

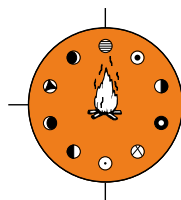
THE ESSENTIAL ROLE  
OF  
*caregivers:*  
A CULTURAL AND  
HUMAN-CENTRED  
APPROACH FOR QUALITY  
CARE AND SERVICES



**BILL 56**  
**An Act to recognize and support caregivers  
and to amend various legislative provisions**



JOINT BRIEF PRESENTED BY



Assembly of First Nations  
Quebec-Labrador



FIRST NATIONS OF QUEBEC  
AND LABRADOR HEALTH  
AND SOCIAL SERVICES  
COMMISSION



This joint brief was prepared in response to Bill 56, *An Act to recognize and support caregivers and to amend various legislative provisions*. It was submitted to the Committee on Citizen Relations, National Assembly of Québec, on September 30.

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#### **Note to the reader**

The masculine pronoun is used generically in the text solely for ease of reading.

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## Abstract

The Assembly of First Nations Quebec-Labrador (AFNQL) and the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) prepared this brief in response to Bill 56 on the recognition of caregivers, introduced June 11, 2020. While both organizations applaud the initiative of Minister Marguerite Blais, they propose recommendations for ensuring that the rights of First Nations are respected and accounted for at every step of the legislative process for Bill 56, as well as in the drafting of subsequent national policy. The ultimate goal is to secure full recognition from local governments of First Nations on their territory and support the work of First Nations caregivers by providing them with a safe and familiar environment, ensuring they are treated fairly and without discrimination, and delivering appropriate training, tools and information.

The brief begins by addressing the definition of “caregiver,” and more specifically the idea of an “emotional bond”. As the value of solidarity is foundational to First Nations culture, it is not uncommon for a professional with no personal relationship or emotional bond with a care receiver, an extended family member or even a visitor in the community to act as a caregiver. In such circumstances, it is not useful, and may even be harmful, to use “emotional bond” as a criterion for determining whether someone is a caregiver. Next, it is crucial to recognize First Nations’ inherent right to self-government and power to draft their own policy, such as a culturally adapted policy for caregivers and action plan. Indeed, any policy that concerns First Nations health and social services must consider the experiences of these populations. It must also recognize the ability of First Nations communities and organizations to properly determine their needs and effectively implement measures to meet them. To get there, agreements could be signed to establish a coordination mechanism between the governments of Canada, Quebec and First Nations to align their caregiver support programs and measures. Other actions could also be taken, such as delivering cultural sensitivity training to care providers in the Quebec health and social services network, creating a network of First Nations caregivers, promoting careers in health and social services in First Nations communities, or providing culturally and linguistically adapted caregiver respite services.

Lastly, who is in a better position to speak for First Nations than First Nations themselves? To this end, First Nations experts must have a place in the structure of institutions planned in Bill 56, and all experts selected must have a thorough knowledge of issues faced by First Nations. First Nations have much to offer to the Committee of Partners, researchers, the observatory, and the committee charged with developing “seniors homes” and “alternative homes”, to the benefit of their Nations and Quebec as a whole.

# Presentation of the organizations

## **ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR**

The Assembly of First Nations Quebec-Labrador (AFNQL) was founded in 1985 as a meeting place for the chiefs of 43 communities across the 10 First Nations in Quebec and Labrador. As a body, it discusses issues related to the defence of First Nation titles and rights, both ancestral and those arising from treaties; federal and provincial policies that have an impact on their customs and lifestyle; governmental laws and relations with both levels of government; economic development; social, economic and cultural issues; and all issues pertaining to governmental autonomy, national relations with the government and international relations.

In association with its regional commissions and organizations (RCOs), the AFNQL secretariat coordinates the files it deems as having priority and the regional chief's representational activities, and implements the decisions made by the chiefs during the assembly.

## **FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION**

The First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) is a non-profit organization that is responsible for supporting the efforts of the First Nations in Quebec and Labrador to, among other things, plan and deliver culturally appropriate and preventive health and social services programs.

### **Vision**

First Nations individuals, families and communities are healthy, have equitable access to quality care and services, and are self-determining and culturally empowered.

### **Mission**

To accompany Quebec First Nations in achieving their health, wellness, culture and self-determination goals.

# Introduction

In their joint press conference on June 12, 2020, the Assembly of First Nations Quebec-Labrador (AFNQL) and the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC) expressed their support for Bill 56 on the recognition of caregivers, introduced on June 11 by the Minister Responsible for Seniors and Informal Caregivers, Marguerite Blais.

In this brief, the AFNQL and FNQLHSSC wish to highlight the main obstacles to recognizing the role and contribution of caregivers and providing them with support. In doing so, they hope to educate the Government of Quebec about the current and future needs of First Nations caregivers, ensure an equitable service offering that goes well beyond legal jurisdictions and bring the government's attention to the potential repercussions of this bill. Recommendations are given on how the Government of Quebec can consider the context and experience of First Nations in Quebec in its reflection process.

This brief begins with a presentation of the context of First Nations in Quebec<sup>1</sup> from a legal, administrative and socio-sanitary standpoint, with a particular focus on the experience of caregivers. It discusses issues related to the definition of caregivers, the national policy on caregivers, the action plan and the new institutions and organizations planned in Bill 56. Recommendations are made in line with each issue.



<sup>1</sup> This brief does not apply to the Cree or Naskapi nations.

# Context of First Nations in Quebec

## LEGAL CONTEXT OF HEALTH AND SOCIAL SERVICES

The *Constitution Act*, 1867 gives the federal Parliament exclusive jurisdiction over “Indians, and lands reserved for the Indians.”<sup>2</sup> That is why the federal government is involved with First Nations communities in all areas of activity, including in financing and supporting basic health and social services in collaboration with Quebec’s health and social services network (RSSS). Provincial laws of general application (including the *Act respecting health services and social services*, R.S.Q. c. S-4.2) apply to reserve land to the extent that they do not replace a federal law or regulation, or so long as the band council has not adopted a regulation or law in that area.<sup>3</sup> In order to exercise the powers conferred on them by the *Indian Act* (R.S.Q. c. I-5), band councils have created services in the areas of health and social services, public infrastructure and housing, education and public safety, to name but a few.

In 2013, Quebec First Nations began a health and social services governance process aiming to develop and support the independence of First Nations communities and organizations with a view to self-determination and improved wellness. As part of this process, in August 2019, a tripartite memorandum of understanding was signed between the AFNQL, the Government of Canada and the Government of Quebec, in which the parties commit to identify “obstacles and possible solutions to facilitate fair and equitable access for the First Nations in Quebec to high quality health and social services and programs according to the roles and responsibilities of each party.”

## FUNDING AND ORGANIZATION OF HOME CARE SERVICES

Funding for residential care services offered in communities is mainly provided by two Indigenous Services Canada (ISC) programs: the First Nations and Inuit Home and Community Care Program (FNIHCC) and the Assisted Living Program.<sup>4</sup>

The FNIHCC provides funds for services such as nursing care, personal care, needs assessment, case management, home respite care, palliative care, nutrition, rehabilitation, respiratory therapy and equipment loans. The service offering depends on the service plan for each community, which is determined based on needs and funding levels. The Assisted Living Program provides non-medical social support services for persons with decreasing independence by subsidizing adult placement and home management services. Currently, 11 communities have residential and care facilities for elders and persons with decreasing independence who require less than two and a half hours of care a day (Iso-SMAF profile 9 or under).<sup>5</sup> Note that community facilities that offer health and social services (health centres, nursing stations, residential and care facilities, etc.) are not recognized as part of the RSSS.<sup>6</sup> It should also be noted that specialized services and care and services for persons with moderately to significantly reduced independence (Iso-SMAF profile 10 or over) most often require staying at an RSSS facility.



2 *Constitution Act*, 1867 R.S.Q. 1985, sec. 91, par. 24.

3 See Sébastien Grammond. 2003. *Aménager la coexistence – Les peuples autochtones et le droit canadien*. Établissement Émile Bruylant, Bruxelles and Éditions Yvon Blais, Cowansville, pp. 361 to 377; MICHEL DESCHÉNES. 1992. “Les pouvoirs d’urgence et le partage des compétences au Canada.” *Les Cahiers de Droit*, vol. 33, no. 4, pp. 1181-1206, esp. 1203 to 1205.

4 <https://www.canada.ca/en/indigenous-services-canada.html>.

5 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2014. *Brief on residential and long-term care resources for Quebec First Nations*. (Presented to the National Assembly of Québec health and social services commission.) Wendake.

6 MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX. 2007. *Delivery and funding of health services and social services for aboriginal people*. Québec City.

## HEALTH STATUS OF FIRST NATIONS IN QUEBEC

A number of risk factors make First Nations more vulnerable and negatively impact their health and well-being. These include geographic isolation, language, transportation issues, inadequate or overcrowded housing, barriers to accessing health and social services, poverty, intergenerational trauma from residential schools and illiteracy.

According to the 2015 Quebec First Nations Regional Health Survey (RHS), the prevalence of chronic health problems rises steeply with age. The majority of adults 35 years and over living in communities deal with at least two chronic health conditions daily and close to half of adults 65 years and over deal with at least five.<sup>7</sup> This survey also found that 13% of adults consider that they need home care. In adults aged 65 or over, this percentage increases to 46%. Yet, the survey results also show that, in many cases, the need for home care needs goes unmet in communities. As a result, less than half of adults actually receive the services they report they need.<sup>8</sup>

## CONTEXT OF CAREGIVERS IN FIRST NATIONS COMMUNITIES IN QUEBEC

There is a clear need for health and social services, and the lack of resources to it puts continuous pressure on communities. In the coming years, this pressure will continue to build, due in no small part to the increased prevalence of chronic health conditions, including comorbidities that may limit the independence<sup>9</sup> of those concerned.

According to the 2015 RHS, nearly **one in five adults** report that they provide support to a friend or a family member who suffers from a health problem. The proportion of caregivers remains steady regardless of age, sex, geographic isolation zone, education level, household income and employment status.<sup>10</sup>

Last, according to this same survey, caregivers provide their loved ones with **an average of 15 hours of support a week**. Just over half of caregivers provide five hours of support or less per week, while one out of ten provide over 35 hours of support per week. The most commonly provided services are grocery shopping, preparing meals, housekeeping, and driving loved ones to various destinations in or outside the community.<sup>11</sup>



7 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2018. *Quebec First Nations Regional Health Survey – 2015*. Health status and chronic health problems section. Wendake.

8 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2018. *Quebec First Nations Regional Health Survey – 2015*. Soins à domicile. Home care section. Wendake.

9 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2006. *Assessing Continuing Care Requirements in First Nations and Inuit Communities*. Wendake.

10 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION (2018). *Quebec First Nations Regional Health Survey – 2015*. Home care section. Wendake.

11 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION (2018). *Quebec First Nations Regional Health Survey – 2015*. Home care section. Wendake.

# Provisions of Bill 56 and issues impacting First Nations caregivers in Quebec

## 1. DEFINITION OF “CAREGIVER”

Section 2 of Bill 56 defines a “caregiver” as (emphasis added): “**any person who continuously or occasionally provides significant support to a member of his or her immediate circle** who has a **temporary or permanent incapacity** and with whom the person **shares an emotional bond** as a **family member or otherwise**.”

The support is provided on a **non-professional basis**, in an **informal setting** and regardless of the care receiver’s age or **living environment** or the nature of the incapacity, whether physical, mental, psychosocial or other. The support may take various forms, such as **transportation, assistance with personal care** and **housekeeping, emotional support** or the **organization of care.**”

It is important to clearly define “caregiver,” as this definition determines who is accorded certain rights.

When placed in the social and cultural context of First Nations, some of the criteria listed in this definition—and, by extension, the definition itself—may apply more broadly than we might expect in Quebec society in general.

## 1.1 Mutual aid is a foundational value for First Nations

Caregiver support is widespread in communities due to the lack of nursing care and staff, but also because solidarity and strong family relationships are highly valued in First Nations cultures.<sup>12</sup>

In some communities, the definition of family extends not only to aunts, uncles, nephews, nieces and cousins, etc.<sup>13</sup>, but also to other community members who are important to the care receiver (knowledge keepers, professionals, spiritual advisors, youth in the community, etc.).

Furthermore, the proximity of community members facilitates the formation of relationships based on mutual aid. These play out on a daily basis, and can be attributed to community involvement, without the need for any particular bond involvement. In this context, it becomes tricky to use an emotional bond as a criterion for caregivers.<sup>14</sup>

However, some people receiving care do not have a support network or have only one person in their support network who can act as a caregiver. There are cases where a professional with no emotional relationship with the care receiver has stepped in to act as a caregiver outside the scope of their work.<sup>15</sup> Such individuals cannot truly be said to be motivated by an emotional bond, familial or otherwise.

12 ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR AND FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2017. *Active Aging in the Quebec First Nations: Everyone’s a Winner!*. (Brief presented to the Secrétariat aux aînés, Ministère de la Famille.) Wendake.

13 In the assessment of continuing care requirements in communities, users with caregivers described their family relationship as follows: daughter (38.6%), son (26.5%), other (niece, nephew, grandchild, professional) (28.8%), sister (14.4%), spouse (12.8%), friend (8.3%), daughter-in-law (7.6%), mother (6.8%), brother (4.5%), son-in-law (4.5%), neighbour (3%), father (1.5%) – (FNQLHSSCL 2006).

14 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on the consultation with First Nations communities in Quebec. Internal document.

15 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on the consultation with First Nations communities in Quebec. Internal document.



In such cases, we believe that it is neither helpful nor wise to include “emotional bond” as a criterion for caregivers.

**Recommendation 1:** Remove “shares an emotional bond” from the legal definition of “caregiver.”

## 1.2 Non-professional support and informal setting

The definition given in Bill 56 implies that the caregiver is performing this role without compensation and, therefore, outside the framework of a contract or service agreement with an institution, an organization or the care receiver.

We believe that serving as a caregiver should be considered a **voluntary act**, performed **free of charge** and **at no cost**: voluntary, because it is the caregiver who chooses to help another person to improve the well-being of the care receiver; free of charge, because no direct compensation is given for the time spent providing support; at no cost, because the costs incurred in the course of the caregiver’s duties (transportation, equipment, products, reduced paid working hours, etc.) should be reimbursed to lighten their financial burden as much as possible and encourage the caregiver to continue providing support.

The criterion of an absence of compensation should therefore not preclude the payment of allowances under a government assistance program (such as employment insurance for caregivers) or under a policy of the institution or organization that assisted the care receiver. Recall that caregiver support complements the professional resources provided by the facility or organization that serves the care receiver and often relieves pressure on these resources.

**Recommendation 2:** *That the notions of “non-professional” support and “informal setting,” as used in the definition, be revised to exclude only paid support provided under an employment contract or a service contract with a public or private organization, a care receiver, or their representative.*

## 2. NATIONAL POLICY FOR CAREGIVERS AND THE ACTION PLAN

In sections 3 to 13 of Bill 56, the Government of Quebec provides that (emphasis added): “the Government is to adopt a “**national policy for caregivers**”. It sets out the guiding principles of the policy and establishes the key areas its policy directions are to focus on. Under the bill, a **government action plan** setting out the measures and actions proposed to implement the national policy is to be adopted every five years.”



## 2.1 Consideration of the realities of First Nations in Quebec in the national policy for caregivers and the government action plan

### The national policy consultation process

An initial consultation on the national policy for caregivers took place in December 2018 to identify key aspects that should be included in the national policy. A second consultation was held in 2019 by invitation. To our knowledge, no First Nations were invited to participate in this online survey consultation. Bill 56 was tabled in June 2020, and on August 27, 2020, the *Ministère de la Santé et des Services sociaux* held a meeting to gain better insight into First Nations and Inuit caregiving. The purpose of this meeting was to discuss the realities and challenges of First Nations and Inuit in Quebec and to ensure work on the national policy for caregivers and the resulting action plan took a more culturally sensitive approach.

It bears noting that the Government of Quebec chose to invite only a handful of First Nations and Inuit organizations, as government representatives said the issue was time sensitive and broader consultation was therefore not possible. To accurately reflect the reality of communities, the FNQLHSSC invited coordinators of home care and support services, health and social services directors and directors of residential and care facilities for elders and persons with decreasing independence to participate in discussion workshops in July 2020 and to fill out a questionnaire in August 2020 so that their concerns regarding Bill 56 and the national policy for caregivers could be better documented.<sup>16</sup>

It should be noted that First Nations had already initiated a wide-ranging reflection on continuing care for persons with decreasing independence, including the realities of caregivers, before the Quebec government reached out for consultation. The recommendations and courses of action that emerged from this reflection are outlined in the *Framework Policy on Continuing Care for Persons with Decreasing Independence in First Nations in Quebec*<sup>17</sup> (hereafter the Framework Policy).

To address the challenges that caregivers face, the Framework Policy put forward the following recommendations:

- Recognize, accompany and support caregivers.
- Implement resources and initiatives that meet caregivers' needs regarding accompaniment, recognition and support.
- Make respite services available in long-term care.
- Make training and tools available to caregivers and adapt such training and tools to their cultural and linguistic needs.<sup>18</sup>

We believe that the national policy for caregivers can support such commitments, so long as the national policy and resulting action plan are flexible enough to promote the commitments.

16 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on consultation with First Nations communities in Quebec. Internal document.

17 First Nations of Quebec and Labrador Health and Social Services Commission. 2020. *Framework Policy on Continuing Care for Persons with Decreasing Independence in First Nations in Quebec*. (Awaiting approval from the Assembly of First Nations Quebec-Labrador).

18 First Nations of Quebec and Labrador Health and Social Services Commission. 2020. *Framework Policy on Continuing Care for Persons with Decreasing Independence in First Nations in Quebec*. (Awaiting approval from the Assembly of First Nations Quebec-Labrador).

*“It is important that the guiding principles need to reflect First Nation community realities, and that these communities would have the flexibility of defining their own guiding principles that closely reflect these, if these would not fit them, and also add additional guidelines in which they would deem suitable. It is important that First Nations communities do not get defined by the «box» of guiding principles, but rather use these as a stepping stone towards more progressive guiding principles and ideologies that fit their needs collectively.”<sup>19</sup>*  
(Home care team lead in a First Nations community)

It is imperative that government policies on issues related directly or indirectly to First Nations health and social services, such as this national policy on caregivers, take into consideration the realities of First Nations. Such policies must also recognize the ability of First Nations and their institutions to develop and implement the necessary measures. First Nations governance capacity is still dependent on the resources available and the willingness of various levels of government to exempt First Nations from the limitations imposed on them by the institutional framework of health and social services and jurisdictional disputes between federal and provincial governments.

One of the guiding principles of the national policy for caregivers refers to “government and collective coordinated action at the national, regional and local levels by involving caregivers, so as to promote responses adapted to their needs.”<sup>20</sup> As First Nations have to deal with the fact that roles and responsibilities are shared between federal, provincial and First Nations stakeholders involved in organizing health and social services, it is important that all stakeholders do work in concert.

A failure to coordinate could generate confusion, lead to interruptions in services and make necessary care difficult to access.

The action plan provides for the signing of agreements between the Government of Quebec and organizations.<sup>21</sup> For example, First Nations could sign one or more agreements granting them status as an independent partner with the authority required to implement a specific policy and their own action plan. These agreements could provide for coordinating mechanisms, as well as simple and effective monitoring periodically conducted by First Nations themselves, with results being sent to the government for its report. Such agreements should outline the resources that are needed to create the action plan, the source of these resources, and the terms and conditions for provincial and federal support.

*“It is important that First Nations communities and respective programs have autonomy and control over what they can do within the policy and action plan, and if possible, having programs and services being provided by First Nations communities to its community members, in order to make this a better reflection of our realities.”<sup>22</sup>*  
(Home care team lead in a First Nations community)



19 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on consultation with First Nations communities in Quebec. Internal document.

20 Section 1, paragraph 2.

21 Section 11.

22 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on consultation with First Nations communities in Quebec. Internal document.

**Recommendation 3:** *Recognize that First Nations have the inherent right to self-government and power to develop their own policy for caregivers.*

**Recommendation 4:** *At the request of First Nations, the Quebec government will sign coordination agreements with First Nations to:*

- *Recognize their status as partners with a right to autonomy and powers to implement their own action plan*
- *Establish simple and effective monitoring mechanisms that respect local autonomy*
- *Provide for the creation of caregiving coordinator positions with financial support from the Quebec government in First Nations communities*
- *Provide for an intergovernmental coordination mechanism (federal-provincial-First Nations) to ensure that programs and support measures for caregivers are aligned at all levels of government.*

## 2.2 Recognition and self-recognition of caregivers

The national policy provided for in Bill 56 (section 6) states that (emphasis added): “the policy directions related to **recognition and self-recognition** of caregivers and to mobilization of the stakeholders concerned must, in particular, be aimed at raising awareness within Québec society of the role and undeniable contribution of caregivers, of the diversity of their realities and of the importance of supporting them through coordinated actions relating to various spheres of their life.”

A recent survey conducted by Léger between July 17 and 23, 2020, confirmed that the vast majority of people in Quebec (58%) have little or no knowledge of the issues and realities of First Nations in Quebec.<sup>23</sup> A campaign to raise awareness of these issues with the Quebec public is needed in order to improve the service offering provided by the RSSS and other organizations for caregivers. Workshops and training sessions could be given to RSSS care providers and community-based agencies dedicated to caregiving or supporting the practice.

To support the recognition of caregivers working within First Nations by their peers and Quebec society at large, First Nations will require financial support to launch an awareness campaign for National Caregivers Week that includes promotional themes and tools that encourage their immediate participation, as well as all kinds of awards and distinctions to recognize the contributions of First Nations caregivers.

**Recommendation 5:** *In collaboration with First Nations, train RSSS care providers to be culturally sensitive toward First Nations.*

**Recommendation 6:** *Financially support First Nations in creating training sessions and information tools on the importance of the caregiving role, their rights and the legitimacy of self recognition.*

**Recommendation 7:** *Ensure First Nations have access to the resources that Quebec will put in place to address the need to recognize, accompany, support and follow up with caregivers.*

**Recommendation 8:** *Grant financial support to First Nations to create an awareness-raising campaign for National Caregivers Week that includes promotional themes and tools to encourage their immediate participation, as well as all kinds of awards and distinctions to recognize the contributions of First Nations caregivers.*

**Recommendation 9:** *Promote access for First Nations communities to any funding that would enable them to hold activities over the course of National Caregivers Week or at other strategic times throughout the year.*

## 2.3 Information sharing and the development of knowledge and skills

The national policy provided for in Bill 56 (section 7) states that (emphasis added): “the policy directions related to **information sharing and the development of knowledge and skills** must, in particular, be aimed at meeting the information and training needs of caregivers and of the various stakeholders concerned, and at supporting research and the transfer of knowledge regarding caregivers.”

Some First Nations caregivers do not have the support they need because they do not know about the services and support resources available to them.<sup>24</sup> There is a need to facilitate access to information, in English and French **at the very least**, for caregivers regarding their rights and the services available to support them. Access to this information will help First Nations to identify and recognize themselves as caregivers and make it easier for them to learn about the available services and support resources to which they are entitled. First Nations are often not aware or have little knowledge of financial measures intended for caregivers. Governments would usually be expected to take a proactive role in sharing information about financial measures for caregivers, but they have not done so in this case.<sup>25</sup>

To foster First Nations access to training and tools created for caregivers by the RSSS, it will be necessary to first ensure that they are available and accessible in English and French in order to decrease the time it takes to access them (translation delays) or share them. These tools and training sessions should be made available to a larger number of professionals, including those who support caregivers, regardless of where they live. To improve the knowledge and skills of caregivers in communities, training sessions and tools could be created that draw on the combined expertise of Quebec professionals and First Nations professionals and their knowledge of their environment.



24 ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR AND FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2016. *Active Aging in the Quebec First Nations: Everyone's a Winner!*. Brief presented to the Secrétariat aux aînés, ministère de la Famille. Wendake.

25 FADOQ NETWORK. 2019. *Mémoire – Vers une politique nationale des proches aidants*. Presented to Marguerite Blais, Minister Responsible for Seniors and Informal Caregivers. September 24, 2019. Montréal.

Finally, depending on how involved and invested in the care receiver they are, the caregiver may develop an extensive knowledge of the environment and specific needs of the person they support. As the Regroupement des aidants naturels du Québec says, caregivers must be “involved in developing, following and evaluating the care and support plans implemented by health and social services professionals.”<sup>26</sup> For First Nations, this involvement is absolutely critical to compensate for the sometimes inadequate mechanisms to ensure communication between community and RSSS care providers. However, the caregiver should be involved in the continuum of care in a way that respects both the care receiver and the caregiver and takes into account their abilities, language and culture.

**Recommendation 10:** *Make information available to First Nations caregivers about the resources at their disposal in communities and in the RSSS so that they can successfully assist and support care receivers.*

**Recommendation 11:** *Help First Nations caregivers access promotional and prevention tools available in the RSSS, in English and French at the very least. Adapt these tools in terms of language and culture, in collaboration with First Nations.*

**Recommendation 12:** *In collaboration with First Nations, create training sessions to develop and strengthen the skills of caregivers and other care providers working with First Nations.*

**Recommendation 13:** *Foster the engagement and involvement of First Nations caregivers in developing, following and evaluating the care and support plans implemented by health and social services professionals from RSSS and the community, with a linguistically and culturally sensitive approach.*

## 2.4 Support the health and well-being of caregivers

The national policy provided for in Bill 56 (section 8) states that (emphasis added): “the policy directions related to the development of health and social services must aim to **support the health and well-being** of caregivers as users, taking into account **their knowledge**, wishes and **engagement capacity** and promoting a **partnership-based** approach.”

It is important that professionals in fields associated with health and social services who work in RSSS or in communities recognize the contributions of caregivers and how their role affects their health, so that caregivers can be provided with the degree of care and treatment they need.<sup>27</sup>

Accessible respite services are essential to ensuring the health and well-being of caregivers. Respite services are funded through federal programs that were touched on earlier in this brief, but these services are sometimes limited by staffing shortages or underfunding. First Nations caregivers often have a hard time accessing short- and long-term respite home services that include specialized physical and mental disability services for care receivers, as these services are located outside of communities. Additionally, such services are sometimes poorly or not at all adapted for culture and language, which limits their use by First Nations caregivers.

An approach based on partnership between the care receiver, care providers and the caregiver, as suggested by Bill 56, would help inform these stakeholders of the caregiver’s knowledge, wishes and engagement capacity. However, creating such partnerships can be challenging in the First Nations context as there are communication issues with RSSS care providers, including a lack of knowledge about the realities and culture of First Nations in Quebec.<sup>28</sup>

As some services in communities can be lacking or insufficient for a variety of reasons, caregivers sometimes end up getting more heavily involved to compensate, and may do so in ways that do not always respect their own physical and mental boundaries. In the medium and long term, the burden on caregivers will need to be reduced, which could be accomplished by making health related professions more attractive, as suggested by the FADOQ network.<sup>29</sup> This effort should also extend to First Nations. It is important to increase the number of professionals working with First Nations, something that is currently lacking from the bill as it stands.

**Recommendation 14:** *Help develop the abilities of RSSS and community care providers to recognize the challenges that community caregivers are faced with when attempting to use RSSS services.*

**Recommendation 15:** *Share information about respite services available in the RSSS.*

**Recommendation 16:** *Make respite homes, long-term respite services and specialized services available to First Nations and ensure that they are adapted for culture and language.*

**Recommendation 17:** *In partnership with First Nations, ensure that the promotion of health and social services professional positions also targets those in First Nations communities.*

## 2.5 Support social participation and promote balance between the caregiver role and other spheres of caregivers' lives

The national policy provided for in Bill 56 (section 9) states that (emphasis added): “the policy directions related to the development of environments that support the **social participation** of caregivers must, in particular, be aimed at promoting **balance between the caregiver role and the other spheres of caregivers' lives.**”

According to the 2015 RHS, 75.1% of caregivers are younger than 55 and 53.2% work a paying job. A large number of caregivers also live with youth aged 0 to 17.<sup>30</sup> Having to balance work, activities (school, volunteering) and family life can make it quite difficult to perform the caregiving role, especially if the care receiver requires accompaniment to medical exams outside of the region. Strategies must be established to promote balance between the various spheres of caregivers' lives and to raise awareness of these realities with the people involved in different aspects of their lives. Caregivers may also need psychosocial support to promote balance between the caregiver role and other spheres of their life.<sup>31</sup> However, in communities where caregivers must travel outside the community for psychosocial support that promotes social participation and balance between the different spheres of life, access to such support is compromised.<sup>32</sup>



27 FADOQ NETWORK. 2019. *Mémoire – Vers une politique nationale des proches aidants*. Presented to Marguerite Blais, Minister Responsible for Seniors and Informal Caregivers. September 24, 2019. Montréal.

28 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on the consultation with First Nations communities in Quebec. Internal document.

29 FADOQ NETWORK. 2019. *Mémoire – Vers une politique nationale des proches aidants*. Presented to Marguerite Blais, Minister Responsible for Seniors and Informal Caregivers. September 24, 2019. Montréal.

The Coalition pour la conciliation famille-travail-études has pointed out that Bill 56 lacks sufficient financial measures to promote balance between the different spheres of caregivers' lives.<sup>33</sup>

Several financial assistance measures put in place by the Quebec government are not accessible to caregivers living in First Nations communities because they are in the form of tax credits, have eligibility criteria that limit First Nations access, or are subject to conflicting jurisdictional authority. This situation increases the disparities in services between First Nations and the non-Indigenous population in Quebec.<sup>34</sup>

*"Caregivers often need to become heavily involved in their role, which can make it hard to perform other social roles (e.g., work, school, etc.). Financial compensation should be offered to caregivers who are obliged to work fewer hours or stop working to take care of someone."<sup>35</sup>*

(Community organizer, First Nations community)

**Recommendation 18:** *Make information regarding financial measures for caregivers available to First Nations.*

**Recommendation 19:** *Develop support measures (financial compensation, psychosocial resources, child care, raising awareness with employers, etc.) and make them available to First Nations in order to promote balance between the different spheres of caregivers' lives.*

**Recommendation 20:** *Ensure access for First Nations, in English and French, to tools that will be developed in order to advocate for caregivers' needs with their employer and promote how a balance between work and caregiving responsibilities can benefit the employer.*

30 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2018. *Quebec First Nations Regional Health Survey – 2015*. Home Care. Wendake.

31 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on the consultation with First Nations communities in Quebec. Internal document.

32 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. *Placing Client Wellness at the Heart of Services. Regional Consultation Process on the Reform of the Income Assistance Program*, Final Report – Quebec Region. Wendake.

33 COALITION POUR LA CONCILIATION FAMILLE-TRAVAIL-ÉTUDES (2020). *Projet de loi 56 pour soutenir les personnes proches aidantes : Un arc-en-ciel pour la proche aide?* Press release issued June 12, 2020. Montréal.

34 ASSEMBLY OF FIRST NATIONS QUEBEC-LABRADOR AND FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2016. *Active Aging in the Quebec First Nations: Everyone's a Winner!*. Brief presented to the Secrétariat aux aînés, ministère de la Famille. Wendake.

35 FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION. 2020. *Les personnes proches aidantes et les services de soins de longue durée : la réalité des communautés des Premières Nations au Québec*. Report on the consultation with First Nations communities in Quebec. Internal document.

### 3. NEW INSTITUTIONS AND ORGANIZATIONS: CONSIDERATION OF FIRST NATIONS REALITIES

Sections 18 to 39 of Bill 56 state that the Government of Quebec will provide for (emphasis added): “the establishment of the **Comité de partenaires concernés par le soutien aux personnes proches aidantes** and the **Observatoire québécois de la proche aide**.”

#### 3.1 Committee of Partners concerned with caregiver support

Under section 24 of Bill 56, the **Committee of Partners’** main function is to make any recommendation to the Minister that it considers necessary regarding the national policy for caregivers, the government action plan or any other matter relating to caregivers. It also has the role of supporting the Minister and the monitoring committee in implementing the national policy for caregivers and the government action plan.

For the Committee of Partners to act as an effective advisor, it must be able to help the Minister consider a variety of situations, such as First Nations caregiving. It is important that First Nations be invited to participate in this process, as the representatives will help the committee, and ultimately the Minister, identify and implement actions consistent with those taken by communities.

To accomplish this, the AFNQL should be appointed by the Minister as one of the non government bodies concerned with caregiver support.<sup>36</sup> The Minister would consult this body in order to choose the member to represent First Nations.

The committee’s work could also be enhanced by including a caregiver who works with First Nations. The public invitation for applications would need to be extended to First Nations, and a third voting member position established to specifically represent this group.<sup>37</sup>

Finally, one of the researchers appointed after consultation with the integrated university health network coordination panel (RUIS)<sup>38</sup> should have actual scientific expertise regarding the specific issues faced by First Nations. The bill allows for this possibility, so if it is necessary, a third researcher from a First Nation could be added to ensure scientific coverage in this regard.

**Recommendation 21:** *That the AFNQL be designated by the Minister as one of the non-government bodies concerned with support for caregivers within the Committee of Partners.*

**Recommendation 22:** *That First Nations be invited to join the Committee of Partners so that a First Nations member can be appointed as a voting member of the committee and may vote after consulting the designated body, as described in recommendation 21.*

**Recommendation 23:** *That the public invitation for applications to choose a caregiver be extended to First Nations communities.*

**Recommendation 24:** *That one of the researchers appointed as a voting member have scientific expertise in First Nations matters.*

<sup>36</sup> Section 19, paragraph 1.

<sup>37</sup> Section 19, paragraph 2.

<sup>38</sup> Section 19, paragraph 3.



### 3.2 Observatory on caregiving

The purpose of the observatory is to provide reliable and objective information regarding caregiving through observation, monitoring, analysis and knowledge sharing.<sup>39</sup> The observatory also:

*“enlightens the Minister by finding and reporting on current knowledge and trends, or those to be developed, concerning evaluation approaches and indicators to measure the quality of life, health and well-being of caregivers, and to measure the impact of the policy directions, measures and actions set out in the national policy for caregivers and the government action plan. To that end, the observatory enhances the value of existing information and data and promotes knowledge transfer and sharing.”<sup>40</sup>*

It is critical that First Nations be represented within the observatory so that they can provide their unique perspective on a setting that is still relatively unknown by the Quebec university network, government bodies and RSSS facilities. First Nations representatives could report on First Nations-specific issues and ensure that they are foregrounded and not downplayed in favour of issues that concern Quebec society as a whole. This would also be an excellent opportunity to build stable collaborative relationships with First Nations organizations and institutions that play a role in health and social services governance or research, evaluation and health monitoring activities on behalf of communities.<sup>41</sup>

**Recommendation 25:** *That one of the researchers appointed to the managing committee have scientific expertise in First Nations matters.*

**Recommendation 26:** *That a member representing First Nations be appointed to the managing committee by the Minister, following consultation with the AFNQL.<sup>42</sup>*

**Recommendation 27:** *That the observatory provide for collaboration mechanisms between government institutions, the RUIS, other research organizations and First Nations organizations in research and evaluation projects and other projects that concern First Nations.*

<sup>39</sup> Section 34, paragraph 1. The primary functions of this committee are to collect, analyze and disseminate information, in particular of a statistical nature, on caregiving; to monitor the evolution of caregivers' needs and of efficient practices, measures and actions to support them; to facilitate the transfer of knowledge for the benefit of the various actors involved in caregiving; to facilitate collaborations with university institutions, research centres, other observatories or the government bodies participating in research activities or activities to promote clinical excellence and efficient use of resources in health and social services.

<sup>40</sup> Section 35.

<sup>41</sup> For example, the FNQLHSSC runs a research sector that conducts population surveys, supports communities with research projects upon request, and collaborates on studies with universities, the INSPQ and provincial and federal departments.

<sup>42</sup> Appointment under Section 28, paragraph 5.

### 3.3 Seniors home and alternative home

Section 40 of Bill 56 amends the *Act respecting health services and social services* by specifying how the terms “seniors home” and “alternative home” can be used. In a press release issued on November 26, 2019, the Minister Responsible for Seniors and Informal Caregivers, Marguerite Blais, explained that the expression “seniors home” will refer to a care facility that houses elderly people with moderately reduced autonomy, supporting them until they have high levels of reduced autonomy. “Alternative homes” will house adult clients younger than 65 with special needs.

Certain residential and care facilities for elders and persons with decreasing independence that are located in communities have long used the term “seniors home.” These facilities house independent or semi-independent clients, and as such, do not look after the same clients as those described by Ms. Blais.<sup>43</sup> Bill 56 prohibits the use of this term if the facility’s activities are likely to be confused with the activities inherent in the mission of a “seniors home”<sup>44</sup> and if the words are not used in the facility’s registration declaration filed under the *Act respecting the legal publicity of enterprises*.<sup>45</sup> As such, under Bill 56, care facilities for elders using this name must cease to use the words “seniors home.” Respect for First Nations culture dictates the need to analyze what consequences this change could have on First Nations. We also believe that a one-year grace period must be granted for facilities to make the necessary changes. Holding information sessions with the RSSS and community care providers would be useful for limiting potential confusion, where necessary.

With few exceptions, First Nations communities do not have long-term residential resources (moderately to significantly reduced autonomy) in their communities. In the vast majority of cases, persons with moderately reduced autonomy must wait for a space in the RSSS. The needs of elders living in communities must be considered when planning and creating new residential care resources in the RSSS. These new resources, like those already in existence, must offer services that are respectful of First Nations cultures and languages. In collaboration with the federal government and First Nations, preference should be given to developing long-term residential care resources that respond specifically to First Nations’ needs.

Finally, in the course of the July 22, 2020, consultation on Bill 56, participants brought up the fact that there was a lack of spaces in and near communities for people younger than 65 with special needs, a situation that poses a major challenge. Alternative homes could address this issue.

**Recommendation 28:** *Where necessary, grant a one-year grace period to care facilities for elders to allow them to cease to use the words “seniors home” in their name.*

**Recommendation 29:** *Hold information sessions between the RSSS and community care providers in order to promote understanding of the terms used by the RSSS and communities based on their service offerings.*

**Recommendation 30:** *Consult First Nations when planning and developing “seniors homes” and “alternative homes.”*

**Recommendation 31:** *Encourage the construction of “seniors homes” and “alternative homes” in and near First Nations communities.*

43 MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX. *CHSLD et maisons des aînés – Le gouvernement du Québec annonce un projet de transformation majeure des milieux d’hébergement pour aînés et adultes ayant des besoins spécifiques au Québec*. Press release issued November 26, 2019. Québec.

44 Section 40, paragraph 2(b).

45 Section 45.



**Recommendation 32:** *Offer services in English or French, depending on the community, and the option of interpretation into English, French or a First Nations language in “seniors homes” and “alternative homes” in order to overcome isolation and provide adapted support.*

**Recommendation 33:** *Improve the cultural competence of staff in “seniors homes” and “alternative homes” by offering educational workshops developed in collaboration with First Nations.*

**Recommendation 34:** *In collaboration with the federal government, the Quebec government and First Nations, encourage and support the development of long-term residential care resources in and near First Nations communities.*

## Conclusion

home care and support services are a growing field in First Nations communities in Quebec. However, the lack of dedicated professionals and funding puts constant pressure on the individuals and staff who provide these services. Caregiving is widespread in First Nations communities both due to this lack of resources and to the values of solidarity and strong relationships that are central to First Nations culture. Everyone would benefit if caregivers were able to continue providing support to people with reduced autonomy and received all of the recognition, assistance and support they need.

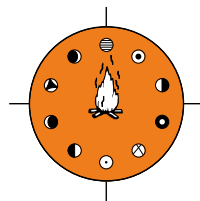
The AFNQL and the FNQLHSSC welcome the efforts to recognize and support caregivers. However, to properly reflect the lived experiences of First Nations in Quebec, the Government of Quebec will need to make amendments to the bill as it stands regarding the definition of caregivers and the organization of institutions provided for under Bill 56.

The recommendations presented in this brief are primarily focused on addressing the needs of First Nations caregivers to provide aid in a familiar and safe environment, self-recognize, and receive adequate training and information, official recognition as caregivers from health professionals, employers and Quebec society, and support in the form of assistance and of accessible and adapted health and social services.

This brief can be used as the basis for establishing action priorities for the national policy for caregivers and guiding government practices so that the importance of caregiving can be recognized and the diverse needs of caregivers can be addressed. The brief also informs the Government of Quebec of the various First Nations concerns regarding the application and impacts of Bill 56, as well as the legislative amendments it proposes.







Assembly of First Nations  
Quebec-Labrador



**FIRST NATIONS OF QUEBEC  
AND LABRADOR HEALTH  
AND SOCIAL SERVICES  
COMMISSION**