different support needs. Residential care settings can include lodges, assisted living, group homes, family care homes, supportive housing and long-term care settings.
[195] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[196] Home adaptations include major and minor modifications to the home environment that help people live at home independently. Examples include handrails, grab bars, walk-in showers, ramps, chair lifts and bath lifts. These types of home modifications are effective in decreasing the incidence of accidents and injury. They can also strengthen home-based social relationships and reduce strain on caregivers.
[197] Using a Seven Generations Continuum of Care approach and Jordan's Principle, access to home, community care and/or long-term care now or in the future needs to be inclusive, equitable and First Nations-led across the lifespan.

children aging out of the supports provided through Jordan's Principle. It is important to recognize that home and community care is not limited to First Nations Elders and seniors. Regardless of residence or age, there is a general desire by First Nations to receive care and remain in their own home and/or community as long as possible.[195]

Recommendation #2.2: Implement Jordan's Principle meaningfully and in full, without excessive barriers and bureaucracy.

- 2.2a: Implement Jordan's Principle, as identified in the Truth and Reconciliation Commission of Canada Call to Action #3.[198, 199] This step includes collaborating with First Nations communities related to Jordan's Principle implementation.[200]

- 2.2b: Commit to a client-first principle that aligns with Jordan's Principle for all First Nations people, regardless of age or residency.[201]

Recommendation #2.3: Decolonize the way caregiving is viewed.[202, 203]

- 2.3a: Enhance collaboration and coordinated partnerships among caregivers and integration of home, community care and long-term care to ensure management of chronic and life-limiting illnesses, early diagnosis and treatment.

- 2.3b: Identify wise practices across communities in bringing back care to the community so First Nations ways of knowing and quality of care can be harmonized with treatments.

- 2.3c: Increase support for caregivers through additional respite care, training on how to provide quality care, information on specific disabilities, chronic and life-limiting illnesses and related conditions. This recommendation includes increased nursing and personal care hours to support caregivers.

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[198] TRC Call to Action #3. We call upon all levels of government to fully implement Jordan's Principle. https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls_to_action_english2.pdf

[199] https://www.sac-isc.gc.ca/eng/1583700168284/1583700212289

[200] https://www.rcaanc-cirnac.gc.ca/eng/1524494379788/1557513026413

[201] It is important to recognize that although Jordan's Principle is a child-first principle, the same jurisdictional gaps exist for First Nations adults with chronic and life-limiting illnesses and people with disabilities regarding jurisdictional disputes in care between provincial/territorial ministries and the First Nations and Inuit Health Branch.

[202] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.

[203] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2020). *The essential role of caregivers: A cultural and human-centred approach for quality care and services. Bill 56 An Act to recognize and support caregivers and to amend various legislative provisions.* FNQLHSSC.

Human resources

Objective #3: To review options for recruitment and retention of health-related staff. This objective includes expanding policies and resources for caregivers and community helpers—rooted in cultural safety, humility and responsiveness.

Recommendations:

Recommendation #3.1: Increase support for First Nations health care providers at all levels as they serve as a bridge between biomedical care and First Nations health, healing and helping practices, particularly for health care services close to home.

- 3.1a: Invest in the Aboriginal Health Human Resources Initiative (AHHRI) totalling $24 million annually and work with First Nations communities to ensure the administration of AHHRI reflects First Nations' priorities.

- 3.1b: Increase access to timely primary care in First Nations communities. For First Nations communities that do not have regular access to a physician, allow nurse practitioners to perform an expanded scope of practice (e.g., referrals to specialists), rather than delay care if there is no access to a doctor in the community or for First Nations communities who are on a limited rotational schedule (i.e., once a month or less).

- 3.1c: Increase the number of skilled health-related staff (i.e., health managers, nurses, home health aides and medical assistants) who are First Nations and/or trained to work in First Nations communities.

- 3.1d: Expand the definition of what constitutes a "health care/wellness worker" and/or "health care professionals" beyond current biomedical terms. The separation and specialization of work based on biomedical designations (e.g., nurse, medical doctor, social worker, psychologist) creates unnecessary barriers in access to care as many First Nations Peoples are often unaware of the healthcare role differences and are looking for support from whomever is involved.

- 3.1e: Take immediate steps to ensure wage parity with provincial/territorial standards in

wages, pension and employee and family assistance programs for all health-related staff working in First Nations.

- 3.1f: Develop a mentorship program that includes peer support networks for nurses working in First Nations communities and access to an Advanced Practice Nurse[204] 24 hours per day.

Recommendation #3.2: Design First Nations-led programs and services that improve the coordination of health services between jurisdictions.

- 3.2a: Implement a multidisciplinary team-based approach, where all staff in each healthcare setting are appreciated, treated as equally important and included in the efforts to handle daily activities to crisis-level emergencies. The purpose of this approach is to improve the continuum of care and the quality of life of First Nations.

- 3.2b: Enhance health human resources that are flexible and First Nations-led to meet the goals of improving First Nations' health status, outcomes and wellness.

- 3.2c: Have First Nations health care professionals working in First Nations (where and when possible). Health care services should be delivered by and for First Nations—*nothing about us, without us.*

Recommendation #3.3: Support training and skills development that lead to employment for future First Nations health care professionals.

- 3.3a: Train 12,000 Indigenous Peoples over the next 10 years for careers in health and social services, including the full range of health-related professional and managerial roles.

- 3.3b: Increase funding for First Nations to pursue careers in health care in First Nations communities. This step includes developing and/or expanding scholarship and bursary funds for First Nations post-secondary students in healthcare, with an emphasis on funding for areas of healthcare where there are shortages.

- 3.3c: Develop or expand targeted funds for post-secondary health care programs to increase First Nations participation and success. This development may include equity seats, preparatory and transition programs, and bridging programs from licensed

[204] Advanced Practice Registered Nurses (e.g., nurse practitioners) are nurses who have met advanced educational and clinical practice requirements (minimum of a master's degree) and often provide services in community-based settings. Their services range from primary and preventive care and mental health to birthing and anesthesia.

practical nurse to registered nurse and licensed nurse practitioner, mentoring and peer support programs and Elders-in-residence.

- 3.3d: Provide loan forgiveness on Canada Student Loans for health care professionals (including midwives and life spectrum doulas) working in First Nations communities, similar to what already exists for family doctors, residents in family medicine, nurse practitioners and nurses who work in underserved rural, remote or northern communities.

- 3.3e: Partner with First Nations communities on recruitment campaigns which includes designing career development opportunities.

- 3.3f: Partner with educational institutions to offer co-op or internship positions, or full-time positions in First Nations communities for recent graduates.

- 3.3g: Offer First Nations Youth development programs with an emphasis at the secondary school level to promote and prepare students for post-secondary education.

Recommendation #3.4: Design and deliver cultural safety, humility and responsiveness training and related professional development.

- 3.4a: Establish health service standards of care for cultural safety, humility and responsiveness. This step involves health care accreditation and regulatory bodies working with First Nations communities and health authorities on these standards of care.

- 3.4b: Provide support to health and social services professional associations across Canada to design and deliver cultural safety, humility and responsiveness training to their members.

- 3.4c: Implement a mechanism for accountability and assurance in the health care system, supported by professional regulatory colleges (e.g., College of Physicians and Surgeons, College of Nurses) whose professionals are not being held accountable for their treatment of First Nations Peoples needing health care services. This mechanism will hold health care professionals accountable for culturally relevant care provided to First Nations Peoples, our families and communities.

- 3.4d: Direct health-related staff to attend First Nations-approved cultural safety and humility courses that outline, orient and improve participants' awareness of First Nations' complex relationship with colonialism and the Canadian health care system. This training includes learning about local First Nations protocols and values.

- 3.4e: Create financial incentives for post-secondary institutions to build, with and alongside First Nations, mandatory courses on cultural safety, humility and responsiveness for all faculties with a role in health care, including direct service and public policy and administration programs.

- 3.4f: Develop and administer work plans related to ensuring cultural safety, humility and responsiveness in the healthcare field.

- 3.4g: Develop and administer cultural safety, humility and responsiveness training for Health Canada headquarters staff.

- 3.4h: Ensure all health care staff that Health Canada employs (to work with First Nations communities) receive mandatory training in cultural safety, humility and responsiveness, particularly nurses.

Case managers/navigators

Objective #4: To develop culturally safer support services that can guide First Nations and their families through cultural healing programs, provincial/territorial and federal health and social care systems.

Recommendations:

Recommendation #4.1: Encourage health care service providers to build healthy and sustainable connections with First Nations to foster trust and increase confidence.

- 4.1a: Recruit and retain case managers and/or medical navigators to assist and advocate for First Nations to receive proper equitable health care (e.g., home, community care and long-term care).

- 4.1b: Ensure health care service providers clearly inform First Nation son the range of services and programs available to them and that those providers develop a wraparound service plan.

Coordinated partnerships

Objective #5: To determine how to improve the siloed and often fragmented health services between federal and provincial/territorial service delivery partners.

Recommendations:

Recommendation #5.1: Develop coordinated partnerships with external health care service organizations to ensure First Nations' needs and priorities are met and First Nations communities' health care operations have the ability to expand and maximize their reach.

- 5.1a: Support First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses, our families, caregivers and communities to manage their disabilities and/or illnesses with follow-up community-based supports (e.g., equipment, services). This approach can improve many aspects of the health care experience for First Nations: access to timely healthcare; health outcomes; efficient and effective healthcare delivery; satisfaction among health care providers; and the ability of First Nations, our families and communities to manage one or more disabilities and/or chronic and life-limiting illnesses.

Recommendation #5.2: Draft policies and/or legislation options that outline medical care required for and entitled to First Nations Peoples living on-reserve and living off-reserve.

Equitable health care access—jurisdiction

Objective #6: To improve access to equitable health care.

Recommendations:

Recommendation #6.1: Engage in a trilateral process with the federal government, provincial/territorial governments and First Nations in our respective jurisdictions, to come to a clear and actionable shared position on jurisdictional responsibilities.

- 6.1a: Challenge the concept of remoteness for First Nations communities as it relates to us receiving inadequate healthcare. Remoteness is a colonial construct.

- 6.1b: Resolve identified health care jurisdictional barriers between First Nations, federal and provincial/territorial governments.[205]

- 6.1c: Support First Nations, both in policy and through stable adequate resourcing, in developing health centres for urban First Nations populations.

- 6.1d: Expand funding to First Nations representative organizations and allow flexibility to ensure that investments in First Nations communities and First Nations organizations for engagement and collaboration is meeting the demands on their valuable time and resources.

- 6.1e: Make meaningful investments, in line with those provided in the Province of British Columbia, to build First Nations health governance capacity.

- 6.1f: Work with First Nations and First Nations organizations in transitioning funding currently being provided to non-Indigenous organizations that carry out work on behalf of First Nations, toward First Nations organizations that are mandated by First Nations themselves and that demonstrate the potential for and interest in taking on that work.

- 6.1g: Explore the development of an ombudsperson for First Nations Health.

- 6.1h: Determine funding levels based, in part, on community membership and citizenship, rather than based on "Indian Status" alone.

- 6.1i: Extend any new investments in First Nations health to First Nations communities in their territories and areas of interest, whether they have signed self-government agreements.

Health data/funding calculations

Objective #7: To address the need for culturally centred and strengths-based First Nations wellness indicators to guide the revision of funding calculations, include assessing current population statistics and future First Nations health needs.

[205] For example, reduce the costs and barriers associated with First Nations Peoples (particularly, First Nations Elders, Seniors, people with disabilities and people with chronic and life-limiting illnesses) who must coordinate and navigate health care issues such as hospital-to-hospital transfers, transportation, prescription drug costs for individuals with chronic and life-limiting illnesses and/or disabilities, home and community care and long-term care costs.

Recommendations:

Recommendation #7.1: Recognize the importance of collecting real-time, relevant data to advocate for necessary changes to the health care system.

- 7.1a: Use a decolonizing approach that includes strengths-based health methodologies and data.[206] This approach includes recognizing Indigenous data sovereignty as a cornerstone for cultural resurgence and nation (re)building.

- 7.1b: Coordinate First Nations regions, data governance champions and national partners to establish a national First Nations data governance strategy. This coordination includes working with First Nations communities in our respective jurisdictions, the Assembly of First Nations and First Nations Information Governance Centre at the national level to develop a set of key indicators on First Nations health outcomes to measure progress over time.

- 7.1c: Increase research that is respectful of First Nations governance, processes and OCAP™ Principles[207] to fully understand disabilities, chronic and life-limiting illnesses and their effects on First Nations, our families and communities. This step includes increasing funding for the First Nations Information Governance Centre related to data on disabilities, chronic and life-limiting illnesses.

- 7.1d: Update population statistics used when allocating funding for the Assisted Living Program and the First Nations and Inuit Home and Community Care Program, estimated at $74.5 million.

Recommendation #7.2: Develop an appropriate funding formula aimed at community wellness across program areas and departments, with support for data analysis and planning and capacity building.

- 7.2a: Determine a First Nations health care funding formula for comprehensive community planning that accounts for geography, levels of community infrastructure and demonstrated need, particularly as this planning relates to home, community and long-term care.[208]

[206] Strengths-based data honour problems and strengths together, within the social determinants of health, and then ask how that data are used to inform the steps moving forward and support future generations. Strengths-based data generate whole-person information and knowledge that can be used to improve health outcomes.

[207] https://fnigc.ca/ocap-training/

[208] As it pertains to demonstrated need, this accounts for caseload, client base and complexity of needs. In addition, funding for demonstrated need is extended to cultural supports (e.g., support for traditional healers and family supports).

- 7.2b: Implement and financially support First Nations communities in developing OCAP™ compliant community-based tools such as Community-based Electronic Medical Records (cEMRs), First Nation-led Client Registries and Health Surveillance systems that provide an electronic source of truth to track health status, trends and outcomes. These systems will be developed at a standard that supports inter-operability with federal/provincial eHealth/Health applications. These systems will not infringe upon current First Nations community wellness initiatives and planning.

Health care infrastructure development and maintenance

Objective #8: To survey infrastructure needs in First Nations communities for construction and maintenance of First Nations-led health centres, healing lodges and related continuing care centres (e.g., long-term care) in the community and/or in close proximity to First Nations communities (e.g., urban areas). This survey includes exploring how to improve housing for the aging population in First Nations communities.

Recommendations:

Recommendation #8.1: Establish and/or expand access to higher-level health and healing centres and related continuing care centres (e.g., long-term care) in and/or in close proximity to First Nations communities.[209]

- 8.1a: Negotiate coordinated partnerships between First Nations communities and orders of government (provincial/territorial and federal) to provide higher levels of care. These negotiations include expanding the federal government's role and authority in higher levels of care; securing new investments in planning, developing, infrastructure, operations and maintenance and human resource management; ensuring provincial/territorial-designated and funded beds in continuing care centres are constructed in First Nations communities and/or ensuring preferred access to continuing care centres near First Nations Peoples' communities.

- 8.1b: Identify available economic diversification and infrastructure funding opportunities that can be used by First Nations communities to subsidize construction projects such as health and healing centres and related continuing care centres.

[209] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

- 8.1c: Expand infrastructure to include more options for care in First Nations communities and better access to health care providers for First Nations.

- 8.1d: Create culturally safer places (e.g., multi-purpose buildings) that support First Nations community wellness. These places include meeting spaces, family friendly and welcoming spaces that feature local First Nations artwork and signage; clinical rooms to meet the needs of interdisciplinary health care teams; in-house laundry, locker rooms and showers; and dedicated spaces for First Nations cultural practices, healing ceremonies and spiritual activities.

Recommendation #8.2: Bring community to the city.

- 8.2a: Establish urban continuing care centres (culturally safe and supportive spaces and environments) for First Nations who, due to their level and type of care, need to leave their communities for health care services. These centres should provide optimal care while being responsive to the rights and cultural values of First Nations families and communities. Urban continuing care centres will also be accessible for First Nations who choose not to live on-reserve.

Recommendation #8.3: Increase investments in ISC Health Facilities Program[210] to reflect demonstrated needs. This process includes beginning with the existing waitlist but also ensuring sufficient resources for maintaining health care infrastructure.

- 8.3a: Affirm that the focus of the Health Facilities Program is to build spaces directed toward wholistic individual, family and community wellness. The Program must include built-in flexibility for First Nations to determine their own infrastructure needs, which may go beyond simple clinical applications.

- 8.3b: Require an initial investment of ~$420 million to clear the existing waitlist and a minimum of ~$25.1 million for ongoing infrastructure support needs and priorities—to avoid future waitlists.

[210] https://www.sac-isc.gc.ca/eng/1613078660618/1613078697574

Emergency preparedness

Objective #9: To keep vulnerable First Nations individuals safe by providing options for responding to public health emergencies (e.g., communicable and non-communicable diseases; exposure to environmental pollutants, toxins and carcinogens; wildfires, flooding, heat waves, tornadoes, hailstorms; civil crises; workplace violence, water shortages, electrical grid blackouts). Vulnerable individuals are those who reside in various types of on-reserve and off-reserve continuing care centres.

Recommendations:

Recommendation #9.1: Provide resources (funding) for First Nations communities to develop their own emergency and evacuation action plans.

- 9.1a: Support the coordination of developing and subsequently implementing First Nations emergency and evacuation action plans with each order of government (provincial/territorial, federal).

Recommendation #9.2: Develop an emergency relief fund that First Nations communities can tap into in the event of unforeseen circumstances, to ensure continuity of health care services.

- 9.2a: Increase the availability of emergency response services (including mental health services) for First Nations, in particular, First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses.

Recommendation #9.3: Increase the use of telemedicine and videoconferencing to bring care closer to First Nations, reduce medical travel and increase cultural relevance.

- 9.3a: Set aside dedicated funding to advance eHealth initiatives in all First Nations communities across Canada based on community needs and priorities. At a minimum, this requires additional investments of $78 million on-going.

- 9.3b: Work with First Nations communities in our jurisdictions to develop solutions related to eHealth needs and priorities. This work may include developing a joint strategy that complements provincial/territorial eHealth strategies.

Chronic and life-limiting illnesses

Objective #10: To examine current access to services for First Nations with chronic and life-limiting illnesses. This examination includes reviewing and implementing equitable health care services options for First Nations.

Recommendations:

Recommendation #10.1: Support First Nations-led wise practices and related initiatives on chronic and life-limiting illnesses.[211]

- 10.1a: Develop and use culturally relevant and validated screening, diagnosis, assessment and treatment methods for First Nations with chronic and life-limiting illnesses, preferably in their home communities.

- 10.1b: Encourage and support continued engagement and collaborative efforts to address various chronic and life-limiting illnesses; their root causes; the consequences of inaction and apathy; and ways forward in a manner where First Nations can adapt, scale and transform wellness programs and services according to First Nations' needs and priorities.

Recommendation #10.2: Increase investments in First Nations communities across Canada to develop and administer multi-year sustainable and community-driven programs ranging from promotion and prevention to screening, diagnosis, assessment and treatment of chronic and life-limiting illnesses.

- 10.2a: Ensure the Government of Canada (e.g., Health Canada) accounts for chronic and life-limiting illnesses in policy and program work with food security as one example.

- 10.2b: Build upon existing capacity in First Nations communities with a focus on culturally relevant promotion, prevention, screening, diagnosis, assessment and treatment of chronic and life-limiting illnesses—meeting specific needs and priorities of First Nations families and communities.

[211] Assembly of First Nations *Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

Recommendation #10.3: Strengthen home and community-based supports (e.g., equipment, services) to meet complex challenges in caring for First Nations diagnosed with chronic and life-limiting illnesses.

- 10.3a: Increase awareness and education for First Nations with chronic and life-limiting illnesses, our families, caregivers and communities.

- 10.3b: Access specialized equipment (e.g., onsite dialysis equipment) in First Nations communities and/or near home communities. This access includes, where necessary, use of portable equipment and travelling teams to increase home, community care and long-term care; and increase prevention, screening and treatment for a range of health conditions (e.g., diabetes, cancer screening) in areas where there are gaps in service delivery to First Nations communities.

- 10.3c: Access should not be denied, and systems should be in place to expedite without delay or disruption—if there is a jurisdictional dispute in coverage for needed equipment.

Aging well and long-term care

Objective #11: To outline recommendations to keep our First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses in their First Nations communities by providing quality care in those communities. This process includes recognition that many First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses are Residential Institution Survivors, Indian Hospital Survivors or Sixties Scoop Survivors and do not want to leave their communities.

Recommendations:

Recommendation #11.1: Expand the definition of First Nations seniors to 55 years of age.

- 11.1a: Support aging well and long-term care for First Nations by aligning government-funded health care policies and programs with specific needs and priorities expressed by diverse voices of First Nations Peoples (particularly First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses), our families and communities.[212]

[212] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada.* Author.

Recommendation #11.2: Have access to both in-home care and community-based long-term care services—with the capacity to safely care for aging First Nations and/or First Nations people with disabilities and people with chronic and life-limiting illnesses.[213, 214, 215]

- 11.2a: Provide necessary supports to First Nations communities to establish and operate long-term care services, where demonstrated needs and priorities are established.

- 11.2b: Provide aging well and long-term care services closer to home. This includes the use of virtual care (as needed and as appropriate) for the level of care needed for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses, our families and communities.[216]

Recommendation #11.3: Harmonize protective factors for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses into planning and care for aging well.[217, 218, 219]

- This recommendation includes the following protective factors:

-participating in cultural practices and healing ceremonies

-having social support (individual, family and community support) that provides practical help, positive interactions, emotional support and friendship

-having access to healthcare supports (e.g., equipment)

-belonging to a community that promotes respect for First Nations' ways of life and cultural values

-belonging to a community that promotes respect for First Nations Elders for their wisdom

-belonging to a community that appreciates First Nations' resilience and diverse narratives of First Nations' lived experiences

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[213] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille.* FNQLHSSC.

[214] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.

[215] First Nations of Quebec and Labrador Economic Development Commission—FNQLEDC (2020). *Social economy innovation: Optimized home care service offer for First Nations Seniors.* FNQLEDC.

[216] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada.* Author.

[217] This harmonization includes health promotion and wellness programs and long-term care services and related supports.

[218] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2017). *Active aging in the Quebec First Nations: Everyone's a winner! Brief presented to the Secrétariat aux aînés, Ministère de la Famille.*: FNQLHSSC.

[219] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2014). *Brief on residential and long-term care resources for Quebec First Nations.* Author.

-having access to social events that respect First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses and incorporate health promotion—making them feel safe, welcome and included

-having interpreters and translators when needed

-having social contact in the form of virtual calls (phone and video), friendly visits, excursions, physical activity programs and/or other interactions (e.g., cultural events, food-related gatherings, crafting, games); and

-having access to culturally relevant health care services in the community.[220]

Recommendation #11.4: Ensure First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses have access to all health benefits.[221, 222, 223]

- 11.4a: Ensure care for the elderly and related funding for First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses are also accessible to their caregivers.[224, 225]

Recommendation #11.5: Develop and implement strategies that improve standards of care in long-term care. [226, 227, 228]

- 11.5a: Have funding in place to plan for improvements in standards of care for First Nations.

- 11.5b: Consider systemic discrimination and the legacy of the Residential Institution System, Indian Hospitals and Sixties Scoop in Canada when addressing abuse and neglect of First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses.

- 11.5c: Improve First Nations Elders, seniors, people with disabilities and people with chronic and life-limiting illnesses' access to information, advocacy and education programs on preventing abuse and neglect.

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[220] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[221] Ibid.
[222] Assembly of First Nations Quebec-Labrador and First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Joint brief: Access for all? Fact or fiction...* FNQLHSSC.
[223] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Portrait of First Nations in Quebec living with disability or having special needs*. FNQLHSSC.
[224] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada*. Author.
[225] Assembly of First Nations (2007). *Sustaining the caregiving cycle: First Nations People and Aging. A report from the Assembly of First Nations to the Special Senate Committee on Aging.* Author.
[226] Assembly of First Nations (2017). *Report: First Nations Seniors health and wellness in Canada.* Author.
[227] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2010). *Living conditions of the Elders of the First Nations of Quebec: Final report.* FNQLHSSC.
[228] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2013). *Portrait of First Nations in Quebec living with disability or having special needs*. FNQLHSSC.

Palliative and end-of-life care

Objective #12: To increase the accessibility of palliative and end-of-life care services for First Nations at the community level.

Recommendations:

Recommendation #12.1: Prioritize palliative and end-of-life care to recognize changing demographics of First Nations.[229]

- 12.1a: Develop a policy framework to provide equitable palliative and end-of-life care in First Nations communities that is complementary yet distinct from a biomedical approach.
- 12.1b: Encourage the sharing of wise practices, national standards of care and common approaches to palliative and end-of-life care planning across First Nations, various continuing care centres and jurisdictions.
- 12.1c: Designate palliative and end-of-life care as an essential service in First Nations communities, with sustainable funding included in the healthcare funding formula.
- 12.1d: Fund palliative and end-of-life care in the First Nations and Inuit Home and Community Care Program, estimated at $60 million annually of new investments.

Recommendation #12.2: Explore collaborations between the AFN, Government of Canada and not-for-profit organizations specializing in palliative and end-of-life care and diseased-based organizations[230] to raise awareness of First Nations palliative and end-of-life care needs at the national level.

- 12.2a: Involve First Nations and broader Indigenous health care professionals in palliative and end-of-life care systems planning.
- 12.2b: Collaborate, cooperate and partner with others (e.g., Indigenous and non-Indigenous health care professionals, service providers, orders of government and educators) to better support families who experience loss. This support is needed as decisions are complex, demands can be significant and grief can be intense.[231]

[229] Ibid.
[230] For example, Canadian Cancer Society, Canadian Hospice Palliative Care Association, Canadian Virtual Hospice, Canadian Partnership Against Cancer and The Way Forward Initiative.
[231] Hordyk, S.R., MacDonald, M.E., & Brassard, P. (2016). *End-of-life care for Inuit living in Nunavik, Quebec: A report written for the Nunavik Regional Board of Health.* p. 25.

Recommendation #12.3: Ensure First Nations communities have palliative and end-of-life care along with other health care services and supports, so community members can receive equitable and wholistic health care support without leaving their homes.[232]

- 12.3a: Increase the availability of home care and palliative and end-of-life care among First Nations communities.

Recommendation #12.4: Take early palliative care approaches to increase quality of life for First Nations Peoples, especially with chronic and life-limiting illnesses.[233]

- 12.4a: Increase palliative care education and focus on capacity building in First Nations.
- 12.4b: Improve post-secondary training for emerging health care professionals to build capacity for providing culturally safer palliative and end-of-life care, including grief and bereavement support.
- 12.4c: Address any lack of access to affordable and equitable palliative and end-of-life care services for First Nations Peoples with chronic and life-limiting illnesses. For example, expand the acceptable diagnoses to qualify for palliative and end-of-life care that goes beyond a cancer diagnosis.

[232] First Nations of Quebec and Labrador Health and Social Services Commission—FNQLHSSC (2016). *Portrait of palliative care provided in First Nations communities in Quebec*. FNQLHSSC.
[233] Ibid.

Appendix E: Assembly of First Nations

The Assembly of First Nations (AFN) is a national advocacy organization that works to advance the collective aspirations of First Nations individuals and communities across Canada, which includes more than 900,000 people living in 634 First Nations and in cities and towns across the country, on matters of national or international nature and concern. First Nations Chiefs, from coast to coast, direct the work of AFN through resolutions passed at Chiefs Assemblies held at least twice a year.

The AFN National Executive Committee is made up of the National Chief, 10 Regional Chiefs and the chairs of the Elders/Knowledge Keepers, Women's, Veterans, Youth and 2SLGBTQQIA+ councils.

It must be understood that, while the AFN is a First Nations mandated organization, it is not a rights- bearing organization and does not replace the voice of First Nations themselves. This is a particularly important point for government departments and government mandated organizations that hold a legal obligation to consult with First Nations when there is potential for their actions or decisions that may affect an Aboriginal person's Aboriginal or Treaty rights. That obligation is to First Nations themselves, and not with the AFN.

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