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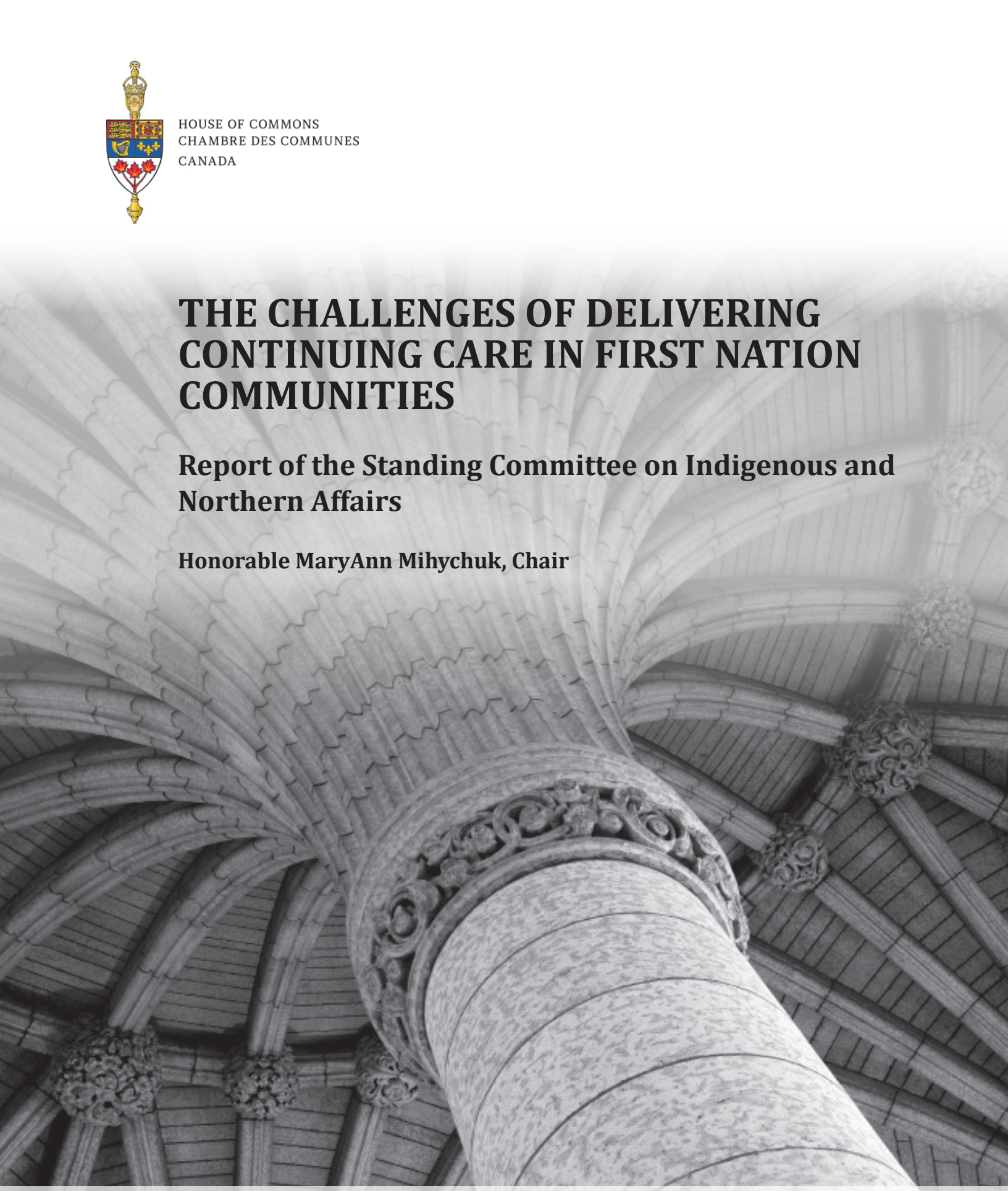
THE CHALLENGES OF DELIVERING CONTINUING CARE IN FIRST NATION COMMUNITIES

Report of the Standing Committee on Indigenous and Northern Affairs

Honorable MaryAnn Mihychuk, Chair



DECEMBER 2018
42nd PARLIAMENT, 1st SESSION

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Report of the Standing Committee on Indigenous and Northern Affairs

Hon. MaryAnn Mihychuk
Chair

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NOTICE TO READER

Reports from committee presented to the House of Commons

Presenting a report to the House is the way a committee makes public its findings and recommendations on a particular topic. Substantive reports on a subject-matter study usually contain a synopsis of the testimony heard, the recommendations made by the committee, as well as the reasons for those recommendations.

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THE STANDING COMMITTEE ON INDIGENOUS AND NORTHERN AFFAIRS

has the honour to present its

SEVENTEENTH REPORT

Pursuant to its mandate under Standing Order 108(2), the Committee has studied long-term care on reserve and has agreed to report the following:

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SUMMARY

Indigenous health outcomes tend to be poorer than the Canadian average. The underlying factors are complex and include historical and intergenerational trauma attributed to colonialism and discriminatory policies, as well as social determinants of health, the current legislative and policy frameworks and gaps in existing federal programming. In addition, First Nation members are more likely to have chronic conditions at a younger age, and the care available in First Nation communities is often limited compared with the care offered to the non-Indigenous population in urban centres.

For First Nations with more complex health needs, access to continuing care on reserve is essential to their well-being. Continuing care covers a range of services, including home care, community support services, long-term facility-based care, respite care and palliative care.[1] Continuing care services are not only for seniors: they are for anyone, of any age, with chronic medical conditions. These services are part of the continuum of care to which all Canadians are entitled until the end of their lives.

Over the course of its study, the House of Commons Standing Committee on Indigenous and Northern Affairs (the Committee) learned that the barriers associated with continuing care on reserve are partly due to the complexity of overlapping responsibilities and current policies between levels of government. Currently, the responsibility to provide health care on reserve is unclear, and the provision of those services is currently shared among the federal and provincial governments, First Nations organizations and communities, and third-party services providers, resulting in a complicated and ambiguous framework. Because both levels of government are "passing the buck," First Nation communities have trouble obtaining the support they need to offer health care services on and off reserves.[2] Continuing care is no exception.

In an effort to address the problems with continuing care on reserve, the federal government put programs in place to provide home care and community care on reserve and to subsidize some expenses in care facilities. As it stands, these programs and the jurisdictional framework are lacking. Current resources for home and community care cannot meet the growing demand for these services on reserve; there are very few

1 House of Commons, Standing Committee on Indigenous and Northern Affairs [INAN], *Evidence*, 1st Session, 42nd Parliament, 24 May 2018, 1530 (Keith Conn, Acting Assistant Deputy Minister, First Nations and Inuit Health Branch, Department of Indian Affairs and Northern Development).

2 INAN, *Evidence*, 1 October 2018, 1535 (Grand Chief Constant Awashish, Conseil de la nation Atikamekw).

long-term facilities on or near reserves; and the services provided in off-reserve care facilities is often very far from First Nation communities and fails to include culturally appropriate care.

Little research has been done on continuing health care services on First Nation reserves. However, First Nation members are "just as human as any other individual" and are entitled to the same level of care as other Canadians.[3] That is why, on 1 February 2018, the Committee passed the following motion :

> That, pursuant to Standing Order 108(2), the Committee undertake a comprehensive study of long-term care on reserve; that the scope of the study include and not be limited to, elder care, persons living with chronic illness, palliative and hospice care and culturally relevant practices and programs; and that the witness list include First Nation community representatives, First Nation organizations responsible for delivering long-term care services, and groups and organizations affiliated with service delivery; and that the Committee report its findings to the House.

The purpose of the study was to consider the main barriers that seniors and those with chronic illness face in obtaining continuing care on reserve (including care provided in long-term care facilities on or off reserve). The study also addressed palliative care and the need for programs and practices adapted to First Nations' cultures and values. The Committee held eight public hearings and heard 48 witnesses, including representatives of the federal government, First Nation communities and organizations, tribal councils, service providers, health authorities and independent experts. Five briefs were also submitted to the Committee.

While the study focused on continuing care on reserve, the Committee recognizes that some of the issues identified during the study also affect the general Canadian population. However, some challenges are unique to First Nation members living on reserve, such as the ambiguity over responsibility of health care provision and the importance of having access to culturally appropriate care. The Committee believes that these issues require special and immediate attention from the federal government and that access to culturally appropriate care should be taken into account at every stage of the continuum of care on reserve.

The Committee also recognizes that the shortage of long-term care facilities on reserves and the gaps in care services offered through federal government programs are not the only barriers. The disproportionately high poverty rates and the greater infrastructure and housing needs on reserve are some of the many issues that must be taken into account when considering strategies for delivering health care, including continuing care

3 INAN, *Evidence*, 26 September 2018, 1700 (Ogimaa Duke Peltier, Wiikwemkoong Unceded Territory).

in First Nation communities.[4] Nevertheless, the Committee hopes that the evidence heard and the recommendations given will open the door to reforming the current policies and practices governing continuing care on reserve.

4 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle, Mohawks of the Bay of Quinte).

LIST OF RECOMMENDATIONS

As a result of their deliberations committees may make recommendations which they include in their reports for the consideration of the House of Commons or the Government. Recommendations related to this study are listed below.

Recommendation 1

That Indigenous Services Canada provide increased funding to the First Nations and Inuit Home and Community Care Program to include palliative care as a service eligible for funding under the program..... 21

Recommendation 2

That Indigenous Services Canada evaluate the current needs regarding in-home respite care under the First Nations and Inuit Home and Community Care Program and report publicly on it; and that Indigenous Services Canada review the funding allocated for the First Nations and Inuit Home and Community Care Program to ensure that in-home respite care on reserve is accessible and adequate..... 24

Recommendation 3

That Indigenous Services Canada:

- **establish a funding formula that provides stable, predictable and long-term funding to projects to build or maintain long-term care facilities on reserves and that the new formula take into account factors such as First Nation population growth, inflation and the remoteness of communities;**

- **facilitate and support partnership initiatives to build long-term care facilities; and**

- **work with First Nations and the provinces and territories, in accordance with the priorities that First Nations set for long-term care on reserves, to develop and implement pilot projects in various regions of Canada to build and maintain long-term care facilities on reserves. 31**

THE CHALLENGES OF DELIVERING CONTINUING CARE IN FIRST NATION COMMUNITIES

INTRODUCTION

First Nation members have complex health needs and many factors may require First Nations people to access continuing care earlier in their lives compared with the non-Indigenous population. A greater proportion of First Nation people are likely to suffer from chronic health conditions at a younger age compared to the general Canadian population. It is also common for aging First Nations people to suffer from multiple chronic conditions.[1] For example, the rate of diabetes within First Nations communities can be "three to five times higher among Indigenous people as compared with the general population,"[2] and diabetes is commonly experienced by younger generations.[3] Thus, First Nation members frequently require continuing care at a younger age. According to witnesses, given the systemic health problems they experience, First Nation members on reserve may require continuing care from the age of 55, compared with 65 or 75 for the non-Indigenous population.[4] The First Nations Health Authority also observed an increase in the incidence of Alzheimer's and

1 INAN, *Evidence*, 24 May 2018, 1530 (Keith Conn, Acting Assistant Deputy Minister, First Nations and Inuit Health Branch); INAN, *Evidence*, 31 May 2018, 1550, (Chief R. Donald Maracle, Mohawks of the Bay of Quinte); 1630 (Graham Mecredy, Senior Health Analyst, Senior Epidemiologist, Institute for Clinical Evaluative Sciences (ICES), Chiefs of Ontario); INAN, *Evidence*, 5 June 2018, 1700 (Natalie Gibson, Researcher and Advisor to the Board, Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788); INAN, *Evidence*, 26 September 2018, 1540 (Sharon Rudderham, Director of Health, Eskasoni First Nation); INAN, *Evidence*, 3 October 2018, 1625 (Gwen Traverse, Director of Health, Pinaymootang First Nation); and Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

In the brief it submitted to the Committee in June 2018, the First Nations Health Authority stated that the data it had collected showed that First Nation members "were two times more likely than other BC residents to have had a stroke, and three times more likely to have rheumatoid arthritis … [and] diabetes, three times more likely to have Osteoarthritis, and two times more likely to have hypertension."

2 INAN, *Evidence*, 26 September 2018, 1650 (Chief Peter Collins, Fort William First Nation). Witnesses also explained that diabetes complications can lead to severe health issues such as cardiovascular diseases or strokes, renal diseases and amputation: INAN, *Evidence*, 26 September 2018, 1655 (Chief Peter Collins); and 1715 (Ogimaa Duke Peltier, Wiikwemkoong Unceded Territory).

3 INAN, *Evidence*, 26 September 2018, 1645 (Ogimaa Duke Peltier).

4 INAN, *Evidence*, 31 May 2018, 1610; 1625 (Bernard Bouchard, Associate, Assured Consulting, Mohawks of the Bay of Quinte); and INAN, *Evidence*, 5 June 2018, 1550 (Bonita Beatty, Professor, University of Saskatchewan).

dementia, among First Nation members,[5] which can increase and accelerate the transition from home and community care to facility-based long-term care.

The First Nations population is also growing at nearly twice the rate of the non-Indigenous population, and the number of First Nations seniors is increasing as a result. In fact, the number of seniors could double by 2036, rising from 28,000 to almost 75,000 First Nations seniors on reserve that will likely need some form or another of continuing care, home care, community care or facility-based care.[6] There are also significant differences in life expectancy between First Nations and the general Canadian population: 73 years for First Nations men and 78 years for First Nations women, compared with 79 years for men and 83 years for women in the Canadian population as a whole.[7]

Furthermore, First Nations continuing care recipients are among the most vulnerable in Canada "due to their health, age and economic situation."[8] Factors that affect their health include historical and intergenerational trauma, which stems from colonization and residential schools. Other factors, such as the social determinants of health,[9] also affect Indigenous peoples and health outcomes.[10] These living conditions can lead to significant differences in health outcomes for Indigenous peoples compared with the rest of the Canadian population.

A combination of these factors may result in First Nation members entering care facilities earlier in their lives. This can have a direct impact on the cost and the current and future needs for continuing care in First Nation communities. Thus, the number of First Nation members needing continuing care will increase in the years ahead.[11]

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5 Brief submitted by the First Nations Health Authority.

6 INAN, *Evidence*, 24 May 2018, 1530 (Keith Conn).

7 Statistics Canada, Aboriginal Statistics at a Glance, Life expectancy, *Chart 13: Projected life expectancy at birth by sex, by Aboriginal identity, 2017*.

8 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

9 According to the National Collaborating Centre for Determinants of Health, "[t]he social determinants of health are the interrelated social, political and economic factors that create the conditions in which people live, learn, work and play;" National Collaborating Centre for Determinants of Health, English Glossary.

10 INAN, *Evidence*, 31 May 2018, 1550 (Chief R. Donald Maracle); INAN, *Evidence*, 7 June 2018, 1615 (Chief Edmund Bellegarde, File Hills Qu'Appelle Tribal Council); and 1715 (Deputy Grand Chief Derek Fox, Nishnawbe Aski Nation).

11 INAN, *Evidence*, 26 September 2018, 1530 (Robin Decontie, Director, Kitigan Zibi Health and Social Services, Kitigan Zibi Anishinabeg First Nation); 1635 (Ogimaa Duke Peltier); 1650 (Chief Peter Collins); and Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

However, despite the growing demand, "current infrastructure and services are inadequate."[12] According to Chief R. Donald Maracle of the Mohawks of the Bay of Quinte, it is important to have in place supports such as home care, assisted living and long-term facility-based care, and First Nation members must have access to these supports "earlier and more often."[13]

In response to the scale and scope of the need for continuing care on reserve, the Committee agreed, on 1 February 2018, to

> [u]ndertake a comprehensive study of long-term care on reserve; that the scope of the study include and not be limited to, elder care, persons living with chronic illness, palliative and hospice care and culturally relevant practices and programs; and that the witness list include First Nation community representatives, First Nation organizations responsible for delivering long-term care services, and groups and organizations affiliated with service delivery; and that the Committee report its findings to the House.[14]

As part of its study, the Committee held eight public hearings to address these matters, in May, June, September and October 2018. It heard from a total of 48 witnesses, including from First Nations and organizations representing health care professionals working with First Nation communities and received five briefs. This report is based on the evidence heard and the content of the briefs submitted. The Committee would like to thank the witnesses who appeared and participated in its study on continuing care in First Nation communities. The Committee would also like to express its gratitude to the First Nation communities and organizations that submitted briefs to provide a greater understanding of the various issues raised during this study.

The report is divided into five parts. The first part defines "continuing care" and "long-term care" for the purposes of this report and provides information on jurisdiction over health care on reserve, including the relevant federal programs. The second part addresses the gaps identified in access to home care and community care, as well as long-term facility-based care. The third part focuses on issues associated with culturally relevant practices and programs; First Nations control of continuing care programs and services; and capacity-building, including through training, recruitment and retention of a skilled labour force on reserve. The fourth part addresses the challenges associated with the complex jurisdiction over health care on reserve. The fifth and final part focuses

12 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

13 INAN, *Evidence*, 31 May 2018, 1555 (Chief R. Donald Maracle).

14 INAN, *Minutes of Proceedings*, 1st Session, 42nd Parliament, Meeting 92, 1 February 2018.

on concerns about the lack of relevant data on the health of First Nation members and their access to continuing care.

1. BACKGROUND

A. Terminology

For sake of clarity, the terms “continuing care” and “long-term care” in this report are not necessarily synonymous. Indigenous Services Canada (ISC) defines “continuing care” as including home care, community support services, supportive and assisted living and long-term facility-based care, as well as respite services and palliative and end-of-life care. “Long-term care” is part of “continuing care” and refers solely to facility-based care.[15] Dr. Bonita Beatty of the University of Saskatchewan identified the three stages of continuing care for Indigenous seniors: “One is at home. Another is during the transition, when they’re moved to a long-term care facility. The third is at the long-term care facility.”[16]

In addition, the terms “elder” and “Elder” are both used in this report, but they are not always interchangeable. The uppercase letter indicates that it is a title or an honorific, while the lowercase letter indicates that it refers to a senior. Not all Indigenous seniors are considered Elders, and First Nation communities may recognize Elders in different ways.

B. Health Care Jurisdiction on reserve

In Canada, health care and the delivery of health care services in First Nation communities is complex. The ultimate responsibility between provincial and federal governments for providing health care on reserve is unclear, and the provision of health services on reserve is currently shared among the federal and provincial governments, First Nations organizations and communities, and third-party services providers.[17] Indigenous health policy in Canada has therefore been described as a “complicated “patchwork” of policies, legislation and agreements that delegate responsibility between federal, provincial, municipal and Aboriginal governments in different ways in different parts of the country.”[18]

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15 INAN, *Evidence*, 24 May 2018, 1530 (Keith Conn).

16 INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty).

17 2015 Spring Reports of the Auditor General of Canada, *Report 4—Access to Health Services for Remote First Nations Communities*; and Indigenous Services Canada, *Indian Health Policy 1979*.

18 National Collaborating Centre for Aboriginal Health, *An Overview of Aboriginal Health in Canada*, 2013.

The *Constitution Act, 1867*, does not outline specifically what level of government (federal or provincial) has the power to legislate on health matters. However, the Constitution lists some powers associated with health. For example, the provinces are responsible for most hospitals,[19] delivering most medical services and training physicians (these powers derive from provincial authority over property and civil rights under section 92(13) and matters of a merely local or private nature under section 92(16)). The provinces provide these services to all Canadians, including First Nations people. However, provincial government will generally not operate health services on reserve.[20]

The federal government's role in First Nations health has been described as flowing from "constitutional and statutory provisions, treaties and customary practice."[21] The federal government's core roles relate to "public health activities on reserves, health promotion, and the detection and mitigation of hazards to health in the environment."[22] Furthermore, section 73(1)(g) of the *Indian Act* authorizes the Governor in Council to make regulations "to provide medical treatment and health services for Indians."[23] However, there are currently no regulations in place in this respect.

While the federal government does not have clear legislative authority or responsibility over the delivery of health care on reserves, it has, for a number of years, provided certain services related to Indigenous health through federal programs. In the course of its study, the Committee heard that the current system and patchwork of policies related to continuing care has left First Nations people in limbo and particularly affects the most vulnerable.

1. First Nations and Inuit Health Branch

For First Nation members living on reserve as well as for Inuit communities, health services are funded and administered by the federal government through the First Nations and Inuit Health Branch (FNIHB), which is now under the purview of ISC.[24]

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19 *Constitution Act, 1867*, ss. 92(7).

20 Health Canada, *The First Nations and Inuit Health Branch Strategic Plan: A Shared Path to Improved Health*, 2012.

21 Indigenous Services Canada, *Indian Health Policy 1979*.

22 Ibid.

23 *Indian Act*, R.S.C., 1985, c. I-5, s. 73(1)(g).

24 INAN, *Evidence*, 14 June 2018, 1625 (Beverly Ward, Director, Health and Social Services, Loon River First Nation). The Department of Indigenous Services also deals with other issues affecting First Nations on reserve and Inuit peoples. It provides funding for First Nation education, community and social services, infrastructure and housing, among others.

Through FNIHB, First Nations are eligible to receive "a specified range of medically necessary health-related goods and services when not covered through private insurance plans or provincial/territorial health and social programs."[25] Since 1989, FNIHB has been working with First Nations to transfer responsibility for health services to Indigenous communities and band councils.[26] In 2013, Health Canada transferred its role in the design, management and delivery of First Nations health programming (previously provided by FNIHB) to the new First Nations Health Authority (operating in British Columbia) as part of the British Columbia Tripartite Framework Agreement on First Nation Health Governance.[27]

2. Federal Continuing Care Programs on Reserves

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

The federal government is involved in continuing care on reserve and in providing home care or funding through the following programs: the First Nations and Inuit Home and Community Care Program (Home Care Program), the Assisted Living Program and the Non-Insured Health Benefits Program, all of which are overseen by the Department of ISC.

a. First Nations and Inuit Home and Community Care Program

The Home Care Program was established in 1999 to bridge a gap in First Nations and Inuit home and community care in the provinces and territories. This program is "actually available in 96% of [First Nation] communities," and is offered to seniors as

25 Health Canada, *Benefits Information - Non-Insured Health Benefits*.

26 Health Canada, *Ten Years of Health Transfer First Nation and Inuit Control*, 2005.

27 Health Canada, *British Columbia Tripartite Framework Agreement on First Nation Health Governance*.

28 INAN, *Evidence*, 24 May 2018, 1545 (Robin Buckland, Executive Director, Office of Primary Health Care, First Nations and Inuit Health Branch, Department of Indian Affairs and Northern Development).

well as First Nation and Inuit individuals of any age who are living with disabilities or chronic or serious illnesses.[29] The Home Care Program's 10-year plan states that its vision is "a continuum of home and community care services that are comprehensive, culturally safe, accessible, effective, and equitable to that of other Canadians and which respond to the unique health and social needs of First Nations and Inuit."[30]

In 2013–2014, program expenditures amounted to $110.8 million, of which 96% was in transfer payments to First Nation communities.[31] In 2017–2018, planned program spending decreased and was estimated at $105 million.[32]

The Home Care Program provides funding through contribution agreements with First Nation and Inuit communities and territorial governments for basic services. The continuum of basic services includes client assessment, case management, home care nursing, in-home respite care, personal care and access to medical supplies and equipment.[33] While the Home Care Program has authority to provide supportive services such as palliative care, mental health home-based care and therapies, it does not directly fund them. According to the most recent internal audit of the Home Care Program, "These services can only be provided once essential service elements are provided and if there are remaining funds."[34] In her appearance before the Committee, an ISC representative noted that the Home Care Program had gaps, such as limited hours of service and limited types of services (i.e., physiotherapy and occupational therapy).[35]

b. Assisted Living Program

The Assisted Living Program provides funds to identified service providers to help provide non-medical social support services. It is available to people living on reserve who have a chronic illness or disability. The ISC representative who appeared before the Committee explained that the Assisted Living Program has a $110-million annual budget

29 INAN, *Evidence*, 24 May 2018, 1535; 1545 (Robin Buckland).

30 Health Canada, *First Nations and Inuit Home and Community Care: 10-Year Plan (2013-2023)*, April 2015.

31 Health Canada, *Audit of the First Nations and Inuit Home and Community Care Program*, October 2014.

32 Health Canada, *Supporting Information on Lower-Level Programs 2017-18 Departmental Plan*, March 2017.

33 Health Canada, *Supporting Information on Lower-Level Programs 2017-18 Departmental Plan*, March 2017; and Health Canada, *Audit of the First Nations and Inuit Home and Community Care Program*, October 2014.

34 Health Canada, *Audit of the First Nations and Inuit Home and Community Care Program*, October 2014.

35 INAN, *Evidence*, 24 May 2018, 1535 (Robin Buckland).

and consists of three major components: in-home care, adult foster care and institutional care.[36]

This program does not offer nursing or medical care. However, eligible individuals can receive light housekeeping services and supervision as part of an in-home care or adult foster care service. For institutional care, the program "helps to subsidize the facility copayment fees related to room and board for those within an institutional environment, long-term care facility, or personal care home, either on or off reserve."[37]

In her appearance before the Committee, an ISC representative said that the scope of the Assisted Living Program is "very limited": the program, which functions like an income support program, is "available to those individuals who cannot pay for institutional care or in-home care supports themselves" and who do not have any available family members who can provide the service for them.[38] In addition, the financial support for institutional care (on or off reserve) is provided only for people requiring Types I and II care.[39] The responsibility to provide funding for delivering care in institutions (on or off reserve) for Types III, IV and V care falls to the provinces and territories. The Committee acknowledges that this system can contribute to the ambiguity in determining what level of government is responsible for providing financial support to First Nations people requiring long-term care and can limit the accessibility to certain levels of care for those who need it the most.

36 INAN, *Evidence*, 24 May 2018, 1535 (Brenda Shestowsky, Senior Director, Social Policy and Programs Branch, Education and Social Development Programs and Partnerships Sector, Department of Indian Affairs and Northern Development).

37 INAN, *Evidence*, 24 May 2018, 1540 (Brenda Shestowsky).

38 Ibid.

39 ISC uses a classification system from I to V. Type I care is residential care for persons requiring primarily supervision and assistance with daily living activities (30 minutes to 90 minutes a day). Type II care is extended care for persons requiring availability of personal care under medical and nursing supervision (1.5 hours to 2.5 hours per day). Type III care is chronic care for persons who require a range of therapeutic services, medical management and skilled nursing care (minimum of 2.5 hours per day). Type IV care is rehabilitative care to restore or improve functional ability. Type V care is for patients who are seriously ill and present a need for investigation, diagnosis or treatment (Indigenous Services Canada, *National Assisted Living Program Guidelines 2018-2019*).

2. ACCESS TO CONTINUING CARE ON RESERVES

A. Home and Community Care

> *Improving access to services such as home and community care, assisted living, and supportive housing availability can often delay or alleviate the need for long-term care.*
>
> Chief R. Donald Maracle

Overall, witnesses agreed that First Nation members should not be removed from their community in order to access long-term facility-based care. Various witnesses stressed the importance of having resources in place so that First Nation members can stay in their homes as long as possible, near their families and within their community.[40] Home and community health care delivery is key to ensuring the health and safety of patients while allowing them to remain in their home and in their community. This type of care refers to the personal care or support care delivered to people with chronic and acute illnesses in their home or community.[41]

Witnesses identified significant gaps in the delivery of home and community care through the Home Care Program. The following sections outline the key concerns that were raised regarding the Home Care Program, the lack of support for caregivers, as well as the housing shortage and lack of equipment, which all limit access to home care.

1. Gaps in the First Nations and Inuit Home and Community Care Program

> *You need enhanced home care programs. You have no palliative care. There's no respite care, and there are no additional hours for the home care … There's no getting around the enhancements. That's only to make it comparable to what the province has.*
>
> Bonita Beatty

The Committee learned that the Home Care Program was a source of concern. Witnesses identified a number of gaps in the Home Care Program that limits access to

40 INAN, *Evidence*, 31 May 2018, 1555 (Chief R. Donald Maracle); and INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty).

41 Government of Canada, *Home and Community Care*.

home and community care for First Nation members. Specifically, the program does not fund home care services in the evenings or on weekends – critical times for seniors requiring care.[42] Although some First Nations have health clinics, many communities do not have the financial and human resources to meet health care needs outside of office hours.[43] Some witnesses said that home and community care must be available outside of the hours of 9 a.m. to 5 p.m., Monday to Friday.[44]

The Committee also heard that the Home Care Program does not provide funding for important care services, such as speech therapy or audiology, physiotherapy, occupational therapy and palliative care on reserve. Yet, certain conditions such as hearing loss are common among seniors requiring continuing care.[45] These gaps in specialized services may be problematic for First Nations that do not have access to the funding or resources required to deliver these services. Committee members learned that patients must often travel outside their community several times a week to obtain specialized services such as dialysis, occupational therapy, physiotherapy and speech therapy, even though transportation services may not always be available.[46]

Access to this type of care is also complicated by the remoteness and isolation of some First Nation communities, where the nearest hospital may be hundreds of kilometres away and where transportation services are limited or nonexistent.[47] In addition, caring for seniors and patients with chronic illnesses in remote areas places a heavy burden on nurses: they have to travel long distances to provide care to First Nation members, which limits the time that can be spent providing home care.[48] The Committee recognizes that these challenges can significantly affect the safety and well-being of clients, and are

42 INAN, *Evidence*, 24 May 2018, 1535 (Robin Buckland); INAN, *Evidence*, 31 May 2018, 1620 (Chief R. Donald Maracle); INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty); and INAN, *Evidence*, 7 June 2018, 1640 (John Cutfeet, Board Chair, Sioux Lookout First Nations Health Authority).

43 INAN, *Evidence*, 7 June 2018, 1530 (Della Mansoff, Director, Dakota Oyate Lodge).

44 INAN, *Evidence*, 14 June 2018, 1625 (Holly Best, Home Care Coordinator, Kee Tas Kee Now Tribal Council, Loon River First Nation); and INAN, *Evidence*, 26 September 2018, 1530 (Robin Decontie).

45 In its brief to the Committee dated 25 September 2018, Speech-Language & Audiology Canada pointed out that "the prevalence of hearing loss in the institutionalized elderly [is] estimated to be 80-97%…. Hearing loss is also a significant risk factor for dementia … and was identified as one of the most promising modifiable risk factors for dementia."

46 INAN, *Evidence*, 7 June 2018, 1535 (Della Mansoff); and 1550 (Florence Willier, Councillor, Driftpile Cree Nation).

47 INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty); INAN, *Evidence*, 1 October 2018, 1530 (Grand Chief Constant Awashish); and Brief submitted by Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788, 5 June 2018.

48 INAN, *Evidence*, 14 June 2018, 1545 (Tania Dick, President, Association of Registered Nurses of British Columbia).

likely contributing to burnout and difficulties in retaining health care professionals in remote First Nations.

Witnesses emphasized the need to improve home care programs and those offered through community health centres. Véronique Larouche of Pekuakamiulnuatsh Takuhikan recommended that existing home care programs be improved and that "funding should be added to promote access to specialized services for elders." She also told the Committee that "The objective is to focus on prevention and to keep people at home."[49] Robin Decontie of Kitigan Zibi Health and Social Services explained that community health centres would like to increase service delivery and include more specialized care services.[50]

The Committee believes that the effectiveness of home and community care depends heavily on the specialized services available and accessible to First Nation members. Th Committee finds that special efforts should be made to guarantee access to these services as part of the Home Care Program while recognizing that specialized care needs vary from region to region.

First Nation communities currently do not receive funding through federal programs to provide palliative care.[51] The Conseil de la Nation Atikamekw stressed the need to provide palliative care training, as "little training and support is offered in the communities in this regard."[52] In addition, Grand Chief Constant Awashish of the Atikamekw Nation explained that drugs for palliative care are not always available in First Nation communities: "It always takes some time for the doctor to agree with the pharmacy to have it ship the drugs to the community. This creates tremendous stress for our members and families."[53]

As should be the case for all Canadians, the Committee acknowledges that a dying person should be surrounded by their loved ones in their own community.[54] According

49 INAN, *Evidence*, 1 October 2018, 1545 (Véronique Larouche, Director, Health and Community Wellness, Pekuakamiulnuatsh Takuhikan).

50 INAN, *Evidence*, 26 September 2018, 1615 (Robin Decontie).

51 INAN, *Evidence*, 7 June 2018, 1535 (Della Mansoff). Palliative care services on reserve are sometimes funded by the provinces, as is the case with the Ontario Ministry of Health and Long-Term Care, which has been funding long-term care services on reserve since 1997, including palliative care: INAN, *Evidence*, 26 September 2018, 1630 (Ogimaa Duke Peltier).

52 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

53 INAN, *Evidence*, 1 October 2018, 1530 (Grand Chief Constant Awashish).

54 INAN, *Evidence*, 26 September 2018, 1545 (Stephen Parsons, General Manager, Eskasoni Corporate Division).

to Grand Chief Constant Awashish of the Atikamekw Nation, since there is an on reserve housing shortage, the solution would be to build palliative care homes within communities.[55] Working toward this solution, however, could require discussions with provincial/territorial governments and First Nations to ensure that these homes be certified by respective health authorities to provide the appropriate levels of care.

Pallium Canada, a national organization that seeks to improve palliative care in Canada, illustrated the numerous advantages of palliative care, for both patients and members of their family. According to this organization, integrating palliative care services into long-term care has the effect of, among other things, improving the patient's quality of life, reducing symptoms of disease, and reducing the number of hospital visits and associated healthcare costs. In the context of its training program on palliative care (LEAP — Learning Essential Approaches to Palliative Care), Pallium Canada worked with managers, Elders and Indigenous healthcare professionals to develop modules on cultural sensitization for healthcare professionals providing palliative care in First Nation communities. Pallium Canada also held basic courses "specifically designated as being 'for, by and with' First Nations groups."[56]

When it appeared before the Committee, ISC recognized the importance of having palliative care programs on reserve and indicated that budgetary funds would be used for palliative care under the Home Care Program according to "a different breakdown, over the next five years, in terms of those monies."[57] The Committee is of the opinion that, in order to ensure adequate palliative care is provided through the Home Care Program, additional funding should be allocated. The Committee also believes that the federal government should support palliative care training initiatives that are culturally relevant and that integrate Indigenous perspectives. To that end, the Committee recommends:

Recommendation 1

That Indigenous Services Canada provide increased funding to the First Nations and Inuit Home and Community Care Program to include palliative care as a service eligible for funding under the program.

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55 INAN, *Evidence*, 1 October 2018, 1615 (Grand Chief Constant Awashish).

56 Brief submitted by The Pallium Foundation of Canada, 7 November 2018.

57 The ISC representative told the Committee that a portion ($19.5 million) of the five-year $184.6-million investment announced in Budget 2017 would be earmarked for palliative care (INAN, *Evidence*, 24 May 2018, 1555; 1615 (Robin Buckland)).

2. Caregivers and Respite Services

> *The second story is about a lady by the name of Maggie Redwood. She passed away about a year ago. She was 101. Her family refused to put her in a home. She was at the stage where her family did everything for her. They changed her and bathed her. They pretty much fed her. The family got very fatigued in the last two years of her life, only because they had to sacrifice their own jobs and their own personal time. They refused to allow her to live in a home off the reserve. It took a toll on the family to honour their grandmother, great-grandmother, great-great-grandmother, but they allowed her to live out her days in a standard house on Cowessess, giving that stage 3 support from within their means.*
>
> Chef Cadmus Delorme

Witnesses told the Committee that home care is often provided by family members when the basic care offered by the community no longer meets seniors' needs.[58] Chief Rupert Meneen of the Tallcree First Nation explained that it is becoming increasingly difficult for the younger generation of First Nation members to look after their elders due to socio-economic factors:

> It used to be that the younger generation would care for our elders, but now with the social crisis around addictions, opioids, housing shortages, and unemployment it has created an environment where the younger family members can't care for our elders.[59]

In addition, caregivers do not have the resources and support necessary to provide care in the long term.[60] While in-home respite care is listed as a basic service in the Home Care Program,[61] according to John Cutfeet, Chair of the Board of the Sioux Lookout First Nations Health Authority, respite care "does not exist in any of the communities to provide relief to family caregivers." Furthermore, caregivers do not receive formal training to help them provide care.[62] Beverly Ward of the Loon River First Nation told the

58 INAN, *Evidence*, 7 June 2018, 1635 (John Cutfeet); 1650 (Chief Cadmus Delorme, Cowessess First Nation); and INAN, *Evidence*, 14 June 2018, 1545 (Tania Dick).

59 INAN, *Evidence*, 5 June 2018, 1640 (Chief Rupert Meneen, Tallcree First Nation).

60 INAN, *Evidence*, 7 June 2018, 1635; 1720 (John Cutfeet); and INAN, *Evidence*, 14 June 2018, 1545 (Tania Dick).

61 Health Canada, *Audit of the First Nations and Inuit Home and Community Care Program*, October 2014.

62 INAN, *Evidence*, 7 June 2018, 1635 (John Cutfeet).

Committee that the Assisted Living Program does not provide financial support to families that look after their own:

> It's kind of not fair, because the family members can't work. Some of them have to resign from their jobs to look after their elders. It's really not fair with that barrier being there to prevent us from compensating the families. Yes, it is their family, but at the same time, they possibly have to go onto social assistance. Some of them really don't want to go that route, but sometimes they have no choice because the assisted living program is so limited in funding. Also, the eligibility criteria to get help there is limited.[63]

In addition to putting caregivers at a significant financial disadvantage, the lack of support can have serious effects on their health and well-being. Caregivers may have to quit their job and sacrifice their own well-being to provide care. Taking care of a family member without the necessary resources or support can often lead to burnout and health problems.[64]

Keith Leclaire of the Mohawk Council of Akwesasne stressed that, in order to meet these care needs, respite services are essential, not only for the well-being of the person requiring care, but also for family members who often assume the role of caregivers.[65] In his view, it is important to look into the possibility of establishing respite services within First Nation communities, so as to avoid sending patients to an outside facility that could be hundreds of kilometres away. As mentioned by Tania Dick of the Association of Registered Nurses of British Columbia, "That's really difficult on the patient and the families."[66]

> **"It used to be that the younger generation would care for our elders, but now with the social crisis around addictions, opioids, housing shortages, and unemployment it has created an environment where the younger family members can't care for our elders."**

The Committee agrees that caregivers should not have to sacrifice their own well-being to look after their loved ones, and that they should have access to basic training to help

63 INAN, *Evidence*, 14 June 2018, 1620 (Beverly Ward).

64 INAN, *Evidence*, 7 June 2018, 1650 (Chief Cadmus Delorme); 1720 (John Cutfeet); and INAN, *Evidence*, 14 June 2018, 1545 (Tania Dick).

65 INAN, *Evidence*, 31 May 2018, 1705 (Keith Leclaire, Director of Health, Mohawk Council of Akwesasne).

66 INAN, *Evidence*, 14 June 2018, 1545 (Tania Dick).

them provide care. The Committee also believes that support measures, such as respite services within First Nation communities, should be made available to caregivers and accessible through the Home Care Program. These resources would clearly be beneficial to both caregivers and their patients. Therefore, the Committee recommends:

Recommendation 2

That Indigenous Services Canada evaluate the current needs regarding in-home respite care under the First Nations and Inuit Home and Community Care Program and report publicly on it; and that Indigenous Services Canada review the funding allocated for the First Nations and Inuit Home and Community Care Program to ensure that in-home respite care on reserve is accessible and adequate.

3. Housing, Equipment and Home Adaptations

Many First Nation communities are facing housing shortages. Existing housing is often overcrowded and substandard.[67] According to witnesses, there is "a chronic number of people [who] can't find affordable housing," and residential facilities for seniors are in high demand.[68] Chief Meneen said that many seniors live in overcrowded houses in the North.[69]

The chronic housing shortage and overcrowded, substandard housing can make it difficult or even impossible to deliver home care. The state of existing housing is not conducive to making the necessary adaptations. The Committee learned that, despite Canada Mortgage and Housing Corporation programs that provide financial assistance for home modifications,[70] many First Nation seniors do not have the means to pay for the maintenance and adaptation work required, such as installing lifting equipment and

67 The Regional Health Survey (2018) indicates that 24.1% of First Nation adults live in crowded households, an increase over 2008–2010 (23%). First Nation adults living in remote communities were more likely (37%) to live in homes in need of major repairs than those living in rural communities (27%) or urban communities (21%). Just under 40% of First Nation adults reported mould or mildew in their homes in the preceding 12 months (First Nations Information Governance Centre, *National Report of the First Nations Regional Health Survey Phase 3: Volume One*, 2018).

68 INAN, *Evidence*, 31 May 2018, 1620; 1625; 1630 (Chief R. Donald Maracle); and 1645 (Grand Chief Abram Benedict, Mohawk Government, Mohawk Council of Akwesasne).

69 INAN, *Evidence*, 5 June 2018, 1655 (Chief Rupert Meneen).

70 The Canada Mortgage and Housing Corporation offers financial assistance for home modifications through its Residential Rehabilitation Assistance Program for Persons with Disabilities (RRAP-D) On reserve and the Home Adaptations for Seniors' Independence Program (HASI) On reserve.

wheelchair ramps.[71] Allan Louis from the Okanagan Indian Band explained that "many homes are in need of repairs" and that proper home maintenance is necessary for the safety of clients and employees providing home care.[72] While the Assisted Living Program provides in-home services, it does not provide funding for home renovations or adaptations.[73] The Committee believes that adapted, affordable and safe housing is essential for the safety and well-being of First Nation members requiring home care and of the First Nation population overall. The Committee therefore supports initiatives that will address the current housing crisis in Indigenous communities.

In addition to the lack of safe and affordable housing, witnesses identified needs for specialized equipment in First Nation communities. Without this equipment, certain types of care cannot be provided. For example, the Conseil de la Nation Atikamekw pointed out that the "lack of adaptive equipment such as adjustable beds, housing and places for comfort and worship are important concerns that limit palliative care available in communities."[74] Ms. Larouche explained that this equipment is necessary, but difficult to access and very expensive.[75]

B. Long-Term Care Facilities On Reserves

In addition to outlining housing and infrastructure needs in First Nation communities, witnesses identified a need for long-term care facilities on reserve so that First Nation members can stay in a familiar environment near their families.[76]

71 INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty); and Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

72 INAN, *Evidence*, 3 October 2018, 1645 (Allan Louis, Band Councillor, Health, Okanagan Indian Band).

73 INAN, *Evidence*, 24 May 2018, 1550 (Brenda Shestowsky).

74 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

75 INAN, *Evidence*, 1 October 2018, 1540 (Véronique Larouche).

76 INAN, *Evidence*, 31 May 2018, 1650 (Grand Chief Abram Benedict); INAN, *Evidence*, 5 June 2018, 1550 (Bonita Beatty); 1635 (Jeff Anderson, Chairman, Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788); INAN, *Evidence*, 7 June 2018, 1550 (Florence Willier); 1640 (John Cutfeet); 1650 (Chief Cadmus Delorme); INAN, *Evidence*, 14 June 2018, 1530 (Beverly Ward); 1540 (Kirsten Sware, Director of Health, Kee Tas Kee Now Tribal Council, Loon River First Nation); 1610 (Tania Dick); INAN, *Evidence*, 1 October 2018, 1620 (Gwen Traverse); and 1630 (Keith Grier, Chair, Health, Aakom Kiyii Health Services).

1. Need for Long-Term Care Facilities

> *I can't figure it out, but the reality is that a senior in long-term care has no problem being buried at home or finding a final resting place, but when it comes time for those last five years of their life, they are not allowed to be on the reserve because we don't have the services. There's something not correct in that area, and I know that when we put all our minds together, we can figure it out.*[77]
>
> Chief Cadmus Delorme

While there are currently over 630 First Nation communities in Canada, very few First Nation communities have their own long-term care facilities. According to information provided by ISC, only 53 long-term care facilities are managed by First Nations across the country.[78] Dr. Beatty pointed out that even provinces with high proportions of First Nation residents do not have very many First Nation long-term care facilities: 10.7% of the population of Saskatchewan are First Nation members (according to the 2016 Census), but the entire province has only two facilities run by First Nations.[79]

In many cases, the existing facilities cannot meet the growing demand.[80] The Committee learned that, in Ontario, "over 3,200 people who are eligible for long-term care [including both First Nation and non-Indigenous populations] can't find a bed to go to." Wait times can be up to two years, and very few First Nation seniors can afford to stay in private or semi-private accommodations.[81] In Ontario in South East Local Health Integration Network, the bed occupancy rate is so high that "people have to wait until someone dies to free up a bed."[82]

77 INAN, *Evidence*, 7 June 2018, 1655 (Chief Cadmus Delorme).

78 Information provided by Indigenous Services Canada, 18 August 2018.

79 INAN, *Evidence*, 5 June 2018, 1555 (Bonita Beatty).

80 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

81 INAN, *Evidence*, 31 May 2018, 1610 (Chief R. Donald Maracle); and 1605 (Bernard Bouchard).

82 INAN, *Evidence*, 31 May 2018, 1610 (Chief R. Donald Maracle).

Various witnesses stressed the importance of building long-term care facilities on reserve.[83] As Ms. Ward pointed out, having long-term care facilities within First Nation communities and in their geographical area "is absolutely critical to the health and well-being of our community members."[84] First Nation members are sometimes forced to stay in their homes longer than they should. In many cases, "Seniors and Elders aren't [choosing to stay] in their homes longer. They're being forced to stay in their homes longer because there's nowhere else to go."[85]

First Nation members who can no longer remain at home are often required to leave their communities to be placed in a facility that could be hundreds or even thousands of kilometres from their home, and are often off reserve.[86] In these cases, First Nation members are not only leaving their homes; they are also leaving their families, their way of life and their language and cultural roots. Various witnesses indicated that these distances inevitably lead to fewer family visits.[87] April Coulson of the Okanagan Indian Band said that "[t]he impact of removal from one's community can be very traumatizing and symbolic of removals endured in childhood."[88] Some First Nation seniors pretend that everything is fine because they do not want to be forced to leave their family and their culture, but according to Chief Cadmus Delorme of the Cowessess First Nation, they often end up injuring themselves when they stay in their home without adequate care.[89]

Some witnesses spoke about the devastating results of this separation, both for the patient admitted to a long-term care facility and for the members of their family and community. The Committee heard that these patients often suffer from social and

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83 INAN, *Evidence*, 31 May 2018, 1650 (Grand Chief Abram Benedict); INAN, *Evidence*, 5 June 2018, 1550 (Bonita Beatty); 1635 (Jeff Anderson); INAN, *Evidence*, 7 June 2018, 1550 (Florence Willier); 1640 (John Cutfeet); 1650 (Chief Cadmus Delorme); INAN, *Evidence*, 14 June 2018, 1530 (Beverly Ward); 1540 (Kirsten Sware); 1610 (Tania Dick); INAN, *Evidence*, 26 September 2018, 1545 (Stephen Parsons); 1615 (Robin Decontie); and 1655 (Chief Peter Collins).

84 INAN, *Evidence*, 14 June 2018, 1530 (Beverly Ward).

85 INAN, *Evidence*, 5 June 2018, 1700 (Natalie Gibson).

86 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle); INAN, *Evidence*, 5 June 2018, 1710 (Jeff Anderson); INAN, *Evidence*, 7 June 2018, 1635 (John Cutfeet); INAN, *Evidence*, 14 June 2018, 1615 (Holly Best); 1535 (Beverly Ward); and Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

87 INAN, *Evidence*, 31 May 2018, 1610 (Bernard Bouchard); INAN, *Evidence*, 5 June 2018, 1710 (Jeff Anderson); and INAN, *Evidence*, 14 June 2018, 1535 (Beverly Ward).

88 INAN, *Evidence*, 3 October 2018, 1650 (April Coulson, Nurse, Home and Community Care, Okanagan Indian Band).

89 INAN, *Evidence*, 7 June 2018, 1650 (Chief Cadmus Delorme).

cultural isolation because they are no longer in close contact with their family.[90] They desperately want to go back to their communities "because of cultural differences and language differences."[91]

Some witnesses explained that First Nation Elders play a key role their community: "They are the knowledge keepers. They are the language keepers."[92] Elders leaving can represent a significant loss for the community, as community members can no longer benefit from the support, advice and knowledge the Elders pass down.[93]

The Committee also heard about the cost involved to make up for the lack of long-term care facilities on or near reserves. Ms. Dick explained that health care professionals on reserves are overworked and spend their time managing chronic illnesses that could be treated in long-term care facilities. She also said that acute care beds are being occupied by people who could be treated in an assisted-living facility, which "is costing unbelievable amounts of money."[94]

2. Funding for Building and Maintaining Facilities

According to some witnesses, the federal government has a duty to fund the construction, operating and maintenance costs of long-term care facilities in First Nation communities, both through capital investments and ongoing funding.[95] At this time, ISC has no programs that provide grants for building and maintaining these facilities. Although the Assisted Living Program "is available to those individuals who cannot pay for institutional care or in-home care supports themselves", it does not provide funding for building or maintaining long-term care facilities.[96] For construction, First Nation communities must rely on independent revenue sources, contributions from the provinces and territories or private-sector partners, or other sources of revenue. Once the facilities have been built, the communities often have to turn to the provinces and

90 Brief submitted by the First Nations Health Authority, June 2018.

91 INAN, *Evidence*, 26 September 2018, 1545 (Stephen Parsons).

92 INAN, *Evidence*, 24 May 2018, 1530 (Keith Conn); INAN, *Evidence*, 31 May 2018, 1655 (Grand Chief Abram Benedict); INAN, *Evidence*, 14 June 2018, 1620 (Beverly Ward); and Brief submitted by the First Nations Health Authority, June 2018.

93 Ibid.

94 INAN, *Evidence*, 14 June 2018, 1610 (Tania Dick).

95 INAN, *Evidence*, 31 May 2018, 1610 (Chief R. Donald Maracle); 1640 (Keith Leclaire); INAN, *Evidence*, 26 September 2018, 1615 (Robin Decontie); and 1700 (Chief Peter Collins).

96 INAN, *Evidence*, 24 May 2018, 1615 (Keith Conn); 1620 (Brenda Shestowsky); and INAN, *Evidence*, 5 June 2018, 1610 (Bonita Beatty).

territories for funding to manage and maintain them.[97] For example, Ms. Larouche explained that the Tshishmishk Centre, built more than 20 years ago, "is in great need of renovation and expansion due to insufficient space. Some seniors even have to eat their meals in the hallway."[98] Ms. Larouche added that renovations are also needed to "comply with building safety standards to ensure the safety and well-being of seniors," and that funding would be needed for renovations.[99]

According to Chief Maracle, obtaining capital funding to build long-term care facilities is a complicated process.[100] Chief Maracle explained to the Committee that capital funding that the Ontario Ministry of Health and Long-Term Care committed to provide will fall short of what is needed to cover the cost of building and operating a long-term care facility in his community. He said that capital funding from the federal government is needed to proceed with the project, adding that the federal and provincial governments need to partner with First Nation communities to coordinate their efforts to facilitate the capital planning process.[101]

The Committee heard that, through discussions on a new fiscal relationship with First Nations, the federal government is developing a 10-year grant that would "provide a certain level of flexibility" for First Nations to plan partnerships in building long-term care facilities on reserves, based on priorities identified by First Nations. According to an ISC representative, the grant arrangement would "have at least 100 recipients". The Committee heard that First Nations would be receptive to this type of funding arrangement.[102] According to Grand Chief Abram Benedict, "Those sorts of initiatives will give the community a better ability to plan long-term and to be able to prioritize longer-term."[103] Committee believes that this approach would be beneficial to First Nations in securing funding for long-term care facilities on reserves. The Committee is also of the view that this type of arrangement should allow funding to flow directly to the communities to provide flexibility in planning and managing their own facilities.

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97 INAN, *Evidence*, 24 May 2018, 1615 (Keith Conn).

98 INAN, *Evidence*, 1 October 2018, 1540 (Véronique Larouche).

99 Ibid.

100 INAN, *Evidence*, 31 May 2018, 1555 (Chief R. Donald Maracle).

101 INAN, *Evidence*, 31 May 2018, 1610; 1630 (Chief R. Donald Maracle).

102 INAN, *Evidence*, 5 June 2018, 1645 (Bill Boese); 1720 (Natalie Gibson); and INAN, *Evidence*, 1 October 2018, 1605 (Grand Chief Awashish).

103 INAN, *Evidence*, 31 May 2018, 1700 (Grand Chief Abram Benedict).

3. Potential Model and Partnership

Providing long-term care on reserves often means forging partnerships.[104] Some witnesses reported that it can be challenging for individual First Nation communities to find the funding needed to build and operate long-term care facilities, especially for small communities that do not have sufficient capital.[105] To address these financial limitations, some witnesses stressed the importance of establishing innovative partnerships to fund continuing and long-term care and improvements to health services.[106]

For example, the Eskasoni First Nation and an operating partner are currently negotiating with the Government of Nova Scotia to establish a long-term care facility. Stephen Parsons, General Manager of the Eskasoni Corporate Division, explained the preferred model and the Eskasoni community's need for a partnership:

> We knew we couldn't do it ourselves. We don't have the expertise or the capacity. We married that up with a joint venture. We have a management contract for a term.… We made a pitch to our provincial government to be a partner, in a per diem per day of 48 beds: If these beds are not filled by all first nations people, we're willing to help out the present waiting list. Empty beds don't pay the per diems that you need to operate. We set this up so that this is not a burden on the band and it's not subsidized by the band annually. It has to run on its own operationally. That's why we went out and got a partner—to create those opportunities, provide the service, and create the jobs for young people that are desperately needed as well.[107]

Other witnesses told the Committee about the possibility of using a hub-based model that follows an "[I]ndigenous-centric" approach.[108] The idea is to have one long-term care facility serving a number of isolated communities of different sizes within the same geographical area. This model would ensure that patients remain in their home region, in culturally familiar surroundings where they could speak their language.[109] However, Ms. Dick raised concerns about this kind of model for geographically scattered

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104 INAN, *Evidence*, 31 May 2018, 1715 (Keith Leclaire); INAN, *Evidence*, 7 June 2018, 1725; 1650 (Chief Cadmus Delorme); and Brief submitted by Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788, 5 June 2018.

105 INAN, *Evidence*, 7 June 2018, 1710 (Lindsay Pratt, Administrator, Heart River Housing).

106 INAN, *Evidence*, 5 June 2018, 1645 (Natalie Gibson); and INAN, *Evidence*, 7 June 2018, 1650 (Chief Cadmus Delorme).

107 INAN, *Evidence*, 26 September 2018, 1545 (Stephen Parsons).

108 INAN, *Evidence*, 7 June 2018, 1725 (Chief Cadmus Delorme).

109 INAN, *Evidence*, 7 June 2018, 1720 (John Cutfeet); 1720 (Deputy Grand Chief Derek Fox); 1725 (Chief Cadmus Delorme).

communities: "It would be difficult to come to terms with where the best access point would be to build a long-term care facility."[110] Similarly, the Committee acknowledges that certain practical realities for some First Nation communities such as relative remoteness could add challenges to building long-term care facilities in certain areas.

> **"We knew we couldn't do it ourselves. We don't have the expertise or the capacity. … That's why we went out and got a partner—to create those opportunities, provide the service, and create the jobs for young people that are desperately needed as well."**

The Committee believes it is time for the federal government to address the shortage of long-term care facilities in First Nation communities and to develop initiatives to deal with the problem. The Committee nonetheless recognizes that these initiatives must be creative. First Nation communities understand the financial obstacles and are in the best position to put forward ideas for funding mechanisms and partnerships. For example, the federal government could consider implementing a pilot project that "would allow some private investment, and some security from that private investment, to allow for these partnerships to exist internally."[111] The Committee therefore recommends:

Recommendation 3

That Indigenous Services Canada:

- **establish a funding formula that provides stable, predictable and long-term funding to projects to build or maintain long-term care facilities on reserves and that the new formula take into account factors such as First Nation population growth, inflation and the remoteness of communities;**

- **facilitate and support partnership initiatives to build long-term care facilities; and**

110 INAN, *Evidence*, 14 June 2018, 1610 (Tania Dick).

111 INAN, *Evidence*, 26 September 2018, 1725 (Ogimaa Duke Peltier).

- **work with First Nations and the provinces and territories, in accordance with the priorities that First Nations set for long-term care on reserves, to develop and implement pilot projects in various regions of Canada to build and maintain long-term care facilities on reserves.**

3. CULTURALLY APPROPRIATE PRACTICES AND CAPACITY-BUILDING

A. Impact of Historical and Intergenerational Trauma on the Perception of Continuing Care

> *I'm the first generation out of residential school. That intergenerational trauma exists. The general feeling overall that I have experienced in my practice is that individuals don't have trust. They have a lot of fear, and they absolutely have a difficult time accessing services or entering these facilities or institutions. It triggers them, I'm sure.*
>
> Tania Dick

According to Ms. Mansoff, First Nations "struggle with the ghosts of the past" and "have difficulty with care from non-[I]ndigenous people."[112] The trauma caused by colonialism and the effects of residential schools are some of the factors that engender fear and suspicion of non-Indigenous health professionals and institutions.[113]

Some witnesses compared the current approach to long-term care to that of residential schools and the current child welfare system, where children were and still are removed from their communities. For First Nation elders who were previously forced to leave their communities to attend residential schools, being moved to a long-term care facility "can be a re-traumatizing experience."[114] Mr. Grier stated that, as a result, "Many [F]irst [N]ation elders delay seeing health care practitioners and professionals regarding their symptoms until they are seriously ill, as they are afraid their diagnosis would mean that they would be sent away and never returned home."[115] Intergenerational trauma necessitates the implementation of continuing care services that are culturally appropriate and sensitive to the discrimination experienced by First Nation patients.

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112 INAN, *Evidence*, 7 June 2018, 1535 (Della Mansoff).

113 INAN, *Evidence*, 7 June 2018, 1535 (Della Mansoff); INAN, *Evidence*, 7 June 2018, 1615 (Chief Edmund Bellegarde); INAN, *Evidence*, 14 June 2018, 1545; 1550 (Tania Dick); and INAN, *Evidence*, 26 September 2018, 1540 (Sharon Rudderham).

114 INAN, *Evidence*, 24 May 2018, 1530 (Keith Conn); INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle); INAN, *Evidence*, 5 June 2018, 1555 (Bonita Beatty); 1615 (Tammy Cumming, Schlegel-UW Research Institute for Aging); and INAN, *Evidence*, 7 June 2018, 1615 (Chief Edmund Bellegarde); INAN, *Evidence*, 3 October 2018, 1650 (April Coulson).

115 INAN, *Evidence*, 3 October 2018, 1635 (Keith Grier).

B. Culturally Appropriate Programs and Practices

> *[T]he vast majority of [F]irst [N]ations residents do not have access to services in their own language, access to the land, traditional cultural activities, or traditional food.*[116]
>
> Chief R. Donald Maracle

The Committee learned that the perception of long-term care needs to be improved by switching from the institutional model to a social, community-based model.[117] For example, Keith Leclaire explained that, in the Akwesasne community, the name of the long-term care facility is "Tsiionkwanonhso:te," which means "our house" in the Mohawk language, and that it is "not an institution; it's an extended part of our community."[118]

However, some witnesses said that continuing care on reserve is not currently culturally appropriate for their needs. For example, long-term care services are generally not provided in the language of First Nation patients. Dr. Beatty noted that language is "an important part" of the equation.[119] Language barriers can increase the risk that inadequate care will be provided. The Conseil de la Nation Atikamekw emphasized that "language and culture may pose significant issues in service delivery, including mistrust, loss of confidence, misunderstanding, and poorly targeted needs."[120]

A lack of culturally appropriate care can affect the mental health of residents. As the First Nations Health Authority explained:

> [residents] will no longer be able to go out on the land or water and take part in traditional activities or have frequent access to traditional food and medicine. This can significantly impact the mental health and well-being of the elders, and open the door not only to emotional effects such as depression or anxiety, but also to possible physical effects such as a worsening physical trajectory of their conditions, or potentially elder abuse.[121]

116 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle).

117 INAN, *Evidence*, 5 June 2018, 1615 (Tammy Cumming).

118 INAN, *Evidence*, 31 May 2018, 1640 (Keith Leclaire).

119 INAN, *Evidence*, 5 June 2018, 1620 (Bonita Beatty).

120 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

121 Brief submitted by the First Nations Health Authority, June 2018.

According to Tammy Cumming of the Schlegel-UW [University of Waterloo] Research Institute for Aging, "when we're restoring culture and we're embracing culture, it can contribute to healing, and it may even have a protective factor for worsening health when in long-term care."[122] Grand Chief Abram Benedict described the benefits of the integrated health system in the Akwesasne community, which incorporates both the culture and values of the community and Western science "through exclusive use of our traditional language, traditional medicine, and traditional ceremonies."[123] Some witnesses also stated that additional community and cultural activities should be offered to members of First Nations in care.[124] According to Teresa Doxtdator David of the Tsiionkwanonhso:te Long Term Care Facility, long-term care facilities should encourage community celebrations, such as sharing a meal, as a way of bringing families and residents together:

> Instead of young people being afraid of the frail elders, especially when the elder no longer lives in his or her own home, generations are encouraged to share stories and eat a meal together, a universal expression of love. The communal celebrations could be hosted by the indigenous residents in the long-term care residence to accommodate those family members and community.[125]

The Committee was also told how important it is to the well-being of First Nation patients receiving continuing care to have access to traditional food. Ms. Dick said that traditional food is "medicine for our people."[126] Ms. Larouche pointed out that Canada's Food Guide recognizes that traditional foods can improve the health of Indigenous people and was adapted to recommend eating game meat.[127]

However, the Committee learned that some barriers prevent First Nation members who receive continuing care at home or in care facilities from having access to traditional foods. For example, provincial and federal food safety standards can prohibit game meat or wild fruit from being served. These foods are central to the traditional diet of First Nation peoples.[128] Ms. Larouche said that "elders are being prevented from maintaining

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122 INAN, *Evidence*, 5 June 2018, 1535 (Tammy Cumming).

123 INAN, *Evidence*, 31 May 2018, 1640 (Grand Chief Abram Benedict).

124 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle); INAN, *Evidence*, 1 October 2018, 1540 (Véronique Larouche); and INAN, *Evidence*, 3 October 2018, 1720 (Allan Louis).

125 INAN, *Evidence*, 5 June 2018, 1545 (Teresa Doxtdator David).

126 INAN, *Evidence*, 14 June 2018, 1555 (Tania Dick).

127 INAN, *Evidence*, 1 October 2018, 1545 (Véronique Larouche).

128 INAN, *Evidence*, 26 September 2018, 1620 (Robin Decontie); INAN, *Evidence*, 1 October 2018, 1530 (Grand Chief Constant Awashish); and 1545 (Véronique Larouche).

their eating habits, even though that food has always been part of their life."[129] Ogimaa Duke Peltier of the Wikwemikong Unceded Indian Reserve made the following comments on this issue:

> That is a challenge. We've had to eliminate those from our menus because the existing provincial regulations do not allow for our own foods to be served within the home. The existing regulations dictate that most of the diet that's required to be served in the home is processed food, which many of you wouldn't appreciate eating every day either. If we have a donation of fish that comes from the lake and is freshly caught, they still can't serve it.[130]

Dustin Wolfe, Director of Health at the Piikani Nation's Aakom Kiyii Health Services, explained that over time, the rules preventing patients from eating a traditional diet have contributed to health problems for First Nation individuals.[131] According to Mr. Grier, "We definitely need to look at getting back to a diet that's consistent with a holistic approach for [F]irst [N]ations people, versus what we eat today."[132]

The Committee acknowledges that replacing traditional foods with processed products can increase food insecurity among First Nation members who need continuing care. The Committee also believes that this kind of approach perpetuates the colonial practices of the past and continues to affect the health of First Nation people and their perception of long-term care facilities. The Committee believes that the federal government should recognize and apply First Nation cultural practices in the delivery of continuing care. The Committee therefore recommends:

Recommendation 4

That Indigenous Services Canada work with First Nations and the provinces and territories to take immediate measures to encourage the implementation of culturally appropriate programming and service delivery including traditional foods in long-term care facilities and as part of home care and community-based care on reserves.

In addition, the Committee was told that cultural training is a key way of ensuring cultural continuity and culturally appropriate care. Ms. Dick said that cultural training programs for health professionals should be developed and deployed.[133] The First

129 INAN, *Evidence*, 1 October 2018, 1545 (Véronique Larouche).

130 INAN, *Evidence*, 26 September 2018, 1630 (Ogimaa Duke Peltier).

131 INAN, *Evidence*, 3 October 2018, 1705 (Dustin Wolfe, Director, Health, Aakom Kiyii Health Services).

132 INAN, *Evidence*, 3 October 2018, 1705 (Keith Grier).

133 INAN, *Evidence*, 14 June 2018, 1615 (Tania Dick).

Nations Health Authority recommended that ISC adopt three principles, or approaches, for delivering culturally appropriate long-term care programs: cultural safety, cultural humility and trauma-informed care.[134]

The Committee heard about the need for the provision of care that is sensitive to traditional customs to improve the quality of life of First Nation members who need continuing care. On this issue, Speech-Language and Audiology Canada emphasized the importance of communication-related care, such as speech-language pathology and audiology services, to delivering high-quality continuing care and preserving the oral traditions of First Nations. Communication is not only essential for patient interactions with care providers; it is critical to the transmission of First Nation Elders' teachings to younger generations.[135] Chief Peter Collins of the Fort William First Nation maintained that language skills must be passed "from our elders into our young people, because we've lost a lot of our elders who used to speak [our] language."[136] The Committee believes that offering this type of program in accordance with First Nation values is an example of culturally appropriate care that should be encouraged throughout the continuum of care.

The Committee agrees that culturally appropriate programs and practices need to be implemented and that First Nation communities must have the support, resources and funding necessary to do so.[137] To that end, the Committee recommends:

Recommendation 5

That Indigenous Services Canada work with First Nations and provincial and territorial partners to develop and implement a mandatory training program for Indigenous and

134 The First Nations Health Authority defined these terms as follows: "**Cultural safety** is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. **Cultural humility** is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience. **Trauma-informed care** recognizes and acknowledges the impact of trauma and the need for awareness and sensitivity to its dynamics in all aspects of service delivery. It teaches practitioners and organizations to avoid and mitigate re-traumatization, understand the cycles of trauma and intergenerational trauma, and recognize trauma symptoms." Brief submitted by the First Nations Health Authority, June 2018.

135 Brief submitted by Speech-Language and Audiology Canada, 25 September 2018.

136 INAN, *Evidence*, 26 September 2018, 1720 (Chief Peter Collins).

137 INAN, *Evidence*, 5 June 2018, 1640 (Chief Rupert Meneen).

non-Indigenous health professionals providing continuing care on reserve about the values, culture and history of Indigenous peoples.

C. Traditional Healing Practices and First Nation Community Control Over Continuing Care

> *There is the spiritual context of health, the mental context of health, and the emotional context of health. The western side is the physical side of health.*[138]
>
> Chief Edmund Bellegarde

Approaches to continuing care must be adapted to First Nations cultures and healing practices.[139] The issue of continuing care on reserve revolves around empowering First Nations peoples in expanding upon holistic care models that meet health standards and incorporate traditional knowledge and healing practices into health care.[140] Chief Collins noted that the Truth and Reconciliation Commission of Canada, in its Calls to Action, recommended that Indigenous healing practices be recognized, valued and used "in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients."[141]

During this study, the Committee heard that the community-based approaches adopted by First Nation communities have had positive effects. However, as Grand Chief Awashish explained, "Caregivers and other community resources are neither recognized nor valued." The Conseil de la Nation Atikamekw emphasized how important it is for First Nations to have more independence and flexibility in delivering and managing continuing care programs on reserve: "Complete or partial takeover of programs and services by Indigenous communities must be encouraged and facilitated in order to better target needs and adjust service offerings."[142]

Promoting policies and strategic frameworks developed by First Nations, First Nations research and research methods, and innovation through traditional healing practices can

138 INAN, *Evidence*, 7 June 2018, 1540 (Chief Edmund Bellegarde).

139 INAN, *Evidence*, 5 June 2018, 1535 (Tammy Cumming); 1540 (Teresa Doxtdator David); and 1555 (Bonita Beatty).

140 INAN, *Evidence*, 7 June 2018, 1610 (Chief Edmund Bellegarde).

141 INAN, *Evidence*, 26 September 2018, 1645 (Chief Peter Collins); and Truth and Reconciliation Commission of Canada, *Calls to Action*.

142 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

help shape new, more effective health care models that are better tailored to First Nations realities.[143] Chief Bellegarde told the Committee that "the foundation [of Western medicine] is through indigenous knowledge and natural processes for healing and medicines."[144] He explained that Indigenous and non-Indigenous peoples are "starting to access the care of traditional healers through our spiritual practice combined with western medicine."[145]

Florence Willier of the Driftpile Cree Nation told the Committee that the Driftpile health centre "have utilized traditional healers along with western healing practices." She added that the physicians who have worked in her community "have been very open to learning from the traditional healers."[146] She also stressed the importance of including and passing on traditional healing methods in continuing care to preserve First Nations' practices and ways of life.[147]

The witnesses were clear: even before strategic plans for continuing and long-term care are developed, a national dialogue with Indigenous peoples must take place to identify gaps and needs, evaluate ways of integrating programs more effectively, and implement lessons learned without making processes unnecessarily complicated or duplicating efforts.[148] Chief Meneen told the Committee that, for too long, his community was excluded from discussions and planning for a long-term care facility in Mackenzie County, in northern Alberta.[149] As Ms. Dick remarked, "If we want full empowerment and ownership of our health, we need to be able to have that conversation with whoever is delivering those services to us."[150] She added that such an initiative should involve First Nation communities, provinces and territories, and First Nation health authorities.

The Committee believes that First Nations' health care knowledge and practices must be recognized and valued in Canada. The Committee also believes the federal government should focus on the many benefits of First Nations' healing practices in continuing care. In addition, the Committee supports making resources available to First Nations to foster

143 INAN, *Evidence*, 7 June 2018, 1600 (Chief Edmund Bellegarde).

144 INAN, *Evidence*, 7 June 2018, 1620 (Chief Edmund Bellegarde).

145 INAN, *Evidence*, 7 June 2018, 1600 (Chief Edmund Bellegarde).

146 INAN, *Evidence*, 7 June 2018, 1620 (Florence Willier).

147 Ibid.

148 INAN, *Evidence*, 14 June 2018, 1600 (Tania Dick).

149 INAN, *Evidence*, 5 June 2018, 1655 (Chief Rupert Meneen).

150 INAN, *Evidence*, 14 June 2018, 1600 (Tania Dick).

greater independence and flexibility in the delivery and management of continuing care on reserve; they understand the needs and priorities of their residents. The Committee therefore recommends:

Recommendation 6

That, in implementing Call to Action 22 of the Truth and Reconciliation Commission of Canada, Indigenous Services Canada work with First Nations, provinces and territories and health authorities to recognize, fund and provide access to First Nation traditional healing practices in the delivery of continuing care.

D. Capacity-Building: Training and Retention of Professionals

> *We're a community that believes in doing the work for our own people, by our own people. We believe in capacity-building.*[151]
>
> Robin Decontie

The Committee heard that increasing the autonomy and self-determination of First Nation communities is the first step toward eliminating socio-economic barriers.[152] Mr. Leclaire explained that, in continuing care, capacity-building is key.[153]

Strengthening the continuing-care capacities of First Nations requires a stable, skilled workforce. Witnesses explained to the Committee that nurses often have to work alone in remote regions, without the training needed to deal with all emergencies.[154] Moreover, the Committee learned that there is currently a shortage of licensed practical nurses and personal support workers in First Nation communities.[155] Vincent Lazore of the Tsiionkwanonhso:te Long Term Care Facility said that staffing levels in long-term care facilities are "sometimes one support worker to 20 patients."[156] According to Ms. Doxtdator David, a 1:10 ratio would be more manageable.[157]

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151 INAN, *Evidence*, 26 September 2018, 1530 (Robin Decontie).

152 INAN, *Evidence*, 1 October 2018, 1605 (Grand Chief Constant Awashish).

153 INAN, *Evidence*, 31 May 2018, 1655 (Keith Leclaire).

154 INAN, *Evidence*, 14 June 2018, 1620 (Tania Dick).

155 INAN, *Evidence*, 5 June 2018, 1615 (Vincent Lazore, Tsiionkwanonhso:te Long Term Care Facility; Teresa Doxtdator David); and 1645 (Natalie Gibson).

156 INAN, *Evidence*, 5 June 2018, 1625 (Vincent Lazore).

157 INAN, *Evidence*, 5 June 2018, 1625 (Teresa Doxtdator David).

The labour shortage is having a serious impact on patients in long-term care facilities. Teresa Doxtdator David reported that personal support workers "don't have the time to provide the interaction that's needed … so [the patient] feels lonely and unworthy."[158] Jeff Anderson of the Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788 said that the lack of staff can also be a factor in patient injuries in facilities, as overworked staff do not always have time to provide the care each resident needs.[159]

Natalie Gibson of the Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788 said it is essential to consider health care training capacity as part of long-term planning.[160] According to Grand Chief Joel Abram of the Association of Iroquois and Allied Indians, the staff training process needs to begin at the same time as the construction of a long-term care facility.[161] However, Chief Meneen noted that it is difficult to start training when it is still unclear whether a long-term care facility in his area will be built.[162]

In addition, some witnesses emphasized the need to train First Nation people to ensure that long-term care facilities provide culturally inclusive care.[163] On this point, Chief Meneen cited the need to recruit staff from the same geographical areas who can speak the local languages.[164] Chief Meneen explained that First Nation youth often leave to study and work elsewhere, as very few jobs are available in their communities. He believes that education programs need to be developed in partnership with the provinces to encourage First Nation students to return to their home regions.[165]

While First Nation communities are "working really hard on education" for their youth, the Committee heard that there is a lack of funding to train and recruit staff on reserve.[166] Grand Chief Awashish stated that occupational training should be available on reserve, as people who look after their families cannot leave the community for

158 INAN, *Evidence*, 5 June 2018, 1620 (Teresa Doxtdator David).

159 INAN, *Evidence*, 5 June 2018, 1710 (Jeff Anderson).

160 INAN, *Evidence*, 5 June 2018, 1655 (Natalie Gibson).

161 INAN, *Evidence*, 31 May 2018, 1615 (Grand Chief Joel Abram, Association of Iroquois and Allied Indians).

162 INAN, *Evidence*, 5 June 2018, 1725 (Chief Rupert Meneen).

163 INAN, *Evidence*, 5 June 2018, 1715 (Chief Rupert Meneen).

164 Ibid.

165 Ibid.

166 INAN, *Evidence*, 1 October 2018, 1620 (Julie Harvey, Director, Seniors' Health, Pekuakamiulnuatsh Takuhikan).

training.[167] She added that these training programs should be funded by the government:

> Maybe there could be more flexibility with education. Right now the government is financing university studies and it's financing college studies, but it's not financing anything other than those two—for instance, if you wanted [occupational training]. We are working on this, but we have to [send them outside of the community].[168]

Chief Maracle explained how important it is for First Nations to forge partnerships with post-secondary institutions that offer health care training programs.[169] He noted that, in Ontario, the Mohawks of the Bay of Quinte work with the First Nations Technical Institute, which partners with "colleges and universities to provide training programs so people get the appropriate job qualifications."[170] In addition, Bill Boese, Treasurer of the Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788, explained that the federal and provincial/territorial governments should "increase commitment for training and outcomes in rural and northern regions."[171]

Some witnesses also called for the development of training standards for nurses and personal support workers and the enhancement of existing occupational resources in order to provide appropriate care and retain staff.[172] Multiple witnesses pointed out that a lack of proper training and work experience has negative effects on nurses and personal support workers, resulting in constant turnover.[173] Moreover, care staff do not always have the option or opportunity to seek emotional or psychological support when they need it.[174]

There are a number of barriers to recruitment and retention. The geographic remoteness and isolation of many First Nation communities, the lack of housing for professionals who relocate, and low pay were identified as major barriers. The Committee heard that few health professionals want to move to isolated or

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167 INAN, *Evidence*, 1 October 2018, 1535 (Grand Chief Constant Awashish).

168 INAN, *Evidence*, 1 October 2018, 1555 (Grand Chief Constant Awashish).

169 INAN, *Evidence*, 31 May 2018, 1615 (Chief R. Donald Maracle).

170 Ibid.

171 INAN, *Evidence*, 5 June 2018, 1645 (Bill Boese).

172 INAN, *Evidence*, 5 June 2018, 1615 (Teresa Doxtdator David; and Vincent Lazore); and INAN, *Evidence*, 7 June 2018, 1700 (John Cutfeet).

173 INAN, *Evidence*, 5 June 2018, 1615 (Teresa Doxtdator David; and Vincent Lazore); INAN, *Evidence*, 14 June 2018, 1545; and 1550 (Tania Dick).

174 INAN, *Evidence*, 14 June 2018, 1555 (Holly Best; and Tania Dick).

semi-isolated First Nation communities.[175] As for the lack of housing, Grand Chief Awashish reported that, "when we ask a professional doctor or nurse to come and work in our community … [t]hey don't have a place, so they don't stay."[176] Witnesses also explained that recruitment difficulties are partially due to the wage gap: nurses hired by First Nations often earn 20% to 30% less than unionized nurses who work for provinces or health authorities.[177] Mr. Louis explained that First Nation communities even have trouble retaining their own members, "with outside agencies like Interior Health, First Nations Health Authority and the private sector stealing away our members because we can't play on a level playing field when it comes to wages."[178]

The Committee members are convinced that delivering adequate and culturally appropriate continuing care requires building the capacity of First Nations to train and recruit health professionals and related staff. The Committee therefore recommends:

Recommendation 7

That Indigenous Services Canada, in partnership with First Nations and other relevant federal departments, improve access to post-secondary health education and occupational training for First Nations learners to provide more opportunities for First Nations people to deliver health care on reserve.

175 INAN, *Evidence*, 14 June 2018, 1605 (Kirsten Sware).

176 INAN, *Evidence*, 1 October 2018, 1555 (Grand Chief Constant Awashish).

177 INAN, *Evidence*, 14 June 2018, 1545; 1620 (Tania Dick); INAN, *Evidence*, 3 October 2018, 1645 (Allan Louis); and 1720 (Keith Grier).

178 INAN, *Evidence*, 3 October 2018, 1645 (Allan Louis).

4. JURISDICTIONAL COMPLEXITY

> *We are often caught between a rock and a hard place. We are caught between the province and Canada, both of which are passing the buck.*[179]
>
> Grand Chief Constant Awashish

As noted above, responsibility for on reserve health matters is ambiguous. As noted by the Office of the Auditor General in its 2015 Spring Reports, "the lack of coordination among jurisdictions can lead to inefficient delivery of health care services to First Nations individuals and to poorer health outcomes for them."[180] The Committee learned that the complexity associated with the different fields of jurisdiction and levels of government creates confusion and causes harm to First Nations members and communities.[181] This considerably complicates access to the continuum of care on reserve, including continuing care.

The Committee heard that coordination of health care services across different levels of government constitutes one of the most significant barriers to access to continuing care on reserve. Chef Maracle explained that "jurisdictional ambiguity is one of the key challenges for [F]irst [N]ations,"[182] and Chief Awashish stated that there is complexity in the "relations between the [F]irst [N]ations communities, the provincial level and the federal level. We are always bouncing from one to the other."[183]

Some witnesses reported that health care services provided by the provinces "stop at the [F]irst [N]ation line" and First Nation residents can be denied provincial health care services. Provinces may decide to send First Nation individuals back to their communities, even when they may not have the resources to provide the services required.[184] Ogimaa Duke Peltier of the Wikwemikong Unceded Indian Reserve said that "the province is very slow in responding to on reserve servicing."[185] As a result, First Nation members can easily face gaps in health care services. Ms. Dick explained that,

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179 INAN, *Evidence*, 1 October 2018, 1535 (Grand Chief Constant Awashish).

180 2015 Spring Reports of the Auditor General of Canada, *Report 4—Access to Health Services for Remote First Nations Communities*.

181 INAN, *Evidence*, 7 June 2018, 1615 (Chief Edmund Bellegarde); and INAN, *Evidence*, 1 October 2018, 1600 (Grand Chief Constant Awashish, Conseil de la nation Atikamekw).

182 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle).

183 INAN, *Evidence*, 1 October 2018, 1600 (Grand Chief Constant Awashish).

184 INAN, *Evidence*, 26 September 2018, 1535 (Robin Decontie); and 1710 (Ogimaa Duke Peltier).

185 INAN, *Evidence*, 26 September 2018, 1700 (Ogimaa Duke Peltier).

because nurses hired by band councils cannot serve First Nation people who live off reserve, "that jurisdictional issue leaves opportunity for … unsafe environments for our elders" that can leave them without care.[186]

The Conseil de la Nation Atikamekw raised the following issue: "There is a considerable amount of red tape in government programs. This becomes tedious and monopolizes the already-limited resources of Indigenous organizations."[187] Chief Edmund Bellegarde of the File Hills Qu'Appelle Tribal Council said that federal policies are often incompatible with provincial ones, leaving it up to First Nations "to close those gaps in jurisdictions."[188]

In addition, some witnesses said that First Nations face a number of administrative barriers relating to the provincial licenses for delivering facilities-based care. For example, Robin Decontie explained that, although the Kiweda group home is funded by ISC's Assisted Living Program,[189] it is not accredited by the province (but by Accreditation Canada): "According to Bill 90 of the Quebec [H]ealth [A]ct, nurses are not allowed to practice services in intermediate resource homes that are not certified by the province."[190] This is the case in other provinces as well. Della Mansoff, Director of the Dakota Oyate Lodge, told the Committee that the lodge, located in the Sioux Valley community of Manitoba, is not authorized to care for people requiring level 4 care, "those who are in most need." She explained that while her community meets the provincial standards, it has been waiting several months for the province to sign a license that enables it to deliver level 4 care.[191]

Furthermore, the Committee learned that provincial autonomy assessment tools (used to assign an autonomy rating to individuals who need continuing care) are different from those used by ISC. While ISC uses a five-point scale, the Province of Quebec uses a scale from one to 15. Ms. Decontie said that these types of differences can create grey areas with respect to authority to deliver care: nurses sometimes provide care that go beyond the levels of care permitted by the province in some care homes on reserves. This kind

186 INAN, *Evidence*, 14 June 2018, 1540 (Tania Dick).

187 Brief submitted by the Conseil de la Nation Atikamekw, 1 October 2018.

188 INAN, *Evidence*, 7 June 2018, 1540 (Chief Edmund Bellegarde).

189 As mentioned above, ISC's Assisted Living Program can help cover the costs of living in a long-term care facility or personal care home on or off reserve (INAN, *Evidence*, 24 May 2018, 1540 (Brenda Shestowsky)).

190 INAN, *Evidence*, 26 September 2018, 1530 (Robin Decontie).

191 INAN, *Evidence*, 7 June 2018, 1530 (Della Mansoff).

of violation can result in serious provincial penalties, including having their licenses revoked by their professional body.[192]

There are also serious challenges relating to responsibility for funding health care – including continuing care – on reserve, which is split between First Nations and the federal and provincial governments. The Committee learned that the process to obtain capital for long-term care facilities from the provincial and federal governments are completely separate and that these governments deny responsibility when it comes to investing in long-term care facilities.[193] These examples of jurisdictional conflicts regarding long-term care funding create disparities in the amounts provided by the provincial and federal governments, which limit access to continuing care on reserve. Keith Grier, Chair of the Piikani Nation's Aakom Kiyii Health Services, stated that the federal government cannot ignore its treaty responsibilities and that it "has a fiduciary duty to uphold the proper funding for the nations." He compared the amount that Alberta spends on health care with those the federal government provides to reserves to illustrate the clear financial inequity:

> In Alberta's budget last year, I think they budgeted $21 billion to go into health care. That's over half their provincial budget. If you work that out, it's about $5,200 in expenses on a per capita basis across the province. The federal transfer dollars, we all know, are probably about $1,075 per capita, and then we're only getting half of that on the reserve.[194]

Jurisdictional disputes and "ineffective policy stacked upon another ineffective policy, stacked yet again on another ineffective policy"[195] often impede access to continuing care.[196] These challenges create significant inequalities in health care for First Nations, and the testimony received shows that these inequalities also exist in continuing care on reserve.[197] Chief Bellegarde pointed out that many people "[fall] through the jurisdictional cracks, because the system is overly complex. There's a lot of procedure

192 INAN, *Evidence*, 26 September 2018, 1555 (Robin Decontie).

193 INAN, *Evidence*, 7 June 2018, 1705 (John Cutfeet).

194 INAN, *Evidence*, 3 October 2018, 1720 (Keith Grier).

195 INAN, *Evidence*, 7 June 2018, 1535 (Chief Edmund Bellegarde).

196 INAN, *Evidence*, 31 May 2018, 1545 (Chief R. Donald Maracle); INAN, *Evidence*, 5 June 2018, 1645 (Natalie Gibson); INAN, *Evidence*, 7 June 2018, 1640; 1655 (John Cutfeet); and INAN, *Evidence*, 14 June 2018, 1540 (Tania Dick).

197 INAN, *Evidence*, 3 October 2018, 1620 (Gwen Traverse).

and policy and paperwork to it, and they don't have all the navigation services or supports they need”[198]

According to Chief Maracle, “There is a responsibility on both governments to address this need, which cries out for some immediate attention.”[199] He added that a coordinated approach is needed in terms of long-term care and health services overall.[200]

The Committee acknowledges that navigating the system can be challenging, and immediate measures could include ensuring access to support, information and guidance to First Nations people and communities on the policies and procedures in place in relation to continuing care services available to them. The federal government must help clarify the roles and responsibilities of each level of government and needs to take the initiative and coordinate approaches to standards for continuing care on reserve. Moreover, the Committee is of the opinion that the Minister of ISC should take the lead in tripartite discussions between provinces/territories and First Nations leaders to address the jurisdictional challenges related to continuing care services on reserve. The Committee therefore recommends:

Recommendation 8

That Indigenous Services Canada co-ordinate with First Nations and the provinces and territories to clarify their respective roles and responsibilities for continuing care on reserves.

Recommendation 9

That the Minister of Indigenous Services Canada facilitate tripartite meetings between the federal government, provinces and territories and First Nations representatives to address the jurisdictional challenges that exist regarding the delivery of home and community care, palliative care and long-term care services on reserves.

198 INAN, *Evidence*, 7 June 2018, 1615 (Chief Edmund Bellegarde).

199 INAN, *Evidence*, 31 May 2018, 1610 (Chief R. Donald Maracle).

200 INAN, *Evidence*, 31 May 2018, 1620 (Chief R. Donald Maracle).

5. DATA COLLECTION

Limited data has been collected on First Nation peoples' health, health services on reserve and the way these services compare to the health services provided to the non-Indigenous population. Data on continuing care on reserve are no exception. Regarding the data that are currently collected, some witnesses pointed out that data collection methods vary substantially from province to province and do not necessarily reflect the situation and needs of each region.

A. Limited Data Available

The Committee learned that very little data is collected about the need for long-term beds and care, waiting times, well-being indicators and socio-economic conditions in First Nation communities.[201] ISC officials confirmed that there is no national system to store the data or report waiting times for long-term care facilities.[202] While the provinces and territories collect information about long-term care facilities and waiting times, the availability of the data collected by the provinces through public sources varies considerably.[203]

> **"Data, we understand now, is an extremely important component to documenting the needs of our [First] [N]ations communities."**
>
> Ms. Sharon Rudderham

Sharon Rudderham, Director of Health for the Eskasoni First Nation, explained that data that was collected for the federal departments (Health Canada and Indigenous and Northern Affairs Canada) "was related to the accountability of funding and the spending of resources, whereas it didn't necessarily support the documentation of needs within the community, and those could be based on stories."[204] According to Mr. Leclaire, collecting data about certain socio-economic indicators can help prevent

201 INAN, *Evidence*, 31 May 2018, 1625 (Chief R. Donald Maracle); 1630 (Graham Mecredy); and 1715 (Keith Leclaire). In its *Report 5—Socio-economic Gaps on First Nations Reserves—Indigenous Services Canada*, published in the spring of 2018, the Office of the Auditor General found that "Indigenous Services Canada's main measure of socio-economic well-being on reserves, the Community Well-Being index, was not comprehensive" and that the "data on education, employment, income, and housing … omitted several aspects of well-being that are also important to First Nations people—such as health, environment, language, and culture."

202 Response prepared by the Department of Indigenous Services, 15 August 2018.

203 Ibid.

204 INAN, *Evidence*, 26 September 2018, 1610 (Sharon Rudderham).

health problems and improve health outcomes for First Nation people.[205] He explained that the current indicators, however, are financially related instead of being focused on health and prevention:

> If we look at home care and home care services, what are the indicators? The indicators are: how many people they went to; how many people they saw; and how many times they went to see them. My only concern is, what are they going there for; what is the issue; and what is the general state of health of that individual elder? That's not really accommodated because we're more fiscally accountable than we are to the best case management of the individual's health.[206]

The lack of information and indicators specific to First Nations health makes it impossible for communities to assess each region's actual continuing care needs or to plan continuing care services according to demand. Ms. Rudderham stated that having data "is an extremely important component to documenting the needs of our [First] [N]ations communities."[207] With regard to funding, Ms. Gibson noted that, because of the lack of appropriate data about Northern regions, the current funding formula "doesn't fit in a northern, rural, and remote community."[208]

B. Data Collected Nationally Is Not Captured or Tracked the Same Way

In addition to the lack of data collected on First Nations health, the Committee learned of problems with the data collection methods currently used by the various levels of government. The Committee heard that health data collected by the provinces, municipalities and federal government departments are "not captured or tracked in the same way."[209] These data are collected through different software programs. For example, Alberta Health Services records data using the Meditech program, while the federal government captures data through another program.

205 INAN, *Evidence*, 31 May 2018, 1715 (Keith Leclaire).

206 INAN, *Evidence*, 31 May 2018, 1705 (Keith Leclaire).

207 INAN, *Evidence*, 26 September 2018, 1605 (Sharon Rudderham).

208 INAN, *Evidence*, 5 June 2018, 1700 (Natalie Gibson).

209 INAN, *Evidence*, 5 June 2018, 1640 (Chief Rupert Meneen).

According to Mr. Anderson, "We want to talk apples to apples."[210] Witnesses informed the committee that the different data collection methods can distort the results and even affect the allocation of funding for long-term care.[211]

The Committee recognizes that adopting a coordinated and comprehensive data collection method across the country would help identify continuing-care needs and priorities, as well as support informed decision-making. The Committee also believes that supporting First Nation in collecting data specific to health and establishing relevant socio-economic indicators for rural areas would support prevention efforts and the development of effective policies and strategies for continuing care on reserve.[212]

The Committee further recognizes that developing a standardized data collection method for access to continuing care services on reserve necessitates cooperating with the provinces and territories and partnering with First Nation communities, without imposing a greater administrative burden on those communities. The Committee also believes that a protocol respecting the way data are collected, analyzed, disseminated and stored should be established. As some witnesses pointed out, any data collected should remain the property of the First Nation communities in question.[213] Keith Leclaire outlined the importance of ensuring that for any data that is collected, "the ownership, the control the access, and the possession should remain with the [F]irst [N]ation."[214] In that regard, the Committee acknowledges the importance of OCAP®, which represents "a set of principles that reflect First Nation commitments to use and share information in a way that brings benefit to the community while minimizing harm. It is also an expression of First Nation jurisdiction over information about the First Nation."[215] The Committee therefore recommends:

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210 INAN, *Evidence*, 5 June 2018, 1700 (Jeff Anderson).

211 INAN, *Evidence*, 5 June 2018, 1640 (Chief Rupert Meneen); 1645 (Natalie Gibson); and 1700 (Jeff Anderson).

212 In its spring 2018 report, the Office of the Auditor General of Canada underscored the importance of collecting data that are "reliable, relevant and up to date' in order to close socio-economic gaps on reserves (*Report 5—Socio-economic Gaps on First Nations Reserves—Indigenous Services Canada* (spring 2018)).

213 INAN, *Evidence*, 31 May 2018, 1720 (Keith Leclaire); and INAN, *Evidence*, 26 September 2018, 1715 (Chief Peter Collins).

214 INAN, *Evidence*, 31 May 2018, 1720 (Keith Leclaire).

215 The First Nations Information Governance Centre. *Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance*. May 2014. (Ottawa: The First Nations Information Governance Centre, May 2014). OCAP™ (ownership, control, access and possession) was developed by the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey which was later incorporated into The First Nations Information Governance Centre.

Recommendation 10

Based on the principles of OCAP® (ownership, control, access and possession) of the First Nations Information and Governance Centre, that Indigenous Services Canada work with First Nations and provinces and territories to develop and implement an integrated data collection protocol specific to the health and well-being of First Nations; and that this data be used to inform the provision of evidence-based health services on reserves.

CONCLUSION

The testimony heard in relation to continuing care on reserves revealed the many barriers First Nations face in delivering and managing continuing care. Socio-economic and historical inequities have exposed First Nation people to greater health risks. Remedying these inequities will require major reforms. Still, some changes can be made to existing programs and funding in order to improve the quality of continuing care services provided on reserves.

While some of the issues raised by witnesses also apply to the non-Indigenous population, a number of the challenges surrounding continuing care are unique to First Nations. The Committee believes that, above all, the roles and responsibilities of the various levels of government need to be clarified and current programs and services must be better coordinated. The Committee is also of the opinion that the delivery and management of continuing care on reserves absolutely must be culturally safe and appropriate. Moreover, to be effective, short- and long-term solutions must recognize and support First Nation medical knowledge and practices and be developed in partnership with First Nations. The Committee believes that Canada has a great deal to learn from First Nations in this respect.

The Committee hopes the recommendations set out in this report will advance the discussion and lead to concrete changes in health care services and the funding of continuing care on reserves. The Committee believes that a long-term approach is needed to carry out these reforms. The well-being of current and future generations is at stake.

APPENDIX A
LIST OF WITNESSES

The following table lists the witnesses who appeared before the Committee at its meetings related to this report. Transcripts of all public meetings related to this report are available on the Committee's webpage for this study.

Organizations and Individuals	Date	Meeting
Department of Indian Affairs and Northern Development	2018/05/24	109
Robin Buckland, Executive Director Office of Primary Health Care, First Nations and Inuit Health Branch		
Keith Conn, Acting Assistant Deputy Minister First Nations and Inuit Health Branch		
Brenda Shestowsky, Senior Director Social Policy and Programs Branch, Education and Social Development Programs and Partnerships Sector		
Association of Iroquois and Allied Indians	2018/05/31	111
Grand Chief Joel Abram		
Chiefs of Ontario	2018/05/31	111
Grand Chief Donna Loft, Home Care Advisor		
Graham Mecredy, Senior Health Analyst Senior Epidemiologist, Institute for Clinical Evaluative Sciences (ICES)		
Mohawk Council of Akwesasne	2018/05/31	111
Grand Chief Abram Benedict Mohawk Government		
Keith Leclaire, Director of Health		
Mohawks of the Bay of Quinte	2018/05/31	111
Bernard Bouchard, Associate Assured Consulting		
Chief R. Donald Maracle		

Organizations and Individuals	Date	Meeting
As an individual	2018/06/05	112
Bonita Beatty, Professor University of Saskatchewan		
Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788	2018/06/05	112
Jeff Anderson, Chairman		
Bill Boese, Treasurer		
Natalie Gibson, Research and Advisor to the Board		
Tallcree First Nation	2018/06/05	112
Chief Rupert Meneen		
Tsiionkwanonhso:te Long Term Care Facility	2018/06/05	112
Teresa Doxtdator David, Recreation and Leisure Supervisor		
Vincent Lazore		
UW-Schlegel Research Institute for Aging	2018/06/05	112
Tammy Cumming		
Cowessess First Nation	2018/06/07	113
Chief Cadmus Delorme		
Dakota Oyate Lodge	2018/06/07	113
Della Mansoff, Director		
Driftpile Cree Nation	2018/06/07	113
Sandra Lamouche, Health Director Treaty 8 First Nations of Alberta		
Florence Willier, Councillor		
File Hills Qu'Appelle Tribal Council	2018/06/07	113
Chief Edmund Bellegarde, Tribal Chief		
Gail Boehme, Executive Director		
Heart River Housing	2018/06/07	113
Lindsay Pratt, Administrator		
Nishnawbe Aski Nation	2018/06/07	113
James Cutfeet, Director Health Policy and Advocacy		
Deputy Grand Chief, Derek Fox		

Organizations and Individuals	Date	Meeting
Sioux Lookout First Nations Health Authority	2018/06/07	113
John Cutfeet, Board Chair		
Association of Registered Nurses of British Columbia	2018/06/14	115
Tania Dick, President		
Loon River First Nation	2018/06/14	115
Holly Best, Home Care Coordinator Kee Tas Kee Now Tribal Council		
Kirsten Sware, Director of Health Kee Tas Kee Now Tribal Council		
Beverly Ward, Director Health and Social Services		
Eskasoni Corporate Division	2018/09/26	118
Stephen Parsons, General Manager		
Eskasoni First Nation	2018/09/26	118
Sharon Rudderham, Director of Health		
Fort William First Nation	2018/09/26	118
Chief Peter Collins		
Kitigan Zibi Anishinabeg First Nation	2018/09/26	118
Robin Decontie, Director Kitigan Zibi Health and Social Services		
Wiikwemkoong Unceded Territory	2018/09/26	118
Ogimaa Duke Peltier, Leader		
Conseil de la nation Atikamekw	2018/10/01	119
Grand Chief Constant Awashish		
Pekuakamiulnuatsh Takuhikan	2018/10/01	119
Julie Harvey, Director Seniors' Health		
Véronique Larouche, Director Health and Community Wellnes		

Organizations and Individuals	Date	Meeting
Aakom Kiyii Health Services	2018/10/03	120
Keith Grier, Chair Health		
Dustin Wolfe, Director Health		
Okanagan Indian Band	2018/10/03	120
April Coulson, Nurse Home and Community Care		
Gareth Jones, Director Community Services Department		
Allan Louis, Band Councillor Health		
Piikani First Nation	2018/10/03	120
Troy Knowlton, Council Member		
Pinaymootang First Nation	2018/10/03	120
Gwen Traverse, Director of Health		
Chief Garnet Woodhouse		

APPENDIX B
LIST OF BRIEFS

The following is an alphabetical list of organizations and individuals who submitted briefs to the Committee related to this report. For more information, please consult the Committee's webpage for this study.

Conseil de la nation Atikamekw

First Nations Health Authority

Fort Vermilion and Area Seniors' and Elders' Lodge Board 1788

Pallium Canada

Speech-Language and Audiology Canada

REQUEST FOR GOVERNMENT RESPONSE

Pursuant to Standing Order 109, the Committee requests that the government table a comprehensive response to this Report.

A copy of the relevant *Minutes of Proceedings* (Meetings Nos. 109, 111, 112, 113, 115, 118, 119, 120, 130 and 132) is tabled.

Respectfully submitted,

Hon. MaryAnn Mihychuk, P.C., M.P.
Chair

A Missed Opportunity: The Conservative Party of Canada's Dissenting Report for the Study of Long-Term Care On-Reserve

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Cathy McLeod, Member of Parliament for Kamloops – Thompson – Cariboo
Kevin Waugh, Member of Parliament for Saskatoon – Grasswood
Arnold Viersen, Member of Parliament for Peace River – Westlock

As the Conservative members of the Standing Committee on Indigenous and Northern Affairs (INAN), we recognize the need to understand issues facing elderly Indigenous people in Canada, and take practical steps to improve long-term care on- and off-reserve.

That is why, on February 1, 2018, we supported the passage of the following motion:

> That, pursuant to Standing Order 108(2), the Committee undertake a comprehensive study of long-term care on reserve; that the scope of the study include and not be limited to, elder care, persons living with chronic illness, palliative and hospice care and culturally relevant practices and programs; and that the witness list include First Nation community representatives, First Nation organizations responsible for delivering long-term care services, and groups and organizations affiliated with service delivery; and that the Committee report its findings to the House.

The Committee's final report contains several parts with which we agree. We believe recommendations 4, 7, 8, 9 and 10 are valuable suggestions for the federal government to consider:

> Recommendation 4: That Indigenous Services Canada work with First Nations and the provinces and territories to take immediate measures to encourage the implementation of culturally appropriate programming and service delivery including traditional foods in long-term care facilities and as part of home care and community-based care on reserve.
>
> Recommendation 7: That Indigenous Services Canada, in partnership with First Nations and other relevant federal departments, improve access to post-secondary health education and occupational training for First Nations learners to provide more opportunities for First Nations people to deliver health care on reserve.
>
> Recommendation 8: That Indigenous Services Canada co-ordinate with First Nations and the provinces and territories to clarify their respective roles and responsibilities for continuing care on reserves.

> Recommendation 9: That the Minister of Indigenous Services Canada facilitate tripartite meetings between the federal government, provinces and territories and First Nations representatives to address the jurisdictional challenges that exist regarding the delivery of home and community care, palliative care and long-term care services on reserves.
>
> Recommendation 10: Based on the principles of OCAP™ (ownership, control, access and possession) trademarked by the First Nations Information and Governance Centre, that Indigenous Services Canada work with First Nations and provinces and territories to develop and implement an integrated data collection protocol specific to the health and well-being of First Nations; and that this data be used to inform the provision of evidence-based health services on reserves.

On Recommendation 9, the Committee heard testimony for this study, and in studies previously, of jurisdictional issues that Indigenous people face. Far too many fall through the cracks between municipal, provincial/territorial and federal services, and work must be done to better coordinate responsibilities.

Further, we agree with the Committee that palliative care is a critical service, and should be eligible under the First Nations and Inuit Home and Community Care Program. This is consistent with a recommendation made by Conservative members in the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities, who called on the federal government to make "palliative care available to every Canadian resident who needs it."

We would support Recommendation 2, if revised to state the following:

> Recommendation 2: That Indigenous Services Canada evaluate the current needs regarding in-home respite care under the First Nations and Inuit Home and Community Care Program and report publicly on it.

A baseline of information would be critical before next steps for funding are determined.

Finally, the implementation of a training program in Recommendation 5 should be amended to support an opt-in training program rather than a mandatory one, since this would be under provincial and territorial jurisdiction:

> Recommendation 5: That Indigenous Services Canada work with First Nations and provincial and territorial partners to develop and implement a training program for Indigenous and non-Indigenous health professionals providing continuing care on reserve about the values, culture and history of Indigenous peoples.

However, while we agree with several of the final recommendations, the Committee failed to live up to its goals for an ambitious and thorough study.

Only eight meetings were held in total, the majority rushed at the end of the spring 2018 Parliamentary session. It was only after MP Cathy McLeod moved a motion to extend that study that additional meetings were added for September 2018. The few topics that were discussed were examined only at a surface level.

The Committee did not do its due diligence with regard to elder care at home, palliative care and culturally-appropriate support for chronic disease. The challenges of rural and remote communities were hardly touched upon. No travel was undertaken for Members of the Committee to witnesses what takes place in communities.

The final report could never be accurately described, as was relayed in the original motion, as "comprehensive".

With Canada's aging population, a study of these issues would be of vital importance. According to Statistics Canada's 2016 census, "the proportion of the First Nations, Métis and Inuit populations 65 years of age and older could more than double by 2036." Parliament now has before it an opportunity to undertake a comprehensive examination of what services are available to Indigenous peoples, both on- and off-reserve, and recommend specific, practical actions for improvement.

However, we are profoundly disappointed that the majority of the Committee failed to comprehend the complexity and importance of these issues. It is our hope that a future Committee will properly undertake the work this Committee neglected.

The Challenges of Delivering Continuing Care in First Nation Communities
Dissenting Report of the New Democratic Party (NDP)

Although the NDP mostly agrees with the recommendations of the study, there are some glaring absences in the report that lead us to write a dissenting report. The main issues are as follows: the lack of time to do the meaningful study the motion asked for, and the lack of acknowledgement of the high level of support that the spirit of Jordan's Principle be used.

Acknowledgement of General Problems Regarding the Study

The original motion concerning this study read:

> That, pursuant to Standing Order 108(2), the Committee undertake a comprehensive study of long-term care on reserve; that the scope of the study include and not be limited to, elder care, persons living with chronic illness, palliative and hospice care and culturally relevant practices and programs; and that the witness list include First Nation community representatives, First Nation organizations responsible for delivering long-term care services, and groups and organizations affiliated with service delivery; and that the Committee report its findings to the House.

The motion clearly states that this study should have been 'comprehensive'. However, the length of the study was far too short to comprehensively look at the issue of Long-Term Care and other healthcare needs and services for First Nations. Additionally, the House of Commons has never done a study on this issue before, making it even more important that comprehensive time be given to it. This simply did not occur, as the study only lasted for 8 sessions hearing from witnesses, from the end of May to the start of October, with a long break over the summer taking up over 2 and half months of the overall study period. To wholly fulfil the goals of the motion a longer and more comprehensive study was needed, supporting this, on June 14th, in response to being asked if she thinks the study should be extended, Tania Dick stated to the Committee:

> "I think it's a complex issue, particularly looking at it through that reconciliation lens, with the trauma that we carry as indigenous people in those generations right now, the residential school survivors. It is so desperately needed because from palliative care to chronic disease management to long-term care to acute care, we have less than adequate access to services, not only by choice but also since systems don't provide it. We have to look at it from both perspectives.
>
> If we're not getting down to those layers and having that comprehensive discussion about it, we're not going to have the impact and the action that really are needed by our communities across the country. We have to pull back those layers much further. I think

> a huge discussion is so desperately needed if we are going to have an impact on the quality of life for this generation and the generations to follow."

The short length of the study has left the committee insignificant time to study: chronic illness, palliative care, hospice care, culturally relevant practices and programmes. There was no significant study of dementia or regional responses either. Nearly all of these issues were specifically named in the original motion.

The NDP's Dissenting Report Recommendation

1. **That Indigenous Services Canada work with First Nations to develop and expand Jordan's Principle for continuing care on and off reserves that applies to all First Nation members.**

What is Jordan's Principle?

The Canadian Human Rights Tribunal (CHRT) defines Jordan's Principle as:

> "Jordan's Principle provides that where a government service is available to all other children, but a jurisdictional dispute regarding services to a First Nations child arises between Canada, a province, a territory, or between government departments, the government department of first contact pays for the service and can seek reimbursement from the other government or department after the child has received the service. It is a child-first principle meant to prevent First Nations children from being denied essential public services or experiencing delays in receiving them."

Therefore, Jordan's Principle can be summarized as a system of care in which the needs of those seeking care are put first. As Tania Dick stated to the Committee on the 14th of June:

> "An important lesson to learn in our practice is about the spirit or the foundation of Jordan's principle. Let's get rid of the boundaries, provide the care, and figure it out later, rather than having people turned away or ignored or not looked at."

Connecting Jordan's Principle to Social Determinants of Health

Jordan's Principle essentially exists to help remedy the vulnerability that First Nation members face. This vulnerability arises through many different aspects of life such as housing, employment, healthcare, mental health, food and security. These poor social determinants of health denote that First Nation peoples' health can deteriorate to a great extent at any age, meaning that considerable vulnerability does not just exist amongst First Nation children but often lasts through a lifetime. Furthermore, for children who need continuing care, those vital services can be cut off when they turn eighteen meaning they are left living within the jurisdictional cracks.

Therefore, the jurisdiction of Jordan's Principle must be expanded to include all First Nation members, to remedy vulnerabilities faced and to prevent First Nation members of all ages from falling through the system into critical circumstances.

As testimony received from Deputy Chief Derek Fox on June 7th shows:

> "When we talked about the social determinants of health, I would say that 90% of those would make up our issues. You're talking about education, infrastructure, and social challenges. All these things combined lead to health issues, whether they're for youth, elders, our people, and so on."

Similarly, on September 26th, Sharon Rudderham stated:

> "Even when you look at children with disabilities, and when they reach the age of 18 then what's going to happen to them? If Jordan's Principle is providing tons of support to the family because of the jurisdictional barriers around their care, then what's going to happen when these children age out of Jordan's Principle? Who is going to be responsible?"

Expanding Jordan's Principle is particularly important for First Nation members in rural and remote settings that lack the necessary transport, infrastructure and supports to access adequate healthcare services nearby.

Testimony received from Jeff Anderson on June 5th demonstrates this:

> **"**The reality is that many First Nations might not even have a car, and to be able to see their family, even from two or three hours away let alone nine hours away, can sometimes be an impossibility. In talking to this person, I found they hadn't seen their own mom for two and a half years, and that's just within the region, let alone considering cases out of the region."

Applying the Lens of Reconciliation to Jordan's Principle

Expanding the jurisdiction of Jordan's Principle is also necessary from the lens of reconciliation. Many First Nation people already adamantly avoid using healthcare services, due to the traumas they have experienced through interactions with residential schools and non-indigenous society and institutions. The jurisdictional mess which currently exists only serves to further confirm feelings of isolation and abandonment, as when First Nation people are turned away from services they become even less likely to return to them despite it becoming critical to their health and well-being.

Therefore to truly begin to fulfil the obligation of reconciliation, Jordan's Principle must be expanded to all First Nation members. With easier access to services and less bureaucracy and

denial of services, First Nation members may start to feel more secure both in regards to accessing healthcare and their place in Canadian society as a whole.

Chief Edmund Bellegarde confirmed this at the Committee on June 7th, stating:

> "It's that institutional aversion, skepticism, or fear for our people; it's access. Some of the stats don't capture all the people falling through the jurisdictional cracks, because the system is overly complex. There's a lot of procedure and policy and paperwork to it, and they don't have all the navigation services or supports they need. When there's transition between reserve and off reserve, especially in more southern communities where that transient lifestyle is very prevalent, those are challenges. They get lost because, are they federal or provincial?"

The importance of expanding Jordan's Principle with regards to reconciliation is further confirmed by the Truth and Reconciliation Commission of Canada's Calls to Action. Call to Action 20, under the category of Health states:

> "In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect and address the distinct health needs of the Métis, Inuit and off-reserve Aboriginal peoples".

Further supporting statements from testimony:

Deputy Grand Chief Derek Fox, 7th June: "As I mentioned earlier, we have 32 remote communities and 49 altogether. You asked us about what conditions are like. As Mike alluded to earlier when we talked about the social determinants of health, I would say that 90% of those would make up our issues. You're talking about education, infrastructure, and social challenges. All these things combined lead to health issues, whether they're for youth, elders, our people, and so on."

Tania Dick, 14th June: "I'm the first generation out of residential school. That intergenerational trauma exists. The general feeling overall that I have experienced in my practice is that individuals don't have trust. They have a lot of fear, and they absolutely have a difficult time accessing services or entering these facilities or institutions. It triggers them, I'm sure. They avoid them as much as they can, and then they get into a critical state in the community where they come in and we are actually having to try to resuscitate them and kind of revive them physically through their chronic disease issues and get them safe again."

Grand Chief Constant Awashish, 1st October: "We are about 60 to 70 years behind socio-economic development. How are we going to assert this problem? Here we have a lot of very smart people around this table and I'm sure we can find something good for our future. Like I said, where do I go to speak to different organizations, or when I do not know where to go? We want to be able to feel good. We want to be able to have a sense of belonging to the society so

we can contribute to the protection of this land, the protection of the country. There's no contradiction to be sovereign within the state here."

Conclusion

The report fell down significantly by not allowing for meaningful time to study the full motion. With those significant gaps, the NDP has concerns that the study's recommendations are not as comprehensive as they should be. The exclusion of the many testimonies on Jordan's Principle is concerning. At the heart of this principle is the point: people before jurisdiction. As elders and seniors are falling between the cracks of this system the honoring of humanity is key. By leaving this out, the continuation of families suffering in a broken system will continue.